



# Improving Quality of Care in Atopic Dermatitis

# Terms of reference

## **Terms of reference:**

The purpose of this report is to document global good practice care in Atopic Dermatitis. This report was commissioned and funded by Sanofi Inc, Genzyme Europe B.V., and Regeneron Pharmaceuticals Inc. (collectively referred to as "Sanofi Genzyme & Regeneron"). KPMG LLP ("KPMG") has had sole responsibility for its contents and editorial oversight. Sanofi Genzyme & Regeneron had no role in collection, management, analysis or interpretation of data, or preparation of the final report.

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- Other contributing specialists: All experts were given an opportunity to review their centre-specific report and this report. Guidance and feedback from all experts were incorporated into this report.
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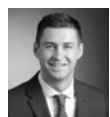
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# Foreword

Chronic inflammatory skin conditions such as Atopic Dermatitis (AD) and the treatment to address them can significantly impact the quality of life of patients, their families and their carers. Public stigmatisation, together with the complex long-term management of the diseases and their comorbidities, can place a substantial social, psychological and financial burden on these individuals.

AD and wider dermatology care have been deprioritised in favour of services deemed more medically urgent – however we are glad to see that things are starting to change. Care teams and patient advocates are raising awareness of AD, and a suite of new therapies is revolutionising our field of practice. In order to maximise the benefits of these, the pathways of diagnosis, treatment and management will need to adapt. In addition, we need to achieve earlier diagnosis, so that more patients receive prompt, specialist care enabling them to self-manage their symptoms. The challenges that we face as providers of AD care require us to work together both amongst ourselves, and with other specialists, community based clinicians and patient groups. This will support us to diagnose patients more effectively, to provide clearer patient, carer and provider education, and to deliver high-quality patient care.

We welcome the release of this report, in which KPMG has documented a plethora of examples of excellence in care from thirty two centres across the world, where dedicated care teams are tackling AD-associated challenges in varied and innovative ways. We hope these examples can inspire readers to advance their own services and ultimately improve quality of life and treatment outcomes for patients living with AD.

**Professor Audrey Nosbaum, Professor Stephan Weidinger, Professor Emma Guttman, Professor Eric Simpson**





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# Executive summary



# The Quality of Care initiative aims to improve AD patient care across the globe

**By exploring, documenting and sharing features of good practice in caring for AD and associated comorbidities, the initiative aims to ensure all patients globally can benefit from the best care possible**

## Aims



Drive improvements in patient quality of care through the development of AD-specific interventions



Facilitate greater collaboration between dermatologists, other specialists and other HCPs



Support centres globally in their pursuit of delivering standardised high quality care



Empower patients through the promotion of active patient participation in managing their disease



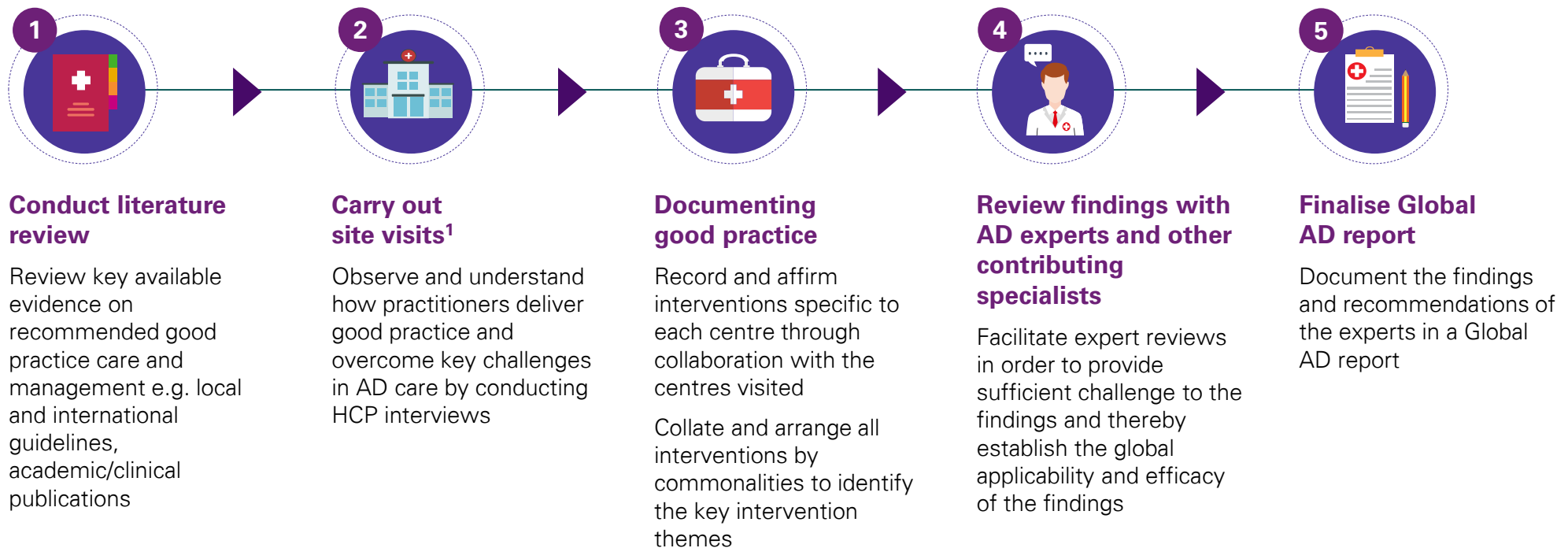
Establish a large and engaged network of AD experts passionate about raising the standard of AD care



Raise awareness of the current challenges faced in the treatment and management of AD

# KPMG combined primary and secondary research with guidance from experts in AD and its associated comorbidities

**Through our established methodology, KPMG conducted a comprehensive examination of AD care in order to find and document examples of good practice**



Note: (1) Please see page 86 for further information regarding site selection criteria

# In order to document examples of AD care, we visited 32 centres from across the globe



# Utilising expert guidance and collaboration, KPMG identified ten good practice interventions along the patient pathway

**To aid implementation, these interventions were prioritised by the experts and substantiated by a series of case studies to demonstrate the multiple ways through which they can be employed in patient care**



# All good practice interventions identified from the centres were mapped across the patient pathway

## 01 Awareness & Presentation

Awareness in patients and especially in primary care physicians (PCPs) to detect atopic dermatitis and possible suspected comorbidities



## 02a Diagnosis

Initial screening by dermatologist / paediatric dermatologist, trainee dermatologist or MA

Conduct tests (e.g. patch and prick tests) to aid diagnosis

Investigation and review by dermatologist

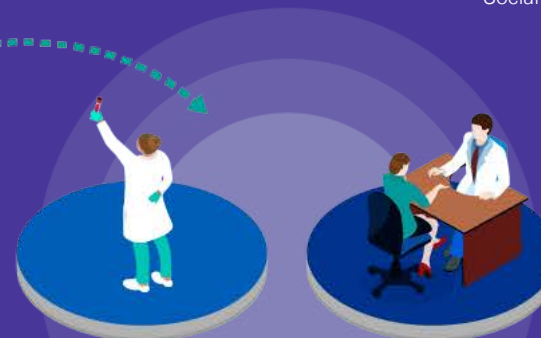
Confirmation of diagnosis



## 02b Referral

Referral via the following pathways:

- Primary care
- Self-referral
- Another specialty to secondary care for specialist assessment



## 03a

### Treatment & management

Medical management

- Management of AD using topical treatments, conventional systemic treatments and biologics
- Management of AD and associated comorbidities by dermatologists / paediatric dermatologists and comorbidity specialists e.g. allergists, pulmonologists, nutritionists

## 03b

### Treatment & management

Non-medical management, including involvement with:

- Occupational therapist
- Psychologist
- Nurse
- Social worker



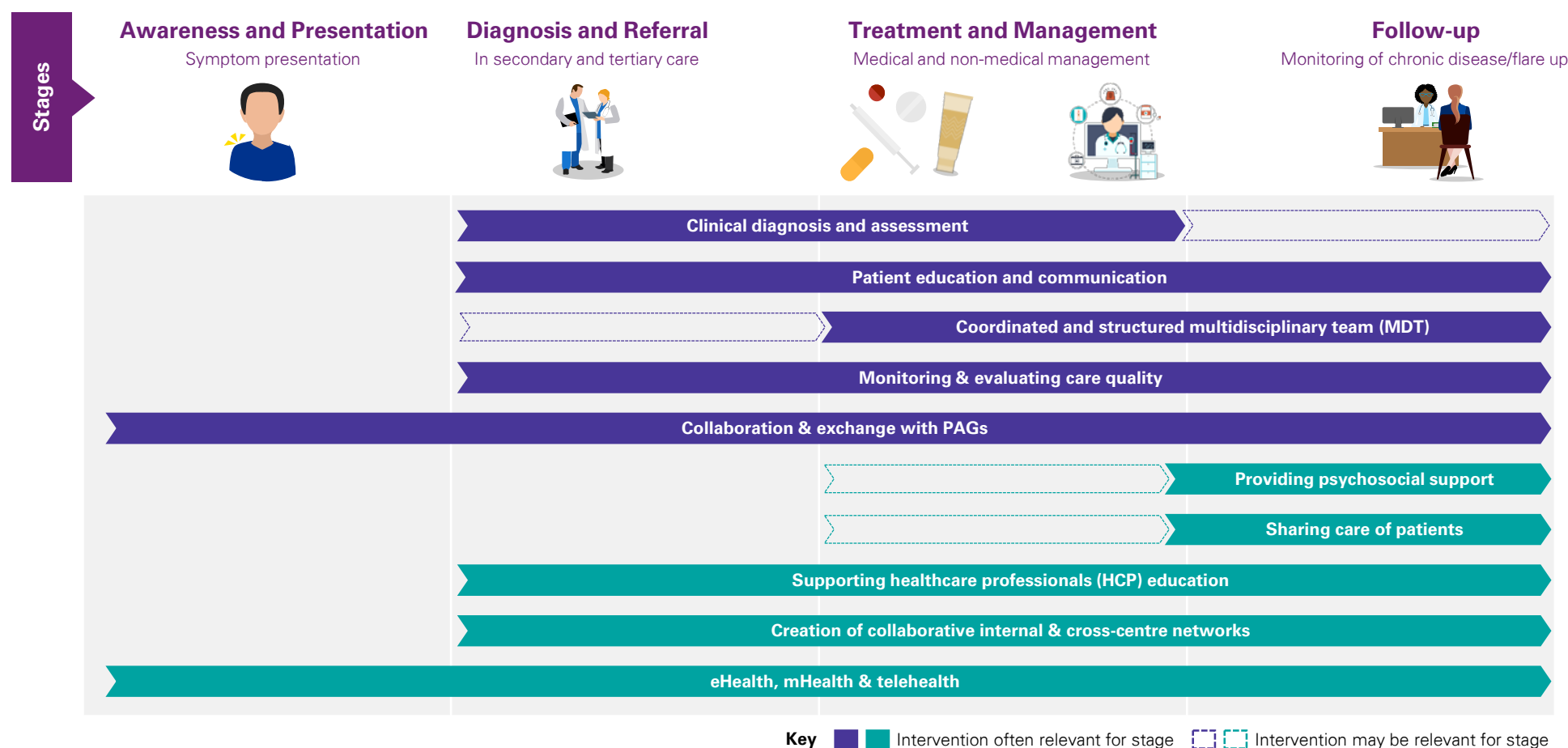
## 04

### Follow-up

Programmed or patient-initiated follow-up  
Dermatologist, nurse and comorbidity specialist periodic review

# These good practice interventions were identified as being relevant across all different stages of the patient pathway

The entirety of the AD patient pathway was identified as having the potential to drive improvements in patient outcomes through the effective implementation of the ten AD interventions







CONTENTS

# Context



# Atopic Dermatitis (AD) is a chronic and complex disease that can significantly impact quality of life

## AD is a chronic, inflammatory skin disease that can affect children and adults



### Definition

Atopic dermatitis, also known as atopic eczema, is a chronically relapsing skin disease that most commonly manifests in children. Although the exact cause is unclear, it is thought to be a combination of immune, genetic and environmental factors<sup>(a)(b)</sup>



### Symptoms

Patients with AD have a dysfunctional skin barrier and biased immune response, which can lead to:<sup>(a)(b)</sup>

- Pruritus
- Dry, scaly skin
- Recurrent inflammatory skin lesions



### Prevalence

AD affects 10–20%<sup>(c)</sup> of children and 5–10%<sup>(d)</sup> of adults in Western countries



### Diagnosis

The diagnosis of AD involves an assessment of clinical (essential, important and associated) features and medical history<sup>(a)</sup>

#### Essential



Features that must be present for a diagnosis of AD are severe itching, and chronic or relapsing eczematous skin lesions. Appearance and distribution of lesions often differs between age groups

#### Important



Features that are common across AD patients and support diagnosis include early onset of the disease (i.e. during childhood), personal/family history of atopy and abnormally dry skin

#### Associated



Features that are associated with AD and may suggest AD diagnosis include hyper linearity of palms and soles, (peri-) ocular changes, scaly skin, bumps on the skin, lateral thinning of the eye brows (Herthoge's sign) and infraorbital folds (Dennie-Morgan sign)

### Impact on Quality of Life

AD can have a significant impact on a patient's quality of life and be burdensome for their families and the wider population. AD can negatively affect a patient's academic, work and social life



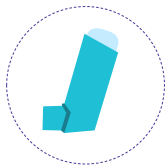
Sources: (a) Eichenfield LF, et al. Guidelines of care for the management of atopic dermatitis. section 1. Diagnosis and assessment of atopic dermatitis. J Am Acad Dermatol. 2014;70(2):338–351. doi:10.1016/j.jaad.2013.10.010;  
 (b) Ring J, et al. Guidelines for treatment of atopic eczema (atopic dermatitis) Part 1. JEADV. 2012;26(8):1045–1060. doi:10.1111/j.1468-3083.2012.04635.x;  
 (c) Weidinger S, et al. Lancet 2016;387(10023):1109–1122;  
 (d) Fabbrocini G, et al. Treatment of Atopic Dermatitis with Biologic Drugs. Dermatol Ther (Heidelberg) 2018; 8(4):527–538. doi: 10.1007/s13555-018-0258-x

# There are a number of comorbidities associated with AD

## AD can progress to conditions linked with the Atopic March and is associated with other comorbidities

### Atopic comorbidities

AD patients can also suffer from other atopic diseases such as:



#### Asthma

Approximately 50-70% of patients with severe AD develop asthma (in comparison to 8% of the general population)<sup>(a)(b)</sup>



#### Allergic rhinitis

An estimated 66-75% of patients with severe AD have/develop allergic rhinitis<sup>(a)(b)</sup>



#### Food allergies

There may be an association between AD and food allergies<sup>(a)(b)</sup>

### Non-atopic comorbidities

AD is also associated with non-atopic conditions, including:



#### Psychological comorbidities

AD is linked to various mental health conditions, such as:<sup>(a)(b)(c)</sup>

- Attention Deficit Hyperactivity Disorder
- Anxiety
- Depression
- Autism



#### Infections

Patients with AD are at risk of developing bacterial, viral and fungal skin infections<sup>(a)(b)</sup>

Sources: (a) Simpson EL. Comorbidity in Atopic Dermatitis. *Curr Dermatol Rep*. 2012;1(1):29–38. doi:10.1007/s13671-011-0003-5;

(b) Bantz SK, et al. The Atopic March: Progression from Atopic Dermatitis to Allergic Rhinitis and Asthma. *J Clin Cell Immunol*. 2014;5(2):202. doi:10.4172/2155-9899.1000202;

(c) Simpson EL, et al. Association of Inadequately Controlled Disease and Disease Severity With Patient-Reported Disease Burden in Adults With Atopic Dermatitis. *JAMA Dermatol*. 2018;154(8):903–912. doi:10.1001/jamadermatol.2018.1572

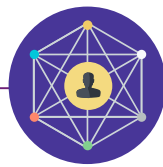
# The psychological and financial impact creates a substantial patient burden

**Patients and their family's quality of life can be significantly impacted by AD symptoms and treatment regimes**



## Public stigmatisation of AD

Patients with visible skin diseases often suffer from public stigmatisation<sup>(a)</sup> which can negatively impact patient mental health



## Psychological impact of symptoms and stigma

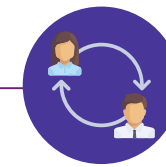
In addition to the psychological comorbidities, patients have reported feeling frustrated, isolated and embarrassed<sup>(b)</sup>



## Financial strain of medical consultations and treatments

To control and manage AD symptoms, patients face significant direct and indirect financial costs<sup>(c)</sup>

Patients can face out-of-pocket expenses for medical consultations and potential loss of income (due to absenteeism)<sup>(d)</sup>



## Ripple effect on families and care givers

Families and care givers of patients with AD can be impacted on a day-to-day basis. Parents of paediatric AD patients may experience distress/anxiety when attempting to manage their child's symptoms<sup>(c)(d)</sup>

Sources: (a) Augustin M, et al. Translating the WHA resolution in a member state: towards a German programme on 'Destigmatization' for individuals with visible chronic skin diseases. J Eur Acad Dermatol Venereol. 2019. doi: 10.1111/jdv.15682;  
(b) Zuberbier T, et al. Patient perspectives on the management of atopic dermatitis. Journal of Allergy and Clinical Immunology. 2006;118(1):226-32;  
(c) The Economist Intelligence Unit. A misunderstood skin disease: Mapping the policy response to atopic dermatitis [Website] <https://eiu.perspectives.economist.com/healthcare/misunderstood-skin-disease-mapping-policy-response-atopic-dermatitis/white-paper/misunderstood-skin-disease-mapping-policy-response-atopic-dermatitis> Accessed 10 Oct 2019;  
(d) Drucker AM, et al. The Burden of Atopic Dermatitis: Summary of a Report for the National Eczema Association. Journal of Investigative Dermatology. 2017;137(1):26-30

# The multi-faceted impact on patients can place a significant economic burden on the broader economy

## AD can impact productivity and consequently place a burden on the wider economy

### Indirect costs due to productivity loss

AD symptoms and AD-associated comorbidities result in productivity loss



An estimated **5.9 million workdays per annum** are lost due to AD in the USA<sup>(a)</sup>



In the Netherlands, a study reported total average direct costs for treating AD as **€5,191 per patient per year**. The cost to productivity was calculated as **€10,040 per person per year**<sup>(b)(1)</sup>



A 4-week long USA study of 2-12 year-old AD patients reported that **8% of children lost at least 1 day of school** due to AD and **9% of caregivers lost at least 1 day of work** due to their child's AD<sup>(c)</sup>

### Wider economy

There are various reports on the economic impact of AD in different countries, all of which highlight the substantial burden AD has on the economy



The total annual cost in the United Kingdom is estimated to be approximately \$598 million USD (£465 million), of which \$380 million (£297 million) is incurred by patients<sup>(d)</sup>



In the United States, the national cost of managing AD is estimated to be up to \$3.8 billion USD per year<sup>(e)</sup>



In Singapore, the total cost per annum per paediatric AD patient is approximately \$1,097<sup>(f)</sup>

Note: (1) Study group of 70 people

Sources: (a) Silverberg JI. Health Care Utilization, Patient Costs, and Access to Care in US Adults With Eczema: A Population-Based Study. *JAMA Dermatol.* 2015;151(7):743–752. doi:10.1001/jamadermatol.2014.5432;  
 (b) Adrians LFM. et al. Economic Burden of Adult Patients with Moderate to Severe Atopic Dermatitis Indicated for Systematic Treatment. *Acta Derm Venereol.* 2019;99(9):762–768. doi: 10.2340/00015555-3212;  
 (c) Drucker A, et al. The Burden of Atopic Dermatitis: Summary of a Report for the National Eczema Association. *Journal of Investigative Dermatology.* 2017;137(1):26–30. doi: 10.1016/j.jid.2016.07.012;  
 (d) Sach TH, et al. Economic evidence for the prevention and treatment of atopic eczema: a protocol for a systematic review. *Syst Rev.* 2016;5:90. doi:10.1186/s13643-016-0262-0;  
 (e) Mancini AJ, et al. The socioeconomic impact of atopic dermatitis in the United States: a systematic review. *Pediatr Dermatol.* 2008;25(1):1–6. doi: 10.1111/j.1525-1470.2007.00572.x;  
 (f) Tsai TF, et al. Burden of atopic dermatitis in Asia. *Journal of Derm* 2019;46. doi: 10.1111/1346-8138.15048.

# To alleviate symptoms, patients can access various medical treatment and non-medical management

## Management of AD can involve topical emollients, immuno-modulating and non-pharmacological treatments

### Topical treatments

The regular and liberal use of emollients and moisturisers form the basis of every AD therapy. Topical corticosteroids are also recognised as a significant component of AD care. Finally, topical calcineurin inhibitors, antimicrobials and antiseptics may also be recommended to support management of AD symptoms<sup>(a)(b)</sup>

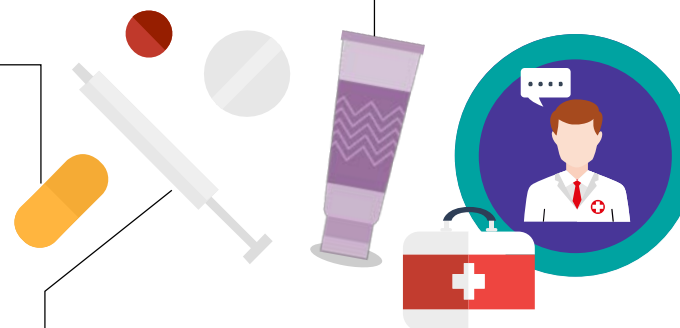
### Conventional systemic treatment

Systemic treatments can be administered orally or by injection, both of which can help with managing AD symptoms (e.g. systemic oral immunosuppressants)<sup>(a)(b)</sup>

Other oral medications (non-systemic) may include antimicrobials (for patients with bacterial infections) and antihistamines (for short-term use in patients with sleep-loss secondary to itch)<sup>(a)(b)</sup>

### Biologics

Currently, AD injections are recombinant therapeutic proteins that target specific inflammatory cells and mediators. Patients with severe AD, refractory to topical and oral treatments, may benefit from these injections<sup>(a)(b)</sup>. Biologics will soon involve pills as well



### Disease flare

A combination of pharmacological (e.g. topical corticosteroids) and non-pharmacological treatments (e.g. wet wraps) can rapidly improve AD symptoms<sup>(a)(b)</sup>

## Non-pharmacological treatments

### Education

Education can enhance medical treatment by providing patients with new knowledge or skills about AD management<sup>(b)</sup>

### Psychosocial support

Psychotherapeutic approaches, such as counselling and therapy, may support the psycho-social facet of AD<sup>(b)</sup>

### Emollient therapy and skin care

Given that dry skin is a major symptom of AD, frequent application of moisturizers and thorough cleansing of the skin are core components of AD skin care. The skin should remain hydrated and soap substitutes utilised where possible<sup>(a)(b)</sup>

### Avoidance of triggers

Patients with AD should avoid, where possible, known physical or biological irritants such as wool and dust mites<sup>(a)(b)</sup>

Sources: (a) Eichenfield LF, et al. Guidelines of care for the management of atopic dermatitis. Section 2. Management and treatment of atopic dermatitis with topical therapies J Am Acad Dermatol. 2014;71(1):116–132. doi: 10.1016/j.jaad.2014.03.023;  
 (b) Ring J, et al. Guidelines for treatment of atopic eczema (atopic dermatitis) Part 1. JEADV. 2012;26(8):1045-1060. doi:10.1111/j.1468-3083.2012.04635.x

# To measure patient progress and treatment impact, various outcome measures can be utilised

## There are objective outcome measures and patient reported measures validated for AD or other skin diseases

### Objective Outcome Measures/Physician-led

AD scoring indices utilised to monitor patients and their disease include:

#### EASI

#### Eczema Area and Severity Index

Grades the physical signs of AD/eczema<sup>(a)</sup>

#### SCORAD

#### SCORing Atopic Dermatitis

Assesses AD disease extent, severity, intensity of itch and sleep disturbance<sup>(b)</sup>

#### vIGA-AD

#### Validated Investigator Global Assessment for Atopic Dermatitis

Utilised in clinical trials to grade the overall appearance of AD lesions based on a series of morphological descriptions<sup>(c)</sup>

#### BSA

#### Body Surface Area

Assesses disease severity based on the percentage of dermatitis-affected body surface area<sup>(d)</sup>

### Patient-Reported Outcome Measures

Quality of life for AD patients can be measured by:

#### DLQI

#### Dermatology Quality of Life Index

Dermatology related quality of life questionnaire<sup>(e)</sup>

#### PaGA

#### Patient Global Assessment

Patients self-evaluate their general illness from baseline to end of treatment<sup>(f)</sup>

#### POEM

#### Patient-Oriented Eczema Measure

Patients self-evaluate the current overall activity of their disease<sup>(g)</sup>

#### Itch NRS

#### Itch Numeric Rating Scale

A single-item tool for monitoring pruritus (itch) intensity in patients with AD and other dermatological conditions<sup>(h)</sup>

Sources: (a) EASI for clinical signs: Harmonising Outcome Measures for Eczema (HOME); [Website] <http://www.homeforeczema.org/research/easi-for-clinical-signs.aspx> Accessed 13 Mar 2019; (b) SCORing Atopic Dermatitis (SCORAD) Calculator (0.9.0). [Website] <http://scorad.corti.li/> Accessed 26 Feb 2019; (c) Validated Investigator Global Assessment For Atopic Dermatitis (vIGA-AD™) Scale [PDF] [https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale\\_vIGA-AD\\_2017.pdf](https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale_vIGA-AD_2017.pdf) Accessed 26 June 2019; (d) Chopra R, et al. Severity strata for Eczema Area and Severity Index (EASI), modified EASI, Scoring Atopic Dermatitis (SCORAD), objective SCORAD, Atopic Dermatitis Severity Index and body surface area in adolescents and adults with atopic dermatitis. Br J Dermatol. 2017;177(5):1316-1321. doi: 10.1111/bjd.15641; (e) Lewis V, et al. 10 Years Experience of the Dermatology Life Quality Index (DLQI). J Investig Dermatol Symp Proc 2004;9:169-180; (f) Al-Dhubaibi MS. The effectiveness of alitretinoin for the treatment of chronic hand eczema: A meta-analysis. Int J Health Sci (Qassim). 2018;12(2):70-79; (g) Charman CR, et al. Translating Patient-Oriented Eczema Measure (POEM) scores into clinical practice by suggesting severity strata derived using anchor-based methods. Br J Dermatol. 2013;169(6):1326-1332; (h) Numerical Rating Scale (NRS) [Website] <http://www.pruritusymposium.de/numericalratingscale.html> Accessed 14 Apr 2019



# Objectives





# The Quality of Care initiative aims to improve AD patient care across the globe

**By exploring, documenting and sharing features of good practice in caring for AD and associated comorbidities, the initiative aims to help all patients globally benefit from the best care possible**

## Our objectives



### **Present a globally representative view on AD**

The publicly available report incorporates centres from across the globe that deal with distinct challenges and utilise different good practice interventions



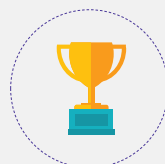
### **Create a report for all centres**

The report ensures all types of centres can find relevant interventions and understand how they may be able to implement them



### **Support expert-relationship building**

The initiative brings together AD experts within/across regions and builds a network of relationships with the joint goal of improving quality of AD care



### **Improve AD patient care**

Ultimately, the initiative helps improve patient outcomes and experience across the AD pathway as a result of centres implementing good practice interventions



# Methodology



# This research followed a five-step approach



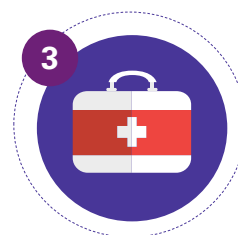
## Conduct literature review

To understand what challenges and good practices in the care and management of AD and associated comorbidities have already been established through published evidence



## Carry out site visits

To observe and understand how leading practitioners deliver good practice and overcome key challenges in AD care



## Documenting good practice

To document how leading care practitioners manage AD and develop a variety of good practice interventions



## Review findings with AD experts

To ensure that our findings capture the key challenges and gaps faced in the delivery of AD care and to work together to define the good practice interventions that can help to overcome these challenges globally



## Finalise Global AD report

To present all findings in one comprehensive report that can be used by any AD centre to improve their management of AD and its associated comorbidities

Why?

How?

KPMG reviewed articles from peer-reviewed journals and internationally recognised guidelines (such as EADV) for evidence-based practice of AD care and management

32 sites that deliver AD care around the world were visited by KPMG. At each visit we conducted semi-structured interviews, a site tour, and open question interviews with core and extended AD team members to ensure that we developed a complete understanding of their activities

Each visit was documented in a centre-specific report (available in the appendix) which summarised the centre's approach to AD care and identified case studies of good practice. The reports were shared with and verified by each centre

Case studies were presented at steering group meetings, in order to define good practice interventions, discuss the global applicability of the interventions and how they might be made relevant to all AD centres

We summarised our findings and created a Global AD report which identifies common themes and challenges in the management of AD and associated co-morbidities as well as outlining interventions and case studies of good practice

# An initial literature review identified existing global challenges and good practice in AD care

**We comprehensively reviewed guidelines and leading publications across AD diagnosis, treatment, management of comorbidities and patient outcomes**



KPMG reviewed academic and clinical publications in addition to high-quality grey literature from a number of reputable sources



Major international recommendations and guidelines for all indications in the scope of this report were also reviewed, including Journal of the American Academy of Dermatology, Journal of the European Academy of Dermatology and Venereology, American Journal of Clinical Dermatology, British Journal of Dermatology, JAMA Dermatology and local recommendations/guidelines



KPMG consulted numerous publications by national governments and private institutions detailing healthcare good practices and future plans

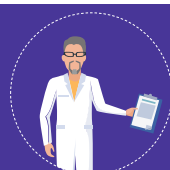
Our literature review formed the basis of our site visit investigation. It helped us form a comprehensive view of the AD care and management landscape, with initial findings providing an insight into where there are potential improvements to be made

# Site visits were conducted to identify current and practical good practice initiatives

## Following a detailed and rigorous process, we selected 32 leading centres



Centres were initially identified via AD publications (including guidelines), congress activity, board/council membership and clinical trial participation. Additional analysis of centre type, size, funding model, location and key AD initiatives in place was used to prioritise from a long list of identified leading centres.



### Working with the core and extended AD care team

In total, KPMG conducted 250+ interviews with a wide range of stakeholders at the selected sites, with each interview lasting ~20 mins to 1 hour.

## Who did we speak to?

### AD

- Dermatologists
- Medical assistants
- Paediatricians
- Dermatology nurses

### Co-morbidity specialists

- Pulmonologists
- Allergists
- Ophthalmologists
- Occupational therapists
- Immunologists

### Other healthcare professionals involved

- Service coordinators
- Psychologists
- Patient Advocacy Group (PAG) representatives
- Pharmacists
- Nutritionists
- Laboratory technicians
- Researchers
- Therapists

## What did we ask them?

### Interview questions were targeted to identify challenges in care and how interventions are used to overcome this:

- Awareness of condition
- Screening
- Diagnosis
- Referral pathway from PCP to HCP
- Medical and non-medical management (including any innovative approaches adopted by the centre)
- Access to multidisciplinary care
- Clinical management
- Follow-up care
- Training of medical staff

## Overview of key themes

### Overview of centre

- Number of patients, services, demographics, funding

### Measurement

- How and when KPIs and outcomes are captured

### Challenges in AD and comorbidity care

### Interventions

- What it is and what challenge does it overcome
- What are the outcomes for patients and healthcare systems

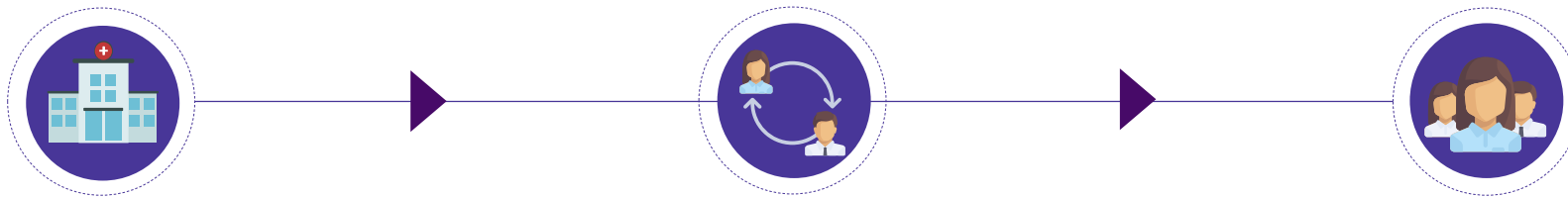
### Implementation

- Who and what is involved
- How is it implemented

# In order to document examples of AD care, we visited 32 centres from across the globe



# Contributors verified and prioritised our key findings and interventions from the site visits



## Centre review of findings

- Following each centre visit, KPMG documented the findings in a centre-specific report identifying specifically:
  - Key challenges faced
  - 'Good practice' interventions
  - Measurement of outcomes from interventions
- The report was shared with the centre for review and approval (to validate the findings)

## Identification of good practice interventions

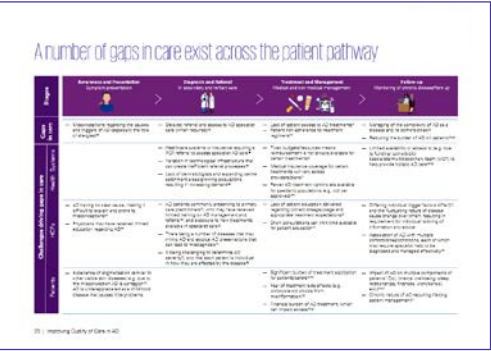
- The case studies were presented and discussed with a steering committee
- This collaboration enabled the identification of an expert-reviewed set of globally relevant interventions capable of effectively assisting in the management of AD and its comorbidities

## Steering Committees

- Four leading dermatologists formed the main steering group to help shape and define the global good practice interventions

# Following this, we created a comprehensive report to help centres to improve AD patient care

The interactive report documents challenges, good practice interventions and case studies from centres across the globe



## Challenges in managing AD and its comorbidities (see page 30)

- With the guidance of the Steering Committee and supported by our literature review, the report identified a series of gaps and challenges faced in the care of AD
- These challenges were categorised by where they manifest along the patient pathway and if they impact the patient, HCP or healthcare system



## Identification of good practice interventions (see page 33)

- The experts identified 10 distinct interventions of good practice AD and comorbidity care management across the patient pathway
- The interventions were collated from across the centres visited and shaped by leading dermatologists
- These were prioritised according to how much of a positive impact they can have on care outcomes in proportion to the resources required for implementation



## Case studies from AD centres visited

- For each of the interventions identified, all relevant case studies were collated to demonstrate the variety of methods of how the intervention can be implemented
- All case studies were described at length in the specific centre report, in order to help illuminate for other centres some of the practical steps taken to implement the intervention and provide some more detail on the key challenges/benefits experienced by the centre and its patients









# Findings

## a) Global challenges in AD care

What were the gaps and challenges in AD care across the patient pathway?



# A number of gaps in care exist across the patient pathway<sup>1</sup>

Stages	<div> <div> <b>Awareness and Presentation</b> Symptom presentation  </div> <div> <b>Diagnosis and Referral</b> In secondary and tertiary care  </div> <div> <b>Treatment and Management</b> Medical and non-medical management  </div> <div> <b>Follow-up</b> Monitoring of chronic disease/flare up  </div> </div>			
	<div> <div> <b>Gaps in care</b> </div> <div> <div>— Misconceptions regarding the causes and triggers of AD (especially the role of allergies)<sup>(a)</sup></div> <div>— Delayed referral and access to AD specialist care (when required)<sup>(d)</sup></div> <div>— Lack of patient access to AD treatments<sup>(j)</sup></div> <div>— Patient non-adherence to treatment regimens<sup>(k)</sup></div> <div>— Managing of the complexity of AD as a disease and its comorbidities<sup>(d)</sup></div> <div>— Reducing the burden of AD on patients<sup>(k)(p)</sup></div> </div> </div>			
Challenges driving gaps in care	<div> <div> <b>Health Systems</b> </div> <div> <div>— Healthcare systems or insurance requiring a primary care practitioner (PCP) referral to access specialist AD care<sup>(e)</sup></div> <div>— Variation in technological infrastructure that can create inefficient referral processes<sup>(e)</sup></div> <div>— Lack of dermatologists and expanding centre catchment areas/growing populations resulting in increasing demand<sup>(e)</sup></div> <div>— Fixed budgets/resources means reimbursement is not always available for certain treatments<sup>(j)</sup></div> <div>— Medical insurance coverage for certain treatments will vary across providers/plans<sup>(l)</sup></div> <div>— Fewer AD treatment options are available for paediatric populations (e.g. not yet approved)<sup>(m)</sup></div> <div>— Limited availability or access to (e.g. due to funding) comorbidity specialists/multidisciplinary team (MDT) to help provide holistic AD care<sup>(d)(q)</sup></div> </div> </div>			
	<div> <div> <b>HCPs</b> </div> <div> <div>— AD having no clear cause, making it difficult to explain and prone to misconceptions<sup>(a)</sup></div> <div>— Physicians may have received limited education regarding AD<sup>(b)</sup></div> <div>— AD patients commonly presenting to PCP<sup>(f)</sup>, who may have received limited training on AD management and referral<sup>(d)</sup>, and exposure to new treatments available in specialist care<sup>(g)</sup></div> <div>— There being a number of diseases that may mimic AD and atypical AD presentations that can lead to misdiagnosis<sup>(h)</sup></div> <div>— It being challenging to determine AD severity<sup>(i)</sup>, and that each patient is individual in how they are affected by the disease<sup>(a)</sup></div> <div>— Lack of patient education delivered regarding correct dosage/usage and appropriate treatment expectations<sup>(j)</sup></div> <div>— Short consultations can limit time available for patient education<sup>(n)</sup></div> <div>— Individual trigger factors differ<sup>(o)(r)</sup>, and the fluctuating nature of disease causes change over time<sup>(s)</sup>, resulting in requirements for individual tailoring of information and advice</div> <div>— Association of AD with multiple comorbidities/conditions, each of which may require specialist help to be diagnosed and managed effectively<sup>(d)</sup></div> </div> </div>			
	<div> <div> <b>Patients</b> </div> <div> <div>— Experience of stigmatisation (similar to other visible skin diseases) e.g. due to the misconception AD is contagious<sup>(c)</sup></div> <div>— AD is underappreciated as it is seen as a childhood disease that causes minor problems<sup>(c)</sup></div> <div>— Significant burden of treatment application for patients/carers<sup>(k)(p)</sup></div> <div>— Fear of treatment side-effects (e.g. corticosteroid phobia from misinformation)<sup>(o)</sup></div> <div>— Financial burden of AD treatment, which can impact access<sup>(k)(p)</sup></div> <div>— Impact of AD on multiple components of patients' QoL (mental well-being, sleep, relationships, finances, work/school, etc.)<sup>(t)(u)</sup></div> <div>— Chronic nature of AD requiring lifelong patient management<sup>(j)</sup></div> </div> </div>			

Note: (1) Please see page 83 for references



# Findings

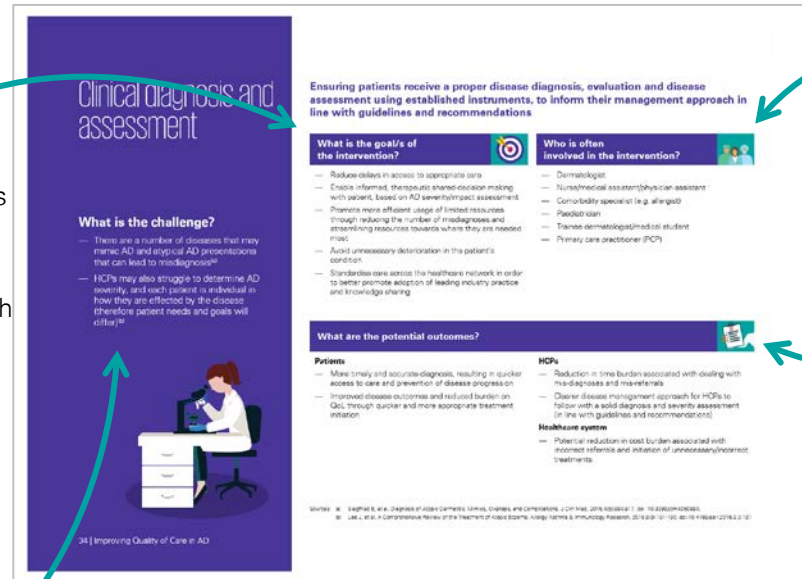
## b) Global good practice interventions



# Further information on each intervention

## What is/are the goal(s) of the intervention?

- Explains what the intervention hopes to achieve
- Success in implementing each intervention could be measured by how effectively these goals are met



## Who is often involved in the intervention?

- Details the medical professionals who are involved in the implementation of the intervention

## What are the potential outcomes?

- Provides an explanation of what positive benefits the intervention has the potential to provide for the following stakeholders: Patients, HCPs and the Healthcare System

## What is the challenge?

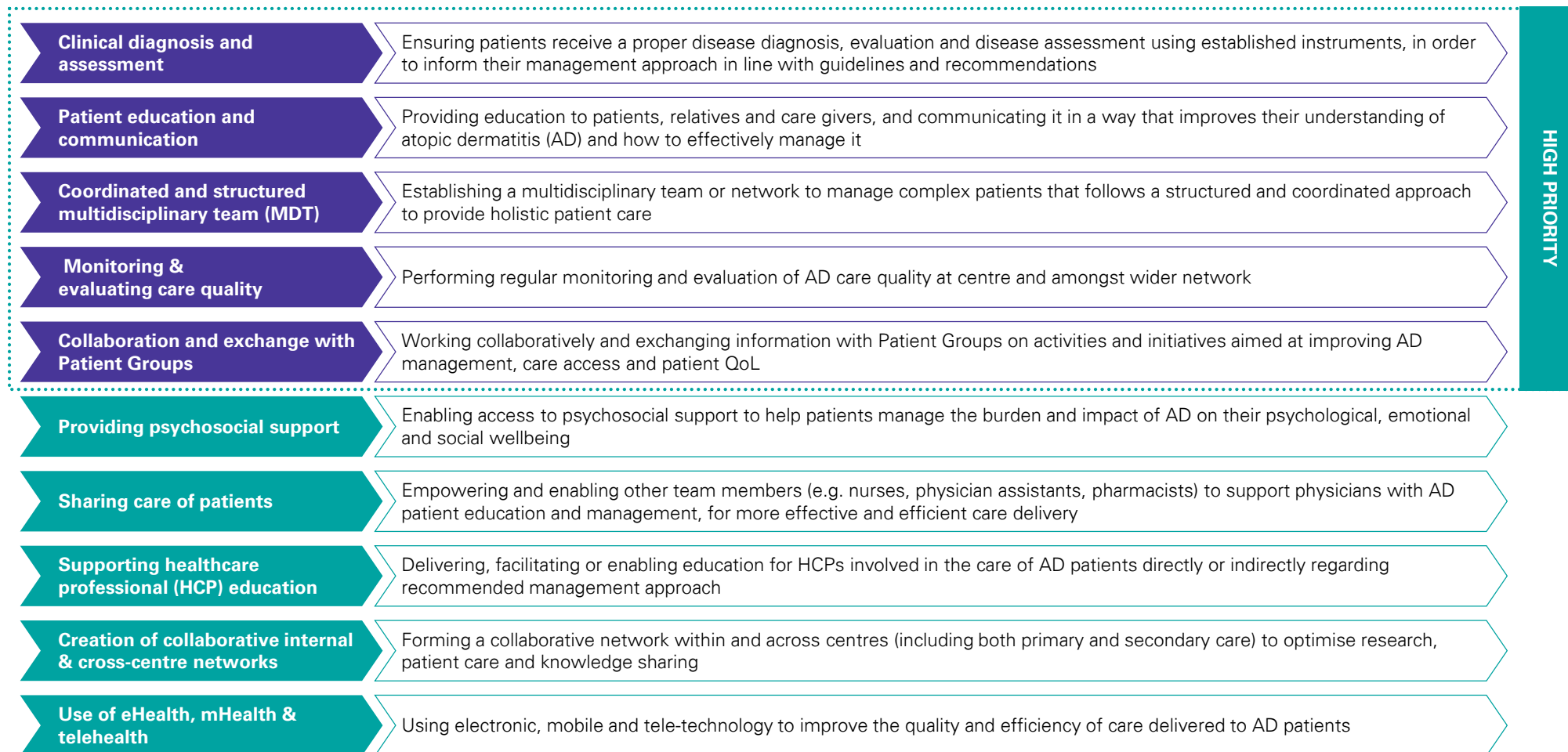
- Describes how the intervention addresses current challenges identified across the patient journey

## What is offered as part of the intervention and how has the intervention been implemented in different centres?

- Provides practical advice on what the intervention includes and examples of how the intervention has been implemented in the past
- The answers to these two questions may be presented together or separately, based on what is more appropriate for each of the 10 good practice interventions

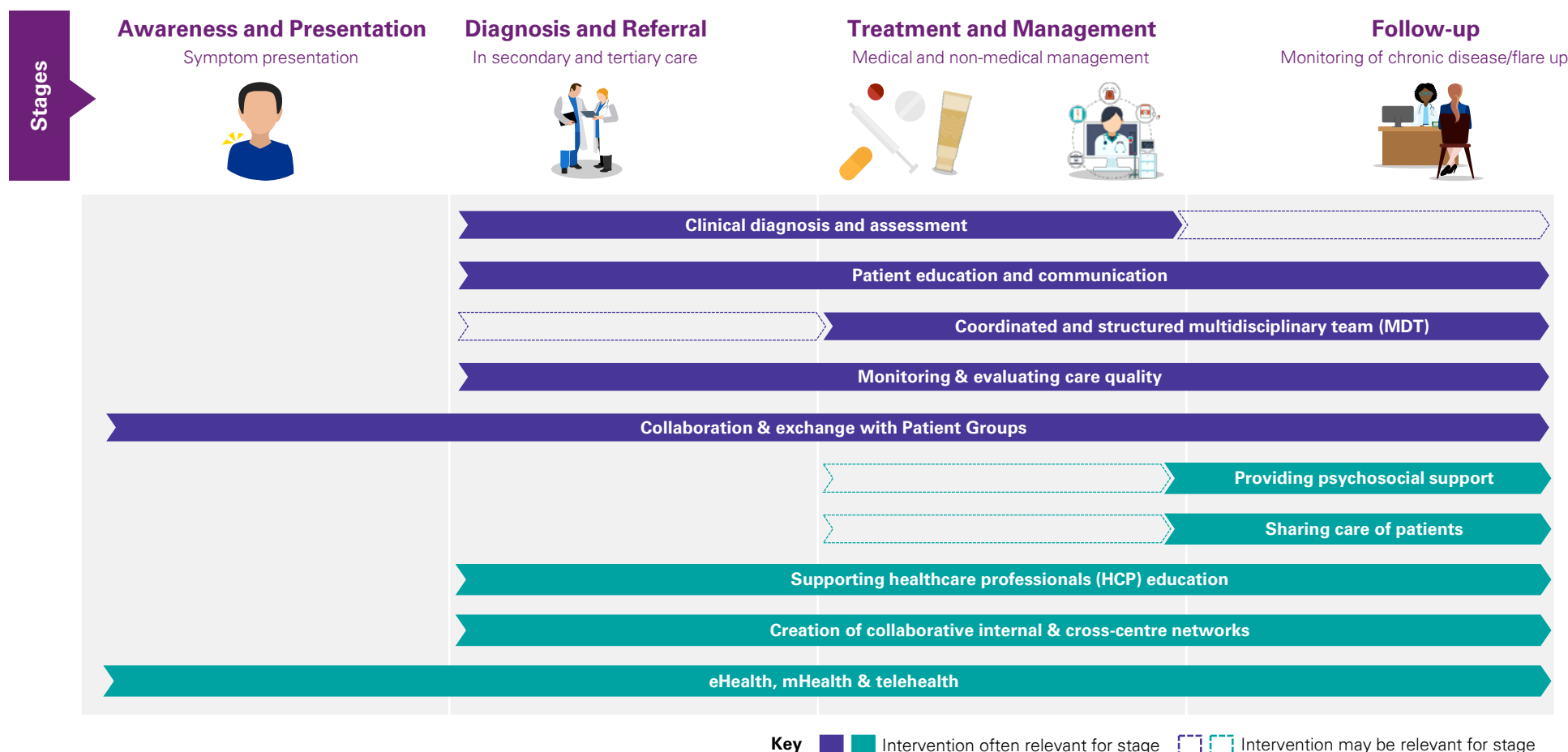


The experts involved identified ten good practice interventions, of which five are deemed 'high priority'



**Note:** These identified good practice interventions should not be viewed as isolated activities, as synergies that exist between them can be leveraged to generate a robust platform for a disease management model for AD globally.

# These good practice interventions are relevant across different stages of the patient pathway



# Clinical diagnosis and assessment (1/2)

## What is the challenge?

- There are a number of diseases that may mimic AD and atypical AD presentations that can lead to misdiagnosis<sup>(a)</sup>
- HCPs may also struggle to determine AD severity, and each patient is individual in how they are affected by the disease (therefore patient needs and goals will differ)<sup>(b)</sup>



## Ensuring patients receive a proper disease diagnosis, evaluation and disease assessment using established instruments, to inform their management approach in line with guidelines and recommendations

### What is the goal/s of the intervention?



- Reduce delays in access to appropriate care
- Enable informed, therapeutic shared-decision making with patient, based on AD severity/impact assessment
- Promote more efficient usage of limited resources through reducing the number of misdiagnoses and streamlining resources towards where they are needed most
- Avoid unnecessary deterioration in the patient's condition
- Standardise care across the healthcare network in order to better promote adoption of leading industry practice and knowledge sharing

### Who is often involved in the intervention?



- Dermatologist
- Nurse/medical assistant/physician assistant
- Comorbidity specialist (e.g. allergist)
- Paediatrician
- Trainee dermatologist/medical student
- Primary care practitioner (PCP)

### What are the potential outcomes?



#### Patients

- More timely and accurate diagnosis, resulting in quicker access to care and prevention of disease progression
- Faster access to support to help manage and reduce symptoms, such as itch
- Improved disease outcomes and reduced burden on QoL through quicker and more appropriate treatment initiation

#### HCPs

- Reduction in time burden associated with dealing with mis-diagnoses and mis-referrals
- Clearer disease management approach for HCPs to follow with a solid diagnosis and severity assessment (in line with guidelines and recommendations)

#### Healthcare system

- Potential reduction in cost burden associated with incorrect referrals and initiation of unnecessary/incorrect treatments

Sources: (a) Siegfried E, et al. Diagnosis of Atopic Dermatitis: Mimics, Overlaps, and Complications. J Clin Med. 2015;4(5):884-917. doi: 10.3390/jcm4050884;

(b) Lee J, et al. A Comprehensive Review of the Treatment of Atopic Eczema. Allergy Asthma & Immunology Research. 2016;8(3):181-190. doi:10.4168/aair.2016.8.3.181

# Clinical diagnosis and assessment (2/2)



## What is offered as part of the intervention and how has the intervention been implemented in different centres?



**Note:** With input from the steering committee, we have categorised these activities by level of resource required to implement, however this may vary across centres/settings (e.g. depending on existing resources)

### Easy



- Performing a clinical history/examination to rule out differential diagnoses
- Conducting clinical assessment of disease severity (e.g. extent and location of AD [presence on face and hands], intensity of inflammation [i.e. redness])
- Identifying patients who are not responding to treatment (and ensuring this is due to treatment resistance versus e.g. incorrect treatment usage due to miseducation), and require step-up treatment
- Assessing AD impact on patients with informal questioning (e.g. mood, anxiety, sleep) or shorter patient reported outcome (PRO) measures (e.g. Itch NRS)

### Medium



- Performing shorter validated diagnostic criteria assessments (e.g. AAD Diagnosis and Assessment consensus criteria)
- Conducting or referring for additional differential diagnoses tests (e.g. patch tests, IgE, biopsies)
- Conducting shorter validated disease assessment measures (e.g. VSA)
- Assessing AD impact on patients with global PRO measures (e.g. GDA)

### Advanced



- Performing more comprehensive validated diagnostic criteria assessments (e.g. Hanifin and Rajka diagnostic criteria)
- Conducting more comprehensive validated disease assessment measures (e.g. EASI, SCORAD)
- Assessing AD impact on patients with longer PRO measures (e.g. POEM, DLQI)





# Patient education and communication (1/5)

## What is the challenge?

- The complexity of AD and lack of known causes can make it challenging to explain/understand, and patients may have misconceptions about the causative role of allergies<sup>(a)(b)</sup>
- Individual tailoring of information and advice is required as trigger factors and disease course differ, and the fluctuating nature of disease can cause changes over time<sup>(b)</sup>
- Lack of patient education can result in poor adherence (e.g. due to fear of corticosteroids)<sup>(c)</sup>



## Providing education to patients, relatives and care givers, and communicating in a way, that improves their understanding of atopic dermatitis (AD) and how to effectively manage it

### What is the goal/s of the intervention?



- Improve patients' awareness and understanding of AD and its causes
- Support patients to effectively manage their AD and adhere to their personalised treatment regimen
- Ensure patients and relatives have access to reliable sources of information and support
- De-mystify any patient misconceptions regarding disease or treatment
- Ensure patients are involved in their care plan (i.e. shared-decision making)

### Who is often involved in the intervention?



- Dermatologist
- Nurse/medical assistant
- Physician assistant
- Comorbidity specialist (e.g. allergist, pulmonologist)
- Psychosocial professional (e.g. psychologist, psychiatrist)
- Paediatrician
- Clinical pharmacist
- Patient Group
- Primary care practitioner (PCP)
- Trainee dermatologist/medical student

### What are the potential outcomes?



#### Patients

- Improved understanding of AD (including clarification of any misconceptions) that empowers patients to take an active role in the management of their disease
- Acceptance that AD is not their fault (i.e. they are not causing it)
- Better management of their condition and its comorbidities, and involvement in care decisions
- Decreased burden of AD and impact on QoL (through improved understanding, management and support)
- Increased support for caregivers, resulting in higher quality of care provided for the patient at home

#### HCPs

- Reduced demand for HCP time as patients are more empowered to self-manage and their AD is better controlled
- Reduced demand for clinical knowledge from HCPs as patients are able to access the information from alternative reliable resources

#### Healthcare system

- With patients managing their condition more effectively, there is reduced demand on centre services/resources, due to fewer appointments required
- Improved long-term AD disease outcomes<sup>(d)</sup>

Sources: (a) Lee J, et al. A Comprehensive Review of the Treatment of Atopic Eczema. 2016;8(3):181-190;  
 (b) Dhar S, et al. Food allergy in Atopic Dermatitis. Indian J Dermatology. 2016;61(6):645-648. doi: 10.4103/0019-5154.193673;  
 (c) Bieber T. How to Define Atopic Dermatitis? Dermatol Clin. 2017;35(3):275-281;  
 (d) Zuberbier T, et al. Patient perspectives on the management of atopic dermatitis. The Journal of Allergy and Clinical Immunology. 2006;118(1):226-232;

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# Patient education and communication (2/5)



## What is offered as part of the intervention?



### Topics often covered in patient education include:

- AD disease
  - Causes of AD (myths/reality, e.g. genetics versus environment)
  - Recognition of AD burden (by HCP)
  - Chronicity and fluctuating course/nature of AD
  - Allergic (atopy) and non-allergic comorbidities
- Medical management of AD
  - Treatment options (available and upcoming)
  - Treatment application and usage (including amount, frequency, duration and location of body)
  - Treatment outcome expectations
  - Management of flares and infections
  - Potential AD triggers (e.g. in the workplace)
- Non-medical management of AD
  - Recommended care regimen (e.g. regarding hand washing, skin care, cosmetics and emollients)
  - Advice for living with the disease (e.g. management of itch, psychological coping mechanisms)
  - Relaxation techniques (e.g. to help manage itch)
- Additional sources of reliable information or support they can access at the centre or elsewhere (e.g. Patient Group)

### Components of good HCP-patient communication may involve:

- Providing sufficient Q&A opportunity for patients and relatives
- Offering access to different types of HCPs (who they may feel more comfortable asking questions to, or are specialised in different areas)
- Allowing patients to contact HCPs between consultations
- Tailoring language and communication approach to patients' age/health literacy level/culture etc. (e.g. using visual aids to support explanation)
- Involving patients in their care plan decisions (i.e. shared decision making)
- Providing access to materials and information to read in personal time (for both patients and wider patient network e.g. teachers)
- Providing the opportunity for peer-to-peer (patient-patient) exchange (i.e. for patients to share medical/non-medical recommendations with each other from a peer perspective) e.g. via Patient Groups
- Ensuring consistent information and treatments recommended across HCPs/specialties
- Repeating information and education to patients and relatives over multiple consultations
- Enabling convenient access to specialist AD advice and care (i.e. close to home)
- Demonstrating empathy in regards to the impact of AD on a patient's life






# Patient education and communication (3/5)



## How has the intervention been implemented in different centres?



**Note:** With input from the steering committee, we have categorised these activities by level of resource required to implement, however this may vary across centres/settings (e.g. depending on existing resources)

<b>Easy</b> 	<ul style="list-style-type: none"> <li>— Dedicating time within existing consultations to provide patient education (e.g. ~5 mins)</li> <li>— Providing patients with written or online tailored intervention plans (e.g. using a patient information checklist)</li> <li>— Providing written or online educational materials (developed by centre, Patient Groups or third party e.g. treatment manufacturer), which may use visual aids to support understanding (e.g. explain AD skin barrier dysfunction)</li> <li>— Sharing websites or names of organisations (e.g. Patient Groups) where patients can access reliable sources of education and support</li> <li>— Ensuring consistency in communication (e.g. having the same HCP in a patient's consultation, sharing the same information to patients across different departments)</li> <li>— Enabling remote patient Q&amp;A opportunities in-between consultations (e.g. via provision of email address or telephone number)</li> </ul>
<b>Medium</b> 	<ul style="list-style-type: none"> <li>— Co-developing educational materials and treatment protocols/approaches across departments (to ensure consistency of information shared and care approach)</li> <li>— Providing access for patients to be seen by other HCPs and specialists in addition to the physician (e.g. advanced practitioner nurses [ANP], social workers, pharmacists)</li> <li>— Providing joint clinics/consultations with two or more specialists (at same time) for patients to receive information and ask questions</li> <li>— Enabling online Q&amp;A opportunities in-between consultations (e.g. via centre online portal, closed electronic medical record communication tools)</li> <li>— Providing more frequent and/or longer patient consultations (e.g. 45 mins) to assist in delivering information to the patient in person</li> <li>— Photographing (or allowing patients to photograph) and saving images of skin to show patient AD progression overtime</li> <li>— Providing intensive education when AD patients are inpatients</li> <li>— Identifying centres that are providing structured patient education programmes (that patients could be referred to)</li> <li>— Providing 'small-medium scale' group education for patients (e.g. meetings, workshops, forums, schools)</li> </ul> <p>Note: for these to be a 'medium' resource, you may consider them being: standalone/infrequent, with small Patient Groups, limited number of HCPs/different HCP specialities involved, and with a wide age range of patients per group</p>
<b>Advanced</b> 	<ul style="list-style-type: none"> <li>— Developing patient education websites/portals, videos, or mobile phone applications (by centre alone, or in collaboration with Patient Group/manufacturer)</li> <li>— Developing a patient education game (for paediatric patients to play)</li> <li>— Providing 'larger scale' and structured group education for patients (e.g. meetings, workshops, forums, schools)</li> </ul> <p>Note: these may be multi-session/frequent, with large patients groups, and a wider range of HCPs/different HCP specialities involved</p> <ul style="list-style-type: none"> <li>— Identifying or creating 'expert patients' to educate and/or support patients at a peer-to-peer level (e.g. through a centre or Patient Group running a 'train-the-trainer' programme for patients)</li> <li>— Organising general public educational events (i.e. open access not only for AD patients)</li> <li>— Visiting patients at home/care home who are unable to attend consultations at centre</li> <li>— Launching community-based/satellite clinics to provide more convenient means of accessing information for the patient</li> </ul>



# Patient education and communication (4/5)



## Relevant centre case studies



### Providing group education (meetings, workshops, forums, schools)

**AD patient/family workshops**, Hospital Italiano de Buenos Aires, Argentina  
**AD patient educational evenings**, Inselspital (Bern), Switzerland  
**Eczema School**, Aarhus Universitetshospital, Denmark  
**Education for different professionals and the general public**, Hiroshima University Hospital, Japan  
**Interactive support groups**, Medical Dermatology Associates of Chicago, USA  
**Multidisciplinary group based education programme**, UKSH (Kiel), Germany  
**Nurse-led patient education**, Linkou Chang Gung Memorial Hospital (Taipei), Taiwan  
**Allergy Camp**, Dokkyo Medical University Hospital, Japan

**Patient and family education**, Hospital Sant Pau (Barcelona), Spain  
**Patient education groups**, Dermatology Treatment & Research Center (Texas), USA  
**Patient forum**, Linkou Chang Gung Memorial Hospital (Taipei), Taiwan  
**Provision of group therapeutic education**, CHRU Brest, France  
**Transitional processes into adult clinic**, UMC Utrecht, Netherlands  
**Involvement with wider AD community**, Mount Sinai & Icahn School of Medicine (New York), USA  
**Role of biologic coordinator**, Dermatology Treatment & Research Center (Texas), USA  
**Patient education materials**, Hiroshima University Hospital, Japan

### Providing consultations with other HCPs in addition to the physician

**Dermatology Advanced Nurse Practitioner**, UMC Utrecht, Netherlands  
**Enhanced role of the nurse**, UMC Groningen, Netherlands  
**Nurse led 1:1 patient education**, CHRU Brest, France  
**Nurse shared responsibilities**, Aarhus Universitetshospital, Denmark  
**Nurse-led paediatric education session**, Harrogate District Hospital, UK  
**Multi-disciplinary patient education**, Cayre Clinical Center, Colombia

**Provision of therapeutic education**, CH Lyon-Sud, France  
**Role of clinical service coordinator**, Hospital La Paz (Madrid), Spain  
**Role of the Advanced Nurse Practitioner**, Inselspital (Bern), Switzerland  
**Nurse-led education consultations**, Dokkyo Medical University Hospital, Japan  
**Medical assistant-led support**, Dermatology Treatment & Research Center (Texas), USA

### Providing personalised written materials

**Cross department educational print outs**, Linkou Chang Gung Memorial Hospital (Taipei), Taiwan  
**Enhanced role of the nurse**, UMC Groningen, Netherlands  
**Extended HCP-patient consultations**, Mount Sinai & Icahn School of Medicine (New York), USA

**'My Eczema Treatment Plan'**, Royal Devon & Exeter Hospital, UK  
**Patient education materials**, Hiroshima University Hospital, Japan  
**Patient treatment checklist**, M.L.F. Knuckles Dermatology (Kentucky), USA  
**Specialised atopic dermatitis outpatient clinic**, Rabin Medical Centre (Petah Tikva), Israel

### Developing patient educational materials/game

**Improving Atopic Dermatitis Care by Paediatricians (IADCBP)**, Rady Children's Hospital (California), USA  
**Innovative education website ("Leef! Met Eczeem")**, UMC Utrecht, Netherlands  
**Innovative smartphone application: "Zalf"**, UMC Utrecht, Netherlands

**Provision of group therapeutic education (including "Walk of Skin" game)**, CHRU Brest, France  
**'Virtual nurse' mobile device application**, McGill University Health Centre (Montreal), Canada



# Patient education and communication (5/5)

## Relevant centre case studies



### Co-developing educational materials and treatment protocols/approaches across departments

**Cross department educational print outs**, Linkou Chang Gung Memorial Hospital (Taipei), Taiwan

**Ophthalmologist screening appointments**, Hospital La Paz (Madrid), Spain  
**Structured ophthalmology referral pathway**, UMC Groningen, Netherlands

### Creating longer and/or more frequent consultations

**Flexible consultation length and frequency**, M.L.F. Knuckles Dermatology (Kentucky), USA

**Emphasis on patient education**, KFMC, Saudi Arabia

**Longer and frequent consultations**, OHSU Hospital (Oregon), USA  
**More frequent and longer patient appointments**, UKSH (Kiel), Germany

### Offering joint HCP consultations to patients

**Joint psychiatry-dermatology clinics**, CHRU Brest, France  
**Joint psycho-derm clinic**, Royal Devon & Exeter Hospital, UK

**Onsite dermatology psychologist**, Hospital Sant Pau (Barcelona), Spain

### Organising general public educational events

**AD patient committee**, McGill University Health Centre (Montreal), Canada  
**National Eczema Day**, CH Lyon-Sud, France

**Public educational presentations**, UKSH (Kiel), Germany

### Providing intensive education to inpatients

**Extensive inpatient and day care facilities**, Rabin Medical Centre (Petah Tikva), Israel  
**Extensive inpatient facilities**, University of São Paulo Hospital, Brazil

**Inpatient education**, UMC Utrecht, Netherlands

### Visiting patients at home/care home or via community-based/satellite clinics

**Community outreach clinics for rural populations**, Harrogate District Hospital, UK  
**Community outreach consultations**, M.L.F. Knuckles Dermatology (Kentucky), USA

**Specialist Satellite Clinics**, Rady Children's Hospital (California), USA  
**Specialised atopic dermatitis outpatient clinic**, The Jikei University Hospital, Japan

### Photographing (or allowing patients to photograph) and saving images of skin to show patient AD progression overtime

**Communication via the patient portal**, UMC Utrecht, Netherlands  
**Structured patient assessment tool**, UKSH (Kiel), Germany

**Dedicated dermatology photographer**, UMC Groningen, Netherlands

### Identifying or creating 'expert patients'

**Provision of therapeutic education**, CH Lyon-Sud, France



# Coordinated and structured Multidisciplinary Team (MDT) (1/6)

## What is the challenge?

- AD is a complex disease that is associated with multiple comorbidities/conditions, each of which may require specialist help to be diagnosed and managed effectively<sup>(a)</sup>
- If not managed effectively, these associated conditions can also negatively impact AD (e.g. an asthma attack can worsen AD severity)<sup>(b)</sup>
- Due to resource constraints and the expense associated with the provision of multidisciplinary care, it is important for HCPs to appropriately identify which patients require an MDT care approach<sup>(c)</sup>



## Establishing a multidisciplinary team or network to manage complex patients, that follows a structured and coordinated approach to provide holistic patient care

### What is the goal/s of the intervention?



- Facilitate efficient identification and appropriate management of complex AD patients
- Improve cross-specialty collaboration to further advance AD understanding/management and homogenise patient care and communication
- Ensure efficient/quicker access to other specialists for comorbidities

### Who is often involved in the intervention?



- Dermatologist
- Nurse/medical assistant/physician assistant
- Clinical pharmacist
- Comorbidity specialist:
  - Allergist
  - Pulmonologist/pneumologist
  - Ophthalmologist
  - ENT specialist
  - Gastroenterologist
  - Immunologist
- Trainee dermatologist/trainee comorbidity specialist/medical student
- Psychosocial professional:
  - Psychologist
  - Psychiatrist
  - Social worker
- Paediatrician
- Nutritionist/dietician
- Occupational health physician
- Physiotherapist
- Primary care practitioner (PCP)
- Laboratory staff (e.g. researcher, scientist)
- Clinical trial members (e.g. study coordinator/recruiter, epidemiologist)

Sources: (a) Allergy UK and Sanofi Genzyme. Seeing Red: Getting under the skin of adult severe eczema. 2017. [Website] [https://www.allergyuk.org/assets/000/001/411/Seeing\\_Red\\_Report\\_FINAL\\_25.04.17\\_original.pdf?1508228476](https://www.allergyuk.org/assets/000/001/411/Seeing_Red_Report_FINAL_25.04.17_original.pdf?1508228476) Accessed 5 Nov 2019;

(b) Simpson E, et al. Major Comorbidities of Atopic Dermatitis: Beyond Allergic Disorders. 2018;19(6):821-838. doi: 10.1007/s40257-018-0383-4;

(c) LeBovidge J. Multidisciplinary interventions in the management of atopic dermatitis. The Journal of Allergy and Clinical Immunology. 2016;138(2):325-334. doi: 10.1016/j.jaci.2016.04.003

# Coordinated and structured Multidisciplinary Team (MDT) (2/6)

## What are the potential outcomes?



### Patients

- Access to diagnostic tests to assess potential differential diagnoses (e.g. contact dermatitis) and/or associated comorbidities
- Access to specialist multidisciplinary advice/education and faster initiation of required treatments, resulting in more effective management
- Effective coordination between treating HCPs/specialists, therefore reducing travel time and cost burden (e.g. through joint consultations)

### HCPs

- Streamlined referral process between HCPs and specialists allowing for more efficient patient management
- Increased communication between teams for education and knowledge sharing
- Reduced burden on resources if patients are referred to correct department initially or jointly managed across departments

### Healthcare system

- Increased effectiveness of healthcare delivery if complex patient is better managed overtime by streamlined team
- Potential for removal of duplication across specialties/departments (e.g. test results)

## What is offered as part of the intervention?



- Identification of AD triggers and comorbidities
- Efficient access for patients to different specialists for the management of their comorbidities (which may be coordinated by a specific team member e.g. patient manager/care coordinator)
- Co-management of patients and/or input on patient management from different specialties
- Holistic patient education regarding disease understanding and management
- Creation of cross-specialty research projects
- Translation of research into clinical management and access to clinical trials for patients
- Identification of when an MDT or referral to an MDT is needed





# Coordinated and structured Multidisciplinary Team (MDT) (3/6)



## How has the intervention been implemented in different centres?



**Note:** With input from the steering committee, we have categorised these activities by level of resource required to implement, however this may vary across centres/settings (e.g. depending on existing resources)

### Easy



- Assessing any relevant known comorbidities (via electronic health record or informal questioning) in consultations
- Identifying appropriate specialists/departments to refer patients for treatment and/or testing and diagnosis (internally or externally), and consequently establishing communication channels
- Identifying a primary point of contact within the team for AD patients to contact (e.g. via telephone) to triage questions to different team members

### Medium



- Assessing symptoms of typical AD comorbidities (e.g. asthma, allergic rhinitis, food allergy)
- Inviting internal or external specialists to team meetings (e.g. to discuss complex cases, or present on area of specialism)
- Ensuring HCPs (especially new HCPs or trainee dermatologists) are familiar with which specialists are available to refer to within/outside the centre
- Holding multidisciplinary team meetings across specialists within/across centres (e.g. to discuss complex patients, joint research ventures)
- Collaborating in cross-specialty research (within centre)
- Providing cross-specialty training for HCPs (e.g. specialism in dermatology and allergy)
- Enabling shadowing of different atopic condition consultations/clinics across specialists (internally and externally)
- Providing roles where HCPs work across atopic specialties (e.g. physician assistant part-time in allergy and dermatology) to share knowledge across
- Developing cross-specialty assessments and treatment protocols (e.g. ophthalmology evaluation for AD patients)
- Having a staff member who collects, collates and distils relevant information from across treating HCPs (e.g. case notes, test results) to share with treating HCPs

### Advanced



- Conducting joint HCP consultations/multidisciplinary clinics for patients with different specialists (from same or different departments)
- Collaborating in cross-specialty research (across centres)
- Forming cross-specialty units and/or co-location of specialties (e.g. joint dermatology and allergology department) to aid collaboration
- Offering a teleconsultation service (between HCPs within or across centres) to discuss patient cases
- Developing a dedicated 'Case manager/patient coordinator' role in the team to support coordination of patient care
- Delivering cross-specialty Patient Group education events and meetings (from same centre or different centres) to provide cross-specialty education and support to patients
- Integrating research (clinical trials and/or basic science research) teams into clinical management team
- Using computer software that automatically collates and distills relevant information from across specialties/treating HCPs (e.g. case notes, test results)





# Coordinated and structured Multidisciplinary Team (MDT) (4/6)



## Relevant centre case studies



### Internal HCP networks

#### Nurse/medical assistants/physician assistants

**Dermatology Advanced Nurse Practitioner (ANP)**, UMC Utrecht, Netherlands  
**Enhanced role of the nurse**, UMC Groningen, Netherlands  
**Enhanced role of the nurse**, Women's College Hospital (Toronto), Canada  
**Extensive inpatient facilities and Collaboration with comorbidity specialists**, University of São Paulo Hospital, Brazil  
**Healthcare assistant led consultations**, CMSS (Selters), Germany  
**Joint Allergy-Dermatology Physician Assistant**, Rady Children's Hospital (California), USA  
**Multidisciplinary approach to AD care**, McGill University Health Centre (Montreal), Canada  
**Nurse led 1:1 education**, CHRU Brest, France  
**Nurse led chronic disease clinic**, Royal Devon & Exeter Hospital, UK  
**Nurse shared responsibilities**, Aarhus Universitetshospital, Denmark  
**Nurse-led drug monitoring clinic**, Harrogate District Hospital, UK

**Nurse-led education consultations**, Hiroshima University Hospital, Japan  
**Nurse-led patient education**, Linkou Chang Gung Memorial Hospital  
**Prior authorisation nurse role**, OHSU Hospital (Oregon), USA  
**Role of biologic coordinator**, Dermatology Treatment and Research Center (Texas), USA  
**Role of the Advanced Nurse Practitioner (ANP)**, Inselspital (Bern), Switzerland  
**Specialist study nurses**, UKSH (Kiel), Germany  
**Telephone consultations**, Harrogate District Hospital, UK  
**Use of medical assistants**, DermAssociates (Washington), USA  
**Medical assistant-led support**, Dermatology Treatment & Research Center (Texas), USA  
**Co-location of key resources**, KFMC, Saudi Arabia

#### Allergist/laboratory

**24-hour allergy testing**, Hospital La Paz (Madrid), Spain  
**Close dermatology-allergy collaboration**, Hospital Italiano de Buenos Aires, Argentina  
**Collaboration with other specialities**, UniCATT (Rome), Italy  
**Collaboration with specialist allergist**, Hospital Sant Pau (Barcelona), Spain  
**Collaborative comorbidity specialist network**, Mount Sinai & Icahn School of Medicine (New York), USA  
**Onsite allergy testing and pathology collection**, CMSS (Selters), Germany

**Onsite dermatology laboratory**, Inselspital (Bern), Switzerland  
**Specialist dermatology-pathologist testing and diagnosis**, Inselspital (Bern), Switzerland  
**Specialist laboratory testing and interpretation**, UNIMORE (Modena), Italy  
**Comorbidity management**, CH Lyon-Sud, France  
**Specialist in contact allergy**, OHSU Hospital (Oregon), USA  
**Collaborative allergy relationships**, OHSU Hospital (Oregon), USA  
**Centre's own biobank**, UKSH (Kiel), Germany

#### Psychosocial

**Dedicated social worker**, UMC Utrecht, Netherlands  
**Onsite psychologist**, CHRU Brest, France  
**Onsite specialist in psychosomatic medicine and psychotherapy**, UKSH (Kiel), Germany

**Paediatric and adult psychological support**, University of São Paulo Hospital, Brazil  
**Provision of psychological care**, UNIMORE (Modena), Italy  
**Psycho-social care network**, UMC Groningen, Netherlands



# Coordinated and structured Multidisciplinary Team (MDT) (5/6)

## Relevant centre case studies



### Internal HCP networks

#### Ophthalmology

**Collaboration with comorbidity specialists**, Rabin Medical Centre (Petah Tikva), Israel  
**Ophthalmologist screening appointments**, Hospital La Paz (Madrid), Spain  
**Specialised ophthalmology consultations**, Hospital Sant Pau (Barcelona), Spain  
**Structured ophthalmology referral pathway**, UMC Groningen, Netherlands

**Established ophthalmologist working relationship**, UMC Utrecht, Netherlands  
**Ophthalmology-dermatology collaboration**, Inselspital (Bern), Switzerland  
**Collaboration with comorbidity specialists**, University of São Paulo Hospital, Brazil  
**Established ophthalmologist working relationship**, OHSU Hospital (Oregon), USA

#### Occupational health physician

**AD occupational training and advice**, UNIMORE (Modena), Italy  
**Role of occupational health physician**, Aarhus Universitetshospital, Denmark

**Role of occupational health physician**, UMC Groningen, Netherlands

#### Pharmacist

**Supportive role of the pharmacist**, Hospital Sant Pau (Barcelona), Spain

**Multidisciplinary approach to patient education**, The Jikei University Hospital, Japan

#### Dietician

**Role of the dietician**, UMC Groningen, Netherlands

### Conducting joint consultations/multidisciplinary clinics

**Allergy centre comorbidity clinic**, Aarhus Universitetshospital, Denmark  
**Joint paediatric dermatology-allergy clinic**, Royal Devon & Exeter Hospital, UK  
**Joint psychiatry-dermatology clinics**, CHRU Brest, France

**Multidisciplinary Atopic Dermatitis Program (MADP)**, Rady Children's Hospital (California), USA  
**Onsite dermatology psychologist**, Hospital Sant Pau (Barcelona), Spain  
**Psycho-derm clinic**, Royal Devon & Exeter Hospital, UK

### Forming cross-specialty units and/or co-location of specialties

**Allergy Centre**, Dokkyo Medical University Hospital, Japan  
**Allergy Centre**, The Jikei University Hospital, Japan (Allergy Centre in development)  
**Chicago Integrative Eczema Centre**, Medical Dermatology Associates of Chicago, USA  
**Coordination of AD care by allergologist**, UNIMORE (Modena), Italy  
**Established dermo-allergy unit**, Hospital La Paz (Madrid), Spain

**Transitional processes into adult clinic**, UMC Utrecht, Netherlands  
**Specialised atopic dermatitis outpatient clinic**, The Jikei University Hospital, Japan  
**In-house contact dermatitis clinic**, Mount Sinai & Icahn School of Medicine (New York), USA  
**Active clinical trials department**, Mount Sinai & Icahn School of Medicine (New York), USA



# Coordinated and structured Multidisciplinary Team (MDT) (6/6)

## Relevant centre case studies



### External HCP networks

**Centre Expert Eczema Network Auvergne Rhone Alpes**, CH Lyon-Sud, France  
**Collaboration with other specialties**, UniCATT (Rome), Italy  
**Comorbidity specialist network**, DermAssociates (Washington), USA

**Established specialist network**, Medical Dermatology Associates of Chicago, USA  
**Referral to co-morbidity specialists**, M.L.F. Knuckles Dermatology (Kentucky), USA

### HCPs working across specialties

**Integrated dermatology-allergy specialists**, UMC Utrecht, Netherlands  
**Joint Allergy-Dermatology physician assistant**, Rady Children's Hospital (California), USA

**Multidisciplinary dermatology and allergy & immunology collaborative fellowship program**, Rady Children's Hospital (California), USA

### Offering a teleconsultation service (between specialties/departments within or across centre)

**Improving Atopic Dermatitis Care by Paediatricians (IADCBP)**, Rady Children's Hospital (California), USA  
**MedPhone application**, CH Lyon-Sud, France

**Teledermatology service**, Royal Devon & Exeter Hospital, UK  
**Teledermatology services**, Rady Children's Hospital (California), USA

### Delivering cross-specialty Patient Group education events and meetings

**AD Patient education evenings**, Inselspital (Bern), Switzerland

**Multidisciplinary group based patient education programme**, UKSH (Kiel), Germany

### Cross-specialty research collaboration

**Research expertise and integration**, CH Lyon-Sud, France

### Developing a dedicated 'Case manager'/patient coordinator

**Role of clinical service coordinator**, Hospital La Paz (Madrid), Spain



# Monitoring & evaluating care quality (1/3)

## What is the challenge?

- Healthcare systems are under pressure to maintain or improve standards of care with depleting resources<sup>(a)</sup>
- There is a lack of an established quality benchmark, hence requiring centres to establish their own goals
- Low quality of care may result in poor patient satisfaction and potentially impact patient outcomes<sup>(b)</sup>



## Performing regular monitoring and evaluation of AD care quality at centre and amongst wider network

### What is the goal/s of the intervention?



- Ensure centres are consistently identifying and addressing areas/gaps to maintain and improve their quality of AD care
- Streamline usage of resources through a systemic approach to evaluating care and identifying what needs improvement
- Facilitate identification of leading industry practices and interventions through standardised metrics to assess patient care across multiple centres
- Greater confidence felt by patients towards the care provided by AD centres

### Who is often involved in the intervention?



- Department head/Lead physician
- Quality manager (if present at centre)
- Patient
- Healthcare system
- Physician
- Nurse
- Administrative staff

### What are the potential outcomes?



#### Patients

- Opportunity to provide input into care experience
- Improvement in quality of care received through centre addressing areas of need
- Greater confidence in the processes that inform the level and type of care provided

addressed to improve patient outcomes, patient satisfaction, care efficiency etc.

- Ability to assess consistency of care delivered across HCPs

#### Healthcare system

- Awareness of areas of care that could be addressed to improve patient outcomes, patient satisfaction, care efficiency etc.
- Ensuring consistency in appropriate standards of care across centres

#### HCPs

- Ongoing ability to identify areas of care that could be

Sources: (a) Understanding NHS financial pressures: How are they affecting patient care? The King's Fund. [PDF] [https://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/Understanding%20NHS%20financial%20pressures%20-%20full%20report.pdf](https://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/Understanding%20NHS%20financial%20pressures%20-%20full%20report.pdf) Accessed 5 Nov 2019;

(b) Public satisfaction with the NHS in 2015. The King's Fund [Website] <https://www.kingsfund.org.uk/publications/public-satisfaction-nhs-2015> Accessed 22 Oct 2019



# Monitoring & evaluating care quality (2/3)



## What is offered as part of the intervention and how has the intervention been implemented in different centres?



**Note:** With input from the steering committee, we have categorised these activities by level of resource required to implement, however this may vary across centres/settings (e.g. depending on existing resources)

### Easy



- Undertaking a manual capture and analysis of patient outcomes (e.g. via excel)
- Defining goals of care as a team (structure, process and outcome measures) and ways to measure/capture these
  - This may involve collection of quantitative measures (e.g. scoring indices, PROs, IgE) and qualitative measures (e.g. patient satisfaction)
- Performing patient surveys before and/or after outpatient consultations (e.g. via paper, iPad)

### Medium



- Participating in cross-centre quality evaluation, involving a mail questionnaire or online survey assessing patient experiences
- Designing a bespoke online database enabling the consistent collection and storage of patient data (e.g. EASI/SCORAD scores) in a format that can be easily analysed
- Bringing together groups of HCPs to review patient care case studies to assess care approach
- Designating dedicated human resources to monitor and evaluate data collection
- Designing a dynamic process to allow for ongoing quality improvement/assessment/evaluation

### Advanced



- Developing a dashboard which demonstrates quality of care through integration of electronic medical records and quality indicators
- Creating automated pop-up alerts and notifications on PCP computers when prescribing certain dermatological medication that may suggest alternative treatments and allows tracking by centre
- Inviting external professional/body etc. to perform an external audit of service



# Monitoring & evaluating care quality (3/3)

## Relevant centre case studies



### Development of online patient databases

**Structured patient assessment tool**, UKSH (Kiel), Germany

**Centre's own biobank**, UKSH (Kiel), Germany

**Registry of patients with severe AD**, Linkou Chang Gung Memorial Hospital (Taipei), Taiwan

### Monitoring PCP prescribing

**Frequent advice for primary care professionals**, Harrogate District Hospital, UK

### Participating in cross-centre quality evaluation/performing patient surveys

**Clinical internal audits**, UMC Utrecht, Netherlands

### Monitoring and evaluating care quality

**Monitoring patient quality of care**, KFMC, Saudi Arabia



# Collaboration & exchange with Patient Groups (1/3)

## What is the challenge?

- Low public awareness and public investment in AD can negatively impact care received by AD patients<sup>(a)</sup>
- Patient Groups can help support public campaigns and policies to improve treatment and care. Broadly, Patient Groups can work with key stakeholders (e.g. government institutions/expert panels) to represent, advocate and support patient-centric solutions<sup>(b)</sup>



## Working collaboratively and exchanging information with Patient Groups on activities and initiatives aimed at improving AD management, care access and patient QoL



### What is the goal/s of the intervention?



- Improve the management of AD patients and QoL
- Raise awareness of the burden of AD and recognition of it as a 'real' disease (i.e. because it has a dedicated Patient Group)
- Advance understanding of AD disease and treatment
- Improve access to care for AD patients
- Ensure centre activities (e.g. research, education) understand and incorporate the patient voice/needs

### Who is often involved in the intervention?



- Patient Group
- Dermatologist
- Nurse/medical assistant
- Comorbidity specialist (e.g. allergist)
- Paediatrician
- Primary care practitioner (PCP)

### What are the potential outcomes?



#### Patients

- Access to additional resources and support from the Patient Group (in addition to care provided by the centre)
- Opportunity to build peer-to-peer networks and share experiences/learnings of living with AD
- Increased awareness of the burden of AD amongst HCPs, general public, payers etc. through Patient Group and collaborative Patient Group-centre activities

#### HCPs

- Effective 'outsourcing' of support to Patient Group and other patients, who have greater practical and personal knowledge of living day-to-day with AD
- Improved engagement of patients leading to improved adherence to treatment plans

- Ability to obtain direct input into the design and implementation of activities or materials from patients (e.g. for research and patient education)
- Access to patients (via Patient Group referrals) who may not have otherwise accessed care (i.e. self-managing)

#### Patient Groups

- Access to expert support from HCPs (e.g. for material development, grant applications)
- Increase awareness of Patient Group/patient numbers and diversity, through centres raising awareness

#### Healthcare system

- Potential cost-reduction through improved patient self-management and access to care (via Patient Group signposting/recommendations)

Sources: (a) International Alliance of Dermatology Patient Organizations. Atopic Dermatitis: A collective Global Voice for Improving Care [PDF] <https://globalskin.org/images/Publications/AtopicDermatitis.pdf> Accessed 1 Oct 2019;

(b) European Patients Forum, European Union. The Added Value of Patient Organisations 2017 [Website] [https://webcache.googleusercontent.com/search?q=cache:w6FWqw\\_zRngJ:https://www.eu-patient.eu/globalassets/library/publications/epf\\_added\\_value\\_report-final.pdf+&cd=10&hl=en&ct=clink&gl=uk](https://webcache.googleusercontent.com/search?q=cache:w6FWqw_zRngJ:https://www.eu-patient.eu/globalassets/library/publications/epf_added_value_report-final.pdf+&cd=10&hl=en&ct=clink&gl=uk) Accessed 5 Nov 2019

# Collaboration & exchange with Patient Groups (2/3)



## What is offered as part of the intervention and how has it been implemented in different centres?



**Note:** With input from the steering committee, we have categorised these activities by level of resource required to implement, however this may vary across centres/settings (e.g. depending on existing resources)

### Easy



- Centres directing patients to the patient advocacy groups (PAGs) for additional support and education
- Patient Groups referring patients to local AD specialists (who they collaborate with) for diagnosis and management (i.e. signposting AD specialists)

### Medium



- Co-creating a webpage of expert answers, incorporating patient FAQs and comprehensive expert responses
- Co-developing therapeutic patient education materials for them to mutually distribute to patients
- Co-creating a map of national AD specialists within country for Patient Group to share with patients who are unable to locate a specialist
- Centre HCPs sitting on the advisory board of Patient Groups/providing strategic guidance
- Co-running of AD support, education and focus groups for patients and their families
- Patient Group representative sitting on the Scientific Board of national AD registry (that the centre is participating in)
- Co-developing and delivering HCP AD training events
- Co-organising local events with HCPs and Patient Groups to discuss the latest AD research and share Patient Group initiatives

### Advanced



- Collaboration on research conducted on lesser known areas of research relating to AD
- Patient Group informing revision of national AD protocols and guidelines
- Patient Group informing AD trial design hosted at centre
- Co-development of patient smartphone application which educates patients on ointment application and provides step down regimes for steroid use
- Centre HCPs supporting formation (or forming) of Patient Group
- Co-organising additional holistic wellbeing activities (e.g. yoga, hiking, make-up workshops)





# Collaboration & exchange with Patient Groups (3/3)

## Relevant case studies



### Access and-development of resources for patient education

**Collaboration with ANDeA**, UNIMORE (Modena), Italy/UniCATT (Rome), Italy

**Innovative smartphone application: “Zalf”**, UMC Utrecht, Netherlands

**Working with Asociación Civil de Dermatitis Atópica Argentina (ADAR)**, Hospital Italiano de Buenos Aires, Argentina

**Working with the Brazilian Atopic Dermatitis Association (AADA)**, University of São Paulo Hospital, Brazil

**Working with the Eczema Society of Canada**, Women’s College Hospital (Toronto), Canada

**Working with the patient advocacy group (aha! Swizz Allergy Centre)**, Inselspital (Bern), Switzerland

**Involvement with wider AD community**, Mount Sinai & Icahn School of Medicine (New York), USA

### Collaboration on research

**Working in combination with the PAG**, CHRU Brest, France

**Working with the Eczema Society of Canada**, Women’s College Hospital (Toronto), Canada

**Working with the VMCE**, UMC Utrecht, Netherlands/UMC Groningen, Netherlands

### Co-running of AD support, education and focus groups

**National Eczema Day**, CH Lyon-Sud, France

**Working with the VMCE**, UMC Utrecht, Netherlands/UMC Groningen, Netherlands

**Working with the NEA**, OHSU Hospital (Oregon), USA/Medical Dermatology Associates of Chicago, USA

### Centre formation of Patient Group/Centre HCPs sitting on the advisory board

**Setting up patient association**, Linkou Chang Gung Memorial Hospital (Taipei), Taiwan

**Working with the NEA**, OHSU Hospital (Oregon), USA

**Working with the VMCE**, UMC Utrecht, Netherlands/UMC Groningen, Netherlands

**Working with the PAG**, CH Lyon-Sud, France

### Co-delivery of HCP AD education (e.g. through symposiums)

**Working with the patient advocacy group (aha! Swizz Allergy Centre)**, Inselspital (Bern), Switzerland

**Working with the VMCE**, UMC Utrecht, Netherlands/UMC Groningen, Netherlands

### Co-revision of national AD protocols and guidelines

**Working with the VMCE**, UMC Utrecht, Netherlands/UMC Groningen, Netherlands

### Establishment of AD specialist referral maps

**Working with the AADA**, Hospital Sant Pau (Barcelona), Spain/Hospital La Paz (Madrid), Spain



# Providing psychosocial support (1/4)

## What is the challenge?

- AD has been associated with a number of mental health conditions, including depression and anxiety<sup>(a)</sup>
- Even if not manifesting into a clinical diagnosis, the burden associated with AD (e.g. due to stigma, access to treatment, travel to consultations) can negatively impact patients' wellbeing, who may benefit from psychosocial support<sup>(b)</sup>



## Enabling access to psychosocial support to help patients manage the burden and impact of AD on their psychological, emotional and social wellbeing

### What is the goal/s of the intervention?



- Reduce the burden and impact of having AD on patients, and promote better adherence to treatment
- Empower patients with the opportunity to self-manage the psychological aspects of their disease
- Enhance the QoL for AD patients, by addressing problems such as stigma and bullying
- Provide holistic support to patients across multiple aspects of daily life, such as managing the impact of AD on sleep and occupation

### Who is often involved in the intervention?



- Dermatologist
- Nurse/medical assistant
- Psychologist
- Social worker
- Psychiatrist
- Physiotherapist
- Patient Group
- Primary care practitioner (PCP)
- Occupational health physician

### What are the potential outcomes?



#### Patients

- Recognition of psychosocial impact of AD and early identification of psychological comorbidities, resulting in improved self/HCP management
- Access to a network of peers, providing the opportunity to share experiences
- Increased public and professional awareness of the stigma experienced by patients with visible skin diseases
- Reduction in physical manifestations that result from low psychosocial management, such as stress, scratching and unhelpful coping mechanisms

#### HCPs

- Improved knowledge regarding psychosocial burden and correct management
- Reduced burden for HCPs through patients better self-managing their disease

#### Healthcare system

- Potential prevention of worsening of associated mental health complications that arise and may impact other areas of care<sup>(c)</sup>

Sources: (a) Slattery MJ, et al. Depression, anxiety, and dermatologic quality of life in adolescents with atopic dermatitis. J Allergy Clin Immunol. 2011;128(3):668–671. doi:10.1016/j.jaci.2011.05.003;  
 (b) Zuberbier T, et al. Patient perspectives on the management of atopic dermatitis. Journal of Allergy and Clinical Immunology. 2006; 118(1):226-32;  
 (c) Spielmanman S, et al. A review of multidisciplinary interventions in Atopic Dermatitis. Journal of Clinical medicine. 2015;4(5):1156-1170. doi: 10.3390/jcm4051156

# Providing psychosocial support (2/4)

## What is offered as part of the intervention?



- Assessing impact of AD on a patient's psychosocial wellbeing
- Providing psychological/emotional support:
  - Talking therapy (e.g. Cognitive Behavioural Therapy [CBT], Short-term Scheme Therapy)
  - Habit reversal techniques
  - Access to medication (e.g. antidepressants)
  - Sleep/relaxation techniques
  - Managing impact on personal relationships (e.g. providing couple's counselling)
- Providing social support with:
  - Housing
  - Employment
  - Finances
  - Access to treatment (e.g. prior authorisation with insurance companies)
- Triaging of patients to other psychosocial professionals (depending on needs)
- Providing access to peer-to-peer support (i.e. from other AD patients) via group education or Patient Groups



# Providing psychosocial support (3/4)



## How has the intervention been implemented in different centres?



**Note:** With input from the steering committee, we have categorised these activities by level of resource required to implement, and whether they are likely to be delivered by all HCPS or psychosocial professionals specifically. The level of resources required may vary across centres/settings (e.g. depending on existing resources)

	All HCPs	Psychosocial professional (specifically)
<b>Easy</b>	<ul style="list-style-type: none"> <li>Assessing patients' wellbeing during standard consultations with informal questioning (e.g. mood, anxiety, sleep) and identifying patients in need of psychosocial support</li> <li>Identifying psychosocial specialist/department to refer patients to and/or receive guidance from (e.g. via telephone or email) at centre or externally, regarding provision of management</li> <li>Recognising burden of AD and impact on patient QoL in consultations</li> <li>Directing patients to peer-to-peer support groups at centre or externally (e.g. by Patient Groups)</li> </ul>	<ul style="list-style-type: none"> <li>n/a</li> </ul>
<b>Medium</b>	<ul style="list-style-type: none"> <li>Using validated PRO measures (e.g. DLQI) to screen or assess patient outcomes</li> <li>Establishing specialist nurses (e.g. Advanced Nurse Practitioners (ANPs), study nurses) who are able to provide longer and more frequent 1:1 consultations to discuss psychosocial burden with patients</li> <li>Having physicians and nurses attend training to increase awareness of psychosocial impact of AD</li> <li>Providing patient group education (for peer-to-peer support)</li> </ul>	<ul style="list-style-type: none"> <li>Providing 1:1 patient consultations at centre, or joint consultations in collaboration with a AD specialist (i.e. patient would see dermatologist and psychologist in the same consultation)</li> <li>Attending multidisciplinary team (MDT) meetings to provide specialist psychosocial advice and review case studies</li> <li>Co-delivering patient group education (with other HCPs, to provide psychosocial related information/support)</li> </ul>
<b>Advanced</b>	<ul style="list-style-type: none"> <li>Creating the role of patient coordinator/case manager to support patients with the psychosocial burden</li> <li>Conducting research to raise awareness of stigma associated with AD</li> <li>Recommending interventions (e.g. mobile phone applications, music therapy) to support patients with relaxation, management of itch</li> </ul>	<ul style="list-style-type: none"> <li>Developing education programmes for HCPs regarding provision of psychosocial support</li> <li>Developing interventions (e.g. mobile phone applications, music therapy) to support patients with relaxation and management of itch</li> </ul>



# Providing psychosocial support (4/4)

## Relevant centre case studies



### Providing access to psychosocial professionals

**Dedicated social worker**, UMC Utrecht, Netherlands  
**Joint psychiatry-dermatology clinics**, CHRU Brest, France  
**Onsite dermatology psychologist**, Hospital Sant Pau (Barcelona), Spain  
**Onsite psychologist**, CHRU Brest, France  
**Onsite specialist in psychosomatic medicine and psychotherapy**, UKSH (Kiel), Germany  
**Patient psychological support**, University of São Paulo Hospital, Brazil  
**Prior authorisation nurse role**, OHSU Hospital (Oregon), USA

**Provision of psychological care**, UNIMORE (Modena), Italy  
**Psycho-derm clinic**, Royal Devon & Exeter Hospital, UK  
**Psycho-social care network**, UMC Groningen, Netherlands  
**Role of clinical service coordinator**, Hospital La Paz (Madrid), Spain  
**Role of the occupational health physician**, Aarhus Universitetshospital, Denmark  
**Comorbidity management**, CH Lyon-Sud, France  
**Psychological support**, Cayre Clinical Center, Colombia

### Providing patient group education (for peer-to-peer support)

**AD patient educational evenings**, Inselspital (Bern), Switzerland  
**Eczema School**, Aarhus Universitetshospital, Denmark  
**Interactive support groups**, Medical Dermatology Associates of Chicago, USA  
**Multidisciplinary group based education programme**, UKSH (Kiel), Germany  
**Nurse-led patient education**, Linkou Chang Gung Memorial Hospital (Taipei), Taiwan

**Allergy Camp**, Dokkyo Medical University Hospital, Japan  
**Patient/family educational workshops**, Hospital La Paz (Madrid), Spain  
**Patient and family education**, Hospital Sant Pau (Barcelona), Spain  
**Patient forum**, Linkou Chang Gung Memorial Hospital (Taipei), Taiwan  
**Provision of group therapeutic education**, CHRU Brest, France

### Establishing specialist nurses (e.g. Advanced Nurse Practitioners (ANPs), study nurses) who are able to provide longer and more frequent 1:1 consultations

**Dermatology Advanced Nurse Practitioner (ANP)**, UMC Utrecht, Netherlands  
**Enhanced role of the nurse**, UMC Groningen, Netherlands  
**Enhanced role of the nurse**, Women's College Hospital (Toronto), Canada

**Nurse shared responsibilities**, Aarhus Universitetshospital, Denmark  
**Role of the Advanced Nurse Practitioner (ANP)**, Inselspital (Bern), Switzerland  
**Specialist study nurses**, UKSH (Kiel), Germany

### Developing interventions to support patient's with relaxation, management of itch etc.

**Music therapy trial**, CHRU Brest, France  
**Physiotherapist relaxation and mobile app**, Inselspital (Bern), Switzerland

**Provision of group therapeutic education, including "Walk of Skin" game**, CHRU Brest, France

### Conducting research to raise awareness of stigma associated with AD

**Involvement in anti-stigmatisation study**, CMSS (Selters), Germany

**Involvement in anti-stigmatisation study**, UKSH (Kiel), Germany

### Using validated PRO measures (e.g. DLQI) to screen or assess patient outcomes

**Bespoke patient reported outcome (PRO) assessment**, OHSU Hospital (Oregon), USA

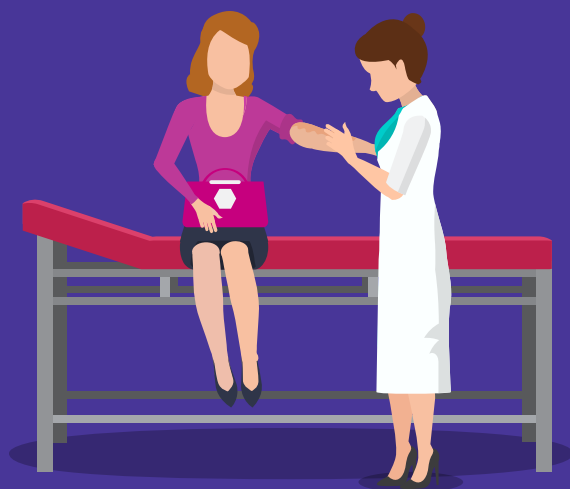
**Structured patient assessment tool**, UKSH (Kiel), Germany



# Sharing care of patients (1/3)

## What is the challenge?

- Due to resource constraints, physicians often have limited time they are able to spend in consultations with patients<sup>(a)</sup>
- Other healthcare professionals (HCPs) such as nurses, can play a key role in the management of AD patients and can be more cost effective in delivering similar patient outcomes and higher patient satisfaction<sup>(a)</sup>



## Empowering and enabling other team members (e.g. nurses, physician assistants, pharmacists) to support physicians with AD patient education and management, for more effective and efficient care delivery

### What is the goal/s of the intervention?



- Enable quicker/more frequent access to the care team
- Provide patients with an additional HCP to give support and answer questions regarding management (that they may feel more comfortable engaging with e.g. asking questions)
- Expand the role of other team members to reduce the burden on the physicians

### Who is often involved in the intervention?



Note: in both primary care and secondary/tertiary care

- Nurse
- Medical assistant
- Physician assistant
- Pharmacist

### What are the potential outcomes?



#### Patients

- Access to additional 1:1 time with a HCP for personalised discussion and support
- Opportunity to engage with another HCP who patients may feel more comfortable discussing/raising concerns and questions to (versus a physician)
- Access to cross-specialty knowledge (e.g. if HCP works across departments)

#### HCPs

- Other team members feel empowered and highly valued by the patients
- Sharing of physician workload with the other team members (which is both time and cost-efficient)
- Upskilling of other team members through patient care experience (in addition to any formal training to perform role)

#### Healthcare system

- More cost-efficient delivery of patient care with similar or improved patient outcomes<sup>(b)</sup>

Sources: (a) Mehta S. Patient Satisfaction reporting and its implications for patient care. AMA Journal of Ethics. 2015 [Website] <https://journalofethics.ama-assn.org/article/patient-satisfaction-reporting-and-its-implications-patient-care/2015-07> Accessed 5 Nov 2019;  
(b) Schuttelaar ML, et al. Costs and cost-effectiveness analysis of treatment in children with eczema by nurse practitioner vs. dermatologist: results of a randomized, controlled trial and a review of international costs. Br J Dermatol. 2011;165(3):600-11

# Sharing care of patients (2/3)

## What is offered as part of the intervention and how has it been implemented in different centres?



**Note:** With input from the steering committee, we have categorised these activities by level of resource required to implement, however this may vary across centres/settings (e.g. depending on existing resources)

### Easy



- Supporting coordination of patient consultations (especially for complex patients)
- Locating a patient's electronic medical record or referral notes ahead of first physician consultation
- Collecting patient information and family history before physician consultation (and presenting information to physician)
- Providing brief education following physician consultations (e.g. disease education, demonstration of treatment application, reviewing treatment plan) (~15 mins)
- Performing AD scoring indices or patient reported outcomes (PROs) before/after or during consultations
- Triageing patient questions received from patients (via telephone, email or online portal) to relevant HCP
- Sharing information about additional support options (e.g. community HCPs, Patient Groups) within or outside consultations
- Attending team meetings (i.e. being integrated into the team for discussion of patients)

### Medium



- Providing telephone consultations for patients
- Providing in-depth education following physician consultations (e.g. disease education, demonstration of treatment application, reviewing treatment plan) (~30-45 mins)
- Performing 1:1 or joint consultation (with physician) with patients, as main HCP contact (~30-45 mins)
- Running specialist AD clinics (e.g. drug-monitoring clinic)
- Collating patient information from cross-specialty consultations (and presenting information to physician and/or team meetings)
- Performing allergy testing and education (patch test or prick test)
- Developing patient education materials (online or paper-based)

### Advanced



- Developing a mobile phone application for education of patients
- Designing and running Patient Group education/panels
- Involvement in the setup of Patient Groups and member of advisory boards
- Managing prior authorisation process of treatment for dermatology patients
- Organising and delivering HCP education (for nurses and PCPs)
- Prescribing treatment and/or creating treatment plans (where allowed)



# Sharing care of patients (3/3)

## Relevant centre case studies



### 1:1 or joint consultations with nurses/medical assistants

**Dermatology Advanced Nurse Practitioner (ANP)**, UMC Utrecht, Netherlands  
**Enhanced role of the nurse**, UMC Groningen, Netherlands  
**Enhanced role of the nurse**, Women's College Hospital (Toronto), Canada  
**Healthcare assistant led consultations**, CMSS (Selters), Germany  
**Medical assistant led consultations**, Dermatology Treatment & Research Center (Texas), USA  
**Nurse led 1:1 education**, CHRU Brest, France  
**Nurse led chronic disease clinic**, Royal Devon & Exeter Hospital, UK  
**Nurse shared responsibilities**, Aarhus Universitetshospital, Denmark

**Nurse-led drug monitoring clinic**, Harrogate District Hospital, UK  
**Nurse-led education consultations**, Hiroshima University Hospital, Japan  
**Nurse-led patient education**, Linkou Chang Gung Memorial Hospital (Taipei), Taiwan  
**Role of the Advanced Nurse Practitioner (ANP)**, Inselspital (Bern), Switzerland  
**Specialist study nurses**, UKSH (Kiel), Germany  
**Telephone consultations**, Harrogate District Hospital, UK  
**Use of medical assistants**, DermAssociates (Washington), USA  
**Medical assistant-led support**, Dermatology Treatment & Research Center (Texas), USA

### Designing and running Patient Group education/panels

**AD patient educational evenings**, Inselspital (Bern), Switzerland  
**Innovative smartphone application: "Zalf"**, UMC Utrecht, Netherlands

**Provision of group therapeutic education, including "Walk of Skin" game**, CHRU Brest, France

### Pharmacists

**Multidisciplinary approach to patient education**, The Jikei University Hospital, Japan

**Supportive role of the pharmacist**, Hospital Sant Pau (Barcelona), Spain

### Physician assistants

**Joint Allergy-Dermatology Physician Assistant**, Rady Children's Hospital (California), USA

**Prior authorisation nurse role**, OHSU Hospital (Oregon), USA

### Organising and delivering HCP education

**HCP education (including nurse platform)**, UMC Utrecht, Netherlands  
**Role of the Advanced Nurse Practitioner (ANP)**, Inselspital (Bern), Switzerland

**Role of biologic coordinator**, Dermatology Treatment & Research Center (Texas), USA





# Supporting healthcare professional (HCP) education (1/5)

## What is the challenge?

- AD can be a complex condition for HCPs to manage e.g. due to its fluctuating nature and associated conditions<sup>(a)</sup>
- High volumes of dermatology patients are often managed in primary care, by professionals who have relatively low levels of dermatology education in their training programmes<sup>(b)</sup>
- Healthcare professionals also play a vital role in educating patients. It is therefore important they understand how best to do this<sup>(c)</sup>



## Delivering, facilitating or enabling education for healthcare professionals (HCPs) involved in the care of AD patients directly or indirectly regarding recommended management approach

### What is the goal/s of the intervention?



- Improve HCPs' understanding of AD and recommended management approach
- Ensure HCPs are aware of when to refer AD patients to specialists
- Empower HCPs to manage AD patients within their centres (where appropriate for the patient)

### Who is often involved in the intervention?



Note: the same type of HCPs may be involved in both the delivery and receiving of education

- Dermatologist
- Comorbidity specialist (e.g. allergist, pulmonologist, ophthalmologist)
- Paediatrician
- Primary Care Practitioner (PCP)
- Trainee dermatologist/trainee comorbidity specialist/medical student
- Nurse/medical assistant/physician assistant
- Clinical Pharmacist
- Psychosocial professional (e.g. psychologist, psychiatrist, social worker)
- Patient Group/Medical society (provision only)

### What are the potential outcomes?



#### Patients

- Improved management of AD by HCPs resulting in better disease outcomes (e.g. reduced likelihood of hospitalisation) and potentially decreased travel burden (if care can be provided closer to patient's home through a PCP who has received AD-specific education)
- Quicker referral to secondary and specialist care (where required)
- Access provided to more detailed and informed AD education that can be provided by more HCPs

#### HCPs

- Sharing of specialist knowledge between HCPs
- Improved management of patients and their symptoms, reducing the demand on clinic resources
- Reduction in unnecessary referrals to HCPs in secondary care if PCPs can confidently manage AD patient, therefore alleviating capacity (e.g. consultation availability and physical resources)

#### Healthcare system

- Potential cost-efficiencies if treatment can remain in primary/secondary care without having to be referred to specialist<sup>(d)</sup>

Sources: (a) Allergy UK and Sanofi Genzyme. Seeing Red: Getting under the skin of adult severe eczema. 2017 [Website] [https://www.allergyuk.org/assets/000/001/411/Seeing\\_Red\\_Report\\_FINAL\\_25.04.17\\_original.pdf?1508228476](https://www.allergyuk.org/assets/000/001/411/Seeing_Red_Report_FINAL_25.04.17_original.pdf?1508228476) Accessed 5 Nov 2019;

(b) Kownacki S. Skin diseases in primary care: what should GPs be doing? Br J Gen Pract. 2014;64(625):380–381. doi:10.3399/bjgp14X680773;

(c) Choumane N, et al. A multicenter, prospective study evaluating the impact of the clinical pharmacist-physician counselling on warfarin therapy management in Lebanon. 2018;18(1):80. doi: 10.1186/s12913-018-2874-7;

(d) TELEDERM®. The MOLE clinic [Website] <http://www.telederm.uk.com/> Accessed 5 Nov 2019

# Supporting healthcare professional (HCP) education (2/5)

## What is offered as part of the intervention?



### Topics often covered in HCP education include:

- Information on AD as a disease
  - Causes and burden of AD
  - Allergic (atopy) and non-allergic comorbidities
- Diagnosis and categorisation of AD and comorbidities
  - Clinical symptoms
  - Indication of allergy tests (e.g. IgE, patch, skin prick)
  - Scoring indices
- Referral of patients (i.e. when, who and how to refer)
  - For AD and comorbidities
- Medical management of AD
  - Treatment guidelines/options (available and upcoming)
  - Treatment application and usage (including amount, frequency, duration and location of body)
  - Management of flares, infections and triggers
  - Patient case studies (e.g. complex cases)
- Non-medical management of AD
  - Recommended care regimen (e.g. hygiene advice, nutrition, wet wrapping)
  - Advice for living with the disease (e.g. psychological coping mechanisms, management of itch)
  - Additional sources of reliable information or support patients can access at the centre or elsewhere (e.g. Patient Advocacy Groups (PAGs))
- Education approach for AD patients, parents and care givers (e.g. how to educate, what to educate on)



# Supporting healthcare professional (HCP) education (3/5)



## How has the intervention been implemented in different centres?



**Note:** With input from the steering committee, we have categorised these activities by level of resource required to implement and whether these would be educational activities delivered or performed by AD specialists for non-AD specialists (e.g. primary care practitioners, general dermatologists, dermatology nurses, AD specialists or both (non-AD specialist and specialist). The level of resource may vary across centres/settings (e.g. depending on existing resources)

	Non-AD specialist	AD specialist	Both
<b>Easy</b>	<ul style="list-style-type: none"> <li>Providing educational materials about AD to non-AD specialists</li> <li>Providing formal or informal specialist contact within own centre to ask management questions to (e.g. via telephone or email)</li> <li>Incorporating management advice and recommendation into referral letters/discussions and/or when providing test results for internal and external HCPs</li> </ul>		<ul style="list-style-type: none"> <li>Enabling shadowing of AD or comorbidity consultations/clinics (for internal HCPs)</li> <li>Inviting different internal HCPs to attend or speak at team meetings to provide specialist input (e.g. dermatologist, comorbidity specialist)</li> </ul>
<b>Medium</b>	<ul style="list-style-type: none"> <li>Delivering the following in collaboration with other centres/experts, Patient Groups, medical societies/groups:                             <ul style="list-style-type: none"> <li>Bespoke remote-access educational meeting or workshops</li> <li>Face-to-face educational sessions or lectures as part of existing events (e.g. conferences)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Collaborating in cross-specialty research within centre (improving knowledge of each others' speciality)</li> <li>Conducting joint HCP consultations for patients (e.g. dermatologist and psychologist)</li> <li>Holding multidisciplinary team meetings across specialists within centre/from other centres</li> </ul>	<ul style="list-style-type: none"> <li>Attending continuing professional development courses (e.g. conferences)</li> <li>Enabling shadowing of AD or comorbidity consultations/clinics (for external HCPs)</li> </ul>
<b>Advanced</b>	<ul style="list-style-type: none"> <li>Employing HCPs that split their time across the community and specialist hospitals, or hiring AD specialists to help upskill other team members</li> <li>Delivering the following in collaboration with other centres/experts, Patient Groups, medical societies/groups:                             <ul style="list-style-type: none"> <li>Bespoke face-to-face educational meeting or workshops</li> <li>Train-the-trainer sessions as part of a 'train-the-trainer model' (i.e. non-specialists would then go educate others about AD)</li> <li>E-learning modules</li> </ul> </li> <li>Creating computer software pop-ups/'smartsets'/forms to guide patient information collected and inform treatment decisions (i.e. nudging)</li> </ul>	<ul style="list-style-type: none"> <li>Creating cross-specialty departments or units (e.g. joint dermatology and allergology department, allergy centre) within centre to facilitate AD education</li> <li>Offering cross-specialty training (e.g. fellowship programme)</li> <li>Establishing a cross-centre network of AD specialists to regularly discuss care, case studies etc.</li> <li>Developing multidisciplinary teams for complex AD patient management within centre</li> </ul>	<ul style="list-style-type: none"> <li>Creating a teleconsultation service to discuss patient cases (specialist or non-specialist)</li> <li>Specialists developing AD management guidelines/ recommendations and AD outcome measures to guide care delivery</li> </ul>



# Supporting healthcare professional (HCP) education (4/5)

## Relevant centre case studies



### Delivering HCP education

#### Face-to-face educational sessions or lectures

**Allergy Centre**, Dokkyo Medical University Hospital, Japan

**Dermatology Academy**, UNIMORE (Modena), Italy

**Educating primary care providers**, Royal Devon & Exeter Hospital, UK

**Educating the wider medical community**, UMC Groningen, Netherlands

**HCP education (including nurse platform)**, UMC Utrecht, Netherlands

**Healthcare professional education seminars**, Hiroshima University Hospital, Japan

**Healthcare professional education**, UniCATT (Rome), Italy

**Provision of educational sessions**, Dermatology Treatment & Research Center (Texas), USA

**Provision of HCP education**, UKSH (Kiel), Germany

**Provision of HCP education**, Women's College Hospital (Toronto), Canada

**Provision of healthcare assistant education**, CMSS (Selters), Germany

**Provision of therapeutic education**, CH Lyon-Sud, France

**Involvement with wider AD community**, Mount Sinai & Icahn School of Medicine (New York), USA

**Focus on healthcare professional education**, Dermatology Treatment & Research Center (Texas), USA

#### Remote-access educational meeting or workshops

**Improving Atopic Dermatitis Care by Paediatricians (IADCP)**, Rady Children's Hospital (California), USA

**Primary care dermatology education**, Hospital La Paz (Madrid), Spain

#### Train-the-trainer sessions

**Healthcare professional education: 'Train-the-trainer'**, University of São Paulo Hospital, Brazil

**Provision of therapeutic education**, CH Lyon-Sud, France

**Education for different professionals and the general public**, Hiroshima University Hospital, Japan

**Healthcare professional education seminars**, Hiroshima University Hospital, Japan

### Conducting joint HCP consultations for patients

**Allergy centre comorbidity clinic**, Aarhus Universitetshospital, Denmark

**Joint paediatric dermatology-allergy clinic**, Royal Devon & Exeter Hospital, UK

**Joint psychiatry-dermatology clinics**, CHRU Brest, France

**Multidisciplinary Atopic Dermatitis Program (MADP)**, Rady Children's Hospital (California), USA

**Onsite dermatology psychologist**, Hospital Sant Pau (Barcelona), Spain

**Psycho-derm clinic**, Royal Devon & Exeter Hospital, UK

**A community-based assessment of skin care, allergies and eczema (CASCADE) trial**, OHSU Hospital (Oregon), USA

### Development of AD management guidelines and outcome measures

**Consensus for the management and treatment of AD**, Linkou Chang Gung Memorial Hospital (Taipei), Taiwan

**Development of Japanese AD guidelines**, Hiroshima University Hospital, Japan

**Development of locally tailored recommendations**, Rabin Medical Centre (Petah Tikva), Israel

**Harmonising Outcome Measures for Eczema (HOME) Initiative**, Rabin Medical Centre (Petah Tikva), Israel/OHSU Hospital (Oregon), USA



# Supporting healthcare professional (HCP) education (5/5)

## Relevant centre case studies



### Creating a teleconsultation service to discuss patient cases

**Emergency department specialist hospital communication**, Rady Children's Hospital (California), USA

**MedPhone application**, CH Lyon-Sud, France

**Teledermatology service**, Royal Devon & Exeter Hospital, UK

### Employing HCPs that split their time across the community and specialist hospitals

**Integrated community dermatologist**, Rabin Medical Centre (Petah Tikva), Israel

**Integration of community dermatologists**, Women's College Hospital (Toronto), Canada

### Creating computer software pop-ups/'smartsets'/forms to guide patient information collected and inform treatment decisions

**Improving Atopic Dermatitis Care by Paediatricians (IADCP)**, Rady Children's Hospital (California), USA

**Structured patient assessment tool**, UKSH (Kiel), Germany

### Incorporating management advice and recommendation into referral letters/discussions and/or when providing test results for internal and external HCPs

**Frequent advice for primary care professionals**, Harrogate District Hospital, UK

**Primary Care professional-Dermatology-Laboratory network**, UNIMORE (Modena), Italy

### Inviting different internal HCPs to attend or speak at team meetings to provide specialist input

**AD occupational training and advice**, UNIMORE (Modena), Italy

**Role of occupational health physician**, UMC Groningen, Netherlands

### Creating cross-specialty departments or units

**Established dermo-allergy unit**, Hospital La Paz (Madrid), Spain

### Offering cross-specialty training

**Multidisciplinary dermatology and allergy & immunology collaborative fellowship program**, Rady Children's Hospital (California), USA

### Establishing a cross-centre network of AD specialists to regularly discuss care

**Centre Expert Eczema Network Auvergne Rhone Alpes**, CH Lyon-Sud, France



# Creation of collaborative internal & cross-centre networks (1/4)

## What is the challenge?

- Centres may not have the resources (nor ability to invest in) the personnel or facilities required for effective AD care delivery<sup>(a)</sup> or research
- A lack of referral networks may further inhibit their ability for patients to access the necessary treatment<sup>(b)</sup>



## Forming a collaborative network within and across centres (including both primary and secondary care) to optimise research, patient care and knowledge sharing

### What is the goal/s of the intervention?



- Share knowledge and experience across HCP networks to collectively improve care
- Create efficient referral pathways and provide patients with access to specialists or facilities that may not be available at own centre
- Enable pooling of resources across centres (e.g. to advocate for research, conduct larger scale research projects)

### Who is often involved in the intervention?



- Dermatologist
- Nurse/medical assistant
- Physician assistant
- Trainee dermatologist
- Comorbidity specialist (e.g. allergist)
- Primary care practitioner (PCP)
- Laboratory staff (e.g. researcher, scientist)
- Clinical trial staff (e.g. study coordinator/recruiter, epidemiologist)

### What are the potential outcomes?



#### Patients

- Access to treatment and holistic care (e.g. for comorbidities) from across specialties
- Reduced travel and time burden for patients, as they are able to receive specialist care close to home
- Opportunity to participate in research projects/clinical trials

#### HCPs

- Greater access to wider patient pool, including those who might not be able to travel to the main treating clinic

- Ability to provide holistic care to patients who require comorbidity treatment
- Sharing of knowledge between care settings and upskilling of community HCPs

#### Healthcare systems

- Potential cost-efficiencies through sharing or pooling resources across centres (versus having to provide at each centre) and providing patient care within community settings (instead of hospitals)

Sources: (a) Le Roux E, et al. GPs experiences of diagnosing and managing childhood eczema, BJGP 2019 [PDF] <https://bjgp.org/content/bjgp/early/2018/01/16/bjgp18X694529.full.pdf> Assessed 21 Mar 2019; (b) Allergy UK and Sanofi Genzyme. Seeing Red: Getting under the skin of adult severe eczema. 2017 [Website] [https://www.allergyuk.org/assets/000/001/411/Seeing\\_Red\\_Report\\_FINAL\\_25.04.17\\_original.pdf?1508228476](https://www.allergyuk.org/assets/000/001/411/Seeing_Red_Report_FINAL_25.04.17_original.pdf?1508228476) Accessed 5 Nov 2019; (c) KPMG interviews

# Creation of collaborative internal & cross-centre networks (2/4)

## What is offered as part of the intervention and how has it been implemented in different centres?



**Note:** With input from the steering committee, we have categorised these activities by level of resource required to implement, however this may vary across centres/settings (e.g. depending on existing resources)

### Easy



- Building relationships with local centres of comorbidity specialists for referrals
- Hosting HCPs from different centres, such as attending team meetings to discuss complex patients cases and providing lectures
- Performing regular internal research meetings between centre clinical research laboratory and university dermatology research laboratory

### Medium



- Providing specialist care in the community via smaller clinics/satellite clinics
- Creating referral networks (between PCPs/general dermatologists and AD specialists)
- Creating a cross-centre regional network of HCPs involved in the management of eczema who meet regularly (e.g. to discuss complex cases)
- Hiring HCPs who have trained at other national or international centres (so have existing relationships)
- Collaborating on local, national or international research projects and clinical trials (with HCPs in primary and secondary care)
- Integrating a community dermatologist into specialist centre outpatient clinics (to increase exposure and treating confidence of severe AD patients and act as liaison with primary care)
- Centres collaborating to support Patient Groups with activities including grant applications, patient education, patient referrals, research and the writing of AD protocols and guidelines
- Providing face-to-face HCP training sessions (for general dermatologists, PCPs, nurses, medical students etc.)
- Enabling teleconsultations between specialists and other specialists or Primary Care Practitioners (PCPs) via mobile phones/computers
- Providing a HCP smartphone application portal for centre network to provide HCPs with immediate access to patient lists, patient medications, research results and referral information
- Developing AD educational and health information technology resources (e.g. 'smartset') for paediatricians (and their patients) in primary care

### Advanced



- Supporting setup and/or running of Patient Groups
- Setting up cross-specialist internal departments
- Establishing smaller community clinics/satellite clinics external to the parent clinic
- Connecting electronic medical records (full or partial) to share referred patient information
- Facilitating cross-centre development of treatment principles/care algorithms, guidelines and recommendations, AD scoring indices, PRO or QoL measures etc.
- Promoting national cross-centre setup and participation in AD registries and biobanks (for clinical research)





# Creation of collaborative internal & cross-centre networks (3/4)

## Relevant centre case studies



### Collaboration on local, national or international research projects

**Clinical trials participation**, DermAssociates (Washington), USA

**Integrated clinical and research laboratories**, Aarhus Universitetshospital, Denmark

**PCP-Dermatology-Laboratory network**, UNIMORE (Modena), Italy

**Specialist laboratory testing and interpretation**, UNIMORE (Modena), Italy

**Working with the VMCE**, UMC Utrecht, Netherlands/UMC Groningen, Netherlands

**Pruritus National Reference Centre**, CHRU Brest, France

**National patient database**, Linkou Chang Gung Memorial Hospital (Taipei), Taiwan

**Development of Japanese guidelines for AD**, Hiroshima University Hospital, Japan

**TREATgermany registry**, UKSH (Kiel), Germany

### Collaboration on the provision of patient and HCP education

**Globally trained dermatologists and residents**, Rabin Medical Centre (Petah Tikva), Israel

**Healthcare professional education**, UniCATT (Rome), Italy

**Healthcare professional education seminars**, Hiroshima University Hospital, Japan

**Primary care dermatology education**, Hospital La Paz (Madrid), Spain

**Provision of HCP education**, UKSH (Kiel), Germany

### Building relationships with local centres of comorbidity specialists for referrals

**Comorbidity specialist network**, DermAssociates (Washington), USA

**Established specialist network**, Medical Dermatology Associates of Chicago, USA

**Referral to co-morbidity specialists**, M.L.F. Knuckles Dermatology (Kentucky), USA

### Enabling teleconsultations between specialists and other specialists or Primary Care Practitioners

**Emergency room specialist hospital communication app**, Rady Children's Hospital (California), USA

**Teledermatology service**, Royal Devon & Exeter Hospital, UK

**Use of telemedicine**, Hospital Italiano de Buenos Aires, Argentina

### Cross-centre development of treatment principles/care algorithms, guidelines and recommendations, AD scoring indices, PRO or QoL measures etc.

**Consensus for the management and treatment of AD**, Linkou Chang Gung Memorial Hospital (Taipei), Taiwan

**Development of Japanese guidelines for AD**, Hiroshima University Hospital, Japan

**Harmonising Outcome Measures for Eczema (HOME) Initiative**, Rabin Medical

Centre (Petah Tikva), Israel/OHSU Hospital (Oregon), USA

**A community-based assessment of skin care, allergies and eczema (CASCADE) trial**, OHSU Hospital (Oregon), USA

### Developing AD educational and health information technology resources (e.g. 'smartset') for paediatricians (and their patients) in primary care

**Healthcare professional education**, UniCATT (Rome), Italy

**Improving Atopic Dermatitis Care by Paediatricians (IADCBP)**, Rady Children's Hospital (California), USA





# Creation of collaborative internal & cross-centre networks (4/4)

## Relevant centre case studies



### Integrating a community dermatologist into specialist centre outpatient clinics

**Integrated community dermatologist**, Rabin Medical Centre (Petah Tikva), Israel

**Integration of community dermatologists**, Women's College Hospital (Toronto), Canada

### National cross-centre setup and participation in AD registries and biobanks

**BioDay registry**, UMC Utrecht, Netherlands/UMC Groningen, Netherlands

**TREATgermany registry**, UKSH (Kiel), Germany/CMSS (Selters), Germany

### Providing specialist care in the community via smaller clinics/satellite clinics

**Community outreach clinics for rural populations**, Harrogate District Hospital, UK

**Hospital Specialist Satellite Clinics**, Rady Children's Hospital (California), USA

### Supporting setup and/or running of Patient Groups

**Working with the VMCE**, UMC Utrecht, Netherlands/UMC Groningen, Netherlands

**Working with the AADA**, Hospital Sant Pau (Barcelona), Spain/Hospital La Paz (Madrid), Spain

**Involvement with wider AD community**, Mount Sinai & Icahn School of Medicine (New York), USA

### Creating a cross-centre regional network of HCPs involved in the management of eczema who meet regularly

**Centre Expert Eczema Network Auvergne Rhone Alpes**, CH Lyon-Sud, France

### Providing a HCP smartphone application portal for centre network

**MedPhone application**, CH Lyon-Sud, France

### Hiring HCPs who have trained at other national or international centres

**Globally trained dermatologists and residents**, Rabin Medical Centre (Petah Tikva), Israel



# Use of eHealth, mHealth & telehealth (1/4)

## What is the challenge?

- Patients with AD (especially complex patients) may be required to travel regularly to HCP consultations, which can be time consuming, stressful and financially costly for them<sup>(a)</sup>
- Depending on their location, there may also be limited access to HCPs with AD expertise<sup>(b)</sup>
- Due to resource constraints physician/patients can have limited time in consultations to provide education, and/or patients may want to access information/support in between consultations<sup>(c)</sup>



## Using electronic, mobile and tele-technology to improve the quality and efficiency of care delivered to AD patients

### What is the goal/s of the intervention?



- More efficient delivery of care through approaches which have the potential to save both time and money
- Increased convenience for patients and HCPs in the delivery of care, thereby reducing patient burden and lessening demands on HCP's time
- Greater access to resources (e.g. patient and HCP information)
- Provision of care to patients who otherwise may have been unable to access it

### Who is often involved in the intervention?



- Dermatologist
- Nurse/medical assistant
- Primary care practitioner (PCP)
- Comorbidity specialist (e.g. allergist)
- Trainee dermatologist
- IT expert
- Data protection and legal expert

### What are the potential outcomes?



#### Patients

- Ability to better manage their own disease through accessing guidance, consultations and condition updates online and at their convenience
- Improved access to specialist care and reduced associated travel burden

#### HCPs

- Efficient storage, transfer and analysis of data (e.g. for internal quality reviews, to create patient cohort for research)

- Improved efficiency of consultations reducing demand on HCPs
- Access to patients who may be unable to make the journey for in-person visits

#### Healthcare system

- Potential reduction in number of patients accessing healthcare services in person and improved ability to analyse patient trends

Sources: (a) Adamson AS. The Economics Burden of Atopic Dermatitis. Adv Exp Med Biol. 2017;1027:79-92. doi: 10.1007/978-3-319-64804-0\_8; (b) Le Roux E, et al. GPs' experiences of diagnosing and managing childhood in primary care. British Journal of General Practice 2018;68(667):73-80. doi:10.3399/bjgp18X694529; (c) Mehta S. Patient Satisfaction reporting and its implications for patient care. AMA Journal of Ethics. 2015 [Website] <https://journalofethics.ama-assn.org/article/patient-satisfaction-reporting-and-its-implications-patient-care/2015-07> Accessed 5 Nov 2019

# Use of eHealth, mHealth & telehealth (2/4)



## What is offered as part of the intervention and how has it been implemented in different centres?



**Note:** With input from the steering committee, we have categorised these activities by level of resource required to implement, however this may vary across centres/settings (e.g. depending on existing resources)

	Patients	HCPs
Easy >	<ul style="list-style-type: none"> <li>— Creating a secure team email address that patients can send photos of their skin to</li> <li>— Establishing a dedicated phone line for patients to call for treatment advice</li> </ul>	<ul style="list-style-type: none"> <li>— Enabling HCPs to perform telephone consultations which can include a discussion of test results and guidance regarding treatment</li> </ul>
Medium >>	<ul style="list-style-type: none"> <li>— Enabling teleconsultations between specialists and patients via mobile phones/computers (e.g. via patient portal), of which can be supplemented with PROs</li> <li>— Creating an educational website containing online training resources for patients as a supplement to what is provided by HCPs during consultations</li> </ul>	<ul style="list-style-type: none"> <li>— Enabling teleconsultations between specialists and other specialists or Primary Care Practitioners (PCPs) via mobile phones/computers</li> <li>— Designing a local or centre database that creates consistency in data collected in patient consultations across team members, and can be used to check quality control processes (e.g. by checking the consistency of EASI/SCORAD measures), or track and monitor patient progress</li> </ul>
Advanced >>>	<ul style="list-style-type: none"> <li>— Developing a smart phone application for patients that provides resources such as treatment information, itch management guidance, treatment plans integrated into the user's diary with set reminders, and educational tips and videos</li> </ul>	<ul style="list-style-type: none"> <li>— Connecting electronic medical records (full or partial) across centres to share referred patient information easily</li> <li>— Developing computer applications for local PCP network that can guide AD management (e.g. through treatment recommendation)</li> <li>— Developing a smart phone application to enable staff within the same network to securely share photos of AD, and gain access to patient lists, patient medications, research results and referral information</li> <li>— Using telemedicine infrastructure to capture patient information through creating e-cohorts</li> </ul>



# Use of eHealth, mHealth & telehealth (3/4)



## Relevant centre case studies



### Enabling teleconsultations/information sharing

#### HCP – HCP

**Emergency department specialist hospital communication**, Rady Children's Hospital (California), USA

**MedPhone application**, CH Lyon-Sud, France

**Use of technology**, KFMC, Saudi Arabia

**Teledermatology service**, Royal Devon & Exeter Hospital, UK

**Use of telehealth services**, Aarhus Universitetshospital, Denmark

**Use of telemedicine**, Hospital Italiano de Buenos Aires, Argentina

**Multi-disciplinary patient education**, Cayre Clinical Center, Colombia

#### Patient – HCP

**Communication via the patient portal**, UMC Utrecht, Netherlands

**Dedicated dermatology photographer**, UMC Groningen, Netherlands

**Digital consultation support**, CMSS (Selters), Germany

**Longer and frequent consultations**, OHSU Hospital (Oregon), USA

**Use of telemedicine**, Hospital Italiano de Buenos Aires, Argentina

**Patient-HCP consultation**, Cayre Clinical Center, Colombia

### Designing a local or centre database

**Development of a local patient registry**, UniCATT (Rome), Italy

**Ongoing electronic health record (EHR) development**, Hospital Italiano de Buenos Aires, Argentina

**Self-designed patient database**, CMSS (Selters), Germany

**Structured patient assessment tool**, UKSH (Kiel), Germany

**National patient database**, Linkou Chang Gung Memorial Hospital (Taipei), Taiwan

### Developing a smart phone application for patients

**Innovative smartphone application: "Zalf"**, UMC Utrecht, Netherlands

**Physiotherapist relaxation and mobile app**, Inselspital (Bern), Switzerland

**'Virtual nurse' mobile device application**, McGill University Health Centre (Montreal), Canada

### Developing computer applications for local PCP network which can guide AD management

**Frequent advice for primary care providers**, Harrogate District Hospital, UK

**Improving Atopic Dermatitis Care by Paediatricians (IADCBP)**, Rady Children's Hospital (California), USA



# Use of eHealth, mHealth & telehealth (4/4)

## Relevant centre case studies



### Facilitation of virtual consultations

**Digital consultation support**, CMSS (Selters), Germany

**Telephone consultations**, Harrogate District Hospital, UK

### Enabling HCPs to perform telephone consultations

**Digital consultation support**, CMSS (Selters), Germany






















**Telephone consultations**, Harrogate District Hospital, UK

### Creating an educational website containing online training resources for patients

**Innovative education website: "Leef! Met Eczeem"**, UMC Utrecht, Netherlands



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# Glossary and bibliography

# Glossary



AAAAI: American Academy of Allergy, Asthma and Immunology  
 AAD: American Academy of Dermatology  
 AADA: Brazilian Atopic Dermatitis Association  
 AD: Atopic Dermatitis  
 ADAR: Asociación Civil de Dermatitis Atópica (Argentina)  
 ADCT: Atopic Dermatitis Control Test  
 ANDeA: Associazione Nazionale Dermatite Atopica (Italy)  
 ANP: Advanced Nurse Practitioners  
 ANPS: Advanced Nurse Practitioners  
 BAD: British Association of Dermatologists  
 BSA: Body Surface Area  
 CBT: Cognitive Behaviour Therapy  
 CCG: Clinical Commissioning Groups  
 CDLQI: Children's Dermatology Life Quality Index  
 CME: Continued Medical Education  
 CoE: Centre of Excellence  
 COS: Core Outcome Set  
 CT: Clinical Trials  
 CTM: Chinese Traditional Medicine  
 DDA: Deutsche Dermatologie Akademie  
 DLQI: Dermatology Quality of Life Index  
 DRG: Diagnosis Related Group  
 EADV: European Association of Dermatology and Venerology  
 EASI: Eczema Area and Severity Index  
 EHR: Electronic Health Record  
 ENT: Ear, Nose & Throat  
 EPD: Electronic Patient Dossier  
 E-RS: Electronic Referral System  
 ESC: Eczema Society of Canada  
 GMoH: German Ministry of Health  
 GP: General Practitioner

GPwSI: GP with a Special Interest  
 GSG: Global Steering Group  
 HADS: Hospital Anxiety and Depression Scale  
 HAEJ: Hereditary Angiodema Patient Association Japan  
 HCP: Healthcare Professional  
 HECSI: Hand Eczema Severity Index  
 HMO: Health Maintenance Organisation  
 HOME: Harmonising Outcome Measures for Eczema  
 HRT: Habit Reversal Therapy  
 IADCBP: Improving Atopic Dermatitis Care by Paediatricians  
 IGA: Investigator Global Assessment  
 IgE: Immunoglobulin  
 IOS: Impulse Oscillometry  
 ISDV: Israel Society of Dermatology & Venereology  
 ISTST: Intensive Short Term Schema Therapy  
 Itch NRS: Itch Numeric Rating Scale  
 JAMA: Journal of the American Medical Association  
 JEADV: Journal of the European Academy of Dermatology and Venereology  
 KPI: Key Performance Indicator  
 KPMG: KPMG LLP  
 LDH: Lactic Acid Dehydrogenase  
 MA: Medical Assistants  
 MADP: Multidisciplinary Atopic Dermatitis Programme  
 MDT: Multidisciplinary Team  
 NEA: National Eczema Association  
 NES: National Eczema Society  
 NHI: National Health Insurance  
 NICE: National Institute for Health and Care Excellence  
 NO: Nitric Oxide  
 NRS: Nonrestorative Sleep

NRS: Numerical Rating Score  
 OHP: Occupational Health Physicians  
 PAE: Paediatric Allergy Educators  
 PAG: Patient Advocacy Group  
 PaGA: Patient Global Assessment  
 PCC: Peripheral Care Centres  
 PCP: Primary Care Professional  
 POEM: Patient Oriented Eczema Measure  
 PPD: private practice dermatologist  
 PPE: Personal Protective Equipment  
 PRO: Patient Reported Outcomes  
 QoC: Quality of Care  
 QoL: Quality of Life  
 QOLHEQ: Quality of Life in Hand Eczema Questionnaire  
 RECAP: Recap of Atopic Eczema  
 SCORAD: SCORing Atopic Dermatitis  
 SOA: Seal of Acceptance  
 SOP: Standard Operating Procedure  
 TARC: Thymus and Activation-Regulated Chemokine  
 TDA: Taiwanese Dermatological Association  
 TREAT: TREATment of Atopic eczema registry taskforce  
 UMC: University Medical Centres  
 UV: Ultraviolet  
 VA: Visual Activity  
 VAS: Visual Analogue Score  
 VHI: Voluntary Health Insurance  
 vIGA-AD: Validated Investigator Global Assessment for Atopic Dermatitis  
 VMCE: Vereniging voor Mensen met Constitutioneel Eczeem  
 WPAI: Work Productivity and Impairment



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# Findings: Global challenges in AD care

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CONTENTS

# Additional notes on methodology



# Contributor roles and responsibilities



This study was solely conducted by KPMG, including the collection, study, management, analysis and interpretation of data, and the preparation and editing of the report.



## Global Strategic Group

Given the large number of participating centres, a smaller working group was formed to help shape this report – the Global Strategic Group (GSG). The GSG consisted of four experts from across the globe who provided guidance and advice throughout the development of the report.



## Other contributing specialists

All experts were given an opportunity to review their centre-specific report and this report. Guidance and feedback from all experts were incorporated into this report.



This report was commissioned and funded by Sanofi Genzyme & Regeneron. Sanofi Genzyme & Regeneron had no role in the collection, management, analysis or interpretation of data, or preparation of the final report.

# The centres and steering committee (GSG) were selected against a set of key criteria and considerations

## Centre Selection

Secondary research was performed using publically available sources to identify potential centres. Centres were initially identified via AD publications (including guidelines), congress activity, board / council membership, clinical trial participation etc.

The centres were then prioritised using a 5-item criteria to ensure a variety of centre types were selected.

### Key criteria for centre selection



Type of centre (hospital-based / office based)



Size of centre (small-medium / large)



Key AD initiatives (e.g. patient education, patient group collaboration)



Funding of centre (public / private / mixed)



Location of centre (urban / rural)

## Steering Committee Selection

Given the large number of participating centres, a smaller global working group was formed to help shape this report. Experts from participating centres were selected based on their expertise and previous experience in global AD care. Four experts (the Global Strategic Group) played a significant role, providing ongoing guidance throughout the research as well as reviewing this report. The GSG provided guidance and advice throughout the development of the report. They helped identify key challenges and shape the good practice interventions.



CONTENTS

# Centre-specific reports



# Aarhus Universitetshospital

Aarhus, Denmark

Site visited by KPMG 21<sup>st</sup> August 2019

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[kpmg.com/uk](https://kpmg.com/uk)



APPENDIX  
CENTRE REPORTS



# Summary



## Context

**Centre type:** University hospital (tertiary care teaching hospital)

**Catchment area:** ~1.2 million people in the Midtjylland region, however the centre receives special referrals from across Denmark (~200,000 AD patients in Denmark overall)

**Funding:** The centre is publically-funded through national health tax revenues

**Services:** The dermatology unit is one of several specialist departments within the centre (which collaborate with each other as necessary)

**Patient population:** Includes the most severe/complex adult and paediatric patients with a variety of dermatological conditions, including atopic dermatitis (AD)



## Key strengths in the delivery of AD care

**Patient education:** Patients receive AD education at the centre through multiple channels, including HCPs (e.g. AD nurse consultations) and 'Eczema School' evenings

**Multidisciplinary approach:** Patients with multiple/complex atopy conditions (e.g. AD, asthma, allergic rhinitis) can receive efficient multidisciplinary support through a cross-functional allergy clinic (i.e. the 'Allergy Centre')

**Nurse empowerment:** AD nurses lead 1:1 consultations with patients to discuss treatment options, provide education and reduce the burden on dermatologists

**AD research:** The centre offers multiple opportunities for patients to participate in AD clinical research, including studies developed by the centre's integrated clinical and research laboratories



## Key challenges faced in delivery of AD care

**There is a lack of qualified dermatologists in the Midtjylland region and across Denmark**, which can lead to shorter consultation times (limiting the amount of time that can be spent educating AD patients)

**AD patients are not always referred soon enough** from primary care to specialist dermatology care

**AD patients and their parents are anxious regarding the use of steroids and other emollients** (e.g. due to fears of skin-thinning), which can impact treatment compliance

**Many patients in the Midtjylland region live far from the centre**, which can make it time-consuming and expensive for them to attend appointments (and may impact treatment compliance)

# Atopic Dermatitis (AD) in Denmark

## The Danish healthcare system:

### Structure<sup>(a)</sup>

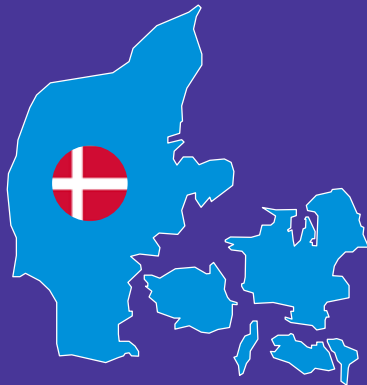
The national government sets the regulatory framework for health services in Denmark. Five administrative regions – governed by democratically elected councils – are responsible for the planning and delivery of specialised care services. The five regions own, manage and finance hospitals, in addition to financing the majority of services delivered by private primary care physicians (PCPs) and office-based specialists.

### Insurance and funding<sup>(a)</sup>

All registered Danish residents are automatically entitled to publically financed health care (financed primarily through a national health tax). National health tax revenues are allocated to regions (and the municipalities they contain), with adjustments based on demographic and social differences. Local services may also receive funding through local taxation. Voluntary, complementary private health insurance may be purchased on an individual basis to cover services not fully covered by the state. Supplementary insurance may also be purchased to increase access to private care providers.

## Prevalence

- AD affects 10–20% of children and 1–3% of adults in Western countries<sup>(b)</sup>



## Care provision:

### Location:

- Mild (or well-controlled) AD care is usually managed by PCPs or private dermatologists (office-based specialists)
- Moderate and severe (or uncontrolled) AD care is usually managed by hospital and office-based dermatologists

### Funding:

- Health care services are generally funded through the national health tax, with local services often supplemented by local taxation
- The collection and distribution of health care funding is managed by the five administrative regions

## Guidelines and societies:

### Guidelines:

- Guidelines for treatment of atopic eczema (atopic dermatitis) part I and part II: European Association of Dermatology and Venerology (EADV)
- Danish guidelines for the 'Evaluation and treatment of patients suffering from atopic dermatitis'
- Danish guidelines for the diagnosis and treatment of hand eczema

### Medical society:








- Danish Dermatological Society

### Patient association group (PAG):

- Danish Association of Atopic Eczema (AEF)

**Sources:** (a) The Danish Health Care System – International Health Care System Profiles [Website] <https://international.commonwealthfund.org/countries/denmark/>. Accessed 27 Aug 2019; (b) Nutten S. Atopic dermatitis: global epidemiology and risk factors. *Ann Nutr Metab.* 2015;66 Suppl 1:8-16. doi: 10.1159/000370220

# The centre and dermatology unit

The centre		
 <b>Type and location</b>	Aarhus Universitetshospital is a large, public university hospital offering specialist treatment to citizens in the Central Denmark Region (Midtjylland) and other regions in Denmark. The centre is also the local hospital for citizens in Aarhus and from the nearby island of Samsø  The main hospital site – The New University Hospital (DNU) – is located on the outskirts of Aarhus and is the largest hospital in Denmark, employing over 10,000 staff	
 <b>Population served</b>	1.8 million people in the Midtjylland and Nordjylland regions (with ~200,000 AD patients in Denmark overall)	
The dermatology unit <sup>(1)</sup>		
 <b>Service Division</b>	<b>Outpatient service</b>	<b>Inpatient service</b>
 <b>Hours of availability</b>	08:00–13:30 ; Mon–Fri	24 / 7
 <b>No. of patients seen</b>	30–40 AD patients / week	5–10 AD patients / year
 <b>Types of patients seen</b>	Moderate to severe (or uncontrolled) AD patients of all ages	
 <b>Facilities on-site<sup>(2)</sup></b>	<div><div><ul style="list-style-type: none"><li>— 25 consulting rooms</li><li>— 5 inpatient beds</li><li>— Phototherapy (UVA/UVB/PUVA)</li><li>— Dermatology laboratory (shared with rheumatology)</li><li>— Allergy testing (skin prick testing; patch testing; Type I and IV allergy testing)</li></ul></div><div><ul style="list-style-type: none"><li>— IV (intravenous) unit (for immunoglobulin injections, biologic therapy injections, and training patients to self-inject)</li><li>— Food provocation testing</li><li>— Potassium permanganate baths</li><li>— Dedicated unit for organ transplant patients</li></ul></div></div>	
<i>Note: Patch testing is also performed by dermatologists in private practice</i>		

**Note:** (1) Basic emergency dermatology services are available via the centre's 24/7 emergency department; (2) List of facilities is not exhaustive

# The team

## Core team profile

-  **11** Dermatologists
-  **14** Trainee dermatologists
-  **22** Dermatology nurses  
(5 AD-specialised)
-  **3** Laboratory technicians
-  **1** Healthcare assistant
-  **17** Secretaries

## Wider team profile

-  **3** Research nurses dedicated to clinical trials (2 full-time, 1 part-time)
-  **10–15** Research assistants
-  **5** AD-specialised ophthalmologists
-  **3** AD-specialised pulmonologists
-  **2** AD-specialised paediatricians
-  **2** AD-specialised ENT specialists
-  **2** AD-specialised occupational health physicians
-  **2** Dieticians

Note: Please see page 94 for further details about the wider team

## Governance and processes

### Team meetings:

- *Dermatologist meeting (07:45–08:00, Mon–Fri):*
  - Attended by: dermatologists, trainee dermatologists
  - Purpose of meeting: to discuss overnight events and a 'case of the day' (presented by trainees)
- *Outpatient team meeting (08:00–08:10, Mon–Fri):*
  - Attended by: dermatologists, trainee dermatologists, nurses, secretaries
  - Purpose of meeting: to discuss matters relating to the outpatient clinic. Meeting concludes at 08:15 on days with specialised clinics (e.g. AD clinic) and an equivalent inpatient team meeting is held each Monday (13:15–14:15)
- *Biologics meeting (13:45–14:15, Mon):*
  - Attended by: dermatologists, trainee dermatologists
  - Purpose of meeting: to discuss whether individual patients meet the criteria required for initiating biologic treatment
- *Specialist meeting (14:00–15:00, Tue):*
  - Attended by: chief dermatologist, dermatologists
  - Purpose of meeting: to discuss trainee dermatologist educational and administrative issues
- *Presentation session (14:15–15:15, Wed):*
  - Attended by: dermatologists, trainee dermatologists
  - Purpose of meeting: to share knowledge of dermatological diseases including AD
- *Patient discussion meeting (13:30–15:00, Thu):*
  - Attended by: dermatologists, trainee dermatologists
  - Purpose of meeting: to discuss individual complex patients as a group, including patient files and biochemistry readings

Note: A dermatologist also attends the Allergy Centre every Tuesday (see case study pg. 102)

### Patient records

- *Electronic patient records:*
  - MidtEPJ (Midtjylland Electronic Patient Journal)



# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients with symptoms of AD (e.g. itching, dryness, eczema) are assessed by a primary care professional (PCP) or private practice dermatologist (PPD)
- All AD patients (adults and children) are referred to the centre's dermatology unit

*Note: PCPs rarely refer AD patients to the centre without first referring to a PPD*

*Note: AD patients with ocular symptoms may be referred directly to the centre's AD-specialised ophthalmologist*

- Out of hours, new patients may present to the centre's emergency department (e.g. during flare-ups) or directly to the dermatology department (providing the patient's PCP has called the department to request treatment). Patients receive temporary treatment and a next day dermatologist follow-up appointment

## Diagnosis and Referral

In secondary care



- Patients referred to the unit are seen within 4 weeks (a national target), or same day if urgent
- Patients are assessed by an AD-specialised dermatologist (often alongside a nurse) and/or comorbidity specialists (e.g. ophthalmologist) (consultation ~20 mins)

*Note: AD patients first seen in the paediatric or ophthalmology department may be referred internally to the dermatology unit (i.e. the most complex / severe cases)*

- AD is diagnosed through clinical examination. Depending on symptoms and medical history, supplementary diagnostic tests may also be performed at first consultation and during follow up (e.g. food provocation tests performed by nurses)
- Paediatric patients usually transition into adult care gradually, aged 16–18 yrs. As part of the transition, at 16yrs parents only attend the end of each consultation

## Treatment and Management

Medical management



- Treatment is initiated by dermatologist (tailored to the severity of the disease)
- Alternative treatment may be provided, with the choice of treatment decided in collaboration with the patient (e.g. UVA/UVB treatment; potassium permanganate baths)
- Patients are referred to the centre's AD comorbidity specialists as required (e.g. pulmonologist)
- AD patients may be referred to the AD clinic for specialist treatment, or may be seen in the dermatology unit's general outpatient clinic
- Patients may be offered the opportunity to participate in clinical trials

Non-medical management



- Patients sign-in for appointments electronically using their unique Danish Civil Registration Number<sup>(a)</sup>
- All patients receive education on AD treatment and management during dermatologist consultation
- Following initial dermatologist consultation, patients may immediately attend an additional education session delivered by a nurse (consultation ~30mins)
- The centre may recommend that AD patients requiring psychosocial support are referred (by their PCP) to a hospital-based or private practice psychologist
- Patients requiring dietary advice may be referred to a dietician (based in the paediatric department or general hospital)

## Follow-up

Monitoring of chronic disease / flare up



- Patients are monitored via regular follow-up consultations with a dermatologist / nurse. (frequency varies with severity, consultation ~20 mins)
- Subsequent blood tests / allergy tests are performed as required
- AD nurses determine the frequency and duration of nurse follow-up appointments

*Note: the centre tries to ensure patients are seen by the same dermatologist / nurse during each visit*

- Well controlled patients may be referred back to their original PCP or PPD for continued treatment
- Patient quality of life (QoL) and disease severity indices (e.g. EASI; SCORAD) are measured at times and frequencies deemed appropriate by the dermatologist

**Sources:** (a) CPR System - Det Centrale Person register [Website] <https://cpr.dk/cpr-systemet/>. Accessed 28 Aug 2019

# Roles of the wider team

## Paediatrician

**Patient type:** paediatric patients exhibiting mild-moderate AD symptoms

**Referral:** ~80% of referrals received from primary care physicians, ~10% from private practice dermatologists and ~10% from the centre's dermatology unit

**Consultations:** Patients attend paediatric clinic for allergy (including AD), asthma and pulmonology (09:00–15:30, Mon–Fri). As part of the transition to adult care, patient participation is increased for patients aged 12+ yrs, and patients aged ~16 yrs attend an initial consultation alone before being joined by parent

**Timing:** First consultation = ~1hr; Follow-up = 45mins–1hr

## Pulmonologist

**Patient type:** AD patients who present allergy and atopic rhinitis symptoms

**Referral:** patients with allergic rhinitis may be treated by a pulmonologist or dermatologist. If symptoms persist after basic treatment, the patient will be referred to an ENT specialist

**Consultations:** 1:1 consultation during which standard lung function tests are performed, including: spirometry, impulse oscillometry (IOS), nitric oxide (NO), provocation

**Timing:** First consultation = ~1hr; Follow-up consultation = ~15 mins



## Ophthalmologist

**Patient type:** patients exhibiting severe / acute ocular symptoms relating to AD (40–50 patients per year)

**Referral:** referred by centre dermatologist (~50%) or from outside the centre (primary care or private practice physician; ~50%). Waiting times range from 1 to 90 days depending on urgency

**Consultations:** Perform standard eye examinations (assisted by nurse / optometrist), including: refraction, acuity, cataract study; retinoscopy, topographic corneal analysis, tear production. Well controlled patients may be referred back to primary care for continued treatment

**Timing:** First consultation = ~15 mins; Follow-up = ~15 mins

## Occupational health physician

**Patient type:** AD patients requiring advice for managing their symptoms at home / work

**Referral:** ~60% of referrals received from primary care physicians, ~25% from private practice dermatologists and ~15% from the centre's dermatology unit

**Consultations:** Detailed patient medical history recorded in a standardised format in MidtEPJ. Allergy tests ordered as required through dermatology unit and practical advice provided for managing AD symptoms at work

**Timing:** First consultation = ~1.5hrs; Follow-up = ~15 mins

*Note: the occupational health physician is a qualified medical doctor*

## Roles of additional team members:

- **Dietician:** dermatologist may refer patients requiring dietary advice to a dietician based in the paediatric or gastroenterology departments
- **Psychologist:** for patients requiring psychosocial support, centre dermatologists typically suggest the patient's primary care physician refers the patient to an appropriate specialist (e.g. psychologist)
- **Otolaryngologist (ENT):** may provide input on AD cases from an ear-nose-throat perspective (e.g. during Allergy Centre – see case study pg. 102)
- **Research nurses:** oversee the involvement of dermatology patients in clinical trials
- **Research assistants:** masters, PhD and post-doctorate researchers assisting with AD testing and research

# Overview of interventions in place for AD

## Awareness and Presentation



Symptom identification

- **Eczema school:** The dermatology unit provides education and training for paediatric AD patients and their families through the Eczema School (hosted at the centre twice per year). Each programme consists of two evening sessions (19:00–21:30, held one or two weeks apart)

See pg. 100-101 for case study

## Diagnosis and Referral



In secondary care

- **Dermatology hotline:** Healthcare professionals (from the centre or private dermatologists) needing to contact dermatology staff may call a dedicated hotline (08:00–24:00, Mon–Sun). A secretary or on-call trainee dermatologist receives the calls and redirects queries as appropriate

*Note: Patients may only call the dermatologists directly on weekday mornings during an open telephone clinic. They may also call the secretaries (08:00–13:00, Mon–Fri) to discuss prescriptions, appointments, etc.*

## Treatment and Management



Medical management

- **Allergy centre comorbidity clinic:** The centre's pulmonology department runs a multidisciplinary 'Allergy Centre', attended by patients with complex atopic symptoms (e.g. AD, asthma, rhinitis) who require input from multiple specialists

See pg. 102 for case study

- **Nurse shared responsibilities:** AD-specialised nurses at the centre attend dermatologist consultations and may run separate 1:1 consultations with patients to provide further education and the opportunity for them to ask questions

See pg. 103-104 for case study

- **Involvement in TREAT registries:** Dermatologists at the centre are co-authors on the TREAT initiative, which aims to seek consensus between key stakeholders internationally on a core set of domains and domain items for AD patient registries<sup>(a)</sup>



Non-medical management

- **Integrated clinical and research laboratories:** staff meet regularly to propose new AD research projects, assess their feasibility and collaborate on other initiatives

See pg. 105-106 for case study

- **Role of the occupational health physician:** The occupational health department aims to identify which substances / practices at work may be causing and exacerbating disease symptoms

See pg. 107-108 for case study

- **MidtEPJ:** The centre helped to develop an electronic patient record ('Midtjylland Electronic Patient Journal') for the secure and consistent collection and storage of patient data

## Follow-up



Monitoring of chronic disease/flare up

- **Use of telehealth services:** The centre uses telehealth services (in the form of secure image sharing and inter-centre videoconferences and) to show patients how their symptoms have changed over time and provide AD education for HCPs outside the centre

See pg. 109-110 for case study

- **Faelles Medicinkort (FMK):** The 'Joint Medicines Card' provides healthcare professionals with a record of patient treatments and outcomes, which can ease the resumption of care (e.g. if a patient is referred by a specialist back to their primary care physician)

### Key:



Case study available

**Sources:** (a) Vermeulen FM, et al. TREATment of ATopic eczema (TREAT) Registry Taskforce: consensus on how and when to measure the core dataset for atopic eczema treatment research registries. *Br J Dermatol*. 2019;181(3):492-504. doi: 10.1111/bjd.17715



# Monitoring AD patients and comorbidities

## The dermatology unit uses a number of measures for monitoring AD and associated comorbidities

### Objective measures (AD):

AD scoring indices are used to monitor patients and their disease, including:

- EASI (Eczema Area and Severity Index)<sup>(a)</sup>: scoring system which grades the physical signs of AD / eczema
- SCORAD (SCORing Atopic Dermatitis)<sup>(b)</sup>: used to assess AD disease severity, itch and quality of life (QoL), and to monitor patient progress

QoL is measured by:

- DLQI (Dermatology Quality of Life Index)<sup>(c)</sup>: dermatology related quality of life questionnaire<sup>(c)</sup>

### Patient-reported outcomes:

HADS (Hospital Anxiety and Depression Scale)<sup>(d)</sup>: a short questionnaire, typically completed in a hospital waiting room, intended to assess patient anxiety and depression

POEM (Patient Oriented Eczema Measure)<sup>(e)</sup>: tool for monitoring AD severity and is recommended for use in outpatient clinics and clinical trials by the Harmonising Outcome measures for Eczema (HOME) initiative

*Note: objective measures and patient-reported outcomes for AD are used at the centre at the dermatologist's discretion. Measures are typically used to provide a baseline indication of patient symptoms, but in special cases may be repeated during follow-up consultations*

---

### Dermatology unit routinely measures comorbidity outcomes by:

- *Allergy*: dermatology unit staff perform skin-prick tests (i.e. for drug and food allergy) and blood tests to assess patient responses to specific allergens
- *Ophthalmology*: AD-specialised ophthalmologists perform screening tests (e.g. corneal examination)
- *Pulmonology*: AD-specialised pulmonologists perform screening tests (e.g. spirometry)

**Sources:** (a) EASI for clinical signs: Harmonising Outcome Measures for Eczema (HOME). [Website] <http://www.homeforeczema.org/research/easi-for-clinical-signs.aspx>. Accessed 30 Aug 2019; (b) SCORing Atopic Dermatitis (SCORAD) Calculator (0.9.0). [PDF] <http://scorad.corti.li/>. Accessed 30 Aug 2019; (c) Lewis V, et al. 10 Years Experience of the Dermatology Life Quality Index (DLQI). *J Invest Dermatol Symp Proc* 2004;9:169–180; (d) Zigmond AS, et al. The hospital anxiety and depression scale. *Acta Psychiatr Scand.* 1983;67(6):361–370; (e) Simpson E, et al. Patient-Oriented Eczema Measure (POEM), a core instrument to measure symptoms in clinical trials: a Harmonising Outcome Measures for Eczema (HOME) statement. *Br J Dermatol* 2017;176:979–84

# Advice to other centres

## What advice would you give less specialised centres?



**Objective of advice:** Listen carefully to patients and help them to address other problems that arise from living with AD

- **Why?** Atopic Dermatitis is a complex disease, which is not always well controlled and can impact patient quality of life in multiple ways<sup>(a)</sup>. For example, living with AD and other atopic conditions (e.g. food allergy, urticaria) can have psychosocial implications, which may affect work, personal relationships and adherence to treatment. An understanding of this complexity may allow treatment plans to be tailored to individual patients in a manner which minimises the daily burden of living with AD



**Objective of advice:** Establish an Eczema School aimed at enhancing education for AD patients and / or their parents

- **Why?** An Eczema School (see case study pg. 100-101) provides patients and their parents with the opportunity to learn more about AD as a disease and the different treatment options that may be available. This is to a degree facilitated by the opportunity for AD patients to meet others with the disease and to ask questions to specialists, which may be limited in regular dermatologist consultations. Notable examples of Eczema Schools have been observed in Germany<sup>(b)</sup>

**Sources:** (a) Lifschitz C. The impact of atopic dermatitis on quality of life. *Ann Nutr Metab* 2015;66(suppl 1):34-40; (b) The Eczema Education Programme – Action Against Allergy [Website] <https://actionagainstallergy.org/the-eczema-education-programme/>. Accessed 2 Sept 2019.

# Next steps for the centre



## What is next for the centre?

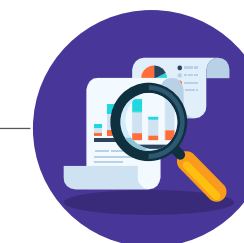
**Objective:** Enhance the level of support provided to adult and adolescent AD patients

- **What?** Establish a new Eczema School programme (or other support services) targeted at adult and / or adolescent patients and their families
- **Why?** The results of qualitative interviews held with patients (during nurse-organised 'patient panels' - see case study pg. 103-104) indicate that patients value and desire personal relationships with HCPs. The centre hopes to facilitate this by establishing an Eczema School, similar to that which already exists for the parents of paediatric AD patients (see case study pg. 100-101). In addition, the centre hopes to set up a dedicated adolescent AD or general dermatology clinic to provide these patients with the individual and specialised attention they require



**Objective:** Translate research findings into clinical practice

- **What?** The centre plans to continue conducting AD clinical trials and implementing the findings into clinical practice
- **Why?** Clinical trials provide HCPs with experience of using novel treatments and provides training in performing rigorous research (e.g. AD-severity index recording). Continued participation in clinical trials may produce results which inform the revision of treatment and care methods for AD patients, both at the centre and elsewhere. The systematic uptake of research findings and other evidence-based practices into routine clinical practice has the potential to improve patient outcomes and quality of life



# Case studies



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APPENDIX  
CENTRE REPORTS

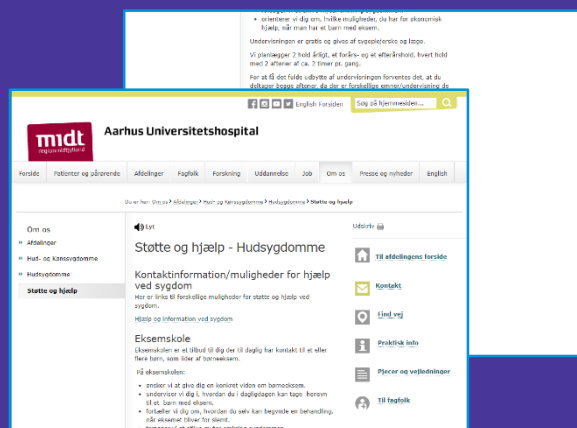
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# Eczema school (1/2)

## Overview

- The dermatology unit provides education and training for paediatric AD patients and their families through the Eczema School (hosted at the centre twice per year). Each programme consists of two evening sessions (19:00–21:30, held one or two weeks apart)



“Eksem-skole” (Eczema School) website<sup>(e)</sup>

## What is the rationale?

- Physicians have limited time to spend with patients and may be unable to cover all the aspects of the disease (e.g. AD self-management techniques) in consultations<sup>(a)</sup>
- Patients do not always understand the full impact of their disease or the treatment options available to them<sup>(b)</sup>, and may experience anxiety relating to the side effects of treatment<sup>(c)</sup>
- Education (especially in the paediatric population) has been shown to have a positive effect on AD patient outcomes<sup>(d)</sup>

## What are the key features of the intervention?

### Practical details:

- The Eczema School programme (established 1999) consists of two evening sessions (19:00–21:30, held one or two weeks apart)
- The programme is hosted at the centre twice a year (once in Spring, once in Autumn)
- Senior dermatologists and nurses (with the latter paid by the centre to attend) share the presentation, demonstration and Q&A responsibilities

*Note: Nurses are paid by the centre to attend; dermatologists are not paid for the additional work*

- The Eczema School maintains a website and Facebook group to share information about upcoming programmes and receive applications (submitted via email to the hospital secretary)
- Attendance:
  - 25–30 families (primarily the parents of AD patients) attend each programme
  - Other attendees include family members of patients who are not being treated at the centre, school teachers who may oversee children with AD, nurses from private practice, and staff from private pharmacies
  - Invites are sent via email by the hospital secretary, following referral from a primary care physician (PCP) or online application
  - The course is free to attend

**Sources:** (a) GlobalSkin Position Paper: “Atopic Dermatitis: A Collective Global Voice for Improving Care”, February 2018; (b) Arkwright P, et al. Management of difficult to treat AD. *American Academy of Allergy, Asthma & Immunology*. 2012;1(2):142-151. doi:10.1016/j.jaip.2012.09.002; (c) Powell K, et al. GP and parent dissonance about the assessment and treatment of childhood eczema in primary care: a qualitative study. *BMJ Open*. 2018;8(2); (d) Grillo M, et al. Pediatric atopic eczema: the impact of an educational intervention. *Pediatr Dermatol*. 2006;23(5):428-36; (e) Aarhus Universitetshospital - Support and Assistance - Skin Diseases – Eczema School [Website] <https://www.auh.dk/om-auh/afdelinger/hud-og-konssygdomme/hudsygdomme/stotte-og-hjalp/>. Accessed 20 Sept 2019



# Eczema school (2/2)

## What are the key features of the intervention? (cont.)

### Typical course contents:

Day 1 (hosted by a senior dermatologist):

- A medical perspective of AD (i.e. AD pathogenesis) and treatments
- Everyday implications of living with AD (e.g. sleep disruption; potential mental health impacts; the time required to apply AD treatments)
- Q&A

Day 2 (hosted by dermatology nurses):

- 30–45min presentation covering living with a child with AD
- Emollient types
- AD self-management tools
- Workshop demonstrations covering: wet-wrap treatments; how to itch without damaging skin; potassium permanganate baths
- Q&A

*Note – the course will usually also cover the latest laws and regulations which may affect AD patients (e.g. potential sources of financial support; subsidies for parents of children with a chronic disease; etc.)*

## What are the outcomes so far?

### Benefits to patients:

- The opportunity to meet other parents of patients, share experiences and ask questions
- Improved understanding of AD as a disease, and thus improved control and quality of life
- Fewer centre visits required

### Benefits to HCPs:

- Time efficient provision of patient education to multiple families simultaneously
- Improved treatment adherence and control in patients

## What's next?

- Source funding to include a social worker in the Eczema School (a social worker was present in previous iterations)
- Establish a new Eczema School programme (or other support services) targeted at adult and / or adolescent patients and their families

“



We answer parents' questions, address their fears and teach them how to apply different creams and dressings

*Dermatology Nurse, Aarhus Universitetshospital*

“



It is important that the families of AD patients have the opportunity to meet and speak with other families – they can educate one another

*Dermatologist, Aarhus Universitetshospital*



# Allergy centre comorbidity clinic

## Overview

- The centre's pulmonology department runs a multidisciplinary 'Allergy Centre', attended by patients with complex atopic symptoms (e.g. AD, asthma, rhinitis) who require input from multiple specialists



The Allergy Centre is very efficient for patients – many things can be ruled out in a short space of time

*Pulmonologist, Aarhus  
Universitetshospital*



## What is the rationale?

- Atopic Dermatitis is a complex disease, the treatment for which may require input from multiple specialists<sup>(a)</sup>

## What are the key features of the intervention?

- The centre's pulmonology department hosts the 'Allergy Centre', which consists of two half-day sessions per week
- Specialists treating patients with complex atopic symptoms (including AD patients) may refer patients to the Allergy Centre to gain insight from other specialists
- Hospital secretaries invite the appropriate specialists to each session, depending on the needs of the patients being seen that day
- 2–4 patients (one patient at a time) are seen by the specialists (simultaneously) per session
- The Allergy Centre mostly sees adult patients, with appointment lengths varying depending on the needs of the patient (waiting list ~4–5 months)
- Specialists may include:
  - ENT physician (otolaryngologist)
  - Ophthalmologist
  - Occupational health physician
  - Paediatrician
  - Dermatologist
  - Pulmonologist
- Patients only attend the Allergy Centre once, before returning to their original specialist

*Note: Ophthalmologists rarely attend the meeting because the testing equipment they require to assess patients cannot easily be transported to the Allergy Centre*

## What are the outcomes so far?

### Benefits to patients:

- Reduces the number and types of appointment each patient must attend
- Specialist multidisciplinary advice and treatment quickly received

### Benefits to HCPs:

- More efficient specialist consultations
- Fewer separate specialist consultations
- Facilitates cross-specialist discussion and knowledge sharing about treatment options

## What's next?

- Secure funding to continue running the Allergy Centre (currently, each participating department funds the service they provide to the Allergy Centre)

**Sources:** (a) American Academy of Allergy, Asthma & Immunology (AAAAI); Atopic Dermatitis (Eczema) Definition [Website] <https://www.aaaai.org/conditions-and-treatments/conditions-dictionary/atopic-dermatitis-eczema> Accessed 28 Aug 2018



# Nurse shared responsibilities (1/2)

## Overview

- AD-specialised nurses at the centre attend dermatologist consultations and may run separate 1:1 consultations with patients, in order to provide further education and the opportunity for them to ask questions

## What is the rationale?

- Patient feedback from Aarhus Universitetshospital patient panels suggests that patients appreciate 1:1 attention from HCPs to assist them with their AD treatment plans and understanding of the disease<sup>(a)</sup>
- However, time constraints limit the amount of patient education that can be delivered during a typical dermatologist consultation (~20 mins)
- Multiple nurses at the centre are specially trained to care for AD patients and can educate patients during other touchpoints

## What are the key features of the intervention?

### Primary responsibilities:

- Dermatology nurses care for both AD inpatient and outpatients
- A dermatology nurse attends a number of dermatologist consultations (especially for paediatric patients and their parents, who usually require more support with treatment)
- One of the centre's 5 AD-specialised nurses may hold a subsequent education session for the patient (~30mins). The session may include:
  - Reinforcing the information received during the dermatologist consultation
  - Giving treatment demonstrations (e.g. cream application; wet wrap application)
  - Allowing patients to ask further questions about treatment
- Following the nurse education session, patients may book a follow-up appointment with the nurse (usually ~3–4 weeks later)

*Note: nurses are empowered to judge the need for follow-up appointments and schedule them as necessary*

- Nurses may also prescribe steroids, emollients, titrates, baths and wet wraps to AD patients
- Patients may call nurses (for issues relating to all dermatological conditions) via the department secretary (08:00–13:00, Mon–Fri)

**Sources:** (a) KPMG interviews



# Nurse shared responsibilities (2/2)

## What are the key features of the intervention? (cont.)

### Additional nurse activities:

#### Nurse education:

- Dermatology nurses at the centre have delivered teaching to nurses based in prison environments, in addition to an annual education session for nurses based in primary care

#### Patient panels:

- Nurses schedule patient panel meetings (~2hrs) in order to understand patient needs and experiences for specific dermatological conditions (including AD). The meetings are scheduled whenever staff wish to ask patients specific questions in a formal setting (i.e. not regularly)
- Previous topics include what patients seek from staff in the outpatient clinic, and the social and mental impacts of AD treatment
- Attendees:
  - Moderator (who may be internal or external, e.g. a nurse based in another department)
  - 3–6 patients (selected at random or from the dermatologist's knowledge of the patients)
  - ~4 physicians and / or nurses who are new to treating AD

#### Food provocation testing:

- Two nurses dedicated to food provocation testing perform the tests (typically following blood tests)
- Each nurse sees 3–4 patients per day, providing 7 increasing doses at 30 minute intervals
- A physician assesses the patient before each test and remains on standby for emergencies

## What are the outcomes so far?

### Benefits to patients:

- Opportunity to ask further questions
- Improved understanding of AD symptoms and disease progression
- Further guidance for AD self-management

### Benefits to HCPs:

- Greater flexibility to schedule follow-ups
- Patient feedback received (e.g. regarding which treatments are a burden for patients), which is used to inform future treatment plans

## What's next?

- Develop specialist tools for managing and educating adolescent patients (aged 12–18 yrs)

“



It is important that doctors and nurses who are new to AD understand the need for the different patient consultations

*Dermatology Nurse,  
Aarhus  
Universitetshospital*

“



Patients appreciate the extra time they have with nurses – it allows them to ask further questions and practice AD self-management techniques

*Dermatology Nurse,  
Aarhus  
Universitetshospital*



APPENDIX  
CENTRE REPORTS

# Integrated clinical and research laboratories (1/2)

## Overview

- Staff from the centre's clinical research laboratory and the university dermatology research laboratory meet regularly to propose new AD research projects. The laboratories together assess the value and feasibility of these projects, and collaborate on other initiatives (e.g. a Biobank established to support future dermatology research)

## What is the rationale?

- AD and atopic march patients often require tests (both general and specialist) during diagnosis, during treatment, and as required when participating in clinical trials<sup>(a)</sup>
- Maintaining a close relationship between hospital-based and university-based laboratory staff can improve the efficiency of hospital testing procedures, and facilitate a balanced assessment of the feasibility of new research ideas<sup>(b)</sup>

## What are the key features of the intervention?

### Hospital dermatology clinical research laboratory:

- A wet lab facility based on the main hospital site, employing 3 laboratory technicians and shared with the rheumatology department

*Note: some core facilities are shared with departments from across the hospital*

- Conducts regular tests for dermatology patients (e.g. blood tests), as well as tests required for patients participating in clinical trials

### University dermatology research laboratory:

- Based on the Aarhus University site, headed by a doctor of molecular biology and employing 2 full-time lab technicians and 10–15 research assistants
- Conducts research using AD patient samples (e.g. blood, skin biopsies (for protein analysis), subcutaneous fat tissue)
- Collaborates on international dermatology studies with institutions from countries around the world, including Germany, the USA and the UK (as well as others in Denmark)
- ~40% of the laboratory's research relates to AD

### Cross-laboratory collaboration:

- Monthly research meeting (1–1.5hrs):
  - Hosted by the dermatology unit and attended by staff from both laboratories
  - Attendees include university researchers, research nurses and dermatologists (and other specialists) with an interest in research
  - The meeting consists of a ~20min presentation from a member of either laboratory explaining their ongoing research or potential new clinical projects
  - Attendees subsequently discuss the value and feasibility of proposed projects (legal restrictions, resource requirements, etc.)

**Sources:** (a) Salvador S, et al. Atopic Dermatitis in Adults: A Diagnostic Challenge. *J Investig Allergol Clin Immunol*. 2017;27(2):78-88; (b) KPMG interviews



# Integrated clinical and research laboratories (2/2)

## What are the key features of the intervention? (cont.)

### Cross-laboratory collaboration (cont.):

- Biobank:
  - The hospital and university have created a dermatology biobank of patient samples (situated on the hospital site), for use in ongoing and future research projects
  - The centre has received approval from the Danish National Committee on Health Research Ethics to collect samples related to all inflammatory skin diseases

*Note: dermatology research projects at the centre are primarily funded by a numerous sources*

## What are the outcomes so far?

### Benefits to patients:

- The opportunity to participate in clinical trials and gain access to novel treatment options

### Benefits to HCPs:

- Input from multiple specialists on the value and feasibility of proposed AD research projects
- A store of AD patient biosamples for use in future, yet to be planned, research projects

## What's next?

- The hospital and university plan to expand the laboratory facilities based on the hospital site in order to support new types of research



APPENDIX  
CENTRE REPORTS



It is a two-way conversation between the laboratories – we both suggest ideas for new research projects and together assess what is feasible

*Molecular biologist, Aarhus University*

# Role of the occupational health physician (1/2)

## Overview

- The centre runs a specialist occupational health department, which aims to identify which substances / practices at work may be causing and exacerbating disease symptoms and advise on ways to manage AD in these environments

## What is the rationale?

- AD can impact a patient's ability to work (e.g. through pruritus [itch] disrupting sleep and subsequently affecting performance)<sup>(a)</sup>
- Symptoms may be aggravated by workplace conditions which involve exposure to allergens (e.g. cleaning detergents, rubber gloves)
- Hospitals employ occupational health physicians to improve employee welfare and reduce absenteeism due to sickness / poor health

## What are the key features of the intervention?

### Occupational health department – overview:

- The centre runs a specialist occupational health department, which employs 10 occupational health physicians (qualified medical doctors specialised in occupational health)
- Occupational health physicians (OHPs) aim to establish what substances / practices may be causing and exacerbating disease symptoms (including AD) at home or in the workplace
- Once these are identified, OHPs aim to provide advice (both to patients and their doctor) for managing AD in these environments
- An OHP may contact a manufacturer (e.g. of a workplace cleaning agent) directly in order to receive a declaration of product contents
- The occupational health department aims to see patients within 4 weeks of referral. The department receives referrals from:
  - Primary care physicians (~60%)
  - Private practice physicians (~25%)
  - Hospital-based dermatologists (~15%)

### OHP consultations:

- ~25% of patients attending an OHP consultation have AD
- During the initial consultation, an OHP records a detailed medical history of the patient (1–1.5hrs)
- Data is recorded in a standardised format in the centre electronic patient record (MidtEPJ)

**Sources:** (a) Schneider L, et al. Atopic dermatitis: A practice parameter update 2012. *The Journal of Allergy and Clinical Immunology*. 2013;131(2):295-299. doi: 10.1016/j.jaci.2012.12.672





# Role of the occupational health physician (2/2)

## What are the key features of the intervention? (cont.)

### Relationship with the dermatology unit:

- OHPs regularly attend the centre's multidisciplinary allergy centre (see case study pg. 102)
- Additionally, OHPs attend a monthly meeting with the dermatology unit, in order to discuss how the home / work lives of new and existing AD patients may impact their treatment plans:
  - ~2 dermatologists and ~6 OHPs attend
  - Up to 15 patients discussed during each session
- Patients can often be referred between the dermatology and occupational health departments on the same day (depending on urgency)
- An OHP may request patch, skin prick and blood tests (performed by the dermatology unit) in order to rule out certain conditions
  - Allergen samples are available from the centre's own store, or can be ordered from stores in the Netherlands and Sweden

## What are the outcomes so far?

### Benefits to patients:

- Practical advice received for managing AD symptoms in the workplace
- AD treatment plans designed to accommodate individual work commitments

### Benefits to HCPs:

- Ability to provide patients with detailed, tailored advice for managing AD at work

“



We regularly meet with dermatology, pulmonology and other specialties to discuss patients requiring occupational health advice

*Occupational health physician, Aarhus Universitetshospital*





# Use of telehealth services (1/2)

## Overview

- The centre uses telehealth services (in the form of secure image sharing and inter-centre videoconferences and) to show patients how their symptoms have changed over time and provide AD education for HCPs outside the centre

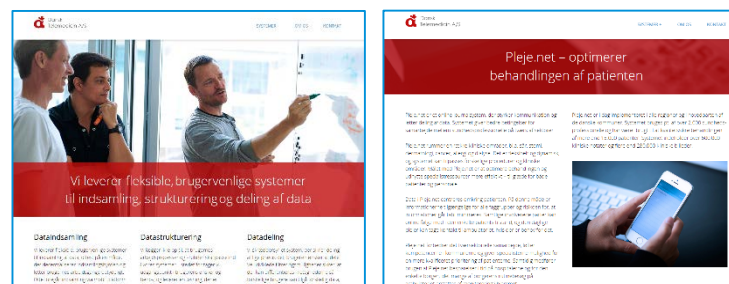
## What is the rationale?

- Telehealth services may allow physicians to monitor changes in patient symptoms over time and access specialist dermatology opinion on behalf of moderate-severe AD patients<sup>(a)</sup>

## What are the key features of the intervention?

### What does it involve?

- Dermatologists and nurses at the centre may store photographs of patient symptoms and transfer them to one another using a mobile phone application named 'Pleje Sundhed'<sup>(b)</sup>
- Images are taken using the app on a smartphone, before being encrypted and wirelessly transferred to a secure electronic database, which currently holds ~110,000 images
- No copies of the images remain on the phone used to photograph the patient
- The patient's identification and diagnosis is acquired through the Danish social number registry (Danish CPR<sup>(c)</sup>) and ICD10<sup>(d)</sup> respectively
- The app is used in all patient cases where it is relevant to obtain photographic documentation of the clinical presentation of skin symptoms, in order to monitor clinical changes over time



Screenshots: Dansk Telemedicin 'Pleje Sundhed' website

### How was it developed?

- The app was co-developed by the company Dansk Telemedicin and a clinician at the centre
- The clinician involved with developing the app has produced a user manual, and the use of the app follows all national Danish rules and guidelines concerning patient confidentiality

*Note: the centre only stores images of patient symptoms once the patient (or patient's parent / guardian) has provided their consent via the app*

**Sources:** (a) British Association of Dermatologists: UK guidance on the use of mobile photographic devices in dermatology (2017). [PDF] <http://www.bad.org.uk/shared/get-file.ashx?itemtype=document&id=5776>. Accessed 2 April 2019; (b) Dansk Telemedicin [Website] <http://www.telemed.dk/newsite/>. Accessed 9 Oct 2019; (c) How do I get a CPR number? Copenhagen – Welcome to Denmark [Website] <https://international.kk.dk/artikel/how-do-i-get-cpr-number>. Accessed 9 Oct 2019; (d) World Health Organization – ICD-10 Online Version [Website] <https://icd.who.int/browse10/2016/en>. Accessed 9 Oct 2019

# Use of telehealth services (2/2)

## What are the key features of the intervention? (cont.)

### Other examples of Telehealth services at the centre:

- The centre may also store images on the centre's main electronic database (the 'MidtEPJ' System), however this lacks the option to search by the patient's 10-digit ID number
- The centre holds regular meetings via videoconference with occupational health physicians based in Aalborg, who do not have access to a dermatologist for advice / guidance relating to AD and other dermatological conditions

## What are the outcomes so far?

### Benefits to patients:

- Access to a visual record of symptom changes over time
- Access to enhanced dermatology care in care settings located far from the centre (through the HCP videoconferencing initiative)

### Benefits to HCPs:

- A secure and consistent system for storing and transferring clinical photographs
- Specialist dermatology advice received by physicians located far from the centre



Teledermatology provides a valuable opportunity to monitor patient progress and share knowledge / advice with other HCPs treating AD patients

*Trainee dermatologist,  
Aarhus Universitetshospital*





# Centre Hospitalier Regional Universitaire (CHRU) Brest

**Brest, France**

Site visited by KPMG 16<sup>th</sup> – 17<sup>th</sup> May 2019

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[kpmg.com/uk](https://kpmg.com/uk)



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CENTRE REPORTS



# Summary



## Context

**Centre type:** University public hospital located in Brest and a national reference centre for pruritus

**Catchment area:** CHRU's catchment area spans half of Brittany, but the centre also receives referrals from the surrounding area (including referrals from other university hospitals)

**Funding:** CHRU Brest is a publically funded hospital

**Services:** The centre provides inpatient and outpatient healthcare to both adult and paediatric AD patients

**Patient population:** The dermatology unit serves adult and paediatric dermatology patients with a range of conditions (including atopic dermatitis [AD])



## Key strengths in the delivery of AD care

**Global leader for pruritus:** National pruritus reference centre with research ranging from fundamental science through to clinical research

**Key focus on patient education:** Centre provides 1:1 and group educational sessions for both paediatric and adult AD patients, emphasising peer-to-peer learning, including their self-designed 'Walk of Skin' game for paediatric patients

**Provision of psycho-social support:** Dermatologists work closely with a psychologist and psychiatrists to provide holistic patient care

**Strong partnerships with patient advocacy group (PAG):** Centre conducts research with the PAG in non-medical related areas that are not well known or prioritised (e.g. effects of AD on a patient's finances)



## Key challenges faced in delivery of AD care

**Shortage of ophthalmologists throughout France (including within Brest):** Limits the dermatology team's ability to collaborate and refer AD patients with ocular symptoms

**Absence of an allergy department:** Outside of Lyon and Paris, there are minimal allergy specialist departments, which has created a barrier to provide specialised dermatology-allergy services

**Lack of internal system to track number of active AD patients:** Difficulty quantifying exact AD patient numbers can impact on internal decision-making and funding/resource obtainment

# Atopic Dermatitis (AD) in France

## French healthcare system:

The French healthcare system provides free healthcare to French residents and is predominantly funded through compulsory statutory health insurance (SHI).<sup>(a)</sup> SHI is largely managed by the state and is financed through:

- Payroll and income tax (85%);
- Taxes levied on tobacco and alcohol, the pharmaceutical industry, and voluntary health insurance companies (13%); and
- State subsidies (2%).

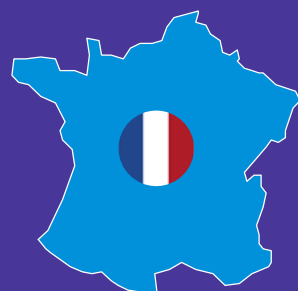
SHI covers 70% of healthcare expenditure and is complemented by private voluntary health insurance (VHI). VHI is provided by employers schemes or a means-tested government vouchers and covers approximately 95% of the population. It partially covers patient costs of publically funded services. The remainder is paid for by the patient or supplementary private health insurance<sup>(a)(b)</sup>

## Brittany healthcare system:

The Brittany Regional Health Agency is responsible for the implementation of health policy in Brittany. The Agency is responsible for planning and delivering population healthcare, which includes healthcare delivery, public health and social care. Broadly, planning is segregated into three areas: hospital sector services, health and social care services for the elderly and disabled and ambulatory care services<sup>(a)</sup>

## Prevalence

- AD affects 10–20% of children and 1–3% of adults in Western countries<sup>(c)</sup>
- In France, the prevalence of adult AD is 8%<sup>(d)</sup>



## Care provision:

### Location:

- Mild (or well-controlled) AD care is usually managed by Primary Care Professionals (PCPs) or private dermatologists
- Moderate and severe (or uncontrolled) AD care is usually managed by hospital dermatologists

### Funding:

- Primary care is generally funded through the SHI through a fee-for-service, yearly capitation per person or monthly income model<sup>(a)</sup>
- Hospital care is funded through the diagnosis-related group (DRG), predominantly subsidised through SHI<sup>(a)</sup>

## Guidelines and societies:

### Guidelines:

- Guidelines for treatment of atopic eczema (atopic dermatitis) part I and part II: European Association of Dermatology and Venerology (EADV)

### Medical society:








- Société Française de Dermatologie et de Pathologie Sexuellement Transmissible – French Society of Dermatology (SFD)

### Patient advocacy group (PAG):

- Association Francaise de l'Eczema

**Sources:** (a) International Health Care System Profiles. The French Health Care System [Website] <https://international.commonwealthfund.org/countries/france/>. Accessed 28 May 2019; (b) The King's Fund [Website] <https://www.kingsfund.org.uk/publications/how-health-care-is-funded>. Accessed 28 May 2019; (c) Nutten S. Atopic dermatitis: global epidemiology and risk factors. *Ann Nutr Metab.* 2015;66 Suppl 1:8-16. doi:10.1159/000370220; (d) Kowalska-Oledzka E, et al. Epidemiology of atopic dermatitis in Europe. *Journal of Drug Assessment.* 2019;8(11):126-128. doi: 10.1080/21556660.2019.1619570

# The centre and dermatology unit

The centre		
 <b>Type and location</b>	<ul style="list-style-type: none"><li>— CHRU Brest is a publically funded university hospital</li><li>— Located in Brest in the Brittany region of France</li></ul>	
 <b>Population served</b>	<ul style="list-style-type: none"><li>— Catchment area: patients from Brest and wider Brittany area</li><li>— Dermatology unit delivers ~16,000 consultation per annum</li></ul>	
The dermatology unit		
 <b>Service Division</b>	<b>Outpatient service</b>	<b>Inpatient service</b>
 <b>Hours of availability</b>	Monday – Friday 09:00 – 17:00	24/7
 <b>No. of patients seen</b>	~250 AD patients in total	15 inpatient beds dedicated to dermatology
 <b>Types of patients seen</b>	Paediatric and adult AD patients (mostly with moderate-severe AD)	
 <b>Facilities on-site<sup>(1)</sup></b>	<ul style="list-style-type: none"><li>— Allergy testing</li><li>— Research laboratory onsite</li><li>— Phototherapy (UVB/PUVA)</li><li>— Day hospital</li><li>— Clinical trial facilities (currently running 10 clinical trials on AD)</li><li>— Inpatient unit (15 beds)</li></ul>	

**Note:** (1) List of facilities is not exhaustive


# The team




## Core team profile

 **5** FTE dermatologists  
(10 private dermatologists provide centre consultations once a week)


 **7** Dermatology interns/residents

 **2** Dermatology nurses (one full-time and one part-time dedicated to outpatients; with 8 – 10 separate inpatient nurses)

## Wider team profile

 **2** Psychiatrists (1 paediatric, 1 adult)

 **1** Psychologist

 **1** Dermatologist (with allergy sub-specialism)

 **3** Pneumologists

 **1** Service co-ordinator

## Governance and processes

### Team meetings:

- *Weekly meeting (11:00am every Thursday):*
  - Attended by: the department's 6 permanent dermatologists and the nurse supervisor
  - Purpose of the meeting: to discuss all departmental administrative, organisational and staff issues



**Note:** Please see pg. 117 for further details about the wider team

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients with symptoms of AD (e.g. itching or dryness of the skin) will present to a primary care physician (PCP) or private dermatologist
- Note: AD patients that are well-controlled or mild may be managed by PCPs and private dermatologists, and not referred to the centre*
- Patients may self-present to the centre's emergency department

## Diagnosis and Referral

In secondary and tertiary care



- Patients are referred to the dermatology department by PCPs or private dermatologists (and sometimes other hospitals)
- The speed at which referred patients are seen varies with symptom severity / urgency
- Patients are assessed by a dermatologist, who will explore patient history and perform a clinical examination. They may perform an IgE blood test and record EASI, SCORAD, VAS and NRS scores (consultation duration varies)
- Patients will usually receive 1:1 therapeutic education from a nurse immediately after their dermatologist consultation (consultation = 30-45 mins), or soon after

## Treatment and Management

Medical management



- Treatment options are discussed with the dermatologist in the first consultation
- Patients are referred to comorbidity specialists if required (e.g. pneumologist)
- Severe patients may be offered hospitalisation for intensive treatment / moisturising and de-stressing if required
- Dermatologists and dermatology nurses manage both paediatric and adult patients (so no formal transition of care from paediatric to adult care is required)
- Patients may be offered the opportunity to participate in different clinical trials (CTs)

Non-medical management



- Patients requiring psychosocial support can be referred to the:
  - Joint dermatologist-psychiatrist clinic (1/fortnight or 1/month, consultations = 30mins – 1hour)
  - 1:1 consultations with the psychologist (consultations = 30 – 45 mins for outpatients, up to 1 hour for inpatients)
  - Group education (which enables peer-to-peer support) provided by the nurses, psychologist and dermatologists (*Note: this is offered to all patients*)

## Follow-up

Monitoring of chronic disease / flare up



- Patients can choose whether to continue care in the centre (or be referred to a private dermatologist with a treatment plan)
- Follow-up dermatologist consultations occur on average every 3 months, but can be more frequent (however, patients are initially followed up by the dermatology nurse for further therapeutic education within 1 week – 1 month, depending on severity)



# Roles of the wider team

## Psychiatrists

**Patient type:** Paediatric and adult patients suffering from psychiatric conditions linked to chronic dermatological conditions

**Referral:** Referred by the dermatologist

**Consultations:** Parents / relatives are encouraged to attend and they involve discussing the patient's skin condition and the resulting psychological impact.

Paediatric patients receive joint consultation with the paediatric dermatologist and paediatric psychiatrist from the centre and the adult patients receive consultations from a dermatologists and adult psychiatrist from outside the centre

**Timing:** Initial joint consultations last 45-60 minutes and joint follow-up consultations last 30 minutes

## Psychologist

**Patient type:** Paediatric and adult AD patients exhibiting psychological symptoms (as a result of AD) or existing psychological pathology (i.e. not related to their AD)

**Referral:** Referred by dermatologist or psychiatrist (from joint clinic)

**Consultations:** Onsite 1:1 consultation (psychologist works at centre 2 days per week) with patient to discuss AD and psycho-social impact

**Timing:** Consultations up once a week (depending on patient need), lasting 30-45 mins for outpatients and 1 hour for inpatients



## Pneumologist

**Patient type:** Adult AD patients with severe or uncontrolled asthma (paediatric patients are seen by paediatric pneumologist, with 2-3 joint consultations with paediatric and adult pneumologists when patients transition care)

**Referral:** Referred by dermatologist (from centre), private dermatologist, PCP or presentation via the centre's emergency unit

**Consultations:** Specialist asthma nurse (L'infirmier en pratique avancée) provides general asthma education, QoL assessment and conducts standard tests (e.g. spirometry and peak flow tests) before physician joins to discuss treatment options

**Timing:** Consultations last 30 mins – 1 hour

## Dermatologist with sub-specialism in allergology

**Patient type:** AD patients with associated allergies

**Referral:** Referred by dermatologist

**Consultations:** Allergologist joins dermatology team for 2-days per week (dermatologist with sub-specialism in allergology)

**Timing:** Consultations last up to 30 mins

**Note:** (1) List of additional centre roles is not exhaustive

# Overview of interventions in place for AD



Key:



Case study available



## Awareness and Presentation



Symptom identification

- **Working in collaboration with the patient advocacy group (PAG) : Association Française de l'Eczéma (FAE).** The dermatology unit closely collaborates with FAE to research and understand the impact of AD. The research areas covered include the AD impact of:
  - living with itch,
  - quality of life,
  - sexual life,
  - financial cost to the patients

See pg. 123 for case study

## Diagnosis and Referral



In secondary care

- **On-site laboratory:** Access to specialist tests for AD patients (e.g. skin prick, immunology tests etc.)
- **Collaboration with private dermatologists:** 10 private dermatologists conduct AD clinics for a few hours once a week at the centre, selected for their complimentary sub-specialties (e.g. psycho-dermatology; allergology) to support the core AD team

## Treatment and Management



Medical management

- **Dermatology team member with allergology sub-specialism:** The teams hosts a dermatologist with allergology sub-specialism twice a week, who sees AD patients with co-morbid allergies

- **Joint psychiatry-dermatology clinics:** AD patients (adult and paediatric) have access to a fortnightly monthly combined clinic with a psychiatrist and dermatologist

See pg. 124-125 for case study

- **Clinical trial recruitment:** AD paediatric and adult patients can utilise novel treatments or therapies through participation in clinic trials at the centre (10 trials are currently ongoing)



Non-medical management

- **Music therapy trial:** AD patients were able to participate in the centre's personalised music therapy study aiming to alleviate pruritus and anxiety and improve quality of life
  - See pg. 126 for case study
- **Onsite psychologist:** A psychologist is available twice a week to provide AD patients with 1:1 psycho-social support
  - See pg. 127-128 for case study
- **Provision of group education (including 'Walk of the skin' game):** Adult and paediatric patients (including their parents) from the centre and outside, can attend group education delivered by the dermatology nurses, dermatologists and psychologist
  - See pg. 129-130 for case study
- **1:1 nurse-led patient education:** All AD patients (both adult and paediatric) receive multiple sessions of 1:1 therapeutic education from the dermatology nurses
  - See pg. 131 for case study

## Follow-up



Monitoring of chronic disease/flare up

- **Emergency dermatology service:** Patients with flares or other urgent dermatological needs may self-present to the general emergency department
- **Pruritus National Reference Centre:** The centre is heavily involved in pruritus-focused research and offers AD patients a variety of pruritus management techniques and programmes
  - See pg. 132-133 for case study



# Monitoring AD patients and comorbidities

## The dermatology unit employs a number of measures for monitoring AD and associated comorbidities

### Objective measures (AD):

AD scoring indices are used by some of the dermatologists to monitor patients and their disease, including:

- SCORAD (SCORing Atopic Dermatitis): to assess AD disease severity and monitor patient progress<sup>(a)</sup>
- EASI (Eczema Area and Severity Index): validated scoring system that grades the physical signs of atopic dermatitis<sup>(b)</sup>

The centre prefers to have a conversation with patients to assess their quality of life (versus using formalised scales), as they prefer to 'de-medicalise' this conversation

### Patient-reported outcomes:

The centre may use the following scales to assess pruritus:

- Peak Pruritus NRS (Numerical Rating Score): involves asking the question "On a scale of 0 to 10, with 0 being 'no itch' and 10 being 'worst itch imaginable', how would you rate your itch at the worst moment during the previous 24 hours?"
- Pruritus VAS (Visual Analogue Scale): involves the same two questions as the NRS, but showing a patient a 10cm line for them to mark X on that represents their itch (0 = no itch; 10 = worst imaginable itch)

---

### Dermatology unit routinely measures comorbidity outcomes by:

- *Psychologist: does not use formal scales to assess psycho-social symptoms as prefers to 'de-medicalise' the conversation*
- *Pneumologist: standard lung function tests*

**Sources:** (a) SCORing Atopic Dermatitis (SCORAD) Calculator (0.9.0). [PDF] <http://scorad.corti.li/>. Accessed 26 Feb 2019; (b) Charman CR, et al. Translating Patient-Oriented Eczema Measure (POEM) scores into clinical practice by suggesting severity strata derived using anchor-based methods. *Br J Dermatol.* 2013;169(6):1326–1332; (d) Lewis V, et al. 10 Years Experience of the Dermatology Life Quality Index (DLQI). *J Invest Dermatol Symp Proc* 2004;9:169–180

# Advice to other centres



## What advice would you give less specialised centres?



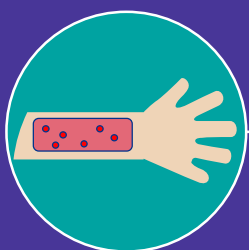
**Objective of advice:** Enable peer-to-peer sharing of AD management techniques, in addition to healthcare professional-led therapeutic education

- **Why?** Patients often enjoy meeting and learning therapeutic / non-therapeutic management techniques from other people with AD who have a shared experience. Group education sessions also enable participants to learn from the questions asked by other attendees, that they may not have thought of or felt comfortable asking otherwise



**Objective of advice:** Recognise the importance of psycho-social support in AD and incorporation of other healthcare professionals into the team to deliver this

- **Why?** The shift towards patient centric care means healthcare professionals need to consider all aspects of the patients life. Embedding different team members, such as psychologists and music therapists, into the dermatology team allows ease of referral and improved co-ordination of care delivery. Having psychological specialists in the team encourages holistic care to be prominent and allows patients to be seen by the appropriate specialists



**Objective of advice:** To recognise the impact of Pruritus on patient quality of life and the effect it has on HCP and treatment engagement

- **Why?** Pruritus represents a large unmet need for patients suffering with AD and whilst it is subjectively felt by patients, the recognition of the effect of pruritus on a patients quality of life is growing. Pruritus can be part of a vicious cycle in that even if AD is well controlled pruritus can persist and is notoriously difficult to treat<sup>(a)</sup>

**Source:** (a) Grundmann S, et al. Chronic pruritus: clinics and treatment. *Ann Dermatol.* 2011;23(1):1-11. doi: 10.5021/ad.2011.23.1.1

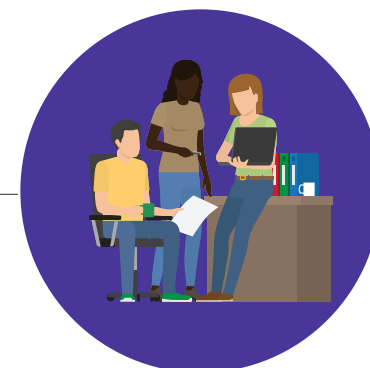
# Next steps for the centre



## What is next for the centre?

### Objective: Expand collaboration with other departments (including setting up joint clinics where needed)

- **What?** The dermatology department would like to begin collaborating with ophthalmology, and explore the potential of setting up a joint clinic with pneumology (who they already collaborate closely with) for AD adults and children with asthma and/or hay fever
  - Dermatology already runs joint consultations with: psychology, plastic surgery, odontology / genetics / rheumatology / paediatric-psychiatry, neurology and paediatric-surgery
- **Why?** Knowledge sharing between HCPs happens fastest when they are co-located and reviewing the same patient. AD patients would also benefit from reduced trips to the hospital in terms of less costs and disruption along with quicker definitive treatment



### Objective: Secure ADCARE<sup>(a)</sup> membership; Atopic Dermatitis Centers of Reference and Excellence.

- **What?** The centre is currently exploring the selection criteria and collating relevant historical data required for ADCARE membership. ADCARE is a (GA<sup>2</sup>LEN) Global Allergy and Asthma European Network of Excellence that consists of leading centres in allergology and asthma. It aims to integrate research activities across centres specialising in allergic diseases. To gain membership, centres are required to demonstrate scientific excellence, multidisciplinary working (such as with ophthalmology and pneumology), international collaboration and delivery of educational activities. The centre has completed 25 of the 32 necessary criteria with only 7 remaining. As a next step the centre plans to build a database of existing patients to understand accurate numbers of patients groups
- **Why?** Qualifying for ADCARE membership will enable the centre to network and collaborate with other well established international centres. The GA<sup>2</sup>LEN ADCARE programme will result in a strong network of atopic dermatitis specialists, promotion of AD research, and harmonisation and improvement of AD management globally<sup>(a)</sup>



**Source:** (a) About us. ADCARE: A GA<sup>2</sup>LEN network. [Website] <http://ga2len-adcare.net/about-us/>. Accessed 10 July 2019

# Case studies



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# Working in combination with the PAG

## Overview

- CHRU Brest collaborates closely with the Association Française de l'Eczéma (FAE), the French AD patient advocacy group (PAG)
- Together they conduct research on lesser known / researched areas relating to AD and pruritus

## Association Française de l'Eczéma (FAE) in France

- The FAE is an association that aims to “communicate and inform (people) about the disease (*AD contact dermatitis*)” and “support patients and their families to contribute to the improvement of their quality of life in collaboration with health professionals.”<sup>(a)</sup>
- Founded in 1901, the FAE focuses on providing patient education materials and raising awareness of eczema treatment options<sup>(b)</sup>

### FAE-CHRU Brest activities:

- Objective: To better understand and inform on disease impact and treatment effectiveness
  - Role of centre:

The centre collaborates with FAE to identify, develop and deliver studies focussing on 4 key areas of research that have been historically lesser known:

- Pruritus (e.g. by exploring the relationship between severity of pruritus in AD to the severity of AD)<sup>(c)</sup>
- Association of AD patient burden with Quality of Life<sup>(d)</sup>
- Understanding and measuring the out-of-pocket expenses for AD patients in France through a self-assessment questionnaire<sup>(d)(e)</sup>
- Assessing the impact of atopic dermatitis on sexual health<sup>(f)</sup>

### FAE activities:

- *Development of patient education materials*
  - FAE have developed a magazine ('Eczema Magazine') and online material to educate patients on eczema, treatment options and general advice<sup>(b)</sup>
  - In September 2016, FAE launched the first web series on eczema types and different treatment options<sup>(b)</sup>
- *Organisation and facilitation of National Day of Eczema in Paris, France*<sup>(b)</sup>
  - Facilitation of day event, focusing on the impact of eczema on the family unit

**Sources:** (a) Association Française de l'Eczéma. [Website] <https://associationeczema.fr/>. Accessed 12 June 2019; (b) French Association of Eczema. Les Thermalies. [Website] <https://www.thermalies.com/paris/pressepartenaires/espace-partenaires/association-francaise-de-leczema/>. Accessed 12 June 2019; (c) Huet F, et al. Characteristics of Pruritus in Relation to Self-assessed Severity of Atopic Dermatitis. *Acta Derm Venereol.* 2019;99(3):279-283; (d) Misery L, et al. Patient Burden is Associated with Alterations in Quality of Life in Adult Patients with Atopic Dermatitis: Results from the ECLA Study. *J Acta Derm Venereol.* 2018;98(7):713-714. doi: 10.2340/00015555-2940; (e) Launois R, et al. Importance of out-of-pocket costs for adult patients with atopic dermatitis in France. *J Eur Acad Dermatol Venereol.* 2019; 33(10):1921-1927. doi:10.1111/jdv.15581; (f) Misery L, et al. The impact of atopic dermatitis on sexual health. *J Eur Acad Dermatol Venereol.* 2019;33(2):428-432. doi: 10.1111/jdv.15223.





# Joint psychiatry-dermatology clinics (1/2)

## Overview

- Hosted alternatively every 2 or 4 weeks. AD patients have a 30 minute – 1 hour combined session with both a psychiatrist and dermatologist. The psychiatrists have developed substantial experience working with patients suffering with dermatology conditions, including AD



## What is the rationale?

- AD can cause significant impact on the psychological health of patients<sup>(a,b,c)</sup>
- A patient's psychological state of mind can impact upon treatment adherence<sup>(d)</sup>
- Adolescents with AD have been found to have elevated rates of anxiety (20%) and depressive disorders (10%) compared to the general population<sup>(e)</sup>

## What are the key features of the intervention?

- Paediatric patients are referred to joint consultations with a paediatric dermatologist and paediatric psychiatrist from within the centre. Paediatric patients are seen together with their parents and doctors from both specialities
- Adult patients are offered a joint clinic with a dermatologist and an adult psychiatrist from outside the centre. Patients are encouraged to bring relatives if they wish
- Patients are referred if the patient (or parent) spontaneously mention psychological suffering or that stress is triggering AD flares
- The psychology and psychiatry departments are interested in the psychological impact of dermatological conditions and HCPs are paired together who work well together, value each other and have a shared interest and vision
- Patients will often start by talking about skin problems and that is a good entry to the conversation. Psychological insights tend to come later after the trust has been built
- Clinic appointments are built with appropriate time for psychological consultations with 45 minutes minimum which compares to the general dermatology clinics lasting 10 minutes

## Consultation format

### Paediatric

45 minute first consultation (and 30 minute follow-up) where doctors let parents and patients talk about their skin and the impact it has on their lives. The doctors may ask questions, guide or purely observe the conversations and are conscious of not letting the parents dominate conversations

### Adult

45 minute first consultation (and 30 minute follow-up) where HCPs talk to patients and their relatives about the impact of AD on the different aspects of their life

**Sources:** (a) Barankin B, et al. Psychosocial effect of common skin diseases. *Can Fam Physician*. 2002;48:712–716; (b) Lifschitz C. The impact of atopic dermatitis on quality of life. *Ann Nutr Metab*. 2015;66(suppl 1):34-40; (c) Gochnauer H, et al. The Psychosocial Impact of Atopic Dermatitis. *Adv Exp Med Biol*. 2017;1027:57-69. doi: 10.1007/978-3-319-64804-0\_6; (d) Reach G. Can we improve treatment adherence in patients with chronic disease? *Bioethics Forum*. 2014;7(3); (e) Slattery MJ, et al. Depression, anxiety, and dermatologic quality of life in adolescents with atopic dermatitis. *J Allergy Clin Immunol*. 2011;128(3):668-71. doi: 10.1016/j.jaci.2011.05.003



# Joint psychiatry-dermatology clinics (2/2)

## Key features continued

### Follow up

The doctors both try to talk equally and provide management advice such as psycho-corporal relaxation techniques. The case is discussed for follow up and they may come to one of the below conclusions:

1. See the patient again in another joint session with both physicians in 2 – 3 months time (after they have had a chance to work on the advice given);
2. Refer the patient to either a psychologists or a psychiatrist clinic
3. Refer the patient to a pure dermatologists clinic; or
4. Refer the patient and parents to attend the walk of skin game workshops if the patient is paediatric and they believe they will benefit from further education

## Challenges

- Patients are not looking for psychological support, they are rather looking for dermatological support<sup>(a)</sup>
  - Patients may not understand the complete benefit of joint consultation with a psychiatrist and may not recognise the need for psychiatric input

## What are the outcomes so far?

### Benefits to patients:

- Patients receive psychological support in a dermatology setting (removes stigma of seeking mental health support)
- Improved mental health promotes disease ownership and treatment adherence

### Benefits to HCPs:

- Less time spent in general clinic dealing with psychological issues as they can refer to the joint clinic for those needing this
- Knowledge that the dermatology team has the correct expertise to manage the psychological needs of their patients

**Sources:** (a) de Zoysa, P. Psychological interventions in dermatology. *Indian J Dermatology*. 2013;58(1):56-60. doi:10.4103/0019-5154.105312

“

“We want to help patients get out of the bubble that their parents have created”

*Paediatric dermatologist, CHRU Brest*



“

“We see patients whose AD has caused blocks in their relationships, intimacy, sexuality”

*Adult psychiatrist working with CHRU Brest*



# Music therapy trial

## Overview

- CHRU Brest conducted a clinical trial (PRURI-MUSIC) to provide music therapy for AD patients with intractable itch. The aim was to alleviate pruritus, anxiety and improve satisfaction and quality of life

## What is the rationale?

- Music therapy has demonstrated positive patient benefits in various conditions such as anxiety and pain<sup>(a)(b)</sup>
- In France, music therapy has been established a complementary therapeutic treatment for pain. It is thought to impact the sensory, cognitive, psychological and behavioural processes<sup>(c)</sup>
- Pruritus is thought to have a similar pathophysiology to pain, suggesting music therapy may be useful as a complementary treatment option

## What are the key features of the intervention?

- CHRU Brest collaborated with a music software company to conduct a clinical trial (PRURI-MUSIC) to provide regular music therapy sessions for 50 AD patients at the centre. The software analyses the musical preferences of a patient beforehand to personalise the therapy
- The aim was to alleviate pruritus and anxiety and improve quality of life
- The idea was based on successful treatment of chronic pain through musical therapy
- Each therapy session (~15 mins) was tailored to the patient's musical preference and patient progress was assessed against outcome measures, including impact on:
  - pruritus intensity, perceived anxiety, quality of life and patient satisfaction towards the music sessions
- The sessions are run for individual inpatients and may involve singing to improvised or familiar songs, listening to music via headphones or moving to different songs

## What are the outcomes so far?

### Benefits to patients:

- Potential alleviation of pruritus and anxiety
- Complementary therapy can improve effectiveness of medical treatment

### Benefits to HCPs:

- Potential to reduce intensity of medical interventions if therapy is effectively managing pruritus and pain

## What's next?

- The centre plans to publish a paper containing the results of the study

**Sources:** (a) Ribeiro MKA, et al. Music therapy intervention in cardiac autonomic modulation, anxiety, and depression in mothers of preterms: randomized controlled trial. *BMC Psychol.* 2018;6(1):57. doi: 10.1186/s40359-018-0271-y; (b) Bradt J, et al. Music interventions for improving psychological and physical outcomes in cancer patients. *Cochrane Database of Systematic Reviews.* 2016(8). doi: 10.1002/14651858.CD006911.pub3; (c) Study Evaluating the Benefit of Music Therapy on Pruritus in Patients With Pruritic Dermatitis (PRURI-MUSIC). ClinicalTrials.gov [Website]. <https://clinicaltrials.gov/ct2/show/record/NCT03701971>. Accessed 12 June 2019.

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# Onsite psychologist (1/2)

## Overview

- The dermatology unit hosts an onsite psychologist 2 days a week, for both adult and paediatric AD patients in need of psychological support



"I prefer to see patients frequently at the start as they may not want to express orally until we have built a relationship"

*Psychologists, CHRU Brest*



## What is the rationale?

- AD is a complex disease that is not always well controlled and can impact patient quality of life in multiple ways<sup>(a)</sup>
- Living with AD can have significant psycho-social implications and patients may disengage with therapy<sup>(a)</sup>

## What are the key features of the intervention?

- Referrals for any adult or paediatric dermatology patient can be made to the team psychologist for a 1:1 consultation.
  - The psychologist works 2 days a week in the dermatology department (and works three days a week in a psychiatry unit within a general hospital)
- The psychologist receives referrals from either the dermatology clinic or the psycho-dermatology adult or paediatric clinics
  - Patients referred either have a type of dermatological conditions that has led to a psychological issue, or they have a concomitant psychological pathologies (e.g. have depression not caused by AD). In the latter case it is believed treatment of their depression will improve management of their dermatological condition
- The psychologist utilises different mediation methodologies and psychoanalytic-derived therapies to help patients

## Consultation format

- Consultations are scheduled as frequently as required (up to once a week for outpatients).
  - They usually last one hour for inpatients, as their disease suffering is often more acute, or 30 to 45 minutes for outpatients
- During consultations, support is tailored to the patient's non-medical needs (e.g. depression) and indexes/scales are generally not utilised, as the psychologist prefers to qualitatively assess patients and aims to de-medicalise conversations
- Patient can either continue to receive centre psychological support or may be referred to a private psychologist or to the attached Medico-Psychological Centre (CMP) for further support. Referral is based upon patient need along with proximity to centre and insurance cover.

**Sources:** (a) Lifschitz C. The impact of atopic dermatitis on quality of life. *Ann Nutr Metab* 2015;66(suppl 1):34-40



# Onsite psychologist (2/2)

## What are the key features of the intervention? (cont.)

### Additional activities

- In addition to the patient facing role, the onsite psychologist also supports the development of centre research, care and education. This includes multiple 1-day taskforce meetings per annum to discuss:
  - updates from international research studies,
  - identification of new psycho-dermatology research opportunities for the centre,
  - preparation of articles for congress presentations and
  - discussions of ways of working between the psychologist, psychiatrists and dermatologists
- The psychologist also delivers regular 1-2 hour educational meetings (of variable frequency) with the inpatient dermatology nurses (1-2 nurses attend) on provision of psychosocial support for dermatology patients

## What are the outcomes so far?

### Benefits to patients:

- Parents of children with AD are able to access psycho-social support to help their child cope
- Improved mental well being has the potential to improve compliance and reduce flares

### Benefits to HCPs:

- Patient psychological needs are addressed
- Broad psychosocial education to healthcare professionals enables holistic patient care
- An in-house psychologist makes peer-2-peer learning a possibility for HCPs

## What's next?

- Develop formal joint psychologist-dermatologist consultation
- Input and share facilitation of the educational walk of the skin game as her predecessor did

“



“I don't use any specific scales as I want to treat patients as individuals and not patients. The support I provide is not meant to be 'medical'. They already receive medical treatment in their dermatologist consultations so I want this to feel relaxed and different”

*Psychologist, CHRU Brest*

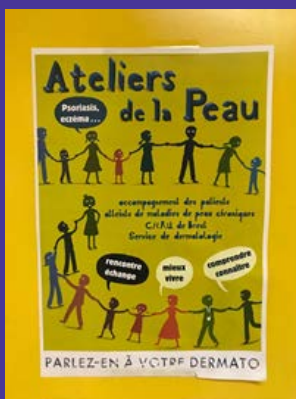


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# Provision of group therapeutic education; including "Walk of Skin" game (1/2)

## Overview

- Group therapeutic educational sessions are offered. This allows patients the opportunity to share their experiences and learn 'tips and tricks' to condition management



## What is the rationale?

- Patient support groups are an effective means of educating patients<sup>(a)</sup>
- Peer networks foster better engagement<sup>(b)</sup> and ownership of their condition management
- Entertainment in education increases participation and information retention<sup>(c)</sup>

## What are the key features of the intervention?

- Dermatology nurses, in collaboration with the psychologist and dermatologist, offer group educational sessions for adults and children. Group sessions have been run at the centre since 2006 and they provide the opportunity for peer-to-peer education (e.g. techniques for pruritus management)

### Adults

- Patients are invited to expression groups (~6 attendees) lasting 2 hours. These have no set agenda but allow patients to talk about issues relating to AD and share experiences, tips and frustrations. The groups run 2-3 times per year

### Paediatrics patients are invited to the "Walk of skin game":

- The game has been part of the therapeutic education offering since 2017. It was developed over 2 years through a collaboration of the dermatologists, nurses and a psychologist. It aims to educate patients about what they need 'in their backpack' in terms of treatments at different times of year or at different environments throughout the day in order to best manage their AD / skin
- The game sessions last 2–3 hours and are facilitated by a dermatology nurse and psychologist. Sessions run 7 times a year usually during school holidays. The game is delivered in groups of children of homogenous age (infant + parent; 6-8; 8-10; 10-13; 13-17). Parents often watch in the background but do not usually participate
- Prior to development of the walk of skin game, therapeutic educational sessions were offered for younger children in the format of puppet shows. Paediatric patients would make a puppet and were handed a baton by HCPs at which point they could talk. This then evolved into a more interactive session and a game idea was developed
  - The walk of skin board game aim was to engage the children and provide a platform to let them teach each other. The game is always under the guidance of the HCPs who can rectify any advice that is incorrect
  - Parents prefer the game as they understand its educational value

**Sources:** (a) Adams RJ. Improving health outcomes with better patient understanding and education. *Risk Manag Healthc Policy*. 2010;3:61–72. doi:10.2147/RMHP.S7500 (b) Optum White Paper [PDF] <https://cdn-aem.optum.com/content/dam/optum3/optum-eon/resources/white-papers/PeersImproveOutcomes.pdf>. Accessed 12 June 2019; (c) Devonshire IM, et al. Risk-based learning games improve long-term retention of information among school pupils. *PLoS One*. 2014;9(7):e103640. doi:10.1371/journal.pone.0103640

# Provision of group therapeutic education (2/2)

## What are the key features of the intervention? (cont.)

### Walk of skin game cont.

- HCPs are there to answer questions / rectify any incorrect information shared, but they encourage peer-to-peer sharing of information
- Doctors from general practice can refer AD patients who may not need secondary dermatology care to the walk of skin game but would benefit from education

## Challenges

- Group members need to be selected properly in order to succeed. This means correct age groups clustered together and the right number of participants (no more than 6)
- Participants can sometimes be shy or dominant but facilitators are adept at managing all types of patients

## What are the outcomes so far?

### Benefits to patients:

- Patients are able to see that they are not alone in managing their condition and are able to meet others who have the same problems
- Patients are able to associate learning about their condition with fun

### Benefits to HCPs:

- Group sessions are an effective use of HCP time
- The game encourages participants to take ownership of their AD management and reduces consultation time spent educating patients

## What's next?

- The game is being presented to other centres in France this summer and will be available for dermatology departments throughout France
- There is potential to amend the game to suit other chronic conditions with poor patient awareness and which could benefit from therapeutic education

“

“The power of putting kids into groups to develop knowledge in a peer network is 10 times more effective than HCPs lecturing patients about education and adherence”

*Psychiatric dermatologist, CHRU Brest*



“

“Group sessions where participants are having fun are a joy to facilitate and are really effective at educating patients”

*Paediatric nurse, CHRU Brest*





# 1:1 nurse-led patient education

## Overview

- Dermatology nurses provide 1:1 therapeutic education sessions with AD patients (and parents/relatives)



“Nurse led education sessions allow patients to ask more questions and ensure we can check they understand our advice”

*Nurse, CHRU Brest*



## What is the rationale?

- Adequate education is a cornerstone of AD care
- Nurse led clinic sessions receive higher parent satisfaction than doctors<sup>(a)</sup>
- Some patients prefer 1:1 consultations rather than group sessions

## What are the key features of the intervention?

- Individual sessions with the dermatology nurses last 30-45 minutes and can sometimes involve trainee dermatologists or nurses. Referrals are from the general dermatology clinic and where possible education sessions are delivered immediately after first dermatologist consultation
- Topics covered in the session include:
  - Hygiene advice
  - Topical corticosteroid anxiety myth busting
  - Treatment quantities and treatment ladder advice
- The nurses may demonstrate how to apply the different topical treatments and ask the patients to show them how they apply it.
- The nurses may test the knowledge of the patients and invite them to try new products so that when they have flares they will know what treatments to use and how to best manage the flare in terms of pain management, hygiene and product application

## Follow up

- Follow up would depend on the severity of disease at the time. Well patients attending for education may not need follow up but patients seen in the middle of a flare or patients who the nurses feel have not fully understood will be asked to book in to be seen a week later
- At a weekly follow up the nurse would ask to see the empty tube of topical treatment to assess if the patients are using the correct amounts
- If schedules do not allow face-2-face follow up then the nurses will call the patient so that they know they will not be lost to follow up

## What are the outcomes so far?

### Benefits to patients:

- Patients are able to build another HCP relationship and to ask more questions
- Patients receive more focussed educational attention

### Benefits to HCPs:

- Nurses feel empowered and are highly valued by the patients
- Doctors are able to spend time with medical issues knowing education is addressed
- Better education improves patient compliance

**Sources:** (a) Sullivan PB, et al. Parent satisfaction in a nurse led clinic compared with a paediatric gastroenterology clinic for the management of intractable, functional constipation. *Arch Dis Child*. 2006;91(6):499-501. doi:10.1136/adc.2005.087486

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# Pruritus National Reference Centre (1/2)

## Overview

- The centre has a strong focus on pruritus-related research and acts as a national reference centre for France. Research topics include the pruritus pathophysiology, management techniques and its psychological impacts.

## What is the rationale?

- AD relates to pruritus in a self-perpetuating cycle. Scratching tends to cause further itching, leading to the so-called “itch-scratch cycle.”<sup>(a)</sup>
- Chronic pruritus is often intractable, difficult to treat and has a high impact on patient's quality of life.<sup>(b)</sup> It is associated with systemic, neurologic and psychological disease<sup>(c)</sup>
- Well managed AD patients may still have pruritus.. The centre recognises that adequate pruritus management represents an unmet need and thus became a pruritus national reference centre in 2011 (the centre employs dermatologists and other specialists with extensive experience managing pruritus)

## What are the key features of the intervention?

- The centre has a strong research focus on pruritus including both its psychological impact and the fundamental science behind its causation. This includes the mechanisms of action of the pruritic sensory pathways and involves collaboration with the laboratory of Neurosciences of Brest

Recent quality of life research conducted at the centre showed that for 170 AD participant subjects the mean intensity of pruritus was 5.8, and the mean sleep loss was 4.7 (from 0 to 10)<sup>(d)</sup>

- Together with researching its impact the centre has also implemented a variety of novel techniques to address the management of pruritus. These include therapies such as:
  - Meditation / Relaxation – performed by psychologists within the centre (see case study on pg. 127 – 128)
  - Cognitive therapies – performed by psychologists within the centre
  - Medication – severe pruritus may involve the use of gabapentin or pregabalin<sup>(d)</sup>
  - Musico-therapy performed by psychologists within the centre (see case study on pg. 126)
  - Therapeutic education performed by dermatology nurses

CHRU Brest held the 6th World Congress of Itch involving researchers and clinicians from all over the world<sup>(e)</sup>. In 2019 the centre was involved in the writing of the European Guidelines on Chronic Pruritus<sup>(f)</sup>

**Sources:** (a) Weisshaar E, et al. Itch intensity evaluated in the German Atopic Dermatitis Intervention Study (GADIS): correlations with quality of life, coping behaviour and SCORAD severity in 823 children. *Acta Derm Venereol.* 2008;88(3):234-9. doi:10.2340/00015555-0432; (b) Yarbrough KB, et al. The effects of treatment on itch in atopic dermatitis. *Dermatol Ther.* 2013;26(2):110-9. doi: 10.1111/dth.12032; (c) Grundmann S, et al. Chronic pruritus: clinics and treatment. *Ann Dermatol.* 2011;23(1): 1–11. doi: 10.5021/ad.2011.23.1.1; (d) Huet F, et al. Characteristics of pruritus in relation to self-assessed severity of atopic dermatitis. *ActaDV.* 2019;99(3):279-283. doi: 10.2340/00015555-3053; (e) Tey HL, et al. Report on the 6th World Congress of Itch. *J Invest Dermatol.* 2012;132(4):1065–1067; (f) European Dermatology Forum 2019 Guidelines on Chronic Itch. [PDF] [https://www.edf.one/dam/jcr:9c925c23-fa0f-4765-8592-a86a75ce0ec3/GL\\_Chronic\\_pruritus.pdf](https://www.edf.one/dam/jcr:9c925c23-fa0f-4765-8592-a86a75ce0ec3/GL_Chronic_pruritus.pdf) Accessed 5 July 2019





# Pruritus National Reference Centre (2/2)

## What are the outcomes so far?

### Benefits to patients:

- Recognition of the high impact pruritus has on a patient's quality of life
- Ability to access different techniques to manage pruritus
- Inclusion in various trials of novel techniques embarked upon by the centre as research studies

### Benefits to HCPs:

- Increased understanding of pruritus management techniques
- Increased access to alternative treatment methods for difficult to manage pruritus
- Improved access to field leading collaborators who are drawn to the expertise at the centre



"Pruritus management represents an unmet need for the AD population"

*Dermatologist, CHRU Brest*



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# Centre Hospitalier Lyon-Sud

Lyon, France

Site visited by KPMG 18–19<sup>th</sup> July, 2019

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CENTRE REPORTS



# Summary



## Context

**Centre type:** University hospital located in Lyon, France

**Catchment area:** The centre treats the metropolitan area of Lyon and its surrounding area with a population of approximately 2,200,000

**Funding:** Centre Hospitalier Lyon-Sud is a publically funded University hospital

**Services:** A full range of medical specialties, including allergy and immunology which is situated in the Service d'allergologie et Immunologie Clinique, Bâtiment 1K

**Patient population:** Demand is growing in Lyon-Sud with 1,122 outpatient consultations in the allergology and immunology unit in 2017, representing growth of 160% since 2016. AD patients seen in clinic can range from moderate disease to severe disease. However all severities of AD patients attend the patient therapeutic education sessions



## Key strengths in the delivery of AD care

**Key focus on patient education:** Centre offers in-depth, therapeutic educational courses for AD patients from across the region. Established in 2010 AD patients have benefitted from a dedicated therapeutic patient education department since 2010 (delivered by expert nurses). Courses are tailored to age and cover a variety of topics

**Multidisciplinary care offered to patients:** The Dermatology unit works closely with other specialties (e.g. psychology) to provide holistic care for patients

**Centre Expert Eczema (CEE) Auvergne Rhone Alpes regional network:** The centre hosts a monthly half-day session to discuss difficult cases, share learning from recent conferences, discuss homogenisation of care, research progress and identify opportunities

**Strong interaction with basic and clinical research:** The centre operates regular meetings to share developments and discuss research opportunities

**MedPhone Application:** The centre utilises a smartphone application to enable patients skin conditions to be photographed and stored confidentially without transferring to the HCP's phone (*see case study on page 149*)



## Key challenges faced in delivery of AD care

**Ongoing PCP diagnostic challenges remain:** PCP referrals continue to be received requesting the centre to diagnose the patients allergen rather than asking for assistance in the management of the patient's AD

**Under estimation of the psychological impact of AD:** HCPs who do deal with AD regularly often do not provide the psychological support required by many patients

**The overstated fear of steroid overuse (corticophobia):** This can be a view held by some PCPs who inadvertently transfer their corticophobia onto both patients and relatives

**AD patients may not comply with treatment:** Adherence, especially to topical treatment, is difficult, of which can negatively impact patient outcomes. The centre is working to improve treatment compliance through therapeutic patient education

**Varied PCP expertise:** There is a variety of capabilities and confidence within the PCP community. The centre wants to level up capabilities so that only the required, complex AD cases are referred



# Atopic Dermatitis (AD) in France

## French healthcare system:

The French healthcare system provides free healthcare to French residents and is predominantly funded through compulsory statutory health insurance (SHI).<sup>(a)</sup> SHI is largely managed by the state and is financed through:

- Payroll and income tax (85%);
- Taxes levied on tobacco and alcohol, the pharmaceutical industry, and voluntary health insurance companies (13%); and
- State subsidies (2%).

SHI covers 70% of healthcare expenditure and is complemented by private voluntary health insurance (VHI). VHI is provided by employers schemes or a means-tested government vouchers and covers approximately 95% of the population. It partially covers patient costs of publically funded services. The remainder is paid for by the patient or supplementary private health insurance<sup>(a)(b)</sup>

## ARS (Agence Régionale de Santé) healthcare system:

Lyon sits within the Auvergne-Rhône-Alpes ARS. It is responsible for the implementation of health policy in Lyon and the surrounding region. The Agency is responsible for planning and delivering population healthcare, which includes healthcare delivery, public health and social care. Broadly, planning is segregated into three areas: hospital sector services, health and social care services for the elderly and disabled and ambulatory care services<sup>(a)</sup>

## Prevalence

- AD affects 10–20% of children and 1–3% of adults in Western countries<sup>(c)</sup>
- In France, the prevalence of adult AD is 8%<sup>(d)</sup>
- Point prevalence of Food Allergy in children with atopic dermatitis attending a multidisciplinary dermatology / paediatric allergy clinic is 17.8%<sup>(e)</sup>



## Care provision:

### Location:

- Mild (or well-controlled) AD care is usually managed by Primary Care Professionals (PCPs) or private dermatologists
- Moderate and severe (or uncontrolled) AD care is usually managed by hospital dermatologists

### Funding:

- Primary care is generally funded through the SHI through a fee-for-service, yearly capitation per person or monthly income model<sup>(a)</sup>
- Hospital care is funded through the diagnosis-related group (DRG), predominantly subsidised through SHI<sup>(a)</sup>
- Social security will pay the hospital for the activity delivered so that patients are not required to pay for hospital visits but may need to pay for private clinics

## Guidelines and societies:

### Guidelines:

- Guidelines for treatment of atopic eczema (atopic dermatitis) part I and part II: European Association of Dermatology and Venerology (EADV)

### Medical society:

- Société Française de Dermatologie et de Pathologie Sexuellement Transmissible – French Society of Dermatology (SFD)

### Patient advocacy group (PAG):









- Association Francaise de l'Eczema

**Sources:** (a) International Health Care System Profiles. The French Health Care System [Website] <https://international.commonwealthfund.org/countries/france/>. Accessed 28 May 2019;

(b) The King's Fund [Website] <https://www.kingsfund.org.uk/publications/how-health-care-is-funded>. Accessed 28 May 2019; (c) Nutten S. Atopic dermatitis: global epidemiology and risk factors. *Ann Nutr Metab*. 2015;66 Suppl 1:8-16.

doi:10.1159/000370220; (d) Kowalska-Oledzka E, et al. Epidemiology of atopic dermatitis in Europe. *Journal of Drug Assessment*. 2019;8(11):126-128. doi: 10.1080/21556660.2019.1619570; (e) Mailhol C, et al. Point prevalence and risk factors for food allergy in a cohort of 386 children with atopic dermatitis attending a multidisciplinary dermatology/paediatric allergy clinic. *Eur J Dermatol*. 2014;24(1):63-9. doi: 10.1684/ejd.2013.2255.




# The centre and allergy and clinical immunology unit

The centre		
 <b>Type and location</b>	<ul style="list-style-type: none"><li>— The allergology and immunology unit consists of both dermatologists and allergists. The centre continues to grow and has over 2017-18 saw a 75% outpatient appointment growth year on year. The unit is attached to the University of Lyon and delivers undergraduate education in allergy and immunology alongside its research and clinical duties. Whilst the hospital has a separate dermatology unit all AD patients are seen in the allergology and immunology unit</li></ul>	
 <b>Population served</b>	<ul style="list-style-type: none"><li>— The centre provides access to allergy and immunology services for patients from across Lyon representing a population of approximately 2,200,000. The centre also provides specialist advice for the region of Auvergne Rhone Alpes via the CEE (see case study on page 150)</li></ul>	
The allergology and immunology unit		
 <b>Service Division</b>	<b>Outpatient service</b>	<b>Inpatient service</b>
 <b>Hours of availability</b>	Consultations are 08:30-18:00 No routine weekend or evening clinics except in exceptional circumstances	24/7 emergency department with rolling on-call dermatologists access. 10 bed allergy inpatient unit for planned admissions open Monday - Friday
 <b>No. of patients seen</b>	1,122 Atopic Dermatitis outpatient consultations held in 2017 (a 75% increase from 2016)	Patients admitted overnight in an unplanned manner will be admitted to internal medicine or dermatology and usually followed up as an outpatient. This is rare however
 <b>Types of patients seen</b>	Patients with allergies, such as food allergy, drug allergy and Atopic Dermatitis. Predominantly adult patients but the department has recently began seeing paediatric patients	
 <b>Facilities on-site<sup>(1)</sup></b>	<ul style="list-style-type: none"><li>— 4 outpatient consultation rooms</li><li>— 1 room for general allergy wrapping</li><li>— 2 rooms for therapeutic education</li><li>— 1 outpatient room with shower attached, to teach patients how to dry themselves and for wrapping</li><li>— Translational research laboratory, within the unit</li></ul>	<ul style="list-style-type: none"><li>— Hôpital de semaine - 10 inpatient beds predominantly managing medication allergy inductions</li><li>— Hôpital de jour – availability for 7 patients per day for drug and food allergy testing</li><li>— Same day ECG, phlebotomy and x-ray capability</li><li>— Patch tests are prepared in the centre however more complicated tests (e.g. medication allergy tests) are made by the hospital pharmacy and transferred</li></ul>
 <b>Affiliations</b>	<ul style="list-style-type: none"><li>— Affiliated with the largest basic research laboratory concentrating on immunology of skin allergy in France (consisting of 15 people, including: technicians, dermatologists, immunologists, infectious disease specialists and geneticists)</li></ul>	

**Note:** (1) List of facilities is not exhaustive

# The team

## Core team profile

-  **8** Dermatologists (6 with allergy specialisation; 1 with paediatric specialisation; 1 with food allergy specialisation)
-  **10** Attachée (GPs with allergy specialisation and general dermatologists who work in private clinics as well as with public patients at CHU Lyon-Sud)
-  **2** Therapeutic education nurses

## Wider team profile

-  **1** Chief nurse
-  **2** Nurse co-ordinators
-  **8** Dermatology nurses
-  **5** Care assistants / auxiliaries
-  **2** Secretaries
-  **1** Psychologist
-  **6** Immunologists (immunology researchers and physician-researchers)

## Governance and processes

### Team meetings:

- *Lyon specific Eczema meeting (monthly):*
  - *Attended by dermatologists, immunologists, pathologists, researchers, nurses and laboratory technicians*
- *CEE, Centre Expert Eczema (2 monthly):*
  - *Attended by dermatologists from across the Auvergne Rhone Alpes along with those HCPs expected at the monthly Lyon meeting*
  - *The purpose of the meeting is to discuss difficult cases, research updates and opportunities, and the harmonisation of Eczema care across the region*
- *Lyon senior team meeting (weekly):*
  - *Senior nurse and doctors discuss operational issues arising; such as decisions over the requirement for extra clinics if the waiting list is too long*

### Patient records:

- *Electronic patient records (EHR):*
  - *Patient records are electronic and accessible via computers and smartphones connected to the hospital Wi-Fi*

Note: Please see page 140 for further details about the wider team

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients with symptoms of AD (e.g. itching or dryness of the skin) present to a primary care physicians (PCPs) or private dermatologists

*Note: AD patients that are mild-moderate or well-controlled may be managed in primary care or by the private dermatologist and may not be referred to secondary / tertiary care*

## Diagnosis and Referral

In secondary care



- PCPs will refer patients to either public or private dermatologists or allergists
- Private dermatologists or allergists may then refer patients to public dermatologists or allergists (e.g. to the centre) for either allergy testing or for more specialist AD care
- Patients referred to the centre from PCPs are seen within 3-6 months on a routine referral (however they can be seen the next day if urgent)
- Severe AD patients can be referred by the centre's allergists or dermatologists for a 3 days' hospitalisation (this currently has a 4 month waiting list)
- EASI (Eczema Area and Severity Index), SCORAD (Scoring of Atopic Dermatitis), IGA (Investigator Global Assessment) and DLQI are performed by the allergists and dermatologists

## Treatment and Management

Medical management



- The first consultation lasts 30-45 minutes. The allergists / dermatologists will ask about symptoms of AD, food allergy, rhinitis and asthma, as well as the impact on quality of life
- Treatment options will be discussed with the patient. Depending on disease severity, this may include systemics
- If a patient has asthma but has not been reviewed recently by a pulmonologist, the centre will refer the patient again
- Severe AD patients may have a planned 3 day admission if they require extra support for topical treatments or further investigation for co-morbid food allergy. Here they will undergo blood tests, chest x-ray, food allergy prick tests, and intensive wrapping therapy. They will also be automatically referred to an ophthalmologist

Non-medical management



- Referrals can be accelerated by the request of pictures of the patient's disease. Physicians can then assess the photograph and book a patient appropriately. Often if asked for evidence patients will restate the request as non-urgent
- After the consultations, patients will be offered the choice of attending therapeutic education training days organised by the centre. Patients attending these will increase their knowledge of AD, meaning that they become more compliant with topical treatments. This can avoid the development of a more severe disease. Therapeutic education sessions are offered every 2-4 weeks and cover 4 milestones (see case study pages 151 - 153)
- Planned inpatient admissions will be arranged to coincide with the days of the therapeutic education sessions. Inpatients will usually receive a patch test on the Monday and will then be admitted on the Wednesday

## Follow-up

Monitoring of chronic disease / flare up



- Frequency of follow-up consultations depend on the severity of disease (but can be within 2 weeks)
  - The follow-up consultation lasts 30 or 45 mins (depending if they have comorbidities)
- The centre aims to discharge patients from their clinic back to their referring physician following their therapeutic education sessions and once their AD has been sufficiently controlled

**Sources:** (a) KPMG interview with Lyon HCPs



# Roles of the wider team

## Therapeutic nurse educator

**Patient type:** All AD patients, adult and paediatric

**Referral:** From the centre dermatologists and allergists and from external dermatologists or allergists

**Consultations:** These can range between 45 mins for the shortest session to an entire day. Therapeutic education events are located in seminar room of the centre

**Timing:** Occurring roughly every 2 weeks

*Note 1: Paediatric education session more frequent during school holidays*

*Note 2: Nurse educators will train external HCPs within the Auvergne Rhone Alpes region so that they are able to deliver patient education. This will be generic patient education training and not necessarily AD specific*



## Ophthalmologists

**Patient type:** All AD patients due to start or currently receiving biologic therapy

**Referral:** All hospitalised AD patients are referred and those deemed appropriate by the allergist or dermatologist at the centre

**Consultations:** Visual acuity, ocular topography

**Timing:** 30 mins in length. At 0, 3 and 6 months whilst on the novel biologic therapy and as required at other times

*Note: The consultations will not be held in the centre but rather in the attached Lyon-Sud ophthalmology department*

## Psychologists

**Patient type:** All AD patients undergoing the 4 milestones of therapeutic education (see case study pages 151 - 153)

**Referral:** Via allergist or dermatologist at the centre or by the therapeutic nurse educators

**Consultations:** Private sessions will last 45 mins in length but group session is also held during the patient therapeutic education sessions

*Note: If the psychologists worry that the patient is severely depressed or suicidal, they can ask the allergist/dermatologist to refer to psychiatry*



# Overview of interventions in place for AD

## Awareness and Presentation



Symptom identification

- **Research expertise and integration:** Lyon has one of the largest basic research centre in France consisting immunologists, infectious disease specialists and geneticists. The clinical and medical research departments have the same co-ordinators and HCPs often working mixed clinical and research roles

See pg. 147 for case study

- **National Eczema Day:** The centre has delivered an annual national eczema day (since 2015). This consists of raising awareness and sharing knowledge within the HCP and patient community

See pg. 148 for case study

## Diagnosis and Referral



In secondary care

- **MedPhone application:** Centre uses a mobile phone application that allows HCPs to access patients notes via their smartphone, for patient referrals between specialists within the Lyon hospital network and the monitoring of patient disease statuses

See pg. 149 for case study

- **Internal management audits:** The centre reviews their management of AD vs psoriasis and chronic urticarial, and audits their treatment types compared to other groups at similar disease severities

- **The CEE (Centre Expert Eczema) Network:** The centre brings together a network of eczema experts from across the Auvergne Rhone-Alpes region. This allows physicians to discuss research opportunities, difficult case presentations and standardise care delivery

See pg. 150 for case study

## Treatment and Management



Medical management

- **Research expertise and integration:** The unit has a strong focus on research. This is matched by access to extensive laboratory facilities. The centre provides integration for patients between service provision and trials

See pg. 147 for case study

- **Inpatient admission:** The centre offers a 10 bed, 3 day hospitalisation for patients with severe AD. During this patients will be provided informal (bedside) and formal education sessions. Patients may also undergo patch testing and food allergy testing. Ophthalmologists and psychologists reviews are arranged as required and patients will undergo intensive wrapping therapy



Non-medical management

- **Therapeutic education:** Since 2010 the centre has delivered patient therapeutic education. Today this involves a methodology covering 4 milestones over a 3-4 month period

See pg. 151-153 for case study

- **Comorbidity management:** The centre manages food allergy internally and operates established referral pathways for comorbidity specialists including: ophthalmologists, pulmonologists and psychologists

See pg. 154 for case study

## Follow-up



Monitoring of chronic disease/flare up

- **PCP communication:** Patients are able to designate the primary care physicians who they want to receive their clinic letters
- The centre will intend to refer any mild and moderate patients back to their referring clinician. More severe patients will remain under the review of the centre. They may be seen in clinic at a minimum of once every year however they are able to call up the centre to arrange immediate appointments if required
- **Patient communication:** Patients requesting an appointment are able to attach photos to their request. Allergists and dermatologists at the centre will then be able to triage urgent cases by the photos and their knowledge of the patient

### Key:



Case study available

# Monitoring AD patients and comorbidities

## The dermatology unit employs a number of measures for monitoring AD and associated comorbidities

### Objective measures (AD):

AD scoring indices are used to monitor patients and their disease, including:

- EASI (Eczema Area and Severity Index): validated scoring system that grades the physical signs of atopic dermatitis<sup>(a)</sup>
- SCORAD (SCORing Atopic Dermatitis): to assess AD disease severity and monitor patient progress<sup>(b)</sup>
- TOPICOP<sup>(c)</sup>, to assess the level of corticophobia

QoL and sleep is routinely measured by:

- DLQI (Dermatology Quality of Life Index): dermatology related quality of life questionnaire<sup>(d)</sup>

These four scoring systems are used at the 1<sup>st</sup> and 4<sup>th</sup> session of patient therapeutic education (see case study on pages 151 - 153)

Physicians will attempt to perform all scoring procedures at initial outpatient consultation and repeat them as required at each repeat attendance

Every AD patient admitted will have EASI, SCORAD, TOPICOP and DLQI performed

Fig. 1. TOPICOP questionnaire <sup>(c)</sup> Created by CHU Nantes 2013

### Comorbidity specialists routinely measure comorbidity outcomes by:

- Pneumologists measure allergic asthma using lung function tests such as peak flow
- Psychologist monitoring psycho-social distress through standardised psychological scales (e.g. Hospital Anxiety and Depression Scale [HADS])
- Ophthalmologist perform surveillance of ocular symptoms using specialist tests such as ocular topography

Sources: (a) EASI for clinical signs: Harmonising Outcome Measures for Eczema (HOME). [Website] <http://www.homeforeczema.org/research/easi-for-clinical-signs.aspx>. Accessed 1 Mar 2019 ]; (b) SCORing Atopic Dermatitis (SCORAD) Calculator (0.9.0). [PDF] <http://scorad.corti.li/>. Accessed 26 Feb 2019; (c) Moret L, et al. TOPICOP®: a new scale evaluating topical corticosteroid phobia among atopic dermatitis outpatients and their parents. PLoS One. 2013;8(10):e76493. doi:10.1371/journal.pone.0076493; (d) Lewis V, et al. 10 Years Experience of the Dermatology Life Quality Index (DLQI). J Invest Dermatol Symp Proc. 2004;9:169 –180

# Advice to other centres

## What advice would you give less specialised centres



### Objective of advice: Focus on therapeutic patient education

- **Why?** Atopic dermatitis is a condition that is heavily affected by the patients level of engagement. AD requires a whole lifestyle approach and a persistent attitude to self management. By investing in specialist therapeutic education activities the centre is able to reduce consultations, build patient self esteem and improve patient outcomes



### Objective of advice: Establish strong connections between patients, physicians and researchers

- **Why?** Patients, physicians and researchers are interconnected. The closer they work together the better outcomes for all. At Lyon-Sud CHU the same nurse co-ordinator supervises the clinical research and outpatient units. This means nurses are encouraged to rotate between the two areas so they are always aware of developments.
- Don't be afraid to collaborate with a wide region in order to build alliances. The CEE (Centre Expert Eczema) network (see page 150) provides research opportunities for a wider geographical area of patients to increase the volumes of selected groups

# Next steps for the centre

## What is next for the centre?

### Objective: Adolescent management

- **What?** The centre is considering whether the setting up of a dedicated adolescent clinic would be beneficial. This may include a dedicated physician and nursing staff so that patients can build rapport
- **Why?** The transition of child to adult care can be challenging. Patients often disengage at this time which can negatively impact their topical treatment compliance. By building rapport and specialisation the centre may be able to combat the disengagement



### Objective: Create E-health solutions for patient communication

- **What?** To build a protocol for remote review of stable patients. This may be via telemedicine, text message or phone call
- **Why?** Patients can be reluctant to travel into a clinic when they feel well and do not want to change their medications. Despite this patients will attend appointments in order to avoid being discharged from outpatient clinic follow up. This is because they prefer to have access to a specialist in case they need it. By having a less intensive clinical review this could save physician and patient travel and appointment time whilst maintaining the doctor-patient relationship
- Many patients expect technological advances in care (especially younger generations of patients). Technological interventions can be used to:
  - Support and reinforce education received in face-to-face consultations remotely (i.e. make consultations accessible at home)
  - Encourage / better enable AD self-management (e.g. through the provision of education, treatment regimen reminders)
  - Enable remote assessments of patients' AD and provision of feedback so they don't have to visit the centres (e.g. via tele-dermatology)



# Case studies



TITLE	Page number
<b>Working with the PAG</b>	146
<b>Research expertise and integration</b>	147
<b>National Eczema Day</b>	148
<b>MedPhone application</b>	149
<b>CEE (Centre Expert Eczema) Network Auvergne Rhone Alpes</b>	150
<b>Provision of therapeutic education</b>	151 – 153
<b>Comorbidity management</b>	154

# Working with the PAG

## Overview

- Lyon-Sud collaborates closely with the Association Française de l'Eczéma (AFE), the French AD patient advocacy group (PAG) and the Fondation Dermatite Atopique
- Together they conduct research on lesser known or researched areas relating to AD and develop therapeutic patient education



## Association Française de l'Eczéma (AFE) in France

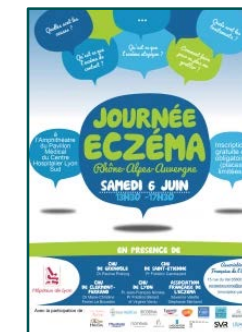
- The AFE is an association that aims to “communicate and inform (people) about the disease (*AD contact dermatitis*)” and “support patients and their families to contribute to the improvement of their quality of life in collaboration with health professionals.”<sup>(a)</sup>
- The AFE focuses on providing patient education materials and raising awareness of eczema treatment options<sup>(b)</sup>

### Activities with Lyon-Sud:

- *Organisation and facilitation of French Annual National Eczema Day*<sup>(b)</sup>.
- Held at Lyon-Sud
  - Co-facilitation and presentation at the day, focusing on the impact of eczema on the family and patient insights on novel treatments

### French Association of Eczema activities:

- *Development of patient education materials*
  - AFE have developed a magazine ('Eczema Magazine') which is published three times a year. This magazine is intended for people affected by eczema, but also to their entourage, as well as health professionals who are interested in the pathology
  - The AFE YouTube channel contains a video series “*The Minute of Eczema*” and the AFE website contains online materials to educate patients on eczema, treatment options and provide general tips and advice for living better with Eczema<sup>(b)</sup>
  - In September 2016, AFE launched the first web series on eczema types and different treatment options<sup>(b)</sup>
- The volunteers of the French Association of Eczema organize events throughout France to publicise the association and the disease and provide information to patients. These activities include:
  - Public conferences
  - “*Dance your skin*”! Workshops (no technical level of dance required!)
  - Exhibition of creations in Lego Brick
  - National Eczema days



## Fondation Dermatite Atopique (FDA)<sup>(c)</sup>

The Foundation for Atopic Dermatitis is an international corporate foundation created by Pierre Fabre dedicated to Atopic Dermatitis. The centre has worked together with the FDA to develop:

- 2 movies (viewable on their website and on YouTube). These show AD patients and relatives how to apply topical steroids and wrap themselves overnight
- Therapeutic Patient Education (TPE) programs and e-learning for pharmacists, also available on their webiste (POPTRAINING)

**Sources:** (a) Association Française de l'Eczéma. [Website] <https://associationeczema.fr/>. Accessed 12 June 2019; (b) French Association of Eczema. Les Thermalies. [Website] <https://www.thermalies.com/paris/pressepartenaires/espace-partenaires/association-francaise-de-leczema/>. Accessed 12 June 2019; (c) Fondation Dermatite Atopique [Website] <https://www.fondation-dermatite-atopique.org/en>. Accessed 22 Sept 2019; (d) Therapeutic education. Pop training. [Website] <https://poptraining.fondation-dermatite-atopique.org>. Accessed 1 Sept 2019



# Research expertise and integration



## Overview

- The unit has a strong focus on research. This is matched by access to extensive laboratory facilities. The centre provides integration for patients between service provision and clinical trial



Patients like the access they have to different clinical trials. The co-location of the research and outpatient units mean we all know which trials are ongoing and upcoming

Allergist, Lyon-Sud



## What is the rationale?

- Research in AD understanding and management has been a large growth area over the last decade<sup>(a)</sup>. Historical systemic treatments for severe AD have been associated with significant adverse effects and low compliance<sup>(b)</sup>
- AD patients have historically had access to fewer treatment options than chronic urticaria and psoriasis patients of similar disease severities and there was an unmet need for better AD treatment<sup>(b,c)</sup>
- Research initiatives can require high volumes of engaged eligible patient cohorts

## What are the key features of the intervention?

- **Research expertise**
  - Lyon has one of only two of France's Biosafety level 4 laboratories the P4 Jean Mérieux-Inserm created in 1999<sup>(d)</sup>. The centre performs translational research with The Research Center for Infectious Disease (CIRI) based on the biosciences Gerland campus
  - Lyon also has one of the largest basic research units in France working on immunology of skin allergy. The team here consist of 15 members: immunologists, infectious disease specialists and geneticists. Throughout 2016-18 the centre published 37 research papers and at the time of writing (Aug 2019) had 9 active research projects
- **Research integration**
  - The clinical research unit, established in 2001, is situated within the allergology and immunology service
  - The centre has research licences including phase 1-4 clinical trials, medical devices, cosmetics and dietary supplements. Research dissemination and education activities include the CEE (see case study: page 150) and National Eczema day (see case study: page 148)
  - The allergology and immunology department and the clinical research unit are able to feed appropriate patients into each other. The co-location of both units within the centre means patients are accustomed to the facilities and staff who have considerable cross over often working in shared research and service delivery roles

## What are the outcomes so far?

### Benefits to patients:

- Improved access to new research medications, trials and HCPs with an interest in AD research

### Benefits to HCPs:

- Access to large patient cohorts for research trial participation
- Access to novel therapies, research collaborations and funding

**Sources:** (a) Lio P. Advances in atopic dermatitis raise bar for treatment. *Dermatology Times*, 2018;39(12); (b) Renert-Yuval, Yael et al. Systemic therapies in atopic dermatitis: The pipeline. *Clinics in Dermatology*. 2017;35(4):387-397. doi: 10.1016/j.clindermatol.2017.03.012; (c) KPMG interview with Lyon-Sud CHU HCPs; (d) What we do. Mérieux Foundation P4 [Website] <https://www.fondation-merieux.org/en/what-we-do/enhancing-research-capabilities/research-laboratories/jean-merieux-inserm-p4-laboratory/> Accessed 15 Aug 2019

# National Eczema Day

## Overview

- The centre hosts a national eczema day in June every year since 2015. This consists of raising awareness and sharing knowledge within the HCP and patient community



## What is the rationale?

- AD remains misunderstood in large parts of the public and with some health care professionals<sup>(a)</sup>
- Patients and relatives often have questions regarding treatment advancements that cannot always be answered by general dermatologists<sup>(a)</sup>
- Peer support and group inclusive activities allows patients to feel less isolated<sup>(b)</sup>

## What are the key features of the intervention?

- CHU Lyon Sud have hosted a National Eczema Day annually since 2015<sup>(a)</sup> in collaboration with *The Fondation Dermatite Atopique*. CHU de Lyon hosted the inaugural event in 2015 at the amphitheatre CHU Lyon Sud - Pierre Bénite
- Attendance is free and each year 100 - 175 people attend from across France. Attendees include patients, relatives, researchers, HCPs, industry representatives and Patient Advocacy Group [PAG] representatives
- The day is intended to promote understanding of AD, improve access of good quality care throughout France and enhance co-operation between HCPs and patients
- The session runs all afternoon. The 2019 agenda encompassed:
  - Exhibitions from PAGs and emollient companies, lectures from dermatologists regarding AD pathophysiology, panel discussions surrounding updates in AD management, patient testimonials and therapeutic education and development in anti-scratch techniques

## What are the outcomes so far?

### Benefits to patients:

- Patients are able to access expert opinion and encouraged to ask questions of the various panel members
- The collegiate atmosphere at the Eczema days allows patients to improve relationships with HCPs and peers

### Benefits to HCPs:

- HCPs are able to share knowledge with peers and hear testimonials from patients
- Physicians are able to talk to related individuals outside of the clinic environment
- Every year 100-175 people attend

## What's next?

- The Eczema day is proving a success and will be hosted next year on June 6<sup>th</sup> 2020

**Sources:** (a) KPMG interviews with Lyon HCPs; (b) Embuldeniya G, et al. The experience and impact of chronic disease peer support interventions: a qualitative synthesis. *Patient Educ Couns*. 2013;92(1):3-12. doi: 10.1016/j.pec.2013.02.002; (c) Fondation Dermatite Atopique. [Website] <https://www.fondation-dermatite-atopique.org/fr/espace-patients-parents-famille/actualites/journee-de-leczema-lyon-le-10-juin-2017> Accessed 31 July 2019



# MedPhone application

## Overview

- The Centre uses a mobile phone application that allows HCPs to access patients notes via their smartphone, for patient referrals between specialists within the Lyon hospital network and the monitoring of patients' disease status



Fig 1. A screenshot from the home screen of a physician using the MedPhone application

## What is the rationale?

- Atopic dermatitis has historically been poorly understood by non-specialist physicians<sup>(a)</sup>
- Technology can encourage a new form of HCP – patient relationship<sup>(b)</sup>
- Patients engage with treatment more when they can visualise and track their progress<sup>(a)</sup>

## What are the key features of the intervention?

- Launched in 2016 the smartphone application (*MedPhone*) is accessible from any smartphone attached to the Lyon public hospitals Wi-Fi. HCPs are then required to enter individual log in credentials to access the application and view or upload patient confidential information
- Once logged into their personalised area HCPs can look up their patient lists, research patients medications or results. Physicians are also able to look up patients that have been referred to them by colleagues from different specialties, for example by internal medicine colleagues
- A key functionality of the application is the ability to take photos of patient's skin and save the photo to that patient file
  - This allows easy comparison in the future to map progress or deterioration of the patient's skin. Additionally this allows other specialties to photograph patients whilst sending a referral and assists in the description of lesions
  - The MedPhone application will not allow photos taken through the application to be saved to the HCPs phone and automatically deletes the image from the camera

## What are the outcomes so far?

### Benefits to patients:

- Patients are able to see a regular comparison of their dermatological condition
- Patients seen at different hospital sites across Lyon but within the Lyon public hospitals network are able to receive input from the correct specialist as required
- Confidentially maintained as the photographs are never saved on the HCP phone

### Benefits to HCPs:

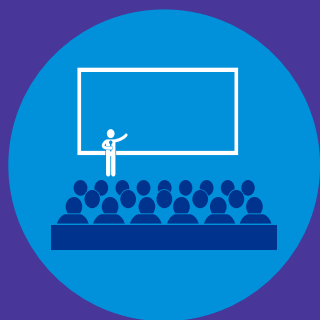
- The ability to make easy comparisons between a patient over time allows better HCP treatment decisions
- Enables HCPs to visually show evidence to patients of condition improvement
- The dictation function allows HCPs to minimise time typing notes
- The ease of availability / access means HCPs are able to quickly capture, upload and review images
- Allergist and dermatologists are able to provide advice to referring colleagues without visiting patients

**Sources:** (a) KPMG interview with Lyon HCPs (b) Rouleau G, et al. Impacts of information and communication technologies on nursing care: an overview of systematic reviews (protocol). *Syst Rev.* 2015;4:75. doi:10.1186/s13643-015-0062-y

# CEE (Centre Expert Eczema) Network Auvergne Rhone-Alpes

## Overview

- The CEE brings together a network of eczema experts from across the Auvergne Rhone-Alpes region. This allows physicians to discuss research opportunities, difficult case presentations and homogenise delivery of care



APPENDIX  
CENTRE REPORTS

## What is the rationale?

- Eczema is a specialised disease area. Understanding of the complex pathogenesis of AD has advanced considerably over the past few decades<sup>(a)</sup> as has treatment therapies
- Collaborative HCP practice can positively affect patient outcomes and lead to positive patient outcomes<sup>(b)</sup>

## What are the key features of the intervention?

- The CEE has been in existence since 2015 and is co-ordinated by Dr Nosbaum at CHU Lyon-Sud. Its aim is to improve the management of eczema across the Auvergne Rhone-Alpes region and includes several CHU including Lyon, Saint-Etienne, Clermont-Ferrand, Grenoble, Annecy and Valence
- Every 2 months the centre hosts a half day session for a collaborative network of physicians involved in the management of eczema across the region. The aims of the CEE are to:
  - Homogenise care and diagnostic tools (such as patch test batteries)
  - Promote clinical research and disseminate updates learned from different conferences
  - Recruit prospective patients for selective studies such as the TISA study (New Tools for the in Vitro Diagnosis of Skin Allergy). The CEE together found 40 participants for TISA
- The experts present and discuss difficult / interesting cases, share learnings from recent conferences, and discuss potential research opportunities
- The CEE also invite external experts to come and speak about a topic of interest. Recent examples include hosting a hand eczema expert from Paris and an expert on allergy to glucose monitoring devices from Belgium. Other visiting experts include pathologists who talked about novel molecular diagnostic approaches and the staphylococcal role of AD sensitisation
- 80% of the attendees are physicians from public hospitals with 20% private HCPs

## What are the outcomes so far?

### Benefits to patients:

- Access to a wider pool of specialist physicians for diagnostic and treatment opinions. In 2017 the CEE discussed 184 patients with specialised epicutaneous reactions
- Improved awareness of specialised clinical trials and eligibility criteria

### Benefits to HCPs:

- Ability to discuss interesting and difficult cases with peers
- Increased likelihood of recruiting sufficient numbers of patients onto clinical trials

**Sources:** (a) McPherson T. Current Understanding in Pathogenesis of Atopic Dermatitis. *Indian J Dermatol.* 2016;61(6):649–655. doi:10.4103/0019-5154.193674; (b) Kelly DV, et al. Pharmacist and physician views on collaborative practice: Findings from the community pharmaceutical care project. *Can Pharm J (Ott).* 2013;146(4):218–226. doi:10.1177/1715163513492642

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# Provision of therapeutic education (1/3)

## Overview

- The centre has built a dedicated department to therapeutic education and delivers training to 3 groups:
  - Qualified PCPs and undergraduate HCPs,
  - External HCPs and
  - Patients and their relatives



Fig. 1.  
Poster produced  
on how to  
customise  
patient education

## What is the rationale?

- Patient education can increase compliance. This is particularly important in AD care<sup>(a)</sup>
- Effective AD control not only improves quality of life but may also prevent the atopic march<sup>(b)</sup>
- In >50% of AD cases referred by PCPs to specialists the primary reason for ineffective treatment is due to incorrect treatment administration<sup>(c)(d)</sup>
- Group inclusive activities allows patients opportunities to meet peers and feel less isolated<sup>(e)</sup>

## What are the key features of the intervention?

- The centre recognised the importance of patient therapeutic education and the inability to provide this within Primary Care. Thus in 2010 2 dermatology nurses established a transversal patient education unit

### HCP training delivered by the Transversal Patient Education Unit (TPEU)

- 1 nurse from the centre works within the TPEU to deliver targeted training for PCPs to provide them with the practical tools required by patients and relatives. Examples include explanations of FTU (fingertip unit), topical treatment ladders and self-management skin care advice. This session also addresses the prevalence of HCP corticophobia and the detrimental effect this can have on the patients should transference occur.
- The TPEU train 80 HCPs per year. Training is delivered as 2 days offered 3 times through the year.
  - Training attendance gains CPD points however it can be challenging to motivate PCPs to attend training sessions due to the time constraints they are under to provide service delivery
- The is aware that 15 years ago ~50% of PCPs in France believed AD was caused by a simple allergen and prescribed diet avoidance advice<sup>(f)</sup>. In 2019 this number is down to 15-20%

### Therapeutic education facilitation training:

- The centre delivers therapeutic education training sessions to the wider region as licenced under the regional health authority. These sessions are all disease agnostic
- Candidates include HCPs and patients from over the region. Notably a number of delegates receiving training have been AD patients who now help facilitate the AD patient education at Lyon-Sud
- Delegates must perform 40 hours supervised training before they can deliver training solo. The 40 hours of training involves 6 days in total; 2 days a month for 3 consecutive months

Training covers how to diagnose a patient's competencies, how to build the first patient consultation and how to negotiate when setting objectives as well as how to facilitate both individual and group sessions and what tools to use

**Sources:** (a) Wollenberg A, et al. Consensus-based European guidelines for treatment of atopic eczema (atopic dermatitis) in adults and children: part II. *J Eur Acad Dermatol Venereol*. 2018;32(6):850-878. doi: 10.1111/jdv.14888; (b) Munidas D, et al. What Should General Practice Trainees Learn about Atopic Eczema? *J Clin Med*. 2015;4(2):360-368. doi:10.3390/jcm4020360; (c) Ellis RM, et al. Potential barriers to adherence in pediatric dermatology. *Pediatr Dermatol* 2011;28:242-4; (d) Arkwright P, et al. Management of Difficult-to-Treat Atopic Dermatitis. *J Allergy Clin Immunol In Practice* 2013;1:142-51 doi: 10.1016/j.jaip.2012.09.002; (e) Embuldeniya G, et al. The experience and impact of chronic disease peer support interventions: a qualitative synthesis. *Patient Educ Couns*. 2013;92(1):3-12. doi: 10.1016/j.pec.2013.02.002; (f) Barbarot S, et al. The management of atopic dermatitis in children by dermatologists, paediatricians, general practitioners and allergologists: a national survey habits. *Ann Dermatol Venereol* 2005;132(1):283-95

# Therapeutic education (2/3)

## What are the key features of the intervention? (cont.)

### Patients and their relatives

Since 2010 the centre has offered a 4 milestone approach to patient therapeutic education. All patients will be offered the 4 stages however they may choose how many to attend

**Milestone 1:** 45 mins – 1 hour individual session with a nurse educator. Will cover basic disease information and management tips, answer any patient questions and agree a set of objectives for the next modules. Patients will also perform a baseline SCORAD, DLQI and TOPICOP questionnaire

- Due to large demand the waiting time between diagnosis and milestone 1 is 3 months

**Milestones 2 and 3:** Sessions run from either 9:00 – 3:30pm or 2pm-5:30pm. Topics covered are how to live with AD and itch, AD terminology, medications and self management approaches

These sessions are tailored to either adults or children with parents. Patients are encouraged to attend a group session however individual sessions can be arranged as the patient prefers. Encouragement is given to attend group sessions so that patients can build peer support and recognise they are not alone. Groups can consist of up to 10 delegates at a time

- Sessions 3-4 are interactive and engaging. They are delivered by a collaboration of dermatology nurse educators, 2 dermatologists, a clinical psychologist and by other AD patients who have been trained in facilitating therapeutic education
- Therapeutic educational games are played such as the *Goose Game* and *Find the intruder*. Role plays are used to help patients see their disease from their doctors view point. For instance: "My doctor wants me to change treatments but I don't like the sound of the side effects". Patients will be asked to play the role of the doctor and the patient
- The psychologists runs a photo expression relaxation session which targets patient self esteem and teaches them how to be comfortable living with a visible chronic disease

**Milestone 4:** 1-1 consultation held 3-4 months after milestone 3. This will check understanding and knowledge retention and answer any follow up questions. They will also perform a follow up SCORAD, DLQI and TOPICOP questionnaire

- Children under 6 are seen with parents whereas children 6-16 are seen separately for a period. They will play an educational game with the nurse whilst the parents spend time with the dermatologists. They then come back together and the children teach the parents

**Sources:** (a) Multimedia Goose Game for atopic eczema. Eczema Foundation. [website] <https://www.fondation-dermatite-atopique.org/en/patients-parents-family-space/news/multimedia-goose-game-atopic-eczema>. Accessed 21 Aug 2019 (b) Le Jeu Des 7 Familles. [website] <https://www.mag-da.fr/accueil/apprendre-en-jouant/le-jeu-des-7-familles/> Accessed 21 Aug 2019

“



Patients are usually quite lost when they are referred to us. They are still doing simple things like washing with hot soap. I never use the word allergens but rather use the word irritants as I don't want to confuse them and make them think AD is something that will go away by removal of an allergen"

*Allergist, Lyon-Sud*

Fig 1. Goose Game, developed by Fondation Dermatite Atopique for children aged 4-15 for 1-4 players<sup>(a)</sup>



Fig 2. Happy families. A card game where participants have to collect 7 families all of whom have eczema in different environments<sup>(b)</sup>



# Therapeutic education (3/3)

## Referrals

- Dermatologists/allergists from the centre, private specialists and GPs can refer patients into the centre for education sessions. Patients do not have to pay and these sessions are classed as consultations so are covered by the social security payment policy
- The centre secretaries will set up the first consultation but then the nurses take over administration and coordination as they will link the groups of patients together (e.g. certain ages)

## Follow-up

- Patients are discharged from the patient education sessions after milestone 4 but can be re-referred as needed. It will not be uncommon for patients to attend events as a child and then again in their own right as young adult to refresh knowledge

## What are the outcomes so far?

### Benefits to patients:

- Opportunity to learn together with peers who have the same condition
- In depth training time with specialists where they can ask questions and trial different products
- 80% of newly diagnosed patients will take up some form of education

### Benefits to HCPs:

- Ability to spend quality time with patients and embed learning over a period of time without the regular consultation time constraints
- Potential for reduced outpatient appointments due to improved patient self-management
- Better management by PCPs so less tertiary referrals

## Challenges

- Motivation of private practitioners and PCP colleagues to attend AD therapeutic education training courses
  - The hope is to upskill PCPs adequately so that they are confident managing non-severe AD to reduce referrals
- For centre dermatologists and allergists to stay up-to-date with research developments. For example therapeutic advice that emollients seem not useful in the primary prevention of AD<sup>(a)</sup>

## What's next?

- To continue training AD patients, relatives and continue training more therapeutic educators

**Sources:** (a) Chalmers JR, et al. Effectiveness and cost-effectiveness of daily all-over-body application of emollient during the first year of life for preventing atopic eczema in high-risk children (The BEEP trial). *Trials* 2017;18(1):343. doi: 10.1186/s13063-017-2031-3

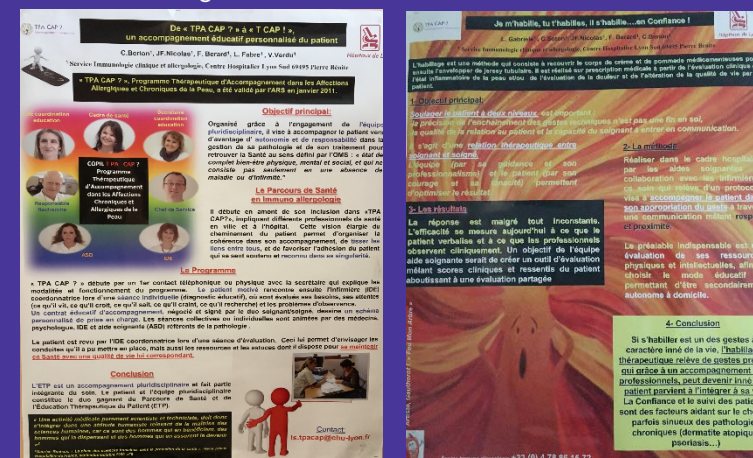


It is so powerful when patients are able to deliver training and education to their peers

*Therapeutic nurse educator, Lyon-Sud*



Fig 1 and 2. Posters displayed on the walls of the centre detailing publications regarding therapeutic patient education and how to dress with confidence with ointment wraps under clothing



# Comorbidity management

## Overview

- The centre manages food allergy internally and operates established referral pathways for comorbidity specialists including: ophthalmologists, pulmonologists and psychologists.



## What is the rationale?

- Atopic march is a complex, multi-faceted condition with comorbidities which span allergy and dermatology<sup>(a)</sup>
- Eye comorbidities are common in AD patients, resulting from the disease itself and/or AD treatment. The risk of development is highest in patients with severe AD<sup>(b)</sup> 25-40% of AD patients have incidence of ocular involvement<sup>(c)</sup> and they are often referred late

## What are the key features of the intervention?

Lyon-Sud CHU offers hôpital de semaine and hôpital de jour to manage patient comorbidities of rhinitis and food allergy within the unit

- The hôpital de semaine consists a 10 bed hospitalisation unit open Monday-Friday for allergy testing and reintroduction / provocation testing. The hôpital de semaine predominantly manages medication allergy inductions. Allergy to chemotherapy and suspected type 4 hypersensitivity reactions are the majority of cases seen here
- Hôpital de jour can treat up to 7 patients per day. Here the unit performs food and drug allergy testing, patch testing and administers intravenous therapies. Drug allergy and food allergy are the two conditions predominantly seen here however patients with severe AD can also be brought in to be shown how to dry themselves after showers and taught intensive topical wrapping therapy

**Ophthalmologist access:** The centre routinely refers patients to an anterior chamber ophthalmologist. All patients who have been admitted to the week day hospital will be referred or any patients who are expected to be started on the novel biologic treatment. They will be referred pre-treatment initiation, at 3 months and at 6 months

**Pulmonologists access:** Patients with moderate to severe rhinitis or asthma will be referred to an otolaryngologist or pulmonologist respectively. The centre refers any new AD patient with concomitant asthma to a pulmonologist

**Clinical psychologist access:** Patient education sessions incorporate psychology sessions with 1:1 consultations arranged on request of the allergologist or dermatologist

## What are the outcomes so far?

### Benefits to patients:

- Specialist management for the separate aspects of a patient's condition

### Benefits to HCPs:

- Physician sub-specialisation opportunities
- Inter-departmental learning potentials from referrals between specialists

## What's next?

- The potential to offer joint consultations with AD comorbidity specialists such as ophthalmologist

**Sources:** (a) Brunner PM, et al. Increasing Comorbidities Suggest that Atopic Dermatitis Is a Systemic Disorder. *Journal of Investigative Dermatology*. 2017;137(1):18 – 25; doi: 10.1016/j.jid.2016.08.022; (b) Thyssen JP, et al. Incidence, prevalence, and risk of selected ocular disease in adults with atopic dermatitis. *J Am Acad Dermatol*. 2017;77(2):280-28; (c) Garrity JA, et al. Ocular complications of atopic dermatitis. *Can J Ophthalmol* 1984;19(1):21-4



CONTENTS



APPENDIX  
CENTRE REPORTS

# Hautklinik des Universitätsklinikums Schleswig-Holstein, Campus Kiel

**Kiel, Germany**

Site visited by KPMG 2<sup>nd</sup>–3<sup>rd</sup> July 2019

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# Summary



## Context

**Centre type:** University Hospital of the University of Kiel (Christian-Albrechts-Universität zu Kiel, CAU)

**Catchment area:** Primarily patients from Schleswig-Holstein, but also from the surrounding areas

**Funding:** The hospital receives reimbursement from both public and private insurance for their care provision. Departments / units (e.g. the Centre for Inflammatory Skin Diseases where AD patients are cared for) may also receive supplementary funding from the State (e.g. for research activities) or from third parties (e.g. through clinical trial participation)

**Services:** The hospital provides inpatient and outpatient healthcare to adult and paediatric AD patients (as well as a day care unit)

**Patient population:** Patients with severe inflammatory skin conditions (primarily psoriasis and AD) are referred to the centre from all over Germany, however the centre also treats mild-moderate cases



## Key strengths in the delivery of AD care

**Highly specialised service:** Dermatologists, trainee dermatologists, an allergologist, nurses, study nurses and a medical specialist in psychosomatic medicine and psychotherapy at the centre have extensive experience treating AD patients who require specialist care

**Involvement in clinical trials and basic research:** Findings from the centre's participation in clinical trials and basic research are regularly shared within the centre team and used to inform clinical practice. The centre is also a coordinating partner of the EU funded BIOMAP project on biomarkers in AD and psoriasis

**A multidisciplinary approach to care:** Regular cross-specialty meetings at the centre aim to optimise treatment for complex AD patients (e.g. those with AD comorbidities, such as asthma)

**AD patient registry and biobank:** The centre is one of three coordinating centres of the TREATgermany AD registry, and leads the associated biobank (in addition to their own)

**Engagement with local private practices:** The centre delivers education programmes to a network of private dermatology offices to help improve referrals and patient management (e.g. for when the centre refers back to private practices)



## Key challenges faced in the delivery of AD care

**Patient fear of topical steroid use:** Myths and misconceptions regarding the risks of corticosteroid usage results in reduced treatment compliance by some patients

**Unnecessary exclusion of food groups by patients:** Some patients are unnecessarily (and unhealthily) excluding food groups from their diets due to the misconception that food is effecting/causing their AD

**Short consultation times in private practice:** Dermatologists commonly face time constraints, which can effect the quality of AD care they are able to provide (e.g. by leaving little time for patient education)

**Lack of willingness to manage AD patients:** Dermatologists in small centres can be unwilling to manage AD (due to its complexity and time requirements) and prefer to refer to large centres, which can result in overburdening





# Atopic Dermatitis (AD) in Germany

## German healthcare system<sup>(a)</sup>:

The German healthcare system is funded by statutory contributions and aims to provide free access to healthcare for all. The health insurance options available to a given individual will vary in line with the following:

- **Statutory health insurance:** Employees earning less than a certain amount per year<sup>1</sup> must take part in the government health scheme (*Gesetzliche Krankenversicherung* or GKV). The scheme is administered by 116 *Krankenkassen*: non-governmental, non-profit 'sickness funds' legally bound to charge a basic rate of 14.6% of your eligible gross salary, with the fee equally split between employee and employer. GKV covers primary care with registered doctors, hospital care (in- and outpatient services) and basic dental treatment. Non-working dependents living at the same address are covered at no extra cost (provided they are registered with the same *Krankenkassen*).
- **Private health insurance:** Certain population segments, including employees earning more than a certain amount per year<sup>1</sup> and self-employed individuals, can choose to opt out of the state insurance plan and pay for private health insurance (*Private Krankenversicherung* or PKV). PKV typically covers a wider range of medical and dental treatments, but on a per person basis (i.e. without covering non-working dependents). Employers may also provide contributions towards private health insurance fees.

## In Germany, there are three organisational levels to the universal healthcare system:

1. Primary care – a network of physician offices (where most dermatologists are based) and primary care centres providing basic medical advice / treatment
  2. Secondary care – a network of public hospitals (run by local and regional authorities), voluntary / non-profit hospitals (run by churches or the German Red Cross) and private hospitals, providing specialist treatment and requiring referral from a primary care physician (with the exception of patients with private health insurance). Secondary care specialists may also be based in physician offices
  3. Tertiary care – a network of specialist hospitals (typically university affiliated) providing specialist care, normally requiring referral from secondary care<sup>(a)</sup>
- Note: public hospitals in Germany often contain their own private wards, including *Universitäts-Hautklinik Kiel*

## Prevalence

- AD affects 10–20% of children and 5–15% of adults in Western countries<sup>(b)</sup>
- In Germany, the one-year prevalence of AD is<sup>(c)</sup>:
  - 9.3% in children
  - 8.7% in adolescents
  - 2.2% in adults



Note: 1. The threshold is subject to change

## Care provision (Germany):

### Location:

- Mild (or well-controlled) AD care is often delivered by PCPs (primary care providers)
- Moderate and severe (uncontrolled) AD care is mostly delivered in specialists' care units (within hospitals)

### Funding:

- Primary care and hospital services are funded through statutory contributions (either through the Government health scheme or private health insurance)

## Guidelines and societies:

### Guidelines:

- Guidelines for treatment of AD part I and part II: European Association of Dermatology and Venerology (EADV)
- Consensus-based European guidelines for treatment of atopic eczema (atopic dermatitis) in adults and children<sup>(d)</sup>
- S2k - Guideline on diagnosis and treatment of atopic dermatitis<sup>(e)</sup>

### Medical societies:

- German Dermatological Society (DDG, Deutsche Dermatologische Gesellschaft)
- German Society for Allergy and Clinical Immunology (DGAKI)

Sources: (a) The German Health Care System – International Health Care System Profiles. The Commonwealth Fund. [Website] <https://international.commonwealthfund.org/countries/germany/> Accessed 8 Aug 2019; (b) Weidinger S, et al. Atopic Dermatitis. *Lancet*. 2016;387(10023):1109-1122. doi: 10.1016/S0140-6736(15)00149-X (c) Barbarot S, et al. Epidemiology of atopic dermatitis in adults: Results from an international survey *Allergy*. 2018;73(6):1284-1293; (d) Consensus-based European guidelines for treatment of atopic eczema (atopic dermatitis) in adults and children: part II. *J Eur Acad Dermatol Venerol*. 2018;32(6):850-878 (e) AWMF online – Guidelines detail view – eczema. [Website] <https://www.awmf.org/leitlinien/detail/II/013-027.html> Accessed 12 Aug 2019

# The centre and dermatology department

## Centre for Inflammatory Skin Diseases



### Type and location

The Centre for Inflammatory Skin Diseases is part of the University Hospital Schleswig-Holstein, providing both public and private dermatology services. The centre is located within the dermatology department and specialises in the treatment of AD, alongside other chronic inflammatory and autoimmune skin conditions (e.g. psoriasis)



### Population served

Patients are referred to the centre from all over Germany, including those participating in clinical trials for treatments they would otherwise not have access to. The centre treats both publically and privately-insured patients (with privately-insured patients referred from a private dermatology clinic within the centre)



### Service Division

#### Outpatient service

#### Inpatient service



### Hours of availability

08:00-12:30, 13:30-17:00 (Mon-Fri)

24 / 7



### No. of patients seen

~1000 patients, ~3,000 appointments per year

56 dermatology inpatient beds (none specifically assigned to AD) and 14 day care places



### Types of patients seen

Primarily AD and psoriasis patients, but also those with other chronic inflammatory or autoimmune diseases. The centre treats mild, moderate and severe AD patients, the majority being moderate-severe or uncontrolled. Patients requiring emergency dermatology care first attend the dermatological emergency service (open 24/7), before attending a follow-up appointment in the Centre for Inflammatory Skin Diseases (during opening hours)



### Facilities on-site<sup>(1)</sup>

- Phototherapy (PUVA, UVB, UVA1)
- Extracorporeal photophoresis
- Dermatological Allergy Unit for in vivo and in vitro diagnostics (e.g. food provocation)

- Day care unit
- Dermatology, Allergy and Immunology laboratories
- Bio-banking facilities

Note: (1) List of facilities is not exhaustive

# The team

## Core team profile

- 1** Full professor of dermatology
- 3** Certified dermatologists
- 5** Trainee dermatologists (2 as clinician scientists [40% research; 60% clinical practice])
- 6** Study nurses

## Wider team profile

- 1** Full professor for Translational Dermatology
- 5** Allergology specialists:
  - 1 Full professor of allergy and immunology
  - 2 Certified allergologists
  - 1 Pneumologist
  - 2 Trainee allergologists
- 2** Nurses (provide admin support and take blood samples for dermatology department)
- 1** Statistician + **2** bioinformaticians (statistician involved in analysing TREATgermany registry data – see case study pg. 181 - 183)
- 3** Scientists (biologist, molecular biologist and geneticist) – biologist in charge of the centre's own BioBank and the bioanalytic module of TREATgermany
- 1** Psychiatrist (specialised in psychosomatic medicine and psychotherapy)



## Governance and processes

### Team meetings:

- *Morning Meeting (08:00 every weekday, 10 mins):*
  - Attended by: Centre for Inflammatory Skin Diseases team
  - Purpose of the meeting: to assign roles for the day to dermatologists, trainees and study nurses, and to discuss any biobank, TREATgermany registry or research study requirements (e.g. biosample)
- *Daily Midday Meeting (13:00 every day, 30 mins):*
  - Attended by: dermatology department
  - Purpose of the meeting: to discuss patients (who often attend the meeting), seek a second opinion from other team members and coordinate interdisciplinary treatment plans
- *'Centre for Inflammation Medicine' team meeting (every Tuesday, 1 hour):*
  - Attended by: dermatology (including allergology), rheumatology, gastroenterology, pulmonology, ophthalmology, etc. (further specialists invited as required)
  - Purpose of the meeting: to discuss complex patients and their in-label / off-label treatment plans

### Patient records:

- *Electronic patient records:*
  - Structured only medical record for AD including established assessment tools (see case study pg. 178 - 180)

Note: Please see page 161 for further details about the wider team

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients with symptoms of AD (e.g. itching or dryness of the skin) are assessed by PCPs (primary care providers) or office-based dermatologists
- Privately insured patients can present directly to dermatologists in private practice or the centre

*Note: Patients with well-controlled or mild AD may be managed in primary care and not referred to the centre*

## Diagnosis and Referral

In secondary and tertiary care



- Publicly insured patients must be referred by their PCP to access a dermatologist in the centre
- Referrals to the centre (from PCPs or office-based dermatologists) will be seen within 2 weeks
- Patients require a referral from their PCP or office-based dermatologist at least every 3 months to continue attending follow-up consultations at the centre
- AD is diagnosed through clinical examination and if necessary supplementary tests (e.g. blood tests) are performed
- The centre provides specialist AD care for both adult and paediatric patients

## Treatment and Management

Medical management



Non-medical management



- Patients attend an initial dermatologist consultation (~1hr), during which a whole body clinical examination, blood tests (IgE levels) and comorbidity assessments (e.g. allergy testing) may be performed
- Note: Food provocation testing is performed in the ward in order to manage food allergy emergencies*
- Patients with AD comorbidities (e.g. allergic rhinitis; conjunctivitis) are referred to a comorbidity specialist as required (e.g. a physician with an allergology sub-specialism can often be seen same day)

- At each consultation patient information (including EASI / SCORAD / DLQI / POEM / IGA / PGA scores) will be inserted into the centre's structured electronic record (see case study pg. 178 - 180)
- If patients are willing and eligible, biomaterials (e.g. blood samples) and questionnaire answers are collected for inclusion in either the centre's own biobank or the German AD registry 'TREATgermany'

## Follow-up

Monitoring of chronic disease / flare up



- Patients attend a first follow-up appointment (20–30 mins) after 4–6 weeks (adults) or 2–4 weeks (children)
- After the first follow-up consultation, patients attend routine follow-up appointments (20–30 mins) every 6-12 weeks
- Mild or well-controlled patients may be referred back to their PCP or to a network of office-based dermatologists to continue treatment. Patients who live far from the centre may choose this option and only return to the centre for annual check-ups

# Roles of the wider team

## Pneumologist

(internal medicine with allergology sub-specialism)

**Patient type:** AD patients with asthma and/or rhinitis symptoms

**Referral:** Referred to by dermatologists at the centre for cases of comorbid asthma and/or rhinitis. The pneumologist reports back to the dermatologist and to the treating pneumologist

**Consultations:** The pneumologist records the patient's medical history and nurses perform lung function tests with on-site equipment (to be interpreted by the pneumologist)

**Timing:** Initial consultation: ~1hr (including lung function test waiting times), but duration may vary. Follow-up appointments: frequency and duration depends on symptom severity

## Allergist

(dermatologist with additional allergy board certification)

**Patient type:** AD patients with suspected contact allergies, food allergies, drug allergies and inhalation allergies

**Referral:** Referred to by dermatologists within the Centre for Inflammatory Skin Diseases. Patients with confirmed food allergies may be referred to a private dietician

**Consultations:** The allergist conducts patch and prick tests (though may be unable to do so during the first appointment, e.g. if the patient has taken antihistamines that day). Patients usually complete a full treatment cycle before attending a follow-up consultation with the allergist

**Timing:** Initial consultations: ~1hr; Follow-up appointments: 20mins-1hr, every 2 weeks to 3 months (depending on individual patient needs)



## Psychiatrist

(specialised in psychosomatic medicine and psychotherapy)

**Patient type:** AD patients requiring psychological support services

**Referral:** Referred to by dermatologists within the Centre for Inflammatory Skin Diseases. The doctor, also based within the centre (working primarily on a research project), acts as a triage point to direct AD patients requiring psychological support to the appropriate service. During the routine dermatologist consultation, a questionnaire concerning psychosomatic comorbidities is completed by all patients, which helps the dermatologist to identify the need for psychological support<sup>(a)</sup>

**Consultations:** The doctor runs initial consultations for AD patients requiring psychological support (2-5 patients per week), employing techniques such as CBT (cognitive behaviour therapy) and intensive short-term Schema Therapy (ISTST). With the patient's approval, findings from these consultations also contribute to AD research (e.g. for the German Ministry of Health's anti-stigmatisation study). The doctor either continues to see patients, refers them to a private practice psychiatrist or refers them to the hospital's psychosomatic unit within the psychiatry department

**Timing:** Initial consultation: ~1hr per consultation. Follow-up appointments: ~1hr per consultation, held for a maximum of 10 appointments

### Roles of additional team members:

- *Study nurses (core team):* responsible for admin and patient visits (including treatment injections, blood tests etc,) associated with the centre's clinical trials. Usually see 1-4 patients per day. Each day they will be assigned across: AD (2); psoriasis (2); autoimmune disease (1) and the centre's biobank (1)
- *Statistician:* involved in analysing data collected for the TREATgermany registry (see case study pg. 181 - 183)
- *Biologist:* responsible for overseeing the collection of biosamples for the centre's own database and biorepository, in addition to the TREATgermany registry

Sources: (a) Wohlrab et al. 2013, Recommendations for detection of individual risk for comorbidities in patients with psoriasis. Arch Dermatol Res. 2013 Mar;305(2):91-8



# Overview of interventions in place for AD



## Key:

 Case study available

## Awareness and Presentation




Symptom identification

- **Patient education programme:** structured educational intervention ("AD school") aimed at consolidating the information provided in dermatologist consultations and improving self-management  
 See pg. 167-168 for case study
- **Public educational presentations:** presentation evenings run by the centre for the general public about basic AD education and treatment, engaging with new patients who need specialist AD treatment  
 See pg. 169 for case study
- **Emergency care:** patients requiring emergency dermatology care first attend the dermatological emergency service (open 24/7), before attending a follow-up in the Centre for Inflammatory Skin Diseases (during opening hours)

## Diagnosis and Referral





In secondary and tertiary care

- **Provision of HCP education:** the centre runs a number of initiatives aimed at educating HCPs both within and outside the centre, and disseminating information on AD diagnosis, treatment and management  
 See pg. 170-171 for case study

## Treatment and Management







Medical management

- **Onsite specialist in psychosomatic medicine and psychotherapy:** a psychosomatic medicine / psychotherapy specialist (primarily working on a research project) runs consultations for and triages AD patients (2-5 per week), directing them to the appropriate psychological support service  
 See pg. 172-173 for case study
- **Longer and more frequent consultations:** the centre offers longer (30–45 mins versus 10–15 mins) and more frequent follow-up consultations with dermatologists for AD patients when compared to common practice  
 See pg. 174-175 for case study
- **Access to AD clinical trials:** patients can access novel treatments through participation in clinical trials




Non-medical management

- **Involvement in anti-stigmatisation study:** a psychosomatic medicine / psychotherapy specialist is researching stigma associated with visible skin conditions (including AD)  
 See pg. 176-177 for case study
- **Structured patient assessment tool:** an online structured database enabling the consistent collection and storage of patient data (e.g. EASI / SCORAD scores)  
 See pg. 178-180 for case study
- **German-wide AD-registry TREATgermany:** Kiel, Hannover and Dresden centres created the TREATgermany registry to ease the pooling and comparison of AD patient data  
 See pg. 181-183 for case study
- **Centre's own biobank:** the centre maintains its own biobank of AD patient bio-samples, for sponsored or investigator-led research  
 See pg. 184 for case study

## Follow-up



Monitoring of chronic disease/flare up

- **Specialist study nurses:** study nurses and physicians rotate between AD, psoriasis, other chronic inflammatory and autoimmune diseases, as well as clinical and investigator-initiated trials, and the centre's biobank. During this, the nurses run patient study consultations, deliver education and support treatment plan development  
 See pg. 185-186 for case study
- Note: general dermatology nurses provide administrative support for dermatology staff*
- **Centre for Inflammatory Skin Diseases:** within the centre, there is a highly specialised Centre for Inflammatory Skin Diseases, that was established to oversee the long-term care of patients with chronic inflammatory and autoimmune diseases (including AD)
  - **Sub-investigator trainee dermatologist:** one trainee dermatologist (supervised by the principal investigator) performs the clinical trial study visits and takes care of the Biobank



# Monitoring AD patients and comorbidities

## The centre employs a number of measures for monitoring AD and associated comorbidities

### Objective measures:

AD scoring indices are used to monitor patients and their disease, including:

- EASI (Eczema Area and Severity Index): scoring system that grades the physical signs of AD / eczema<sup>(a)</sup>
- SCORAD (SCORing Atopic Dermatitis): to assess AD disease severity<sup>(b)</sup>
- vIGA-AD™ (Validated Investigator Global Assessment for Atopic Dermatitis): scoring system for use in clinical trials which grades the overall appearance of AD lesions based on a series of morphological descriptions

### Patient-reported outcomes:

QoL is routinely measured by:

- DLQI (Dermatology Quality of Life Index): dermatology related quality of life questionnaire<sup>(c)</sup>
- PGA (Patient global assessment)<sup>(e)</sup>: patients self-evaluate their overall disease severity
- POEM (Patient-Oriented Eczema Measure)<sup>(f)</sup>: tool for monitoring AD severity

*Note: indices are recorded during daily clinical practice (i.e. during regular dermatologist consultations) as part of the patient assessment tool (see case study pg. 178 - 180). Other measures for monitoring AD and associated comorbidities may be used in specific clinical trials as required*

---

### The dermatology department routinely measures comorbidity outcomes by performing:

- *Patch tests* - performed by dermatologists with an allergology sub-specialism
- *Skin prick tests* - performed by dermatologists with an allergology sub-specialism
- *Blood-specific IgE (Immunoglobulin E) tests* - performed by dermatologists
- *Lung function tests* – performed by nurses during pneumologist consultations

**Sources:** (a) EASI for clinical signs: Harmonising Outcome Measures for Eczema (HOME); [Website] <http://www.homeforeczema.org/research/easi-for-clinical-signs.aspx> Accessed 13 Mar 2019 (b) SCORing Atopic Dermatitis (SCORAD) Calculator (0.9.0). [PDF] <http://scorad.corti.li/> Accessed 26 Feb 2019; (c) Validated Investigator Global Assessment For Atopic Dermatitis (vIGA-AD™) Scale [PDF] [https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale\\_vIGA-AD\\_2017.pdf](https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale_vIGA-AD_2017.pdf) Accessed 26 June 2019 (d) Lewis V, et al. 10 Years Experience of the Dermatology Life Quality Index (DLQI). *J Invest Dermatol Symp Proc* 2004;9:169 –180; (e) Al-Dhubaibi MS. The effectiveness of alitretinoin for the treatment of chronic hand eczema: A meta-analysis. *Int J Health Sci (Qassim)*. 2018;12(2):70–79; (f) Charman CR et al. Translating Patient-Oriented Eczema Measure (POEM) scores into clinical practice by suggesting severity strata derived using anchor-based methods. *Br J Dermatol*. 2013;169(6):1326–1332

# Advice to other centres



## What advice would you give less specialised centres?



**Objective of advice:** Employ physicians and nurses who sub-specialise in AD care

- **Why?** AD can be a complex disease to manage, and patient needs can differ from other dermatological conditions (including other inflammatory skin diseases such as psoriasis). Physicians and nurses with a sub-specialism in AD are able to provide patients with tailored treatment plans informed by the latest guidelines and research (e.g. emphasis on the importance of topical treatment), in addition to providing the necessary holistic support (e.g. emphasis on therapeutic education and recognising the implications of AD on quality of life)



**Objective of advice:** Employ physicians and nurses with clinical trial experience

- **Why?** Involvement in AD clinical trials allows patients to access pioneering therapies and potentially achieve improved treatment outcomes. Additionally, clinical trials are typically run on a national / international basis, and can therefore facilitate collaboration and information sharing between participating centres. HCPs with past clinical trial experience can help ensure clinical trials and basic research are set-up and run successfully (e.g. by ensuring data is collected in a timely and consistent manner). This will help to quickly translate research findings into practice. Examples may include dermatology nurses trained in recording AD severity indices scores (e.g. EASI; SCORAD) and collecting biosamples (e.g. skin swabs)



**Objective of advice:** Develop the role of the specialist in psychosomatic medicine and psychotherapy

- **Why?** AD is a complex disease that is not always well controlled and can impact patient quality of life in multiple ways. The disease can have significant psycho-social implications that can impact adherence to treatment. A psychosomatic medicine / psychotherapy specialist, based in the Centre for Inflammatory Skin Diseases, acts as a triage point to efficiently direct AD patients requiring psychological support services to the appropriate specialist



**Objective of advice:** Create a structured electronic data collection tool for use in consultations

- **Why?** Large amounts of patient data (both qualitative and quantitative) are often collected during consultations. Creating an online tool that can be efficiently completed in consultations helps to ensure consistent data is collected across staff / consultations, whilst creating a patient data pool that can be easily analysed for research purposes or internal quality reviews



# Next steps for the centre

## What is next for the centre?

### **Objective:** New hospital building

- **What?** The centre plans to move into a new hospital facility which will house all the Centre for Inflammatory Skin Diseases amenities on one floor (including its own reception desk, psychosomatic consulting room and research facilities)
- **Why?** Co-location of all the centre's services in a new facility will support improved communication and collaboration between the team and increase convenience for patients (e.g. when navigating between appointments/rooms)



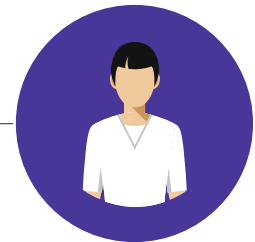
### **Objective:** Provide study nurses with further training in food allergies

- **What?** The centre would like to provide study nurses with food allergy training in addition to their existing nutrition sub-training
- **Why?** Currently, 3 of the centre's study nurses have received sub-training in nutrition. The centre would like to provide these nurses with further training so that they may support with the management of food allergies or suspected food allergies (as an AD comorbidity)



### **Objective:** Increase the number of clinical scientists operating at the centre

- **What?** The centre intends to increase the number of clinical scientists based at the centre from 2 to approximately 6
- **Why?** Increasing the number of clinical scientists based at the centre will enable the centre to contribute to more research at any given time, allowing more patients the opportunity to receive pioneering AD treatments and potentially improved treatment outcomes. It will also allow their trainee dermatologists to gain skills in research in addition to clinical practice during their specialisation



*Note: The centre receives funding from the DFG (Deutsche Forschungsgemeinschaft – German Research Foundation) to finance clinical scientists, with the workload of these individuals split 40% research : 60% clinical practice*

# Case studies



	#
<b>Patient education programme</b>	167 – 168
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# Patient education programme (1/2)

## Overview

- The centre offers highly structured and standardised multidisciplinary, group-based education programmes ('AD schools'), which are developed by the German Arbeitsgemeinschaft Neurodermitisschulung e.V. (AGNES) working group and paid for by most insurance companies<sup>(a)</sup>

## What is the rationale?

- Designing and delivering education initiatives for patients and their families represents an opportunity to consolidate the information provided in dermatologist consultations and provide further information on AD treatment and self-management<sup>(a)</sup>
- Educational interventions have shown to improve quality of life for paediatric patients and their parents<sup>(b)</sup>

## What are the key features of the intervention?

### *Who is it for?*

- The centre currently runs an education programme for paediatric AD patients (toddlers specifically) and their parents, which follows the German Arbeitsgemeinschaft Neurodermitisschulung e.V. (AGNES) model (an established programme requiring presenters to attend a training course and gain an accreditation)<sup>(c)</sup>

### *Who delivers it?*

- The programme is run as a collaboration between the centre's Professor of Dermatology, three trainee dermatologists, a nutritionist, a psychologist, a specialist nurse, and a private practice paediatrician

### *What does it cover?*

- The teaching covers different approaches to AD care, current therapies, the role of food in AD, and mechanisms for coping with the disease

### *What is the format?*

- The curriculum is delivered at least twice per year over 12 hours of teaching (during 2 x 6hr or 3 x 4hr educational sessions), for 6–8 parents or patients at a time
- A public AGNES website has been developed for patients to access information about participating centres and available training material<sup>(d)</sup>

### *What are the benefits?*

- A 1-year randomised, controlled multicentre study on the ARNE adult training program showed significant beneficial effects on a variety of psychosocial parameters (including itch management and QoL), as well as AD severity<sup>(e)</sup>

**Sources:** (a) Stabb D, et al. The double benefits of educational programmes for patients with eczema. *BMJ*. 2006;332. doi: 10.1136/bmj.38796.426736; (b) Ersser SJ, et al. Psychological and educational interventions for atopic eczema in children. *Cochrane Database of Systematic Reviews*. 2014,1. doi: 10.1002/14651858.CD004054.pub3; (c) N. van den Berg et al. AGNES: Supporting General Practitioners With Qualified Medical Practice Personnel. *Dtsch Arztebl Int*. 2009;106(1-2):3–9; (d) Arbeitsgemeinschaft Neurodermitis Schulung [Website] <https://www.neurodermitisschulung.de/index.php?id=22>. Accessed Aug 5 2019; (e) Heratizadeh A. et al. Effects of structured patient education in adults with atopic dermatitis: Multicenter randomized controlled trial. *J Allergy Clin Immunol*. 2017;140(3):845-853. doi: 10.1016/j.jaci.2017.01.029



# Patient education programme (2/2)

## What are the key features of the intervention? (cont.)

### Additional patient education – AD study nurses:

- The centre employs a number of AD-specialised study nurses who provide tailored, 1-on-1 education to patients, covering AD treatment and self-management
- Initial AD study nurse consultations last ~45 minutes, with ~30 minute follow-up consultations
- These consultations are longer than other outpatient consultations (~10-15 minutes) to allow sufficient time to explain the disease and the treatment option(s) prescribed, and to produce a written treatment plan alongside the patient

## What are the challenges?

- Reimbursement by insurance companies is insufficient

## What are the outcomes so far?

### Benefits to patients:

- Consolidation of information provided in dermatologist consultations
- Opportunity to ask questions to AD specialists
- Further useful information received regarding AD treatment and self-management

### Benefits to HCPs:

- Improved patient attitudes towards treatment and hence improved treatment compliance
- The opportunity to provide patient education outside the time constraints of consultations

## What's next?

- Expand the education programme to include adult patients (aged 18+ years; planned for April 2020) and adolescent patients



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We follow the AGNES model - an established programme requiring teachers to attend a training programme in order to tailor patient education to different age groups



*Trainee dermatologist,  
Universitätsklinikums  
Schleswig-Holstein*

# Public educational presentations

## Overview

- The centre runs presentation evenings for the general public about basic AD education and treatment. The dermatologists engage with new AD patients who require specialist advice and attention



We actually receive a number of new patients from these public presentations, as they see we are specialists in these conditions



*Dermatologist,  
Universitätsklinikums  
Schleswig-Holstein*

## What is the rationale?

- In addition to the chronic pruritus, atopic dermatitis patients suffer from the associated negative social stigmatization of the disease<sup>(a)</sup>
- There is a need for public education to increase awareness about AD and the potential treatment options<sup>(b)</sup>

## What are the key features of the intervention?

*Who is it for?*

- The presentation evenings are open to the public (~50 people usually attend each session, most of whom are not existing patients at the centre)

*What are the benefits?*

- Raising public awareness about chronic skin conditions. Past events have resulted in new patients approaching the centre for specialist treatment

*Who delivers it?*

- Centre dermatologists and trainee dermatologists. The presentations are funded by the University Hospital, which also organises the logistics for the events and hosts them in a patient information campus of the university medical centre, located within a shopping centre in central Kiel

*What does it cover?*

- Sessions focus on basis disease education and emerging treatments for AD and psoriasis (with time for the audience to ask questions)

*What is the format?*

- An evening session of 1 hour presentations followed by 1 hour of Q&A (held once a month, with a dermatology focus 4-6 times per year)

## What are the outcomes so far?

### Benefits to patients:

- Opportunity to ask questions to AD specialists
- Able to learn about different AD treatments

### Benefits to HCPs:

- Opportunity to provide patient education without clinic time constraints
- New patients received following the public presentations

## What's next?

- Continue to optimise and deliver public educational presentations

**Sources:** (a) Werfel T, et al. The Diagnosis and Graded Therapy of Atopic Dermatitis. *Dtsch Arztebl int.* 2014;111(29-30): 509–520; (b) Ring J, et al. Atopic eczema: burden of disease and individual suffering – results from a large EU study in adults. *J Eur Acad Dermatol Venereol.* 2019;33:1331-1340. doi: 10.1111/jdv.15634



# Provision of HCP education (1/2)

## Overview

- The centre runs a number of initiatives aimed at educating HCPs both within and outside the centre. Disseminating good practices in AD diagnosis, treatment and management has the potential to improve the quality of AD care delivery throughout the health system and reduce referrals to specialist care

## What is the rationale?

- Healthcare professional education has the potential to improve the physician knowledge and confidence of HCPs and patient health outcomes<sup>(a)</sup>
- The literature suggests primary care education interventions can reduce unnecessary referrals to specialists<sup>(b)</sup>

## What are the key features of the intervention?

### Office-based dermatologists:

- The centre's first HCP education initiative covered psoriasis. It still runs today and includes:
  - Regular afternoon training sessions (half-day) for office-based dermatologists (2 per session). The centre plans to run similar sessions covering AD when more systemic therapies are available
  - Following this, the office-based dermatologists attend an evening session to discuss the day's patients and give short presentations on current therapies (and their course of action)
- Specifically for AD, the centre has delivered:
  - Two afternoon preceptorship meetings, covering: how to use the new biologic therapy, which patients are currently being treated with it, potential switch patients, and side-effect profile

### Office-based dermatologists and PCPs:

- A 1hr bi-annual symposium, presented by dermatologists and trainee dermatologists. The symposia are held for PCPs (primary care practitioners) and office-based dermatologists, and include:
  - Information on inflammatory skin diseases (primarily AD and psoriasis)
  - Information on new treatments and research findings, including comorbidity screening

### Medical students (trainee physicians and trainee dermatologists):

- 'DermStartup' (run by centre dermatologists for over 10 years and privately sponsored):
  - A 1-day 'crash course' held four times per year
  - The courses are held either for current medical students (to provide a basic introduction to topical therapies) or for second year trainee dermatologists (covering the initiation of systemic treatment)

**Sources:** (a) Cervero RM, et al. The Impact of CMA on Physician Performance and Patient Health Outcomes: An Updated Synthesis of Systematic Reviews. *Journal of Continuing Education in the Health Professions*. 2015;35(2):131-139; (b) Schopf T et al. Impact of interactive web-based education with mobile and email based support of general practitioners on treatment and referral patterns of patients with atopic dermatitis: randomized controlled trial. *J Med Internet Res*. 2012;5:14(6):e171



# Provision of HCP education (2/2)

## What are the key features of the intervention? (cont.)

### Office-based practice nurses:

- Regular office-based practice nurse education sessions (1.5hrs):
  - Centres that wish to collaborate organise for their nurses (who care for inflammatory patients) to attend
  - Sessions are either delivered at the centre or at an appropriate location in the community
  - Nurses learn about communication strategies, diagnostic tools and how to correctly use dermatology scoring systems (e.g. SCORAD)

## What are the outcomes so far?

### Benefits to patients:

- Receive recommended AD education and treatment in primary / secondary care (without having to wait until referral to specialist care)
- Reduced travel burden, as patients can receive treatment closer to home
- Quicker and more appropriate referrals to specialist care

### Benefits to HCPs:

- Non-AD specialised HCPs are empowered to manage mild AD cases without referring
- Fewer inappropriate referrals (freeing up consultation time)

## What's next?

- When the centre offers more systemic AD therapies, the team plans to follow a similar HCP education model to that which is used for psoriasis

“

Educating office-based dermatologists allows us to refer AD patients back to them, to continue effective treatment away from the centre

*Dermatologist,  
Universitätsklinikums  
Schleswig-Holstein*



“

Local dermatologists are often unwilling to prescribe certain therapies and would rather refer patients with inflammatory skin diseases to specialist centres like ours. Educating HCPs may reduce this and prevent patients having to travel long distances for treatment

*Dermatologist,  
Universitätsklinikums  
Schleswig-Holstein*





# Onsite specialist in psychosomatic medicine and psychotherapy (1/2)

## Overview

- The centre's onsite psychosomatic medicine and psychotherapy specialist supports the dermatologists to triage patients in need of psychological support to the appropriate professional, in addition to working on research projects (primarily the anti-stigmatisation study)

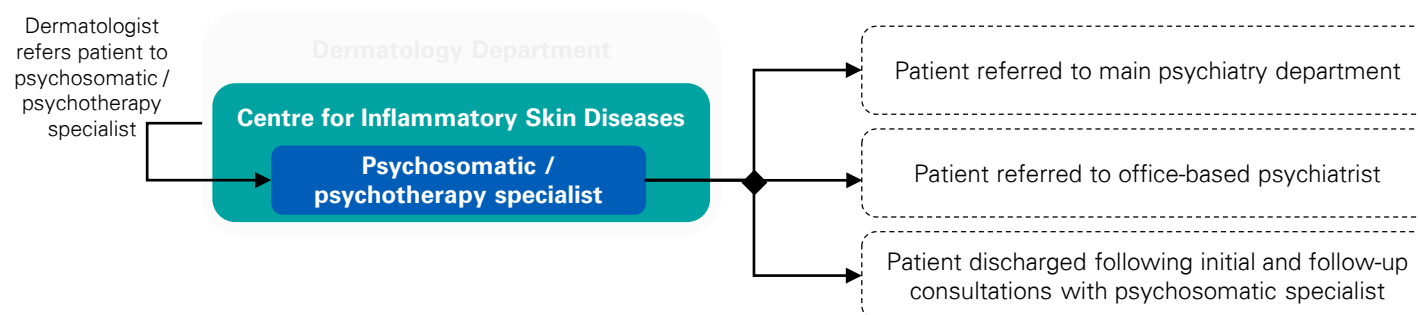
## What is the rationale?

- Atopic Dermatitis is a complex disease, which (like many chronic skin conditions) is not always well controlled and can impact patient quality of life in multiple ways<sup>(a,b,c)</sup>
- Living with a chronic skin condition can have significant psycho-social implications, which in turn can impact upon treatment adherence<sup>(d)</sup>
- Adolescents with AD have been found to have elevated rates of anxiety (20%) and depressive disorders (10%) compared to the general population<sup>(e)</sup>

## What are the key features of the intervention?

- Psychosomatic medicine and psychotherapy is a specific form of training offered in German hospitals<sup>(ref)</sup>
- A medical doctor specialised in psychosomatic medicine and psychotherapy is based in the Centre for Inflammatory Skin Diseases, funded by German Ministry of Health (GMOH) to run an anti-stigmatisation study (see case study pg. 176 - 177)
- The doctor also runs initial consultations for AD patients (referred by dermatologists within the centre) requiring psychological support (~1hr per consultation; 2–5 patients per week) and supports triaging of the patients. With the patient's approval, findings from these consultations are included in research
- During these sessions, the doctor offers multiple forms of psychosocial support, including CBT (cognitive behaviour therapy) and ISTST (intensive short-term Schema Therapy)
- Depending on the patient's requirements, the doctor either:
  - Continues to see these patients (for a maximum of 10 appointments)
  - Refers them to a private practice psychiatrist (or local PCP), or:
  - Refers them to the hospital's main psychiatry department

### Psychosomatic referral pathway:



**Sources:** (a) Barankin B et al. Psychosocial effect of common skin diseases. *Can Fam Physician*. 2002;48:712–716; (b) Lifschitz C. The impact of atopic dermatitis on quality of life. *Ann Nutr Metab* 2015;66(suppl 1):34-40; (c) Gochbauer H, et al. The Psychosocial Impact of Atopic Dermatitis. *Adv Exp Med Biol*. 2017;1027:57-69. (d) Reach G. Can we improve treatment adherence in patients with chronic disease? *Bioethics Forum*. 2014;7(3); (e) Slattery MJ, et al. Depression, anxiety, and dermatologic quality of life in adolescents with atopic dermatitis. *J Allergy Clin Immunol*. 2011;128(3):668-71.



# Onsite specialist in psychosomatic medicine and psychotherapy (2/2)

## What are the outcomes so far?

### Benefits to patients:

- Access to initial psychological support onsite at the centre
- Prompt referral to an appropriate source / level of psychological support

### Benefits to HCPs:

- Quick and straight-forward referral to obtain a specialist opinion
- Potential for improved patient treatment outcomes through the provision of psychological support (e.g. by improving treatment compliance)

## What's next?

- Once the anti-stigmatisation project concludes (Q4 2020), the centre's dermatologists intend to employ the psychosomatic psychologist on a full-time basis (though must first establish feasibility (i.e. the likelihood of securing reimbursement))

“

It's easy for patients to come straight here [the psychosomatic sub-unit] after their dermatology appointment, compared to visiting a psychiatrist separately (which can seem more daunting for them)

*Psychosomatic / psychotherapy specialist ,  
Universitätsklinikums  
Schleswig-Holstein*



“

It is really convenient having the psychosomatic specialist so close by. We can easily send them patients to be triaged to quickly determine whether further psychological support is required

*Dermatologist,  
Universitätsklinikums  
Schleswig-Holstein*



# Longer and more frequent consultations (1/2)

## Overview

- The centre offers longer (30–45 mins versus 10–15 mins) and more frequent follow-up consultations with dermatologists for AD patients, compared to office-based dermatologists



We are keen to establish trust-based relationships with patients. AD is a complex disease and we aim to provide patients with extensive support

*Dermatologist, Universitätsklinikums Schleswig-Holstein*



## What is the rationale?

- Consultations with office-based or local dermatologists in the community are often only 10–15 minutes<sup>(a)</sup>
- AD patients can have complex treatment regimens<sup>(b)</sup>, and are not always compliant e.g. due to fears of treatment side effects<sup>(c)</sup>

## What are the key features of the intervention?

- First consultations at the centre will usually last 45 mins–1 hour with a dermatologist / resident, who will perform an extensive assessment and aim to establish a trusting relationship with the patient. Within these they will discuss the following, whilst completing the centre's patient assessment tool (see pg. 178 – 180 for case study):
  - o Medical history
  - o Prior AD treatments
  - o Clinical evaluation (of the whole body)
  - o AD disease scores (EASI, SCORAD, DLQI, IGA and PGA)
  - o Presence of comorbidities (e.g. asthma)
  - o Patient education (usually delivered by the physician, who are occasionally supported by nurses or physician assistants)
  - o Q&A (from patients)
- The follow-up consultation will last 20–30 mins, and will be within 4–6 weeks (paediatric) or 6–8 weeks (adult) of their initial consultation
  - o Patients will then be routinely followed up every 3 months on average (if well-controlled)
  - o If patients live far away from the centre, they may be referred back to an office-based dermatologist (their own, or one from the centre's network that they have trained) or Primary Care Physician for continued care, and only return the centre for an annual check-up
- Patients with suspected co-morbidities will be referred to the centre's specialists as required (e.g. allergist, psychosomatic medicine and psychotherapy specialist), and are often seen the same day
- There are always consultation slots left available for urgent patients, and one resident at the centre is always "on stand-by" to help where needed

**Sources:** (a) KPMG interviews at Universitätsklinikums Schleswig-Holstein; (b) Wollenburg A, et al. Guidelines for treatment of atopic eczema (atopic dermatitis) part I and part II: European Association of Dermatology and Venerology (EADV); (c) EFA (2019). Atopic Eczema: Itching for life. Quality of Life and costs for people with severe atopic eczema in Europe

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# Longer and more frequent consultations (2/2)

## What are the outcomes so far?

### Benefits to patients:

- Improved understanding of AD and treatment regimen
- Opportunity to ask (more) questions in time given
- Potential for improved treatment outcomes from correct usage

### Benefits to HCPs:

- Additional time to educate patients regarding their AD self-management
- Opportunity to reinforce patient education across multiple sessions close together
- Flexibility to arrange follow-up appointments as required



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“



In my experience, when compared to other skin diseases, AD patients often need more reassurance and support due to the impact on their QoL. In addition, diagnosis and treatment of AD tends to be more complex. This is why consultations with these patients take on average 30 minutes vs. 15 minutes

*Study nurse,  
Universitätsklinikums Schleswig-Holstein*

“



AD patients often require more in-depth support and reassurances (than psoriasis patients), and are more likely to be affected by comorbidities and in particular psychological disorders, such as stress

*Dermatologist, Universitätsklinikums  
Schleswig-Holstein*

# Involvement in anti-stigmatisation study (1/2)

## Overview

- The centre's wider team includes a psychosomatic medicine and psychotherapy specialist medical doctor (see case study pg. 172 - 173), who contributes to the ongoing German Ministry of Health visible skin disease anti-stigmatisation study
- With the initial research phase complete, interventions are now being designed to educate HCPs and the public and reduce the stigma associated with chronic skin conditions (including AD)



## What is the rationale?

- A recent WHA/WHO psoriasis report (part of a 'people-centred care' initiative) demonstrated how, for all visible skin conditions, there is limited understanding of the relationship between stress and these conditions (and hence psychological interventions in care are limited also)<sup>(a)</sup>
- A substantial number of individuals with visible skin diseases suffer from stigmatisation (including ~10million people in Germany alone)<sup>(b)</sup>
- The German Ministry of Health (GMOH) is therefore funding research focused on chronic visible conditions (in the form of a 3-year project, ending Q4 2020). Psoriasis is the model disease, with the aim to apply learnings to chronic conditions including AD, acne, alopecia, etc.

## What are the key features of the intervention?

The project will proceed in two phases:

**Phase 1:** researchers gain a holistic understanding of visible skin disease stigmatisation and how to reduce / prevent it (including ~40 interviews of patients, their relatives and HCPs)

**Phase 2:** use the learnings from literature research and focus groups / interviews to design interventions (namely education programmes for medical students and school teachers, with these groups prioritised based on their potential impact and feasibility)

Progress and immediate next steps:

- Pilot education programmes (Phase 2) have been conducted and the results are currently being evaluated. The programmes will be adjusted accordingly and re-delivered later in 2019
- School teachers (Phase 2) will be provided with a 'workpack' to guide the delivery of education, which will include videos if HCPs can't speak with patients directly

## Key features of project methodology:

- With the support of the GMOH, the stigmatisation experience was recorded from the perspective of affected persons, their relatives and HCPs using qualitative surveys and group and individual interviews
- Separate guidelines were designed in advance for interviewing each group of participants, and were subjected to pre-testing before use
- All interviews were transcribed verbatim and evaluated by a second independent assessor before being transferred to a category system (including participant main and sub-categories for data interpretation purposes)

**Sources:** (a) World Health Organization. Global report on psoriasis. [PDF] [https://apps.who.int/iris/bitstream/handle/10665/204417/9789241565189\\_eng.pdf?sequence=1&isAllowed=y](https://apps.who.int/iris/bitstream/handle/10665/204417/9789241565189_eng.pdf?sequence=1&isAllowed=y). Accessed 8 Aug 2019; (b) Augustin M, et al. Translating the WHA resolution in a member state: towards a German programme on 'Destigmatization' for individuals with visible chronic skin diseases. J Eur Acad Dermatol Venereol. 2019. doi: 10.1111/jdv.15682

# Involvement in anti-stigmatisation study (2/2)

## What are the key features of the intervention? (cont.)

### Analysis of results:

- Statements obtained from participants were assigned to categories, including:
  - For those with the disease:*
    - *Reaction:* statements concerning dealing with the disease from a patient's perspective, including experiences at work and with friends, family, HCPs and strangers
    - *Hiding skin from others:* statements including sentiments such as feeling the need to cover their skin during leisure activities and at work
    - *Experienced rejection:* statements concerning feeling rejected in various social contexts
    - *Assumptions and attitudes of non-affected people:* statements concerning assumptions made by others about living with the disease
- Statements from relatives and HCPs were assigned to similar categories based on their perceived experience of stigmatisation towards patients

## What are the expected outcomes?

### Benefits to patients:

- Increased public / professional awareness of stigma experienced for visible skin diseases

### Benefits to HCPs:

- Opportunity to learn how to reduce stigmatisation of patients with visible skin diseases

## What's next?

- Seeking additional funding to research areas highlighted by the original study, such as self-stigmatisation (agreeing with public stigma and applying it to one's self) and the impact of personal resilience on patient behaviour
- Exploring how the centre can hire the psychosomatic medicine and psychotherapy specialist on a full-time basis upon project completion to provide psychological support for the patients



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“

There is a high medical need for research regarding the psychological impacts of chronic skin conditions, which no one is addressing



*Psychosomatic medicine  
and psychotherapy  
specialist,  
Universitätsklinikums  
Schleswig-Holstein*

# Structured patient assessment tool (1/3)

## Overview

- The centre's dermatologists and trainee dermatologists, alongside the IT department, created a structured patient assessment tool by programming the centre's electronic records with internationally recognised AD metrics
- The centre has developed online electronic records that are connected to an anonymised database and can be used for quality control and research purposes



## What is the rationale?

- Large amounts of patient data (both qualitative and quantitative) are collected during each dermatology consultation. Collecting, storing and using this data in a consistent and manageable format can be challenging for HCPs and administrative support staff
- Using a structured online data collection tool can help alleviate these challenges and allow the senior staff to easily perform internal quality control checks

## What are the key features of the intervention?

### Development:

- The online patient assessment tool for AD has been in use for the last two years (with a separate form created first for psoriasis cases)
- Dermatologists and trainee dermatologists within the Centre for Inflammatory Skin Diseases, alongside the IT department, programmed the centre's electronic records to record various internationally agreed metrics for assessing AD. It was aimed at ensuring the secure and consistent collection and storage of patient data
- The selection of these metrics was informed by the data points typically collected in clinical trial consultations, to make it easy for dermatologists when switching between the two types of patients (i.e. trial participants and non-participants), and enable historical data collection
- The dermatology department maintains a relationship with the IT department, allowing the data collection tool to receive regular updates (e.g. the recent addition of shorthands to auto-populate the most common answers and therefore save time)

### Usage:

- The data required by the assessment tool is collected by a dermatologist or trainee dermatologist during every AD consultation (either directly on a computer, or printed off and completed by hand before being inputted later), and approved by the heads of the centre
- The assessment tool contains all the information typically recorded during a dermatologist consultation and doctors are automatically reminded which data points they need to gather
- All data is stored on a local database (not accessible by other centres) and is compliant with data protection rules
- Dermatologists use the tool to check their quality control processes (e.g. by allowing the consistency of EASI / SCORAD measures recorded by trainee dermatologists over time to be reviewed)



# Structured patient assessment tool (2/3)

## What are the key features of the intervention? (cont.)

### Form contents:

The assessment tool consists of a series of tick boxes, drop-down selections and free text boxes, provided to answer a series of questions on topics including:

- *Diagnostic criteria*
  - Essential features (itching; AD-distribution of eczema; frequency of recurrence)
  - Common features (occurrence before 2yrs old; occurrence of AD in 1st-degree relatives; personal history of asthma / hay fever; type-1 sensitisation(s))
  - Associated characteristics (hyperlinearity of the palms and soles; keratosis pilaris; periorbital shadows; Dennie-Morgan infraorbital fold; sign of Hertoghe)
- *First manifestation information:*
  - Any AD-related signs and symptoms in the last 12 months?
  - Age of first manifestation?
  - Any history of allergic rhinitis?
  - Any history of asthma?
  - Any history of other comorbidities and concomitant medication?
  - Any history of smoking?
- *Family history* (family members; year of birth; any pre-existing conditions)
- *Basic care routine* (showering; bathing; use of emollients)
- *Past AD treatments and responses*
- *Current topical therapy*
- *Current systemic therapy*
- *Objective assessments of disease severity and patient-reported outcomes (PROs):*
  - SCORAD
  - EASI
  - IGA
  - PGA
  - DLQI
  - POEM
- *Extent:*
  - Front (face, body, upper/lower extremities, hands, genitals)
  - Back
  - Number of areas totalled to assess coverage
- *Intensity of AD:*
  - Crusting / oozing
  - Excoriation (impulse to pick skin)
  - Lichenification (thickened and leathery skin)
  - Dry skin / oedema / infiltration
- *Subjective symptoms:*
  - Itching
  - Insomnia

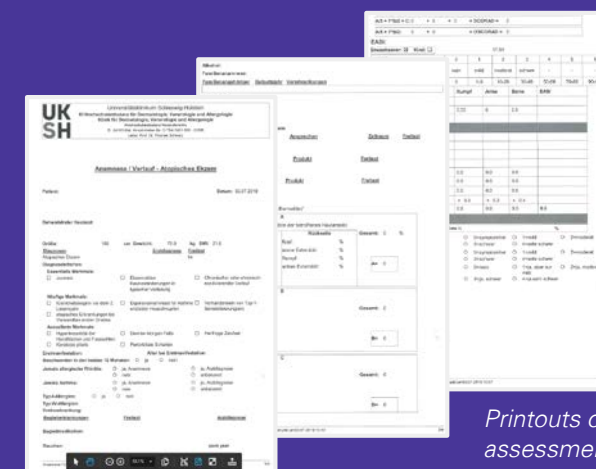
The assessment concludes with a final free-text summary of the consultation findings (e.g. body areas where inflammation is observed and a description of symptoms)

“

Using this system allows us to easily track a patient's medical history. While completing the questionnaire, we are automatically reminded which questions we need to ask the patients



*Dermatologist,  
Universitätsklinikums  
Schleswig-Holstein*



*Printouts of the  
assessment tool*



# Structured patient assessment tool (3/3)

## What are the outcomes so far?

### Benefits to patients:

- Can see treatment progress using consistent data collection points
- Quicker and more efficient consultations<sup>(a)</sup> (as dermatologists and patients learn / anticipate which questions will be asked)

### Benefits to HCPs:

- Prior and recent treatments are easier to follow, helping dermatologists to make treatment decisions in routine care
- Internal quality checks can be performed more easily, resulting in improved quality control
- Facilitates patient selection for clinical trials and research projects

## What's next?

- Continue to optimise the online data collection tool in collaboration with the centre's IT department
- Provide Universitätsklinikums Schleswig-Holstein's sister centre in Lubeck with a template of questions for use in their own system (as they were requested access to re-create a similar system)

**Sources:** (a) KPMG interviews

“

We are in regular contact with the IT team to help evolve the tool, for example by adding shorthands. This update should make it easier and quicker to complete the form

*Dermatologist,  
Universitätsklinikums  
Schleswig-Holstein*



# German-wide AD-registry TREATgermany (1/3)

## Overview

- Centre staff, in collaboration with University Hospital Hannover and the Center for Evidence Based Healthcare (ZEGV) of the University of Dresden, have established the TREATgermany registry: part of an international effort to ease the pooling and comparison of AD patient data across countries. The 3 principal investigator's centres have recruited participating centres from across Germany and plan to expand the registry to include paediatric patient data (having initially included only adults)

**Sources:** (a) Heratizadeh A, et al. Baseline characteristics, disease severity and treatment history of patients with atopic dermatitis included in the German AD Registry TREATgermany JEADV 2019 (b) The German Atopic Dermatitis Registry: TREATgermany [Website] <http://www.treatgermany.org/english/> Accessed 2 Oct 2019; (c) Gerbens, L. et al. TREATment of ATopic eczema (TREAT) Registry Taskforce: protocol for an international Delphi exercise to identify a core set of domains and domain items for national atopic eczema registries. *Trials*. 2017;18(1):87

## What is the rationale?

- TREATgermany emerged from the previous German AD-registry TREATeczema, and is part of the European TREAT (TREATment of ATopic Eczema) registry family<sup>(a)</sup>
- TREATgermany is a national evidence-based clinical registry and research network with the following objectives<sup>(b)</sup>:
  1. Characterization of medical care and pharmaceutical therapies of adults with moderate-to-severe AD
  2. Investigation of comparative effectiveness, tolerability and safety of systemic therapies for moderate-to-severe AD
  3. Development of a platform for further AD investigations

## What are the key features of the intervention?

### Establishment:

- The TREATgermany registry collected data from 2011 to 2016. TREATgermany first collected data in 2016
- The design and set-up of the registry was lead by academics based at 2 university hospitals (Kiel and Hannover) and the Center for Evidence Based Healthcare (ZEGV, Dresden), who used their medical networks to recruit centres (both hospitals and private practices, with ~32 across Germany now participating)

### Key features:

- TREATgermany captures the core set of domains and all domain items identified by the TREAT Registry Taskforce<sup>(c)</sup>
- TREATgermany currently holds clinical data on 1000 adult patients, as well as molecular data and biosamples on 400 adult patients:
  - Clinical data: collected by physicians during the examination and patients through the questionnaires
  - Questionnaire data: completed by all patients, while ~50% have provided biosamples
  - Basic biosample data: skin swab, blood and stool
  - Extended biosample data: lesion and non-lesion skin biopsies, blood, skin swabs and stool samples (recorded during the week preceding systemic therapy and repeated 3 months later)
- TREATgermany biosamples from across Germany are sent to the Kiel laboratory for storage and analysis
- A biologist based at the centre regularly visits participating centres to provide 1:1 biosample training for physicians and nurses, in order to minimise training bias and standardise data collection. The centre has produced a detailed SOP (standard operating procedure) document to supplement the training (which the dermatologists contributed to, to ensure it was practical)
- Similarly, Dresden staff provide participating centres with training on how to complete TREATgermany questionnaires (hosted on tablet devices)



# German-wide AD-registry TREATgermany (2/3)

## What are the key features of the intervention? (cont.)

### Specialist contributors:

- A statistician cleans the data collected, analyses registry data and performs quality controls
- A *Kiel University Biologist* co-wrote (with physician input) a probe protocol for use by participating centres, which details how to appropriately collect and transport biosamples (e.g. considering aspects such as: are there skin lesions?; was the skin recently washed?; are corticosteroids being used?)

### Patient questionnaire:

- The 3 founding centres together designed the TREATgermany patient questionnaire, agreeing on a set of questions which satisfy medical ethics guidelines and comply with data protection regulations
- Patient completes at: baseline consultation, 3 and 6 months later, then every subsequent 6 months
- ~40 questions, with topics including:
  - attitudes towards the disease
  - past treatments attempted
  - AD's impact on sexual relationships
  - how frequently the patient visits a specialist
- All questionnaire data is anonymised and stored on a database in Dresden

## What are the challenges?

- Getting approval for new protocols to pool and compare data from the adult registry and planned paediatric (due to differences in the data sets collected) from all participating centres' ethics committees (approvals are currently in progress)



We have written our own biosampling protocols and I personally visit new centres to provide training and minimise cross-trainer bias

*Biologist,  
Universitätsklinikums  
Schleswig-Holstein*



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# German-wide AD-registry TREATgermany (3/3)

## What are the outcomes so far?

### Benefits to patients:

- Insights into the safety and effectiveness of AD therapies
- Registry data may contribute to research aimed at improving treatment outcomes and healthcare delivery
- Better healthcare delivery<sup>(a)</sup>

### Benefits to HCPs:

- All participating centres may access TREAT data for quality control purposes and for research
- Participating centres are listed as an author on TREATgermany publications

## What's next?

- Expand the registry in 2020 to include paediatric patients. The Center for Evidence Based Healthcare (ZEGV, Dresden) will coordinate the registry, which will involve a paediatric questionnaire and paediatric biosamples (excluding biopsies)
- Capture 2,500 adult patients through additional centre recruitment and funding

Sources: (a) KPMG interviews



Centres are incentivised to participate by giving them access to the database and recognising them as authors on any publications which use the data



*Dermatologist,  
Universitätsklinikums  
Schleswig-Holstein*



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# Centre's own biobank

## Overview

- The centre maintains its own biobank of AD patient biosamples, which in combination with a tailored questionnaire provides a regularly updated source of data for use in research



## What is the rationale?

- Maintaining a biobank of patient biosamples provides a valuable data source for use in research<sup>(a)</sup>

## What are the key features of the intervention?

- The centre maintains its own biobank of AD patient biosamples. Patients are invited to participate in the biobank by providing their samples to the centre
- Biosamples include blood and skin swab samples from paediatric patients (aged 2-17 yrs) and, in addition to these, skin biopsies and stool samples from adults (aged 18+ yrs)
- Samples are collected at baseline consultation, as well as 3 months before and after the initiation of systemic therapy, and annual thereafter (conducted simultaneously with TREATgermany sampling for efficiency)
- A biologist affiliated with the centre has written biosampling protocols in collaboration with dermatologists and paediatricians also based at the centre
- Along with routine data obtained during scheduled visits, patients also complete a questionnaire tailored to different age groups / audiences (e.g. using images for paediatric patients who are not yet literate, or questions for patients' parents to complete on their behalf)
- The biosamples are pre-processed in the centre's own laboratories, before being stored long-term in a certified biobank at Hannover Medical School

## What are the outcomes so far?

### Benefits to patients:

- Research using biobank data may lead to new treatments and improved treatment outcomes

### Benefits to HCPs:

- A regularly updated source of data for use in sponsored or investigator-led research

## What's next?

- Continue collecting data and biosamples from new AD patients
- Expand and improve biosampling for single cell analyses

**Sources:** (a) De Souza YG, et al. Biobanking past, present and future: responsibilities and benefits. *AIDS*. 2013;27(3):303–312. doi:10.1097/QAD.0b013e32835c1244

# Specialist study nurses (1/2)

## Overview

- The centre employs 6 specialist study nurses that rotate between AD, psoriasis, autoimmune diseases and the centre's biobank, to run patient study consultations, deliver education and support treatment plan development



I am always keen to establish a close relationships with AD patients, provide extensive support activities, and I'm happy to answer their doubts and questions



*Study nurse,  
Universitätsklinikums  
Schleswig-Holstein*

## What is the rationale?

- AD is a complex, multi-faceted condition, with comorbidities spanning allergy and dermatology. Effective treatment requires sufficient time for testing and diagnosis, and educating patients<sup>(a)</sup>
- Approximately 10% of all AD patients in the Centre for Inflammatory Skin Diseases are taking part in clinical trials at the centre<sup>(b)</sup>

## What are the key features of the intervention?

- The Centre for Inflammatory Skin Diseases employs 6 specialist dermatology study nurses
- At each daily morning meeting (between 08:00-08:10) the study nurses will be assigned to:
  - o AD (2)
  - o Psoriasis (2)
  - o Autoimmune diseases / stand-by (to support others) (1)
  - o Centre's biobank (1) (*see case study pg. 184*)

### Primary role of the AD study nurse:

- Study nurses see 1–4 AD patients per day who are participating in the trials (first consultation 1–2 hours; follow-ups progressively shorter)
- As part of the study nurses role, in their 1:1 consultations they will:
  - o Complete AD scoring indices (e.g. EASI) – depending on trial protocol
  - o Provide psychosocial / emotional support to patients
  - o Sample collection (e.g. blood draw, biosample)
  - o Teach patients treatment application / delivery
  - o Deliver disease and therapeutic education
  - o Be their contact person for the trial
  - o Completes the documentation / administration required for medical studies
- One study nurse (the 'Study Coordinator') oversees study implementation and works between the centre and the organisation(s) funding the research

**Sources:** (a) Brunner PM, et al. Increasing Comorbidities Suggest that Atopic Dermatitis Is a Systemic Disorder. *Journal of Investigative Dermatology*, 2017;137(1):18-25; (b) KPMG interviews at Universitätsklinikums Schleswig-Holstein



# Specialist study nurses (2/2)

## What are the key features of the intervention? (cont.)

### Additional roles of the AD study nurse:

- Outside of the trials, the nurses support the centre's dermatologists with AD patient education and the formation of treatment plans
- AD study nurses may run training sessions (1-1.5hr sessions) for office-based practice nurses caring for inflammatory patients (e.g. teaching the correct use of AD severity scoring systems). These sessions are typically privately funded and may be delivered at centre or in the community
- The centre's study nurses spend more time with patients than any other staff and may therefore form lasting relationships with patients

## What are the outcomes so far?

### Benefits to patients:

- Additional 1:1 time with a HCP to ask questions
- Opportunity to participate in clinical trials / registries

### Benefits to HCPs:

- Team of nurses who are well-trained in 'best-practice' techniques (e.g. completion of AD scoring indices), from following trial protocols
- Dissemination of knowledge from specialist care nurses to those in the wider health system
- Support resource to reduce time burden on physicians

## What's next?

- Currently, the study nurses have received sub-training in nutrition (originally focused on obesity management – a psoriasis comorbidity). The centre hopes to provide study nurses with further nutrition training so that they may support patients with food allergies (an AD co-morbidity) in the future



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Nurse-led consultations allow patients to ask more questions. It allows us to make sure they have understood our advice



*Study nurse,  
Universitätsklinikums  
Schleswig-Holstein*





# Centre for Medical Study & Service

Selters (Westerwald), Germany

Site visited by KPMG 1<sup>st</sup> August 2019

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[kpmg.com/uk](https://kpmg.com/uk)



# Summary



## Context

**Centre type:** Privately owned medical centre

**Catchment area:** Patients are referred to the centre usually from regions between Rhine-Westphalia, Rhineland-Palatinate and Hesse

**Funding:** The centre predominantly receives funding from public health insurance, which is supplemented by some private health insurance funding. The centre may also receive private funding from third parties (e.g. sponsor funded clinical trials)

**Services:** The centre provides dermatological advice and treatment to adult and paediatric atopic dermatitis (AD) patients. Patients can also access novel treatments through clinical trials

**Patient population:** Paediatric and adult patients with dermatological diseases, focusing on atopic dermatitis, psoriasis, skin cancer and urticaria



## Key strengths in the delivery of AD care

**Digitally enabled centre:** Through the installation of a user-friendly technology platform, the centre has been able to improve their internal processes and increase their efficiency in documentation

**Healthcare assistant education:** The centre provides healthcare assistants with regular opportunities to help optimise AD care within the centre (e.g. understanding new treatment). Healthcare assistants receive training from the centre's dermatologist and can also access third party training

**Tailored patient database:** The centre has developed a data collection tool that enables consistent and thorough recording of all patient progress. All staff can understand and review patient response to treatment and tailor treatment accordingly

**Established relationships with local dermatologists:** The centre is part of an established local network of dermatologists. Patients suffering from various conditions, such as AD, from other centres to be easily referred as and when required



## Key challenges faced in delivery of AD care

**Variable technology infrastructure:** There is a wide range of technology capabilities and infrastructure in primary care. The efficiency of external communication between primary care providers (PCPs) and the centre can be affected if the PCPs are unable to receive or process email referrals / communication letters

**Communicating with other specialists:** Outside of the centre's network of specialists, it can be difficult to engage with various physicians.

# Atopic Dermatitis (AD) in Germany

## German healthcare system<sup>(a)</sup>:

The German healthcare system is funded by statutory contributions and aims to provide free access to healthcare for all. The health insurance options available to a given individual will vary in line with the following:

- **Statutory health insurance:** Employees earning less than €57,600 per year must take part in the government health scheme (*Gesetzliche Krankenversicherung* or GKV). The scheme is administered by 116 *Krankenkassen*: non-governmental, non-profit 'sickness funds' legally bound to charge a basic rate of 14.6% of your eligible gross salary, with the fee equally split between employee and employer. GKV covers primary care with registered doctors, hospital care (in- and outpatient services) and basic dental treatment. Non-working dependents living at the same address are covered at no extra cost (provided they are registered with the same *Krankenkassen*).
- **Private health insurance:** Certain population segments, including employees earning more than €57,600 per year and self-employed individuals, can choose to opt out of the state insurance plan and pay for private health insurance (*Private Krankenversicherung* or PKV). PKV typically covers a wider range of medical and dental treatments, but on a per person basis (i.e. without covering non-working dependents). Employers may also provide contributions towards private health insurance fees.

## In Germany, there are three organisational levels to the universal healthcare system:

1. Primary care – a network of physician offices (where most dermatologists are based) and primary care centres providing basic medical advice / treatment
  2. Secondary care – a network of public hospitals (run by local and regional authorities), voluntary / non-profit hospitals (run by churches or the German Red Cross) and private hospitals, providing specialist treatment and requiring referral from a primary care physician (with the exception of patients with private health insurance). Secondary care specialists may also be based in physician offices
  3. Tertiary care – a network of specialist hospitals (typically university affiliated) providing specialist care, normally requiring referral from secondary care
- Note: public hospitals in Germany often contain their own private wards*

## Prevalence

- AD affects 10–20% of children and 1–3% of adults in Western countries<sup>(b)</sup>
- In Germany, AD affects 3.5% of adults, and 13.2% of children<sup>(c)</sup>



## Care provision (Germany):

### Location:

- Mild (or well-controlled) AD care is primarily delivered by PCPs (primary care providers)
- Moderate and severe (uncontrolled) AD care is mostly delivered in specialist secondary (within hospitals)

### Funding:

- Primary care and hospital services are funded through statutory contributions (either through the Government health scheme or private health insurance)

## Guidelines and societies:

### Guidelines:

- Guidelines for treatment of atopic eczema (atopic dermatitis) part I and part II: European Association of Dermatology and Venerology (EADV)
- S2k - Guideline on diagnosis and treatment of atopic dermatitis<sup>(d)</sup>
- Guidance from the Onkoderm e.V. on diagnosis and treatment of atopic dermatitis<sup>(e)</sup>

### Medical society:

- German Dermatological Society (DDG, Deutsche Dermatologische Gesellschaft)
- Berufsverband der Deutschen Dermatologen (BVDD)

**Sources:** (a) The German Health Care System – International Health Care System Profiles, The Commonwealth Fund, [Website] <https://international.commonwealthfund.org/countries/germany/> Accessed 8 Aug 2019 (b) Weidinger S, et al. Atopic Dermatitis. *Lancet*. 2016;387(10023):1109–1122. doi: 10.1016/S0140-6736(15)00149-X (c) Bergmann KC, et al. Current status of allergy prevalence in Germany. Position paper of the Environmental Medicine Commission of the Robert Koch Institute. *Allergo J Int*. 2016;25:6–10 (d) AWMF online – Guidelines detail view – eczema. [Website] <https://www.awmf.org/leitlinien/detail/II/013-027.html> Accessed 12 Aug 2019 (e) Onkoderm – data library [Website] <https://www.onkoderm.de/#infothek> Accessed 4 Sept 2019

# The centre and dermatology unit

## The centre



### Type and location

The privately owned medical centre in Germany provides public and private dermatology services. The centre specialises in treating atopic dermatitis (AD), psoriasis, skin cancer and urticaria. In addition to dermatology services, the centre provides patients access to novel treatment by organising and / or facilitating clinical trials



### Population served

Patients are referred to the centre usually from regions between Rhine-Westphalia, Rhineland-Palatinate and Hesse, including patients who seek to participate in clinical trials for novel treatments

## Dermatology services



### Service Division

#### Clinical practice service

#### Clinical trials service



### Hours of availability

Monday to Friday: 8am – 5pm  
(no appointments between 12pm – 1pm)

Monday: 9am – 7pm  
Tuesday: 8am – 6pm  
Wednesday: 8am – 2pm  
Thursday: 8am – 5pm  
Friday: Closed



### No. of patients seen

Approximately 100 patients per day

Approximately 280 patients per annum



### Types of patients seen

Mild-to-severe paediatric and adult AD patients



### Facilities on-site<sup>(1)</sup>

- Four consultation rooms
- PUVA/UVB phototherapy
- Bath (for salt baths)
- Day surgery room
- Pathology collection
- Storage facility for biosamples
- Patch and prick testing

Note: (1) List of facilities is not exhaustive

# The team

## Core team profile



**1** Dermatologist



**4** Healthcare assistants



**1** Registered nurse



## Governance and processes

### Team meetings:

- *Clinical practice meeting (monthly):*
  - Attended by the dermatologist, registered nurse and four healthcare assistants
  - The purpose of the meeting is to: discuss any clinical practice issues, patient experience issues and potential process improvements
- *Clinical trials meeting (monthly):*
  - Attended by the dermatologist and two healthcare assistants
  - The purpose of the meeting is to: discuss progress of ongoing and new clinical trials, trial recruitment and clinical trial protocols

### Patient records:

- *Electronic health records (EHR):*
  - Self-designed patient data collection tool (see case study pg. 205 – 206)



# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients present to their local dermatologist (in local health centres), private dermatologist or primary care physician (PCP) with AD symptoms (e.g. itching or dryness of the skin). The physician will assess and refer if required
- Patients may present directly to the centre

*Note: Mild paediatric AD patients tend to be managed by local paediatricians or PCPs. Mild adult AD patients tend to be managed by local dermatologists or PCPs. As a result, mild AD patients may not be seen by the centre*

## Diagnosis and Referral

In secondary care



- Paediatric and adult AD patients are referred to the centre and are required to complete patient questionnaire (detailing medical history and symptoms) prior to seeing the healthcare assistant and dermatologist
- Healthcare assistant reviews the patient questionnaire and has an initial review consultation with the patient that usually takes 15 to 20 mins. An EASI score may be collected
- Once the questionnaire has been reviewed, the first consultation with the dermatologist usually takes 20 mins
- Based on the patient symptoms, the dermatologist will instruct the healthcare assistants to perform various tests, including blood testing, patch testing and prick testing

## Treatment and Management

Medical management



- Dermatologist mainly manages moderate to severe patients and initiates / modifies treatment as required
- Baseline EASI, BSA and DLQI scores are taken and repeated at the start and throughout the treatment by healthcare assistants
- Patients may be offered the opportunity to participate in clinical trials (CT) at the centre
- Patients who are well managed and only require a new prescription are able to consult the healthcare assistant
- Patient notes, photographs, emails and any other relevant documents are recorded electronically on the patient management software

Non-medical management



- Dermatologist refers to external psychologists (in close proximity to the patient's home) when required
- PUVA/UVB phototherapy is provided at the centre by healthcare assistants as required
- Healthcare assistants educate patients on self-management and care
- Patients receive educational leaflets at initial consultation and follow-up consultations if required. Frequency is dependent on disease severity and may occur every 2 weeks to 3 months

## Follow-up

Monitoring of chronic disease / flare up



- Patients are followed up every 2–3 months with the healthcare assistants. Patients may be seen more frequently if they start a new treatment or their existing treatment is modified
- Patients may see the dermatologist if there is an issue with treatment or if they are experiencing an adverse event
- Rural patients may be offered telephone or video consultations
- Patients tend to remain at the centre for continued care (rather than being referred back to their PCP)

# Overview of interventions in place for AD

## Awareness and Presentation



Symptom identification

- **Collaboration with DDA:** The centre is collaborating with the DDA (German Academy of Dermatology) to develop a healthcare assistant curriculum that is focused on dermatological conditions (including AD)
- **Regular bulletins in local newspaper:** The centre places advertisements in the local newspaper that contains information about their clinical trials to raise awareness and attract new patients
- **Communication with local PCPs and dermatologists:** The centre emails their local network of PCPs and private dermatologists to inform the local medical community about new AD treatments, findings / available trials

## Diagnosis and Referral



In secondary care

- **Healthcare assistant led consultations:** Healthcare assistants lead and perform patient consultations throughout the AD patient pathway  
 See pg. 198-199 for case study
- **Provision of healthcare assistant education:** The centre runs initiatives aimed at educating healthcare assistants both within and outside the centre  
 See pg. 200 for case study
- **Allocated timeslots for self-referral:** Patients are able to schedule an appointment in the centre without a referral letter. Patients are expected to have completed the initial questionnaire and assessment prior to the appointment. The centre allocates a total of five hours per week for walk-in appointments

## Treatment and Management



Medical management

- **Digital consultations and support:** Rural adult patients with well-managed AD can access telephone and video consultations. The centre can also easily document patient progress through photo tracking  
 See pg. 201 for case study
- **Onsite allergy and pathology collection:** The centre is able to perform patch and prick testing onsite. Trained healthcare assistants are also able to perform blood tests  
 See pg. 202 for case study
- **Participation in clinical trials:** Adults are able to participate in observational and treatment clinical trials. The centre currently has one AD-related treatment clinical trial



Non-medical management

- **Involvement in anti-stigmatisation programme:** The centre is part of a working group that aims to support anti-stigmatisation of visible skin diseases (with a focus on psoriasis)  
 See pg. 203-204 for case study
- **Referral to psychologists:** Dermatologists refer to external psychologists when required
- **Centre storage facility:** The centre maintains a storage facility for AD patient biosamples (for clinical trials)

## Follow-up



Monitoring of chronic disease/flare up

- **Self-designed patient database:** A tailored local database for source and comprehensive collection of patient data  
 See pg. 205-206 for case study
- **TREAT Germany registry:** The centre is recording data for select clinical trial patients, which is then inputted into the TREAT Germany registry  
 See pg. 207 for case study
- **Open access policy for patients:** Patients have the option to call for advice and / or organise urgent appointments with the healthcare assistants when required. Patients taking part in clinical trials are given an emergency contact to speak to the dermatologist directly

### Key:



Case study available





# Monitoring AD patients and comorbidities

## The dermatology unit employs a number of measures for monitoring AD and associated comorbidities

### Objective measures (AD):

AD scoring indices are utilised to monitor patients and their disease, including:

- EASI (Eczema Area and Severity Index): validated scoring system that grades the physical signs of atopic dermatitis<sup>(a)</sup>
- BSA (Body Surface Area): assesses disease severity based on the percentage of dermatitis-affected body surface area<sup>(b)</sup>

### Patient-reported outcomes:

QoL is routinely measured by:

- DLQI (Dermatology Quality of Life Index): dermatology related quality of life questionnaire<sup>(b)</sup>

*NOTE: EASI, BSA, DLQI indexes are recorded during daily clinical practice (i.e. during dermatology and healthcare assistant consultations) as part of patient data collection. Other AD measures, such as SCORAD (SCORing Atopic Dermatitis) and vIGA-AD<sup>TM</sup> (Validated Investigator Global Assessment scale of Atopic Dermatitis) may be utilised for specific clinical trials when required.*

---

### Dermatology unit routinely measures comorbidity outcomes by:

- *Prick and patch tests (for allergens)*: performed by healthcare assistant who specialises in diagnostic testing
- *Radioallergosorbent (RAST) testing*: performed by healthcare assistant who specialises in diagnostic testing to detect IgE antibodies against allergens
- *Evaluating the risk of developing metabolic syndrome* (e.g. blood pressure, weight, etc.): performed by healthcare assistant / dermatologist

**Sources:** (a) HOME for eczema.org. EASI for clinical signs. [Website] <http://www.homeforeczema.org/research/easi-for-clinical-signs.aspx> Accessed 1 Mar 19; (b) Chopra R, et al. Severity strata for Eczema Area and Severity Index (EASI), modified EASI, Scoring Atopic Dermatitis (SCORAD), objective SCORAD, Atopic Dermatitis Severity Index and body surface area in adolescents and adults with atopic dermatitis. *Br J Dermatol.* 2017;177(5):1316-1321. doi: 10.1111/bjd.15641. (c) Lewis V, et al. 10 Years Experience of the Dermatology Life Quality Index (DLQI). *J Investig Dermatol Symp Proc* 2004;9:169-180

# Advice to other centres



## What advice would you give less specialised centres?



### **Objective of advice: Support healthcare professionals involved in AD care with practical tools**

- **Why?** AD is a chronic disease which can require a range of treatment and impact all aspects of a person's daily living. Providing consistent and clear guidance to all healthcare professionals involved in AD care can ensure that patients receive holistic treatment. Practical tools, like simple checklists, can support decision making and act as triggers for healthcare professionals to address a patient's medical and non-medical needs. Other tools that can support AD care include electronic proformas and tailored data collection tools



### **Objective of advice: Focus on small incremental steps to become a specialised centre**

- **Why?** Shifting from a general dermatology centre to a specialised AD centre requires investment in time and training. Centres may benefit from focusing on short-term achievable steps, such as additional training for healthcare professionals, to begin specialising in AD. In the medium term, centres can aim to collaborate with local networks of dermatologists and become involved in AD related clinical trials

# Next steps for the centre



## What is next for the centre?

### Objective: Provide patients with more access to specialised AD care

- **What?** Healthcare assistants at the centre will continue to receive internal and external AD training
- **Why?** AD is a complex disease that requires specialised guidance and treatment. Investing in training and education of healthcare assistants can help the centre better manage and treat AD patients. As most of the consultations are healthcare assistant led at the centre, providing training on different aspects of the AD lifecycle can support better patient outcomes. Previous training topics the centre may build on include patient communication, new treatments and application techniques



### Objective: Finalise AD patient reference materials to support patient education

- **What?** The centre plans to finalise AD patient educational materials on their online website
- **Why?** Providing patients with a reliable source of information can support improved self-care and management. Patients would be able to easily access practical guidance on how to manage their symptoms and treatment as often as they require. The materials have the potential to reduce demand for non-urgent medical consultations and enable the dermatologist / healthcare assistants to focus on other medical issues



# Case studies



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# Healthcare assistant led consultations (1/2)

## Overview

- Healthcare assistants lead and perform patient consultations throughout the AD patient pathway. This includes initial triage, compliance and prescription consultations. During the consultations, healthcare assistants speak to patients, assess their condition and progress of treatment (when applicable)

CMSS patient questionnaire for atopic dermatitis

## What is the rationale?

- To help minimise the demand on the dermatologist's time and provide patients with timely access to advice, healthcare assistants are able to lead patient consultations throughout the patient pathway
- According to a UK study, utilising healthcare assistants in the primary care setting can help improve performance of the practice, provide opportunities for new or extended services and improve care for specific patient groups<sup>(a)</sup>

## What are the key features of the intervention?

- Healthcare assistants lead a number of patient consultations at the centre with support from the dermatologist
- The consultations can occur throughout the AD patient pathway and healthcare assistants are able to consult the dermatologist if required
- All healthcare assistant led consultations are documented in the patient's medical history and can be accessed by other healthcare assistants and the dermatologist

## Types of consultations:

### Initial review:

- Prior to the initial consultation with the dermatologist, healthcare assistants speak to patients to review their health questionnaire and document the patient's medical history
- The initial review by the healthcare assistant enables the dermatologist to focus on the patient's AD symptoms and issues
- Based on the patient's medical history, the healthcare assistant may also measure the patient's EASI score

### Compliance checking:

- As the patient progresses with treatment, the healthcare assistant will monitor and check the patient's adherence and compliance to treatment
- The compliance checking consultations are performed for all patients, including AD patients, every two to three months
- At each consultation, the healthcare assistant will evaluate if the patient has been adherent to treatment based on the estimated amount of topical treatment the patient should have. This involves a conversation with the patient and discussing how much medication the patient has remaining

**Sources:** (a) Petrova M, et al. Benefits and challenges of employing health care assistants in general practice: a qualitative study of GPs' and practice nurses' perspectives. *Family Practice*, 2010;27(3):303–311. doi: 10.1093/fampra/cm011

# Healthcare assistant led consultations (2/2)

## What are the key features of the intervention? (cont.)

*Types of consultations:*

### Continuation of prescription supply:

- Healthcare assistants are able to continue supply of medication for well-established patients at the centre. The dermatologist reviews and signs off all continuing prescription supplies
- Patients can speak to healthcare assistants to discuss their treatment and when they require a new prescription
- The healthcare assistant consultations enable patients to receive guidance from a healthcare professional and ensures that they access timely supply of medication

### General advice:

- Patients are able to contact the centre and speak to the healthcare assistants when required for assistance or general guidance

## What are the challenges?

- Healthcare assistants may require further training to ensure accurate assessment of patient symptoms. The centre is focused on continuing education and open discussion at weekly meetings to minimise this challenge

## What are the outcomes so far?

### Benefits to patients:

- Frequent interactions with a healthcare professional

### Benefits to HCPs:

- Dermatologists have more time in consultations to focus on medical issues or adverse events

“



Healthcare assistants are provided with regular opportunities to participate in education, to help support them with their consultations  
*Dermatologist, CMSS*

“



Patients can easily ask us about their treatment in person or on the phone

*Healthcare assistant, CMSS*



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# Provision of healthcare assistant education

## Overview

- The centre runs initiatives aimed at educating healthcare assistants both within and outside the centre. Previous training topics include new treatments and patient communication techniques. Healthcare assistants within the centre are also regularly encouraged to attend training facilitated by third party providers



We are always encouraged to take up learning opportunities about AD and other conditions

*Healthcare assistant, CMSS*



## What is the rationale?

- Healthcare assistants are responsible for a number of consultations at the centre
- Providing healthcare professional education has the potential to improve the knowledge and confidence of HCPs (such as healthcare assistants) and patient health outcomes<sup>(a)(b)</sup>

## What are the key features of the intervention?

- The centre runs initiatives aimed at improving the skills of healthcare assistants within and outside of the centre
- The sessions are run by the dermatologist and the healthcare assistants have the option to set the topic of the course (e.g. healthcare assistants may ask to learn about a specific new treatment or aspect of the condition)
- The centre has previously run internal training sessions that have focused on new treatments and patient communication techniques. Training may also occur during the centre's weekly team meeting and in preparation for specific clinical trials
- The centre has previously invited healthcare assistants from other practices to attend and participate in these training sessions
- Healthcare assistants are also encouraged to participate in third party training to gain additional experience and education. Third party training varies in frequency and topics
- A previous external psoriasis training day has included: a presentation of current therapy options, workshops on how to interpret laboratory parameters, wound care and patient adherence and side effect management in systemic therapy

## What are the outcomes so far?

### Benefits to patients:

- Better management of AD related symptoms by healthcare assistants
- Able to build relationship with a healthcare professional and receive AD advice

### Benefits to HCPs:

- Healthcare assistants receive regular training and remain up to date with new AD treatments

## What's next?

- The centre's dermatologist is currently working with DDA (the German Academy of Dermatology) to develop a dermatology focused curriculum for healthcare assistants

**Sources:** (a) Cervero RM, et al. The Impact of CMA on Physician Performance and Patient Health Outcomes: An Updated Synthesis of Systematic Reviews. *Journal of Continuing Education in the Health Professions*. 2015;35(2):131-139 (b) Kownacki S. Skin diseases in primary care: what should GPs be doing?. *Br J Gen Pract*. 2014;64(625):380-381. doi:10.3399/bjgp14X680773



# Digital consultations and support

## Overview

- The centre provides rural patients with the option of telephone or video consultations. Additionally, photos of patient symptoms can be attached to the patient's file on the practice management software to track progress and response to treatment



Patients often come from far away and therefore very much appreciate the possibility of getting in touch with us without having to physically come to the centre

*Healthcare assistant, CMSS*



## What is the rationale?

- Digital consultations and support provides patients with the option to receive guidance and advice in the comfort of their own home
- In an IBD study, telephone consultations were shown to be a cost-effective alternative to face-to-face consultations and do not appear to provide an inferior service<sup>(a)</sup>

## What are the key features of the intervention?

- The centre is equipped with digital infrastructure to perform virtual consultations and digitally track patient symptoms

### Telephone and video consultations:

- The centre provides rural patients with the option to have telephone or video consultations with the dermatologist
- To perform the video consultations, the dermatologist speaks to the patient via a webcam and virtually assesses changes to the patient's skin (including areas of flare up or irritated patches)

### Photo tracking:

- Patient symptoms and treatment progress can be tracked with photographs that can be seamlessly attached to the patient's medical record
- Photos can either be sent in by the patient or taken on the centre's iPad. Each photo is tagged to a part of a virtual body map linked to the patient's record

## What are the outcomes so far?

### Benefits to patients:

- Access to HCP advice in the comfort of their own home
- Visual indication on treatment progress and impact through photo tracking

### Benefits to HCPs:

- Photo tracking helps the HCP demonstrate the impact of treatment, in particular topical treatments

## What's next?

- Continue to provide patients with the option of digital consultations and photo tracking

**Sources:** (a) Akobeng AK, et al. Telephone Consultation as a Substitute for Routine Out-patient Face-to-face Consultation for Children With Inflammatory Bowel Disease: Randomised Controlled Trial and Economic Evaluation. *EBioMedicine*. 2015;2(9):1251–1256. doi:10.1016/j.ebiom.2015.08.011



# On-site allergy testing and pathology collection

## Overview

- The centre provides prick testing, patch testing, and blood collection onsite for patients. Samples are stored on site, however, are mostly processed and analysed by a third party. RAST tests for patients can be analysed onsite by a healthcare assistant once a month



## What is the rationale?

- Atopic Dermatitis (AD) patients may require allergy testing, as allergies are often linked with AD (e.g. food allergy)<sup>(a)</sup>
- Tests range from low complexity tests (e.g. patch tests) to highly complexity tests (e.g. specific allergen provocation tests)

## What are the key features of the intervention?

- The centre has on-site facilities to provide patients with testing and pathology collection
- Tests are performed by the healthcare assistants. There are two dedicated healthcare assistants who respectively perform pathology collection and patch / prick testing
- Services offered include:
  - Patch testing (for food and drug allergy)
  - Prick testing (for hay fever allergy – can be processed in 30 mins on average)
  - RAST testing (radioallergosorbent testing to detect IgE antibodies – processed in two to four weeks on average)
  - Pathology collection (e.g. histology tests – processed in 10 days on average)
- All samples are stored on-site. Blood, patch and prick tests are processed and analysed by a third party. RAST testing is analysed by a healthcare assistant from the centre once a month
- The dermatologist and healthcare assistant are able to discuss the results at the patient's next appointment

## What are the outcomes so far?

### Benefits to patients:

- Convenient access to testing and pathology collection services

### Benefits to HCPs:

- Testing can be initiated and performed without any delays

**Sources:** (a) Chiesa Fuxench ZC. Atopic Dermatitis: Disease Background and Risk Factors. *Adv Exp Med Biol.* 2017;1027:11-19. doi: 10.1007/978-3-319-64804-0\_2

# Involvement in anti-stigmatisation study (1/2)

## Overview

- The centre's dermatologist is part of the working group for the German Ministry of Health's (GMOH) anti-stigmatisation programme. The working group is currently evaluating the impact of pilot programmes and designing the implementation for the pilot roll-out

## What is the rationale?

- A recent WHA/WHO psoriasis report (part of a 'people-centred care' initiative) demonstrated how, for all visible skin conditions, there is limited understanding of the relationship between stress and these conditions (and hence psychological interventions in care are limited also)<sup>(a)</sup>
- A substantial number of individuals with visible skin diseases suffer from stigmatisation (including ~10million people in Germany alone)<sup>(b)</sup>
- The German Ministry of Health (GMOH) is therefore funding research focused on chronic visible conditions (in the form of a 3-year project, ending Q4 2020). Psoriasis is the model disease, with the aim to apply learnings to chronic conditions including AD, acne, alopecia, etc.

## What are the key features of the intervention?

### Overview of the anti-stigmatisation study

The project will proceed in two phases:

**Phase 1:** researchers gain a holistic understanding of visible skin disease stigmatisation and how to reduce / prevent it (including ~40 interviews of patients, their relatives and HCPs)

**Phase 2:** use the learnings from literature research and focus groups / interviews to design interventions (namely education programmes for medical students and school teachers, with these groups prioritised based on their potential impact and feasibility)

Progress and immediate next steps:

- Pilot education programmes (Phase 2) have been conducted and the results are currently being evaluated. The programmes will be adjusted accordingly and re-delivered later in 2019
- School teachers (Phase 2) will be provided with a 'workpack' to guide the delivery of education, which will include videos if HCPs can't speak with patients directly

### Key features of project methodology:

- With the support of the GMOH, the stigmatisation experience was recorded from the perspective of affected persons, their relatives and HCPs using qualitative surveys and group and individual interviews
- Separate guidelines were designed in advance for interviewing each group of participants, and were subjected to pre-testing before use

**Sources:** (a) World Health Organization. Global report on psoriasis. [PDF]

[https://apps.who.int/iris/bitstream/handle/10665/204417/9789241565189\\_eng.pdf?sequence=1&isAllowed=y](https://apps.who.int/iris/bitstream/handle/10665/204417/9789241565189_eng.pdf?sequence=1&isAllowed=y) Accessed 8 Aug 2019

(b) Augustin M, et al. Translating the WHA resolution in a member state: towards a German programme on 'Destigmatization' for individuals with visible chronic skin diseases. *J Eur Acad Dermatol Venereol*. 2019. doi: 10.1111/jdv.15682



# Involvement in anti-stigmatisation study (2/2)

## What are the key features of the intervention? (cont.)

### Centre's involvement in the study:

- The centre's dermatologist is part of the AD working group for anti-stigmatisation programme
- The AD working group is comprised of clinical delegates. The group is currently evaluating the impact of pilot education programmes and designing future programme roll-outs (i.e. Phase 2 of the study)
- The evaluation process involves speaking to different stakeholders to understand their views on the potential impact of the pilot

## What are the expected outcomes?

### Benefits to patients:

- Increased public / professional awareness of stigma experienced for visible skin diseases

### Benefits to HCPs:

- Opportunity to learn how to reduce stigmatisation of patients with visible skin diseases

## What's next?

- The results of the study will influence how the centre considers supporting and implementing the anti-stigmatisation programme

# Self-designed patient database (1/2)

## Overview

- The centre's nurse adapted the existing practice management software and created a tailored local database for secure and comprehensive collection of patient data. The system is utilised by the centre to monitor and track all patient progress (including AD, psoriasis and skin cancers) and has been in operation since October 2018



A brief look at the patient's file shows me key information about the patient's condition and what treatment they are currently undergoing.

*Healthcare assistant, CMSS*



## What is the rationale?

- A local patient database creates a single point of access for relevant patient data that can be extracted and analysed for different research purposes
- A database (or registry) can act as a quality control check and the data can help drive professional development and service improvement<sup>(a)</sup>

## What are the key features of the intervention?

- The centre has adapted a commercial practice management software to create a tailored local database for secure and comprehensive collection of patient information
- The database enables the centre's healthcare assistants and dermatologist to track and monitor patient progress and provides an immediate overview of the patient and their treatment
- The centre has a dedicated iPad for patients to complete questionnaires and photo tracking. Information and photos captured on the iPad is linked to the patient's file on the database
- The database documents:
  - All patient characteristics
  - Patient progress (including photos)
  - Treatment duration
  - External communication
  - Timing of next appointment
  - Patient forms (including questionnaire completed on the iPad)
  - Objective measures (such as EASI, DLQI, BSA etc.)
  - Treatment guidelines
- To support ease of use, the system is colour coded based on the type of information recorded. The legend is:
  - **Blue** for notes/comments related to therapy and treatment
  - **Black** for medical notes (e.g. symptoms)
  - **Green** for scores and measures (e.g. EASI score)
  - **Pink** for lab and pathology results
  - **Highlighted blue** for external emails and communication (e.g. referral letters)
- Patients in the TREAT registry are tagged on the local database

**Sources:** (a) Nelson Eugene C, et al. Patient focused registries can improve health, care, and science. *BMJ*. 2016;354(8065) doi: 10.1136/bmj.i3319



# Self-designed patient database (2/2)

## What are the key features of the intervention? (cont.)

- Healthcare assistants are able to easily extract a range of reports and information from the database. Example reports include: information letters and physician communication letters
- The centre's dermatologist initiated the development of the database. The centre's nurse developed the initial database in October 2018. It can only be accessed by internal staff members
- The database is continually updated and improved based on requests from healthcare assistants and the dermatologist. Updates generally take an hour to be tested and implemented

## Challenges

- PCPs may not have the technology infrastructure to receive information and communication emails from the database. In these instances, healthcare assistants are required to print and mail the referral / information

## What are the outcomes so far?

### Benefits to patients:

- Able to view treatment progress with consistent data collection points
- Improved efficiency in consultations as HCPs are able to easily review patient progress

### Benefits to HCPs:

- Data is collected and stored in a consistent and reliable manner, enabling easy tracking of patient progress
- Internal quality checks can be performed to drive improvement in patient care and process improvement

## What's next?

- Continue to optimise patient database, incorporating new data points when necessary

“



Before the software was implemented we tracked everything manually and to take a picture we had to use a camera. Now it all happens seamlessly using the iPads that are connected with the solution

*Dermatologist, CMSS*

“



Patients use the iPad to fill out the forms, thus reducing paper waste and the time for us to transcribe all the findings

*Healthcare assistant, CMS*



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CENTRE REPORTS

# TREAT Germany registry

## Overview

- The centre is part of the established TREAT Germany registry: an international effort to ease the pooling and comparison of AD patient data across countries. The centre collects patient data and documents this information in the registry



## What is the rationale?

- The international TREATment of Atopic eczema (TREAT) Registry Taskforce seeks to find consensus on core domain items for AD research registries, and to harmonise data collection on adult and paediatric patients receiving photo- and / or systemic immuno-modulatory therapies<sup>(a)</sup>
- The ultimate goal of the taskforce is to enhance the interoperability of national AD registries, allowing the direct pooling and comparison of data from different countries in order to gain international insight into the safety and effectiveness of AD therapies (and therefore inform treatment guidelines)

## What are the key features of the intervention?

- The centre is recording data for selected clinical trial patients and is then inputting this information into the German TREAT registry
- The German TREAT registry is focused on AD patients who are either three months pre-treatment or three months post-treatment
- The healthcare assistant who specialises in clinical trials is responsible for inputting data into the TREAT registry. The centre has been inputting data into the registry since 2017 and documents information based on the TREAT patient questionnaire. This includes:
  - The patient's attitude towards the disease
  - Past treatments
  - Impact on other aspects of life

## What are the outcomes so far?

### Benefits to patients:

- Registry data can drive future research and treatments, leading to improved patient care and outcomes

### Benefits to HCPs:

- Participating centres can access TREAT data for their own studies
- Participating centres are listed as authors on German TREAT publications

## What's next?

- The centre will continue to inputting data into the German TREAT registry

**Sources:** (a) TREAT Registry Taskforce [Website] <https://treat-registry-taskforce.org/> Accessed 2 Aug 2019





# Università di Modena e Reggio Emilia (UNIMORE)

**Modena, Italy**

Site visited by KPMG 12–13<sup>th</sup> February 2019

[kpmg.com/uk](https://kpmg.com/uk)



APPENDIX  
CENTRE REPORTS



# Summary



## Context

- **Centre type:** Public hospital located in the city of Modena, Italy. It is affiliated with the University of Modena and Reggio Emilia (UNIMORE)
- **Catchment area:** Patients from Modena and across Italy are seen at the centre
- **Funding:** The centre is funded by the Italian government
- **Services:** The allergology and dermatology units work within a joint dermatology and allergology department. Other specialist services are offered at the centre, which the allergology-dermatology department works closely with
- **Patient population:** Adult and paediatric patients with dermatological and allergic diseases are treated at the allergology-dermatology unit (managed by allergologists). Mild, moderate and severe Atopic dermatitis (AD) patients are seen at the centre



## Key strengths in the delivery of AD care

- **Innovative model of care:** The dermatology and allergology unit are fully integrated, providing coordinated care for AD patients
- **Focus on treating AD as a systemic disease:** Specialist allergologists, with knowledge and experience of internal medicine, manage all AD patients and treat AD as a systemic pathology
- **Access to specialist laboratory:** On-site laboratory provides testing for patients across Modena (once requested by primary care professionals [PCPs] and specialists). The laboratory offers specialist tests and advice (e.g. specialist nutritionist performs food allergy testing)
- **Commitment to medical education:** The dermatology unit hosts the “Dermatology Academy”, which is attended by physicians and nurses from across Italy



## Key challenges faced in the delivery of AD care

- **Coordinating frequent appointments** for patients with comorbidities / Atopic March. Patients may attend follow-up appointments as often as every 10 days, placing a burden on patients and increasing demands on the centre’s resources
- **AD is a complex disease** which can have a significant impact on patient quality of life (QoL). Patients may have a variety of needs which the centre must cater for (medical and non-medical), requiring input from a range of specialists (e.g. psychologists)
- **Supporting patients to comply with treatment** (e.g. topical treatments) is of great importance in AD care, but can be challenging as patients may lose patience or be deterred by the complications / side effects of treatment

# Atopic Dermatitis (AD) in Italy

## Italian healthcare system<sup>(a)</sup>:

A national health plan, 'Servizio Sanitario Nazionale' (SSN), is in place in Italy, which provides medical care for all Italian citizens. Healthcare provided by the SSN is a public service financed by tax revenue of the Italian constitution<sup>(b)</sup>. Healthcare is a decentralised system and based on three levels:

State - *defines guidelines and contracts*

Region (20) - *controls health services within the region*

Local health boards - *day-to-day management of services*

## Prevalence:

- Prevalence of AD in adults across the EU is 4.4%<sup>(c)</sup>
- In a study in Italy, the prevalence of AD was 8% and prevalence of AD with asthma and / or hay fever was 3.4%<sup>(d)</sup>



## Care provision:

### Location:

- The majority of AD care is delivered by community dermatologists
- Community dermatologists manage mild (or well-controlled) AD patients
- Moderate and severe (or uncontrolled) AD care is delivered by specialist hospitals

### Funding (general)<sup>(a)</sup>:

- Funding takes place at three levels:
  - **State:** finances research hospitals
  - **Region:** finances health services within the region and independent hospitals
  - **Local:** finances public and private hospitals under contract in the region

## Guidelines and societies:

### Guidelines:

- Guidelines for treatment of atopic eczema (atopic dermatitis) part I and part II: European Association of Dermatology and Venerology (EADV)
- Diagnosis and management of moderate to severe adult atopic dermatitis: a Consensus by the Italian Society of Dermatology and Venereology (SIDeMaST), the Italian Association of Hospital Dermatologists (ADOI), the Italian Society of Allergy, Asthma and Clinical Immunology (SIAAIC), and the Italian Society of Allergological, Environmental and Occupational Dermatology (SIDAPA)

### Medical society:

- Italian Society of Dermatology (SIDeMaST)








### Patient association group (PAG):

- Associazione Nazionale della Dermatite Atopica (ANDeA)

**Sources:** (a) Health Management. Facts & Figures: the Italian Healthcare System [Website] <https://healthmanagement.org/c/it/issuearticle/facts-figures-the-italian-healthcare-system> Accessed 7 Mar 2019; (b) The Commonwealth Fund. International Health Care System Profiles: The Italian Health Care System [Website] <https://international.commonwealthfund.org/countries/italy/> Accessed 8 May 2019; (c) Barbarot S, et al. Epidemiology of atopic dermatitis in adults: Results from an international survey. *Allergy*. 2018;73(6):1284-1293; (d) Pesce G et al. Adult eczema in Italy: prevalence and associations with environmental factors. *J Eur Acad Dermatol Venereol*. 2015;29(6):1180-7. doi: 10.1111/jdv.12784



# The centre and allergology-dermatology unit


The hospital		
 <b>Type and location</b>	A large, public hospital, governed by the Emilia-Romagna region. The hospital has two sites: Policlinico di Modena and Civil Hospital of Baggiovara, both located in Modena, Northern Italy.	
 <b>Population served</b>	Patients from Modena and across Italy attend the hospital. In 2017, there were 46,000 hospital admissions, ~2,000,000 outpatient appointments, and ~9,000 day hospital visits	
 <b>Service Division</b>	The allergology-dermatology department	
	<b>Outpatient clinic (allergology unit)</b> Treats moderate to severe AD patients referred from the dermatology unit	<b>General dermatology (dermatology unit)</b> Treats all dermatology cases and refers patients with moderate to severe AD into the allergology clinic
	Mon-Fri: 07:00-18:00	Mon-Fri: 07:00-19:00 Weekend dermatology cover is available for emergency cases
	20 AD patients per day (on average)	20 AD patients per day (on average)
	Adult and paediatric patients (mild, moderate and severe); 70% adults and 30% paediatric patients	
	 <b>Facilities on-site</b>	<ul style="list-style-type: none"><li>— Phototherapy (PUVA and narrow band UVB)</li><li>— 2 laboratories (1 general laboratory providing general tests (e.g. full blood count) and 1 specialist laboratory providing specialist tests (e.g. allergy tests))</li><li>— Dermatology laboratory (in vivo and in vitro testing)</li></ul>
 <b>Hours of availability</b>		
 <b>No. of patients seen</b>		
 <b>Types of patients seen</b>		


Note: (1) List of facilities is not exhaustive


# The team




## Core team profiles


 **30** Dermatologists and allergologists (based at the hospital and in the territory)


 **20** residents (dermatology and allergology)

 **3** allergology nurses (1 full-time; 2 part-time)


 **10-15** dermatology nurses  
*Note: nurses also perform an administrative role for the centre*

## Wider team profiles

 **1** pulmonologist specialised in asthma (10 in wider pulmonology team and nurses)


 **1** psychologist

 **3** ophthalmologists (supported by residents)

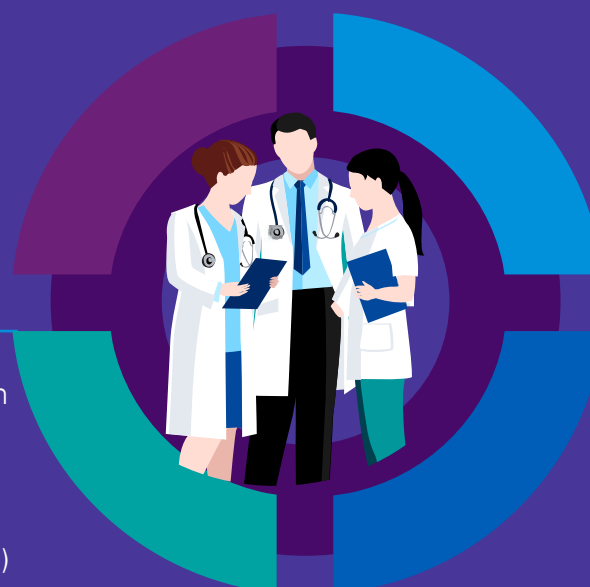
 **2** rheumatologists (supported by residents)

 **1** clinical trials pharmacist

 **1** data manager

 **1** specialist immunologist (10-15 in wider immunology team)

 **1** nutritionist (working in the laboratory)



## Governance and processes

### Team meetings:

- *Ad-hoc meetings (when required):*
  - Attended by: allergologists, nurses and other specialties (e.g. pulmonologists, rheumatologists, etc.)
  - Purpose: to discuss patient cases / ask for advice (e.g. allergologist and pulmonologist may meet to discuss patient care)

### Patient records:

- Electronic patient records (EHR):
  - Accessible by all specialties across the hospital

*Note: Please see page 214 for further details about the wider team*

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients present to primary care professionals (PCPs), the general dermatology unit at the hospital or dermatologists in territory hospitals

*Note: Patients require an appointment at the general dermatology unit (and may be referred here by their PCP)*

## Diagnosis and Referral

In secondary care



- Patients are referred to the allergologists by the general dermatologists (in unit), other specialities in the centre (e.g. pulmonologist), community (PCPs) or other hospitals (dermatologists / allergologists)
- Paediatric patients transition into adult care aged 16-18 years (but this can vary and patients may transition earlier)

*Note: the allergologist coordinates care for all AD patients*

- AD is diagnosed at initial appointment (initial consultation 20 mins) through clinical examination and supplementary tests (e.g. allergy tests). Severity of AD determined by scoring indices (e.g. SCORAD, EASI, vIGA, BSA, NRS itch/sleep) and QoL questionnaire (e.g. DLQI)

## Treatment and Management

Medical management



- Treatment is initiated by allergologists. SCORAD and EASI scores determine treatment plan and are used to monitor responses to treatment (and adapt plan if need be)
- Nurses provide treatment education (e.g. how to apply creams / medications / dressings; how to self-inject medications). The duration of nurse education consultations varies with patient treatment compliance and the therapy prescribed
- Allergologists coordinate care with other specialities (ophthalmology, psychology and pulmonology)

Non-medical management



- Patients are monitored for psychological symptoms (related to AD), using the allergologist's judgement and results of Quality of Life (QoL) questionnaires. If required, patients are referred to the psychologist for psycho-social support

*Note: the psychologist works across multiple specialities at the hospital*

- ANDeA (PAG) provides advice and support for patients (non-medical advice)
- Occupational advice (e.g. what to avoid at work; how to cope with allergies in the workplace) provided by allergologists (trained by occupational physicians)

## Follow-up

Monitoring of chronic disease / flare up



- AD patients with mild AD or remission of dermatitis are referred back to the referring physician, with the possibility of returning in case of exacerbation or worsening of AD
- Allergy follow-up consultations (duration depending on patient needs) occur every 3-6 months, though may be more frequent if required. Nurses schedule appointments and are available to answer questions over the phone
- Frequency of follow-up with comorbidity specialists depends on patient need (complex / severe patients may require an appointment up to every 10 days with different specialists)
- Tests (e.g. allergy tests) will be performed as required based on clinical symptoms / disease control

# Roles of the wider team

## Pulmonologist

**Patient type:** AD patients with asthma (<5% of asthma patients at the centre have AD, however 30-40% of AD patients have asthma)

**Referral:** Referred by primary care physicians (PCPs) or from other departments at the centre (e.g. allergology)

**Consultations:** Pulmonologists diagnose and treat asthmatic patients (and AD patients with asthma). They perform tests (e.g. lung function test) to monitor disease symptoms

**Timing:** Consultations last 20 minutes, every 3–4 months

### Roles of additional team members:

- *Nutritionist:* Works within the laboratory to conduct and advise on specialist allergy tests, including interpretation of test results. Nutritionist provides advice for specialists within the centre and wider community
- *Immunologist:* Provides specialist input regarding immunology tests and treatment at the centre. The immunology group studies immune responses in a range of physiopathological conditions (including AD) through laboratory methods including flow cytometry, transcriptomics and in vitro stimulation tests
- *Occupational physicians:* Work with allergology to provide specialist training and guidance to physicians regarding occupational allergies, for them to inform and guide their AD patients
- *Rheumatologist:* Works with allergology to manage non-atopic AD comorbidities associated with autoimmune diseases



## Ophthalmologist

**Patient type:** Severe AD patients with eye comorbidity symptoms (e.g. upper or lower eyelid inflammation), ocular pathologies related to atopy (e.g. keratoconus) or ocular side effects from systemic therapies. Patients also include those requiring treatment for specific pathologies (e.g. vernal keratoconjunctivitis)

**Referral:** Referred by allergology

**Consultations:** Ophthalmologist conducts a range of tests (e.g. general lamp examination) and provides treatment (e.g. antihistamine eye drops or steroid eye drops). Nurses support by administering treatments and delivering patient education

**Timing:** Consultations last 20-30 mins and will be followed up once after 1–4 weeks

## Psychologist

**Patient type:** AD patients (mild, moderate and severe) displaying psychological symptoms

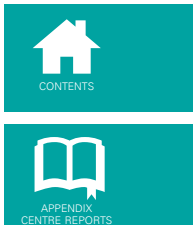
**Referral:** Referred by allergology (and the wider centre)

**Consultations:** Psychologist conducts 1:1 consultations with patients to understand their attitudes towards their AD and reasons for their behaviour

**Timing:** Consultations last 1 hour and patients are followed up as required



# Overview of interventions in place for AD



## Key:

 Case study available

## Awareness and Presentation




Symptom identification

- **Collaboration with ANDeA (PAG):** The centre works with the PAG to raise awareness of AD and provide additional support for patients  
 See pg. 220 for case study
- **Primary Care Professional (PCP)-Dermatology-Laboratory network:** Network of PCPs, laboratory staff and dermatologists in the Modena region  
 See pg. 221-222 for case study
- **Dermatology Academy:** Monthly, nationwide dermatology education events for healthcare professionals (HCPs) from the centre and the community  
 See pg. 223-224 for case study

## Diagnosis and Referral




In secondary care

- **"Fast track" referrals:** Community dermatologists based at the centre may urgently refer patients to allergology specialists within the unit (same day or within a few days, subject to condition and urgency)
- **General dermatology day unit (emergencies):** The outpatient department (10 consulting rooms) provides "walk-in" care (though patients still require an appointment) for dermatology patients referred by PCPs
- **Specialist laboratory testing and interpretation:** 2 laboratories provide general testing (e.g. full blood count test) and specialist testing (e.g. allergy testing), with a nutritionist present to provide advice  
 See pg. 225-226 for case study

## Treatment and Management





Medical management

- **Coordination of AD care by allergologist:** Allergologists coordinate and manage AD care (including scheduling consultations for patients). Treatment and testing is provided by allergology (using 3 consulting rooms and 1 treatment room)  
 See pg. 226-228 for case study
- **Involvement in clinical trials (interventional and observational):** Patients have the opportunity to access specialist treatment through "profit" and "non-profit" clinical trials. A pharmacist and data manager assist with the supply of medicines and data management



Non-medical management

- **Provision of psychological care:** A full-time psychologist works at the centre (specialised in chronic inflammatory disease), to provide psychological support to AD patients  
 See pg. 229-230 for case study
- **AD occupational training and advice:** Allergologists receive training from occupational physicians (OPs). For example, allergologists learn what advice to give AD patients who are exposed to workplace allergens. Training is also provided to external HCPs  
 See pg. 231-232 for case study
- **Complex allergy treatment:** Specialists provide complex treatment for allergies at the centre, including immunotherapy and desensitisation (provided to patients from across the province)

## Follow-up



Monitoring of chronic disease/flare up

- **Established network with other specialities:** The allergologists work closely with other specialists to ensure patients receive appropriate follow-up care, through collaborations with pulmonology (allergic asthma), ophthalmology (patients with eye comorbid conditions) and rheumatology (patients with non-atopic comorbidities, such as autoimmune disorders)



# Monitoring AD patients and comorbidities

## The dermatology unit employs a number of measures for monitoring AD and associated comorbidities

### Objective measures (AD):

AD scoring indices are used to monitor patients, including:

- SCORAD (SCORing Atopic Dermatitis): a clinical tool used to monitor disease severity<sup>(a)</sup>, performed at each consultation
- EASI (Eczema Area and Severity Index): a validated scoring system which grades the physical symptoms of atopic dermatitis<sup>(b)</sup>, performed at each consultation
- Validated Investigator Global Assessment for Atopic Dermatitis (vIGA-AD<sup>TM</sup>)<sup>(c)</sup>: scoring system for use in clinical trials which grades the overall appearance of AD lesions based on a series of morphological descriptions
- BSA (Body Surface Area): To calculate BSA the centre uses estimated percentage of body surface involved or DuBois calculation, which assesses the patient's height and weight<sup>(d)</sup>

### Patient reported outcomes:

QoL questionnaire:

- DLQI (Dermatology Quality of Life Index): dermatology related quality of life questionnaire<sup>(e)</sup>, performed at each consultation

Itch NRS (Numeric Rating Scale<sup>(f)</sup>): a single-item tool for monitoring pruritus (itch) intensity in patients with AD and other dermatological conditions

---

### The Centre routinely measures comorbidity outcomes through:

- Pulmonologist: clinical monitoring and objective measures (e.g. spirometry)
- Ophthalmologist: follow-up appointments as required and objective tests (e.g. topography)
- Psychologist: follow-up appointments as required (including outputs from DLQI questionnaires)

**Sources:** (a) SCORing Atopic Dermatitis (SCORAD) Calculator (0.9.0) [Website] <http://scorad.corti.li/> Accessed 26 Feb 2019; (b) HOME for eczema.org. EASI for clinical signs [Website] <http://www.homeforeczema.org/research/easi-for-clinical-signs.aspx> Accessed 01 Mar 2019; (c) Validated Investigator Global Assessment For Atopic Dermatitis (vIGA-AD<sup>TM</sup>) Scale [PDF] [https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale\\_vIGA-AD\\_2017.pdf](https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale_vIGA-AD_2017.pdf) Accessed 26 June 2019; (d) Redlarski G, et al. Body surface area formulae: an alarming ambiguity. *Sci Rep.* 2016;6:27966. doi: 10.1038/srep27966; (e) Lewis V, et al. 10 Years Experience of the Dermatology Life Quality Index (DLQI). *J Invest Dermatol Symp Proc* 2004;9:169 –180; (f) Numerical Rating Scale (NRS) [Website] <http://www.pruritussymposium.de/numericalratingscale.html> Accessed 14 April 2019

# Advice to other centres



## What advice would you give less specialised centres



**Objective of advice:** Include allergologists as core members of the AD care team

- **Why?** Allergologists provide specialist input for AD / Atopic March patients. For example, allergologists have received specialist education and training in internal medicine, which they may use when caring for AD patients. Having this specialist knowledge and experience allows allergologists to care for many aspects of AD / Atopic March and provide highly complex treatment for patients. Patients receive streamlined AD care and continuity in the physicians that provide it



**Objective of advice:** Create a network of AD comorbidity specialists

- **Why?** The collaboration between allergology and dermatology represents one example of specialists at the centre working closely to improve AD patient treatment outcomes. Creating a network of AD comorbidity specialists has the potential to improve communication between these parties, facilitate idea sharing and reduce patient appointment burden

# Next steps for the centre



## What is next for the centre?

**Objective:** Region-based healthcare in the Emilia-Romagna

- **What?** The Emilia-Romagna region is looking to establish a network of hospitals and doctors. This will include multiple specialities, including the centre's dermatology and allergology teams
- **Why?** Establishing such a network allows hospitals to work closely together (e.g. through project collaboration and resource sharing), with the ultimate aim of improving care for patients in the region



# Case studies



<b>Collaboration with Associazione Nazionale della Dermatite Atopica (ANDeA)</b>	220
<b>Primary Care Professional (PCP)-Dermatology-Laboratory network</b>	221 – 222
<b>Dermatology Academy</b>	223
<b>Specialist laboratory testing and interpretation</b>	224 – 225
<b>Coordination of AD care by allergologist</b>	226 – 228
<b>Provision of psychological care</b>	229 – 230
<b>AD occupational training and advice</b>	231 – 232

# Collaboration with ANDeA

## Overview

- The centre works closely with ANDeA, the Italian patient advocacy group (PAG), which provides non-medical support for patients with AD and asthma across Italy

## What is the rationale?

- The National Association of Atopic Dermatitis (ANDeA) is the national PAG for AD and asthma patients in Italy<sup>(a)</sup>
- ANDeA was set up 2 years ago and collaborates with centres and the scientific community<sup>(a)</sup>
- Physicians and centre staff may have little time to support patients with the non-medical aspects of their disease. ANDeA therefore plays a key role in supporting patients

## What are the key features of the intervention?

- ANDeA is involved in activities helping to support patients and raise awareness of the disease

### Key activities:

- *Raising awareness*
  - ANDeA proactively raises awareness of the disease, diagnosis and treatment options via social media, events and publications
- *Providing non-medical advice to patients via specialists ("Ask the Expert")*
  - Patients may ask questions to specialist allergologists, dermatologists and immunologists from the centres (and from across Italy) on the "Ask the Expert" online portal
  - Non-medical advice is provided (not intended to replace advice / guidance from a patient's home centre, but to support patients with lifestyle issues, etc.)

*Note: no medical advice (e.g. treatment decisions) will be provided to patients through this channel*

- *Collaborating with the scientific community and HCPs*
  - ANDeA works with centres (including UNIMORE) to support research and promotes the use of patient registries
  - ANDeA works closely with specialist HCPs in AD and hosted the "First national day of atopic dermatitis" in 2017. This event brought together a number of well recognised physicians and HCPs in AD, with the aim to bring AD "to the attention of the institutions and public"<sup>(b)</sup>
- *Hosting events*
  - ANDeA organises a number of meetings for physicians and patients (outside of centre) so the group can discuss AD, share experiences and learn from one another

**Sources:** (a) ANDeA - Associazione Nazionale Dermatite Atopica: Homepage [Website] <https://www.andea.it/> Accessed 4 Mar 2019; (b) First national day of atopic dermatitis [Website] <https://www.andea.it/giornata-nazionale-della-dermatite-atopica/> Accessed on 4 Mar 2019



# PCP- Dermatologist- Laboratory network (1/2)

## Overview

- A specialist laboratory at the centre works closely with dermatologists and primary care physicians (PCPs), through a network which facilitates improved communication and streamlining of the testing process

**Sources:** (a) Silvestre SJF, et al. Atopic Dermatitis in Adults: A Diagnostic Challenge. *J Investig Allergol Clin Immunol* 2017;27(2):78-88. doi:10.18176/jiaci.0138; (b) Interviews from KPMG UNIMORE site visit

## What is the rationale?

- AD and Atopic March patients often require tests (both general or specialist) at diagnosis and throughout their disease lifecycle<sup>(a)</sup>
- A large number of tests in the region are requested by PCPs<sup>(a)</sup>, with this number currently rising (increasing pressure on the laboratory). 120,000 allergology tests are performed by the laboratory annually, of which 60% are for dermatology patients (20% of whom are AD patients)
- PCPs may request tests that have already been performed for a patient (i.e. repeat tests), or tests that are not necessary, representing an efficient use of centre resources

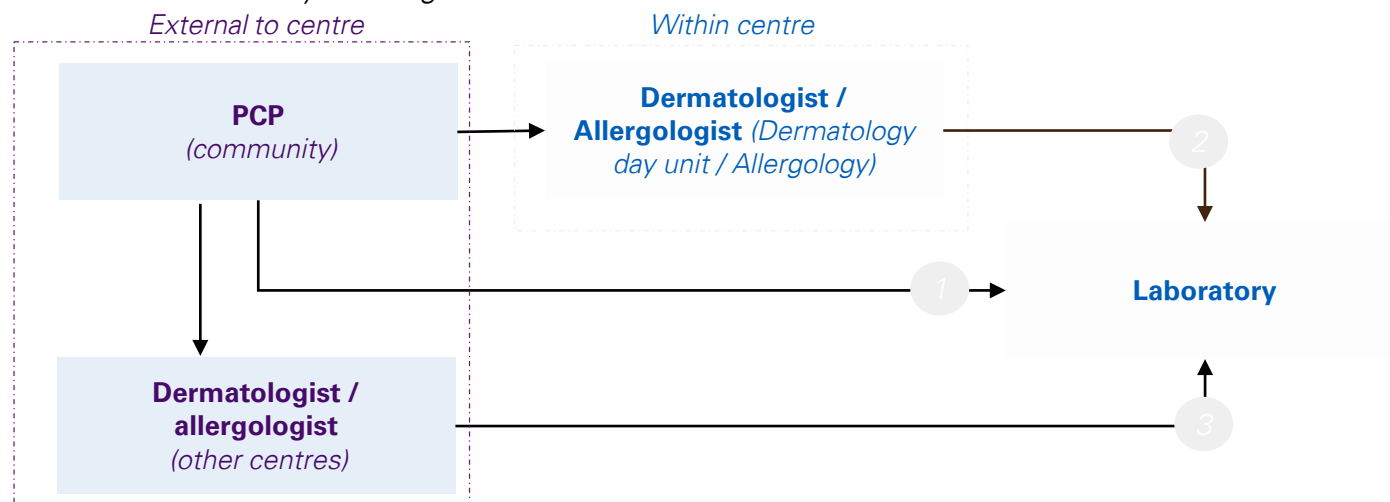
## What are the key features of the intervention?

- The hospital built a diagnostic pathway testing network based on the recommendations of a collection of 11 international articles. These defined the process of an allergy and immunology laboratory testing network
- The Laboratoria di allergologica e immunologia clinica follow these guidelines and perform patch tests, IgE specifics, IgE total, ECP, anticorpi, anti-FCeRI and ecc tests. The laboratory staff work closely with both PCPs and hospital physicians, to provide two-way communication

### Network structure and process:

- If patients present with signs and symptoms of AD / allergy, PCPs may request tests directly from the laboratory based on their experience and knowledge of AD / allergy ([route 1](#))
- PCPs may also refer patients to dermatologists / allergologists (within or outside the centre), with these specialists in turn requesting tests for their patients ([route 2 and 3](#))

### Routes for laboratory ordering of tests





# PCP-Dermatologist-Laboratory network (2/2)

## What are the key features of the intervention? (cont.)

- Once tests are conducted results will be sent back to requesting physician (general practitioner or specialist) who will communicate the results to the patient

### Outreach activities:

- *Medical education:* laboratory specialists (including a nutritionist) provide formalised education and training session for PCPs every 2-3 months, focusing on:
  - Effectiveness of requesting tests, i.e. selecting the right test for the right patient at the right time
- *Congress activities:* Specialists from the laboratory present outcomes at national congresses:
  - This has included a video of a patient interview, presented at a nutrition / allergology congress, discussing experiences and expectations around sample collection and test results
  - Aim of the video was to help HCPs understand the patient's perspective throughout this process and identify areas for improvement
  - Other videos presented concern: diagnostic tests and the concept of precision medicine (presented by allergologist); ordering tests to be performed (presented by general practitioner)

## What are the outcomes so far?

### Benefits to patients:

- Quicker access to diagnosis / test results
- Potentially less un-necessary tests being performed

### Benefits to HCPs:

- Defined pathway reduces costs (fewer repeated tests)
- Time efficiency savings due to streamlined pathway

## What's next?

- Provide specialist assistance / guidance to other Italian cities / regions looking to establish a similar network (e.g. Florence is currently in the planning stage). Modena was the first Italian city to implement this network structure based on the international guidelines

“



I am able to refer patients directly to the laboratory for specialist testing based on my clinical experience with AD and allergy patients

*Primary Care Practitioner, Modena*

“



In Modena, we are the first to implement this structure and we are looking to replicate this network in Florence

*Laboratory director, UNIMORE*



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## Overview

- The allergology-dermatology unit hosts the “Dermatology Academy”, consisting of monthly training sessions for healthcare professionals (HCPs) from across Italy in a range of dermatology conditions

**Sources:** (a) Le Roux E, et al. GPs experiences of diagnosing and managing childhood eczema. *Br J Gen Pract.* 2018;68(667):e73-e80; (b) European Academy of Dermatology and Venereology. Intermediate Advanced Surgery [Website] <https://www.eadv.org/eadv-school/217> Accessed 28 Feb 2019

## What is the rationale?

- There is a continuing need for education and training in dermatology for non-specialist HCPs<sup>(a)</sup>, in order to reduce the time between diagnosis and the prescription of optimal treatment
- The centre recognises the importance of medical education in dermatology and has a long history of educational affiliations with the University of Modena and Reggio Emilia (UNIMORE)

## What are the key features of the intervention?

### Format of the “Dermatology Academy”:

- *When?* Every month
- *Where?* The centre’s allergology-dermatology unit
- *Who attends?* HCPs from across Italy, including physicians (e.g. dermatologists), nurses (e.g. dermatology nurses) and primary care professionals (e.g. physicians and nurses). Medical students and trainee dermatologists at the centre will attend as part of their basic medical education or medical specialisation
- *Who facilitates?* Specialist dermatologists and allergologists
- *What is covered?* Topics vary month-by-month and cover a wide range of dermatological conditions. Example topics include: atopy; atopic dermatitis (future of diagnosis and therapy, allergy, cutaneous and systemic drug reactions, importance of emollients in AD); AD and contact dermatitis and limitations of GCP management of AD patients
- Sessions combine theory and practice (including real-time patient clinical demonstrations). AD-specific sessions are hosted once a year (on average)
- Select courses / sessions are delivered in collaboration with EADV (e.g. Intermediate Advanced Dermatology Surgery)<sup>(b)</sup>
- Courses count towards continued medical education (CME) as awarded by Accordo Stato-Regioni in Italy

## What are the outcomes so far?

### Benefits to HCPs:

- Sharing of specialist knowledge between HCPs
- Improved standards of clinical care for patients through education and training

### Benefits to patients:

- Potentially quicker referrals as PCPs may have improved knowledge of how / when to refer different dermatological conditions
- HCPs are more knowledgeable about dermatological conditions and may provide more specialist advice

# Specialist laboratory testing and interpretation (1/2)

## Overview

- A specialist laboratory serves the region of Modena (the community and other centres), providing a wide range of general and specialist tests across a wide disease spectrum



## What is the rationale?

- There are a large number of tests (~100) available for AD and Atopic March (e.g. food allergy testing)
- Requesting appropriate tests and interpreting the data they produce is challenging and requires specialist input
- Testing for allergies is challenging, as many results give false-positives and are limited in what they can identify<sup>(a)</sup>
- Specialist technicians working within the laboratory help to ensure physician requests are accurate and tests results are meaningful (i.e. they interpret test results)

## What are the key features of the intervention?

- The hospital has two laboratories: a general laboratory (providing common tests, e.g. full blood count tests) and a specialist laboratory (providing specialist tests, e.g. allergy testing)
- The specialist laboratory provides 3 levels of testing for adults and children:
  - 1<sup>st</sup> level: Specific tests (e.g. IgE testing) can be requested by a general practitioners and internal and external specialists
  - 2<sup>nd</sup> level: Enhanced diagnostic tests can only be requested by specialist (external or internal allergologists and dermatologists)
  - 3<sup>rd</sup> level: Further specific tests (e.g. molecular allergy testing) can only be requested by specialists (external or internal allergologists and dermatologists)

## Sample processing at the laboratory:

- *Requests:* Tests are requested by PCPs / hospital HCPs throughout Modena, with samples sent to the laboratory. Clinical information (e.g. DOB, known sensitivities, symptoms) are specified with the samples to provide the laboratory with the necessary information

*Note: this clinical information is collected from a patient questionnaire which is consistent across the Modena region*

- *Assessment of request:* Specialists, including 2 specialist nutritionist, will assess the suitability of requests (i.e. if the physician has ordered the most appropriate test for the patient). If there is a more optimal / effective test available, they will perform this test instead. In recent years, this has become a more detailed review with more attention paid to personalised medicine
- *Processing:* The samples are processed by the technician using specialist equipment
- *Interpretation:* Specialists interpret results (e.g. the nutritionist in the case of food allergy testing) and provide the requesting physician with feedback. Test results are available on the laboratory's electronic record, which PCPs and physicians from other hospitals can access

**Sources:** (a) Fleischer DM, et al. Oral Food Challenges in Children with a Diagnosis of Food Allergy. *Journal of Pediatrics*; 2011;158(4):578-583

# Specialist laboratory testing and interpretation (2/2)

## What are the outcomes so far?

### Benefits to patients:

- Reliable test results and diagnosis of allergies
- More meaningful advice following test results (e.g. predicting which other foods they may be allergic to (3<sup>rd</sup> level tests only))

### Benefits to HCPs:

- Optimised test selection (i.e. the most appropriate tests are conducted for patients)
- Reduced ambiguity in test results which are more informative, allowing physicians to better advise patients
- Cost efficiencies (as less allergy tests may be performed)

## What's next?

- To develop and expand the biobank of allergy samples (the centre currently stores 400 samples in 3-monthly cycles)
  - In the future, it is hoped this will assist with identifying specific biomarkers for the diagnosis of AD or evaluating the effectiveness of AD treatment(s)
- To present the laboratory structure at national congress in April 2019, held for PCPs and specialists from across Italy

“



The number of tests available is increasing. 5 years ago, we had 4-5 tests for autoimmune disorders - now we have over 100 tests

*Laboratory director,  
UNIMORE*

“



We don't just provide the results of tests. We interpret the results and advise on what they mean for the patient

*Laboratory nutritionist,  
UNIMORE*

“



Some of our tests are very specialist. They will tell you which molecule (in the food) you are allergic to and predict which other foods you may be allergic to

*Laboratory nutritionist,  
UNIMORE*



# Coordination of AD care by allergologist (1/3)

## Overview

- AD patients are managed by allergology. Allergologists will coordinate all care for these patients, including collaborating with and referring to comorbidity specialists

“

We focus on treating AD as a systemic disease

Allergologist,  
UNIMORE



## What is the rationale?

- AD may progress into Atopic March, a multi-organ disease which may include asthma and allergic rhinitis<sup>(a)</sup> and is also linked to food allergy<sup>(b)</sup>
- These comorbidities (allergic asthma, allergic rhinitis and food allergy) require specialist input from allergology

## What are the key features of the intervention?

- Dermatology and allergology joined 10 years ago through the collaboration of professors in both specialities. Today, AD care is coordinated through allergology
- Adults and children are managed by allergology throughout the patient pathway (i.e. from diagnosis through to monitoring and follow up)
- Allergology perform diagnosis and provide treatment
- Specialist treatments (e.g. biologics) are administered by physicians
- Allergologists are responsible for coordinating care between different comorbidity specialists, including:
  - Pulmonology: allergic asthma
  - Ophthalmology: conjunctivitis and AD eye comorbidities
  - Gastroenterologist: eosinophilic esophagitis
  - Psychologist: for psychological issues and support
  - Rheumatology: diagnosis and management of autoimmune diseases often associated with atopy
  - ENT (ear-nose-throat): for rhinitis (allergic and non-allergic), nasal polyposis, rhinosinusitis, etc.

**Sources:** (a) Darlenski R, et al. Atopic dermatitis as a systemic disease. *Clin Dermatol.* 2014;32(3):409-13; (b) Roerdink EM, et al. Association of food allergy and atopic dermatitis exacerbations. *Ann Allergy Asthma Immunol.* 2016;116(4):334-8; (c) Tsakok T, et al. Does atopic dermatitis cause food allergy? A systematic review. *J Allergy Clin Immunol.* 2016;137(4):1071-1078

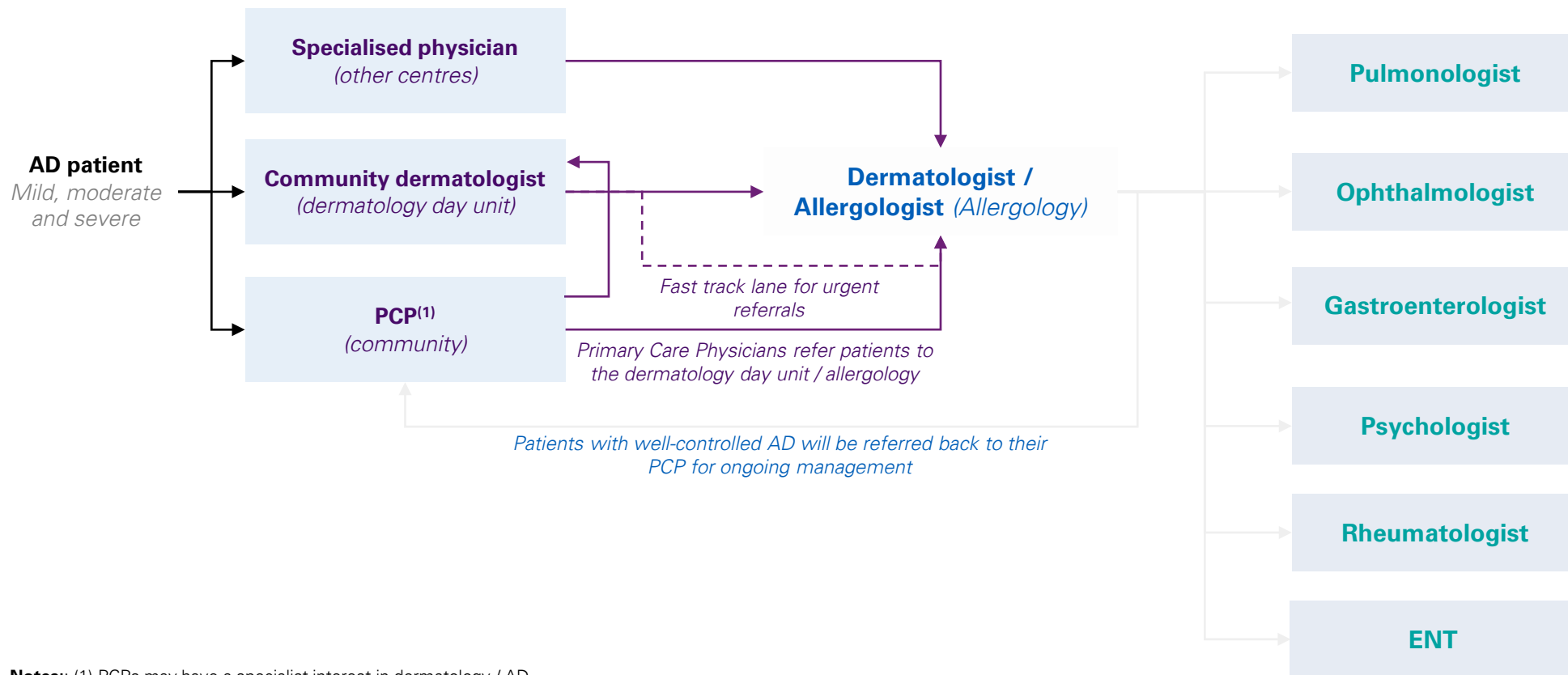


# Coordination of AD care by allergologist (2/3)

## What are the key features of the intervention? (cont.)

### Patient referral pathway:

- Patients present to a variety of HCPs in different settings and are subsequently referred to allergology
- Allergology will coordinate care for all AD patients (allergic and non allergic), including testing, treatment and collaboration with comorbidity specialists



**Notes:** (1) PCPs may have a specialist interest in dermatology / AD

# Coordination of AD care by allergologist (3/3)

## Challenges

- AD manifests in many different ways and over different time scales, and may therefore require input from different specialists
- Adult patients can be more challenging to treat (vs. children), as they are often less compliant with treatment
- AD patients may require follow up appointments up to every 10 days, meaning coordination between specialities is essential

## What are the outcomes so far?

### Benefits to patients:

- Access to coordinated care from different specialists
- Strong relationships established with the allergologists and with the allergology unit as a whole

### Benefits to HCPs:

- Strong collaboration between allergology and other specialities
- Knowledge sharing between dermatologists and allergologists (e.g. an allergologist's knowledge of internal medicine)

“



Patients often require many follow-up appointments from different comorbidity specialists. This can be up to every 10 days, so it is very important we work closely with our comorbidity specialists

*Allergologist, UNIMORE*

“



We build strong relationships with patients because we maintain an open dialogue with them throughout their treatment

*Allergologist, UNIMORE*



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# Provision of psychological care (1/2)

## Overview

- The hospital employs a psychologist, who works across different specialties to provide psychological support for patients
- The psychologist works closely with the allergology unit, providing support for AD patients



## What is the rationale?

- AD is a chronic and complex disease which can affect the psychological well-being and quality of life (QoL) of patients<sup>(a)</sup> and their families<sup>(b)</sup>
- Psychological symptoms and AD symptoms have been seen to correlate, with psychological distress worsening as AD symptoms are aggravated (and vice versa)<sup>(a)</sup>
- Psychologist input in the holistic management of AD is important, as patients with severe AD have an increased risk of developing psychological issues<sup>(c)</sup>

## What are the key features of the intervention?

- A centre psychologist (specialised in chronic inflammatory skin diseases and cognitive behaviour) works across different specialties (including allergology, oncology, cardiovascular)
- Adult and child patients who display psychological issues / distress (identified through the physician's professional judgement and the QoL questionnaire) will be referred to the psychologist

*Notes: only patients within the centre are seen by the psychologist*

### Format of psychology consultations:

- Psychologist-patient consultations are held on a 1:1 basis
- During the consultation, the psychologist attempts to understand the underlying reasons and motivations behind behaviour / psychological symptoms
- Consultations last 1 hour and primarily take the format of a conversation between the psychologist and the patient. Patients are followed up as needed (at the psychologist's discretion)
- The psychologist does not have a fixed job plan with the different departments and is flexible to attend specialties as a consultant based on the psychological condition of the patient. After the first visit, the psychologist will decide the interval of the follow-up appointment based on the patient's psychological needs

### Outreach work:

- The psychologist also works in the community (specifically with beauticians and hairdressers), educating them about particular diseases and helping them to support patients through their work

*Note: this outreach work is conducted only with beauticians and hairdressers for oncology patients (those on chemotherapy who suffer with hair loss)*

**Sources:** (a) Lifschitz C. The impact of atopic dermatitis on quality of life. *Ann Nutr Metab* 2015;66(suppl 1):34-40. doi: 10.1159/000370226; (b) Reed B, et al. The burden of atopic dermatitis. *Allergy Asthma Proc.* 2018;39(6):406-410. doi: 10.2500/aap.2018.39.4175; (c) Noh S et al. Comparison of the psychological impacts of asymptomatic and symptomatic cutaneous diseases: vitiligo and atopic dermatitis. *Ann Dermatol.* 2013;25(4):454-61. doi: 10.5021/ad.2013.25.4.454

# Provision of psychological care (2/2)

## What are the key features of the intervention? (cont.)

### Nurse education:

- The psychologist works at the University of Modena and Reggio Emilia (UNIMORE) and delivers nurse education
- Education sessions cover the management of atopic patients in real life (the explanation of use of the correct use of emollients, the frequency of application, the use of topical therapy and the modalities of systemic therapy)

## What are the outcomes so far?

### Benefits to patients:

- The development of coping strategies and ways to control their disease
- Support received for non-medical issues

### Benefits to HCPs:

- Shared learning between allergology and psychology (i.e. allergologists learn from the psychologist's approach and visa versa)

## Challenges

- Children are unable to express themselves in the same way as adults, so the psychologist works with parents / caregivers to provide support to the whole family
- Patients can be non-compliant with AD treatment<sup>(a)</sup> and not follow the psychologist's advice

## What's next?

- Implement group sessions (in addition to individual sessions) for AD patients to provide further psychological support
- Formalise regular meetings between the psychologist and allergology in order to discuss patient cases and encourage knowledge sharing
- Conduct outreach work in AD, empowering more members of the community (e.g. beauticians) to support patients with their lifestyle needs

**References:** (a) KPMG Interviews

“



I work with patients to understand their attitudes to their disease

*Psychologist,  
UNIMORE*

“



AD is a chronic disease. It is essential that we focus on the person, not the pathology

*Psychologist,  
UNIMORE*

“



Self esteem is very important and we must confront any issues that arise in this area

*Psychologist,  
UNIMORE*



# AD occupational training and advice (1/2)

## Overview

- Occupational physicians (OPs) based at the University collaborate with and provide education and training to allergologists. This is in regard to AD in the workplace, so that they may advise their patients accordingly

## What is the rationale?

- In Italy, there are a number of people who suffer with conditions which are exacerbated by the workplace. This includes ~3000 patients with respiratory diseases and 25-30 patients with conjunctivitis<sup>(a)</sup>
- These patients require additional support with regards to their working conditions (e.g. avoiding or reducing exposure to allergens in the workplace)
- A legal framework in Italy protects these groups of patients from potential harm in the workplace<sup>(b)</sup>. For example, every company with >1 employees must:
  - Appoint a safety officer
  - Evaluate all occupational risks
  - Appoint an occupational health physician if, for particular working conditions, the law requires health surveillance of workers

## What are the key features of the intervention?

- 3 occupational physicians (based at the University of Modena and Reggio Emilia [UNIMORE]) and 1 resident of occupational medicine work with the centre. The resident is replaced approximately every 3 months with a new resident of occupational medicine

### Role of the occupational physician:

- OPs visit the centre to provide advice, oversee the health of the centre staff (i.e. physicians, nurses and other HCPs) and perform health surveillance of specific patients (with personnel seen on an annual basis)

### Education at the allergology-dermatology unit:

- The OPs educate allergologists / physicians regarding occupational considerations for AD and allergy patients, including:
  - Knowledge of new allergens and irritants in the environment
  - Pathophysiology of disease exacerbation (caused by environmental factors)
  - Advising patients about workplace and environmental factors (e.g. wearing personnel protective equipment [PPE] in the workplace)

**Sources:** (a) Testo Unico sulla salute e sicurezza sul lavoro [PDF] <https://www.lavoro.gov.it/documenti-e-norme/studi-e-statistiche/Documents/Testo%20Unico%20sulla%20Salute%20e%20Sicurezza%20sul%20Lavoro/Testo-Unico-81-08-Edizione-Giugno%202016.pdf> Accessed 12 Sept 2019; b) Union Europeenne des Medecines Specialistes of Occupational Medicine [Website] <http://www.uems-occupationalmedicine.org/node/74> Accessed 20 May 2019



# AD occupational training and advice (2/2)

## What are the key features of the intervention?(cont.)

### Wider education provided:

- Both public and private specialists may access the courses (including allergologists)
- Education is accredited and forms part of continued medical education (CME). Credits are awarded to those completing the courses (with the number of credits awarded depending on course length)
- Some courses are delivered in a F2F “summer school” format, including a course on UV and skin cancer (held ~3 years ago) for dermatologists

## What are the outcomes so far?

### Benefits to patients:

- Advice for managing / avoiding allergens in their work place (potentially leading to improved productivity, ability to work etc.)
- Enhanced care delivered by the HCPs as they receive training from the OPs

### Benefits to HCPs:

- Specialist knowledge shared between occupational physicians, allergologists and dermatologists
- Allergologists and dermatologist may provide better advice to patients regarding the wider aspects of their disease (e.g. exacerbations caused by environmental allergens)

## What's next?

- Continue to conduct research into allergens in the workplace, in order to identify new vectors and avoidance strategies
- Develop courses alongside dermatologists, specifically designed for AD patients



All health workers have health surveillance - we are here to protect the workers

*Occupational physician,  
UNIMORE*



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APPENDIX  
CENTRE REPORTS



# Università Cattolica del Sacro Cuore

**Rome, Italy**

Site visited by KPMG 11–12<sup>th</sup> July 2019

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[kpmg.com/uk](https://kpmg.com/uk)



# Summary



## Context

- **Centre type:** Private teaching hospital located in Rome that is part of Università Cattolica del Sacro Cuore
- **Catchment area:** Patients from Rome and across Southern Italy are seen at the centre
- **Funding:** Accredited with the Italian National Health system, which enables reimbursement by the National Health System for both drugs and health care services (tests, visits, etc.). The centre also receives private funding
- **Services:** The AD-specialised physician team operates within the dermatology department (although it is located on a separate floor to general dermatology). Other specialist services are offered at the centre, which the team works closely with (such as allergology)
- **Patient population:** Paediatric and adult patients with dermatological diseases are treated in the dermatology department. Mild, moderate and severe AD patients are seen by the AD-specialised physician team



## Key strengths in the delivery of AD care

- **Specialised team for AD patients:** AD patients are referred to the AD-specialised physician team, which is a sub-speciality team within dermatology. Paediatric and adult patients are able to access dermatologists who have extensive experience treating AD
- **Healthcare professional education:** The centre provides regular healthcare professional education to help optimise AD care within the community
- **Collaboration with allergology:** The team actively engages with allergology to co-manage AD patients with allergic associated comorbidities (e.g. asthma), and refer across AD patients who initially presented to the centre via the allergology department
- **Local AD patient registry:** The centre has developed a local registry of their AD patients, that will form a foundation for research and service improvements in the future



## Key challenges faced in the delivery of AD care

- **Resourcing constraints and limited specialist knowledge:** Community dermatologists and general practitioners are limited by short appointment times and minimal AD-specific skills. There can be a tendency for the physicians to avoid prescribing systemic/immuno-modulating treatments, potentially creating the unnecessary risk of AD flare ups
- **Centralised regional call centres do not directly allocate patients to the AD team:** Patients can directly phone the hospital call centre or the regional call centre (RCC), which is responsible for booking patient hospital appointments (across Italy). The local RCC allocates AD patients to the hospital dermatology department. The department then refers patients to the AD-specialised physician team
- **Delayed access to timely care:** AD patients are often referred to the allergology department, where they undergo various allergy tests prior to referral to the AD-specialised physician team, thereby delaying patient access to dedicated AD ambulatory care

# Atopic Dermatitis (AD) in Italy



## Italian healthcare system<sup>(a)</sup>:

A national health plan, 'Servizio Sanitario Nazionale' (SSN), is in place in Italy, which provides medical care for all Italian citizens. Healthcare provided by the SSN is a public service financed by tax revenue of the Italian constitution<sup>(b)</sup>. Healthcare is a decentralised system and based on three levels:

State - *defines guidelines and contracts*

Region (20) - *controls health services within the region*

Local health boards - *day-to-day management of services*

## Prevalence:

- Prevalence of AD in adults across the Europe is 4.4%<sup>(c)</sup>
- In a study in Italy, the prevalence of adult AD was 8% and prevalence of AD with asthma and / or hay fever was 3.4%<sup>(d)</sup>



## Care provision:

### Location:

- The majority of AD care is delivered by community dermatologists
- Community dermatologists manage mild (or well-controlled) AD patients
- Moderate and severe (or uncontrolled) AD care is delivered by specialist hospitals

### Funding (general)<sup>(a)</sup>:

- Funding takes place at three levels:
  - **State:** finances research hospitals
  - **Region:** finances health services within the region and independent hospitals
  - **Local:** finances public and private hospitals under contract in the region

## Guidelines and societies:

### Guidelines:

- Guidelines for treatment of atopic eczema (atopic dermatitis) part I and part II: European Association of Dermatology and Venerology (EADV)
- Diagnosis and management of moderate to severe adult atopic dermatitis: a Consensus by the Italian Society of Dermatology and Venereology (SIdMaST), the Italian Association of Hospital Dermatologists (ADOI), the Italian Society of Allergy, Asthma and Clinical Immunology (SIAAIC), and the Italian Society of Allergological, Environmental and Occupational Dermatology (SIDAPA)

### Medical society:

- Italian Society of Dermatology (SIdMaST)








### Patient association group (PAG):

- Associazione Nazionale della Dermatite Atopica (ANDeA)

**Sources:** (a) Health Management. Facts & Figures: the Italian Healthcare System [Website] <https://healthmanagement.org/c/it/issuearticle/facts-figures-the-italian-healthcare-system> Accessed 7 Mar 2019; (b) The Commonwealth Fund. International Health Care System Profiles: The Italian Health Care System [Website] <https://international.commonwealthfund.org/countries/italy/> Accessed 8 May 2019; (c) Barbarot S, et al. Epidemiology of atopic dermatitis in adults: Results from an international survey. *Allergy*. 2018;73(6):1284-1293; (d) Pesce G et al. Adult eczema in Italy: prevalence and associations with environmental factors. *J Eur Acad Dermatol Venereol*. 2015;29(6):1180-7. doi: 10.1111/jdv.12784



# The centre and AD-specialised physician team

The centre		
 <b>Type and location</b>	The centre, also known as University Policlinic ‘Agostino Gemelli’, is a teaching hospital for Università Cattolica del Sacro Cuore, a large research university	
 <b>Population served</b>	Patients from Rome and across the Southern Italy attend the hospital	
Inflammatory Skin Disease Unit		
 <b>Service Division</b>	<b>Outpatient service</b> (Public and private clinics)	<b>Inpatient service</b>
 <b>Hours of availability</b>	Daily morning sessions (08:15 - 14:30) Afternoon sessions, Wednesday and Friday (14:30 - 18:00) <i>Note: only select AD patients attend Friday afternoon sessions</i>	24/7
 <b>No. of patients seen</b>	~30 AD patients seen per dermatologist per week (~150–200 in total)	2 dedicated beds (not necessarily all AD patients)
 <b>Types of patients seen</b>	Children (mild, moderate and severe); Adults (mild, moderate and severe) Moderate to severe AD patients may be referred to the AD-specialised physician team due to: <ul style="list-style-type: none"><li>— An unstable condition (frequent flares) or a partial/temporary response to conventional therapies</li><li>— A need for intravenous therapies (corticosteroids / antibiotics for superinfections)</li><li>— The need for hospitalisation following poor management of AD-related conditions</li><li>— Challenging diagnoses</li></ul>	
 <b>Facilities on-site<sup>(1)</sup></b>	<ul style="list-style-type: none"><li>— Phototherapy (UVB / PUVA)</li><li>— Day hospital</li><li>— Access to allergy tests (e.g. on-site patch testing and skin prick testing)</li></ul> <i>Note: the centre employs an ambulatory allergologist within the dermatology department, who may perform patch testing with without involving the allergology department</i> <ul style="list-style-type: none"><li>— Dermatology laboratory</li><li>— 2 inpatient beds</li><li>— Skin biopsies</li></ul>	

**Note:** (1) List of facilities is not exhaustive

# The team



## Core team profile



**5** dermatologists (1 sub-specialising in paediatric dermatology)



**1** trainee dermatologist

## Wider team profile



**1** allergist



**2** paediatricians



**1** ophthalmologist



**1** pneumologist



## Governance and processes

### Team meetings:

- *Complex cases meeting (fortnightly)*
  - Attended by: multiple specialists required by the dermatologist to improve patient management, including dermatology, pulmonology, allergology and psychology
  - Purpose of the meeting: to discuss complex cases

### Patient records:

- *Electronic Health Records (EHR)*
  - Electronic health records can be accessed regionally by primary and secondary health care professionals from the public and private sector

*Note: Please see page 239 for further details about the wider team*

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients present to their local dermatologist (in local health centres), private dermatologist or primary care physician (PCP) with AD symptoms (e.g. itching or dryness of the skin). The physician will assess and refer if required
- Note: Mild AD patients tend to be managed by private dermatologists, local dermatologists or by PCP. As a result, a limited number of mild AD patients may be seen by the AD team*
- Patients may present to the general Accident and Emergency department at the centre

## Diagnosis and Referral

In secondary and tertiary care



- Paediatric and adult AD patients are referred to the centre and may be seen in: general dermatology, allergology or AD-specialised physician team
- Allergology will usually perform allergy tests first, and refer to the AD-specialised physician team if they are negative (but show skin symptoms)
- Once referred, the first consultation with dermatologists usually takes 15 to 20 mins. To confirm AD diagnosis, the dermatologist explores / discusses:
  - Family / personal history
  - Allergy tests (if performed)
  - Behaviour of disease
  - Treatment utilised
  - Patient education
- IgE test performed for all patients
- Depending on patient symptoms, a patch or prick test is performed
- In case of uncertain diagnosis, a skin biopsy may be performed

## Treatment and Management

Medical management



- Dermatologists mainly manage moderate to severe patients and initiate / modify treatment as required
- Baseline EASI, IGA, NRS and sleep survey scores at taken and repeated at the start of treatment. POEM, itchNRS and DLQI may also be measured
- Patients may be offered the opportunity to participate in clinical trials (CT) at the centre

Non-medical management



- Dermatologists refer to external psychologists when required. The referral process usually takes one month
- Adjuvant therapy (e.g. phototherapy (PUVA/UVB), intravenous antibiotics and intravenous steroids) is provided when necessary at the day hospital (overseen by one of the centre's dermatologists) as required

## Follow-up

Monitoring of chronic disease / flare up



- Patient follow-up frequency depends on patient condition (e.g. stable vs. flare-ups) and the treatment(s) prescribed. Patients may be seen more frequently if they have recently started using a new medication
- Paediatric patients generally remain in the care of the centre's dermatologist with a paediatric sub-specialism (as they see adult patients as well), but may transition to one of the adult-focused dermatologists at around 12 years of age
- Patients tend to remain at the centre for continued care (versus being referred back to community dermatologists or PCPs)

# Roles of the wider team

## Allergist

**Patient type:** All patients suffering from chronic dermatological conditions (including AD, psoriasis etc.) with an allergy related comorbidity (including allergic rhinitis, food allergies and asthma)

*Note: not all patients seen by the allergist have AD*

**Referral:** Referred by dermatologist to allergology department

**Consultations:** Allergist will perform standard tests and provide treatments as required. This includes performing skin pricks and patch testing during outpatient clinic appointments

**Timing:** Consultations vary in length depending on patient requirements and the allergy test(s) performed

## Ophthalmologist

**Patient type:** Mild to severe AD patients may be seen if they present with ocular symptoms

**Referral:** Referred by dermatologist to ophthalmology department

**Consultations:** Ophthalmologist will perform standard tests and provide treatments as required

**Timing:** Consultations last ~ 30-45 minutes. Follow-up frequency (every 3-6 months) depends on patient condition and the prescribed therapy



## Paediatrician

**Patient type:** Mild to moderate paediatric patients up to 18 years of age suffering from chronic dermatological conditions (including AD, psoriasis etc.).

**Referral:** Usually referred by a paediatrician in primary care to the centre's paediatric department, who in turn may refer to the centre's dermatology department

**Consultations:** The paediatrician aims to define the patient's therapeutic management. A dermatologist determines the tests to be performed (by a dermatologist or allergist dedicated to paediatric diseases) and the choice of AD treatment

**Timing:** Consultations last ~30 minutes. Follow-up frequency is every 2-3 months

*Note: Paediatric patients suffering from severe AD are usually solely treated by the AD-specialised physician team*

# Overview of interventions in place for AD

## Awareness and Presentation



Symptom identification

- **Collaboration with local patient advocacy group (PAG):** The centre aims to collaborate with the local PAG to provide patient education and awareness of AD

See pg. 245-246 for case study

- **Monthly hospital newsletter:** The hospital creates a newsletter that is printed and publically available. It contains information about their dedicated outpatient clinics, screening days. AD-specialised physician team often publishes information in the newsletter to raise awareness of their AD services

## Diagnosis and Referral



In secondary and tertiary care

- **Healthcare professional education:** The centre delivers a range of healthcare professional education, including two-day meetings on dermatological conditions

See pg. 247 for case study

- **AD-specialised physician team:** The dermatology department has a highly specialised team that manages and treats AD patients (in addition to other inflammatory skin diseases such as psoriasis)

## Treatment and Management



Medical management

- **Collaboration with other specialties:** The Dermatology Department currently collaborates with various departments to manage comorbid patients and identify AD patients incorrectly referred to other specialists (from PCPs and private or local dermatologists / allergists). The department is currently planning some collaborative research with allergology and ophthalmology around AD to further improve their joint working

See pg. 248-250 for case study

- **Participation in clinical trials:** Adolescent (12+ years) and adults are able to participate in observational and treatment clinical trials. The centre currently has 12 ongoing trials – one observational and 11 treatment trials (on a range of treatment types)



Non-medical management

- **Referral to psychologists:** Dermatologists refer to external psychologists when required. The referral process usually takes a month

## Follow-up



Monitoring of chronic disease/flare up

- **Development of a local patient registry:** A local patient registry has been developed by the centre to monitor and track AD patients response to different treatments for future research purposes. The centre is also in the process of becoming a contributing centre to the Italian dermatology registry (AtopyReg)

See pg. 251-252 for case study

### Key:



Case study available



# Monitoring AD patients and comorbidities

## The AD-specialised physician team employs a number of measures for monitoring AD and associated comorbidities

### Objective measures (AD):

AD scoring indices are utilised to monitor patients and their disease, including:

- EASI (Eczema Area and Severity Index): validated scoring system that grades the physical signs of atopic dermatitis<sup>(a)</sup>
- vIGA-AD<sup>TM</sup> (Validated Investigator Global Assessment scale of Atopic Dermatitis): scoring system used to describe the appearance of lesions and AD in clinical trials<sup>(b)</sup>
- SCORAD (SCORing Atopic Dermatitis): to assess AD disease severity and monitor patient progress<sup>(c)</sup>

Sleep disturbance is routinely measured by:

- A 0-10 NRS (Numerical Rating Scale)

The dermatologists perform patch testing to determine if an allergen is triggering a skin reaction

### Patient-reported outcomes:

Quality of life (QoL) is routinely measured by:

- POEM (Patient-Oriented Eczema Measure): to monitor patient AD disease severity<sup>(d)</sup>
- DLQI (Dermatology Life Quality Index): ten-question questionnaire designed to measure the impact of skin diseases on quality of life. Performed as required by regulations relating to the prescription of AD biologic therapies<sup>(e)</sup>
- The Peak Pruritus NRS (Numerical Rating Score)<sup>(f)</sup>: involves asking the question “On a scale of 0 to 10, with 0 being ‘no itch’ and 10 being ‘worst itch imaginable’, how would you rate your itch at the worst moment during the previous 24 hours?”

---

### AD-specialised physician team routinely measures comorbidity outcomes by:

- *Allergist*: response to allergens/control of atopy disease (e.g. prick testing)
- *Ophthalmologist*: surveillance of symptoms and specialist tests (e.g. topography)

**Sources:** (a) HOME for eczema.org. EASI for clinical signs. [Website] <http://www.homeforeczema.org/research/easi-for-clinical-signs.aspx> Accessed 1 Mar 19; (b) International Eczema Council (IEC): Investigator Global Assessment Scale [Website] <http://www.eczemacouncil.org/research/investigator-global-assessment-scale/> Accessed: 20 Mar 2019; (c) SCORing Atopic Dermatitis (SCORAD) Calculator (0.9.0) [Website] <http://scorad.corti.li> Accessed: 26 Feb 2019; (d) Charman CR, et al. Translating Patient-Oriented Eczema Measure (POEM) scores into clinical practice by suggesting severity strata derived using anchor-based methods. *Br J Dermatol.* 2013;169(6):1326–1332; (e) Dermatology Quality of Life Index (DLQI), Cardiff University; [Website] <http://sites.cardiff.ac.uk/dermatology/quality-of-life/dermatology-quality-of-life-index-dlqi/> Accessed 13 Mar 2019; (f) Numerical Rating Scale (NRS) [Website] <http://www.pruritussymposium.de/numericalratingscale.html> Accessed 14 April 2019

# Advice to other centres



## What advice would you give less specialised centres



**Objective of advice:** Focus on the patient's quality of life (QoL) and provision of holistic care

- **Why?** AD is a chronic disease which requires long-term treatment and can affect all aspects of a person's quality of life. Dermatologists and healthcare professionals need to develop a deep understanding of what matters most to the patient. This may be their sleep, continuity of care, effective treatment, other social needs, etc., or a combination. Understanding how AD impacts a patient's QoL can result in improved decision making and treatment choice



**Objective of advice:** Establish a multidisciplinary team approach for timely and effective patient care

- **Why?** Creating an environment where different healthcare professionals can learn from other specialties can help improve patient care. It can support the healthcare professionals to make better informed treatment decisions and potentially drive earlier diagnosis and treatments. Whilst a formal AD network can support a multidisciplinary approach, an informal collaborative network where healthcare professionals regularly communicate may also improve diagnosis and treatment decision making



**Objective of advice:** Optimise existing treatment and become familiar with new treatments

- **Why?** Optimising the application and use of topical treatments can help improve patients' response to treatment. This may involve additional patient education and demonstrating appropriate application techniques. If patients continue to inadequately respond to treatment, new treatment options can potentially help improve the patient's QoL. Dermatologists should consider referring to other centres who are able to prescribe new treatments or enrol the patient into a clinical trial if it not possible to access the new treatments



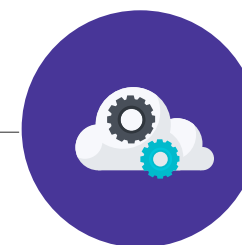
# Next steps for the centre



## What is next for the centre?

**Objective:** Strengthen existing collaboration with allergology and ophthalmology through joint research

- **What?** The centre aims to collaboratively research how AD patients with different allergology comorbidities differ in terms of presentation and response to treatment. The centre proposes to perform the joint research with the allergology and ophthalmology unit
- **Why?** By creating a research study with a common interest and shared goal, the centre aims to solidify existing cross-speciality relationships. The research will also support diagnosis and treatment related decision making



**Objective:** Deliver a patient centred approach for AD patients through cross-specialty collaboration

- **What?** Create an informal multidisciplinary (MDT) network for AD with dermatology, allergology, pneumology, psychology and ophthalmology. Specialties related to additional AD comorbidities would also be incorporated into the MDT network, such as dieticians to advise AD patients on a safe and balanced diet (e.g. no dyes / preservatives). Yoga, autogenic training and teaching relaxation techniques may also improve quality of life for patients, in addition to an education programme covering how AD patients can appropriately engage with sports and physical activities
- **Why?** Focusing on a collaborative approach across different specialties can help improve patient outcomes and experience. Working with other specialties can help reduce the delay in patient access to specialists in areas outside of dermatology



**Objective:** Minimise the need for manual entry of data into the local patient registry

- **What?** The centre is currently working with a technology company to develop an interface that links the electronic health record with the registry
- **Why?** Developing an interface that removes the need for manual entry will minimise the administrative burden of the registry and increase the capacity of the dermatologists and trainee dermatologist. The interface could also support the development of any future dermatology (or wider) registries within the centre



# Case studies



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# Working with the PAG (1/2)

## Overview

- The centre aims to collaborate with the local PAG to provide patient education and increase awareness of AD. Various ideas have been proposed to the local PAG, including a webpage of expert answers. This would collect patient frequently asked questions and provide comprehensive expert responses.

## What is the rationale?

- The National Association of Atopic Dermatitis (ANDeA) is the national PAG for AD and asthma patients in Italy<sup>(a)</sup>
- ANDeA was set up 2 years ago and collaborates with centres and the scientific community<sup>(a)</sup>
- Physicians and centre staff may have little time to support patients with the non-medical aspects of their disease. ANDeA therefore plays a key role in supporting patients

## What are the key features of the intervention?

- ANDeA is involved in activities to support patients and raise awareness of the disease

### Key activities:

- *Raising awareness*
  - ANDeA proactively raises awareness of the disease, diagnosis and treatment options via social media, events and publications
- *Providing non-medical advice to patients via specialists ("Ask the Expert")*
  - Patients may ask questions to specialist allergologists, dermatologists and immunologists from the centres (and from across Italy) on the "Ask the Expert" online portal
  - Non-medical advice is provided (not intended to replace advice / guidance from a patient's home centre, but to support patients with lifestyle issues, etc.)

*Note: no medical advice (e.g. treatment decisions) will be provided to patients through this channel*

- *Collaborating with the scientific community and HCPs*
  - ANDeA works with centres (including UNIMO) to support research and promotes the use of patient registries
  - ANDeA works closely with specialist HCPs in AD and hosted the "First national day of atopic dermatitis" in 2017. This event brought together a number of well recognised physicians and HCPs in AD, with the aim to bring AD "to the attention of the institutions and public"<sup>(b)</sup>

**Sources:** (a) ANDeA - Associazione Nazionale Dermatite Atopica: Homepage [Website] <https://www.andea.it/> Accessed 4 Mar 19; (b) First national day of atopic dermatitis [Website] <https://www.andea.it/giornata-nazionale-della-dermatite-atopica/> Accessed: 4 Mar 2019



# Working with the PAG (2/2)

## What are the key features of the intervention? (cont.)

### Key activities the centre has proposed to ANDeA

- The centre has proposed developing a webpage that contains 'expert answers' against frequently asked questions
  - The centre proposes to collect patient frequently asked questions and provide comprehensive responses for each question
  - The centre has previously run live 'expert answers' sessions, however it was difficult to find a time that suited experts and patients
- They have also suggested an open day at the centre for patients to have education sessions or consultations, which ANDeA would support with advertising to patients
  - The centre proposes either half or full day open days on Saturday in October or November where existing and new patients are able to walk in and have an education / consultation session with the team
  - The centre's team would be split into different groups and talk about different aspects of AD care and treatment
  - ANDeA would support advertisement of the event
- The centre aims to support educational sessions or programmes facilitated by ANDeA that aim to dispel 'fake news' about AD
- The centre aims to develop a map of where to find AD experts across Italy



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# Healthcare professional education

## Overview

- The centre provides intensive two-day meetings for private dermatologists that involve a practical morning session and theoretical afternoon session. The morning session involves interaction with patients in the outpatient clinics. The afternoon sessions involve case presentations and supporting theory.



The private dermatologists are able to familiarise themselves with a variety of skin conditions and therapies through practical training

*Dermatologist, Università Cattolica del Sacro Cuore*



## What is the rationale?

- Healthcare professional education has the potential to improve the knowledge and confidence of HCPs and patient health outcomes<sup>(a)(b)(c)</sup>

## What are the key features of the intervention?

- The centre provides intensive two-day meetings for private dermatologists (5-10 participants), which includes a practical morning session and a theoretical afternoon session:
  - **Morning session:** participants may attend the outpatient clinic of their choice with one of the clinic's dermatologists. The private dermatologists learn about their condition of interest and have the opportunity to interact with patients in the clinic
  - **Afternoon session:** participants receive presentations on patient case studies and supporting theory (e.g. treatment options, disease information). Topics include:
    - Different clinical variants of AD
    - How to measure disease severity and assess responses to treatment
    - Overview of (and new perspectives on) current AD therapies
- The sessions are most frequently focused on psoriasis (run four times per year), but the centre plans to run similar sessions focused on AD when more treatments become available

## What are the outcomes so far?

### Benefits to patients:

- Better management of skin conditions in the community care setting
- Patients are able to build relationship with private dermatologists and receive consistent advice

### Benefits to HCPs:

- Improved management of patients in the community (requiring less referral to specialist care)
- Strengthening / forming of professional relationships between community and hospital-based care providers

## What's next?

- The centre plans to adapt existing educational session model to focus on AD and AD related treatments in the near future

**Sources:** (a) Cervero RM, et al. The Impact of CMA on Physician Performance and Patient Health Outcomes: An Updated Synthesis of Systematic Reviews. *Journal of Continuing Education in the Health Professions*. 2015;35(2):131-139; (b) Kownacki S. Skin diseases in primary care: what should GPs be doing? *Br J Gen Pract*. 2014;64(625):380-381. doi:10.3399/bjgp14X680773; (c) Schopf T, et al. Impact of interactive web-based education with mobile and email-based support of general practitioners on treatment and referral patterns of patients with atopic dermatitis: randomized controlled trial. *J Med Internet Res*. 2012;14(6):e171



# Collaboration with other specialties (1/3)

## Overview

- The Dermatology Department currently collaborates with various departments to manage co-morbid patients and identify AD patients incorrectly referred to other specialists (from PCPs and private or local dermatologists / allergists). The department is currently planning some collaborative research with allergology and ophthalmology around AD to further improve their joint working

**Sources:** (a) Bantz SK, et al. The Atopic March: Progression from Atopic Dermatitis to Allergic Rhinitis and Asthma. *J Clin Cell Immunol.* 2014;5(2):202; (b) Leung DYM, et al. Deciphering the Complexities of Atopic Dermatitis: Shifting Paradigms in Treatment Approaches. *J Allergy Clin Immunol.* 2014;134(4):769–779. doi: 10.1016/j.jaci.2014.08.008



## What is the rationale?

- AD is a complex disease which can progress into Atopic March and patients may present with other associated diseases (e.g. asthma or allergic rhinitis)<sup>(a)</sup>
- Atopic March patients often require input from both dermatology, allergology and ophthalmology to receive optimal care for their condition(s)
- AD is also linked with food allergies<sup>(b)</sup> which are usually managed by allergists

## What are the key features of the intervention?

### Collaboration with allergology:

- The AD-specialised physician team currently collaborates with the allergology department to manage AD patients with allergic associated comorbidities through coordination of care and research
- The collaboration between the two specialties was established by a dermatologist who had trained at the centre and had an existing relationship with the allergists

### *Collaboration through coordination of care:*

- The collaboration aims to capture AD patients who have incorrectly been referred to the allergology department from PCPs, local dermatologists and private dermatologists in the community
  - There is a misconception that AD is an allergic condition and that an allergist should be the first HCP to treat the condition
  - Three to four AD patients are referred to the team per week, however there may be a larger number of AD patients who have not yet been referred
- Conversely, the AD-specialised physician team refers to the allergology department through a phone call consultation if an allergy or allergology related comorbidity is suspected.
  - A consultation and / or a day hospital visit would be organised by the team to bypass the three month long waiting list, enabling patients to be seen within one week

### *Potential impact of collaboration:*

- Increasing referrals from allergology will also have a positive impact on patient waiting times. The AD-specialised physician team has a short waiting list period of two to three days, in comparison to general dermatology, which has a waiting list of three months
  - In Italy, regional call centres are responsible for booking hospital outpatient appointments. As a result, AD patients are referred to general dermatology, rather than the AD-specialised physician team



# Collaboration with other specialties (2/3)

## What are the key features of the intervention? (cont.)

### Collaboration with allergology (cont.):

#### Supporting features:

- The two teams have an informal working relationship that has been facilitated by the co-location of the allergology and the AD-specialised physician team on the same floor

#### Collaboration through research:

- The AD-specialised physician team aims to initiate scientific research with the allergology unit to explore how different allergology comorbidities (e.g. allergic rhinitis and food allergies) impacts patient AD treatments and therapy
- A local study is currently being conducted jointly by dermatology and allergology, which evaluates the clinical features and epidemiological aspects of AD patients being referred to allergists

*Note: The allergology department and AD-specialised physician team are currently part of a formal psoriasis multidisciplinary team which has a dedicated outpatient clinic for joint patient consultations*

### Collaboration with ophthalmology:

- All dermatologists may contact the ophthalmology department through the day-hospital service
- AD-specialised dermatologists work with one ophthalmologist to manage patients with AD treatment side-effects
- Each ophthalmologist at the centre is specialised in a specific set of eye conditions. AD-specialised dermatologists therefore work most closely with the ophthalmologist specialised in ocular AD comorbidities (e.g. conjunctivitis)
- AD patients with mild-moderate eye conditions will first be treated by the dermatologist. Patients with severe eye conditions will be referred to ophthalmology for further treatment

*Note: patients referred internally to ophthalmology will be seen by an ophthalmologist within 7-10 days (compared to ~2 weeks via external referral or self-presentation at the centre)*



A multi-disciplinary approach to disease management makes a big difference - you cannot believe the benefit. It allows for quicker diagnoses and treatment

*Dermatologist,  
Università Cattolica del  
Sacro Cuore*



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# Collaboration with other specialties (3/3)

## Collaboration with ophthalmology (cont.):

### Potential impact of collaboration:

- Interdisciplinary clinical studies between dermatology and ophthalmology may improve communication and cooperation between specialists and positively impact the patient's experience during treatment (e.g. shared decision making between specialists)

### Collaboration through research:

- AD-specialised dermatologists are collaborating with ophthalmology in ongoing clinical trials, primarily relating to the treatment and management of ocular AD comorbidities

## What are the outcomes so far?

### Benefits to patients:

- More convenient for patients as they are able to receive co-ordinated care
- Decreased waiting time for patients, enabling them to see the appropriate healthcare professional quicker
- Improved access to specialists and specialist tests / treatments

### Benefits to HCPs:

- Opportunity for joint, collaborative decision making through easy access to cross-speciality opinion with increased collaboration and networking
- Improved communication and cooperation between specialists during interdisciplinary medical studies

## What's next?

- Collaborating with allergology on AD-related research to improve patient outcomes
- Establishing a formal, institutional AD MDT with allergology (including other specialties) to enable easier joint-working and cross-referrals between the two teams
- Building on the existing collaboration with pneumology due to the prevalence of asthma in AD patients



It is nice to work on projects with other specialists (and not just refer patients to them) because we can help to increase their knowledge of AD

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# Development of a local patient registry (1/2)

## Overview

- Approximately 1 year ago the centre created its own AD patient registry (currently ~150 patients) to inform future research, which is managed by the centre's trainee dermatologist. The centre is also in the process of becoming a contributing centre to the Italian dermatology registry (AtopyReg)

## What is the rationale?

- A local registry creates a single point of access for relevant patient data that can be extracted and analysed for different research purposes
- A registry can act as a quality control check and the data can help drive professional development and service improvement<sup>(a)</sup>

## What are the key features of the intervention?

- The centre proactively created a database approximately 1 year ago to monitor the centre's AD patients and their response to treatment

*Note: the local patient registry was created for internal use, however it now contributes to the Italian Registry for AD, which is supported by the Italian Society of Dermatology (SIDEMAST)*

- The database creates a single point of access for a complete view of patients at the centre
  - There are currently around 150 patients and each patient is asked a standardised set of questions during their consultation
  - Sub-databases are being iteratively created for different studies and research projects
  - The hospital statistician is able to extract and analyse the data for different studies
- The trainee dermatologist manages the database and is responsible for writing relevant clinical protocols to ensure consistent data collection
  - Patient information is initially captured in the patient's history. The trainee dermatologist will insert patient data if it has not been entered by the dermatologist. They will also document when different objective measures should be recorded (e.g. timeline of EASI)
- The registry involves capturing patient data on:
  - Patient characteristics (including personal data, disease type, phenotypes and comorbidities)
  - Initial test outcomes and scores (e.g. EASI, vIGA-AD)
  - Initial blood test results
  - Patch test results (where applicable)

**Sources:** (a) Nelson EC, et al. Patient focused registries can improve health, care, and science. *BMJ*. 2016;354(8065) doi: 10.1136/bmj.i3319



# Development of a local patient registry (2/2)

## What are the outcomes so far?

### Benefits to patients:

- Practice-based quality improvements can support better patient outcomes

### Benefits to HCPs:

- Drive future research in the centre to improve patient care
- Able to monitor and track patient progress, acting as a quality control check

## What's next?

- The centre is currently developing an interface with an external technology company that will link the registry to the Italian Electronic Health Records (EHR). This aims to reduce the need manual entry and duplication
- The centre is in the process of setting up a procedure to capture data in the Italian Registry (AtopyReg)



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# University Medical Center Groningen (UMCG)

**Groningen, Netherlands**

Site visited by KPMG 10 –12<sup>th</sup> April 2019

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# Summary



## Context

**Centre type:** University Medical Center (tertiary care teaching hospital) located on one site in central Groningen

**Catchment area:** ~3.2 million people from Groningen and across the five northern provinces of the Netherlands (in addition to referrals from other university hospitals)

**Funding:** UMC Groningen is funded by both the State and through insurance reimbursement (for the provision of patient care)

**Services:** The dermatology department is one of several specialist departments within the centre (which collaborate with one another as necessary)

**Patient population:** Includes the most severe / complex adult and paediatric patients with a variety of dermatological conditions, including atopic dermatitis (AD)



## Key strengths in the delivery of AD care

**AD-specialised outpatient clinics:** Run by AD-specialised dermatologists or trainee dermatologists (under dermatologist supervision)

**Nurse empowerment:** Advanced Nurse Practitioners (ANPs) lead 1:1 consultations with AD patients to educate them, discuss treatment options and reduce the burden on physicians

**Cross-functional referrals:** The centre makes prompt, standardised referrals between AD and AD comorbidity specialists. Patients receive effective multidisciplinary support without becoming overburdened

**Patient education:** Patients receive education through multiple channels, including HCPs (e.g. nurse consultations) and patient advocacy group (PAG) materials on day-to-day AD management

**Provision of psychosocial support:** AD patients can access psychosocial support via dermatology referral to onsite social worker, psychologists and psychiatrists, or external psychologists (located in primary care if symptoms are not related to their AD)

**AD research:** The centre offers multiple opportunities for patients to participate in phase 2, 3 and 4 studies, including studies involving biologic and small molecule therapies



## Key challenges faced in the delivery of AD care

**Patients often desire 1:1 care and education from specialist AD healthcare professionals (HCPs)**, as opposed to reading materials and / or attending support groups, which can be difficult with busy HCP schedules

**Management of adolescent patients** where compliance and consultation attendance can be a challenge (as patients take charge of their treatment regimens from their parents)

**Educating patients around relative risk of AD treatment side effects** (e.g. skin thinning effects from corticosteroids) to prevent non-compliance

**Motivating mild patients to comply with treatment regimens (when disease may not be so visible / burdensome)** to reduce unnecessary disease progression and referral to secondary / tertiary care

**Ensuring primary care professionals (PCPs) appropriately step up AD treatment (in line with guidelines)** to reduce unnecessary referrals to secondary care



# Atopic Dermatitis (AD) in the Netherlands

## Netherlands healthcare system:

The Netherlands operates a universal healthcare system which provides healthcare and financial protection to all citizens, through two mandatory forms of health insurance<sup>(a)</sup>:

1. All adults living / working in the Netherlands must pay a basic level of health insurance, through a government-approved insurance company, which covers common **short-term** care provision (e.g. primary care consultations)
2. Individuals are automatically insured by the government to cover **long-term** nursing and care

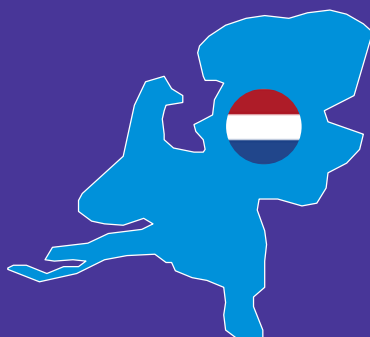
It is generally illegal for insurance companies to refuse an individual basic health insurance or to charge for it above the legal maximum price<sup>(b)</sup>. Services not covered by the basic package will require an excess to be paid or a higher level of insurance. Those aged under 18 are not required to pay health insurance as they are automatically covered by their parent's / guardian's premium. Health services in the Netherlands are financed by a combination of general taxation and health insurance reimbursements

## In the Netherlands, there are three organisational levels in the universal healthcare system:

1. Primary care – a network of primary care centres providing basic medical advice / treatment
2. Secondary care – a network of public and private peripheral care centres (PCCs) providing specialist treatment and preferably requiring referral from a primary care physician
3. Tertiary care – a network of 8 university medical centres (UMCs) providing special investigation and treatment and preferably requiring referral from a secondary care physician (or another UMC). The Dutch government discourages referring patients directly from primary to tertiary care

## Prevalence:

- AD affects 10–20% of children and 1–3% of adults in Western countries<sup>(c)</sup>
- 2.3% of the Dutch population have AD<sup>(d)</sup>



## Care provision (Netherlands):

### Location:

- Mild (or well-controlled) AD care is primarily delivered by PCPs (primary care providers)
- Moderate and severe (uncontrolled) AD care is primarily delivered in specialist secondary or tertiary care (within hospitals)

### Funding:

- Primary care and hospital services are funded through a combination of general taxation and health insurance reimbursements

## Guidelines and societies:

### Guidelines:

- Guidelines for treatment of atopic eczema (atopic dermatitis) part I and part II: European Association of Dermatology and Venerology (EADV)
- The Dutch College of General Practitioners practice guideline 'Eczema'

### Medical society:








- NVDV (Dutch Society of Dermatology and Venerology)

### Patient advocacy group (PAG):

- VMCE (Dutch Society of Patients with Atopic Eczema)

Sources: (a) NHS. Healthcare in the Netherlands [Website] <https://www.nhs.uk/using-the-nhs/healthcare-abroad/healthcare-when-travelling-abroad/healthcare-in-the-netherlands/> Accessed 24 April 2019; (b) International Health Care System Profiles. The Dutch Health Care System [Website] <https://international.commonwealthfund.org/countries/netherlands/> Accessed 24 April 2019; (c) Nutton S. Atopic dermatitis: global epidemiology and risk factors. *Ann Nutr Metab.* 2015;66 Suppl 1:8-16; (d) Verboom P, et al. The cost of atopic dermatitis in the Netherlands: an international comparison. *Br J Dermatol.* 2002;147(4):716-24

# The centre and dermatology department

University Medical Center Groningen (UMCG)		
 <b>Type and location</b>	A large, publicly funded University Medical Centre (UMC) located on one site in central Groningen. The centre is the teaching hospital of the University of Groningen Faculty of Medical Sciences. UMCG delivers tertiary care to patients referred from general practice (primary care) and PCCs (secondary care)	
	 <b>Population served and services delivered</b>	
~3.2 million people across the five northern provinces of the Netherlands		
 <b>Service Division</b>  <b>Hours of availability</b>  <b>No. of patients seen</b>  <b>Types of patients seen</b>   <b>Facilities on-site<sup>(1)</sup></b>	<b>The dermatology department</b>	
	<b>Outpatient service</b>	<b>Inpatient dermatology care</b>
	08:00–16:30 Mon–Fri	24 / 7
	~1700 patients / week (~80 of which are AD patients)	Maximum 6 patients at once (as 6 inpatient beds)
	Adult and paediatric patients with dermatological conditions, including AD (primarily severe / complex cases)	
<div><div><ul style="list-style-type: none"><li>— Phototherapy (UVA / UVB / PUVA)</li><li>— On-site testing laboratory</li><li>— Hospital pharmacy</li><li>— Access to allergy tests (e.g. skin prick testing, patch testing)</li></ul></div><div><ul style="list-style-type: none"><li>— Dermatology consultation rooms</li><li>— 3 Dermatology operating theatres</li><li>— Dermatology photography studio</li></ul></div></div>		

**Note:** (1) List of facilities is not exhaustive







# The team

## Core team profiles

-  **3** AD-specialised dermatologists
-  **15** trainee dermatologists
-  **3** research physicians
-  **3** Advanced Nurse Practitioner (ANPs)
-  **12** medical assistants
-  **1** dermatology photographer

## Wider team profiles

-  **3** adult allergologist
-  **1** paediatric allergologist
-  **12** dieticians
-  **3** ophthalmologists
-  **3** pulmonologists
-  **1** social worker
-  **3** psychologists
-  **1** psychiatrists
-  **1** otolaryngologist (ENT specialist)
-  **1** occupational health physician (OHP)



## Governance and processes

### Team meetings (*note: all are attended by the centre lead*):

- *Daily closure session: (every day except Thursday)*
  - Attended by: dermatologists and trainee dermatologists
  - Purpose: 30 minutes to discuss complex cases from the day
- *Dermatologist / ANPs meeting (every Monday and Tuesday):*
  - Attended by: dermatologists and ANPs
  - Purpose: 30 minutes to discuss complex cases from the day
- *Multidisciplinary allergy meeting: (every Tuesday, 4–5pm):*
  - Attended by: adult and paediatric allergologists, lead dermatologist, trainee dermatologists and nurses
  - Purpose: to discuss complex cases with type 1 allergies, drug hypersensitivity, and difficult to treat atopic-morbidities other than AD
- *Multidisciplinary meeting with OHP: (every 4 weeks):*
  - Attended by: OHP, dermatologists, trainee dermatologists, ANPs and a retired UMCG professor of dermatology (invited to provide experienced specialist input)
  - Purpose: to discuss work-related AD cases
- *Dermatology team meeting (every week):*
  - Attended by: entire dermatology team
  - Purpose: to discuss quality of care (QoC), complex cases and other departmental issues
- *Centre lead / nurses meeting (every 8 weeks):*
  - Attended by: centre lead (dermatologist) and all ANPs
  - Purpose: to discuss QoC, review case reports and ensure alignment on AD treatment approach
- *Research Meeting (every 4 weeks):*
  - Attended by: dermatologists, trainee dermatologists, nurses and researchers
  - Purpose: to present ongoing and upcoming AD studies to the department
- *Contact allergy meeting (every 6 weeks, 2–3pm):*
  - Attended by: lead dermatologist, trainee dermatologists and nurses / medical assistants of the patch test unit
  - Purpose: to discuss QoC, protocols and complex allergy cases

### ● Patient records:

- *Electronic patient dossier (EPD):* secure electronic storage of patient records (feedback forms, photographs, etc.) only accessible by the dermatology department

# Roles of the wider team

## Ophthalmologist

**Patient type:** Primarily adult patients exhibiting AD eye comorbidities

**Referral:** Referred by the dermatologist

**Consultations:** 1:1 consultation during which standard eye exams are performed (e.g. visual acuity, slit lamp), atopic conjunctivitis symptom severity is graded if relevant (using an unofficial anatomic scale) and electronic feedback form is completed for those returning to dermatology

**Timing:** First consultation = ~15 mins; Follow-up consultations = 8–10 mins. Follow-up occurs 2 weeks later and every subsequent 6 weeks



## Social worker

**Patient type:** Adult and paediatric patients exhibiting mild psychological symptoms

**Referral:** Referred by dermatologist or nurse (internal and external)

**Consultations:** 1:1 consultations employing various techniques aimed at improving mental health (e.g. cognitive behaviour therapy (CBT); body language training). Social worker also assists patient with practical aspects of AD treatment. Patients may request follow-up appointments directly via email

**Timing:** ~1 hour per consultation

## Pulmonologist

**Patient type:** Severe asthma patients who may also present AD symptoms

**Referral:** Referred by the dermatologist

**Consultations:** On the day of the first consultation, each patient is seen by a 'standard package' of specialists: pulmonologist, ear-nose-throat (ENT) physician, asthma nurse, physiotherapist and psychologist. Pulmonology and dermatology may refer to one another should asthma and AD symptoms co-occur

**Timing:** First consultation = ~40 mins; Follow-up consultations = ~20 mins

## Psychologist

**Patient type:** Adult and paediatric patients exhibiting serious AD-related psychological symptoms

**Referral:** Referred by dermatologist / social worker

**Consultations:** ~80% of dermatology referrals are for habit-reversal therapy (HRT), where patients attend a weekly 1:1 session for 5 weeks with the aim of reducing scratching habits. ~20% of referrals aim to address issues relating to anxiety / self-esteem

**Timing:** ~45 mins per consultation

## Dietician

**Patient type:** Adult and paediatric patients who potentially have food allergies

**Referral:** Referred by dermatologist or other UMCG specialist

**Consultations:** 1:1 consultations in which patient completes food questionnaire and discusses suspected food allergies. Dietician reviews results with allergology to determine which food abstinence or double-blind testing should be undertaken

**Timing:** First consultation = ~45 mins; Follow-up consultations = ~30 mins

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients with symptoms of AD (e.g. itching or dryness of the skin) present to a primary care physician (PCP) who will assess them and refer as required

*Note: AD patients that are well-controlled or mild may be managed in primary care and not referred to the centre*

- Patients may present directly to the emergency department of the centre with atopic symptoms

## Diagnosis and Referral

In secondary / tertiary care



- PCPs will refer moderate-severe patients to secondary care (a peripheral care centre [PCC])
- AD may be diagnosed in PCCs through clinical examination and supplementary diagnostic tests (e.g. blood tests)
- Complex patients and / or those not responding to treatment will be referred to UMCG. The centre may also have patients referred from other UMCs and the VMCE (the Dutch AD patient advocacy group)
- Patients may be referred to UMCG directly from PCPs (but the Dutch Government is now requesting PCPs to refer to PCCs first)<sup>(a)</sup>

## Treatment and Management

Medical management



- Dermatologists initiate treatment tailored to patient need. All AD patients complete blood tests (IgE) at first consultation (~30min)
- Patient progress is monitored using selected indices: EASI; Itch NRS; POEM; and HECSI and a photoguide (for hand eczema only)
- Directly after each dermatologist consultation, patients receive 1:1 education and self-treatment demonstrations from a dermatology nurse (~30min)
- Patients are referred to AD comorbidity specialists as required (e.g. pulmonologist, dietician / allergologist) and are often seen on the same day
- Paediatric patients transition into adult care aged 16–18 years

Non-medical management



- Dermatologists assess patients for psychological symptoms and may refer individuals to:
  - hospital social worker (mild symptoms)
  - hospital psychologist (moderate symptoms)
  - hospital psychiatrist (severe symptoms)
  - psychological support in primary care (if not AD-related)
- Alternative treatment may be provided (e.g. hand / foot or full-body PUVA / UVB treatment for patients not on systemic therapy)

## Follow-up

Monitoring of chronic disease / flare up



- Patients attend follow-up appointments (with frequency decided by dermatologist on a per patient basis). Nurses may perform routine check-ups over the phone or during outpatient clinics
- The centre aims to see emergency cases within 1 day of referral, during emergency hours
- At every visit, POEM, Itch NRS and EASI severity indices are measured. POEM and Itch NRS are completed either by patients on a computer or tablet in the waiting room
- Patients are directed to VMCE (the Dutch patient advocacy group) resources for ongoing support

# Overview of interventions in place for AD



**Key:**



Case study available

## Awareness and Presentation



Symptom identification

- **Educating the wider medical community:** Centre staff (including dermatologists, nurses, trainee dermatologists and ophthalmologists) deliver regular AD training sessions and lectures to primary and secondary care professionals (including general practitioners, nurses and general dermatologists)

See pg. 267-268 for case study

## Diagnosis and Referral



In secondary / tertiary care

- **Role of the dietician:** AD patients with suspected food allergies will be referred to the dietician, who provides dietary advice and may subsequently refer to the allergologist to plan food-allergy testing
- **Quick turnaround diagnostic testing:** Patients can receive diagnostic test results on the same day (e.g. from blood tests)

See pg. 269-270 for case study

## Treatment and Management



Medical management

- **Enhanced role of the nurse:** In addition to providing 1:1 AD patient education, Advanced Nurse Practitioners (ANPs) will also discuss treatment options with patients (overseen by a dermatologist, in parallel to dermatology-trainee consultations)
- **Structured ophthalmology referral pathway:** Patients with AD eye comorbidities / complications are referred to ophthalmology using a standardised feedback e-form (designed with dermatology)
- **Standardisation of first AD consultation:** Physicians / nurses complete a standard list of questions and perform set severity indices in the first consultation of all AD patients
- **Clinical trial (CT) recruitment:** Patients can participate in interventional and observational AD studies

See pg. 271-273 for case study

See pg. 274-275 for case study



Non-medical management

- **Role of the occupational health physician:** Informs and supports the dermatology team to advise their AD patients regarding exposure to allergens and irritants in the workplace and advise on the law and regulations concerning absenteeism
- **Psycho-social care network:** AD patients requiring psychological support may be referred to a centre psychologist / social worker / psychiatrist, or primary care psychologist for support
- **Patient registries:** The centre participates in a cross-centre patient registry and observational study for all patients receiving a novel biologic AD therapy, while also maintaining centre-specific hand eczema and patch testing registries

See pg. 276-277 for case study

See pg. 278-279 for case study

See pg. 280-281 for case study

## Follow-up



Monitoring of chronic disease/flare up

- **Collaboration with VMCE:** The centre and VMCE (the Dutch patient advocacy group) collaborate on various AD projects and refer patients to one another where appropriate
- **Dedicated dermatology photographer:** Photographs patients' AD-affected skin during initial and follow-up consultations to visually track disease progression
- **"Leef! Met Eczeem" educational website:** Allows patients / parents to access advice and guidance for living with Eczema (created by UMC Utrecht, see case study in UMCU report)

See pg. 265-266 for case study

See pg. 282-283 for case study



# Monitoring AD patients and comorbidities

## The dermatology department uses a number of measures for monitoring AD and associated comorbidities

### Objective measures:

- EASI (Eczema Area and Severity Index): scoring system which grades the physical signs of AD / eczema. It is completed by the physician / nurse during every dermatology consultation at the centre<sup>(a)</sup>
- HECSI (Hand Eczema Severity Index): completed by the physician / nurse during each hand eczema consultation at the centre (including both atopic and contact dermatitis cases)<sup>(b)</sup>
- SCORAD (SCORing Atopic Dermatitis): clinical tool used to assess the severity of the disease and monitor disease progression. It is only used at the centre during clinical trials<sup>(c)</sup>
- Validated Investigator Global Assessment for Atopic Dermatitis (vIGA-AD<sup>TM</sup>): scoring system for use in clinical trials which grades the overall appearance of AD lesions based on a series of morphological descriptions<sup>(d)</sup>
- Hand Eczema Photographic Guide: a photographic guide (designed and validated at the centre) composed of five severity levels, made to assess the morphological severity of hand dermatitis and for use in international multicentre clinical trials<sup>(e)</sup>

### Patient reported outcomes:

- POEM (Patient Oriented Eczema Measure)<sup>(f)</sup>: tool for monitoring AD severity and is recommended for use in outpatient clinics and clinical trials by the Harmonising Outcome measures for Eczema (HOME) initiative<sup>(g)</sup>. It is completed by each patient (or parent / guardian for those aged 0-7 years) on a computer in the waiting room before every dermatology consultation, or is alternatively completed by a physician / nurse during the consultation.
- Itch NRS (Numeric Rating Scale<sup>(h)</sup>): a single-item tool for monitoring pruritus (itch) intensity in patients with AD and other dermatological conditions. If the dermatologist deems it appropriate, patients complete the measure on a computer during each visit.

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### Centre routinely measures comorbidity outcomes by:

- Allergy: the allergology department performs skin-prick tests (for drug and food allergy) and blood tests to assess patient responses to specific allergens
- Ophthalmology: an AD-specialised ophthalmologist performs screening tests (e.g. corneal examination)

**Sources:** (a) EASI for clinical signs: Harmonising Outcome Measures for Eczema (HOME) [Website] <http://www.homeforeczema.org/research/easi-for-clinical-signs.aspx> Accessed 13 March 2019; (b) E. Held et al. The hand eczema severity index (HECSI): a scoring system for clinical assessment of hand eczema. A study of inter- and intraobserver reliability. *Br J Dermatol.* 2005;152(2):302-7; (c) SCORing Atopic Dermatitis (SCORAD) Calculator (0.9.0) [Website] <http://scorad.corti.li> Accessed 15 April 2019; (d) Validated Investigator Global Assessment For Atopic Dermatitis (vIGA-AD<sup>TM</sup>) Scale [PDF] [https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale\\_vIGA-AD\\_2017.pdf](https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale_vIGA-AD_2017.pdf) Accessed 26 June 2019; (e) Coenraads PJ, et al. Construction and validation of a photographic guide for assessing severity of chronic hand dermatitis. *Br J Dermatol.* 2005;152(2):296-301; (f) Charman CR, et al. Translating Patient-Oriented Eczema Measure (POEM) scores into clinical practice by suggesting severity strata derived using anchor-based methods. *Br J Dermatol.* 2013;169(6):1326-1332; (g) Simpson E, et al. Patient-Oriented Eczema Measure (POEM), a core instrument to measure symptoms in clinical trials: a Harmonising Outcome Measures for Eczema (HOME) statement. *Br J Dermatol* 2017;176:979-84; (h) Numerical Rating Scale (NRS) [Website] <http://www.pruritussymposium.de/numericalratingscale.html> Accessed 14 April 2019

# Advice to other centres



## What advice would you give less specialised centres?



**Objective of advice:** Ensure optimal use of topical treatments

- **Why?** Topical therapies are a key component of the treatment regimen (as a standalone or complementary therapy) for most AD patients<sup>(a)</sup>. With a wide variety of topical therapies available (in the form of creams and ointments) it is important that AD patients are able to test a range of products in order to identify which is most effective for them – something that often varies between patients<sup>(b)</sup>. Prescribing effective topical therapies can help reduce referrals to secondary / tertiary care (if the disease can be controlled by topical treatments in primary care)<sup>(b)</sup>



**Objective of advice:** Empower nurses to provide an additional layer of support for patients

- **Why?** Time constraints often limit the amount of patient education (disease and treatment-related) that can be delivered during dermatologist consultations. Patients also often prefer 1:1 time to ask questions and discuss their treatment plans (as opposed to group sessions or reading materials). A 1:1 consultation with a specialised AD nurse is often a more cost-effective way to offer patients further treatment advice / education (including treatment application demonstrations and practical advice tailored to each patient's work / life commitments). These sessions may allow patients to ask further questions, including those questions that they may be uncomfortable asking a dermatologist<sup>(b)</sup>

**Sources:** (a) Wollenberg A. et al. Consensus-based European guidelines for treatment of atopic eczema (atopic dermatitis) in adults and children: part I. J Eur Acad Dermatol Venereol. 2018 May;32(5):657-682  
(b) Interviews from UMCG site visit



# Next steps for the centre



## What is next for the centre?

### Objective: Co-location of some allergology services in the dermatology department

- **What?** The centre plans to improve collaboration between dermatology and paediatric allergology by reserving some rooms in the dermatology department for multidisciplinary consultations. Subsequently, specialists from the two departments will co-host clinics for patients (paediatric only) requiring both dermatologist and allergologist input. PUVA (phototherapy) facilities will also be re-located to the dermatology department
- **Why?** AD patients referred to the dermatology department often require allergologist input (e.g. for food / drug allergy testing) and / or PUVA. Co-locating dermatology and allergology facilities – and running joint clinics – will reduce patient burden and improve the speed and quality of communication between the specialties



### Objective: Providing quick contact allergy diagnostics for patients with eczema

- **What?** The centre is developing a new care trajectory for eczema. Patients will be patch tested with not only a baseline series but also an additional (work-related) series during their first visit
- **Why?** Patch testing at the first visit saves time for the patient, and this system would allow general dermatologists to refer more patients for complex patch testing. Patients can then continue their AD treatment (follow-up appointments) with their local dermatologist



### Objective: Continue to enhance the multidisciplinary approach taken to AD care with pulmonology

- **What?** When treating severe asthma patients, pulmonologists at the centre work closely with other specialties in order to promptly address and manage associated comorbidities (e.g. allergic rhinitis). On the day of the first consultation, each patient is seen by a 'standard package' of specialists: pulmonologist, ear-nose-throat (ENT) physician, asthma nurse, physiotherapist and psychologist. The specialists hold a monthly meeting to discuss treatment for the most complex patients.
- **Why?** The pulmonologist hopes to replicate this joint-clinic approach with dermatology for AD patients with comorbid asthma, in order to promptly identify and treat associated comorbidities and reduce patient burden (e.g. by scheduling patient appointments with different specialists on the same day)



# Case studies



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# Collaboration with VMCE (PAG) (1/2)

## Overview

- The centre works closely with Vereniging voor Mensen met Constitutioneel Eczeem (VMCE), the Dutch AD patient advocacy group (PAG)
- Centre staff and the PAG collaborate on projects and may refer patients to one another for support where appropriate



We [the VMCE] and the centres only refer patients to each other who actually need it, so as to not overburden one another. A mutual trust has grown over the years.

PAG representative,  
VMCE



## Vereniging voor Mensen met Constitutioneel Eczeem (VMCE) in the Netherlands

- The VMCE is a not-for-profit association for people with atopic eczema (and their parents) aimed at “improving the quality of life of people with eczema”<sup>(a)</sup>
- The VMCE was formed in 1994 in direct collaboration with University Medical Center Utrecht (UMCU)
- UMCU, University Medical Center Groningen (UMCG), and the PAG assist each other with activities including: grant applications, patient education, patient referrals, research and the writing of AD protocols and guidelines

### VMCE-centre joint activities (with UMCG and UMCU) include:

- *Revising national AD protocols and guidelines:*
  - Objective: To devise and revise national AD guidelines (including for atopic eczema; hand eczema; topical corticosteroid treatment) to reflect the latest developments in AD care and incorporate the voice of the patient<sup>(b)</sup>
  - Role of centre: To communicate with PAG representatives and ensure their knowledge and experience is considered when revising AD guidelines
- *Organising the 10<sup>th</sup> Georg Rajka (International AD symposium held in Utrecht):*
  - Objective: To discuss the latest AD research and share PAG initiatives
  - Role of centre:
    - The event’s local organising committee included the VMCE representative and the head dermatologists from UMCG and UMCU
    - The event hosted leading AD dermatologists from around the world, as well as PAG representatives from 10 countries (including the USA, Canada, Brazil and the UK)
    - The symposium (held ever 2 years) encourages idea sharing and the dissemination of global research findings at a local level
- *Informing AD research<sup>(c)</sup>:*
  - Objective: To utilise the experience and knowledge of PAG representatives in AD trial design
  - Role of centre: Coordinating AD clinical research and including PAG representatives to participate in research and disseminate findings

**Sources:** (a) Vereniging voor Mensen met Constitutioneel Eczeem [Website] <https://www.vmce.nl/> Accessed 15 Apr 19; (b) NVDV Guidelines [Webpage] <http://www.nvdv.nl/informatie-voor-de-professional/richtlijnen-2/> Accessed 22 May 19; (c) Spuls PI, et al. The International TREATment of ATopic Eczema (TREAT) Registry Taskforce: An Initiative to Harmonize Data Collection across National Atopic Eczema Photo- and Systemic Therapy Registries. *Journal of Investigative Dermatology* 2017;137(9):2014–2016. doi: 10.1016/j.jid.2017.05.014



- *Other:*
  - Collaboration with UMCU to develop a smartphone application named “Zalf”, which educates patients on ointment application and provides step down regimes for steroid use (see UMCU report for ‘Zalf’ case study)
  - The head of UMCU’s National Expertise Centre of AD is chair of the VMCE Advisory board
  - Alongside UMCU, UMCG and two peripheral dermatologists, the VMCE participates in the National Audit Committee for the novel AD biologic therapy

#### Additional VMCE activities include:

- *AD focus groups:* Held twice a year for UMCU AD patients to discuss patient needs, self-management and the latest in AD care. Separate meetings are held for VMCE members across the Netherlands (for families with children with eczema (0-12yrs); children (12-18yrs); adults)
- *TREAT (TReatment of Severe Atopic Eczema Trial) study:* the VMCE is represented on both the international and national taskforces, helping to write protocols to harmonise data collection for atopic eczema for both photo- and systemic therapies. TREAT aims to enable cross border data pooling and international collaboration<sup>(d)</sup>
- *BioDay registry:* the VMCE participates in the BioDay registry, alongside UMCG and UMCU<sup>(e)</sup>. The VMCE sit on the Scientific Board of BioDay to provide a patient perspective on the results and assist in their dissemination to the non-scientific world
- *BIOMAP project:* the VMCE is also represented on the PAG of the BIOMAP EU/IMI initiative<sup>(f)</sup>
- *Working with the food hypersensitivity network (Stichting Voedselallergie):* VMCE and Stichting Voedselallergie have had shared back and front office services since 2002. They work closely together and consult each other when food allergy and eczema overlap. They exchange insights on relevant scientific research and provide each other with information for brochures and websites
- *Participating in an EU study to assess the burden of disease in AD:* Three manuscripts were produced and published<sup>(g)(h)(i)</sup>, of which two are open access<sup>(g)(i)</sup>

#### What’s next?

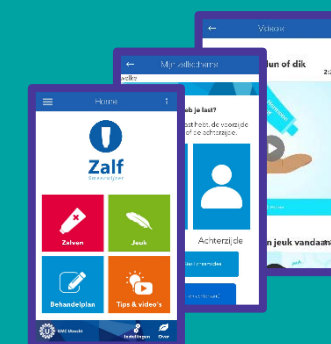
- VMCE and the centres will continue to exchange information on a regular basis, in order to maintain and strengthen the benefits of their collaboration
- VMCE will continue working closely with the centres on improving AD care and research (e.g. BioDay; a systematic review of emollients in hand eczema; efficacy of eczema bandages)
- VMCE (together with the centres) hopes to further assess the impact of AD on a patient’s family members (e.g. the day-to-day burden on parents, including sleep disruption, mental health aspects, work implications)

## Collaboration with VMCE (PAG) (2/2)



When we speak with either UMCG or UMCU, it is clear they really value the opinion of VMCE representatives. We are treated as equals.

*PAG representative, VMCE*



*‘Zalf’ (English: ‘Ointment’) mobile phone application co-developed by UMCU and VMCE*

**Sources:** (d) Vermeulen F, et al. TReatment of ATopic eczema (TREAT) Registry Taskforce: consensus on how and when to measure the core dataset for atopic eczema treatment research registries *Br J Dermatol* 2019;181(3):492-504. doi: 10.1111/bjd.17715; (e) BioDay Registry [Website] <http://www.bioday.nl/the-registry/> Accessed 22 May 2019; (f) BIOMAP project [Website] <http://www.biomap-imi.eu/> Accessed 22 May 2019; (g) Zink A, et al. Out-of-pocket costs for individuals with atopic eczema in Europe. *Acta Derma Venereol* 2018;99:263–67 (h) Ring J, et al. Atopic Eczema: Burden of disease and individual suffering – Results from a large EU-Study in adults. *J Eur Acad Dermatol Venereol* 2019;33:1331-40; (i) Arents BW, et al. The Atopic Eczema Score of Emotional Consequences (AESEC) - A scoring system to measure emotional consequences of atopic eczema. *Allergo J Int* 2019;28(7):277-288. doi: 10.1007/s40629-019-0098-y

# Educating the wider medical community (1/2)

## Overview

- The centre is involved in educating primary and secondary healthcare professionals (HCPs) around the latest developments in AD care, to improve AD patient management across the health system

**Sources:** (a) Oosterhaven JAF, et al. Guideline for translation and national validation of the Quality of Life in Hand Eczema Questionnaire (QOLHEQ). *Contact Dermatitis*. 2017;77(2):106-115; (b) Flokstra-de Blok BM, et al. Development of an allergy management support system in primary care. *J Asthma Allergy*. 2017;10:57-65; (c) BioDay Eczema and Atopic Diseases Registry [Website] <http://www.bioday.nl/> Accessed 10 May 2019; (d) KPMG interviews

## What is the rationale?

- University medical centres (UMCs) in the Netherlands play a key role in AD clinical research and the writing of national / international dermatology protocols and guidelines<sup>(a)(b)(c)</sup>
- Disseminating the latest developments in AD care from UMCs to primary and secondary care healthcare professionals (HCPs) can help to improve AD care across the health system

## What are the key features of the intervention?

- Various UMCG HCPs organise and deliver a number of different initiatives, held on a regular basis, aimed at educating the wider medical community with the latest developments in AD care

UMCG HCP	Education initiative
<i>AD Medical Assistants</i>	<p><b>Content:</b> Educate nurses and medical assistants from peripheral care centres (PCCs) about best practice in allergy testing</p> <p><b>Logistics:</b> 1 hour session, held 3x per year either at UMCG or in PCCs</p>
<i>Ophthalmologists (with interest in AD)</i>	<p><b>Content:</b> Deliver an annual lecture to dermatologists from PPCs and UMCs, covering the different forms of conjunctivitis and eye complaints specific to AD treatments</p> <p><b>Logistics:</b> 3 hour lecture hosted at UMCG</p>
<i>Pharmacists</i>	<p><b>Content:</b> Run classes for pharmacy students and trainee doctors, focusing on drug-drug interactions</p> <p><b>Logistics:</b> Hosted at UMCG</p>
<i>Trainee dermatologists</i>	<p>1.</p> <p><b>Content:</b> Deliver lectures (alongside the AD-lead dermatologist) to general practitioners (GPs) and PCC dermatologists on different topics in dermatology. Past topics include dermatoscopy, diagnostics and treatments for the most common skin diseases</p> <p><b>Logistics:</b> Hosted at UMCG, 5 evenings per year, with 60–80 attendees per session</p> <p>2.</p> <p><b>Content:</b> GPs from the North Netherlands region are invited by UMCG to attend sessions focusing on different themes, including pruritus, infection, eczema and occupational dermatitis. Each session includes a presentation and Q&amp;A. A qualified dermatologist is always present and GPs may also deliver case study presentations based on past experiences</p> <p><b>Logistics:</b> 2 hour evening session, held every 3 months at UMCG with ~30 attendees</p>

# Educating the wider medical community (2/2)

## What are the key features of the intervention (cont.)?

UMCG HCP	Education initiative
<i>Advanced Nurse Practitioners (ANPs)</i>	<p><b>Content:</b> ANPs help to educate other nurses from the region, for example by hosting community nurse workshops to ensure they are providing patients with accurate, up-to-date AD management advice</p> <p><b>Logistics:</b> 1.5-2 hour sessions, held every few months</p>

## What are the outcomes so far?

### Benefits to patients:

- Receive up-to-date AD information and management approach
- More prompt and appropriate referrals to secondary care specialists (when required)

### Benefits to HCPs:

- PCPs (primary care providers) more confidently manage AD patients (if referral not required)
- Reduction in unnecessary referrals to the centre (freeing up consultation time and other resources)

## What's next?

- Primary care providers (PCPs) in the region have expressed a desire for more frequent education on the latest AD therapy developments<sup>(d)</sup>



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AD specialists from UMCG and UMCU spread their AD treatment approach throughout the Netherlands

*PAG representative,  
VMCE*



# Role of the dietitian (1/2)

## Overview

- The dermatology team may refer AD patients with suspected food allergies to a dietitian for assessment, who in turn consults an allergologist to determine which food elimination (or other) tests should be carried out

**Sources:** (a) Schneider L. Eczema, Atopic Dermatitis and Allergies: What Is The Connection? National Eczema Association [Website] <https://nationaleczema.org/atopic-dermatitis-and-allergies-connection> Accessed 07 May 2019; (b) KPMG interviews during UMCG site visit

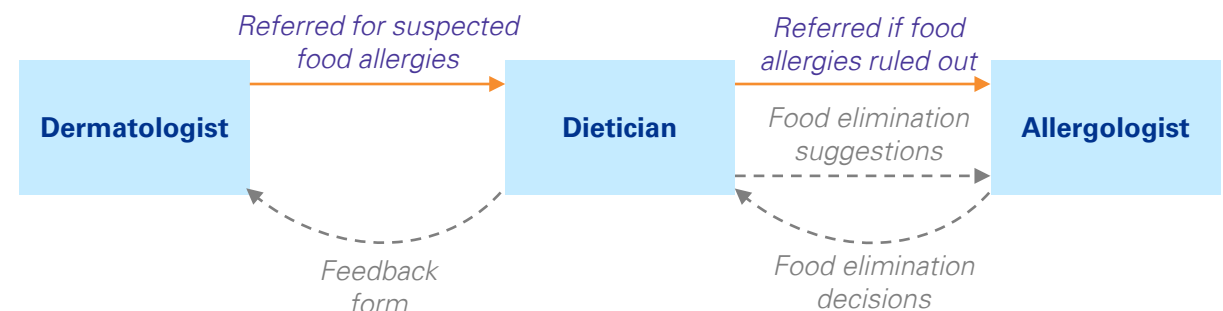
## What is the rationale?

- AD patients commonly experience allergic symptoms to everyday substances – including food – however they may not know specifically which substances they are most sensitive to<sup>(a)</sup>
- Approximately 50% of AD patients at the centre have at least one food allergy<sup>(b)</sup>
- There is a shortage of allergologists at the centre, therefore the dietitian provides a filter to help identify patients with true food allergies<sup>(b)</sup>

## What are the key features of the intervention?

- The dietitian only receives referrals from UMCG specialists (e.g. dermatology) who suspect their patients have food allergies
- During the first 1:1 consultation (~45 mins), the dietitian provides general dietary advice, performs a food questionnaire and explores which foods the patient suspects they are allergic to
- If the dietitian suspects a true food allergy, they will share their suggested food elimination plan with the allergologist, who decides which foods the patient should now eliminate from their diet
  - If they suspect the allergy is not food-related, the patient remains with allergology for further tests
- The dietitian will communicate which food elimination tests are required via a standardish feedback form to the dermatology department (as organised by the dermatology nurses)
- Patients attend follow up appointments (~30 mins) 4–5 weeks later with the dietitian to assess symptom changes
- The dietitian also carries out double-blind food challenge testing alongside allergology (over a 1-day session)

## Dermatology food allergy referral pathway



# Role of the dietician (2/2)

## What are the key features of the intervention? (cont.)

- The dietician plays a key role in educating the parents / guardians of paediatric patients with food allergies
- Background information on food allergies, for example, is provided by directing patients to educational websites including:
  - 'Children's Allergy & Asthma Center': website specially created for UMCG providing information about the centre, allergies, asthma, and research<sup>(a)</sup>
  - 'Food Allergy Foundation': a website built in association with the VMCE (see case study pg. 265 – 266) providing background information and advice for living with food allergies (e.g. food label reading)<sup>(b)</sup>

## What are the outcomes so far?

### Benefits to patients:

- 1:1 education received about managing food allergies (patient-specific)
- Food allergy support received in the same centre (reduced patient travel burden)

### Benefits to HCPs:

- Dermatologists receive dietician and allergy specialist input for management of potential food allergies
- Dermatology nurses receive the information required for setting up allergy food elimination tests in a clear, standardised format

## What's next?

- Engage in initiatives to educate primary and secondary care providers about food allergies in order to reduce the diagnostic burden on tertiary care university medical centres (UMCs)

**Sources:** (a) Children's Allergy & Asthma Center [Website] <https://www.kinderallergieenastmacentrum.nl/> Accessed 23 July 2019; (b) Food Allergy Foundation [Website] <https://www.voedselallergie.nl/> Accessed 23 July 2019



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Patients come to us with suspicions about their food allergies but without help can't say exactly what they're allergic to

*Dietician, UMCG*



# Enhanced role of the nurse (1/3)

## Overview

- Advanced Nurse Practitioners (ANPs) specialised in AD run 1:1 AD patient consultations (during a dermatologist-supervised clinic) and play a key role in patient education. Nurses produce their own educational materials, give self-treatment demonstrations, coordinate follow-up appointments and are qualified to prescribe AD therapies

## What is the rationale?

- Patient feedback at UMCG suggests that patients appreciate 1:1 attention from HCPs to assist them with their AD treatment plans and understanding of the disease<sup>(a)</sup>
- Time constraints however limit the amount of patient education that can be delivered during a typical dermatologist consultation (~30 mins)
- The Advanced Nurse Practitioners (ANPs) at UMCG are specially trained in AD

## What are the key features of the intervention?

### Overview:

- 3 ANP AD nurses run 1:1 consultations (~30 mins) directly after each dermatologist consultation (patients will see the same dermatologist / nurse at each follow-up consultation if possible)
- For patients with severe AD and hand eczema (who require intensive and continuous counselling), the main treatment discussion will be held by a nurse (rather than a dermatologist)

*Note: these treatment plans will still require dermatologist approval*

- Patients usually attend a follow-up appointment after 1–2 weeks (initially), before nurses organise follow-up consultations as required (e.g. every 3 months for mild / well-controlled cases)
- Patients with severe / uncontrolled symptoms will attend an outpatient clinic, while mild / well-controlled cases receive check-ups over the phone
- Patients are able to call the nurses directly for further advice or questions

### 1:1 ANP consultations involve:

- *Initial assessment / monitoring:*
  - Establishing how much / what information patients understood from their dermatologist consultation
  - Providing opportunity for patients to ask further questions about treatment (including questions they may feel uncomfortable asking a dermatologist)
  - Clarifying patient treatment expectations
  - Recording POEM / EASI scores during each visit to track disease progression (in combination with the HECSI photo guide for hand eczema cases)
  - Prescribing non-biologic AD therapies if required

**Sources:** (a) KPMG interviews





## What are the key features of the intervention? (cont.)

### 1:1 ANP consultations involve (cont.):

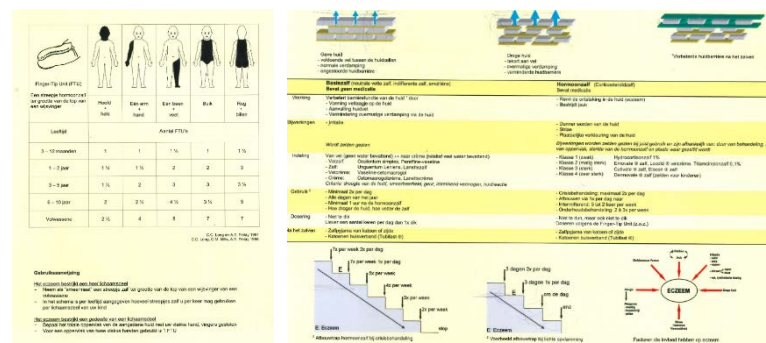
#### — Disease and treatment education:

- Treatment application demonstrations and advice on when / how to apply treatments (considering individual work / life commitments)
  - Patients are given the opportunity to test a range of topical emollient creams / ointments to identify their preference
  - Nurses also ask patients to bring their treatment tubes with them to follow-up consultations to determine if they are over / under-applying (with the latter common due to fears of corticosteroid side effects<sup>(a)</sup>)
- Providing educational materials, including materials nurses designed themselves and those provided by the VMCE (Vereniging voor Mensen met Constitutioneel Eczeem (VMCE), the Dutch AD patient advocacy group (PAG))
- Using picture book teaching aids, songs and sticker books to educate paediatric patients and engage them with treatment

#### — Assistance with day-to-day management:

- Providing patients with gloves / dressings to prevent scratching at night
- Offering patients personalised glove advice (e.g. which to use; how to use them) in order to protect hands from irritant / allergic factors and improve topical treatment compliance
- Training patients to self-administer biologic therapy at home
- Directing patients to the “Leef! Met Eczeem” educational website (developed by UMC Utrecht, see case study in UMCU report)

Example patient education materials created and used by UMCG staff – treatment application guide (left side); treatment tapering guide (right side)



# Enhanced role of the nurse (2/3)



People can be afraid to use their treatments, so we make sure they are properly educated and receive the support they require



ANP, UMCG

Sources: (a) Interviews during UMCU site visit

# Enhanced role of the nurse (3/3)

“

We give patients the opportunity to try different creams and ointments, to find one that works for them

ANP, UMCG



## Additional ANP activities:

- AD ANP nurses may refer patients to a social worker for psychological support (~50% of AD patients) or other AD comorbidity specialists (e.g. ophthalmologist; habit-reversal psychologist)

*Note: All nurse referrals require approval from the supervising dermatologist (except referrals to a social worker, which may occur directly)*

- UMCG's AD ANPs also help to educate other nurses from the region, for example by hosting community nurse workshops (1.5-2 hour sessions) every few months, to ensure they are providing patients with accurate, up-to-date AD management information
- The ANPs meet every 6 weeks with the AD-lead dermatologist and wider eczema team in order to discuss complex patients, UMCG policies and new trends / developments in the AD care area

## What are the outcomes so far?

### Benefits to patients:

- Opportunity to ask further questions, including those they may be uncomfortable asking a dermatologist
- Improved understanding of AD symptoms and disease progression
- Increased guidance for AD self-management

### Benefits to HCPs:

- Additional time to educate patients regarding their AD self-management
- Further flexibility to arrange follow-up appointments as required (i.e. not constrained by physicians availability only)
- Dissemination of knowledge from specialist care nurses to those in the wider health system

## What's next?

- In the future, nurses at the centre expect a shift towards electronic advice (e.g. more online information, videos, etc.) and for more treatment plans to be home-based



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# Structured ophthalmology referral pathway (1/2)

## Overview

- An established dermatology–ophthalmology referral pathway exists for AD patients with ocular symptoms, aimed at speeding up referrals and improving communication between the specialties

## What is the rationale?

- AD patients may suffer from ocular comorbidities (as a result of the disease itself or treatment used)<sup>(a)</sup>
- Standardisation of this referral relationship is required in order to speed up referrals and improve communication between the specialties (e.g. regarding severity of symptoms, treatments prescribed, etc.)

## What are the key features of the intervention?

- The dermatology department works closely with 2 ophthalmologists and 1 trainee ophthalmologist who are cornea and anterior segment specialists
- The ophthalmologists see all AD patients with conjunctivitis (that can't be managed by non-steroidal eye drops prescribed by dermatologists) and other ocular symptoms (often on the day of referral)
  - Referrals are only received from specialists at peripheral care centres (PCCs), other university medical centres (UMCs) or within UMCG (i.e. not from primary care)
- UMCG dermatologists and ophthalmologists have worked together for many years to design appropriate treatment regimens for AD patients (considering their ocular and skin health)

## Standard ophthalmologist consultation format for AD patients:

- Initial consultation = ~15 mins; Follow-up consultations = 8–10 mins (each ophthalmologist sees ~20 patients in a half day clinic)
- Standard ophthalmology examinations are performed (e.g. visual acuity, slit lamp)
- For patients with conjunctivitis, ophthalmologist will informally grade conjunctivitis symptom severity (using an unofficial anatomic scale)
- Ophthalmologist completes electronic feedback form (designed in collaboration with dermatology, and stored on the EPD [electronic patient dossier]), which informs the referring dermatologist of the severity of the patient's eye symptoms and any treatments prescribed
- A follow-up appointment occurs 2 weeks later and every subsequent 6 weeks (as required)

**Sources:** (a) Thyssen JP, et al. Incidence, prevalence, and risk of selected ocular disease in adults with atopic dermatitis. *J Am Acad Dermatol* 2017;77(2):280-286.e1. doi: 10.1016/j.jaad.2017.03.003.



# Structured ophthalmology referral pathway (2/2)

## What are the outcomes so far?

### Benefits to patients:

- Quick access to ophthalmology and specialised treatment after developing ocular symptoms
- Reduced time burden on patient (as can see two specialists – dermatology and ophthalmology – in the same location)
- Ophthalmology care standardised across the AD patients referred from dermatology (with electronic feedback form)

### Benefits to HCPs:

- Quick referrals to ophthalmology and management of ocular symptoms
- Dermatology receive feedback from ophthalmology regarding ocular health in a clear, consistent format (via electronic feedback form)
- Knowledge sharing between specialists to better understand associated conditions

“

We use a standard feed e-form, designed with the dermatology department, to provide the referring dermatologist with clear information on symptom severity and any treatments prescribed

*Ophthalmologist, UMCG*



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# Role of the occupational health physician (1/2)

## Overview

- An occupational health physician regularly educates the dermatology team on AD in the workplace, so they can advise their AD patients regarding exposure to allergens and irritants in the workplace and advise on the law and regulations concerning absenteeism



The trainee dermatologists who attend our regular meetings have commented how useful they find the information



*Occupational health physician,  
University of Groningen*

## What is the rationale?

- AD can impact a patient's ability to work (e.g. if pruritus [itch] disrupts sleep, thereby affecting performance)<sup>(a)</sup>
- Symptoms may be aggravated by workplace conditions which involve exposure to allergens or irritants (e.g. cleaning detergents, rubber gloves)<sup>(a)</sup>
- Companies employ occupational health physicians to protect the welfare of their employees and reduce absenteeism due to sickness / poor health<sup>(b)</sup>

## What are the key features of the intervention?

- The occupational health physician (OHP) is a lecturer at the University of Groningen and teaches occupation health to medical students training at UMCG
- The OHP attends a multidisciplinary meeting at UMCG every 4 weeks with dermatologists, trainee dermatologists, dermatology nurses and a retired UMCG dermatology professor (invited to provide experienced specialist input)
- During these MDT (multidisciplinary team) meetings they discuss AD patients whose occupation plays a role in their symptoms, including:
  - Which allergens may be present in the workplace
  - How the patient may decrease exposure to allergens e.g. wearing cotton gloves under plastic gloves (and regularly washing both)
  - Advising on which information UMCG dermatologists should include in letters to a patient's OHP (contracted by the patient's employer)
- The dermatology team use this information to guide the care advice given to these patients during follow-up consultations (including those held during the specialised occupational dermatology outpatient clinic)

*Note: the OHP also performs the traditional role of an OHP (i.e. contracted by employers unrelated to the centre and patients)*

**Sources:** (a) Schneider L. et al. Atopic dermatitis: A practice parameter update. *J Allergy Clin Immunol.* 2013;131(2):295–299. doi: 10.1016/j.jaci.2012.12.672; (b) U.E.M.S Occupational Medicine: Netherlands [Website] <http://www.uems-occupationalmedicine.org/node/14> Accessed 17 May 2019



# Role of the occupational health physician (2/2)

## What are the challenges?

- With an increase in short-term / 'zero-hour' contracts in the Netherlands, more people are exhibiting presenteeism (i.e. working when they are not fit to do so in order to retain employment), and further worsening their condition

## What are the outcomes so far?

### Benefits to patients:

- Receive practical advice for managing AD symptoms in the workplace
- AD treatment plans designed to accommodate work commitments
- Additional support received from employer's OHP (if dermatologist contacted them directly)

### Benefits to HCPs:

- Dermatology team are able to give better advice to patients regarding impact of work environment on AD / management strategies
- Dermatology team receive assistance with writing letters to patient's employer's OHPs (i.e. ensuring correct information is included to help patient)

“

I provide advice while considering that the interests of employers and employees may differ

*Occupational health physician,  
University of Groningen*



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# Psycho-social care network (1/2)

## Overview

- AD patients at the centre requiring psycho-social support can be referred by their dermatologist to a social worker, psychologist (within centre or outside) or psychiatrist depending on the severity of their psychological symptoms

## What is the rationale?

- Atopic Dermatitis is a complex disease, which is not always well controlled and can impact patient quality of life in multiple ways<sup>(a)</sup>
- Living with AD can have significant psycho-social implications (e.g. social anxiety; bullying; insomnia) and may leave patients depressed and disengaged with therapy<sup>(a)</sup>

## What are the key features of the intervention?

- A dermatologist / ANP at the centre can refer a patient to a social worker, psychologist or psychiatrist depending on the severity / cause of their psychological symptoms
- If the psychological symptoms identified do not directly relate to a patient's dermatological condition, centre staff may refer patients to primary care (general practice offices) for psychological support (where patients may have an existing relationship with their local psychologist)

### Social worker consultations:

The centre employs one social worker who sees patients with any dermatological condition (though they work across multiple departments)

- ~50% of dermatology consultations involve AD patients (primarily adults)
- During the ~1hr consultation the social worker may use various techniques to assist patients with their treatment and improve mental health, including:
  - Cognitive behavioural therapy (CBT)
  - Body language training (i.e. acting confident)
  - AD-centric career advice (using a career suitability test)
  - Advising children how to explain AD to classmates
  - Prescribing rest to prevent presenteeism (working when they are not fit to do so)
  - Directing patients to the "Leef! Met Eczeem" educational website (see case study in UMCU report)
- The patient and social worker together agree follow-up consultation frequency and duration (depending on patient requirements) and patients may request extra appointments directly via email
- If a patient exhibits depression and other serious psycho-social symptoms (usually not just related to their AD), the social worker may refer to a UMCG psychologist

**Sources:** (a) Lifschitz C. The impact of atopic dermatitis on quality of life. *Ann Nutr Metab* 2015;66(suppl 1):34-40. doi: 10.1159/000370226





## What are the key features of the intervention? (cont.)

### Psychologist consultations:

The psychologist works across multiple departments but is specialised in caring for AD patients

- ~80% of dermatology referrals to a psychologist are for habit-reversal therapy (HRT)<sup>(a)</sup>, and ~20% of referrals aim to address issues relating to anxiety / self-esteem
- For HRT, AD patients attend 5 sessions (1:1 for ~45 minute a week, with the final session 3 months after) with the aim of reducing scratching habits
- *Habit reversal therapy (key features):*

Week #	Session objectives
1	<b>Introduce</b> – discuss and understand severity of symptoms and scratching habits
2	<b>Motivate</b> – discuss the advantages and disadvantages of scratching in order to motivate patients; patients also complete scratching register to track scratching habits
3	<b>Review</b> – more in-depth review of scratching habits (e.g. in what situations; where; does patient scratch in the absence of itch)
4	<b>Intervene</b> – new habits / exercises suggested to reduce scratching (e.g. sitting on hands; using stress balls; rewards for reduced scratching)
5	<b>Check-up (3 months later)</b> – to review the long-term effects of HRT

### Psychiatrist consultations

- AD patients who are exhibiting severe psycho-social symptoms (e.g. severe depression; suicidality) may be referred to a psychiatrist at the centre (note: these cases are rare)
- Patients who are not responding to social worker / psychologist support may also be referred

## What are the outcomes so far?

### Benefits to patients:

- Access to 1:1 psychosocial support (both within the centre and locally)
- Practical help and advice received relating to their AD condition (e.g. career advice)

### Benefits to HCPs:

- Ability to offer patients psycho-social support (tailored to severity / cause) with the centre
- Shared knowledge by social workers during multidisciplinary meetings with wider dermatology team

# Psycho-social care network (2/2)



Many patients have trouble adjusting to chronic diseases and need help to lessen their symptoms

*Psychologist, UMCG*



**Sources:** (a) Jaspers JPC. Psychological interventions in atopic dermatitis. *Psychologie & Gezondheid* 2008;36(2):63-71

# Patient registries (1/2)

## Overview

- UMCG contribute to a cross-centre registry which collects data on efficacy, safety, drug survival and side effects for patients receiving the new AD biologic therapy. Alongside this, the centre maintains its own centre-specific hand eczema and patch test registries

**Sources:** (a) Wollenberg A, et al. Consensus-based European guidelines for treatment of atopic eczema (atopic dermatitis) in adults and children: part II. *J Eur Acad Dermatol Venereol*. 2018;32(5):657-682. doi: 10.1111/jdv.14891; (b) Garritsen FM, et al. Use of oral immunosuppressive drugs in the treatment of atopic dermatitis in the Netherlands. *J Eur Acad Dermatol Venereol* 2018;32(8):1336-1342. doi: 10.1111/jdv.14896; (c) BioDay. BioDay Register [Website] <http://www.bioday.nl/> Accessed 10 May 2019; (d) Nelson EC, et al. Patient focused registries can improve health, care, and science. *BMJ* 2016;354(8065) doi: 10.1136/bmj.i3319; (e) U.S. National Library of Clinical Trials [Website] <https://clinicaltrials.gov/ct2/show/NCT03549416> Accessed 26 April 2019; (f) European Surveillance System on Contact Allergies [Website] <http://essca-dc.org/> Accessed 08 Aug 2019



## What is the rationale?

- European AD Guidelines recommend the use oral immunosuppressive drugs in difficult to treat AD cases<sup>(a)</sup>. Daily practice studies however indicate high treatment discontinuation rates due to side effects and/or ineffectiveness<sup>(b)</sup>
- A new biologic therapy for AD patients has been available in the Netherlands since January 2018, at which point effectiveness and safety data had only been collected in clinical trials (not daily practice)<sup>(c)</sup>
- Maintaining a patient registry for the new biologic therapy – alongside centre-specific patch test and hand eczema registries – can act as a quality control check and the data collected can help drive professional development and service improvement<sup>(d)</sup>

## What are the key features of the intervention?

### BioDay registry:

- BioDay is a prospective registry consisting of patients who are receiving / are expected to receive the biologic therapy in the Netherlands (expected enrolment of 1200 patients, with a 10-year target study follow up duration, finishing December 2028)
- Primary objectives include examining safety and effectiveness (including patient-reported outcome measures [PROs]), drug survival (and factors effecting it) and objective / subjective side effects
  - As the new biologic may impact AD-related comorbidities, such as asthma, the BioDay registry also includes asthma-related outcomes for the subpopulation of patients that have concomitant asthma
- Participants are treated at 10 centres across the Netherlands, with the majority from UMC Utrecht and UMC Groningen<sup>(e)</sup>. UMC Nijmegen and 7 local hospitals are also involved
- UMC Utrecht and UMC Groningen own the data. All participating centres have access to only their own data. Utrecht and Groningen have access to all data

### Patch test registry:

- The centre maintains a centre-specific patch-test registry, run as part of the ESSCA initiative aimed at collecting allergic contact dermatitis data on a European scale (e.g. allergen exposure patterns)<sup>(f)</sup>
- To date, data from the registry has been analysed for a number of purposes, including:
  - Reviewing patch testing guidelines (e.g. timing and frequency of subsequent patch tests)
  - Assessing the clinical relevance of contact allergy prevalence in response to certain allergens

## What are the key features of the intervention? (cont.)

### Hand Eczema registry:

- The centre maintains a registry of hand eczema patients with concomitant AD, who are currently receiving a new AD biologic therapy
- Patients are included who exceed a baseline hand eczema severity level, in accordance with a photoguide
- The registry currently includes data from 65 adult patients from UMCG

Treatment outcomes recorded include:

- *Primary outcomes:*
  - HECSI score changes
- *Secondary outcomes:*
  - Perceived hand eczema severity changes (based on photoguide)
  - Quality of life changes based on PROs (patient-reported outcomes), including DLQI, QOLHEQ<sup>(a)</sup> (quality of life in hand eczema questionnaire) and WPAI<sup>(b)</sup> (work productivity and impairment)
  - EASI and IGA AD severity score changes

## What are expected outcomes?

### Benefit to patients / HCPs:

- Real-world assessment of biologic's effectiveness and safety, drug survival and side effects (to further inform treatment decision making)

## What's next?

- There is the potential to add further novel treatments (biologics and others) to the BioDay registry as they become available
- As the entire registry is in English, it is available to countries outside The Netherlands. As soon as a centre has interest in participating, inclusion of this centre can be considered. The registry was presented at ADCARE (Lisbon) in Spring 2019
- The hand eczema registry only contains UMCG data, though may be expanded to include data from multiple centres

**Sources:** (a) Oosterhaven JAF, et al. Guideline for translation and national validation of the Quality of Life in Hand Eczema Questionnaire (QOLHEQ). *Contact Dermatitis*. 2017;77(2):106-115; (b) Yano C, et al. Impact of disease severity on work productivity and activity impairment in Japanese patients with atopic dermatitis. *J Dermatol*. 2013;40(9):736-9

# Patient registries (2/2)



APPENDIX  
CENTRE REPORTS



Many patients have trouble adjusting to chronic diseases and need help to lessen their symptoms

*Psychologist, UMCG*



*BioDay Eczema and Atopic Diseases Registry website<sup>(b)</sup>*

# Dedicated dermatology photographer (1/2)

## Overview

- The centre employs a dedicated dermatology photographer who photographs patients' skin (and collates patients' own photos) to support the dermatology team with diagnosis, tracking disease progression and clinical research



## What is the rationale?

- AD severity indices (e.g. POEM, EASI) whilst well-validated, can still have some subjective elements (i.e. they rely on the patient / HCP's interpretation of the scale)<sup>(a)</sup>. Photographs therefore provide an additional comparative record for each patient (and between healthcare professionals)
- Photographs also allow patients to see how their skin symptoms have changed over time, particularly if there have been only small changes (which may be hard to notice from memory alone)

## What are the key features of the intervention?

- The dermatology department employs its own, full-time, professionally trained photographer (with a studio located in the dermatology clinic) to photograph patient skin symptoms
- A standard set of 25 images are taken, under the recommended light conditions, during the first AD patient consultation (and at follow-up consultations as required)
- Images are uploaded to the secure EPD (electronic patient dossier – only accessible by the dermatology department)
- The photographer has assisted with writing protocols (internal use only) for photographing different body areas in a professional manner, which is suitable for publishing (in the results of clinical trials)

### Atopic Dermatitis / Hand Eczema photography protocol:

#### Summary:

- Photographs are taken in front of a Nassau blue background to aid erythema assessment<sup>(b)</sup>
- Work in a fixed order in order to speed up the photographing process and allow patients to re-dress as soon as possible
- Record overview photographs: e.g. upper body (front); upper body (back); upper body (left); upper body (right)
- Record closer photographs of affected areas: e.g. left hand (front); left hand (back)
- Record areas with eczema in greater detail: e.g. erythematous plaque at the sacral area; AD related conjunctivitis
- Use identical cameras, lenses and lighting in the studio during each visit to aid comparison over time

**Sources:** (a) KPMG interviews; (b) Oosterhaven JAF, et al. Effect of dupilumab on hand eczema in patients with atopic dermatitis: An observational study. *J Dermatol.* 2019;46(8):680-685. doi: 10.1111/1346-8138.14982

# Dedicated dermatology photographer (2/2)

## What are the key features of the intervention? (cont.)

- Dermatologists / ANPs may ask patients to send photos (including their UMCG patient number) to a dedicated email inbox managed by the photographer (e.g. if their symptoms turn more severe)
- The photographer collates the photographs and informs the patient's dermatologist that new images have been received. The dermatologist may ask a colleague for a second opinion and / or contact the patient for further information, but will aim to provide patients with feedback within 24 hours

## What are the outcomes so far?

### Benefits to patients:

- Ability to receive quick feedback on symptoms that are of concern
- Ability to visually track changes in skin symptoms over time

### Benefits to HCPs:

- Ability to visually monitor patient disease progression (in combination with severity indices)
- Ability to visually demonstrate improvements in condition (e.g. if patient does not believe treatment has been effective)
- Access to professional images of patient symptoms to use in journal publications, etc.

“

Eczema varies in severity. Using this system, the physician is informed about the disease over time

*Dermatologist, UMCG*





# University Medical Center Utrecht (UMCU)

**Utrecht, Netherlands**

Site visited by KPMG 8–9<sup>th</sup> April 2019

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[kpmg.com/uk](https://kpmg.com/uk)



APPENDIX  
CENTRE REPORTS



# Summary



## Context

**Centre type:** University public hospital located in Utrecht

**Catchment area:** Patients are referred from Utrecht and all across the Netherlands (including referrals from other university hospitals)

**Funding:** UMC Utrecht (UMCU) is funded by both the State and through insurance reimbursement (for provision of patient care)

**Services:** The centre was founded in 2000 through the merger of the Academic Hospital, Wilhelmina Children's Hospital (WKZ) and the Medical Faculty of Utrecht University. The dermatology unit sits within the Medical Faculty of the General Hospital, alongside a number of other specialities

**Patient population:** The dermatology unit serves adult and paediatric dermatology patients with a range of conditions (including atopic dermatitis [AD])



## Key strengths in the delivery of AD care

**Specialism in range of dermatological conditions:** UMCU is the National Expertise Centre for AD and food allergy, and a top referral centre for drug allergy, urticaria and angioedema

**Provision of holistic care for AD and associated comorbidities:** The centre employs an integrated group of specialists (including AD comorbidity specialists and dermatologists with allergy and immunology experience)

**Advanced nurse practitioners (ANPs):** 5 ANPs (2 specialised in AD) supervised by dermatologists, deliver patient consultations involving diagnosis, treatment and education

**Innovative patient education:** The centre developed a website resource allowing patients and parents to access online Eczema education. A newly developed smartphone application provides information on ointment application, itch and treatment plans

**Patient communication:** The centre runs a patient portal where patients may upload photos and ask questions to centre staff (with a target response time of 48 hours)



## Key challenges faced in delivery of AD care

**Delayed presentation of some severe AD patients** until they are experiencing a severe flare and require admission

**Poor compliance of topical treatment application by some patients** which can negatively effect treatment outcomes

**Delayed diagnosis and treatment of AD-related ocular involvement** by physicians in the community (including dermatologists, ophthalmologists and primary care physicians [PCPs]), often due to lack of awareness of ocular AD comorbidities or how to screen for them

**Managing the side effects of some treatments** which are not easily avoided (e.g. where there are no alternative treatment options available)





# Atopic Dermatitis (AD) in the Netherlands

## Netherlands healthcare system:

The Netherlands operates a universal healthcare system which provides healthcare and financial protection to all citizens, through two mandatory forms of health insurance<sup>(a)</sup>:

1. All adults living / working in the Netherlands must pay a basic level of health insurance, through a government-approved insurance company, which covers common **short-term** care provision (e.g. primary care consultations)
2. Individuals are automatically insured by the government to cover **long-term** nursing and care

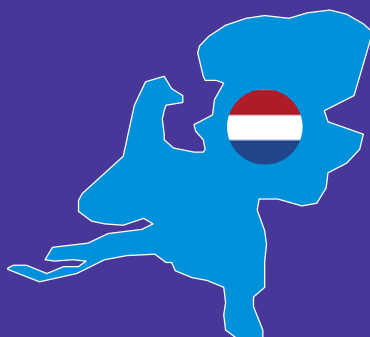
It is generally illegal for insurance companies to refuse an individual basic health insurance or to charge for it above the legal maximum price<sup>(b)</sup>. Services not covered by the basic package will require an excess to be paid or a higher level of insurance. Those aged under 18 are not required to pay health insurance as they are automatically covered by their parent's / guardian's premium. Health services in the Netherlands are financed by a combination of general taxation and health insurance reimbursements

## In the Netherlands, there are three organisational levels in the universal healthcare system:

1. Primary care – a network of primary care centres providing basic medical advice / treatment
2. Secondary care – a network of public and private peripheral care centres (PCCs) providing specialist treatment and preferably requiring referral from a primary care physician
3. Tertiary care – a network of 8 university medical centres (UMCs) providing special investigation and treatment and preferably requiring referral from a secondary care physician (or another UMC). The Dutch government discourages referring patients directly from primary to tertiary care

## Prevalence:

- AD affects 10–20% of children and 1–3% of adults in Western countries<sup>(c)</sup>
- 2.3% of the Dutch population have AD<sup>(d)</sup>



## Care provision (Netherlands):

### Location:

- Mild (or well-controlled) AD care is primarily delivered by PCPs (primary care providers)
- Moderate and severe (uncontrolled) AD care is primarily delivered in specialist secondary or tertiary care (within hospitals)

### Funding:

- Primary care and hospital services are funded through a combination of general taxation and health insurance reimbursements

## Guidelines and societies:

### Guidelines:

- Guidelines for treatment of atopic eczema (atopic dermatitis) part I and part II: European Association of Dermatology and Venerology (EADV)
- The Dutch College of General Practitioners practice guideline 'Eczema'

### Medical society:








- NVDV (Dutch Society of Dermatology and Venerology)

### Patient advocacy group (PAG):

- VMCE (Dutch Society of Patients with Atopic Eczema)

**Sources:** (a) NHS. Healthcare in the Netherlands [Website] <https://www.nhs.uk/using-the-nhs/healthcare-abroad/healthcare-when-travelling-abroad/healthcare-in-the-netherlands/> Accessed 24 April 2019; (b) International Health Care System Profiles. The Dutch Health Care System [Website] <https://international.commonwealthfund.org/countries/netherlands/> Accessed 24 April 2019; (c) Nutten S. Atopic dermatitis: global epidemiology and risk factors. *Ann Nutr Metab.* 2015;66 Suppl 1:8-16; (d) Verboom P, et al. The cost of atopic dermatitis in the Netherlands: an international comparison. *Br J Dermatol.* 2002;147(4):716-24








# The centre and dermatology unit

University Medical Center Utrecht (UMCU)		
 <b>Type and location</b>	A large, publicly funded university medical centre (UMC) located within Utrecht (central Netherlands). The UMCU delivers tertiary care to patients referred from peripheral care centres (secondary care) and general practice (primary care). Within dermatology the centre is the national expertise centre for atopic dermatitis (AD) and food allergy and is a national top referral centre for drug allergy, urticaria and angioedema	
	 <b>Population served and services delivered</b>	
The centre delivers 13,000 dermatology patient visits per year and 300 inpatient attendances. UMCU provides 600 food and drug allergy provocation tests per year in their day case unit, with delayed phase reaction tests carried out in inpatient facilities. The centre delivers 400 (adult) and 240 (paediatric) new AD outpatient appointments per year, and 2,800 (adult) and 1,200 (paediatric) follow-up AD appointments per year		
The dermatology unit		
 <b>Service Division</b>	<b>Outpatient service</b>	<b>Emergency dermatology service</b>
	08:30–16:30 Mon–Fri	24 / 7
 <b>Hours of availability</b>		
 <b>No. of patients seen</b>	AD patients seen: ~54 new and 333 follow up patients per month	Maximum 8 patients (as 8 inpatient beds)
 <b>Types of patients seen</b>	Adults with all dermatological conditions (primarily severe / complex cases) Children with all dermatological conditions are seen in the connected children’s hospital (5 minutes walk)	Adults with a dermatology condition causing A&E attendance may be admitted Children over 5 years with a dermatology condition but no specific paediatric requirements may be admitted to the dermatology ward
 <b>Facilities on-site<sup>(1)</sup></b>	— Phototherapy (UVA / UVB / PUVA) — On-site hospital pharmacy with outpatient service — Wide variety of allergy tests (e.g. skin prick testing, patch testing) — Dermatology consulting rooms and operating theatres — Dermatology photography studio — 2 on-site laboratories: 1 providing a range of dermatology-specific tests and another providing translational immunology testing	








**Note:** (1) List of facilities is not exhaustive

# The team

## Core team profiles

-  **9** dermatologists (including 1 professor of allergy and dermatology and 1 paediatric dermatologist)
-  **1** clinical immunologist
-  **17** dermatology trainees
-  **5** dermatology Advanced Nurse Practitioners (ANPs; 2 AD-specialised)
-  **1** dermatology social worker
-  **3** dermatology trial nurses
-  **2** research fellows

## Wider team profiles

-  **1** ophthalmologist (with specific expertise in atopy-related ocular comorbidities)
-  **1** pharmacist (available for advice and assigned to the drug-allergy clinic for drug dilutions)
-  **2** paediatric allergologists
-  **2** dieticians
-  **1** psychologist, behavioural habit reversal therapy also offered by the dermatology ANPs
-  **1** pulmonologist
-  **1** otolaryngologist (ENT specialist)

## Patient records:

- *Electronic patient records:*
  - Shared and accessible by all UMCU specialities
- *Electronic prescribing:*
  - Prescriptions are written online

## Governance and processes

### Team meetings:

- *AD clinical case presentation (every Monday afternoon):*
  - Attended by: dermatologists, dermatology trainees, social workers, research fellows and ANPs
  - Purpose of meeting: to discuss every newly referred patient seen since the last meeting, discuss difficult cases, admitted patients and validate / update management plans
- *Biologics meeting (twice a week):*
  - Attended by: dermatologists and dermatology trainees with pharmacist advice on call as required
  - Purpose of meeting: review patients on biologics and agree new patients to be started on biologics
- *Dermatology departmental meeting (once a month):*
  - Attended by: entire department
  - Purpose of meeting: to review critical incidences and discuss lessons learned

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients with symptoms of AD (e.g. itching or dryness of the skin) present to a primary care physician (PCP) who assess them and refer as required
- Note: AD patients that are mild or well-controlled may be managed in primary care and may not be referred to secondary / tertiary care*
- Patients may present directly to the centre's emergency department with atopic symptoms. After receiving adequate emergency treatment, patients are referred back to their general practitioner

## Diagnosis and Referral

In secondary / tertiary care



- GPs refer moderate-severe patients to a peripheral care centre (PCC) or directly to University Medical Center Utrecht (UMCU). Referrals directly from primary care to UMCs are phasing out, with PCPs actively encouraged to refer to secondary care only
- AD may be diagnosed in primary / secondary care through clinical examination and supplementary diagnostic tests (e.g. skin biopsy), performed by general dermatologists. Secondary care appointments last ~10 minutes
- Complex cases - or those not responding well to treatment in secondary care, TRFs [top reference centres] or other UMCs - will be referred to the centre as the "National TRF Expertise Center"

## Treatment and Management

Medical management



- AD patients attend a consultation with either the dermatologist or the Advanced nurse practitioner (ANP). Each consultation lasts ~30 minutes. Patients then receive 1:1 education and treatment demonstrations from the ANP (also lasting ~30 minutes). The ANP can deliver both consultations
- Patients are referred to AD comorbidity specialists as required (e.g. ophthalmologist; pulmonologist; otolaryngologist) and may be seen on the same day if required
- Paediatric patients transition into adult care aged 16-18 years

Non-medical management



- Dermatologists assess patients for psycho-social impacts and may refer individuals to:
  - hospital social worker (who helps with the lifestyle impacts of AD, e.g. employment; financial stresses)
  - hospital psychiatrist (who treats severe psychiatric symptoms)
  - community psychologists located in primary care (if psychological symptoms are not AD-related)
- Alternative treatment may be provided (e.g. hand / foot or full-body UVA / UVB treatment for patients contraindicated to systemic therapy but non-adherent to topical therapy)
- Dermatologists may refer patients to the dietician for suspected food allergies (who may subsequently refer to the allergologist)

## Follow-up

Monitoring of chronic disease / flare up



- Frequency of follow-up consultations will be determined by the dermatologist (depending on severity, treatment, etc.)
- vIGA (validated Investigator Global Assessment scale for Atopic Dermatitis) and EASI (Eczema Area and Severity Index) will be measured at each consultation
- Patients may access emergency dermatology advice by posting questions and pictures on their electronic patient portal. Dermatologists aim to respond within 48 hours
- Patient reported outcomes (PROs) may be entered at home through the patient portal, via their personalised login
- Patients are directed to VMCE (the Dutch patient advocacy group) resources for ongoing support, in addition to the UMCU patient website and educational smartphone App (once launched)

# Roles of the wider team

## Dermatologist (with an allergy sub-specialty)

**Patient type:** AD patients with suspected additional food or drug allergy

**Referral:** Referred by dermatologist, Advanced Nurse Practitioner (ANP) or primary care physician

**Consultations:** The first consultation includes a blood test, skin prick testing and dietary advice. The second consultation involves a food challenge if skin prick testing is inconclusive

**Timing:** Consultations take ~1.5–2 hours. Provocation tests last all day and may require admission if a late phase reaction is suspected. Patients usually attend 3 consultations, but this depends on the outcomes of each appointment

## Pulmonologists

**Patient type:** AD patients with asthma (severe / non-severe)

**Referral:** Referred by dermatologist or ANP

**Consultations:** Pulmonologists conduct standard lung function tests (e.g. spirometry and peak flow tests). The dermatology clinical immunologists also manage asthmatic Atopic March patients

**Timing:** Consultations typically last up to 30 mins



## Social worker

**Patient type:** AD patients who are referred from the outpatient dermatology clinic

**Referral:** Referred by dermatologist or ANP

**Consultations:** Social worker performs a psychosocial assessment, looking at the impact of AD on a patient's work, finances and relationships. Inpatients watch a 90 minute video about living with a chronic disease before participating in a group discussion with other AD patients

**Timing:** Consultations range from 45 mins to 2+ hours

*Note: The social worker shares feedback on relevant developments during the weekly case presentation meeting*

## Ophthalmologist

**Patient type:** AD patients ocular AD comorbidities or treatment side effects

**Referral:** Referred by dermatologist or ANP

**Consultations:** Ophthalmologists perform a variety of tests to assess visual acuity, intraocular pressures, refraction and corneal topography. They then provide education, treatment and follow-up care

**Timing:** Appointments range from 30–50 minutes, this includes consultation time and all testing required

*Note: The time between follow-up appointments varies depending on test results*

**Notes:** (1) List of additional centre roles is not exhaustive





# Overview of interventions in place for AD

Key:



Case study available



CONTENTS



APPENDIX  
CENTRE REPORTS

## Awareness and Presentation





Symptom identification

- **Working with the VMCE (PAG):** The dermatology unit works closely with the Dutch AD patient advocacy group (PAG) VMCE (Vereniging voor Mensen met Constitutioneel Eczeem) to raise awareness of AD in the community  
 See pgs. 296-297 for case study
- **Innovative smartphone application: "Zalf":** Developed in partnership with the VMCE to educate patients on the correct application of topical treatments and support them to monitor their treatment plan / consultation schedules  
 See pgs. 298-299 for case study

## Diagnosis and Referral







In secondary / tertiary care

- **HCP education (including nurse platform):** As a national reference centre for AD, the centre delivers regular training for PCPs (GPs and nurses), general dermatologists and trainee healthcare professionals (HCPs)  
 See pg. 300-301 for case study
- **Established ophthalmologist working relationship:** AD patients are regularly screened for ocular symptoms by dermatologists, who have established a standard referral procedure with an anterior chamber ophthalmologist (experienced in ocular manifestations of AD)  
 See pg. 302-304 for case study
- **24-hour allergy testing:** The centre offers allergy diagnosis, ranging from outpatient skin prick testing through to day case unit and inpatient provocation testing

## Treatment and Management






Medical management

- **Integrated dermatology-allergy specialists:** Dermatologists with a sub-specialism in allergy are fully integrated into the department  
 See pg. 305-306 for case study
- **Dermatology Advanced nurse practitioner (ANP):** can prescribe and lead consultations, to discuss treatment options and provide in-depth patient education  
 See pgs. 307-308 for case study
- **Inpatient education:** Covering disease background, treatment, etc.  
 See pg. 309 for case study
- **Clinical internal audits:** Regular assessments of service provision, with a working group dedicated to service improvement  
 See pg. 310 for case study
- **Transitional process into adult clinic:** Managed by ensuring HCP consistency for each patient across paediatric and adult outpatient clinics  
 See pg. 311 for case study




Non-medical management

- **Innovative education website: "Leef! Met Eczeem":** The centre offers multi-media education resources to patients and their parents, through dedicated webpages on the hospital website  
 See pgs. 312-313 for case study
- **Dedicated social worker:** Access to team social worker (shared with rheumatology), who performs psychosocial assessments looking at the impact of AD on a patient's work, finances and relationships (for all AD inpatients and referred outpatients)  
 See pg. 314 for case study
- **BioDay registry:** The centre developed and leads a cross-centre patient registry and observational study for all patients receiving the novel biologic AD therapy  
 See pg. 315 for case study

## Follow-up



Monitoring of chronic disease/flare up

- **Communication via the patient portal:** Patients already known to the centre may upload photos and questions to a personal and confidential online portal, found within their electronic patient record. Patients receive a response from a dermatologist within 48 hours (treatment advice or a request for further information)  
 See pg. 316 for case study
- **UMC Utrecht Biobank:** The UMC's Biobank involves >20,000 AD patient samples (e.g. on blood / serum samples) from UMCU patients. This is available for use in international studies, and to date has been used to explore endotyping in AD patients using serum biomarker analysis<sup>(a)</sup>

**Source:** (a) Thijs JL, et al. Moving toward endotypes in atopic dermatitis: Identification of patient clusters based on serum biomarker analysis *J Allergy Clin Immunol* 2017;140(3):730-737. doi: 10.1016/j.jaci.2017.03.023



# Monitoring AD patients and comorbidities

## The dermatology unit employs a number of measures for monitoring AD and associated comorbidities

### Objective measures (AD):

AD scoring indices are used to monitor patients and their disease, including:

- vIGA-AD™ (Validated Investigator Global Assessment scale of Atopic Dermatitis): scoring system used to describe the appearance of lesions and AD in clinical trials<sup>(a)</sup>
- EASI (Eczema Area and Severity Index): validated scoring system that grades the physical signs of atopic dermatitis<sup>(b)</sup>
- SCORAD (SCORing Atopic Dermatitis): used to assess AD disease severity and monitor patient progress<sup>(c)</sup>

### Patient-reported outcomes (PROs):

QoL is routinely measured by:

- POEM (Patient-Oriented Eczema Measure): to monitor patient AD disease severity<sup>(d)</sup>
- DLQI (Dermatology Quality of Life Index): dermatology-related quality of life questionnaire<sup>(e)</sup>, which is performed by the centre on patients 4 times per year. This consists of 10 questions covering topics such as clothing, sport, work and relationships. The patients will score each question between 0-3, relating to the impact of the skin disease on the patient's life over the previous week
- The Peak Pruritus NRS (Numerical Rating Score) is also commonly used. This requires patients to be asked: "On a scale of 0 to 10, with 0 being 'no itch' and 10 being 'worst itch imaginable', how would you rate your itch at the worst moment during the previous 24 hours?"

Validated Investigator Global Assessment scale for Atopic Dermatitis	
vIGA-AD™	
<b>Instructions:</b> The vIGA score is selected using the descriptors below that best describe the overall appearance of the lesions at a given time point. It is not necessary that all characteristics under Morphological Description be present.	
Score	Morphological Description
0 - Clear	No inflammatory signs of atopic dermatitis (no erythema, no induration/papulation, no lichenification, no oozing/crusting). Post-inflammatory hyperpigmentation and/or hypopigmentation may be present.
1 - Almost clear	Sparsely perceptible erythema, sparsely perceptible induration/papulation, and/or minimal lichenification. No oozing or crusting.
2 - Mild	Slight but definite erythema (pink), slight but definite induration/papulation, and/or slight but definite lichenification. No oozing or crusting.
3 - Moderate	Clearly perceptible erythema (dull red), clearly perceptible induration/papulation, and/or clearly perceptible lichenification. Oozing and crusting may be present.
4 - Severe	Marked erythema (deep or bright red), marked induration/papulation, and/or marked lichenification. Disease is widespread in extent. Oozing or crusting may be present.

**Notes:**

- In indeterminate cases, please use extent to differentiate between scores.

**For example:**

- Patient with marked erythema (deep or bright red), marked papulation and/or marked lichenification that is limited in extent, will be considered "3 - Moderate".

- Excoriations should not be considered when assessing disease severity.

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Validated Investigator Global Assessment scale for Atopic Dermatitis<sup>(a)</sup>

### Dermatology unit routinely measures comorbidity outcomes by:

- Allergy response to allergens is measured through tests such as skin prick and provocation testing
- Ophthalmologists perform screening tests (e.g. topography, corneal examination) and have recently developed a standardised assessment form for conjunctivitis related to AD treatments (awaiting validation)
- Otolaryngologists use nasal endoscopes to assess nasal polyps

**Sources:** (a) International Eczema Council (IEC): Investigator Global Assessment Scale [Website] <http://www.eczemacouncil.org/research/investigator-global-assessment-scale/> Accessed 20 Mar 2019; (b) HOME for eczema.org. EASI for clinical signs [Website] <http://www.homeforeczema.org/research/easi-for-clinical-signs.aspx> Accessed 1 Mar 19; (c) SCORing Atopic Dermatitis (SCORAD) Calculator (0.9.0) [Website] <http://scorad.corti.li/> Accessed 26 Feb 2019; (d) Charman CR, et al. Translating Patient-Oriented Eczema Measure (POEM) scores into clinical practice by suggesting severity strata derived using anchor-based methods. *Br J Dermatol* 2013;169(6):1326–1332; (e) Lewis V, et al. 10 Years Experience of the Dermatology Life Quality Index (DLQI) *J Investig Dermatol Symp Proc* 2004;9:169 –180



# Advice to other centres

## What advice would you give less specialised centres?



**Objective of advice:** Build strong ophthalmology-dermatology collaboration

- **Why?** Ophthalmic AD comorbidities have historically been under-recognised in primary and secondary care, resulting in late referrals and more progressive eye conditions. AD treatment, which can cause eye side effects, is also being used more frequently<sup>(a)</sup>
- Strong collaboration between dermatologists and ophthalmologists in secondary / tertiary care (e.g. established referral pathways, joint protocols, cross-specialty education) can improve management of eye comorbidities and side effects of AD treatments, improving patients' eye outcomes



**Objective of advice:** Integrate social workers into the AD team

- **Why?** The effect of AD on a patient's psychosocial well-being is widely recognised (including on relationships, finances, sleep patterns and employment). Enabling patients access to a social worker to provide holistic support can help improve their quality of life and treatment adherence (e.g. through encouraging patients to take ownership of their AD management)



**Objective of advice:** Create E-health solutions

- **Why?** Many patients expect technological advances in care (especially younger generations of patients). Technological interventions can be used to:
  - Support and reinforce education received in face-to-face consultations remotely (i.e. accessible at home)
  - Encourage / better enable AD self-management (through the provision of education, treatment regimen reminders etc.)
  - Enable remote assessments of patients' AD and provision of feedback (so they don't have to visit the centres) e.g. via teledermatology

**Sources:** (a) KPMG interviews at UMCU

# Next steps for the centre



## What is next for the centre?

**Objective:** Cross-specialty dermatology and ophthalmology AD outpatient polyclinic

- **What?** UMCU plan to set up an allergic eye clinic in June 2019 and are considering a polyclinic with ophthalmology and dermatology specialists
- **Why?** Co-location of the ophthalmology and dermatology clinics will enable better coordination of care and improve convenience for comorbid patients (as they will only need to visit the centre once for two consultations)



**Objective:** Continue to contribute to the BioDay registry and Biobank, and analyse data

- **What?** UMCU currently contributes to the BioDay registry and BioBank, which are used to inform research to better understand AD and AD treatment effects (including exploring the identification of four endotypes in AD based on serum biomarker analysis<sup>(a)</sup>)
- **Why?** Improving understanding of AD disease mechanisms and patients' treatment response (e.g. by endotype), has the potential to enable more targeted treatment decisions in the future



**Objective:** Launch 'Zalf' smartphone application and explore opportunities to translate into other languages

- **What?** The dermatology unit in collaboration with the national patient advocacy group (VMCE) has developed the 'Zalf' smartphone application to support patients in effective topical therapy application (due to launch in June 2019). The app will launch in Dutch only, but the centre hopes to translate it into further languages in the future for multi-lingual / non-Dutch speaking nationals and international AD patients
- **Why?** AD patients do not always effectively apply their topical treatments (e.g. amount, skin location, timing / frequency) and / or struggle with compliance, which can negatively impact treatment outcomes



**Source:** (a) Thijs JL, et al. Moving toward endotypes in atopic dermatitis: Identification of patient clusters based on serum biomarker analysis *J Allergy Clin Immunol* 2017;140(3):730-737. doi: 10.1016/j.jaci.2017.03.023

# Case studies



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# Collaboration with VMCE (PAG) (1/2)

## Overview

- The centre works closely with Vereniging voor Mensen met Constitutioneel Eczeem (VMCE), the Dutch AD patient advocacy group (PAG)
- Centre staff and the PAG collaborate on projects and may refer patients to one another for support where appropriate



We [the VMCE] and the centres only refer patients to each other who actually need it, so as to not overburden one another. A mutual trust has grown over the years.

PAG representative,  
VMCE



## Vereniging voor Mensen met Constitutioneel Eczeem (VMCE) in the Netherlands

- The VMCE is a not-for-profit association for people with atopic eczema (and their parents) aimed at “improving the quality of life of people with eczema”<sup>(a)</sup>
- The VMCE was formed in 1994 in direct collaboration with University Medical Center Utrecht (UMCU)
- UMCU, University Medical Center Groningen (UMCG), and the PAG assist each other with activities including: grant applications, patient education, patient referrals, research and the writing of AD protocols and guidelines

### VMCE-centre joint activities (with UMCG and UMCU) include:

- *Revising national AD protocols and guidelines:*
  - Objective: To devise and revise national AD guidelines (including for atopic eczema; hand eczema; topical corticosteroid treatment) to reflect the latest developments in AD care and incorporate the voice of the patient<sup>(b)</sup>
  - Role of centre: To communicate with PAG representatives and ensure their knowledge and experience is considered when revising AD guidelines
- *Organising the 10<sup>th</sup> Georg Rajka (International AD symposium held in Utrecht):*
  - Objective: To discuss the latest AD research and share PAG initiatives
  - Role of centre:
    - The event’s local organising committee included the VMCE representative and the head dermatologists from UMCG and UMCU
    - The event hosted leading AD dermatologists from around the world, as well as PAG representatives from 10 countries (including the USA, Canada, Brazil and the UK)
    - The symposium (held ever 2 years) encourages idea sharing and the dissemination of global research findings at a local level
- *Informing AD research<sup>(c)</sup>:*
  - Objective: To utilise the experience and knowledge of PAG representatives in AD trial design
  - Role of centre: Coordinating AD clinical research and including PAG representatives to participate in research and disseminate findings

**Sources:** (a) Vereniging voor Mensen met Constitutioneel Eczeem [Website] <https://www.vmce.nl/> Accessed 15 Apr 19; (b) NVDV Guidelines [Webpage] <http://www.nvdv.nl/informatie-voor-de-professional/richtlijnen-2/> Accessed 22 May 19; (c) Spuls PI, et al. The International TREATment of ATopic Eczema (TREAT) Registry Taskforce: An Initiative to Harmonize Data Collection across National Atopic Eczema Photo- and Systemic Therapy Registries. *Journal of Investigative Dermatology* 2017;137(9):2014–2016. doi: 10.1016/j.jid.2017.05.014



- *Other:*
  - Collaboration with UMCU to develop a smartphone application named “Zalf”, which educates patients on ointment application and provides step down regimes for steroid use (see UMCU report for ‘Zalf’ case study)
  - The head of UMCU’s National Expertise Centre of AD is chair of the VMCE Advisory board
  - Alongside UMCU, UMCG and two peripheral dermatologists, the VMCE participates in the National Audit Committee for the novel AD biologic therapy

#### Additional VMCE activities include:

- *AD focus groups:* Held twice a year for UMCU AD patients to discuss patient needs, self-management and the latest in AD care. Separate meetings are held for VMCE members across the Netherlands (for families with children with eczema (0-12yrs); children (12-18yrs); adults)
- *TREAT (TREAtment of Severe Atopic Eczema Trial) study:* the VMCE is represented on both the international and national taskforces, helping to write protocols to harmonise data collection for atopic eczema for both photo- and systemic therapies. TREAT aims to enable cross border data pooling and international collaboration<sup>(d)</sup>
- *BioDay registry:* the VMCE participates in the BioDay registry, alongside UMCG and UMCU<sup>(e)</sup>. The VMCE sit on the Scientific Board of BioDay to provide a patient perspective on the results and assist in their dissemination to the non-scientific world
- *BIOMAP project:* the VMCE is also represented on the PAG of the BIOMAP EU/IMI initiative<sup>(f)</sup>
- *Working with the food hypersensitivity network (Stichting Voedselallergie):* VMCE and Stichting Voedselallergie have had shared back and front office services since 2002. They work closely together and consult each other when food allergy and eczema overlap. They exchange insights on relevant scientific research and provide each other with information for brochures and websites
- *Participating in an EU study to assess the burden of disease in AD:* Three manuscripts were produced and published<sup>(g)(h)(i)</sup>, of which two are open access<sup>(g)(i)</sup>

#### What’s next?

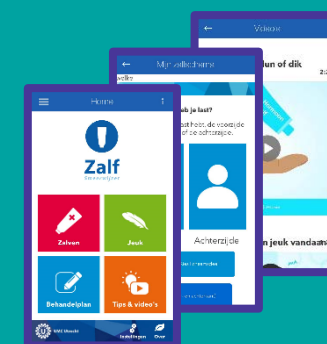
- VMCE and the centres will continue to exchange information on a regular basis, in order to maintain and strengthen the benefits of their collaboration
- VMCE will continue working closely with the centres on improving AD care and research (e.g. BioDay; a systematic review of emollients in hand eczema; efficacy of eczema bandages)
- VMCE (together with the centres) hopes to further assess the impact of AD on a patient’s family members (e.g. the day-to-day burden on parents, including sleep disruption, mental health aspects, work implications)

## Collaboration with VMCE (PAG) (2/2)



When we speak with either UMCG or UMCU, it is clear they really value the opinion of VMCE representatives. We are treated as equals.

*PAG representative, VMCE*



*‘Zalf’ (English: ‘Ointment’) mobile phone application co-developed by UMCU and VMCE*

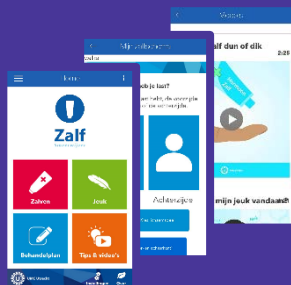
**Sources:** (d) Vermeulen F, et al. TREAtment of ATopic eczema (TREAT) Registry Taskforce: consensus on how and when to measure the core dataset for atopic eczema treatment research registries *Br J Dermatol* 2019;181(3):492-504. doi: 10.1111/bjd.17715; (e) BioDay Registry [Website] <http://www.bioday.nl/the-registry/> Accessed 22 May 2019; (f) BIOMAP project [Website] <http://www.biomap-imi.eu/> Accessed 22 May 2019; (g) Zink A, et al. Out-of-pocket costs for individuals with atopic eczema in Europe. *Acta Derma Venereol* 2018;99:263–67 (h) Ring J, et al. Atopic Eczema: Burden of disease and individual suffering – Results from a large EU-Study in adults. *J Eur Acad Dermatol Venereol* 2019;33:1331-40; (i) Arents BW, et al. The Atopic Eczema Score of Emotional Consequences (AESEC) - A scoring system to measure emotional consequences of atopic eczema. *Allergo J Int* 2019;28(7):277-288. doi: 10.1007/s40629-019-0098-y

# Innovative smartphone application: "Zalf" (1/2)

## Overview

Alongside the Dutch atopic dermatitis patient advocacy group (VMCE), the centre has developed a smartphone application for use by anyone applying topical treatments

- "Zalf" translates to English as 'ointment'



## What is the rationale?

- The majority of AD patients require topical treatment as part of their disease management (either as a standalone treatment or combined with systemic therapy)
- AD patients often incorrectly use topical treatments (e.g. amount; frequency; body location) for a variety of reasons (e.g. misinformation; inconvenience; perceived inefficacy)
- Smartphones are a convenient education channel, with over 91% of the Dutch population aged 13+ years owning one in 2018<sup>(a)</sup>

## What are the key features of the intervention?

- Zalf was developed for all patients who need to apply ointments (not just AD patients)
- It was developed by 2 Advanced Nurse Practitioners (ANPs) and 2 dermatologists from UMCU in association with the Dutch atopic dermatitis patient advocacy group (VMCE)
- The application allows the user to choose either an adult or child version at the login stage, with content subsequently tailored to suit an adult / paediatric audience
- Zalf was co-funded by private companies and has received positive feedback from the 4 AD patients who have trialled it to date
- The Dutch language version is planned to launch Summer 2019

The App includes 4 main sections:

- **Ointments (Zalven):** Covers the rationale behind the treatments prescribed and explains their regular application and tapering requirements
- **Itch (Jeuk):** Discusses why people itch and useful methods for resisting the urge to itch
- **Treatment plans (Behandelplan):** Integrated into the user's diary to set reminders, so that busy patients or parents with young children may find it easier to remember when to apply which treatments
- **Tips and videos:** Video animations illustrate how to apply treatments and why they are important. The animations are easy to understand and allow the user to pause and rewind as they please



"Zalf" application home screen

**Sources:** (a) Statistics. Statista [Website] <https://www.statista.com/statistics/451495/smartphone-penetration-internet-users-the-netherlands/> Accessed 3 May 2019

# Innovative smartphone application: "Zalf" (2/2)

## What are the outcomes so far?

### Benefits to patients:

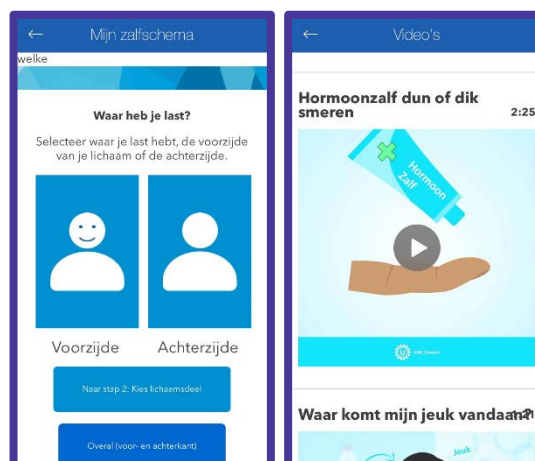
- Convenient education tool to supplement information from healthcare professionals (during consultations)
- Empowered to self-manage their AD
- Reminders received for when to apply treatments (via diary function)
- Ability to tailor information and format for adult and paediatric patients

### Benefits to HCPs:

- Less face-to-face consultation time spent educating patients on topical treatment application
- Simple resource available to direct patients to (application will be available for free)
- Improved patient treatment compliance and consultation attendance (via diary reminder function)

## What's next?

- Zalf is in the last stage of development (implementing final changes based on initial trials with AD patients)
- Once final alterations are complete, Zalf will be submitted to the App stores for review and both iPhone and Android versions will be made available
- The team hopes to make Zalf available in multiple languages in the future (for national and international AD patients)



"Zalf" application screenshots

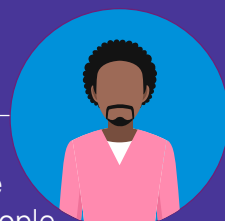
“



While we were educating patients, a few asked us why there wasn't an app available to guide their treatment. That got us thinking. The patients who have tried it so far have really loved it

*Advanced dermatology practitioner nurse, UMCU*

“



All patients have smartphones - and we were seeing fewer people use the website - so we wanted to innovate from e-health to mobile health

*Dermatologist, UMCU*

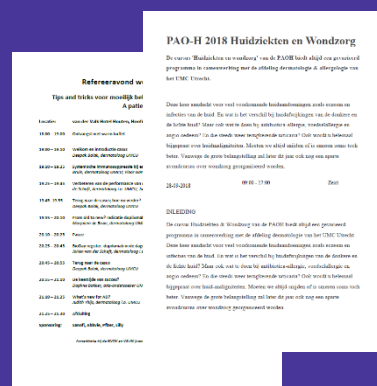




# HCP education (including nurse platform) (1/2)

## Overview

The centre delivers a range of AD-specific training initiatives to the wider general HCP community



## What is the rationale?

- Skin conditions are a common reason for primary care consultations<sup>(a)</sup>. Primary care physicians (PCPs) need to understand how to identify and manage AD patients, and when to refer them to specialist care<sup>(a)</sup>
- Effective AD control not only improves quality of life but may also prevent the atopic march<sup>(a)</sup>
- Moderate-severe AD eye comorbidities require prompt and effective referral to specialist treatment to prevent permanent vision loss<sup>(b)</sup>
- Where a patient has been referred for specialist treatment that has proved to be ineffective, in >50% of cases the primary reason for this is the treatment not being administered correctly<sup>(c)(d)</sup>

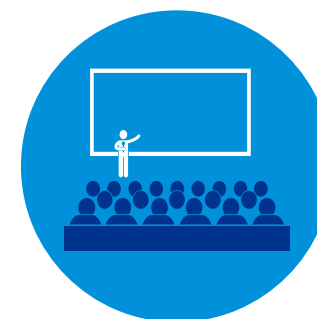
## What are the key features of the intervention?

### Training for general dermatologists:

- UMCU delivers symposiums to general dermatologists, trainee dermatologists and ANPs in the region every 4 months (covering AD and other dermatology topics). This takes place in a hotel conference centre in Houten. The structure is plenary sessions followed by discussions and runs from 6pm-10pm with a hotel buffet provided

### Training for GPs, trainee GPs and trainee dermatologists:

- UMCU runs a bi-annual dermatology training event in collaboration with the PAO-H (Post Academisch Onderwijs voor Huisartsen / Post Academic Education for General Practitioners) and UMCU's Julius centrum for Health sciences and primary care
- PCPs and PCP trainees travel from across the Netherlands for these full day sessions which encompass lectures on many dermatological conditions, including AD. Registration is via the PAO-H website
- Other lectures for trainee dermatologists are arranged by Cursorisch Onderwijs (COCOM) committee / Dutch national teaching committee for dermatologists in training and delivered by members of UMCU faculty and sometimes hosted at UMCU. These are full day lecture and discussion sessions



**Sources:** (a) Munidasa D, et al. What Should General Practice Trainees Learn about Atopic Eczema? *J Clin Med* 2015;4(2):360–368. doi:10.3390/jcm4020360; (b) Chen JJ, et al. Atopic keratoconjunctivitis: A review. *Journal of the American Academy of Dermatology* 2014;70(3):569 – 575; (c) Ellis RM, et al. Potential barriers to adherence in pediatric dermatology. *Pediatr Dermatol* 2011;28:242-4 (d) Arkwright P, et al. Management of Difficult-to-Treat Atopic Dermatitis. *J Allergy Clin Immunol: In Practice* 2013;1:142-51. doi: 10.1016/j.jaip.2012.09.002

# HCP education (2/2)

## Key features of the intervention continued

### Training for nurses:

- 2 AD Advanced nurse practitioners (ANPs) offer bedside teaching to nurses less experienced in AD, particularly paediatric nurses in the children's hospital
- The ANPs have also established a regular training afternoon (every 4 months) called the "Nurse Platform", which runs 4-7pm within UMCU and sees specialist dermatologists lecture nurses on different topics. Lectures have 30-40 attendees, consisting of dermatology nurses (paediatric and adult), primary care nurses and trainee dermatologists from across the region

### Challenges

- Primary and secondary care consultations are often very short, making it difficult to provide in-depth education and treatment information for patients<sup>(a)</sup> (e.g. primary care physicians [PCPs] and general dermatologists in peripheral care centres [PCCs] have ~10 minutes per consultation)

## What are the outcomes so far?

### Benefits to patients:

- Quicker access to expert information from community HCPs with up-to-date knowledge
- Improved AD control in primary and secondary care settings
- Reduced need to travel to specialist centres

### Benefits to HCPs:

- PCPs and general dermatologists have the opportunity to receive AD-specialist education and ask questions
- Fewer inappropriate referrals and avoidable disease progression reduced (e.g. flares)
- Strengthened specialist-primary / secondary care relationship (improving formal and informal referral / knowledge pathways)

## What's next?

- The centre plans to continue innovating and expanding its training initiatives (e.g. more symposia providing general dermatologists with training and recent research developments)
- Future initiatives hope to highlight the importance of early ophthalmology referral for ocular conditions in patients with AD

“



A high proportion of our referrals involve patients who could be managed by topical steroids alone, but they are either non-compliant or have never been taught correctly

*Dermatologist, UMCU*

“



We regularly deliver bedside teaching to patients, parents and general paediatric nurses who haven't had specific AD training

*Dermatology specialist nurse, UMCU*

**Sources:** (a) Arkwright P, et al. Management of Difficult-to-Treat Atopic Dermatitis. *J Allergy Clin Immunol: In Practice* 2013;1:142-51. doi: 10.1016/j.jaip.2012.09.002

# Established ophthalmologist working relationship (1/3)

## Overview

- The dermatology department collaborates closely with 1 ophthalmologist (anterior chamber specialist, with a special interest in dermatology) to manage AD patient eye comorbidities and treatment side effects

**Sources:** (a) Thyssen JP, et al. Incidence, prevalence, and risk of selected ocular disease in adults with atopic dermatitis. *J Am Acad Dermatol.* 2017;77(2):280-28; (b) Garrity JA, et al. Ocular complications of atopic dermatitis. *Can J Ophthalmol* 1984;19(1):21-4; (c) Eiseman AS. The ocular manifestations of atopic dermatitis and rosacea. *Curr Allergy Asthma Rep.* 2006;6(4):292-8.



## What is the rationale?

- Eye comorbidities are common in AD patients, resulting from the disease itself and / or AD treatment. The risk of development is highest in patients with severe AD<sup>(a)</sup>
- 25-40% of AD patients have incidence of ocular involvement<sup>(b)</sup> and they are often referred late
- Ocular disease is not directly correlated with disease control (i.e. if AD is well-controlled, this does not always mean eye comorbidities are well-controlled)<sup>(c)</sup>
- Ophthalmologists are required to manage exacerbations that need aggressive treatment in order to reduce ocular inflammation (which can lead to permanent loss of vision if untreated<sup>(c)</sup>)

## What are the key features of the intervention?

- The dermatology department works closely with an anterior chamber specialist ophthalmologist experienced in ocular dermatological conditions

*Note: the relationship with the ophthalmology department was established over 10 years ago and has continued following the retirement and recruitment of new clinicians*

- All AD patients are screened for ocular involvement during dermatologist consultations and are referred to ophthalmology as required (i.e. patients presenting with eye comorbid conditions). Approximately 10% of the specialist ophthalmologist's patients are referred from the AD clinic

*Note: patients may be referred from outside the centre but this happens rarely*

### Format of consultation:

- First consultation lasts ~50 minutes
- Tests conducted:
  - Visual Acuity (VA)
  - Intraocular pressures
  - Refraction
  - Corneal topography
- Patients are prescribed treatment (e.g. lubricating eye drops/cyclosporine/tacrolimus) if required
- All patients receive education regarding their eye condition, treatment and aftercare (e.g. how to properly clean their eyes themselves)
- Follow-up appointments take place 2–4 months later and involve repeats of relevant tests conducted previously

# Established ophthalmologist working relationship (2/3)

## What are the key features of the intervention? (cont.)

- Ophthalmologists also deliver medical education by publishing articles and training colleagues both within ophthalmology and dermatology and both within UMCU and outside UMCU. Teaching frequency is every 6 months and delivered on AD ocular comorbidities and treatment side effects

## Challenges

- A growing number of patients are being referred to the specialist ophthalmologist, as more physicians are becoming aware of AD eye comorbidities and ocular treatment side effects<sup>(a)</sup>

## What are the outcomes so far?

### Benefits to patients:

- Improved eye health and regular monitoring
- Quick access to a specialist ophthalmologist for AD eye comorbidity treatment

### Benefits to HCPs:

- Easy referrals for AD-specialised eye care
- Improved control of eye conditions through early intervention(s)

## What's next?

- Continue the impression cytology clinical pilot developed at UMCU, exploring AD patient ocular goblet cells and how they may be impacted by new therapy regimens
- Validate the scoring system developed by the UMCU ophthalmology department (developed by adapting the current literature to create a standardised assessment for AD related eye manifestations)
- Establish an outpatient polyclinic in June 2019 (every Tuesday afternoon) for allergic eye conditions, in which AD patients with ocular involvement will be seen by both the dermatologist and the ophthalmologist in one clinic

**Sources:** (a) Interviews during UMCU site visit

“

Ocular manifestations of AD are hard to diagnose but can be very debilitating

Ophthalmologist, UMCU



“

I'd like to see my patients earlier than I do. Unfortunately, I often receive referrals after damage has occurred and is somewhat irreversible

Ophthalmologist, UMCU



CONTENTS



APPENDIX  
CENTRE REPORTS

# Established ophthalmologist working relationship (3/3)

## UMCU developed an ophthalmology screening form

Ophthalmologists and dermatologists at UMCU developed the below registration form (in Dutch) to monitor eye complaints from AD patients on biologic treatment

- This registration form includes subjective patient complaints as well as criteria for ophthalmologists to check for during ophthalmic examination. These signs include:
  - Bulbar / ocular conjunctivitis
  - Palpebral conjunctivitis
  - Blepharitis
  - Meibomian gland dysfunction
  - Limbal oedema / Limbitis, Limbal stem cell deficiency
  - Cornea punctate epithelial erosions
  - Superficial and Stromal vascularisation

Cornea; cornea punctate epithelial erosions  
☐ yes ☐ no ☐ right eye ☐ left eye  
☐ mild ☐ moderate ☐ serious

Superficial vascularization  
☐ yes ☐ no ☐ right eye ☐ left eye  
☐ mild ☐ moderate ☐ serious

Stromal (deep) vascularization  
☐ yes ☐ no ☐ right eye ☐ left eye  
☐ mild ☐ moderate ☐ serious

Other relevant information about the cornea: .....

Other relevant clinical information: .....

Appendix: Registratieformulier bij oculaire manifestaties van dupilumabbehandeling versie 03/07/2018

**Algemene informatie**

Naam: .....  
 Geboortedatum: .....  
 Geslacht: .....  
 Adres: .....  
 Telefoon: .....  
 E-mail: .....

**Oculaire manifestaties**

Bulbaire conjunctivitis: .....  
 Palpebrale conjunctivitis: .....  
 Blepharitis: .....  
 Meibomiair gland dysfunctie: .....  
 Limbitis: .....  
 Limbaal oedeem: .....  
 Limbaal stamceldeficiëntie: .....  
 Cornea: cornea punctate epithelial erosions: .....  
 Superficiële vascularisatie: .....  
 Stromale (diepe) vascularisatie: .....

**Overige relevante informatie**

Overige relevante informatie omtrent conjunctivitis: .....  
 Overige relevante informatie omtrent blepharitis: .....  
 Overige relevante informatie omtrent meibomiair gland dysfunctie: .....  
 Overige relevante informatie omtrent limbitis: .....  
 Overige relevante informatie omtrent cornea: .....  
 Overige relevante klinische informatie: .....

Verzorgd door: ..... ingesloten door: ..... ingesloten door: .....

Datum: .....

De registratieformulier wordt toegezonden in het UMCU en het UMCU geeft het aan de behandelende arts en de arts van de ophthalmologie wordt hiervan in kennis gesteld.

Utrecht, 14 oktober 2018

“

It is important to monitor ocular manifestations in AD

Ophthalmologist, UMCU



Cornea; cornea punctate epithelial erosions  
☐ yes ☐ no ☐ right eye ☐ left eye  
☐ mild ☐ moderate ☐ serious

Superficial vascularization  
☐ yes ☐ no ☐ right eye ☐ left eye  
☐ mild ☐ moderate ☐ serious

Stromal (deep) vascularization  
☐ yes ☐ no ☐ right eye ☐ left eye  
☐ mild ☐ moderate ☐ serious

Other relevant information about the cornea: .....

Other relevant clinical information: .....

**Complaints:**

redness: .....  
 flood of tears: .....  
 itching: .....  
 pain: .....  
 photophobia: .....

**Ophthalmic examination**

Bulbar conjunctivitis: .....  
 Palpebral conjunctivitis: .....  
 Other relevant information regarding conjunctivitis: .....

Eyelid; blepharitis: .....  
 Other relevant information regarding blepharitis: .....

Eyelid; Meibomian gland dysfunction: .....  
 Other relevant information regarding glandular dysfunction: .....

Limbus; Limbal oedema: .....  
 Limbitis: .....  
 Limbal stem cell deficiency: .....  
 Hurricane flu pattern: .....

Other relevant information regarding limbus: .....

Sources: (a) Balak DMW et al, Conjunctivitis als bijwerking van dupilumab bij constitutioneel eczeem, NTVDV 2018-08

# Integrated dermatology-allergology specialists (1/2)

## Overview

The centre has embedded physicians throughout the department with both dermatology and allergy expertise



## What is the rationale?

- Atopic march is a complex, multi-faceted condition with comorbidities which span allergy and dermatology<sup>(a)</sup>. Recognising the relationship between allergy and AD is important for ensuring continuity of care for AD patients
- The allergy and dermatology specialities involve different training pathways. There are very few allergologists in the Netherlands (since the speciality lost recognition in 1996<sup>(b)</sup>) and therefore dermatologists with a sub-specialism in allergy are more common<sup>(b)</sup>

## What are the key features of the intervention?

- The centre has **3** cross-trained dermatologists with an allergy sub-specialism who, in addition to seeing AD patients (in the AD clinic), see patients with comorbidities / other allergic conditions:

**1 Professor of Dermatology-Allergology** (one of only 2 professors of Dermatology-Allergology in the Netherlands)

- Sees patients with AD, food allergy, drug allergy, urticarial angioedema and allergic rhinitis
- Is assisted with rhinitis and mild asthma patients by an otolaryngologist (ENT) trainee and rhinitis Advanced Nurse Practitioner (ANP)

**2 Dermatologist with food allergy sub-specialisms** (which makes the centre the only tertiary treatment centre in the Netherlands treating both food allergy and AD)

- Sees patients with AD and food allergy

Note: There is a dedicated food allergy clinic with a waiting time of 1-4 weeks, depending on referral urgency. Clinics include skin prick tests, blood allergy tests, interpreted by the dermatologist, and food diary discussions (with a dietician)

If required, patients are offered food and drug allergy provocation testing in either the day case unit or as inpatients (if the allergy is suspected to be a late phase reaction)

**3 Clinical immunologist-allergologist**

- Sees patients with AD, asthma (on immunotherapy) and suspected syndromes mimicking asthma and allergy (e.g. mast cell activation syndrome)

**Sources:** (a) Brunner PM, et al. Increasing Comorbidities Suggest that Atopic Dermatitis Is a Systemic Disorder. *Journal of Investigative Dermatology* 2017;137(1):18 – 25. doi: 10.1016/j.jid.2016.08.022; (b) Fyhrquist N, et al. The roadmap for the Allergology specialty and allergy care in Europe and adjacent countries. An EAACI position paper. *Journal of Clinical and Translational Allergy* 2019;9:3. doi: 10.1186/s13601-019-0245-z



# Integrated dermatology-allergology specialists (2/2)

## What are the outcomes so far?

### Benefits to patients:

- Dermatology and allergology advice received in one consultation (reduced patient burden)
- Access to a holistic dermo-allergy perspective regarding their condition(s)

### Benefits to HCPs:

- Fewer consultations required across specialties
- Patients may be segmented by sub-speciality, enabling specific care (e.g. AD patients with allergic rhinitis see the appropriate specialist)
- HCPs are able to learn from experts in the variety of AD comorbidities and referral between individuals is easier as they work under the same department and often share clinics

## What's next?

- The centre is currently training two clinical immunologist-allergologists on a new training pathway

“



Allergic rhinitis with concomitant AD is better suited with dermatologists rather than pulmonologists, however if they are severe we will refer to pulmonology for joint care

*Dermatologist, UMCU*

“



Most patients with AD and mild asthma prefer to be seen by us for both conditions rather than having to attend two appointments

*Dermatology ANP with rhinitis sub-specialism, UMCU*



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CENTRE REPORTS



# Dermatology Advanced nurse practitioner (ANP) (1/2)

## Overview

Dermatology-specialised Advanced Nurse Practitioners (ANPs) at the centre run patient consultations covering treatment plans (overseen by a dermatologist) and provide in-depth patient education

**Sources:** (a) Schuttelaar ML, et al. Costs and cost-effectiveness analysis of treatment in children with eczema by nurse practitioner vs. dermatologist: results of a randomized, controlled trial and a review of international costs. *Br J Dermatol.* 2011;165(3):600-11; (b) Dutch Professional Nurse Practitioner Organisation (V&VN VS) [Website] <https://venvnvs.nl/venvnvs/information-in-english/> Accessed 25 July 2019



## What is the rationale?

- Consultations with Advanced Nurse Practitioners (ANPs) in the Netherlands have been found to produce similar AD patient outcomes to consultations delivered by dermatologists. ANP consultations actually result in higher patient satisfaction<sup>(a)</sup> (and are more cost effective)
- Nurses are often able to have longer patient consultations than dermatologists, allowing them to provide more in-depth education and answer questions from patients

## What are the key features of the intervention?

- In order to become an ANP, nurses must complete a two year Master level study at a University of Applied Sciences and graduates receive a Master of Science degree. This involves two years of study<sup>(b)</sup>
- UMCU employ 5 ANPs (also called 'specialist nurses') in the dermatology department, who work in both the inpatient and outpatient settings
- Each nurse has a sub-specialty, including:
  - Atopic dermatitis (2)
  - Provocation testing (1)
  - Rhinitis and urticaria angioedema (1)
  - Food allergy (1)

### Outpatients

- During the first consultation AD patients will have a treatment discussion (with a dermatologist, a trainee dermatologist or ANP) and an education session (with a dermatology nurse [if visited by the trainee dermatology first] or the same ANP)

1

#### Dermatologists / trainee dermatologist or ANP performs (30 mins):

- history / atopy
- physical examination
- eczema score
- treatment goals
- laboratory tests

2

#### Dermatology nurse or ANP performs (30–45 mins) :

- skin care / FTU / emollient
- instruction of topical steroids
- flare management
- website and patient portal
- psychological problems

- ANPs receive supervision and support from a dermatologist at all times, and all patients are discussed in the weekly multidisciplinary team meeting (including: therapeutic options and timeline; indication for systemic treatments / biologics; requirements for additional tests and consultation / referrals to other specialists)

# Dermatology ANP (2/2)

## Outpatients (cont.)

- Patients seen by ANPs are followed-up in the same manner as if they were seen by a dermatologists or trainee dermatologist. They are booked into the next available clinic required for their case prioritisation and may be seen by an ANP or dermatologist at their next clinic appointment

## Inpatients

- The AD ANPs run a group discussion with AD inpatients once a week, followed by an informal quiz to test patient knowledge and revisit any knowledge gaps

## Challenges

- Patients sometimes prefer to see a doctor rather than a specialised nurse. However, once it has been explained that all consultations are supervised by a dermatologist - and that all cases are discussed as a team - patients are usually satisfied with attending an ANP consultation

## What are the outcomes so far?

### Benefits to patients:

- Faster access to specialist advice and treatment (as more consultations are available)
- Some patients feel more comfortable asking questions to / discussing wider disease impact with a nurse

### Benefits to HCPs:

- Sharing of workload with nurses (which is both time and cost-efficient)
- Offering patients access to a multi-disciplinary team involving nurses

## What's next?

- Increase the number of dermatology nurses (who are unable to prescribe) to train to become ANPs and thus become qualified to prescribe
- Increase the number of nurses who may deliver day case allergy provocation testing
- ANPs continue to arrange AD-specific training for general dermatology nurses (paediatric and adult) and primary care nurses via the centre's Nurse Platform programme (see case study pg. 300 - 301)

“



The ANPs are very capable and are very useful in educating patients and performing provocation testing. We are hoping to train more

*Dermatologist, UMCU*

“



Most patients don't mind who they are seen by, as long as the information is correct. We are often less rushed than the dermatologists also

*Dermatology specialist nurse, UMCU*



APPENDIX  
CENTRE REPORTS

# Inpatient education

## Overview

- The centre utilises their time with inpatients to improve patient education and build patient relationships

**Sources:** (a) Wollenberg A, et al. Consensus-based European guidelines for treatment of atopic eczema (atopic dermatitis) in adults and children: part II. *J Eur Acad Dermatol Venereol* 2018;32(6):850-878. doi: 10.1111/jdv.14888



## What is the rationale?

- The centre is one of the only hospitals in the Netherlands with an inpatient dermatology unit
- Patient education and its link to compliance are extremely important in AD care<sup>(a)</sup>
- Inpatients are a captive audience (and often have severe and/or poorly managed AD), and can benefit from additional education

## What are the key features of the intervention?

- The dermatology department has beds available for 6-10 patients
- Inpatients include:
  - Patients admitted with AD flares
  - Patients with concomitant infection of their AD
  - Patients who are undergoing allergy provocation testing and require longer periods of observation (as late phase allergic reaction is suspected)
- During the first days of admission for AD flares, nurses apply topical therapies for the patients. As patients improve, they are taught the correct methods, amounts and frequencies of application and nurses supervise administration
- Nurses also advise patients on the best way to shower, wash hands and dry themselves
- Social workers also meet with inpatients. They watch a 90-minute video together which discusses AD and the impacts of living with a chronic disease. An informal quiz follows, which allows patients to test their knowledge and revisit topics as required
- There may also be a group discussion for AD inpatients, facilitated by the social worker

## What are the outcomes so far?

### Benefits to patients:

- Improved understanding of their condition
- Practical training on best management approaches (e.g. how to shower/wash hands, apply topical therapy and dry yourself)
- Improved patient-HCP relationships

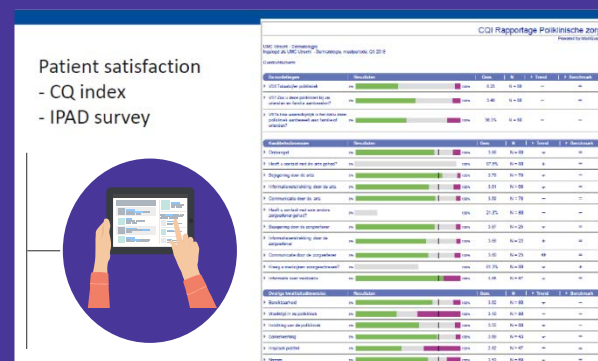
### Benefits to HCPs:

- Less time required in clinic to educate patients
- Time with patients is optimised while they are in the hospital

# Clinical internal audits

## Overview

- UMCU performs regular internal audits of their services and patient satisfaction levels, and has a working group dedicated to improving care provision



## What is the rationale?

- The centre seeks continuous improvement to provide a better service for AD patients
- In order to maintain its TRFE (top reference centre) and TRE (top referral centre) statuses, the centre must continue its expertise in the following targeted disease areas:
  - TRFE for: Constitutional Eczema; Allergy in children; Eczema in children; Food allergy
  - TRE for: Drug reactions; Photo dermatology

## What are the key features of the intervention?

### National CQI (consumer quality index):

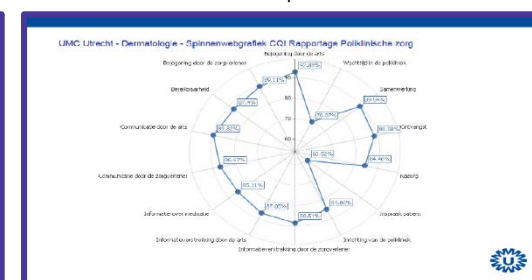
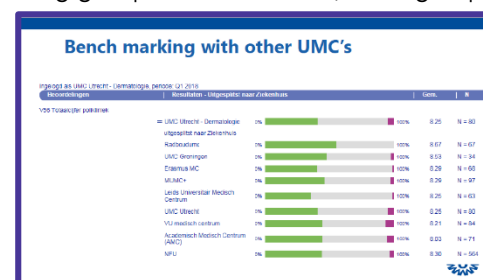
- The centre participates in the national CQI report on outpatient dermatology care, involving a mail questionnaire or online survey assessing patient experiences. The results are then benchmarked against the other 8 University Medical Centres in the Netherlands

### Centre iPad survey:

- UMCU also performs its own iPad survey every quarter, in which patients fill out questionnaires on iPads provided before and after their outpatient appointments. This has been in place for 1.5 years
- The centre has a working group named S.V.P. (*Samen voor de patient*), which translates as "Together for the patient". This working group creates the questions for the iPad survey
- The S.V.P. involves doctors, nurses and reception staff. They then analyse and address the feedback from the survey in order to implement improvements in the department

## What are the outcomes so far?

- The iPad surveys identified two areas for improvement (*waiting for appointments* and *patient participation*)
- The S.V.P. investigated further with patients to understand the reasons behind these lower scores
- The working group addressed this, seeing improvements in their next quarter iPad results



iPad survey questionnaire results benchmarking and analysis

# Transitional processes into adult clinic

## Overview

The period of transition into adulthood can be difficult for those with chronic conditions, so the centre offers consistency in HCPs seeing these patients



AD patients prefer to have their HCPs consistent for the transition into adulthood

*Advanced dermatology nurse practitioner, UMCU*



## What is the rationale?

- The majority of patients outgrow atopic dermatitis in childhood or early adolescence, but approximately 25% continue to have eczema into adulthood<sup>(a)</sup>
- Adolescents with AD have been found to have elevated rates of anxiety (20%) and depressive disorders (10%) compared to the general population<sup>(b)</sup>
- Factors such as poor compliance or incorrect medication use can be common in adolescent populations<sup>(c)</sup>. Health care professionals (HCPs) must address these observations to improve treatment outcomes for adolescent patients<sup>(d)</sup>

## What are the key features of the intervention?

- It is normal for patients to be seen in either paediatric or adult clinics from the ages of 16-18, with transition occurring when the clinician feels the patient is ready to move to adult care
- AD patients requiring admission to hospital will generally be admitted to the dermatology ward of the adult hospital, so they can receive specialist nurse care
- Younger patients (below ~7 years) requiring admission will be admitted to the children's hospital
- A number of HCPs work across paediatric and adult services. These HCPs see patients in the paediatric clinic and continue to see the patient once they have transitioned to the adult clinic
- Transitional HCPs include 2 dermatologists, 3 ANPs, 1 dermatologist-allergologist and 2 dieticians:
  - AD-specialised Advanced nurse practitioners (ANPs) travel to visit these patients twice a day and teach the paediatric nurses, patients and parents about the child's condition
  - The dermatologists, dermatology-allergologist and dieticians will visit paediatric patients in the paediatric hospital as required

## What are the outcomes so far?

### Benefits to patients:

- Paediatric patients are familiarised with adult HCPs and have opportunities to ask questions
- Strong relationships built between patients, parents and specialists

### Benefits to HCPs:

- Continuity of care means HCPs are familiar with a patient's treatment history
- HCPs can build relationships with patients and establish improved treatment compliance

**Sources:** (a) Thomsen SF. Epidemiology and natural history of atopic diseases. *Eur Clin Respir J*. 2015;2:10 doi:10.3402/ecrj.v2.24642; (b) Slattery MJ, et al. Depression, anxiety, and dermatologic quality of life in adolescents with atopic dermatitis. *J Allergy Clin Immunol* 2011;128(3):668–671. doi:10.1016/j.jaci.2011.05.003; (c) Johnson BB, et al. Treatment-resistant atopic dermatitis: challenges and solutions. *Clin Cosmet Investig Dermatol* 2019;12:181–192. doi:10.2147/CCID.S163814; (d) Taddeo D, et al. Adherence to treatment in adolescents. *Paediatr Child Health*. 2008;13(1):19–24

# Innovative educational website: "Leef! Met Eczeem" (1/2)

## Overview

- Website resource with protected login allows patients and their families to access education around various aspects of living with Eczema
- "Leef! Met Eczeem" translates in English to "Live! With Eczema"

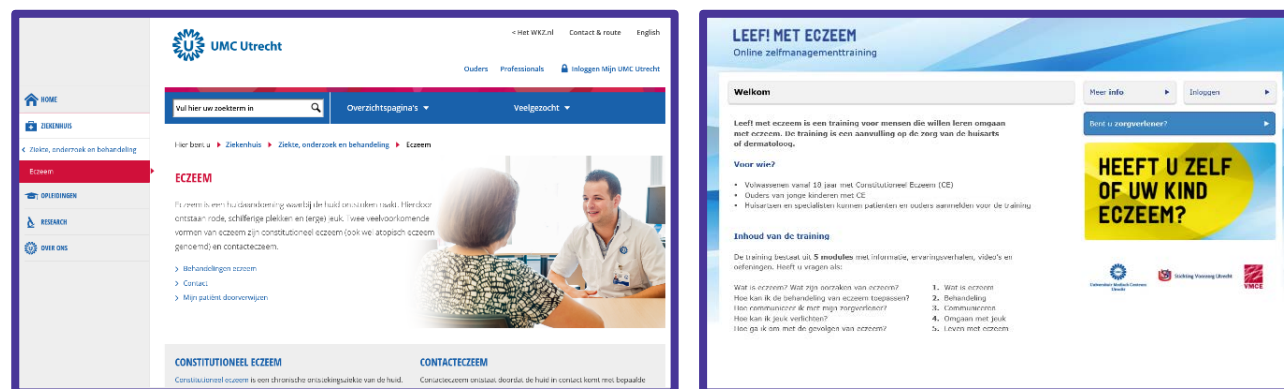
**Sources:** (a) Tarn DM, et al. New prescriptions: how well do patients remember important information? *Fam Med* 2011;43(4):254–259; (b) Tonsaker T, et al. Health information on the Internet: gold mine or minefield? *Can Fam Physician* 2014;60(5):407–408; (c) Leef! Met Eczeem [Website] <https://leefmeteczeem.nl/> Accessed 10 May 2019

## What is the rationale?

- Patients often receive a lot of information during consultations and may struggle to remember more than ~66% of it<sup>(a)</sup>
- Patients may also have additional questions which they either forgot to ask, did not have time to ask or did not wish to ask (due to embarrassment etc.) during their consultation
- With large amounts of eczema / AD information available on the internet, it can be difficult for patients to determine which websites contain the most up-to-date information<sup>(b)</sup>

## What are the key features of the intervention?

- The website contains 5 modules of online training aimed at patients. The training includes background information, patient experience stories, videos, exercises and questions to test knowledge
- The 5 modules are intended as a supplement to the training received from healthcare professionals (HCPs) during consultations, and consist of:
  1. What is eczema?
  2. Treatment types and application methods
  3. Communication with the healthcare provider
  4. Dealing with itching
  5. Living with eczema
- The website is targeted at adults aged 18+ years (i.e. adult AD patients and the parent / guardian of children with AD)



Leef! Met Eczeem website<sup>(c)</sup>



# Innovative educational website: "Leef! Met Eczeem" (2/2)

## What are the key features of the intervention (cont.)?

- The website was developed by UMCU but is available for use by all patients across the country. Many hospitals refer their patients to the website
- As of summer 2019 the number of participants logged with an account include: 1143 adult patients with AD and 1292 parents of a child with AD

## Challenges

- Patient preferences (especially those of young patients, e.g. adolescents) are moving towards mobile applications rather than websites. Patients prefer not needing to remember login details
- As updates are required the funding to update the content will need to be sought

## What are the outcomes so far?

### Benefits to patients:

- Ability to learn about their illness and treatment from a trusted source, and take more accountability for AD management
- Opportunity to test knowledge and reinforce learnings where required
- Allows flexibility in learning as patients may complete it at home and in their own time

### Benefits to HCPs:

- Less face-to-face consultation time spent educating patients (especially those on topical treatments)
- Useful resources available for directing patients to (especially those who are not engaged by traditional learning resources)
- Reduced costs as fewer physical materials are printed and distributed in clinics

## What's next?

- The centre is planning to continue to innovate and mature from e-health to mobile health through the development of a smartphone application - "Zalf" (see case studies pg. 298 - 299)

“

Patients like the ease of access of web pages. They like to know they are reading information approved by us

*Dermatologist, UMCU*



“

We are always trying to innovate. Patients are now using smartphones more, so we came up with the idea to develop an application

*Dermatology nurse, UMCU*





# Dedicated social worker

## Overview

The dermatology and rheumatology department have a shared social worker (with over 30+ years experience) to whom they may refer patients as required



## What is the rationale?

- The effects of skin diseases, such as AD, on the psychosocial well-being of patients is under-appreciated<sup>(a)</sup>
- Improved understanding of the psychiatric comorbidities associated with skin diseases and a biopsychosocial approach to management can improve quality of life for patients<sup>(a)</sup>

## What are the key features of the intervention?

- The department shares a dedicated social worker with the rheumatology department, who splits their time 2/3 dermatology, 1/3 rheumatology. They have attended special training for social work in dermatology ("RINO"<sup>(b)</sup>, based in Amsterdam)
- All dermatology inpatients are assessed by the social worker, along with any outpatients referred by physicians or nurses having identified signs of psychological distress:
  - A psychosocial assessment evaluates the impact of AD on a patient's work, finances and relationships
  - The social worker provides talking therapy, where they discuss what could be changed (and talk to the parents / partners of patients, if the patient consents)
  - (For inpatients only) Patients watch a 90-minute video about living with a chronic disease and participate in a group discussion with other AD patients
- The social worker offers practical help by contacting a patient's employer, arranging transport and liaising with insurance companies. They may refer patients to community psychologists if required

## What are the outcomes so far?

### Benefits to patients:

- Access to psychosocial support
- Improved relationships with centre staff
- Assistance with minimising the lifestyle impacts of AD (e.g. employment)
- Access to community psychologists

### Benefits to HCPs:

- Patient insights received from the social worker at the weekly multidisciplinary team discussion
- Flexibility to allow the different aspects of consultations to be managed and delivered by the appropriate specialists

**Sources:** (a) Barankin B, et al. Psychosocial effect of common skin diseases. *Can Fam Physician*. 2002;48:712–716; (b) Amsterdam post graduate training programmes [Website] <https://www.rino.nl/over-rino> Accessed 03 May 2019

# BioDay registry

## Overview

- A cross-centre registry collecting data on efficacy, safety, drug survival and side effects for patients receiving the new AD biologic therapy



*BioDay Eczema and Atopic Diseases Registry website<sup>(b)</sup>*

**Sources:** (a) Wollenberg A, et al. Consensus-based European guidelines for treatment of atopic eczema (atopic dermatitis) in adults and children: part II. *J Eur Acad Dermatol Venereol* 2018;32(6):850-878; (b) Garritsen FM, et al. J Use of oral immunosuppressive drugs in the treatment of atopic dermatitis in the Netherlands *Eur Acad Dermatol Venereol* 2018;32(8):1336-1342; (c) BioDay. BioDay Register [Website] <http://www.bioday.nl/> Accessed 10 May 2019; (d) U.S. National Library of Clinical Trials [Website] <https://clinicaltrials.gov/ct2/show/NCT03549416> Accessed 26 April 2019



## What is the rationale?

- European AD Guidelines recommend the use oral immunosuppressive drugs in difficult to treat AD cases<sup>(a)</sup>. Daily practice studies however indicate high treatment discontinuation rates due to side effects and/or ineffectiveness<sup>(b)</sup>
- A new biologic therapy for AD patients has been available in the Netherlands since January 2018, at which point effectiveness and safety data had only been collected in clinical trials (not daily practice)<sup>(c)</sup>

## What are the key features of the intervention?

- BioDay is a prospective registry consisting of AD patients who are receiving biologic therapy in the Netherlands (expected enrolment of 1200 patients, with a 10-year target study follow up duration, finishing December 2028)
- Its primary objectives include examining: safety and effectiveness (including patient-reported outcome measures [PROs]), drug survival (and factors effecting it) and objective / subjective side effects
  - As the new biologic may impact AD-related comorbidities, such as asthma, the BioDay registry also includes asthma-related outcomes for the subpopulation of patients that have concomitant asthma
- Participants are treated at 10 centres across the Netherlands, with the majority from UMC Utrecht and UMC Groningen<sup>(d)</sup>. UMC Nijmegen and 7 local hospitals are also involved
- UMC Utrecht and UMC Groningen hold joint IP rights over the data. All participating centres have access only to their own data, however Utrecht and Groningen have access to all the data

## What are expected outcomes?

### Benefit to patients / HCPs:

- Real-world assessment of biologic's effectiveness and safety, drug survival and side effects (to further inform treatment decision making)

## What's next?

- There is the potential to add further novel treatments (biologics and others) to the registry as they become available
- As the whole registry is in English it is suitable for countries outside The Netherlands. The registry is open to other countries and was presented at ADCARE (Atopic Dermatitis Centres of Reference and Excellence) during EAACI (European Academy of Allergy and Clinical Immunology) in spring 2019

# Communication via the patient portal

## Overview

For over 10 years, patients have been able to contact their UMCU dermatologist online (without the need for a physician visit) and receive advice and guidance within 48 hours



The portal helps us reduce unnecessary appointments whilst increasing patient contact

*Dermatologist, UMCU*



## What is the rationale?

- Long waiting times for specialist advice and care can deter patients from seeking and attending appointments<sup>(a)</sup>. Patients are often limited by the inflexibility of their own schedules and the inability of specialist centres to arrange consultations at short notice
- Most patients have access to the internet via a computer, tablet or smartphone, with over 98% of homes in the Netherlands connected to the internet<sup>(b)</sup>

## What are the key features of the intervention?

- For the past 10+ years, patients already known to UMCU have been able to upload photos and questions to a confidential personal online portal within their electronic patient file
- A secretary monitors uploads and forwards photos / questions to the appropriate dermatologist. This equates to 1-2 hours of work a week for the centre dermatologists
- Patients receive a response from a dermatologist within 48 hours (either treatment advice or repeat prescription confirmation or reply with a request for further information). Dermatologists may call the patient directly or respond to the comment through the patient portal
- Patients may also fill in patient reported outcome (PRO) measures through the portal
- While the dermatology department is the main user of the portal, it is also used by other specialisms within the centre, including diabetologists and rheumatologists

## What are the outcomes so far?

### Benefits to patients:

- 20% of the centre's AD patients use the portal
- Faster receipt of specialist advice
- Reduced financial and logistical burden (from traveling to centre)
- Ability for patients to track their progress (using historic photos) and access previous advice

### Benefits to HCPs:

- Reduced number of face-to-face appointments
- Ability to provide advice quicker and more frequently (reducing the likelihood of disease progression / flares)
- Increased opportunity and likelihood of data capture (as patients can fill in PROs at their convenience)

**Sources:** (a) Van Dijk CE, et al. Compliance with referrals to medical specialist care: patient and general practice determinants: a cross-sectional study. *BMC Fam Pract* 2016;17:11; (b) Centraal Bureau voor de Statistiek [Website] <https://www.cbs.nl/en-gb/news/2018/05/the-netherlands-leads-europe-in-internet-access> Accessed 3 May 2019





# Hospital La Paz

**Madrid, Spain**

Site visited by KPMG 5–6<sup>th</sup> March 2019

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[kpmg.com/uk](https://kpmg.com/uk)



APPENDIX  
CENTRE REPORTS



# Summary



## Context

**Centre type:** Public hospital located in Madrid

**Catchment area:** ~700,000 patients from Madrid (and across Spain)

**Funding:** The centre is funded by the Community of Madrid, which then allocates resources to each department within the hospital

**Services:** The centre has a General Hospital, Maternal Hospital, Children's Hospital and Hospital of Traumatology and Rehabilitation. The dermatology unit has two sections: one in the General Hospital and the other in the Children's Hospital (with consulting rooms in both sites)

**Patient population:** The dermatology unit serves adult and paediatric dermatology patients with a range of conditions (e.g. atopic dermatitis [AD], angioedema, psoriasis)



## Key strengths in the delivery of AD care

**Provision of holistic care for AD and comorbidities:** An integrated group of different specialists (e.g. dermatologists, allergists, ophthalmologists, pulmonologists) coordinate closely to provide streamlined, holistic care for AD patients which reduces duplication of workload across teams

**Specialism in range of dermatological conditions:** All dermatologists within the dermatology unit specialise in AD, in addition to individually specialising in other dermatological conditions (e.g. angioedema, urticaria)

**Established centre-community network:** The centre works closely with community care providers (primary care physicians and peripheral care centres) through referral networks and the provision of education and training



## Key challenges faced in delivery of AD care

**Complicated layout of centre:** Can make navigating between specialties difficult for patients

**Very severe patients are more likely to be referred to the centre:** They can be more difficult / resource-intensive to manage (e.g. require specialist treatment)

**Limited human resources and funding:** This constraint can put pressure on the existing dermatology staff

**AD patients (severe) may not always present to the unit / community practices:** As they may opt to stay at home and self-treat, it can make it difficult to identify and treat these patients

**High demand for dermatology unit:** As patients from across Madrid may self-select La Paz as their hospital of choice (in addition to it being a national reference centre), the dermatology unit is in very high demand

# Atopic Dermatitis (AD) in Spain

## Spanish healthcare system:

The Spanish National Healthcare System ("Instituto Nacional de la Salud") provides free healthcare for Spanish nationals (and resident foreigners), funded through taxation<sup>(a)</sup>

There are three organisational levels:

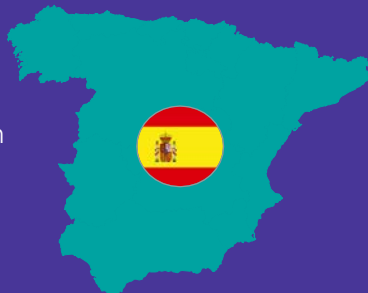
1. Central (Organizacion de la Administracion Central) – in charge of issuing health proposals and planning and implementing government health guidelines
2. Autonomous Community (Organizacion Autonómica) – responsible for offering integrated health services to the regional population
3. Local (Areas de Salud) – accountable for unitary management of the health services offered at Autonomous Community level

## Madrid healthcare system:

Madrid is an Autonomous Community (AC) responsible for its own healthcare funding<sup>(b)</sup>. The AC is divided into 7 areas, each with their own hospitals, peripheral care centres (PCCs) and health centres (employing primary care professionals [PCPs])<sup>(c)</sup>. Each of the 7 areas has 1 medical director and 1 nursing director. Patients in Madrid may self-select which hospital in Madrid they receive specialist AD treatment from (note: not all hospitals provide specialist AD care)<sup>(c)</sup>

## Prevalence

- AD affects 10-20% of children and 1-3% of adults in Western countries<sup>(d)</sup>
- In Spain, the prevalence of severe AD in adults is approximately 5%<sup>(e)</sup>
- The prevalence of AD associated comorbidities with severe AD in Spain includes: asthma (24%); depression (21%) and allergic rhinitis (19%)<sup>(e)</sup>



## Care provision:

### Location:

- Mild and moderate (or well-controlled) AD care is usually managed by PCPs
- Severe and very severe (or uncontrolled) AD care is usually managed by dermatologists within hospitals

### Funding:

- Primary care is funded by autonomous communities<sup>(f)</sup>
- Hospital funding is negotiated through a contract programme between the hospital and a regional authority third-party payer<sup>(e)</sup>

## Guidelines and societies:

### Guidelines:

- Guidelines for treatment of atopic eczema (atopic dermatitis) part I and part II: European Association of Dermatology and Venerology (EADV)
- Clinical practice guidelines in Dermatology: Spanish Academy of Dermatology and Venereology (AEDV)

### Medical society:








- Spanish Academy of Dermatology and Venereology (AEDV)

### Patient association group (PAG):

- Asociación de afectados por la dermatitis atópica (AADA)

**Sources:** (a) Health management. Overview of the Spanish Healthcare System [Website] <https://healthmanagement.org/c/hospital/issuearticle/overview-of-the-spanish-healthcare-system> Accessed 5 Feb 2019; (b) Economist Intelligence Unit (EIU): Value-based healthcare in Spain, Regional experimentation in a shared governance setting [PDF] <https://eiuPerspectives.economist.com/sites/default/files/ValuebasedhealthcareEurope.pdf> Accessed 1 Feb 2019; (c) KPMG interviews; (d) Nutten S. Atopic dermatitis: global epidemiology and risk factors. *Ann Nutr Metab*. 2015;66 Suppl 1:8-16; (e) Sicras-Mainar A, et al. Prevalence of Severe Atopic Dermatitis in Adults in 3 Areas of Spain. *J Investig Allergol Clin Immunol* 2018;28(3):195-197; (f) Garcia-Armesto S, et al. Spain: Health system review (2010) [Website] [http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0004/128830/e94549.pdf](http://www.euro.who.int/__data/assets/pdf_file/0004/128830/e94549.pdf) Accessed on 7 Mar 2019

# The hospital and dermatology unit





The hospital				
 <b>Type and location</b>	Large public hospital, located in Madrid, which collaborates with 3 Peripheral Care Centres (PCCs) and 20 health centres (i.e. family doctors). Hospital La Paz is a National Reference Centre for Spain. IdiPaz is a research institute located at the centre (which performs studies across specialties).			
 <b>Population served</b>	530,000 patients in Madrid with an additional 20% from external referrals (total ~700,000 patients)			
The dermatology unit				
 <b>Service Division</b>	<b>Outpatients</b>	<b>Day hospital</b>	<b>Emergency department (dermatology)</b>	<b>Inpatients</b>
 <b>Hours of availability</b>	08:00 – 17:00	24 / 7	24 / 7	24 / 7
 <b>No. of patients seen</b>	60,000 consultations / year in dermatology (in the centre and PCCs); 70% of these are conducted in the PCCs (>40,000)	30 patients / month (including 40 patients / day for phototherapy)	6000 patients / year (25-30 patients / day; 50% are new patients and 50% are patients with flare)	70 admissions / year
 <b>Types of patients seen</b>	AD patients including children (mild, moderate and severe) and adults (mild, moderate and severe [10% of patients are severe; 2-3% of patients are very severe]). The unit has ~400 moderate-severe patients and ~50 very severe patients			
 <b>Facilities on-site<sup>(1)</sup></b>	<ul style="list-style-type: none"><li>— Phototherapy (PUVA)</li><li>— Laboratory (in vivo and in vitro testing)</li><li>— Hospital pharmacy</li><li>— Day hospitals (1 for paediatrics and 1 for adults) with low complexity allergy tests (e.g. skin prick testing, spirometry), high complexity allergy tests (e.g. bronchial challenge, food / drug challenge) and treatment (immunotherapy)</li><li>— Allergy (classified to disorder, e.g. general allergy, drug allergy, dermo-allergy) and dermatology consulting rooms</li></ul>			

**Note:** (1) List of facilities is not exhaustive




# The team

## Core team profiles

-  16 dermatologists (including 1 clinical trial manager)
-  8 dermatology residents
-  4 dermatology nurses
-  13 clinical (healthcare) assistants

## Wider team profiles

- Allergy centre:
  -  1 head allergist
  -  10 allergists (including 1 clinical trial manager and 1 allergist with a special interest in psychology)
  -  5 paediatric allergists
  -  7 residents
  -  1 pharmacist (based in laboratory)
  -  1 senior researcher
  -  10 nurses
  -  2 administrative staff
-  1 hospital pharmacist (specialised in biologics)
-  1 ophthalmologist
-  1 clinical service coordinator (based in allergology)
-  1 primary care coordinator



## Governance and processes

### Team meetings:

- *Clinical case presentation (once a week for both dermatology and allergy):*
  - Attended by all staff at the centre
  - Purpose of the meeting: discuss patient case studies and disseminate knowledge
- *Biologics meeting (once a month):*
  - Attended by dermatologists and pharmacists
  - Purpose of meeting: review patients on biologics / agree new patients to be started on biologics
- *Dermatology department meeting (once a month):*
  - Attended by entire department
  - Purpose of meeting: to share complex cases from the skin allergy unit with dermatology
- *Centre-community meeting (every 2 months):*
  - Attended by primary care coordinator and primary care professionals (PCPs)
  - Purpose of meeting: educate PCPs about referring to specialities at the centre

### Patient records:

- *Electronic patient records (EHR):*
  - Shared and accessible by all specialities (across Hospital La Paz and the PCCs)
- *Electronic prescribing:*
  - Prescriptions are written and issued online (within the centre)

# The role of the wider team



## Clinical service coordinator<sup>(1)</sup>

**Patient type:** 'High-need' AD patients at the centre (e.g. severe patients, those with multiple comorbidities or poorly controlled)

**Referral:** referred by dermatologist

**Consultations:** Clinical service coordinator will identify any unmet patient needs (e.g. timing of appointments, holistic care needs) and work to address these. Treatment application / counselling will also be provided

**Timing:** Consultations are estimated to take 30 minutes, every ~2 months (flexible)



## Ophthalmologist

**Patient type:** All severe AD patients and mild-moderate AD patients are seen on an ad-hoc basis

**Referral:** referred by dermatologist

**Consultations:** Ophthalmologist conducts a range of comprehensive screening tests and provides treatment for eye comorbidities

**Timing:** Consultations last 10–30 minutes, every 2 months



## Hospital pharmacist

**Patient type:** AD patients who receive 'hospital only' treatment (dispensed by hospital pharmacist)<sup>(2)</sup>

**Referral:** N/A (patients visit the pharmacy when collecting their 'hospital only' treatment)

**Consultations:** pharmacist provides education (e.g. on self-administration) alongside supply of medicine

**Timing:** First consultation lasts ~10 minutes, while follow-up consultations vary in duration



## Allergist

**Patient type:** AD patients with asthma (severe / non-severe) and those with food and / or drug allergies

**Referral:** referred by dermatologist / referred by primary care professional (PCP) or peripheral care centre (PCC)

**Consultations:** Allergists conduct testing (e.g. food allergy tests [samples are prepared on-site in the laboratory by a specialist pharmacist]), provide immunotherapy treatment (e.g. desensitisation) and give advice to patients. Allergists also manage asthmatic Atopic March patients

**Timing:** Consultations last ~20 minutes

## Additional centre roles<sup>(3)</sup>:

- **Primary care coordinator:** Manages relationship with PCPs (20 health centres in the centre's network). Delivers education and training to PCPs, meetings with PCPs and develops referral protocols between PCPs and the centre
- **Clinical trial managers (1 in allergy and 1 in dermatology):** Identifies potential patients for clinical trials. Completes inclusion criteria to confirm trial participation and manages patient throughout trial. Nurses support with trials patients (e.g. blood tests, caring for patient's wider needs)

**Notes:** (1) Role currently being established and due to be implemented March 2019 (2) Non-hospital treatment (e.g. topical steroids) are dispensed by community pharmacists (3) List of additional centre roles is not exhaustive

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients with symptoms of AD (e.g. itching or dryness of the skin) present to a primary care physician (PCP) who will assess them and refer as required

*Note: AD patients that are mild or well-controlled may be managed in primary care and may not be referred to the centre*

- Patients may present directly to the emergency department of the centre (20% of patients access the centre via this route)

## Diagnosis and Referral

In secondary care



- Patients are contacted by a central call centre in Madrid to schedule their dermatology appointment (patients may select their treatment centre)

- Patients are initially seen at the centre or one of the Peripheral Care Centres (PCCs), which may then refer patients to the centre

- Patients are referred via a "routine" (~1 month), "preferential" (<1 month) or "urgent" (<2 weeks) route

*Note: Patients are required to meet specific criteria to obtain an eczema appointment at the centre (e.g. persistent and chronic eczema not responding to treatment)*

- Dermatologists discuss characteristics, predisposing factors, exposures and carry out tests (e.g. epicutaneous tests) to diagnose AD (consultations ~15mins)

## Treatment and Management

Medical management



- Dermatologists will manage those with severe AD and initiate / modify AD treatment
- Clinical trials (CTs) at the centre provide an opportunity for patients to receive new treatments. CT managers work with dermatologists and allergists to identify potential patients for CTs

*Comorbidity management (not exhaustive):*

- **Allergy:** Allergists will manage Atopic March patients with asthma and food / drug challenges
- **Ophthalmology:** All severe AD patients are referred to an ophthalmologist for screening tests. Mild-moderate patients are referred on an ad-hoc basis (and patients may be referred from outside the centre)
- **Nutrition:** Paediatric and adult nutritionists work with AD patients with food allergies, conducting body composition tests and providing nutritional support

Non-medical management



- Patients are assessed for psycho-social symptoms and are referred to the centre's psychology department for support
- Adjuvant therapy (e.g. phototherapy [PUVA]) provided by the centre
- Patients receive education about AD and treatment during consultations (from physicians and nurses)
  - If patient is receiving hospital-only dispensed treatment (e.g. biologics), pharmacist will also provide education
- AD workshops for adults and children are hosted at the centre (by physicians and nurses), which provide supplementary education and training for patients and their families

## Follow-up

Monitoring of chronic disease / flare up



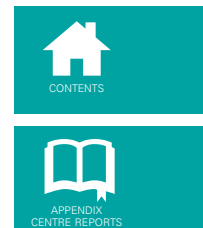
- Patients are followed up at the centre (once / twice a month, with frequency depending on patient need) or referred back to primary care (if well-controlled)

- A clinical service coordinator at the centre provides additional support for 'high-need' AD patients (e.g. additional education on treatment application, consultation booking support)

*Note: The clinical service coordinator role is new and will be implemented in March 2019*

- Dermatologists refer patients to comorbidity specialists (e.g. rheumatologists / gastroenterologists) for specialist input as required

# Overview of interventions in place for AD



**Key:**



Case study available

## Awareness and Presentation

Symptom identification



- **Working relationship with the patient advocacy group (PAG) (AADA):** The dermatology unit works closely with the Spanish AD PAG to raise awareness of AD in the community


 See pg. 329 for case study

## Diagnosis and Referral

In secondary care



- **24-hour allergy testing:** Patients can receive a diagnosis from low-complexity allergy tests on the same day as initial testing (other tests take longer)
- **Primary care dermatology education:** Centre is part of a wider network including 4 peripheral care centres (PCCs) and 20 health centres, established during the government's healthcare restructuring in Madrid. Dermatologists at Hospital La Paz provide education and training for PCPs in this network, including clinical aspects of dermatological conditions (including AD) and referral pathways

 See pg. 330 for case study

 See pg. 331-332 for case study

## Treatment and Management

Medical management



- **Established dermo-allergy unit:** Dermatology and allergy combined ~1 year ago to provide coordinated patient care (currently not co-located)
- **Allergy day hospital:** Day hospital conducts allergy tests (low and high complexity) and provides immunotherapy (desensitisation) and biologics administration
- **High level of specialisation in AD:** All dermatologists at the centre and PCCs are specialists in AD (through training from the AD-lead physician)
- **Ophthalmologist screening appointments:** All severe AD patients are referred to the ophthalmologist for screening tests and monitoring

 See pg. 333-334 for case study

 See pg. 335-336 for case study

Non-medical management



- **Patient / family educational workshops:** Patients and families are invited to workshops at the centre (hosted by physicians and nurses), which aim to provide education across a range of dermatological conditions (including AD)
- **Role of clinical service coordinator:** The centre's clinical service coordinator works with patients to identify unmet needs and provide holistic care (*Note: This role is new and will be implemented in March 2019*)

 See pg. 337-338 for case study

 See pg. 339-340 for case study

## Follow-up

Monitoring of chronic disease / flare up



- **Occupational clinic:** A clinic hosted by the pulmonologist to advise respiratory patients (allergic asthma) on workplace allergens
- **Gastroenterology clinic:** Dermo-allergy unit works with gastro to co-manage patients with eosinophilic esophagitis (a rare condition linked with Atopic March)
- **Collaboration with rheumatology:** Rheumatology is consulted for AD patients with long-term steroid treatment (and therefore at risk of osteoporosis)
- **Pharmacy blog and hotline:** The centre's pharmacists run an online blog and hotline, through which patients can ask questions about treatments (all diseases)



# Monitoring AD patients and their comorbidities

**The centre uses a number of indices and measures for monitoring AD and associated comorbidities.**

## Objective measures (AD):

AD scoring indices are used for monitoring patients and their disease, including:

- SCORAD (SCORing Atopic Dermatitis): clinical tool used to assess the severity of the disease and monitor disease progression<sup>(a)</sup>
- vIGA-AD<sup>TM</sup> (Validated Investigator Global Assessment scale of Atopic Dermatitis): scoring system used to describe the appearance of lesions and AD in clinical trials<sup>(b)</sup>
- EASI (Eczema Area and Severity Index): validated scoring system that grades the physical signs of atopic dermatitis<sup>(c)</sup>

## Patient reported outcomes (PROs)

- DLQI (Dermatology Quality of Life Index): dermatology-related quality of life questionnaire<sup>(d)</sup>
- HADS (Hospital anxiety and depression scale): questionnaire designed to identify depression in patients<sup>(e)</sup>

Standard HADS questionnaire<sup>(e)</sup>

## Centre routinely measures comorbidity outcomes by:

- Allergy: response to allergens / control of atopy disease (e.g. allergy tests [skin prick tests])
- Ophthalmologist: results of screening tests (during regular appointments, e.g. topography, corneal examination)

**Sources:** (a) SCORing Atopic Dermatitis (SCORAD) Calculator (0.9.0) [Website] <http://scorad.corti.li/> Accessed 26 Feb 2019; (b) International Eczema Council (IEC): Investigator Global Assessment Scale [Website] <http://www.eczemacouncil.org/research/investigator-global-assessment-scale/> Accessed 20 Mar 2019; (c) HOME for eczema.org. EASI for clinical signs [Website] <http://www.homeforeczema.org/research/easi-for-clinical-signs.aspx> Accessed 1 Mar 2019; (d) Lewis V, et al. 10 Years Experience of the Dermatology Life Quality Index (DLQI). *J Invest Dermatol Symp Proc* 2004;9:169 –180; (e) Snaith RP. The Hospital Anxiety And Depression Scale. *Health Qual Life Outcomes*. 2003;1:29. doi: 10.1186/1477-7525-1-29

# Next steps for the centre



## What is next for the centre?

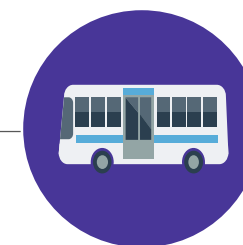
### Objective: Co-location of dermatology and allergy clinics

- **What?** The Hospital La Paz buildings are being redeveloped in a large regeneration programme. The centre's clinics and wards will be re-located
- **Why?** Co-location of the clinics will improve the coordination of care and sharing of resources, which will improve patient experience at the centre



### Objective: Shuttle service to connect Hospital La Paz with Peripheral Care Centres (PCCs) and other hospitals within the network

- **What?** Hospital La Paz is associated with 4 PCCs (located across Northern Madrid) and 2 other hospitals in their network. A shuttle service has recently been implemented to provide patient and staff travel between the sites
- **Why?** Patients may be seen at multiple sites and may be required to travel between them. Sites are not all within walking distance, so providing a shuttle service will assist patients during multi-site visits



### Objective: Develop tools to understand the burden of AD on patient families and wider society

- **What?** The dermatology unit is committed to conducting / contributing to research in order to understand the wider burden of AD on families and society. Specifically, the centre would like to develop tools to understand the wider economic and societal impact of the disease (e.g. the burden of the disease on families) to help improve care for AD patients and their families
- **Why?** An improved understanding of the impact and burden of AD can help centres and healthcare professionals improve care for patients and increase awareness of the disease





# Advice to other centres



## What advice would you give less specialised centres



**Objective of advice:** Provide education for primary care professionals (PCPs) and external centres

- **Why?** Incorrect or unnecessary referrals place additional pressure on centres (specialised and less specialised) and cause stress for patients. Educating and training PCPs (and physicians from smaller centres) helps to reduce unnecessary referrals and ensure patients are sent to the correct specialist / speciality. Accurate and quick referrals may reduce diagnosis times, allowing patients to obtain specialist treatment quicker



# Case studies



<b>Working with the AADA (Patient Association Group)</b>	329
<b>24-hour allergy testing</b>	330
<b>Primary care dermatology education</b>	331 – 332
<b>Established dermo-allergy unit</b>	333 – 334
<b>Ophthalmologist screening appointments</b>	335 – 336
<b>Patient / family educational workshops</b>	337 – 338
<b>Role of clinical service coordinator</b>	339 – 340

# Working with the AADA

## Overview

- The centre works closely with Asociacion de afectados por la dermatitis atópica (AADA), the Spanish AD patient advocacy group (PAG)
- Centre dermatologists assist the PAG with projects and activities and refer patients to them for non-medical support



Asociacion de afectados por la dermatitis atópica



## Asociación de afectados por la dermatitis atópica (AADA) in Spain

- The AADA is a not-for-profit organisation which aims to “bring people affected by AD together to improve their quality of life<sup>(a)</sup>”
- The AADA was set up 2 years ago when the centres (Hospital La Paz and Hospital Sant Pau) introduced the 3 founders to one other and encouraged them to set up the PAG
- The centres have supported the PAG by helping them write AD protocols and introducing them to an existing PAG (so they may learn from their experiences)

### AADA-centre activities:

- *Mapping Spanish AD specialist dermatologists (with Hospital La Paz and Hospital Sant Pau) – in progress*
  - Objective: To map the location of AD specialists across Spain, in order for AD patients (or suspected patients) to locate local specialists
  - Role of centres: Helping to identify AD specialists across Spain, via their own networks
- *Co-organising events for patients and HCPs (with Hospital La Paz and Hospital Sant Pau)*
  - Objective: Educate patients about AD in a patient-friendly way and provide an opportunity for patients to network and socialise
  - Role of centres: Hosting events at the centres and organising educational speakers for patients (dermatologists and psychologist)

*Note: patient and HCP event in April 2019 in Barcelona and following event (date TBC) in Madrid*

### AADA activities:

- *Yoga events:* First event hosted in Jan 2019 in Madrid. PAG organised a yoga instructor to teach a specialist yoga class for AD patients (~15 people attended)
- *Make up and beauty workshop (in progress, April 2019):* Event held in Madrid to educate AD patients about make-up (product education / application tips) in collaboration with a commercial company
- *Patient welcome pack (in progress):* Information pack in development for patients including information on the disease, lifestyle tips and advice for families / to share with schools
- *Participation in national PAG meetings:* AADA attended ADVANCE meeting to meet with other AD PAGs from across the world to discuss AD care, PAG initiatives and develop networks

**Sources:** (a) Asociación de afectados por la dermatitis atópica. About us. [Website] <http://asociacionafectadosdermatitisatopica.com/quienes-somos/> Accessed 8 Mar 2019

# 24-hour allergy testing

## Overview

- The unit, where possible, provides patients with a test and diagnosis on the same day as their initial consultation



A high number of cases are resolved at the centre and we are able to give diagnoses on the same day

*Allergist, Hospital La Paz*



**Note:** (1) the remaining 50% receive their diagnosis in subsequent consultations



## What is the rationale?

- AD increases the risk of food allergy and other allergic disorders (e.g. allergic rhinitis)<sup>(a)</sup>
- Allergic diseases are a great burden on patients (especially children) and there is a need to identify allergies (and atopy) as early as possible<sup>(b)</sup>
- Some allergy tests are conducted over the space of a week (e.g. patch testing)<sup>(c)</sup> and can burden patients. Combining test and diagnosis on the same day can help to reduce this burden

## What are the key features of the intervention?

- For new suspected allergies in AD patients, allergists will aim to test (first consultation) and diagnose (second consultation) on the same day where possible (e.g. skin prick tests)
- The allergy testing team consists of 2 allergists, 1 dermatologist and 2 nurses. Testing decisions are usually shared between dermatology / allergology and are made on a per patient basis
- Patients (adults) will attend the adult day hospital where the testing will be performed. If required, patients may be seen on the same day as their dermatology consultation (2-3 free appointments per day are kept free for these patients)
- Most patients are referred from other dermatologists, allergologists or PCPs (primary care physicians)

*Note: a clinical evaluation within the unit is required for each patient before testing can proceed. The centre does not accept evaluations from outside the unit*

- Food allergies are typically indicated by allergists, while cutaneous drug eruptions or cosmetic reactions are usually indicated by a dermatologist
- Where additional / more complex testing is required, patients will attend follow up consultations (e.g. skin patch testing completed over 3 visits, each involving tests and readings)

## What are the outcomes so far?

### Benefits to patients:

- 50% of patients receive a diagnosis on their first visit to the centre<sup>(1)</sup>
- Reduced number of visits to the centre (and associated disruption to personal / work life)

### Benefits to HCPs:

- Reduced number of appointments and workload
- Ability to provide diagnosis / initial diagnosis to patients more quickly (and treat as required)

**Sources:** (a) Weidinger S, et al. Atopic dermatitis. *Lancet*. 2016;387(10023):1109-1122; (b) Mastorilli C, et al. Food allergy and atopic dermatitis: Prediction, progression, and prevention. *Pediatr Allergy Immunol*. 2017;28(8):831-840; (c) British Association of Dermatologists. Patch testing [Leaflet] <http://www.bad.org.uk/for-the-public/patient-information-leaflets> Accessed 2 April 2019

# Primary care dermatology education (1/2)

## Overview

- The centre works closely with its network of 20 health centres in order to educate and train primary care professionals (PCPs) about AD, including clinical signs, diagnosis, and referral pathways

**Sources:** (a) Le Roux E, et al. GPs experiences of diagnosing and managing childhood eczema, *BJGP* 2019;68(667):e73-e80. doi:10.3399/bjgp18X694529; (b) Schofield JK, et al. Skin conditions are the commonest new reason people present to general practitioners in England and Wales. *Br J Dermatol* 2011;165(5):1044–1050; (c) Schopf T, et al. Impact of interactive web-based education with mobile and email-based support of general practitioners on treatment and referral patterns of patients with atopic dermatitis: randomized controlled trial. *J Med Internet Res*. 2012;5;14(6):e171



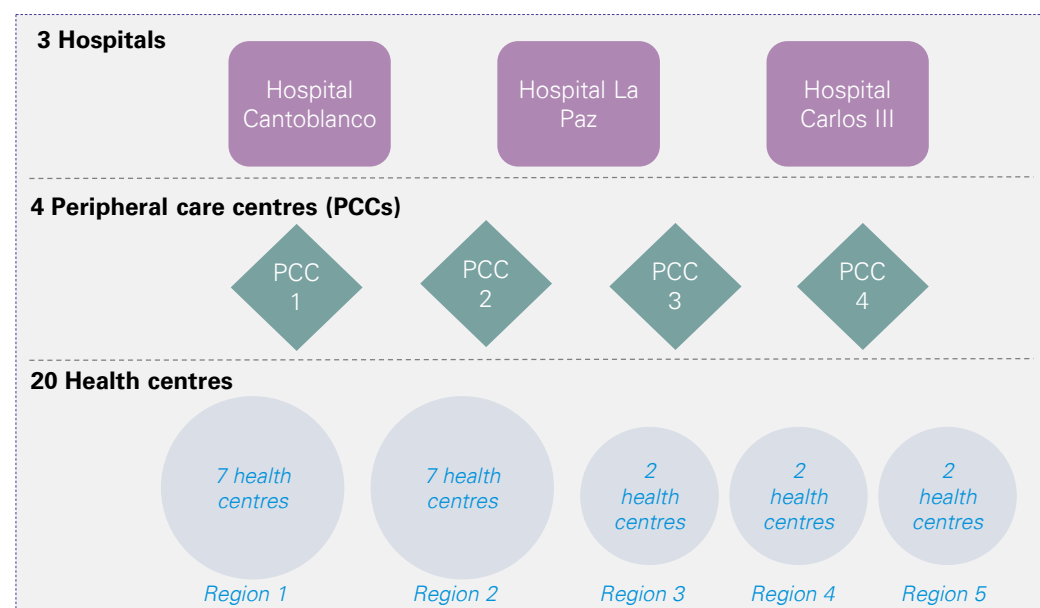
## What is the rationale?

- Primary care professionals (PCPs) may have limited training in dermatology (including AD)<sup>(a)</sup>, and AD patients commonly present to PCPs and / or are managed in primary care<sup>(b)</sup>
- Incorrect referrals and / or diagnosis of AD in primary care creates an unnecessary burden on secondary care centres and patients
- Literature suggests primary care educational interventions can reduce referrals made to specialists<sup>(c)</sup>
- PCPs in the network requested dermatology education from the centre to aid their diagnosis, treatment and referral of dermatology patients

## What are the key features of the intervention?

- 4–5 years ago, the centre set up educational sessions for PCPs (with support from the centre's 'primary care coordinator', who manages relationships with health centres in the network)
- Education is provided for PCPs within the network (which consists of 3 hospitals, 4 peripheral care centres and 20 health centres)

### Network structure:



# Primary care education (2/2)

## What are the key features of the intervention? (cont.)

- Centre dermatologists and the 'primary care coordinator' host online monthly / bi-monthly training sessions (9 per year)
- Sessions last for 1 hour and cover a variety of dermatological conditions (including AD)
  - Hosted at 2–3pm to enable as many PCPs to join as possible (in between clinic times)
- PCPs may request particular topics for upcoming sessions, including:
  - Disease information (e.g. pathophysiology, epidemiology)
  - Treatments (e.g. new and existing treatments)
  - Diagnosis tests (e.g. allergy testing [IgE testing] for AD)
- The software used allows the specialists to project images and slides to participants. It was developed and supplied by Consejería de Sanidad de la Comunidad de Madrid (regional authorities)
  - The platform allows secure, live communication with all 20 peripheral care centres
- PCPs may ask additional questions and request advice from centre specialists on an ad hoc basis (i.e. outside these training sessions)

## What are the outcomes so far?

### Benefits to primary care professionals (PCPs):

- Opportunity to learn from dermatology specialists and ask questions
- A convenient (in between clinic hours and online) and engaging (via slides and visuals) form of education
- PCPs can provide improved patient care (e.g. through enhanced understanding of AD)

### Benefits to specialists:

- Helps build strong relationship with PCPs
- Improves quality of referrals to the dermatology unit

## What's next?

- Assist other specialist units at the centre to deliver similar training (e.g. rheumatology). Dermatology is the most advanced unit in PCP education, so can share knowledge / learnings

“



PCPs can request topics for educational sessions which we will then deliver for them

*Primary care coordinator, Hospital La Paz*

“



PCPs are crucial for us - they need to correctly refer and diagnose dermatology patients

*Head dermatologist, Hospital La Paz*



# Established dermo-allergy unit (1/2)

## Overview

- The dermatology and allergy departments are integrated, providing a highly specialist, coordinated service for patients
- Specialists work closely together to care for patients with a range of allergic-dermatology conditions, including AD

## What is the rationale?

- AD is a complex disease which can progress into Atopic March and patients may present with other associated diseases (e.g. asthma or allergic rhinitis)<sup>(a)</sup>
- Atopic March patients often require input from both dermatology and allergy to receive optimal care for their condition(s)
- AD is also linked with food allergies<sup>(b)</sup> which are usually managed by allergists

## What are the key features of the intervention?

- The dermatology and allergy units were integrated approximately 1 year ago (in early 2018)
  - Integration involved the introduction of shared rooms, combining protocols, periodic reviews of the unit's clinical aspects and quality of control
- Patients are referred to the unit via health centres, peripheral care centres (PCCs) or other hospitals in Madrid / Spain
- The specialists work in a collaborative manner, sharing resources and patients in order to provide multi-speciality care for patients with Atopic March

### Unit objectives:

- Improve patient management and care
- Optimise diagnosis and protocols
  - Common protocols, based on published guidelines, outline processes and ways of working between the two specialities
- Increase adherence to treatment
- Provide opportunities for clinical trials
- Train healthcare professionals at the centre

### Conditions treated:

- AD
- Contact dermatitis (occupational and non-occupational)
- Angioedema
- Chronic urticaria

**Sources:** (a) Bantz SK, et al. The Atopic March: Progression from Atopic Dermatitis to Allergic Rhinitis and Asthma. *J Clin Cell Immunol.* 2014;5(2):202; (b) Leung DYM, et al. Deciphering the Complexities of Atopic Dermatitis: Shifting Paradigms in Treatment Approaches. *J Allergy Clin Immunol.* 2014;134(4):769–779



# Established dermo-allergy unit (2/2)

## What are the key features of the intervention? (cont.)

### Day hospital (allergy):

- In vivo and in vitro allergy tests are conducted at the day hospital, including:
  - Food and drug challenges

*Note: the laboratory prepares extracts on-site for in vitro and in vivo testing for food and drug challenges*

- Skin prick tests
  - Autologous serum skin tests
- Treatment is provided at the day hospital, including biologics and immunotherapy

### Medical education:

- Education provided to healthcare professionals (from Madrid and across Spain) covers specific areas of dermo-allergy (e.g. severe asthma or AD) and is continuing medical education (CME) accredited

## What are the outcomes so far?

### Benefits to patients:

- More convenient for patients, who receive co-ordinated care
- Improved access to specialities and specialist tests / treatment, due to shared resources across dermatology and allergy

### Benefits to HCPs:

- Reduced duplication of workload
- Easy access to cross-specialty opinion (via dermo-allergy sessions covering complex patients who require both specialties)
- Defined protocols for the management of patients
- Ability to co-run dermo-allergy clinical trials

## What is next?

- Co-location of the dermatology unit, allergy unit and day hospital space to create a single area for care delivery

“



We collaborate when it comes to patient care, teaching and research – we share resources across the two specialities

*Dermatologist, Hospital La Paz*

“



Improving quality of care is our main goal. We aim to provide the best possible allergology care to patients that is also cost effective

*Allergist, Hospital La Paz*





# Ophthalmologist screening appointments (1/2)

## Overview

- Dermatology unit collaborates closely with 1 ophthalmologist (with a special interest in dermatology) to manage AD patient eye comorbidities, especially in severe AD patients

**Sources:** (a) Thyssen JP, et al. Incidence, prevalence, and risk of selected ocular disease in adults with atopic dermatitis. *J Am Acad Dermatol.* 2017;77(2):280-286; (b) Eiseman AS. The ocular manifestations of atopic dermatitis and rosacea. *Curr Allergy Asthma Rep.* 2006;6(4):292-8.



## What is the rationale?

- Eye comorbidities are common in AD patients as a result of the disease and / or AD treatment, and the risk of development is highest in patients with severe AD<sup>(a)</sup>
- Ocular disease is not directly correlated with disease control (i.e. if AD is well-controlled, this does not always mean eye comorbidities are well-controlled)<sup>(b)</sup>
- Ophthalmologists are required to manage these disease manifestations / comorbidities

## What are the key features of the intervention?

- The dermatology-allergy unit works closely with an ophthalmologist experienced in dermatological conditions (relationship established 2 years ago)
- Common protocols were developed by the dermatology unit in collaboration with the ophthalmologist, which defined the processes and ways of working between the two specialities (including a proforma for AD patients)
- All severe AD patients are referred to the ophthalmologist, along with mild-moderate AD patients as required (i.e. patients presenting with eye comorbid conditions)

*Note: patients can be referred from outside the centre*

- Ophthalmologists diagnose and treat eye comorbidities (and treatment reactions) in AD patients

### Format of consultation:

- Consultations last 10–30 minutes
- The “ophthalmological exam in atopic dermatitis” proforma guides the consultation, which covers personal information, medical background, test results and symptom assessment
- Tests conducted:
  - Visual Acuity
  - Refraction
  - Corneal topography
- Patients will be prescribed treatment (e.g. lubricating eye drops) if required
- All patients will receive education regarding their eye condition, treatment and aftercare (e.g. how to properly clean their eyes)

*Note: nurses conduct the tests and also provide patient education (e.g. on eye lid cleaning)*

- Patients will be followed up as frequently as required (routinely every 2 months)
- Ophthalmologists also provide medical education for dermatologists and primary care professionals, including basic education on eye disease and eye screening tools

# Ophthalmologist screening appointments (2/2)

## Challenges

- An increasing number of patients are referred to the ophthalmologist, thereby increasing service demand

## What are the outcomes so far?

### Benefits to patients:

- Improved eye health and regular monitoring
- Quick access to ophthalmologist for eye comorbidities (through referral pathway)

### Benefits to HCPs:

- Easy referral for AD specialist eye care
- Improved control of eye conditions through early intervention(s)

## What's next?

- Monitoring the impact of new treatments on AD patients and their subsequent ophthalmology care needs

“



We organise the service so the same ophthalmologist sees all AD patients – it is good for the same person to review each patient

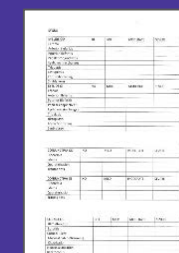
*Ophthalmologist, Hospital La Paz*

“



We complete a number of tests during a patient's first consultation, providing a baseline to refer to during follow-up appointments

*Ophthalmologist, Hospital La Paz*



*Ophthalmological exam in atopic dermatitis proforma*

# Patient and family education workshops (1/2)

## Overview

- Patients and families are invited to workshops at the centre (hosted by physicians and experienced nurses), which provide education across a range of dermatological conditions (including AD)

## What is the rationale?

- Short consultations may give healthcare professionals insufficient time to educate patients, and patients may in turn have few opportunities to ask questions<sup>(a)</sup>
- Patients / family members often feel isolated not knowing other individuals with the disease

## What are the key features of the intervention?

- The unit hosts patient workshops to educate patients and families about different dermatology conditions (including AD)
- Separate sessions are offered for adults and children (and their families) with AD and have been running for 1.5 years

### Adult workshop:

- Hosted 3-4 times per year
- Delivered in a face-to-face workshop (1 hour), followed by questions
- Workshops are attended by 15-20 patients per session from across Spain
- Dermatologists, allergists, dermatology / allergy nurses (including a nurse experienced in creating and delivering patient education) and a psychologist (not dermatology-specific) deliver the workshops
- Topics include:
  - Definition of an expert patient (i.e. living and coping with the disease)
  - Concept of health (i.e. preventing illness and being well)
  - Values and attitudes to health (i.e. viewing health holistically)
  - AD treatment (i.e. patient information)
  - Self-administration of treatment (i.e. benefits of self-administration, why it is important, self-administration methods and training [delivered by a specialist nurse experienced in patient education])
- Educational materials are also provided to patients, including techniques on self-administration, hygiene and other themes

*Note: patients often attend multiple sessions, helping to reinforce and embed learnings*

**Sources:** (a) GlobalSkin Position Paper: "Atopic Dermatitis: A Collective Global Voice for Improving Care" February 2018 [PDF] <https://www.semanticscholar.org/paper/GlobalSkin-Position-Paper-Atopic-Dermatitis-%3A-A-for/e08b204478263f64f02a5f1285fd0e59a68ad91a> Accessed 2 April 2019



# Patient and family education workshops (2/2)

## What are the key features of the intervention (cont.)?

### Children (and family members) workshop:

- Hosted 4 times per year
- Delivered in a face-to-face setting for 3-4 patients / families (from across Spain)
- Paediatric dermatologists, paediatric allergist, paediatric dermatology / allergy nurses and a psychologist (not dermatology-specific) deliver the workshops
- Content and structure is similar to that of the adult workshops but is delivered in a child-friendly manner (e.g. role playing with puppets)

### Wider AD population (online):

- The allergist at the centre (in collaboration with the AADA and other centres) delivers online patient education with the CEAIC (Centro de Estudios para Invidentes Asociación Civil)

### Role of the nurse:

- A specialist nurse at the centre helps to develop and deliver patient education (and has experience in doing so for other disease areas)

## What are the outcomes so far?

### Benefits to patients:

- Improved satisfaction due to increased face-time / 'intimacy' with HCPs
- Opportunity to meet other patients / families
- Information presented in a patient-friendly and easy-to-follow manner

### Benefits to HCPs:

- Improved patient compliance with treatment (nurses assert that patients take more responsibility for their treatment)
- Opportunity to educate patients and reinforce messages without the restriction of short consultation times

## What's next?

- Continue to develop and implement nurse-led sessions (led by a nurse experienced in designing and delivering patient education)

“

We make the workshops fun for children by using puppets to demonstrate how to apply their topical treatments

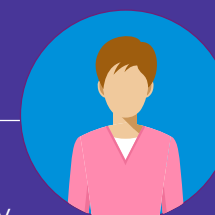
*Paediatric dermatologist,  
Hospital La Paz*



“

We play a key role in educating patients. They like to spend time with us outside of consultations, when they feel they have more time to ask questions

*Nurse, Hospital La Paz*



# Role of the clinical service coordinator (1/2)

## Overview

- The centre is in the process of introducing a 'clinical service coordinator' role to provide additional support for 'high-need' AD patients

## What is the rationale?

- The AD patient experience can be stressful<sup>(a)</sup>, especially for patients with severe AD and / or multiple comorbidities
- Patients may need to attend multiple appointments (e.g. blood tests / allergy tests) with different specialists (e.g. ophthalmologists / dermatologists)
- Clinical space and specialists at the centre are not co-located, which can increase inconvenience and confusion for patients

## What are the key features of the intervention?

- The unit is currently introducing a clinical service coordinator role, due to "go-live" in March 2019
- The role will be funded by the dermatology department, using funds obtained from clinical trials and study protocols
- The role has been filled by an experienced AD-specialist physician (paediatrician / nutritionist) from La Paz, who is also an AD patient
- Dermatologists will be able to refer patients to the clinical service coordinator, and patients will also be able to request time with the coordinator themselves
- The service coordinator will support 'high-need' patients (i.e. those with severe AD, multiple comorbidities or poorly controlled) with:
  - Logistics (e.g. booking multiple specialist consultations on the same day, navigating around the hospital)
  - Education (e.g. importance of treatment compliance, emollient application, self-administration of treatment)
  - Additional / non-medical needs (e.g. AD-induced stress or reduction in quality of life [QoL])
- Consultations will last 30 minutes but may vary depending on patient needs
- Patients will be followed up every 2 months, though follow-ups may be more / less frequent depending on the patient
- Appointments will be available 3 days per week

*Note: the clinical service coordinator will act in their capacity as a paediatric nutritionist for the remaining 2 days*

**Sources:** (a) Gochnauer H et al. The Psychosocial Impact of Atopic Dermatitis. *Adv Exp Med Biol.* 2017;1027:57-69



# Role of the clinical service coordinator (2/2)

## What are the expected benefits?

### Benefits to patients:

- Receive additional logistical, practical and emotional support
- Opportunity to speak with centre staff in a non-medical capacity
- Can relate to the clinical service coordinator and share experiences (as coordinator is also an AD patient)

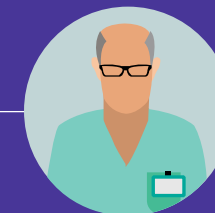
### Benefits to HCPs:

- Able to provide more holistic care to patients
- Save time in medical consultations (as non-medical aspects can be discussed separately with the clinical service coordinator)
- Opportunity to identify and address AD-related (or other) conditions, which may impact AD management and / or quality of life

## What's next?

- Following the introduction of the role, measures will be designed to track the progress / benefits of the role (e.g. via anonymous email questionnaires to gather patient feedback)
- Obtain additional funding to extend the role beyond 1 year

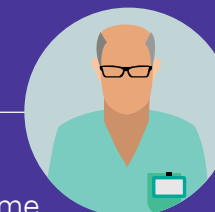
“



I understand what it's like to have AD. I am a patient myself and can relate to the patients we care for

*Clinical service coordinator, Hospital La Paz*

“



Patients have so many appointments. They come in for blood tests and allergy tests, all on different days, and it can be really stressful for them

*Clinical service coordinator, Hospital La Paz*



CONTENTS



APPENDIX  
CENTRE REPORTS



# Hospital Sant Pau

Barcelona, Spain

Site visited by KPMG 5–6<sup>th</sup> February, 2019

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[kpmg.com/uk](https://kpmg.com/uk)





# Summary



## Context

**Centre type:** Public hospital located in central Barcelona

**Catchment area:** 350,000 patients from Barcelona and the wider Catalonia area

**Funding:** The centre is funded by the government of Catalonia, with funds then distributed between different operating units (including the dermatology centre)

**Services:** The dermatology unit is one of several outpatient clinics and collaborates closely with a number of other specialist clinics

**Patient population:** Includes adult and paediatric patients with a variety of skin conditions, including patients with Atopic Dermatitis (AD) (mild, moderate and severe)



## Key strengths in the delivery of AD care

**Access to AD and comorbidity specialists:** Providing access to a number of dermatologists and other comorbidity specialists (e.g. allergists) specialised in AD patient management

**Cross-speciality collaboration:** Ongoing collaboration between dermatology and other specialities to continually improve AD care

**Strong relationship with patient association group (PAG):** Supporting PAG activities to ensure the provision of holistic patient care and additional support to patients

**Commitment to patient education:** Hosting Atopy Schools (for children) and Atopy Workshops (for adults)

**Commitment to research:** Involvement in several adult and paediatric multi-centre trials in AD and other dermatological conditions



## Key challenges faced in delivery of AD care

**Supporting patients with treatment compliance** (e.g. with emollients). Patient non-compliance may arise for a number of reasons, including time-consuming treatment regimens

**Need for access to alternative AD treatment** for patients not responding to current options

**Complexity of AD as a disease and significant impact on patient quality of life (QoL)**

**Resource/funding constraints** for the provision of AD care

**Delayed patient access to specialist AD healthcare professionals (HCPs) and treatments.** This may be due to a patient not being referred from primary care, being lost to follow-up in primary care, or not presenting to a HCP in primary care

# Atopic Dermatitis (AD) in Spain

## Spanish healthcare system:

The Spanish National Healthcare System ("Instituto Nacional de la Salud") provides free healthcare for Spanish nationals, funded through taxation<sup>(a)</sup>

There are three organisational levels:

1. Central (Organizacion de la Administracion Central) – in charge of issuing health proposals and planning and implementing government health guidelines
2. Autonomous Community (Organizacion Autonómica)-responsible for offering integrated health services to the regional population
3. Local (Areas de Salud) – accountable for unitary management of the health services offered at Autonomous Community level

## Barcelona healthcare system:

The Catalan Public Health Care Service ("CatSalut") provides healthcare for residents of Catalonia<sup>(b)</sup>. Hospital care is provided through the public hospital network which exists throughout Catalonia including: specialist outpatient care, surgical interventions, urgent care, etc.<sup>(c)</sup>

## Prevalence

- AD affects 10-20% of children and 1-3% of adults in Western countries<sup>(d)</sup>
- In Spain, the prevalence of adult AD is 5%<sup>(e)</sup> and approximately 30% of these patients have severe AD
- The prevalence of AD associated comorbidities with severe AD in Spain include: asthma (24%); depression (21%) and allergic rhinitis (19%)<sup>(e)</sup>



## Care provision:

### Location:

- Mild (or well-controlled) AD care is usually managed by Primary Care Professionals (PCPs)
- Moderate and severe (or uncontrolled) AD care is usually managed by dermatologists within hospitals

### Funding:

- Primary care is funded by autonomous communities<sup>(f)</sup>
- Hospital funding is negotiated through a contract programme between the hospital and a regional authority third-party payer<sup>(e)</sup>

## Guidelines and societies:

### Guidelines:

- Guidelines for treatment of atopic eczema (atopic dermatitis) part I and part II: European Association of Dermatology and Venerology (EADV)
- Clinical practice guidelines in Dermatology: Spanish Academy of Dermatology and Venereology (AEDV)

### Medical society:








- Spanish Academy of Dermatology and Venereology (AEDV)

### Patient association group (PAG):

- Asociación de afectados por la dermatitis atópica (AADA)

**Sources:** (a) Health management. Overview of the Spanish Healthcare System [Website] <https://healthmanagement.org/c/hospital/issuearticle/overview-of-the-spanish-healthcare-system> Accessed 5 Feb 2019; (b) Barcelona.cat. Healthcare system [Website] <https://meet.barcelona.cat/en/study-and-research/information-catalonia/health-care-system> Accessed on 19 March 2019; (c) Generalitat de Catalunya. CatSalut. Catalan Health Service. Specialised and hospitalised acute care. [Website] <https://catsalut.gencat.cat/ca/serveis-sanitaris/atencio-especialitzada-hospitalaria-aguts/> Accessed 19 March 2019; (d) Nutten S. Atopic dermatitis: global epidemiology and risk factors. *Ann Nutr Metab.* 2015;66 Suppl 1:8-16; (e) Sicras-Mainar A et al. Prevalence of Severe Atopic Dermatitis in Adults in 3 Areas of Spain. *J Investig Allergol Clin Immunol* 2018;28(3):195-197; (f) Garcia-Armentoso S et al. Spain: Health system review (2010) [PDF] [http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0004/128830/e94549.pdf](http://www.euro.who.int/__data/assets/pdf_file/0004/128830/e94549.pdf) Accessed 07 March 2019

# The centre and dermatology unit


The centre		
 <b>Type and location</b>	<ul style="list-style-type: none"><li>— Large, public hospital, governed by the Fundació de Gestió Sanitària (Healthcare Management Foundation), with representatives from the Catalan Government (Generalitat de Catalunya), the Barcelona City Council and the Archdiocese of Barcelona</li><li>— Located in Northern Barcelona in the Catalonia region of Spain</li></ul>	
 <b>Population served</b>	Catchment area: patients from Barcelona and the wider Catalonia area Patient numbers: treats 35,000 inpatients, >145,000 emergencies and 350,000 outpatient appointments/year	
The dermatology unit		
 <b>Service Division</b>	<b>Outpatient service</b>	<b>Emergency dermatology service</b>
 <b>Hours of availability</b>	Mon-Fri: 8am–5pm	Mon-Fri: 8:30am–1pm (Note: during out-of-hours, dermatology patients can attend the general emergency department)
 <b>No. of patients seen</b>	An average of 23–27 patients seen daily per dermatologist (in total ~23,000 per annum)	~30 patients / day (in total ~7,500 per annum)
 <b>Types of patients seen</b>	Children (moderate and severe); adults (mild, moderate and severe)	
 <b>Facilities on-site<sup>(1)</sup></b>	<ul style="list-style-type: none"><li>— Phototherapy (UVA/UVB/PUVA)</li><li>— 2 laboratories (1 specialist laboratory providing specialist immuno-tests [including immunocap, immunoblotting and basophil liberation] and genetic testing; 1 dermatology laboratory providing a range of dermatology specific testing tools)</li><li>— Wide variety of skin prick and patch tests</li><li>— On-site outpatient pharmacy</li><li>— On-site ophthalmology department (including access to specialist tests e.g. topography)</li><li>— Laser suite</li></ul>	

**Note:** (1) List of facilities is not exhaustive

# The team



## Core team profile

 **15** Dermatologists (working in both the centre and the community; 2 specialised in eczema/urticaria, 2 in paediatric dermatology)

 **2** Clinical trials nurses


 **1** PUVA nurse

 **1** Dermatology nurse


## Wider team profile

 **1** Allergist

 **3** Allergy nurses

 **3** Ophthalmologists (1 specialised in patients on biologics)

 **3** Outpatient pharmacists

 **1** Psychologist

 **2** Immunologists (within the laboratory)

*Note: Please see page 347 for further details about the wider team*



## Governance and processes

### Team meetings:

- *Clinical sessions (once a week):*
  - Attended by all colleagues in the dermatology unit
  - The meeting is held to discuss medication protocols, complex patient cases and recent activities in the unit
- *Staff meeting (once a month):*
  - Attended by all colleagues in the dermatology unit
  - The meeting is held to disseminate information about the unit/team and discuss ad-hoc issues

### Patient records:

- *Electronic patient records (EHR):*
  - Accessible by all specialities – a key component of patient monitoring and follow-up

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients with symptoms of AD (e.g. itching or skin DRYNESS) are assessed by a primary care professional (PCP) or community dermatologist (CD)
- Patients are referred to either the dermatology unit or allergy unit by the PCPs and CDs
- Patients may present to the centre's emergency dermatology service (8:30am-1pm) when urgent care is required (e.g. for flare-ups)

*Note: AD patients that are well-controlled will likely be managed in primary care and not referred to the unit*

## Diagnosis and Referral

In secondary care



- Patients referred to the unit will be seen within 1 month, or on the same day if urgent
- Patients are assessed by an AD specialist dermatologist and/or a comorbidity specialist (e.g. pulmonologist), [consultation ~25 mins]

*Note: allergists may refer patients to the dermatology unit if they have been incorrectly referred – see case study 354 – 355*

- AD is diagnosed through clinical examination and supplementary diagnostic tests (e.g. patch tests), which are performed at first appointment and during follow up
- Paediatric patients transition into adult care aged 16-18 years (though this can vary and patients may remain in paediatric care)

## Treatment and Management

Medical management



- Treatment is initiated (tailored to the severity of the disease)
- Alternative treatment may be provided (e.g. UVA/UVB treatment [for patients not on systemic therapy]; paraffin hand baths)
- Patients are referred to comorbidity specialists if required (e.g. ophthalmologist)
- Patient may be offered the opportunity to participate in clinical trials (CTs), including interventional and observational trials (~50% of the unit's patients are engaged in trials)

*Note: the unit also accepts patients from other hospitals for CTs*

Non-medical management



- Consultation with psychologist conducted for patients displaying psycho-social distress (at the discretion of the dermatologist) [consultation ~45 mins]
  - Joint consultations with the dermatologist-psychologist also offered [~20 mins]
- All patients receive AD education (including treatment) during nurse and dermatologist consultations
- Patients can attend the Atopy school (children)/Atopy workshop (adults) for additional education

## Follow-up

Monitoring of chronic disease / flare up



- Patients are monitored via consultations with a dermatologist, on average every 3 months (varying by severity/individual patient needs) [consultations ~15 mins]
  - Blood tests/allergy tests/immune tests performed as required
- Patients may access the emergency dermatology service if required
- Patient quality of life (QoL) and disease scoring index (e.g. SCORAD) is measured during every visit to the dermatologist/pharmacist

*Note: patients are encouraged to monitor and track their scoring index (PO-SCORAD) on a weekly basis and feed back to the dermatologist*

# Roles of the wider team

## Allergist

**Patient type:** AD patients (mild, moderate and severe) with associated allergies

**Referral:** Referred by primary care professionals (PCPs) or dermatologists

**Consultations:** Allergist performs allergy diagnosis, tests (e.g. IgE tests), treatment and provides advice. Specialist allergy nurses support allergy testing process

**Timing:** Every 3-6 months, depending on the severity of the patient. Consultations last 15-20 minutes

*Note: some patients are followed-up in primary care*

## Pharmacist

**Patient type:** AD patients receiving hospital only treatment (i.e. dispensed by hospital pharmacist)

**Consultations:** Pharmacist educates patients about treatment and measures SCORAD indices, which are shared with the dermatologists

**Timing:** Consultations every 2 weeks (if on biologics) or longer, lasting 20-30 minutes



## Ophthalmologist

**Patient type:** Severe AD patients with eye comorbidities (or are at risk of developing eye comorbidities)

**Referral:** Referred by dermatologist

**Consultations:** Ophthalmologist conducts a range of tests (general examination; topography [analysis of cornea]; examination of retina and optic nerve; visual accuracy test; tear film and osmolality test) and treats eye comorbidities

**Timing:** Consultations every 3-6 months (depending on patient need), lasting up to 45 minutes

## Psychologist

**Patient type:** AD patients (mild, moderate and severe) displaying psychological symptoms

**Referral:** Referred by dermatologists

**Consultations:** Psychologist conducts consultations with patients (with or without a dermatologist present) in order to provide psychological support. Psychological scales (e.g. Hospital Anxiety and Depression Scale [HADS]) are used to support assessment and monitoring

**Timing:** Consultations every 1-2 weeks (flexible), lasting 20-45 minutes

# Overview of interventions in place for AD

## Awareness and Presentation



Symptom identification

- **Primary care professional (PCPs) training:** Provision of face-to-face monthly PCP educational workshops delivered by dermatologists and allergists. Workshops focus on the clinical symptoms of allergy, referral pathways, etc.
- **Working relationship with the PAG (AADA):** The dermatology unit collaborates with the PAG to raise awareness of AD in the patient community through events

See pg. 353 for case study

## Diagnosis and Referral



In secondary care

- **Access to specialist allergist:** Allergist at the centre provides allergy/Atopic March diagnosis and treatment. Patients are referred to allergist by dermatologists (and vice versa)
- **Network of centres:** Dermatology unit accepts referrals from other hospitals, including: clinical trials participants, poorly-controlled patients, or those requiring specialised treatments provided by the centre (e.g. PUVA)
- **On-site specialist laboratory:** Access to specialist tests (e.g. immunology tests) and scientists. 2 specialist immunologists within the laboratory are responsible for tests conducted for AD patients

See pg. 354-355 for case study

## Treatment and Management



Medical management

- **Provision of personalised treatment:** PUVA dose tapering; personal paraffin hand baths (daily for 1 month for hand eczema)
- **Clinical trial (CT) recruitment:** Patients (adults and children) can access novel treatments through participation in CTs (interventional and observational). 2 CT nurses support CT patients
- **Supportive role of the pharmacist:** Pharmacists provide additional support to the dermatology team and AD patients
- **Specialist ophthalmologist consultations:** AD patients (either with or at risk of eye comorbidities) are seen by the ophthalmologist

See pg. 356 for case study

See pg. 357-358 for case study

See pg. 359-360 for case study



Non-medical management

- **Patient/family education and training:** Unit hosts the Atopy school (children) and workshop (adults) 3 times a year – delivered by dermatologists, nurses and psychologists
- **On-site dermatology psychologist:** see pg. 363 - 364 for detailed role
- **Clinical trials nurse:** Nurses provide additional support for patients enrolled in clinical trials (e.g. extended appointment time slots)

See pg. 361-362 for case study

See pg. 363-364 for case study

## Follow-up



Monitoring of chronic disease/flare up

- **Emergency dermatology service:** Accessible for patients with flare-ups/other urgent dermatology needs at the centre. During out-of-hours, dermatology provide an on-call service at the emergency department
- **Use of e-health tools:** Patients are encouraged to use a phone application to record their PO-SCORAD every week and share (digitally) with dermatologists during consultations
- **Centre biobank:** Central storage unit in the laboratory containing patient samples from across the centre (across specialities) for research purposes

**Key:**



Case study available





# Monitoring AD patients and comorbidities

## The dermatology unit employs a number of measures for monitoring AD and associated comorbidities

### Objective measures (AD):

AD scoring indices are used to monitor patients and their disease, including:

- SCORAD (SCORing Atopic Dermatitis): to assess AD disease severity and monitor patient progress<sup>(a)</sup>
- POEM (Patient-Oriented Eczema Measure): to monitor patient AD disease severity<sup>(b)</sup>

QoL and sleep is routinely measured by:

- QoL questionnaire (developed by the unit): includes questions regarding symptom control from the patient's perspective
- Sleep questionnaire (developed by the unit): includes questions relating to the patient's sleeping pattern and the effects of AD on sleeping patterns

### Patient-reported outcomes:

Patients monitor their own disease through measurement and tracking of their PO-SCORAD via a phone application (developed by Fondation pour la Dermatite Atopique)

- The scores can then be shared digitally with specialist dermatologists during consultations

QoL questionnaire

Sleep questionnaire



PO-SCORAD phone application

### Dermatology unit routinely measures comorbidity outcomes by:

- *Allergist*: response to allergens/control of atopy disease (e.g. monitoring allergic asthma using standardised asthma measurement scales)
- *Psychologist*: monitoring psycho-social distress through standardised psychological scales (e.g. Hospital Anxiety and Depression Scale [HADS])
- *Ophthalmologist*: surveillance of symptoms and specialised tests

**Sources:** (a) SCORing Atopic Dermatitis (SCORAD) Calculator (0.9.0). [Website] <http://scorad.corti.li/> Accessed 26 Feb 2019; (b) Charman CR et al. Translating Patient-Oriented Eczema Measure (POEM) scores into clinical practice by suggesting severity strata derived using anchor-based methods. *Br J Dermatol.* 2013;169(6):1326–1332.

# Advice to other centres



## What advice would you give less specialised centres



**Objective of advice:** Refer to and network with other specialist centres

- **Why?** Some centres in Catalonia can provide specialist testing (e.g. different levels of allergy tests) and treatments for AD patients. Typically, these centres are larger/serve a larger population group and hence have the ability to provide these specialist services. These resources may not be accessible for smaller or less specialised centres, however smaller centres may utilise these resources via patient referrals or by creating formal/informal networks with specialised centres. For example, the Sant Pau dermatology unit occasionally sends certain allergy tests to community HCPs (which they may not have access to), so they may perform these tests themselves rather than referring patients to the centre



**Objective of advice:** Be practical when investing and invest in the most essential resources

- **Why?** Larger centres may have access to more funding than smaller, less specialised centres. Therefore, smaller centres should try to invest in the resources that will have the greatest impact. For example, when designing a skin prick testing service, it would be advisable to select a small range of testing equipment to give physicians an overall picture of a patient's allergies (those most common), as opposed to investing in the full range of skin prick tests to obtain very detailed results

# Next steps for the centre



## What is next for the centre?

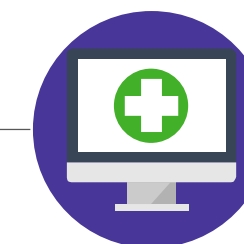
### **Objective:** Immuno-allergy functional unit set up

- **What?** The centre is working to set up a “functional unit” by formalising the referral networks between dermatology and other specialities in the hospital (i.e. ophthalmology) for the treatment of conditions such as AD, pruritus and urticaria
- **Why?** This formal title of “functional unit” will further improve the coordination between dermatology and the other specialities (i.e. through regular meetings with dermatologists, allergist, psychologist, ophthalmologists, pharmacists, immunologists, etc.) and help to raise the profile of the unit both internally and externally



### **Objective:** Develop patient registry

- **What?** The dermatology unit has developed a patient registry (in collaboration with two other Spanish centres) containing epidemiology data from AD patients including: age of onset, family history, history of pets, etc. The centre is working to expand the registry by increasing the number of patients and centres that contribute to the registry (currently has approximately 60 samples across the 3 centres)
- **Why?** Developing the registry will help to advance research in AD and the treatment of AD in Spain, e.g. in the identification of risk factors for AD/comorbidities. This research may contribute to improving diagnosis and care for patients in the future



# Case studies



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# Working with the AADA

## Overview

- The centre works closely with Asociación de afectados por la dermatitis atópica (AADA), the Spanish AD patient association group (PAG)
- Centre dermatologists assist the PAG with projects and activities and refer patients to them for non-medical support

## Asociación de afectados por la dermatitis atópica (AADA) in Spain

- The AADA is a not-for-profit organisation which aims to “bring people affected by AD together to improve their quality of life<sup>(a)</sup>”
- The AADA was set up 2 years ago when the centres (Hospital La Paz and Hospital Sant Pau) introduced the 3 founders to one other and encouraged them to set up the PAG
- The centres have supported the PAG by helping them write AD protocols and introducing them to an existing PAG (so they may learn from their experiences)

### AADA-centre activities:

- *Mapping Spanish AD specialist dermatologists (with Hospital La Paz and Hospital Sant Pau) – in progress*
  - Objective: To map the location of AD specialists across Spain, in order for AD patients (or suspected patients) to locate local specialists
  - Role of centres: Helping to identify AD specialists across Spain, via their own networks
- *Co-organising events for patients and HCPs (with Hospital La Paz and Hospital Sant Pau)*
  - Objective: Educate patients about AD in a patient-friendly way and provide an opportunity for patients to network and socialise
  - Role of centres: Hosting events at the centres and organising educational speakers for patients (dermatologists and psychologist)

*Note: patient and HCP event in April 2019 in Barcelona and following event (date TBC) in Madrid*

### AADA activities:

- *Yoga events:* First event hosted in Jan 2019 in Madrid. PAG organised a yoga instructor to teach a specialist yoga class for AD patients (~15 people attended)
- *Make up and beauty workshop (in progress, April 2019):* Event held in Madrid to educate AD patients about make-up (product education / application tips) in collaboration with a commercial company
- *Patient welcome pack (in progress):* Information pack in development for patients including information on the disease, lifestyle tips and advice for families / to share with schools
- *Participation in national PAG meetings:* AADA attended ADVANCE meeting to meet with other AD PAGs from across the world to discuss AD care, PAG initiatives and develop networks

**Sources:** (a) Asociación de afectados por la dermatitis atópica. About us. [Website] <http://asociacionafectadosdermatitisatopica.com/quienes-somos/> Accessed 8 Mar 2019



# Collaboration with specialist allergist (1/2)

## Overview

- An allergist, employed by the pulmonology department, works with the centre and manages AD patients with Atopic March comorbidities (e.g. allergic asthma)

**Sources:** (a) Darlenski R, et al. Atopic dermatitis as a systemic disease. *Clin Dermatol.* 2014;32(3):409-13; (b) Roerdink EM, et al. Association of food allergy and atopic dermatitis exacerbations. *Ann Allergy Asthma Immunol.* 2016;116(4):334-8; (c) Tsakok T, et al. Does atopic dermatitis cause food allergy? A systematic review. *J Allergy Clin Immunol.* 2016;137(4):1071-1078

## What is the rationale?

- AD may progress into Atopic March, which is a multi-organ disease and may include asthma and allergic rhinitis<sup>(a)</sup>
- AD can be associated with food allergy in children and adults<sup>(b)(c)</sup>, however the relationship between the two is not fully understood<sup>(c)</sup>
- These comorbidities (allergic asthma, allergic rhinitis and food allergy) are often managed by allergists

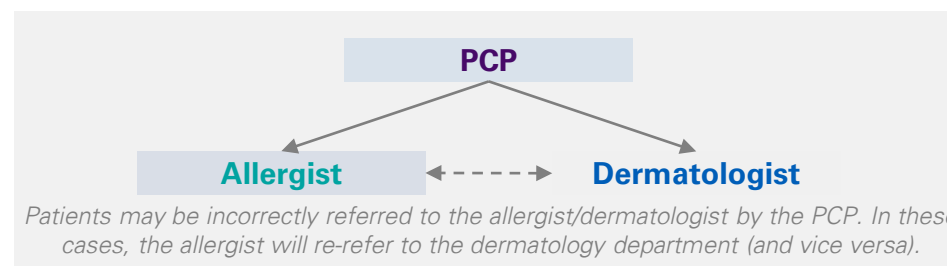
## What are the key features of the intervention?

- An allergist is employed by the pulmonology department (there is no allergy department at the hospital) who sees ~20 patients per year
- The allergist looks after patients in the hospital and within the community (in the catchment area of the hospital) across different specialities, including dermatology
- Conditions which fall under the remit of the allergist include:
  - AD
  - Asthma
  - Rhinitis
  - Food allergy

*Note: the allergist will not see AD patients without associated allergies (these patients will be managed in the dermatology centre)*

## Referral pathway:

- Patients are referred to the allergist by the dermatology department or via primary care professionals (PCPs)



# Collaboration with specialist allergist (2/2)

## What are the key features of the intervention? (cont.)

### Role of the allergist:

- *Patient consultations*: cares for inpatients and outpatients at the centre. Once patients are well controlled they may be referred back to primary care
- *Allergy testing*: provides a wide range of tests for patients, with 3 nurses providing assistance
- *PCP education*: runs biannual interactive workshops for PCPs (1 hour) at the centre's ambulatory care facility, focused on dermatology and allergy conditions (co-hosted with a dermatologist) to support appropriate referrals. 10-12 GPs / paediatricians from the local area attend
- *Internal teaching*: works to raise the profile of the internal specialist teaching sessions (held biannually and aimed at dermatologists of the national Dermatology Society Congress and the Work group of Contact Dermatitis and Skin Allergy). ~70 dermatologists usually attend
- *Outreach consultations in the community*: the allergist (employed by the hospital) organises education activities for the general public, hosted at the centre or Patient Advocacy Group facilities

## Challenges

- Lack of capacity: few allergists operate in Catalonia
- Rising demand from patients: increasing numbers of adults are becoming affected by and seeking medical advice for allergies

## What are the outcomes so far?

### Benefits to patients:

- Access to specialist treatment and advice for allergy conditions

### Benefits to HCPs:

- Increased visibility and understanding of allergist role and remit
- Improved knowledge of when and how to refer patients (a benefit of PCP education)

## What's next?

- Expand allergy team to cope with rising patient demands (note: another allergist has recently been contracted by the hospital)

“



More and more adults are presenting to the centre with allergy symptoms, this could be due to availability of better information and communication regarding allergies (e.g. on social media)

*Allergist, Sant Pau*



APPENDIX  
CENTRE REPORTS



# Provision of personalised patient therapy

## Overview

- For patients with hand eczema/AD which affects their hands, the dermatology unit provides personal paraffin hand baths to help alleviate symptoms

## What is the rationale?

- An AD specialist dermatologist in the unit had experience using paraffin baths in another speciality, and noticed they were useful in breaking down/softening the dry skin on the hands (a common symptom of hand eczema, contact dermatitis or AD)
- The specialist dermatologist conducted a trial of their usefulness in the dermatology centre, which was successful and led to the implementation of this adjuvant treatment in patient care

## What are the key features of the intervention?

- A specialist dermatologist trialled the paraffin baths on staff in order to understand their effectiveness and the possible benefits to patients
- After the trial was successful, they were rolled out to hand eczema patients and the unit has 6 baths in operation (with 1 bath assigned per patient)
- Patients have daily treatment for 1 month as part of their adjuvant therapy (with a specific bath assigned to one individual for that month). Each session is recommended to last roughly 20 minutes
- Once treatment has finished, patients may privately purchase a machine if they wish (though not from the centre directly)
- The centre published their findings in the Spanish (AEDV) medical society journal: *"Paraffin Wax Baths for the Treatment of Chronic Hand Eczema"*<sup>(a)</sup>

## What are the outcomes so far?

### Benefits to patients:

- Patients receive effective, non-invasive, supportive symptomatic treatment (many patients have subsequently purchased the baths for home use)
- Allows patients to trial the machines before purchasing them for home use

## What's next?

- Continue to increase the number of paraffin baths available for patients



Paraffin bath machine

**Sources:** (a) Mir-Bonafé JF, et al. Paraffin Wax Baths for the Treatment of Chronic Hand Eczema. *Actas Dermosifiliogr.* 2017;108(3):261-264

# Supportive role of the pharmacist (1/2)

## Overview

- Outpatient pharmacists work with the dermatology unit to dispense AD medication, provide medication counselling, administer treatments, record patient SCORAD measures and provide specialist advice to dermatologists

## What is the rationale?

- AD patients often require a number of different treatments for AD and associated comorbidities
- The side-effects of the different treatments are problematic for patients and may reduce treatment compliance<sup>(a)</sup>
- Non-adherence to treatment limits disease control and may complicate future treatment<sup>(b)</sup>
- Pharmacists can play a key role in educating patients about their treatment regimens and the importance of compliance for disease control

## What are the key features of the intervention?

- Three outpatient pharmacists provide support to dermatology patients (and work with other specialist departments in the hospital)

### Role of the pharmacist:

- *Dispensing medication*: the outpatient pharmacy dispenses medication for AD patients including topical, oral and injectable (biologic) therapies
- *Patient consultations*: pharmacist consultations (20-30 minutes) cover the following:
  - *Medication counselling*: how to take medication (e.g. how to apply creams), potential side-effects and how to store medicines. Pharmacists use patient educational materials to support these conversations and assist patients with AD self-management
  - *Medication administration*: pharmacists administer certain medications (e.g. biologics)
- *Provision of specialist advice for HCPs*: providing advice to the dermatology department, e.g. advising on drug-drug/drug-disease interactions. This helps to inform prescribing decisions and ensure medication/treatment regimens are safe for patients
- *Recording SCORAD*: recording AD patient SCORAD scores during consultations, which are uploaded to the hospital's EHR and fed back to dermatologists
- *Refer patients*: the pharmacist may refer patients to specialist departments in the centre according to patient need (e.g. to the dermatology unit if the patient requires dermatological care)

**Sources:** (a) Yoke C, et al. A review on the role of moisturizers for atopic dermatitis. *Asia Pac Allergy*. 2016;6(2):120–128; (b) Snyder A, et al. A review of patient adherence to topical therapies for treatment of atopic dermatitis. *Cutis*. 2015;;96(6):397-401



# Supportive role of the pharmacist (2/2)

## What are the outcomes so far?

### Benefits to patients:

- Opportunities to ask specialist questions relating to their medication
- Better understanding of medication (including side effects, how to use, etc.)
- Improved knowledge of medication and understanding may lead to improved compliance and thus disease control

### Benefits to HCPs:

- Regular monitoring of SCORAD
- More effective use of HCP time (i.e. expanding the role of the pharmacist can reduce reliance on physicians)
- Safer use of medication (through the specialist input of the pharmacist)
- Effective communication between dermatology and pharmacy leading to improved knowledge sharing

## What's next?

- Initiate regular meetings with the dermatology department once the immuno-allergy functional unit is established

“



We educate patients about their therapy. We help them understand how to use their therapy and how to obtain more supplies of their medication

*Pharmacist, Sant Pau*

“



We are here to provide the best service for patients and give them what they need

*Pharmacist, Sant Pau*



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# Specialised ophthalmology consultations (1/2)

## Overview

- AD patients with or at risk of eye comorbidities are referred to a specialist ophthalmologist, who provides diagnosis, treatment and monitoring of comorbid eye conditions

## What is the rationale?

- Many AD patients suffer from eye comorbidities<sup>(a)</sup>. Patients are particularly at risk if they have face lesions or are on particular forms of AD treatment (as these may cause side effects, including conjunctivitis)<sup>(b)</sup>
- AD patients may require care from an ophthalmologist for eye comorbidities

## What are the key features of the intervention?

- The dermatology unit works closely with the ophthalmology department, with regular cross-referrals to provide specialist, multidisciplinary care for AD patients
- 3 of the department's 15 ophthalmologists are specialised in seeing AD patients
  - 1 ophthalmologist is a specialist in treating conjunctivitis in patients on biologics
- AD patients (adults only) are referred to the ophthalmologists for:
  - *General check up and monitoring*: atopy patients (moderate - severe) are referred to ophthalmology
  - *Ophthalmology treatment*: patients displaying comorbid eye conditions/presenting with symptoms requiring ophthalmology will be referred to the specialist ophthalmologists
- Patients are referred on a routine basis (maximum wait time: 1 month) or an urgent basis (maximum wait time: 1–2 days, although patients may be seen on the same day)
- Ophthalmologists upload details of consultations/clinical interventions to the electronic clinical record (HER), which dermatologists may access as required
- Consultations last up to 45 minutes and include tests and patient education
- Tests performed include:
  - General examination
  - Topography (cornea analysis)
  - Examination of retina and optic nerve
  - Visual accuracy test
  - Tear film and osmolality test: allows the specialist to optimise the lubricant used to alleviate dry eye symptoms (i.e. lubricant selection is based on this test outcome)

**Sources:** (a) Darlenski R, et al. Atopic dermatitis as a systemic disease. *Clin Dermatol*. 2014;32(3):409-13; (b) Electronic Medicines Compendium (EMC). Summary of Product Characteristics. Dupixent 300 mg solution for injection in pre-filled syringe [Website] <https://www.medicines.org.uk/emc/product/8553/smpc> Accessed 22 Feb 2019



# Specialised ophthalmology consultations (2/2)

## What are the key features of the intervention? (cont.)

### Format of the consultation (general check up/monitoring):

- Patient education includes disease (eye comorbidity) and treatment information
- Ophthalmologists provide required treatment(s) and patients attend follow-up appointments as necessary (every 3-6 months on average)

### Participation in an AD-comorbidity round table:

- A Sant Pau ophthalmologist recently participated in an AD-comorbidity focused 'round table' at the centre, with other Spanish AD-focused specialists
  - The Sant Pau ophthalmologist presented a 30 minute lecture on AD eye comorbidities and care, followed by Q&A
  - ~120 specialists were in attendance

## What are the outcomes so far?

### Benefits to patients:

- Better clinical outcomes: comorbid eye conditions are better controlled
- Improved QoL and reduced eye symptoms
- Tailored treatment received (e.g. lubricant selection on the basis of test results)

### Benefits to HCPs:

- Better coordination with comorbidity specialists
- Improved knowledge sharing between ophthalmology and dermatology
- Objective tracking of comorbid eye conditions

## What's next?

- Develop patient feedback questionnaire to collect patient experience data and improve the service
- Design specialised scoring index for AD comorbid eye conditions

“



We spend up to 45 minutes with patients, in which time we perform a variety of tests and educate patients about the tests, their results and their disease

*Ophthalmologist, Sant Pau*

“



We have a good collaboration with the dermatology department and have been working together for 2 years

*Ophthalmologist, Sant Pau*



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CENTRE REPORTS

# Patient and family education (Atopy school/workshop) (1/2)

## Overview

- The dermatology unit provides education and training for patients and their families through the Atopy school/Atopy workshop
- Each school/workshop is held 2-3 times a year for all AD patients and their families



Patients often feel more comfortable when they are with other patients - they can ask each other questions which they may be embarrassed to ask a Doctor

*Specialist dermatologist, Sant Pau*



## What is the rationale?

- Physicians have limited time to spend with patients and may be unable to cover all the aspects of the disease in consultations<sup>(a)</sup>
- Patients do not always understand the full impact of their disease or the treatment options available to them<sup>(b)</sup>. They may experience anxiety relating to the side effects of treatment<sup>(c)</sup>, which patient education may help overcome
- Education (especially in the paediatric population) has been shown to have a positive effect on AD patient outcomes<sup>(d)</sup>

## What are the key features of the intervention?

- The dermatology unit hosts the Atopy School “*Escola d’atopia*” (for children and their families) and Atopy workshops (for adults), which have been running for 6 years
- They are supplementary to the 1-on-1 education provided during consultations

### Frequency and attendees:

- These educational events are held 2-3 times a year and take place in the evenings (4:30pm-8pm)
- On average, ~40 patients and family members attend each session
- A team of AD specialists delivers the training, including:

#### *Atopy school:*

- Specialist dermatologist (AD)
- Paediatric dermatologist
- Psychologist
- Nurse
- Volunteering association (Atopy School only): volunteers help to make the session fun and enjoyable for children (e.g. through games and activities)

#### *Atopy workshop:*

- Specialist dermatologist (AD)
- Psychologist
- Nurse

**Sources:** (a) GlobalSkin Position Paper: “Atopic Dermatitis: A Collective Global Voice for Improving Care” February 2018 [PDF] <https://www.semanticscholar.org/paper/GlobalSkin-Position-Paper-Atopic-Dermatitis-%3A-A-for/e08b204478263f64f02a5f1285fd0e59a68ad91a> Accessed 22 Feb 2019; (b) Arkwright P, et al. Management of difficult to treat AD. *American Academy of Allergy, Asthma & Immunology*. 2012;1(2):142-151; (c) Powell, K, et al. GP and parent dissonance about the assessment and treatment of childhood eczema in primary care: a qualitative study. *BMJ Open*. 2018; (d) Grillo M, et al. Pediatric atopic eczema: the impact of an educational intervention. *Pediatr Dermatol*. 2006;23(5):428-36



# Patient and family education (2/2)

## What are the key features of the intervention (cont.)?

### Content of the sessions:

- *Pathophysiology* – disease context, explanation of the disease and triggers
- *Treatment options* – topical and oral treatments, including dispelling misconceptions around the risks of prolonged steroid use/the safety profile of steroid use in AD
- *Question and answer (Q&A) session* – patients and families ask questions about their disease, either to the HCPs or other patients, providing a “safe space” for patients to talk about their condition

## What are the outcomes so far?

### Benefits to patients:

- An opportunity to meet other patients, share experiences and ask questions (and listen to those of others)
- Better understanding of the disease and thus improved control and quality of life
- Reduced visits to the centre

### Benefits to HCPs:

- Time effective, providing patient education to many patients simultaneously
- Improved treatment adherence and control in patients
- Opportunity to provide holistic care to patients

## Tips to replicate this intervention

- Involve nurses – nurses play a key role, especially with paediatric patients. They help reassure patients and their families, teach them how to apply creams and generally build rapport
- Q&A sessions are very important – patients often feel more comfortable when speaking with other patients, as opposed to HCPs



We help make the treatment seem fun and teach children and parents how to apply their creams

*Nurse, Atopy School,  
Sant Pau*



Poster advertising the Escola d'atopia





# On-site dermatology psychologist (1/2)

## Overview

- The dermatology unit employs a specialist dermatology psychologist, who provides support for patients with AD and other skin conditions (e.g. psoriasis)

## What is the rationale?

- AD can affect the psychological well-being and quality of life of patients<sup>(a)</sup> and their families<sup>(b)</sup>, making psycho-social support in AD an important aspect of patient care

## What are the key features of the intervention?

- A full-time specialist dermatology psychologist provides psycho-social support and care for adult and paediatric patients with dermatological conditions (e.g. AD, psoriasis)
- AD patients are referred to the psychologist by their dermatologist – patients will be referred if they display psycho-social symptoms (e.g. decreased quality of life, sleep disturbance)
- The psychologist conducts patient consultations, either with or without the dermatologist present:
  - Consultations with the dermatologist occur once a month and last for 20 minutes
  - Consultations without the dermatologist occur on an on-going basis and last for up to 45 minutes
- The psychologist has approximately 20 patients (mainly severe AD) that are seen on a regular basis

### Treatment provided:

- *Relaxation:*
  - The psychologist works with patients to help them relax, alleviate anxiety and develop coping strategies
- *Psychotherapy (individual):*
  - The psychologist organises individual therapy for AD patients
- *Pharmacological therapy:*
  - Dermatologists can prescribe pharmacological therapy (e.g. antidepressants) if required, in addition to relaxation or psychotherapy
- The psychologist may refer patients to the Spanish patient association group (AADA) for additional support
- Patients are monitored and tracked using standardised mental health scoring indices (e.g. Hospital Anxiety and Depression Scale [HADS]) and are followed up every 1-2 weeks

**Sources:** (a) Noh S, et al. Comparison of the psychological impacts of asymptomatic and symptomatic cutaneous diseases: vitiligo and atopic dermatitis. *Ann Dermatol.* 2013;25(4):454-61; (b) Reed B, et al. The burden of atopic dermatitis. *Allergy Asthma Proc.* 2018;39(6):406-410.



# On-site dermatology psychologist (2/2)

## Challenges

- Even though the literature highlights the advantages of having a psychologist as part of the multidisciplinary team, obtaining resources and funding for a psychologist can be difficult
- Patients may struggle to find the time for psychotherapy sessions (especially group therapy)

## What are the outcomes so far?

### Benefits to patients:

- Receipt of holistic care
- Patients may feel more comfortable receiving psychological treatment at the dermatology centre vs. the psychiatry department
- An opportunity to ask questions to dermatologists and psychologists simultaneously (during joint consultation)

### Benefits to HCPs:

- Shared decision making between psychologist and dermatologist (during joint consultation)
- Allows dermatologists to better understand their patients and their behaviours

## What's next?

### Within the centre:

- Telepsychology: Develop a service to provide psychology appointments via online consultations
- Patient questionnaires: Design and implement patient questionnaires to collect and incorporate patient feedback regarding the service (i.e. on different aspects of their experience)
- Group psychotherapy: Implement group therapy for AD patients (1.5 hours per week (for 6 weeks) with groups of 10-12 patients)

### Outside of the centre:

- Conduct further trials/research regarding the effectiveness of psychology in dermatology, in order to demonstrate to the wider scientific community (and possible sources of funding) the value of psychology services within dermatology

“

If you improve the mental health of a patient, you improve their disease

*Psychologist, Sant Pau*



“

Patients reassure other patients in group psychotherapy sessions

*Psychologist, Sant Pau*





# Inselspital

**Bern, Switzerland**

Site visited by KPMG 26–28<sup>th</sup> March, 2019

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[kpmg.com/uk](https://kpmg.com/uk)



APPENDIX  
CENTRE REPORTS



# Summary



## Context

**Centre type:** University hospital located in Bern

**Catchment area:** Canton of Bern (population of approximately 1,000,000) and adjacent cantons

**Funding:** Inselspital is part of the Insel Gruppe AG which is managed by the 'Management Insel Group' (owned by the Inselspital Foundation and the Canton of Bern)

**Services:** A range of medical specialities, including adult and paediatric dermatology, which are situated in the adult clinic (Haus) and paediatric hospital (Kinderkliniken) respectively

**Patient population:** 23,000 outpatient consultations in the dermatology unit (2016)



## Key strengths in the delivery of AD care

**Key focus on patient education:** Centre offers in-depth, high-quality educational courses for AD patients from across Switzerland. AD patients also benefit from 1:1 patient education (delivered by an Advanced Practitioner Nurse [APN])

**Multidisciplinary care offered to patients:** The Dermatology unit works closely with other specialities (e.g. psychology) to provide holistic care for patients

**Efficient and streamlined operations:** Throughout the centre's testing facilities and laboratories, effective protocols and processes reduce inefficiencies (e.g. the duplication of work)

**Integral role of the nurse:** The dermatology unit employs an APN who supports dermatologists in patient consultations and provides additional, education-focused consultations for patients



## Key challenges faced in delivery of AD care

**Ensuring paediatric patients have a smooth transition into adult care** and remain engaged and compliant with their care regimen

**Management of adolescent patients** (especially during transition of care) where compliance and consultation attendance can be an issue

**Disease severity may not correlate with a patient's perception of the disease**, which can impact patient treatment compliance and / or lead to unrealistic treatment expectations

**AD patients may not comply with treatment** (especially topical treatment), which may negatively impact patient outcomes. The centre is working to improve treatment compliance through patient education

# Atopic Dermatitis (AD) in Switzerland

## Swiss healthcare system<sup>(a)</sup>:

The Swiss healthcare system is broadly divided into three levels including: federal, cantonal and municipal. The Cantons play a key role by licensing providers, co-ordinating hospital care and subsidising institutions. The system is financed in four ways:

### Publicly financed:

1. Direct financing – tax-financed budgets allocated to the Swiss Confederation, cantons and municipalities
2. Mandatory health insurance (MHI) premiums – residents are legally required to purchase MHI, which covers elements of primary and secondary care (with hospital services subsidised by the cantons)
3. Social insurance contributions – for accident insurance, old-age insurance, disability insurance and military insurance

### Privately financed:

4. Private health insurance – paid for by residents, covering services not covered by MHI

Hospitals may receive payment either by invoicing the patient (who pays upfront and claims reimbursement from the insurer, or forwards the invoice to the insurer for payment) or the insurer directly (who makes the payment and bills any balance to the patient).<sup>(a)</sup>

## Bern healthcare system:

The Canton of Bern provides funding to hospitals (through tax-financed budgets). Patients in Bern may choose which centre they receive treatment from.

## Prevalence

- AD affects 10–20% of children<sup>(b)</sup> and ~4% of adults<sup>(c)</sup> in Western countries
- Globally, approximately 1/3 of people are affected by an atopic disease (AD, asthma and allergic rhinoconjunctivitis)<sup>(d)</sup>
- The lifetime risk of developing asthma and allergic rhinitis in patients with AD is up to 75%<sup>(c)</sup>



## Care provision:

### Location:

- Mild (or well-controlled) AD care is usually managed by dermatologists in private practices
- Moderate and severe (or uncontrolled) AD is usually managed by dermatologists within hospitals

### Funding:

- Specialist outpatient care is covered by insurance (MHI and private insurance)<sup>(a)</sup>

## Guidelines and societies:

### Guidelines:

- Guidelines for treatment of atopic eczema (atopic dermatitis) part I and part II: European Association of Dermatology and Venerology (EADV)

### Medical society:








- Swiss Society of Dermatology and Venereology (SGDV/SSDV)

### Patient advocacy group (PAG):

- Aha! Swiss Allergy Centre

**Sources:** (a) The Commonwealth Fund. International Health Care System Profiles: The Swiss Health Care System [Website] <https://international.commonwealthfund.org/countries/switzerland/> Accessed 10 April 2019; (b) Nutton S. Atopic dermatitis: global epidemiology and risk factors. *Ann Nutr Metab.* 2015;66 Suppl 1:8-16; (c) Barbarot S, et al. Epidemiology of atopic dermatitis in adults: Results from an international survey. *Allergy* 2018;73:1284-1293; (d) Clausen, ML, et al. Skin Barrier Dysfunction and the Atopic March. *Curr Treat Options Allergy* 2015;2:218

# The centre and dermatology unit

The centre		
 <b>Type and location</b>	— Inselspital is a university hospital located in central Bern, managed by the ‘Management Insel Group’ (owned by the Inselspital Foundation and the Canton of Bern)	
 <b>Population served</b>	— It is a tertiary referral centre for dermatology patients from across the Canton of Bern	
The dermatology unit		
 <b>Service Division</b>	<b>Polyclinic (Eczema clinic)</b>	<b>Inpatient dermatology ward</b>
 <b>Hours of availability</b>	Tuesday–Friday: half day clinic (alternating mornings and afternoons)	24/7
 <b>No. of patients seen</b>	200–250 eczema consultations / month (~30% of these patients are AD patients)	8 bed capacity; 1–2 AD patients per month; AD patients typically stay 4–5 days
 <b>Types of patients seen</b>	Adult patients (18+ years), adolescents (16–18) and select paediatric patients (paediatric patients are normally seen in the paediatric hospital)	
 <b>Facilities on-site<sup>(1)</sup></b>	<ul style="list-style-type: none"><li>— Phototherapy</li><li>— 3 allergy laboratories (paediatric dermatology, adult dermatology and the allergology department)</li><li>— 1 main laboratory (which serves the entire centre)</li><li>— Pathology department (dermato-pathology)</li><li>— Inpatient dermatology ward (8 beds)</li><li>— Outpatient dermatology unit (polyclinic)</li><li>— Clinical trial facilities (currently running 10 clinical trials covering a range of dermatological conditions, including 4 AD clinical trials)</li><li>— Wound care centre</li><li>— Photographic laboratory</li></ul>	

**Note:** (1) List of facilities is not exhaustive






# The team



## Core team profile

-  **14** Dermatologists
-  **10** Trainee dermatologists
-  **24** Nurses (including 12 inpatient nurses [general dermatology], 10 outpatient nurses and 2 clinical trials nurses)
-  **3** Dermato-pathologists
-  **2** Dermatology biomedical analytics technicians

## Wider team profile

-  **9** Allergists (including 1 dermatology trainee specialising in allergology)
-  **3** Ophthalmologists (specialised in the anterior segment)
-  **2** Physiotherapists
-  **1** Nutritionist
-  **1** Psychologist

*Note: Please see pg. 371 for further details on the wider team*



## Governance and processes

### Team meetings:

- *Dermatology meetings (4 times per week)*
- *Dermatology-pulmonology meetings (upon request)*
- *Allergy meeting (2 times per week):*
  - Attendees: allergists at the centre
  - Purpose: to discuss complex patients
- *Pulmonology-allergy meeting (once a month):*
  - Attendees: allergists and pulmonologists
  - Purpose: to plan care for asthma patients
- *National meeting (twice a year):*
  - Attendees: clinicians from across the centre
  - Purpose: to provide an update on research and clinical practice
- *Clinical pathology sessions (twice a week):*
  - Attendees: dermatologists and pathologists
  - Purpose: to present and discuss interesting patient cases

### Patient records:

- *Electronic patient records:*
  - Centre has an electronic record and database for laboratory results



# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients present to either private dermatologists, primary care professionals (PCPs) or directly to the centre
- The dermatology department works with the patient advocacy group (aha! Swiss Allergy Centre) to raise awareness of AD (and other allergy disorders)

*Note: Patients with mild / well-controlled AD may be managed in primary care*

## Diagnosis and Referral

In secondary / tertiary care



- Patients requiring specialist dermatology care are referred to the centre
- Note: Approximately 30% of patients present directly to the centre, while 70% are referred (from all over Switzerland)*
- AD is diagnosed by dermatologists through clinical examination
- Dermato-pathologist may (upon request) provide diagnosis and inputs based on biopsy samples (processed in the laboratory in the dermatology unit)
- Patients may undergo allergy testing (e.g. skin prick testing) in the dermatology unit or allergology unit in order to identify allergic triggers. More complex tests are available in the allergology unit
- Note: External patients attend the centre for allergy tests and treatment*

## Treatment and Management

Medical management



- AD patients are managed by the dermatology department. New patients are trialled on a treatment for 6–8 weeks before being reviewed
- AD patients with asthma are referred to pulmonology. Allergology may also treat AD patients (providing specialist immunotherapy) but will refer severe cases to dermatology
- Clinical trials (in AD) provide an opportunity for patients to access new / novel treatments
- Comorbidity management (not exhaustive):*
  - *Asthma:* AD patients with asthma are treated by pulmonology (if referred by dermatology) or allergy (if initially referred into allergy)
  - *Gastroenterology:* AD patients with eosinophilic esophagitis (EoE) are referred to gastroenterology
  - *Ophthalmology:* Patients are referred if they display ocular symptoms

Non-medical management



- Advanced Practitioner Nurses (APNs) supplement each dermatologist consultation with patient education sessions (30 mins) covering AD treatment (e.g. treatment application)
- AD patients are actively encouraged to attend patient education courses (evening sessions) which run twice a year (spring and summer) [see case study pg. 387 - 389]
- Dermatologists refer patients exhibiting psycho-social distress to the psychologist (within the psychosomatic department)
- Note: The psychologist is specialised in AD but also sees patients with other diseases*

## Follow-up

Monitoring of chronic disease / flare up



- Patients with flares present to the emergency dermatology service and are seen on the same / next day by a trainee dermatologist and staff dermatologist in the polyclinic. Patients are then followed up by the specialist dermatologist within 2 weeks
- SCORAD and DLQI indices are recorded by the APN and dermatologist during biologic follow-up and clinical trial consultations
- Patients are followed up every 4–8 weeks at the centre

# Roles of the wider team

## Allergist

**Patient type:** AD patients requiring allergy tests or treatment. Mild AD patients are managed by allergists

**Referral:** Allergy patients are mostly referred by primary care physicians (70–80%) or by community allergists / the centre's dermatologists

**Consultations:** Provide allergy tests (wide spectrum of tests available), immunotherapy and vaccinations for allergy patients. Patients are "discharged" from allergology when they no longer require treatment / allergies have been identified

**Timing:** Consultations are scheduled as required and typically last 30 minutes (though may be longer for specialist treatment)

## Psychologist

**Patient type:** AD patients exhibiting psycho-social symptoms / complications

**Referral:** Dermatologists refer patients

**Consultations:** Psychologist conducts 1:1 patient consultations to uncover how the patient feels, how they are coping with their disease and the impact on their quality of life

**Timing:** Consultations last 1 hour every month (depending on patient need)



## Ophthalmologist

**Patient type:** AD patients with ocular symptoms

**Referral:** Dermatologists refer patients

**Consultations:** Initial consultations include basic dry eye testing to assess tear duct function and examine eye lids. The ophthalmologist provides topical treatment for patients. Following each appointment, a nurse provides patient education (i.e. for eye care and cleaning)

**Timing:** Ophthalmologist consultations last 30 minutes and additional nurse consultations last 10 minutes; follow up consultations occur 2 weeks after the initial consultation and last 20 minutes

## Physiotherapist

**Patient type:** All AD patients who attend patient education sessions and those who request relaxation therapy

**Consultations:** Group sessions are conducted during AD education sessions and at the psychosomatic unit<sup>(1)</sup> (1:1 sessions). The physiotherapist teaches patients relaxation techniques and encourages them to practice in their own time (using a mobile phone application)

**Timing:** Physiotherapy during AD patient education sessions (and at each of the 5 evening sessions) lasts 20-25 mins; 1:1 sessions (in the psychosomatic unit) held following referral

## Roles of additional team members:

- *Dermato-pathologist:*  
This specialist dermatologist examines samples (processed by the on-site laboratory) and provides opinion on the diagnosis of the patient (i.e. if they have inflammatory skin disease)
- *Dermatology biomedical analytics technician:*  
Laboratory staff within the dermatology allergy laboratory prepare samples (food and drug) for allergy testing, conduct testing on patients and provide additional counselling for hand eczema patients

**Note:** (1) Group sessions are held for chronic pain patients, AD patients are able to join these sessions

# Overview of interventions in place for AD

## Awareness and Presentation



Symptom identification

- **Working with the patient advocacy group:** The centre works with the aha! Swiss Allergy Centre to create patient materials and provide patient education sessions

See pg. 377 for case study

## Diagnosis and Referral



In secondary / tertiary care

- **Specialist dermatopathologist testing and diagnosis:** A specialist dermatopathologist, based in the centre, provides pathological and clinical inputs during the diagnosis of dermatology patients (i.e. will provide an opinion on the AD diagnosis)

See pg. 378-379 for case study

- **On-site dermatology laboratory:** The on-site dermatology laboratory performs patch tests and skin prick tests (for drugs and other allergens) for patients within and outside the hospital (either by preparing samples or using those which are commercially available)

See pg. 380-381 for case study

## Treatment and Management



Medical management

- **Ophthalmology-dermatology collaboration:** Ophthalmologist conducts consultations with AD patients with ocular symptoms. They provide treatment and education (along with nurses) for AD patients and follow up as required

See pg. 382 for case study

- **Joint dermatology-allergy consultations (paediatrics):** Paediatric patients are jointly seen by dermatologists and allergists and are co-managed by these physicians

- **Clinical trials:** The centre is running 10 clinical trials (all interventional) in a range of dermatology conditions, including 4 for AD



Non-medical management

- **Role of the advanced Practitioner Nurse (APN):** The centre employs an APN, who co-conducts consultations with the specialist dermatologist and provides additional 1:1 patient support (e.g. treatment application advice)

See pg. 383-384 for case study

- **Physiotherapist relaxation training and mobile app:** Physiotherapists provide relaxation training for AD patients (as a group or 1:1) and have developed a mobile application allowing patients to practice relaxation therapy at home

See pg. 385-386 for case study

- **AD patient education evenings:** Evening education sessions for adult AD patients are delivered by dermatologists, nurse, psychologist, nutritionist and physiotherapist

See pg. 387-389 for case study

## Follow-up



Monitoring of chronic disease / flare-up

- **Dermato-pathologist education and training sessions:** Specialist dermatopathologist provides 1-hour training for trainees regarding diagnosis (pathology) of a range of dermatological conditions (including AD), with topics rotating on a 2-yearly basis



# Monitoring AD patients and comorbidities

## The dermatology unit employs a number of measures for monitoring AD and associated comorbidities

### Objective measures (AD):

AD scoring indices are used to monitor patients and their disease, including:

- SCORAD (SCORing Atopic Dermatitis): used to assess AD disease severity and monitor patient progress<sup>(a)</sup>. SCORAD is measured for patients on systematic therapy during each consultation with the dermatologist (and Advanced Practitioner Nurse [APN])

Quality of life (QoL) is routinely measured by:

- DLQI (Dermatology Quality of Life Index): dermatology-focused quality of life questionnaire<sup>(b)</sup>. DLQI is also measured for patients on systematic therapy during each consultation with the dermatologist and APN

---

### Comorbidity outcomes are routinely measured by:

- *Allergist*: response to allergens / control of atopy disease (e.g. monitoring allergic asthma using peak flow tests)
- *Psychologist*: monitoring psycho-social distress through psychological questionnaires (e.g. Fragebogen zur Bewältigung von Hautkrankheiten (FBH)<sup>(c)</sup>)
- *Ophthalmologist*: monitoring of symptoms and basic tests (e.g. dry eye testing)
- *Pneumologist*: lung function testing for asthma patients
- *Gastroenterologist*: endoscopy including biopsies for patients with eosinophilic esophagitis (EoE; diagnosis and monitoring severity)

**Sources:** (a) SCORing Atopic Dermatitis (SCORAD) Calculator (0.9.0). [Website] <http://scorad.corti.li/> Accessed 26 Feb 2019; (b) Lewis V, et al. 10 Years Experience of the Dermatology Life Quality Index (DLQI). *J Invest Dermatol Symp Proc* 2004;9:169–180; (c) Stangier U, et al. Fragebogen zur Bewältigung von Hautkrankheiten:(FBH). *Hogrefe, Verlag für Psychologie* 1996:367-405

# Advice to other centres



## What advice would you give less specialised centres



**Objective of advice:** Empower nurses to expand their role within AD care

- **Why?** AD is a chronic disease which requires long-term treatment. Centres therefore have the opportunity to develop long-standing relationships with patients, which can be beneficial from both in terms of treatment compliance and patient satisfaction. Nurses are well placed to develop patient relationships, as they often hold longer consultations and are sometimes perceived as less-intimidating than dermatologists (i.e. patients feel more comfortable asking questions). Empowering nurses to provide specialist AD care, alongside physicians, facilitates the delivery of high-quality patient care and saves time for physicians. For example, nurses may deliver patient education regarding treatment (e.g. application advice), allowing physicians to focus their time on other responsibilities. Importantly, longer nurse consultations offer patients the opportunity to ask questions and improve their knowledge of their condition



**Objective of advice:** Invest in AD patient education

- **Why?** Patient education is essential for managing chronic diseases – especially AD – as it helps patients to understand their disease and how to comply with treatment. Physicians and healthcare professionals (HCPs) are often limited in the time they can spend with patients in the consultation environment. Holding separate patient education sessions is therefore beneficial, as it enables patient education to be delivered without consuming valuable consultation time. Patient education may be delivered by a multidisciplinary team consisting of all those involved in the care of AD patients (e.g. nurses, dermatologists, psychologists, nutritionists, allergists)

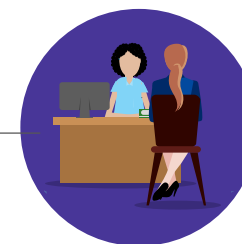
# Next steps for the centre



## What is next for the centre?

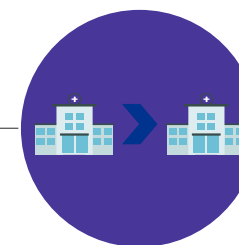
### Objective: Implement patient education for paediatric patients

- **What?** The dermatology unit currently provides patient education for adult patients (delivered by Advanced Practitioner Nurses [APNs] following dermatologist consultations) and are planning to expand this service to include paediatric patients. An additional nurse may be required to meet the educational demands of this new patient population
- **Why?** Patients benefit from the strong relationships they build with APNs and appreciate the opportunity to discuss things not solely related to their AD. Nurses at the centre play a key role in educating patients about their disease and treatment, with the aim of empowering patients and improving treatment compliance. The centre is committed to extending these benefits to the paediatric patient population



### Objective: Design and establish transitional clinic

- **What?** Adult patients are cared for at the dermatology unit, whereas paediatric patients are cared for at the paediatric hospital and transition into adult care aged 16+ years. Patients may find it difficult to transition between these care settings (as it is unfamiliar) and may be at risk of dropping out of care. The centre is working with the paediatric hospital to develop a transitional clinic, aimed at supporting patients through this difficult period. A clinic will be established between the lead (adult) dermatologist and paediatric dermatologists, in which patients will be transitioned ("handed over") from paediatric care into adult care. The clinic is due to open in summer 2019
- **Why?** Supporting adolescents and patients transitioning from paediatric to adult care may help to keep these patients in care and in regular contact with the centre. Providing additional support at this time can improve patient treatment compliance and subsequently quality of life



# Case studies



<b>Working with the patient advocacy group (aha! Swiss Allergy Centre)</b>	377
<b>Specialist dermatopathologist testing and diagnosis</b>	378 – 379
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<b>AD patient educational evenings</b>	387 – 389



# Working with the patient advocacy group (aha! Swiss Allergy Centre)

## Overview

- The patient advocacy group (PAG), aha! Swiss Allergy Centre, works with hospitals such as Inselspital to deliver additional support for allergy (and AD) patients

**Sources:** (a) aha! Swiss Allergy Centre. About us: Commitment [Website] <https://www.aha.ch/swiss-allergy-centre/about-us/commitment?oid=1554&lang=en> Accessed 10 April 2019; (b) aha! Swiss Allergy Centre. About us: Mission Statement [Website] <https://www.aha.ch/swiss-allergy-centre/about-us/our-vision?oid=1557&lang=en> Accessed 10 April 2019



## aha! Swiss Allergy Centre

- The aha! Swiss Allergy Centre aims to improve quality of life for millions of people living with allergies in Switzerland<sup>(a)</sup>. aha! Swiss Allergy Centre is an independent patient advocacy group that works together with different hospitals and institutions throughout Switzerland
- They produce patient education materials, deliver education sessions for allergy patients (including atopic dermatitis patients) and raise awareness of allergic disorders<sup>(b)</sup>

### aha! Swiss Allergy Centre - Inselspital activities:

- *Development of patient education materials*
  - Objective: To improve the knowledge and understanding of allergic disorders (including AD) in the patient community, through the provision of patient brochures containing scientific data and patient friendly information
  - For example, aha! Swiss Allergy Centre has developed a brochure containing general information about and a description of food allergies, house dust mite allergies, drug allergies, etc. Each allergy description page includes symptoms, therapies and practical 'tips and tricks'
  - Role of Inselspital: Physicians from the centre review and ensure the clinical and medical accuracy of information. An allergist from Inselspital sits on the aha! Scientific Advisory Board
- *Provision of patient education sessions (one for paediatric patients with their parents, one for parents only)*
  - Objective: To educate patients (and their families) about allergic disorders, treatment options and how to cope with the disease(s)
  - For example, a previous session schedule has included basic treatment advice, skin and special clothing care, allocated discussion time and opportunities for questions
  - Role of Inselspital: To provide clinicians (dermatologists, paediatric dermatologists and nurses) to deliver the sessions and answer questions from patients and their families

### aha! Swiss Allergy Centre activities:

- *Patient helpline:*
  - aha! Swiss Allergy Centre provides a helpline for patients (Monday-Friday; 8:30am-12pm) to answer questions regarding the wider (non-medical) aspects of AD and support patients and their families

*Note: no medical advice is provided over the helpline*

- *Nurse counselling:*
  - aha! Swiss Allergy Centre is working with hospitals in Switzerland to develop patient counselling courses (for paediatric and adult patients), provided by nurses
  - Counselling sessions will be for patients (paediatric and adult) and delivered in collaboration with the hospitals. Sessions are co-funded by CK-CARE
- *Courses for medical assistants:*
  - 5-hour workshops for medical assistants (working in specialist practice) on Atopic Dermatitis. Each workshop is run by different speakers who have individualised schedules
  - The frequency of workshops is dependent on external requests and the availability of relevant speakers



# Specialist dermato- pathologist testing and diagnosis (1/2)

## Overview

- A specialist dermato-pathologist (who is also a dermatologist) works in the dermatology unit's pathology department and provides input and opinion on dermatology diagnoses (including those for AD)

## What is the rationale?

- Pathological examination of skin samples can be a component of the AD diagnostic process
- The clinical diagnosis of dermatological conditions (e.g. AD) can be challenging and often requires a skin biopsy<sup>(a)</sup>

## What are the key features of the intervention?

- 3 dermato-pathologists (2 dermatologists and 1 autoimmune specialist) work in the pathology department, based in the dermatology unit
- They spend 0.5–1 day per week in clinical practice and 4–4.5 days per week in pathology
- They process skin samples and provide specialist input on patient diagnosis (covering a range of dermatological conditions)

### Process overview:

- Dermatologists / dermatologist trainees from the centre and external dermatologists (community-based or from other hospitals) can request dermato-pathology input for their patient diagnoses

*Note: 40% of biopsies are for the centre and 60% are received from external HCPs*

Biopsies are sent to the dermatology laboratory (via an external courier if from external HCPs)

- The laboratory processes these biopsies (within 24 hours) into slide samples and sends them to dermato-pathology
- The dermato-pathologist examines the samples and provides an opinion on the likely diagnosis of the patient (i.e. melanoma / inflammatory skin condition)
- Initial diagnosis is “blinded” at this stage. Here, the dermato-pathologist does not read the initial diagnosis from the requesting physician before examining the sample, in order to reduce bias
- The opinion of the dermato-pathologist is fed back to the requesting physician
- All samples (and outcomes) are recorded on the results database, where data is stored for 20 years and may be used for trend analysis / further research

**Sources:** (a) Silvestre SJF et al. Atopic Dermatitis in Adults: A Diagnostic Challenge. *J Investig Allergol Clin Immunol* 2017;27(2):78-88.



# Specialist dermato-pathologist testing and diagnosis (2/2)

## What are the key features of the intervention? (cont.)

### Education and training:

- Dermato-pathology provides education and training for healthcare professionals across the centre:
  - *Clinical pathology sessions:*
    - Held twice a week (Monday and Thursday)
    - Sessions last 30 minutes
    - Attended by dermatologists (including trainees) and pathologists
    - Interesting / unusual cases are discussed for educational purposes
  - *Evening training sessions:*
    - Held weekly (on Monday evenings)
    - Sessions last 1 hour
    - Attended by trainee dermatologists from the centre
    - Different topics are covered each week, including histopathology and different dermatological conditions
    - All dermatological conditions are covered over a 2 year period (topics rotate)

## What are the outcomes so far?

### Benefits to patients:

- Improved / more accurate diagnosis of their dermatological condition

### Benefits to HCPs:

- Dermato-pathologists may utilise their clinical knowledge and experience in the diagnostic process (within pathological examinations)
- Improved / more accurate diagnoses
- Trainees may learn from the input / opinion of the dermato-pathologist

“



I will perform an examination of the sample before I look at the requesting physician's diagnosis. This means I am removing bias from my diagnosis

*Dermato-pathologist, Inselspital*

“



I use my knowledge and clinical experience as a dermatologist during the examination of samples. I understand both the laboratory and clinical practice

*Dermato-pathologist, Inselspital*



CONTENTS



APPENDIX  
CENTRE REPORTS

# On-site dermatology laboratory (1/2)

## Overview

- The on-site dermatology laboratory performs patch tests and skin prick tests (for drugs and other allergens) for patients within and outside the hospital (either by preparing samples or using those which are commercially available). Dermatologists interpret test results and discuss them with patients during consultations



We have flexible opening hours to accommodate different patient needs

*Lab technician, Inselspital*



## What is the rationale?

- Atopic Dermatitis (AD) patients may require allergy testing, as allergies are often linked with AD (e.g. food allergy)<sup>(a)</sup>
- Tests range from low complexity tests (e.g. patch tests) to high complexity tests (e.g. specific allergen provocation tests)
- Patients may be required to visit the dermatology department multiple times for testing / reading of results, which can be time-consuming and inconvenient for patients

## What are the key features of the intervention?

- The dermatology unit has a specialist laboratory on-site which offers a range of testing for patients
- The laboratory is specialised in Type 4 tests, used to diagnose contact allergy as a trigger factor of AD (patch testing takes ~48h, with subsequent patch test readings at days three and four)
- Patients are primarily sent to the laboratory from the polyclinic (within the centre) or occasionally from dermatologists outside the centre for patch testing

### Tests offered:

- Patch tests
- Skin prick tests
- Samples are either prepared on-site by laboratory staff (with substances brought in by patients or available in the laboratory) or procured directly from commercial companies

### Type IV patch testing process:

- The patch tests are completed over a 4 day period:
  - Patches are applied (with a sample of the suspected allergen) on Monday or Tuesday
  - Initial readings are taken (by the physicians) on Wednesday or Thursday (48 hours later)
  - The 2<sup>nd</sup> readings are taken (by the physicians) on Thursday or Friday (72 hours later)
- Physicians provide patients with an outcome / diagnosis in written form and record it on a database (accessible by dermatologists)
- The laboratory has flexible opening hours throughout this process to accommodate patient schedules. Patients typically arrive between 7–7:30am and are seen by a dermatologist at approximately 8am

**Sources:** (a) Chiesa Fuxench ZC. Atopic Dermatitis: Disease Background and Risk Factors. *Adv Exp Med Biol.* 2017;1027:11-19.



# On-site dermatology laboratory (2/2)

## What are the key features of the intervention? (cont.)

### Referral training:

- The dermatology unit teaches other physicians at the centre how to write referrals. The head dermatologist conducts training integrated into CME symposia for dermatologists, allergists and GPs. Ad hoc referral training is also delivered in outpatient clinics to resident dermatologists

### Hand eczema patient education:

- Patients with hand eczema receive 1:1 education on their condition
- The session lasts for approximately 30 minutes and is delivered by a laboratory staff member
- Information is presented in leaflets and on an iPad, which includes: how to cope with the disease, hand eczema background and the correct use of gloves
- Patients suffering with hand eczema may request a consultation

## Challenges

- Referral letters do not always specify if the patient is bringing in their own samples. Preparing samples can be time-consuming and may cause delays, where the need to prepare a sample is not communicated before the patient attends their appointment

## What are the outcomes so far?

### Benefits to patients:

- Quick and convenient access to specialist allergy tests (and diagnosis)
- Specialist information about hand eczema through a dedicated session

### Benefits to HCPs:

- Improved knowledge of the referral pathway (i.e. when and how to refer patients) which results in better referrals from non-dermatology specialist physicians

## What's next?

- Continue to update and extend the set of allergens tested for at the centre

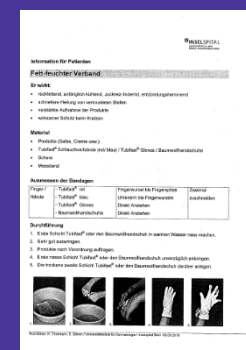
*Note: Allergy currently provides Type 1 testing for patients*

- Increase the number of drug tests available for patients (in drug allergy testing)

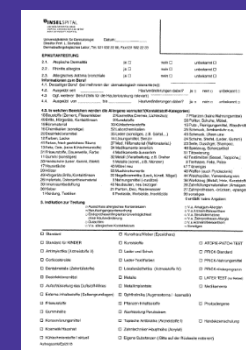


The patients arrive on a Monday and have their patch applied. They will then see the Doctor on Wednesday and Thursday for their 1<sup>st</sup> and 2<sup>nd</sup> readings

*Lab technician, Inselspital*



Hand eczema patient leaflet (1)



Order form for physicians



Hand eczema patient leaflet (2)



Prick test patient leaflet

# Ophthalmology-dermatology collaboration

## Overview

- AD patients displaying ocular symptoms are referred to specialist ophthalmologists, who conduct basic testing and provide treatment for ocular AD comorbidities



## What is the rationale?

- Atopic dermatitis (AD) has both dermatologic and ocular manifestations<sup>(a)</sup>
- The severity of the dermatologic conditions is not always directly correlated with ocular symptoms, meaning ophthalmology input is necessary<sup>(a)</sup>

## What are the key features of the intervention?

- The ophthalmology department has 3 ophthalmologists who specialise in the anterior segment of the eye and see AD patients
- AD patients are either referred to the ophthalmology department (if they display ocular symptoms) or present directly:
  - 70% of patients are referred (40% from private ophthalmologists; 60% from dermatologists)
  - 30% of patients present directly to the department

### Format of the consultation:

- Consultations last for 30 minutes
- The ophthalmologist conducts a number of tests (e.g. basic dry eye testing to test tear function and check eye lids)
- Treatment is provided for patients. If patients require systemic treatment, they are referred to dermatology
- Following the consultation, a nurse educates the patient (e.g. about basic eye hygiene) during a 10 minute consultation

### Post-consultation pathway:

- Patients are followed up as required (usually within 2 weeks) to check their ocular symptoms
- If patients are stable and well-controlled, they are referred back to their private ophthalmologist (in the community)
- If a patient was referred from a dermatologist, the ophthalmologist sends a letter to the referring dermatologist with the outcome of the consultation (including details of any treatment provided)

## Challenges

- Educating patients and helping them to accept they have a chronic condition

**Sources:** (a) Bielory B, et al. Atopic dermatitis and keratoconjunctivitis. *Immunol Allergy Clin North Am.* 2010;30(3):323-36



# Role of the Advanced Practitioner Nurse (1/2)

## Overview

- The centre employs an Advanced Practitioner Nurse (APN) who is specialised in AD, providing specialist input either during the co-consultation with the dermatologist or during 1:1 sessions with the patients

**Sources:** (a) Cork MJ, et al. Comparison of parent knowledge, therapy utilization and severity of atopic eczema before and after explanation and demonstration of topical therapies by a specialist dermatology nurse. *Br J Dermatol.* 2003;149(3):582-9; (b) Nicol NH, et al. The role of the nurse educator in managing atopic dermatitis. *Immunol Allergy Clin North Am.* 2010;30(3):369-83; (c) Brown MH. A nurse-led clinic in chronic and allergic contact dermatitis. *Br J Nurs.* 2005;14(5):260-3



## What is the rationale?

- Nurses (especially specialist nurses<sup>(a)</sup>) play a key role in the management of AD patients<sup>(b)</sup>
- Physician time is often limited, which can negatively impact patient outcomes. The role of the nurse (e.g. through nurse-led clinics) provides additional support to alleviate this issue<sup>(c)</sup>

## What are the key features of the intervention?

- There is one APN (set up 2 years ago) specialised in AD
  - The APN has completed additional qualifications (e.g. Masters in Nursing Science) which exceed standardised nursing education and training

### Role of the APN:

- *Co-conducts AD patient consultations (all ages and AD severities with dermatologists)*
  - The APN assists with measuring patient SCORAD (SCORing Atopic Dermatitis) and DLQI (Dermatology Quality of Life Index) scores
  - These indices are only measured for patients on systemic therapy
  - The APN completes the clinical assessment and discusses the findings and treatment with a dermatologist
  - The APN also performs patch test readings
- *Conducts 1:1 education sessions with patients*
  - Patients include severe AD patients and / or non-compliant patients
  - These patients are identified by the dermatologists or by the APN
  - If the APN is not available, the session is delivered by another dermatology nurse
- *Attends the eczema clinic*
- *Delivers patient education during evening education sessions (see case study pg. 387 - 389)*
- *Provides training for registered nurses*
  - 1–2 training sessions provided per year for registered nurses and AD healthcare assistants employed across Switzerland
  - These are either half or full day sessions, attended by 10-15 nurses per session
  - Agenda includes lectures on pathogenesis, management of AD and benefits of patient education, with educational materials provided for delegates to take home
  - The training sessions are advertised by Aha! Swiss Allergy centre (see case study pg. 377)



# Role of the Advanced Practitioner Nurse (2/2)

## What are the key features of the intervention? (cont.)

### Format of the 1:1 education:

- Patients will attend their regular appointment with the APN (this will be supervised by a dermatologist, but they will only see the APN)
- Sessions are conducted on a 1:1 basis (first consultation lasts approximately 45 minutes)
- The APN discusses the whole treatment process, including:
  - Treatment information (i.e. how it works)
  - Treatment application (e.g. for emollients)
  - How AD affects day-to-day life
- The APN will subsequently discuss the whole treatment process and any findings with a dermatologist
- Patients are followed up as needed, normally every 4 weeks–2 months (follow-up consultations last approximately 30 minutes)

## What are the outcomes so far?

### Benefits to patients:

- Continuity by seeing the same healthcare professional (HCP) during each visit (the APN)
- More time with a specialist HCP and therefore more opportunities to ask questions
- Improved understanding of treatment and application

### Benefits to HCPs:

- Shared decision making considers multiple points of view (e.g. APN specialist input)
- Nurses are given more responsibility, often leading to improved patient compliance and disease control
- A time effective method for delivering patient-specific education

## What's next?

- Replicate the nurse 1:1 education sessions for paediatric patients (at the paediatric hospital), following a similar structure to the existing adult education sessions (provided by the adult hospital APN)

“



Patients determine the contents of the sessions and I adapt the sessions around their needs

*Advanced Practitioner Nurse, Insepsital*

“



Patients know that nurses can focus on their individual needs and they like continuity. They like to see the same face each time they come to the centre

*Advanced Practitioner Nurse, Insepsital*



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# Physiotherapist relaxation and mobile app (1/2)

## Overview

- Physiotherapists at the psychosomatic unit (based at the centre) deliver relaxation therapy for chronic disease patients (including AD patients), which involves contracting and relaxing different muscle groups according to Dr Jacobson's theory<sup>(c)</sup>



Our patients enjoy the treatment. They feel relaxed after the sessions and give us positive feedback

*Physiotherapist, Inselspital*



## What is the rationale?

- The relationship between AD and psychological stress is well documented<sup>(a)</sup>
- Relaxation techniques can be beneficial for AD patients by reducing stress<sup>(b)</sup> and helping them cope with certain aspects of the disease (e.g. by reducing the temptation to scratch)

## What are the key features of the intervention?

- Two physiotherapists, based in the centre's psychosomatic unit, provide relaxation training for AD patients
- The relaxation therapy is based on Dr Jacobson's theory (tensing and relaxing 16 muscle groups<sup>(c)</sup>) and was originally introduced for chronic pain patients (before being extended to AD patients)
- Therapy sessions aim to teach patients the technique and enable them to practice at home

### The physiotherapists provide the training in several formats:

#### *Relaxation training at the AD educational sessions:*

- Provided at all 5 sessions (see case study pg. 387 - 389)
- The physiotherapists spend 30 minutes with the patients practising the technique
- It takes place in the final 30 minutes of each session
- The physiotherapists guide the patients through a sequence of muscle contractions and releases, focusing on different muscle groups and in different positions (e.g. sitting or standing), so they may be performed in different environments (e.g. at home, at work, on the bus)

#### *Relaxation training at other specialist sessions:*

- AD patients may join group sessions hosted for chronic pain patients
- Sessions follow a similar format to those delivered in the AD patient education sessions

#### *1:1 relaxation training:*

- Patients may visit the psychosomatic unit for 1:1 sessions with the physiotherapist following referral from the dermatologist
- Alternatively, patients may self-train using a CD or smartphone application

**Sources:** (a) Mestrovic-Stefekov J, et al. Psychological Stress in Patients with Atopic Dermatitis. *Acta Dermatovenerol Croat.* 2018;26(4):297-303; (c) Martha S, et al. Progressive Muscle Relaxation. *Journal of Human Behavior in the Social Environment* 2006;13(3):51-66

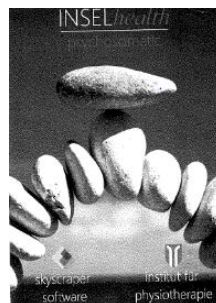


# Physiotherapist relaxation and mobile app (2/2)

## What are the key features of the intervention? (cont.)

### Mobile application

- In 2018, the centre's psychosomatic unit developed a free, publically available mobile phone application ('INSELhealth') to guide patients through practicing relaxation techniques at home
- Patients with a variety of chronic conditions (including AD patients) may use the application
- Patients complete a questionnaire when they first open the app, with questions relating to patient symptoms and the impact of AD on quality of life
- The app provides users with personalised recommendations, including specific relaxation techniques to help patients cope with their disease



Leaflet for the INSELhealth application

## What are the outcomes so far?

### Benefits to patients:

- Relaxation and reduced stress levels
- Ability to practice relaxation techniques at home
- Opportunity to meet other chronic disease patients

### Benefits to HCPs:

- Involved in pioneering the use of relaxation techniques in AD patients

## What's next?

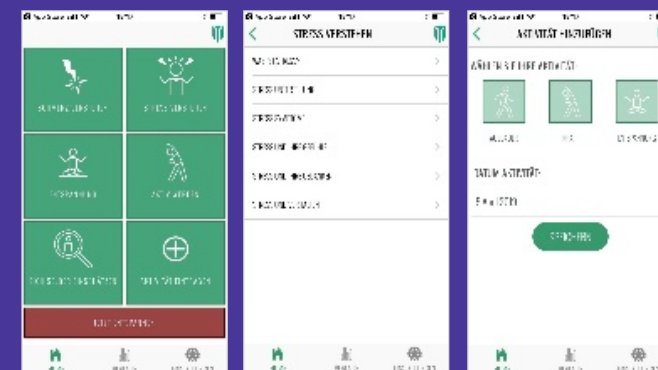
- Publish outcomes / findings from the implementation of the service with AD patients (e.g. benefits and challenges)

“



We conduct group sessions [during the AD education evenings] and guide the patients through each technique. We speak to patients after the session and they tell us what they enjoyed about it

*Physiotherapist, Inselspital*



INSELhealth mobile phone application



# AD patient education evenings (1/3)

## Overview

- The centre provides evening education sessions for AD patients twice a year (series of 5 x 2 hour sessions), covering a wide range of topics, including disease background information and AD's impact on quality of life



I come to the centre to deliver these sessions for patients. I talk to them about eating healthily and what they should and should not eat

*Nutritionist, Inselspital*



## What is the rationale?

- Patient education can benefit those trying to manage chronic diseases such as AD, by improving a patient's ability to cope with the disease and reduce symptom severity<sup>(a)</sup>
- Education may cover a range of topics, including treatment education (which has been highlighted as an area requiring particular attention<sup>(b)</sup>)
- Treatment compliance, in particular for topical treatments, is a complex issue in AD care<sup>(c)</sup> and requires continual patient education
- Educational interventions are recommended for patients at all levels of AD therapy<sup>(d)</sup>

## What are the key features of the intervention?

- The centre offers patient education evenings to adult AD patients across Switzerland (running since 2001)
- Patients are recruited onto the course through the polyclinic (in the dermatology unit) and the eczema clinic
- External patients from across Switzerland may attend the session
- All moderate-severe patients are recruited. Mild patients are also encouraged to attend if their physician has recommended it
- The programme was informed by the lead dermatologist's experience of AD patient education approaches in German centres (e.g. training from Arbeitsgemeinschaft Neurodermitis Schulung [AGNES])

### Session logistics:

- Runs twice a year (spring and summer)
- Includes 5 x 2 hour sessions (5:30pm – 7:30pm)
- 6 – 12 patients attend each session
- Hosted at the centre's psychosomatic unit
- Adults only (though ages vary from 18 – 50+ years old)

**Sources:** (a) Grossman SK, et al. Experiences with the first eczema school in the United States. *Clin Dermatol*. 2018;36(5):662-667; (b) Charman CR, et al. Topical corticosteroid phobia in patients with atopic eczema. *Br J Dermatol*. 2000;142(5):931-6; (c) Aubert H, et al. Non adherence and topical steroids. *Ann Dermatol Venereol*. 2012;139 Suppl 1:S7-12; (d) Nicol NH, et al. The role of the nurse educator in managing atopic dermatitis. *Immunol Allergy Clin North Am*. 2010;30(3):369-83 (e) Arbeitsgemeinschaft. Schulungen. [Website] [www.neurodermitisschulung.de/index.php?id=1](http://www.neurodermitisschulung.de/index.php?id=1) Accessed 8 May 2019



# AD patient education evenings (2/3)

## What are the key features of the intervention? (cont.)

### Format of the sessions:

- Sessions are run as open, informal discussions where patients are encouraged to ask questions
- Education is delivered via presentations and supporting written materials, including:
  - Slide presentations (with content created by the different healthcare professionals [HCPs] involved)
  - Handouts (e.g. effect of AD over lifetime)
- Group discussions are facilitated by the HCPs, during which they ask questions, capture patient responses on flipcharts and discuss the issues raised as a group
- Several different HCPs are involved in the delivery of the training sessions (some attend all sessions, while some only attend selected sessions)
- HCPs adapt session contents based on the group's needs / requests (e.g. if the group consists of mainly academics, HCPs may focus more on the science of the disease and the evidence behind treatments)

### Topics covered (illustrative first session):

- Coping with AD (self confidence and communicating with others, exchange of patient experiences)
- Disease background (causes of the disease, potential triggers, psychology and nutrition)
- Treatment types and application of treatment (including relaxation techniques, development of itching strategies, applications of topical wet wraps and emollients)
  - Sample products (e.g. emollients) are distributed during the session for patients to try

### Healthcare professionals (HCPs) involved:

- 2 dermatologists (including 1 specialised in allergy, who provides disease information)
- 1 psychologist (delivers the "coping with AD" session and psychological support)
- 1 nutritionist (external to the centre, who delivers general nutrition information for AD patients)
- 2 physiotherapists (deliver relaxation training)
- 1 Advanced Practitioner Nurse (delivers treatment information and application education)



We were the first centre in Switzerland to adopt this approach to patient education and we are very proud of what we have achieved

*Dermatologist, Inselspital*



Example handouts

# AD patient education evenings (3/3)

## What are the outcomes so far?

### Benefits to patients:

- Opportunity to discuss experiences with other AD patients
- Opportunity to discuss issues with HCPs in an informal setting
- Opportunity to speak with multiple types of HCP simultaneously and benefit from their different perspectives on AD management

### Benefits to HCPs:

- Additional opportunity to educate patients in an informal (non-clinical) environment
- An informal peer-to-peer format can put patients at ease and increase engagement, aiding the delivery of patient education

## What's next?

- Develop a centre-run education session for paediatric patients and their families in collaboration with the aha! Swiss Allergy Centre and the paediatric hospital

*Note: The aha! currently run a similar course for children and their families which is paid for by patients*



During the sessions, we discuss the burden of the disease on their day-to-day life to better understand their behaviours and motivations

*Psychologist,  
Inselspital*



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# Harrogate District Hospital

**Harrogate, United Kingdom**

Site visited by KPMG 1<sup>st</sup>–2<sup>nd</sup> July 2019

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[kpmg.com/uk](https://kpmg.com/uk)



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# Summary



## Context

**Centre type:** NHS Foundation Trust teaching hospital located across two sites in Harrogate and Ripon

**Catchment area:** Harrogate and District NHS Foundation Trust (HDFT) cares for the population of Harrogate and surrounding areas. The geographic catchment area technically covers Harrogate, Knaresborough, Ripon and surrounding areas (c.220,000 people), but due to demand on surrounding areas actually covers a larger area (c.650,000 people)

**Funding:** The hospital is state funded through general taxation and national insurance contributions

**Services:** The dermatology department is one of several departments within the centre

**Patient population:** Adult and paediatric patients with a variety of dermatological conditions, including atopic dermatitis (mild, moderate and severe AD)



## Key strengths in the delivery of AD care

**Nurse-led interventions:** Empowering dermatology nurses has enabled the centre to reduce the demand for dermatologist time. As a result, patients can easily request time with a nurse for AD treatment and advice. For example, adult dermatology nurses are able to monitor and adjust the dose for systemic AD medication

**Open access policy for patients:** Patients can contact the centre for urgent advice or appointments. The flexible appointment times provide patients with a safeguard if they require urgent AD advice

**Community outreach to rural populations:** HDFT provides services to rural populations through general dermatology and drug monitoring clinics at multiple sites. Patients can engage with consultants, PCPs with specialist interests in dermatology, and dermatology nurses in Wetherby and Ripon community hospitals

**Remote telephone consultations:** Patients with established and well-managed AD can access telephone consultations with dermatology nurses. Remote consultations enable patients to receive care and advice at home



## Key challenges faced in delivery of AD care

**Limited number of dermatologists:** Resourcing constraints due to the limited number of qualified dermatologists at a national level can impact the number of clinic appointments available

**Increase in time-critical dermatological conditions:** The prevalence of skin cancer and other conditions has increased demand for dermatologists and reduced time available to treat less time-dependent conditions such as AD

**Movement of patients from other catchment areas:** Due to the closure of surrounding dermatology clinics, there is an increase in demand for HDFT dermatology services

**Patient expectations with AD and food allergies:** Patients may have pre-conceived ideas that food allergies trigger eczema. Patients ask for allergy tests or present with allergy test results that have not been correctly interpreted or shared with the patient

**Patient non-compliance with topical treatment:** Patients can underutilise topical treatments and underestimate the importance of daily moisturisers, creating a misperception that topical treatments are ineffective



# Atopic Dermatitis (AD) in the UK

## UK healthcare system:

The National Health Service (NHS) provides free access to healthcare for all citizens. The service is financed through general taxation and governed by the Department of Health. Medical services are also available through private healthcare<sup>(a)</sup>. Each constituent country of the United Kingdom (England, Northern Ireland, Scotland and Wales) runs its own NHS, with elements in Northern Ireland, Scotland and Wales either overseen by the Department of Health and Social Care (DHSC) or devolved to the Northern Ireland Executive, Scottish Government or Welsh Government respectively.

## English healthcare system:

In England, there are three organisational levels in the state-funded health system:

1. Department of Health and Social Care (DHSC) – *governing body*
2. National Health Service (NHS) England – *commissions specialist services and primary care*
3. Local Clinical Commissioning Groups (CCGs) – *commissions community services, mental health, hospital services, ambulance services, primary care and specialised services*<sup>(b)</sup>

## Prevalence:

- AD affects 10–20% of children and 1–3% of adults in Western countries<sup>(c)</sup>
- In the UK, the prevalence of moderate-to-severe AD in adults and children is approximately 3-10% <sup>(d)</sup> and 2-20% respectively<sup>(e)</sup>
- 38% of AD patients in the UK are adults<sup>(f)</sup>



## Care provision:

### Location:

- Mild (or well-controlled) AD care is primarily delivered by PCPs (primary care providers)
- Moderate and severe (uncontrolled) AD care is primarily delivered in specialist secondary care (within hospitals)

### Funding:

- Primary care and hospital services are funded through local CCGs (clinical commissioning groups)

## Guidelines and societies:

### Guidelines:

- Guidelines for treatment of atopic eczema (atopic dermatitis) part I and part II: European Association of Dermatology and Venerology (EADV)
- Atopic Eczema in under 12s: diagnosis and management: National Institute for Health and Care Excellence (NICE)
- Treating eczema in people over 12 (NICE)

### Medical society:

- British Association of Dermatologists (BAD)

### Patient association group (PAG):

- National Eczema Society (NES)

Sources: (a) Health Management. Facts & Figures: The UK Healthcare System [Website] <https://healthmanagement.org/c/it/issuearticle/facts-figures-the-uk-healthcare-system> Accessed 13 March 2019; (b) The King's Fund. How is the NHS structured? [Website] <https://www.kingsfund.org.uk/audio-video/how-new-nhs-structured> Accessed 21 March 2019; (c) Nutton S. Atopic dermatitis: global epidemiology and risk factors. *Ann Nutr Metab.* 2015;66 Suppl 1:8-16; (d) Taylor et al. Treatment of moderate-to-severe atopic eczema in adults within the U.K.: results of a national survey of dermatologists. *Br J Dermatol.* 2017;176(6):1617-1623; (e) National Institute for Health and Care. NICE support for commissioning for atopic eczema in children [Website] <https://www.nice.org.uk/guidance/qs44/resources/support-for-commissioning-for-atopic-eczema-in-children-pdf-253673821> Accessed 30 July 2019; (f) Tidman MJ. Improving the management of atopic eczema in primary care. *Practitioner.* 2012;256(1750):21-3

# The centre and dermatology unit

## The centre



### Type and location

— A large, publicly funded teaching hospital across two sites in Harrogate and Ripon and three community sites. The centre is an NHS Foundation Trust – a status awarded based on hospital performance. This allows greater freedom to decide, with their governors and members, their own strategy and the way services are run<sup>(a)</sup>



### Population served

— The geographic catchment area covers Harrogate, Knaresborough, Ripon and surrounding regions. Due to pressures on surrounding regions, people from other catchment areas are also cared for by the centre, increasing the actual catchment area to c.650,000 people. HDFT also provide children's services in the North East in County Durham, Darlington, Middlesbrough, Stockton-on-Tees, Gateshead and Sunderland

— HDFT also provide children's services for the wider community. Roughly 50% of patients are from the local catchment area (NHS Harrogate and the Rural Clinical Commissioning Group area)

## The dermatology unit



### Service Division

#### Outpatient service

#### Emergency dermatology service



### Hours of availability

08:00 – 17:30

24 / 7 on-call dermatologists and junior doctor. PCPs and other departments can also contact on-call dermatologist



### No. of patients seen

20,000 patient interactions per year



### Types of patients seen

Paediatric AD (mild, moderate and severe); Adults AD (mild, moderate and severe)



### Facilities on-site<sup>(1)</sup>

- Phototherapy (UVB/PUVA)
- On-site testing laboratory and pathology department
- Hospital pharmacy
- Access to allergy tests (e.g. on-site patch testing and paediatric skin prick testing)
- 11 dermatology consulting rooms
- 2 dermatology surgical rooms and access to 1 day case operating theatre (1 afternoon per week)
- Research facility

Note: (1) List of facilities is not exhaustive

Sources: (a) NHS foundation trust directory [Website] <https://www.gov.uk/government/publications/nhs-foundation-trust-directory/nhs-foundation-trust-directory#what-are-foundation-trusts> Accessed 02 April 2019

# The team

## Core team profile

-  **5.5** full time equivalent dermatologists
-  **2** trainee dermatologists
-  **1** GP (general practitioner) registrar
-  **1** associate specialist
-  **1** clinical research assistant
-  **8** general dermatology nurses (including 1 matron)
-  **1** paediatric dermatology nurse
-  **3** adult dermatology nurses

## Wider team profile

-  **1** paediatric allergist
-  **1** ophthalmologist
-  **7** healthcare assistants

*Note: Please see page 396 for further details about the wider team*



## Governance and processes

### Team meetings:

- *Departmental business / educational meeting (monthly):*
  - Attended by: all departmental staff (medical, nursing and administrative)
  - The purpose of the meeting: to discuss MHRA advice/guidance, determine departmental policy, and troubleshoot logistical and operational issues
- *General Dermatology Case Presentation (weekly):*
  - Attended by: all dermatologists and trainee dermatologists
  - The purpose of the meeting: to discuss difficult patient cases and create consensus on clinical management plans. Patients on systemic medication are then discussed
- *Senior Management meeting (monthly):*
  - Attended by: dermatologists and senior dermatology nurses
  - The purpose of the meeting: to discuss financial and operational issues

### Patient records:

- *Paper-based filing system*
- *NHS electronic record system (ERS):*
  - Electronic patient record of consultations. Patients referred through NHS e-Referral system

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients with symptoms of AD (e.g. itching or dryness of the skin) present to a primary care physician (PCP) who will assess and refer if required
- Note: AD patients that are mild or well-controlled may be managed in primary care and not be referred to the centre*
- Patients may present directly to the emergency department
- Patients in hospital may also have AD symptoms and require a dermatology assessment
- Patients (existing or general public) may contact the dermatology department's on-call dermatologist or general telephone line for advice

## Diagnosis and Referral

In secondary care



- PCPs refer paediatric and adult patients to the centre via NHS e-referral system (e-RS). Routine referrals are seen within three months; urgent referrals may be seen within 1-2 days
- Patients are contacted by the medical records unit with their appointment date once dermatologist has reviewed the patient's referral (patients may select their treatment centre – Harrogate, Ripon or Wetherby)
- Dermatologists perform a diagnosis by discussing patient history, symptoms (including EASI/DLQI), predisposing factors and exposures
- All patients with severe AD or a history of contact allergy, recalcitrant disease or hand eczema receive patch testing (waiting list ~3 months on average)

## Treatment and Management

Medical management



- Dermatologists manage paediatric and adult AD patients, ranging from mild to severe, and initiate/modify treatment (depending on response to treatment and EASI/DLQI scores)
- Initial and follow-up consultations last ~30 minutes and ~20 minutes respectively
- Patients on systemic medication may be reviewed by the adult dermatology nurse at the drug monitoring clinic
- Patient notes and information are recorded in proformas
- Patients may be offered the opportunity to participate in clinical trials (CT)
- Dermatologists refer to comorbidity specialists (e.g. allergist and ophthalmologist) as required

Non-medical management



- Patients receive education about AD treatment and self-management during consultations with dermatologists
- Patients receive educational leaflets at initial consultation and follow-up consultations if required
- Dermatologists refer paediatric patients who may benefit from additional counselling and advice to the paediatric dermatology nurse educational sessions for further support
- Adjuvant therapy (e.g. phototherapy – PUVA and UVB) is provided by the centre as required

## Follow-up

Monitoring of chronic disease / flare up



- Patient follow-up occurs every month to a year (depending on the patient needs)
- Patients may contact the dermatology department or emergency dermatology on-call number (via accident and emergency) if they require urgent follow-up
- Well controlled patients may be referred back to a PCP for continued treatment

# Roles of the wider team

## Paediatric Allergist

**Patient type:** Paediatric patients suffering from dermatological conditions (including AD, psoriasis, etc.)

**Referral:** Referred by dermatologist (via email) to allergology department (~1 patient every 3 months)

**Consultations:** Allergist will perform standard tests, such as prick or patch tests, and provide treatments as required. Allergists may also perform a radioallergosorbent test (RAST - a blood test using a radioimmunoassay to detect specific IgE antibodies and determine which substances a patient is allergic to)

**Timing:** Consultations vary in length depending on patient requirements (usually around 20 minutes)

## Healthcare Assistant

**Patient type:** All AD patients (including paediatric and adult)

**Referral:** Referred by dermatologist

**Consultations:** Acts as a chaperone and provides support for patients during dermatology appointments

**Timing:** Dependent on patient and dermatologist needs

## Ophthalmologist

**Patient type:** Mild to severe AD patients may be seen if they present with ocular symptoms

**Referral:** Referred by dermatologist to the ophthalmology department (the centre does not with specific ophthalmologists for AD patients)

**Consultations:** Ophthalmologist will perform standard tests and provide treatments (e.g. lubricating eye drops, systemic therapies) as required. All patients receive education regarding their eye condition, treatment and aftercare (e.g. how to properly clean their eyes themselves)

Standard tests are likely to include:

- Visual Acuity (VA)
- Intraocular pressures
- Refraction
- Corneal topography

**Timing:** Consultations vary in length depending on patient requirements



Notes: (1) List of additional centre roles is not exhaustive



# Overview of interventions in place for AD

## Awareness and Presentation




Symptom identification

- **Frequent advice for primary care professionals:** Dermatologists utilise various high frequency and low intensity automated techniques to educate PCPs on the management of AD  
 See pg. 402-403 for case study
- **Adhoc education sessions for newly qualified PCPs:** Dermatologists from the centre provide an informal cohort of newly qualified PCPs with 1–2 hour education sessions on dermatology conditions once or twice a year
- **Primary care physician education on NHS deanery day sessions:** Dermatologists provide full-day training for PCPs annually. Lectures are provided on AD, psoriasis, skin cancer and acne

## Diagnosis and Referral





In secondary care

- **Community outreach clinics for rural populations:** Dermatologists, an adult dermatology nurse and a GP with a special interest (GPwSI) run regular general dermatology and drug monitoring clinics at two community sites: Wetherby and Ripon  
 See pg. 404 for case study
- **Rapid review of urgent AD cases:** Patients may be seen on the same day of referral depending on the urgency of their condition

## Treatment and Management



Medical management

- **Nurse-led drug monitoring clinic:** An adult dermatology nurse may monitor and adjust systemic treatment for AD patients at the centre. The nurse is able to escalate or de-escalate medication dosage based on a range pre-agreed between the dermatologist and patient  
 See pg. 405 for case study
- **Telephone consultations:** Patients with established and well-managed AD can access telephone consultations with an adult dermatology nurse  
 See pg. 406 for case study
- **Departmental meetings:** During weekly departmental meetings, patients with difficult or complex care plans are reviewed. Commissioning updates and operational issues are also discussed



Non-medical management

- **Nurse-led education sessions:** A paediatric dermatology nurse at the centre provides individual education sessions for AD patients and their relatives  
 See pg. 407-408 for case study
- **Nurse education during phototherapy sessions:** Patients are educated on how to apply topical steroids and emollients during PUVA/UVB sessions. The nurse may also apply the emollients after these sessions
- **Patient education handouts:** Patients are routinely provided with information on how to self-manage their AD symptoms. Patients receive information on triggers, symptoms, medical and non-medical treatment, self-care, fingertip units and fire safety hazards

## Follow-up



Monitoring of chronic disease/flare up

- **Open access policy for patients:** Patients have the option to call and organise urgent appointments with dermatology nurses and dermatologists when required
- **Email for patient dermatology photographs:** Patients are provided with an email address to send in photos of their skin during flare up episodes. The department administrative staff monitor the email inbox and alert the rostered dermatologist about any photos. The dermatologist will then review the photo and contact the patient if necessary. The photo is then deleted from the email inbox

### Key:



Case study available





# Monitoring AD patients and comorbidities

## The dermatology unit employs a number of measures for monitoring AD and associated comorbidities

### Objective measures (AD):

AD scoring indices are utilised to monitor patients and their disease, including:

- EASI (Eczema Area and Severity Index): validated scoring system that grades the physical signs of atopic dermatitis<sup>(a)</sup>
- SCORAD (SCORing Atopic Dermatitis): to assess AD disease severity and monitor patient progress<sup>(b)</sup>

### Patient-reported outcomes measures:

- QoL is measured by:
  - DLQI (Dermatology Quality of Life Index): measures impact of dermatology condition on patient's quality of life<sup>(c)</sup>
- The centre does not regularly utilise other patient reported outcome measures, however a dermatology-specific patient satisfaction survey has been developed. Patients complete the survey before and after their clinic appointment

**Dermatology Life Quality Index (DLQI)**

Hospital No: \_\_\_\_\_ Date: \_\_\_\_\_

Name: \_\_\_\_\_ Score: \_\_\_\_\_

Address: \_\_\_\_\_

Diagnosis: \_\_\_\_\_

The aim of this questionnaire is to measure how much your skin problem has affected your life OVER THE LAST WEEK. Please tick or use box for each question.

- Over the last week, how itchy, sore, painful or stinging has your skin been?  
Very much ☐ A lot ☐ A little ☐ Not at all ☐
- Over the last week, how embarrassed or self-conscious have you been because of your skin?  
Very much ☐ A lot ☐ A little ☐ Not at all ☐
- Over the last week, how much has your skin interfered with you going shopping or looking after your home or garden?  
Very much ☐ A lot ☐ A little ☐ Not at all ☐ Not relevant ☐
- Over the last week, how much has your skin influenced the clothes you wear?  
Very much ☐ A lot ☐ A little ☐ Not at all ☐ Not relevant ☐
- Over the last week, how much has your skin affected any social or leisure activities?  
Very much ☐ A lot ☐ A little ☐ Not at all ☐ Not relevant ☐
- Over the last week, how much has your skin made it difficult for you to do any sport?  
Very much ☐ A lot ☐ A little ☐ Not at all ☐ Not relevant ☐
- Over the last week, has your skin prevented you from working or studying?  
Yes ☐ No ☐ Not relevant ☐
- If "Yes", over the last week how much has your skin been a problem at work or studying?  
A lot ☐ A little ☐ Not at all ☐
- Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives?  
Very much ☐ A lot ☐ A little ☐ Not at all ☐ Not relevant ☐
- Over the last week, how much has your skin caused any sexual difficulties?  
Very much ☐ A lot ☐ A little ☐ Not at all ☐ Not relevant ☐
- Over the last week, how much of a problem has the treatment for your skin been, for example by making your home messy, or by taking up time?  
Very much ☐ A lot ☐ A little ☐ Not at all ☐ Not relevant ☐

Please check you have answered EVERY question. Thank you.

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# Advice to other centres



## What advice would you give less specialised centres?



### **Objective of advice: Enable nurses to expand their role in patient education and AD care**

- **Why?** Providing nursing staff with an opportunity to expand their roles can be beneficial for treatment compliance and patient satisfaction. In comparison to dermatologists, nursing staff can usually hold longer consultations with patients and provide extensive education, counselling and advice. Nurses can develop a relationship with patients, who may feel more comfortable asking questions in order to improve their knowledge and self-management of AD. Enabling nurses to deliver patient education can also minimise demand for physician time and allow physicians to focus on other responsibilities



### **Objective of advice: Proactively monitor demand for clinic appointments**

- **Why?** By working closely with hospital administrative and management staff, a centre can ensure patients receive access to timely care. Proactively implementing waiting list initiatives during expected periods of high demand, such as changing clinic types or temporarily opening another clinic, minimises the risk of extensive waiting times. For instance, the centre receives weekly reports from medical records on waiting times and adjusts the type of appointments accordingly to reflect demand
- If waiting lists are consistently low, it encourages confidence in timely care of patients. Short waiting times are also thought to stimulate more referrals. The overall impact helps minimise the potential for primary care physicians to inappropriately refer patients through the urgent pathway

# Next steps for the centre



## What is next for the centre?

### Objective: Improve patient self-management and education through group education sessions

- **What?** The centre aims to adapt their existing skin cancer education sessions, which are currently tailored for different skin cancer patients (e.g. melanoma, non-melanoma and highly anxious patients), to suit paediatric and adult AD patients. Currently, the 1 hour skin cancer sessions run once a week and provide patients with information on self-surveillance techniques and general support. The informal setting enables patients to learn from each other's experiences and share different solutions. It is expected that the AD sessions will have similar interactive material, samples and videos
- **Why?** Group education sessions provide patients with an informal environment in which to learn about and discuss different ways to self-manage their condition. Patients may discuss real life situations with each other and learn from other patients. From an internal resourcing perspective, it reduces the need for individual appointments, which in turn increases capacity for the paediatric dermatology nurse



### Objective: Generate additional capacity for dermatologists by creating a nurse consultant role

- **What?** The centre is actively investigating the requirements to create a nurse consultant role
- **Why?** Creating a nurse consultant role aims to reduce the workload for dermatologists whilst maintaining a high level of care for patients. In comparison to dermatology nurses, nurse consultants are able to prescribe and treat specific groups of patients (depending on training undertaken)<sup>(a)(1)</sup>. Patients who have stable AD symptoms could be solely seen by the nurse consultant, instead of by a dermatologist. The nurse consultant would be able to prescribe, treat and manage AD patients and refer patients to the dermatologist as required



**Notes:** (1) A qualified nurse needs to obtain a nursing qualification and register with the Royal College of Nursing in the United Kingdom. To become a nurse consultant, a qualified nurse needs to complete additional training and achieve the relevant Master's degree.

**Sources:** (a) Dyson S, et al. Scoping the Role of the Nurse Consultant [PDF] [https://www.mdx.ac.uk/\\_\\_data/assets/pdf\\_file/0030/198057/6.-scoping-report\\_new.pdf](https://www.mdx.ac.uk/__data/assets/pdf_file/0030/198057/6.-scoping-report_new.pdf) Accessed 30 July 2019

# Case studies



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CENTRE REPORTS

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# Frequent advice for primary care professionals (1/2)

## Overview

- The dermatologists utilise high frequency and low intensity automated techniques to educate PCPs on the management of AD. PCPs receive detailed progress and referral letters and alerts on their medication choice

**Note:** (1) Centre did not publish study of local findings

**Sources:** (a) Kownacki S. Skin diseases in primary care: what should GPs be doing? *Br J Gen Pract.* 2014;64(625):380–381. doi:10.3399/bjgp14X680773; (b) Schopf T et al. Impact of interactive web-based education with mobile and email-based support of general practitioners on treatment and referral patterns of patients with atopic dermatitis: randomized controlled trial. *J Med Internet Res.* 2012;14(6):e171



## What is the rationale?

- A local study at the centre suggests that low intensity educational techniques at a high frequency produce a similar impact to high intensity educational interventions (based on prescribing data)<sup>(1)</sup>
  - The low intensity education intervention involved sending an email with an attached PDF
  - The high intensity education intervention involved three 1-hour face to face training sessions
  - To measure the impact of the interventions, prescribing patterns were analysed. Although there was a small positive impact in the cohort who received high intensity educational intervention, there was a limited sustained benefit
- PCPs (primary care practitioners) perform high volumes of dermatology consultations and relatively low levels of dermatology education in their training programmes<sup>(a)</sup>
- Primary care education interventions can reduce referrals to specialist care<sup>(b)</sup>

## What are the key features of the intervention?

- The centre regularly communicates educational information to PCPs within their prescribing catchment area
- Guidance and information is included in each PCP letter. Notifications on medication choice and management are communicated through the local primary care electronic systems

### Education through PCP letters

- To ensure continuity of care, the centre regularly communicates via letters to PCPs. This may be replying to referrals or updating PCPs about patient treatment plans
- The centre has chosen to include detailed eczema information in each PCP letter (for AD patients) to increase PCP awareness of AD management and treatment options, and make it as easy as possible for PCPs to access appropriate advice
- Each letter includes information on xerosis, signs of a cutaneous infection, stress and the impact and food and contact allergies
- The letter also emphasises the importance of regular emollient application and the limited scientific evidence on food allergies and their links to eczema

### Medication alerts and notifications

- The centre engages with a local primary care software company to create automated pop-up alerts and notifications when PCPs are attempting to prescribe certain medications in dermatology and all other specialities (e.g. branded medication)
- The alerts and notifications pop up and suggests another medication based on the prescribed choice. For example, when GPs prescribe topical steroids, there is an electronic hyperlink to the fingertip dosing advice to print out for the patient

# Frequent advice for primary care professionals (2/2)

## What are the key features of the intervention? (cont.)

### Medication alerts and notifications (cont.)

- The medication selected for notifications and alerts is dependent on medication usage and formulary availability
- Medication usage is tracked by a team member within the centre and compared against a national benchmark

### Challenges

- Generally, it is difficult to engage with PCPs across a catchment area. Due to time constraints, PCPs may prioritise time with patients, rather than engage with specialists. The local study showed that only 3% of PCPs interacted with low intensity education (i.e. opening email attachments)
- Creating a lasting impact on prescribing habits will require a consistent and sustained effort

## What are the outcomes so far?

### Benefits to patients:

- Better management of eczema-related conditions in the primary care setting
- Ability to build relationships with PCPs and receive consistent AD information

### Benefits to HCPs:

- PCPs receive regular information on the treatment and management of AD
- PCPs have an additional source of practical AD treatment advice
- Dermatologists have decreased demand for AD care if patients can access AD in primary care

## What's next?

- The centre plans to streamline AD guidelines to ensure they are extremely simple with easily measured objective outcomes
- Continue to provide PCPs with educational information on a low intensity and high frequency basis

“



We've found that repeating information in PCP letters has been an effective method for educating primary care professionals about AD

*Dermatologist,  
Harrogate and District  
Hospital*

“



There is very little dermatology education in our PCP training program

*GP Registrar in  
training, Harrogate and  
District Hospital*

# Community outreach clinics for rural populations

## Overview

- The centre runs general dermatology and drug monitoring clinics at two community sites on a weekly basis (Wetherby and Ripon, both of which are located in rural areas). Patients may choose to see the dermatologist and dermatology nurse at a location that is most convenient for them



The local clinics mean patients can travel less and be closer to home

*Dermatology Nurse,  
Harrogate and District  
Hospital*



## What is the rationale?

- The centre's catchment area is geographically large, which can be inconvenient for patients who reside in rural and less accessible areas
- Community-based outpatient clinics provide patients with the option to receive care closer to home and increases access to healthcare professionals<sup>(a)</sup>

## What are the key features of the intervention?

- There are general dermatology and drug monitoring clinics at two community sites, Wetherby and Ripon. The clinics were established by the nurse unit manager and operate in the same manner as the district hospital clinics
- At Wetherby, there are two dermatologists who run general dermatology clinics, and one dermatology nurse (every other week) who runs drug monitoring clinics
- At Ripon, there is a dermatologist and a PCP with a specialist interest who run general dermatology clinic sessions every week
- Patients can choose to be seen at the community clinics or the main hospital (Harrogate District Hospital). They receive guidance and advice on AD treatment and self-management of their condition
- Each clinic involves a morning and afternoon session. Each consultation lasts around 20 minutes

## What are the outcomes so far?

### Benefits to patients:

- Improved patient experience as patients can receive advice at a centre closer to home
- Assurance that they will receive the same high quality care as a specialist centre

### Benefits to HCPs:

- Greater access to rural patients who may not have been able to reach the main centre site

## What's next?

- Potential to organise additional clinics at community sites (dependent on clinic room availability)

**Sources:** (a) Fortney JC, et al. VA community-based outpatient clinics: access and utilisation performance measures. *Med Care*. 2002;40(7):561-9. doi: 10.1097/01.MLR.0000017787.25488.CE



# Nurse-led drug monitoring clinic

## Overview

- A dermatology nurse may monitor and adjust systemic treatment for AD patients at the centre. The dermatology nurse is able to titrate the patient's medication dose based on the plan, patient response and blood results



The patients can speak to us frequently about their medications

*Nurse, Harrogate and District Hospital*



**Notes: (1)** See 'Next Steps' for additional information on nurse consultant role

## What is the rationale?

- Nurse-led clinics have demonstrated a positive impact on patient outcomes, satisfaction and experience<sup>(a)</sup>
- Additionally, implementing nurse-led clinics may help to alleviate dermatologist demand and time constraints<sup>(b)</sup>
- Nurse-led drug monitoring does not negatively impact patient clinical outcomes<sup>(c)</sup>

## What are the key features of the intervention?

- A dermatology nurse monitors and adjusts systemic treatment for dermatology conditions, including AD, for HDFT patients. On average, 2–3 AD patients per week are seen at the clinic
- Dermatologists determine which AD patients can be referred to the drug monitoring clinic
- The nurse is able to titrate the medication dose based on the patient's care plan and blood tests
- The care plan is established between the dermatologist and patient prior to referral to the drug monitoring clinic. The plan includes an agreed medication and dosage range
- Each consultation lasts around 30 minutes and involves assessing the patient's skin and measuring the patient's EASI and DLQI scores
- Initially, patients are seen every two weeks (for 2–6 weeks). Once stabilised, patients will be seen at the drug monitoring clinic every 1–3 months, unless urgent dermatologist advice is required
- The dermatology nurse also provides patient education and advice during each consultation

## What are the outcomes so far?

### Benefits to patients:

- Frequent interactions with a healthcare professional
- Opportunity to build a relationship with nurses and receive consistent AD information

### Benefits to HCPs:

- Dermatologists have more time in consultations to discuss medical issues (as the nurse can provide patient education)
- Reduces demand for consultant time

## What's next?

- Establish a nurse consultant role to increase the scope of services provided by a dermatology nurse<sup>(1)</sup>

**Sources:** (a) Randall S, et al. Impact of community based nurse-led clinics on patient outcomes, patient satisfaction, patient access and cost effectiveness: A systematic review. *Int J of Nursing studies*. 2017;73:24-33. doi: 10.1016/j.ijnurstu.2017.05.008; (b) Brown MH. A nurse-led clinic in chronic and allergic contact dermatitis. *Br J Nurs*. 2005;14(5):260-3; (c) Larsson I, et al. A nurse-led rheumatology clinic versus rheumatologist-led clinic in monitoring of patients with chronic inflammatory arthritis undergoing biological therapy: a cost comparison study in a randomised controlled trial. *BMC Musculoskelet Disord*. 2015;16:354. doi:10.1186/s12891-015-0817-6



# Telephone consultations

## Overview

- Patients with established and well-managed AD can access telephone consultations with adult dermatology nurses. Only patients who are deemed eligible by the dermatologist will be given the option to participate in telephone consultations



Telephone consultations means that patients can receive advice without needing to travel to hospital

*Nurse, Harrogate and District Hospital*



## What is the rationale?

- Telephone consultations give patients the option to receive treatment guidance and advice in the comfort of their own home
- In an IBD study, telephone consultations were shown to be a cost-effective alternative to face-to-face consultations and do not appear to provide an inferior service<sup>(a)</sup>

## What are the key features of the intervention?

- Patients can receive AD treatment and guidance through a telephone appointment with an adult dermatology nurse. Telephone consultations were established in late 2018
- The dermatologist will determine whether or not a patient is appropriate for telephone appointments. Generally, patients who are stable on systemic therapy are eligible
- Depending on the treatment, some patients may need regular blood tests. The adult dermatologist provides the patient with blood test forms during a face-to-face appointment
- The blood tests can be performed at their local PCP practice or pathology clinic. Established patients will usually have their blood taken once every three months
- The adult dermatology nurse reviews the blood test results before speaking with patients over the phone. Each consultation usually lasts around 10 minutes
- The dermatology nurse will phone the patient at the allocated time and date. The nurse will discuss the patient's AD treatment, management regime and any impacts on QoL. If required, the nurse will refer the patient to the dermatologist for medical review

## What are the outcomes so far?

### Benefits to patients:

- Gives patients the option to receive treatment and guidance in their location of choice
- Reduces need to travel to the centre if they do not have any issues or require urgent care

### Benefits to HCPs:

- Dermatologists are able to prioritise difficult patients or medical issues
- Potential to increase availability in clinics if patients do not need to be seen by a dermatologist

## What's next?

- The centre is looking to continue delivering telephone consultations

**Sources:** (a) Akobeng AK, et al. Telephone Consultation as a Substitute for Routine Out-patient Face-to-face Consultation for Children With Inflammatory Bowel Disease: Randomised Controlled Trial and Economic Evaluation. *EBioMedicine*. 2015;2(9):1251–1256. doi:10.1016/j.ebiom.2015.08.011



# Nurse-led paediatric education sessions (1/2)

## Overview

- A paediatric dermatology nurse at the centre provides individual education sessions for AD patients and their relatives
- The education sessions were established and developed in 2008, following the release of the associated NICE guidance

**Sources:** (a) DiAnna-Kinder F, et al Satisfaction with Nurse Practitioners and Intent to Adhere to Plan. *The Journal for Nurse Practitioners*. 15(3):245 - 248.e1; (b) Bass AM, et al. Interventions to Increase Treatment Adherence in Pediatric Atopic Dermatitis: A Systematic Review. *Journal of clinical medicine* 2015;4(2):231-42. doi:10.3390/jcm4020231; (c) Charman CR, et al. Topical corticosteroid phobia in patients with atopic eczema. *Br J Dermatol*. 2000;142(5):931-6; (d) Brown MH. A nurse-led clinic in chronic and allergic contact dermatitis. *Br J Nurs*. 2005;14(5):260-3



## What is the rationale?

- Nurse led education sessions have been shown to demonstrate high levels of patient satisfaction and positive patient outcomes<sup>(a)</sup>
- Poor adherence to treatment is a major factor limiting treatment outcomes in patients with AD<sup>(b,c)</sup>
- The role of the nurse (e.g. through nurse-led clinics) alleviates physician time constraints<sup>(d)</sup>

## What are the key features of the intervention?

- A paediatric dermatology nurse provides individual education sessions once a week for paediatric AD patients and their parents. All paediatric patients who are not easily managed with topical therapy are referred to the educational sessions
- Having conducted initial consultations, dermatologists refer patients who may benefit from additional education sessions. Each patient generally receives one series of education sessions (usually 12 sessions, 30 minutes in duration)
- The child and parents are educated on their care plan and relevant self-management techniques, and have the opportunity to ask the nurse practical questions. Topics covered include:
  - How to apply and use topical steroids, including the FTU (finger tip unit)
  - When to escalate and de-escalate topical steroid treatment
  - The importance of emollients
  - General skin care advice, including weather impacts
  - Bathing / hygiene advice
- The nurse will often show parents how to apply topical treatments, before watching them repeat the application (to advise and build their confidence)
- Each session lasts one hour. Patients and parents may see the nurse on a routine basis and may contact the nurse for additional advice when required
- Nursing staff have a proforma available for consistent documentation during education sessions (See Figure 1). The proforma was developed 15 years ago and includes assessing the patient understanding of eczema, patient's QoL, severity of symptoms, current treatment and management plan
- To reinforce the education sessions, parents are given leaflets to take away containing information including: BAD (British Association of Dermatology) materials, HDFT-specific recommendations and information on FTUs

**Figure 1:** Nurse Eczema Proforma, Harrogate District NHS Foundation Trust

# Nurse-led education sessions (2/2)

## Challenges

- There is currently a high demand for the education sessions, however there is only one nurse who has been trained to deliver them
- Individual education sessions can be repetitive and resource intensive for the nurse delivering them
- Nurses receive on-site training, by shadowing dermatologists and senior nurses in consultations. The nurses are also able to attend national nursing education meetings for additional training and support

## What are the outcomes so far?

### Benefits to patients:

- Parents and children receive thorough education from a HCP and have the opportunity to ask questions
- Parents are exposed to self-management techniques and advice that may improve the treatment and management of AD symptoms
- Patients can build close relationships with HCPs

### Benefits to HCPs:

- Dermatologists are able to prioritise and focus on medical issues in their consultations
- Reduced demand for clinic appointments if parents and children can better self-manage their symptoms

## What's next?

- Develop group paediatric education sessions to enable parents to share their experiences and learn from each other
- Establish an adult education clinic to improve disease understanding and AD treatment compliance, similar to the existing skin cancer education sessions held at HDGT
- Create online educational videos to improve the efficiency of education delivery and allow patients to cover the content in their own time



Involving nurses in care tends to result in improved patient satisfaction, as patients have more time with the nurses (compared to dermatologists) and can ask more questions

*Dermatologist,  
Harrogate and District  
Hospital*



APPENDIX  
CENTRE REPORTS



# Royal Devon & Exeter Hospital

Exeter, UK

Site visited by KPMG 11<sup>th</sup> March 2019

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[kpmg.com/uk](https://kpmg.com/uk)



APPENDIX  
CENTRE REPORTS



# Summary



## Context

**Centre type:** NHS Foundation Trust teaching hospital located across two sites in Exeter

**Catchment area:** 450,000 patients across Exeter and East and Mid Devon

**Funding:** The hospital is state funded through the local Clinical Commissioning Group (NHS Devon CCG), with funds distributed to each department (including the dermatology department)

**Services:** The dermatology department is one of several specialist departments within the centre (which collaborate with each other as necessary)

**Patient population:** Includes both adult and paediatric patients with a variety of dermatological conditions, including atopic dermatitis (mild, moderate and severe AD)



## Key strengths in the delivery of AD care

**Nurse empowerment:** Nurses organise, lead and prescribe eczema follow-up clinics which provide additional support to patients and reduce the burden on consultants

**Investment in primary care education:** Teaching initiatives, such as lecture series, provide local primary care providers (PCPs) with clinical guidance on AD management and appropriate AD referral to secondary care

**Utilising new technologies:** A teledermatology service enables PCPs to receive advice and guidance from secondary care specialists within 48hrs, enabling prompt and appropriate prescriptions and referrals

**Cross-functional clinics:** Psycho-derm and dermo-allergy clinics provide patients with comorbidities convenient access to multidisciplinary support

**Development of materials to improve consistency in care delivery:** 'Tick sheets' developed by the unit ensure the treatment approach is standardised across the team. Tailored eczema treatment plans help guide patient AD self-management



## Key challenges faced in delivery of AD care

**Delayed patient access to specialist AD healthcare professionals (HCPs) and treatments:** This can be due to:

- Patients not presenting to HCPs (i.e. staying at home and self-managing)
- Challenges associated with educating PCPs to ensure AD referrals are prompt and appropriate

**Patients may have fixed ideas concerning topical therapies:** This can occur after unsuccessful treatment attempts (exacerbated by time-consuming treatment regimens), and of which can result in poor treatment compliance

**Complexity of AD as a disease:** AD is a very complex diseases that can have a significant impact on patient quality of life (QoL)

**Difficulties balancing targets for skin cancer referrals:** There is a limit on clinical capacity for patients with inflammatory skin disease and a fixed consultant workforce

**Lack of clinic space within the dermatology unit:** This is in part due to a nearby dermatology clinic closing and a growing patient population

# Atopic Dermatitis (AD) in the UK

## UK healthcare system:

The National Health Service (NHS) provides free access to healthcare for all citizens. The service is financed through general taxation and governed by the Department of Health. Medical services are also available through private healthcare<sup>(a)</sup>. Each constituent country of the United Kingdom (England, Northern Ireland, Scotland and Wales) runs its own NHS, with elements in Northern Ireland, Scotland and Wales either overseen by the Department of Health and Social Care (DHSC) or devolved to the Northern Ireland Executive, Scottish Government or Welsh Government respectively.

## English healthcare system:

In England, there are three organisational levels in the state-funded health system:

1. Department of Health and Social Care (DHSC) – *governing body*
2. National Health Service (NHS) England – *commissions specialist services and primary care*
3. Local Clinical Commissioning Groups (CCGs) – *commissions community services, mental health, hospital services, ambulance services, primary care and specialised services<sup>(b)</sup>*

## Prevalence:

- AD affects 10–20% of children and 1–3% of adults in Western countries<sup>(c)</sup>
- In the UK, the prevalence of moderate-to-severe AD in adults is approximately 3-10%<sup>(d)</sup>
- 38% of AD patients in the UK are adults<sup>(e)</sup>



## Care provision:

### Location:

- Mild (or well-controlled) AD care is primarily delivered by PCPs (primary care providers)
- Moderate and severe (uncontrolled) AD care is primarily delivered in specialist secondary care (within hospitals)

### Funding:

- Primary care and hospital services are funded through local CCGs (clinical commissioning groups)

## Guidelines and societies:

### Guidelines:

- Guidelines for treatment of atopic eczema (atopic dermatitis) part I and part II: European Association of Dermatology and Venerology (EADV)
- Atopic Eczema in under 12s: diagnosis and management: National Institute for Health and Care Excellence (NICE)
- Treating eczema in people over 12 (NICE)

### Medical society:

- British Association of Dermatologists (BAD)

### Patient association group (PAG):

- National Eczema Society (NES)

**Sources:** (a) : (a) Health Management. Facts & Figures: The UK Healthcare System [Website] <https://healthmanagement.org/c/it/issuearticle/facts-figures-the-uk-healthcare-system> Accessed 13 March 2019; (b) The King's Fund. How is the NHS structured? [Website] <https://www.kingsfund.org.uk/audio-video/how-new-nhs-structured> Accessed 21 March 2019; (c) Nutton S. Atopic dermatitis: global epidemiology and risk factors. *Ann Nutr Metab.* 2015;66 Suppl 1:8-16; (d) Taylor et al. Treatment of moderate-to-severe atopic eczema in adults within the U.K.: results of a national survey of dermatologists. *Br J Dermatol.* 2017;176(6):1617-1623; (e) Tidman MJ. Improving the management of atopic eczema in primary care. *Practitioner.* 2012;256(1750):21-3



# The centre and dermatology unit

## The centre



### Type and location

A large, publicly funded teaching hospital, located across two sites in Exeter (Wonford and Heavitree) and 12 community sites across East and Mid Devon. The centre is an NHS Foundation Trust – a status awarded based on hospital performance, which allows greater freedom to decide, with their governors and members, their own strategy and the way services are run<sup>(a)</sup>



### Population served

450,000 patients across Exeter and East and Mid Devon

## The dermatology unit



### Service Division

#### Outpatient service

#### Emergency dermatology service



### Hours of availability

08:00 – 18:00

24/7



### No. of patients seen

~650 patients / week

10-12 patients / week



### Types of patients seen

Children (mild, moderate and severe); Adults (mild, moderate and severe)



### Facilities on-site<sup>(1)</sup>

- Phototherapy (UVA / UVB / PUVA)
- On-site testing laboratory
- Hospital pharmacy
- Access to allergy tests (e.g. on-site patch testing and paediatric skin prick testing)
- Dermatology consulting rooms
- 3 dermatology operating theatres

Note: (1) List of facilities is not exhaustive

**Sources:** (a) NHS foundation trust directory [Website] <https://www.gov.uk/government/publications/nhs-foundation-trust-directory/nhs-foundation-trust-directory#what-are-foundation-trusts> Accessed 02 April 2019

# The team



## Core team profile

-  10 dermatologists (full / part-time, including 2 paediatric dermatologists)
-  3 dermatology registrars
-  1 GP (general practitioner) registrar
-  2 CESR (Certificate of eligibility for specialist registration) doctors
-  4 associate specialists
-  10+ nurses (including 2 senior nurses who run the nurse eczema clinic and can prescribe topical treatment independently)

## Wider team profile

-  1 paediatric allergist
-  1 psychologist
-  1 department manager
-  1 admin manager

*Note: Please see page 415 for further details about the wider team*



## Governance and processes

### Team meetings:

- *Joint consultant clinic (weekly):*
  - Attended by: entire dermatology team
  - Purpose: to discuss the diagnosis, treatment and management of complex cases
- *Regional meeting (monthly):*
  - Attended by: centre representatives
  - Purpose: to discuss complex cases with 40+ dermatologists from the region (and present clinical audits)
- *Capacity meeting (every Thursday AM)*
  - Attended by: department manager, matron, clinical lead, administrative manager
  - Purpose: to assess department finances, performance, safety issues and quality issues

### Patient records:

- *NHS electronic record system (ERS):*
  - Electronic patient record of consultations stored in Clinical Document Manager. Patients referred through NHS e-Referral system

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients with symptoms of AD (e.g. itching or dryness of the skin) are assessed by PCPs (primary care providers)
- Note: AD patients that are well-controlled or mild may be managed in primary care and not referred to the centre*
- PCPs may consult the centre's dermatologists via the teledermatology e-RS (electronic referral system) Advice and Guidance service before AD diagnosis and / or referral

## Diagnosis and Referral

In secondary care



- PCPs will refer patients to the centre's dermatology department via NHS e-RS<sup>(a)</sup>. Routine referrals are seen within 1-3 months; urgent referrals within 2 weeks
- AD is diagnosed through clinical examination and supplementary diagnostic tests (e.g. blood tests)
- Diagnosis performed (and EASI / DLQI / POEM scores recorded) at first dermatologist consultation (15 mins) and nurse follow-ups
- Paediatric patients transition into adult care aged 16-18 years (but may stay in paediatric care<sup>(1)</sup>)

## Treatment and Management

Medical management



- Dermatologists initiate treatment tailored to patient need and monitor progress using EASI / DLQI / POEM indices
- To receive further support, patients may be referred to the dermatology nurse clinic (e.g. education for emollient / topical steroid application)
- Patients will be referred to comorbidity specialists as required (e.g. ophthalmologists), usually within 4 weeks

Non-medical management



- Dermatologists assess patients for psycho-social symptoms and may refer individuals to the hospital's adult or paediatric psychologist
- Patients receive education about AD treatment and management from both consultants and nurses (during consultations)
- Alternative treatment may be provided (e.g. hand / foot or full-body UVA / UVB treatment for patients not on systemic therapy)

## Follow-up

Monitoring of chronic disease / flare up



- Patients are followed up every 1-3 months (depending on disease severity) at the centre or via phone (routine check-ups)
- Well-controlled patients are referred back to primary care
- Patients may access the emergency dermatology service if they require urgent follow-up (by calling the emergency dermatology hotline or presenting to accident & emergency)
- Patient DLQI / EASI / POEM severity indices are recorded at every visit
- Patients are directed to NES (National Eczema Society) resources for ongoing support

**Sources:** (a) NHS: Referrals for specialist care [Website]: <https://www.nhs.uk/using-the-nhs/nhs-services/gps/referrals-for-specialist-care/> Accessed 02 April 2019

Note: (1) Paediatric patients who have formed good relationships with their paediatric dermatologist (through years of treatment) often prefer to remain in their care

# Roles of the wider team

## Paediatric Allergist

**Patient type:** paediatric patients only

**Referral:** referred by dermatologist

**Consultations:** 6 patients are seen during the cross-functional allergy clinic, held one morning every other month for AD patients requiring allergist input. A pulmonology nurse and dietician provide multidisciplinary support. EASI / CDLQI / POEM severity scores are recorded and parents / guardians are provided with tailored treatment plans to guide AD self-management. The joint allergy clinic includes skin prick tests, adrenaline auto-injector training, asthma and rhinitis management, dietician review and eczema optimisation

**Timing:** consultations are ~30 mins, but patients may be seen for up to 2 hours depending on their requirements



## Psychologist

**Patient type:** adult and paediatric patients displaying symptoms of psycho-social comorbidities

**Referral:** referred by dermatologist

**Consultations:** patients are seen at pre-arranged times during the bi-monthly psycho-derm clinic (either with or without a dermatologist present) in order to provide psychological support

**Timing:** consultations vary in length depending on patient requirements

## Ophthalmologist

**Patient type:** mild to severe AD patients may be seen on an ad-hoc basis if they present with ocular symptoms

**Referral:** referred by dermatologist to the ophthalmology department (the centre has no AD-specific ophthalmologists)

**Consultations:** ophthalmologist will perform standard tests and provide treatments as required

**Timing:** consultations vary in length depending on patient requirements

# Overview of interventions in place for AD

## Awareness and Presentation



Symptom identification

- **Educating primary care providers:** PCP (primary care provider) training is provided by the centre's dermatologists (e.g. via lecture series) covering clinical aspects of dermatology and referral pathways. Targeted nurse education days are also held for both primary and secondary care nurses.

See pg. 421-422 for case study

- **Emergency care:** Patients may call the urgent dermatology helpline (8am-6pm, Mon-Fri) or be seen by an on-call emergency dermatologist via A&E. PCPs may alert the on-call dermatology registrar via bleep device

## Diagnosis and Referral



In secondary care

- **Teledermatology service:** Community PCPs can use the teledermatology service to receive input from the centre's AD specialists before referring. Promoting quicker and more appropriate referrals

See pg. 423 for case study

- **Quick turnaround diagnostic testing:** Patients can receive diagnostic test results after 1-2 days (e.g. blood tests)

- **Joint consultant clinic:** Dermatologists meet weekly to discuss complex cases and attend monthly regional meetings to source opinions from other dermatologists – patients being discussed will be present at both

## Treatment and Management



Medical management

- **Nurse-led chronic disease clinic:** Provides additional patient support and reduces consultant burden. Involves 20-30 min consultations, with one nurse-scheduled 45-min 'eczema evaluation session' for patients requiring special assistance

See pg. 424-425 for case study

- **Joint paediatric dermatology-allergy clinic:** Delivered by paediatric dermatologists and a paediatric allergist, with a pulmonology nurse and dietician offering multidisciplinary support

See pg. 426 for case study

- **AD treatment 'tick sheet':** Doctors and nurses track AD systemic treatment via a 'tick-sheet' (developed themselves) to ensure relevant screening and monitoring tests are requested



Non-medical management

- **'My Eczema Treatment Plan':** Created by the dermatology unit for paediatric patients / parents, to track their tailored treatment plan (completed by nurses) and provide information to guide their AD self-management (e.g. application quantities of topical therapies)

See pg. 427 for case study

- **Psycho-derm clinic:** Held every 2 months, aimed at addressing psychological comorbidities associated with AD and other dermatological conditions

See pg. 428 for case study

## Follow-up



Monitoring of chronic disease/flare up

- **Home-delivery of treatments:** Biologic treatments are delivered to the patient's home by a home care company, who also train patients (when delivery takes place) to self-administer

### Key:



Case study available



# Monitoring AD patients and comorbidities

## The dermatology unit employs a number of measures for monitoring AD and associated comorbidities

### Objective measures (AD):

- EASI (Eczema Area and Severity Index): scoring system that grades the physical signs of AD / eczema. It may be used in the first consultation in secondary care, and may be repeated in subsequent consultations for comparison<sup>(a)</sup>

### Patient-reported outcomes:

- DLQI (Dermatology Life Quality Index): ten-question questionnaire (completed by patients) designed to measure the impact of skin diseases on quality of life. It is usually used in the first consultation in secondary care, and is repeated during each subsequent consultation for comparison<sup>(b)</sup>
- CDLQI (Children's Dermatology Life Quality Index): child-specific, cartoon version of the DLQI<sup>(c)</sup>
- POEM (Patient Oriented Eczema Measure): tool for monitoring AD severity (completed by patients) which is recommended for use in outpatient clinics and clinical trials by the National Institute for Health and Care Excellence (NICE)<sup>(d)</sup>. It is usually used in the first consultation in secondary care, and is repeated during each subsequent consultation for comparison

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### Centre routinely measures comorbidity outcomes by performing:

- Patch tests (performed by dermatologists)
- Skin prick tests (performed by allergists)
- Blood-specific IgE (Immunoglobulin E) tests (performed by both dermatologists and allergists)

**Sources:** (a) EASI for clinical signs: Harmonising Outcome Measures for Eczema (HOME); [Website] <http://www.homeforeczema.org/research/easi-for-clinical-signs.aspx> Accessed 13 March 2019; (b) Dermatology Quality of Life Index (DLQI), Cardiff University; [Website] <http://sites.cardiff.ac.uk/dermatology/quality-of-life/dermatology-quality-of-life-index-dlqi/> Accessed 13 March 2019; (c) Children's Dermatology Quality of Life Index (CDLQI), Cardiff University; [Website] <http://sites.cardiff.ac.uk/dermatology/quality-of-life/childrens-dermatology-life-quality-index-cdlqi/> Accessed 13 March 2019; (d) Charman CR, et al. Translating Patient-Oriented Eczema Measure (POEM) scores into clinical practice by suggesting severity strata derived using anchor-based methods. *Br J Dermatol.* 2013;169(6):1326–1332

# Advice to other centres



## What advice would you give less specialised centres



**Objective of advice:** Establish a consultant-led 48-hour turnaround teledermatology advice and guidance service for primary care specialists

- **Why?** Teledermatology has the potential to better connect primary and secondary care specialists earlier in the patient pathway. Prompt advice from secondary care can speed up referral and diagnosis for moderate-severe AD patients, enabling them to access specialists / specialist treatment quicker (including for management of comorbidities). The system has the potential to reduce costs and patient appointments by minimising inappropriate prescriptions and unnecessary referrals (where only mild topical treatment is required)



**Objective of advice:** Establish a telephone clinic for follow-up appointments to free up clinic space and consultant capacity

- **Why?** Consultant capacity and physical space are two factors which can limit care provision. Holding routine follow-up appointments over the phone for well-controlled patients reduces the resources (consultant time and physical space) required for delivering AD consultations. Telephone clinics can be effective, providing patients have been educated on how to effectively assess and communicate their AD / treatment status (e.g. AD severity, treatment side effects). Patient self-assessment outcome measures (e.g. POEM and DLQI) can also be utilised in telephone clinics



**Objective of advice:** Establish a joint formulary and referrals app to optimise prescribing across primary and secondary care, and provide clinical guidance on AD management

- **Why?** A joint formulary and referrals app provides a convenient way for PCPs (primary care professionals) and specialists to ensure patients receive access to the same therapies in both primary and secondary care (where appropriate). Such an app also represents a form of primary care education, whereby secondary care specialists provide PCPs with the latest advice and guidance for AD management. This can improve AD referral rates and promote safe, effective and economic prescriptions



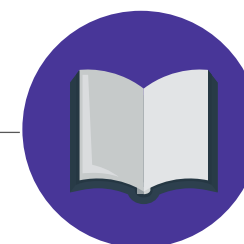
# Next steps for the centre



## What is next for the centre?

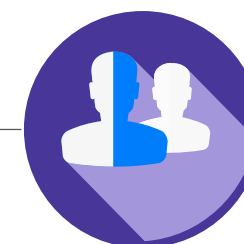
**Objective:** Invest further in primary care education

- **What?** The centre plans to continue investing in primary care education regarding the latest in AD diagnosis, treatment and management. This may include educating community pharmacists (to whom patients often first present their symptoms) and employing a community dermatology nurse (to educate primary care nurses on a peer-to-peer level)
- **Why?** Educating PCPs (primary care providers) with the latest in AD care has the potential to drive quicker and more appropriate referrals to secondary specialist care. This would likely result in cost savings across the health system and allow patients to receive the correct treatment quicker. Subject to financial constraints, this education could extend to pharmacists and community dermatology nurses, enabling both to empower patients to self-manage their AD treatment



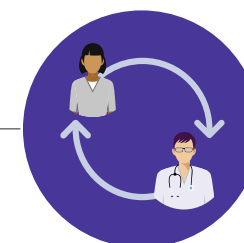
**Objective:** Establish a transitional dermatology clinic

- **What?** Centre staff hope to soon establish a clinic specifically for adolescent dermatology patients who are transitioning between paediatric and adult dermatology care
- **Why?** The burden of AD self-management for paediatric patients typically sits with the patient's parent/guardian. Adolescents, however, may over time look to reduce this level of parent/guardian input and assume responsibility for their own AD care. They will also ideally transition from the care of a paediatric dermatologist to an adult dermatologist. Establishing a dedicated transitional clinic would help meet these patients' unique educational needs and familiarise them with their new adult dermatologist



**Objective:** Deliver more frequent cross-functional clinics

- **What?** The centre hopes to run cross-functional clinics for AD patients more frequently and with specialists for other AD comorbidities, such as ophthalmologists (in addition to allergists)
- **Why?** Cross-functional clinics allow patients to receive multi-disciplinary support with managing AD and AD comorbidities. These 'one-stop-shops' improve communication between secondary care specialists, reduce the appointment burden for patients and provide a more holistic form of care for patients (especially complex patients). Feedback from the existing paediatric-allergy and psycho-derm clinics has been very positive



# Case studies



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# Educating primary care providers (1/2)

## Overview

- The centre invests time and resources into educating local primary care providers (PCPs) with the latest AD protocols, in order to improve the speed and accuracy of referrals to the centre

## What is the rationale?

- Primary care professionals (PCPs) may have limited training in dermatology (including AD)<sup>(a)</sup> and AD patients commonly present to PCPs and / or are managed in primary care<sup>(b)</sup>
- Incorrect referrals and / or overdiagnosis of AD from primary care creates an unnecessary burden on secondary care centres and patients
- Literature suggests primary care education interventions can reduce unnecessary referrals to specialists<sup>(c)</sup>
- The centre's catchment area has grown recently, which makes educating PCPs with the latest AD care (to ensure appropriate referrals) even more important

## What are the key features of the intervention?

### Primary care teaching channels:

- Regular evening and weekend meetings held by the dermatology unit with PCPs from the centre's catchment area (named the 'Pentagon Group')
  - Pharmaceutical representatives working locally often set up and facilitate the meetings and catering
  - The meetings are attended by GPs, nurses and other HCPs involved in AD. Most meetings include 1-2 hours of interactive teaching
  - Education is provided on when to refer, as well as treatments such as topical steroids, topical immunosuppressants and emollients
  - The presentations are usually case-based and use a combination of clinical photos and text slides
  - Presentations / interactive teaching are usually followed by a meal to build relationships between HCPs in primary and secondary care
- Targeted nurse education days (held every 1-2 months in individual primary care centres, focusing on specific dermatological conditions, including AD)

**Sources:** (a) Le Roux E, et al., GPs experiences of diagnosing and managing childhood eczema (2019). *BJGP*. [PDF] <https://bjgp.org/content/bjgp/early/2018/01/16/bjgp18X694529.full.pdf>. Accessed 21 Mar 2019; (b) Schofield JK, et al. Skin conditions are the commonest new reason people present to general practitioners in England and Wales. *Br J Dermatol* 2011; 165(5):1044–1050; (c) Schopf T, et al. Impact of interactive web-based education with mobile and email-based support of general practitioners on treatment and referral patterns of patients with atopic dermatitis: randomized controlled trial. *J Med Internet Res*. 2012;14(6):e171;



# Educating primary care providers (2/2)

## What are the key features of the intervention? (cont.)

- 5x monthly lecture series for 1<sup>st</sup> year PCPs from the centre's catchment area (delivered by dermatologists, special interest PCPs and nurses), covering different skin conditions (e.g. eczema, psoriasis, skin cancer)
- The North & East Devon Formulary and Referral app: promotes safe, effective, and economic prescribing in primary and secondary care, and provides guidance on locally recommended drug choices<sup>(d)</sup>
- Teaching in association with NES (National Eczema Society): a registered charity in England, Scotland and Wales dedicated to improving the quality of life of people with eczema and their carers<sup>(e)</sup>
- The database of teledermatology cases is also used as a basis for PCP teaching

## What are the outcomes so far?

### Benefits to patients:

- Receive recommended AD education and treatment in primary care (without having to wait until referral to secondary care)
- Prompt and appropriate referrals to secondary care specialists (when required)

### Benefits to HCPs (primary and secondary care):

- PCPs empowered to manage mild conditions without referring
- Reduced inappropriate referrals (freeing up consultation time)
- Improved local PCP alignment
- Cost reductions resulting from more appropriate prescriptions and referrals

## What's next?

- Continue to invest in educating PCPs within the catchment area
- Consider expanding education to pharmacists (as many patients present symptoms directly to pharmacists), and hiring a community dermatology nurse to focus on educating nurses specifically in primary care

**Sources:** (d) North & East Devon Formulary and Referral Website [Website] <https://northeast.devonformularyguidance.nhs.uk/> Accessed 02 April 2019; (e) National Eczema Society [Website] <http://www.eczema.org/> 02 April 2019



PCPs are overloaded and send us too many referrals which have not received the recommended primary care treatment (e.g. NICE guidelines) or do not require secondary care

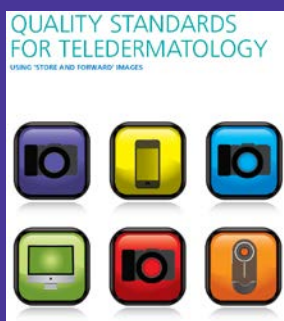


*Consultant dermatologist,  
Royal Devon & Exeter Hospital*

# Teledermatology service

## Overview

- System allowing the secure sharing of images of patient symptoms between primary and secondary care specialists, helping to ensure patients are treated by the right person in the right place at the right time



UK guidance on the use of mobile photographic devices in dermatology (BAD)<sup>(a)</sup>

## What is the rationale?

- Teledermatology allows PCPs to access urgent specialist dermatology opinion on behalf of moderate-severe AD patients<sup>(a)</sup>
- Local PCPs may use teledermatology before referrals in order to seek advice and guidance from the centre's secondary care specialists

## What are the key features of the intervention?

### The process:

- 1) PCPs capture images (in accordance with UK guidelines<sup>(a)</sup>) of patients presenting symptoms of atopic skin conditions
  - 2) Images are uploaded to the secure NHS e-RS (electronic referral system) and shared with secondary care specialists via the national electronic referral pathway (NHS e-Referral)
  - 3) Secondary care specialists review these images and provide PCPs with AD treatment advice and guidance (and possibly a recommendation for referral). The centre has a target turnaround time of 48 hours
- Royal Devon & Exeter staff co-authored the BAD (British Association of Dermatologists) UK guidelines for the safe use of mobile photographic devices in dermatology<sup>(a)</sup> and are members of the British Teledermatology Society subcommittee<sup>(b)</sup>

## What are the outcomes so far?

### Benefits to patients:

- More appropriate AD management in primary care
- Quicker and more appropriate referrals to secondary care (i.e. preventing unnecessary referrals)
- Patients require fewer appointments

### Benefits to HCPs:

- More effective prescriptions (reducing costs)
- More appropriate referrals (reducing cost and time burden for specialists)
- Patients accessing specialist care quicker, where required (allowing for earlier disease / symptom intervention)

## What's next?

- Maintain regular communication with NHS England in order to further develop UK teledermatology guidelines, standardise the referral pathway, maximise service efficacy and establish the UK as a leader in the field of teledermatology

**Sources:** (a) British Association of Dermatologists: UK guidance on the use of mobile photographic devices in dermatology (2017) [PDF] <http://www.bad.org.uk/shared/get-file.ashx?itemtype=document&id=5776> Accessed 02 April 2019; (b) British Teledermatology Society, British Association of Dermatologists [Website] <http://www.bad.org.uk/healthcare-professionals/specialist-groups/british-teledermatology-society> Accessed 04 June 2019



# Nurse-led chronic disease clinic (1/2)

## Overview

- The centre runs a nurse-led chronic disease clinic (primarily for AD and psoriasis patients), which includes a 45-minute slot dedicated to AD patients requiring additional help with their treatment management

## What is the rationale?

- AD is a chronic disease which is not always well controlled<sup>(a)</sup>. As a result, patients may form fixed ideas and become disengaged with their treatment plan (i.e. become non-compliant)
- Short consultation durations can result in healthcare professionals not having sufficient time to explain information to patients and patients not having an opportunity to ask questions<sup>(b)</sup>
- Patients can benefit from additional 1:1 assistance to receive further education on AD disease and management (especially for more complicated and time-consuming treatment regimens)

## What are the key features of the intervention?

- The half-day, nurse-led clinic is held once a week for adult and paediatric patients (for all chronic skin conditions, though mainly AD and psoriasis) and runs in parallel with a consultant clinic
- The clinic is intended for patients already on regular treatment (primarily on systemic therapy) and allows dermatology nurses the opportunity to:
  - Monitor patient progress
  - Check treatment compliance
  - Perform tests as required (e.g. blood tests)
- Patients are allocated 20-30 minute slots in the clinic (organised by the dermatologist)
- Within each clinic there is one 45-minute 'eczema evaluation session' (which nurses organise) for patients who require extra help with managing their AD treatment

### Eczema evaluation session objectives:

- Record EASI, DLQI and/or POEM severity scores
- Provide BAD (British Association of Dermatologists) drug information leaflets
- Dispel myths and fixed ideas surrounding AD treatment
- Give demonstrations (e.g. for effective emollient application) and empower patients to self-manage AD more effectively
- The centre's dermatology nurses have also attended drug prescription courses, allowing them to prescribe and dispense topical and oral therapies for atopic eczema on the spot

**Sources:** (a) Abuabara K, et al. The Long-Term Course of Atopic Dermatitis. *Dermatol Clin.* 2017;35(3):291-297



# Nurse-led chronic disease clinic (2/2)

## What are the outcomes so far?

### Benefits to patients:

- Receive regular, ongoing support for chronic skin conditions (including AD)
- Access to additional 1:1 disease and treatment education
- Empowered to self-manage AD more effectively

### Benefits to HCPs:

- Reduces time spent in specialist consultations re-educating patients
- Ability to closely monitor chronic patients (e.g. can quickly adapt treatment regimens)
- Patients are more empowered to self-manage their AD

## What's next?

- Continue to provide ongoing, 1:1 support to 'high-need' AD patients through the clinics
- Continue training nurses to prescribe



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Eczema evaluation sessions are required for patients who repeatedly present at the centre and have lost their way with treatment

*Dermatology nurse, Royal Devon & Exeter Hospital*





# Joint paediatric dermatology-allergy clinic

## Overview

- The dermatology unit runs a joint clinic with the centre's paediatric allergist for children with multisystem allergic disease (e.g. eczema, asthma, food allergies, rhinitis). The clinic acts as a 'one-stop-shop' for patients requiring multidisciplinary treatment



The clinic has a high satisfaction rate but we would like to run them more frequently and with more psychological support



*Paediatric allergist, Royal Devon & Exeter Hospital*

**Sources:** (a) American Academy of Allergy, Asthma & Immunology (AAAAI); Atopic Dermatitis (Eczema) Definition [Website] [https://www.aaaai.org/conditions-and-treatments/conditions-dictionary/atopic-dermatitis-\(eczema\)](https://www.aaaai.org/conditions-and-treatments/conditions-dictionary/atopic-dermatitis-(eczema)) Accessed 02 April 2019



## What is the rationale?

- Atopic Dermatitis is a complex disease, the treatment for which may require specialist input from allergists<sup>(a)</sup>
- Patients at the centre typically wait 6-8 months to see an allergist due to capacity limitations

## What are the key features of the intervention?

- A morning paediatric clinic is held every other month, delivered by the dermatology department and the centre's paediatric allergist (with a pulmonology nurse and dietician also present)
- The clinic sees patients with various skin conditions requiring allergist input, though most cases involve AD
- Up to 6 patients are seen across the morning clinic, with 30-minute slots allocated to each (though patients may be seen for up to 2 hours depending on requirements)
- EASI, CDLQI and/or POEM severity index scores are recorded at each visit to track disease control
- A tailored 'My Eczema Treatment Plan' is produced for the parent / guardian of each patient to guide AD self-management (see pg. 427)

*Note: The paediatric allergist also runs separate cross-functional clinics with gastroenterology and respiratory medicine (on an ad hoc basis)*

## What are the outcomes so far?

### Benefits to patients:

- Reduces the number and type of appointments each patient is required to attend
- Receive specialist multidisciplinary advice and treatment quickly

### Benefits to HCPs:

- Improves efficiency of specialist consultations
- Decreases number of separate specialist consultations
- Enables 'joined-up thinking' across specialties (i.e. cross-specialist discussion about treatment options for patient)

## What's next?

- More frequent joint dermatology clinics (with allergists and other AD comorbidity specialists)
- Running an equivalent dermatology-allergy clinic for adults (currently restricted by resource limitations: the nearest adult allergy clinic is at University Hospitals Plymouth)
- Increasing the psychological support available to patients who attend the paediatric cross-functional allergy clinic

# 'My Eczema Treatment Plan'

## Overview

- Families of paediatric AD patients are provided with a tailored 'My Eczema Treatment Plan', to help guide the management of their child's AD in a clear, easy-to-follow format



'My Eczema Treatment Plan' extracts

## What is the rationale?

- The centre manages a large number of paediatric AD patients
- AD is a complex and multi-faceted disease, and patients may require tailored treatment plans<sup>(a)</sup>
- Parents generally take responsibility for their child's AD treatment (which may be complex), and can significantly affect their quality of life<sup>(b)</sup>

## What are the key features of the intervention?

- A tailored 'My Eczema Treatment Plan' (developed by the centre) is completed by the dermatology nurses during consultations for the parents of each patient

### Pamphlet includes:

- Child's tailored treatment regimen (treatment name, frequency of usage, etc.)
  - Treatment categories: emollient, soap substitute, bath oil/emollient and medicated creams (face/neck, scalp, body and limbs)
- Topical treatment descriptions, including guidelines for use and precautions
- Topical steroid volumes (with figures illustrating steroid cream / ointment application for different parts of the body, and for different ages)
- Additional guidance: signs of infection; antihistamine usage; increased risk of food allergies; additional treatment options; National Eczema Society (NES) website and helpline details

## What are the outcomes so far?

### Benefits to patients:

- A structured, easy-to-follow treatment plan for the parent / guardian overseeing their child's AD self-management
- A useful reference tool for answering basic questions on AD treatment

### Benefits to HCPs:

- A standardised approach to educating parents on AD self-management and tracking treatment regimens
- The information provided reduces the time nurses spend educating patients directly

## What's next?

- Continuing the 'My Eczema Treatment Plan' initiative to guide patient AD self-management and reduce the time required to educate parents

**Sources:** (a) Bieber T. How to Define Atopic Dermatitis? *Dermatol Clin.* 2017;35(3):275-281; (b) Lifschitz C. The impact of atopic dermatitis on quality of life. *Ann Nutr Metab* 2015;66(suppl 1):34-40

# Psycho-derm clinic

## Overview

- The centre runs a clinic for dermatology patients (including AD) requiring additional psychological support, aimed at improving patient attitudes towards treatment and addressing the psycho-social comorbidities associated with dermatological conditions



It is well recognised that AD can have significant psychological implications and we need more services in this area

*Consultant dermatologist,  
Royal Devon & Exeter  
Hospital*



**Sources:** (a) Lifschitz C. The impact of atopic dermatitis on quality of life. *Ann Nutr Metab* 2015;66(suppl 1):34-40

## What is the rationale?

- Atopic Dermatitis is a complex disease, which is not always well controlled and can impact patient quality of life in multiple ways<sup>(a)</sup>
- Living with AD can have significant psycho-social implications and leave patients depressed and disengaged with therapy<sup>(a)</sup>
- Chronic patients at the centre have presented with self-inflicted skin conditions and delusional parasitosis
- The hospital currently employs one adult and one paediatric psychologist, both of whom are oversubscribed with long waiting lists

## What are the key features of the intervention?

- The clinic is for complex adult patients (not eczema specific) who, following a psycho-social assessment, are referred by dermatologists who believe that the patient would benefit from additional psycho-social support. The clinic is intended to provide insight and help patients self-manage their condition
- Consultation duration is approximately 1 hour, however this can vary depending on patient requirements
- The clinic is comprised of a Consultant Psychiatrist, a Consultant Dermatologist and a psychologist. The dermatologist and psychologist are both present in the consultations, and work collaboratively to educate patients on the latest in AD care, address psycho-social concerns and re-engage patients with treatment
- A psycho-derm half-day clinic is held once every 2 months (for adult patients only), with a psychologist and dermatologist
- Patients may be directed to NES (National Eczema Society) to participate in their support groups

## What are the outcomes so far?

### Benefits to patients:

- Access to additional (dermatology-specific) psychological support
- Cross-specialty clinic reduces appointment burden

### Benefits to HCPs:

- Patient dermatological and psychological needs are addressed in a single consultation
- Enables 'joined-up thinking' across specialties (i.e. cross-specialist discussion about patient management approach)

## What's next?

- Increasing access to the psycho-derm clinic (as it is only once every 2 months currently)





# Hospital Italiano de Buenos Aires

**Buenos Aires, Argentina**

Site visited by KPMG 21<sup>st</sup> and 23<sup>rd</sup> October 2019

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APPENDIX  
CENTRE REPORTS



# Summary



## Context

- **Centre type:** A large university health care network in the city of Buenos Aires, involving two hospitals (one in Buenos Aires city centre and another in Buenos Aires province, San Justo) and 20 primary care centres
- **Catchment area:** The majority of patients live in the city of Buenos Aires and the wider Buenos Aires Province, however patients may visit from across Argentina
- **Funding:** Centre services are funded by private health insurance payments
- **Services:** The hospital sites offer in- and outpatient services in multiple medical specialties
- **Patient population:** The network caters for ~200,000 patients who are members of the network's health insurance plan



## Key strengths in the delivery of AD care

- **Focus on group patient/HCP initiatives:** The centre promotes group patient therapy sessions (e.g. during patient committee meetings) and is planning to integrate the services of different AD specialists in shared spaces (e.g. to improve communication and collaboration between specialties)
- **Use of telemedicine:** The centre offers teledermatology and telementoring services, which respectively enable long-distance patient consultations and specialist knowledge dissemination to HCPs across Argentina
- **Increasing access to AD care:** The centre offers specialist AD care and advice through multiple channels, which can reduce the burden experienced by patients (i.e. travel, time and cost) by providing support in the format that is most convenient for them (e.g. the ability for patients to contact their dermatologist through an instant messaging mobile device application)



## Key challenges faced in delivery of AD care

- **Supporting physicians with AD diagnosis:** Physicians may find it challenging to correctly diagnose AD and prescribe appropriate treatments. There are also common misconceptions among physicians and patients about the causes of AD
- **Managing the quality of life (QoL) of severe AD patients:** AD can have wide-ranging QoL implications, which can interfere with treatment and require careful management (e.g. sleep disruption)
- **Access to medication from an economic perspective:** AD medications can be expensive and it is not guaranteed insurance policies will cover the required treatments
- **Access to medication from a time perspective:** Establishing if a patient's insurance will cover their treatment can be a slow process, requiring extensive paper work to be completed by their physician
- **Access to medication from a geographic perspective:** Large portions of the Argentine population live in rural areas, where access to AD specialists can be limited and may require patients to travel long distances to access care



# Atopic Dermatitis (AD) in Argentina

## Healthcare system<sup>(a)</sup>:

The Argentinian health system is predominately serviced by Social Security coverage through *Obras Sociales* ('Insurance Plans'), as well as through private healthcare. The country's federal structure defines the provision of healthcare, whereby each of the 24 provinces retains their autonomy regarding the leadership, financing and delivery of health services.

## Social Security coverage<sup>(b)</sup>:

- There are over 300 *Obras Sociales* in Argentina which are organised according to the occupation of the beneficiary. These are further split into provincial health insurance plans for civil servants (*Obras Sociales Provinciales*), national level health insurance plans for the general population (*Obras Sociales Nacionales*), and social security plans for pensioners (*El Instituto Nacional de Seguridad Social de Jubilados y Pensionados*). The three schemes are each funded through compulsory employee and employer payroll contributions

## Publically funded healthcare<sup>(c)</sup>:

- The Argentine government (*Es Estado*) provides tax-funded universal healthcare that is free to access. Services include vaccines, primary care, medicines, clinical studies, hospitalisation, surgery and other procedures

## Privately funded healthcare:

- The private sector encompasses private health insurance (PHI) funds and private health facilities. PHI funds include not-for-profit and for-profit organisations known as *mutuales* and *prepagas* respectively. Private health facilities provide health care service to the insured through contracts with health insurance funds and to the uninsured through user fees<sup>(b)</sup>. There are 150 health plans currently offered by insurers, with the top five plans covering approximately 60% of this "pre-paid" market segment<sup>(d)</sup>

## Prevalence

- AD affects more than 4 million people in Argentina, with 4-5% of all adults diagnosed with the condition<sup>(e)</sup>
- Prevalence of AD in children is 41.1%, according to a study of children aged 12-60 months from Great Buenos Aires<sup>(f)</sup>



## Care provision:

### Location:

- Moderate and severe (or uncontrolled) AD care is usually managed by hospital-based dermatologists
- Mild (or well-controlled) AD care may be managed by PCPs (Primary Care Physicians), private (office-based) dermatologists or hospital-based dermatologists (i.e. patients often continue to see the same specialist dermatologist, even if symptoms are stable / well-controlled)
- Funding:** Health care services are primarily funded through private health plans, however certain tax-funded public services are available free of charge

## Guidelines and societies:

### Guidelines:








- National Dermatology Committee consensus of Atopic Dermatitis – 2013 report<sup>(g)</sup>
- SAD (Sociedad Argentina de Dermatología) guidelines 2004 position statement<sup>(h)</sup>

### Medical societies/PAGs:

- Asociación Argentina de Dermatología (AAD)
- Asociación Civil de Dermatitis Atópica Argentina (ADAR)
- SAD (Sociedad Argentina de Dermatología)

**Sources:** (a) Arce HE. Organización y financiamiento del sistema de salud en la Argentina. *Medicina*, Buenos Aires 2012;72(5):414–418; (b) Cavagnero E, Carrin G. A National Social Health Insurance Plan for Argentina: Stimulating its financial feasibility. *World Health Organisation*. 2010; (c) Armando Barrientos "Reforming Health Insurance in Argentina and Chile" *Health Policy and Planning* 15(4): 420; (d) Global Health PR. *Argentina' Payer Stakeholders*. [online]. Accessed: 01/11/2019. <http://www.globalhealthpr.com/services/argentina/>; (e) OMICS International. *Atopic Dermatitis*. [online] Date accessed: 01/11/2019. <https://www.omicsonline.org/argentina/atopic-dermatitis-peer-reviewed-pdf-ppt-articles/>; (f) Dei-Cas I, Dei-Cas P, Acuna K. Atopic dermatitis and risk factors in poor children from great Buenos Aires, Argentina. 2009 Apr. 34(3):299-303. doi: 10.1111/j.1365-2230.2008.02916.x; (g) Giachetti A, Greco M, Scacchi M, Flores R, Castro C. National Consensus of Atopic Dermatitis. 2013. doi.org/10.5546/aap.2014.e195.; (h) Consenso Nacional de Dermatitis Atópica. Sociedad Argentina de Dermatología 2004. Available at <http://www.sad.org.ar/publicaciones/consensos>

# The centre and dermatology unit







The centre		
 <b>Type and location</b>	Hospital Italiano de Buenos Aires is a large university health care network in the city of Buenos Aires, involving two hospitals (one in the city of Buenos Aires and one in the Buenos Aires province) and 20 peripheral care centres (located in the Buenos Aires province and across Argentina). The network is associated with the Hospital Italiano School of Medicine	
 <b>Population served</b>	The centre caters for the ~200,000 patients who are members of the health care system’s health insurance plan. The majority of patients live in the city of Buenos Aires and the wider Buenos Aires province, however patients may travel from across Argentina for treatment	
The dermatology department		
 <b>Service Division</b>	<b>Outpatient service</b>	<b>Emergency dermatology service</b>
 <b>Hours of availability</b>	07:00–20:00 (Mon–Fri) 08:00–13:00 (Sat)	24/7
 <b>No. of patients seen</b>	~12,000 dermatology patients per month (including ~120 AD patients)	~10 patients per year (children and adults) are referred from the emergency room to the dermatology department
 <b>Types of patients seen</b>	Patients with all dermatological conditions, including mild to severe AD	
 <b>Facilities on-site<sup>(1)</sup></b>	<ul style="list-style-type: none"><li>— 2 operating rooms</li><li>— 2 dermatoscopy rooms</li><li>— 10 consulting rooms (including 3 rooms dedicated to wound care)</li><li>— 4 cosmetic / laser surgery consulting rooms</li><li>— PUVA and UVB phototherapy</li></ul>	<ul style="list-style-type: none"><li>— Photophoresis</li><li>— Teledermatology office</li><li>— General inpatient department (not specific to dermatology; admits 1–2 AD patients per year)</li><li>— General pharmacy (serving all hospital departments)</li></ul>

Note: (1) List of facilities is not exhaustive







# The team

## Core team profile ●

-  **3-4** AD-specialised dermatologists
-  **21** trainee dermatologists
-  **10** dermatology fellows
-  **~20** medical students
-  **6** dermatology nurses (2-3 work in the morning; 2-3 work in the afternoon)
-  **1** allergy testing nurse

*Note: 15 dermatologists are based at the centre, with ~80 in total working across the health network (based in the other hospital and PCCs)*

## Wider team profile ●

-  **2** AD-specialised allergists
-  **3** AD-specialised paediatricians
-  **3** AD-specialised pulmonologists (1 sees adults; 2 see paediatric patients)
-  **1** AD-specialised ophthalmologist

*Note: fellows, trainee physicians and medical students may attend specialist consultations*

*Note: see pg. 434 for further details about the wider team*



## ● Governance and processes

### Team meetings:

- *Dermatology-allergy meeting (12:30-13:30, one Wednesday per month):*
  - Attended by: dermatologists and allergists (both paediatric and adult specialists)
  - Purpose of the meeting: specialists present complex cases in order to educate each other and seek further medical opinion
- *MDT consultation (duration and frequency as required):*
  - Attended by: all specialists relevant to the patient in question
  - Purpose of the consultation: all relevant specialists meet with and assess an AD patient, before discussing the case (without the patient) to agree the course of treatment
- *Inpatient dermatology-pathology meeting (08:00-09:00, every Thursday):*
  - Attended by: inpatient dermatology team and pathology team. The head dermatologist or head paediatric dermatologist may attend for the most severe cases
  - Purpose of the meeting: to review photos of patient symptoms and test results in order to reach a more accurate diagnosis
- *Cross-centre dermatology meeting (08:00-09:00, every Wednesday):*
  - Attended by: dermatologists and trainee dermatologists from the network's two hospitals (often via videoconference)
  - Purpose of the meeting: to present and discuss complex / interesting cases

### ● Patient records:

- *Electronic health record (EHR):*
  - The centre has developed its own EHR, which is updated on an ongoing basis (see case study pg. 447 - 449)



# Roles of the wider team



## Psychodermatologist (dermatologist with a master's degree in psychology)

**Patient type:** 1-2 dermatology patients per week (of all ages, sometimes with parents present). The psychodermatologist sees all patient types but specialises in AD and contact dermatitis

**Referral:** The psychodermatologist is based in the dermatology department and will speak with most patients following their initial dermatologist consultation. Patients may approach the psychodermatologist for assistance without an appointment. Patients requiring further psychosocial support may be referred to the centre's psychiatry department

**Consultations:** Patients are asked about their quality of life (QoL), before receiving advice and guidance about living with AD (e.g. itch management techniques). Guidance is tailored to the individual, for example to suit the needs / preferences of adolescent patients. Three versions of DLQI are used to monitor patient QoL for different age groups: <4yrs; 4-16yrs; >16yrs.

**Timing:** Initial consultation: 20-30mins (depending on severity)



## Inpatient dermatologist

**Patient type:** Dermatology patients requiring inpatient care (including 1-2 AD patients per year)

**Referral:** Patients may be admitted to the general inpatient ward by the dermatology department (e.g. if their diagnosis is not certain)

**Treatment:** The inpatient dermatologist (with input from other specialists as required) aims to make a clear diagnosis and commence treatment as soon as possible. Skin biopsies may be taken and analysed in the histopathology laboratory to rule out conditions which mimic AD symptoms (inpatient tests are prioritised, with results available in 2-5 days)

**Timing:** Patients typically stay in the inpatient ward for 7-20 days and are only discharged once their condition has started to improve

*Note: The inpatient dermatologist also educates inpatient nurses, for example on how to bathe patients with appropriate substances*



## Inpatient nurse

**Role and responsibilities:** Each inpatient bed is assigned to an inpatient nurse, who is usually the first staff member to interview a newly admitted inpatient. The nurse verifies the patient's data (i.e. checks they are correctly identified), asks the patient if they have any known allergies and records any medications they are already taking. The nurse will also evaluate the patient's risk of developing bed sores and will flag potential negative interactions between the new and existing medications (which the dermatologist and pharmacist (via the EHR) also review). Inpatient nurses can apply most prescribed therapies which are non-injectable

*Note: AD patients experiencing flare-ups usually present at the emergency room first, before being referred to the inpatient ward by an emergency physician and/or the dermatology team (following a meeting between the emergency physician and dermatology team in the emergency room)*

## Roles of additional team members:

- **DERMATOLOGY NURSE:** Provides general assistance for dermatologists (e.g. by organising materials for minor procedures, holding patients in position)
- **ALLERGY NURSE:** Conducts patch and skin prick tests when requested by a dermatologist / allergist. The nurse sees 5-7 AD patients per week (adults only). A nurse in the paediatric department performs paediatric allergy tests
- **BIOLOGIST (Genetics PhD):** Acts as a liaison between the dermatology department and research institutes (which provide support with clinical trials). The biologist is currently working on an AD epidemiology study and is responsible for designing the methodology. Additional roles include searching for project funding and working with the hospital ethics committee to secure project approval

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients with symptoms of AD (e.g. itching or dryness of the skin) may present to a public primary care physician (PCP) or a private dermatologist in a peripheral care centre (PCC), depending on whether they pay for a private health plan
- Alternatively, patients may first present directly to the Hospital Italiano dermatology department
- Patients may be attended to at the centre if they have Hospital Italiano prepaid health insurance, or another private health insurance plan. Patients without health insurance may pay for services privately
- A local public hospital may refer complex cases to the centre for specialist treatment

## Diagnosis and Referral

In secondary care



- PCPs or paediatricians will refer AD patients to the centre's dermatology or allergy department for an initial consultation, which is often also attended by a trainee physician. The consultation lasts ~30-45min (depending on symptom severity) and involves:
  - Asking the patient/parent questions about their AD and AD comorbidity symptoms, family history, the products and treatments already being used, psychological symptoms, and whether any psychological support is already in place
  - Performing a physical examination (including a full-body skin assessment)
  - Explaining the diagnosis and educating the patient regarding AD treatment / management

## Treatment and Management

Medical management



- The initial AD consultation is conducted by an allergist or dermatologist (depending on who the patient was referred to). These consultations are identical in terms of duration, examinations, etc.
- Dermatologists and allergists together decide which allergy tests (if necessary) to order
- An allergy nurse may perform skin prick and patch tests (e.g. for AD, contact dermatitis, foot dermatitis) if requested (usually by an allergist)
- The allergy nurse may also perform vaccination injections (e.g. to test for allergic conjunctivitis or rhinitis)
- *Note: AD education for patients / family members is mostly delivered by physicians (nurses are not trained to)*
- Where appropriate, patients are offered the opportunity to choose their medications (e.g. in order to reduce travel burden, the likelihood of adverse events)
- Patients visit the centre's blood testing laboratory as required to have blood samples taken by an extractionist (qualified technician). Test results can be produced in 3-12 hours

Non-medical management



- Patients transitioning from paediatric to adult care are generally seen by the same dermatologist / allergist to ensure continuity of care
- Physicians book follow-up appointments. Patients are reminded of their booking either via phone call, text message or the online patient portal
- A general pharmacy serves all departments at the centre. Patients may call the pharmacist directly, who can deliver treatments to patients by post if appropriate (e.g. treatment top-ups)
- Dermatologists may approach research institutes (including one based at the hospital) for support with ongoing clinical research

## Follow-up

Monitoring of chronic disease / flare up



- A dermatologist may refer severe AD patients to the general inpatient department if required. Referrals may also occur in the other direction (e.g. for inpatients originally admitted for reasons not relating to dermatology)
- Adult and paediatric patient progress is monitored using select AD severity indices: SCORAD, EASI and vIGA-AD™
- AD patients (including those who are well controlled) are rarely referred away from the centre for further treatment / monitoring
- Patients attend follow-up appointments at the centre (~15-20min) with their preferred specialist, at a frequency agreed by the patient and physician (e.g. severe patients usually once per week, which may reduce as symptoms improve)
- The parents of AD patients may be directed to Asociación Civil de Dermatitis Atópica Argentina (ADAR) for further education and support (see case study pg. 441 – 442)

# Overview of interventions in place for AD



**Key:**



Case study available



## Awareness and Presentation



Symptom identification

- **Working with Asociación Civil de Dermatitis Atópica Argentina (ADAR):** AD specialists at the centre are members of the ADAR Medical Advisory Council and provide the association with expert medical information to support their activities

See pg. 441-442 for case study

- **Use of telemedicine:** The centre uses telemedicine (in the form of teledermatology and telementoring) to enhance AD care by offering video consultations to patients (both initial and follow-up) and disseminating specialist AD knowledge to HCPs in less-specialised care settings

See pg. 443-445 for case study

- **Emergency hotline:** Staff at the centre can call an emergency hotline at any time to contact an appropriate specialist who may urgently assess / treat their patient

## Diagnosis and Referral



In secondary care

- **Close dermatology-allergy collaboration:** The centre's dermatology and allergy departments work closely to correctly diagnose AD and provide appropriate treatments and management advice. There are plans to further integrate their AD services in the form of a shared office space

See pg. 446 for case study

## Treatment and Management



Medical management

- **Contribution to national AD guidelines:** In collaboration with the Argentine Society of Dermatology and the Argentine Association of Allergy and Clinical Immunology, centre staff have written national guidelines for the treatment of AD in adults and children (publication due December 2019)



Non-medical management

- **Ongoing electronic health record (EHR) development:** The centre has developed its own EHR which contains detailed information on each patient. The system allows staff to book appointments, order tests and request input from other specialists, and is regularly updated to include new functions
- **AD patient / family workshops:** Dermatologists at the centre run regular workshops for AD patients and their families aimed at improving their understanding of AD, explaining different treatment / management options and demonstrating how make-up can be used to boost self-esteem

See pg. 447-449 for case study

See pg. 450-452 for case study

## Follow-up



Monitoring of chronic disease/flare up

- **Online patient forum:** The centre runs an online forum for psoriasis patients and their friends/families (with the view to expand it to AD and other conditions). Patients can post thoughts, doubts, comments and adverse events on the forum, with every post pre-approved by a dermatologist. The forum contains videos and podcasts (e.g. about correctly applying creams) aimed at encouraging patients to speak to and learn from one another



# Monitoring AD patients and comorbidities

## The dermatology unit employs a number of measures for monitoring AD and associated comorbidities

### Objective measures (AD):

AD scoring indices are used to monitor patients and their disease, including:

- EASI (Eczema Area and Severity Index)<sup>(a)</sup>: scoring system which grades the physical signs of AD / eczema
- SCORAD (SCORing Atopic Dermatitis)<sup>(b)</sup>: used to assess AD disease severity and monitor patient progress
- Validated Investigator Global Assessment for Atopic Dermatitis (vIGA-AD<sup>TM</sup>)<sup>(c)</sup>: scoring system for use in clinical trials which grades the overall appearance of AD lesions based on a series of morphological descriptions

*Note: EASI, SCORAD and vIGA-AD<sup>TM</sup> indices are used as the dermatologist / allergist deems necessary (e.g. in special cases or as required by clinical trial participation)*

QoL and sleep is routinely measured by:

- DLQI (Dermatology Quality of Life Index)<sup>(d)</sup>: dermatology related quality of life (QoL) questionnaire

*Note: a DLQI score is usually only recorded in the first consultation with the psychodermatologist (see 'Roles of the wider team' on pg. 434), though it may be repeated when necessary (e.g. if a complex patient has started a new treatment). During AD consultations, the dermatologist / allergist also asks questions relating to QoL and records the patient's answers in the EHR*

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### Dermatology unit routinely measures comorbidity outcomes by:

- Allergy: dermatology unit staff perform skin-prick tests (for drug and food allergy) and blood tests to assess patient responses to specific allergens
- Psychology: a psychodermatologist assesses psycho-social symptoms and QoL using standardised scales (e.g. DLQI)
- Pulmonology: AD-specialised pulmonologists perform screening tests (e.g. spirometry)
- Ophthalmology: AD-specialised ophthalmologists perform screening tests (e.g. corneal examination)

**Sources:** (a) EASI for clinical signs: Harmonising Outcome Measures for Eczema (HOME) [Website] Accessed 30 08 2019. Available at: <http://www.homeforeczema.org/research/easi-for-clinical-signs.aspx>; (b) SCORing Atopic Dermatitis (SCORAD) Calculator (0.9.0). Available from: <http://scorad.corti.li/> [Accessed on 26 Feb 2019]; (c) Validated Investigator Global Assessment For Atopic Dermatitis (vIGA-AD<sup>TM</sup>) Scale [PDF] Accessed 26 06 2019. Available at: [https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale\\_vIGA-AD\\_2017.pdf](https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale_vIGA-AD_2017.pdf); (d) Lewis et al. 10 Years Experience of the Dermatology Life Quality Index (DLQI). J Invest Dermatol Symp Proc 9:169 –180, 2004;

# Advice to other centres



## What advice would you give less specialised centres?



**Objective of advice:** Offer multiple ways for patients to access specialist AD care

- **Why?** Appropriate AD diagnosis, treatment and management can be complex and time-consuming for patients, often requiring multiple touchpoints with different HCPs (dermatologists, allergists, nurses, etc.). Offering specialist AD care and advice through multiple channels can reduce the burden experienced by patients, by providing support in a format that is more convenient for them (e.g. teledermatology appointments to reduce travel burden; written advice available at all times on the online patient portal)



**Objective of advice:** Establish a system for accepting patients with no health plan or appointment, but who are in need of AD care

- **Why?** Every patient is a learning opportunity for trainee dermatologists and medical students, as well as more established dermatologists. Higher patient numbers can provide more data for use in publications, which are particularly valuable for university-affiliated hospitals

*E.g. Three mornings per week (09:00-13:00) in the paediatric department, patients can present themselves for an assessment without having booked an appointment. These patients must first register with the emergency room and be referred to dermatology by an emergency physician (to prevent abuse of the system)*



**Objective of advice:** Invest time and resources in educating both dermatology staff and patients

- **Why?** AD is a complex, multi-faceted disease which can be challenging to treat and manage from both a HCP and a patient perspective. Initiatives aimed at educating HCPs and patients with the latest developments in AD care (e.g. workshops, leaflets, video content) have the potential to improve the understanding of AD as a disease and ultimately improve patient treatment outcomes



# Next steps for the centre



## What is next for the centre?

**Objective:** Build a new dermatology department

- **What?** In 2020 the centre plans to build a new dermatology department with more consulting rooms and a multidisciplinary office space (shared by dermatology and allergy)
- **Why?** A larger facility will allow the centre to employ more dermatology staff and see more patients. The dermatology-allergy shared office space will enhance communication and collaboration between the two specialties and reduce the appointment burden experienced by AD patients

**Objective:** Gain membership of the GA<sup>2</sup>LEN Network of Excellence<sup>(a)</sup>

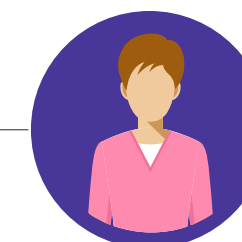
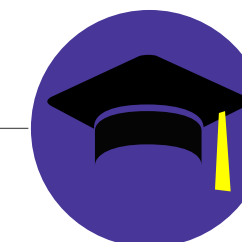
- **What?** The centre has applied for membership of the GA<sup>2</sup>LEN Network of Excellence
- **Why?** In association with the European Academy of Allergy and Clinical Immunology (EAACI), the GA<sup>2</sup>LEN network aims to address growing public health concerns regarding allergic diseases. Participating research teams are chosen for their scientific excellence, their record on multidisciplinary working and international collaboration, and their educational activities. Gaining membership has the potential to secure new funding for research and attract further allergy specialists to work at the centre

**Objective:** Increase engagement in AD research

- **What?** The centre plans to participate in more clinical trials relating to AD treatment and management
- **Why?** The centre currently runs dermatology research programmes in a number of areas, including the use of artificial skin in wound care. Participation in AD clinical research has the potential to improve understanding of AD pathophysiology, treatment and management, and may provide learnings for translation into clinical practice. The centre plans to increase its involvement in AD research following the recent approval of a new AD biologic therapy (approved for adults in Argentina in October 2019)

**Objective:** Equip dermatology nurses to educate patients

- **What?** The centre hopes to train dermatology nurses to deliver education to patients (currently not part of their role)
- **Why?** Training nurses to educate AD patients about their disease has the potential to reduce the demand on physicians (who are currently responsible for delivering most patient education) and reinforce the information patients receive during consultations, workshops, etc. The hospital already invites nurses to certain internal training courses (although none are AD-specific)



**Sources:** (a) GA<sup>2</sup>LEN – Supporting and Promoting Excellence in Allergy and Asthma – About us [Website] <http://www.ga2len.net/aboutus.html> Accessed 12 Nov 2019



# Case studies



<b>Working with Asociación Civil de Dermatitis Atópica Argentina (ADAR)</b>	441 – 442
<b>Use of telemedicine</b>	443 – 445
<b>Close dermatology-allergy collaboration</b>	446
<b>Ongoing electronic health record (EHR) development</b>	447 – 449
<b>AD patient / family workshops</b>	450 – 452

# Working with Asociación Civil de Dermatitis Atópica Argentina (ADAR) (1/2)

## Overview

- AD specialists at the centre are members of the ADAR Medical Advisory Council, and offer assistance by answering members' questions and providing reliable medical information (e.g. for publications)

## Asociación Civil de Dermatitis Atópica Argentina (ADAR)

### Background:

- The 'Civil Association of Atopic Dermatitis Argentina' (ADAR) consists of ~4,000 AD patients and their relatives<sup>(a)</sup>
- ADAR was the first nationwide association created by and for those affected by AD<sup>(a)</sup>
- The association began through the creation of a Facebook group intended to provide a space for affected individuals to exchange experiences and ideas relating to AD<sup>(a)</sup>

### Main objectives include:

- Promoting research and training in the medical community, and disseminating advances in the diagnosis and early treatment of AD
- Promoting active participation by the families of patients affected by AD
- Increasing public awareness of AD and its quality of life implications

### Main activities include:

- *Maintaining a National Medical Directory of AD specialists (e.g. dermatologists and allergists)*
  - It is a challenge for AD patients throughout Argentina to find an appropriate specialist within their area of residence
  - The National Medical Directory enables patients to locate AD specialists which minimise the travel (and consequently financial) burden of seeking treatment
- *Lobbying for new legislation to ensure accessibility of AD treatments for all patients*
  - Many AD patients in Argentina struggle to afford even basic topical therapies, which can be expensive and are usually not covered by public health services (as they are considered of 'cosmetic use')
  - ADAR is working to ensure such treatments are included under the country's Mandatory Medical Plan in the future (i.e. will be publicly and readily available)
- *Providing AD patients and their families with information, advice and guidance about the disease*
  - ADAR never make diagnoses or provide treatment recommendations. For this they may direct patients to the appropriate HCP (utilising the National Medical Directory)

**Sources:** (a) KPMG interviews



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# Working with Asociación Civil de Dermatitis Atópica Argentina (ADAR) (2/2)

## How does ADAR work with the centre?

- The association has a Medical Advisory Council consisting of AD-specialists from across Argentina, who act to answer members' questions and provide expert medical information
- The council includes a senior dermatologist and senior allergist from Hospital Italiano de Buenos Aires, who help to spread awareness of the association by suggesting to their patients that they join

## How does ADAR work with other hospitals?

- ADAR members frequently attend workshops in care settings across Argentina in order to publicise the association and recruit new members
- Hospitals may also send ADAR details of their AD-related events / activities, which the association post on their website and disseminate through their networks (e.g. at ADAR events)
- Example of previous activities:
  - World Atopic Dermatitis Day (Sep 14): ran campaigns on social networks aimed at increasing public awareness of the disease
  - Interviews held with various media bodies including those in television, radio, and local and national newspapers
  - Conducted an online survey (early 2019) titled 'Study of Quality of Life in Patients with Atopic Dermatitis', which involved 416 Argentinians with AD

## What's next?

- ADAR are currently advising a group of patients from Uruguay who are interested in forming their own national patient association
- The association is planning a series of workshops and talks for AD patients across Argentina, in addition to running a webinar on AD (which will be broadcasted online on 'Dermatitis TV')
- ADAR hopes to form relationships with AD reference centres across Argentina, in order to promote multidisciplinary AD care (focusing in particular on the disease's mental health implications)

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Our members know first-hand what it means to live with AD. We function as a reference point for the disease to help patients and their families cope with the various demands placed upon them

*ADAR representative*



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# Use of telemedicine (1/3)

## Overview

- The centre uses telemedicine to enhance AD care in two main ways:
  1. Teledermatology – the centre offers new and existing patients video consultation services
  2. Telementoring – a soon to-be-launched HCP education programme will use video conferencing technology to disseminate specialist AD knowledge to less-specialised care settings

## What is the rationale?

- Telemedicine services can help physicians to monitor changes in patient symptoms over time<sup>(a)</sup>
- Telemedicine can also be a useful tool for providing outreach dermatology training to healthcare professionals based far from specialist centres (e.g. rural areas)<sup>(b)</sup>

## What are the key features of the intervention?

### Teledermatology:

- Teledermatology services at the centre are used by ~15 patients per week. They are mostly delivered in a designated teledermatology office on Tuesdays (16:00-18:00) and Wednesdays (09:00-11:00)
- Dermatologists, trainee dermatologists or fellows may conduct teledermatology consultations

*Note: trainee dermatologists and fellows must be accompanied by a supervising dermatologist*

- Dermatologists may also host video consultations from home (however, in the interests of patient security, they require special authorisation from the hospital to do so)
- During teledermatology consultations, the physician attempts to resolve the case (e.g. provide a diagnosis and treatment / management advice), however may refer the patient to an appropriate specialist if required (e.g. allergist)
- The centre offers teledermatology services for patients with a range of dermatological conditions in two main forms:
  1. Deferred teledermatology
    - To request an appointment with a centre dermatologist, a patient populates a form on the online health portal with their personal and medical details and attaches photographs of their symptoms
    - Patients are either directed to the service by external dermatologists or discover the service themselves online (i.e. it is not restricted to Hospital Italiano patients)
    - Physicians receive an alert in the EHR whenever a patient requests a consultation in this way. Dermatologists at the centre aim to hold a video call and provide feedback (e.g. an initial diagnosis and/or a recommendation for a face-to-face consultation) within 3 days of the initial request
    - Deferred consultations may be held at any time which suits the patient and physician (i.e. not restricted to the dermatology office hours)
    - Patients must pay a fee for the service (2400 ARS)

**Sources:** (a) British Association of Dermatologists: UK guidance on the use of mobile photographic devices in dermatology (2017). [PDF] <http://www.bad.org.uk/shared/get-file.ashx?itemtype=document&id=5776> Accessed 2 April 2019; (b) Chang A. Y. et al. Providing dermatological care in resource-limited settings: barriers and potential solutions. *Br J Dermatol.* 2017 Jul; 177(1): 247–248



# Use of telemedicine (2/3)

## What are the key features of the intervention? (cont.)

### 2. Online teledermatology

- Existing Hospital Italiano patients may speak with a dermatologist via video chat using their smartphone / tablet (e.g. for routine follow-up appointments or providing test results)
- The physician records the results and prescription information from the teleconsultation in the electronic health record (EHR) (see case study pg. 447 - 449)
- Patients must however visit the centre in person in order to collect their prescription (as pharmacies in Argentina will not accept a photocopy)

*Note: both forms of teledermatology may be used for initial and follow-up consultations*

### Telementoring:

- The centre is planning to launch an educational programme for dermatologists called 'ECHO dermatitis' (Extensive Community Healthcare Outcomes in Dermatitis), due to launch November 2019
- ECHO dermatitis will be an extension of an existing programme for psoriasis at the centre<sup>(a)</sup> (which itself is based on a system the head dermatologist observed while training in the USA)
- The system uses videoconferencing software to share best practices in dermatology with community physicians / nurses (who do not work in large cities / university hospitals)
- A 'hub and spokes' model will aim to move knowledge from the central hub (Hospital Italiano) to the community HCPs (rather than moving patients in the other direction)
- The teleconferences will be held every few weeks, during which community physicians will present real-life AD cases (e.g. via PowerPoint) to the hub to gain expert opinion
- Physicians from across Argentina will be allowed to participate (i.e. not just physicians in the Hospital Italiano health system)
- An existing psoriasis project has been running for five years, has received private sponsorship, and has reduced the number of psoriasis patients that come to the centre for treatment (due to more patients successfully receiving treatment in peripheral care centres)

**Sources:** (a) Mazzuocolo LD et al. WhatsApp: A Real-Time Tool to Reduce the Knowledge Gap and Share the Best Clinical Practices in Psoriasis. *Telemed J E Health*. 2019;25(4):294-300. doi: 10.1089/tmj.2018.0059



Many departments in the hospital are utilising this technology, however we were the first due to the very visual nature of AD and other dermatological diseases

*Dermatologist,  
Hospital Italiano de  
Buenos Aires*



# Use of telemedicine (3/3)

## What are the outcomes so far?

### Benefits to patients:

- Access to specialist dermatology care in settings located far from the centre (through teledermatology consultations)
- Ability to speak with dermatologists at a convenient time and location (e.g. outside regular working hours)
- Ability to self-refer to the deferred teledermatology service, which can minimise appointment burden

### Benefits to HCPs:

- Physicians located far from the centre can conveniently receive specialist dermatology advice / training
- A reduced demand for consultation space at the centre

## What's next?

- The centre launched the 'ECHO' (Extensive Community Healthcare Outcomes) programme in November 2019, including a video conference attended by over 40 dermatologists from across Argentina. The centre will continue to hold monthly ECHO meetings (on a Thursday, 12:30-14:00)



The telemedicine services are primarily used by patients and physicians in rural areas. As a whole the hospital is encouraging the use of these systems

*Dermatologist, Hospital Italiano de Buenos Aires*



# Close dermatology-allergy collaboration

## Overview

- The centre's dermatology and allergy departments work closely to diagnose AD and provide appropriate treatments and management advice. There are plans to further integrate their AD services in the form of a shared office space

## What is the rationale?

- AD is part of the Atopic March: a multi-organ disease which may include asthma, allergic rhinitis<sup>(a)</sup> and food allergies<sup>(b)</sup>
- Such comorbidities may require specialist input from an allergist in order to diagnose and treat the associated symptoms

## What are the key features of the intervention?

- AD patients may be referred by their primary care physician (PCP) or paediatrician to either the centre's dermatology or allergy department for a first AD consultation
- Depending on the patient's symptoms, the dermatology and allergy departments may refer the patient to one another for further specialist input
- How soon the patient is seen depends on symptom severity and the availability of physicians in the other department. Severe AD patients may be seen by the other department on the same day, however the majority of patients are seen within 4 weeks
- The two departments communicate readily via email or mobile messaging, or (given the two departments are relatively close to one another) they may discuss complex cases face-to-face

## What are the outcomes so far?

### Benefits to patients:

- Access to coordinated care from different AD and AD comorbidity specialists
- More convenient treatment for patients (due to quick referrals between the dermatology and allergy departments, which are also located close to one another)

### Benefits to HCPs:

- Enhanced communication and collaboration between the dermatology and allergy specialties

## What's next?

- The centre plans to establish a shared dermatology-allergy office space for the multidisciplinary treatment of AD patients (due 2020). As a result, patients will have to attend fewer consultations and specialists will have the opportunity to learn from one another more readily

**Sources:** (a) Darlenski R et al. Atopic dermatitis as a systemic disease. *Clin Dermatol*. 2014;32(3):409-13; (b) Roerdink EM et al. Association of food allergy and atopic dermatitis exacerbations. *Ann Allergy Asthma Immunol*. 2016;116(4):334-8





# Ongoing electronic health record (EHR) development (1/3)

## Overview

- The centre has developed its own EHR which contains detailed information on each patient. The system allows staff to book appointments, order tests and request input from other specialists, and is regularly updated to include new functions

## What is the rationale?

- Electronic health records (EHRs) have the potential to enhance the efficiency and consistency of data collection (compared to traditional paper records), which in turn can enhance patient care and facilitate clinical research<sup>(a)</sup>
- EHRs can be updated on an ongoing basis to include new functionality requirements identified through clinical practice<sup>(b)</sup>

## What are the key features of the intervention?

### How was it developed?

- The centre developed its own EHR (the first in Argentina), created and regularly updated by the hospital's Medical Informatics Department (MID) (involving physicians dedicated exclusively to the development of medical computer systems)
- The MID meet as required (ad hoc) with staff from dermatology and other specialties, in order to discuss and design changes to the system (e.g. a form was recently added which was required to record patient biopsy results)
- New physicians at the centre must complete one month of training to learn how to use the EHR effectively

### Who has access and how is it controlled?

- All physicians and nurses in the Hospital Italiano health system wishing to use the EHR must log in using a personal username and password
- The same EHR is used throughout the health system (including the two hospitals, ~20 Periphery Care Centres (PCCs) and dermatologists based in private offices)
- A physician / nurse can initially only access the medical records of the patients assigned to them. In order to access the files of other patients, a reason for doing so must be submitted (which is recorded and subsequently audited)
- For all files, the EHR will record who accesses what, when and where (and if appropriate, why)
- The EHR can be accessed from hospital computers or from home (with each login from home recorded). A separate access code can be used to access the system via a mobile device application (where, once more, each app login is recorded)

**Sources:** (a) Cowie M. R, et al. Electronic health records to facilitate clinical research. *Clin Res Cardiol.* 2017;106(1):1–9; (b) KPMG interviews



# Ongoing electronic health record (EHR) development (2/3)

## What are the key features of the intervention? (cont.)

### What information does it contain?

- A schedule of past and upcoming appointments for each physician (including the reason(s) for each consultation)
- Personal and medical information on each patient (e.g. BMI, known allergies, vaccinations received)
- A record of the patient's past symptoms and treatments (which staff must populate in a format adhering to hospital protocol)
- A record of the specialists who previously saw the patient and when (i.e. touchpoints)
- The patient's inpatient record (why and for how long inpatient care was required)
- A record of the patient's test results, which the physician / nurse may print and give to the patient. The EHR can also produce graphs to illustrate how test results may have changed over time

*Note: patients may access their own medical records separately via the patient portal*

### What functionality does it involve?

- Physicians can order blood / allergy tests through the EHR, meaning patients must simply show their membership card at the testing facility (rather than carry a paper order with them). Urgency can also be indicated, with urgent test results provided in 3-12hrs and routine test results provided in 12+hrs
- Booking patient appointments (either face-to-face or telemedicine consultations)
- Physicians may also request 'interconsults' with other specialists to seek multidisciplinary input on a per patient basis (e.g. with AD comorbidity specialists). The system provides a timeframe in which the interconsult must take place
- Patients can contact physicians directly via the EHR app's messaging system (e.g. for quick and convenient advice)
- A physician may filter the patient records to specific types of patients (e.g. to identify appropriate patients for clinical trials)
- Prescriptions may also be ordered and monitored via the 'Prescriptions' section

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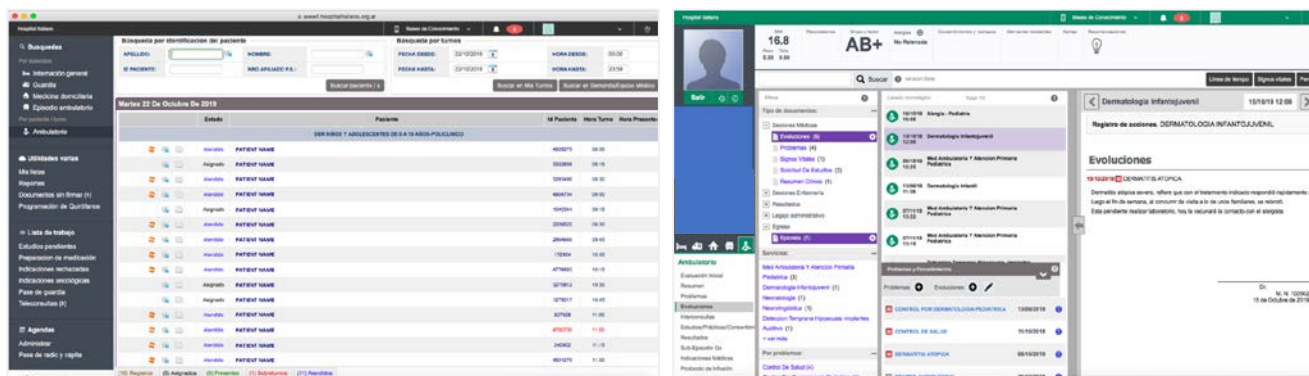
We regularly meet with the EHR's developers to discuss potential updates. The system is always evolving

*Dermatologist, Hospital Italiano de Buenos Aires*



APPENDIX  
CENTRE REPORTS

# Ongoing electronic health record (EHR) development (3/3)



Hospital Italiano de Buenos Aires EHR screenshots



The EHR provides convenient access to many medical records and makes our lives as physicians much easier

*Dermatologist,  
Hospital Italiano de  
Buenos Aires*



## What are the challenges?

- Locating the medical professionals who are also proficient in computer science that are required to create a dedicated Medical Informatics Department

## What are the outcomes so far?

### Benefits to patients:

- All physicians and nurses can readily access the records of each patient, which can improve continuity of care following internal referrals (e.g. if a patient is seeing a new specialist for the first time, they will not need to explain their symptoms and medical history)
- A single, unified record of personal medical history at the centre which patients may access

### Benefits to HCPs:

- Readily accessible up-to-date medical records for each patient treated in the health system
- Enhanced communication between different AD and AD comorbidity specialists
- A structured approach to organising and following appointment schedules

# AD patient / family workshops (1/3)

## Overview

- Dermatologists at the centre run regular workshops for AD patients and their families aimed at improving the understanding of AD, explaining different treatment / management options and demonstrating how make-up can be used to boost self-esteem

## What is the rationale?

- The time physicians can spend with patients is generally limited, meaning they may be unable to cover all the aspects of the disease during regular consultations<sup>(a)</sup>
- Patients and their parents (who often assume responsibility for the patient's home care) may not understand the full impact of the disease or the treatment options available<sup>(b)</sup>. They may also experience anxiety relating to the possible side-effects of treatment, which effective patient education may help to overcome<sup>(c)</sup>
- Education (especially in paediatric populations) has been shown to positively impact AD treatment outcomes<sup>(d)</sup>

## What are the key features of the intervention?

### Logistics:

- The dermatology department run educational AD workshops (lasting ~2hrs each) three times per year for AD patients and their families. The sessions are open to everyone, therefore patients and family members from other hospitals may also attend
- A team of three dermatologists deliver presentations, covering a range of relevant topics
- The workshops are held in a designated classroom in the dermatology department
- The workshops are publicised using flyers (distributed throughout the hospital, including consulting rooms), via social media (e.g. the hospital Instagram page) and on the hospital website



AD patient workshop flyer



AD patient workshop advertisements on the hospital website

**References:** (a) GlobalSkin Position Paper: "Atopic Dermatitis : A Collective Global Voice for Improving Care", February 2018; (b) Arkwright P. D, et al. Management of difficult to treat AD. *American Academy of Allergy, Asthma & Immunology*. 2012 Sep; 1(2):142-151; (c) Powell K, et al. GP and parent dissonance about the assessment and treatment of childhood eczema in primary care: a qualitative study. *BMJ Open*. 2018 Feb; (d) Grillo M, et al. Pediatric atopic eczema: the impact of an educational intervention. *Pediatr Dermatol*. 2006;23(5):428-36

# AD patient / family workshops (2/3)

## What are the key features of the intervention? (cont.)

### Workshop content:

- Past presentation topics have included:
  - The pathology of AD (illustrated using cross-section diagrams of the skin)
  - Explanations and recommendations for different AD treatments / products
  - Factors which may exacerbate AD symptoms
- The workshops are interactive, not just presentations
- They provide an opportunity for patients and their parents to interact with dermatologists and with each other, by asking questions and discussing their personal experiences
- Patients are also provided with printed educational materials to take home

### Other educational initiatives:

- The centre has recently launched make-up workshops for dermatology patients treated at the centre, aimed at teaching patients how to use make-up to boost self-esteem
- The workshops are held in the department's designated classroom and are run by an external make-up artist specialised in corrective make-up (including for AD)
- Patients of all ages and genders are taught which products will not exacerbate their symptoms and how to apply them appropriately
- Dermatologists, trainee dermatologists and fellows also attend in order to learn about corrective make-up themselves and give advice to future patients
- 4 patients attended the previous workshop, where over the course of two hours each patient received 20-25mins of 1:1 teaching from the make-up artist



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*Patients are provided with printed educational materials, including the above AD awareness campaign by the Argentinian Society of Dermatology*

# AD patient / family workshops (3/3)

## What are the outcomes so far?

### Benefits to patients:

- The opportunity to meet other AD patients, share experiences and ask questions
- Enhanced understanding of AD
- Potential for improved disease control and thus quality of life

### Benefits to HCPs:

- Efficient delivery of patient education (to multiple patients / family members simultaneously)
- Potential for improved treatment adherence and disease control in patients
- The opportunity to learn from patients about their personal experiences with AD

## What's next?

- The centre's psychiatry department, psychodermatologist and wider dermatology department plan to establish a shared office space where they will hold group therapy / education sessions for dermatology patients in need of psychosocial support



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Patients often think they are alone and are unaware that others are dealing with the same symptoms. They take comfort in meeting and speaking with other AD patients

*Dermatologist, Hospital Italiano de Buenos Aires*





# University of São Paulo Hospital

São Paulo, Brazil

Site visited by KPMG on 19<sup>th</sup> September 2019

[kpmg.com/uk](https://kpmg.com/uk)



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# The team



## Context

**Centre type:** Largest public hospital in South America and part of the São Paulo Medical School

**Catchment area:** The centre receives patients from across Brazil and Latin America

**Funding:** The centre receives funding from the State Department of Health

**Services:** University of São Paulo Hospital provides various specialty services to paediatric and adult patients, such as cardiology and dermatology. The dermatology department provides advice and treatment to paediatric and adult atopic dermatitis (AD) patients

**Patient population:** Paediatric and adult patients with conditions related to skin, hair, mucous membranes and nails are treated by the dermatology department. Patients with moderate to severe AD are seen at the specialised AD clinic



## Key strengths in the delivery of AD care

**Specialised atopic dermatitis (AD) clinic:** The centre established a specialised AD clinic in 1990. Patients are able to access highly specialised care and treatment for AD and associated comorbidities

**Access to psychological support:** The dermatology department has a psychologist to provide patients with psychological support. Patients can be referred by the dermatologist or speak directly to the psychologist before / after their consultation to discuss any psychological issues

**Established relationship with the local patient advocacy group:** The centre has an established relationship with Associação de Apoio à Dermatite Atópica (AADA) and is able to easily refer patients to the organisation's patient support group. Patients can attend the support group sessions and learn from other AD patients



## Key challenges faced in delivery of AD care

**Access and adherence to medication:** A number of patients have a low socioeconomic status and may not be able to afford treatment required for their atopic dermatitis. Inconsistent access to treatment can negatively impact patient adherence and their AD symptom management. The centre provides medications for free to support patient access (including topical corticosteroids, oral antihistamines and antibiotics)

**Limited time and resources to thoroughly educate patients:** Patients can seek a comprehensive cure to AD. Dermatologists and other healthcare professionals may not have enough time and resources to thoroughly educate patients on the complexity of AD and realistic treatment expectations

**Limited educational resources available for adolescents:** Currently, educational AD patient resources are either targeted at young children or adults, therefore there is a need for adolescent-specific materials to educate this population

# Atopic Dermatitis (AD) in Brazil

## Brazilian healthcare system:

The Brazilian healthcare system underwent major reform in 1988 and shifted from a private system to a mixed public-private system. Brazilian citizens can access free health coverage through the Unified Health System (Sistema Único de Saúde – SUS) or purchase private health insurance plans / pay directly for private services.<sup>(a)</sup> In 2017, it was estimated that 22.7% of the population had private health insurance plans<sup>(c)</sup>

## Publically funded healthcare

- SUS provides free access to healthcare for all citizens. The three objectives of SUS are to provide universal access to health services, enable equality of access to health services and ensure comprehensive continuity of care<sup>(a)</sup>
- State governments and local municipalities are responsible for the provision and execution of healthcare services. The governing bodies are required to allocate at least 12% of their total budgets respectively to healthcare. The federal government also provides funding through statutory taxes<sup>(a)</sup>
- The Family Health Strategy is recognised as a critical component of SUS and focuses on providing integrated primary care. Multidisciplinary teams provide preventive and basic primary care to all Brazilian citizens<sup>(b)</sup>
- SUS has progressively expanded to include the provision of public health programmes (e.g. immunisation initiatives) and complex services (e.g. organ transplants)<sup>(c)</sup>
- Individuals may access SUS through public or private healthcare providers<sup>(a)</sup>

## Privately funded healthcare

- Medical Private Plans (PPs) can be purchased by individuals to access private healthcare treatment. Individuals may also pay direct out-of-pocket payments for treatments and services<sup>(a)</sup>

## Prevalence

- The lifetime prevalence<sup>1</sup> of AD in Brazil is around 14%<sup>(d)</sup>
- Prevalence of AD in children is 13% and 7.9% in adolescents<sup>(e)</sup>



## Care provision:

### Location:

- Initial diagnosis of AD is usually performed by primary care providers such as general practitioners (GPs) and private dermatologists
- Moderate and severe AD patients are then referred to specialist hospitals

### Funding:

- Primary care and hospital services are funded through statutory contributions

## Guidelines and societies:

### Guidelines:

- Consensus on the therapeutic management of atopic dermatitis – Brazilian Society of Dermatology<sup>(f)</sup>
- Atopic Dermatitis Guideline – Guidance from the Latin American Society of Allergy, Asthma and Immunology<sup>(g)</sup>







### Medical societies/PAGs:

- Brazilian Atopic Dermatitis Association (AADA)

Note: (1) Lifetime prevalence is the percentage of people within the population who will have AD at some point in their life

**Sources:** (a) World Bank. Twenty Years of Health System Reform in Brazil: An Assessment of the Sistema Único de Saúde 2013 [Website] <https://openknowledge.worldbank.org/handle/10986/15801> Accessed October 10, 2019; (b) Wadge H, et al. Brazil's Family Health Strategy: Using Community Health Care Workers to Provide Primary Care. *The Commonwealth Fund* 2016; (c) Massuda A, et al. The Brazilian health system at crossroads: progress, crisis and resilience. *BMJ Glob Health*. 2018;3(4); doi:10.1136/bmjgh-2018-000829 (d) Understanding atopic dermatitis in Brazil. The Economist Intelligence Unit [Website] <https://eiuPerspectives.economist.com/healthcare/misunderstood-skin-disease-mapping-policy-response-atopic-dermatitis/article/understanding-atopic-dermatitis-brazil> Accessed 9 Oct 2019; (e) Sole D, et al. Prevalence of atopic eczema and related symptoms in Brazilian schoolchildren: results from the International Study of Asthma and Allergies in Childhood (ISAAC) phase 3. *J Invest Allergol Clin Immunol*. 2006; 16(6):367-76. (f) Aoki V, et al. Consensus on the therapeutic management of atopic dermatitis - Brazilian Society of Dermatology. *An Bras Dermatol*. 2019;94(2 Suppl 1):67–75. doi:10.1590/abd1806-4841.2019940210; (g) Sánchez J, et al. Atopic dermatitis guideline. Position paper from the Latin American Society of Allergy, Asthma and Immunology. *Revista Alergia México* 2014;61:178-211

# The centre and dermatology department

The centre		
 <b>Type and location</b>	<ul style="list-style-type: none"><li>— The University of São Paulo Hospital is the largest public hospital in South America and is part of the São Paulo Medical School. The hospital is one of the major referral centres for South America</li><li>— The hospital receives funding from the State Department of Health</li></ul>	
	<ul style="list-style-type: none"><li>— Catchment area: patients across Brazil, predominantly from São Paulo</li><li>— Patients from across South America (e.g. Bolivia, Chile, Argentina) are also referred to the centre</li></ul>	
The dermatology department		
 <b>Service Division</b>  <b>Hours of availability</b>  <b>No. of patients seen</b>  <b>Types of patients seen</b>  <b>Facilities on-site<sup>(1)</sup></b>	General dermatology services	Specialised atopic dermatitis (AD) Clinic
	Monday to Friday: 07:00 – 18:00	Wednesday 08:00 – 12:00 Thursday 13:00 – 17:00
	Approx. 2,000 patients per annum	Approx. 15 to 20 patients per clinic
	Primarily paediatric (over the age of 5 years old) and adult patients with moderate to severe AD	
	<ul style="list-style-type: none"><li>— 20 inpatient dermatology beds</li><li>— Diagnostic laboratory</li><li>— Phototherapy (PUVA / UVB)</li><li>— 1 suture room</li><li>— Surgical centre</li><li>— Microbiology lab</li></ul>	

Note: (1) List of facilities is not exhaustive

# The team



## Core team profile

-  **4** Dermatologists
-  **6** Trainee dermatologists
-  **30** Dermatology residents
-  **5** Dermatology nurses
-  **1** Psychologist

## Wider team profile

-  **2** Ophthalmologists
-  **2** Paediatricians
-  **1** Allergist
-  **1** Immunologist
-  **1** Nutritionist
-  **2** Social workers

*Note: Please see page 459 for further details about the wider team*



## Governance and processes

### Team meetings:

- *Clinical meeting – complex cases (weekly 1 hour meeting):*
  - Attended by all dermatologists, trainee dermatologists and interns
  - The purpose of the meeting is to present and discuss complex patient cases
- *Grand round (weekly):*
  - Attended by all dermatologists, trainee dermatologists, interns, physiotherapists, social workers and the nutritionist / dietician
  - The purpose of the meeting is to discuss the management of current hospital patients, their symptoms and treatment progress

### Patient records:

- *Electronic patient records (EHR):*
  - Accessible by all specialists at the centre

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Paediatric and adult patients present to their community physician (general practitioner or private dermatologist) with AD symptoms (e.g. itch, dry skin)
  - Patients may present directly to the emergency department at the centre
- Note: Paediatric and adult patients with mild AD may be managed in the community and not seen at the centre. Additionally, the centre generally does not see paediatric patients under the age of 5 (referred to the centre's paediatric department)*

## Diagnosis and Referral

In secondary care



- The community physician refers the patient to the centre's general dermatology services
- The patient undergoes an initial screening, where a dermatologist and trainee dermatologist will assess AD symptoms, any other potential diagnoses and assess suitability for clinical trial participation (consultation = approximately 15 minutes)
- Patients with mild AD will be referred to a private or public dermatologist (depending on their socio-economic circumstances) for on-going management (i.e. not referred to the specialised AD clinic)
- Patients with moderate to severe AD are given an appointment at the specialised AD clinic within 7–15 days (timing is dependent on patient symptoms). All patients are required to complete an admission form (which details a brief medical history and severity of AD) prior to the first appointment at the specialised AD clinic
- Very severe and complex AD patients are admitted to the inpatient facility

## Treatment and Management

Medical management



- The dermatologist will assess the patient's AD symptoms and history. SCORAD, EASI and v-IGA-AD scores are performed (consultation = approximately 20–30 minutes)
- Based on the assessment, the dermatologist will initiate or modify existing treatment
- Patients may be given the opportunity to participate in a clinical trial (if appropriate)

### Comorbidity management

- All adult patients are referred to the hospital's ophthalmologist to prevent / treat AD-related ocular symptoms
- Patients will be referred to an allergist / psychologist / psychiatrist as required
- Inpatients will be managed by a multidisciplinary team consisting of dermatologists, dermatology nurses, nutritionists / dieticians and social workers

Non-medical management



- Patients are provided with educational materials developed by the local patient advocacy group Associação de Apoio à Dermatite Atópica (AADA). Patients can access online videos and brochures / leaflets
- Paediatric and adult patients may be referred to the patient support group, run by the local patient advocacy group
- The dermatologist may refer paediatric patients to the paediatric group psychology sessions (facilitated by psychologist)
- For patients in the dermatology ward, nurses provide the patients with education on AD care (including basic AD self-management, application of topical treatment and bathing advice)

## Follow-up

Monitoring of chronic disease / flare up



- AD patients are usually followed up in the clinic 3 weeks after their initial visit (consultation = approximately 20 minutes)
- Thereafter, patients are seen every 3–6 months, depending on the severity of their symptoms and treatment
  - Once the patient's AD is well controlled, the patient is given the option to have annual appointments with the dermatologist
- Patients are able to receive medication directly from the centre's pharmacy
- During follow-up consultations, patients are educated on AD self-management and care by the dermatologist

# Roles of the wider team

## Ophthalmologist

**Patient type:** All adult AD patients

**Referral:** Referred by dermatologist to the ophthalmology department

**Consultations:** Ophthalmologist will perform standard tests and provide treatments (e.g. lubricating eye drops; systemic therapies) as required. All patients receive education regarding their eye condition, treatment and aftercare (e.g. how to properly clean their eyes themselves)

**Timing:** Consultations last 15-30 minutes and follow-up frequency is every 2-3 months, however consultation length and frequency are dependent on patient requirements

## Allergist

**Patient type:** All patients suffering from dermatological conditions with an allergic comorbidity (including allergic rhinitis and asthma)

**Referral:** Referred by dermatologist to the immunology and allergy department

**Consultations:** Allergist will perform standard tests and provide treatments as required (e.g. screening and management of asthma and allergic rhinitis, performing skin prick / RAST testing during outpatient clinic appointments)

**Timing:** Consultations last 15-30 minutes and follow-up frequency is every 2-3 months, however consultation length and frequency are dependent on patient requirements



## Paediatrician

**Patient type:** Moderate to severe paediatric patients up to 18 years of age suffering from chronic dermatological conditions (including AD, psoriasis etc.) and potential food allergies

**Referral:** Referred by dermatologist to the paediatric department

**Consultations:** Paediatrician will perform the standard tests and provide food allergy (prick / RAST / food challenging) testing where appropriate

**Timing:** Consultations last 15-30 minutes and follow-up frequency is every 2-3 months, however consultation length and frequency are dependent on patient requirements

## Immunologist

**Patient type:** All paediatric and adult AD patients

**Referral:** Referred by dermatologist to the immunology and allergy department

**Consultations:** Immunologist will assess for any immuno-deficiencies and conduct immunology tests (e.g. IgE testing) and provide advice / treatment as required. The immunologist will communicate the results with the dermatologist to inform the patient's AD plan

**Timing:** Consultations last 15-30 minutes and follow-up frequency is every 2-3 months, however consultation length and frequency are dependent on patient requirements

## Roles of other team members

*The inpatient dermatology team includes 2 social workers and nutritionist*

- *Social worker:* All AD patients are seen by the social worker when they are admitted as a patient on the dermatology ward. The social worker aims to ensure the patient is discharged to appropriate living conditions
- *Nutritionist:* The nutritionist develops a specialised dietary plan / provides guidance to AD patients who may have food allergies



# Overview of interventions in place for AD

## Awareness and Presentation



Symptom identification

- **Working with the Brazilian Atopic Dermatitis Association (AADA):** The centre frequently refers patients to the AADA support groups and hands out educational material developed by AADA. The material aims to educate patients on how to self-manage AD

See pg. 465-466 for case study

### Key:



Case study available

## Diagnosis and Referral



In secondary care

- **Specialised atopic dermatitis (AD) clinic:** The centre runs a twice-weekly specialised atopic dermatitis half-day clinic for patients with moderate to severe AD. Paediatric and adult patients are initially screened in the general dermatology clinic to assess the patient's suitability for the clinic  
 See pg. 467-468 for case study
- **Healthcare professional education:** The centre delivers education to healthcare professionals within and outside of the centre  
 See pg. 469-470 for case study
- **Initial assessment screening:** Each patient is required to undergo an initial assessment to determine if they are eligible for the specialised AD clinic

## Treatment and Management



Medical management

- **Extensive inpatient facilities:** AD patients are able to access dedicated dermatology hospital beds for intensive AD treatment and care. Patients are managed by a multidisciplinary team (MDT) which consists of a dermatologist, dermatology nurse, physiotherapist, nutritionist / dietician and social worker  
 See pg. 471 for case study
- **Collaboration with comorbidity specialists:** The dermatology department has a holistic patient approach and collaborates with different specialties. In addition to the inpatient team specialties, the dermatologists work with the hospital's ophthalmologists, paediatricians and allergists  
 See pg. 472 for case study
- **Involvement in clinical trials:** Patients may have the opportunity to participate in clinical trials



Non-medical management

- **Paediatric and adult psychological support:** Patients are able to receive psychological support from a dedicated dermatology psychologist. Patients can either be referred or speak to the psychologist directly before / after their dermatology appointment. If required, patients may also be referred to a psychiatrist  
 See pg. 473-474 for case study

## Follow-up



Monitoring of chronic disease/flare up

- **Patient education during follow-up consultations:** For each AD consultation, the dermatologist provides extensive counselling and educational advice to patients (approximately 20 minutes)
- **Medication supply:** Patients are able to obtain AD medication directly from the centre's pharmacy
- **Ongoing dermatologist access:** Once their AD is well-managed, patients are able to receive continued care at the centre. Patients have the option of scheduling an appointment with the dermatologist once a year, whilst being managed by their PCP in-between appointments





# Monitoring AD patients and comorbidities

## The dermatology department employs a number of measures for monitoring AD and associated comorbidities

### Objective measures (AD):

AD scoring indices are used to monitor patients and their disease, including:

- EASI (Eczema Area and Severity Index): validated scoring system that grades the physical signs of atopic dermatitis<sup>(a)</sup>
  - vIGA-AD™ (Validated Investigator Global Assessment for Atopic Dermatitis): scoring system for use in clinical trials and clinical practice which grades the overall appearance of AD lesions based on a series of morphological descriptions<sup>(b)</sup>
  - SCORAD (SCORing Atopic Dermatitis): to assess AD disease severity and monitor patient progress<sup>(c)</sup>
- Hanifin and Rajka diagnostic criteria: support diagnosis of AD based on set of major and minor criteria<sup>(d)</sup>

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### Dermatology department routinely measures comorbidity outcomes by:

- *Allergist*: response to allergens/control of atopy disease (e.g. monitoring allergic asthma using standardised asthma measurement scales)
- *Psychologist*: monitoring psycho-social distress through Dermatology Quality of Life Index (DLQI – dermatology related quality of life questionnaire)<sup>(e)</sup>
- *Ophthalmologist*: surveillance of symptoms and specialist tests (e.g. topography)

**Sources:** (a) HOME for eczema.org. EASI for clinical signs [Website] <http://www.homeforeczema.org/research/easi-for-clinical-signs.aspx> Accessed 1 Mar 19; (b) Validated Investigator Global Assessment For Atopic Dermatitis (vIGA-AD™) Scale [PDF] [https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale\\_vIGA-AD\\_2017.pdf](https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale_vIGA-AD_2017.pdf) Accessed 26 June 2019; (c) SCORing Atopic Dermatits (SCORAD) Calculator (0.9.0) [Website] <http://scorad.corti.li/> Accessed 26 Feb 2019; (d) Rothe M, et al. Diagnostic criteria for atopic dermatitis. *Lancet*. 1996;348(9030):769-779. doi: 10.1016/S0140-6736; (e) Lewis V, et al. 10 Years Experience of the Dermatology Life Quality Index (DLQI). *J Investig Dermatol Symp Proc* 2004;9:169 –180

# Advice to other centres



## What advice would you give less specialised centres



### **Objective of advice: Emphasise the importance of topical treatments and self-management techniques**

- **Why?** Patients may have misconceptions regarding AD treatments and the impact on their symptoms. Patients may believe that the topical treatments, such as emollients and topical corticosteroids, are not required on a regular basis. By emphasising regular use of such products and investing in patient education, this could subsequently improve and reduce the need for more intensive treatments



### **Objective of advice: Provide tailored information to stakeholder type (patients, carers and general dermatologists / primary care physicians [PCPs])**

- **Why?** AD is a complex disease that can require intricate treatment plans and there are a number of new emerging therapies / care recommendations. Dermatologists should aim to provide ongoing education tailored to the stakeholder type (patient, carer and general dermatologists / PCPs) to ensure up-to-date recommendations and guidelines are followed for AD care. It is important to address patient expectations on the treatment of AD. Given the chronic nature of AD, patients and caregivers should be educated to expect a gradual improvement with the use of medication

# Next steps for the centre



## What is next for the centre?

### Objective: Increase access to innovative AD treatment

- **What?** The centre plans to improve access to innovative AD treatment through clinical trials
- **Why?** Access to novel AD treatments can be difficult for patients. The treatments may not be commercially available or patients with low socioeconomic status may have financial difficulty accessing the products. By initiating / facilitating clinical trials, there is potential for more patients to access the new treatments and improve patient symptoms



### Objective: Focus on providing AD education to healthcare professionals

- **What?** The centre will continue to focus on delivering / facilitating healthcare professional education on AD care and treatment through preceptorships
- **Why?** The preceptorships in AD will focus on utilising a 'train-the-trainer' model, to improve dissemination of good practice in AD care. The preceptorships aim to support future training of other healthcare professionals and improvement in patient care. In addition to delivering the educational sessions face-to-face, the centre plans to increase the number of tele-dermatology educational sessions provided



### Objective: Supporting paediatric patients with psychological care

- **What?** The dermatology psychologist plans to provide psychology group sessions for paediatric AD patients. The psychologist and two post-graduate students will work with patients and their parents in separate groups to provide counselling and advice
- **Why?** AD can affect the psychological well-being and quality of life of patients<sup>(a)</sup> and their families<sup>(b)</sup>, making psycho-social support in AD an important aspect of patient care



**Sources:** (a) Noh S, et al. Comparison of the psychological impacts of asymptomatic and symptomatic cutaneous diseases: vitiligo and atopic dermatitis. *Ann Dermatol.* 2013;25(4):454-61; (b) Reed B et al. The burden of atopic dermatitis. *Allergy Asthma Proc.* 2018;39(6):406-410; (c) Optum White Paper [PDF] <https://cdn-aem.optum.com/content/dam/optum3/optum/en/resources/white-papers/PeersImproveOutcomes.pdf> Accessed 12 June 2019

# Case studies



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# Working with the Brazilian Atopic Dermatitis Association (1/2)

## Overview

- The Associação de Apoio à Dermatite Atópica (AADA), the Brazilian Atopic Dermatitis Association was initially established at the centre and continues to work closely with the centre's dermatologists. The centre frequently refers patients to the AADA support groups and utilises the educational material developed by AADA



## Associação de Apoio à Dermatite Atópica (AADA) in Brazil

- After identifying a need for patient focused support, a dermatologist from the centre founded the Brazilian Atopic Dermatitis Association (AADA) in 1997
- AADA's mission is to '*transform AD into an opportunity for growth and self-development through art, science and education*'. It aims to promote health through self-development and self-improvement<sup>(a)</sup>
- AADA is comprised of patients and their families, physicians, volunteers and other healthcare professionals (e.g. dermatologists, psychologists)

### Centre-AADA activities:

- *Development of patient education materials*
  - A dermatologist from the centre recognised the lack of patient friendly educational material in Brazil. The materials available were either designed for healthcare professionals or did not incorporate a patient's perspective
  - In collaboration with AADA, the dermatologist created various educational material for patients. This includes leaflets specifically targeted at adolescent patients with AD
- *Creation of support groups*
  - A dermatologist from the centre identified a pattern in the challenges AD patients faced (approximately 25 years ago). Patients often thought AD was an acute condition rather than a complex chronic condition that required on-going treatment
  - The dermatologist initiated the patient support group to enable patient focused discussion and to enable patients to learn from others (*see below for additional detail*)
- Other ad-hoc activities include: educational lectures and workshops for patients (on moisturisers, nutrition, relaxation, art [origami, music, drawing]) and scientific meetings for HCPs

### AADA activities:

- *Provision of patient support groups across Brazil*
  - AADA organises and supports the facilitation of patient support groups across Brazil. AADA aims to ensure there is a physician and patient representative (and sometimes a psychologist) at each support group meeting to facilitate discussion amongst patients. The face-to-face support group meetings are generally run on a monthly basis, however they are dependent on the city
  - In São Paulo, a patient support group meeting occurs once a month on Sundays and lasts for around 1-2 hours. Paediatric and adult patients are split into different groups and each meeting has between 5-10 attendees. During the support group meetings, the patients are able to discuss their preferred topics and ask the physician / psychologist questions. The physician / psychologist ensures that patients are aware that the meeting is not an opportunity to receive therapy or act as a consultation
  - The support groups are advertised on the AADA website, social media and word of mouth. Physicians are also able to refer patients directly to the support groups

**Sources:** (a) About AADA. AADA [Website]. <http://www.aada.org.br/apresentacao/boas-vindas/> Accessed 8 Oct 2019



# Working with the Brazilian Atopic Dermatitis Support Association (2/2)

## Associação de Apoio à Dermatite Atópica (AADA) in Brazil

### AADA activities (cont.):

- *Facilitation of Design thinking workshops*
  - AADA organises and facilitates Design thinking workshops to identify and understand the true challenges and needs of AD patients
  - Workshops are typically held at least once a year, with 20-30 participants in attendance
  - Previous workshops have been attended by physicians and patients. They create an opportunity for open discussion
  - As a result of the design thinking workshops, AADA created comic (manga) books as an educational tool for adolescent AD patients
- *Organisation of scientific meetings for physicians and other healthcare professionals*
  - AADA organises workshops to support healthcare professional education on AD every month
  - AADA also organises a symposium for healthcare professionals every two years
- Additionally, AADA is present at international AD meetings and symposiums, and often helps to organise meetings with other AD organisations around the world

### What's next?

- AADA is currently working with a patient representative to develop a mobile application focused on providing AD education and self-management support
- AADA aims to continue facilitating design thinking workshops and focus on creating patient centric solutions

“

We need to learn how to work with patients and understand their needs



*Dermatologist, University of São Paulo*



Figure 1. Leaflets and comic books produced by AADA

# Specialised Atopic Dermatitis clinic (1/2)

## Overview

- The centre runs a twice weekly specialised atopic dermatitis half-day clinic for patients with moderate to severe AD. A dermatologist who subspecialises in AD provides paediatric and adult patients with AD guidance and treatment



Most of the complex AD cases in Brazil end up at the AD clinic

*Dermatologist, University of São Paulo Hospital*



## What is the rationale?

- To appropriately treat patients with innovative therapeutic options, dermatologists need to understand them<sup>(a)</sup>
- Providing education to AD patients is also important in supporting effective patient care. A dermatologist who subspecialises in AD may be better positioned to provide specialised AD care, treatment and education
- The specialised AD clinic has become a referral centre for complex and severe AD patients across Brazil

## What are the key features of the intervention?

- The centre runs a twice weekly specialised AD clinic for paediatric and adult patients with moderate-to-severe AD. The specialised AD clinic begun approximately 30 years ago and there is roughly an even number of paediatric to adult patients
- There are between 15-25 patients at each half-day clinic and each appointment lasts between 15-30 mins
- Patients are generally referred to the general dermatology outpatient clinic from primary care physicians (i.e. general practitioners) and private dermatologists
- Patients undergo an initial assessment during their initial general dermatology appointment to determine the clinical need for attendance at the AD clinic. The dermatologist / trainee resident will assess the patient's AD symptoms against the Hanifan and Rajka diagnostic criteria to determine if they are eligible to attend the specialised AD clinic
- Patients with mild AD are not eligible for the AD clinic and will be referred back to the referring primary care physician or private dermatologist

### Initial consultation

- Severe AD patients are seen in the specialised AD clinic within 7 days of their initial appointment at the general dermatology clinic, whereas moderate AD patients are seen within 10-15 days
- During the initial consultation at the clinic, the dermatologist and trainee dermatologist will aim to:
  - Identify potential triggers (including psychological triggers like stress)
  - Examine and assess the severity of AD (including measuring SCORAD, v-IGA and EASI scores)
  - Initiate / modify treatment
  - Provide self-management advice
- Patients receiving systemic therapy are required to undergo routine blood tests

**Sources:** (a) Napolitano M, et al. Adult atopic dermatitis: new and emerging therapies. *Expt Review of Clin Pharm.* 2018;11(9):867-878. doi: 10.1080/17512433.2018.1507734

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# Specialised Atopic Dermatitis clinic (2/2)

## What are the key features of the intervention? (cont.)

### Management of comorbidities

- When necessary, the dermatologist will refer AD patients to other specialties for management of AD comorbidities (*see case study – collaboration with comorbidity specialists*)

### Follow-up

- Patients are seen within one month after their initial consultation at the specialised AD clinic. Thereafter, patients are seen every 3-6 months
- Once their AD symptoms are well controlled and managed, patients are given the option to see the dermatologist on an annual basis

## Challenges

- Patients can have a misunderstanding about the causes of AD and the treatment required. As a result, the dermatologist may need to invest more time to provide patients with the necessary treatment and advice

## What are the outcomes so far?

### Benefits to patients:

- Improved access to specialist tests / treatment through specialised AD service

### Benefits to HCPs:

- Access to specialised team dedicated to AD management
- Insight into AD trends (and potentially the effectiveness of AD therapies) as a large pool of AD patients are seen

## What's next?

- The centre will seek to identify trends in patient challenges and develop tailored solutions where possible (e.g. materials on specific topics) in collaboration with AADA



Severe AD patients can be seen in the AD clinic within a week of their initial assessment

*Dermatologist,  
University of São Paulo*



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# Healthcare professional education (1/2)

## Overview

- The centre delivers education to healthcare professionals within and outside of the centre. The centre is planning to develop 'train-the-trainer' preceptorships, which will involve organised visits to the centre for primary care professionals to learn how moderate to severe AD is managed within the secondary care setting



We aim to educate patients and HCPs in all aspects of the patient pathway

*Dermatologist, University of São Paulo Hospital*



## What is the rationale?

- Healthcare professional education has the potential to improve the knowledge and confidence of HCPs and patient health outcomes<sup>(a)</sup>
- Additionally, primary care professionals (PCPs) may have limited training in dermatology (including AD)<sup>(b)</sup>, and AD patients commonly present to PCPs and / or are managed in primary care<sup>(c)</sup>

## What are the key features of the intervention?

- The centre delivers education to healthcare professionals within and outside of the centre, with the aim of:
  - Improving clinical diagnosis of AD
  - Optimising the use of basic AD treatment (e.g. topical treatments)
  - Ensuring HCPs are aware of challenges and potential solutions along the entire AD pathway

### Education of healthcare professionals within the centre

- All members of the dermatology department, including the multidisciplinary inpatient team, attend a weekly grand round. At the grand round, complex cases are presented and discussed, providing attendees with the opportunity to learn about management of severe AD patients

### Primary care provider education

- The centre supports education events for primary care providers, which has previously included symposiums (in collaboration with AADA)
  - The symposiums are organised 2-3 times per year. Each event is advertised online (via department website) and through the AADA website. The centre also utilises the AADA social media channels and patient representatives to increase awareness of their events
  - Primary care providers are also welcome to attend the AADA patient and care giver support groups, which are offered across Brazil each month

**Sources:** (a) Cervero RM, et al. The Impact of CMA on Physician Performance and Patient Health Outcomes: An Updated Synthesis of Systematic Reviews. *Journal of Continuing Education in the Health Professions*. 2015;35(2):131-139; (b) Kownacki S. Skin diseases in primary care: what should GPs be doing? *Br J Gen Pract*. 2014;64(625):380-381. doi: 10.3399/bjgp14X680773; (c) Schofield JK, et al. Skin conditions are the commonest new reason people present to general practitioners in England and Wales. *Br J Dermatol* 2011;165(5):1044-1050

# Healthcare professional education (2/2)

## Challenges

- Primary care physicians may find it problematic to allocate time to external training
- With the release of new and novel AD treatment, physicians may experience difficulty to remain up-to-date with the latest treatment options

## What are the outcomes so far?

### Benefits to patients:

- Potential for improved access to specialised AD care within the community

### Benefits to HCPs (including PCPs):

- Increased capability to address moderate and severe cases of AD
- Increased visibility and understanding of different AD treatment and management techniques
- Improved knowledge of when to refer to hospital specialists

## What's next?

- The centre aims to organise events to encourage HCP education through preceptorships and other initiatives. The preceptorships will focus on a 'train-the-trainer' model, which will involve organised visits to the centre for PCPs to learn how moderate to severe AD is managed within the secondary care setting. The PCPs may then become more confident in managing severe AD in the community setting
- Given the geographical spread of HCPs in Brazil, the centre aims to organise teleconferences for regional and rural healthcare professionals to improve AD care
- The centre also plans to provide educational lectures at private universities to spread AD awareness and appropriate management

“



We want to show primary care physicians the key steps to managing AD

*Dermatologist,  
University of São Paulo  
Hospital*

“



We have the opportunity to optimise basic treatment and management techniques (through PCP education and engagement)

*Dermatologist,  
University of São Paulo  
Hospital*



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# Extensive inpatient facilities

## Overview

- AD patients are able to access dedicated hospital beds for intensive AD treatment and care. Patients are managed by a multidisciplinary team (MDT) that consists of the dermatologist(s), dermatology nurse(s), trainee dermatologists, nutritionist / dietician and social worker. The team has a daily ward round, where they discuss patient progress and treatment options

## What is the rationale?

- AD can have a significant impact on a patient's quality of life, self-esteem and ability to self-manage their condition<sup>(a)</sup>
- AD patients who require intensive treatment or situational support may benefit from inpatient services and treatment<sup>(b)</sup>

## What are the key features of the intervention?

- The centre has a dedicated dermatology unit with 20 inpatient beds. Patients with severe AD are able to access inpatient treatment and facilities when necessary. Additionally all patients are assessed by an immunologist to determine if there is an immunodeficiency present
- Patients are managed by a multidisciplinary team who conduct a daily ward round to assess, discuss and monitor patient progress. Each healthcare professional will consider different aspects of the patients care to ensure the patient is holistically managed
  - Dermatologists / trainee dermatologist: will provide AD treatment plan / advice
  - Nutritionist / dietician: will provide dietary advice
  - Social worker: will see the patient upon admission, and organise and provide living assistance where necessary
  - Immunologist: will assess if there is an immunodeficiency present (however may not always participate in the ward round)
- Day-to-day, the nurses will provide patients with bathing support and application of topical medication and emollients
- Additionally, there is a weekly grand round, where the MDT along with dermatology interns and residents discuss complex patient cases and management options (approximately 1 hour duration)

## What are the outcomes so far?

### Benefits to patients:

- Able to receive expert advice and intensive care

### Benefits to HCPs:

- Physicians are able to closely monitor patient progress and response to treatment

**Sources:** (a) Sibbald C, et al. Patient Burden of Atopic Dermatitis. *Dermatol Clin*. 2017;35(3):303-316. doi: 10.1016/j.det.2017.02.004; (b) van der Schaft J, et al. Is There an Additional Value of Inpatient Treatment for Patients with Atopic Dermatitis? *Acta Derm Venereol*. 2016;96(6):797-801. doi: 10.2340/00015555-2410

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# Collaboration with comorbidity specialists

## Overview

- The dermatology department has a holistic patient approach and collaborates with different specialties. In addition to the inpatient team specialties, the dermatologists have a working relationship with the hospital's ophthalmologists, immunologists, psychologists / psychiatrist, paediatricians and allergists



We regularly interact with the children's hospital physicians, who are the experts in food allergies

*Dermatologist, University of São Paulo Hospital*



## What is the rationale?

- AD is a complex disease and patients may present with other associated diseases (e.g. asthma or allergic rhinitis)<sup>(a)</sup>
- AD patients may also suffer from ocular comorbidities (as a result of the disease itself or treatment used)<sup>(b)</sup>
- The centre has an effective working relationship across specialties, which can help speed up referrals and improve communication (e.g. regarding severity of symptoms, treatments prescribed)

## What are the key features of the intervention?

- The dermatology department engages with other hospital specialists and healthcare professionals to ensure patients receive comprehensive care for their AD-associated comorbidities
- There is a multidisciplinary team who is responsible for the treatment and management of inpatient dermatology patients (*see case study – Extensive inpatient facilities*)
- The dermatologist may refer to the following specialists through the centre's intranet service:
  - Ophthalmologist: assesses and reviews any AD-associated ocular symptoms
  - Immunologist: determines if the patient may be suffering from an immunodeficiency
  - Psychologist / psychiatrist: assesses patient's psychological symptoms
  - Allergist: reviews AD patients who present with respiratory symptoms
  - Paediatrician: assesses paediatric patients with a suspected food allergy (usually more common in paediatric patients with severe AD)

## What are the outcomes so far?

### Benefits to patients:

- Quick access to other specialists (through established referral pathway)
- Able to receive holistic care for comorbidities (e.g. improved eye health and regular monitoring with ophthalmologist support)

### Benefits to HCPs:

- Opportunity to learn from other specialties
- Improved management of comorbidities

**Sources:** (a) Bantz SK, et al. The Atopic March: Progression from Atopic Dermatitis to Allergic Rhinitis and Asthma. *J Clin Cell Immunol.* 2014;5(2):202; (b) Thyssen JP, et al. Incidence, prevalence, and risk of selected ocular disease in adults with atopic dermatitis. *Journal of the American Academy of Dermatology.* 2017;77(2):280-286.e1. doi: 10.1016/j.jaad.2017.03.003

# Patient psychological support (1/2)

## Overview

- Patients are able to receive psychological support from a dedicated dermatology psychologist. Patients can either be referred or speak to the psychologist directly before / after their dermatology appointment



Patients can request my help, as I have a dedicated psychology support room in the dermatology department

*Psychologist, University of São Paulo Hospital*



## What is the rationale?

- AD can affect the psychological well-being and quality of life of patients<sup>(a)</sup> and their families<sup>(b)</sup>, making psycho-social support in AD an important aspect of patient care

## What are the key features of the intervention?

- The dermatology department has a dedicated psychologist to provide all AD patients with psychological support and counselling
- The psychologist may refer paediatric AD patients to the psychology group sessions
- 100–150 AD patients attend psychology sessions each year and there is currently a waiting list of around 4 months

### Informal support

- The psychologist has an allocated room within the general dermatology clinic and patients are able to informally speak with the psychologist before / after their dermatology appointment

### Formal psychology sessions

- Dermatologists can refer patients to the psychologist if they present with any psychosomatic symptoms (e.g. depression / anxiety)
- The psychologist will conduct an initial screening to determine the patient's needs
- If appropriate, the psychologist may then offer the patient psychology sessions. Each patient is able to receive up to 12 weekly sessions
- The psychologist generally focuses on improving the patient's self-image and provide support on how to engage with others
- During each session, the psychologist will measure the patient's stress, anxiety and levels of depression through the DLQI measure
  - The psychologist will also provide the patient with cognitive behavioural exercises to help patients improve their situations. For example, patients may be educated on:
    - Filtering: focusing on positive items and helping the patient see the disease as an opportunity for growth and self-development
    - Emotional reasoning: enabling the patient to see them as more than the disease
- Once the 12 sessions are completed, the psychologist will refer the patient to a public psychologist in the primary care setting if required (usually near the patient's place of residence or work)

**Sources:** (a) Noh S, et al. Comparison of the psychological impacts of asymptomatic and symptomatic cutaneous diseases: vitiligo and atopic dermatitis. *Ann Dermatol.* 2013;25(4):454-61; (b) Reed B, et al. The burden of atopic dermatitis. *Allergy Asthma Proc.* 2018;39(6):406-410

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# Patient psychological support (2/2)

## What are the outcomes so far?

### Benefits to patients:

- Access to holistic care
- Able to conveniently receive psychological support within the hospital (before or after dermatology appointments)
- Patients may feel more comfortable speaking to dermatology psychologist (rather than external psychologist)

### Benefits to HCPs:

- Direct referral pathway from dermatologist to psychologist
- Collaboration between dermatologist and psychologist to support patient progress

## What's next?

- The psychologist is currently assessing the potential benefits of psychological support for patients with different dermatological conditions
- The centre aims to develop one-day workshops to provide patients with an opportunity to participate in AD related psychological activities (e.g. cognitive behavioural therapies) and learn more about specific topics. The workshops will focus on providing more AD patients with access to psychosocial support



Patients often experience psychological issues with their personal image

*Psychologist,  
University of São Paulo*



We want to provide more AD patients with psychological support through workshops

*Psychologist, University  
of São Paulo*







# Women's College Hospital

Toronto, Canada

Site visited by KPMG on 1<sup>st</sup> – 2<sup>nd</sup> October 2019

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APPENDIX  
CENTRE REPORTS



# Summary



## Context

**Centre type:** Large teaching hospital located in downtown Toronto

**Catchment area:** Patients are predominantly from Toronto (population of around 2.9 million people) and the Greater Toronto Area. However, patients from neighbouring suburbs may also access the centre's facilities

**Funding:** The centre is majority publicly funded through the regional health authority (via public health insurance contributions)

**Services:** The dermatology department is one of many departments within the centre

**Patient population:** The dermatology department provides treatment and advice to adult patients with any dermatological disease (paediatric patients are seen at the local children's hospital). It offers general dermatology, cosmetic dermatology and other dermatological services.



## Key strengths in the delivery of AD care

**Reference centre:** The centre is a well-regarded hospital for dermatological care in Canada. It provides treatment to patients with a range of dermatological diseases and provides secondary opinions to other dermatologists in the country

**Focus on research:** Within the dermatology department, there are dermatologists who primarily focus on research on pathogenesis, treatment and management of various dermatological diseases (including AD)

**Large phototherapy facility:** The centre has one of the largest phototherapy facilities in Canada. As a result, a number of local and regional moderate to severe AD patients can receive highly specialised dermatological care



## Key challenges faced in delivery of AD care

**Variation in access to treatment:** Due to restrictions in their insurance coverage, patients may not have access to certain treatments recommended by their dermatologist

**Patient expectations of treatment:** Patients may have pre-conceived ideas of how effective a treatment should be, or what results it should produce. This can lead to non-adherence if the patient does not achieve these results. As such, HCPs must invest time educating patients to overcome these misconceptions

# Atopic Dermatitis (AD) in Canada

## Canadian healthcare system:

The Canadian healthcare system is primarily financed through provincial / federal general tax revenue, which accounts for 70% of total healthcare spending and 11.3% of GDP. This is supplemented by expenditure through private health insurance for non-covered benefits<sup>(a)</sup>

## Publicly funded healthcare:

- Healthcare is administrated by provinces and territories through local universal health insurance programmes. Each provincial healthcare insurance plan is required to be publicly administered, provides comprehensive and universal coverage and is accessible across different provinces<sup>(b)</sup>
- Provincial healthcare plans coverage for additional benefits can vary. For example, individuals will have variable coverage for services such as outpatient prescription drugs, non-physician mental healthcare, vision care, dental care, home care and hospice care<sup>(b)</sup>

## Privately funded healthcare

- Private health insurance can be purchased by individuals and covers services excluded from public reimbursement, such as vision and dental care, prescription drugs, rehabilitation services, home care and private rooms in hospitals<sup>(b)</sup>
- As of 2018, private insurance accounted for approximately 12.4% percent of total health spending.<sup>(a)</sup> In 2014, around 94% of premiums for private health plans were paid through employers, unions, or other organizations<sup>(b)</sup>
- In 2018, out-of-pocket payments represented approximately 15.4% of total health spending. This has risen from 14% in 2014, where out-of-pocket payments mainly involved prescription drugs (21%) and non-hospital institutions (22%) as well as dental care (16%), vision care (9%), and over-the-counter medications (10%)<sup>(b)</sup>

## Prevalence

- The lifetime prevalence of AD in Canada is 17%<sup>(1)(c)</sup>
- Prevalence of adult AD in Canada is approximately 3.5%<sup>(d)</sup>



## Care provision:

### Location:

- Mild (or well-controlled) AD care is primarily delivered by community physicians (family doctors and private dermatologists)
- Moderate and severe (uncontrolled) AD care is generally managed by hospital dermatologists

### Funding:

- Primary care services are privately owned, however, are predominantly funded through public health insurance
- Hospital services are primarily funded through public health insurance

## Guidelines and societies:

### Guidelines:

- Eczema Society of Canada – Atopic Dermatitis: A Practical Guide to Management, 2018<sup>(e)</sup>
- Guidelines of care for the management of AD: American Academy of Dermatology

### Medical societies/PAGs:

- Eczema Society of Canada (ESC)
- Canadian Dermatology Association

**Note:** (1) Lifetime prevalence is the percentage of people within the population who will have AD at some point in their life

**Sources:** (a) How Much Does Canada Spend on Health Care. Effective Public Healthcare Panacea Project [Website] <https://www.epphp.ca/healthcare-funding-policy-in-canada/> Accessed 20 Sept 2019; (b) The Canadian Health Care System. International Health Care System Profiles [Website] <https://international.commonwealthfund.org/countries/canada/> Accessed 20 Sept 2019; (c) Eczema. Canadian Dermatology Association [Website] <https://dermatology.ca/public-patients/skin/eczema/> Accessed 16 Oct 2019; (d) Barbarot S, et al. Epidemiology of atopic dermatitis in adults: Results from an international survey. *Allergy*. 2018;73(6):1284-1293. doi: 10.1111/all.13401; (e) Atopic Dermatitis: A Practical Guide to Management. Eczema Society of Canada [PDF] [https://eczemahelp.ca/wp-content/uploads/2019/03/ESC\\_AD\\_Practical-Guide-to-Management-for-HCP\\_2019.pdf](https://eczemahelp.ca/wp-content/uploads/2019/03/ESC_AD_Practical-Guide-to-Management-for-HCP_2019.pdf) Accessed 20 Sept 2019

# The centre and dermatology department

## The centre



### Type and location

- Women's College Hospital is a large teaching hospital located in downtown Toronto, Canada
- The centre receives public funding through the regional health authority



### Population served

- The centre's catchment area includes Toronto (approximately 2.9 million people) and the Greater Toronto Area
- Patients from neighbouring suburbs, such as Kitchener and Barrie, are also referred to the centre

## The dermatology department



### Service Division

**Rickey Kanee Schachter Dermatology Centre**  
(general dermatology outpatient clinic)

**Phototherapy Education and Research Centre (PERC)**



### Hours of availability

Monday – Friday: 8am – 12pm; 1pm – 4pm

Monday: 7am – 6:15pm  
Tuesday: 8am – 3:45pm  
Wednesday: 7am – 6:15pm  
Thursday: 7am – 6:15pm  
Friday: 7am – 2:45pm



### No. of patients seen

Approximately 40,000 dermatology patient visits per annum



### Types of patients seen

All dermatological conditions

Photo-responsive dermatological diseases (including psoriasis, cutaneous T-Cell Lymphoma and atopic dermatitis)



### Facilities on-site<sup>(1)</sup>

- 9 general dermatology outpatient clinic rooms
- Wound healing clinic
- 5 phototherapy (narrowband UVB and broadband UVB) rooms
- Surgical day clinic

Note: (1) List of facilities is not exhaustive



# The team



## Core team profile

-  **20** Dermatologists
-  **35** Trainee dermatologists
-  **15** Research fellows
-  **4** Dermatology nurses

## Wider team profile

-  Allergist
-  Pulmonologist

*Note: Please see page 481 for further details about the wider team*



## Governance and processes

### Team meetings:

- *Operations meeting (monthly)*
  - Attended by all dermatologists, trainee dermatologists and dermatology nurses
  - The purpose of the meeting is to discuss operational issues / processes and potential solutions
- *Complex cases (weekly)*
  - Attended by all dermatologists, trainee dermatologists and research fellows
  - The purpose of the meeting is to discuss the treatment and management of patients with complex dermatological conditions, including patients with severe AD

### Patient records:

- *Electronic patient records (EHR)*
  - Accessible by all specialists across the centre

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Adult patients present to their community physician (family doctor or private dermatologist) with AD symptoms (e.g. dryness of skin or itching). The physician will assess and refer to the centre if required

*Note: Mild adult AD patients tend to be managed by community physicians. Paediatric AD patients tend to be managed by community physicians or at the local children's hospital (The Hospital for Sick Children). As a result, these patients may not be seen at the centre*

## Diagnosis and Referral

In secondary care



- Adult AD patients are referred to the centre and attend an initial consultation in the general dermatology clinic
- The trainee dermatologist will perform an initial assessment of the patient (~5 minutes)
- The trainee dermatologist will assess the patient's symptoms, symptom severity and review any previous / current treatments (~10 minutes)
- Once the trainee dermatologist has performed an initial assessment of the patient, the dermatologist will then review the patient with the trainee dermatologist (~10 minutes)
- The dermatologist will review the patient and consider if medical management / phototherapy is required
- Patients who require phototherapy are referred to the internal Phototherapy Education and Research Centre (PERC)

## Treatment and Management

Medical management



- The dermatologist initially aims to optimise topical therapy. If this has been achieved, the dermatologist will then consider more advanced therapies
- Baseline vIGA-AD, BSA, EASI, POEM and DLQI may be measured before treatment commencement and repeated throughout
- Dermatologists will assess if the patient requires pathology tests and additional monitoring
  - Pathology tests are performed by the hospital pathology staff
- The dermatologist will refer to other specialties for AD associated comorbidities as required
- Patients may be offered an opportunity to participate in clinical trials internally (at centre) or externally (referred to private dermatologists)

Non-medical management



- Patients may be offered phototherapy sessions (with narrowband UVB or broadband UVB) in PERC
- Dermatology nurses will educate patients during each phototherapy visit on topics such self-management techniques and importance of topical emollients and corticosteroids
- Patients may call PERC for nursing support and advice (e.g. patients may require guidance on topical application of corticosteroids, symptom flare-ups). Depending on the patient's request, the nurse may provide advice, schedule a follow-up appointment with the dermatologist or alert the dermatologist immediately

## Follow-up

Monitoring of chronic disease / flare up



- Frequency of consultations and advice is dependent on disease severity and patient's self-management capabilities (appointment = ~15 minutes)
- Generally, a follow-up appointment for severe AD patients will be scheduled 2 –4 weeks after the initial appointment. Mild to moderate AD patient follow-up appointments are scheduled approximately 3 months after the initial appointment
- Mild AD patients are generally referred back to the referring physician (i.e. family doctor or private dermatologist) for continued management

# Roles of the wider team

## Allergist

**Patient type:** All patients suffering from dermatological conditions with an allergy-related comorbidity (including allergic rhinitis and food allergies)

**Referral:** Referred by dermatologist

**Consultations:** Allergist (from the centre) will perform standard tests and provide treatments as required. This includes performing skin prick testing during outpatient clinic appointments

**Timing:** Consultations vary in length depending on patient requirements



## Pulmonologist

**Patient type:** Patients with AD who may be suffering from respiratory symptoms or other respiratory conditions (e.g. asthma)

**Referral:** Referred by the dermatologist

**Consultations:** Pulmonologist (from the centre) will perform standard pulmonary function tests (e.g. FVC and FEV<sub>1</sub>) and treatment as required

**Timing:** Consultations vary in length depending on patient requirements



# Overview of interventions in place for AD

## Awareness and Presentation



Symptom identification

- **Working with the Eczema Society of Canada (ESC):** A dermatologist from the centre works closely with the local patient advocacy group, Eczema Society of Canada (ESC). Upon request, the dermatologist delivers patient education sessions, reviews patient educational material and supports applications for research grants

See pg. 487-488 for case study

## Diagnosis and Referral



In secondary care

- **Healthcare professional education:** The centre delivers education to healthcare professionals within and outside of the centre. A dermatologist from the centre has previously delivered education sessions to primary care providers

See pg. 489-490 for case study

- **Transition for paediatric AD patients:** Paediatric AD patients are referred to the centre on a case by case basis. The dermatologist and paediatrician will discuss each patient individually to determine the appropriate age for transition

## Treatment and Management



Medical management

- **Integration of community dermatologists:** The centre has enabled community dermatologists to work within the hospital setting by allocating outpatient clinics to them. This enables the community dermatologists to be exposed to more severe AD patients and become comfortable with prescribing and managing systemic treatments, such as immuno-modulating medication

See pg. 491 for case study

- **Referral to comorbidity specialists:** Dermatologists refer to other specialists when required
- **Access to clinical trials:** Patients can participate in interventional and observational trials



Non-medical management

- **Enhanced role of the nurse:** Dermatology nurses within the Phototherapy Education and Research Centre (PERC) are able to triage patient requests and provide advice to patients regarding their AD management

See pg. 492-493 for case study

- **Phototherapy sessions:** Patients may be offered phototherapy (UVB) sessions to help manage their AD symptoms

## Follow-up



Monitoring of chronic disease/flare up

- **Referral to primary care physicians:** Once well-controlled, patients will be referred back to the referring physician to receive care closer to home
- **Ongoing education:** The dermatologist and dermatology nurses provide education at each follow-up appointment and phototherapy session. Each session may have a different focus and the healthcare professional may start to introduce different topics

### Key:



Case study available



# Monitoring AD patients and comorbidities

## The dermatology department employs a number of measures for monitoring AD and associated comorbidities

### Objective measures (AD):

AD scoring indices are used to monitor patients and their disease, including:

- EASI (Eczema Area and Severity Index): validated scoring system that grades the physical signs of atopic dermatitis<sup>(a)</sup>
- vIGA-AD™ (Validated Investigator Global Assessment for Atopic Dermatitis): scoring system for use in clinical trials and clinical practice which grades the overall appearance of AD lesions based on a series of morphological descriptions<sup>(b)</sup>
- BSA (Body Surface Area): assesses disease severity based on the percentage of dermatitis-affected body surface area<sup>(c)</sup>

### Patient-reported outcomes:

Quality of Life is routinely measured by:

- DLQI (Dermatology Quality of Life Index): dermatology related quality of life questionnaire<sup>(d)</sup>
- POEM (Patient Oriented Eczema Measure)<sup>(e)</sup>: tool for monitoring AD severity and is recommended for use in outpatient clinics and clinical trials by the Harmonising Outcome measures for Eczema (HOME) initiative<sup>(a)</sup>

---

### Dermatology department routinely measures comorbidity outcomes by:

- *Allergist*: response to allergens/control of atopy disease (e.g. monitoring allergic asthma using standardised asthma measurement scales)
- *Pulmonologist*: changes in pulmonary function tests (e.g. changes in FVC or FEV<sub>1</sub> results)

**Sources:** (a) HOME for eczema.org. EASI for clinical signs [Website] <http://www.homeforeczema.org/research/easi-for-clinical-signs.aspx> Accessed 1 Mar 2019; (b) Validated Investigator Global Assessment For Atopic Dermatitis (vIGA-AD™) Scale [PDF] [https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale\\_vIGA-AD\\_2017.pdf](https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale_vIGA-AD_2017.pdf) Accessed 26 June 2019; (c) Chopra R, et al. Severity strata for Eczema Area and Severity Index (EASI), modified EASI, Scoring Atopic Dermatitis (SCORAD), objective SCORAD, Atopic Dermatitis Severity Index and body surface area in adolescents and adults with atopic dermatitis. *Br J Dermatol.* 2017;177(5):1316-1321. doi: 10.1111/bjd.15641; (d) Lewis V, et al. 10 Years Experience of the Dermatology Life Quality Index (DLQI). *J Invest Dermatol Symp Proc* 2004;9:169–180; (e) Charman CR, et al. Translating Patient-Oriented Eczema Measure (POEM) scores into clinical practice by suggesting severity strata derived using anchor-based methods. *Br J Dermatol.* 2013;169(6):1326–1332

# Advice to other centres



## What advice would you give less specialised centres?



### Objective of advice: Create an aligned, cross-specialty team

- **Why?** Patients with AD can experience a range of symptoms and require advice from different specialties. Creating a diverse team of healthcare professionals with a common objective can enable comprehensive and effective patient care. It is important team are aligned to optimise teamwork and identification of high priority patients



### Objective of advice: Build a referral base for AD patients

- **Why?** Community physicians are often the first point of call when patients begin to experience symptoms of AD. By ensuring local community physicians are aware of the centre's services and capabilities, the centre can begin building a referral base. To support appropriate referral, the centre can provide education to community physicians on the symptoms / patient types that require specialist advice and support, and the referral process

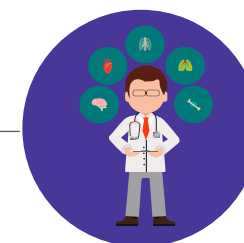
# Next steps for the centre



## What is next for the centre?

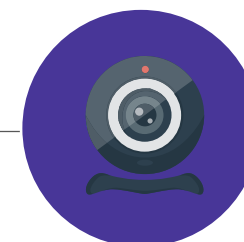
**Objective:** Understand the real-world impact of biological treatment for AD patients

- **What?** The centre aims to collect data on the real world impact of biological treatments for AD patients
- **Why?** By collating data, the centre aims to understand the effect of the medication on patient's daily activities and quality of life. By assessing the available efficacy and safety data on biological treatments, the centre is able to make informed clinical decisions about the patient's treatment and care



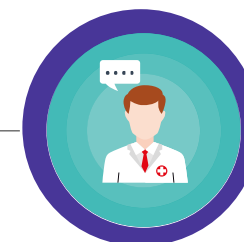
**Objective:** Extend virtual consultations to dermatology services

- **What?** The centre currently offers virtual consultations for selected specialties and is expected to extend the service to dermatology
- **Why?** Virtual consultations enable patients to receive care and advice in the comfort of their own home. Patients are able to minimise the travel time required to move to and from hospitals. There is also a potential to increase the availability of the clinic appointments for patients with urgent medical needs



**Objective:** Create engaging educational AD material (e.g. video) for patients

- **What?** The centre aims to develop an educational video for AD patients to explain the pathogenesis of AD and self-management techniques
- **Why?** AD is a complex disease that may not be easily understood by patients. Similar to the established psoriasis and T-cell lymphoma educational videos, an AD video would support the delivery of consistent information to patients about their disease and how to best manage their symptoms and treatment. The video would also reduce the need for nursing staff to repeat introductory educational information about AD



**Sources:** (a) British Association of Dermatologists: UK guidance on the use of mobile photographic devices in dermatology (2017) [PDF] <http://www.bad.org.uk/shared/get-file.ashx?itemtype=document&id=5776> Accessed 2 April 2019

# Case studies



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# Working with the Eczema Society of Canada (ESC) (1/2)

## Overview

- A dermatologist from the centre works closely with the local patient advocacy group, Eczema Society of Canada (ESC). Upon request, the dermatologist delivers patient education sessions, reviews patient educational material and supports applications for research grants. The dermatologist has also previously supported the development of the group's strategic goals

**Sources:** (a) The Eczema Society of Canada home page. The Eczema Society of Canada [Website] <https://eczemahelp.ca/> Accessed 15 Oct 2019

## The Eczema Society of Canada

- The Eczema Society of Canada (ESC) is a Canadian charity that aims to '*improve the lives of Canadians living with eczema*' through education, support, awareness, advocacy and research<sup>(a)</sup>
- The charity is run by healthcare professionals and supported by volunteers
- The charity has previously worked with a dermatologist from the centre for various activities

### The Eczema Society of Canada – WCH activities:

- *Patient education*
  - Objective: To support the development of comprehensive patient educational materials and facilitate patient education sessions
  - Role of centre: As an expert healthcare provider, a dermatologist from the centre has previously reviewed patient resources and facilitated the delivery of patient information sessions
- *Development of research grants*
  - Objective: Provide an expert opinion on research grant applications
  - Role of centre: To optimise the opportunity for research grant acceptance, a dermatologist from the centre has previously reviewed the charity's research grant applications
- *Review of strategic goals*
  - Objective: Ensure the charity has a clear, future-focused strategy
  - Role of centre: A dermatologist from the centre was part of the review process when the charity was developing their strategic goals

### The Eczema Society of Canada activities:

- *Provision of healthcare professional and patient resources<sup>(a)</sup>*
  - Patients and healthcare professionals can access guides and educational resources through ESC
  - Adult and paediatric focused materials are available and include: 'Managing Eczema Guide', 'Eczema Skin Care Made Simple' and 'School and Day Care Guide'
  - Healthcare resources include guiding documents, such as the 'Atopic Dermatitis: A Practical Guide to Management' and 'Topical Treatments for Atopic Dermatitis'



# Working with the Eczema Society of Canada (2/2)

## The Eczema Society of Canada activities:

- *Quality of Life Insight Projects*
  - ESC has previously facilitated a quality of life project to understand the impact of AD on patient lives. The project involves a patient survey which assesses all aspects of patient life, including access to treatment, disease management and mental health.<sup>(a)</sup> There are two separate surveys for paediatric and adult AD patients
  - The most recent survey in 2016/17 was completed by 1,035 patients and their carers. Key patient concerns highlighted through the survey included the significant impact on quality of life, pain and itch, and long waiting times
- *Patient Support*
  - ESC provides telephone and email support for patients and their careers. The support is facilitated by volunteers and external funding<sup>(a)</sup>
- *Seal of Acceptance programme*
  - ESC has a programme that identifies commercial products (e.g. moisturisers) that are suitable for AD patients<sup>(a)</sup>
  - The products undergo testing and scientific review to be part of the programme and earn a 'Seal of Acceptance' (SOA)<sup>(a)</sup>
- *Continuing medical education*
  - To support healthcare professional education, ESC has Continuing Medical Education programmes. Healthcare professionals can undertake online programmes to improve their knowledge and understanding of AD treatment and care<sup>(a)</sup>
  - Programmes are targeted at different healthcare providers, including primary care physicians and pharmacists<sup>(a)</sup>
- *Research Grant Program*
  - ESC has a competitive Research Grant Program that aims to financially support programmes aimed at improving quality of life for AD patients<sup>(a)</sup>

“



If a patient needs support, we can easily put them in contact with the Eczema Society of Canada

*Dermatologist, Women's College Hospital*



**Sources:** The Eczema Society of Canada home page. The Eczema Society of Canada [Website] <https://eczemahelp.ca/> Accessed 15 Oct 2019



# Healthcare professional education (1/2)

## Overview

- The centre delivers education to healthcare professionals within and outside of the centre. A dermatologist from the centre has previously delivered education sessions to community physicians (family doctors and community dermatologists). Dermatology nurses are also engaged with regular training sessions and external programmes

**Sources:** (a) Cervero RM, et al. The Impact of CMA on Physician Performance and Patient Health Outcomes: An Updated Synthesis of Systematic Reviews. *Journal of Continuing Education in the Health Professions*. 2015;35(2):131-139; (b) Kownacki S. Skin diseases in primary care: what should GPs be doing? *Br J Gen Pract*. 2014;64(625):380-381. doi:10.3399/bjgp14X680773; (c) Schofield JK, et al. Skin conditions are the commonest new reason people present to general practitioners in England and Wales. *Br J Dermatol* 2011;165(5):1044-1050



## What is the rationale?

- Healthcare professional education has the potential to improve the knowledge and confidence of HCPs and patient health outcomes<sup>(a)</sup>
- Additionally, primary care professionals (PCPs) may have limited training in dermatology (including AD)<sup>(b)</sup>, and AD patients commonly present to PCPs and / or are managed in primary care<sup>(c)</sup>

## What are the key features of the intervention?

- **Provision of education to primary care physicians and other healthcare professionals**
  - A dermatologist from the centre delivers educational lectures at seminars to community physicians (e.g. family doctors and private dermatologists) and other healthcare professionals (e.g. allergists)
  - Pharmaceutical companies / medical societies organise the seminars and ask dermatologists to speak on specific topics. Generally, a dermatologist may deliver a lecture 1-4 times per year
  - Previous lecture topics include different treatment options for AD and systemic therapy in AD
- **Dermatology nurse education**
  - Dermatology nurses are engaged in regular training and advice on how to manage patient issues
  - Nurses are provided with guidance from dermatologists on potential solutions to different patient situations
    - Sessions usually occur once a month and nurses may request discussion / education on specific topics
- **Teaching programmes**
  - Dermatologists from the centre are involved in educating undergraduate medical students, post-graduate residents and dermatology fellows
  - Post-graduate residents complete an education programme that spans the duration of their residency. They participate in full teaching days each Friday
  - In addition to training the post-graduate residents, the dermatologists also deliver lectures at the affiliated university (University of Toronto)

# Healthcare professional education (2/2)

## What are the key features of the intervention? (cont.)

### — Dermatology nurse education (cont.)

- A nurse from the centre established a journal club with dermatology nurses from other hospitals
  - The nurses review journal articles with practical learnings and share everyday practice techniques with each other
  - The meetings are held every 2–3 months and usually have between 12–15 participants
  - The location of the meeting is dependent on the sponsor, who may be either a society or pharmaceutical company
  - Occasionally, a speaker may be invited to present at the journal club meeting

## What are the outcomes so far?

### Benefits to patients:

- Improved management of AD symptoms and comorbidities within the community

### Benefits to HCPs:

- Cross-care setting collaboration (e.g. to improve referral pathways)
- Improved knowledge and understanding of specialised AD care for primary care practitioners

## What's next?

- A dermatologist from the centre is currently working with a dermatology society to develop a website for community physicians. The website will include information on systemic AD therapy and focus on knowledge translation of treatment regimens between community and hospital dermatologists

“



We want to share our learnings with other centres to improve patient care

*Dermatology nurse,  
Women's College  
Hospital*

“



HCP education is a major aspect of our work – we want to make sure all of our residents are well-trained

*Dermatologist,  
Women's College  
Hospital*



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# Integration of community dermatologists

## Overview

- The centre has enabled community dermatologists to work within the hospital setting by allocating outpatient clinics to them. This enables the community dermatologists to be exposed to severe AD patients and become comfortable with prescribing and managing systemic treatments, such as immuno-modulating medication



## What is the rationale?

- Patients often seek advice and treatment for atopic dermatitis from a primary care provider<sup>(a)</sup>
- Generally, there is a limited primary care provider understanding of atopic dermatitis treatments<sup>(b)</sup>
- There is an opportunity to improve patient outcomes by increasing the knowledge and awareness of AD symptoms and treatment through a community physician

## What are the key features of the intervention?

- The centre has a community dermatologist within the team at the Phototherapy Education and Research Centre (PERC)
- The community dermatologist is responsible for a list of patients at the hospital outpatient clinic once a week
  - A dermatology nurse will usually support the dermatologist during patient consultations
- The community dermatologist is able to advance their clinical experience in the clinic setting
  - The community dermatologist is exposed to more severe cases of AD and is able to recognise when treatment should be initiated or modified to improve patient outcomes
  - Additionally, with the support of the hospital dermatologists, the community dermatologist is able to prescribe and manage systemic treatments, such as immuno-modulating medication
- If a patient does not have a community based dermatologist, they may continue to see the community dermatologist in the hospital or community setting

## What are the outcomes so far?

### Benefits to patients:

- Access to specialised dermatology care in the community
- Potentially enhances continuity of care if the patients are able to continue receiving care from the dermatologist in the community

### Benefits to HCPs:

- Improved AD management in the community
- Potential to solidify relationships and increase collaboration between community and hospital based dermatologists

**Sources:** (a) Eichenfield L, et al. Translating Atopic Dermatitis Management Guidelines Into Practice for Primary Care Providers. *Pediatrics*. 2015;136(3); (b) Miyar ME, et al. An Atopic Dermatitis Management Algorithm for Primary Care Providers and Assessment of Its Usefulness as a Clinical Tool. *Pediatr Dermatol*. 2017;34(4):402-407. doi: 10.1111/pde.13157

# Enhanced role of the nurse (1/2)

## Overview

- Dermatology nurses within the Phototherapy Education and Research Centre (PERC) are able to triage patient requests and provide advice to patients regarding their AD management. Patients can contact the nurses directly through the PERC telephone number and speak to nurses before / after their phototherapy appointments

**Sources:** (a) DiAnna-Kinder, Frances et al. Satisfaction with Nurse Practitioners and Intent to Adhere to Plan. *The Journal for Nurse Practitioners*. 2019;15(3):245-248.e1; (b) Bass AM, et al. Interventions to Increase Treatment Adherence in Pediatric Atopic Dermatitis: A Systematic Review. *Journal of clinical medicine* 2015;4(2):231-42. doi: 10.3390/jcm4020231; (c) Charman CR, et al. Topical corticosteroid phobia in patients with atopic eczema. *Br J Dermatol*. 2000;142(5):931-6; (d) Brown MH. A nurse-led clinic in chronic and allergic contact dermatitis. *Br J Nurs*. 2005;10-23;14(5):260-3



## What is the rationale?

- Nurse-led education sessions have been shown to demonstrate high levels of patient satisfaction and positive patient outcomes<sup>(a)</sup>
- Poor adherence to treatment is a major factor limiting treatment outcomes in patients with AD<sup>(b)(c)</sup>
- The role of the nurse (e.g. through nurse-led education) alleviates physician time constraints<sup>(d)</sup>

## What are the key features of the intervention?

- Dermatology nurses within the Phototherapy Education and Research Centre (PERC) are able to provide advice and guidance throughout the patient pathway
- At every interaction, the nurses aim to provide counselling and education to support the patient's self-management of AD
- To enable the provision of specialised AD care and advice, the dermatologists provide the nurses with regular training (*see case study – Healthcare professional education*)

## Triaging patient requests

- Dermatology nurses are able to triage patient queries and provide support where appropriate
- Patients are able to contact nurses through the PERC telephone line and discuss any symptoms or treatment issues they may have
- Based on the patient's query, the nurse can either provide advice or refer to the dermatologist for further support and guidance

## Education during phototherapy sessions

- Patients receive advice and guidance from the dermatology nurses during every phototherapy session
- Prior to commencing the phototherapy, patients will be scheduled for an educational session. During the session, the nurse will focus on understanding the patient's experience and incorporating educational advice throughout the consultation
  - The session usually lasts 30 minutes however it can be extended for up to 1 hour depending on the patient requirements
  - A common topic during the session is bathing care and the use of emollients and topical corticosteroids

# Enhanced role of the nurse (2/2)

## What are the key features of the intervention? (cont.)

### Education during phototherapy sessions (cont.)

- Subsequent delivery of education / advice will occur during or after the patient's phototherapy session
  - Nurses may introduce the concept of systemic AD treatment and highlight other potential treatment options for the patient
- During the sessions, if a nurse identifies that the patient may need psychosocial support, this is flagged with the dermatologist

## Challenges

- Patients may have preconceived ideas about the use and safety of topical treatments in AD. As a result, nursing staff are required to tailor information and education for each patient

## What are the outcomes so far?

### Benefits to patients:

- Able to build a relationship with another healthcare professional (in addition to the physician)
- Improved access to timely advice and support

### Benefits to HCPs:

- Upskilling of nurses
- Dermatologists have more time during patient consultations to discuss medical issues

## What's next?

- The centre is focused on developing an educational video for patients to understand the pathogenesis of AD and self-management techniques

“



We invest in our patient relationship and allow patients to tell their story during each session

*Dermatology nurse,  
Women's College  
Hospital*

“



Nurses are often the first point of contact for our patients

*Dermatologist,  
Women's College  
Hospital*





# McGill University Health Center

**Montreal, Canada**

Site visited by KPMG 5<sup>th</sup> November 2019

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[kpmg.com/uk](https://kpmg.com/uk)



# Summary



## Context

**Centre type:** Large university teaching hospital located in a single facility in Montreal, Quebec, which operates as part of the wider McGill University Health network

**Catchment area:** Patients are predominantly from Montreal (population ~1.7 million), however patients from across the province of Quebec and across Canada may access the centre's facilities

**Funding:** The centre is primarily funded through regional taxation, administered by the Ministry of Health and Social Services. Private health insurance can be purchased by individuals to cover services excluded from public reimbursement

**Services:** The dermatology department (one of many specialist departments in the hospital) offers specialist treatment for all dermatological conditions

**Patient population:** Paediatric and adult patients with a range of dermatological conditions. The majority of AD patients at the centre are classified as moderate to severe



## Key strengths in the delivery of AD care

**Patient involvement in AD clinic activities:** The centre runs a patient committee which has helped to shape and optimise the services offered by the AD clinic

**Use of technology to enhance AD care:** The centre is developing an educational mobile application for patients and plans to utilise video / imaging technology to monitor AD symptoms, host video consultations and share specialist knowledge between HCPs

**Focus on AD research:** The centre is involved in ongoing AD research, with clinical projects managed by the centre's own *Centre of Excellence for AD* (CoE AD)



## Key challenges faced in delivery of AD care

### Addressing the psychosocial needs of AD

**patients:** Patients often express they feel alone with their disease and may experience stress and anxiety related to AD

**Non-specialist psychosocial support:** In the public health system, patients are assigned to a psychologist (or other relevant HCP) based on their address. This HCP may not be experienced with, or aware of, AD-related issues

**Mobile device application development:** Legal and technical challenges associated with app / technology development are currently delaying the launch of a new patient educational resource



# Atopic Dermatitis (AD) in Canada

## Canadian healthcare system:

The Canadian healthcare system is primarily financed through provincial / federal general tax revenue, which accounts for 70% of total healthcare spending and 11.3% of GDP. This is supplemented by expenditure through private health insurance for non-covered benefits<sup>(a)</sup>

## Publically funded healthcare:

- Healthcare is administrated by provinces and territories through local universal health insurance programmes. Each provincial healthcare insurance plan is required to be publicly administered, provides comprehensive and universal coverage and is accessible in different provinces<sup>(b)</sup>
- Provincial healthcare plan coverage for additional benefits can vary. For example, individuals will have variable coverage for services such as outpatient prescription drugs, non-physician mental healthcare, vision care, dental care, home care and hospice care<sup>(b)</sup>

## Privately funded healthcare

- Private health insurance can be purchased by individuals and covers services excluded from public reimbursement, such as vision and dental care, prescription drugs, rehabilitation services, home care and private rooms in hospitals<sup>(b)</sup>
- As of 2018, private insurance accounted for approximately 12.4% percent of total health spending.<sup>(a)</sup> In 2014, around 94% of premiums for private health plans were paid through employers, unions, or other organizations<sup>(b)</sup>
- In 2018, out-of-pocket payments represented approximately 15.4% of total health spending. This has risen from 14% in 2014, where out-of-pocket payments mainly involved prescription drugs (21%) and non-hospital institutions (22%) as well as dental care (16%), vision care (9%), and over-the-counter medications (10%)<sup>(b)</sup>

## Prevalence

- The lifetime prevalence of AD in Canada is 17%<sup>(1)(c)</sup>
- Prevalence of adult AD in Canada is approximately 3.5%<sup>(d)</sup>



## Care provision:

### Location:

- Mild (or well-controlled) AD care is mostly delivered by community physicians (family doctors and private dermatologists)
- Moderate and severe (uncontrolled) AD care is generally managed by hospital dermatologists

### Funding:

- Primary care services are privately owned, however, are predominantly funded through public health insurance
- Hospital services are primarily funded through public health insurance

## Guidelines and societies:

### Guidelines:

- Eczema Society of Canada – Atopic Dermatitis: A Practical Guide to Management, 2018<sup>(e)</sup>

### Medical societies/PAGs:

- Eczema Society of Canada (ESC)
- Canadian Dermatology Association

**Note:** (1) Lifetime prevalence is the percentage of people within the population who will have AD at some point in their life

**Sources:** (a) How Much Does Canada Spend on Health Care. Effective Public Healthcare Panacea Project [Website] <https://www.ehp.ca/healthcare-funding-policy-in-canada/> Accessed 20 Sept 2019; (b) The Canadian Health Care System. International Health Care System Profiles [Website] <https://international.commonwealthfund.org/countries/canada/> Accessed 20 Sept 2019; (c) Eczema. Canadian Dermatology Association [Website] <https://dermatology.ca/public-patients/skin/eczema/> Accessed 16 Oct 2019; (d) Barbarot S, et al. Epidemiology of atopic dermatitis in adults: Results from an international survey. *Allergy* 2018;73(6):1284-1293. doi: 10.1111/all.13401; (e) Atopic Dermatitis: A Practical Guide to Management. Eczema Society of Canada [PDF] [https://eczemahelp.ca/wp-content/uploads/2019/03/ESC\\_AD\\_Practical-Guide-to-Management-for-HCP\\_2019.pdf](https://eczemahelp.ca/wp-content/uploads/2019/03/ESC_AD_Practical-Guide-to-Management-for-HCP_2019.pdf) Accessed 20 Sept 2019

# The centre and dermatology clinic

## The centre



### Type and location

- McGill University Health Centre is a large university teaching hospital (within one of Montreal's two major healthcare networks) located in a single facility in Montreal, Quebec
- The centre is primarily funded through regional taxation (administered by the Ministry of Health and Social Services)



### Population served

- Patients are predominantly from Montreal (population ~1.7 million), however patients from across the province of Quebec and across Canada may access the centre's facilities
- The head dermatologist tends to AD patients at multiple sites across Montreal

## The dermatology clinic



### Service Division

#### Outpatient service

#### Emergency dermatology service



### Hours of availability

8am – 12pm (Wednesdays)

24/7



### No. of patients seen

~150 patients per week at General Dermatologist Clinic  
20-25 patients per week at AD clinic



### Types of patients seen

All dermatological conditions



### Facilities on-site<sup>(1)</sup>

- 3 consulting rooms
- 1 surgery room
- Wet laboratory (for skin biopsy analysis, blood sample analysis, fluorescent imaging, etc.)
- Biobank of patient blood and skin samples
- Narrow-band UVB phototherapy

Note: (1) List of facilities is not exhaustive








*Note: Canadian phototherapy services are offered at the local level, so patients may attend the facility that is closest to home*

# The team

## Core team profile

-  **1** Head dermatologist (also assistant university professor)
-  **2-3** Residents of Dermatology
-  **1-2** Medical students
-  **1** Dermatology nurse
-  Team of administrators

## Wider team profile

-  *Centre of Excellence for AD* Project Director
-  Infectious disease specialists
-  Immunologists
-  Respiriologists
-  ENT physicians
-  Ophthalmologists
-  Laboratory staff  
(Research Associate and Laboratory Technician)

## Governance and processes

**Patient records:** *Electronic health records (EHR):*  
An electronic health records system known as OASIS is accessed and used regularly by trained physicians and team members

### Roles of the wider team

#### ***Centre of Excellence for AD* Project Director**

The Centre of Excellence for AD (CoE AD) Project Director is responsible for planning, securing funding for and implementing CoE AD initiatives. They work closely with the AD patient committee (see case study pg. 506 – 508) to coordinate patient involvement in these initiatives. The Project Director is involved with organising multiple live CoE AD events throughout the year, including educational initiatives for patients (e.g. support groups; forums) and HCPs (e.g. AD nurse training workshops; trainee dermatologist EASI scoring workshops)

#### **Assistant to the Head Dermatologist**

The Assistant to the Head Dermatologist assumes responsibility for coordinating a patient's treatment once the head dermatologist has diagnosed that patient as having AD. The Assistant may also ask patients for their consent to participate in clinical research (if they satisfy the criteria for ongoing/upcoming trials at the centre)

*Note: AD patients may be referred to an appropriate AD comorbidity specialist as required*

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- AD patients present to their community physician (family doctor or private dermatologist) with AD symptoms (e.g. skin dryness, itching). The physician assesses these symptoms and may refer to the centre if required

*Note: a patient may or may not have received an AD diagnosis from their physician prior to attending the centre*

## Diagnosis and Referral

In secondary care



- The majority of AD patients referred to and treated at the centre exhibit moderate to severe symptoms, having received some form of initial AD screening from their family doctor / private dermatologist
- Paediatric AD patients referred from paediatricians are seen at the AD clinic at 18 years old
- AD-specialised dermatologists at the centre regularly work with laboratory staff and AD comorbidity specialists during diagnosis. These include infectious disease specialists, and immunologists (who perform on-site allergy testing)
- Ophthalmologists, respiratory specialists and ENT physicians may also be consulted but are located off-site
- After patient consultation and agreed consent, extent and severity assessment of the AD is documented through photos taken at the clinic. Assessment is only for patients who visit the clinic, with the images electronically locked and stored securely

## Treatment and Management

Medical management



- Patients with suspected AD attend an initial consultation at the centre, which follows a stepped structure (45-60mins)
- The dermatologist first assesses the patient's symptoms and their severity (which may involve a photographic assessment)
- If the case is classified as AD, the dermatologist's assistant coordinates the patient's continued treatment at the centre (and may seek consent from patients for study enrolment)
- Various dermatology team members subsequently meet with the patient to record their medical history, explain the AD treatment options available and formulate a personalised AD management plan
- For example, every AD patient receives a standard written questionnaire, designed to 'stage' patients (classify them in terms of symptom severity) and collect data to illustrate themes / trends among AD patients

Non-medical management



- AD and AD comorbidity symptoms / outcomes may be recorded at the dermatologist's discretion, or as required by clinical studies (e.g. POEM, SCORAD)
- A wet laboratory located at the centre is used to analyse blood samples and skin biopsies (e.g. via fluorescent imaging)
- Patients are asked (though not obliged) to provide blood and skin samples for the centre's biobank, with samples used in the centre's clinical research (e.g. ongoing studies to identify molecular markers specific to AD pathophysiology)

## Follow-up

Monitoring of chronic disease / flare up



- AD patients on systemic therapy attend a follow-up appointment at the centre (within ~4 weeks of initial consultation). The dermatologist re-assesses symptoms and identifies any adjustments required to the prescribed therapies (e.g. due to adverse events)
- AD patients not on systemic therapy return to the clinic within ~4 months after initial consultation, unless the disease flares
- During centre consultations, AD patients are supplied with educational materials to provide an overview of AD and advice for monitoring and self-managing the disease
- Patients may be encouraged to use the app 'EczemaLess' to monitor their symptoms<sup>(a)</sup>
- AD patients may be referred back to their community physician once stable / well-controlled
- AD patients requiring psychosocial support are assigned to an appropriate HCP (e.g. psychologist)

# Overview of interventions in place for AD

## Awareness and Presentation



Symptom identification

- **Center of Excellence for Atopic Dermatitis:** McGill University Health Center has established an internal network of doctors, nurses, allied healthcare professionals, trainees and patients, which aims to develop tools to assist adult AD patients in Montreal with managing the disease

## Diagnosis and Referral



In secondary care

- **Community dermatology practice:** The head dermatologist runs a separate dermatology practice in a nearby community hospital (as part of the university's family medicine training programme). AD patients requiring specialist care are referred to the centre for treatment. It is a resource intended primarily to provide community access to specialist care for AD patients and to educate HCPs

## Treatment and Management



Medical management

- **Multidisciplinary approach to AD care:** The centre employs a network of specialists that enables the multidisciplinary diagnosis, treatment and management of AD and AD comorbidities

See pg. 505 for case study



Non-medical management

- **Focus on AD research:** The centre is actively involved in basic science and clinical research studies relating to the diagnosis, treatment and management of AD and other dermatological conditions. The centre has an on-site laboratory for the analysis of patient samples (for both day-to-day clinical practice and clinical studies)

## Follow-up



Monitoring of chronic disease/flare up

- **AD patient committee:** A committee of AD patients and family members meet regularly at the centre to discuss different topics relating to AD, share personal experiences and provide support for the centre's AD research initiatives
- **Eczema App:** The centre's AD patient committee and dermatology team have co-developed a mobile device application, designed to deliver AD-related education to patients and record PROs (patient-reported outcomes) in an efficient and convenient manner

See pg. 506-508 for case study

See pg. 509-510 for case study

### Key:



Case study available



# Monitoring AD patients and comorbidities

## The dermatology unit employs a number of measures for monitoring AD and associated comorbidities

### Objective measures (AD):

AD scoring indices are used to monitor patients and their disease, including:

- SCORAD (SCORing Atopic Dermatitis): to assess AD disease severity and monitor patient progress<sup>(a)</sup>
- POEM (Patient-Oriented Eczema Measure): to monitor patient AD disease severity<sup>(b)</sup>
- BSA (Body Surface Area): assesses disease severity based on the percentage of dermatitis-affected body surface area<sup>(c)</sup>

### Objective measures (AD):

- PGA (Patient Global Assessment): generally assessed by a single question with a 0–10 or 0–100 response<sup>(d)</sup>

---

### Dermatology unit routinely measures comorbidity outcomes by:

- *Allergist*: response to allergens/control of atopy disease (e.g. monitoring allergic asthma using standardised asthma measurement scales)
- *Psychologist*: monitoring psycho-social distress

**Sources:** (a) SCORing Atopic Dermatitis (SCORAD) Calculator (0.9.0) [Website] <http://scorad.corti.li/> Accessed 26 Feb 2019; (b) Charman CR, et al. Translating Patient-Oriented Eczema Measure (POEM) scores into clinical practice by suggesting severity strata derived using anchor-based methods. *Br J Dermatol.* 2013;169(6):1326–1332; (c) Chopra R, et al. Severity strata for Eczema Area and Severity Index (EASI), modified EASI, Scoring Atopic Dermatitis (SCORAD), objective SCORAD, Atopic Dermatitis Severity Index and body surface area in adolescents and adults with atopic dermatitis. *Br J Dermatol.* 2017;177(5):1316–1321. doi: 10.1111/bjd.15641 (d) Nikiphorou E, et al. Patient global assessment in measuring disease activity in rheumatoid arthritis: a review of the literature. *Arthritis Research & Therapy* 2016;18(251)

# Advice to other centres



## What advice would you give less specialised centres



**Objective of advice:** Establish an AD patient committee and ask patients directly if they would like to contribute to activities

- **Why?** The centre's AD patient committee has strongly influenced the formation and development of the AD clinic since it was established (e.g. by providing feedback on services and developing educational tools / materials). Patient committee meetings are a form of 'experiential learning', whereby patients learn by listening to one another's experiences. The personal anecdotes and discussions covered in patient committee meetings are also regarded as valuable learning opportunities for HCPs. The AD care team at the centre have found asking patients directly (rather than via email, leaflet, etc.) to be the most effective way to recruit new committee members



# Next steps for the centre

## What is next for the centre?

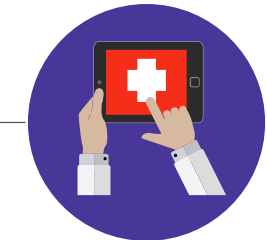
**Objective:** Integrate psychosocial support staff into the dermatology department on a permanent basis

- **What?** The centre hopes to provide on-site psychosocial support for patients with AD and other dermatological conditions
- **Why?** Effective AD treatment and management can require input from multiple specialists, including psychosocial support staff (e.g. psychologists, social workers) who aim to minimise the stress, anxiety, depression and stigma often experienced by patients with chronic visible skin conditions. Employing such staff on-site and on a permanent basis could minimise the waiting times and travel burden for AD patients at the centre who require psychosocial support services. Alternatively, the centre is considering developing a 'virtual psychologist' which could provide support to patients on-demand (e.g. via a mobile device application)



**Objective:** Assess the impact of the Eczema App ('Virtual Nurse') on real-world treatment outcomes

- **What?** Following the upcoming launch of the centre's self-developed 'Virtual Nurse' application (see case study pg. 509 – 510), the patient committee (see case study pg. 506 - 508) and dermatology team plan to study the use of the app and how it impacts AD treatment outcomes at the centre. The centre plans to seek funding from the Canadian Institute of Health Research
- **Why?** The app has been designed to provide patients with convenient AD educational materials and allow patients to complete PRO (patient-reported outcome) measures in virtual form for use in clinical trials, etc. Analysing how AD treatment outcomes vary with the use of the app could inform future updates and attract funding for the initiative. Analysis will include the use of the app by adolescent patients, who are more likely to not show up for appointments



**Objective:** Develop ways to use mobile imaging / video technology to enhance the AD care services offered to patients

- **What?** The centre hopes to use teledermatology services to improve the monitoring of AD symptoms, facilitate long-distance patient consultations and enhance knowledge sharing between HCPs
- **Why?** Mobile devices could be used by patients to document the temporal variations of their AD symptoms (e.g. flare-ups experienced when not at the centre) and provide an extended visual record for dermatologists to use when making treatment decisions. Teledermatology services could be used to host long-distance patient consultations via video conference, and could facilitate the dissemination of specialist AD knowledge to HCPs based outside the centre



# Case studies



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# Multidisciplinary approach to AD care

## Overview

- The centre employs a network of specialists which enables the multidisciplinary diagnosis, treatment and management of AD and AD comorbidities



We use an MDT approach in the AD clinic because patients almost always have to deal with other related conditions

*Dermatologist, McGill University Health Centre*



## What is the rationale?

- Patients with atopic dermatitis are at risk of developing several comorbidities. Understanding and effectively managing these comorbidities has the potential to improve patient outcomes and minimise the cost and other burdens associated with these conditions<sup>(a)</sup>
- Establishing a network of AD comorbidity specialists can improve access for patients to multidisciplinary care. Collaboration between dermatology and other specialties can facilitate an integrated and comprehensive approach to disease management<sup>(b)</sup>

## What are the key features of the intervention?

- The AD clinic promotes an MDT (multidisciplinary team) approach to care, whereby AD patients are promptly referred between different AD comorbidity specialists depending on the patient's symptoms
- Many AD comorbidity specialists are located on-site, however some are located off-site at other centres (i.e. not within the McGill Health System)
- Whilst there are no regular meetings currently established between the AD comorbidity specialists, communication is facilitated however through clinic consultations and / or phone calls

### Located on-site:

- Laboratory staff
- Infectious disease specialists
- Immunologists (perform on-site allergy testing)

### Located off-site:

- Ophthalmologists
- Respiriologists
- ENT physicians

## What are the outcomes so far?

### Benefits to patients:

- Increased access to AD comorbidity specialists
- Reduced appointment burden (as patients may see multiple specialists during one visit)

### Benefits to HCPs:

- Multidisciplinary management of AD and AD comorbidities facilitated by increased communication and collaboration between specialists
- Peer-to-peer teaching between HCPs

**Sources:** (a) Paller A, et al. Major Comorbidities of Atopic Dermatitis: Beyond Allergic Disorders. *Am J Clin Dermatol.* 2018;19(6):821-838. doi: 10.1007/s40257-018-0383-4; (b) LeBovidge JS, et al. Multidisciplinary interventions in the management of atopic dermatitis. *J Allergy Clin Immunol.* 2016;138(2):325-34. doi:10.1016/j.jaci.2016.04.003

# AD patient committee (1/3)

## Overview

- A committee of AD patients and family members meet regularly at the centre to discuss different topics relating to AD, share personal experiences and provide support for the centre's AD research initiatives

## What is the rationale?

- AD patients often believe they are alone with their disease, which can exacerbate the stress and anxiety often experienced by these individuals
- Group patient initiatives can allow patients to meet others with AD and minimise the psychosocial impact of the disease<sup>(b)</sup>
- Patients can sometimes provide support to each another as effectively as professionals, because they can relate to one another regarding their medications, frequency of hospital visits, etc.<sup>(b)</sup>

## What are the key features of the intervention?

### What are the aims of the committee?

- The committee aims to support AD initiatives at the centre and acts as a support group for patients, with each meeting covering different themes / topics (e.g. 'planning for the holidays' shortly before the Christmas period)

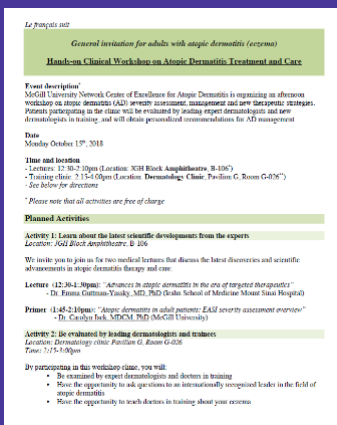
### How was the committee formed?

- The patient committee was created by AD patients for AD patients and their families, and every AD patient treated at the centre is invited to join
- Patient attendees are primarily sourced through the centre's clinics, however they are starting to attract attendees from the wider public (e.g. AD patients treated at other centres; family / friends of AD patients)

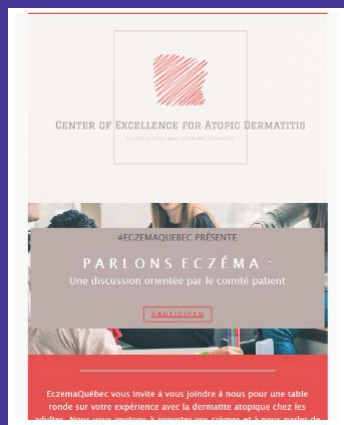
### How are meetings organised?

- Members have allocated administrative roles amongst themselves, including:
  - Scheduling each meeting
  - Hosting / compering the meeting
  - Recruiting participants (e.g. new AD patients and HCPs involved with AD care)
  - Managing logistics (e.g. venue booking, printing materials)
  - Managing social media channels (e.g. Facebook events / ads aimed at the wider public)
  - Graphic design (e.g. of promotional materials)
  - Recording AD patient video testimonials (i.e. for promotional materials)
- Members meet at the centre approximately every 3 months
- The latest meeting was attended by thirteen patients, two dermatologists and three researchers

**Sources:** (a) Barankin B, et al. Psychosocial effect of common skin diseases. *Can Fam Physician*. 2002;48:712–716; (b) KPMG interviews



Patient invitation



Invitation to a discussion event

# AD patient committee (2/3)

## What are the key features of the intervention? (cont.)

### What have past meetings involved?

- The patient committee discuss different topics relating to AD and contribute thoughts and ideas which influence the general running of the AD clinic
- The patient committee initially suggested the Eczema App (see case study pg. 509 - 510) and have been actively involved with its development (e.g. by testing its functionality and providing qualitative and quantitative feedback)
- Direct input has also been provided by the patient committee regarding what is needed at the clinic (e.g. increased provision of psychosocial support)
- The patient committee has also helped shape the Eczema App design and content (e.g. what topics should be included)

### Lotions Testimonial:

- The committee recently hosted a forum titled 'Lotions Testimonial'
- Patients were asked to bring in their lotions from home and share personal AD care testimonials with the group, including what they would like to see done differently with their treatment
- The head dermatologist and a trainee dermatologist were present for the session, however primarily in a listening capacity. The session was intended to be a platform for patients to communicate with each other and share their experiences

*Note: attending dermatologists staff may interject if the matters being discussed are not medically accurate (e.g. claims linking diet and flare-ups with little/no supporting scientific evidence)*



The members of the patient committee are very engaged and have influenced how the AD clinic is run since it began last year

*Dermatologist, McGill University Health Centre*



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# AD patient committee (3/3)

## What are the outcomes so far?

### Benefits to patients:

- The opportunity to learn from the experiences of other AD patients / family members
- The opportunity to influence the centre's approach to AD care

### Benefits to HCPs:

- Support received with publicising and running AD-related initiatives
- The opportunity to learn from the experiences of AD patients / family members

## What's next?

- The centre plans to hold further patient forums on different AD-related topics
- The sources of psychosocial support available to AD patients are regularly discussed in committee meetings, and they expect psychologists and psychosocial support staff to attend future events



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# Eczema App (1/2)

## Overview

- The centre's AD patient committee and dermatology team have together developed a mobile device application, designed to deliver AD-related education to patients and record PROs (patient-reported outcomes) in an efficient and convenient manner

**Sources:** (a) KPMG interviews; (b) Statista: Mobile usage in Canada - Statistics & Facts [Website] <https://www.statista.com/topics/3529/mobile-usage-in-canada/> Accessed 19 Nov 2019; (c) EczémaQuébec: McGill University Hospital Network Center for Excellence in Atopic Dermatitis [Website] <https://eczemaquebec.com/home/> Accessed 19 Nov 2019



## What is the rationale?

- The time available for dermatologists to spend educating AD patients is limited. Education relating to AD diagnosis, treatment and management must therefore be supplemented through other channels<sup>(a)</sup>
- Mobile devices represent a convenient education channel for patients, with 69% of the Canadian population owning a smartphone in 2018<sup>(b)</sup>

## What are the key features of the intervention?

### How did it start?

- A team of post-doctoral researchers and research assistants support the head dermatologist with their clinical research, which includes AD investigations (e.g. into the pathophysiology of the disease)
- AD clinical projects are run by McGill's *Centre of Excellence for AD*<sup>(c)</sup>. One such project involves a mobile device application titled *Virtual Nurse*
- Development of the application is being funded by the Eczema Society of Canada

### What are the aims?

- The *Virtual Nurse* aims to provide AD patients and their families with education relating to AD diagnosis, treatment and management, without consuming physician time (which is typically limited)
- The platform aims to integrate AD patients and HCPs involved with AD care across Canada (i.e. they intend for it to be accessible by all Canadian dermatologists)
- The app will initially be aimed at moderate-severe patients, but may be expanded to cater for mild patients in the long-term

### What will it involve?

- Dermatology staff will be required to oversee both content and software development for the application, which will be publically available on app stores for anyone to download
- *Virtual Nurse* will contain interactive AD-focused information for patients to read and engage with in their own time (e.g. while they're waiting to attend an appointment). For example, it will contain an interactive body map which will allow users to review how AD is manifested in different body parts and what specific treatments are assigned to that body part
- A photo upload function may be available in later versions of the app and enable patients to capture and store images of their symptoms with AD specialists
- Any *Centre of Excellence for AD* initiatives are followed by a questionnaire in order to collect feedback from participants. For *Virtual Nurse*, they plan to run an app feature which allows patients to provide feedback on both their personal condition (e.g. by recording POEM / SCORAD scores) and app content

*Note: patients must sign a consent form to allow their images to be shared through the app*



# Eczema App (2/2)

## What are the key features of the intervention? (cont.)

### What is the progress so far?

- The patient committee (see case study pg. 506 – 508) have provided ideas and feedback throughout the app's development. For example, committee members have previously been paired with medical students to review proposed content together
- Feedback on the app was also collected during a recent interactive nurse workshop held at the centre (attended by ~17 nurses from different specialties, covering many topics including the *Virtual Nurse*)

### Challenges

- The legal and technical challenges associated with app / technology development can delay the launch of patient resources such as *Virtual Nurse*. These challenges include:
  - Review of contract terms, conditions and technical software development details to ensure that they are complete and accurately reflect the centre's needs
  - Communication with software developer to align goals and objectives
  - Contract negotiations and establishing intellectual property ownership

## What are the expected outcomes?

### Benefits to patients:

- AD educational content received in an interactive and convenient format (i.e. the app can be used at times/locations which suit the patient)

### Benefits to HCPs:

- Less face-to-face consultation time spent educating patients
- Potential for improved patient treatment compliance and self-management

### What's next?

- The app is in the final stages of achieving approval from the hospital Ethics Committee
- Studying the use of the *Virtual Nurse* application to assess its usability and if / how it affects AD treatment outcomes
- Expand the app to cater for mild AD patients (in addition to moderate-severe)

“



The app will be useful for providing patients with information which I would ideally explain myself, but I usually don't have the time

*Dermatologist, McGill University Health Centre*



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# Rabin Medical Centre

Petah Tikva, Israel

Site visited by KPMG 4–5<sup>th</sup> September

[kpmg.com/uk](https://kpmg.com/uk)



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# Summary



## Context

**Centre type:** Large public medical centre with services across two hospital sites, Beilinson Hospital and Hasharon Hospital

**Catchment area:** Provides care for a population of around 2 million people who are covered by the affiliated Health Maintenance Organisation (HMO). Patients are predominantly from Petah Tikva and surrounding areas

**Funding:** The centre predominantly receives funding through public health insurance and managed by a HMO

**Services:** The dermatology department provides advice and treatment to adult atopic dermatitis (AD) patients. Patients may be referred to other specialist services at the centre. Paediatric AD patients are seen at Schneider Children's Medical Centre

**Patient population:** Adult patients with dermatological diseases are treated by the dermatology department. Patients with moderate to severe AD are seen at the specialised AD clinic



## Key strengths in the delivery of AD care

**Specialised AD clinic:** The centre has established a dedicated clinic for AD patients. Patients can receive highly specialised care and treatment for their AD symptoms

**Digitally enabled centre:** The centre has access to an electronic health system that supports efficient communication with healthcare professionals within and outside of the centre. The system also enables patients to easily contact their treating physician for queries and questions

**Established relationships with other specialists:** The dermatologists have an effective working relationship with other specialties in the centre. Patients who have associated comorbidities are able to receive holistic care for their AD

**Integrated clinical trial services:** Patients who are not responding to treatment are able to easily access innovative or new drug treatments at the centre. The dedicated research coordinator for dermatology is currently managing four active AD-related clinical trials



## Key challenges faced in delivery of AD care

**Limited psychological support:** AD is a complex disease that can impact patient's quality of life. There is a recognised need for psychological care in AD, however the centre has been unable to secure a psychologist position due to limited resources within the public health system

**Data management of outcome measures:** There are currently a number of different outcome measures that dermatologists can use. As a result, the variability in the choice of measures can impact the comparability of treatment effectiveness

**Local payment mechanisms:** In general, the field of Dermatology experiences difficulties competing with large specialties such as oncology for resource allocation

# Atopic Dermatitis (AD) in Israel

## Israeli healthcare system:

The Israeli healthcare system is primarily funded through salary taxes and state funding. Broadly, government healthcare expenditure comprised of 64% of the total healthcare spending in 2018. Private expenditure and foreign donations comprised 34.2% and 1.8% of total healthcare spending respectively<sup>(a)</sup>

## Publically funded healthcare:

- Israel has an insurance-based healthcare system, where contributions are paid out of salaries at a progressive rate and supplemented by state funding. For salaries up to 60% of the average wage, 3.1% is deducted as a "health tax". Above that level, the deduction is 5% of salary. While the government is responsible for financing and ensuring level of access, non-governmental bodies are responsible for the provision of care<sup>(a)</sup>
- The health tax deductions are collected by the National Insurance Institute and transferred to four non-government, not-for-profit Health Maintenance Organisations (HMOs). The funds are utilised to control and operate medical services (the range of services is specified under the National Health Insurance [NHI] law)
- The government uses its health budget to finance transfers to the HMOs. It also funds health services through government bodies and capital investment in buildings and equipment
- Clalit is the largest HMO, providing for 1,500 clinics and 30% of hospital beds. Maccabi, Meuhedet and Leumit are the other HMOs<sup>a)</sup>
- All residents have to register with one of the four HMOs. Patients are entitled to choose their doctors, hospitals and other medical services from a list of providers that work with their HMO

## Privately funded healthcare

- Private voluntary health insurance (VHI) is of two types: health plan VHI (HP-VHI) which is offered by each health plan to its members, and commercial VHI (C-VHI), which is offered by for-profit insurance companies to individuals or groups
- Israelis purchase VHI to secure coverage of services not included in the NHI package (e.g., dental care, certain lifesaving medications), care in private hospitals, or a premium level of services covered by NHI (e.g., choice of surgeon and reduction of waiting time).<sup>(b)</sup>

## Prevalence

- The lifetime prevalence<sup>1</sup> of AD in Israel is 9%<sup>(c)</sup>
- Overall prevalence of AD among adolescent males and females is 0.5% and 0.7% respectively<sup>(d)</sup>
- Prevalence of mild AD amongst adolescents is higher amongst females (0.9%) than males (0.7%)<sup>(d)</sup>



## Care provision:

### Location:

- Mild (or well-controlled) AD care is primarily delivered by PCPs (primary care providers)
- Moderate and severe (uncontrolled) AD care is mostly delivered in specialist secondary (within hospitals)

### Funding:

- Primary care and hospital services are primarily funded through public health insurance and provided through HMOs

## Guidelines and societies:

### Guidelines:

- There are no Israeli-specific guidelines for AD diagnosis / treatment <sup>(c)</sup>
- The centre is currently leading the development of local recommendations for the diagnosis / treatment of AD. This effort is supported by the Israeli Society of Dermatology and is conducted in collaboration with a group of experts from various Dermatology departments in Israel
- Medical societies and associations refer to US and European treatment guidelines<sup>(f)</sup>

### Medical societies/PAGs:

- Israeli Association for Atopic Dermatitis
- Israel Society of Dermatology & Venereology (ISDV)

**Note:** (1) Lifetime prevalence is the percentage of people within the population who will have AD at some point in their life

**Sources:** (a) The Economist Intelligence Unit Healthcare Industry Report. Israel (2019) [Website] <http://country.eiu.com/Industry.aspx?Country=Israel&topic=Industry&subtopic=Healthcare> Accessed 9 Sep 2019; (b) International Health Care System Profiles. The Israeli Health Care System. [Website] <https://international.commonwealthfund.org/countries/israel/> Accessed 9 Sept 2019; (c) The Economist Intelligence Unit, A misunderstood skin disease: Mapping the policy response to atopic dermatitis (2018) [Website] <https://eiuPerspectives.economist.com/healthcare/misunderstood-skin-disease-mapping-policy-response-atopic-dermatitis/white-paper/misunderstood-skin-disease-mapping-policy-response-atopic-dermatitis> Accessed 9 Sep 2019; (d) Wohl Y, et al. Atopic Dermatitis in Israeli Adolescents – A Large Retrospective Cohort Study. *Acta Derm Venereol* 2014;94:695–698; (e) Shalom G, et al. Healthcare Service Utilization by 116,816 Patients with Atopic Dermatitis in Israel. *Acta Derm Venereol* 2019;99(4):370–374. doi: 10.2340/00015555-3117; (f) The Economist Intelligence Unit, Understanding Atopic Dermatitis in Israel (2018) [Website] <https://eiuPerspectives.economist.com/healthcare/misunderstood-skin-disease-mapping-policy-response-atopic-dermatitis/article/understanding-atopic-dermatitis-israel> Accessed 9 Sept 2019

# The centre and dermatology department

## The centre



### Type and location

A large public medical centre that is owned and operated by Clalit Health Services (a Health Maintenance Organisation [HMO]). The centre has two sites, Beilinson Hospital and Hasharon Hospital, both of which are located in Petah Tikva



### Population served

The centre provides care for a population of around 2 million people who are covered by the affiliated Health Maintenance Organisation (HMO). Adult patients are predominantly from Petah Tikva and surrounding areas. Paediatric patients are served by Schneider Children's Medical Center, located adjacent to Beilinson Hospital

## The dermatology department



### Service Division

#### General dermatology clinic

#### Specialised AD clinic



### Hours of availability

Monday: 8am – 3pm  
Tuesday: 8am – 3pm  
Wednesday: 8am – 3pm  
Thursday: 8am – 3pm  
Friday: 8am – 3pm

Wednesday: 9am – 2pm



### No. of patients seen

Approximately 35,000 visits annually

Approximately 10 to 15 patients per week



### Types of patients seen

All dermatological conditions

Moderate to severe AD patients



### Facilities on-site<sup>(1)</sup>

- 13 consultation rooms
- 17 inpatient beds
- PUVA/UVA/UVB phototherapy
- Day care facilities
- Pathology collection
- Patch testing

Note: (1) List of facilities is not exhaustive




# The team



## Core team profile

-  **14** Dermatologists
-  **19** Trainee dermatologists
-  **9** Registered nurses
-  **2** Research coordinators

## Wider team profile

-  **1** Ophthalmologist
-  **1** Allergist
-  **1** Paediatric Dermatologist

*Note: Please see page 517 for further details about the wider team*

## Patient records:

- *Electronic patient records (EHR):*
  - Accessible by all specialists across the centre and primary care physicians registered with the centre's Health Maintenance Organisation (HMO)

## Team meetings:

- *Seminar (fortnightly, 60 minutes):*
  - Attended by all dermatologists and trainee dermatologists
  - The purpose of the meeting is to broaden the team's understanding on a variety of medical and scientific subjects, learning from expertise outside the centre (dermatologists or other fields)

## Governance and processes

### Team meetings:

- *Journal club meeting (weekly, 90 minutes):*
  - Attended by all dermatologists and trainee dermatologists
  - The purpose of the meeting is to: discuss new journal articles and share relevant findings
- *Special cases meeting (weekly, 60 minutes):*
  - Attended by all dermatologists and trainee dermatologists
  - The purpose of the meeting is to: discuss complex cases and potential treatments
- *Pathology meeting (weekly, 60 minutes):*
  - Attended by all dermatologists and trainee dermatologists and one or two pathologists
  - The purpose of the meeting is to: review / discuss pathology findings and improve clinical knowledge
- *Clinical practice meeting (monthly):*
  - Attended by all dermatologists
  - The purpose of the meeting is to: discuss any clinical practice issues and potential improvement processes

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients present to their community dermatologist or primary care physician (PCP) with AD symptoms (e.g. itching or dryness of the skin). The physician will assess and refer to the centre if required
- Patients may present directly to the emergency department at the centre

*Note: Mild adult AD patients tend to be managed by community dermatologists or PCPs. As a result, mild AD patients may not be seen at the centre*

## Diagnosis and Referral

In secondary care



- Paediatric AD patients are referred to the adjacent paediatric centre
- Paediatric patients generally transition into adult care aged between 18 – 20 years old
- Adult AD patients are referred to the centre and are allocated an initial consultation with the dermatologist
- The dermatologist will perform an initial assessment of the patient and discuss their symptoms, medical history and any previous / current treatments (consultation = 30-40 minutes)
- The dermatologist's assessment of the patient history and clinical examination determines the severity of AD. Validated Investigator Global Assessment for Atopic Dermatitis (vIGA-AD) is also recorded

## Treatment and Management

Medical management



- The dermatologist manages moderate to severe patients and initiates / modifies treatment as required
- Baseline vIGA-AD scores are taken and repeated at the commencement and throughout treatment
- Patients who are not responding to treatment may be offered the opportunity to participate in clinical trials
- Dermatologists assess which patients require pathology tests (i.e. patients who may need additional monitoring)
- Patient progress, notes and pathology results are recorded electronically on the health management software
- The dermatologist will refer to other specialties for AD associated comorbidities as required (e.g. ophthalmologist)

Non-medical management



- UVA/UVB phototherapy is provided at the centre by dermatology nurses as required
- Dermatology nurses educate patients during each phototherapy visit
- Patients may access day care services for nursing support with topical application of corticosteroids, moisturisers and emollients
- Dermatologists refer to psychologists outside the centre when required

## Follow-up

Monitoring of chronic disease / flare up



- The dermatologist will provide extensive education at each consultation and provide follow up consultations if required. For example, education on self-care and application of topical treatments is provided
- Frequency of consultations and advice is dependent on disease severity and the patient's ability to self-manage. Each follow-up consultation usually lasts 20 minutes
- Patients with mild AD may be referred back to the referring physician
- Tests (e.g. allergy tests or blood tests) will be performed as required based on disease control and clinical presentation



# Roles of the wider team

## Ophthalmologist

**Patient type:** Moderate to severe AD patients with ocular symptoms

**Referral:** Referred by dermatologist directly to ophthalmologist

**Consultations:** Ophthalmologist will perform standard tests and provide treatments (e.g. lubricating eye drops; systemic therapies) as required. All patients receive education regarding their eye condition, treatment and aftercare (e.g. how to properly clean their eyes themselves)

**Timing:** Consultations last 10 minutes and follow-up frequency vary depending on patient requirements

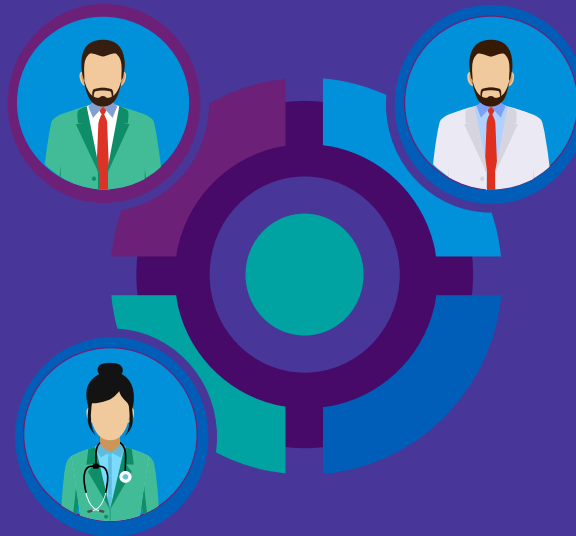
## Allergist

**Patient type:** All patients suffering from dermatological conditions with an allergy related comorbidity (including allergic rhinitis, food allergies and asthma)

**Referral:** Referred by dermatologist directly to allergist

**Consultations:** Allergist will perform standard tests and provide treatments as required. This includes performing skin prick testing during outpatient clinic appointments

**Timing:** Consultations last 10-20 minutes and follow-up frequency can vary depending on patient requirements



## Paediatric Dermatologist

**Patient type:** Mild to severe paediatric patients up to 18 years of age suffering from chronic dermatological conditions (including AD and psoriasis)

**Referral:** Referred by a paediatric dermatologist to the centre's dermatology department when the child reaches 18 years old

**Consultations:** Paediatric dermatologist initially manages the patient's therapeutic management and will perform the standard tests


**Timing:** Consultations last 20 minutes. Follow-up frequency is every 2-3 months

# Overview of interventions in place for AD

## Awareness and Presentation





Symptom identification

- **Integrated community dermatologist:** The department has a community dermatologist working within the centre who acts as a liaison between general practitioners, community dermatologists and the dermatology department  
 See pg. 523-524 for case study
- **Education for PCPs:** Dermatologists from the centre provide PCPs with education sessions on dermatology conditions twice a year
- **Emergency care:** Patients can present at the emergency department at the centre for urgent review of AD related symptoms. Patients may then attend a follow-up appointment at the outpatient clinic

## Diagnosis and Referral



In secondary care

- **Specialised Atopic Dermatitis outpatient clinic:** A dermatologist who sub-specialises in AD runs a weekly AD clinic at the centre. Patients are able to receive highly specialised care and advice for the management of their AD  
 See pg. 525 for case study
- **Globally trained dermatologists and residents:** Each dermatologist within the department has sought to receive training from leading international dermatology departments  
 See pg. 526-527 for case study

## Treatment and Management




Medical management

- **Collaboration with comorbidity specialists:** The department has an established connection with the ophthalmology, allergy / immunology and pulmonology department, as well as the paediatric centre  
 See pg. 528-529 for case study
- **Extensive inpatient and day care facilities:** The unit has 17 inpatient beds and day care facilities, which can be accessed by atopic dermatitis patients who require additional support and treatment (e.g. wet wrapping and application of topical treatment)  
 See pg. 530 for case study
- **Involvement in clinical trials:** Patients have the opportunity to access interventional and observational clinical trials




Non-medical management


- **Development of locally tailored recommendations:** The unit is leading an expert group in finalising local recommendations for the treatment of AD patients in Israel  
 See pg. 531-532 for case study
- **Patient education during each consultation:** For each AD consultation, the dermatologist provides extensive counselling and educational advice to patients (approximately 20 minutes)
- **Nurse education during phototherapy sessions:** Patients are educated on how to apply topical steroids and emollients before / after their phototherapy sessions. The nurse may also help the patient apply the topical treatments after each session

## Follow-up



Monitoring of chronic disease/flare up

- **Harmonising Outcome Measures for Eczema (HOME) initiative:** The dermatology unit was part of the international working group which established a core outcome set to measure and assess patient reported symptoms in AD related clinical trials. The unit will also be participating in the development of a core outcome set to use in clinical practice  
 See pg. 533-534 for case study
- **Direct access to dermatologist:** Patients are provided with an email address to contact the dermatologist in-between consultations. The dermatologist will either provide guidance or schedule the patient in for an earlier appointment

**Key:**  
 Case study available



# Monitoring AD patients and comorbidities

## The dermatology department employs a number of measures for monitoring AD and associated comorbidities

### Objective measures (AD):

To monitor patients and their disease, the centre utilises:

- Validated Investigator Global Assessment for Atopic Dermatitis (vIGA-AD™)<sup>(a)</sup>: a scoring system for use in clinical trials and clinical practice which grades the overall appearance of AD lesions based on a series of morphological descriptions

### Patient-reported outcomes:

QoL is not routinely measured by using a scoring index. The dermatologist will focus on having an extensive discussion with the patients on their symptoms and progress

*Note: AD measures such as Eczema Area and Severity Index (EASI), Dermatology Quality of Life Index (DLQI) and Scoring Atopic Dermatitis (SCORAD) may be utilised for specific clinical trials when required*

---

### The centre routinely measures comorbidity outcomes by:

- *Patch tests*: performed by dermatology nurse
- *Ophthalmology tests*: performed by the ophthalmologist as required
- *Allergy tests*: prick tests performed by allergist as required

**Sources:** (a) Validated Investigator Global Assessment For Atopic Dermatitis (vIGA-AD™) Scale [PDF] [https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale\\_vIGA-AD\\_2017.pdf](https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale_vIGA-AD_2017.pdf) Accessed 26 June 2019

# Advice to other centres



## What advice would you give less specialised centres?



### Objective of advice: Invest in training of dermatology residents and community physicians

- **Why?** The treatment of AD is currently evolving, with new forms of treatments available for patients<sup>(a)</sup>. Providing appropriate training and support for dermatology residents and community physicians (including community dermatologists and primary care physicians) can help ensure patients receive optimal treatment and advice. As treatment options continue to progress, incremental and frequent education will help ensure patients receive the most appropriate treatment for their condition(s)



### Objective of advice: Create a network of comorbidity specialists

- **Why?** AD is a complex disease that has a number of different comorbidities<sup>(b)</sup>. To optimise the care and treatment of AD patients, engagement and collaboration with other specialties (such as within ophthalmology and allergology) is required. Establishing an effective relationship with other physicians not only has the potential to improve patient outcomes, it can also increase physician knowledge and facilitate future partnerships



### Objective of advice: Allocate more time to the initial consultation with the patient

- **Why?** Given the intricacies of AD, the initial consultation with the patient is highly important. The physician needs to appropriately identify and diagnose the condition and allow for appropriate counselling and education. By increasing the amount of time allocated to the initial consultation, it can remove the unnecessary time pressure that some physicians may have. As such, there is a greater opportunity for physicians to adequately inform and discuss the patient's understanding of AD and self-management

**Sources:** (a) Vakharia P, et al. New therapies for atopic dermatitis: Additional treatment classes. *JAAD*. 2018;78(3):S76-S83. (b) Bantz SK, et al. The Atopic March: Progression from Atopic Dermatitis to Allergic Rhinitis and Asthma. *J Clin Cell Immunol*. 2014;5(2):202.

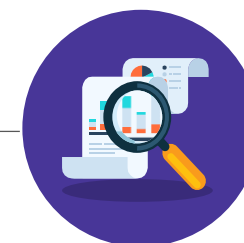
# Next steps for the centre



## What is next for the centre?

### Objective: Promote consistency of outcome measures in AD clinical practice

- **What?** The centre is planning to participate in the Harmonising Outcome Measures for Eczema (HOME) initiative for clinical practice in AD
- **Why?** The HOME initiative aims to build a core outcome set to measure and assess the clinical progress for AD patients. Dermatologists from the centre will participate in the future working groups to discuss and develop the set. Previous clinical experience and research will enable the dermatologists in providing useful insights on the tangible use of outcome measures in practice



### Objective: Develop an accessible patient brochure on the treatment and management of AD

- **What?** The dermatologists are developing a patient education brochure on atopic dermatitis
- **Why?** To support and reinforce counselling provided during consultations, the dermatologists are creating an educational brochure for patients. The brochure will act as a physical reference for patients to refer to at home. Information on skin care and treatment guidance will be included in the brochure to support patient self-management and care



### Objective: Finalise the locally tailored recommendations for the treatment of AD patients in Israel

- **What?** The centre is currently leading an expert group in finalising local recommendations for AD treatment in Israel
- **Why?** After identifying a lack of local guidance in AD treatment, dermatologists within and outside of the centre collaborated to develop practical recommendations to support diagnosis and treatment of AD. Multiple centres throughout Israel are involved, including adult and paediatric dermatologists. The centre's dermatologists are leading the editing and finalisation of the guidelines, which aim to improve AD treatment within the community and hospital setting



*Note: For additional information on the recommendations, please refer to the case study on page 531 - 532*

# Case studies



<b>Integrated community dermatologist</b>	523 – 524
<b>Specialised Atopic Dermatitis outpatient clinic</b>	525
<b>Globally trained dermatologists and residents</b>	526 – 527
<b>Collaboration with comorbidity specialists</b>	528 – 529
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<b>Development of locally tailored recommendations</b>	531 – 532
<b>Harmonising Outcome Measures for Eczema (HOME) initiative</b>	533 – 534

# Integrated community dermatologist (1/2)

## Overview

- The department has secured a position for a community dermatologist to work within the centre and act as a liaison between primary care physicians and the dermatology department

**Sources:** (a) Eichenfield L, et al. Translating Atopic Dermatitis Management Guidelines Into Practice for Primary Care Providers. *Pediatrics*. 2015;136(3):554-65. doi: 10.1542/peds.2014-3678; (b) Miyar ME, et al. An Atopic Dermatitis Management Algorithm for Primary Care Providers and Assessment of Its Usefulness as a Clinical Tool. *Pediatr Dermatol*. 2017;34(4):402-407. doi: 10.1111/pde.13157.



## What is the rationale?

- Patients often seek advice and treatment for atopic dermatitis from a primary care provider<sup>(a)</sup>
- Generally, there is a lack of primary care provider understanding of atopic dermatitis treatments<sup>(b)</sup>
- There is an opportunity to improve patient outcomes by increasing the knowledge and awareness of AD symptoms and treatment through a community physician

## What are the key features of the intervention?

- The department has a dedicated position for a community dermatologist to work within the outpatient clinic. The position is funded by the HMO and was established by the community dermatologist
  - The community dermatologist completed a rotation at the hospital as part of the dermatology residency training programme. Since completing the programme, the dermatologist has been working at the HMO and initiated a conversation with the department to establish the role
- Like the hospital dermatologists, the community dermatologist is responsible for a list of patients at the hospital outpatient clinic once a week
  - Patients are then able to access the community dermatologist in the primary care setting, enabling consistent continuity of care and progression of the patient and physician relationship
- The community dermatologist is able to progress and advance their clinical knowledge and experience through the outpatient clinic
  - The community dermatologist is exposed to more severe cases of AD and is able to recognise when treatment should be initiated or modified to improve patient outcomes
- Given the community dermatologist's position within primary care, they are more able to communicate and share learnings with other primary care physicians, such as general practitioners
- The community dermatologist also supervises the dermatology residents in the clinic
  - The residents perform the patient intake assessment and design a therapeutic plan. The assessment and plan is then presented to the community dermatologist
  - The community dermatologist supervises patient case management and provides feedback / guidance when necessary
- To further support integration of community services, each senior dermatologist runs a community dermatology clinic outside of the centre



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# Integrated community dermatologist (2/2)

## What are the key features of the intervention? (cont.)

- In addition to supporting the community dermatologist's position, the centre supports upskilling of other community physicians
  - Dermatologists from the centre help organise and facilitate national education conferences on atopic dermatitis and provide lectures to general practitioners in various capacities (e.g. continuing medical education training sessions and quarterly HMO meetings)
  - Additionally, general practitioner trainees may also rotate through the department as part of their residency programme to gain exposure to different dermatological conditions
- As evidence of collaboration, a journal article recently written jointly by the dermatology and ophthalmology department was published in the British Journal of Ophthalmology<sup>(a)</sup>

## What are the outcomes so far?

### Benefits to patients:

- Access to specialised dermatology care in the community
- Reduces travel burden for appointments

### Benefits to HCPs:

- Upskilling community dermatologists
- Opportunity to build and establish network between community and hospital dermatologists to facilitate future referrals

**Sources:** (a) Nahum Y, et al. Dupilumab-induced ocular surface disease (DIOSD) in patients with atopic dermatitis: clinical presentation, risk factors for development and outcomes of treatment with tacrolimus ointment. *Br J Ophthalmol.* 2019; doi: 10.1136/bjophthalmol-2019-315010



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We can improve our relationships with GPs through the community dermatologist

*Dermatologist, Rabin Medical Centre*

# Specialised atopic dermatitis outpatient clinic

## Overview

- A dermatologist who sub-specialises in atopic dermatitis (AD) runs a weekly atopic dermatitis clinic at the centre. Patients are able to receive comprehensive care and advice for the treatment and management of their atopic dermatitis and associated comorbidities



Having subspecialties in dermatology means we can provide patients with highly specialised advice

*Dermatologist, Rabin Medical Centre*



## What is the rationale?

- New and emerging therapies are becoming available for AD patients<sup>(a)</sup>
- To appropriately treat patients with the innovative therapeutic options, dermatologists need to understand new treatment options<sup>(a)</sup>
- A dermatologist who subspecialises in AD may be better positioned to provide specialised AD care and treatment
- The dermatologist established the clinic after recognising the emerging need for specialised care in AD

## What are the key features of the intervention?

- A dermatologist who sub-specialises in AD established a weekly AD full day clinic at the centre in 2015
- Primary care providers, including general practitioners, can refer moderate to severe AD patients to the clinic
- On average, 10 to 12 patients are seen at the clinic and each appointment lasts around 20 mins to 1 hour (depending on patient severity and need for patient counselling)
- Patients are able to receive highly specialised advice and care on AD from the dermatologist
- At the initial consultation, the dermatologist will perform an initial assessment and diagnosis before commencing / modifying treatment
- The dermatologist will provide extensive counselling on self-care and management of AD
- All AD patients are followed up in the specialised AD clinic

## What are the outcomes so far?

### Benefits to patients:

- Improved access to specialist tests / treatment through specialised dermatology service

### Benefits to HCPs:

- Ability to address highly complex and severe cases of AD
- Insight into AD trends (and potentially the effectiveness of AD therapies)

## What's next?

- The centre is expanding their investigator-led studies based on AD to focus on AD comorbidities

**Sources:** (a) Napolitano M, et al. Adult atopic dermatitis: new and emerging therapies. *Expt Review of Clin Pharm.* 2018; 11(9):867-878. doi:10.1080/17512433.2018.1507734



# Globally trained dermatologists and residents (1/2)

## Overview

- Each dermatologist within the department has sought to receive training from leading international dermatology units, such as the Oregon Health & Science University Hospital

## What is the rationale?

- With the trend of globalisation across every sector and increasing international migration, there is a need for physicians to understand medicine on a global level<sup>(a)</sup>
- International training and education can help broaden a physician's medical knowledge and understanding of the global burden and epidemiology of diseases<sup>(a)</sup>
- Engagement in international clinical training and rotations has the potential to expose physicians to conditions and diseases they may not have seen locally<sup>(a)</sup>

## What are the key features of the intervention?

- There is high academic standing amongst the department's senior staff, with training and experience from across the globe<sup>(b)</sup>
- Each senior dermatologist has completed training abroad in different subspecialties. As a result, the department has established the largest dermatology specialisation program in Israel
  - International training is thought to support trainees<sup>(a)</sup>:
    - Improve their clinical and diagnostic skills
    - Develop a deeper understanding of public health issues and cultural sensitivities
- Following the completion of their residency training programme, high-performing trainee dermatologists who aim to sub-specialise seek participation in an international training programme
  - With the support of the department's leadership, the trainee dermatologist(s) contact leading international departments for acceptance into training / fellowship programmes
  - Residents can apply for grants / educational programmes for financial support
- Multiple programmes have been completed by the department's dermatologists, ranging from training to full fellowships
  - One of the department's dermatologist has completed a fellowship program at the Oregon Health & Science University Hospital. The dermatologist was able to establish a specialised AD clinic based on the insights and knowledge gained from training
  - Other sub-speciality programmes completed include dermato-pathology, autoimmune bullous diseases, skin lymphomas, translational dermatology, genetics, melanoma research and psoriasis

**Sources:** (a) Drain PK, et al. Global health training and international clinical rotations during residency: current status, needs, and opportunities. *Acad Med.* 2009;84(3):320–325. doi:10.1097/ACM.0b013e3181970a37; (b) KPMG interviews



# Globally trained dermatologists and residents (2/2)

## What are the outcomes so far?

### Benefits to patients:

- Dermatologists may be more attuned to different cultural sensitivities

### Benefits to HCPs:

- Opportunity to learn about other subspecialties from fellow peers
- Incorporation of international best practice into clinical care

## What's next?

- Continue to develop and progress subspecialties in dermatology and incorporate learnings from international practice



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# Collaboration with comorbidity specialists (1/2)

## Overview

- The department has an established connection with the ophthalmology, allergy/immunology and pulmonology department. Currently, a dermatologist and ophthalmologist from the centre are in the process of publishing a joint study on side effects related to atopic dermatitis treatment



We work well with the dermatologists and have been able to learn from each other

*Ophthalmologist, Rabin Medical Centre*



## What is the rationale?

- AD is a complex disease and patients may present with other associated diseases (e.g. asthma or allergic rhinitis)<sup>(a)</sup>
- AD patients may also suffer from ocular comorbidities (as a result of the disease itself or treatment used)<sup>(b)</sup>
- An effective working relationship across specialties can help speed up referrals and improve communication (e.g. regarding severity of symptoms, treatments prescribed, etc.)

## What are the key features of the intervention?

- The department has an established working relationship with other specialties in the centre to support effective management of AD associated comorbidities
- The relationships were established based on personal connections and they were then formalised
- AD patients are referred to other specialties as required

### Ophthalmology

- The dermatologist refers patients directly to the centre's ophthalmologist when required (and vice versa). This typically involves a phone call or email
- The ophthalmologist will review and assess the patient's ocular symptoms and provide treatment when appropriate
- The dermatology and ophthalmology department have been collaborating for the past two years
- Currently, a dermatologist and ophthalmologist are submitting a journal article on the side-effects of biologic treatment for AD and how to effectively manage the symptoms
  - The article has been co-presented at a dermatology and ophthalmology conference by the respective physicians

### Allergy / Immunology and Pulmonology

- The dermatologist refers patients directly to the centre's allergist or pulmonologist when required for review of related comorbidities. This typically involves a phone call or email
- The allergist will then perform the necessary tests and communicate the results directly to the dermatologist

**Sources:** (a) Bantz SK, et al. The Atopic March: Progression from Atopic Dermatitis to Allergic Rhinitis and Asthma. *J Clin Cell Immunol.* 2014;5(2):202; (b) Thyssen JP, et al. Incidence, prevalence, and risk of selected ocular disease in adults with atopic dermatitis. *Journal of the American Academy of Dermatology* 2017;77(2):280-286.e1. doi: 10.1016/j.jaad.2017.03.003

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# Collaboration with comorbidity specialists (2/2)

## What are the key features of the intervention? (cont.)

Outside of AD, the dermatology department has established joint clinics for the management of other dermatological diseases. This includes:

- Joint dermatology and rheumatology clinic (for arthritis related conditions)
- Joint dermatology and haematology clinic (for skin lymphomas)
- Joint gastroenterology and dermatology (for Inflammatory Bowel Disease)

## Challenges

- There is an increasing number of AD patients presenting with AD-related ocular symptoms, which may potentially increase waiting times
- There may be knowledge gaps (about dermatological diseases) between the different specialties. The department aims to bridge the gaps through meetings and educational lectures

## What are the outcomes so far?

### Benefits to patients:

- Quick access to other specialists (through established referral pathway)
- Able to receive holistic care for comorbidities (e.g. improved eye health and regular monitoring with ophthalmologist support)

### Benefits to HCPs:

- Opportunity to learn from other specialties
- Improved management of comorbidities

## What's next?

- Finalise the journal article jointly written by the dermatology and ophthalmology department
- The department aims to develop their collaboration and working relationship with dermatology. Currently, pulmonologists can directly refer patients with untreated atopic dermatitis to the dermatology clinic for immediate consultation and treatment

“



We are able to work with the ophthalmologists to understand how to best manage ocular symptoms associated with AD

*Dermatologist, Rabin Medical Centre*



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# Extensive inpatient and day care facilities

## Overview

- The department has 17 inpatient beds and day care facilities, which can be accessed by atopic dermatitis patients who require additional support and treatment



Sometimes patients need our help with creams and wet wraps. They can come here for topical application support and continue with the rest of the day

*Dermatology Nurse, Rabin Medical Centre*



## What is the rationale?

- AD can have a significant impact on a patient's quality of life, self-esteem and ability to self-manage their condition<sup>(a)</sup>
- AD patients who require intensive treatment or situational support may benefit from inpatient services and treatment<sup>(b)</sup>

## What are the key features of the intervention?

- The department has 17 dedicated dermatology inpatient beds and day care facilities

### Day care facilities

- Patients can receive intravenous infusions, application of topical treatment, application of wet wraps and phototherapy treatment
  - Patients may also be initiated on systemic therapy if there are medical or pragmatic concerns about initiating treatment at home
- The specialised dermatology nurses can also provide extensive counselling with each interaction with the patient. For instance, patients are provided guidance on self-care, how to apply corticosteroids and bathing care

### Inpatient beds

- There are dedicated resources, including dermatology nurses and equipment, to support the care of dermatology patients in the centre
- All dermatology patients, including patients suffering from AD, are able to receive the intensive and specialised care they require to support their recovery and ongoing management
- Each morning there is a dermatology ward round, where the dermatologists and trainee dermatologists will discuss, assess and manage dermatology patients in the department
- AD patients typically stay for a week and are referred to the department by hospital dermatologists

## What are the outcomes so far?

### Benefits to patients:

- Able to receive expert advice and intensive care
- Environmental change may support in controlling eczema flare

### Benefits to HCPs:

- Physicians are able to closely monitor patients progress and response to treatment
- Nurses are able to develop highly specialised dermatology skills

## What's next?

- The department will continue to provide inpatient and day care services for dermatology patients

**Sources:** (a) Sibbald C, et al. Patient Burden of Atopic Dermatitis. *Dermatol Clin*. 2017;35(3):303-316. doi: 10.1016/j.det.2017.02.004; (b) van der Schaft J, et al. Is There an Additional Value of Inpatient Treatment for Patients with Atopic Dermatitis? *Acta Derm Venereol*. 2016;96(6):797-801. doi: 10.2340/00015555-2410.



# Development of locally tailored recommendations (1/2)

## Overview

- The department is in the process of finalising local recommendations for the treatment of atopic dermatitis patients in Israel. The document has been formulated based on regional payment mechanisms and policies to ensure community and hospital dermatologists can access useful and practical support

**Sources:** (a) Eichenfield L, et al. Translating Atopic Dermatitis Management Guidelines Into Practice for Primary Care Providers. *Pediatrics*. 2015.136(3):554-65. doi: 10.1542/peds.2014-3678



## What is the rationale?

- Currently, there are no existing Israeli specific AD guidelines. Primary care physicians and dermatologists generally rely on international guidelines
- Guidelines are generally written for use by specialists and may not contain adequate information for primary care providers<sup>(a)</sup>
- There is a need for practical suggestions to support primary care providers and community dermatologists develop individualised of AD treatment plans<sup>(a)</sup>

## What are the key features of the intervention?

- The department formed a working group to drive the development of the Israeli-specific AD recommendations for primary care physicians and dermatologists in early 2018
- The working group consists of dermatologists and paediatric dermatologists
- The working group convened for two days in March 2018 and two days in March 2019 to discuss and draft the recommendations
- Each physician was involved in developing and drafting a section of the recommendations
- The department's director and a dermatologist were responsible for editing and reviewing the recommendations
- The recommendations were designed to be a practical and useful everyday tool for primary care physicians and dermatologists. Each section has been developed to adhere to the local policies and regional payment mechanisms

## Local recommendations

The recommendations provide support for a range of sections, including:

- Diagnosis of atopic dermatitis
- Workup
- Recommended outcome measurements
- Management of atopic dermatitis (including subsections on: basic skin care, topical treatments, treating skin infection, anti-pruritics, deciding on initiating systemics, phototherapy, conventional systemics and biologics)
- Management of comorbidities
- Complementary medicine

# Development of locally tailored recommendations (2/2)

## Challenges

- Ensuring the recommendations were practical and easy to use required effective discussion during the working group meetings
- Dissemination and uptake within the primary care setting may be a challenge, given the time constraints primary care providers may experience

## What are the outcomes so far?

### Benefits to patients:

- Potential to improve access to specialist tests / treatment, due to practical recommendations on care and treatment

### Benefits to HCPs:

- Practical guidance on the treatment of AD
- Improved understanding of how AD treatment applies to local policy and payment setting

## What's next?

- The department is currently in the process of finalising the locally tailored recommendations. The recommendations are expected to be published, in hard copy and electronically, in the coming months
- The department will continue to participate in dissemination activities to support the uptake of the guidelines. Dermatologists have previously presented the recommendations in a national Dermatology conference and in dermatologist meetings

“

We wanted to make the recommendations tailored to the local policies and guidelines

*Dermatologist, Rabin Medical Centre*



“

Each contributor provided subject knowledge, tailored to relevant Israeli policies and systems

*Dermatologist, Rabin Medical Centre*



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# Harmonising Outcome Measures for Eczema (HOME) initiative (1/2)

## Overview

- A dermatologist from the department is part of the Harmonising Outcome Measures for Eczema (HOME) international working group. The group aimed to establish a set of core outcome domains and instruments to measure effects in atopic dermatitis clinical trials

## What is the rationale?

- There is a current lack of standardisation of the assessment of clinical signs and core patient outcomes of AD<sup>(a)</sup>
- Outcomes from different AD clinical trials are difficult to assess and compare
- Standardisation of core patient outcomes to assess clinical signs of AD could advance evidence-based decision making and improve patient care<sup>(a)</sup>

## What are the key features of the intervention?

- The Harmonising Outcome Measures for Eczema (HOME) initiative aimed to achieve international consensus on a core set of outcome measures for the clinical assessment of AD in future trials
- Patients, leading physicians, nurses, methodologists, and pharmaceutical industry representatives across the world were involved in the study
- The initiative was coordinated by the Centre of Evidence-based Dermatology in the United Kingdom

## Method:

- The HOME Roadmap was utilised to identify a Core Outcome Set (COS) to measure and assess AD symptoms and quality of life in clinical trials
  - The HOME Roadmap methodology has previously been utilised to develop validated core sets of outcomes in osteoarthritis and childhood asthma
- The methodology involved a literature review and working groups to discuss, identify and determine appropriate measures and domains via consensus
- Four core outcome domains were recognised as critical areas to assess in each clinical trial
- Measures for each domain were then selected based on their validity and ease of use

## The agreed Core Outcome Set (COS) for AD clinical trials is:

- *Clinical signs*: Eczema Area and Severity Index (EASI)
- *Patient-reported symptoms*: Patient-orientated Eczema Measure (POEM) and Numeric Rating Scale (NRS-11 – for peak itch over last 24 hours)
- *Long term control*: Recap of Atopic Eczema (RECAP) or Atopic Dermatitis Control Test (ADCT)
- *Quality of life*: Dermatology Life Quality Index (DLQI – adults), Children's Dermatology Life Quality Index (CDLQI) or Infants' Dermatitis Quality of Life Index

**Sources:** (a) American Academy of Allergy, Asthma & Immunology. The Harmonising Outcome Measures for Eczema (HOME) statement to assess clinical signs of atopic eczema in trials [Website] <https://www.ncbi.nlm.nih.gov/pubmed/25282560> Accessed 12 Sept 2019

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# Harmonising Outcome Measures for Eczema (HOME) initiative (2/2)

## What are the key features of the intervention? (cont.)

### Implementation:

- All stakeholders involved in designing, reporting and using clinical trials on AD were asked to comply with the COS in all future AD trials
- Researchers can also choose to include other clinical sign scales such as SCORAD, in addition to using the EASI, when measuring progress in the four different domains

## What are the outcomes so far?

### Benefits to patients:

- Evidenced-based decision making can improve patient care and quality of life

### Benefits to HCPs:

- Better comparison of treatment impact across different clinical trials, due to consistent use of measurements
- Enables greater collaboration internationally

## What's next?

- The centre is employing the HOME COS in clinical trials
- The international working group is now focusing on developing a similar set of instruments for use in clinical practice. This is being led by dermatologists from OHSU and the centre



HOME will help dermatologists compare outcomes from different trials more effectively

*Dermatologist, Rabin Medical Centre*



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# Dokkyo Medical University Hospital

Tochigi, Japan

Site visited by KPMG 3<sup>rd</sup> – 4<sup>th</sup> October 2019

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# Summary



## Context

**Centre type:** University Hospital (tertiary care teaching hospital) located in Mibu Town in the Tochigi Prefecture (Shimotuga distict). There are two other hospitals within the network, located at Saitama Prefecture and Tochigi Prefecture (Nikko City)

**Catchment area:** Patients from the Tochigi Prefecture in the Northern Kanto region of Japan (population of approximately 2 million people)

**Funding:** The hospital is mainly run by its own revenues

**Services:** A range of medical specialties including dermatology, pulmonology, paediatrics, rheumatology, neurology, urology and psychiatry are provided

**Patient population:** The hospital caters to adult and paediatric patients with a variety of dermatological conditions, including atopic dermatitis (mild, moderate and severe)



## Key strengths in the delivery of AD care

**Focus on allergy:** The Dokkyo Hospital founded the first Department of Allergy in Japan and has a strong focus on allergy. The hospital now has a dedicated Allergy Center that aims to provide specialised patient care through collaboration with various departments

**Establishment of an Allergy Camp:** an Allergy Camp aimed at paediatric patients is organised and run by the centre, which aims to provide further education about the condition

**Co-operation between departments:** The hospital promotes co-operation between departments to provide multi-disciplinary and holistic care to patients (e.g. the dermatology department works with pulmonology, paediatric and ENT)

**Clinical trials and research:** The hospital focuses on clinical research and consequently has a substantial number of clinical trials for innovative treatments



## Key challenges faced in delivery of AD care

**Patient adherence:** Patients and carers may struggle to integrate their treatment regimens into their daily routine, as they may have an especially intense AD treatment regime. This burden can have a detrimental impact on how able they are to maintain their treatment into the long term

**Limited availability of antibody and immunosuppressant drugs:** Controlling paediatric AD symptoms can be difficult as paediatric antibody drugs and most immunosuppressant drugs still have limited availability

**Rapid increase in number of outpatients :** The growing number of referrals from Primary Care Physicians (PCPs) and the approval of biologics in Japan has significantly increased the number of outpatients at the hospital



# Atopic Dermatitis (AD) in Japan

## Japanese healthcare system:

The Japanese healthcare system is primarily funded by statutory contributions through the Statutory Health Insurance System (SHIS). This is supplemented by expenditure through private health insurance<sup>(a)</sup>

## Publicly funded healthcare:

- The SHIS comprises of more than 3,400 insurers and provides universal primary coverage for all Japanese citizens. It is compulsory for citizens to enrol in an SHIS plan. Whilst the SHIS coverage is the same for everyone, premiums can vary based on age, employment status, and / or place of residence, and are determined by the national government (usually following a decision made by the Central Social Insurance Medical Council)<sup>(a)</sup>
- SHIS plans cover hospital, primary, specialty, and mental health care. They may also cover approved prescription drugs, home care services by medical institutions, hospice care, physiotherapy, and most dental care<sup>(a)</sup>
- Aside for children up to the age of 6, adults ages 70 to 74 with lower incomes, and those age 75 and older with lower incomes, all SHIS enrollees pay a 30 percent coinsurance fee for services and goods received<sup>(a)</sup>
- Insurance premiums vary between types of insurance funds and municipalities. Government employees, as well as some doctors in private practises, are covered by their own insurers

## Privately funded healthcare

- The majority of the population hold some form of private health insurance, however, it only plays a supplementary or complementary role<sup>(a)</sup>
- Health insurance provides additional income in case of sickness, mainly in the form of lump-sum payments when insured persons are hospitalised or diagnosed with cancer or another specified chronic disease. Income may also be paid in daily during hospitalization over a defined period<sup>(a)</sup>

## Prevalence

- Prevalence of childhood AD is 12-13% in mainland Japan<sup>(c)</sup>
- The lifetime prevalence for AD in adults is 6.5% and 11.2% in elementary school children<sup>(1)(d)</sup>



## Care provision:

### Location:

- Mild (or well-controlled) AD care is primarily delivered by community physicians (primary care providers)
- Moderate and severe (uncontrolled) AD care is primarily delivered in specialist secondary care (within hospitals)

### Funding:

- Payments for primary care are based on a national fee-for-service schedule

## Guidelines and societies:

### Guidelines:

- Japanese Society of Allergology – Japanese guidelines for atopic dermatitis 2018<sup>(b)</sup>

### Medical societies/PAGs:








- Japanese Dermatological Association

**Note:** (1) Lifetime prevalence is the percentage of people within the population who will have AD at some point in their life

**Sources:** (a) The Japanese health care system. International health care system profiles [Website] <https://international.commonwealthfund.org/countries/japan/> Accessed Sept 10 2019; (b) Japanese guidelines for atopic dermatitis 2017. Allergology International [Website] [https://www.allergologyinternational.com/article/S1323-8930\(16\)30172-1/pdf](https://www.allergologyinternational.com/article/S1323-8930(16)30172-1/pdf) Accessed Sept 10 2019; (c) Furue M, et al. Current status of atopic dermatitis in Japan. *Asia Pac Allergy*. 2011;1(2):64–72; (d) Atopic dermatitis disease registry in Japanese adult patients with moderate to severe atopic dermatitis. Japanese Dermatological Association [Website] <https://onlinelibrary.wiley.com/doi/full/10.1111/1346-8138.14787> Accessed 12 Sept 2019



# The centre and dermatology unit

The Centre		
 <b>Type and location</b>	<ul style="list-style-type: none"><li>— Dokkyo Medical University Hospital opened in 1974 in Mibu-cho, in the Tochigi Prefecture (Shimotsuga district) in Japan. In addition to providing medical care, the centre offers pre-graduate training and advanced physician training. The hospital also has two other hospital sites located within the Saitama Prefecture and Tochigi Prefecture (Nikko City).</li><li>— There are 2,614 staff members (of which 448 are doctors), as well as 1,153 beds for medicine / surgery and 42 beds for psychiatric care<sup>(a)</sup></li></ul>	
 <b>Population served</b>	<ul style="list-style-type: none"><li>— Patients from the Tochigi Prefecture in the Northern Kanto region of Japan (population 2 million people)<sup>(b)</sup></li></ul>	
Department of Dermatology		
 <b>Service Division</b>	<b>Outpatient service</b>	<b>Inpatient service</b>
 <b>Hours of availability</b>	Monday – Friday: 09:00 – 16:30 Saturday – Sunday: 09:00 – 12:30 (Afternoon slots available for non-AD related surgery)	24/7
 <b>No. of patients seen</b>	<ul style="list-style-type: none"><li>— 300-400 patients with AD are seen every year (currently a total of 534 adult and 600 paediatric patients with AD)</li></ul>	Limited number of inpatients per year
 <b>Types of patients seen</b>	Both paediatric and adult patients with AD and other dermatological diseases	Patients with severe AD and other dermatological diseases (e.g. skin tumour, collagen disease, burns)
 <b>Facilities on-site<sup>(1)</sup></b>	<ul style="list-style-type: none"><li>— Phototherapy (predominantly UVB therapy, however PUVA treatment is also available)</li><li>— CO<sub>2</sub> laser treatment</li><li>— Patch testing</li><li>— Prick test</li></ul>	

**Note:** (1) List of facilities is not exhaustive




**Sources:** (a) Hospital Overview. Dokkyo Medical University Hospital Website [Website] <https://www.dokkyomed.ac.jp/hosp-m/hospital/overview/> Accessed 22 Oct 2019; (b) Kitajima T. Introduction to and Activities of the Dokkyo Medical University Medical Association. University Medical Associations in Japan. *JMAJ* 2011;54(1): 53–55

# The team

## Core team profile

-  **20+** Dermatologists
-  **3** Dermatology
-  **1** Healthcare assistant

## Wider team profile

-  **15** Pulmonologists
-  **7** Paediatricians (including 1 licensed Paediatric Allergy Educator 'PAE')
-  **3** Dieticians

*Note: Please see page 541 for further details about the wider team*



## Governance and processes

### Team meetings:

- *Case conference (2-hour weekly meeting):*
  - Attended by all dermatologists
  - Purpose: To discuss and review treatment and management of general dermatology patients. It is held together with the daily professor round
- *Photograph conference (weekly, 15 mins):*
  - Attended by all dermatologists
  - Purpose: To discuss and review photographs of difficult AD cases

### Patient records:

- *Electronic medical records (EMR):*
  - Electronic medical records are used by the centre that can be shared between the two branch hospitals (Nikko Medical Centre and Saitama Medical Centre) across all specialties. Sharing of records is only possible when the patient and the two branch hospitals provide consent

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Paediatric and adult patients with symptoms of AD (e.g. allergies or skin itch) are referred by Primary Care Physicians (PCPs) and community dermatologists to the Dokkyo Hospital (as most patients with AD live in the Tochigi prefecture which does not have many large-sized hospitals)
- Referrals are also received from the pulmonology department

*Note: Patients with mild atopic dermatitis may be well managed by the PCP. As a result, patients with mild AD may not be seen at the hospital*

## Diagnosis and Referral

In secondary care



- The physician in charge (on the day the patient visits the centre) will assign a dermatologist to each patient, depending on the patient's referral details and the registration form
- The dermatologist will perform the clinical inspection. The initial consultation duration for paediatric and adult patients with severe symptoms is 10–15 minutes. Consultations for well-controlled cases normally lasts 5-10 minutes
- Following the initial consultation with the dermatologist, the nurses ask patients about their reason for visiting the hospital and follow-up questions about their lifestyle
- Patch tests and blood tests for IgE are conducted for patients when required (depending on the skin condition)

## Treatment and Management

Medical management



- The dermatologist will initiate and modify treatment for AD, for example, updating the patient's topical corticosteroid treatment plan
- IGA and EASI scores are collected for paediatric patients
- For patients on biologics, baseline EASI, DLQI, POEM and VAS are measured and repeated at each visit

Non-medical management



- The dermatologist will assess the patient's understanding of AD and teach patients how to adopt ideal lifestyles (e.g. avoiding triggers, bathing regularly). The dermatologist may provide educational leaflets, refer patients to educational websites and draw illustrations to visually explain AD to patients. This will usually occur during the initial consultation
- A dermatology nurse will then educate patients on how to apply treatments (e.g. self-injections). The nurse will then try to understand the patient's background / lifestyle and teach patients how to prioritise therapy in their daily life
- Paediatric patients may be offered the opportunity to participate in the Allergy Camp (for patient education activities)
- Phototherapy (UVB) may also be offered to patients

*Note: As there are only two dermatology nurses available to deliver non-medical treatment, the order in which patients receive information can vary*

## Follow-up

Monitoring of chronic disease / flare up



- Patients with AD typically visit the hospital once a fortnight or once a month depending on the severity of AD
- If additional education is required, the dermatologist may ask the dermatology nurse to provide the patient with an education session
- Generally, patients with AD are not referred back to PCPs
- Patients with AD may be taken by ambulance to a hospital if required (for example, when they contract a bacterial infection), however this is very rare

# Roles of the wider team

## Pulmonologist

**Patient type:** Predominantly AD patients with asthma (however patients with food allergies may also be seen)

**Referral:** Primarily referred by dermatologists, who they may refer back to. Patients may also be referred by Primary Care Physicians (PCPs)

**Consultations:** Assess the patient's respiratory condition, conduct patch / prick tests, and provide treatments as required

**Timing:** Consultations vary in length depending on patient requirements

## Dietician

**Patient type:** AD patients with suspected food allergies

**Referral:** Referred by dermatologist through the Allergy Centre

**Consultations:** Conduct specialist allergy tests, including interpretation of test results. During Allergy Camp, the dietician may also instruct students how to use treatment for anaphylaxis and how to deal with a food allergy

**Timing:** Consultations vary in length depending on patient requirements



## Paediatrician

**Patient type:** AD paediatric patients with food allergies, asthma and anaphylactic shock

**Referral:** Referred by dermatologist

**Consultations:** Perform standard tests (such as IGA and EASI) and provide allergy testing where appropriate

**Timing:** Consultations vary in length depending on patient requirements

## Roles of other team members:

### *PAE (Paediatric Allergy Educator)*

PAE is a qualification entitled to pharmacists, dieticians and nurses approved by the Japanese Society of Paediatric Allergy and Clinical Immunology. The PAE system started in 2009.

PAEs support doctors in the treatment of paediatric patients with allergy such as AD, food allergy, asthma and anaphylactic shock. PAEs teach patients how to apply topical medications / inhale oral medications (where applicable)

# Overview of interventions in place for AD

## Awareness and Presentation



Symptom identification

- **HCP and patient education:** The Allergy Centre (see case study 'Allergy Centre') promotes healthcare provider (HCP) and patient education through lectures and sessions on asthma, AD and allergies

## Diagnosis and Referral



In secondary care

- **Referral to healthcare professionals:** The Allergy Centre (see case study 'Allergy Centre') increases collaboration between various departments and enables easy referrals to specialists in other departments

## Treatment and Management



Medical management

- **Allergy Centre:** The Allergy Centre provides multi-disciplinary care to patients with allergies and is composed of 9 departments (including paediatrics, dermatology and pulmonology)

See pg. 547-548 for case study

- **Use of Patient Reported Outcomes (PROs):** The hospital uses several indices to monitor and assess treatment outcomes for adult on biologics and paediatric patients, such as EASI, DLQI, POEM and VAS

- **Access to clinical trials:** Patients may have the opportunity to participate in AD related clinical trials



Non-medical management

- **Allergy Camp:** An experimental learning camp for children with allergies. Children are invited to meet with physicians, discuss their problems and interact with other allergy patients

See pg. 549-550 for case study

- **Paediatric Allergy Educators (PAE):** The hospital has 1 PAE (with 3 more medical staff due to take the PAE exam). The PAEs support allergists and dermatologists in the treatment of paediatric patients with allergy and by teaching patients how to apply ointments and other medication

- **Phototherapy sessions:** Patients may be offered phototherapy (UVB) sessions to help manage their AD symptoms

## Follow-up



Monitoring of chronic disease/flare up

- **Nurse-led education consultations:** The dermatology nurses provide patient education on how to apply topical medication and provide advice on medication management

See pg. 551 for case study

- **Educational material:** The dermatologists provide patients with leaflets and links to websites of pharmaceutical companies containing information on AD, allergies and how to use certain medication such as inhalers

### Key:



Case study available



# Monitoring patients with AD and comorbidities

## The dermatology unit uses scoring to measure disease activity for paediatric patients and patients on biologics

### Objective measures (AD):

AD scoring indices are utilised to monitor patients and their disease, including:

- EASI (Eczema Area and Severity Index): a tool used to measure the extent (area) and severity of atopic eczema<sup>(a)</sup>
- POEM (Patient Oriented Eczema Score): a practical self-assessed measurement tool for monitoring aspects of atopic eczema that are important to patients in routine clinical practice or in the clinical trial setting<sup>(b)</sup>
- IGA (Investigator's Global Assessment) Scale: a 5-point scale that provides a global clinical assessment of AD severity<sup>(c)</sup>

### Patient-reported outcomes:

- DLQI (Dermatology Life Quality Index): dermatology related quality of life questionnaire<sup>(d)</sup>
- VAS (Visual Analogue Scale): a scale to assess pruritus severity<sup>(e)</sup>

---

### Dermatology unit routinely measures comorbidity outcomes by:

- *Pulmonologist*: performs skin prick test, patch testing and metal inspection of teeth
- *Dermatology nurse*: performs blood tests / patch testing as requested by the dermatologist (dependent on the patient's skin condition)

**Sources:** (a) Leshem YA, et al. What the Eczema Area and Severity Index score tells us about the severity of atopic dermatitis: an interpretability study. *Br J Dermatol*. 2015;172(5):1353-7. doi: 10.1111/bjd.13662; (b) Charman CR, et al. The patient-oriented eczema measure: development and initial validation of a new tool for measuring atopic eczema severity from the patients' perspective. *Arch Dermatol*. 2004;140(12):1513-9; (c) Futamura M, et al. A systematic review of Investigator Global Assessment (IGA) in atopic dermatitis (AD) trials: Many options, no standards. *J Am Acad Dermatol*. 2016;74(2):288-94. doi: 10.1016/j.jaad.2015.09.062; (d) Lewis V, et al. 10 Years Experience of the Dermatology Life Quality Index (DLQI). *J Invest Dermatol Symp Proc*. 2004;9(2):169-80; (e) Reich A, et al. Visual Analogue Scale: Evaluation of the Instrument for the Assessment of Pruritus. *Acta Derm Venereol*. 2012;92(5):497-501. doi: 10.2340/00015555-1265

# Advice to other centres

## What advice would you give less specialised centres



### Objective of advice: Balance old and new treatments for AD

- **Why?** New and innovative treatments for AD are now available in Japan. Whilst it is important to optimise existing regimens, incorporating new medications can help support patient progress. Care must be taken however regarding potential side effects and interactions. This can be mitigated by ensuring risks and potential interactions are monitored



### Objective of advice: Visit larger and more experienced hospitals and medical centres

- **Why?** Smaller and less experienced centres can learn about interventions in the treatment of AD from the larger and more experienced centres. The learnings can subsequently be translated into clinical practice by the smaller centres. In Japan, many centres listed on the webpage of the Japanese Society of Allergology are open to visitors from other centres



### Objective of advice: Adapt the goal of the therapy to each patient

- **Why?** To improve the outcomes for patients with AD, it is essential for dermatologists to understand the patient's issues and to formulate a therapy in line with the patient's needs. The dermatologist should lay special emphasis on improving patient adherence and helping to eliminate stress in the patient's daily life



# Next steps for the centre

## What is next for the centre?

**Objective:** Expand the Allergy Camp to other parts of Japan

- **What?** The centre is considering expanding the annual Allergy Camps to other cities in Japan. There are approximately 20 other allergy camps held in Japan (all of which are organised by the local government)
- **Why?** Expansion of the camp to other cities will help spread patient education of allergy conditions and treatment. In addition, the camps are an effective means of educating healthcare providers (HCPs) and spreading awareness



**Objective:** Develop the Allergy Centre as a one-stop centre for all allergy-related problems

- **What?** The Allergy Centre currently delivers virtual services. It plans to have a physical building in order to gradually become a centre of excellence for allergy related diseases
- **Why?** The Allergy Centre can be developed as a hub for the treatment and management of allergies. It can also help in the education of medical professionals as part of the centre's plan to standardise the treatment of allergies



# Case studies



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# Allergy Centre (1/2)

## Overview

- The Allergy Centre was established in August 2018 with the aim to increase collaboration between departments in order to provide multi-disciplinary care to patients with allergies. It is comprised of 9 different departments, including Paediatrics, Dermatology and Pulmonology
- The Centre focuses on spreading standardised therapy to local hospitals in the same prefecture, and promoting healthcare provider (HCP) education through lectures and sessions on asthma, AD and allergies

## What is the rationale?

- An impaired skin barrier function in patients with AD increases susceptibility to microbial colonisation and infection, as well as the risk for allergen sensitisation and development of asthma / food allergies<sup>(a)</sup>
- Multidisciplinary teams play an important role in the provision of therapeutic AD patient education, in order to improve patient / caregiver knowledge of the condition, address barriers to adherence, and develop skills for self-management<sup>(a)</sup>
- The Allergy Centre was established to increase collaboration between departments and to provide multi-disciplinary care to patients with allergies

## What are the key features of the intervention?

- The Allergy Centre was established in August 2018 with the aim of increasing collaboration amongst the various departments within the hospital. The Centre is comprised of 9 different departments: Paediatrics, Dermatology, Pulmonology, ENT (Ear-Nose-Throat), Oral & Maxillofacial Surgery, Ophthalmology, Anaesthesiology, General Medicine, Rheumatology & Collagen Diseases
- Each of the 9 departments within the centre have a morning slot on weekdays for patients with allergic symptoms

### Healthcare provider and patient education

- The Allergy Centre focuses on improving HCP and patient education through:
  - Organising lectures and educational events for PCPs and specialist allergy doctors with the aim of achieving standardisation of allergy treatment
  - Organising the 'Allergy Cooperation Forum' to educate doctors, nurses and other PCPs regarding allergies. Each forum lasts two hours
  - Supporting nurses, pharmacists and dieticians to obtain a Paediatric Allergy Educator (PAE) license
  - Working with organisations linked to children (such as schools) in order to provide education regarding how to take care of students with allergies and how to use medication

### Collaboration amongst healthcare providers

- In the Allergy Centre, patients are referred between departments, with doctors often communicating with each other about the patient / case via e-mail. To support collaboration, electronic medical records are also shared between the two branch hospitals (Nikko Medical Centre and Saitama Medical Centre), if both the hospitals and the patient agree

**Sources:** (a) LeBovidge JS, et al. Multidisciplinary interventions in the management of atopic dermatitis. *J Allergy Clin Immunol.* 2016;138(2):325-34. doi: 10.1016/j.jaci.2016.04.003.

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# Allergy Centre (2/2)

## What are the key features of the intervention? (cont.)

### Collaboration amongst healthcare providers (cont.)

- The Centre promotes co-operation between medical professionals, the local government and people around paediatric patients (such as school teachers) in order to improve the quality of life of patients with allergies

### Challenges

- The Allergy Centre is currently a virtual organisation with no physical ward or building. This makes it difficult to establish the Centre as a one-stop place to treat all allergy-related diseases

## What are the outcomes so far?

### Benefits to patients:

- Can help increase access to specialists and the most appropriate treatment

### Benefits to HCPs:

- Increases collaboration amongst departments
- Helps deliver PCP education through lectures and sessions

## What's next?

- The Allergy Centre currently only provides virtual services. However it plans to incorporate a physical building in order to gradually become a centre of excellence for allergy related diseases
- The dermatologists at the Allergy Centre also intend to become involved in the prospective epidemiologic study to investigate local allergy data in Tochigi
- In addition, the Allergy Centre (in cooperation with the Tochigi Medical Association) is planning to organise a lecture about asthma, AD and other allergies for PCPs in the Tochigi Prefecture. For the lecture, the Centre plans to:
  - Invite various types of allergy specialists and staff from the paediatrics, pulmonology and other related departments. The centre will also invite clinical engineers and administrative staff
  - Organise conference-style sessions on AD and asthma. Proposed topics include AD, nettle rashes, drug eruptions and the recent approval of biologics in Japan
  - Award PCPs who attend with a certificate



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Doctors can co-operate with each other across the departments and one allergy can be seen by different departments

*Dermatologist, Dokkyo University Hospital*

# Allergy Camp (1/2)

## Overview

- The Allergy Camp was started in 1989 (originally called the 'Asthma Camp') and is organised every August for children with allergies
- The aim of the camp is to instruct paediatric patients about the treatment and management of their allergy, whilst also making it a fun experience

## What is the rationale?

- AD patients can suffer from other atopic diseases, such as asthma, allergic rhinitis and food allergies<sup>(a)</sup>
- Patients with AD and concomitant atopic conditions (such as asthma and allergic rhinitis) are likely to experience poor outcomes<sup>(b)</sup>
- The Allergy Camp aims to make children aware of the importance of controlling their disease before adolescence

## What are the key features of the intervention?

### Overview

- The Allergy Camp was started in 1989 and is organised every August. It is aimed at children with allergies and lasts for two nights / three days. The participation cost is 200 USD per patient and the hospital receives some subsidiary aid from the local government
- Approximately 20 patients, aged between 6 and 15 years, join the camp each year. Parents of the children do not join the camp. The camp participants mostly have asthma, AD or food allergies
- Patients are recruited by doctors at the centre through a medical examination. Posters are put up in the hospital in order to advertise the camp. Some participants also come from outside the hospital
- The camp is managed by 10 doctors, 5-10 nurses, 2-3 nutritionists and approximately 5 pharmacists. In addition, students from the Medical/Nursing Department, medical professionals from the Kyorin University, and graduates (who were former participants of the camp) volunteer in running the camp
- Some participating nurses have a Paediatrics Allergy Educator license. They consequently support doctors in treating the paediatric patients by teaching patients how to use inhalants and apply medicines

### Key activities

- In the camp, nurses teach paediatric patients how to wash their face and body, and apply ointment / medicines, as well as other treatment related education
- For AD paediatric patients, the nurses prepare a photo scale of the skin condition at different stages. As an activity at the camp, the participating children are made to check their own skin condition by comparing it with the images on the scale
- In addition to being educated about their allergies, the children also participate in outdoor activities such as outdoor cooking and swimming

**Sources:** (a) Simpson EL. Comorbidity in Atopic Dermatitis. *Curr Dermatol Rep.* 2012;1(1):29–38. doi:10.1007/s13671-011-0003-5; (b) Kapur S, et al. Atopic dermatitis. *Allergy Asthma Clin Immunol.* 2018;14(Suppl 2):52. doi: 10.1186/s13223-018-0281-6



# Allergy Camp (2/2)

## What are the key features of the intervention? (cont.)

### Schedule

- The schedule of the camp is as follows:
  - **Day 1:** Seminar for children
  - **Day 2:** Speech by former participants of the camp who are now medical practitioners (doctors or nurses). A cooking session is also organised that provides experimental education to participants regarding how to mitigate food allergies
  - **Day 3:** Swimming (a treatment for asthma patients, through which patients with AD can learn how to take care of their skin). A ceremony is also organised in which all the participants are awarded a certificate and speeches are made by the medical staff and participants

### Challenges

- Patient adherence after returning home from the camp is generally low. As a result, the gains achieved during camp activities may be lost and the condition of the patients may worsen
- Integrating therapy into a patient's daily life is a challenge. It is crucial for a nurse to fully understand each patient's family background and lifestyle before finalising therapy

## What are the outcomes so far?

### Benefits to patients:

- Patients spend dedicated time with healthcare providers and receive education on treatment of AD
- Improve paediatric psychological wellbeing
- Positive impact on career development (as some participants may become HCPs)

### Benefits to HCPs:

- Medical professionals can spend a whole day with patients, have direct interaction with them and listen to patient problems
- Helps to check for symptoms which may be difficult to detect during normal outpatient consultations
- Effective method of educating medical staff

### What's next?

- The hospital plans to expand this camp to other parts of Japan



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"It [Allergy Camp] is effective to treat paediatric patients as I can spend 24 hours together with them"

*Dermatology nurse, Dokkyo University Hospital*

# Nurse-led education consultations

## Overview

- The dermatology nurses provide patient education on how to apply topical medication and provide advice on medication management

## What is the rationale?

- Nurse led education sessions have been shown to demonstrate high levels of patient satisfaction and positive patient outcomes<sup>(a)</sup>
- Poor adherence to treatment is a major factor limiting treatment outcomes in patients with AD<sup>(b)(c)</sup>
- The role of the nurse (e.g. through nurse-led education) alleviates physician time constraints<sup>(d)</sup>

## What are the key features of the intervention?

- The dermatology nurses teach AD patients on how to care for their skin during short education sessions
- Topics covered during this session include:
  - An explanation of the medications to patients
  - Education on how to use ointments and self-injections (if applicable)
  - Skincare techniques for patients (e.g. how to wash their face)
- During the education session, the dermatology nurse / patient / family member of the patient applies ointment
- The dermatology nurse receives internal / external training to support their abilities to educate patients on the management of AD
  - The nurses may attend lectures facilitated by pharmaceutical companies or internal seminars by healthcare professionals within the Allergy Centre

## What are the outcomes so far?

### Benefits to patients:

- Improved access to timely advice and support
- Opportunity to clarify any concerns related to AD treatment
- Ability to build relationships with HCPs

### Benefits to HCPs:

- Dermatologists get more time to discuss medical issues during consultations

**Sources:** (a) DiAnna-Kinder F, et al. Satisfaction with Nurse Practitioners and Intent to Adhere to Plan. *The Journal for Nurse Practitioners*. 15(3):245-248.e1; (b) Bass AM, et al. Interventions to Increase Treatment Adherence in Pediatric Atopic Dermatitis: A Systematic Review. *Journal of clinical medicine* 2015;4(2):231-42. doi:10.3390/jcm4020231; (c) Charman CR, et al. Topical corticosteroid phobia in patients with atopic eczema. *Br J Dermatol*. 2000;142(5):931-6; (d) Brown MH. A nurse-led clinic in chronic and allergic contact dermatitis. *Br J Nurs*. 2005;14(5):260-3







# Hiroshima University Hospital

Hiroshima, Japan

Site visited by KPMG on 7<sup>th</sup> – 8<sup>th</sup> October 2019

[kpmg.com/uk](https://kpmg.com/uk)



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# Summary



## Context

**Centre type:** Public general hospital and medical school with a main hospital site in Higashi-Hiroshima City and two other hospital sites in Kasumi and Higashi Senda

**Catchment area:** Patients from across the Hiroshima prefecture (population of around 2.8 million people)

**Funding:** The hospital receives funding from the government.

**Services:** The hospital has several speciality departments including Neurology, Ophthalmology, Pulmonary, Gastroenterology, Endocrinology and Dermatology. The dermatology unit provides advice and treatment to paediatric and adult atopic dermatitis (AD) patients

**Patient population:** Paediatric and adult patients with dermatological diseases are treated by the dermatology unit



## Key strengths in the delivery of AD care

**Leading AD centre in Hiroshima:** The centre has long been recognised as the specialist centre for AD treatment in Hiroshima. It acts as a referral centre for community physicians who require specialised AD advice or patient guidance across the prefecture of Hiroshima<sup>(a)</sup>

**Developing the Japanese AD guidelines:** Dermatologists from the centre were involved in creating Japan specific AD guidelines which help in standardising treatment and improving the quality of care received by patients

**Novel AD treatments:** The centre is involved with a number of AD related observational and interventional clinical trials and epidemiological studies

**Engagement with local government:** The hospital is currently collaborating with the Hiroshima Prefectural Government and receives support from the Japanese Ministry of Health, Labour and Welfare



## Key challenges faced in delivery of AD care

**Limited time and resources to provide patient education:** Healthcare providers (HCPs) may have limited time and resources to thoroughly educate patients about AD and manage their expectations. Patients may become demotivated and less adherent to treatment

**Mixed capabilities amongst community physicians:** Physicians within the community have variable degrees of training and exposure to moderate and severe cases of AD. As a result, patients may have difficulty accessing specialised AD care within the community

**Sources:** (a) About selection of Hiroshima allergic disease medical base hospital [Website] <https://www.pref.hiroshima.lg.jp/soshiki/57/allergikyotenbyouin.html> Accessed 8 Nov 2019

# Atopic Dermatitis (AD) in Japan

## Japanese healthcare system:

The Japanese healthcare system is primarily funded by statutory contributions through the Statutory Health Insurance System (SHIS). This is supplemented by expenditure through private health insurance<sup>(a)</sup>

## Publically funded healthcare:

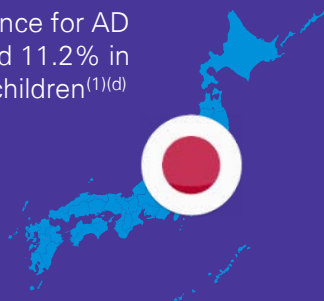
- The SHIS comprises of more than 3,400 insurers and provides universal primary coverage for all Japanese citizens. It is compulsory for citizens to enrol in an SHIS plan. Plans can vary based on age, employment status, and / or place of residence and are determined by the national government (usually following a decision made by the Central Social Insurance Medical Council)<sup>(a)</sup>
- SHIS plans cover hospital, primary, specialty, and mental health care. They may also cover approved prescription drugs, home care services by medical institutions, hospice care, physiotherapy, and most dental care<sup>(a)</sup>
- Aside for children up to the age of 6, adults ages 70 to 74 with lower incomes, and those age 75 and older with lower incomes, all SHIS enrollees pay a 30 percent coinsurance fee for services and goods received<sup>(a)</sup>
- Insurance premiums vary between types of insurance funds and municipalities. Government employees, as well as some doctors in private practises, are covered by their own insurers

## Privately funded healthcare

- The majority of the population hold some form of private health insurance, however, it plays only a supplementary or complementary role. Health insurance provides additional income in case of sickness, mainly in the form of lump-sum payments when insured persons are hospitalised or diagnosed with cancer or another specified chronic disease. Income may also be paid in daily during hospitalisation over a defined period

## Prevalence

- Prevalence of childhood AD is 12-13% in mainland Japan<sup>(c)</sup>
- The lifetime prevalence for AD in adults is 6.5% and 11.2% in elementary school children<sup>(1)(d)</sup>



## Care provision:

### Location:

- Mild (or well-controlled) AD care is primarily delivered by community physicians (primary care providers or private dermatologists)
- Moderate and severe (uncontrolled) AD care is primarily delivered in specialist secondary care (within hospitals)

### Funding:

- Payments for primary care are based a complex national fee-for-service schedule

## Guidelines and societies:

### Guidelines:

- Japanese Society of Allergology – Japanese guidelines for atopic dermatitis 2017 <sup>(b)</sup>

### Medical societies/PAGs:

- Japanese Dermatological Association

Note: (1) Lifetime prevalence is the percentage of people within the population who will have AD at some point in their life

Sources: (a) The Japanese health care system. International health care system profiles [Website] <https://international.commonwealthfund.org/countries/japan/> Accessed 10 Sept 2019; (b) Japanese guidelines for atopic dermatitis 2017. Allergology International [PDF] [https://www.allergologyinternational.com/article/S1323-8930\(16\)30172-1/pdf](https://www.allergologyinternational.com/article/S1323-8930(16)30172-1/pdf) Accessed 10 Sept 2019; (c) Furue M, et al. Current status of atopic dermatitis in Japan. *Asia Pac Allergy*. 2011;1(2):64–72; (d) Atopic dermatitis disease registry in Japanese adult patients with moderate to severe atopic dermatitis. Japanese Dermatological Association [Website] <https://onlinelibrary.wiley.com/doi/full/10.1111/1346-8138.14787> Accessed 12 Sept 2019

# The centre and dermatology department

## The centre



### Type and location

- The Hiroshima University Hospital is a general hospital and medical school located in the Hiroshima Prefecture of Japan. The main campus of the hospital is located in Higashi-Hiroshima City and two other campuses (Kasumi and Higashi Senda) are located in Hiroshima city
- The total capacity of the hospital is 746 beds. In 2018, it treated over 241,000 inpatients and 567,000 outpatients<sup>(a)</sup>



### Population served

- Patients from the Hiroshima Prefecture (population of around 2.8 million people) and the surrounding areas

## The dermatology department



### Service Division

#### Outpatient service

#### Inpatient service



### Hours of availability

Monday to Friday: 8:30am – 4pm

24/7



### No. of patients seen

Approximately 10–15 AD patients half a day per doctor

Limited number of AD patients seen through ED



### Types of patients seen

All dermatological conditions, including paediatric and adult patients with moderate to severe AD. The ratio of adult to paediatric AD patients is 9 to 1

Rare cases of septic shock and anaphylaxis shock



### Facilities on-site<sup>(1)</sup>

- Phototherapy (UVB therapy)
- Allergy tests (patch tests, histamine release tests, skin prick tests, etc.)
- Pathology collection

**Note:** (1) List of facilities is not exhaustive

**Sources:** (a) Hospital, Hiroshima University Hospital [Website] <https://www.hiroshima-u.ac.jp/en/about/about/hospital> Accessed 30 Oct 2019

# The team

## Core team profile



**14** Dermatologists



**15** Trainee dermatologists



**5** Dermatology nurses

## Wider team profile



**30** Ophthalmologists\*



**40** Paediatricians\*

*\*Including both full-time and part-time doctors*

*Note: Please see page 558 for further details about the wider team*



## Governance and processes

### Team meetings:

- *Complex cases (weekly, 30 mins)*
  - Attended by all dermatologists, trainee dermatologists and research fellows
  - The purpose of the meeting is to discuss the diagnosis, treatment and management of patients with complex dermatological conditions, including patients with severe AD
- *Nurse meeting (weekly, 30 mins)*
  - Attended by all dermatology nurses
  - The purpose of the meeting is to discuss the management of difficult AD cases

### Patient records:

- *Electronic patient records (EHR):*
  - Accessible by all specialists across the centre

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Paediatric and adult patients present to their community physician (e.g. general practitioner or private dermatologist) with AD symptoms (e.g. itch or dry skin)
- The physician will assess and refer to the centre if required
- Patients may present directly to the emergency department at the centre

*Note: Paediatric and adult patients with mild AD symptoms may be well-managed in the community. As a result, mild AD patients may not be seen at the centre*

## Diagnosis and Referral

In secondary care



- Paediatric and adult patients are referred to the general dermatology department
- The dermatologist will perform an initial assessment of the patient and evaluate the patient's primary symptom(s), medical history and previous / current AD treatments (usually 15-30 minutes)
- Baseline EASI, TARC and POEM are measured to help determine the patient's AD severity. Patients who potentially require systemic treatment may also undergo routine blood tests
- Based on the patient symptoms, the dermatologist may perform various tests (prick / patch / histamine releasing testing) or may instruct the dermatology nurse to conduct a blood test

## Treatment and Management

Medical management



- The dermatologist creates an AD treatment plan for patients with moderate to severe AD. The dermatologist focuses on explaining the goal of the treatment and expected changes throughout the plan
  - Patients with mild AD are referred back to their community physician (if they do not require medication)
- The dermatologist will initiate / modify treatment as required
- TARC and POEM are measured at every consultation to monitor and evaluate patient progress
- Patients who are not responding to treatment may be offered the opportunity to participate in an observational / interventional clinical trial

Non-medical management



- During the first consultation, the dermatologist uses educational material (such as leaflets) to explain the treatment plan and any side-effects associated with medication
- For paediatric patients, the dermatologist will also explain AD and the treatment to the parents
- After the initial consultation with the dermatologist, the patient will receive education from a dermatology nurse and trainee dermatologist. The consultation involves application of topical treatments and self-care of AD symptoms (usually lasts 20 minutes)
- Narrowband UVB is provided at the centre by dermatology nurses as required
- Dermatologists refer to the ophthalmologists in the centre when required

## Follow-up

Monitoring of chronic disease / flare up



- Patients are initially seen 1 week after their initial appointment. The dermatologist will re-assess their progress and treatment compliance
- If additional education is required, the dermatologist will refer the patient to the dermatology nurse for an additional education session (on self-care techniques, topical application etc.)
- Frequency of consultations and advice is dependent on disease severity and the patient's ability to self-manage (usually lasts 15 minutes)
- Patients with well-managed AD symptoms may be referred back to the referring physician if they do not require medication (usually 18-24 months)
- Tests (e.g. blood tests) will be performed as required based on clinical presentation

# Roles of the wider team

## Ophthalmologist

**Patient type:** Moderate to severe paediatric and adult AD patients with ocular symptoms

**Referral:** For outpatients, dermatologists will refer the patient back to the ophthalmologist in the patient's community. For inpatients, ophthalmologists in Hiroshima University Hospital will check if the patient has any eye symptoms.

**Consultations:** Ophthalmologist will perform a basic eye examination, assess IgE levels and provide treatments (e.g. lubricating eye drops; systemic therapies) as required. All patients receive education regarding their eye condition, treatment and aftercare (e.g. how to properly clean their eyes themselves)

**Timing:** Each consultation lasts around 20 minutes. Follow-up frequency is dependent on patient symptoms



## Paediatrician

**Patient type:** Paediatric patients suffering from chronic dermatological conditions (including AD, psoriasis etc.)

**Referral:** Referred by a paediatrician / general practitioner who specialises in paediatric care to dermatologist

**Consultations:** Paediatrician / general practitioner initially manages the patient's therapeutic management and refers moderate / severe paediatric cases to the dermatologist

**Timing:** Consultations vary in duration depending on patient severity. Follow-up frequency is every 2-3 months



# Overview of interventions in place for AD

## Awareness and Presentation



Symptom identification

- **Education for different professionals and the general public:** Upon request from the local government, a dermatologist at the centre delivers lectures to teachers and the general public

See pg. 564 for case study

## Diagnosis and Referral



In secondary care

- **Healthcare professional education seminars:** A dermatologist at the centre provides regular educational seminars to general practitioners and paediatricians. The seminars may be organised by pharmaceutical companies or physician organisations

See pg. 565 for case study

- **Development of country guidelines:** Dermatologists at the centre were involved with the development of country guidelines for management of AD

See pg. 566 for case study

## Treatment and Management



Medical management

- **Referral to comorbidity specialists:** Dermatologists will refer to other specialists in the centre / community when required
- **Access to clinical trials:** Patients may be given the opportunity to participate in investigational / observational clinical trials



Non-medical management

- **Patient education materials:** The centre utilises patient education pamphlets to reinforce education provided during consultations. The pamphlets include a range of sources, including information from pharmaceutical companies and material created by a centre's dermatologist
- **Phototherapy sessions:** Patients may be offered narrowband UVB phototherapy sessions to help manage their AD symptoms

See pg. 567 for case study

## Follow-up



Monitoring of chronic disease/flare up

- **Nurse-led education consultations:** After seeing the dermatologist, the patient attends a nurse-led education session. A dermatology nurse teaches patients how to apply topical medication and provides advice on how the patient can self-manage the disease
- **Referral to community physicians:** Once well-controlled and managed, patients may be referred back to the referring physician

See pg. 568 for case study

### Key:



Case study available



# Monitoring AD patients and comorbidities

## The dermatology unit employs a number of measures for monitoring AD and associated comorbidities

### Objective measures (AD):

AD scoring indices are used to monitor patients and their disease, including:

- EASI (Eczema Area and Severity Index): validated scoring system that grades the physical signs of atopic dermatitis<sup>(a)</sup>
- POEM (Patient-Oriented Eczema Measure): to monitor patient AD disease severity<sup>(b)</sup>

### Routine monitoring of clinical biomarker

The centre routinely measures Thymus and Activation-Regulated Chemokine (TARC) serum levels to monitor treatment progress. TARC is a biomarker for remission and can be used for accurately monitoring proactive treatment for long-term control of AD<sup>(c)(d)</sup>

---

### Dermatology unit routinely measures comorbidity outcomes by:

- *Dermatologist*: response to allergens/control of atopic disease (e.g. prick / patch testing)
- *Ophthalmologist*: surveillance of symptoms and specialist tests (e.g. topography / basic eye examination)
- *Dermatology nurse*: collects blood tests such as Immunoglobulin E (IgE) and Lactic Acid Dehydrogenase (LDH) are performed upon request from the dermatologist

**Sources:** (a) HOME for eczema.org. EASI for clinical signs [Website] <http://www.homeforeczema.org/research/easi-for-clinical-signs.aspx> Accessed 1 Mar 1029; (b) Charman CR et al. Translating Patient-Oriented Eczema Measure (POEM) scores into clinical practice by suggesting severity strata derived using anchor-based methods. *Br J Dermatol.* 2013;169(6):1326–1332; (c) Yasukochi Y, et al. Reduction of serum TARC levels in atopic dermatitis by topical anti-inflammatory treatments. *Asian Pac J Allergy Immunol.* 2014;32(3):240-5. doi: 10.12932/AP0419.32.3.2014; (d) Kataoka Y. Thymus and activation-regulated chemokine as a clinical biomarker in atopic dermatitis. *J Dermatol.* 2014;41(3):221-9. doi: 10.1111/1346-8138.12440.

# Advice to other centres

## What advice would you give less specialised centres?



### Objective of advice: Follow standard treatment guidelines for AD and its comorbidities

- **Why?** Significant improvement can be achieved for many patients with AD by following treatment guidelines. Following treatment guidelines allows patients to receive the necessary care and increases their confidence in treatment methods. There is a risk of treatment failure if the guidelines are not followed (e.g. allergic conjunctivitis treatments for patients may fail if doctors try to avoid the use of steroids)



### Objective of advice: Focus on patient education

- **Why?** Treatment of AD is affected by the patient's level of engagement. AD requires a holistic approach and a persistent attitude to self management. Investing in patient education activities can help to build patient self-esteem and improve patient outcomes. Patient education also helps HCPs develop a relationship with patients, who may feel more comfortable asking questions in order to improve their knowledge and self-management of AD



# Next steps for the centre

## What is next for the centre?

### Objective: To establish a multidisciplinary allergy centre

- **What?** The hospital is planning to establish an allergy centre which will consist of a multidisciplinary team (MDT) to treat allergy related diseases. The team will increase co-operation between departments (such as pulmonology, ENT, ophthalmology and paediatrics)
- **Why?** Establishing an MDT can help provide holistic treatment to patients with allergic diseases and help incorporate different perspectives into treatment



### Objective: Continue investing in clinical research

- **What?** The centre is involved in a number of AD related clinical trials, epidemiological and pathophysiological studies. The centre plans to continue investing in these studies
- **Why?** Involvement in clinical trials helps the dermatologists at the centre learn about emerging therapies and how to adopt them into clinical practice. Participation in clinical trials also increases patient access to newer therapies



# Case studies



	#
<b>Education for different professionals and the general public</b>	564
<b>Healthcare professional education seminars</b>	565
<b>Development of Japanese guidelines for AD</b>	566
<b>Patient education materials</b>	567
<b>Nurse-led education consultations</b>	568

# Education for different professionals and the general public

## Overview

- A dermatologist at the centre delivers lectures to teachers and the general public on how to manage AD symptoms and how to optimise treatment



We've worked with school committees and local governments to improve the understanding of AD in the community

*Dermatologist, Hiroshima University Hospital*



## What is the rationale?

- AD is a chronic skin condition affecting children and adults, with a significant negative impact on patient and caregiver quality of life (QOL). Although effective treatments for AD are available, outcomes are often limited by poor adherence to treatment plans<sup>(a)</sup>
- Effective patient and caregiver education about the disease (AD) and its management is a necessary and important component of AD care<sup>(a)</sup>
- Delivering broader educational sessions to the general public can help reinforce AD management and increase general knowledge and awareness about the condition

## What are the key features of the intervention?

- Upon request from the local government / school committees, a dermatologist at the centre delivers lectures to teachers and nutritionists at the Hiroshima University Hospital, external healthcare providers (HCPs) and the general public. This initiative was started back in 2001
- Topics covered during lectures include:
  - **Teachers (once a year):** Mechanism of AD and how to manage it
  - **Dieticians (once a year):** Proper knowledge of food allergy and how to avoid food allergens while preventing unnecessary avoidance of food
  - **General Public (once a year):** Diagnosis and management of AD, proper application of medicines and general information on steroids
  - **Other HCPs (every 2-3 months):** Topics vary based on type of HCPs (dermatologists, paediatricians, ENT doctors, etc.)

## What are the outcomes so far?

### Benefits to patients:

- Raises awareness about AD
- Helps patients and their family members to learn about AD and its treatment
- Opportunity to ask follow-up questions about the treatment regimen

### Benefits to HCPs:

- Helps increase AD treatment adherence levels
- Helps manage patient expectations in AD treatment

**Sources:** (a) LeBovidge J, et al. Atopic dermatitis: therapeutic care delivery: therapeutic education, shared decision-making, and access to care. *Semin Cutan Med Surg.* 2017;36(3):131-136. doi: 10.12788/j.sder.2017.029.

# Healthcare professional education seminars

## Overview

- A dermatologist at the centre provides regular educational seminars to general practitioners and paediatricians. The seminars may be organised by pharmaceutical companies or physician organisations



I typically talk about how to manage complex patient cases

*Dermatologist, Hiroshima University Hospital*



## What is the rationale?

- AD is a chronic illness which has a significant impact on the quality of life of affected children and their families, often necessitating multiple and at times complex treatments<sup>(a)</sup>
- Education of health care professionals and patients improves management of AD. Healthcare professional education has the potential to improve the knowledge and confidence of HCPs and patient health outcomes<sup>(a)(b)</sup>

## What are the key features of the intervention?

- A dermatologist at the centre provides weekly educational seminars to general practitioners / paediatricians in Hiroshima and other parts of Japan
  - The dermatologist usually discusses complex cases and how to best manage the patient's symptoms during these lectures
  - Other topics include new AD treatments and findings from recent studies and information on AD guidance
- The lectures may be organised by pharmaceutical companies, physician organisations, medical school or other local companies
- Each lecture lasts around 1 hour
- Over the past decade, the dermatologist has also conducted annual lectures for medical associations

## What are the outcomes so far?

### Benefits to patients:

- Improved access to standardised care and enhanced management of AD symptoms and comorbidities

### Benefits to HCPs:

- More opportunities for HCPs to collaborate
- Improved knowledge and understanding of specialised AD care
- Helps HCPs learn good practices for AD treatment from experts and implement comparative quality improvement standards

## What's next?

- The centre aims to continue delivering AD education seminars that focus on practical management of AD symptoms

**Sources:** (a) Munidasa D, et al. What Should General Practice Trainees Learn about Atopic Eczema? *J Clin Med*. 2015;4(2):360–368. doi: 10.3390/jcm4020360; (b) Cervero RM, et al. The Impact of CMA on Physician Performance and Patient Health Outcomes: An Updated Synthesis of Systematic Reviews. *Journal of Continuing Education in the Health Professions*. 2015;35(2):131–139

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# Development of Japanese guidelines for AD

## Overview

- Dermatologists at the centre are involved in the development of country guidelines for management of AD

## What is the rationale?

- The principal benefit of clinical guidelines is to improve the quality of care received by patients<sup>(a)</sup>
- Clinical improvements can be achieved in patients with AD by following standard treatment as per AD guidelines

## What are the key features of the intervention?

- The dermatologists at the hospital play an active role in the development of guidelines for the treatment of AD in Japan
- Dermatologists at the centre were involved in the development of:
  - Guidelines for Management of Atopic Dermatitis 2009 (the first Japanese guidelines on AD)<sup>(b)</sup>
  - Clinical Practice Guidelines for the Management of Atopic Dermatitis 2016 (by the Japanese Dermatological Association)<sup>(c)</sup>
  - Atopic Dermatitis Clinical Practice Guideline 2018 (by the Japanese Society of Allergology)<sup>(d)</sup>
- The dermatologists have working relationships with patient advocacy groups and engage with patients when drafting guidelines

## What are the outcomes so far?

### Benefits to patients:

- Increases access to standardised care
- Helps improve patient outcomes

### Benefits to HCPs:

- Helps to standardise treatment for AD
- Educates HCPs about good practices and newer methods in the treatment of AD

## Challenges

- Awareness of standard treatments as per AD guidelines is low among community physicians (e.g. general practitioner or private dermatologist) and doctors in some university hospitals. This reduces patient access to necessary care and lowers patient confidence in some cases

**Sources:** (a) Woolf SH, et al. Potential benefits, limitations, and harms of clinical guidelines. *BMJ*. 1999;318(7182):527–530. doi: 10.1136/bmj.318.7182.527; (b) Saeki H, et al. Guidelines for management of atopic dermatitis. *J Dermatol*. 2009;36(10):563-77. doi: 10.1111/j.1346-8138.2009.00706.x; (c) Saeki H, et al. Clinical Practice Guidelines for the Management of Atopic Dermatitis 2016. *J Dermatol*. 2016;43(10):1117-1145. doi: 10.1111/1346-8138.13392; (d) Kato N, et al. Atopic dermatitis clinical practice guideline 2018. *The Japan Society of Allergology, J-Stage*. 2018;67(10):71-72 doi: 10.15036/arerugi.68.71

# Patient education materials

## Overview

- The centre utilises patient education pamphlets to reinforce education provided during consultations
- The pamphlets include a range of sources, including information from pharmaceutical companies and material created by a centre's dermatologist. They contain advice and guidance on the side effects of topical steroids, the patient's medication plan and how to use topical medication



The materials help patients realise the benefit of AD treatment

*Dermatologist, Hiroshima University Hospital*



## What is the rationale?

- Patient education is an important aspect of patient care in dermatology. Successful education increases patient satisfaction and results in improved outcomes and adherence<sup>(a)</sup>
- Atopic dermatitis (AD) can be more effectively controlled if patients understand the disease mechanism, trigger avoidance, and proper skin care<sup>(a)</sup>

## What are the key features of the intervention?

- During the initial consultation, the dermatologist spends approximately 20 minutes on patient education
  - The dermatologist uses patient education material such as pamphlets and leaflets to explain AD and its treatment
- The material is created by both pharmaceutical companies and a dermatologist at the centre
- Topics covered in the patient education material include:
  - The treatment pathway
  - The correct way of applying topical medication
  - Advice and guidance on the side effects of medication (e.g. steroids)
  - Diagrams showing the cross section of skin to explain how treating AD involves curing inflammation both on the skin surface and below the surface
- The material is then reinforced by the dermatology nurse if the patient requires additional education. The practical application of topical treatments (such as moisturisers and corticosteroids) help solidify the patient's understanding of how to apply medication

## What are the outcomes so far?

### Benefits to patients:

- Patients are exposed to self-management techniques and advice that may improve the treatment and management of AD symptoms
- Helps alleviate concerns about certain treatment methods (e.g. use of steroids)
- Patients can develop good relationships with HCPs

### Benefits to HCPs:

- Improved treatment adherence and control in patients
- Opportunity to provide holistic care to patients and manage patient expectations
- Can reduce demand for clinic appointments as patients can better self-manage their symptoms

**Sources:** (a) Zirwas MJ, et al. Patient Education Strategies in Dermatology, Part 1: Benefits and Challenges. *J Clin Aesthet Dermatol.* 2009;2(12):24–27

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# Nurse-led education consultations

## Overview

- A dermatology nurse teaches patients how to apply topical medication and provides advice on how the patient can self-manage the disease
- After an initial consultation with the dermatologist, the patient attends a nurse-led education session



I listen to the patient's stories carefully as most of them have a number of severe symptoms

*Nurse, Hiroshima University Hospital*



## What is the rationale?

- Nurse led education sessions have been shown to demonstrate high levels of patient satisfaction and positive patient outcomes<sup>(a)</sup>
- Poor adherence to treatment is a major factor limiting treatment outcomes in patients with AD<sup>(b)(c)</sup>
- The role of the nurse (e.g. through nurse-led education) alleviates physician time constraints<sup>(d)</sup>

## What are the key features of the intervention?

- After the first consultation with the dermatologist, a dermatology nurse and trainee dermatologist educates the AD patient on how to care for their skin. Topics covered during this session include:
  - An explanation of the treatment plan to patients
  - Education on how to use ointments and self-injections (if applicable). Patients are also informed about other topical treatment medications (such as steroids) to alleviate any concerns which they may have
  - Skincare techniques for patients (e.g. how to wash their face)
- During the education session, the nurse or a family member of the patient applies ointment
- The nurse listens carefully to the patient concerns as most of them have severe conditions and might be feeling depressed. Each consultation lasts around 20 minutes
- The nurses receive training from the pharmaceutical companies to support their abilities to educate patients (e.g. on how to administer self-injections)
- A weekly meeting is organised between nurses to discuss difficult AD cases and share management techniques

## What are the outcomes so far?

### Benefits to patients:

- Improved access to timely advice and support
- Opportunity to clarify any doubts or concerns related to the treatment plan
- Ability to build relationships with HCPs

### Benefits to HCPs:

- Dermatologists get more time to discuss medical issues during consultations
- Supports up-skilling of nurses

## Challenges

- Patients may have pre-conceived ideas about the use and safety of topical treatments in AD (for example, some patients believe that steroids are dangerous). Nurses are required to tailor information and education for each patient

**Sources:** (a) DiKinder F, et al. Satisfaction with Nurse Practitioners and Intent to Adhere to Plan. *The Journal for Nurse Practitioners*. 2019;15(3):245-248; (b) Bass AM, et al. Interventions to Increase Treatment Adherence in Pediatric Atopic Dermatitis: A Systematic Review. *Journal of clinical medicine* 2015;4(2):231-42. doi:10.3390/jcm4020231; (c) Charman CR, et al. Topical corticosteroid phobia in patients with atopic eczema. *Br J Dermatol*. 2000;142(5):931-6; (d) Brown MH. A nurse-led clinic in chronic and allergic contact dermatitis. *Br J Nurs*. 2005;14(5):260-3





# The Jikei University Hospital

Tokyo, Japan

Site visited by KPMG on 1<sup>st</sup> October 2019

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CONTENTS



APPENDIX  
CENTRE REPORTS



# Summary



## Context

**Centre type:** Main hospital of the Jikei University School of Medicine hospital system. This system includes four other sites: Katsushika Medical Center (Katsushika City), Daisan Hospital (Komae City), Harumi Triton Clinic (Chuo City), and Kashiwa Hospital (Kashiwa City)

**Catchment area:** Patients from Tokyo and other neighbouring prefectures including Kanagawa, Chiba, and Saitama. The furthest patients come from Osaka

**Funding:** Initially a charity hospital which received funding through voluntary contributions. It is now a private hospital run by its own revenues

**Services:** The centre has several specialty departments in addition to dermatology, including cardiology, neurology, ophthalmology and endocrinology

**Patient population:** Paediatric and adult patients with dermatological conditions (including atopic dermatitis)



## Key strengths in the delivery of AD care

**Specialised AD clinic:** The centre has a specialised atopic dermatitis outpatient clinic three days a week, for patients to receive highly specialised care and treatment for their AD

**Multidisciplinary approach to patient education:** Patients (especially those struggling with treatment adherence) will receive further education and guidance regarding treatment usage from the dermatology nurses and clinical pharmacists, in addition to from their dermatologist (during their standard consultations)

**Expertise in allergy treatment:** In February 2019, the centre was one of the four hospitals in Tokyo selected by the Tokyo Metropolitan Government as a "Tokyo Allergic Disease Medical Core Hospital". Whilst the Allergy Centre at Jikei is still being developed, it will aim to increase collaboration between allergy specialists from different departments and provide multidisciplinary care to complex allergy patients



## Key challenges faced in delivery of AD care

**Supporting patients with topical treatment**

**compliance:** Patient non-compliance can arise from various reasons, including time-consuming treatment regimens (especially during busy periods in their lives) and corticosteroid phobia, which can negatively impact AD and result in hospitalisation

**Delayed access to timely care:** AD patients are often referred to the department after attempting a number of treatments for a long duration of time. The delayed referral can impact successful management of patient symptoms

**Time constraints in clinics:** Healthcare providers (dermatologists, nurses and pharmacists) often have a large number of patients to see in a limited amount of time at the outpatient clinics



# Atopic Dermatitis (AD) in Japan

## Japanese healthcare system:

The Japanese healthcare system is primarily funded by statutory contributions through the Statutory Health Insurance System (SHIS). This is supplemented by expenditure through private health insurance<sup>(a)</sup>

## Publically funded healthcare:

- The SHIS comprises of more than 3,400 insurers and provides universal primary coverage for all Japanese citizens. It is compulsory for citizens to enrol in an SHIS plan. Whilst the SHIS coverage is the same for everyone, premiums can vary based on age, employment status, and / or place of residence, and are determined by the national government (usually following a decision made by the Central Social Insurance Medical Council)<sup>(a)</sup>
- SHIS plans cover hospital, primary, specialty, and mental health care. They may also cover approved prescription drugs, home care services by medical institutions, hospice care, physiotherapy, and most dental care<sup>(a)</sup>
- Aside for children up to the age of 6 and adults aged 70+ with lower incomes, all SHIS enrolees pay a 30 percent coinsurance fee for services and goods received<sup>(a)</sup>
- Insurance premiums vary between types of insurance funds and municipalities. Government employees, as well as some doctors in private practises, are covered by their own insurers

## Privately funded healthcare

- The majority of the population hold some form of private health insurance, however, it only plays a supplementary or complementary role<sup>(a)</sup>
- Health insurance provides additional income in case of sickness, mainly in the form of lump-sum payments when insured persons are hospitalised or diagnosed with cancer or another specified chronic disease. Income may also be paid in daily during hospitalization over a defined period<sup>(a)</sup>

## Prevalence

- Prevalence of childhood AD is 12-13% in mainland Japan<sup>(c)</sup>
- The lifetime prevalence for AD in adults is 6.5% and 11.2% in elementary school children<sup>(1)(d)</sup>



## Care provision:

### Location:

- Mild (or well-controlled) AD care is primarily delivered by community physicians (primary care providers)
- Moderate and severe (uncontrolled) AD care is primarily delivered in specialist secondary care (within hospitals)

### Funding:

- Payments for primary care are based on a national fee-for-service schedule

## Guidelines and societies:

### Guidelines:

- Japanese Society of Allergology – Japanese guidelines for atopic dermatitis 2018<sup>(b)</sup>








### Medical societies/PAGs:

- Japanese Dermatological Association

**Note:** (1) Lifetime prevalence is the percentage of people within the population who will have AD at some point in their life

**Sources:** (a) The Japanese health care system. International health care system profiles [website] <https://international.commonwealthfund.org/countries/japan/>. Accessed Sept 10 2019 (b) Japanese guidelines for atopic dermatitis 2018. Allergology International. [website] [https://www.jstage.jst.go.jp/article/arerugi/67/10/67\\_1297/\\_article-char/ja/](https://www.jstage.jst.go.jp/article/arerugi/67/10/67_1297/_article-char/ja/). Accessed Sept 10 2019 (c) Furue M, et al. Current status of atopic dermatitis in Japan. *Asia Pac Allergy*. 2011;1(2):64–72. (d) Atopic dermatitis disease registry in Japanese adult patients with moderate to severe atopic dermatitis. Japanese Dermatological Association. [website] <https://onlinelibrary.wiley.com/doi/full/10.1111/1346-8138.14787>. Accessed 12 Sept 2019

# The centre and dermatology department

The centre		
 <b>Type and location</b>	<ul style="list-style-type: none"><li>— The Jikei University Hospital is part of the Jikei University School of Medicine located in the Tokyo prefecture of Japan. It was initially established as a charity hospital in 1882 (as the Kyoritsu Tokyo Hospital)</li><li>— In addition to the main hospital in Minato, the Jikei University has four other university sites, including: Katsushika Medical Centre in Katsushika City, Daisan Hospital in Chofu Komae, Kashiwa Hospital in Chiba and Jikei University School of Medicine Triton Clinic in Harumi<sup>(a)</sup></li></ul>	
 <b>Population served</b>	<ul style="list-style-type: none"><li>— Patients are primarily from Tokyo (population of around 9 million) and other neighbouring prefectures including Kanagawa, Chiba, and Saitama. The furthest patients come from Osaka</li></ul>	
The dermatology department		
 <b>Service Division</b>	<b>Outpatient service</b>	<b>Inpatient service</b>
 <b>Hours of availability</b>	<i>General dermatology</i> <ul style="list-style-type: none"><li>• Monday to Friday: 08:00 – 15:00</li><li>• Saturday: 08:00 – 11:00 (emergency care only in the afternoon)</li></ul> <i>Specialised atopic dermatitis clinic</i> <ul style="list-style-type: none"><li>• Tuesday, Wednesday and Thursday: 11:00 – 15:00</li></ul>	24/7
 <b>No. of patients seen</b>	154 general dermatology patients per day on average (~45 patients with AD per week)	10 patients per day on average (but rarely have AD inpatients)
 <b>Types of patients seen</b>	All dermatological conditions, including paediatric and adult patients with AD	
 <b>Facilities on-site<sup>(1)</sup></b>	<ul style="list-style-type: none"><li>— 1,075 inpatient beds (including 49 beds for psychiatric care and 1,026 beds for general care)</li><li>— Phototherapy (narrowband UVB therapy)</li><li>— Allergy tests</li><li>— Laser treatments (Vbeam laser and Ruby laser)</li><li>— Clinical trials</li></ul>	

**Note:** (1) List of facilities is not exhaustive

**Sources:** (a) The Jikei University. [website] <http://www.jikei.ac.jp/hospital/kashiwa/index.html> Accessed 15 Nov 2019



# The team

## Core team profile



**20+** Dermatologists



**5** Dermatology nurses (for outpatients, with 3 available each day)



General nurses (for inpatients)

## Wider team profile



**7** Ophthalmologists



**5** Clinical pharmacists



## Governance and processes

### Team meetings:

- *Allergy Centre logistics meeting (monthly)*
  - Attended by allergy specialists from different departments (Dermatology, Paediatrics, ENT, Internal Medicine Pulmonology)
  - The purpose of the meeting is to discuss the logistical setup of the Allergy Centre (scheduled to open in April 2020)

### Patient records:

- *Electronic medical records (EMR):*
  - Accessible by all specialists across the centre

*Note: Please see page 575 for further details about the wider team*

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients can either present to their community physician (community dermatologist or general practitioner) or directly to the centre (for a fee of ~5,000¥)
- Patients may present directly to the emergency department

*Note: Patients tend to present late at the hospital. Around 50% of patients will visit the hospital without a reference*

## Diagnosis and Referral

In secondary care



- New AD patients (either referred or directly presenting) will visit the morning general dermatology clinic at the centre
- The dermatologist will perform an initial assessment of the patient (usually 15 minutes). It is determined on a case by case basis whether the dermatologist who attends the patient is a general dermatologist or a dermatologist specialised in AD
- If the patient has AD, an appointment will be scheduled at the specialised Atopy afternoon clinic
  - If available, the patient will attend the specialised clinic on the same day

## Treatment and Management

Medical management



- The dermatologist will initiate / modify treatment based on patient assessment and preference. Topical ointment treatment choices include petroleum jelly, lotion / cream or Chinese medicine (Kampo) (consultation = 15-30 mins)
- Patients are able to collect systemic medication directly from the centre's pharmacy
- Patients may be given the opportunity to participate in clinical trials (SCORAD and EASI scores, and IgE will be collected for these patients)
- Patients will be referred to the centre's comorbidity specialists as required (e.g. ophthalmologist). Many AD patients with asthma / depression will already have been diagnosed and will be managed by a specialist
- The dermatologist will perform patch and prick testing as required (although general practitioners may have already performed patch test)

Non-medical management



- During the dermatology consultation the dermatologist will provide an overview of AD and educate the patient on how to apply topical treatments, amount to be applied, etc.
- Phototherapy is provided at the centre by the dermatologist as required

## Follow-up

Monitoring of chronic disease / flare up



- Patients requiring systemic treatment are followed up 3 days after their initial consultation. Patients on other therapies are followed up within 2-3 weeks. Thereafter, patients are generally seen every 1-2 months
- If patient symptoms are not controlled / patient requires additional guidance, the dermatologist may request the dermatology nurse (consultations = <30 minutes) or a hospital pharmacist (consultations = ~10-15 mins) to provide additional education
- Patients tend to remain at the centre for continued care (to keep monitoring the symptoms of AD) and are not referred back to the community physicians
- AD patients with infections may be admitted to the centre as an inpatient for treatment (usually 1-2 week stay)

# Roles of the wider team

## Ophthalmologist

**Patient type:** Patients with AD who have ocular comorbidities (e.g. conjunctivitis)

**Referral:** Referred by the dermatologist

**Consultations:** Ophthalmologist will perform a basic eye examination (e.g. corneal observation), perform tests (e.g. tear test) and provide treatments (e.g. lubricating eye drops, systemic therapies) as required

**Timing:** Each consultation varies depending on the patient symptoms. Follow-up frequency is dependent on patient symptoms



## Pharmacist

**Patient type:** Patients with AD (both outpatient and inpatient)

**Referral:** Referred by the dermatologist or a nurse

**Consultations:** Pharmacist educates patients on how to apply topical treatments, side effects of medications, and how to use self-injections (for biologics)

**Timing:** Outpatient consultations last 10-15 minutes. Inpatient consultations last 30 minutes

# Overview of interventions in place for AD

## Awareness and Presentation



Symptom identification

- **Public education:** The dermatologists occasionally perform public educational events on Saturdays or Sundays. The events are funded by pharmaceutical companies

## Diagnosis and Referral



In secondary care

- **Specialised AD clinic:** The centre has established a specialised atopic dermatitis outpatient clinic that runs every Tuesday, Wednesday and Thursday afternoon. Patients are able to receive care and advice for the management of their AD

See pg. 581 for case study

- **Cross-speciality communication:** Specialties are able to easily communicate with each other for advice / direct referrals through their advanced IT systems (including via a mobile phone application)

## Treatment and Management



Medical management

- **Referral to comorbidity specialists:** Dermatologists will refer patients to other specialists (e.g. ophthalmologist) in the centre when required
- **Access to clinical trials:** Patients are given the opportunity to participate interventional / observational clinical trials. The department has 2 ongoing AD trials
- **Traditional Chinese Medicine:** Before recommending biologic treatment, the dermatologists at the centre may provide access to Traditional Chinese Medicine (Kampo) made onsite, depending on patient preference



Non-medical management

- **Multidisciplinary approach to patient education:** Dermatologists, nurses and pharmacists at the centre provide extensive counselling and educational advice to patients  
 See pg. 582-583 for case study
- **Psychological support:** Patients are able to self-refer to the centre's psychologist for psychological support
- **Phototherapy sessions:** Patients may be offered narrowband UVB phototherapy sessions to help manage their AD symptoms

## Follow-up



Monitoring of chronic disease/flare up

- **Nurse-led education consultations:** During follow-up consultations at the specialised AD clinic, the dermatology nurse educates patients on AD management (see 'Multidisciplinary patient education' case study)

### Key:



Case study available



# Monitoring AD patients and comorbidities

## The dermatology unit employs measures to monitor AD in patients on clinical trials

### Objective measures (AD):

To monitor clinical trial patients and their disease, the centre utilises:

- EASI (Eczema Area and Severity Index): validated scoring system that grades the physical signs of atopic dermatitis<sup>(a)</sup>
- SCORAD (SCORing Atopic Dermatitis): to assess AD disease severity and monitor patient progress<sup>(b)</sup>

---

### Dermatology unit routinely measures comorbidity outcomes by:

- *Dermatologist*: response to allergens/control of atopic disease (e.g. prick testing, patch testing)
- *Dermatologist*: measuring IgE levels by conducting blood tests depending on the skin condition of each patient
- *Ophthalmologist*: surveillance of symptoms and specialist tests (e.g. topography / basic eye examination)

**Sources:** (a) HOME for eczema.org. EASI for clinical signs. [website] <http://www.homeforeczema.org/research/easi-for-clinical-signs.aspx> Accessed 1 Mar 19; (b) SCORing Atopic Dermatitis (SCORAD) Calculator (0.9.0) [website] <http://scorad.corti.li/> Accessed 26 Feb 2019

# Advice to other centres

## What advice would you give less specialised centres?



### Objective of advice: Optimise the use of topical treatments

- **Why?** Ensuring optimal application of topical treatments (e.g. moisturisers and topical corticosteroids) can help improve patients' response to treatment. Dermatologists and healthcare professionals can provide clear instructions about the amount and frequency of use for topical treatments. This can support patient understanding and overall treatment adherence



### Objective of advice: Understand the patient perspective

- **Why?** AD is a chronic disease which requires long-term treatment and can affect all aspects of a patient's quality of life. Dermatologists and other healthcare professionals need to consider the patient perspective to truly recognise what matters most to the patient. For example, many patients have corticophobia which can hinder treatment outcomes, however this can be circumvented through educating patients with accurate information. Developing an understanding of how AD impacts the patient's quality of life is therefore of paramount importance to developing better treatment and decision making abilities

# Next steps for the centre

## What is next for the centre?

### Objective: Launch the Allergy Centre

- **What?** In 2019, the centre was one of the four hospitals in Tokyo selected by the Japanese Government as a “Tokyo Allergic Disease Medical Core Hospital”. Currently, there is a monthly meeting where representatives from different specialties are discussing the logistical set-up of the Allergy Centre. Once established, there will be planned weekly meetings to discuss complex patients, comorbidities and agree on a multi-disciplinary treatment approach amongst the different specialties
- **Why?** The Allergy Centre aims to increase collaboration between allergy specialists from different departments, including internal medicine, dermatology, paediatrics and ear, nose and throat (ENT). The Allergy Centre will allow the specialists to provide holistic treatment and education to patients with an allergy





# Case studies



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# Specialised atopic dermatitis outpatient clinic

## Overview

- The centre has established a specialised AD clinic that runs every Tuesday, Wednesday and Thursday afternoon. Patients are able to receive care and advice for management of their AD



“My suggestion (on treatments) is important but the patient is more important”

*Dermatologist, Jikei University Hospital*



**Sources:** (a) Napolitano M, et al. Adult atopic dermatitis: new and emerging therapies. *Expt Review of Clin Pharm.* 2018 11(9): 867-878. doi: 10.1080/17512433.2018.1507734



## What is the rationale?

- New and emerging therapies are becoming available for AD patients<sup>(a)</sup>
- To appropriately treat patients with the innovative therapeutic options, dermatologists need to understand new treatment options<sup>(a)</sup>
- A dermatologist who subspecialises in AD may be better positioned to provide specialised AD care and treatment
- The dermatologist established the clinic after recognising the emerging need for specialised care in AD

## What are the key features of the intervention?

- The centre runs a specialised atopic dermatitis half-day clinic on Tuesday, Wednesday and Thursday afternoons (established ~20 years ago in response to growing AD outpatient numbers)
- Community physicians, including general practitioners and private dermatologists, initially refer AD patients to the general dermatology clinic. Following an initial assessment, patients with AD will then be referred to the specialised AD clinic
  - Where possible, patients will be seen at the specialised AD clinic on the same day (otherwise patients will be seen within the coming week)
- There are 3 dermatologists at the clinic who provide patient consultations. On average, 15 patients are seen at the clinic per week by each dermatologist. Each appointment lasts around 15 minutes
- Patients are able to receive highly specialised advice on atopic dermatitis from the dermatologist
- At the initial consultation at the specialised AD clinic, the dermatologist will perform an initial assessment and diagnosis before commencing / modifying treatment
  - The dermatologist will suggest which ointments / creams the patient should try. The patient will also be given an opportunity to try different treatments (if required)
  - The dermatologist will also assess if the patient's comorbidities are being managed
- After the consultation, depending on the doctor's instructions or the patient's request, the dermatology nurse may provide additional counselling and education
- Only severe AD cases are followed up at the AD centre

## What are the outcomes so far?

### Benefits to patients:

- Improved access to specialist treatment through specialised dermatology service

### Benefits to HCPs:

- Able to address complex and severe cases of AD

# Multidisciplinary approach to patient education (1/2)

## Overview

- Dermatologists, dermatology nurses and pharmacists are involved in providing education to patients throughout the patient pathway

**Sources:** (a) Zirwas MJ et al. Patient Education Strategies in Dermatology, Part 1: Benefits and Challenges. *J Clin Aesthet Dermatol.* 2009;2(12):24–27.



## What is the rationale?

- Patient education is an important aspect of patient care in dermatology. Successful education increases patient satisfaction and results in improved outcomes and adherence<sup>(a)</sup>
- Atopic dermatitis (AD) can be more effectively controlled if patients understand the disease mechanism, trigger avoidance, and proper skin care<sup>(a)</sup>

## What are the key features of the intervention?

- Approximately 10 years ago, the centre established a multidisciplinary approach (involving dermatologists, dermatology nurses and pharmacists) to delivering AD education throughout the patient pathway (i.e. not solely delivered by dermatologists)
- To upskill the nurses and pharmacists, dermatologists demonstrated FTUs (Finger Tip Units) by applying ointments/creams to their skin, and used practical tools to provide injection training

### Dermatologists

- During the initial consultation at the specialised AD clinic, the dermatologist educates patients on AD symptoms and management. Topics include:
  - How to apply topical treatments (e.g. ointments, corticosteroids)
  - How much of each topical treatment should be applied (and how frequently)
- Each consultation (inclusive of diagnosis and assessment) will last around 15 minutes

### Dermatology nurses

- After a follow-up consultation, if the patient is not controlling their symptoms or if there is low patient adherence, the dermatologist may refer the patient to a dermatology nurse. Nurses can speak to the patient in order to answer any further questions or concerns that the patient may have
- Nurses can also provide additional education on:
  - How to apply topical treatments without additional support (e.g. if there is no other family members and the patient requires topical application on their back)
  - Advice on which bathing products to utilise (e.g. soap free washes)
  - How to use wet wraps
  - How to dry the body without irritating the skin further
- Each consultation lasts up to 30 minutes
- Dermatology nurses are trained prior to giving this education, in how to apply ointment, the safety of steroids, etc

# Multidisciplinary approach to patient education (2/2)

## What are the key features of the intervention? (cont.)

### Pharmacists

- If a dermatologist / dermatology nurse identifies that the patient is not utilising the medication appropriately, an internal medication request form will be created on the electronic medical record
- Using leaflets produced by pharma companies, the pharmacist will receive a notification and identify which patients need to be educated upon medication collection
- The pharmacist will educate the patient on:
  - The amount of corticosteroid that should be applied
  - How to use self-injections
  - Side effects of medication
- Pharmacists are trained prior to giving this education, in how to apply ointment and about the safety of steroids

## What are the outcomes so far?

### Benefits to patients:

- Enhanced ability to build relationships with multiple healthcare professionals
- Better able to address patients questions about certain treatments (e.g. use of steroids)

### Benefits to HCPs:

- Improved treatment adherence and control of AD symptoms
- Dermatologists more able to focus on medical issues if patient education is provided by nurses / pharmacists

## Challenges

- The healthcare professionals may find it difficult to allocate time to providing education
- Patients may have a preconceived idea about the side effects of corticosteroids and resist healthcare professional education
- Treatment regimens may be lengthy, which can affect patient adherence



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"We focus on holistic education for patients"

*Dermatologist, Jikei University Hospital*





APPENDIX  
CENTRE REPORTS

# Linkou Chang Gung Memorial Hospital

Taoyuan City, Taiwan

Site visited by KPMG 25<sup>th</sup> September 2019

[kpmg.com/uk](https://kpmg.com/uk)



# Summary



## Context

**Centre type:** Chang Gung Memorial Hospital (CGMH) is a health care services provider in Taiwan, comprised of a total of 29 specialty health care centres of mixed size. This includes a network of 7 large hospital branches located in Linkou, Taipei, Taoyuan, Keelung, Yunlin, Chiayi, and Kaohsiung

**Catchment area:** Most patients are from the local areas of Taipei or Taoyuan. Patients may also come from overseas

**Funding:** Patient funding is provided primarily through the National Health Insurance (NHI) Programme, though services may be supplemented by private health insurance or self-funding

**Services:** A wide range of outpatient and inpatient specialty services, including medical and surgical dermatology care

**Patient population:** Paediatric and adult patients with dermatological conditions. The centre provides care to patients from all over Taiwan and overseas, with 10,000 outpatients seen a day and 10,000 international patients seen a year<sup>(a)</sup>



## Key strengths in the delivery of AD care

**Contribution to consensus AD management guidelines:** CGMH is a key contributor to the creation of a new Taiwanese consensus for the treatment and management of AD<sup>(b)</sup>, of which is intended to improve the standard of AD care across the health system

**Provision of AD patient education:** The centre invests time and resources during consultations and out-of-hours events to ensure patients receive adequate and ongoing education about their condition

**Use of patient registries / databases:** The centre has an internal data registry system that captures all patient information. Due to the size of the centre, this data encompasses ~90% of the Taiwanese population. This data can be used for AD research through application

**Collaboration with paediatric allergists:** The centre collaborates very closely with paediatricians who sub-specialise in allergies, in order to provide tailored guidance and support to paediatric patients



## Key challenges faced in the delivery of AD care

**Supporting primary care physicians (PCPs) with AD diagnosis:** AD is often over misdiagnosed by other specialties due to the similarity in symptoms with other causes of dermatitis (e.g. scabies and allergic contact dermatitis can manifest as a similar skin rash)

**Managing patient fears of treatment side-effects:** Patients / parents may exhibit steroid phobia (e.g. fears of skin-thinning due to overuse, which can in turn result in underuse) and concern over the side-effects of oral medications

**Supporting patients with treatment adherence:** AD patients may attempt to treat themselves or disengage with treatment altogether, due to time-consuming treatment regimens, disappointment with treatment outcomes, or the false self-diagnosis that they are stable when in reality they are not

**Managing the AD psychological impact:** AD patients may experience psychosocial problems, such as depression, anxiety, stress and sleep loss. This is particularly prevalent for adolescent patients, who may struggle to deal with stigma or forming friendships

**Sources:** (a) About Us. Chang Gung Memorial Hospital [Website] <http://www.chang-gung.com/en/about.aspx?id=11&bid=1> Accessed 15 Oct 2019; (b) Chung WH, et al. Taiwanese Dermatological Association consensus for the definition, classification, diagnosis, and management of urticarial *J Formos Med Assoc.* 2016;115(11):968-980. doi: 10.1016/j.jfma.2015.09.009

# Atopic Dermatitis (AD) in Taiwan

## Healthcare system<sup>(a)</sup>:

The Taiwanese healthcare system is primarily funded via payroll-based premiums through the National Health Insurance (NHI) Programme. Enrolment is mandatory for all citizens as well as foreigners residing longer than six months. Healthcare may be supplemented through private health insurance payments. The NHI is ultimately controlled by Taiwan's Ministry of Health and Welfare (MoHW). In Taiwan, citizens can see any doctor without a referral, and may go to any level of hospital directly<sup>(b)</sup>

## Publically-funded healthcare<sup>(a)</sup>:

- The NHI is predominantly a premium-based social health insurance system, with the majority of revenue derived from payroll-based premiums and premiums levied on non-payroll income. Premium contributions are calculated on a per capita basis and limited to a maximum of four members per household (the insured plus three dependents). Any additional members are covered for free. As at 2017, 99.9% of the population were enrolled
- NHI plans cover prescription drugs, dental care, Chinese Traditional Medicine (CTM), childbirth care, physical rehabilitation, home care, chronic mental health care, end-of-life care and inpatient and outpatient care (both primary and specialist care)
- Coinsurance for inpatient care and co-payments for physician visits are mandated, subject to limits and exemptions. The coinsurance rate for inpatient care varies by length of stay and type of bed (acute or chronic)
- Out-of-pocket spending for necessary healthcare (medical care, dental care, and prescription drugs) accounted for 12.1% of Taiwan's national health expenditure as at 2012

## Privately funded healthcare<sup>(a)</sup>:

- Private healthcare in Taiwan does not cover medical services covered by the NHI and does not guarantee faster access to specialists or diagnostic tests, or a greater choice of specialists. Private insurance therefore only plays a supplementary role. Patients can use private insurance to fund products which are not covered by the NHI

## Prevalence

- The lifetime prevalence of AD in Taiwan is approximately 6.7%<sup>(c)</sup>
- Lifetime prevalence for children between 6-7 is 6.7% and 4.1% for children aged 13-14<sup>(d)</sup>



## Care provision:

### Location:

- The majority of patients are self-referred. If not, initial diagnosis of AD will be performed by primary care physicians who then refer patients to a specialist dermatologist to finalise a treatment plan

### Funding:

- AD care is primarily funded through the NHI Programme, though services may be supplemented by private health insurance or self-funding

## Guidelines and societies:

### Guidelines:

- Taiwanese Dermatological Association consensus for the management of atopic dermatitis – 2014 report<sup>(c)</sup>

### Medical societies/PAGs:








- Taiwanese Dermatological Association (TDA)

**Note:** (1) Lifetime prevalence is the percentage of people within the population who will have AD at some point in their life

**Sources:** (a). The Taiwan Health Care System. International Health care Systems Profiles. [Website] <https://international.commonwealthfund.org/countries/taiwan/> Accessed 11 Sept 2019; (b) Wu T, et al. An overview of the healthcare system in Taiwan. *London Journal of Primary Care*. 2010;3(2):115-119; (c) Taiwanese Dermatological Association consensus for the management of atopic dermatitis, Taiwanese Dermatological Association. [Website] <https://www.sciencedirect.com/science/article/pii/S1027811715000749> Accessed 11 Sept 2019; (d) Advances in systemic treatment for adults with moderate-to-severe atopic dermatitis. Department of Dermatology, National Taiwan University. [Website] <http://www.dermisnica.org/article.asp?issn=1027-8117;year=2019;volume=37;issue=1;page=3;epage=3;aulast=Cho#ref5> Accessed 11 Sept 2019



# The centre and dermatology unit






The centre		
 <b>Type and location</b>	<ul style="list-style-type: none"><li>— Chang Gung Memorial Hospital (CGMH) is a health care services provider in Taiwan, comprised of a total of 29 specialty health care centres of mixed size. This includes a network of 7 large hospital branches located in Linkou, Taipei, Taoyuan, Keelung, Yunlin, Chiayi, and Kaohsiung</li><li>— Dermatologists at three key branches (Linkou, Taipei and Keelung) rotate to provide dermatology services</li></ul>	
	<ul style="list-style-type: none"><li>— The hospital network treats at least 2.4 million patients each year, including 167,460 surgical patients. It is estimated that one-third of the Taiwanese population have sought treatment at CGMH<sup>(a)</sup></li><li>— The network accounts for almost 10,000 outpatients per day and receives the highest number of international patients in Taiwan (over 10,000 patients per year)<sup>(a)</sup></li><li>— Most patients who are treated at the Linkou branch are from the local areas of either Taipei or Taoyuan</li></ul>	
 <b>Population served</b>		
Dermatology services		
 <b>Service Division</b>	<b>Outpatient service</b>	<b>Inpatient service</b>
	08:30 – 12:00 13:30 – 17:00	24 / 7
 <b>Hours of availability</b>		
 <b>No. of patients seen</b>	1,000 patients per month (40 – 50 patients per clinic)	10 – 15 patients per month (about 120 patients per year), with average stay ~1 week <i>Note: paediatric inpatients are managed in the paediatric department</i>
 <b>Types of patients seen</b>	Paediatric and adult patients with mild to severe AD	Patients with severe AD
 <b>Facilities on-site<sup>(1)</sup></b>	<ul style="list-style-type: none"><li>— UVB phototherapy (rarely used to treat AD patients, especially children with school commitments)</li><li>— Allergy testing facilities (skin prick and patch tests)</li><li>— Blood testing facilities</li><li>— Education Centre</li><li>— 3700 inpatient beds (25 beds in dermatology)</li></ul>	

**Note:** (1) List of facilities is not exhaustive





**Sources:** (a) About Us. Chang Gung Memorial Hospital [Website] <http://www.chang-gung.com/en/about.aspx?id=11&bid=1> Accessed 15 Oct 2019

# The team

## Core team profile ●

-  **35** Dermatologists (inc. 8 AD-specific dermatologists)
-  **3** Nurses for outpatients / studies
-  **12** Nurses for inpatients
-  **2-3** Dermatologist trainees
-  **5-6** Medical students

## Wider team profile ●

-  **70** Paediatricians (based at Linkou branch)
-  **8** Paediatricians (of the above) who specialise in allergies
-  **1** Chinese medicine specialist
-  **1** Ophthalmologist

## ● Governance and processes

### Team meetings:

- Clinical pathology conference (07:30-08:30am, twice per week):
  - Attended by: dermatology and pathology staff, with other specialists invited on a case-by-case basis
  - Purpose: to discuss complex or interesting cases, or departmental collaborations (e.g. research projects)

### Patient records:

- Electronic patient records (EHR):
  - The centre uses electronic health records for patients, of which is connected and available to use across the hospital network

### Note:

- Dermatologists, trainee dermatologists and medical students rotate their time between sites in the hospital network (Linkou, Taipei and Keelung)
- Please see page 590 for further details about the wider team

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients present to the centre through three main channels:
  - Self-referral (with awareness raised by medical / patient societies, for example through TV campaigns)
  - Internal referral (e.g. from the Chinese Traditional Medicine (CTM) department)
  - External referral (e.g. family physician, paediatrician, dermatologist)
- Patients may self-fund allergy testing (for 33 basic allergens) in primary care, if the tests are not covered by their insurance policy (e.g. if their IgE levels are too low to record)

*Note: The health system does not require referral for a patient to visit a specialist hospital (e.g. Chang Gung)*

## Diagnosis and Referral

In secondary care



- Paediatric AD patients may present / be treated in the Paediatric or Dermatology department
- An initial dermatologist consultation lasts up to 30 minutes, during which EASI and sometimes VAS / POEM scores (depending on the dermatologist) are recorded (repeated during every subsequent visit) and the patient's current skin care regimen is reviewed (e.g. which soaps and emollients they use)
- The dermatologist provides advice for using bleach baths, avoiding certain foods, avoiding mites, using dehumidifiers, choosing clothes, applying moisturisers and using soaps

*Note: the dermatologist may also record DLQI scores (decided on a case-by-case basis)*

## Treatment and Management

Medical management



- Treatments prescribed include steroid / non-steroid topical therapies, oral therapies (including antihistamines) and immunosuppressants
- Skin prick, patch and blood tests may be performed in the dermatology department, however patients may be referred to the allergy department for blood tests (IgE) if the patient has a skin rash, a serious food allergy or is due to begin systemic therapy
- Patients with AD-related psychosocial symptoms / ADHD may be referred to an in-house psychiatrist (~2% of patients)
- Paediatric patients presenting with allergic rhinitis, allergies and / or asthma will be referred to a general paediatrician or a paediatrician with a sub-speciality in allergies. Adult patients will be referred to an allergist
- The centre is currently participating in ~10 AD clinical trials (involving adult and paediatric patients), facilitated by dedicated research nurses

Non-medical management



- The dermatologist or nurse provide tailored advice on appropriate emollients and wet-wraps (given their individual needs / preferences) including when and how to apply them
- After the initial consultation, a dermatology resident and nurse may provide additional educational materials and information to the patient about AD and the treatments available
- Phototherapy is offered at the centre but is rarely used

*Note: A recent change in local law means insurance now allows phototherapy to be provided by local clinics, not just large hospitals*

- Adolescent patients (aged 12-18yrs) may be managed in either the Dermatology or Paediatric department (at age 18+ they would be in Dermatology)

## Follow-up

Monitoring of chronic disease / flare up



- Follow-up appointments with the dermatologist are generally shorter (5-30 minutes) than the initial consultation
- An initial cycle of 3 months is prescribed for each drug. If ineffective, the drug is switched for an alternative
- If a patient requires further AD education, they may be hospitalised as an inpatient and managed by trainee dermatologists and nurses. Education will be provided by the dermatologist, with assistance from medical residents and nurses (on wet-wrap application, etc.)
- Patients may be referred to the onsite CTM department for alternative treatment (who is also a qualified physician) if they refuse to have conventional therapy
- Well-controlled patients may be referred back to their local clinic for continued treatment

# Roles of the wider team



## Paediatrician

**Patients:** Paediatric patients (all ages, however most patients are aged 3+ years) with severe AD, as well as those with asthma, food allergies, allergic rhinitis, mite allergies and rheumatic diseases

**Referral:** Referrals are primarily through self-referral (80-90% of total), with the remainder from local clinics (~70% from pediatricians, ~30% from dermatologists)

**Consultations:** The principle focus of the first 1-3 consultations will be spent educating the patient and care-givers, where topics covered include moisturizing, avoiding certain foods and how to do wet wrap therapy. Patients may also undergo a specific allergy test, such as a skin prick or blood (IgE) test, and will have their weight assessed in order to help inform how the patient should manage any food allergies (i.e. food avoidance is less advisable for patients who are underweight)

**Timing:** First consultation = 15 – 30mins; Follow-up = ~15mins



## Paediatric allergist

**Patients:** Severe AD patients (aged 3 years+), and those with asthma, food allergies, allergic rhinitis, mite allergies

**Referral:** Majority of patients (80-90%) are self-referred. Patients may also be referred for a specific allergy test, or if they need further education (from the local clinic)

**Consultations:** The pediatric allergist will assess serum (IgE levels) and the weight of the paediatric patients, in order to formulate a plan to manage food allergies (since food avoidance is not recommended for underweight patients)

**Timing:** First consultation lasts up to 30 minutes (generally 15-20 minutes including general education). Follow-ups are scheduled within 1 month (1 or 2 weeks if the patient is acute), and then 2-3 months (maximum gap between visits is 3 months)



## Ophthalmologist (with specialist training in uveitis)

**Patients:** Mild to severe AD patients with ocular symptoms (corneal trauma, conjunctivitis, etc.)

**Referral:** Referred by dermatologist

**Consultations:** The ophthalmologist will perform standard tests and provide appropriate treatments as required (e.g. topical steroids for conjunctivitis). A nurse may assist with the ophthalmology tests

**Timing:** Initial consultation = 10 – 15mins. AD patients with conjunctivitis are usually only seen once. Follow-up consultations may be scheduled once a week, once a month, every 6 months or annually

*Note: The ophthalmologist is currently working on an AI (artificial intelligence) project exploring whether images of the eye can be used to predict AD disease progression. The project involves a large repository of images which the ophthalmologist adds to during each AD consultation (~3-5mins)*



## Chinese Traditional Medicine (CTM) specialist (also a qualified physician)

**Patient type:** Paediatric and adult patients with AD who desire CTM

**Referral:** Patients are primarily self-referred from outside the hospital. The CTM specialist rotates between the three northern centres in the hospital network

**Consultations:** The CTM specialist will perform a whole body evaluation (10-30mins) and educate the patient on the cause(s) of their disease. CTM treatments recommended are produced and patented by the hospital's own laboratory. Patients may be referred to dermatology (e.g. AD patients with severe infections)

**Timing:** Initial consultation = 10-30 minutes; Follow-up = ~5 minutes, scheduled every 1–2 weeks for severe cases initially and every 4 weeks for mild cases (but patients will then decided on their follow-up frequency)

*Note: CTM is only partially funded by Taiwan national insurance. Most CTM medicine is therefore paid out-of-pocket by the patient*



# Overview of interventions in place for AD

## Key:



Case study available

## Awareness and Presentation



Symptom identification

- **Establishing a patient advocacy group (PAG):** In 2018, a dermatologist at the centre helped to establish the Atopic Dermatitis Patient Association (ADPA), a Taiwanese society of AD patients. The society aims to raise awareness of AD, improve access to medications, and educate HCPs, patients and their families about AD treatment and management

See pg. 596 for case study

## Diagnosis and Referral



In secondary care

- **Use of Patient Reported Outcomes (PROs):** The centre uses various metrics to measure PROs, in order to assist in the future diagnosis of patients

## Treatment and Management



Medical management

- **Consensus for the management and treatment of AD:** The centre is one of seven centres currently involved in the creation of a new Taiwanese consensus for the treatment and management of AD (due to be published December 2019)

See pg. 597 for case study

- **Participation in clinical trials:** Both adult and pediatric patients are able to participate in clinical trials. The centre currently has 10 AD-related clinical trials



Non-medical management

- **Nurse-led patient education:** Physicians, dermatology nurses and nurses are involved in the education of the patient, through attending consultations, providing educational materials, and holding educational / follow-up appointments as required

See pg. 598 for case study

- **Patient education materials:** Patients / parents are provided with educational materials to take home, either developed by the manufacturers of medical products (e.g. wet wraps) or printed from the educational resources on the hospital website (created and proofread internally by the centre's specialists)

See pg. 599-600 for case study

## Follow-up



Monitoring of chronic disease/flare up

- **Registry of patients with severe AD:** The centre maintains a registry of severe AD patients, which includes over 300 DNA, blood and serum samples (used to monitor patient progress and for use in ongoing and future clinical research)

See pg. 601 for case study

- **National patient database:** The Chang Gung Memorial Hospital Network records data from ~90% of the Taiwanese population, representing a valuable data source for use in AD research

- **Patient forum and support group:** The centre hosts forums for patients with severe AD. These events involve physician presentations and patient discussions to facilitate knowledge sharing and improve self-management

See pg. 602-603 for case study



# Monitoring AD patients and comorbidities

## The dermatology department measures disease activity at each patient visit and stores all results electronically

### Objective measures (AD):

AD scoring indices are used to monitor patients and their disease, including:

- EASI (Eczema Area and Severity Index): a tool used to measure the extent (area) and severity of atopic eczema<sup>(a)</sup>
- vIGA-AD™ (Validated Investigator Global Assessment for Atopic Dermatitis): scoring system for use in clinical trials which grades the overall appearance of AD lesions based on a series of morphological descriptions<sup>(b)</sup>

### Patient-reported outcomes:

- DLQI (Dermatology Quality of Life Index): dermatology related quality of life questionnaire<sup>(c)</sup>
- POEM (Patient Oriented Eczema Score): a practical self-assessed measurement tool for monitoring aspects of atopic eczema that are important to patients in routine clinical practice or in the clinical trial setting<sup>(d)</sup>
- VAS (Visual Analogue Score): used to assess pruritus intensity using a 12-Item Pruritus Severity Score (12-PSS) and VAS<sup>(e)</sup>

---

### Dermatology unit routinely measures comorbidity outcomes via:

- Blood tests (including IgE and LDH): used if patient is going on systemic therapy, in order to assess allergy severity and provide a measurable goal for patients (i.e. change in IgE levels)
- Skin prick test: performed by the paediatric allergist
- Patch testing: performed by the dermatologist

**Sources:** (a) EASI for clinical signs: Harmonising Outcome Measures for Eczema (HOME) [Website] <http://www.homeforeczema.org/research/easi-for-clinical-signs.aspx> Accessed 13 March 2019; (b) Validated Investigator Global Assessment For Atopic Dermatitis (vIGA-AD™) Scale [PDF] [https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale\\_vIGA-AD\\_2017.pdf](https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale_vIGA-AD_2017.pdf) Accessed 26 June 2019; (c) Lewis V, et al. 10 Years' Experience of the Dermatology Life Quality Index (DLQI). *J Invest Dermatol Symp Proc.* 2004;9(2):169-80; (d) Charman CR, et al. Translating Patient-Oriented Eczema Measure (POEM) scores into clinical practice by suggesting severity strata derived using anchor-based methods. *Br J Dermatol.* 2013;169(6):1326-1332; (e) Reich A, et al. 12-Item Pruritus Severity Scale: Development and Validation of New Itch Severity Questionnaire. *Biomed Res Int.* 2017

# Advice to other centres

## What advice would you give less specialised centres?



**Objective of advice:** Attempt to understand specifically what each patient needs to manage their symptoms

- **Why?** Atopic dermatitis is a complex, multi-faceted disease which can vary significantly between patients. Patients themselves have different backgrounds and lifestyles, and may have different preferences regarding treatment options. Understanding the needs of individual AD patients will increase the likelihood of selecting a treatment that they are satisfied with and will adhere to



**Objective of advice:** Assign adequate time and resources to educating patients

- **Why?** Due to the complexity of the disease (e.g. there being a variety of causal factors) and AD treatment regimens (e.g. multiple topical treatments) it is important to spend sufficient time educating patients to ensure that they understand how to best manage their disease. In addition to providing 1:1 education between healthcare professionals and patients (i.e. in consultations), activities such as conferences / group education sessions allow patients to share their experiences and 'top tips' (i.e. specific information that only long-term AD patients would know) with each other, and build peer-to-peer relationships (i.e. patient to patient)



**Objective of advice:** Support HCPs to remain up-to-date on the latest developments in AD care

- **Why?** Dermatologists, nurses and other HCPs who care for AD patients should receive ongoing education regarding the latest developments in AD treatment and management. Understanding new and existing treatments (i.e. when and how each should be used and monitored) and methods will ensure patients benefit from the most up-to-date knowledge and advice, therefore improving the likelihood of good treatment outcomes



**Objective of advice:** When required, refer AD patients to HCPs with more experience and / or access to new treatments

- **Why?** AD patients with a moderate-severe diagnosis of AD are at risk of developing comorbidities. As a result, they require more support and input from multiple specialists (e.g. allergists, ophthalmologists and pulmonologists), as well as access to new treatments available via trials. Promptly referring patients to appropriate specialists has the potential to start patients on appropriate treatments sooner, which may prevent avoidable worsening of symptoms and improve patient outcomes

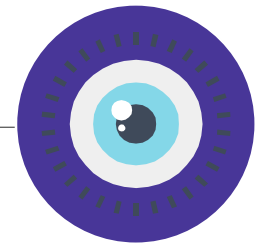


# Next steps for the centre

## What is next for the centre?

**Objective:** Utilise AI to help manage AD eye comorbidities

- **What?** Develop understanding of AD eye comorbidities through using AI to take images of the patient's eyes, in order to track AD disease progression over time
- **Why?** By visually recording how AD impacts the eyes and its progression, it will improve assessment of AD eye comorbidities and how this can be managed through predicting how it will advance



**Objective:** Create materials which help paediatric patients learn to self-manage their AD symptoms from an early age

- **What?** Develop a contact book for children to track their usage of different treatments
- **Why?** Atopic dermatitis is a complex, chronic disease. Teaching patients to self-manage their symptoms at a young age has the potential to improve long-term patient engagement with treatment, help patients reach a 'well-controlled' condition sooner and reduce the care burden on parents



**Objective:** Expand provision of new AD therapies to a wider patient pool

- **What?** Work with different phenotypes of AD patients to assess and evaluate the effectiveness of new therapies in development
- **Why?** By testing new therapies amongst a variety of AD manifestations, it may potentially expand what treatments are available to more patients and enhance the efficacy of care provided



# Case studies



	#
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# Establishing a patient advocacy group (PAG)

## Overview

- In 2018, a dermatologist at the centre helped to establish a Taiwanese society of AD patients
- The society aims to raise awareness of AD, improve access to medications, and educate HCPs, patients and their families about AD treatment and management

## What is the rationale?

- AD patient associations / societies have the potential to raise public and government awareness of the disease, which may improve funding and access to medication for patients<sup>(a)</sup>
- Educational initiatives run by these societies can improve the understanding of AD for HCPs, patients and their families, which can improve treatment outcomes and the extent to which patients can self-manage their symptoms<sup>(b)</sup>

## What are the key features of the intervention?

- The Taiwanese society of AD patients was established in 2018, assisted by a Chang Gung dermatologist who is now a society board member
- The society aims to support the patient through making the government aware of the burden experienced by AD patients. This is to make reimbursement for treatments more likely and improve access to medications
- It has been argued that government bodies are swayed predominantly by physicians and pharmacists. The lobbying power of PAGs was therefore a key reason for the society's establishment, as funding for new AD treatments must be secured from the government's existing budget<sup>(c)</sup>

### PAG activities:

- Education programmes developed by the society for schools aim to educate children and teachers about AD and prevent bullying
- The society runs events every 3-4 months, including:
  - a) Patient workshops (attended by 20-30 people per session):
    - Last 30-40 minutes, facilitated by a dermatologist and often a nurse
    - The physician / nurse advises patients how to apply moisturiser samples and other treatments, and provide additional support as required
  - b) Annual meeting (attended by 70-80 HCPs and 100+ patients):
    - Hosted at the centre
    - Lasts 2-3 hours, hosted and presented by two dermatologists from the centre (followed by Q&A)
    - Intended to provide the public with new information relating to AD and to correct common misconceptions about the disease:
- Society events are promoted via social media, newspaper adverts and by HCPs directly. A previous PAG associated with the centre even used a well-known film actor to publicise events

**Sources:** (a) Wong I, et al. Guidelines for the management of atopic dermatitis (eczema) for pharmacists, *Can Pharm J (Ott.)* 2017;150(5):285-297. doi: 10.1177/1715163517710958; (b) Cervero RM, et al. The Impact of CMA on Physician Performance and Patient Health Outcomes: An Updated Synthesis of Systematic Reviews. *J Contin Educ Health Prof.* 2015;35(2):131-139; (c) KPMG interviews at Linkou Chang Gung Memorial Hospital



# Consensus for the management and treatment of AD

## Overview

- The centre is one of seven currently involved in the creation of a new Taiwanese consensus for the treatment and management of AD (due to be published December 2019)



It is important there are up to date recommendations to help guide and support healthcare professionals in their management of patients

*Dermatologist, Linkou Chang Gung Memorial Hospital*



## What is the rationale?

- A Taiwanese consensus for the management of atopic dermatitis has not been produced since 2014<sup>(a)</sup>
- There is also a current lack of standardisation of the assessment of clinical signs and core patient outcomes of AD<sup>(b)</sup>

## What are the key features of the intervention?

- Chang Gung Memorial Hospital is one of seven centres currently involved in the creation of a new algorithm / consensus for the treatment and management of AD
- Each centre involved has designated representatives for the project who are responsible for composing a specific section of the document (for example, the two Chang Gung representatives are responsible for the section regarding systemic management of immunotherapy)
- Participants began writing the Taiwanese AD treatment and management guidelines in 2019
- The aim is to publish the guidelines in the Taiwanese Dermatological Association journal (DermatologicaSinica<sup>(c)</sup>) in time for the association's winter conference (December 2019)
- The final document will be reviewed by physicians from a wider group of centres (beyond the 7 main contributors)
- The second core team meeting for the project was held in October 2019
- The next upcoming guidelines are in submission to the Journal of the Formosan Medical Association<sup>(d)</sup>

## What are the desired outcomes?

### Benefits to patients:

- Enhanced patient care and quality of life through the facilitation of evidence-based decision making (as outlined in treatment guidelines)

### Benefits to HCPs:

- Advice and guidance made readily available regarding the latest developments in AD treatment and management in Taiwan

## What's next?

- Publish the guidelines in the Taiwanese Dermatological Association journal (DermatologicaSinica) in time for the association's winter conference

**Sources:** (a) Taiwanese Dermatological Association consensus for the management of atopic dermatitis, Taiwanese Dermatological Association [Website] <https://www.sciencedirect.com/science/article/pii/S1027811715000749> Accessed 11 Sept 2019; (b) American Academy of Allergy, Asthma & Immunology. The Harmonising Outcome Measures for Eczema (HOME) statement to assess clinical signs of atopic eczema in trials [Website] <https://www.ncbi.nlm.nih.gov/pubmed/25282560> Accessed 12 Sept 2019; (c) DermatologicaSinica [Website] <http://www.dermsinica.org/> Accessed 17 Oct 2019 (d) Journal of the Formosan Medical Association [website] <https://www.journals.elsevier.com/journal-of-the-formosan-medical-association> Accessed 14 Feb 2019

# Nurse-led patient education

## Overview

- Following the initial dermatologist consultation, dermatology nurses run separate appointments intended to teach patients what AD is and how to use their prescribed treatments (e.g. applying wet-wraps)
- The nurses print out educational materials for patients to take home and schedule follow-up appointments as required



The advice we give patients really depends on the individual. It's important to remember that different things work better for different people

*Dermatology nurse, Linkou Chang Gung Memorial Hospital*



## What is the rationale?

- Nurse-led clinic sessions have been shown to receive higher patient / parent satisfaction than physician appointments<sup>(a)</sup>
- Patients often prefer 1:1 consultations (rather than group sessions) and may need help consolidating and building upon the AD education received during their dermatologist appointment<sup>(b)</sup>

## What are the key features of the intervention?

- There are three ways that education is provided:
  1. Via the physician (dermatologist or paediatrician with allergy sub-specialism) (~30–60 mins)
    - They will provide education to the patient (and care-givers, if applicable) over 1-3 consultations, where the nurse will be present. Patient information will be printed out from the hospital website during consultations (by physician or nurse)
    - Topics covered will include moisturizing, avoiding certain foods and how to apply wet-wrap therapy (same for the dermatology nurses). Education will be provided selectively (1-2 items) to ensure that the patient retains as much information as possible
  2. Via nurses in the Education Centre (~20–30 mins)
    - The Education Centre is based in the 'Pediatric Allergy and Asthma Centre', and is targeted at allergy / asthma patients
    - Patients will be seen by the nurse after the consultations briefly to reinforce learnings from the paediatrician
  3. Via dermatology nurses (~20–30 mins)
    - Dermatology nurses will be present at the dermatology patient consultations, where they may print out educational material from the hospital website that covers the disease and treatment available
    - They may also provide additional education to patients during the consultations. They will be trained by the dermatologist to ensure they are able to do this

## What are the outcomes so far?

### Benefits to patients:

- Reinforced learning and more opportunities to ask more questions
- Opportunity to build relationships with other HCPs (beyond the physician)

### Benefits to HCPs:

- Increased potential to improve patient treatment adherence through education
- Physicians have more time to address other medical issues (if nurse is providing education)

**Sources:** (a) Sullivan PB, et al. Parent satisfaction in a nurse led clinic compared with a paediatric gastroenterology clinic for the management of intractable, functional constipation. *Arch Dis Child*. 2006;91(6):499–501. doi:10.1136/adc.2005.087486; (b) KPMG interviews

# Patient education materials (1/2)

## Overview

- Patients / parents are provided with educational materials to take home, either developed by the manufacturers of medical products (e.g. wet-wraps) or printed from the educational resources on the hospital website (which were created and proofread internally by the centre's specialists)

## What is the rationale?

- Patient education can improve adherence to treatment, which is particularly important in AD care<sup>(a)</sup>
- For over 50% of AD patients referred to specialists by PCPs, the primary reason for ineffective treatment is incorrect treatment administration (which patient education can begin to address)<sup>(b)(c)</sup>

## What are the key features of the intervention?

- The centre provides educational materials for patients via the hospital website (for AD and other conditions)
- The dermatologist provides patients with a 'tips and tricks' booklet regarding wet-wraps, and talks patients through applying them step-by-step



Pages from the wet-wraps 'tips and tricks' booklet (developed by the wet wrap manufacturer)

- The booklet contains useful guidance regarding:
  - Which wet-wrap materials to use and in what quantities
  - How to prepare the materials for application
  - How to apply the materials to specific body areas (e.g. wrist, knee, ankle, torso, head)
  - How to wash wet-wrap materials for re-use
- HCPs in local clinics often refer patients to the centre to learn the correct wet-wrap procedure (e.g. if they have too few physicians / nurses to teach all their patients)
- Patients may source wet-wrap materials from outside the centre (e.g. from their local PCP or purchasing their own) and bring them to the centre to learn application techniques

**Sources:** (a) Wollenberg A, et al. Consensus-based European guidelines for treatment of atopic eczema (atopic dermatitis) in adults and children: part II. *J Eur Acad Dermatol Venereol*. 2018;32(6):850-878. doi: 10.1111/jdv.14888; (b) Ellis RM et al. Potential barriers to adherence in pediatric dermatology. *Pediatr Dermatol* 2011;28:242-4; (c) Arkwright P, et al. Management of Difficult-to-Treat Atopic Dermatitis. *J Allergy Clin Immunol Pract*. 2013;1(2):142-51. doi: 10.1016/j.jaip.2012.09.002



# Patient education materials (2/2)

## What are the key features of the intervention? (cont.)

- Supplementary wet-wrap advice offered includes applying the materials during the day rather than at night (as the process requires ~8 hours in total)
- Wet-wrap materials may not be covered by a patient's insurance policy, however the materials are generally considered affordable for the majority of the population
- . Gauze may be used instead (though is considered less convenient)
- The paediatrician provides in-person education to AD patients and their parents, while also printing out educational materials from the hospital website (see right)

*Note: all materials provided have been created and proofread internally by the centre's specialists*

## What are the outcomes so far?

### Benefits to patients:

- A structured, easy-to-follow guide for the patients / parents regarding how to self-apply wet-wrap treatments away from the centre
- Useful and convenient reference tools for answering basic questions on AD treatment / management

### Benefits to HCPs:

- A standardised approach to educating patients / parents on wet-wrap application
- Potential for fewer outpatient appointments due to improved patient self-management
- Readily available materials to reinforce the AD education delivered in dermatologist / nurse consultations



CENTRE REPORTS



We try to fix our patients' skin and teach them to manage their symptoms themselves, which should reduce the psychological impact of the disease"

*Dermatologist, Linkou Chang Gung Memorial Hospital*



*AD patient education materials lifted from the hospital website*



# Registry of patients with severe AD

## Overview

- The centre maintains a registry of patients with severe AD, which includes a collection of over 300 DNA, blood and serum samples
- New samples are collected regularly to monitor patient progress and for use in ongoing and future clinical research



The AD patient registry is a valuable resource. We recommend the structured collection of biosamples if you have a focus on clinical research

*Dermatologist, Linkou Chang Gung Memorial Hospital*



## What is the rationale?

- A local patient registry creates a single point of access for relevant patient data that can be extracted and analysed for different research purposes<sup>(a)</sup>
- A registry can act as a means of quality control and the data can help drive service improvement and professional development<sup>(a)</sup>

## What are the key features of the intervention?

- Linkou Chang Gung Memorial Hospital (CGMH) has a registry of patients with moderate to severe AD (EASI>7). It consistently collects data from these patients, including those patients being treated with recently developed and marketed therapy
- DNA samples have been collected from these patients for the last 5 years to support an ongoing genotype and phenotype assessment
- The collection of samples has recently been expanded to include blood and serum samples from patients on biologic therapy
- Over 300 samples have been collected and recorded to date in the collection of samples, for use in ongoing and future studies at the centre
- Only CGMH contributes to the registry. The data is stored in the CGMH lab and managed by the core team of AD-specific dermatologists

## What are the desired outcomes?

### Benefits to patients:

- Potential for care quality improvements and enhanced patient outcomes

### Benefits to HCPs:

- A consistently updated source of relevant patient data for use in ongoing and future clinical research
- Ability to monitor patient progress over time
- A mean of quality of control

**Sources:** (a) Nelson EC, et al. Patient focused registries can improve health, care, and science. *BMJ*. 2016;354(8065). doi: 10.1136/bmj.i3319



# Patient forum and support group (1/2)

## Overview

- Approximately every 3 months, the centre hosts a forum for patients with severe AD (and their families). These events involve physician presentations and patient discussions to facilitate knowledge sharing and improve self-management

## What is the rationale?

- AD can negatively impact the quality of life of patients and their families<sup>(a)</sup>
- Support groups can enhance patient education and provide patients (and their families) with a platform to share their experiences and learn from one another<sup>(b)</sup>
- Medical professionals may also learn new ways to counsel patients and their families<sup>(c)</sup>
- Evidence suggests support groups can help to improve the quality of life (QoL) of AD patients (especially children)<sup>(d)</sup>

## What are the key features of the intervention?

- Approximately every 3 months, the hospital hosts a forum for patients with severe AD symptoms. The initiative has been running for ~10 years
- Each forum lasts for around 4 hours and involves lectures / presentations from 3 physicians (e.g. dermatologists, paediatricians)
- The forums aim to teach AD patients how to improve the self-management of their symptoms
- Patients also educate each other during the sessions, by asking each other questions, sharing past experiences and providing examples of effective self-management techniques. Many patients therefore attend multiple forums in order to continue exchanging ideas
  - For example, previous forum agenda involved:
    - Panel speech (i.e. presentation) on knowledge sharing about atopic dermatitis
    - Panel speech (i.e. presentation) on treatment and caring for atopic dermatitis
    - Q&A to enable patients to share knowledge with each other
- The forums are primarily publicised using posters and over the internet (e.g. hospital website). Physicians may also invite patients directly who they feel would benefit from the sessions
- Nurses will assist in arranging the forums, and usually do not provide consultation at the events
- The most recent patient forum was attended by 70-80 patients (a mix of children and adults)

**Sources:**(a) Lifschitz C. The impact of atopic dermatitis on quality of life. *Ann NutrMetab.* 2015;66(1); (b) Eczema: Overview. Institute for Quality and Efficiency in Health Care (IQWiG). <https://www.informedhealth.org/how-does-skin-work.2534.en.html>. Published 2013 Sep 26 Accessed 09 September 2019; (c) Cestari T, Weber M, Neto PF, et al. The role of support groups in the treatment of atopic dermatitis. *JAAD.* Volume 52, Issue 3, P74-P74; (d) Weber MB, Neto PF, Prati C, et al. Improvement of pruritus and quality of life of children with atopic dermatitis and their families after joining support groups. *J Eur Acad Dermatol Venereol.* 2008;22(8):992-7

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# Patient forum and support group (2/2)



## What are the outcomes so far?

### Benefits to patients:

- Provision of a platform to interact with other AD patients, share personal experiences and ask questions
- Opportunity to learn new self-management techniques

### Benefits to HCPs:

- Opportunity to learn first-hand about the challenges faced by patients and develop patient-focused care methods

## What's next?

- At the next forum, it is anticipated that the patients who have received the new biological therapy for AD (that has been available in Taiwan for less than two years) will share their experience of treatment so far



# Mount Sinai & Icahn School of Medicine Main Campus

**New York, United States of America**

Site visited by KPMG 12<sup>th</sup> September 2019

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[kpmg.com/uk](https://kpmg.com/uk)



# Summary



## Context

- **Centre type:** Based in New York City, The Mount Sinai health system was founded in 1852 with the network consisting of eight hospitals and the Icahn School of Medicine
- **Catchment area:** Primarily patients from New York and New Jersey but also patients from outside the state, including internationally
- **Funding:** Mount Sinai health system is a not-for-profit organisation, receiving funding from donations and philanthropy. Physicians working at Mount Sinai all accept Mount Sinai insurance plans and have the autonomy to accept further public and private insurers and patient self-pay
- **Services:** Mount Sinai employs over 7,400 physicians and provides 3,815 inpatient beds treating both adult and paediatric patients. The dermatology department provides services for acute and chronic care for medical, surgical and cosmetic dermatology for both adult and paediatric patients (including specialists in atopic dermatitis [AD])
- **Patient population:** Paediatric and adult patients with moderate to severe dermatological conditions



## Key strengths in the delivery of AD care

- **Centre of excellence in eczema:** Patients have access to physicians across the Mount Sinai network due to the department's collaborative relationship (e.g. MDTs) with comorbidity specialists, such as allergists, dermatologists, gastroenterologists, psychiatrists, psychologists and ophthalmologists
- **Access to clinical trials:** One of the largest dedicated Clinical Trials Unit in the USA, which is embedded within the dermatology department and provides eligible patients the opportunity to participate in a number of leading clinical trials
- **Training:** Trainee doctors have access to extensive training programs in inflammatory skin diseases, and are involved in cutting-edge research with access to Laboratories of Inflammatory Skin Diseases
- **Extended consultations:** Dermatologists provide in-depth consultations for all patients, with longer consultations for new and chronic patients (20-30mins). Patients are given in-depth treatment plans, which they discuss with medical assistants or residents (15 mins) following their specialist consultation



## Key challenges faced in delivery of AD care

- **Complex and time consuming treatment regimens:** Patients and families can struggle to adhere to their self management plans due to their complexity (i.e. multiple treatments required) and the chronic nature of the disease, requiring comprehensive education from the team
- **Managing patient expectations:** Patients and relatives will attend with a range of expectations shaped from prior experience (e.g. previous healthcare professional consultations) which the team need to appropriately manage. For example, some patients may believe they can be cured whilst others are resigned to the idea that their condition cannot be improved



# Atopic Dermatitis (AD) in the USA

## USA healthcare system

The USA healthcare system is publically and privately funded, with government spending accounting for 49% of the total health spending in 2014<sup>(a)(b)</sup>

### Publically funded healthcare

- The main channels of public spending are Medicare, Medicaid and Affordable Care Act (ACA) subsidies.<sup>(a)</sup>
  - Medicare is a national health insurance program in the USA which primarily provides health insurance to Americans aged 65 and older
  - Medicaid is a health coverage program for Americans with low income and resources
  - The Affordable Care Act (ACA), is a USA law to establish shared responsibility between the government, employers, and individuals for ensuring that all Americans have access to affordable and good-quality health insurance
- The ACA expanded Medicaid to make policies affordable, by extending the fund subsidies to nearly all low-income individuals with incomes at or below 138% of the poverty level. However innovative medicines are not often covered by Medicaid<sup>(a)</sup>

### Privately funded healthcare

- Private insurance is regulated mostly at the state level. In 2014, state and federally administered health insurance marketplaces were established to provide additional access to private insurance coverage, with income-based premium subsidies for low- and middle-income people<sup>(b)</sup>
- The five biggest commercial health insurers are UnitedHealth, Anthem, Aetna, Cigna and Humana, together representing about 43% of the total insured population. There is increasing consolidation of Pharmacy Benefit Managers (PBMs), which act as intermediaries between insurers and providers<sup>(a)</sup>
- As part of private healthcare insurance, an individual may have to pay a set amount of deductibles before their insurance begins to cover their treatment. Deductibles on employer-based health plans averaged US\$1,350 per person in 2019<sup>(a)</sup>
- There are different types of insurances. Some plans may restrict patients from seeing physicians who are part of the insurance group or are not part of a preferred list of providers. However patients can opt to use other providers, but will only be recouped a certain percentage. This requires some patients to pay out of pocket for services<sup>(e)</sup>.

## Prevalence

- In the USA, AD affects 12.98% of children<sup>(c)</sup> and 7.3% of adults<sup>(d)</sup>
- Of the USA adults with AD, 60.1% have mild AD while 28.9% and 11% have moderate and severe AD respectively<sup>(d)</sup>



## Care provision

### Location:

- Mild (or well-controlled) AD care is primarily delivered by PCPs (primary care providers)
- Moderate and severe (uncontrolled) AD care is mostly delivered by specialist dermatologists

### Funding:

- The practice receives funding from both public and private insurance for their care provision

## Guidelines and societies

### Guidelines:

- Guidelines of care for the management of atopic dermatitis: American Academy of Dermatology
- Recommendations for atopic dermatitis care: Annals of Allergy, Asthma & Immunology

### Medical societies/PAGs:

- American Academy of Dermatology
- National Eczema Association (NEA)
- Asthma and Allergy Foundation of America
- Global Parents for Eczema Research
- Pediatric Dermatology Research Alliance
- AltogetherEczema

**Sources:** (a) The Economist Intelligence Unit. Industry Report: Healthcare United States of America. Published 2nd Quarter 2019. Accessed 4 Sept 2019; (b) International Health Care System Profiles. The U.S. Health Care System. [Website] [https://international.commonwealthfund.org/countries/united\\_states/](https://international.commonwealthfund.org/countries/united_states/) Accessed 4 Sept 2019; (c) Silverberg J. Public Health Burden and Epidemiology of Atopic Dermatitis. *Dermatol Clin*. 2017;35(3):283-289; (d) Chiesa Fuxench ZC, et al. Atopic Dermatitis in America Study: A Cross-Sectional Study Examining the Prevalence and Disease Burden of Atopic Dermatitis in the US Adult Population. *J Invest Dermatol*. 2019;139(3):583-590. doi: 10.1016/j.jid.2018.08.028; (e) Different Types of Health Plans: How They Compare [Website] <https://www.webmd.com/health-insurance/types-of-health-insurance-plans#1> Accessed 20 Sept 2019

# The Eczema centre and dermatology department

## The Centre



### Type and location

- The Mount Sinai Health System is an integrated health care system which consists of eight hospital campuses and the Icahn School of Medicine, as well as a large regional ambulatory footprint in the New York metropolitan area
- Dermatology services are provided at 10 clinics and practices located across New York, with numerous additional satellites in Brooklyn, Queens and Scarsdale

*Note: this report covers only the dermatology department located at Mount Sinai Doctors East 98<sup>th</sup> Street (Icahn School of Medicine)*



### Population served

- Mount Sinai primarily caters to the population of the New York metropolitan area, with the majority of patients residing in New Jersey and New York City (catering for two thirds of the City's population). It also receives patients from all over the world, who come to the USA due to the reputation of its healthcare



### Service Division



### Hours of availability



### No. of patients seen



### Types of patients seen by the AD specialist dermatologists

## Dermatology department at Mount Sinai Doctors East 98<sup>th</sup> Street

### Outpatient service

Monday to Friday: 6:30am – 7pm

Approximately 500 patients per week

Type of patient varies between clinics, however within the Inflammatory Skin Disease clinic, dermatologists see paediatric and adult AD patients (more than half of the patients seen are adults). 50-60% of patients seen are with suspected or confirmed AD, the remainder are a mix of psoriasis, alopecia areata, keloids, contact dermatitis, vitiligo and other inflammatory conditions. Trainee dermatologists will see any patients referred from the Emergency Room

70% of patients seen in the clinic are follow-ups. The remainder 30% are new patients and may be one-off attender

### Inpatient service

24/7

Shared across departments (none specifically dedicated)

Patients requiring admission (e.g. with an acute infection) will be admitted under internal medicine however admission is rare



### Facilities on-site<sup>(1)</sup>

- Phototherapy (PUVA and UVB located on same floor with 2 full bath tubs and 2 hand baths)
- Patch testing
- Clinical trials unit (on same floor) with in-unit freezers
- 6 surgical rooms for minor operations
- ~20 Consultation rooms





Note: (1) List of facilities is not exhaustive



# The team







## Core team profile

-  **15** Dermatologists (~30 at other centres)
-  **30** Medical assistants
-  **6** Clinical Fellows
-  **3** Physician assistants

## Clinical Trials team profile

(Mount Sinai Hospital and Mount Sinai St. Lukes)


-  **3** Clinical pharmacological fellows (MD)
-  **1** Registered nurse
-  **1** Director of Clinical Trial Unit
-  **6** Clinical Trial coordinators

## Laboratory team profile

-  **1** Full professor; **1** assistant professor (bioinformatician)
-  **1** Lab manager; **6** technicians
-  **2** data analysts
-  **2** PhD / masters students; **3** MD / PhD post-doctoral fellows; **3** medical students






Note: Please see page 610 for further details

## Affiliates

-  **200** physicians (part of the wider MS network)



## Wider team profile

-  **5** Allergists (paediatric and adults)
-  **3** Pulmonologists
-  Gastroenterologists (team)
-  Psychologists and psychiatrists
-  Ophthalmologist

## Governance and processes

### Team meetings:

- *Pre-clinic informal meeting (Monday and Thursday of each week):*
  - Attended by: dermatologist, medical assistant and trainee doctors
  - The purpose of the meeting is to discuss upcoming patients and consider any foreseeable challenges in the clinic
- *Attending's meeting (1-hour each month):*
  - Attended by: All Attendings at the centre and senior management staff
  - The purpose of the meeting is to discuss interesting patients, potential improvements for the practice, new updates on research and treatments, clinical trials and clinic operational matters
- *Clinical trials meeting (Monday and Thursday of each week):*
  - Attended by: dermatology team and clinical trials team
  - The purpose of the meeting is to discuss running of clinical trials, potential candidates and outcomes

### Patient records:

- *Electronic patient records (EHR):*
  - Electronic health records can be accessed by health care professionals within the clinic. The clinic has read-only access at present but are due to upgrade to read and write access imminently

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients present to their primary care physician (PCP) or office-based dermatologist with AD symptoms (e.g. itching or dryness of the skin). The physician will assess and refer to the centre if required
- Patients may present directly to the centre after researching it online or hearing about it via word of mouth. Patients may self-present from a wide geographic dispersion (e.g. Africa)

*Note: Mild paediatric and adult patients with AD tend to be managed by PCPs or general dermatologists. As a result, more mild AD patients are not often seen by the centre*

## Diagnosis and Referral

In secondary care



- Approximately 50% of referrals are received from PCPs and private dermatologists and 50% are self-referrals
- The standard waiting time from referral to consultation is 2 weeks
- Prior to the consultation medical assistants (MAs) will review a patient's electronic medical record (EMR, if accessible)
- For new patients, the initial appointment is approximately 30-45 minutes in total
- The MA or trainee dermatologist will take a full medical history from the patient, including previous treatments, AD symptoms and a full family history of atopy
- The MA or trainee dermatologist will present the patient to the dermatologist

## Treatment and Management

Medical management



- Patch testing is performed within the clinic by one dermatologist (supported by a trainee dermatologist and MA) for cases where contact dermatitis is suspected
- The dermatologist will review the patient and compose a management plan. They will explain the disease and the recommended care regimen (including where, when and how to apply what treatment, use of bleach baths)
- The dermatologist will refer patients to comorbidity specialists as required (e.g. allergists, gastroenterologists, psychologists)
- Patients (if eligible) are also offered the opportunity to participate in clinical trials. These patients can be referred by specialist AD physicians from other treating hospitals

Non-medical management



- Patients and their relatives are educated throughout the consultation process by the dermatologists, trainee dermatologists and MAs
- The patients and relatives are provided with educational literature to take away and read in their own time
- UVB phototherapy is provided at the centre as required
- Patients will be referred to the National Eczema Association (NEA, patient advocacy group) for additional education and support groups

## Follow-up

Monitoring of chronic disease / flare up



- Follow-up depends on both clinical need and patient assessment (e.g. if the dermatologists feel that the patient has not been able to take in all the information)
- First follow-up is usually after 4-8 weeks, then every 2-3 months. Follow up frequency is gradually extended to every 4-6 months (unless they are patients on injectable therapy who cannot self-administer)
- Follow-up consultations will follow a similar format and last ~15 minutes
- Patients (especially those who travel long distances) can be referred back to their referring physician once they are stable and have a treatment plan in place. However, patients will often choose to continue their treatment at the centre, returning every 6-12 months

# Roles of the wider team

## Allergists

**Patient type:** Paediatric and adult patients suffering from allergic rhinitis, asthma, food allergy or those desiring a thorough allergy assessment

**Referral:** Referred by the dermatologist. The average waiting time for an appointment is 2–3 months but may be faster if clinically urgent. The clinic has an established relationship with specific allergists who will also refer patients they see independently with AD to the clinic

**Consultations:** The allergy department physicians specialise in both allergy and asthma. Allergist will perform skin prick tests, provide treatments and assurance, and refer back to the dermatologist as required

**Timing:** Consultations vary in length depending on patient requirements and patients can require full day observation periods if looking for delayed hypersensitivity

## Gastroenterologists

**Patient type:** AD patients with suspected EOE (eosinophilic esophagitis)

**Referral:** Referred by the dermatologist (but the onus is on the patient to make the appointment themselves to avoid conflict of diaries). Reverse referrals back to the dermatology department also occurs

**Consultations:** This will entail a full history of dysphagia and discomfort and perform a biopsy. They may also refer to an allergist

**Timing:** Dependent on the severity of the condition



## Psychologists / Psychiatrists

**Patient type:** Pediatric and adult patients with AD exhibiting psychological symptoms (as a result of AD) or existing psychological pathology (i.e. not related to their AD)

**Referral:** Referred by the dermatologist to the psychiatry department who will then decide if the psychiatrist, psychologist or both will see the patient. Some psychologists are based outside of the Mount Sinai network

**Consultations:** Cognitive behavioural therapy will be provided by the psychologists and medication may be prescribed by the psychiatrist

**Timing:** Dependent on the severity of the condition

*Note: The centre finds that a number of patients have reactive depression related to their AD, whereby if AD is treated effectively, the depression is likely to improve*

## Pulmonologists

**Patient type:** Pediatric and adult patients with AD with severe asthma

**Referral:** Referred by the dermatologist to the pulmonology department

**Consultations:** The pulmonologists will review the records from the EHR referral letter and take a full asthma history and typically perform lung function tests

**Timing:** Dependent on the severity of the condition

*Note: If the dermatologist believes the patient to be suffering from allergic asthma only then they may decide to refer the patient to an allergist instead*

# Overview of interventions in place for AD

## Awareness and Presentation



Symptom identification

- **Raising awareness of AD:** The centre utilises its high profile and promotes awareness of AD through media interviews and campaigns on social networks. The centre also has relationships with international platforms such as the International Eczema Council (IEC) with patients from the centre often being asked to speak at IEC events

- **Involvement with the wider AD community:** The centre collaborates with a number of PAGs (e.g. National Eczema Foundation) and medical societies (e.g. presenting at Inflammatory Skin Disease Summit) to raise awareness of AD

See pg. 616 for case study

## Diagnosis and Referral



In secondary care

- **Collaborative comorbidity specialist network:** The centre has an established relationship with a number of comorbidity specialists within the hospital, which enables patients to be referred internally to suitable experts. This includes and is not limited to allergists, pulmonologists, gastroenterologist, psychiatrists, psychologists and ophthalmologists

See pg. 617 for case study

## Treatment and Management



Medical management

- **In-house contact dermatitis clinic:** The centre operates a patch test clinic which allows diagnosis of contact dermatitis within the department
- **Extended HCP-patient consultations:** Consultations are 30–45 mins long, and delivered by a combination of the medical assistant, trainee dermatologist and dermatologist. Together they establish a solid patient-HCP relationship that helps to reinforce patient education and facilitate adherence

See pg. 618 for case study

See pg. 619-620 for case study

- **Active clinical trials department:** The centre operates an integrated clinical trials unit on the same floor as the patient consultations. A number of staff work across both trials and standard delivery of care. This enables patients to experience and benefit from the most recent and advanced treatments for AD

See pg. 621 for case study



Non-medical management

- **Psychological support services:** If the dermatologist believes the patient may benefit from psychological input they will be referred to the psychiatry department where patients may see both a psychologist who is skilled in cognitive behavioural therapy. The centre will also mention local online support groups for patients with AD

## Follow-up



Monitoring of chronic disease/flare up

- **Reinforced patient education and follow up:** The centre attempts to follow up with patients as quickly as 2 weeks after their first consultation to re-enforce the regimen and answer any outstanding or new questions. The centre provides written copies of treatment regimens and provides patients with an email address that can be contacted should the patients have follow-up questions between consultations

### Key:



Case study available



# Monitoring patients with AD and comorbidities

## The dermatology unit employs scoring measures in the first clinic meeting and at the 6-monthly follow up meetings

### The centre uses AD scoring indices to monitor patients and their disease, including:

- EASI (Eczema Area and Severity Index): a tool used to measure the extent (area) and severity of atopic eczema<sup>(a)</sup>
- IGA (Investigator Global Assessment): a method of assessing the overall severity of the clinical signs of atopic dermatitis. It includes a 0-4 point scoring system of the overall severity of the atopic dermatitis skin lesions<sup>(c)</sup>
- Body surface area

### Patient-reported outcomes:

- Quality of life is routinely measured by DLQI (Dermatology Quality of Life Index): dermatology related quality of life questionnaire<sup>(d)</sup>
- The dermatology department is in the process of initiating a registry for patient-reported outcomes (PROs)

---

### Dermatology unit routinely measures comorbidity outcomes by:

- Patch testing: performed by the dermatology department
- Skin prick test: performed by the allergy department

**Sources:** (a) Leshem YA, et al. What the Eczema Area and Severity Index score tells us about the severity of atopic dermatitis: an interpretability study. *Br J Dermatol*. 2015;172(5):1353-7. doi: 10.1111/bjd.13662; (b) Reich A, et al. Visual Analogue Scale: Evaluation of the Instrument for the Assessment of Pruritus. *Acta Derm Venereol*. 2012;92(5):497-501. doi: 10.2340/00015555-1265; (c) IGA efficacy results. Dupixent [Website] <https://www.dupixenthcp.com/atopicdermatitis/efficacy-safety/iga-clinical-trial> Accessed 20 Sept 2019; (d) Lewis V, et al. 10 Years Experience of the Dermatology Life Quality Index (DLQI). *J Invest Dermatol Symp Proc* 2004;9:169 –180;

# Advice to other centres



## What advice would you give less specialised centres?



**Objective of advice: Difficulties arising in the treatment of AD often requires good relationships with specialists treating comorbidities**

- **Why?** Patients with AD are at risk of developing several comorbidities. Providing access to a network of comorbidity specialists enables dermatologists to deploy a multidisciplinary approach to care and provide AD patients with the specific comorbidity treatment needed, thereby helping to improve their quality of life and treatment outcomes



**Objective of advice: Time dedicated to patient education is an effective long-term strategy**

- **Why?** AD is a condition that requires patients to adhere to a self-managed treatment regimen that can often be complex and time consuming. Healthcare professionals need to spend adequate time with patients during consultations to educate them about their treatment, discuss strategies to control triggers and teach them how to apply topicals, as well as provide a forum to answer any questions. Provision of in-depth written treatment plans, as well as an email address for questions, can help to reinforce the regimen, support patients in the interim between appointments and improve treatment adherence



**Objective of advice: Continued development and education of dermatologists**

- **Why?** It is critical for HCPs to keep updating their knowledge whilst they practice. Participation in continued education and training is key to ensuring professional competence. This extends beyond residents to specialist dermatologists. Knowledge of new research findings both within dermatology and associated fields of medicine (especially where comorbidities arise) can be critical to ensure best practice care and treatment is given at the highest level

# Next steps for the centre



## What is next for the centre?

**Objective:** Provide an educational course for external physicians on the management of AD

- **What?** The centre wants to provide a 1-2 day preceptorships for external physicians. This would be a cross-speciality training course, using multiple specialists working across the fields involved in AD treatment (e.g. allergists, ophthalmologists) to provide holistic education around the management of patients
- **Why?** The centre believes it is important to educate physicians around the appropriate management of AD in order to help improve management across the wider AD community. This course will inform attendees about AD, the associated-comorbid disorders and how to manage them effectively. The dermatology department has already run a number of large scale meetings for AD and PsA with >250 trainee doctors attending and pre-/post-training assessments, so are well-versed in running these events



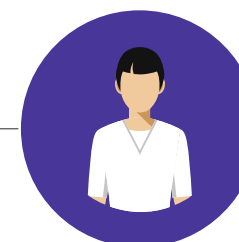
**Objective:** Expand research focus of AD comorbidities

- **What?** The centre is intending to extend its research focus to include Alopecia Areata
- **Why?** The centre recognises that as there may be a connection between AD and Alopecia Areata, it wishes to explore this relationship further



**Objective:** To build a relationship with the oncology and plastic surgery teams to manage keloids

- **What?** The centre plans to build a relationship with the oncology and plastic surgery teams to help in the treatment and management of keloid in AD
- **Why?** The centre values established connections with comorbidity specialists and recognises that some patients with AD develop keloid. Expanding the network of specialists will allow dermatologists to develop efficient referral pathways for the convenience of the patients and allow for improved knowledge sharing and faster initiation of treatment for patients with comorbid conditions



**Sources:** (a) KPMG Interviews with centre dermatologists



# Case studies



CONTENTS



APPENDIX  
CENTRE REPORTS

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# Involvement with wider AD community

## Overview

- The centre has built relationships with a number of leading patient association groups (PAGs) and medical societies, to help support patients, further research and disseminate findings to help raise awareness of AD amongst the wider HCP community and across society as a whole

**Sources:** (a) Dermatology. Mount Sinai [Website] <https://www.mountsinai.org/care/dermatology> or KPMG interviews; (b) Scientific Advisory Committee. National Eczema Association [Website] <https://nationaleczema.org/about-nea/scientific-advisory-committee/>. Accessed 4 Oct 2019; (c) Emma Guttman, MD, PhD. Mount Sinai [Website] <https://www.mountsinai.org/profiles/emma-guttman> Accessed 4 Oct 2019; (d) Final Programme, Inflammatory Skin Disease Summit: The Translational Revolution, December 12-15, 2018.



## What is the rationale?

- Providing superior and comprehensive support to improve the quality of care provided for patients is at the forefront of Mount Sinai's ambitions<sup>(a)</sup>, alongside the advancement of the science of dermatology through research and education
- Both these ambitions can be supported through partnerships with PAGs who play a leading role in helping improve the quality of life for individuals living with AD through research, support and education; as well as collaborating with medical societies, gaining knowledge from the network of expertise to help advance AD care and treatment practices<sup>(c)</sup>

## What are the key features of the intervention?

- A number of the centre's physicians are involved in leadership positions within both national and international PAGs and medical societies. They donate their time and expertise to help shape and improve the quality of care for patients with AD
  - Prof. Emma Guttman (who directs the Dermatology Centre for Excellence) is on the Scientific Advisory Committee for the National Eczema Association (NEA), an American PAG. Her role is to guide patient and professional education and give insights on new clinical developments, provide education to HCPs but are also used to help shape policy and reimbursement<sup>(b)</sup>
  - She also co-founded the International Eczema Council (IEC), for which she functions as president. This organisation comprises of a number of top experts in atopic dermatitis/eczema worldwide, who work together as a global network to shape AD care<sup>(c)</sup>
- Collaboration with PAGs for scientific research and taking a leading role in conducting clinical trials
  - PAGs (such as NEA) have had access to research grants, helping fund clinical trials at the centre which contributes to the launch of new drugs. This leads to the development of numerous publications advancing the science of dermatology<sup>(b)</sup>
- Physicians participate as keynote speakers at multiple international and national meetings (e.g. the Inflammatory Skin Disease Summit<sup>(d)</sup>), helping disseminate new knowledge and educate the wider HCP population

## What are the outcomes so far?

### Benefits to patients:

- Access to leading clinical trials and research projects to help shape the future of AD treatment and management across the patient pathway
- Improved satisfaction with care and quality of life with holistic support and HCP engagement

### Benefits to HCPs:

- Better access to resources and education about recent findings and treatments in AD. Sharing of best practices amongst the community to improve care, internationally
- Improved engagement of patients, leading to better adherence to treatment plans

# Collaborative comorbidity specialist network

## Overview

- The centre has an established relationship with a number of other specialist teams based within the centre. These teams specialise in treating the comorbid conditions associated with AD

**Sources:** (a) Darlenski R, et al. Atopic dermatitis as a systemic disease. *Clin Dermatol.* 2014;32(3):409-13; (b) Roerdink EM, et al. Association of food allergy and atopic dermatitis exacerbations. *Ann Allergy Asthma Immunol.* 2016;116(4):334-8; (c) Southerland JH, et al. Interprofessional collaborative practice models in chronic disease management. 2016. (d) Caffarelli C, et al. Skin prick test to foods in childhood atopic eczema: pros and cons. *Ital J Pediatr.* 2013;39:48. doi:10.1186/1824-7288-39-48



## What is the rationale?

- AD is a complex disease which can progress to other comorbid conditions such as allergic rhinitis<sup>(a)</sup>, food allergies, asthma as well as non-allergic conditions such as infections, mental health conditions, gastrointestinal immune-mediated disorders etc.<sup>(b)</sup>
- Successful treatment requires effective collaboration and communication between dermatologists and specialists in charge of these associated comorbidities, in order to create the necessary multidisciplinary approach<sup>(c)</sup>

## What are the key features of the intervention?

- The centre has developed a close working relationship with a number of Mount Sinai departments, which has led to collaborations with allergists, pulmonologists, gastroenterologists, psychiatrists, psychologists and ophthalmologists
- The comorbidity specialist will receive referrals from primary care physicians (PCPs), internal specialists (e.g. dermatologists) as well as some self-referrals
- During the first consultation the specialist will review the Electronic Health Record (EHR) and perform a full history of the associated comorbidity (e.g. allergies) of both the patient and the family
- Tests will be performed (e.g. skin prick testing to identify any potential allergens that will induce the eczematous flare)<sup>(d)</sup>
- The patient will then be referred back to their initial treating physician or the comorbidity specialist will continue to follow up with the patient if clinically necessary
- Cross-referrals across this network of comorbidity specialist departments is common

## What are the outcomes so far?

### Benefits to patients:

- Clear referral pathways and therefore easier access to a required specialists to investigate and manage any potential associated comorbidities

### Benefits to HCPs:

- Established referral pathway, with trusted colleagues, enabling streamlined movement of patients between specialists care settings

## What are the challenges?

- However there are longer wait times to see some comorbidity specialists at Mount Sinai (e.g. for allergists there is typically a ~3 months wait due to high patient load). Cases can be expedited in extreme / urgent cases

# In-house contact dermatitis clinic

## Overview

- The centre operates a patch test clinic which allows diagnosis of contact dermatitis within the department

**Sources:** (a) Siegfried E, et al. Diagnosis of Atopic Dermatitis: Mimics, Overlaps, and Complications. *J Clin Med.* 2015;4(5):884–917. doi:10.3390/jcm4050884; (b) Vigneshkarthik N, et al. Patch Test as a Diagnostic Tool in Hand Eczema. *J Clin Diagn Res.* 2016;10(11): WC04–WC07. doi: 10.7860/JCDR/2016/23994.8884



## What is the rationale?

- Contact dermatitis is the most common form of dermatitis and like all dermatitis, is characterised by cutaneous erythema and edema<sup>(a)</sup>. Contact dermatitis is a common differential diagnosis for AD<sup>(a)</sup>
- Patch testing is the only investigatory process available to prove the diagnosis of allergic contact dermatitis.<sup>(b)</sup> It is useful to help with diagnoses where it is unclear whether the patient has AD or contact dermatitis

## What are the key features of the intervention?

- If a pattern of distribution is atypical for AD and is not improving with adequate application of therapy, or if the history of symptoms sound unusual then patients can be referred to the contact dermatitis clinic to investigate with patch testing
- Patch test clinics are run weekly. Typically patients will be seen every 24-48 hours:
  - Monday: patches are applied
  - Wednesday: patches are taken off by either the medical assistant or trainee doctor
  - Thursday: patch test results are interpreted by the dermatologist
- Allergens are ordered and the patch test items are put together by the team (typically a trainee dermatologist and medical assistant) before the patient visits. Usually 3 patch patients are seen per week and typically around 80 allergens will be tested on each patient
- Referrals to the patch clinic come from dermatologists within and external to the centre with some patients self-referring. If the patients' insurance includes cover for the patch test then the team will require pre-authorisation before applying a patch
- Once the test has been interpreted the patient will be referred back to their referring physician with the result

## What are the outcomes so far?

### Benefits to patients:

- Convenient access to a patch test within a familiar clinical setting
- Knowledge and understanding of any allergens that are causal factors to their eczema

### Benefits to HCPs:

- Supports a differential diagnosis of AD or contact dermatitis
- Avoidance of delay or referral miscommunication by hosting the clinic within the same location

## What are the challenges?

- Some insurers may cover a limited number of allergens for testing

# Extended HCP-patient consultations (1/2)

## Overview

- Consultations are 30–45 mins long, and delivered by a combination of the medical assistant, trainee dermatologist and dermatologist. Together they establish a solid patient-HCP relationship that helps to reinforce patient education and facilitate adherence

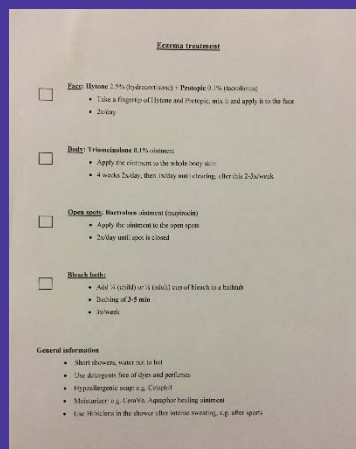


Fig 1. Mild-to-moderate patient eczema treatment plan

## What is the rationale?

- Short consultations may give healthcare professionals insufficient time to adequately educate patients. Physicians acknowledge that they can be too focused on pharmacological treatment and consequently do not have enough time to talk about other strategies to help control triggers<sup>(a)</sup>
- Insufficient education regarding the condition can prevent the patient from correctly adhering to their treatment regimen. Poor adherence is a major factor limiting treatment outcomes in patients with AD<sup>(b)(c)</sup>

## What are the key features of the intervention?

- Consultations usually last 30–45 minutes to ensure that there is sufficient time to educate patients. A typical consultation consists of:
  - 5–10 minutes for the medical assistant or trainee dermatologist to room the patient, take a history and perform AD scoring indices (EASI, VAS, IGA [see page 611])
  - 15–20 minutes with the dermatologist who will take an in-depth history and create a treatment plan
  - 10–20 minutes with the trainee dermatologist or medical assistant afterwards to recap the consultation and reinforce educational messages. Patients can be shown how to apply medication and administer injections
- At the end of this consultation patients are then given a written copy of their treatment regimen to take home. This treatment plan is built according to current guidelines and gives an explanation of all the treatment steps the patient needs to follow (see Fig. 1)

### Eczema treatment

#### Face: hydrocortisone and fujimycin (creams)

- Take a fingertip of each cream, mix it and apply it to the face 2x/day

#### Body

- Apply ointment to whole body skin
- 4 weeks 2x/day, then 1x/day until clearing after 2–3 weeks

#### Open spots

- Apply mupirocin ointment to open spots 2x/day

#### Bleach bath

- Add ¼ (child) or ½ adult) cup of bleach to a bathtub
- Bathing of 3–5 mins, 3x/week

### General information

- Short shower, water not too hot
- Use detergent free of dyes and perfumes
- Hypoallergenic soap
- Moisturizer (healing ointments)
- Use ointment in the shower after intense sweating, e.g. after sports

Transcripts of team's protocols (Fig. 1)

**Sources:** (a) GlobalSkinPosition Paper: "Atopic Dermatitis: A Collective Global Voice for Improving Care", February 2018; (b) DiAnna-Kinder F, et al. Satisfaction with Nurse Practitioners and Intent to Adhere to Plan. *The Journal for Nurse Practitioners* 15(3):245 - 248.e1; (c) Bass AM, et al. Interventions to Increase Treatment Adherence in Pediatric Atopic Dermatitis: A Systematic Review. *Journal of clinical medicine* 2015;4(2):231–42. doi:10.3390/jcm4020231

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# Extended HCP-patient consultations (2/2)



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CENTRE REPORTS

## What are the key features of the intervention?

- After the first consultation follow-up with the patient will typically occur after 2 weeks to re-enforce the regimen, answer further questions and assess the treatment plan. Thereafter follow-up intervals expand depending on clinical need. Ideally the patient will be seen every 6 months as a minimum
- The patients are provided with the medical assistant's email so that they can contact the centre with any follow-up or new questions

## What are the outcomes so far?

### Benefits to patients:

- Consolidation of information provided in dermatologist consultations
- More time available to ask questions to HCPs

### Benefits to HCPs:

- Supports treatment adherence and reduces need for urgent appointments during flares (due to improved self-management)

## What are the challenges?

- Delivering detailed consultations can be time consuming and additional time is required to reply to email queries sent by patients

# Active clinical trials department

## Overview

- The centre operates an integrated Clinical Trials Division located on the same floor as the patient consultations. A number of staff work across both trials and standard delivery of care. This enables patients to experience and benefit from the most recent and advanced treatments for AD

## What is the rationale?

- Research into AD diagnosis, treatment and management has seen a significant increasing in funding over the last decade<sup>(a)</sup>. Historical systemic treatments for severe AD have been associated with significant adverse effects and low compliance<sup>(b)</sup>
- AD is increasingly common, and it lacked effective, safe, long lasting treatments for many years.<sup>(b)</sup> Participating in clinical trials gives patients access to newer drugs and therapies<sup>(a)</sup>

## What are the key features of the intervention?

- At the time of centre visit (September 2019), the centre had 24 active dermatological clinical trials with 2 trials enrolling participants
- The Clinical Trials Unit has been fully integrated within the dermatology clinic. It is located on the same floor as the department, and a number of dermatology staff are shared between the services. In addition the dedicated clinical research unit staff include two clinical pharmacological fellows, one registered nurse, six research coordinators and one research manager
- **Trial recruitment:**
  - All attending physicians, fellows and trainee doctors refer patients to the Clinical Trials Unit and are made aware of the developments and recruitment windows in trials through monthly meetings
  - Potential patients will hear about the trial on local news TV segments, word of mouth, via multimedia adverts or through researching individual dermatologists online
  - Private dermatologists also refer patients for trials (contributes ~5% of total patients)

## What are the outcomes so far?

### Benefits to patients:

- Improved access to new research medications, trials and HCPs with an interest in AD research
- Single place to attend for clinical trials and clinical appointments

### Benefits to HCPs:

- Dermatologists are able to better understand emerging therapies and adopt them into clinical practice
- Access to novel therapies, research collaborations with comorbidity specialists and access to funding

**Sources:** (a) Lio P. Advances in atopic dermatitis raise bar for treatment. *Dermatology Times*. 39(12); (b) Renert-Yuval Y, et al. Systemic therapies in atopic dermatitis: The pipeline. *Clinics in Dermatology*. 35(4):387 -397; (c) Doval DC, et al. Post-trial access to treatment for patients participating in clinical trials *Perspect Clin Res*. 2015;6(2):82-85. doi: 10.4103/2229-3485.154003







APPENDIX  
CENTRE REPORTS

# Oregon Health & Science University (OHSU) Hospital

**Oregon, United States of America**

Site visited by KPMG 10-11<sup>th</sup> September

[kpmg.com/uk](https://kpmg.com/uk)



# Summary



## Context

**Centre type:** Public academic health centre within the Oregon Health & Science University (OHSU)

**Catchment area:** Patients from across Oregon. Other patients from across the north-western United States are also treated, primarily from Idaho and Washington State, as well as from Canada

**Funding:** The centre accepts both public and private health insurance, or patients may self-fund

**Services:** Services provided include acute and chronic care for medical, surgical and cosmetic dermatology for both adult and paediatric patients (including specialists in paediatric and adult atopic dermatitis [AD])

**Patient population:** Paediatric and adult patients with mild to severe dermatological conditions (including AD)



## Key strengths in the delivery of AD care

**Collaborative relationships with comorbidity specialists:** Patients have access to both skin prick and patch testing within the centre. These tests are respectively performed by an allergist and a contact dermatitis specialist. The centre has also established strong relationships with four anterior chamber ophthalmologists

**Research expertise:** The centre has a dedicated clinical trials unit focused on improving research across prevention, disease burden, basic science and treatment of AD. In addition it works closely with the Oregon Rural Practice-based Research Network (ORPRN) to conduct studies in primary care

**Extended consultations:** Patient consultations are approximately 30-45 mins (can be up to 1.5 hours for new patients) to ensure there is sufficient time to assess the patient, record scoring indices (including patient reported outcomes [PROs]), provide patient education and allow for patient Q&As



## Key challenges faced in delivery of AD care

**Lengthy pre-authorisation process:** Insurance pre-authorisation processes for AD treatment can result in delayed access to prescribed treatment for patients

**Access to psychological support:** The centre has access to a social worker but it is difficult to find mental health providers with availability and accept state insurance. If they believe a patient requires antidepressants or cognitive behavioural therapy (CBT) they will refer to primary care (as they are more aware of local psychologists that accept different insurances)

**Allergy waiting time:** The waiting time for an appointment for patch testing is 2-3 months whilst the wait for skin prick testing is 4 months (due to a high patient demand). However, the allergy team is in the process of hiring additional allergists

# Atopic Dermatitis (AD) in the USA

## USA healthcare system:

The USA healthcare system is publically and privately funded, with government spending accounting for 49% of the total health spending in 2014<sup>(a)(b)</sup>

## Publically funded healthcare:

- The main channels of public spending are Medicare, Medicaid and Affordable Care Act (ACA) subsidies.<sup>(a)</sup>
  - Medicare is a national health insurance program in the USA which primarily provides health insurance to Americans aged 65 and older
  - Medicaid is a health coverage program for Americans with low income and resources
  - The Affordable Care Act (ACA), is a USA law to establish shared responsibility between the government, employers, and individuals for ensuring that all Americans have access to affordable and good-quality health insurance
- The ACA expanded Medicaid to make policies affordable, by extending the fund subsidies to nearly all low-income individuals with incomes at or below 138% of the poverty level<sup>(a)</sup>

## Privately funded healthcare

- Private insurance is regulated mostly at the state level. In 2014, state and federally administered health insurance marketplaces were established to provide additional access to private insurance coverage, with income-based premium subsidies for low- and middle-income people<sup>(b)</sup>
- The five biggest commercial health insurers are UnitedHealth, Anthem, Aetna, Cigna and Humana, together representing about 43% of the total insured population. There is increasing consolidation of Pharmacy Benefit Managers (PBMs), which act as intermediaries between insurers and providers<sup>(a)</sup>
- As part of private healthcare insurance, an individual may have to pay a set amount of deductibles before their insurance begins to cover their treatment. Deductibles on employer-based health plans averaged US\$1,350 per person in 2019<sup>(a)</sup>
- There are different types of insurance. Some plans may restrict insurance restricts patients to seeing physicians who are part of the insurance group or are on a preferred list of providers<sup>(e)</sup>

## Prevalence

- In the USA, AD affects 12.98% of children<sup>(c)</sup> and 7.3% of adults<sup>(d)</sup>
- Of the USA adults with AD, 60.1% have mild AD while 28.9% and 11% have moderate and severe AD respectively<sup>(d)</sup>



## Care provision:

### Location:

- Mild (or well-controlled) AD care is primarily delivered by PCPs (primary care providers)
- Moderate and severe (uncontrolled) AD care is mostly delivered by specialist dermatologists

### Funding:

- The centre receives accepts by both public and private insurance
- Research projects are either industry sponsored or funded through NIH (National Institute for Health) grants

## Guidelines and societies:

### Guidelines:







- Guidelines of care for the management of atopic dermatitis:
  - American Academy of Dermatology
  - Annals of Allergy, Asthma & Immunology

### Medical societies/PAGs:

- American Academy of Dermatology
- National Eczema Association (NEA)
- Global Parents for Eczema Research
- Asthma and Allergy Foundation of America
- Pediatric Dermatology Research Alliance
- AltogetherEczema

**Sources:** (a) The Economist Intelligence Unit. Industry Report: Healthcare United States of America. Published 2nd Quarter 2019. Accessed 04 Sept 2019 (b) International Health Care System Profiles. The U.S. Health Care System. [https://international.commonwealthfund.org/countries/united\\_states/](https://international.commonwealthfund.org/countries/united_states/). Accessed 04 Sept 2019; (c) Silverberg J. Public Health Burden and Epidemiology of Atopic Dermatitis, *Dermatol Clin*. 2017 Jul;35(3):283-289 (d) Chiesa Fuxench ZC, et al. Atopic Dermatitis in America Study: A Cross-Sectional Study Examining the Prevalence and Disease Burden of Atopic Dermatitis in the US Adult Population, *J Invest Dermatol*. 2019 Mar;139(3):583-590 doi: 10.1016/j.jid.2018.08.028 (e) Different Types of Health Plans: How They Compare. <https://www.webmd.com/health-insurance/types-of-health-insurance-plans#1>. Accessed 20 Sept 2019

# The centre and dermatology unit

The centre		
 Type and location	Oregon Health and Science University OHSU is a public academic health centre in Portland, Oregon	
	<p>The dermatology department delivers care at OHSU’s main campus and at satellite locations:</p> <ul style="list-style-type: none"><li>— Center for Health and Healing, Portland (Medical and Pediatric Dermatology; Surgical and Cosmetic Dermatology and Multidisciplinary Melanoma Clinic)</li><li>— Doernbecher Children's Hospital, Portland (Pediatric Dermatology)</li><li>— Sunset Crossing Medical Center, Lake Oswego (Medical and Pediatric Dermatology)</li><li>— OHSU Beaverton, Beaverton (Medical Dermatology)</li></ul> <p>Services provided include acute and chronic care for medical, surgical and cosmetic dermatology for both adult and paediatric patients (including specialists in paediatric and adult atopic dermatitis [AD])</p>	
 Population served	The clinic serves the population from across the north-western United States however patients predominantly attend from Oregon, Idaho, Vancouver and Washington	
The dermatology unit		
 Service Division	Outpatient service	Emergency dermatology service OR Inpatient service
	Monday to Friday: 8am - 4pm (Evening clinics run until 7pm every other day)	24/7 located at OHSU main campus. Any dermatology patients requiring admission will be admitted under general internal medicine or family medicine On call advice available to Primary Care Physicians 7 days a week 8-8. Calls answered by residents
 No. of patients seen	Approximately 400 patients per week	
 Types of patients seen	Mild to severe patients with a dermatological condition, across all ages	
 Facilities on-site <sup>(1)</sup>	The main site for dermatology care is located at the Centre for Health and Healing building 1. This is in Portland's South Waterfront district at the base of the Portland Aerial Tram. Facilities include:	
	<ul style="list-style-type: none"><li>— 21 consultation rooms</li><li>— Dermatological surgical rooms</li><li>— Phototherapy (UVB, PUVA)</li><li>— Pharmacy</li></ul>	<ul style="list-style-type: none"><li>— Dermatology pathology laboratory</li><li>— Dermatology clinical trials laboratory</li><li>— Basic research laboratory</li><li>— Allergy testing (patch test, allergology perform skin prick tests)</li></ul>

Note: (1) List of facilities is not exhaustive





# The team

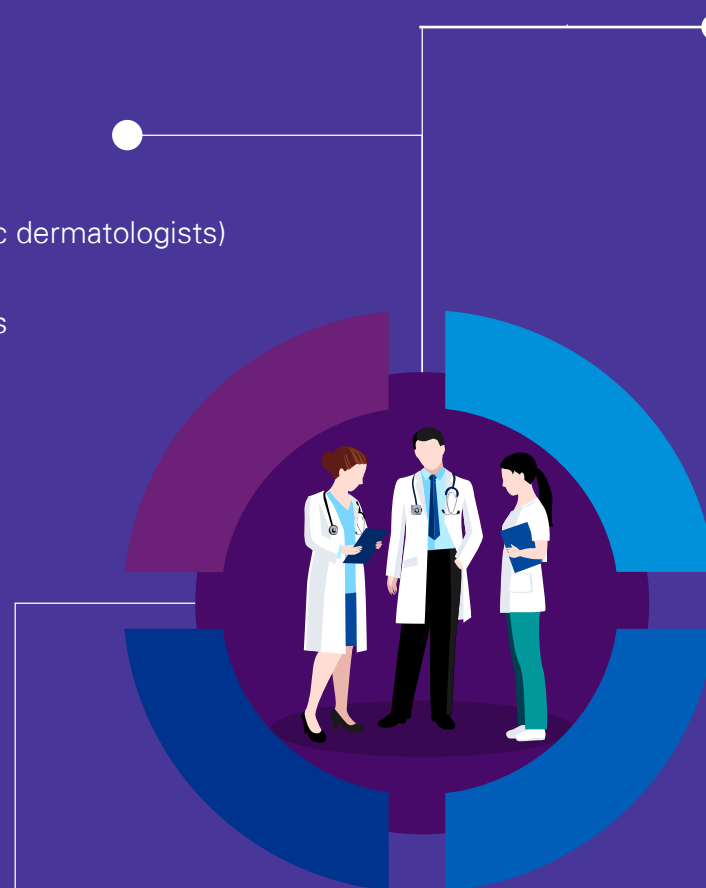


## Core team profile

-  **6** Dermatologists (inc. 4 paediatric dermatologists)
-  **2** Dermatology medical assistants
-  **1** Family nurse practitioner
-  **1** Physician Assistant
-  **1** Licensed practical nurse
-  **1** Pre-authorisation manager
-  **1** Clinical trials manager
-  **1** Clinical trials recruiter
-  **4** Clinical trials co-ordinators

## Wider team profile

-  **10** Basic scientist researchers
-  **4** Allergists (2 full-time; 2 part-time)
-  **1** Social worker
-  **4** Ophthalmologists with a corneal specialism
-  **1** Programme Manager (*Oregon Rural Practice-based Research Network [ORPRN]*)



## Governance and processes

### Team meetings:

- *Principle Investigator meetings (weekly)*
  - One-to-one meetings with clinical trial team members (30mins)
  - The purpose of the meeting is to discuss trial status and other clinical trial information / issues
- *Clinical staff meeting (bi-monthly)*
  - Attended by all clinical staff (1 hour)
  - The purpose of the meeting is to discuss clinical practice issues
- *Dermatology clinical trial meeting (bi-monthly):*
  - Attended by all dermatologists, residents and clinical trials staff (1.5 hours)
  - The purpose of the meeting is to discuss interesting cases, recent publications, open trials, recruitment strategy and upcoming clinical trials
- *Dermatology faculty meeting (monthly):*
  - Attended by all dermatologists and managerial staff (1 hour)
  - The purpose of the meeting is to discuss operational issues and announce trials

### Patient records:

- OHSU uses an electronic health records system which allows hospital files, primary care files and pharmacy prescriptions to be seen in one place

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients present to their primary care physician (paediatrician or family doctor) or office-based specialist (e.g. dermatologist)
- Note: Mild or well-controlled AD patients are often managed in the community, and are therefore not referred to the centre
- Patients may present directly to the centre via the Emergency Department. This is rare and will be managed by emergency care physicians in the first instance. A resident and attending are available 24 hours a day to attend to patients in the Emergency Department if necessary. Dermatology advice is available on the phone

## Diagnosis and Referral

In secondary care



- Prior to the consultation medical assistants (MAs) will review the patient's electronic medical record (EMR, if accessible on shared system)
- The MAs will get new paediatric and adult AD patients to complete a bespoke Patient Reported Outcomes assessment (PRO, see pg. 647). They will then ask further questions regarding their medical / family history (e.g. allergies, asthma), what treatments they are currently using, and exactly how they are being used. MA consultation = ~15 mins
- Patients may then either a trainee dermatologist and dermatologist (for ~30 mins and ~30-45 mins respectively), or just the dermatologist. Consultation will include collection of detailed medical and family history, formation of treatment plan and patient education

## Treatment and Management

Medical management



- The dermatologists and paediatric dermatologists will treat adults and children with AD respectively, with the condition ranging from mild to severe
- All dermatologists and trainee dermatologists focus on a shared decision making model with the patient
- Patients may be offered the opportunity to participate in clinical trials and will be referred to the trial recruitment team for screening if the dermatologists believes they may be a candidate
- Patients suspected of potentially having contact dermatitis will be referred to the contact allergy specialist (within Dermatology) for patch testing
- Dermatologists will refer patients to the comorbidity specialists as required (e.g. allergist and ophthalmologist)
- Patients with contact allergies are provided with educational material and access to the American Contact Dermatitis Society database, regarding recommended product use based on their specific allergy

Non-medical management



- Medical assistants and dermatologists can refer patients to a hospital social worker who can provide counselling, benefits and housing support. The social worker will call the patients and will book a face-to-face session. The waiting list for the social worker is short and the appointment can sometimes take place the same day as the referral
- Dermatologists will liaise with a patient's PCP to ask them to consider referring to psychological services or starting antidepressants
- Phototherapy (PUVA/UVB), is available as required
- Patients are educated throughout the consultation process by the MAs, residents and physicians and through receiving educational leaflets to take away. They are also directed to the NEA (National Eczema Association)

## Follow-up

Monitoring of chronic disease / flare up



- Patient follow-up frequency will depend on AD severity. Patients with severe AD (e.g., needing systematic therapy) will be seen again within the week, and their treatment will remain at the centre
- Patients with milder AD will be followed up at least once. Thereafter they may be referred back to the PCP
- Follow-up consultations will be ~30 mins (and will include a PRO questionnaire and modified EASI score collection)
- Patients will have clinic contact details and access to a health portal to book further appointments and ask questions
- Follow up with a social worker will usually be by phone

# Roles of the wider team

## Allergists (based within Pulmonology department)

**Patient type:** Paediatric and adult AD patients with asthma, food allergies and/or allergic rhinitis

**Referral:** Patients are primarily referred by the dermatology department at OHSU. Paediatric asthmatic patients may also be referred by the pulmonology department if the asthma is very severe or there is an allergic component

**Consultations:** A detailed history and questionnaire will be used to assess potential allergens

Allergist may perform skin prick tests, drug desensitisation and food provocation

**Timing:** The first consultation typically lasts 45 mins

Allergists currently host joint-clinics with pulmonology (for asthma, weekly) and ENT (allergic rhinitis, monthly)

## Programme Manager (at Oregon Rural Practice-based Research Network [ORPRN])

**Patient type:** Adult and paediatric patients in the surrounding rural area

**Dermatology involvement:** The current involvement between dermatology and the rural research network regards a specific study (CASCADE)<sup>(a)</sup> looking at infants response to emollients (*see Case study on pg. 635 - 636*)

**Consultations:** The programme manager will on-board primary care practices involved in the CASCADE study



## Ophthalmologists (anterior chamber)

**Patient type:** Paediatric and adults AD patients with ocular symptoms (e.g. conjunctivitis, herpetic infections, cataracts and keratoconus) and drug-induced eye disease

**Referral:** Patients are referred from dermatology and are usually seen within 2–6 weeks

**Consultations:** The ophthalmologists will collect new patients' medical history and perform a slit lamp assessment

New patients are assessed through examination and discussion. After treatment follow up is usually

**Timing:** First consultation = ~25 mins, and follow-up consultations = ~10 mins (around 4-6 months later, then annually)

*Note: Patients tend to self select out of follow-up after 1-2 sessions*

**Sources:** (a) CASCADE A Community-based Assessment of Skin Care, Allergies, and Eczema [website] <https://clinicaltrials.gov/ct2/show/NCT03409367> Accessed 11 Oct 2019



# Overview of interventions in place for AD

## Awareness and Presentation



Symptom identification

- **Working with the NEA:** Dermatologists from OHSU founded the National Eczema Association (NEA) in 1988. This is a non-profit organisation with a mission to improve the health and quality of life for individuals with eczema through research, support, and education

See pg. 634 for case study

- **Community-based Assessment of Skin Care, Allergies, and Eczema (CASCADE) trial:** The centre and Oregon Rural Practice-based Research Network are involved in conducting a real-world, community-based trial exploring whether emollient application starting in the first 2 months of life prevents AD

See pg. 635-636 for case study

## Diagnosis and Referral



In secondary care

- **Longer and frequent consultations:** AD patient consultations are intentionally longer and more frequent, and often delivered by a combination of a medical assistant, dermatologist trainee and dermatologist, in order to reinforce patient education

See pg. 637-638 for case study

- **Prior authorisation nurse role:** The dermatology department has recently created a role dedicated to obtaining prior authorisations, to increase efficiency

See pg. 639 for case study

- **Specialist in contact allergy:** The centre has a dermatologist and 2 research assistants (part-time) who are dedicated to contact dermatitis. They will take a full allergy history and perform a customised patch test with the suspected allergen over the course of a week

See pg. 640 for case study

## Treatment and Management



Medical management

- **Collaborative allergy relationships:** The centre has an established relationship with the allergy unit based at OHSU main hospital site. The allergists performs skin prick tests and works within the adult pulmonology department

See pg. 641-642 for case study

- **Established ophthalmologist working relationship:** The dermatology department collaborates closely with four anterior chamber specialist ophthalmologists who have experience in ocular manifestations of AD

See pg. 643-644 for case study



Non-medical management

- **HOME Initiative:** The department was part of the Harmonising Outcome Measures for Eczema (HOME) international working group. The group aimed to establish a set of core instruments to measure patient reported symptoms and quality of life for patients with atopic dermatitis

See pg. 645-646 for case study

- **Research expertise:** The centre has a dedicated team of 6 people working to deliver dermatological clinical trials. They are fully integrated into the clinical staff and are able to take blood as well as manage trials. At time of writing the centre is involved in 30 active ongoing trials with 15 further actively enrolling

## Follow-up



Monitoring of chronic disease/flare up

- **Bespoke AD patient reported outcome (PRO) assessment:** A dermatologist at the centre designed a bespoke patient reported outcome (PRO) assessment to be performed at each AD patient consultation to assess disease impact against patient orientated goals

See pg. 647 for case study

### Key:



Case study available



# Monitoring AD patients and comorbidities

## The dermatology unit employs a number of measures for monitoring AD and associated comorbidities

### Objective measures (AD):

- Modified EASI (Eczema Area and Severity Index) scale: scoring system that grades the physical signs of AD / eczema<sup>(a)</sup>. The trainee dermatologist will usually perform the scoring with the patient before the dermatologists attends. It allows for the disease activity to be recorded using a standardised clinician-reported outcome scale

### Patient-reported outcomes:

- Bespoke PRO questionnaire (*see case study on pg. 647*): Utilised frequently throughout the clinic. There are plans to change the PRO sheet to include an indication of the long term control of the disease. This may come out of the HOME initiative working group that the centre has been part of<sup>(c)</sup>. PROs also allow the healthcare system to identify unmet needs, such as utilising the SKINdex-Mini that measures the symptoms of emotional impact, and the impact of the disease on activities

The dermatologists and trainee dermatologists also proactively ask about mental health signs and symptoms and the status of allergic diseases

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### The dermatology clinic will test for contact allergy and drug/food allergy will be performed by the allergist:

- *Patch testing (for contact dermatitis)*: performed by the dermatologist with a specialist interest internal to the clinic
- *Prick testing (for food/drug allergens)*: performed by centre allergists

**Sources:** (a) EASI for clinical signs: Harmonising Outcome Measures for Eczema (HOME); [Website] <http://www.homeforeczema.org/research/easi-for-clinical-signs.asp> Accessed 13 Mar 2019; (b) SCORing Atopic Dermatitis (SCORAD) Calculator (0.9.0). [website] <http://scorad.corti.li> Accessed 26 Feb 2019; (c) Charman CR et al. Translating Patient-Oriented Eczema Measure (POEM) scores into clinical practice by suggesting severity strata derived using anchor-based methods. *Br J Dermatol*. 2013;169(6):1326–1332; (c) Simpson EL, et al. Patient-Oriented Eczema Measure (POEM), a core instrument to measure symptoms in clinical trials: a Harmonising Outcome Measures for Eczema (HOME) statement. *Br J Dermatol* 2017;176:979–84

# Advice to other centres



## What advice would you give less specialised centres



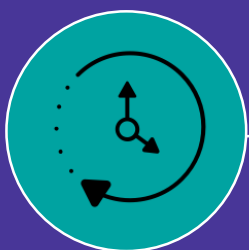
### Objective of advice: Utilise the whole team when managing moderate-severe AD patients

- **Why?** AD is a chronic disease that is associated with a number of atopy and non-atopy comorbidities. Patients with moderate-severe AD / complex AD patients can benefit from access to multiple HCPs (e.g. allergists, psychologists, primary care practitioners [PCPs]) and centres should aim to provide them with a multidisciplinary team where possible



### Objective of advice: Get involved in AD research associated with prevention, burden assessment, basic science and treatment

- **Why?** Research into AD across the four areas will collectively help to evolve the understanding, management and QoL of patients living with AD. Providing patients with opportunities to participate in AD clinical trials (at your centre, or referring to others that can) can give them access to treatments that may otherwise be unobtainable (if not commercialised or included in patient's insurance coverage). Additionally, utilise patient-reported outcomes in research to obtain a more holistic view of how AD is affecting the patient



### Objective of advice: Ensure sufficient time in consultations for each patient

- **Why?** All AD patients (i.e. with mild-severe AD) benefit from sufficient time in consultations with HCPs. Most importantly, sufficient time in the first consultation is critical to allow for assessment of AD (or confirmation of diagnosis) and related comorbidities (e.g. food allergy), shared-treatment decision making, provision of disease and treatment education, answering of patient questions, and assessment of AD burden of patients (especially moderate-severe patients, e.g. with patient reported outcomes measures). Consider repeating instructions and providing individualised treatment material after each visit

# Next steps for the centre

## What is next for the centre?

**Objective:** Set up a more standardised AD patient registry

- **What?** The centre is currently working towards auto-population of a database from standard Electronic Medical Record fields as part of an automatic statistical analysis process. This will create a standardised AD patient registry, with all patient data logged and assessed using the same metrics
- **Why?** Through standardising how patient care in AD is recorded and stored, it will improve quality of care assessments. This will enable the centre to identify where and how the provision of patient care can be enhanced

**Objective:** Acquire resources necessary to develop new AD therapies

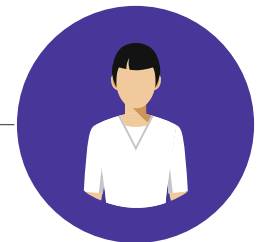
- **What?** The centre intends to hire a new member of staff who will have responsibility for identifying subjects and obtaining patient skin samples for research
- **Why?** Research activities will enable the centre to facilitate translational science, in the development of new AD treatments. By centralising these activities under one role, it will streamline communication between the patients who take part and a single point of contact within the centre

**Objective:** Establish tele-dermatology follow-up visits

- **What?** The centre plans to incorporate tele-dermatology follow-up visits for patients in rural areas
- **Why?** The effective use of tele-dermatology (e.g. through virtual consultations) will help patients in rural areas receive the treatment that they need if making visits in person is too difficult. By providing a more convenient alternative, it is hoped that this will encourage the necessary follow up care and treatment adherence

**Objective:** Develop decision aids

- **What?** The centre aims to develop decision aids to improve shared decision making between physicians and patients
- **Why?** As new therapies for AD continue to emerge, the development of decision aids that can be shared with patients will help facilitate shared decision making between the HCPs and the patients. By proactively involving the patient in the decision process regarding their treatment, it will help promote patient engagement in managing their condition. This is especially useful when systemic therapy is warranted



# Case studies



TITLE	#
<b>Working with the NEA</b>	634
<b>A Community-based Assessment of Skin Care, Allergies, and Eczema (CASCADE) trial</b>	635 – 636
<b>Longer and frequent consultations</b>	637 – 638
<b>Prior authorisation nurse role</b>	639
<b>Specialist in contact allergy</b>	640
<b>Collaborative allergy relationships</b>	641 – 642
<b>Established ophthalmologist working relationship</b>	643 – 644
<b>Harmonising Outcome Measures for Eczema (HOME) initiative</b>	645 – 646
<b>Bespoke AD patient report outcome (PRO) assessment</b>	647

# Working alongside the National Eczema Association (NEA)

## Overview

- Centre dermatology staff from OHSU founded the National Eczema Association (NEA) in 1988. This is a non-profit organization with a mission to improve the health and quality of life for individuals with eczema through research, support, and education



## What is the rationale?

- The National Eczema Association (NEA) is the largest patient advocacy group for AD and other forms of eczema in the USA<sup>(a)</sup>
- NEA's mission to improve the health and quality of life for individuals with eczema through research, support, and education<sup>(a)</sup>

## What are the key features of the intervention?

### NEA-centre engagement

- NEA was established in 1988 by a dermatologist and nurse based at OHSU dermatology department and who continue to be involved in both OHSU and NEA
- *Directorships:* The centre has 2 Directors Emeritus on the NEA Board of Directors
  - The centre also has 1 current member and 1 Emeritus Member on the NEA Scientific Advisory Committee who provide guidance for and/or participation in the NEA activities below

### NEA activities

Some of NEA's activities include:

- Producing patient education resources (quarterly magazine, weekly webinars, articles, research findings, etc.) Webinars are accessed via the NEA website with archived webinars available
- Eczema research funding through the NEA research grant program
- Advocacy through raising awareness among members of Congress, increasing federal funding for eczema research and pressing for policies and laws that ensure access to affordable, effective eczema treatments
- Mobilising the patient community to advocate for access to quality treatments and care
- Eczema Expo: A four-day transformative conference that brings together hundreds of patients, caregivers, health care and industry professionals for education, support and connection<sup>(b)</sup>

**Sources:** (a) The National Eczema Association. National Eczema Association. [website] <https://nationaleczema.org/> Accessed 11 Sept 2019  
(b) Eczema Expo. National Eczema Association. [website] <https://nationaleczema.org/eczema-expo/> Accessed 5 Sept 2019

# A Community-based Assessment of Skin Care, Allergies, and Eczema (CASCADE) trial (1/2)

## Overview

- The centre and Oregon Rural Practice-based Research Network (in collaboration with other centres and PBRNs) are conducting a real-world, community-based trial (involving 25 primary care clinics) exploring whether emollient application starting in the first 2 months of life prevents atopic dermatitis

## What is the rationale?

- Atopic dermatitis (AD) affects over 9 million children in the U.S. and often heralds the development of asthma, food allergy, skin infections and neurodevelopmental disorders. Recent advances identify skin barrier dysfunction to be the key initiator of AD and possibly allergic sensitisation
- An international multi-centred clinical trial found enhancing early skin barrier function with daily emollient use from birth significantly reduces the risk of AD development in high-risk populations by 50%<sup>(a)</sup>

## What are the key features of the intervention?

### Overview

- A multi-site, randomised community-based trial, where research is performed in the place where the intervention will be implemented
- The trial promotes collaboration between specialists and PCPs, where all parties (including patients) are equal partners in the research
- Pragmatic in design as there are no follow-up visits required, there is a choice of interventions available, few exclusion criterias are applied, and patients are recruited during routine care
- As part of clinical practice, where dermatologists and trainee dermatologists stress a shared decision making model (following the Elwyn model) with the patient, especially in circumstances where systemic therapy is warranted
- Involves the centre (Oregon Health and Science University, with a dermatologist as the Principal Investigator); University of Wisconsin; University of Colorado and Duke University
- The trial's central hypothesis is that emollient therapy from birth can prevent the development of AD. The findings of this trial will support the development of evidence-based skin care clinical guidelines for infants that currently do not exist
- Dyads of infants aged 0–2 months and their parent or legal guardian, are being enrolled from 25 primary care clinics that are members of practice-based research networks (PBRNs) in Oregon (the Oregon Rural Practice-based Research Network [ORPRN]<sup>(b)</sup>), Colorado, Wisconsin and North Carolina
- The study is planned to run from July 2018 – March/June 2022, and aims to enrol 1250 dyads

### Study arms

- Dyads are randomly assigned into two arms:
  - *Every day moisturiser group (intervention)*: receive lipid-rich emollient with web-based instructions for daily use to infants plus routine skin care instructions

**Sources:** (a) Clinical Trials. CASCADE A Community-based Assessment of Skin Care, Allergies, and Eczema [Website] <https://clinicaltrials.gov/ct2/show/NCT03409367> Accessed 11 Oct 2019 (b) OHSU. Oregon Rural Practice-based Research Network (ORPRN). [Website] <https://www.ohsu.edu/oregon-rural-practice-based-research-network> Accessed 22 Oct 2019





# CASCADE trial (2/2)

## What are the key features of the intervention? (cont.)

### Study arms (cont.)

- *Natural skin group (control)*: receive educational materials promoting general infant skin care guidelines only and will be asked to refrain from emollient use unless dry skin develops (current standard of care guidelines)
- Both groups will receive e-mail and text message reminders to follow protocol instructions based on their group allocation until the infant reaches 24 months old
- Participating primary care clinicians receive a 10-minute training presentation on AD diagnosis developed by the centre's dermatologist (which generates a 'completion certificate'), in addition to a study kick-off meeting with the relevant PBRN director and facilitator

### Outcome measures

- The Primary Outcome Measure is: Cumulative incidence of AD at 24 months (as recorded by the trained clinicians), with 13 of other Secondary Outcome Measures (e.g. asthma risk, food allergy symptoms and clinician diagnosed)
  - Measures will be taken at one or multiple of the following time frames: 3, 6, 9, 12, 15, 18 and 24 months

### Progress so far

- Approximately 520 dyads have been recruited to date

## What's next?

- Finalise recruitment for the trial, following the recent publishing of the trial's protocol and methodology<sup>(a)</sup>
- Identify AD outcomes in health records related to trial
- Assess pilot sample results at 12 months

**Source:** (a) Eichner B, et al. A Community-based Assessment of Skin Care, Allergies, and Eczema (CASCADE): an atopic dermatitis primary prevention study using emollients-protocol for a randomized controlled trial. *Trials*. 2020;21(1):243.



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The primary care physician receiving training how to diagnose AD, to inform the primary outcome measure (health record of AD incidence)

*Programme Manager ,  
Oregon Rural Practice-based  
Research Network (ORPRN)*

# Longer and frequent consultations (1/2)

## Overview

- AD patient consultations are intentionally longer and more frequent than for other dermatological conditions. They are also often delivered by a combination of a medical assistant, dermatologist trainee and dermatologist, in order to reinforce patient education

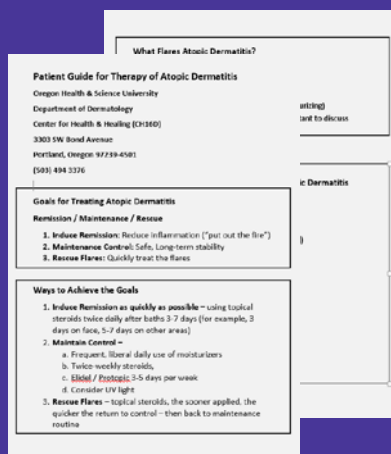


Fig 1: Eczema care plan provided to patients after their first consultation with a dermatologist

Not all different dermatologists have created their own documents

## What is the rationale?

- Experts recommend providing sufficient time to educate AD patients, their family members and care givers regarding the chronic nature of AD and their personalised treatment plans. It also provides HCPs the opportunity to correct any misconceptions they may have
- It has also been suggested shorter duration to initial follow-up consultations may improve adherence and treatment outcomes<sup>(a)</sup>

## What are the key features of the intervention?

- Every patient will be asked to complete a medical intake form at first attendance in clinic; this covers basic demographic information
- The first consultations at the clinic will typically last up to 1 hour 30 mins. The patient will be seen by a combination of a medical assistant, trainee dermatologist and dermatologist. During this time, the following information will be collected from the patient:
  - Full medical history (taken from the EPIC electronic health record, the medical intake form and physician consultations)
  - Prior and current AD treatments
  - Full personal and family allergy history

The trainee dermatologist will perform a modified EASI score and assist the patient to complete a patient reported outcome measure so that baseline results are taken. This will be completed at future consultations and compared to

Patient education will be delivered primarily by the dermatologist and reinforced by the trainee dermatologist and medical assistant. Following each visit, NEA handouts and written instructions are provided to all patients

- The follow up consultation most commonly occurs one week after the first consultation. During this time it will be assessed how effective the topical therapy has been in treating the patient's condition. This is in order to demonstrate that topical therapies can work, which in turn can improve patient adherence to therapy
- If there has been no improvement, the centre will then turn to systemic therapy. Patients that require systemic therapy after their follow up consultation will have their treatment managed at the centre. Ensuing follow up consultations will occur every 1-6 months depending on disease control and medications

**Sources:** (a) Eichenfield L, et al. Translating Atopic Dermatitis Management Guidelines Into Practice for Primary Care Providers. *Pediatrics* 2015;136(3):554-65

# Longer and frequent consultations (2/2)

## What are the key features of the intervention? (cont.)

- After the first consultation the patients will be given written instructions for care, NEA handouts, and a document containing useful information regarding AD, treatment, answers to frequently asked questions, an eczema care plan for what to do in a flare, and a guide on hygiene. See Fig 1.
- Patients with suspected comorbidities will be referred to the centre's specialists as required (e.g., the allergist for food or drug allergy or the anterior chamber ophthalmologist for ocular involvement). For suspected contact dermatitis the dermatologist will refer to the centre's specialist dermatologist with an expertise in contact dermatitis who will perform patch testing

## What are the challenges?

- Longer HCP consultations require greater resources and can increase waiting times
- The amount of reimbursement provided by insurers does not always match directly with the time billed for the consultations, which may de-incentivise longer consultations

## What are the outcomes so far?

### Benefits to patients:

- Improved understanding of AD and treatment regimen
- Opportunity to ask (more) questions in time given
- Potential for improved treatment outcomes from correct usage

### Benefits to HCPs:

- Additional time to educate patients regarding their AD self-management
- Opportunity to reinforce patient education across multiple sessions close together
- Flexibility to arrange follow-up appointments as required



We find the patients respond much better once they have had a proper explanation and been able to ask questions about the condition

*Dermatologist, OHSU*



# Prior authorisation nurse role

## Overview

- The dermatology department has recently created a role dedicated to obtaining prior authorisations from insurances, to increase efficiency



Almost 100% of pre-authorisations are rejected first time and it can be frustrating for patients



*Nurse, OHSU*

**Sources:** (a) NEA. Hope With New Atopic Dermatitis Drugs But Will They Be Covered? [website] <https://nationaleczema.org/insurance-for-atopic-dermatitis-drugs/> Accessed 23 Oct 2019; (b) Jones LK, et al. Understanding the medication prior-authorisation process: A case study of patients and clinical staff from a large rural integrated health delivery system. *American Journal of Health-System Pharmacy*. 2019; 76(7):453–459



## What is the rationale?

- Patients may require prior authorisation (approval from their insurance company) before their physician is able to prescribe certain AD treatments, especially those in higher tiers (within insurers' formularies)<sup>(a)</sup>
- The insurance pre-authorisation process can be lengthy and frustrating for patients and medical staff involved<sup>(b)</sup>, and cause delays in patients' access to treatments<sup>(a)</sup>

## What are the key reasons for the intervention?

- The centre currently has multiple nurses completing prior authorisations for AD patients (in addition to their patient care roles)
- However, the application process can be time consuming and due to the complexity of different requirements across insurers, can result in the submission of applications that do not include all the necessary information (e.g. EASI score)
- The majority of applications are initially rejected and require remedial work through appeals in order for the patients to access the prescribed treatment, creating an additional resource burden

## What are the key features of the intervention?

- The dermatology department has recently approved a new role dedicated to obtaining prior authorisations
- All prior authorisations are going to be centralised and performed by 1 nurse (medical assistant) within the dermatology team. This individual already has extensive knowledge of prior authorisation procedure and will now:
  - Further develop knowledge of the process across all treatments and insurers and develop the necessary relationships
  - Create pre-written letter templates
  - Inform physicians what information needs to be included in prior authorisation letters
  - Check chart notes are up to date / included necessary information before submission
  - Enable the other medical assistants to focus wholly on their patient care role (instead of rotating between prior authorisation and patient care)

## What's next?

- The department plans to trial the role for 6 months and compare the % of prior authorisation acceptances in comparison to the baseline

# Specialist in contact allergy

## Overview

- The centre has a dermatologist and research assistant who are dedicated to contact dermatitis. They will take a full allergy history and perform a customised patch test with the suspected allergen over the course of a week

**Sources:** (a) Siegfried E, et al. Diagnosis of Atopic Dermatitis: Mimics, Overlaps, and Complications. *J Clin Med.* 2015;4(5):884–917 (b) Aquino M, et al. The role of contact dermatitis in patients with atopic dermatitis. *J Allergy Clin Immunol Pract.* 2014;2(4):382-7. (c) ACDS. ACDS Camp. [Website] <https://www.contactderm.org/resources/acds-camp> Accessed 23 Oct 2019



## What is the rationale?

- Contact dermatitis is the most common form of dermatitis and like all dermatitis, is characterised by cutaneous erythema and edema<sup>(a)</sup>. Contact dermatitis is a common differential diagnosis for AD<sup>(a)</sup>
- Patients with AD have similar if not higher rates of positive patch test results to common contact allergens, including metals and fragrance, than those patients without AD<sup>(b)</sup>

## What are the key features of the intervention?

- If a pattern of distribution is atypical for eczema or not improving with adequate application of therapy or if the history of symptoms sound odd for AD then patients can be referred to the OHSU contact dermatitis specialist to investigate for contact dermatitis
- The contact allergy clinic has a 2–3 month waiting list and operates on a Monday, Wednesday and Friday schedule seeing up to 15 patients per week (90% are adults)
- 60–70% of referrals are received from the centre's dermatologists. The remainder are from paediatricians, allergists, PCPs or external dermatologists
- The first consultation will be up to 1 hour and includes an exhaustive potential allergen history incorporating home, work and social life and detailing product ingredients. This history will focus on the allergens chosen for testing and the patients may be asked to bring in products they use
- Typically the patch will test between 30 and 80 allergens depending on suspected allergies (from the history) and the patient's insurance coverage (i.e. number of allergens included within). The patch will be in place for 48 hours before removal and the results will be interpreted 48 hours after removal

### Follow-Up

- The last visit will be a 1 hour session to interpret the results and educate the patient and relatives
- Patients will be provided with handouts and provided access to a database (ACDS Contact Allergen Management Program [CAMP]) through the American Contact Dermatitis Society (ACDS) to see which products contain their allergens. Follow-up will be after 2 months

## What are the outcomes so far?

### Benefits to patients:

- Opportunity to vastly improve their skin condition without the need for any medication
- Access to the ACDS database of products and ingredients

### Benefits to HCPs:

- Verification / exclusion of diagnosis by expert
- Shared responsibility for management

## Challenges

- Medicaid does not cover patch testing and private insurers cover different numbers of allergens. This means the clinic often appeals to the insurer to grant approval before applying the patch

# Collaborative allergy relationships (1/2)

## Overview

- The centre has an established relationship with the allergy unit based at OHSU main hospital site. The allergists perform skin prick tests and work within the adult pulmonology department



## What is the rationale?

- AD is a complex disease which can progress into Atopic March, a multi-organ disease which may include allergic rhinitis<sup>(a)</sup> and food allergy<sup>(b)</sup>
- Successful treatment requires effective collaboration and communication between dermatologists and allergists in order to create the necessary multidisciplinary approach<sup>(c)</sup>

## What are the key features of the intervention?

- In 2018 OHSU adult pulmonology department decided to employ a team of allergists
- Over the past year the centre has established relationships with the allergy team which consists of two full-time and two part-time allergists
- Patients are referred to the allergy team by both dermatologists and pulmonologists. They see 60% adult and 40% paediatric patients
- The allergy clinic sees 40 patients per week, 10% of these are patients with AD
  - Dermatology will refer adult and paediatric patients with AD who have either suspected food allergy or allergic rhinitis
  - The referral waiting time for an allergy appointment is ~4 months, however clinically urgent patients are seen quicker
- The allergist is able to prescribe the same suite of medications as the dermatologist. This means that patients who have both food allergy and AD will be able to remain under the management of the specialist with which their condition is most severe
  - The allergist may refer back to the dermatologist if they feel the patient will benefit from supportive care for their AD, which is provided within the dermatology department

Further allergy clinic activities include:

- Drug desensitisation for agents such as chemotherapy, antibiotics, immunosuppressants and aspirin

Note: Previously to this clinic OHSU were sending patients 3 hours away for drug desensitisation so this has improved patient journey times considerably

- Food provocation / desensitisation testing
- Joint clinics with respiratory and ENT (see next page)

**Sources:** (a) Darlenski R, et al. Atopic dermatitis as a systemic disease. *Clin Dermatol.* 2014;32(3):409-13; (b) Roerdink EM, et al. Association of food allergy and atopic dermatitis exacerbations. *Ann Allergy Asthma Immunol.* 2016;116(4):334-8; (c) Southerland JH et al. Interprofessional collaborative practice models in chronic disease management. *Dent Clin North Am.* 2016;60(4):789-809

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# Collaborative allergy relationships (2/2)

## What are the key features of the intervention? (cont.)

### Joint Clinic with pulmonology

- For the past year OHSU have provided a weekly allergy and pulmonology joint clinic where physicians from both teams see adult severe asthma patients with allergic triggers
  - The patients will see both physicians separately for ~45 mins each and then they will come together to discuss their findings and produce a joint management plan
  - The hospital divisional management is aware that the joint clinic is not currently as efficient as other clinics (in terms of cost-effectiveness and patient processing times) but they can see the benefits to the wider community. They are keen to add value through this initiative as well as building a patient registry and a database that can be used for future research projects
- Additionally the allergy team have initiated a monthly joint clinic with ENT (ear, nose, throat) with the aim to become “*The severe sinus clinic*” for the region. Referrals are received from pulmonology, rheumatology, ENT, private allergists and dermatology
  - The clinic sees patients with severe allergic rhinitis and nasal polyps. Revenue generated from this clinic is taken by ENT with a payment per patient to the pulmonology department

### Challenges

- Joint clinics require dual payments which can pose an issue for insurers
- The ~4 month wait to be seen by the allergist is a longer wait than the community allergists but they are not comfortable seeing the more complex cases seen by the OHSU team

## What are the outcomes so far?

### Benefits to patients:

- Access to an experienced allergist to investigate and manage allergic comorbidities

### Benefits to HCPs:

- Referrals between allergy and dermatology is a smooth transition with both clinicians working within the same organisation

## What's next?

- The centre is currently exploring the idea of setting up a virtual clinic between two clinical immunologist–allergologists on a new training pathway
- The centre is also developing a multi-disciplinary clinic with a focus on allergies and contact allergies



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We are not as efficient as some private clinics but that is because we deal with all the complex cases. It is important for the administration to know that and be on-board

*Allergist, OHSU*



# Established ophthalmologist working relationship (1/2)

## Overview

- The dermatology department collaborates closely with four anterior chamber specialist ophthalmologists who have experience in ocular manifestations of AD

**Sources:** (a) Thyssen JP, et al. Incidence, prevalence, and risk of selected ocular disease in adults with atopic dermatitis. *J Am Acad Dermatol.* 2017;77(2):280-28; (b) Garrity JA et al. Ocular complications of atopic dermatitis. *Can J Ophthalmol* 1984;19(1):21-4 (c) Eiseman AS. The ocular manifestations of atopic dermatitis and rosacea. *Curr Allergy Asthma Rep.* 2006;6(4):292-8

## What is the rationale?

- Eye comorbidities are common in AD patients, resulting from the disease itself and/or treatment<sup>(a)</sup>
- 25-40% of AD patients have incidence of ocular involvement<sup>(b)</sup>
- Ocular disease is not directly correlated with disease control (i.e. if AD is well-controlled, this does not always mean eye comorbidities are well-controlled)<sup>(c)</sup>
- Ophthalmologists are required to manage exacerbations that need aggressive treatment in order to reduce ocular inflammation (which can lead to permanent loss of vision if untreated<sup>(c)</sup>)
- Some new systematic treatments have a frequent side effect of conjunctivitis, which may require specialist management

## What are the key features of the intervention?

- The dermatology department has access to four anterior chamber specialist ophthalmologists based at the main OHSU hospital site and who are experienced in ocular manifestations of AD
- The ophthalmology department will see 1-2 patients with AD per month. These patients are always referred from a dermatologist with 90% referred from OHSU and the remainder from non-OHSU private dermatologists
- Referrals from the dermatology department are seen within 2-6 weeks depending on the level of clinical urgency noted by the referring dermatologists
- Symptoms on referrals tend to be heterogeneous in presentation and include keratoconjunctivitis, keratoconus, cataracts along with opportunistic infections such as herpetic ulcerations
- Ophthalmologists recognise that patients with AD have required ophthalmology input previously but that referral numbers have increased since the introduction of novel AD therapies

### Format of consultation:

- First consultation lasts ~30 minutes and include an in-depth assessment of patient history and an examination
- Tests conducted:
  - Visual Acuity (VA)
  - Refraction
  - Intraocular pressures
  - Corneal topography
- Patients will have images taken and saved onto their file from their initial presentation as a record to show progression
- Patients will be prescribed treatment (e.g. lubricating eye drops or immunosuppressants) if required
- All patients receive education regarding their eye condition, treatment and aftercare (e.g. how to properly clean their eyes themselves)

# Established ophthalmologist relationship (2/2)

## What are the key features of the intervention? (cont.)

- Follow-up appointments take place 4-6 months later and involve repeats of relevant tests conducted previously such as corneal topography mapping
  - Follow-up appointments will last 10-15 minutes
  - After the first follow-up, and if symptoms are adequately controlled, the ophthalmology department would like to see patients annually
- OHSU ophthalmologists deliver education regarding ocular manifestations of AD to the ~100 ophthalmologists in the region on a bi-annual basis

## Challenges

- Sparsity of long term side effect data to map disease progression / remission / relapse of those patients with AD who are receiving the novel treatment
- Lack of a validated grading system for patients with ocular manifestations of AD<sup>(a)</sup>
- Ocular manifestations of AD are under-recognised by community dermatologists and ophthalmologists<sup>(a)</sup>

## What are the outcomes so far?

### Benefits to patients:

- Improved eye health and regular monitoring
- Quick access to a specialist ophthalmologist for AD eye comorbidity management

### Benefits to HCPs:

- Improved control of eye symptoms through early intervention(s) by specialist ophthalmologists
- Increased numbers seen of specialised cases providing potential for research

## What's next?

- The centre ophthalmologists may look at developing a grading system for ocular AD manifestations to include clinical symptoms and examination features
- The centre is putting together a case study manuscript for the Journal of American Academy of Dermatology and additionally hopes to publish in an ophthalmology journal

“



Once patients have received reassurance from us and received some treatment in the form of drops they tend to stop attending for follow up.

This means that we have a lack of long term observational data at the moment

*Ophthalmologist, OHSU*



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# Harmonising Outcome Measures for Eczema (HOME) initiative (1/2)

## Overview

- The department was part of the Harmonising Outcome Measures for Eczema (HOME) international working group. The group aimed to establish a set of core instruments to measure clinical signs, patient reported symptoms, long term control and quality of life for patients with atopic dermatitis

## What is the rationale?

- There is a current lack of standardisation of the assessment of clinical signs and core patient outcomes of AD<sup>(a)</sup>
- Outcomes from different AD clinical trials are difficult to assess and compare
- Standardisation of core patient outcomes to assess AD could advance evidence-based decision making and improve patient care<sup>(a)</sup>

## What are the key features of the intervention?

- The Harmonising Outcome Measures for Eczema (HOME) initiative aimed to achieve international consensus on a core set of outcome measures for the clinical assessment of AD in future trials.
- Patients, leading physicians (including dermatologists from the centre), nurses, methodologists, and pharmaceutical industry representatives across the world were involved in the study
- The initiative was coordinated by the Centre of Evidence-based Dermatology in the United Kingdom

### Method:

- The HOME Roadmap was utilised to identify a Core Outcome Set (COS) to measure and assess AD symptoms and quality of life in clinical trials
  - The HOME Roadmap methodology has previously been utilised to develop validated core sets of outcomes in osteoarthritis and childhood asthma
- Four core outcome domains were recognised as critical areas to assess in each clinical trial
- The methodology involved a literature review and working groups to discuss, identify and determine appropriate measures and domains. The department was part of the international working group looking at clinical signs and patient reported outcomes. 80 different named instruments were reviewed
- Measures for each domain were then selected based on their validity and ease of use

### The agreed Core Outcome Set (COS) for AD clinical trials is:

- *Clinical signs*: Eczema Area and Severity Index (EASI)
- *Patient-reported symptoms*: Patient-orientated Eczema Measure (POEM)
- *Long term control*: Recap of Atopic Eczema (RECAP) or Atopic Dermatitis Control Test (ADCT)
- *Quality of life*: Dermatology Life Quality Index (DLQI – adults), Children's Dermatology Life Quality Index (CDLQI) or Infants' Dermatitis Quality of Life Index

**Sources:** (a) J Schmitt, et al. The Harmonising Outcome Measures for Eczema (HOME) statement to assess clinical signs of atopic eczema in trials. *J Allergy Clin Immunol.* 2014;134(4):800-7



# Harmonising Outcome Measures for Eczema (HOME) initiative (2/2)

## What are the key features of the intervention? (cont.)

### Implementation:

- All stakeholders involved in designing, reporting and using clinical trials on AD were asked to comply with the COS in all future AD trials
- Researchers can also choose to include other clinical sign scales such as the SCORAD, in addition to using the EASI, when measuring progress in the four different domains
- The OHSU PRO form will align with the PRO set recommended by the HOME clinical practice initiative
- HOME is also now embarking on outcomes for clinical practices. For this, the working group have selected POEM, NRS itch and PO-SCORAD. Whilst these are not clinically mandatory, they are recommended to help promote quality improvement and enhanced patient tracking / evaluation.

## What are the outcomes so far?

### Benefits to patients:

- Evidenced-based decision making can improve patient care and quality of life

### Benefits to HCPs:

- Better comparison of treatment impact across different clinical trials, due to consistent use of measurements
- Enables greater collaboration internationally

## What's next?

- The international working group is now focusing on developing and implementing a similar set of instruments for use in clinical practice, as identified in the publication of a recent report from the group<sup>(a)</sup>

**Source:** (a) Leshem YA, et al. Harmonising Outcome Measures for Eczema (HOME) initiative. Measuring atopic eczema symptoms in clinical practice: The first consensus statement from the Harmonising Outcome Measures for Eczema in clinical practice initiative. *J Am Acad Dermatol.* 2020;82(5):1181-1186



HOME will help dermatologists compare outcomes from different trials more effectively

*Dermatologist, OHSU*



# Bespoke AD patient reported outcome (PRO) assessment

## Overview

- A dermatologist at the centre designed a bespoke patient reported outcome (PRO) assessment to be performed at each AD patient consultation to assess disease impact against patient orientated goals



PROs let you find info that you may not otherwise find from physician's clinically validated outcomes

*Dermatologist, OHSU*



## What is the rationale?

- Patient reported outcome (PRO) measures capture patients' subjective experience of illness, impairment and disability, and are increasingly useful in research to evaluate therapies<sup>(a)</sup>
- Routine measurement of patient-reported outcomes enable a shift to providing goal-oriented care instead of traditional problem-oriented care<sup>(a)</sup>
- A growing consensus has emerged about patient-reported outcome measures as important tool in the evaluation of services<sup>(b)</sup>

## What are the key features of the intervention?

- A dermatologist at the centre created a brief PRO measure to be used regularly during consultations. It includes scoring for:
  - SKINdex-Mini, including:
    - Skin symptoms (itch, stinging, burning, pain)
    - Emotional effects of skin condition (embarrassed, worried, annoyed)
    - Effect on activities (going out, activities of daily living)
  - Average itch over past week
  - Overall control of the skin problem

**Fig 1: OHSU AD PRO**

- The PRO is completed by the patient at each consultation. It is used to guide patient treatment alongside Recap of Atopic Eczema (RECAP) and the Atopic Dermatitis Control Test (ADCT)
- The resident / MA will input the information into the electronic record for future comparisons

## What are the outcomes so far?

### Benefits to patients:

- Ability to compare how their AD / the effects of their AD have changed overtime
- Creates the opportunity for patients to reflect and discuss how their AD is effecting them to their HCP

### Benefits to HCPs:

- Enables efficient tracking of PROs over time
- Creates the opportunity to ask patients how their AD is effecting them
- Informs decision-making gaining information around the patient perspective / voice

## What's next?

- The centre intends to start using the HOME PRO POEM (Patient Oriented Eczema Measure) as agreed by the HOME group and the Association of Certified Dermatology Techs ACDT<sup>(c)</sup>

**Sources:** (a) Frosch DL. Patient-Reported Outcomes as a Measure of Healthcare Quality. *J Gen Intern Med.* 2015;30(10):1383–1384 (b) Gibbons E, et al. Patient-reported outcome measures and the evaluation of services. In: Raine R, et al. Challenges, solutions and future directions in the evaluation of service innovations in health care and public health. Southampton (UK): NIHR Journals Library; 2016. Essay 4. (c) Spuls P et al. Patient-Oriented Eczema Measure (POEM), a core instrument to measure symptoms in clinical trials: a Harmonising Outcome Measures for Eczema (HOME) statement *Br J Dermatol.* 2017;176(4):979-984

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# DermAssociates

Rockville, United States of America

Site visited by KPMG 27<sup>th</sup> August 2019

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# Summary



## Context

**Centre type:** An office-based dermatology centre located just outside Washington DC, which provides medical, surgical, and cosmetic dermatologic care across 2 sites

**Catchment area:** Patients from a 40–50 mile radius primarily (but also from Maryland, Pennsylvania, Washington DC, West Virginia and New York State)

**Funding:** The centre accepts both public and private health insurance

**Services:** The centre provides outpatient care to both adult and paediatric patients with inflammatory skin conditions (including AD). The centre also consists of a dedicated clinical trials teams who deliver clinical research studies for adult, adolescent and paediatric patients

**Patient population:** Patients requiring mild to severe medical and surgical dermatologic care



## Key strengths in the delivery of AD care

**Participation in clinical research:** The centre is involved in multiple clinical trials, enabling a good understanding of emerging therapies and how to use them, which can be translated into clinical practice

**Cost conscious treatment:** Physicians work with pharmacists to prescribe the most cost-effective, efficacious medication covered by the patient's health insurance

**Informal comorbidity referral networks:** The centre has a close collaboration with comorbidity specialists through their informal network of comorbidity physicians



## Key challenges faced in delivery of AD care

**Access to innovative treatments:** Some AD patients are not responsive, able to have (e.g. due to side effects) or able to access existing treatments. Therefore, would benefit from innovative therapies

**Treatment developments:** A large proportion of the AD population are treated by primary care physicians (PCPs) and smaller community dermatology practices, who are not always aware / confident or able to use novel AD therapies

**Patient corticophobia:** Some patients and PCPs have misconceptions regarding the relative risks of corticosteroid usage, which negatively impacts patient compliance



# Atopic Dermatitis (AD) in the USA

## USA healthcare system:

The USA healthcare system is publically and privately funded, with government spending accounting for 49% of the total health spending in 2014<sup>(a)(b)</sup>

### Publicly funded healthcare:

- The main channels of public spending are Medicare, Medicaid and Affordable Care Act (ACA) subsidies.<sup>(a)</sup>
  - Medicare is a national health insurance program in the USA which primarily provides health insurance to Americans aged 65 and older
  - Medicaid is a health coverage program for Americans with low income and resources
  - The Affordable Care Act (ACA), is a USA law to establish shared responsibility between the government, employers, and individuals for ensuring that all Americans have access to affordable and good-quality health insurance
- The ACA expanded Medicaid to make policies affordable, by extending the fund subsidies to nearly all low-income individuals with incomes at or below 138% of the poverty level<sup>(a)</sup>

### Privately funded healthcare

- Private insurance is regulated mostly at the state level. In 2014, state and federally administered health insurance marketplaces were established to provide additional access to private insurance coverage, with income-based premium subsidies for low- and middle-income people<sup>(b)</sup>
- The five biggest commercial health insurers are UnitedHealth, Anthem, Aetna, Cigna and Humana, together representing about 43% of the total insured population. There is increasing consolidation of Pharmacy Benefit Managers (PBMs), which act as intermediaries between insurers and providers<sup>(a)</sup>
- As part of private healthcare insurance, an individual may have to pay a set amount of deductibles before their insurance begins to cover their treatment. Deductibles on employer-based health plans averaged US\$1,350 per person in 2019<sup>(a)</sup>
- There are different types of insurance. Some plans may restrict patients to seeing physicians who are part of the insurance group or are on a preferred list of providers<sup>(e)</sup>

## Prevalence

- In the USA, AD affects 12.98% of children<sup>(c)</sup> and 7.3% of adults<sup>(d)</sup>
- Of the USA adults with AD, 60.1% have mild AD while 28.9% and 11% have moderate and severe AD respectively<sup>(d)</sup>



## Care provision:

### Location:

- Mild (or well-controlled) AD care is primarily delivered by PCPs (primary care providers)
- Moderate and severe (uncontrolled) AD care is mostly delivered by specialist dermatologists

### Funding:

- The practice receives funding from both public and private insurance for their care provision

## Guidelines and societies:

### Guidelines:

- Guidelines of care for the management of AD: American Academy of Dermatology
- Practice parameter for AD care: American Academy of Allergy, Asthma & Immunology (AAAAI)

### Medical societies/PAGs:

- American Academy of Dermatology
- National Eczema Association (NEA)
- Asthma and Allergy Foundation of America
- Global Parents for Eczema Research
- Pediatric Dermatology Research Alliance
- AltogetherEczema

**Sources:** (a) The Economist Intelligence Unit. Industry Report: Healthcare United States of America. Published 2nd Quarter 2019. Accessed 4 Sept 2019; (b) International Health Care System Profiles. The U.S. Health Care System. [Website] [https://international.commonwealthfund.org/countries/united\\_states/](https://international.commonwealthfund.org/countries/united_states/) Accessed 4 Sept 2019; (c) Silverberg J. Public Health Burden and Epidemiology of Atopic Dermatitis. *Dermatol Clin*. 2017;35(3):283-289; (d) Chiesa Fuxench ZC, et al. Atopic Dermatitis in America Study: A Cross-Sectional Study Examining the Prevalence and Disease Burden of Atopic Dermatitis in the US Adult Population. *J Invest Dermatol*. 2019;139(3):583-590. doi: 10.1016/j.jid.2018.08.028; (e) Different Types of Health Plans: How They Compare [Website] <https://www.webmd.com/health-insurance/types-of-health-insurance-plans#1> Accessed 20 Sept 2019

# The dermatology clinic



## The centre



### Type and location

DermAssociates is a private dermatological clinic and research centre located across two sites in Rockville and Silver Spring. It provides medical, surgical, and cosmetic dermatologic care, specialising in the treatment of inflammatory medical skin diseases. The centre is affiliated with US Dermatology Partners, a larger physician network with 70–80 offices across 10 states



### Population served

DermAssociates primarily receives referrals from across a 40–50 mile radius but also receives patients from Maryland, Pennsylvania, West Virginia and New York State

## The dermatology unit



### Service Division

#### Outpatient service



### Hours of availability

- 07:45–18:45 (Mon–Fri)
- 08:00–14:00 (Alternate Saturdays)
- Closed on Sunday



### No. of patients seen

~ 45 AD patients per day across the 2 clinics (~5 patients every day per physician)



### Types of patients seen

Paediatric and adult dermatology patients (including patients with mild, moderate and severe AD)



### Facilities on-site<sup>(1)</sup>

- Phototherapy (NB-UVB)
  - Surgical dermatology
  - Photodynamic therapy
  - Rockville: 2 clinical trial rooms, 6 consultations rooms and 1 surgical room
  - Silver Spring: 8 exam rooms and 4 surgical rooms
- Note: Patch testing performed by allergists, as well as dermatologists specializing in patch testing (available through referral, not in the centre)

Note: (1) List of facilities is not exhaustive

# The team



## Core team profile



**10** Dermatologists (*5 of which work at both sites*)

- 7 dermatologists are involved in performing clinical trials
- 1 paediatric dermatologist



**25** Medical assistants

## Wider team profile



**4** Research coordinators



**1** Senior research manager



**2** Deputy senior researchers

*Note: Please see page 654 for further details about the wider team*



## Governance and processes

### Team meetings:

- *Practice meetings (ad-hoc)*
  - Attended by the dermatologist, study coordinator and research assistant
  - The purpose of the meeting is to discuss patients and consider any potential improvements for the centre

### Patient records:

- Electronic Health Medical Record (EMR) is used to keep standard of care medical records
  - These electronic health records can be accessed by health care professionals within the clinic and within linked organisations using the same system

**Sources:** (a) KPMG interviews

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Typically 60% of patients are self-referrals<sup>(a)</sup>. They either have a family history of a skin condition or attend the centre because they have noticed a skin problem
- New patients can complete an e-registration form on the centre's website which takes less than 5 minutes<sup>(b)</sup>
- The remaining 40% of patients are referred from primary care (family physicians, nurse practitioners and paediatricians)

### Clinical research/trials

- Patients sit in the reception or waiting room and fill preliminary information on paper or iPad
- Participants are then brought to an exam room to complete their consultation as per study protocol

## Diagnosis and Referral

In secondary care



- Patients fill out a questionnaire regarding their medical and family history (focusing on allergy / asthma) on arrival at reception. This can be performed either on iPads or paper
- Medical assistants (MAs) will spend approximately 10 minutes (depending if it is a new patient) reviewing results and asking follow-up questions to the patient, such as effectiveness of previous treatments
- The physician then conducts follow-up questioning. This will be in order to confirm previous findings and the diagnosis (e.g. they may assess likelihood of contact dermatitis in order to establish if a patch test is required)

## Treatment and Management

Medical management



- Dermatologists will agree appropriate treatment with the patient during an approximately 10 minute consultation
- MAs will perform wound care (after skin biopsies), and provide therapeutic education, treatment application instructions and team wet wrapping
- This can take up to 10 minutes for follow-up patients (depending on the clinical need), but ~20 minutes for new patients
- If the patient is prescribed biologic therapy, the patient will be taught how to self-inject by the MA during this consultation

### Comorbidity management

- Patients with comorbidities will be referred to the appropriate specialist through the centre's informal referral network

Non-medical management



### Clinical research/trials

- Patients are often invited to take part in clinical trials if they fulfill the acceptance criteria by the attending dermatologist and research coordinators

## Follow-up

Monitoring of chronic disease / flare up



- Patients almost always book the follow-up as they leave, but they are also able to call up to change the appointment if needed
- Patients using intensive topical therapies alone will have a follow up consultation in 3–4 weeks to see if they require more intensive therapy. If they are stable, they will be followed up thereafter every 6 months
- Patients on biologic therapy will be followed-up after 3 months. This will be then every 6–12 months if they are stable

### Clinical research/trials

- There is always a research coordinator available to answer patients' questions over the phone or in person (regarding their trial, treatment etc.)

**Sources:** (a) KPMG interviews (b) DermAssociates – E-Registration [Website] <https://dermassociates.com/patient-resources/e-registration/> Accessed 9 Oct 2019

# Roles of the wider team

## Research coordinator

**Patient type:** All patients at the centre with either confirmed or potential involvement in clinic trials

**Referral:** Patients are recruited for trials via the dermatologists or patient self-referral.

*Note: Trials are advertised through TV, radio and newspapers, as well as online, through the DermAssociates website and by word of mouth*

### Activities include:

- Recruitment assessment, medication reviews and study consent
- Assisting dermatologists with physical examinations, recording of vital signs and participant education
- Administrative co-ordination and site management

**Timing:** Dependent on stage of clinical trial recruitment process and clinical trial protocol



## Medical Assistant (MA)

**Patient type:** All AD patients at the centre receiving standard care

**MA background:** Most MAs at the centre are pre-med , pre-nursing or pre-pharmacy students

All MAs are required to pass a dermatology technician qualification within 60 days of starting to work at the centre

### Consultation activities include:

- Collecting a full medical and family history (for AD, allergy and asthma)
- Reviewing patient information and asking detailed follow-up questions
- Checking for prior-authorization cover and drafting appeal letters

The MAs will provide follow-up patient education and information on wound care if required

**Timing:** Dependent on AD severity / treatment type and the patient's educational requirements

# Overview of interventions in place for AD

## Awareness and Presentation



Symptom identification

- **Electronic patient questionnaire:** All patients are required to fill in a patient questionnaire on an iPad (or paper) at their first consultation. This will cover questions on their medical and family history (focusing on allergy / asthma)
- **Provision of HCP education:** The centre provides training for HCPs, comprised of on-demand webinars. There are approximately 12-15 of these trainings and they are self-paced

## Diagnosis and Referral



In secondary care

- **Comorbidity specialist network:** The centre has a network of comorbidity specialist which enables patients to be referred as required. The network includes allergists, ophthalmologists, gastroenterologists, psychiatrists and paediatricians

See pg. 660-661 for case study

## Treatment and Management



Medical management

- **Clinical trials:** The centre is heavily involved in a number of clinical trials for adult, adolescent and paediatric patients (including some in collaboration with comorbidity specialists)

See pg. 662 for case study

- **Use of medical assistants (MAs):** MAs will support dermatologists by performing tasks such as patient education, history taking, and medication review. They will summarise the patient information collected via the questionnaire and their additional questioning to the dermatologist, in order to enable an informed and efficient consultation

See pg. 663 for case study



Non-medical management



Monitoring of chronic disease/flare up

- **Follow-up booking:** Follow-up appointments are almost always booked as patients leave. Patients have an option to call and change the appointment later if needed
- **Educational material on the centre's website:** The centre provides educational information for patients regarding AD disease information, treatment options and care recommendations (e.g. bathing)

### Key:



Case study available



# Monitoring AD patients and comorbidities

**The dermatology unit does not tend to use scoring measures aside from the Physician's Global Assessment for monitoring AD and associated comorbidities unless it is required (e.g. by insurance providers):**

**Objective measures (AD):**

AD scoring indices used include:

- SCORAD (SCORing Atopic Dermatitis): to assess AD disease severity and monitor patient progress<sup>(a)</sup>
- EASI (Eczema Area and Severity Index): a tool used to measure the extent (area) and severity of atopic eczema<sup>(b)</sup>
- Physician's Global Assessment: to measure the severity of a variety of skin diseases, including atopic dermatitis, acne and psoriasis<sup>(c)</sup>

**Patient-reported outcomes:**

- DLQI (Dermatology Quality of Life Index): dermatology related quality of life questionnaire<sup>(d)</sup>
- PGA (Patient Global Assessment): generally assessed by a single question with a 0–10 or 0–100 response<sup>(e)</sup>

**Sources:** (a) SCORing Atopic Dermatitis (SCORAD) Calculator (0.9.0). [Website] <http://scorad.corti.li/> Accessed 26 Feb 2019; (b) Leshem YA, et al. What the Eczema Area and Severity Index score tells us about the severity of atopic dermatitis: an interpretability study. *Br J Dermatol.* 2015;172(5):1353-7. doi: 10.1111/bjd.13662; (c) Gooderham MJ, et al. Approach to the Assessment and Management of Adult Patients With Atopic Dermatitis: A Consensus Document. Section II: Tools for Assessing the Severity of Atopic Dermatitis. *J Cutan Med Surg.* 2018;22(1\_suppl):10S-16S. doi: 10.1177/1203475418803628; (d) Lewis V, et al. 10 Years Experience of the Dermatology Life Quality Index (DLQI). *J Invest Dermatol Symp Proc* 2004;9:169 –180; (e) Nikiphorou E, et al. Patient global assessment in measuring disease activity in rheumatoid arthritis: a review of the literature. *Arthritis Research & Therapy* 2016;18(251)



# Advice to other centres



## What advice would you give less specialised centres



### Objective of advice: Active participation in clinical trials

- **Why?** Participation in clinical trials can make a centre more attractive from both a patient and physician perspective. Patients (if they meet study requirements) can access novel treatments and/or those that may not be covered by their insurance. Physicians can advance their knowledge of new treatments / techniques



### Objective of advice: Recognise the relationship between psychological and dermatological wellbeing for patients with AD

- **Why?** AD can negatively impact patients psychological well-being and QoL<sup>(a)</sup>. Given AD is a chronic condition that requires ongoing patient self-management, being conscious of psychosocial impacts can support effective long-term management



### Objective of advice: Establish a referral system in order to promote the provision of holistic care for the patient

- **Why?** AD is a complex, multi-faceted disease with many associated co-morbidities. Each of these co-morbidities require specialist care if they are to be treated effectively. Establishing a referral network through which patients can be directed towards the appropriate specialist best ensures that the co-morbidities can be treated and managed before they cause further damage to the patient's quality of life



### Objective of advice: Understand the full array of AD treatment options available

- **Why?** There are multiple treatment options available for AD, with many varying risks and benefits attached to each option. Understanding the full range of these treatments (available both within the centre and elsewhere) and communicating this to the patient helps counsel the patient on their treatment and enables them to find a treatment with associated risks that is most appropriate for them

**Source:** (a) Slattery MJ, et al. Depression, anxiety, and dermatologic quality of life in adolescents with atopic dermatitis. *J Allergy Clin Immunol*. 2011;128(3):668–671. doi:10.1016/j.jaci.2011.05.003

# Next steps for the centre



## What is next for the centre?

**Objective:** Increase the number of subspecialists available in dermatology

- **What?** Add more subspecialists to the team, such as cutaneous oncologists and mucous membrane disease specialists
- **Why?** Increased provision of subspecialist care will enhance the quality of patient care that is provided, through being able to help an increased pool of patients and provide medical treatment that is not as readily available



**Objective:** Increase the clinical trial centre portfolio

- **What?** Expand the number of trials currently being undertaken by the centre and increase advertising accordingly to raise public awareness of this
- **Why?** By increasing the number of clinical trials, it will advance the quality of care that is delivered to the patient through developing centre knowledge of new treatments and raising awareness of the condition. It will further help to establish the centre as a leader of research and provider of innovative therapies



# Case studies



CONTENTS



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CENTRE REPORTS

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# Comorbidity specialist network (1/2)

## Overview

- The centre has a network of comorbidity specialists who they call upon and refer their patients to when required
  - The network includes allergists, ophthalmologists, gastroenterologists and paediatricians

## What is the rationale?

- Patients with atopic dermatitis are at risk of developing several comorbidities - both allergic (e.g. food allergy, asthma, allergic rhinitis, allergic conjunctivitis, and eosinophilic esophagitis) and non-allergic (e.g. cutaneous bacterial infections)<sup>(a)(b)</sup>

## What are the key features of the intervention?

- DermAssociates have been building relationships over many years with physicians (other specialists and PCPs) across the healthcare community, principally through a well-established position in the psoriasis patient population. This was achieved through staff members at the centre publishing multiple articles covering the risk of cardiovascular disease in psoriatic patients
- In order to emulate this position in the care of AD, relationships have been built across a comorbidity specialist network through joint research projects, joint publications, delivery of training and by accepting referrals from each other
- Established links have been made with:
  - Allergists (for skin prick and patch testing, and management of allergic rhinitis and food allergy
    - *Note: asthma is managed by primary care physicians*
  - Ophthalmologists (for conjunctivitis)
  - Gastroenterologists (for eosinophilic esophagitis)
  - Paediatricians (for chronic recalcitrant disease)
- Referral waiting times to specialists depend on clinical urgency

### Information sharing between specialist

- The dermatologists will generally provide patients with a specific comorbidity specialist name. More junior dermatologists who might not have an established network will ask the more experienced dermatologists at the centre for physician recommendations
- Referral notes are printed by reception staff and made available to patients. Many patients prefer their notes to be sent directly to the comorbidity specialist they have their appointment with. This can be arranged by fax to be sent on the day of their appointment so that the receiving clinic has the notes to hand

**Sources:** (a) Paller A, et al. Major Comorbidities of Atopic Dermatitis: Beyond Allergic Disorders. *Am J Clin Dermatol.* 2018;19(6):821-838. doi: 10.1007/s40257-018-0383-4; (b) Brunner PM, et al. Increasing Comorbidities Suggest that Atopic Dermatitis Is a Systemic Disorder. *Journal of Investigative Dermatology* 2017;137(1):18 – 25; (c) KPMG interviews with DermAssociates



# Comorbidity specialist network (2/2)



## What are the outcomes so far?

### Benefits to patients:

- Recommendations of specific comorbidity specialists located close by
- Convenient transfer of patients' notes directly to specialist

### Benefits to HCPs:

- Allows HCPs to concentrate on their specialty knowing that comorbidity management is available through collaboration of care
- More efficient transfer of patient information due to prior experience working together

## What's next?

- The centre is planning to explore the potential of setting up a joint clinic with allergists

# Clinical trials participation

## Overview

- The centre is heavily involved in clinical trials for adult, adolescent and paediatric patients. Trials allow dermatologists to further advance their knowledge and develop / strengthen connections with other comorbidity specialists<sup>(a)</sup>

## What is the rationale?

- Research in AD understanding and management has developed over the last decade<sup>(b)</sup>. Involvement in clinical trials allows dermatologists to stay abreast of developments and translate this into clinical practice
- AD patients have historically had access to fewer treatment options than chronic urticaria and psoriasis patients of similar disease severities representing an unmet need for AD patients<sup>(c,d)</sup>

## What are the key features of the intervention?

- The centre has 21 active clinical trials (ranging from Phase 1-4), of which 12 are for AD (all of the current AD studies are Phase 2 and 3 clinical trials)<sup>(d)</sup>
- The centre has 2 main research dermatologists with 5 further dermatologists involved in trials, and collaborates with their wider co-morbidity specialist network as required (e.g. allergists)

### *What is composition of the patient pool?*

- The centre has 300 active research participants currently on trials (August 2019). 75-100 of those participants are for AD clinical trials<sup>(b)</sup>
- Research studies include adult, adolescent and paediatric participants (half of the total AD participants are children)<sup>(b)</sup>

### *How are participants referred for the trials?*

- Participants are usually referred via the practice. Some are also recruited through advertising campaigns and a minority of patients call in and express their desire to be involved with a research study (i.e. through word of mouth)

## What are the outcomes so far?

### Benefits to patients:

- Enables patients to access novel treatment / care

### Benefits to HCPs:

- Helps physicians understand emerging therapies and adopt them into clinical practice
- Helps physicians make better connections with comorbidity specialists

## What are the challenges?

- Recruiting patients onto a clinical trial poses a key challenge. Studies often require patients to be treatment naïve from certain existing therapies, which can exclude a number of patients. Furthermore, patients may already have access to innovative agents via their insurance, so they may not see the benefits of joining a trial

**Sources:** (a) Mease PJ, et al. Impact of Clinical Specialty Setting and Geographic Regions on Disease Management in Patients with Psoriatic Arthritis in the United States: A Multicenter Observational Study. *Am J Clin Dermatol*. 2019;20(6):873-880. doi: 10.1007/s40257-019-00470-6; (b) Lio P, et al. Advances in atopic dermatitis raise bar for treatment. *Dermatology Times*. 2018;39(12); (c) Renert-Yuval Y, et al. Systemic therapies in atopic dermatitis: The pipeline. *Clinics in Dermatology* 2017;35(4):387 – 397; (d) KPMG interview with DermAssocites

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# Use of medical assistants

## Overview

- The centre uses medical assistants (MAs) to minimise demand on physicians by performing tasks such as patient education, history taking and medication review. MAs will ask targeted follow up questions based on the completion of the patient questionnaire

## What is the rationale?

- A 2015 report released by the Association of American Medical Colleges projects a shortage of up to 90,000 physicians by 2025<sup>(a)</sup>
- Working under the supervision of dermatologists, medical assistants have been able to extend the reach of the physician and improve patient access to quality dermatologic care<sup>(a)</sup>

## What are the key features of the intervention?

- The centre employs 25 medical assistants with 2 MAs per dermatologist clinic. All medical assistants are required to pass a dermatology technician qualification within 60 days of starting work at the centre
- Medical assistants will engage with patients both before (10–20 mins) and after (time dependent on clinical need) the dermatologist consultations

### *Tasks of the medical assistants:*

#### In day-to-day clinical practice:

- Review patient information and history (from the e-registration form and patient questionnaire)
- Ask detailed follow-up questions based on completion of the patient questionnaire
- Summarise the patient questionnaire findings to the dermatologist
- Recap the dermatologists care recommendations and provide patient education (as required)
- Provide information on post-biopsy wound care
- Checking for prior-authorization cover and drafting appeal letters

#### For clinical trials:

- Performs recruitment assessment of patients
- Performs trial enrolment
- Provides treatment application instructions and therapeutic education (as required)

## What are the outcomes so far?

### **Benefits to patients:**

- Opportunity to have extra time with health professionals (dermatologist and medical assistant)
- Some patients feel more comfortable asking questions to a medical assistant

### **Benefits to HCPs:**

- More time to spend with patients since the administrative burden is lessened and workflow improved
- Important information can be reinforced by MAs
- Increased patient engagement and experience (as evidenced by 10,000+ positive patient surveys)<sup>(b)</sup>

**Source:** (a) Zurfley F Jr, et al. Association Between the Use of a Physician Extender and Dermatology Appointment Wait Times in Ohio. *JAMA Dermatol.* 2017;153(12):1323–1324. doi:10.1001/jamadermatol.2017.3394; (b) KPMG interviews

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# Dermatology Treatment and Research Center

**Dallas, Texas, United States of America**

Site visited by KPMG 1<sup>st</sup> November 2019

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[kpmg.com/uk](https://kpmg.com/uk)



# Summary



## Context

**Centre type:** Private dermatology practice that is part of the DermCare network

**Catchment area:** Patients from the States of Texas (approximately 28 million people) and Oklahoma (approximately 3.9 million people)

**Funding:** Receives funding through private and public health insurance (i.e. Medicare) and patient out of pocket

**Services:** Services provided include Medical Dermatology (e.g. acne, psoriasis, skin allergies, atopic dermatitis), Surgical Dermatology, Paediatric Dermatology, Cosmetic Dermatology (e.g. botox, laser treatment, fillers) and Dermatopathology

**Patient population:** Paediatric and adult patients with dermatological conditions who require clinical / cosmetic treatment



## Key strengths in the delivery of AD care

**Familiarity with all current AD treatments:** Although the centre is relatively small, it has access to a variety of treatments, (e.g. biologics) to help enhance patient treatment outcomes

**Extensive experience managing AD:** Through treating a substantial number of patients with AD, the dermatologist has developed AD treatment expertise

**Long standing relationship with patients:** The centre has developed long-term relationships with numerous patients



## Key challenges faced in delivery of AD care

**Variable access to treatment:** Due to the different insurance plans / providers, patients may not have financial coverage for the recommended AD treatments

**Limited time to provide patient education:** Patients require sufficient AD education to encourage adherence to treatment regimens. This often requires multiple trips to the centre however for the patient to receive the education necessary

# Atopic Dermatitis (AD) in the USA

## USA healthcare system:

The USA healthcare system is publically and privately funded, with government spending accounting for 49% of the total health spending in 2014<sup>(a)(b)</sup>

### Publicly funded healthcare:

- The main channels of public spending are Medicare, Medicaid and Affordable Care Act (ACA) subsidies<sup>(a)</sup>
  - Medicare is a national health insurance program in the USA which primarily provides health insurance to Americans aged 65 and older
  - Medicaid is a health coverage program for Americans with low income and resources
  - The Affordable Care Act (ACA), is a USA law to establish shared responsibility between the government, employers, and individuals for ensuring that all Americans have access to affordable and good-quality health insurance
- The ACA expanded Medicaid with the intention of making policies affordable, by extending the fund subsidies to nearly all low-income individuals with incomes at or below 138% of the poverty level<sup>(a)</sup>

### Privately funded healthcare

- Private insurance is regulated mostly at the state level. In 2014, state and federally administered health insurance marketplaces were established to provide additional access to private insurance coverage, with income-based premium subsidies for low- and middle-income people<sup>(b)</sup>
- The five biggest commercial health insurers are UnitedHealth, Anthem, Aetna, Cigna and Humana, together representing about 43% of the total insured population. There is increasing consolidation of Pharmacy Benefit Managers (PBMs), which act as intermediaries between insurers and providers<sup>(a)</sup>
- As part of private healthcare insurance, an individual may have to pay a set amount of deductibles before their insurance begins to cover their treatment. Deductibles on employer-based health plans averaged US\$1,350 per person in 2019<sup>(a)</sup>
- There are different types of insurance. Some plans may restrict insurance restricts patients to seeing physicians who are part of the insurance group or are on a preferred list of providers<sup>(e)</sup>

## Prevalence

- In the USA, AD affects 12.98% of children<sup>(c)</sup> and 7.3% of adults<sup>(d)</sup>
- Of the USA adults with AD, 60.1% have mild AD while 28.9% and 11% have moderate and severe AD respectively<sup>(d)</sup>



## Care provision:

### Location:

- Mild (or well-controlled) AD care is mainly delivered by PCPs (primary care providers)
- Moderate and severe (uncontrolled) AD care is mostly delivered by specialist dermatologists

### Funding:

- The centre receives accepts by both public and private insurance
- Research projects are either industry sponsored or funded through NIH (National Institute for Health) grants

## Guidelines and societies:

### Guidelines:







- Guidelines of care for the management of atopic dermatitis:
  - American Academy of Dermatology
  - Annals of Allergy, Asthma & Immunology

### Medical societies/PAGs:

- American Academy of Dermatology
- National Eczema Association (NEA)
- Global Parents for Eczema Research
- Asthma and Allergy Foundation of America
- Pediatric Dermatology Research Alliance
- AltogetherEczema

**Sources:** (a) The Economist Intelligence Unit. Industry Report: Healthcare United States of America. Published 2nd Quarter 2019. Accessed 4 Sept 2019; (b) International Health Care System Profiles. The U.S. Health Care System. [Website] [https://international.commonwealthfund.org/countries/united\\_states/](https://international.commonwealthfund.org/countries/united_states/) Accessed 4 Sept 2019; (c) Silverberg J. Public Health Burden and Epidemiology of Atopic Dermatitis. *Dermatol Clin.* 2017;35(3):283-289; (d) Chiesa Fuxench ZC, et al. Atopic Dermatitis in America Study: A Cross-Sectional Study Examining the Prevalence and Disease Burden of Atopic Dermatitis in the US Adult Population. *J Invest Dermatol.* 2019;139(3):583-590. doi: 10.1016/j.jid.2018.08.028; (e) Different Types of Health Plans: How They Compare [Website] <https://www.webmd.com/health-insurance/types-of-health-insurance-plans#1> Accessed 20 Sept 2019





# The centre and dermatology unit

The centre		
 <b>Type and location</b>	<ul style="list-style-type: none"><li>— The Dallas Dermatology Treatment and Research Center is a private clinic that is part of the DermCare network of dermatologist clinics</li><li>— Services provided include acute and chronic care for clinical and cosmetic dermatology for adult and paediatric patients</li></ul>	
	<ul style="list-style-type: none"><li>— Patients from the State of Texas (approximately 28 million people) and Oklahoma (approximately 3.9 million people)</li></ul>	
Dermatology services		
 <b>Service Division</b>	<b>Clinical practice services</b>	<b>Cosmetic practice services</b>
	Monday to Thursday: 8am – 5pm Friday: 8am – 4pm	Monday to Thursday: 8am – 5pm Friday: 8am – 4pm
	Approximately 40 AD patients per week	
	Paediatric and adult patients with a dermatological condition requiring clinical intervention	Paediatric and adult patients requiring cosmetic dermatological treatment
	<ul style="list-style-type: none"><li>— Dermatological surgical rooms / consultation rooms</li><li>— Phototherapy (UVA and narrowband UVB)</li><li>— Research laboratory</li><li>— Pathology collection</li><li>— Storage facility for biosamples (for clinical trials)</li></ul>	
 <b>Hours of availability</b>		
 <b>No. of patients seen</b>		
 <b>Types of patients seen</b>		
 <b>Facilities on-site</b>		

# The team



## Core team profile ●

-  **3** Dermatologists
-  **4** Medical assistants (including 1 dedicated biologics coordinator)
-  **1** Research supervisor
-  **3** Research co-ordinators
-  **2** Rotating medical students / post-graduate residents
-  **1** Office manager
-  **2** Front Office personnel (receptionist and billing clerk)



## Governance and processes

### Team meetings:

- *Administrative meetings (ad-hoc, variable duration)*
  - Attended by all staff
  - The purpose of the meeting is discuss current / upcoming clinical trials, assess any operational issues (e.g. insurance coverage) and review different types of medication available

### Patient records:

- *Electronic patient records*
  - Electronic health management system and electronic health records

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients present to their paediatrician / primary care physicians (PCP) / office-based specialist (e.g. dermatologist) with AD symptoms (e.g. itching or dryness of the skin)
- Note: AD patients that are mild or well-controlled may be managed by their PCP / paediatrician and may therefore not be referred to the centre*
- Severe patients are referred to the centre, often by a PCP / other dermatologist / specialist
- Patients may present directly to the centre

## Diagnosis and Referral

In secondary care



- Paediatric and adult patients are referred to the centre for an initial consultation with the dermatologist
- At the initial consultation, the dermatologist performs an assessment of the patient's symptom, medical history and current / previous treatment (~20mins)
- A medical assistant and medical student are present during the consultation to support the dermatologist:
  - Based on the assessment, the dermatologist will instruct the medical assistant to perform various tests, including blood tests or biopsy
  - The medical student observes the consultation for educational purposes

## Treatment and Management

Medical management



- The dermatologist will initiate / modify patient treatment. Generally, the patient will start a treatment regimen that includes emollients, topical steroids / calcineurin inhibitors
- Baseline EASI scores are taken and repeated at the start and throughout treatment by the dermatologist
- The dermatologist will refer to comorbidity specialists as required
- Patients may be offered the opportunity to participate in clinical trials at the centre

Non-medical management



- Throughout the initial consultation, the patient will receive various educational materials, such as leaflets and pamphlets. Patients may also receive individualised, written treatment plans / materials
- The dermatologist may run group patient educational sessions to provide advice on AD symptoms and treatment
- PUVA / UVB phototherapy is provided at the centre by medical assistants as required
- The dermatologist may refer the patient to the National Eczema Association's support group (via a general referral telephone line)

## Follow-up

Monitoring of chronic disease / flare up



- Patients are seen 2 weeks after the initial consultation to assess treatment progress, discuss the long-term treatment plan and review test results (where applicable)
- Thereafter, patients are followed up every 1-3 months depending on the severity of their condition
- Patients are able to call the centre if they have any side effects / concerns at any point in time
- Patients tend to remain at the centre for continued care (rather than being referred back to the PCP)

# Overview of interventions in place for AD




## Key:

 Case study available

## Awareness and Presentation




Symptom identification

- **Patient education groups:** The centre hosts education groups to provide patients with an opportunity to learn about AD, ask questions and seek support  
 See pg. 675 for case study
- **Referral to patient support groups:** The dermatologist may refer a patient to the local patient support group which is facilitated by the National Eczema Society

## Diagnosis and Referral



In secondary care

- **Focus on healthcare professional education:** The centre provides medical student / post-graduate resident rotations and healthcare professional (HCP) lectures. This provides HCPs with up-to-date knowledge regarding diagnosis of AD and newly available AD treatments  
 See pg. 676 for case study

## Treatment and Management





Medical management

- **Onsite pathology collection:** The medical assistants are able to perform pathology collection onsite
- **Participation in clinical trials:** Patients may have the opportunity to participate in observational and interventional clinical trials. The centre currently has 6 AD-related interventional trials
- **Onsite sample storage facility:** The centre maintains a storage facility for AD patient biosamples (for clinical practice and clinical trials)



Non-medical management

- **Medical assistant-led support:** Medical assistants perform a variety of tasks to support the dermatologist in their provision of patient care, as well as provide additional direct support to the patient  
 See pg. 677 for case study
- **Role of biologic coordinator:** To facilitate and arrange biologic treatments for patient, the centre has a dedicated biologic coordinator  
 See pg. 678 for case study

## Follow-up



Monitoring of chronic disease/flare up

- **Open access for patients:** Patients have the option to call the centre for advice / organise appointments as required





# Monitoring AD patients and comorbidities

## The dermatology centre employs a number of measures for monitoring AD and associated comorbidities

### Objective measures:

AD scoring indices are utilised to monitor patients and their disease, including:

- EASI (Eczema Area and Severity Index): scoring system that grades the physical signs of AD / eczema<sup>(a)</sup>
- VAS (Visual Analogue Scale): scale used in clinical trials for measuring itch intensity<sup>(b)</sup>
- Dermatologist may also measure patient sleep disturbances via motion-watch detector

### Patient-reported outcomes:

QoL is routinely measured by:

- DLQI (Dermatology Quality of Life Index): dermatology related quality of life questionnaire<sup>(c)</sup>

---

### The dermatology centre routinely measures comorbidity outcomes by:

- *Blood tests*: performed by medical assistant in diagnostic testing
- *Allergy patch tests*: conducted using Expanded American Contact Dermatitis sets
- *Biopsy collection*: performed by medical assistant in diagnostic testing
- *Radioallergosorbent (RAST) testing*: performed by medical assistant to detect IgE antibodies against allergens

**Sources:** (a) EASI for clinical signs: Harmonising Outcome Measures for Eczema (HOME) [Website] <http://www.homeforeczema.org/research/easi-for-clinical-signs.asp> Accessed 6 Nov 2019; (b) Visual Analogue Scale (VAS). Pruritus Resources [Website] <http://www.pruritussymposium.de/visualanaloguescale.html> Accessed 6 Nov 2019; (c) Validated Investigator Global Assessment For Atopic Dermatitis (vIGA-AD™) Scale [PDF] [https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale\\_vIGA-AD\\_2017.pdf](https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale_vIGA-AD_2017.pdf) Accessed 6 Nov 2019

# Advice to other centres



## What advice would you give less specialised centres



### Objective of advice: Refer patients to specialists to aid in the treatment of comorbidities

- **Why?** AD is a chronic disease that is associated with a number of atopic and non-atopic comorbidities. Patients with moderate-severe AD / complex AD patients can benefit from access to multiple HCPs (e.g. allergists, psychologists, primary care practitioners[PCPs]) and centres should aim to provide them with direct access where possible



### Objective of advice: Increase patient exposure to dermatologists

- **Why?** Patient exposure to HCPs is a key determinant behind how much education the patient receives, how well this communication is received and the impact this has on encouraging patient treatment compliance. Every dermatologist should see every patient at least once a year or every third visit (if utilising a nurse practitioner / other healthcare provider support). Increasing exposure to dermatologists is therefore of primary importance to enhancing patient quality of care



### Objective of advice: Invite dermatologist to multidisciplinary team meetings

- **Why?** AD can be a complex disease to manage, and patient needs can differ from other dermatological conditions. Inviting dermatologists to multidisciplinary team meetings enables physicians to receive access to specialist advice, which they can then utilise to develop and tailor their treatment plans to individual patients

# Next steps for the centre



## What is next for the centre?

### Objective: Establish recognised post-graduate university programme with local university

- **What?** The centre aims to enhance their existing relationship with the local university and form an official post-graduate training programme. A 1-year training rotation for up to 5 residents a year will be created based on the existing 1-month rotation at the centre
- **Why?** The programme can support the development of medical students and provide them with practical training and exposure to a range of dermatological conditions



### Objective: Continue to participate in the development of medical textbooks

- **What?** A dermatologist at the centre has been heavily involved in co-authoring dermatology textbooks and aims to participate in the development of future textbooks
- **Why?** Medical textbooks are a definitive source of information that dermatologists, trainee dermatologists and medical students can refer to for information on diagnosis and treatment of conditions. Supporting the creation of textbooks can help the broader medical community in advancing their knowledge of dermatological conditions



# Case studies



CONTENTS



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CENTRE REPORTS

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# Patient education groups

## Overview

- Patient education groups have been hosted at the centre for a number of years, in order to provide a more informal environment for patients to ask questions and harness support from other patients



In addition to individualised education, we can provide patient education group sessions

*Dermatologist, Dermatology Treatment and Research Center*



## What is the rationale?

- Patient education and its link to compliance are important in AD care<sup>(a)</sup>
- Patient education can also improve a patient's ability to cope with the disease and reduce symptom severity<sup>(b)</sup>
- Educational interventions are recommended for patients at all levels of AD therapy<sup>(c)</sup>

## What are the key features of the intervention?

- For the last 15 years, the centre has utilised patient education groups to provide practical advice and support to patients with AD and other dermatological conditions
- The content for any given session will depend on the patients attending. Patients are referred to the session by the dermatologist
  - Previous topics include treatment / management of dermatological diseases and information on new treatments
- The sessions are held in the centre's waiting room and between 10-30 patients attend each session
- Each session is usually sponsored by a pharmaceutical company and occurs on an ad-hoc basis

## What are the outcomes so far?

### Benefits to patients:

- Increased awareness and ability to manage the condition, resulting in better treatment compliance
- Access to a supportive network to promote psychosocial support

### Benefits to HCPs:

- Reduced demand on HCP time as the patient is empowered to manage their condition more effectively

## What's next?

- Continue to support patient education groups

**Sources:** (a) Wollenberg A, et al. Consensus-based European guidelines for treatment of atopic eczema (atopic dermatitis) in adults and children: part II. *J Eur Acad Dermatol Venereol*. 2018;32(6):850-878. doi: 10.1111/jdv.14888; (b) Grossman SK, et al. Experiences with the first eczema school in the United States. *Clin Dermatol*. 2018;36(5):662-667; (c) Nicol NH, et al. The role of the nurse educator in managing atopic dermatitis. *Immunol Allergy Clin North Am*. 2010;30(3):369-83; (e) Schlungen. Arbeitsgemeinschaft [Website] [www.neurodermitisschulung.de/index.php?id=1](http://www.neurodermitisschulung.de/index.php?id=1) Accessed 8 May 2019

# Focus on healthcare professional education

## Overview

- The centre provides medical student rotations and healthcare professional lectures. This provides HCPs with up-to-date knowledge regarding new treatments available, which can then be used to assist patients



## What is the rationale?

- Healthcare professional education has the potential to improve the physician knowledge and confidence of HCPs and patient health outcomes<sup>(a)</sup>

## What are the key features of the intervention?

- To support local healthcare professional (HCP) education, the centre provides medical students to participate in 1-month long rotations and healthcare professional educational lectures

### Medical student rotations

- Medical students are able to observe patient consultations with the dermatologist and medical assistant
- After the patient consultation, the medical students are able to discuss patient cases with the dermatologist and receive treatment guidance and advice
- Currently, there are 1-2 medical students on rotation at the centre each month

### Healthcare professional educational lectures

- A dermatologist from the centre provides lectures on various dermatological conditions and treatments. For example, a previous lecture have involved presenting new treatment options for different diseases
- The lectures are targeted at HCPs. They are usually sponsored by a pharmaceutical company and occur once a month
- A range of professionals (e.g. 2 primary care physicians, 2 nurses and 4 medical assistants), usually attend
- The average group size for a HCP lecture is around 8 participants.

## What are the outcomes so far?

### Benefits to patients:

- HCPs receive formal education regarding new treatments available, which can then be applied to patient treatment plans

### Benefits to HCPs:

- Increased awareness of new treatments to further enhance the quality of care provided to patients

## What's next?

- The centre aims to enhance their existing relationship with the local university and form an official post-graduate training programme

**Sources:** (a) Cervero RM, et al. The Impact of CMA on Physician Performance and Patient Health Outcomes: An Updated Synthesis of Systematic Reviews. *Journal of Continuing Education in the Health Professions*. 2015;35(2):131-139,

# Medical assistant-led support

## Overview

- Medical assistants perform a variety of tasks to support the dermatologist in their provision of patient care, as well as provide additional direct support to the patient
- Tasks can vary from discussing treatment with the patient over the phone, to providing further patient education



We can provide advice or refer to the dermatologist if required”

*Medical assistant,  
Dermatology Treatment and  
Research Center*



## What is the rationale?

- Due to resource constraints, physicians often have limited time which they are able to spend in consultations with patients<sup>(a)</sup>
- This can limit the amount of education that the patient receives<sup>(a)</sup>, which in turn can have a negative impact on long term management of the condition and overall patient outcomes<sup>(b)</sup>
- According to a UK study, utilising healthcare assistants in the primary care setting can help improve performance of the practice, provide opportunities for new or extended services and improve care for specific patient groups<sup>(c)</sup>

## What are the key features of the intervention?

- The medical assistant provides advice to patients outside of the dermatologist consultation through a variety of communication channels
  - Patients are able to contact the centre and speak to a medical assistant via phone, email or SMS
  - Depending on the patient’s symptoms / request, the medical assistant can triage the patient request and either provide advice or refer the patient to the dermatologist
- If required, the medical assistant will also be available to provide face-to-face counselling on any areas of treatment / symptom management raised by the patient after the initial dermatologist consultation
- Medical assistants are also utilised as biologic coordinators for patients who are being treated with biologics (*see case study: Role of a biologic coordinator*). This function includes medication approval, drawing blood, performing tests and providing patient education regarding injection training
- Medical assistants are given the opportunity to take part in external training programmes, sponsored by pharmaceutical companies, to support their role

## What are the outcomes so far?

### Benefits to patients:

- More opportunities to discuss care plans as dermatologists are less burdened by administrative tasks
- Patients may feel more comfortable asking questions to a medical assistant

### Benefits to HCPs:

- Dermatologists have more time to spend with patients since the administrative burden is lessened
- Important information can be reinforced by medical assistants

**Sources:** (a) Mehta S. Patient Satisfaction reporting and its implications for patient care. *AMA Journal of Ethics*. *AMA J Ethics*. 2015;17(7):616-621. doi: 10.1001/journalofethics.2015.17.7.ecas3-1507; (b) International Alliance of Dermatology Patient Organizations. Atopic Dermatitis: A collective Global Voice for Improving Care, February 2018; (c) Petrova M, et al. Benefits and challenges of employing health care assistants in general practice: a qualitative study of GPs’ and practice nurses’ perspectives. *Family Practice*. 2010;27(3):303-311. doi: 10.1093/fampra/cmqq011



# Role of biologic coordinator

## Overview

- To facilitate and arrange biologic treatments for patient, the centre has a dedicated biologic coordinator. The role involves completing medication approval forms and providing patient education regarding injection training



The biologic coordinator (role) helps with the quick approval of medication”

*Dermatologist, Dermatology Treatment and Research Center*



## What is the rationale?

- Biologic therapies are an emerging treatment option for the management of AD. However, there are a number of issues which can cause delays to patient's accessing these therapies<sup>(a)(b)</sup>
- For example, the insurance pre-authorisation process can be lengthy for the patients and medical staff involved<sup>(c)</sup>, with each prescription requiring a different form<sup>(d)</sup>

## What are the key features of the intervention?

- The centre has a dedicated medical assistant who acts as a biologic coordinator who focuses solely on coordinating patient access to biological treatments
- The medical assistant will initially apply for treatment approval through the patient's medical insurance company. During the application process, the medical assistant will explain to the patient what to expect from the application process and next steps (depending on approval outcome)
  - If the treatment is approved, the medical assistant can also provide education to the patient regarding treatment administration. The consultation takes approximately 15 minutes and involves teaching patients the to inject the treatment
    - Patients are required to stay in the centre for observation for 20-30 minutes after the administration of the medication
  - If the treatment is not approved, the medical assistant can apply for the patient to access the medication through the pharmaceutical company's patient support programme
    - Patients may be rejected for biologic approval if they have not previously attempted other treatment options
- The centre is generally able to complete the application and approval process for clinical treatment in 2 weeks

## What are the outcomes so far?

### Benefits to patients:

- Quicker access to new treatments otherwise untried by the patient
- Provision of additional support regarding application for funding and management of treatment

### Benefits to HCPs:

- Through utilising specialists to manage certain aspects of the treatment pathway, dermatologist time is freed up to focus on other holistic aspects of care unrelated to biologics

**Sources:** (a) Fabbrocini G, et al. Treatment of Atopic Dermatitis with Biologic Drugs. *Dermatol Ther (Heidelberg)*. 2018;8(4):527-538. doi: 10.1007/s13555-018-0258-x; (b) NEA. Hope With New Atopic Dermatitis Drugs But Will They Be Covered? [Website] <https://nationaleczema.org/insurance-for-atopic-dermatitis-drugs/> Accessed 23 Oct 2019; (c) Jones LK, et al. Understanding the medication prior-authorisation process: A case study of patients and clinical staff from a large rural integrated health delivery system. *American Journal of Health-System Pharmacy*. 2019;7. doi: 10.1093/ajhp/zxy083; (d) KPMG interviews



# Medical Dermatology Associates of Chicago

Chicago, United States of America

Site visited by KPMG 22<sup>nd</sup> August 2019

[kpmg.com/uk](https://kpmg.com/uk)



APPENDIX  
CENTRE REPORTS



# Summary



## Context

**Centre type:** Privately owned medical practice

**Catchment area:** Patients from across Illinois, usually from the city of Chicago. Other patients from across the United States may also be treated

**Funding:** The practice predominantly receives funding from public health insurance, which is supplemented by some private health insurance funding

**Services:** Services provided include medical, paediatric, surgical and cosmetic dermatology

**Patient population:** Paediatric and adult patients with dermatological conditions, including medical, surgical and cosmetic treatment



## Key strengths in the delivery of AD care

**Enabling patients timely access to care and treatment:** Although the centre is a small practice, the dermatologist is able to see moderate to severe AD patients quickly and regularly. In between follow-up appointments, the dermatologist arranges a follow-up phone call with patients who are on new or modified treatment regimes, enabling patients to raise concerns in a timely manner

**Active involvement in clinical trials:** The practice is currently involved in four clinical trials, helping patients access novel treatments. The practice is therefore also able to stay informed about the developments and advancements in AD treatment

**Network of comorbidity specialists:** Patients are able to easily access comorbidity care, through the dermatologist's network of specialists or specialists located at the centre



## Key challenge faced in delivery of AD care

**Resourcing limitations of a small practice:** The dermatology practice has limited resources and new patients usually have to wait two to three months for an appointment. Additionally, obtaining insurance coverage for medications can be difficult, as the practice does not have a dedicated team or 'biologic coordinator' for support

# Atopic Dermatitis (AD) in the USA

## USA healthcare system:

The USA healthcare system is publically and privately funded, with government spending accounting for 49% of the total health spending in 2014<sup>(a)(b)</sup>

### Publicly funded healthcare:

- The main channels of public spending are Medicare, Medicaid and Affordable Care Act (ACA) subsidies.<sup>(a)</sup>
  - Medicare is a national health insurance program in the USA which primarily provides health insurance to Americans aged 65 and older
  - Medicaid is a health coverage program for Americans with low income and resources
  - The Affordable Care Act (ACA), is a USA law to establish shared responsibility between the government, employers, and individuals for ensuring that all Americans have access to affordable and good-quality health insurance
- The ACA expanded Medicaid to make policies affordable, by extending the fund subsidies to nearly all low-income individuals with incomes at or below 138% of the poverty level<sup>(a)</sup>

### Privately funded healthcare

- Private insurance is regulated mostly at the state level. In 2014, state and federally administered health insurance marketplaces were established to provide additional access to private insurance coverage, with income-based premium subsidies for low- and middle-income people<sup>(b)</sup>
- The five biggest commercial health insurers are UnitedHealth, Anthem, Aetna, Cigna and Humana, together representing about 43% of the total insured population. There is increasing consolidation of Pharmacy Benefit Managers (PBMs), which act as intermediaries between insurers and providers<sup>(a)</sup>
- As part of private healthcare insurance, an individual may have to pay a set amount of deductibles before their insurance begins to cover their treatment. Deductibles on employer-based health plans averaged US\$1,350 per person in 2019<sup>(a)</sup>
- There are different types of insurance. Some plans may restrict insurance restricts patients to seeing physicians who are part of the insurance group or are on a preferred list of providers<sup>(e)</sup>

## Prevalence

- In the USA, AD affects 12.98% of children<sup>(c)</sup> and 7.3% of adults<sup>(d)</sup>
- Of the USA adults with AD, 60.1% have mild AD while 28.9% and 11% have moderate and severe AD respectively<sup>(d)</sup>



## Care provision:

### Location:

- Mild (or well-controlled) AD care is primarily delivered by PCPs (primary care providers)
- Moderate and severe (uncontrolled) AD care is mostly delivered by specialist dermatologists

### Funding:

- The practice receives funding from both public and private insurance for their care provision

## Guidelines and societies:

### Guidelines:








- Guidelines of care for the management of atopic dermatitis: American Academy of Dermatology
- Recommendations for atopic dermatitis care: Annals of Allergy, Asthma & Immunology

### Medical societies/PAGs:

- American Academy of Dermatology
- National Eczema Association (NEA)
- Asthma and Allergy Foundation of America
- Global Parents for Eczema Research
- Pediatric Dermatology Research Alliance
- AltogetherEczema

**Sources:** (a) The Economist Intelligence Unit. Industry Report: Healthcare United States of America. Published 2nd Quarter 2019. Accessed 4 Sept 2019; (b) International Health Care System Profiles. The U.S. Health Care System. [Website] [https://international.commonwealthfund.org/countries/united\\_states/](https://international.commonwealthfund.org/countries/united_states/) Accessed 4 Sept 2019; (c) Silverberg J. Public Health Burden and Epidemiology of Atopic Dermatitis. *Dermatol Clin.* 2017;35(3):283-289; (d) Chiesa Fuxench ZC, et al. Atopic Dermatitis in America Study: A Cross-Sectional Study Examining the Prevalence and Disease Burden of Atopic Dermatitis in the US Adult Population. *J Invest Dermatol.* 2019;139(3):583-590. doi: 10.1016/j.jid.2018.08.028; (e) Different Types of Health Plans: How They Compare [Website] <https://www.webmd.com/health-insurance/types-of-health-insurance-plans#1> Accessed 20 Sept 2019

# The centre and dermatology unit

The practice		
 <b>Type and location</b>	<ul style="list-style-type: none"><li>— Medical Dermatology Associates of Chicago (MDA) is a private dermatological clinic located in Chicago, Illinois. Services provided include medical, paediatric, surgical and cosmetic dermatology</li><li>— The Chicago Integrative Eczema Center is located within the Medical Dermatology Associates of Chicago and provides AD patients with holistic care by emphasising natural therapies, in addition to medicines. It also gives patients an opportunity to participate in research related to understanding the causes and treatment of AD</li></ul>	
	 <b>Population served</b>  Patients from across Illinois, usually from the city of Chicago	
Dermatology services		
 <b>Service Division</b>  <b>Hours of availability</b>   <b>No. of patients seen</b>   <b>Types of patients seen</b>   <b>Facilities on-site<sup>(1)</sup></b>	<b>General dermatology (MDA)</b>	<b>Chicago Integrative Eczema Center</b>
	08:00–17:00 (Monday – Friday)	08:00–12:00 (Saturdays)
	<ul style="list-style-type: none"><li>— On average, 600 patients are seen at the practice per week</li><li>— The dermatologist who specialises in atopic dermatitis sees 120 patients per week (of which ~40 to 60 are AD patients)</li></ul>	Approximately 4 to 5 new patients per week
	<ul style="list-style-type: none"><li>— Mild-to-severe paediatric and adult AD patients</li><li>— Severe or complicated cases are seen at the Chicago Integrative Eczema Center on Saturday</li></ul>	
	<ul style="list-style-type: none"><li>— Patch testing</li><li>— Biopsy equipment</li><li>— Phototherapy (UVB only)</li></ul>	<ul style="list-style-type: none"><li>— Acupuncture</li><li>— Hypnotherapy</li></ul>

**Note:** (1) List of facilities is not exhaustive

# The team

## Core team profile

### MDA:



**5** Dermatologists (including 1 dermatologist who is part of the eczema centre)



**1** Physician assistant



**1** Medical aesthetician

### Chicago Integrative Eczema Center:



**1** Dermatologist



**1** Study co-ordinator (part-time)



**1** Physician assistant



**1** Acupuncture and herbal medicine expert

## Wider team profile

(based outside of the practice)



**1** Allergist



**1** Hypnotherapist



**1** Nutritionist



**1** Ophthalmologist

Please see page 685 for further details about the wider team



## Governance and processes

### Team meetings:

- Practice meetings (ad-hoc)
  - Attended by the dermatologist, study coordinator and research assistant
  - The purpose of the meeting is to discuss patients and consider any potential improvements for the practice

### Patient records:

- Electronic patient records (EHR):
  - Electronic health records can be accessed by health care professionals within the clinic

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients present to their primary care physician (PCP) with AD symptoms (e.g. itching or dryness of the skin). The physician will assess and refer if required
- Patients may present directly to the practice

*Note: Mild paediatric and adult AD patients tend to be managed by less specialised dermatologists or PCPs. As a result, mild AD patients may not be seen by the practice*

## Diagnosis and Referral

In secondary care



- Pediatric and adult AD patients referred to the practice are seen by the dermatologist. For new patients, the initial appointment is approximately 15 minutes
- During the initial consultation, the dermatologist will perform an assessment on the patients clinical symptoms and medical history
- Patients with severe AD or complicated symptoms are usually asked to attend a secondary consultation at the specialised eczema centre
- After the initial consultation, patients are encouraged to follow up for the Integrative Eczema Center meeting where more detailed education and support can occur. During the second consultation, the physician assistant continues to develop treatment plan (*see medical management section*). Approximate visit duration for complex cases is 30 minutes
- Patients can access clinical trials and be a part of novel diagnosis and treatment methods at the practice

## Treatment and Management

Medical management



- Treatment is initiated by the dermatologist who considers whether:
  1. The patient's immediate symptoms can be easily treated
  2. The patient can get treated safely. For example, prescribing strong medication only for occasional use
  3. The patient can be kept clear of AD consistently
- Based on the steps above, a tailored treatment plan is made for the patient

### Comorbidity management

- A multidisciplinary approach is adopted through a network of specialists
- The dermatologist refers or discusses the patient with comorbidity specialists located outside of the practice (including a nutritionist, hypnotherapist and ophthalmologist)
- The communication between the doctors is generally over the phone and reports are faxed when required

Non-medical management



- The dermatologist refers to the nutritionist, acupuncture and hypnotherapist in the clinic when required
- UVB phototherapy is provided at the practice by the physician assistant
- An eczema support group is available for patients and their families to meet other patients and share their experiences and tips on AD management. The group is generally hosted at the practice and involves an educational and practical session

## Follow-up

Monitoring of chronic disease / flare up



- A follow-up phone call is organised within 1-2 weeks of the initial visit (follow-up emails are sent to confirm the call)
- Patients are followed up in person every 4-6 weeks (4 weeks for severe cases)
- Patients can either remain at the practice or be referred back to their initial dermatologist or PCP



# Roles of the wider team

The dermatologist's established network of specialists is considered to be the wider team. The specialists are located outside of the practice.

## Ophthalmologist

**Patient type:** Mild to severe AD patients may be seen if they present with ocular symptoms

**Referral:** Referred by dermatologist through the specialist network

**Consultations:** The ophthalmologist conducts a range of tests to diagnose and treat eye comorbidities. Tests may include: general eye examination, topography, examination of retina, and optic nerve or visual accuracy test

**Timing:** Consultations vary in length depending on patient requirements

## Hypnotherapist

**Patient type:** Paediatric and adult AD patients exhibiting psychological symptoms (as a result of AD – e.g. stress or difficult to manage behaviors such as picking / rubbing) or existing psychological pathology (i.e. not related to their AD)

**Referral:** Referred by dermatologist through the specialist network

**Consultations:** The hypnotherapist conducts consultations with patients to discuss AD and psycho-social impact and to provide psychological support

**Timing:** Consultations vary in length depending on patient requirements



## Allergist

**Patient type:** Moderate to severe AD patients who have not consulted an allergist, or AD patients with suspected contact allergies, food allergies, drug allergies, inhalation allergies and eye infections (conjunctivitis)

**Referral:** Referred by dermatologist through the specialist network

**Consultations:** The allergist performs standard tests, such as prick tests, and provides treatments as required

**Timing:** Consultations vary in length depending on patient requirements

## Nutritionist

**Patient type:** AD patients with suspected food allergies or patients who may have dietary issues / overall nutrition health support

**Referral:** Referred by dermatologist through the specialist network

**Consultations:** The nutritionist works with the allergist to conduct and advise on specialist allergy tests, including interpretation of test results. As part of the eczema support group, the nutritionist also provides advice for specialists within the practice and wider community

**Timing:** Consultations vary in length depending on patient requirements

## Roles of other team members

*Traditional Chinese Medicine and Acupuncture (TCM):*

For patients who prefer to avoid or minimise western medications, the dermatologist works in tandem with a Traditional Chinese Medicine and Acupuncture specialist. The TCM specialist is located within the eczema centre and performs an intake questionnaire and detailed exam. On average, each consultation takes approximately 1 hour

# Overview of interventions in place for AD

## Awareness and Presentation



Symptom identification

- **Working alongside the National Eczema Association:** The eczema centre works alongside the National Eczema Association (NEA) to improve AD management. NEA provides the eczema centre with their interactive support group and all dermatologists with patient-centric tools to complement traditional care models



See pg. 691 for case study

- **Regular social media posts:** The practice raises awareness of symptoms and treatment of AD through the practice's social media pages which are publically accessible (i.e. the practice's Facebook page)

## Diagnosis and Referral



In secondary care

- **Chicago Integrative Eczema Center:** There is a specialised eczema centre (Chicago Integrative Eczema Center) within the dermatology practice which caters to AD patients with complicated symptoms who might require additional counselling



See pg. 692-693 for case study

## Treatment and Management



Medical management

- **Established specialist network:** The dermatologist at the Chicago Integrative Eczema Center has a network of specialists to improve access to AD patients and manage comorbidities. The dermatologist refers or discusses the patient as required and each healthcare professional considers a different aspect of the patient's comorbidities



See pg. 694-695 for case study

- **Participation in clinical trials:** Adults are able to participate in interventional clinical trials. The clinic currently has four AD-related treatment clinical trials



Non-medical management

- **Interactive support group:** A public support group to enable people affected by AD to meet with other patients and share their experiences. The support group sessions also include practical sessions for AD management and guest speaker lectures



See pg. 696-697 for case study

- **Referral to healthcare professionals:** The dermatologist refers to external healthcare professionals, such as psychologists, as required

## Follow-up



Monitoring of chronic disease/flare up

- **Phone call follow-up:** A follow-up phone call is organised after 1-2 weeks of the visit. The dermatologist will call the patient to discuss their symptoms and treatment progress
- **Educational material on the practice's website:** Patients are able to search the practice's public website for educational videos and information
- **Access to the dermatologist:** Existing and new patients have direct access to the dermatologist through the practice's Facebook page and website

### Key:



Case study available



# Monitoring AD patients and comorbidities

## The eczema centre employs a number of measures for monitoring AD and associated comorbidities

### Objective measures (AD):

Immunoglobulin E (IgE) levels: Patients with severe AD have elevated serum IgE levels. High serum total IgE predicts poor long-term outcome in AD<sup>(a)</sup>

### Patient-reported outcomes:

The eczema centre does not regularly record patient-reported outcomes

*Note: EASI (Eczema Area and Severity Index) is occasionally utilised during clinical practice<sup>(b)</sup>*

---

### The eczema centre routinely measures comorbidity outcomes by:

- *Patch testing*: performed by the physician assistant
- *Prick testing (for allergens)*: performed by an external allergist

**Sources:** (a) Kiiski V, et al. High serum total IgE predicts poor long-term outcome in atopic dermatitis. *Acta Derm Venereol.* 2015;95(8):943-7. doi: 10.2340/00015555-2126; (b) Leshem YA, et al. What the Eczema Area and Severity Index score tells us about the severity of atopic dermatitis: an interpretability study. *Br J Dermatol.* 2015;172(5):1353-7. doi: 10.1111/bjd.13662

# Advice to other centres



## What advice would you give less specialised centres?



### **Objective of advice: Utilise existing infrastructure and resources to create a specialised centre**

- **Why?** Existing dermatology clinics have the opportunity to establish a specialised AD clinic with minimal capital investment. Clinics do not necessarily need expensive infrastructure and a large workforce to begin specialising in AD. Dermatologists can begin by encouraging team members to learn more about atopic dermatitis and investing time in AD specific training



### **Objective of advice: Create interesting educational sessions and material for patients**

- **Why?** AD is a chronic condition that is reliant on appropriate patient self-management and care. Providing interesting education material can be an effective method of informing patients of how to treat and manage their symptoms. For example, inviting well-known speakers or creating educational videos may be more interactive for patients. If patients are engaged, they may be more inclined to learn about self-management techniques

# Next steps for the centre



## What is next for the centre?

### Objective: Expand the practice's network of specialists across the country

- **What?** The practice plans to continue to develop its network of specialists within dermatology and other specialities
- **Why?** Expanding a network of specialists enables dermatologists to create a multidisciplinary team and develop an integrated and comprehensive approach to comorbidity management. Given that the practice treats patients from across the country, the network increases access to AD patients and helps refer patients to specialists who are closer to their home



# Case studies



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# Working alongside the National Eczema Association (NEA)

## Overview

- The eczema centre works alongside the National Eczema Association to complement the care delivered to patients
- The eczema centre organises bi-monthly eczema support groups for patients and their families to meet other patients and share remedies with each other

**Sources:** (a) Welcome to the National Eczema Association. National Eczema Association [Website] <https://nationaleczema.org/> Accessed 11 Sept 2019; (b) J Block. Improving Value for Patients with Eczema. *Value Health*. 2018;21(4):380-385. doi: 10.1016/j.jval.2018.01.014; (c) National Eczema Association Chicago Support Group [Website] <https://chicagoeczema.webs.com/> Accessed 5 Sept 2019; (d) Eczema Expo. National Eczema Association [Website] <https://nationaleczema.org/eczema-expo/> Accessed 5 Sept 2019



## What is the rationale?

- The National Eczema Association (NEA) is the largest patient advocacy group for AD and other forms of eczema in the USA<sup>(a)</sup>
- NEA was established in 1988 and organises events / materials independently and in collaboration with centres
- NEA provides patient-centric tools and resources to complement traditional care models. These aim to inspire patients to actively participate in their care and help create an understanding of shared responsibility in patient outcomes<sup>(b)</sup>

## What are the key features of the intervention?

### NEA-centre's activities

- *Eczema support group:* The dermatologist works closely with NEA and patient leaders to host a patient support group:
  - The Chicago eczema support group was established over 10 years ago by the eczema centre's dermatologist
  - The bi-monthly support group meetings are facilitated by the eczema centre's dermatologist and NEA patient leaders
  - Patients and their families can meet other patients, to exchange ideas and remedies for managing eczema<sup>(c)</sup>

### NEA activities

NEA aims to improve eczema patient care through research, support, and education. Some of the activities include:

- Patient education resources (for example webinars, articles and research findings)
- Eczema research funding through NEA's research grant program
- Mobilising the patient community to advocate for access to quality treatments and care
- Eczema Expo: A four-day transformative conference that brings together hundreds of patients, caregivers, health care and industry professionals for education, support and connection<sup>(d)</sup>

## What are the outcomes so far?

### Benefits to patients:

- Access to educational resources, disease management tips, and a patient community for emotional support

### Benefits to HCPs:

- Tools and resources to complement traditional care techniques and create shared responsibility in patient outcomes



# Chicago Integrative Eczema Center (1/2)

## Overview

- A specialised eczema centre (Chicago Integrative Eczema Center) is established within the dermatology practice which caters to patients with severe AD



We can give patients with complicated symptoms more time during our Saturday clinics

*Dermatologist, Chicago Integrative Eczema Center*



## What is the rationale?

- AD is a complex disease with a number of associated comorbidities<sup>(a)</sup>
- A specialised clinic enables patients to receive tailored care and advice on the treatment and management of their AD symptoms<sup>(b)</sup>

## What are the key features of the intervention?

- The Chicago Integrative Eczema Center is part of the dermatology practice and consists of a dermatologist (with AD sub-specialism), physician assistant and a part-time study coordinator

## Management of AD

- The Chicago Integrative Eczema Center is open every Saturday morning (08:00–12:00) and generally caters to patients with severe AD, who have complicated symptoms and / or require additional counselling
  - Approximately 4-6 patients and their families are seen at the center every Saturday
  - The patient will initially see the dermatologist, who will perform an initial diagnosis / assessment of treatment progress (depending on whether it is a new or existing patient)
  - The physician assistant will then spend time with the patient (without the dermatologist) providing patient education on their treatment plan. This usually takes 15-30 minutes
  - The dermatologist may also see mild to moderate AD patients during the week outside of the center as part of the general practice
- The dermatologist will refer to external specialists as required, including allergists, dietitians, hypnotherapists and psychologists<sup>(c)</sup> – *see case study on page 694 - 695*
- The center also offers the following services to patients and their families:
  - Support groups to meet with other patients and families with eczema
  - Educational sessions on skin care techniques and management of eczema
  - Access educational videos and material through the center's website

## Clinical trials and research

- The dermatologist is able to refer appropriate patients to clinical trials and research studies at the center
- The study coordinator, with the supervision of the dermatologist, organises patient participation in clinical trials and research

**Sources:** (a) Simpson EL. Comorbidity in Atopic Dermatitis. *Curr Dermatol Rep*. 2012;1(1):29–38. doi: 10.1007/s13671-011-0003-5; (b) LeBovidge J, et al. Multidisciplinary interventions in the management of atopic dermatitis. *J Allergy Clin Immunol*. 2016;138(2):325-34. doi: 10.1016/j.jaci.2016.04.003; (c) Welcome to The Chicago Integrative Eczema Centre. Chicago Integrative Eczema centre [Website] <http://www.chicagoeczema.com/> Accessed 4 Sept 2019

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# Chicago Integrative Eczema Center (2/2)



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## What are the outcomes so far?

### Benefits to patients:

- Access to patient support groups and educational sessions to help cope with AD
- Opportunity to participate in research studies and get exposure to newer treatments for AD

### Benefits to HCPs:

- Participating in research studies helps physicians understand emerging therapies and adopt them into clinical practice
- Enables the team to focus on AD, ensuring they have protected time and resources to focus on AD care

## What's next?

- The centre plans to continue running the specialised eczema centre

# Established specialist network (1/2)

## Overview

- The dermatologist at the Chicago Integrative Eczema Center has a network of specialists to support holistic management of AD comorbidities. There is a nutritionist, ophthalmologist, allergist and hypnotherapist

**Sources:** (a) Paller A, et al. Major Comorbidities of Atopic Dermatitis: Beyond Allergic Disorders. *Am J Clin Dermatol.* 2018;19(6):821-838. doi: 10.1007/s40257-018-0383-4; (b) LeBovidge JS, et al. Multidisciplinary interventions in the management of atopic dermatitis. *J Allergy Clin Immunol.* 2016;138(2):325-34. doi: 10.1016/j.jaci.2016.04.003.

## What is the rationale?

- Patients with atopic dermatitis are at risk of developing several comorbidities. Understanding these comorbidities has the potential to improve patient outcomes, as well as help mitigate the cost and burdens associated with these conditions<sup>(a)</sup>
- A specialist network improves access to all AD patients, and enables dermatologists to collaborate with a multidisciplinary team and develop an integrated and comprehensive approach to disease management<sup>(b)</sup>

## What are the key features of the intervention?

- The Chicago Integrative Eczema Center has an established network of external specialists, located outside of the centre, to manage AD comorbidities
- The network was established through the dermatologist's personal contacts and medical interactions (e.g. delivering lectures)
  - The network includes an allergist, nutritionist, ophthalmologist, hypnotherapist and acupuncture and herbal medicine expert. Patients are normally seen within 1-2 weeks of referral
  - The acupuncture and herbal medicine expert is located within the centre
  - The types of patients typically referred to the specialists are:

Specialist	Patient type
Allergist	AD patients with suspected allergies
Nutritionist	AD patients with suspected food allergies
Ophthalmologist	AD patients with ocular symptoms
Hypnotherapist	AD patients with psychological symptoms
Acupuncture and herbal medicine expert	AD patients who prefer to avoid or minimise western medication

- The dermatologist is the core physician responsible for the patient's AD treatment and utilises the specialist network as required
- The dermatologist discusses / refers the patient symptoms and clinical history with the relevant healthcare professional. Each healthcare professional considers a different aspect of the patient's comorbidities
  - The communication between the doctors is generally over the phone and reports are faxed when required
  - Each healthcare professional maintains their own patient record

# Established specialist network (2/2)

## What are the outcomes so far?

### Benefits to patients:

- Increases patient access to specialists
- Patients are referred to specialists who are located closer to home

### Benefits to HCPs:

- Specialised management of comorbidities through collaboration of care
- Allows for the dermatologist to learn from other specialists

## What's next?

- The practice aims to have a network across the country to be able to refer patients to specialists closer to where they live



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# Interactive support group (1/2)

## Overview

- A public support group that enables people affected by AD to meet with other AD patients and share their experiences
- The support group sessions also include practical sessions for AD management and guest speaker lectures

**Sources:** (a) Lifschitz C. The impact of atopic dermatitis on quality of life. *Ann Nutr Metab.* 2015;66(1); (b) Eczema: Overview. Institute for Quality and Efficiency in Health Care (IQWiG) [Website] <https://www.informedhealth.org/how-does-skin-work.2534.en.html> Accessed 9 Sept 2019; (c) Cestari T, et al. The role of support groups in the treatment of atopic dermatitis. *JAAD.* 2017;52(3):P74-P74; (d) Weber MB, et al. Improvement of pruritus and quality of life of children with atopic dermatitis and their families after joining support groups. *J Eur Acad Dermatol Venereol.* 2008;22(8):992-7



## What is the rationale?

- AD can negatively impact the quality of life of patients and their families<sup>(a)</sup>
- Support groups help improve patient education, and can provide patients and their families with a platform to share their stories and learn from other patients<sup>(b)</sup>. They also provide guidance to medical professionals on new ways to counsel patients and their families<sup>(c)</sup>
- There is evidence that support groups can be effective at improving the quality of life (QoL) of AD patients, especially children<sup>(d)</sup>

## What are the key features of the intervention?

- The Chicago Integrative Eczema Center facilitates a regular, public support group for AD patients. The Chicago Eczema Support Group was created through National Eczema Association (NEA) for all people affected by AD to meet with other AD patients and their families
- The support group is free to join and is open to all AD patients and their families. Patients can attend multiple groups. Each group contains between 4-50 patients
- Meetings are generally advertised through email, word-of-mouth, website and social media platforms (including Facebook and Twitter)
- Patients also learn about the support group through referrals when they are looking to try new techniques of care
- Each session includes a practical component, discussion group and guest speaker:
  - **Practical component** (duration – approximately 60 minutes)
    - The practical component is a hands on session where the dermatologist or physician assistant will demonstrate self-management techniques
    - For example, patients are shown how to apply wet wraps and are able to apply and test different moisturisers
  - **Group discussion** (duration – approximately 60-90 minutes)
    - A small group discussion takes place after the practical session. In the groups, patients are able to ask questions and learn from other AD patients
    - The groups are facilitated by the dermatologist or the physician assistant. An 'expert patient' and a patient's parent are also facilitators
    - Previous discussion topics include new therapies for eczema, 'Maximizing Topical Skin Care', 'What is Topical Steroid Withdrawal?', 'Eczema Basics', 'Choosing Skin Care Products'

# Interactive support group (2/2)

## What are the key features of the intervention? (cont.)

- Each session includes a practical component, discussion group and guest speaker (cont.):
  - **Guest speaker:**
    - Guest speakers may be local health care professionals (e.g. nutritionists) or global leading dermatologists
- The support group has six sessions per year which are organised on alternate months on a Saturday. Sessions are held at the eczema centre or at an external venue (depending on the number of attendees)
- The support group is funded by the eczema centre's dermatologist

## Challenges

- Organising meetings for large groups poses logistical challenges
- Finding specialists to invite as guest speakers who may be interesting for AD patients to hear from can also be difficult

## What are the outcomes so far?

### Benefits to patients:

- Opportunity to learn new techniques and improve self-care
- Platform to interact with other AD patients / families and share personal experiences

### Benefits to HCPs:

- Can learn first-hand about patient challenges and develop patient-focussed care methods

## What's next?

- The centre aims to expand the support group to a larger number of patients and increase advertising reach to AD patients across the country



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“



People come from all over depending on who the speaker is. We've had 150 people attend a session

*Dermatologist, Chicago  
Integrative Eczema Center*

“



We try to make the sessions as interesting as possible so more patients can learn about AD

*Dermatologist, Chicago  
Integrative Eczema Center*



# M.L.F. Knuckles Dermatology

**Kentucky, United States of America**

Site visited by KPMG 22<sup>nd</sup>–23<sup>rd</sup> August 2019

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# Summary



## Context

**Centre type:** An office-based dermatology centre located in the state of Kentucky, which provides medical, surgical, and cosmetic dermatology care across two sites (Corbin and Richmond)

**Catchment area:** Patients are referred (or self-refer) from approximately a 75 mile radius around the centre's two sites

**Funding:** The centre accepts both public (Medicaid and Medicare) and private health insurance, or patients' self-paying

**Services:** The centre provides outpatient care to both adult and paediatric dermatology patients, especially those with inflammatory skin conditions (including AD)

**Patient population:** Patients requiring mild to severe medical, surgical, and cosmetic dermatology care



## Key strengths in the delivery of AD care

**Patient-centred care approach:** Each consultation with the dermatologist lasts 10–30 minutes (or longer) as required, to ensure each patient is sufficiently educated about their condition and treatment plan. Severe AD patients will usually be asked to return within 7–10 days. The centre focuses on 'treating patients, how they themselves would like to be treated'

**Acceptance of public health insurance:** The dermatologist is one of the few in the area that accepts Medicare / Medicaid patients (in addition to privately-insured patients), enabling access to specialist care

**Patient education regarding novel treatments:** The centre emphasises the importance of providing AD patients with knowledge of novel / upcoming treatments during consultations (in addition to existing options), to keep patients engaged with treatment and offer 'hope' for the future



## Key challenges faced in delivery of AD care

**Access to medication:** It can be difficult for patients (especially those who are not commercially insured) to receive access to certain, often more costly, AD treatments

**Supporting patients with treatment adherence:** The typically complex and long-term nature of AD treatment plans can lead to reduced treatment adherence in patients, particularly adolescents

**Treating a wide demographic of patients:** The centre treats patients from a variety of socioeconomic and ethnic backgrounds, which can require tailoring in how they educate patients and communicate their treatment plans (e.g. due to language barriers, healthcare literacy levels)

# Atopic Dermatitis (AD) in the USA

## USA healthcare system:

The USA healthcare system is publically and privately funded, with government spending accounting for 49% of the total health spending in 2014<sup>(a)(b)</sup>

### Publically funded healthcare:

- The main channels of public spending are Medicare, Medicaid and Affordable Care Act (ACA) subsidies<sup>(a)</sup>
  - Medicare is a national health insurance programme in the USA which primarily provides health insurance to Americans aged 65 and older
  - Medicaid is a health coverage programme for Americans with low income and resources
  - The Affordable Care Act (ACA), is a USA law to establish shared responsibility between the government, employers, and individuals for ensuring that all Americans have access to affordable and good-quality health insurance
- The ACA expanded Medicaid to make policies affordable, by extending the fund subsidies to nearly all low-income individuals with incomes at or below 138% of the poverty level<sup>(a)</sup>

### Privately funded healthcare

- Private insurance is regulated mostly at the state level. In 2014, state and federally administered health insurance marketplaces were established to provide additional access to private insurance coverage, with income-based premium subsidies for low- and middle-income people<sup>(b)</sup>
- The five biggest commercial health insurers are UnitedHealth, Anthem, Aetna, Cigna and Humana, together representing about 43% of the total insured population. There is increasing consolidation of Pharmacy Benefit Managers (PBMs), which act as intermediaries between insurers and providers<sup>(a)</sup>
- As part of private healthcare insurance, an individual may have to pay a set amount of deductibles before their insurance begins to cover their treatment. Deductibles on employer-based health plans averaged US\$1,350 per person in 2019<sup>(a)</sup>
- There are different types of insurance. Some plans may restrict insurance restricts patients to seeing physicians who are part of the insurance group or are on a preferred list of providers<sup>(e)</sup>

## Prevalence

- In the USA, AD affects 12.98% of children<sup>(c)</sup> and 7.3% of adults<sup>(d)</sup>
- Of the USA adults with AD, 60.1% have mild AD while 28.9% and 11% have moderate and severe AD respectively<sup>(d)</sup>



## Care provision:

### Location:

- Mild (or well-controlled) AD care is primarily delivered by PCPs (primary care providers)
- Moderate and severe (uncontrolled) AD care is mostly delivered by specialist dermatologists

### Funding:

- The practice receives funding from both public and private insurance for their care provision

## Guidelines and societies:

### Guidelines:

- Guidelines of care for the management of atopic dermatitis: American Academy of Dermatology
- Recommendations for atopic dermatitis care: Annals of Allergy, Asthma & Immunology

### Medical societies/PAGs:

- American Academy of Dermatology
- National Eczema Association (NEA)
- Asthma and Allergy Foundation of America
- Global Parents for Eczema Research
- Pediatric Dermatology Research Alliance
- AltogetherEczema

**Sources:** (a) The Economist Intelligence Unit. Industry Report: Healthcare United States of America. Published 2nd Quarter 2019. Accessed 4 Sept 2019; (b) International Health Care System Profiles. The U.S. Health Care System. [Website] [https://international.commonwealthfund.org/countries/united\\_states/](https://international.commonwealthfund.org/countries/united_states/) Accessed 4 Sept 2019; (c) Silverberg J. Public Health Burden and Epidemiology of Atopic Dermatitis. *Dermatol Clin.* 2017;35(3):283-289; (d) Chiesa Fuxench ZC, et al. Atopic Dermatitis in America Study: A Cross-Sectional Study Examining the Prevalence and Disease Burden of Atopic Dermatitis in the US Adult Population. *J Invest Dermatol.* 2019;139(3):583-590. doi: 10.1016/j.jid.2018.08.028; (e) Different Types of Health Plans: How They Compare [Website] <https://www.webmd.com/health-insurance/types-of-health-insurance-plans#1> Accessed 20 Sept 2019

# The centre



## The centre



### Type and location

M.L.F. Knuckles Dermatology is a private dermatology clinic in Kentucky, located across two sites (Corbin and Richmond). The centre treats patients requiring mild-to-severe medical, surgical, and cosmetic dermatology care



### Population served

Patients are referred (or self-refer) from within a ~75 mile radius of the centre



### Service Division

#### Clinic services



### Hours of availability

#### Corbin office:

Tuesdays and Thursdays: 08:00–17:00  
Note: The clinic is occasionally open on Saturdays

#### Richmond office:

Mondays, Wednesdays and Fridays: 08:00–16:00  
Tuesdays and Thursdays: 09:00–17:00



### No. of patients seen

Approximately 10 AD patients per day (60% adults; 40% paediatrics)



### Types of patients seen

Paediatric and adult dermatology patients (including patients with mild, moderate and severe AD)



### Facilities on-site<sup>(1)</sup>

— 1 consulting room (per office)

Note: (1) List of facilities is not exhaustive

# The team



## Core team profile ●



-  **1** Dermatologist (working across both offices)

## Wider team profile ●

### **Corbin office:**

-  **2** Medical assistants
-  **1** Study coordinator
-  **1** Insurance appeals officer
-  **4** Clerical staff

### **Richmond office:**

-  **1** Licensed vocational nurse (LVN)
-  **4** Medical assistants

## ● Patient records:

- The centre maintains its own system of paper patient records



*Note: Please see page 704 for further details on the wider team*

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients may be referred to the centre by their primary care physician (PCP, e.g. family physician or paediatrician), out-of-hours clinics (which employ PCPs) or physicians at local hospital Emergency Rooms
- Patients may also present directly to the centre (if permitted by their insurer)

## Diagnosis and Referral

In secondary care



- The majority of patients referred to the centre are seen within 3 weeks (at a time that suits their personal schedule). Patients are sent a reminder for their appointment the day before their visit
- In the event of consultation cancellations, other patients may be notified in order to book them an earlier appointment
- Patients with AD comorbidity symptoms are referred to an appropriate specialist (e.g. allergist, ophthalmologist) outside the centre, using the centre's informal referral network
- Patients requiring urgent specialist allergy care may visit a large, separate allergy centre (~1-1.75hrs drive from the dermatologist). Less urgent cases may be seen by an external allergist within ~4 weeks of referral

## Treatment and Management

Medical management



- Patients attend an initial 10-30min consultation with the dermatologist, which includes: an assessment of patient AD and co-morbidity symptoms (e.g. asthma, allergic rhinitis), formation of personalised treatment plan, delivery of patient education (including referral to National Eczema Association [NEA] resources) and sometimes a body surface area [BSA] assessment (if required for prior authorisation)
- Prior to the consultation the nurse / medical assistants will take a medical history and provide injection training and further education regarding patients' treatment plans and general care regimen (e.g. recommend soaps and laundry detergents) post-consultation
- Patients requiring patch / skin prick tests are referred to an external allergist (waiting time ~4 weeks). The external allergists identify the allergy / allergies before referring the patient back to the centre for continued treatment

Non-medical management



- Patients are provided with a printed patient information checklist (developed by the dermatologist) which provides detailed advice and guidance for bathing, using soaps, applying different topical therapies and using home remedies (all on a daily basis)
- If blood tests are required, the dermatologist will send a request to an appropriate specialist or PCP at a local facility (as there are no blood-testing facilities on-site)
- All biopsies are performed by the physician, which are then sent to a laboratory in Ohio for analysis (results available in 3-5 days)
- Nurse / medical assistants at the centre assist patients with insurance prior authorisations

## Follow-up

Monitoring of chronic disease / flare up



- Severe AD patients will generally return for a follow-up consultation within 7-10 days. Patients will then be seen as frequently as required (usually every 3 months)
- Patients may call the centre (or the dermatologist directly) during working hours if they are experiencing problems with their AD self-management / treatment
- Mild / well-controlled AD patients may be referred back to their PCP for continued management
- The dermatologist visits local nursing homes approximately once per month to provide specialist dermatology care (e.g. recommending non-sedative anti-histamines) to patients who are unable to visit the centre

# Roles of the wider team

## Nurses (Licensed Vocational Nurse (LVN) / Medical Assistants)

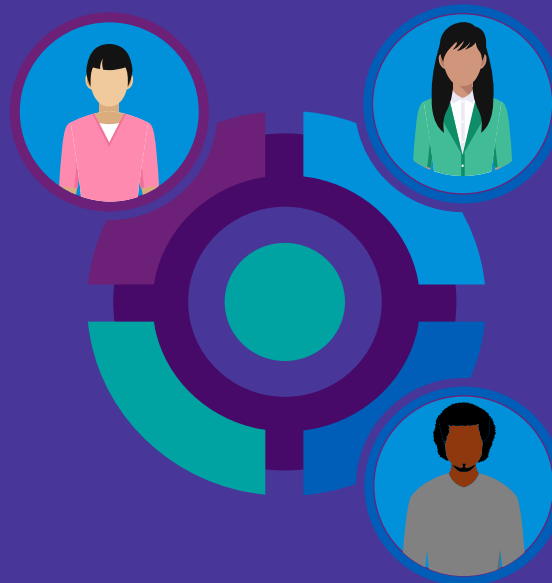
**Patient type:** mild to severe AD patients of all ages

**Referral:** referred to external facility by the dermatologist (as there are no nurse practitioners, physicians' assistants or licensed medical assistants at the centre)

**Consultation:** The nurses will assist the dermatologist by:

- Recording patients' medical history
- Providing subcutaneous injection training (where self-administration is required)
- Revisiting and educating patients regarding the dermatologist's personalised treatment plan and general skin care advice, e.g. recommended soaps (see case study pg. 713 - 714)
- Completing health insurance prior authorisations (performed on the days where the dermatologist is located in the alternative office location, i.e. patients are not being seen at that office)
- Scheduling appointments at the centre (although the clerical staff in the Corbin office will also assist with this)

**Timing:** First consultation and follow-up: ~20mins (duration flexible depending on patient need)



## Study coordinator

The study coordinator's main role is to provide administrative support for the clinical trials and registries in which the centre participates (e.g. by reporting adverse events)

## Insurance appeals officer (IAO)

**Role:** The IAO helps oversee and assist nurses with the health insurance prior authorisation submissions, and any appeals (e.g. by phoning or faxing insurance companies)

# Overview of interventions in place for AD



**Key:**



Case study available



CONTENTS



APPENDIX  
CENTRE REPORTS

## Awareness and Presentation



Symptom identification

- **Referencing National Eczema Association (NEA):** During the first consultation, the dermatologist directs all new AD patients to NEA to access further AD education materials, information about NEA events, etc.
- **Community outreach consultations:** The dermatologist speaks to staff and pupils in local schools in order to improve understanding and awareness of AD and their chronic skin conditions in these settings

See pg. 715 for case study

## Diagnosis and Referral



In secondary care

- **Referral to AD comorbidity specialists:** Following an assessment in the consultation, the dermatologist may refer patients who appear to have an AD comorbidity (or whose AD cannot be managed) to a local specialist (e.g. allergist; pulmonologist; ophthalmologist) for further assessment / treatment. Patients usually return to the dermatologist from the specialist concerned once their AD comorbidity has been diagnosed (e.g. allergies via patch testing, blood tests)

See pg. 710 for case study

## Treatment and Management



Medical management

- **Flexible consultation length and frequency:** The centre offers longer AD patient consultations (over 30 minutes if required) and frequent follow-up consultations with the dermatologist to allow more time to monitor patient symptoms, deliver patient education and try to minimise the burden of AD on the patient's quality of life

See pg. 711-712 for case study



Non-medical management

- **Patient treatment checklist:** The dermatologist will write a tailored treatment plan for patients (especially paediatric) using a centre-designed checklist template for each patient. The patient is talked through their plan during the dermatologist consultation and sometimes with the nurses additionally. The plan provides recommendations on type and frequency of use for substances including: steroid / non-steroid creams; facial cleansers; bathing / showering soaps; fabric softeners; baby wipes

See pg. 713-714 for case study

## Follow-up



Monitoring of chronic disease/flare up

- **Community outreach consultations:** The dermatologist regularly visits local care homes to provide dermatology consultations for older patients (including those with AD) who are unable to be transported to the centre. The dermatologist often focuses on pruritus management with these AD patients and emphasises the importance of using appropriate medications (e.g. non-sedative anti-histamines)

See pg. 715 for case study





# Monitoring AD patients and comorbidities



## The dermatology department uses a number of measures for monitoring AD and associated comorbidities:

### Objective measures (AD):

AD scoring indices used include:

- BSA (Body surface area) tool<sup>(a)</sup>: calculates percentage of patients' body area covered with AD. This tool will be used if required for health insurance prior authorisation

### Patient-reported outcomes:

- All clinical and patient responses to treatment are documented and evaluated by the physician

**Source:** (a) National Eczema Association (NEA). Take charge of your eczema! [Website] <https://nationaleczema.org/take-charge-eczema/> Accessed 30 Oct 2019

# Advice to other centres



## What advice would you give less specialised centres?



**Objective of advice:** Identify AD comorbidities and refer patients to appropriate comorbidity specialists

- **Why?** AD is a complex, multi-faceted condition, with comorbidities spanning dermatology, allergy and other specialties. Identifying AD comorbidities and promptly referring patients to the appropriate specialist(s) has the potential to minimise comorbidity symptoms, impact on AD and improve patient quality of life (QoL). To facilitate this, the dermatologist refers patients to pulmonary, gastroenterology and ophthalmology specialists, as well as allergists



**Objective of advice:** Reach out to patients to provide education and 'hope' for the future

- **Why?** Providing education regarding AD treatment and self-management has been shown to improve patient QoL<sup>(a)</sup>. The centre focuses on providing AD patients with knowledge of novel / upcoming treatments (in addition to existing options), to keep patients engaged with treatment and offer 'hope' for the future. The centre also directs patients to external AD organisations – such as NEA (National Eczema Association) – for further support



**Objective of advice:** Ensure AD patients have sufficient time with the dermatologist

- **Why?** AD patients can have complex treatment regimens which they may not always adhere to (e.g. due to time demands or fears of treatment side-effects). Longer consultations have the potential to improve a patient's understanding of AD (and their treatment options) by allowing more time for the dermatologist to educate patients and answer questions

**Sources:** (a) Ersser SJ, et al. Psychological and educational interventions for atopic eczema in children. *Cochrane Database of Systematic Reviews*. 2014;1. doi: 10.1002/14651858.CD004054.pub3

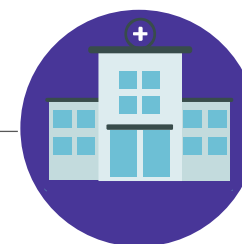
# Next steps for the centre



## What is next for the centre?

**Objective:** Expand provision of AD injection therapy

- **What?** Provide injection therapy to paediatric patients (following FDA approval)
- **Why?** Widening the scope of who can be treated by the centre to include a larger proportion of paediatric patients will increase access to AD patients and help ensure a greater number of patients are supported in managing their condition



# Case studies



	#
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<b>Flexible consultation length and frequency</b>	711 – 712
<b>Patient treatment checklist</b>	713 – 714
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# Referrals to AD comorbidity specialists

## Overview

- Following an assessment in the consultation, the dermatologist may refer patients who appear to have an AD comorbidity (or whose AD cannot be managed) to a local specialist (e.g. allergist, pulmonologist, ophthalmologist) for further assessment / treatment. Patients usually return to the dermatologist from the specialist concerned once their AD comorbidity has been diagnosed (e.g. allergies via patch testing, blood tests)



It is important to assess for the presence of comorbidities in AD patients

*Dermatologist, M.L.F  
Knuckles Dermatology*



## What is the rationale?

- Patients with atopic dermatitis are at risk of developing several comorbidities. Understanding these comorbidities has the potential to improve patient outcomes and to mitigate the costs and other burdens associated with these conditions (e.g. asthma or allergic rhinitis)<sup>(a)</sup>
- Atopic March patients often require input from multiple specialists including dermatology, allergy and ophthalmology, in order to receive optimal care for their comorbid condition(s)<sup>(b)</sup>
- AD is also linked with food allergies, which are usually managed by allergists<sup>(c)</sup>

## What are the key features of the intervention?

- The dermatologist performs an initial consultation (10–30mins) during which the patient's medical history is recorded, symptoms are assessed, medical education is delivered and appropriate treatment prescribed (see case study pg. 713 – 714)
- The patient is also assessed for AD comorbidity symptoms, including allergic rhinitis, asthma, conjunctivitis, nasal polyps and psychosocial wellbeing (e.g. anxiety and depression) and referred to the appropriate local specialist:
  - Allergist
  - Pulmonologist
  - Ophthalmologist
  - Gastroenterologist

## Example AD comorbidity referral pathway:

### Allergy symptoms:

Patients requiring patch / skin prick tests are referred to local office-based allergists. The external allergists (who tend to work seasonally) identify the allergy / allergies before referring the patient back to the centre for continued treatment. Patients requiring urgent specialist allergy care may visit a large, separate allergy centre (~1-1.75hrs drive from the dermatologist)

## What are the outcomes so far?

### Benefits to patients:

- Improved access to AD comorbidity specialists and specialist tests / treatments
- Patients receive co-ordinated care without needing to identify appropriate specialists themselves (more convenient)
- Enhanced quality of life through supporting management of the condition in wider aspects of the patient's life

### Benefits to HCPs:

- Improved management of AD comorbidities (which can negatively impact AD)
- Cross-specialty learning through referral / co-management of patients

**Sources:** (a) Paller A, et al. Major Comorbidities of Atopic Dermatitis: Beyond Allergic Disorders. *Am J Clin Dermatol.* 2018;19(6):821-838. doi: 10.1007/s40257-018-0383-4; (b) KPMG interviews; (c) Leung DYM, et al. Deciphering the Complexities of Atopic Dermatitis: Shifting Paradigms in Treatment Approaches. *J Allergy Clin Immunol.* 2014;134(4):769–779.

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# Flexible consultation length and frequency (1/2)

## Overview

- The centre offers longer AD patient consultations (over 30 minutes if required) and frequent follow-up consultations with the dermatologist to allow more time to monitor patient symptoms, deliver patient education and try to minimise the burden of AD on the patient's quality of life



We aim to treat patients how we would like to be treated. Which includes taking the time for them to properly understand everything

*Nurse, M.L.F Knuckles  
Dermatology*



## What is the rationale?

- AD patients can have complex treatment regimens which they may not always adhere to (e.g. due to time demands or fears of treatment side-effects)<sup>(a)</sup>
- Longer consultations have the potential to improve a patient's understanding of AD (and treatment options) by allowing more time for the dermatologist to educate patients and answer questions<sup>(b)</sup>

## What are the key features of the intervention?

- The dermatologist sees a minimum of 10 AD patients per day (~60% adults, ~40% children)
- Each AD consultation (initial or follow-up) with the dermatologist lasts 10–30 minutes (although though consultations may be longer, depending on patient need)
- During the consultation, the dermatologist may:
  - Record the patient's medical history
  - Perform a body surface area (BSA) assessment (if required for insurance prior authorisation purposes)
  - Assess for allergic rhinitis, asthma and nasal polyp symptoms
  - Prescribe appropriate medications (taking into account the age of the patient), e.g. topical therapies, anti-histamines, antibiotics
  - Complete a tailored patient information checklist (see case study pg. 713 - 714)
  - Provide education on general AD care (e.g. bleach baths, trimming finger nails to minimise itching damage)
  - Refer patients to NEA (National Eczema Association) for further information / support
- Patients may also see nurses following the dermatologist consultation to revisit / further education regarding their personalised treatment plan and general skin care advice, e.g. recommended soaps (see case study pg. 713 - 714)
- Severe AD patients will generally return for a follow-up consultation within 7–10 days. Patients will then be seen as frequently as required (usually every ~3 months for controlled patients), or as they desire (as long as their health insurance allows them to)

**Sources:** (a) Hajar T, et al. A systematic review of topical corticosteroid withdrawal ("steroid addiction") in patients with atopic dermatitis and other dermatoses. *J Am Acad Dermatol.* 2015;72(3):541-549.e2. doi: 10.1016/j.jaad.2014.11.024; (b) KPMG interviews

# Flexible consultation length and frequency (2/2)

## What are the outcomes so far?

### Benefits to patients:

- Improved understanding of AD and treatment plans
- More time to ask clarifying questions, and understand information shared
- Potential for improved treatment outcomes following correct usage of therapies

### Benefits to HCPs:

- Additional time to educate patients regarding AD self-management
- Opportunity to reinforce patient education across multiple, frequent sessions

## What's next?

- Promotion of increased family involvement in the treatment and education of AD
- Expanded coordination of care with other treating physicians (e.g. paediatricians, pulmonologists, allergists, ophthalmologists)

“

I will see patients for approximately 10–30 mins but it could be more or less, depending on their needs. I may run late sometimes, but I will always give the patients the time they need as the quality of care is our priority



*Nurse, M.L.F Knuckles  
Dermatology*





# Patient treatment checklist (1/2)

## Overview

- The dermatologist will write a tailored treatment plan for patients (especially paediatric) using a centre-designed checklist template for each patient. The patient is talked through their plan during the dermatologist consultation and sometimes with the nurses additionally. The plan provides recommendations on type and frequency of use for substances including:
  - Steroid / non-steroid creams
  - Facial cleansers
  - Bathing / showering soaps
  - Fabric softeners
  - Baby wipes

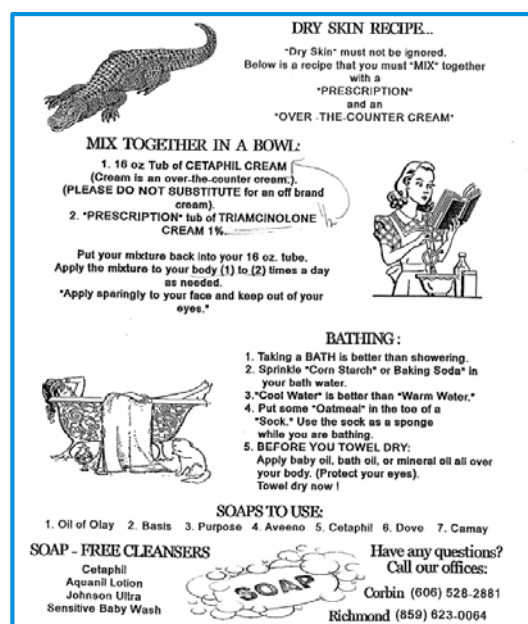
## What is the rationale?

- AD is a complex and multi-faceted disease, and patients may require tailored treatment plans<sup>(a)</sup>
- Parents generally take responsibility for their child's AD treatment, which can significantly affect their quality of life<sup>(b)</sup>

## What are the key features of the intervention?

- The centre's dermatologist designed a checklist template which is used during the first consultation with AD patients, especially for paediatric patients (and subsequent consultations if required) to guide them through their tailored treatment plan
- The template is an educational tool used by the dermatologist and nurses to explain treatment and care recommendations to the patients in a structured format, and a useful guide for patients to read / use at home

### Page 1



Patient information checklist (page 1)

### Contents

- Instructions for combining prescription and over-the-counter treatments (including specific products, concentrations and volumes)
- Instructions for applying the treatment mixture to different body areas at the correct times and frequencies
- Recommendations for bathing in beneficial additives (e.g. corn starch / baking soda)
- Guidance for towel drying safely after bathing (e.g. by first applying baby / mineral oil to affected areas)
- Recommendations for soap brands and soap-free cleansers
- Medical advice relating to keeping nails clipped short and lining the nasal areas with an antimicrobial cream / ointment
- Contact details for the centre's two practices (if any questions)

**Sources:** (a) Bieber T. How to Define Atopic Dermatitis? *Dermatol Clin.* 2017;35(3):275-281; (b) Lifschitz C. The impact of atopic dermatitis on quality of life. *Ann Nutr Metab* 2015;66(suppl 1):34-40

# Patient treatment checklist (2/2)

## Page 2

DRY/ATOPIC SKIN CARE FOR PATIENTS	Physician's Comments:
Apply Derna-Smoother Body Oil 3 to 5 times a week from your neck to your feet after bathing/showering. (Apply before towel drying)	
Apply Cetaphil/TMC 1% (steroid) mixture 2 times a day from your neck to your feet.	
Ectone/Atopicair/Mimyx Cream (non-steroid) apply to your as needed.	
Pandel/Chlorom/Locoid Creams (steroids) apply as needed. Apply sparingly to your eyelids.	
Zyrtec Syrup: ½ tsp. 1 tsp. po q am and ½ tsp. 1 tsp. qhs	
Nizoral Cream for pustules to your face: Bid	
Ahdene Cleanser: Facial cleansing 2 times a day.	
Vanicream/Stelatopia Cleanser/Bar: These are Hypo-allergenic lines of shampoo/cream/cleanser products available over the counter.	
Water: Bathing/Showering with Cool water is the Best! Add ½ cup bleach to bathwater to decrease skin bacteria.	
Detergent: Hypo-allergenic must be used: Dreft, Tide Free, All, Cheer Free, etc.	
Fabric Softener/Sheets: Hypo-allergenic: Downey Free	
Baby Wipes: Hypo-allergenic: Pampers Sensitive	
New Clothing! Always wash before wearing.	
Benedryl/Atarax Elixir: Add ½ tsp. 1 tsp. po at night to	
Foods to Avoid: milk, cheese, eggs, strawberries, peanuts, tomatoes	
AVOID USE OF: Topical Benedryl and Anti-itch Creams	
HONEY colored crusts develops, apply ALTABAX OINTMENT 2 times a day.	
Tough Spots! Apply Cutivate Lotion/Verdeso Foam sparingly for 2 weeks at 2 times a day.	
Register on-line: "NATIONAL ATOPIC FOUNDATION"	
KEEP YOUR REGULARLY SCHEDULED FOLLOW-UP APPOINTMENTS and FOLLOW DIRECTIONS!	

Patient information checklist (page 2)

### Contents

- Instructions for which products to apply to which body areas, in what quantities, at what times (e.g. after bathing) and in what frequencies
- The products / methods covered include body oils, steroid / non-steroid creams, sun cream, facial cleansers, cosmetics, bleach baths, fabric detergents / softeners and baby wipes
- The template also covers advice for wearing new clothing and applying treatments to certain 'tough to reach spots' on the body
- A 'Physician's comments' column provides a space for the dermatologist to provide detailed, tailored instructions for each AD patient
- A prompt to register online with National Atopic Foundation (National Eczema Association [NEA])



We will talk patients through the sheet e.g. showing them how to use the creams and mix up the medication



Nurse, M.L.F Knuckles  
Dermatology

## What are the outcomes so far?

### Benefits to patients:

- A structured, easy-to-follow treatment plan for the patient (or the parent / guardian overseeing their child's AD self-management)
- A useful reference tool for guiding basic AD self-management

### Benefits to HCPs:

- A standardised approach for educating patients / parents on AD self-management and formulating tailored treatment plans

# Community outreach consultations

## Overview

- The dermatologist regularly visits local care homes to provide dermatology consultations for older patients (including those with AD) who are unable to be transported to the centre. The dermatologist often focuses on pruritus management with these AD patients and emphasises the importance of using appropriate medications (e.g. non-sedative anti-histamines)



It's important to offer care to these patients who may otherwise not have access

*Dermatologist, M.L.F  
Knuckles Dermatology*



**Sources:** (a) KPMG interviews; (b) Fortney JC, et al. Community-based outpatient clinics: access and utilisation performance measures. *Med Care*. 2002;40(7):561-9



## What is the rationale?

- The centre's catchment area is geographically large, which can be inconvenient for patients who reside in rural and less accessible areas (especially those with restricted mobility)<sup>(a)</sup>
- Community outreach services provide patients with the option to receive specialist dermatology care closer to home<sup>(b)</sup>

## What are the key features of the intervention?

### Care home consultations

- For approximately 30 years, the centre's dermatologist has visited local care homes on a ~monthly basis to provide specialist dermatology care for patients who cannot be easily transported to the centre
  - The care home staff will contact the dermatologist when / if a patient requires a consultation (if not a regular appointment)
  - These care home facilities include those located in Berea and Hyden, as well as the veterans home facilities located in Hazar
- Through these visits the care home staff are also educated regarding how to care for AD patients better
- The local transit authority provides an ambulance to transport patients from local care homes to and from the centre, however the dermatologist often visits the homes in person
- The care homes visited include one in Manchester which houses WW2 veterans (situated ~2.5hours drive from the centre)

### Other community outreach consultations / initiatives

- The dermatologist has also spoken to staff and pupils in local schools in order to improve understanding and awareness of AD and other chronic skin conditions in these settings

## What are the outcomes so far?

### Benefits to patients:

- Access to specialist care that otherwise may have been unobtainable (if not able to be transported to specialist)

### Benefits to HCPs:

- Access to patients not currently being treated by the centre
- Opportunity to educate nursing home staff to care for AD patients (and may subsequently support other AD patients in the future)



# Rady Children's Hospital

San Diego, USA

Site visited by KPMG 19–20<sup>th</sup> August 2019

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CONTENTS



APPENDIX  
CENTRE REPORTS



# Summary



## Context

**Centre type:** A non-profit paediatric care facility and research centre located in San Diego, associated with the University of California, San Diego (UCSD) School of Medicine

**Catchment area:** The centre covers a large catchment area. The majority of patients are based in San Diego, however a proportion travel from the surrounding areas (including Los Angeles and Orange County)

**Funding:** The centre is funded by a variety of sources including governmental programmes, private health insurance and private grants

**Services:** The dermatology division is co-located in the same building (and in some cases on the same floor) as a number of other specialties it collaborates closely with (e.g. allergy & immunology)

**Patient population:** Paediatric patients with dermatological conditions (including mild, moderate and severe AD) are seen in the dermatology division. Adult AD patients are seen at University of California, San Diego (UCSD) School of Medicine



## Key strengths in the delivery of AD care

**Paediatric dermatology:** The centre specialises in treating paediatric patients, who may be less able to communicate their condition and may have fewer treatment options available

**Collaboration with allergy:** The dermatology division runs joint clinics with allergy & immunology for comorbid / complex AD patients, to promote shared decision making and more efficient multidisciplinary care delivery

**Primary care engagement:** The centre runs multiple initiatives to educate primary care physicians (PCPs) with the latest in dermatology treatment and management (including AD) to improve alignment across the health system

**Community outreach:** The centre's dermatologists and dermatology physician assistants rotate around 4 satellite clinics, aimed at improving access to specialist AD care in the areas surrounding the centre (e.g. by reducing the travel burden for patients)

**Clinical trial involvement:** The centre participates in a number of dermatological clinical trials (~46 currently active in dermatology), in collaboration with UCSD, which are funded by a combination of the National Institute of Health (NIH) and private funding



## Key challenges faced in delivery of AD care

**There are fewer treatment options available to paediatric patients (<12 years old)** compared to adult patients (e.g. due to the new therapies not yet being approved for these age groups). It is therefore very important to optimise the use of topical therapies for paediatric patients

**Allergies are increasingly common**, which can complicate both the diagnosis and treatment of AD cases (e.g. by requiring supplementary tests, such as patch tests, and input from multiple specialists)

**Language barriers (between healthcare professional and patient or parent)** can make it more difficult to provide in-depth AD treatment and care information

**The centre has struggled to find a psychologist or nutritionist to join the AD team**, as they have a high number of patients to clinically review, however there is no specific funding to cover the service

**Paediatric patients may be reluctant to let their parents apply topical treatments and may have concerns with systemic agents**, which can negatively impact treatment compliance



# Atopic Dermatitis (AD) in the USA

## USA healthcare system:

The USA healthcare system is publically and privately funded, with government spending accounting for 49% of the total health spending in 2014<sup>(a)(b)</sup>

### Publicly funded healthcare:

- The main channels of public spending are Medicare, Medicaid and Affordable Care Act (ACA) subsidies.<sup>(a)</sup>
  - Medicare is a national health insurance programme in the USA which primarily provides health insurance to Americans aged 65 and older
  - Medicaid is a health coverage programme for Americans with low income and resources
  - The Affordable Care Act (ACA), is a USA law to establish shared responsibility between the government, employers, and individuals for ensuring that all Americans have access to affordable and good-quality health insurance
- The ACA expanded Medicaid to make policies affordable, by extending the fund subsidies to nearly all low-income individuals with incomes at or below 138% of the poverty level<sup>(a)</sup>

### Privately funded healthcare

- Private insurance is regulated mostly at the state level. In 2014, state and federally administered health insurance marketplaces were established to provide additional access to private insurance coverage, with income-based premium subsidies for low- and middle-income people<sup>(b)</sup>
- The five biggest commercial health insurers are UnitedHealth, Anthem, Aetna, Cigna and Humana, together representing about 43% of the total insured population. There is increasing consolidation of Pharmacy Benefit Managers (PBMs), which act as intermediaries between insurers and providers<sup>(a)</sup>
- As part of private healthcare insurance, an individual may have to pay a set amount of deductibles before their insurance begins to cover their treatment. Deductibles on employer-based health plans averaged US\$1,350 per person in 2019<sup>(a)</sup>
- There are different types of insurance. Some plans may restrict insurance restricts patients to seeing physicians who are part of the insurance group or are on a preferred list of providers<sup>(e)</sup>

## Prevalence

- In the USA, AD affects 12.98% of children<sup>(c)</sup> and 7.3% of adults<sup>(d)</sup>
- Of the USA adults with AD, 60.1% have mild AD while 28.9% and 11% have moderate and severe AD respectively<sup>(d)</sup>



## Care provision:

### Location:

- Mild (or well-controlled) AD care is primarily delivered by PCPs (primary care providers)
- Moderate and severe (uncontrolled) AD care is mostly delivered by specialist dermatologists

### Funding:

- The practice receives funding from both public and private insurance for their care provision

## Guidelines and societies:

### Guidelines:

- Guidelines of care for the management of AD: American Academy of Dermatology
- Recommendations for AD care: American Academy of Allergy, Asthma & Immunology (AAAAI); American College of Allergy, Asthma & Immunology (ACAAI)








### Medical societies/PAGs:

- American Academy of Dermatology
- National Eczema Association (NEA)
- Asthma and Allergy Foundation of America
- Global Parents for Eczema Research
- Pediatric Dermatology Research Alliance
- AltogetherEczema

**Sources:** (a) The Economist Intelligence Unit. Industry Report: Healthcare United States of America. Published 2nd Quarter 2019. Accessed 4 Sept 2019; (b) International Health Care System Profiles. The U.S. Health Care System. [Website] [https://international.commonwealthfund.org/countries/united\\_states/](https://international.commonwealthfund.org/countries/united_states/) Accessed 4 Sept 2019; (c) Silverberg J. Public Health Burden and Epidemiology of Atopic Dermatitis. *Dermatol Clin.* 2017;35(3):283-289; (d) Chiesa Fuxench ZC, et al. Atopic Dermatitis in America Study: A Cross-Sectional Study Examining the Prevalence and Disease Burden of Atopic Dermatitis in the US Adult Population. *J Invest Dermatol.* 2019;139(3):583-590. doi: 10.1016/j.jid.2018.08.028; (e) Different Types of Health Plans: How They Compare [Website] <https://www.webmd.com/health-insurance/types-of-health-insurance-plans#1> Accessed 20 Sept 2019



# The centre and dermatology division

 <b>Type and location</b>	<b>The centre</b>	
	<ul style="list-style-type: none"><li>— Rady Children’s Hospital, San Diego (RCHSD) is a non-profit paediatric-care facility and research centre. It is the only hospital in the San Diego area which is dedicated exclusively to paediatric healthcare, and is the largest children’s hospital in California based on number of admissions</li><li>— In affiliation with the University of California, San Diego (UCSD) School of Medicine Eczema and Inflammatory Skin Disease Centre, it is also the region’s teaching hospital for paediatric physicians</li><li>— Over 40 active clinical and translational studies are performed per year at the Rady Children’s Hospital/UCSD Eczema and Inflammatory Skin Disease Center<sup>(a)</sup></li></ul>	
 <b>Population served</b>	<ul style="list-style-type: none"><li>— Patients are primarily from the San Diego region, but may also travel from the surrounding areas (including Los Angeles and Orange County)</li></ul>	
 <b>Service Division</b>	<b>The dermatology division</b>	
	<b>Outpatient service</b>	<b>Inpatient service</b>
	8:00am – 5:00pm (Monday – Friday)	24/7 (part of general emergency room)
	~3,000 AD patients (in total, excluding new patients)	36 inpatients per year
	<i>Note: In a 1.5 year timeframe, there have been over 24,000 individuals coded with eczema or AD</i>	(not including Emergency Department visits)
	Mild, moderate and severe AD paediatric patients (adult AD patients are seen at UCSD)	
 <b>Hours of availability</b>		
 <b>No. of patients seen</b>		
 <b>Types of patients seen</b>		
 <b>Facilities on-site<sup>(1)</sup></b>		
	<ul style="list-style-type: none"><li>— 22 dermatology consultation rooms</li><li>— Waiting room (shared with endocrinology)</li><li>— 2 research rooms (for consultations with clinical trial participants and capturing study photographs (i.e. for publication))</li><li>— Phototherapy (UVB)</li></ul>	<ul style="list-style-type: none"><li>— 2 laser procedural rooms</li><li>— Allergy patch testing (prick tests are performed by allergy &amp; immunology)</li><li>— Electronic computer system (linked to Primary Care Network and regional hospitals)</li></ul>

**Note:** (1) List of facilities is not exhaustive

**Sources:** (a) KPMG interviews







# The team



## Core team profile ●

-  **8** Paediatric dermatologists
-  **4** Physician assistants (PAs)
-  **2** LVNs (Licensed Vocational Nurses)
-  **6** Medical assistants
-  **1-3** Clinical pediatric dermatology fellows
-  **2-3** Research fellows
-  **2** Research nurses

## Wider team profile ●

-  **2** Allergist-immunologists
-  **1** Dermatologist (at UCSD, involved in patch testing)
-  **1** Joint physician assistant (working across dermatology and allergy & immunology)
-  **1** Clinical Pharmacist (involved with Multidisciplinary Atopic Dermatitis Program (MADP) clinic)

*Note: Please see page 722 for further details about the wider team*

## Governance and processes

### Team meetings:

- *Paediatric Dermatology Teaching Conference (every week):*
  - Attended by: All physicians, PA, research fellows, trainees
  - Purpose of meeting: To review difficult cases and conduct a Journal Review
- *Dermatology Grand Rounds (every 2 weeks):*
  - Attended by: Paediatric dermatologists, research fellows, PAs, trainees
  - Purpose of meeting: To discuss inpatients, challenging outpatient cases, and State of the Art Research Presentations
- *Journal club (every week):*
  - Attended by: All physicians, PA, research fellows, trainees
  - Purpose of meeting: To share brief summaries (created by fellows) of interesting studies
- *Administrative Meeting (every 2 weeks):*
  - Attended by: All paediatric dermatologists, administrative directors
  - Purpose of meeting: To review clinical enterprise, special programs, research and teaching programs

### Patient records:

- *Electronic patient records:*
  - The centre runs an electronic health record (EHR) linked to a Primary Care Network and regional hospitals

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Paediatric patients present to their primary care physician (paediatrician or family doctor) or office-based specialist (dermatologist or allergist-immunologist)

Note: Mild or well-controlled AD patients are often managed in the community, and may not be referred to the centre

- Patients may present to the general Emergency Room at the centre

## Diagnosis and Referral

In secondary care



- Paediatric AD patients are usually either referred to the dermatology or allergy & immunology program (which takes ~1–4 weeks)
- Initial dermatologist or physician assistant (PA) consultations are ~20 minutes and explore:
  - History (disease and treatment)
  - Outstanding patient questions
  - Presence of allergies
  - Any treatment reactions
- If a contact allergy is suspected, a patch test (by dermatology [UCSD] or allergy & immunology) or skin prick test (by allergy & immunology) will be performed
  - Medical assistants will assist in performing patch testing in dermatology
- Comorbid or complex AD patients may be referred to other specialties as required (primarily allergy & immunology), or to the MADP (Multidisciplinary Atopic Dermatitis Program) clinic

## Treatment and Management

Medical management



- Dermatologists or physician assistants will initiate / modify treatment as required
  - LVNs (Licensed Vocational Nurses) / medical assistants may provide additional education post-consultation as required
  - LVNs support prescription insurance authorization and fulfilment
- Scoring indices (e.g. EASI) are usually only performed if the patient is starting systemic therapy (for insurance companies)
- Patients may be offered the opportunity to participate in clinical trials (CTs) at the centre
- Aged 18–22 years, patients transition to UCSD for continued treatment (although some dermatologists and allergist-immunologists work in both centres, so will continue to see the same patients)

Non-medical management



- Dermatologists may refer to an internal or local psychologist if required
- Adjuvant therapy (UVB and wet wrapping) is provided (performed by the LVNs)
- LVNs will support with insurance provision (where required)

## Follow-up

Monitoring of chronic disease / flare up



- Patients are usually followed up every ~2–6 weeks (uncontrolled) or ~3 months (controlled) by a dermatologist or PA, for a 10–20 minute consultation
  - Depending on a patient's proximity to the centre, they may be followed up at a satellite dermatology clinic
- Patients on systemic therapy may attend the dermatology Systemic Therapy Clinic (held every 1–2 months; initial consultation = 1 hour; follow-up consultation = 20–30 mins)
- Patients can phone or send photos to LVNs (via the Electronic Medical Record [EMR] tool), who triage questions in-between consultations
- Patients tend to remain at the centre for continued care (versus being referred back to community dermatologists, allergist-immunologists or PCPs)

# Roles of the wider team



## Allergist-immunologist

**Patient type:** AD patients with suspected allergic comorbidities (including food allergy, eosinophilic esophagitis, severe asthma, auto-inflammatory disease / recurrent fevers and immunodeficiency)

**Referral:** Referred by dermatologist. AD patients (without other allergic comorbidities) may also be referred directly to the allergist-immunologist by primary care physicians (PCPs) or private dermatologists / allergist-immunologists. Asthmatic inpatients will be managed by pulmonology, and eosinophilic esophagitis patients jointly by allergy & immunology and gastroenterology

**Consultations:** AD patients are seen in the general allergy clinic (cases where the disease is driven and triggered by environmental and food allergens). Patients with complex AD are also managed in the Primary Immunodeficiency clinic (e.g. patients with underlying immune dysregulation syndromes and infection-driven disease)

**Timing:** First consultation ~20-30mins; Follow-up ~10-20mins

## Clinical pharmacist

**Patient type:** AD patients attending the MADP clinic (in addition to asthma patients attending the asthma MDT clinic)

**Referral:** AD patients are referred to the MADP clinic by dermatologists or allergist-immunologists

**Consultations:** The clinical pharmacist is responsible for AD patient injection training and providing further AD education (see case study pg. 731 - 735)

**Timing:** First consultation 15-20mins; Follow-up 10-15mins



## Joint physician assistant

(works across dermatology and allergy & immunology)

**Patient type:** AD patients referred to the MADP clinic or regular dermatology or allergy & immunology clinics

**Referral:** Patients may be referred to a general dermatology or allergy & immunology clinic by their PCP. Patients may in turn be referred to the MADP clinic by their dermatologist or allergist-immunologist (following a regular consultation with their physician)

**Consultations:** Physician assistant provides AD education to patients (up to 50mins) in the MADP clinic, and provides AD education (alongside a personal treatment plan) for patients in general clinics (see case study pg. 731 - 735)

**Timing:** First consultation ~20mins; Follow-up ~15-20mins

## Dermatologist (at UCSD)

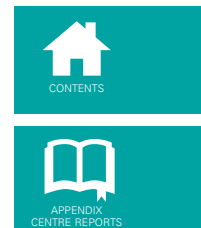
**Patient type:** AD patients with suspected complex contact dermatitis or patients transitioning to adult care

**Referral:** AD patients may be referred by a Rady Children's Hospital dermatologist to a UCSD dermatologist

**Consultations:** A UCSD dermatologist either performs an evaluation of a complicated contact dermatitis case (as one of the dermatologists specialises in patch testing), or works to transition patients from paediatric to adult care. Some dermatologists and allergist-immunologists work in both centres, so continue to see the same patients

**Timing:** First consultation ~20-30mins; Follow-up ~10-20mins

# Overview of interventions in place for AD



## Key:



Case study available

## Awareness and Presentation



Symptom identification

- **Improving Atopic Dermatitis Care by Paediatricians (IADCBP):** The centre is working to develop AD educational and health information technology resources for paediatricians and their patients, to improve the management of AD in primary care

See pg. 728-730 for case study

- **Access to patch test specialist:** Paediatric dermatologists can refer suspected contact dermatitis patients to a UCSD dermatologist who specialises in patch testing, in order to conduct a thorough investigation of potential contact allergens

## Diagnosis and Referral



In secondary care

- **Multidisciplinary Atopic Dermatitis Program (MADP):** A monthly joint clinic for comorbid / complex AD patients, with a multidisciplinary team including allergy, dermatology and pharmacology

See pg. 731-735 for case study

- **Joint dermatology-allergy physician assistant:** A physician assistant (recruited as clinical co-ordinator for the MADP) splits their time between dermatology and allergy & immunology, helping to improve the consistency of care for AD

See pg. 736 for case study

- **Emergency room specialist hospital communication app:** Emergency care staff can securely exchange messages and photos of patients with the relevant on-call specialist to receive rapid remote guidance

See pg. 737 for case study

## Treatment and Management



Medical management

- **Multidisciplinary dermatology and allergy & immunology collaborative fellowship program:** An integrated fellowship programme intended to minimise fragmentation of care across specialties, by providing comprehensive multidisciplinary experience of AD clinical practice and research (and related conditions)

See pg. 738 for case study

- **Dermatology clinical and translational research:** The Dermatology Research Unit at Rady Children's Hospital and the Rady/UCSD Eczema and Inflammatory Skin Disease Center are involved in a range of AD research initiatives, clinical trials and registries

- **Dermatology-specific systemic therapy clinic:** Dermatology patients on systemic therapies (including AD patients) attend a specialist clinic run by a dermatologist with extensive experience of these treatment options



Non-medical management

- **Tele-dermatology services:** Several tele-dermatology services are active and in development, including "online" patient follow-up, inpatient consultations for external / paediatric hospitals, and use of an EMR (Epic) portal

See pg. 739-740 for case study

## Follow-up



Monitoring of chronic disease/flare up

- **Specialist satellite clinics:** Dermatology physicians and physician assistants (in addition to allergy & immunology) offer consultations at the centre's 4 satellite clinics several times per week, to provide regionalised specialist care

See pg. 741 for case study

- **Online patient contact tool:** Patients may send photos and questions to the dermatology team remotely via an online tool: 'MyChart'. Messages are delivered to the dermatology nurse pool, which acts as a triage point to forward each message to the appropriate HCP for answering

- **Consistent HCPs across paediatric-adult AD care:** Many dermatologists and allergist-immunologists at the centre also see adult AD patients at UCSD, allowing paediatric patients to continue seeing the same physician after transitioning to adult care

Sources: (a) KPMG interviews



# Monitoring AD patients and comorbidities

## The dermatology division employs a number of measures for monitoring AD and associated comorbidities

### Objective measures (AD):

The centre uses multiple measures to monitor patients, including EASI<sup>(a)</sup>, vIGA-AD<sup>TM(b)</sup> and BSA<sup>(c)</sup>. These are not generally used in consultations, unless the patient requires a systemic therapy or attends the Specialised Multidisciplinary Atopic Dermatitis Program (MADP) (see case study pg. 731 - 735). Body Surface Area (BSA) estimates and vIGA-AD<sup>TM</sup> are commonly recorded in moderate to severe patients:

- BSA (Body Surface Area): assesses disease severity based on the percentage of dermatitis-affected body surface area<sup>(c)</sup>
- vIGA-AD<sup>TM</sup> (Validated Investigator Global Assessment for Atopic Dermatitis): scoring system for use in clinical trials which grades the overall appearance of AD lesions based on a series of morphological descriptions<sup>(b)</sup>

### Patient-reported outcomes (PROs):

PROs (e.g. POEM<sup>(e)</sup>) are generally not in use at the centre, because it can be more challenging to collect patient-reported data from paediatric patients

---

### Dermatology division routinely measures comorbidity outcomes through the:

- Specialised Multidisciplinary Atopic Dermatitis Program (MADP): Monitoring for this where possible includes BSA, v-IGA, EASI and POEM, as well as other multiple PROs
- Behavioral Health Center (situated in Rady Children's Hospital): Includes standard depression screening of patients in all clinics, with access also provided to a Psychiatric Emergency Department

**Sources:** (a) EASI for clinical signs: Harmonising Outcome Measures for Eczema (HOME) [Website] <http://www.homeforeczema.org/research/easi-for-clinical-signs.aspx> Accessed 13 Mar 2019; (b) Validated Investigator Global Assessment For Atopic Dermatitis (vIGA-AD<sup>TM</sup>) Scale [PDF] [https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale\\_vIGA-AD\\_2017.pdf](https://www.eczemacouncil.org/wp-content/uploads/2018/02/Validated-Investigator-Global-Assessment-Scale_vIGA-AD_2017.pdf) Accessed 26 June 2019; (c) Chopra R, et al. Severity strata for Eczema Area and Severity Index (EASI), modified EASI, Scoring Atopic Dermatitis (SCORAD), objective SCORAD, Atopic Dermatitis Severity Index and body surface area in adolescents and adults with atopic dermatitis. *Br J Dermatol.* 2017;177(5):1316-1321. doi: 10.1111/bjd.15641. (d) Charman CR, et al. Translating Patient-Oriented Eczema Measure (POEM) scores into clinical practice by suggesting severity strata derived using anchor-based methods. *Br J Dermatol.* 2013;169(6):1326-1332

# Advice to other centres



## What advice would you give less specialised centres



**Objective of advice:** Engage in initiatives to educate healthcare professionals (HCPs) in primary care

- **Why?** Initiatives aimed at educating HCPs in primary care with the latest developments in AD treatment and management have the potential to reduce the 'practice gap' between primary and secondary care (i.e. to increase the level of specialist AD care available in primary care centres and to improve the understanding of AD care across the health system)



**Objective of advice:** Focus on understanding the complex needs of patients

- **Why?** AD is a complex, multi-faceted disease and patients can become overwhelmed when trying to remember all the information given to them by HCPs regarding AD treatment and management. It is important to gradually introduce information and management techniques to patients (e.g. through regular follow-up appointments / educational initiatives) and to provide extra support as required throughout their treatment plan. Managing patient expectations is also key for keeping patients engaged with treatment long term



**Objective of advice:** Foster relationships with other specialists (especially allergist-immunologists)

- **Why?** Close associations between dermatology and other specialties (e.g. allergy & immunology) can lead to more effective and efficient treatment of AD and associated comorbidities through knowledge sharing and consistency in care / instructions (e.g. recommending same treatment and usage to joint-care patients). This multidisciplinary approach to care could, for example, take the form of shared clinics, parallel services or collaborative research projects



# Next steps for the centre

## What is next for the centre?

**Objective:** Analyse the findings from the MADP clinic (due April 2020 - one year after launch)

- **What?** Perform systematic statistical analysis of the data and metrics obtained during the cross-specialist MADP clinic (see case study pg. 731 - 735)
- **Why?** Insights drawn will allow the centre to assess the initial impact of the MADP clinic and identify any adjustments required for the remaining year of the grant



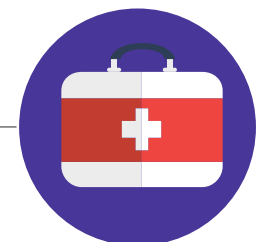
**Objective:** Fully roll-out the centre's primary care network education programme (within 2020)

- **What?** Complete the launch of the Improving Atopic Dermatitis Care by Paediatricians (IADCBP) programme to 100-120 providers (see case study pg. 728 - 730)
- **Why?** The IADCBP programme aims to improve the ability of primary care paediatricians to manage mild-moderate AD patients, without referring them to Rady Children's hospital



**Objective:** Utilise the clinical research centre to help establish routine utilisation of newer therapies in care regimens

- **What?** Incorporate newly approved systemic and topical therapies (by age approval, and off-label where applicable)
- **Why?** The Eczema and Inflammatory Skin Disease Centre is a regional resource for expertise in new and traditional therapies





# Case studies



	#
<b>Improving Atopic Dermatitis Care by Paediatricians (IADCBP)</b>	728 – 730
<b>Multidisciplinary Atopic Dermatitis Program (MADP)</b>	731 – 735
<b>Joint dermatology-allergy physician assistant</b>	736
<b>Emergency room specialist hospital communication app</b>	737
<b>Multidisciplinary dermatology and allergy &amp; immunology collaborative fellowship programme</b>	738
<b>Teledermatology services</b>	739 – 740
<b>Specialist satellite clinics</b>	741

# Improving Atopic Dermatitis Care by Pediatricians (IADCBP) (1/3)

## Overview

- The centre is working to develop AD educational and health information technology resources for paediatricians and their patients, to improve the management of AD in primary care

## What is the rationale?

- The centre is linked to a primary care network (Children's Primary Care Medical Group) of ~150 providers (paediatricians, paediatric nurse practitioners and physician assistants) throughout San Diego and Southwest Riverside counties<sup>(a)</sup>
- The centre believes a proportion of the AD patients referred to it from this network (i.e. less severe / complex AD patients) could be effectively managed in primary care instead<sup>(b)</sup>
- Referral to specialist care can take up to 4 weeks, which can be frustrating for patients / parents, especially those with very young children. Given patients can choose their primary care provider, paediatricians aim to maintain high patient satisfaction (e.g. through provision of effective treatment, without the burden of specialist wait time)<sup>(b)</sup>
- Literature suggests primary care education interventions can reduce unnecessary referrals to specialists<sup>(c)</sup>

## What are the key features of the intervention?

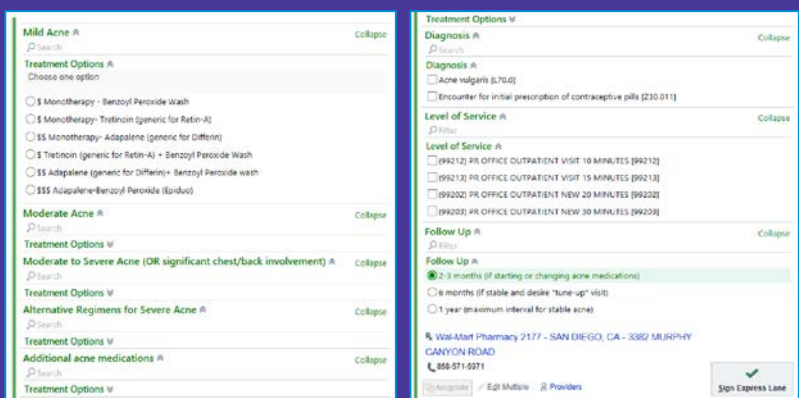
### What are the objectives?

- To develop and pilot educational and health information technology resources to improve the quality of atopic dermatitis care delivered to paediatric patients by paediatricians

### How did the project start?

- The primary care network previously developed a similar training / educational programme (in 2013) with the centre's paediatric dermatology team for paediatricians, focusing on acne<sup>(d)</sup>
- The programme involved:
  - An educational training conference on acne treatment guidelines and other topics, such as: basic principles of acne care; acne's potential psychosocial impacts; trends in the age at which patients are presenting symptoms; categories of acne therapeutics
    - The education had previously been found to improve paediatricians' self-reported knowledge and confidence in following acne guidelines<sup>(d)</sup>
  - A treatment ordering tool (SmartSet) embedded in the paediatricians' electronic medical record system, which automatically populates patient prescriptions based on the patient's symptoms and medical history
  - Paediatrician survey (to measure work burden), in addition to a chart-review of patients with acne-coded visits
- 116 paediatricians participated, and it resulted in an increase in acne-coded visits (+17.7%) and decreased burden of acne care for paediatricians (with 67.8% assessing the work as minimal)<sup>(e)</sup>

**Sources:** (a) Children's Primary Care Medical Group [Website] <https://www.cpcmg.net/about/> Accessed 10 Oct 2019; (b) KPMG interviews; (c) Schopf T, et al. Impact of interactive web-based education with mobile and email-based support of general practitioners on treatment and referral patterns of patients with atopic dermatitis: randomized controlled trial. *J Med Internet Res*. 2012;14(6):e17; (d) Eichenfield L. Managing Acne: Patient by Patient and Practice by Practice [PDF] <https://www.rchsd.org/documents/2017/09/managing-acne.pdf> Accessed 10 Oct 2019; (e) Feldstein S, et al. *J Adolesc Health*. 2016;59(5):549-554;



Screenshots: Acne paediatrician training programme 'SmartSet'

# Improving Atopic Dermatitis Care by Paediatricians (IADCBP) (2/3)

## What are the key features of the intervention? (cont.)

### How did the project start? (cont.)

- The primary care network has also worked with other specialist departments to develop similar programmes (e.g. for headache, asthma, abdominal pain, concussion and constipation)
- The AD programme's development is being funded through a third-party research grant, focused on quality improvement projects

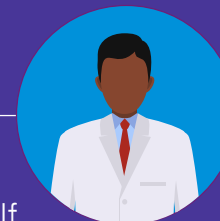
### What will the programme involve?

- The centre has recruited ~16–18 'core' providers (via email / word of mouth from network), with 2–3 providers from each area covered (e.g. South Bay, East County) to receive provider education and help inform the programme's contents (i.e. provide feedback)
  - The eventual aim is to roll out the programme to an additional ~130 providers, with support from the core providers (i.e. they will deliver the education previously provided by the dermatology division)
- The programme was 'soft-launched' ~1 year ago, but was fully launched during the last 2 months
  - The soft launch involved delivery of educational presentations by the dermatology team (at key dermatology congresses/meetings) and remotely (via teleconference) to the core providers, covering: background on AD (e.g. demographics / epidemiology), treatment (and potential side effects / complications), key research and upcoming treatments
- Similar to the acne programme, the AD programme will eventually include:
  - *Provider education:*
    - PowerPoint presentation to be delivered to core providers (on the topics mentioned above)
    - PowerPoint training module to be completed by providers at home, with pre- and post- case study knowledge assessments
  - *SmartSet:*
    - Electronic prescriptions (i.e. the system automatically populates treatment, based on patient history / disease information collected)



The aim of both the acne and AD programmes has been to improve access to care amongst paediatric patients in the community

*CEO and President of Children's Primary Care Medical Group*



You see such a vast range of things [in primary care]. If paediatricians can be trained correctly, the straight-forward patients can be treated and managed. There are things primary care should be well versed in

*Paediatric dermatologist, Rady Children's Hospital*

# Improving Atopic Dermatitis Care by Paediatricians (IADCBP) (3/3)

## What are the key features of the intervention? (cont.)

### What will the programme involve? (cont.)

- *Patient education materials*
  - PowerPoint slide show, appropriate for 4-5<sup>th</sup> grade literacy levels
  - The team is considering creating a ~20 min video for patients that could be viewed at the office (in a spare consultation room) or at the patient's home
  - The 'SmartSet' system will also automatically populate care instructions for the patient, including a topical medication "volume calculator" tool (i.e. how much treatment to apply) and a "How long a tube of topical steroid should last" section to further guide self-application volumes
- The programme contents are being created / reviewed by a multi-disciplinary team of paediatric dermatologists, paediatricians, a nurse practitioner and a research associate

## What are the desired outcomes?

### Benefits to patients:

- Better standardisation of AD care across primary care providers
- Access to more timely delivery of high-quality AD care and structure care plans / educational materials
- Support facilitation of shared decision making (SDM) with care providers

### Benefits to HCPs:

- Improved paediatrician confidence and efficiency in AD care provision
- Fewer inappropriate referrals (freeing up secondary care consultation time)
- Strengthening of primary-secondary care network through collaboration

## What's next?

- The centre aims to roll-out the programme to the 100-120 providers at the end of 2019
- The team hopes to expand the programme to other health systems nationwide, and develop an Implementation Guide explaining the process for implementing such a paediatrician programme



I provide feedback regarding the IADCBP materials, such as adapting the patient educational content to match the literacy level of the paediatric readers

*Paediatric dermatologist,  
Rady Children's Hospital*



The SmartSets are very useful for holding 'specialist' dermatology consultations more efficiently

*Primary Care Paediatrician,  
San Diego*

# Multidisciplinary Atopic Dermatitis Program (MADP) (1/5)

## Overview

- The MADP is a collaborative project between dermatology and allergy & immunology, providing a monthly joint clinic for comorbid / complex AD patients, with a multidisciplinary team (including a physician assistant, clinical pharmacist, paediatric allergist-immunologist, paediatric dermatologist and research assistant)

**Sources:** (a) Brunner PM, et al. Increasing Comorbidities Suggest that Atopic Dermatitis Is a Systemic Disorder. *Journal of Investigative Dermatology*. 2017;137(1):18–25; (b) KPMG interviews



## What is the rationale?

- AD is a complex condition which can closely relate to other allergic atopic march comorbidities<sup>(a)</sup>
- The allergy & immunology program already has a successful multi-disciplinary team (MDT) joint-clinic that has been running for ~4 years, which a pulmonologist (for asthma) and pharmacist participate in<sup>(b)</sup>
- The centre secured funding for a 2-year independent industry grant for quality improvement projects<sup>(b)</sup>

## What are the key features of the intervention?

### How did it start?

- A dermatologist and an allergist-immunologist at the centre, with a shared interest in AD and good working relationship, wanted to collaborate on an MDT model of care for AD (launched April 2019)
- The MADP is based on a similar MDT clinic at the centre for asthma patients (run between allergy & immunology and pulmonology). The asthma clinic runs twice per month (attended by 3 allergist-immunologists and 1 pulmonologist) and is supported by internal and clinical research funding

### What does it involve?

- MADP is a collaborative effort between the Allergy & Immunology Program and the Division of Pediatric and Adolescent Dermatology at Rady Children's Hospital
- The first MADP clinic was in April 2019
- It consists of a 1-day clinic, held once per month (involving in-clinic visits as well as out-of-clinic phone call follow-up assessments)
- The clinic is reserved for complex / comorbid AD patients, who have previously been seen by a specialist at the centre (allergist or dermatologist)
  - Patients are primarily from the centre, however a few have been referred from external providers (they will be seen by the centre's allergist or dermatologist before attending the clinic)
- Key MADP team members include: physician assistant, clinical pharmacist, paediatric allergist-immunologist, paediatric dermatologist and research assistant (hired specifically for this project)
- The MADP physician assistant is also known as the clinic's 'clinical coordinator'. The physician assistant works across both dermatology and allergy & immunology and was hired specifically for this project (see case study pg. 736)
- The clinical coordinator is responsible for scheduling MADP patient appointments and recruiting patients for the clinic

# Multidisciplinary Atopic Dermatitis Program (MADP) (2/5)

## What are the key features of the intervention? (cont.)

### What is the format?

—Patients rotate between three rooms (supported by a medical assistant) in order to see different specialists / staff. 7 patients are currently seen per clinic (this number has expanded from 3–4 at the start)

- New patients can take ~2.5 hours in total, so will generally be scheduled at the start of the clinic
- Patients typically return to the clinic every 2–3 months

### Order of appointments / team roles:

1. Physician assistant (PA) - provides AD education to patients (up to 50mins) and acts as a scribe in physician appointments (for dermatologist and allergist-immunologist). Education includes:

- An overview of AD (definitions; causes; links to other allergies)
- Self-management advice (bathing; moisturisers)
- Safe use of topical steroids and non-steroids (frequency; volumes)
- Other AD medications / therapies (systemic therapy; antihistamines; antibiotics)
- Guidance for applying wet wraps



Example patient educational materials provided by the physician assistant

*Note: the MADP educational materials were developed by a shared allergy-dermatology physician assistant and research associate, and subsequently reviewed by an allergist-immunologist and dermatologist. They also act as the basis for the IADCBP educational materials (see case study pg. 728)*



“



If specialists don't communicate, the dermatologist may tell patients to use one cream, whereas the allergist-immunologist may say to use another. As a result, the patient may use neither

*Paediatric dermatologist, Rady Children's Hospital*

“



Patients often say “I've never had an appointment like this - I usually don't get the opportunity to ask so many questions”

*Paediatric allergist-immunologist, Rady Children's Hospital*



# Multidisciplinary Atopic Dermatitis Program (MADP) (3/5)

## What are the key features of the intervention? (cont.)

### What is the format? (cont.)

2. Clinical pharmacist (CP) – provides additional drug-specific education and training in treatment usage / wider AD care. The CP also monitors how many prescriptions are collected by patients (for outcome data)
  - The first CP consultation (with a new patient) would last 15-20mins, with follow-up appointments lasting 10-15 mins
  - The first consultation may involve:
    - Recording the patient's medical history (e.g. symptoms, sleep profile)
    - Recording the current treatment regimen and level of compliance
    - The opportunity for patients to ask questions (e.g. about information provided by the physician assistant)
    - Discussing insurance issues (e.g. if the patient requires co-pay)
    - Providing free treatment samples
    - Assisting patients receiving biologic therapy with their first subcutaneous injection (subsequently self-injected at home)
    - Showing parents how apply wet wraps
    - Explaining drug-to-drug interactions (e.g. of strong topical steroids)
    - Demonstrating bleach therapy baths

*Note: two pharmacy residents assist the CP, for example, by calling the pharmacy before certain consultations to check the patient's re-fill history (to monitor their treatment compliance)*



The MADP is a big thing. Both diseases (AD and asthma) have multiple components, and we have more time to discuss them

*Paediatric dermatologist,  
Rady Children's Hospital*



We give patients samples and discuss the different topical treatments. It is sometimes better to go with the option they will tolerate and use more, rather than the optimal treatment

*Paediatric dermatologist,  
Rady Children's Hospital*



# Multidisciplinary Atopic Dermatitis Program (MADP) (4/5)

## What are the key features of the intervention? (cont.)

3. Allergist-immunologist – runs a 30 min consultation in each visit to assess patient allergy symptoms, review prior allergy evaluations and work-up, monitor treatment reactions, perform skin prick tests, and assess itch and quality of life
4. Dermatologist – provides a 30 min consultation to perform an assessment of the patient's AD symptoms (including skin care regimen and response to prior therapies), record EASI and POEM scores, and determine the need for laboratory/microbial testing and patch tests if required
5. Research assistant – collects patient-reported outcomes (PROs) at the end of each visit, and will perform basic data analysis (if the time is available)
6. Physician or Physician assistant – shares integrated care plan with the patient before they leave

### Other features:

- Patients are encouraged to use an online shared decision making tool by NEA<sup>(a)</sup>
  - Patients are asked to complete the form at least once a week and/or before every visit to the centre (however they may choose to do so more frequently)
  - Patients can print the form at the clinic, so they can discuss the form and complete it during their consultation with the physician
  - The form includes information on topical steroids, systemic therapies, hygiene, AD triggers and AD comorbidities
- The collaborative MADP clinic has its own specific intake and follow-up history forms, created by utilising an evidence-based approach from existing literature and clinical expert guidelines. The history forms record atopic dermatitis history, prior treatments and response, allergy history and prior evaluations, skin care regimen utilised, quantity of prescription medication used over time, and an assessment of comorbidities (asthma, allergic rhinitis, depression / anxiety / ADHD)
- The dermatologist and allergist-immunologist each bill separately for their consultations. The other team members (i.e. clinical pharmacist, clinical coordinator and research assistant) do not bill for their time, but are funded by the grant



Screenshot: National Eczema Association (NEA) website



You really need to optimise the usage of topical treatments for AD patients aged under 12, as there are fewer options available

*Pharmacist, Rady Children's Hospital*

**Sources:** (a) Eczema Made Easier. [Website] <https://www.eczemawise.org/> Accessed 2 Dec 2019

# Multidisciplinary Atopic Dermatitis Program (MADP) (5/5)

## What are the key features of the intervention? (cont.)

### Outcome measures being collected include:

- PROs (patient-reported outcomes) collected by clinical pharmacist and research assistant (i.e. patient sleep profile; no-show frequency; number of telephone calls received from patients to ask questions)
- PROs from National Eczema Association (NEA) shared decision making tool
- POEM
- EASI
- SCORAD
- vIGA-AD™

## What are the outcomes so far?

### Benefits to patients:

- Convenient access to a cross-specialty team
- More time to ask questions, understand care plan and allow for shared decision making

### Benefits to HCPs:

- Increased cross-specialty communication / collaboration for AD management
- Standardisation and streamlining of care across AD-related specialties

## What's next?

- A fellow will soon join the clinic to support the physician assistant's work during the physician consultations (which will allow the two physician consultations to occur in parallel)
- The preliminary data will be analysed after 1 year (Q1 2020)
- The current industry grant funding the MADP clinic covers San Diego, but the centre hopes to use the findings to educate specialists elsewhere (i.e. to expand the initiative beyond San Diego), and the outcome findings to provide rationale for continued internal funding of the clinic

## Scans: EASI score report forms

**Appendix 3.1: Eczema Area and Severity Index (EASI) case report form – ages <8 years**

Area of involvement: Each body region has potentially 100% involvement. Score 0-36 based on the following table:

% involvement	0	1-9%	10-29%	30-49%	50-69%	70-89%	90-100%
Region score	0	1	2	3	4	5	6

Severity of signs: Grade the severity of each sign on a scale of 0-3:

0	None
1	Mild
2	Moderate
3	Severe

✓ Take an average of the severity across the involved area.  
✓ Half points may be used e.g. 2.5.

Scoring table:

Body region	Erythema (0-3)	Edema/ Papulation (0-3)	Excitation (0-3)	Lichenification (0-3)	Wheal score (0-4)	Multiplier	Score per body region
Head/neck	( )	( )	( )	( )	( )	X 0.1	
Trunk	( )	( )	( )	( )	( )	X 0.3	
Upper extremities	( )	( )	( )	( )	( )	X 0.2	
Lower extremities	( )	( )	( )	( )	( )	X 0.3	

The final EASI score is the sum of the 4 region scores: (0-36)

EASI guideline December 14

**Appendix 3.2: Eczema Area and Severity Index (EASI) case report form – ages ≥8 years**

Area of involvement: Each body area has potentially 100% involvement. Score 0-36 based on the following table:

% involvement	0	1-9%	10-29%	30-49%	50-69%	70-89%	90-100%
Region score	0	1	2	3	4	5	6

Severity of signs: Grade the severity of each sign on a scale of 0-3:

0	None
1	Mild
2	Moderate
3	Severe

✓ Take an average of the severity across the involved area.  
✓ Half points may be used e.g. 2.5.

Scoring table:

Body region	Erythema (0-3)	Edema/ Papulation (0-3)	Excitation (0-3)	Lichenification (0-3)	Wheal score (0-4)	Multiplier	Score per body region
Head/neck	( )	( )	( )	( )	( )	X 0.1	
Trunk	( )	( )	( )	( )	( )	X 0.3	
Upper extremities	( )	( )	( )	( )	( )	X 0.2	
Lower extremities	( )	( )	( )	( )	( )	X 0.3	

The final EASI score is the sum of the 4 region scores: (0-36)

EASI guideline December 14

## Scan: vIGA-AD™ report form

**Validated Investigator Global Assessment scale for Atopic Dermatitis**  
vIGA-AD™

Instructions:  
The vIGA score is selected using the descriptors below that best describe the overall appearance of the lesions at a given time point. It is not necessary that all characteristics under Morphological Description be present.

Score	Morphological Description
0 – Clear	No inflammatory signs of atopic dermatitis (no erythema, no induration/papulation, no lichenification, no scaling/crusting). Post-inflammatory hyperpigmentation and/or hypopigmentation may be present.
1 – Almost clear	Barely perceptible erythema, barely perceptible induration/papulation, and/or minimal lichenification. No scaling or crusting.
2 – Mild	Slight but definite erythema (pink), slight but definite induration/papulation, and/or slight but definite lichenification. No scaling or crusting.
3 – Moderate	Clearly perceptible erythema (salmon red), clearly perceptible induration/papulation, and/or clearly perceptible lichenification. Scaling and crusting may be present.
4 – Severe	Marked erythema (deep or bright red), marked induration/papulation, and/or marked lichenification. Disease is widespread in extent. Scaling or crusting may be present.

Notes:  
1. In intermediate cases, please use extent to differentiate between scores.  
For example:  
• Patient with marked erythema (deep or bright red), marked papulation and/or marked lichenification that is limited in extent, will be considered "3 – Moderate".  
2. Excoriations should not be considered when assessing disease severity.



CONTENTS



APPENDIX  
CENTRE REPORTS

# Joint dermatology-allergy physician assistant

## Overview

- The centre employs a physician assistant (recruited as clinical co-ordinator for the MADP) who splits their time 50:50 between dermatology and allergy & immunology



Working together helps the two divisions to streamline treatment. For example, we can provide patients with consistent education and topical treatment recommendations (including amounts and frequencies of use). I am there to spot any inconsistencies. The collaboration is also an opportunity for the allergy unit to learn about AD management from dermatology

*Physician Assistant, Rady Children's Hospital*

## What is the rationale?

- AD is a complex disease which may require input from multiple specialists<sup>(a)</sup>, which can in turn result in inconsistencies in the education delivered to patients<sup>(b)</sup>
- Large patient numbers and short consultation durations can limit the time available for dermatologists to focus on treating and managing complex AD patients<sup>(c)</sup>

## What are the key features of the intervention?

- The centre employs a physician assistant who splits their time 50:50 between the dermatology and allergy & immunology divisions
- Physician assistants can work in primary and secondary care settings, and must satisfy specific training criteria to qualify<sup>(d)</sup>:
  - Successful completion of an appropriate academic qualification
  - 2,000 hours of clinical experience
  - Successful completion of the Physician Assistant National Certifying Exam (PANCE)
- The physician assistant was originally recruited to coordinate the MADP (see case study pg. 731 - 735)
- During regular clinics (i.e. not the MADP), the physician assistant will act as an 'extender' for a physician. In other words, the physician assistant will perform a consultation and formulate a treatment plan for AD patients, which a physician will subsequently review (though mild / simple AD cases may not require a review)

*Note: ~10% of cases managed by the physician assistant are reviewed by a physician*

- The dermatology and allergy & immunology divisions work closely to streamline the treatment of AD patients, for example by ensuring the AD education delivered to AD patients is consistent across specialties (i.e. no contradictory advice)

## What are the outcomes so far?

### Benefits to patients:

- The opportunity to build rapport / a lasting relationship with HCPs at the centre (by seeing the same HCPs across specialties)
- Consistent AD education received across specialties

### Benefits to HCPs:

- Enhanced AD knowledge sharing between the dermatology and allergy & immunology divisions
- The 'extender' role of the physician assistant leaves more time available for physicians to see other patients

**Sources:** (a) American Academy of Allergy, Asthma & Immunology (AAAAI); Atopic Dermatitis (Eczema) Definition [Website] [https://www.aaaai.org/conditions-and-treatments/conditions-dictionary/atopic-dermatitis-\(eczema\)](https://www.aaaai.org/conditions-and-treatments/conditions-dictionary/atopic-dermatitis-(eczema)) Accessed 2 April 2019; (b) KPMG interviews; (c) Abuabara K, et al. The Long-Term Course of Atopic Dermatitis. *Dermatol Clin*. 2017;35(3):291-297; (d) Physician Assistant License and Certification [Website] <https://www.physicianassistantedu.org/> Accessed 1 Oct 2019

# Emergency room specialist hospital communication app

## Overview

- Emergency care staff at the centre use a mobile application which allows them to securely exchange photos of patient symptoms with the relevant on-call specialist, in order to receive rapid remote guidance

## What is the rationale?

- Emergency service staff (who may not be specialised in AD care) will need to make the decision whether to hospitalise a patient, or refer them to an outpatient clinic (if not urgent)<sup>(a)</sup>
- Teledermatology can improve access to dermatology care in public hospital settings<sup>(b)</sup>

## What are the key features of the intervention?

- The centre's emergency room is open 24/7 and encourages the use of an internal teledermatology app. The app was established ~2 years ago and is integrated with the centre's electronic health record (EHR)
- The 'store-and-forward' system allows emergency physicians to securely capture and share photos of patient symptoms (e.g. AD patient skin symptoms) with the relevant specialist on call (e.g. dermatologist), who can provide remote advice and guidance quickly
- Patients must provide verbal consent for their photos to be used by the system
- If their case is not considered an emergency, AD patients will receive a temporary treatment to manage their symptoms, before having an outpatient consultation booked with a dermatologist at the centre during the next 1–2 days

## What are the outcomes so far?

### Benefits to patients:

- Access to specialist AD care advice quickly in the emergency room
- Accurate diagnoses preventing unnecessary admissions into inpatient care

### Benefits to HCPs:

- Efficient and convenient assessment of 'emergency' dermatology patients
- Accurate diagnoses preventing unnecessary admissions into inpatient care

## What's next?

- Assess the efficacy and reliability of the system in improving access to specialist AD care for patients
- Consider expansion of tele-dermatology to non-emergency room primary care and/or urgent care settings

**Sources:** (a) KPMG interviews; (b) Carter ZA, et al. Creation of an Internal Teledermatology Store-and-Forward System in an Existing Electronic Health Record. *JAMA Dermatol.* 2017;153(7):644–650



# Multidisciplinary dermatology and allergy & immunology collaborative fellowship program

## Overview

- The centre has established a novel 1-year training programme which provides comprehensive multidisciplinary experience in dermatology and allergy & immunology for trainee physicians



## What is the rationale?

- Atopic dermatitis is a complex, multi-faceted condition with comorbidities which span dermatology and allergy and may require input from multiple specialists<sup>(a)</sup>
- Providing HCPs with experience and training across multiple disciplines can improve alignment on care and understanding of AD across specialties<sup>(b)</sup>

## What are the key features of the intervention?

*How is it being funded?*

- With a competitive grant award for the 2019–2020 academic year

*Who is it for?*

- Prospective trainees who have completed previous post-graduate internships and / or residencies in paediatrics or medicine and are interested in pursuing careers in dermatology or allergy
  - Two fellows have been recruited for the 2020 academic year

*What does it include?*

The fellowship programme involves a unique split of 70% clinic time and 30% research time, including:

- Regular rotations through paediatric dermatology and allergy & immunology outpatient clinics and inpatient consultations
- Participation in the IADCBP and MADP (see case studies pg. 728 - 730 and pg. 731 – 735 respectively)
- Participation in research projects relating to AD and associated conditions

## What are the outcomes so far?

### Benefits to patients:

- Treatment received from HCPs with multidisciplinary experience
- Improved consistency of AD care and education received from different specialists

### Benefits to HCPs:

- Multidisciplinary experience and training across dermatology and allergy & immunology
- Improved alignment on care and understanding of AD across specialties

## What's next?

- The 2 fellows will be starting their programme in late 2019. The effectiveness of the program will be evaluated at 9 months and 1 year

**Sources:** (a) Brunner PM, et al. Increasing Comorbidities Suggest that Atopic Dermatitis Is a Systemic Disorder. *Journal of Investigative Dermatology*, 2017;137(1):18-25; (b) KPMG interviews

# Tele-dermatology services (1/2)

## Overview

- The centre provides tele-dermatology consultation services for patients, hospitals outside of the Rady Children's Hospital network and PCPs
- The services facilitate fast access to specialist advice, aids diagnosis and referral, and provides the patient with a follow-up consultation that can be conducted online at their convenience

## What is the rationale?

- Long waiting times for specialist advice and care can deter patients from seeking and attending appointments<sup>(a)</sup>
- Tele-dermatology consultations give patients the option to receive treatment guidance and advice in the comfort of their own home
- In a recent study of skin diseases, the use of tele-dermatology was seen to improve access to specialty care, diagnostics and treatment, whilst also reducing cost<sup>(b)</sup>

## What are the key features of the intervention?

There are several tele-dermatology services active or in development at the centre that are intended to enhance the quality of patient care delivered:

### Active services

- 1) *"Online" patient follow-up*
  - Enables patients to follow up with the centre through Electronic Medical Records patient portal technology
  - Patient signs and treatment progress can be tracked with photographs that can be seamlessly attached to the patient's medical record
- 2) *Consultation dermatology service for external hospitals*
  - Developed specifically for Children's Hospital of Orange County, to support access to specialist advice from Rady Children's Hospital
  - Utilised for inpatient consultations as requested by paediatric hospitals
  - Uses Electronic Medical Records and communication platforms to facilitate communication between hospitals

### Services in development

- *Consultation dermatology service for PCPs*
  - Will utilise EMR portal and a mobile application, to allow PCPs to securely exchange messages and photos of patient symptoms with the relevant on-call specialist in order to deliver remote guidance for diagnosis and referral
  - Patients must provide verbal consent for their photos to be used by the system

The Dermatology Division and Centre Administration referenced applicable law and developed guidelines to govern the use of tele-dermatology service

**Sources:** (a) Akobeng AK, et al. Telephone Consultation as a Substitute for Routine Out-patient Face-to-face Consultation for Children With Inflammatory Bowel Disease: Randomised Controlled Trial and Economic Evaluation. *EBioMedicine*. 2015;2(9):1251–1256; (b) Bashur RL, et al. The Empirical Foundations of Teledermatology: A Review of the Research Evidence *Telemed J E Health*. 2015;21(12):953–979. doi: 10.1089/tmj.2015.0146





# Tele-dermatology services (2/2)

## What are the outcomes so far?

### Benefits to patients:

- Gives patients the option to receive treatment and guidance in their location of choice
- Reduces need to travel to the centre if they do not have any issues or require urgent care

### Benefits to HCPs:

- Increased access to specialist advice to aid treatment
- Potential to increase availability in clinics if patients do not need to be seen by a dermatologist



# Specialist satellite clinics

## Overview

- The centre runs 4 satellite clinics in the surrounding region which aims to improve access to specialist dermatology care (including for AD) for patients living in these areas



## What is the rationale?

- The centre's catchment area is geographically large, which can be inconvenient for patients who live further away<sup>(a)</sup>
- Long waiting times and travel distances for specialist advice and care can deter patients from seeking and attending appointments<sup>(b)</sup>

## What are the key features of the intervention?

- As part of a hospital-wide initiative, the dermatology division hosts satellite clinics (active for ~20 years) in four locations:
  1. Encinitas (Coastal)
  2. Oceanside (between Northern Coastal and Inland) – captures patients from Orange County and Los Angeles
  3. Escondido (Northern Inland)
  4. Murrietta (North East Inland) – incorporates patients from Temecula and Riverside
- These may be used for initial consultations, or follow-up consultations from the centre (e.g. if patient is located further away from the centre)
- The dermatologists and physician assistants split their time 30:70 (at the centre versus satellite clinics), and rotate around the four satellite clinics
- Each clinic will generally involve 2 dermatology team members
- Consultations typically last 20-40 minutes
- Severe / complex patients may be sent to the MADP (see case study pg. 731 - 735)

*Note: the centre's Allergy & Immunology Program runs 5 similar satellite clinics*

## What are the outcomes so far?

### Benefits to patients:

- More convenient access to specialist care

### Benefits to HCPs:

- Greater access to patients that may not have been able to reach the main centre site
- Expands relationships of centre specialists to primary care and other specialists

**Sources:** (a) KPMG interviews; (b) van Dijk CE, et al. Compliance with referrals to medical specialist care: patient and general practice determinants: a cross-sectional study. *BMC Fam Pract.* 2016;17:11



# Cayre Clinical Center

**Bogota, Colombia**

Site visited by KPMG 11<sup>th</sup> March 2020

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[kpmg.com/uk](https://kpmg.com/uk)



# Summary



## Context

- **Centre type:** Cayre Clinical Center is a community-based organisation in Bogota, Colombia. The centre is part of the Riesgo de Fractura S.A. (Fracture Risk) group, which also has three health clinics outside Bogota (Cali, Pereira and Armenia)<sup>(a)</sup>
- **Catchment area:** Most patients are from the region of Bogota, with a catchment area of ~7.4million
- **Funding:** The centre is funded by the state insurance system. Most patients are referred by private entities, however patients with private insurance can present without a referral for treatment
- **Services:** Cayre Clinical Center provides outpatient healthcare to children and adult AD patients (usually over 12 years old). Whilst the centre previously focused on dispensing medication, a clinical research programme was launched in March 2020
- **Patient population:** The centre offers care mostly to adolescent and adult patients with moderate to severe AD (along with other dermatological diseases), however children are also seen



## Key strengths in the delivery of AD care

- **Fast adaptation to insurance requirements:** The requirements of insurance companies to gain access to specific treatments can vary between different medication. To manage this, Cayre Clinical Center has implemented fast and adaptable processes to respond to these insurance changes
- **Efficient data analysis:** Data processing capabilities within the team enable detailed risk assessment of patients and can predict expected patient volumes. As a result, the team can respond accordingly to patient demand
- **Cost-effectiveness assessments:** Programmes at the centre help effectively capture and communicate the cost-effectiveness of projects and initiatives (e.g. new treatments and clinical trials)
- **Usage of models integrated with EPS:** Patients diagnosed with moderate to severe AD are identified within the nationwide database (EPS – Entidades Promotoras de Salud<sup>(1)</sup>). Once identified, the centre reaches out to the patient to provide care. Using this system, patients have the opportunity to be seen within 1 week



## Key challenges faced in the delivery of AD care

- **Patient adherence to treatment:** Young patients with AD may not understand the importance of adhering to treatment regimes. This can potentially limit long-term recovery
- **Treatment burden:** AD requires an extensive time and travel commitment from patients, particularly in regards to attending consultations. The challenge is exacerbated if the patient has a mobility problem and is unable to attend the consultation in person. In this circumstance, medical personnel can help administer care in the patient's home

**Source:** (a) Cayre [website] <https://cayre.co/> Accessed 18 March 2020

**Note:** (1) Please see page 744 (Atopic Dermatitis (AD) in Colombia) for further details about EPS



# Atopic Dermatitis (AD) in Colombia

## Colombian healthcare system:

The healthcare system in Colombia is publically and privately funded and accounts for up to 7.2% of total GDP expenditure<sup>(a)</sup>. The funding, design and delivery of healthcare is the responsibility of The Ministry of Health and Social protection (*Ministerio de Salud y Protección Social*). By law, everyone in Colombia must have access to the same standard of medical, dental and vision care. In 2009, over 80% of Colombians were enrolled in a public healthcare scheme<sup>(b)</sup>, however 17% (vs 16.3% in 2017) of healthcare expenditure was still out-of-pocket<sup>(c)</sup>

Healthcare is delivered through three schemes that aim to provide all citizens with a form of health coverage<sup>(d)</sup>:

- **Entidades Promotoras de Salud (EPS):** Public healthcare system that is mandatory for all residents, who are required to be insured for the basic provision of care. The monthly premium is 12.5% of monthly gross income. Family members and dependents can be added to an individual's EPS plan. This includes a spouse, partner, children under 18 or individuals dependent on the insured. Whilst EPS registers all residents, the Instituciones Prestadoras de Servicios de Salud (IPS) is responsible for providing the healthcare services
- **Medicina Prepagada:** In addition to purchasing EPS, citizens are able to purchase private health insurance for various additional services
- **Sistema de Identificación de Potenciales Beneficiarios de Programas Sociales (SISBEN):** A free government-subsidised healthcare system that is only for the very poor or those who are homeless in Colombia

## Prevalence:

- In Colombia, AD affects 14% of people every year<sup>(e)</sup>
- Lifetime prevalence for self-reported symptoms is 24%. Prevalence of physician-diagnosed AD is 6%<sup>(e)</sup>
- Occurrence tends to be higher in females than males<sup>(e)</sup>



## Care provision:

### Location:

- Mild (or well-controlled) AD care is usually managed by Primary Care Professionals (PCPs) or private dermatologists
- Moderate and severe (or uncontrolled) AD care is usually managed by hospital dermatologists

### Funding:

- Primary care and minor secondary care services are predominantly funded by the public health scheme. In more severe cases, patients tend to fund their care privately

## Guidelines and societies:

### Guidelines:

- Atopic dermatitis guidelines from the Latin American Society of Allergy, Asthma and Immunology<sup>(e)</sup>
- Atopic dermatitis guidelines from the American Academy of Dermatology<sup>(f)</sup>

### Medical society:

- The Latin American Society of Allergy Asthma and Immunology

**Sources:** (a) Colombia. World Health Organisation [Website] <https://www.who.int/countries/col/en/> Accessed 16 March 2020 (b) Giedion U, et al. Colombia's Universal Health Insurance System. *Health Affairs*. 2009;28(3) (c) Out-of-pocket share of total health expenditure in Colombia from 2010 to 2017. Statista. (d) Healthcare in Colombia. Medellín [website] <https://medellinguru.com/health-insurance/> Date accessed: 16 March 2020. (e) Sánchez J, et al. Atopic Dermatitis Guideline. Position Paper from the Latin American Society of Allergy, Asthma and Immunology. *Revista Alergia México*, 2014;61(3):178-211 (f) American Academy of Dermatology. Atopic dermatitis guidelines [website] <https://www.aad.org/member/clinical-quality/guidelines/atopic-dermatitis> Accessed 9 April 2020

# The centre and dermatology division

The centre	
<b>Type and location<sup>(a)</sup></b>	<ul style="list-style-type: none"> <li>— Cayre Clinical Center is a community-based organisation in Bogota, Colombia</li> <li>— It is part of the Riesgo de Fractura S.A. (Fracture Risk) group, which initially had a rheumatology focus. The Riesgo de Fractura S.A. group also has three health clinics outside Bogota, located in Armenia, Cali and Pereira</li> <li>— Whilst Cayre Clinical Center does not have a specialist dermatology department, the centre provides a dermatology-focused consultation service</li> </ul>
<b>Population served</b>	<ul style="list-style-type: none"> <li>— Most patients at Cayre Clinical Center are from the region of Bogota, which has a catchment area of ~7.4million</li> </ul>
Dermatology services	
<b>Service Division</b>	<b>Outpatient service</b>
<b>Hours of availability</b>	Monday – Friday: 7:00am – 7:00pm Saturday: 7:00am – 1:00pm
<b>No. of patients seen</b>	For AD consultations: ~10 - 12 patients seen per day The centre has approximately 600 patients in the AD programme
<b>Types of patients seen</b>	The centre mostly treats adult and adolescent patients (over 12 years old) with moderate to severe AD, however a small proportion of paediatric patients are also seen
<b>Facilities on-site<sup>(1)</sup></b>	<ul style="list-style-type: none"> <li>- Consultation and treatment administration rooms</li> </ul> <p>Within the wider group, there is access to:</p> <ul style="list-style-type: none"> <li>- Allergy unit</li> <li>- Clinical laboratory</li> </ul>

**Note:** (1) List of facilities is not exhaustive

**Source:** (a) Cayre [website] <https://cayre.co/> Accessed 18 March 2020








# The team



## Core team profile ●

-  **2** Dermatologists
-  **1** Head nurse
-  **4** Nurses
-  Administrative staff

## Wider team profile ●

-  **1** Nutritionist
-  **1** Pharmacist
-  **1** Psychologist
-  **1** Allergist
-  **1** Pulmonologist
-  **1** Cardiologist
-  **1** General Practitioner trained in AD

## ● Governance and processes

### Team meetings:

- Whole team meeting (once per month):
  - Attended by: all staff
  - Purpose: Discussion is operational focused, with topics including EPS patient characteristics, successful clinical trials, and the cost-effectiveness programmes

### Patient records:

- Electronic Health Records (EHR):
  - The centre uses electronic health records for patients (accessible by all staff)



*Note: Please see page 748 for further details about the wider team*

# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- All patients will be recorded on the EPS (nationwide patient base)
- Patients with symptoms of AD (e.g. itching or dryness of the skin) will present to a family doctor for an initial diagnosis
- If patients are mild, they will continue to receive care through EPS, which usually entails receipt of medication at local clinics

## Diagnosis and Referral

In secondary care



- Patients diagnosed with moderate to severe AD however will be referred via EPS to the dermatologist at the centre
- An initial dermatologist consultation lasts ~30 minutes, depending on patient symptoms. The dermatologist will perform a physical examination of the patient and assess disease severity
- The dermatologist will collect various objective measures (e.g. SCORAD and EASI) and patient reported outcomes
- After the first consultation, the dermatologist will inform the patient of the disease severity and the treatment required
- All patients will be provided with the opportunity for a mental health examination through referral to the psychologist at the centre
- Patients can also be referred to various other specialists through the centre's external referral network, including nutritionists, pharmacists, allergists, cardiologists and pulmonologists

## Treatment and Management

Medical management



- Core medical treatment is provided by the dermatologist. Treatments prescribed primarily include topical AD treatments

### Comorbidity management

- Patients with very severe AD and significant allergy symptoms will be immediately referred to an allergist located within the wider centre group
- A psychologist is available to provide an assessment of the patient's mental health, along with other forms of psychological support. Consultations with the psychologist last ~30 minutes
- In response to the psychological examination, a nutritionist offers dietary tests and BMI assessments in order to determine if the patient has a mental health-induced eating disorder
- A pulmonologist and cardiologist are also available to discuss other AD related comorbidities, such as asthma and cardiovascular disease respectively
- If the patient requires treatment for a comorbidity that is not covered in the immediate external referral network, the patient is referred back to EPS

Non-medical management



- Patient education is delivered through a plethora of healthcare professionals located within the centre and externally
- The dermatologist also educates the patient on the different treatments available to help find the most suitable medication for the patient
- The majority of patient education is provided through nurses after the first consultation, with a focus on disease severity and managing the condition
- Once treatment has been agreed, treatment administration education is provided by the pharmacist

## Follow-up

Monitoring of chronic disease / flare up



- The Head Nurse will organise patient follow-up appointments and ongoing care at the centre
- Follow-up appointment frequency is dependent on the risk analysis of the patient. Patients will generally see a dermatologist once every three months. Follow up consultations last ~20 minutes
- Patients with controlled AD will be monitored by a General Practitioner specially trained in AD, who will be in charge of monitoring and reformulating treatments
- Patients will also be able to see the pharmacist once a year and the nutritionist twice a year
- To promote patient communication with the centre, patients have access to a preferential phone line. The phone line can allow the patient to contact the centre and speak to a nurse should they have any questions and need urgent assistance

*Note: The centre was developing a new model of care during the visit*



# Roles of the wider team

## Nutritionist

**Patient type:** Mild to severe AD patients with a suspected mental health illness

**Referral:** Referred by dermatologist

**Consultations:** Assesses BMI and conducts nutritional tests to determine if patient is malnourished. Discusses good eating practices and how to control anxiety if it is suspected that AD is causing anxiety

**Timing:** Consultations vary in length depending on patient symptoms (typically ~20 minutes with a follow up appointment every 6 months)



## Psychologist

**Patient type:** Mild to severe AD patients (mainly young adults and adolescents)

**Referral:** Referred by dermatologist

**Consultations:** Consultation content varies depending on patient assessment, which also impacts patient prioritisation. With half of AD patients at the centre receiving a formal diagnosis of anxiety or depression, consultations tend to involve talking to the patient about their mental health history, managing the mental impact of their condition and detailing what support is available

**Timing:** Consultations vary in length depending on patient assessment (typically ~30 minutes)

## Pharmacist

**Patient type:** Mild to severe AD patients who have been prescribed treatment from the centre

**Referral:** Referred by dermatologist

**Consultations:** Compiles a medical history of the patient's previous medication and provides patient education for any prescribed treatment during the first consultation

**Timing:** Typically ~20 minutes

## Allergist

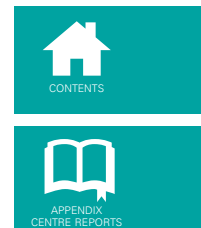
**Patient type:** Mild to severe AD patients with a suspected allergy

**Referral:** Referred by dermatologist

**Consultations:** Assesses allergy severity and provides guidance for management if allergy is suspected or confirmed

**Timing:** Consultations vary in length depending on patient assessment (typically ~30 minutes)

# Overview of interventions in place for AD



## Key:



Case study available

## Awareness and Presentation



Symptom identification

- **Database integrated with EPS:** Patients with moderate to severe AD are identified within the EPS database and notifications are sent out to dermatology providers. Once informed, Cayre Clinical Center can reach out to the patient to offer immediate secondary care

## Diagnosis and Referral



In secondary care

- **Use of Patient Reported Outcomes (PROs):** The centre uses various metrics to measure PROs. This assists with provision of care to patients

## Treatment and Management



Medical management

- **Psychological support:** Cayre Clinical Center provides patients with access to a psychologist and a nutritionist. The psychologist looks at the patient's general mental health state, whereas the nutritionist addresses the impact the patient's mental health could be having on their eating habits

See pg 754 for case study

- **Participation in clinical trials:** Adult AD patients are now able to participate in clinical trials, following the start of a new initiative at the centre



Non-medical management

- **Multi-disciplinary patient education:** Patient education is provided through a multitude of healthcare professionals (HCPs), who each cover a wide variety of topics
- **Involvement of nurses in coordination of care:** The Head Nurse at the centre is responsible for managing each patient. The role entails managing the patient from their arrival at Cayre Clinical Center through to the consultations, referral process and the follow-up care. This helps provide a seamless patient experience and can ease the burden on patients

See pg. 755 for case study

## Follow-up



Monitoring of chronic disease/flare up

- **Patient-HCP communication:** The centre provides patients with fast access to HCPs and specialist information through a variety of mediums during the entirety of their care. Patients can access a dedicated phone line and patient messaging groups

See pg. 756 for case study



# Monitoring patients with AD and comorbidities



## The dermatology department measures disease activity at each patient visit and stores all results electronically

### Objective measures (AD):

- AD scoring indices are used to monitor patients and their disease, including:
  - EASI (Eczema Area and Severity Index): used to measure the extent (area) and severity of atopic eczema<sup>(a)</sup>
  - SCORAD (SCORing Atopic Dermatitis): used to assess AD disease severity and monitor patient progress<sup>(b)</sup>
  - BSA (Body Surface Area): used to assess disease severity based on the percentage of dermatitis-affected body surface area<sup>(c)</sup>

### Patient-reported outcomes:

- DLQI (Dermatology Quality of Life Index): a dermatology-related quality of life questionnaire<sup>(d)</sup>
- POEM (Patient Oriented Eczema Score): a practical self-assessed measurement tool for monitoring aspects of atopic eczema that are important to patients in routine clinical practice or in the clinical trial setting<sup>(e)</sup>
- NRS (Numerical Rating Score): a single-item tool for monitoring pruritus (itch) intensity in patients with AD and other dermatological conditions<sup>(f)</sup>

---

### Dermatology unit routinely measures comorbidity outcomes via:

- All patients are screened for comorbidities related to mental health, such as anxiety or depression

**Sources:** (a) EASI for clinical signs: Harmonising Outcome Measures for Eczema (HOME) [Website] <http://www.homeforeczema.org/research/easi-for-clinical-signs.aspx> Accessed 13 March 2019; (b) SCORing Atopic Dermatitis (SCORAD) Calculator (0.9.0). [PDF] <http://scorad.corti.li/>. Accessed 26 Feb 2019; (c) Chopra R, et al. Severity strata for Eczema Area and Severity Index (EASI), modified EASI, Scoring Atopic Dermatitis (SCORAD), objective SCORAD, Atopic Dermatitis Severity Index and body surface area in adolescents and adults with atopic dermatitis. *Br J Dermatol.* 2017;177(5):1316-1321. doi: 10.1111/bjd.15641; (d) Lewis V, et al. 10 Years' Experience of the Dermatology Life Quality Index (DLQI). *J Investig Dermatol Symp Proc.* 2004;9(2):169-80; (e) Charman CR, et al. Translating Patient-Oriented Eczema Measure (POEM) scores into clinical practice by suggesting severity strata derived using anchor-based methods. *Br J Dermatol.* 2013;169(6):1326-1332; (f) Numerical Rating Scale (NRS) [Website] <http://www.pruritussymposium.de/numericalratingscale.html> Accessed 14 Apr 2019

# Advice to other centres



## What advice would you give less specialised centres?



**Objective of advice:** Involvement of the nurse in coordination of care

- **Why?** Atopic dermatitis is a complex disease with multiple related comorbidities that can place a major burden on AD patients. By establishing a nurse coordinator role, AD centres can help patients manoeuvre along the care pathway and ease any problems with referral



**Objective of advice:** Organise resources before the arrival of your first patient

- **Why?** There is a high administrative burden associated with AD, for example, through referral and financial paperwork. If resources are prepared in advance of the patient consultation, this can reduce the time required of staff. In addition, ensuring topical AD treatments are covered fully under the insurance policy can also help ease the burden on patient stress and finances



**Objective of advice:** Establish multidisciplinary teams to help provide patient care

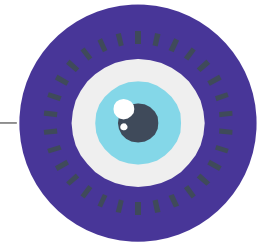
- **Why?** Atopic dermatitis necessitates holistic treatment from multiple specialists and multi-disciplinary teams are often required to successfully treat AD and its associated comorbidities. Facilitating this care through the involvement of various specialists (e.g. pulmonologists, allergists, nutritionists) can help the patient gain access to the care that they require

# Next steps for the centre

## What is next for the centre?

**Objective:** Further development of external referral system

- **What?** Expand the external referral network currently utilised to include more specialists, such as ophthalmologists to manage patients with eye-related comorbidities
- **Why?** The current strategy involves referring the patient back to EPS if the patient has a certain AD comorbidity that cannot be treated by anyone in the existing external referral network (e.g. eye-related comorbidities). By expanding the external network, the centre aims to provide more holistic care to their patients and enhance their own internal knowledge



**Objective:** Development of a routine screening process for AD

- **What?** Establish a systematic process for screening all patients who present at the centre with skin-related conditions
- **Why?** Most patients who visit the centre with skin-related issues believe that they have psoriasis or eczema, yet 25% don't know that they also have atopic dermatitis. An automatic screening process for AD can help ensure that patients receive a faster diagnosis of the condition and access to the necessary treatment sooner



**Objective:** Expansion of clinical trials

- **What?** Increase clinical trials available at the centre to include treatments not currently available for AD in Colombia
- **Why?** As the first clinic in Colombia to provide medical treatment specific to AD, the centre aims to play a pioneering role in providing treatment guidance to other centres. Expanding the provision of clinical trials will support the centre in carrying out this role



# Case studies



CONTENTS



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CENTRE REPORTS

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# Psychological support

## Overview

- The centre provides patients with access to a psychologist and nutritionist who both provide psychological support
- The psychologist looks at the patient's general mental health state, whereas the nutritionist addresses the impact the patient's mental health could be having on their eating habits



Half of our patients have a depression or anxiety diagnosis, so we like to talk to them



*Dermatologist, Cayre Clinical Center*

**Sources:** (a) Lifschitz C. The impact of atopic dermatitis on quality of life. *Ann Nutr Metab* 2015;66(suppl 1):34-40. doi: 10.1159/000370226; (b) Reed B, et al. The burden of atopic dermatitis. *Allergy Asthma Proc.* 2018;39(6):406-410. doi: 10.2500/aap.2018.39.4175; (c) Noh S et al. Comparison of the psychological impacts of asymptomatic and symptomatic cutaneous diseases: vitiligo and atopic dermatitis. *Ann Dermatol.* 2013;25(4):454-61. doi: 10.5021/ad.2013.25.4.454



## What is the rationale?

- AD is a chronic and complex disease which can affect the psychological well-being and quality of life (QoL) of patients<sup>(a)</sup> and their families<sup>(b)</sup>
- Psychological symptoms and AD symptoms have been seen to correlate, with psychological distress worsening as AD symptoms are aggravated (and vice versa)<sup>(a)</sup>
- Psychologist input in the holistic management of AD is important, as patients with severe AD have an increased risk of developing psychological issues<sup>(c)</sup>

## What are the key features of the intervention?

- The centre provides access to psychological care for patients through a psychologist and a nutritionist
- Psychological support is common amongst adolescent patients, who are more worried about the impact that AD can have on their appearance. Patients may be more susceptible to AD-related mental health problems

### *Psychologist consultations*

- Access to a psychologist is provided routinely to all patients at the centre
- During these consultations, the psychologist will record an in-depth history of the patient's mental health and will discuss the symptoms of anxiety and depression with the patient. Further mental health topics related to AD will also be discussed
- Parents are invited to attend the psychologist consultations if the patient is an adolescent

### *Nutritionist consultations*

- The centre also provides access to a nutritionist through external referral if the patient has a suspected eating disorder
- If it is established that the eating disorder is the result of an AD-induced mental health illness, the nutritionist will discuss good eating practices and measures to control the disorder

## What are the desired outcomes?

### **Benefits to patients:**

- Access to nutritional support regarding any eating disorders
- Awareness of what can cause mental health to deteriorate and how this can be avoided

### **Benefits to HCPs:**

- Direct referral pathway from dermatologist to psychologist / nutritionist





# Multi-disciplinary patient education

## Overview

- Patient education is provided through a variety of healthcare professionals (HCPs), who each cover a wide selection of topics
- Education is delivered to the patient via a multitude of mediums

**Sources:** (a) Wollenberg A, et al. Consensus-based European guidelines for treatment of atopic eczema (atopic dermatitis) in adults and children: part II. *J Eur Acad Dermatol Venereol* 2018;32(6):850-878. doi: 10.1111/jdv.14888 (b) Sullivan PB, et al. Parent satisfaction in a nurse led clinic compared with a paediatric gastroenterology clinic for the management of intractable, functional constipation. *Arch Dis Child*. 2006;91(6):499–501. doi:10.1136/adc.2005.087486



## What is the rationale?

- Patient education and its link to supporting treatment compliance is extremely important to delivering effective AD care<sup>(a)</sup>
- Education can be successfully provided through a variety of HCPs in multi-disciplinary teams
- In particular, some studies have shown that nurses have been shown to receive higher patient satisfaction outcomes than doctors<sup>(b)</sup>

## What are the key features of the intervention?

- Patient education is provided throughout the patient care pathway by multiple HCPs:
  - **Dermatologist:** During the first consultation, the patient is educated by the dermatologist on the different treatments available and what might work best for the patient
  - **Nurse:** Patient education is provide by the nurse immediately after the first consultation. Topics covered include information on the disease itself, disease severity, the importance of treatment adherence and how the condition can be managed
  - **Pharmacist:** Once treatment has been agreed, the pharmacist provides education on treatment administration
- The education can be delivered through several mediums:
  - **Face-to-face:** Patient education is primarily delivered 1:1 through face-to-face consultations with HCPs
  - **Patient messaging group:** Patients can join a phone messaging group set up by the centre, which provides patients with daily care reminders and advice for applying treatments
  - **Preferential phone line access:** Patients are provided with a preferential phone line so that they can call the centre and access HCP guidance when needed

## What are the desired outcomes?

### Benefits to patients:

- Access to holistic information from multiple sources regarding AD
- Patients are empowered to self-manage their condition using more resources

### Benefits to HCPs:

- The full team of HCPs at the centre are engaged in educating the patient, thereby sharing the educational responsibility

# Patient-HCP communication

## Overview

- The centre provides patients with fast access to healthcare professionals (HCPs) and specialist information through a variety of communication channels
- Communication channels include access to a preferential phone line and patient messaging groups



Patients have access to a preferential phone line. This means they can get in touch with a nurse straight away if needed

*Dermatologist, Cayre Clinical Center*



## What is the rationale?

- Long waiting times for specialist advice and care can deter patients from seeking and attending appointments<sup>(a)</sup>. Time-limited consultations may also leave HCPs with insufficient time to fully address the concerns and queries that patients may have<sup>(b)</sup>
- Digital forms of communication can provide patients with the option to receive expert advice and ask additional questions from the comfort of their own home, potentially reducing patient waiting times
- In an IBD study, digital forms of communication were shown to be a cost-effective alternative to face-to-face consultations and do not appear to provide an inferior service<sup>(c)</sup>

## What are the key features of the intervention?

- The centre provides patients with multiple communication channels through which they can contact the centre, with links to specific HCPs. These innovative forms of communication are provided throughout the course of the patient's care and can include:
  - **Patient messaging group:** The centre uses patient messaging groups to send round mass reminders to patients regarding the provision of their daily treatment. The groups are also utilised to provide patients with educational resources and tips for good care
  - **Preferential phone line access:** Patients are provided with access to a preferential phone line. Through this, the patient is able to speak to a nurse at the centre and receive advice without needing to visit the centre in person or wait for a face-to-face consultation

## What are the desired outcomes?

### Benefits to patients:

- Fast access to HCP guidance without needing to wait for an appointment
- Provision of additional patient education

### Benefits to HCPs:

- Ability to send treatment reminders to patients

**Sources:** (a) Van Dijk CE, et al. Compliance with referrals to medical specialist care: patient and general practice determinants: a cross-sectional study. *BMC Fam Pract* 2016;17:11; (b) GlobalSkin Position Paper: "Atopic Dermatitis: A Collective Global Voice for Improving Care" February 2018 [PDF] <https://www.semanticscholar.org/paper/GlobalSkin-Position-Paper-Atopic-Dermatitis-%3A-A-for/e08b204478263f64f02a5f1285fd0e59a68ad91a> Accessed 2 April 2019; (c) Akobeng AK, et al. Telephone Consultation as a Substitute for Routine Out-patient Face-to-face Consultation for Children With Inflammatory Bowel Disease: Randomised Controlled Trial and Economic Evaluation. *EBioMedicine*. 2015;2(9):1251–1256. doi:10.1016/j.ebiom.2015.08.011



# King Fahad Medical City

Riyadh, Saudi Arabia

Site visited by KPMG on 25<sup>th</sup> – 26<sup>th</sup> February 2020

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[kpmg.com/uk](https://kpmg.com/uk)



# Summary



## Context

- **Centre type:** Large tertiary hospital located in central Riyadh
- **Catchment area:** Patients are mostly referred from secondary care centres within Riyadh. However, patients may be referred from anywhere within Saudi Arabia
- **Funding:** Public hospital, funded by the Ministry of Health
- **Services:** The centre offers care across a comprehensive range of specialties in addition to dermatology, including a children's hospital, women's hospital, heart centre and cancer centre
- **Patient population:** Paediatric and adult patients with dermatological conditions



## Key strengths in the delivery of AD care

- **Proactive approach to patient education:** The centre has adopted a proactive approach to patient education in order to tackle key issues, such as; fear of certain treatments, importance of patient adherence to medication, and correct application methods of treatment. Education is provided throughout the patient pathway via a variety of channels
- **Strong inter-departmental relationships:** Various measures at KFMC encourage high levels of informal communication throughout the hospital. In turn, this promotes knowledge sharing amongst specialists and facilitates an efficient referrals system
- **Use of technology:** Technology is integral to the treatment provided and patient experience at KFMC. This includes an online check-in service, patient-focused app and usage of electronic patient records



## Key challenges faced in delivery of AD care

- **Health beliefs:** Patients and their carers have certain health beliefs that may impact treatment adherence. For example, some male patients believe that emollients are primarily used by females. In addition, home remedies may be preferred to medical therapies, and certain foods are considered to be the cause of AD and are therefore avoided. Finally, patients are often wary of taking corticosteroids as they perceive them to have severe side effects
- **Lack of patient advocacy:** There is no AD patient advocacy group in Saudi Arabia, meaning that patients often only have their dermatologist as a clear reference point
- **Unnecessary referrals to tertiary care:** The quality of referrals to the centre from primary care physicians is not as high as those from secondary care. This means that patients with mild diseases are often seen at the centre unnecessarily

# Atopic Dermatitis (AD) in Saudi Arabia

## Saudi Arabian healthcare system<sup>(a)</sup>:

Healthcare in Saudi Arabia operates nationally and is funded by the Ministry of Finance through public funds (75%) and out-of-pocket expenditures (25%). Healthcare is viewed as a right but with an increase in the population of foreign nationals (25% of general population), private financial contributions through out-of-pocket spending and private insurance<sup>(b)</sup> are now encouraged. Health services are provided via three main sectors:

- **Ministry of Health (62%):** Focuses on prevention and primary care through a network of hospitals and primary healthcare centres. The country is divided into 20 Healthcare Directories that are autonomous in decision making but typically follow guidelines set out by the Ministry of Health. Each Directory is provided a lump-sum by the Ministry through budgets and payments
- **Other governmental institutions (20%):** Ministry of Health care provision is supplemented by services provided by the Ministry of Defence and Aviation, Saudi Arabian National Guard and Ministry of Interior. Other governmental agencies are responsible for financing particular healthcare services (e.g. Ministry of Education provides immediate care to students)
- **Private facilities (17%):** Employers of expatriates are required to cover aspects of their healthcare coverage. Individuals seeking special requirements and access to services can also opt for independently-funded private services

## There are three organisational levels to the healthcare system<sup>(c)</sup>:

1. Primary healthcare: Basic prevention and health services as well as general health promotion
2. General and community hospitals: Curative and diagnostic services through hospitalisation, minor surgeries, outpatient clinics and emergency departments
3. Central hospitals: Provision of advanced and specialised curative, surgical, diagnostic and rehabilitative services. These centres are also responsible for research and medical training

## Prevalence

- In Saudi Arabia, AD affects 3% of adults (ages 19 – 23)<sup>(d)</sup> and about 13% of children (ages 8 – 12)<sup>(e)</sup>
- Of the Saudi Arabian children with AD, 53.5 % show mild symptoms, 31.6 % show moderate symptoms and 14.9 % show severe symptoms<sup>(h)</sup>



## Care provision: Saudi Arabia

### Location:

- Mild (or well controlled) AD care is typically delivered by primary healthcare centres
- Moderate to severe AD cases are managed in general or central hospitals depending on severity

### Funding:

- Primary care and hospital services are primarily funded by the Ministry of Health. In some cases, patients fund their care privately

## Guidelines and societies:

### Guidelines:

- There are no Saudi-specific guidelines for the treatment and management of AD. Guidelines are typically adopted from European or American guidelines and regional practices<sup>(f, g)</sup>

### Medical society:

- Saudi Society of Dermatology and Dermatologic Surgery

**Sources:** (a) Walston, S., et al. The changing face of healthcare in Saudi Arabia. *Annals of Saudi Medicine*. 2008;28(4):243-250. (b) Alharbi, M.F. Does health financing in Saudi Arabia need a national health accounts framework? *Int J Health Sci* 2018;12(4):72–77 (c) Al Asmri, M., et al. The public healthcare system and primary care services in Saudi Arabia: a system in transition. *Eastern Mediterr Health J*. 2019. doi:10.26719/emhj.19.049. (d) Alqahtani, J. M. Atopy and allergic diseases among Saudi young adults: A cross-sectional study. *Journal of International Medical Research*. 2020; 48(1) (e) Al Frayh AR, et al. Increased prevalence of asthma in Saudi Arabia. *Ann Allergy Asthma Immunol* 2001;86:292–296. (f) Al-Afif, J. et al. Understanding the Burden of Atopic Dermatitis in Africa and the Middle East. *Dermatol Ther (Heidelb)* 2019;9:223–241 (g) Reda AM, et al. A practical algorithm for topical treatment of atopic dermatitis in the Middle East emphasizing the importance of sensitive skin areas. *Journal of Dermatological Treatment*, 2019;30(4):366-373 (h) Alzoliban AA. Impact of atopic dermatitis on the quality of life of Saudi children. *Saudi Med J* 2014;35(4):391-396

# The centre and dermatology division

## The centre



### Type and location

- The King Fahad Medical City is a collection of hospitals located on one site in central Riyadh
- The Main Hospital is one of five tertiary referral centres in Riyadh, that offers a comprehensive range of medical care. Further hospitals are located on-site that provide specific services for children, women, neuroscience, cardiology, cancer care and rehabilitative medicine. There is also a primary care service within the centre



### Population served

- Patients are primarily referred from secondary care hospitals in Riyadh (population ~7 million), however patients can also be referred from any hospital within Saudi Arabia. Staff and their family members are also treated at the hospital

## The dermatology unit



### Service Division

#### Outpatient service

#### Emergency dermatology service



### Hours of availability

Sunday – Thursday: 8am – 5pm

24/7



### No. of patients seen

Approximately 12,872 visits annually (around 2160 are AD paediatric and adult patients)



### Types of patients seen

AD patients must be referred from secondary care with poorly controlled moderate disease, or severe disease. The centre also treats some mild patients who present at the primary care centre within KFMC







### Facilities on-site<sup>(1)</sup>

- 8 general dermatology outpatient clinic rooms
- Surgical day clinic
- Narrowband, broadband and localised UVB
- Laser therapy facilities
- Prick and RAST testing
- Inpatient beds


Note: (1) List of facilities is not exhaustive

# The team

## Core team profile

-  **4** Consultant dermatologists
-  **2** Acting consultant dermatologists
-  **2** Assistant consultant dermatologists
-  **4** Resident doctors
-  **19** Clinic nurses (shared with internal medicine)

## Wider team profile

-  Pulmonologists
-  Immunologists
-  ENT physicians
-  Ophthalmologists
-  Health educators
-  Clinical pharmacists
-  Psychologists



## Governance and processes

### Team meetings:

- *Dermatology teaching (weekly, 120 minutes):*
  - Attended by all dermatology resident doctors and most of the other dermatology doctors. A comorbidity specialist may be invited to give a talk
  - The purpose of the meeting is to educate the resident doctors through clinical updates, discussions surrounding of a disease area, or talking about a specific patient case study
- *Journal club (fortnightly, 90 minutes):*
  - Attended by all dermatology doctors
  - The purpose of the meeting is to discuss updates to guidelines or advancements in clinical evidence

### Patient records:

- *Electronic patient records (EHR):*
  - Accessible by all specialists and primary care physicians within the centre

*Note: Please see page 763 for further details about the wider team*



# Overview of AD patient pathway

## Awareness and Presentation

Symptom presentation



- Patients present to their Primary Care Physician (PCP) with AD symptoms (e.g. itching or dryness of the skin). Waiting times are typically very short, with patients seen the same day. The physician will assess and refer to secondary care if required
- Patients can also directly attend a dermatology appointment at a secondary care hospital without a formal referral, where they will be diagnosed

*Note: The team manages staff members and their families with AD of any severity. Aside from these individuals, all patients should be referred from secondary care when they arrive at KPMC for tertiary care*

## Diagnosis and Referral

In tertiary care



- All paediatric and adult AD patients should be referred from secondary care to KPMC for tertiary care. Some may be referred by a PCP within the centre
- An initial appointment takes place with a consultant dermatologist, which lasts around 30 minutes
- The dermatologist will perform an initial examination and assessment of the patient and discuss their symptoms, medical history and any previous / current treatments. Symptoms of comorbidities are also explored at the initial appointment
- Although a clinical diagnosis will already have been made in secondary care, this is validated at the first appointment for tertiary care at KPMC
- EASI or SCORAD (either are acceptable) are used to assess disease severity. Laboratory tests completed in secondary care may also be repeated

## Treatment and Management

Medical management



- The team manage all patients with AD, from mild to severe. Patients from secondary care will have moderate to severe disease
- The patient's treatment plan must be approved by their consultant
- If approved, the pharmacist is then responsible for dispensing the medicines
- Patients requiring systemic therapy have their clinical history taken to explore for tuberculosis (TB) symptoms, plus a chest x-ray, and TB Interferon Gamma Release Assay testing
- The dermatologist can refer to other specialties for the management of comorbidities via a simple electronic referral system
- If facilities aren't available at the centre to provide treatment, patients may be referred to another tertiary care centre that can provide the required access to a specialist

Non-medical management



- The initial appointment is heavily focused on patient education, with the need for rigorous emollient application reiterated
- The patient may be referred to a health educator for support with this
- Patients may be offered phototherapy sessions (with narrowband or broadband UVB)
- Dermatologists can refer to psychologists within the centre if required
- If AD is well controlled, the patient is referred back to secondary or primary care

## Follow-up

Monitoring of chronic disease / flare up



- Baseline EASI or SCORAD scores are recorded at initial assessment, and monitored throughout follow-up
- DLQI scores are also used to guide treatment effectiveness
- Follow-up appointments typically take 10-30 minutes depending on the level of symptom control
- A new patient with severe AD will typically be followed up 2-3 weeks after an initial appointment
- If mild AD is well controlled, the centre will cease actively managing the patient's condition
- Patients with moderate to severe AD tend to remain under the care of the centre. This is reviewed every six months

# Roles of the wider team

## Health educator

**Patient type:** Predominantly patients that have been initiated on new therapies

**Referral:** Referred by dermatologist

**Consultations:** Assess the patient's understanding of the disease before educating them on the importance of treatment and how to practically administer therapies, e.g. injectable drugs

**Timing:** Consultations vary in length depending on patient requirements. Typically 10-15 minutes

*Note: The health educator is allocated to the internal medicine department and does not exclusively see dermatology patients*

## Other specialists

**Patient type:** Patients who suffer from comorbidities (e.g. bronchial asthma, chronic rhinosinusitis with nasal polyps, food allergy, allergic rhinitis)

**Referral:** Referred by dermatologist to associated specialty

**Consultations:** Perform a review and assess the patient's comorbidity symptoms

**Timing:** Consultations vary in length depending on patient requirements

*Note: Other specialists include pulmonologists, general paediatricians and allergologists*



## Clinical pharmacist

**Patient type:** Patients that have been initiated on a new systemic therapy

**Referral:** Referred by dermatologist

**Consultations:** Perform a review of the patient's medication and medical history to check for any drug-drug interactions or contraindications

**Timing:** Consultations vary in length depending on patient requirements. Typically 10-15 minutes

# Overview of interventions in place for AD

## Awareness and Presentation



Symptom presentation

- **Primary Care Professional (PCP) education:** The centre provides education to local PCPs to improve their understanding of AD, reduce inaccurate referrals and allow for greater management of mild AD in primary care
- **Departmental meetings:** The full clinical team (including residents) meets each Thursday morning to discuss complex cases, management of co-morbidities, and recently published journal articles

## Diagnosis and Referral



In tertiary care

- **Same day diagnostic tests:** Patients can have investigations on the day that they are requested in clinic, including hepatitis and TB screens and chest x-rays
- **Informal network of leading centres:** Five tertiary hospitals in Riyadh regularly communicate to understand the services each hospital provides. If one centre does not have the facilities to provide a specific therapy, AD patients can easily be referred to another centre for this treatment

## Treatment and Management



Medical management

- **Clinical pharmacist in patient facing role:** Patients that are started on systemic therapies are reviewed by a pharmacist, who will check for drug-drug interactions and contraindications
- **Close relationships with co-morbidity specialists:** Dermatologists have close relationships with colleagues who manage comorbidities (e.g. Pulmonology, ENT, Immunology). This speeds up referral and is supported by an electronic referral system
- **Co-location of key resources:** The dermatology clinic is co-located on the 7th floor of the hospital with a pharmacy (which specialises in dermatological products) and phlebotomy. This allows for quick referral and an improved patient experience

See pg. 769 for case study



Non-medical management

- **Emphasis on patient education:** Initial appointments are heavily focused on ensuring that patients have a good understanding of their disease and the importance of adequate self-care
- **Health educator integrated into team:** A designated Healthcare Professional sees patients following their first appointment to ensure that patients can administer and store medications correctly
- **Continuity of care:** Patients will be seen by the same consultant each time they attend the clinic. This is believed to boost adherence and improve patient engagement

See pg. 770 for case study

## Follow-up



Monitoring of chronic disease/flare up

- **Use of technology:** The centre has integrated several technological measures to improve patient experience, including a phone app and an electronic appointment check-in system
- **Monitoring patient quality of care:** physicians make use of objective (e.g. SCORAD) and patient reported (e.g. DLQI) measures to inform treatment decisions and runs an annual patient satisfaction survey
- **Open access policy for patients:** Patients have the option to organise urgent appointments at the clinic in the event of a flare up

See pg. 771 for case study

See pg. 772 for case study

### Key:

Case study available



# Monitoring AD patients and comorbidities

## The dermatology unit employs a number of measures for monitoring AD and associated comorbidities

### Objective measures (AD):

- To monitor clinical trial patients and their disease, the centre utilises:
  - EASI (Eczema Area and Severity Index): validated scoring system that grades the physical signs of atopic dermatitis<sup>(a)</sup>
  - SCORAD (SCORing Atopic Dermatitis): to assess AD disease severity and monitor patient progress<sup>(b)</sup>

### Patient-reported outcomes:

- DLQI (Dermatology Quality of Life Index): dermatology related quality of life questionnaire<sup>(c)</sup>

**Sources:** (a) HOME for eczema.org. EASI for clinical signs. [website] <http://www.homeforeczema.org/research/easi-for-clinical-signs.aspx> Accessed 1 Mar 2019 (b) SCORing Atopic Dermatitis (SCORAD) Calculator (0.9.0) [website] <http://scorad.corti.li/> Accessed 26 Feb 2019 (c) Lewis V, et al. 10 Years Experience of the Dermatology Life Quality Index (DLQI). *J Investig Dermatol Symp Proc* 2004;9:169 –180

# Advice to other centres



## What advice would you give less specialised centres?



### Objective of advice: Ensure a heavy emphasis on patient education

- **Why?** A lack of understanding on behalf of the patient can lead to poor treatment adherence, thereby resulting in sub-optimal clinical outcomes. Poor adherence may be due to false perceptions regarding side effects of therapy, alleviated symptoms leading to a reduction in medicine administration, or a lack of regular routine. Education to improve patient adherence should therefore be fundamental to patient consultations and tailored to individual patient need. The education process can also extend to the family of younger patients, with an emphasis put on the consequences of mismanagement



### Objective of advice: Hold specific AD clinics

- **Why?** As AD can be a complex and multifaceted condition to manage, the expertise of several specialties is often required. By holding clinics that focus exclusively on AD, a diverse range of healthcare professionals can see patients in one location. This helps to remove delays caused by referrals, improve patient access to holistic care, and enhance the quality of AD care provided by the centre

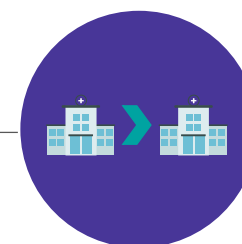
# Next steps for the centre



## What is next for the centre?

### Objective: Standardise care pathways

- **What?** The centre hopes to incorporate protocols based on clinical guidelines that will standardise the care received by patients
- **Why?** Currently, two different objective measures are used by physicians to measure disease severity and control. These measures are SCORing Atopic Dermatitis (SCORAD) and the Eczema Area and Severity Index (EASI). Although both measures are based on internationally recognised scoring systems, it is leaving patients with similar clinical problems liable to receiving different treatments. By agreeing on a standardised care protocol and disseminating this to the team however, it is anticipated that all patients would receive the same care regardless of which physician they were treated by



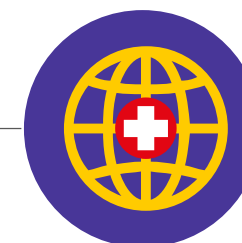
### Objective: Integrate new computer software

- **What?** The centre will be using a new programme to store patient records from December 2020
- **Why?** The current patient record system is entirely digital, however sections of patient notes may be missing or disjointed, and objective scores to monitor disease progression must be entered manually. By having input towards the design of a bespoke computer programme that is tailored to the dermatology department's needs, patient records will be presented in a more logical and accessible manner. Providing access to more complete patient medical histories and facilitating the ability to track quantitative patient outcomes will ultimately lead to a higher quality of clinical decision making



### Objective: Form predefined hospital "clusters"

- **What?** A network will be formed with four secondary care hospitals and 30 primary care practices
- **Why?** There will be a clear referral route for patients transferring between each level of care. This should create accountability between hospitals, and also form a network through which physicians can educate their peers. It is hoped that the quality of referrals to tertiary care will consequently be improved



# Case studies



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# Co-location of key resources

## Overview

- There is a dermatology unit that runs daily on the 7<sup>th</sup> floor of the outpatient department of the main hospital. This is co-located with a pharmacy, a facility for taking blood and a phototherapy room
- By doing this, it provides quick access for physicians and patients, therefore making the patient experience of using the clinic as simple as possible



## What is the rationale?

- Inconvenient access to treatment is a key driver behind poor patient adherence to treatment<sup>(a)</sup> and sub-optimal health outcomes<sup>(b)</sup>
- Centralising resources however can make treatment more convenient to access. In turn, this can increase adherence and enhance patient outcomes

## What are the key features of the intervention?

- The dermatology unit on the 7<sup>th</sup> floor has a welcome desk, self-check in, pharmacy, phototherapy room, and laboratory all within close proximity to one another
- The pharmacy dispenses the medicine for the unit. Staff within the pharmacy are also able to provide additional patient education
- Phototherapy can be initiated on the same day as consultation if required. This helps facilitate fast access to the treatment
- The laboratory can conduct blood tests, with the samples being performed within the same day. This reduces patient waiting times
- The shorter waiting times are supported by the use of technology, as self-registration lets patients pick their appointment time. The system then texts the patient at the time of their appointment so that they can head to a different part of the hospital if needed

## What are the outcomes so far?

### Benefits to patients:

- Seamless patient pathway through centralised access to resources
- Use of technology in the patient pathway that can facilitate easy access to different services
- Provision of education about the condition and the various treatments available

### Benefits to HCPs:

- Easy access to expertise (e.g. a clinical pharmacist)
- Fast turnaround of blood work due to the close proximity of the testing facilities

**Sources:** (a) Patel N, et al. Adherence in Atopic Dermatitis. *Adv Exp Med Biol.* 2017;1027:139-159. (b) Choi J, et al. Adherence to Topical Therapies for the Treatment of Psoriasis: Surveys of Physicians and Patients. *Ann Dermatol.* 2017;29(5):559-564

# Emphasis on patient education

## Overview

- Education is a core feature of the services provided by the centre
- Patients are kept informed at each stage of their treatments and during the consultations about their health. This education covers what they can do to ease their symptoms and minimise future flare-ups
- The education provided is relayed by consultants and specialist health educators

**Sources:** (a) Bass AM, et al. Interventions to Increase Treatment Adherence in Pediatric Atopic Dermatitis: A Systematic Review *J Clin Med.* 2015;4(2):231-242 (b) Patel N, et al. Adherence in Atopic Dermatitis. *Adv Exp Med Biol.* 2017;1027:139-159 (c) Hachem M, et al. Topical corticosteroids phobia in parents of pediatric patients with atopic dermatitis: a multicentre survey. *Ital J Pediatr* 2017;43:22 (d) KPMG interviews (e) Shin JY, et al. An Educational Program that Contributes to Improved Patient and Parental Understanding of Atopic Dermatitis. *Ann Dermatol* 2014;26(1):66-72



## What is the rationale?

- Patients often have anxiety surrounding certain treatments, of which can result in low adherence<sup>(a)</sup> and poor outcomes<sup>(b)</sup>
- Examples of anxiety surrounding treatments include patient fear of using topical corticosteroids<sup>(c)</sup> and the belief that emollients should be used by women and not men<sup>(d)</sup>
- Providing patient education however can address these anxieties, and lead to better outcomes<sup>(e)</sup>

## What are the key features of the intervention?

- Initial appointments are heavily focused on patient education and ensure an understanding of:
  - 1) The implications of AD
  - 2) The importance of patient ownership, responsibility and adherence
  - 3) How to correctly apply medications
- Education is always delivered by a consultant in order to provide the patient with the necessary technical knowledge and support. The educational material is also tailored to meet the individual's need and disease severity
- Brochures are given to patients explaining how to manage AD. These highlight the importance of treatment, instructions on how to apply medications, and an easy reference point for lifestyle advice (e.g. what clothing to wear, hygiene guidance)
- There is a health educator integrated into the team who explains to patients in more detail how to take medication correctly and, if appropriate, how to store it. They also reiterate the need to adhere to medication

## What are the outcomes so far?

### Benefits to patients:

- Engagement with physicians and medical condition
- Patient satisfaction with healthcare experience

### Benefits to HCPs:

- Patients are able to self-manage their condition

## What's next?

- A paediatric dermatologist, who is currently training in Canada, is due to join the team in three months. They will be able to give additional advice to parents of patients with severe AD

# Use of technology

## Overview

- Technology is integral to KFMC and the patient experience
- Examples of the centre's use of technology include a digital check-in system, an interactive app for patients, and digitalisation of patient records
- There are further plans to update the electronic record system used by KFMC and tailor it to the centre's exact needs

**Sources:** (a) Patel N, et al. Adherence in Atopic Dermatitis. *Adv Exp Med Biol.* 2017;1027:139-159 (b) Choi J, et al. Adherence to Topical Therapies for the Treatment of Psoriasis: Surveys of Physicians and Patients. *Ann Dermatol.* 2017;29(5):559-564 (c) Rosen T. Dermatology Roundup: The Latest Tips, Techniques and Technologies for Busy Clinicians. *J Clin Aesthet Dermatol.* 2017;10(3):26-31



## What is the rationale?

- Inconvenient access to medical resources is a prominent driver behind low treatment adherence rates<sup>(a)</sup>, of which can lead to negative patient outcomes<sup>(b)</sup>
- The effective utilisation of technology however can hasten patient access to information and care, thereby improving treatment convenience and overall patient care<sup>(c)</sup>

## What are the key features of the intervention?

- Digital check-in system in outpatients (operational for one year)
  - Patients attend with a slip containing a barcode that they retain from their last appointment and scan this in a machine
  - Physicians can see on their computer when patients have checked in and how long they have been waiting
  - When the patient's appointment is due, an SMS is sent to their phone. This means that the patient can be notified of their appointment irrespective of where they are in the hospital (e.g. café)
  - **Benefits:** Improves patient convenience, eases capacity management, and maintains patient confidentiality
- KFMC app (operational for two years)
  - Enables the patient to book appointments, check medications, view lab results and see their appointment history
  - **Benefits:** Increases patient engagement and ownership of disease. It also allows for an easier transition if the patient sees other physicians
- Electronic patient records
  - All records (including hospital records not integrated with primary or secondary care records) are digitised and consolidated all records in one place
  - **Benefits:** Access to a comprehensive medical record facilitates better clinical decision making, faster access to information and easier referrals to comorbidity specialist

## What's next?

- An updated electronic record system that is tailored to the hospital's needs, through the team contributing towards its design
- The team will be able to input and track various measures (e.g. quality of life). These measures will be available to be viewed graphically and correlated against treatment or against each other



# Monitoring patient quality of care

## Overview

- The centre uses various measures to track and quantify the health of patients, including:
  - SCORing Atopic Dermatitis (SCORAD) / Eczema Area and Severity Index (EASI) for objective measurement of the condition
  - Dermatology Life Quality Index (DLQI) for measurement of Quality of Life (QoL)
  - Patient satisfaction survey for service improvements

**Sources:** (a) Johnson B, et al. Treatment-resistant atopic dermatitis: challenges and solutions. *Clin Cosmet Investig Dermatol* 2019;12:181-192 (b) Barrett A, et al. Patient-Reported Outcome Measures in Atopic Dermatitis and Chronic Hand Eczema in Adults



## What is the rationale?

- AD is a complex disease with multiple symptoms and comorbidities that can be challenging to assess and monitor<sup>(a)</sup>
- Multiple objective measures and patient reported outcomes however can be used to track the development of AD and patient QoL, thereby assisting with treatment of the condition<sup>(b)</sup>
- Close monitoring of these measures has been reported as being particularly effective in bringing about positive patient outcomes<sup>(a)</sup>

## What are the key features of the intervention?

- KFMC uses various objective measures to assess the severity of AD, including SCORAD and EASI. These tests are conducted at every appointment
- The centre uses DLQI to assess patient QoL. This test is carried out in the waiting room before every appointment
- All tests are fed into a monitoring process. For example, if severity of the condition is not high but is having a disproportionate impact on patient QoL, then a more powerful treatment option might be considered
- Changes in patient response is tracked over time and is considered a key metric for the centre. The new computer system that is currently being implemented will increase the ease of comparing the results between patients
- KFMC also conducts an annual survey of patient satisfaction. This comprises 10 questions and takes two minutes to complete. This is used to monitor quality of service provision and in turn implement improvements. For example, the centre has started providing education in the waiting room in response to patient feedback
- Ultimately, KFMC aspires to be the benchmark for AD quality of care in the Kingdom through the effective utilisation of these measures in its provision of AD care

## What are the outcomes so far?

### Benefits to patients:

- Clear understanding provided of health levels and disease severity through a numerical metric

### Benefits to HCPs:

- Easy tracking of outcomes
- Support provided to HCPs with decisions regarding diagnosis and treatment

## What's next?

- Standardisation of measures used across different consultants
- Automatic tracking using new computer software

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