

GETTING UNDER THE  
SKIN OF ADULT  
SEVERE ECZEMA

# SEEING **RED**

This report was written and funded by Sanofi Genzyme, working in collaboration with Allergy UK. The content was approved by Allergy UK and reviewed by Sanofi Genzyme to ensure compliance with the ABPI Code of Practice.

Date of preparation:  
April 2017  
Job Bag Code:  
SAGB.SA.17.04.0413

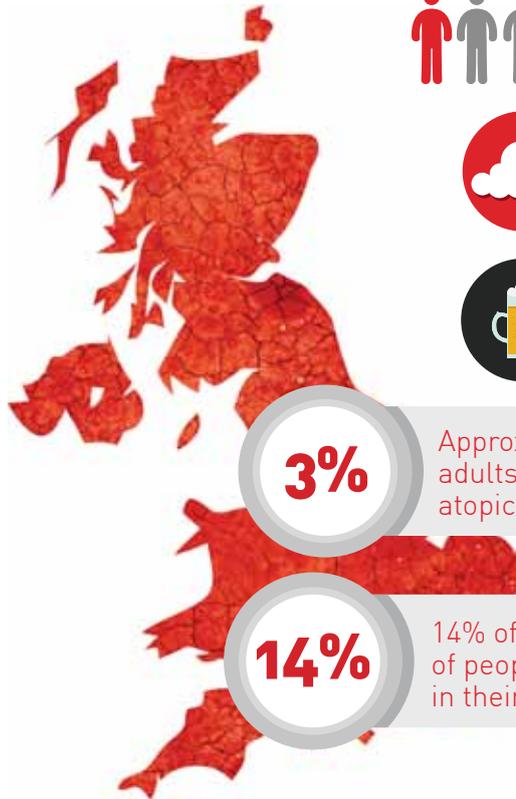
# CONTENTS

---

GETTING UNDER THE SKIN OF ADULT SEVERE ECZEMA .....	3
FOREWORD .....	4
EXECUTIVE SUMMARY .....	5
WHAT IS SEVERE ECZEMA? .....	7
THE IMPACT ON PEOPLE WITH SEVERE ECZEMA .....	8
THE BURDEN ON THE NHS .....	9
THE BURDEN ON THE WIDER ECONOMY .....	10
NEED TO PRIORITISE SEVERE ECZEMA .....	11
WHAT THIS MEANS FOR THE TREATMENT AND MANAGEMENT OF SEVERE ECZEMA .....	12
CALLS TO ACTION .....	16

# GETTING UNDER THE SKIN OF ADULT SEVERE ECZEMA

A survey of patients with severe eczema found that...



Nearly **1/4** missed more than 6 days of work per year due to their condition, whilst approximately 15% missed 16 or more days<sup>1</sup>



**Over 70%** reported feeling depressed as a result of their condition<sup>1</sup>



**1 in 10** consume more alcohol when their eczema is at its worst<sup>1</sup>

**3%**

Approximately 1.5 million adults in the UK have atopic dermatitis<sup>2,3</sup>

**14%**

14% of CCGs know the number of people with atopic dermatitis in their area<sup>4</sup>

**86%**

said that the management of the condition impacts their day-to-day activities<sup>1</sup>

**73%** stated that their social life is impacted<sup>1</sup>



**10%** spent over 30 days a year managing their eczema e.g. by applying cream<sup>1</sup>

**58%** said their disease impacts their personal relationships<sup>1</sup>



**7 in 10** said that their sleeping habits are affected<sup>1</sup>

Despite this...

Around **30%** of respondents had to wait 4-7 months before being seen after referral<sup>1</sup>



**1 in 10** had to wait more than 8 months<sup>1</sup>

And an FOI found that...

**17%** of NHS Trusts have standards to support healthcare professionals to deliver psychodermatological care<sup>4</sup>

**87%** of CCGs do not have a commissioning policy on severe eczema<sup>4</sup>

Allergy UK ran this survey of patients with severe eczema from 15th November 2016 until Friday 9th December 2016. The number of respondents to the survey was 305. Not all respondents gave an answer to every question. The project was funded by Sanofi Genzyme, who had no editorial control over the content or the outputs from the survey.

A Freedom of Information request was sent to 153 NHS Trusts and 209 Clinical Commissioning Groups in June 2016 regarding the management of dermatology services broadly and atopic dermatitis specifically. Results were collated between August and September 2016. The work was funded by Sanofi Genzyme. Sanofi Genzyme holds the data on file.

# FOREWORD

---

The Patient Experience Research summarised in this Report presents powerful evidence on a topic that is neither well recognised nor properly understood. While eczema may be widely regarded as a relatively minor skin condition, the fact is that severe eczema can have a devastating effect on the quality of life of people with the condition.

For anyone who has never experienced this condition, it can be difficult to imagine how constant itching, cracked, infected and bleeding skin, pain that makes it difficult to move, and constant sleep disturbance impacts on a person's life. The testimonies in this Report are incredibly powerful in describing the depression, lack of self-esteem, exhaustion, embarrassment and anxiety that make many of the usual day to day aspects of life, such as holding down a job or going out on social occasions, difficult and sometimes even impossible. This Report also examines the knock-on socio-economic burden of eczema on the NHS and the wider community.

While the personal burden of atopic dermatitis is carried by around 1.5 million people in the UK<sup>2,3</sup> the astonishing fact is that there are no national guidelines or quality standard for the treatment and management of severe atopic eczema in adults in England, Wales and Northern Ireland, so it is not prioritised by the NHS or policy makers. Whilst a guideline on the condition does exist in Scotland, it was published in March 2011.<sup>5</sup>

Allergy UK is a patient organisation that provides support services across the breadth of allergic disease. In 2017 our focus and the topic for our Allergy Awareness Week is 'improving the skin barrier' in atopic (allergic) eczema, so we welcome this initiative at this time.

We look forward to playing our part in the Steering Group – Building Severe Eczema Services for the Future – which will take this forward, developing a clear action plan to address the challenges faced by the NHS in the management of severe eczema to improve the lives of people with this debilitating condition.



A handwritten signature in black ink that reads "Carla Jones". The signature is fluid and cursive, with the first letters of the first and last names being capitalized and prominent.

**Carla Jones**  
CEO  
Allergy UK

# EXECUTIVE SUMMARY

Severe eczema, also known as atopic dermatitis (AD) and atopic eczema, is a chronic inflammatory autoimmune disease, where the skin barrier can be defective, leading to loss of function which means allergens can sensitise through the skin. It is characterised by itchy, non-contagious, inflamed skin that can be present on any part of the body. Despite affecting approximately 1.5 million adults (3%) in the UK<sup>2,3</sup>, it is significantly under prioritised by policy makers and the NHS. This has led to significant challenges in the diagnosis, treatment and management of the condition in adults. This report seeks to raise awareness of the condition and to highlight the significant burden it has on patients, the NHS and the wider UK economy.

“ I’m constantly physically and mentally exhausted. I have blood and skin in my bed every morning, skin coming off in my clothing, and have to cover myself in emollients etc... My children don’t want to be near me when I’m sticky.

Patient with severe eczema<sup>1</sup> ”

## IMPACT OF PEOPLE WITH SEVERE ECZEMA

In addition to the visual and physical issues, severe eczema can have a significant impact on the quality of life of people with this condition. For example, nearly 10% of respondents to an Allergy UK survey of patients with eczema spent more than 30 days a year managing their condition e.g. by applying cream<sup>1</sup>. The survey also unearthed the significant psychological, social and emotional impact that many people with severe eczema experience on a daily basis. Indeed, over 80% of respondents said their mood is affected by their eczema, whilst more than 70% said they felt depressed and 6 in 10 said they want to stay indoors because of their eczema.<sup>1</sup>

## BURDEN ON THE NHS

The condition also places additional financial burden on the NHS. Skin diseases alone account for around 13 million GP consultations<sup>6</sup> and 717,000 new referrals to secondary care each year<sup>7</sup>. The survey found that the majority of eczema patients see healthcare professionals regularly regarding their eczema, with nearly 70% visiting their GP, practice nurse, allergy or dermatology team more than twice a year and more than 40% doing so more than four times per year.

“ Life is passing by and I’m being prevented from achieving my potential because of this condition...I have been hampered academically and in career terms by something so overwhelming but so misunderstood by most people. It’s a living hell and the prospect of death is the only thing that really soothes me when it’s really bad.

Patient with severe eczema<sup>1</sup> ”

## BURDEN ON THE WIDER ECONOMY

Long-term skin conditions, such as severe eczema, also have an impact on the wider economy, particularly in relation to employment. Over 46% of respondents to Allergy UK’s survey stated that they had been forced to take days off of work in the last year due to their eczema: nearly a quarter missed more than six days of work per year, while nearly 15% missed 16 days or more<sup>1</sup>.

## KEY CHALLENGES

Despite the significant burden of the disease on patients, the NHS and the UK economy, severe eczema is evidently under-prioritised. At present, for example, there are no specific indicators or incentives for dermatology and no national guidelines or quality standards in England, Wales and Northern Ireland for severe eczema in adults. This makes prioritisation by healthcare professionals and commissioners a challenge. A freedom of information (FOI) request to Clinical Commissioning Groups and NHS Trusts in England found that only 3% of CCGs had a commissioning policy on atopic dermatitis.<sup>4</sup>

This under prioritisation has led to a number of challenges in the treatment and management of severe eczema in England, Wales and Northern Ireland. There exists:

- Variable knowledge of skin conditions in primary care due to workload pressures and poor undergraduate and postgraduate training.
- An under-provision of consultant dermatologists in the UK, with just one consultant to every 130,000 people in the UK.<sup>6</sup>
- A lack of national guidelines or quality standards that has led to patients receiving sub-optimal treatment and delays in diagnosis, with almost one in ten survey respondents stating that they were forced to attend more than ten primary care appointments before being diagnosed.
- Lengthy waiting times, with more than 60% of patients who responded to the patient survey being forced to wait between one and three months for a secondary care appointment after being referred.
- Variable access to psychological care and support, with only 17% of NHS Trusts supporting healthcare professionals to deliver psychodermatological care with standards or through the use of national guidelines.<sup>4</sup>

## CALLS TO ACTION



**Urgently address the delay in recognition, diagnosis and management of severe eczema in adults by improving the education and training of front line healthcare professionals.**

**Establish guidelines across the UK for the diagnosis, management and treatment of severe eczema in adults, including a nationally standardised scoring tool.**

**Facilitate a care pathway with appropriate coding and funding for people with adult severe eczema to get the appropriate treatment and care through policy changes.**

# WHAT IS SEVERE ECZEMA?

Severe eczema, also known as atopic dermatitis (AD) and atopic eczema, is a chronic inflammatory autoimmune disease where the skin barrier can be defective, leading to loss of function which means allergens can sensitise through the skin. It is characterised by itchy, non-contagious, inflamed skin that can be present on any part of the body.<sup>8</sup>

It is estimated that approximately 1.5 million (3%) adults in the UK have atopic dermatitis, many of whom have a more chronic and severe form.<sup>2,3</sup> Some may have co-existence of other allergic disease, such as food allergy.<sup>9</sup> Despite the prevalence of the disease, information on atopic dermatitis is not routinely held by Clinical Commissioning Groups (CCGs), the local NHS bodies responsible for planning and commissioning healthcare services. Indeed, in 2016 only 14% of CCGs confirmed that they hold data on the prevalence of atopic dermatitis in their area, which means that an exact figure on the number of adults with the disease in the country is not currently available.<sup>4\*</sup>

“ It’s mentally exhausting being itchy all the time and having people tell you not to scratch. It makes me feel disgusting when people comment on my skin... I feel like I’m defined by my eczema now, not by who I am as a person. ”

— Patient with severe eczema<sup>1</sup>

## THE FACTS

Eczema flare ups are fuelled by a breakdown in proper regulation of the immune system,<sup>10</sup> which can lead to changes in the upper layer of the skin, such as redness, blistering, oozing, crusting, scaling, thickening and pigmentation.<sup>11</sup> As a result, the skin’s barrier can become weakened and increase a person’s susceptibility to environmental triggers, such as dust and pollen. A genetic disposition to allergy can increase the likelihood of eczema being severe.<sup>12</sup>

The main symptom of severe eczema is extreme and persistent itching and therefore skin affected by the disease often gets sore and broken from scratching. Once the skin becomes broken from scratching, infections can set in which can cause even more discomfort.<sup>13</sup> Those with the disease typically experience cycles of flare ups and remission.<sup>13</sup> People with eczema also often experience a range of challenges as a result of the disease, including sleep disturbance, as well as challenges which can affect their mental and social wellbeing.<sup>14</sup>

The disease usually develops in the first weeks or months of life, although it can also develop in adulthood.<sup>11</sup> Whilst some people ‘outgrow’ the disease a number of adults continue to experience symptoms for life.<sup>11</sup>

*\*A Freedom of Information request was sent to 153 NHS Trusts and 209 Clinical Commissioning Groups in June 2016 regarding the management of dermatology services broadly and atopic dermatitis specifically. Results were collated between August and September 2016. The work was funded by Sanofi Genzyme. Sanofi Genzyme holds the data on file.*

# THE IMPACT ON PEOPLE WITH SEVERE ECZEMA

The impact of the disease can affect every aspect of a person's life. The persistent itch during a flare up – which can occur several times a month in some cases<sup>15</sup> – can be extremely difficult for people to manage. During flare ups, skin can become infected from scratching and this can manifest in the following ways:<sup>15</sup>

- eczema getting a lot worse;
- fluid oozing from the skin;
- a yellow crust on the skin surface or small yellowish-white spots appearing in the eczema;
- the skin becoming swollen and sore; and,
- a high temperature (fever) and generally feeling unwell.

“Several GPs have repeatedly refused to refer me despite their fails attempts to control it [eczema]. They say there is nothing a specialist can do that they can't.”

Patient with severe eczema<sup>1</sup>

As a condition that can present on any part of the body, these symptoms of infections, as well as the inflamed and dry skin that are a symptom of eczema itself, can be extremely difficult for people to deal with – both physically due to the pain and discomfort, as well as psychologically, socially and emotionally. Severe eczema can be painful and itchy, as well as affecting a person's ability to sleep, concentrate, their personal relationships, their confidence to socialise and their careers. This is not widely understood in society, where eczema is often viewed as a purely physical condition. Many patients express feelings of frustration, embarrassment and anger about their appearance.<sup>16</sup>

“It's horrible because it weeps so everything you touch leaves a mark and people shy away from touching you like you will contaminate them too”

Patient with severe eczema<sup>1</sup>

In November and December 2016, Allergy UK undertook a survey of adults who have severe eczema.\* The results of the survey found that when eczema is at its worst:<sup>1</sup>

- **82%** of respondents said their mood is affected
- More than **70%** of respondents said they felt depressed
- It can have a significant impact on a person's self-esteem, with **73%** of respondents reporting difficulties
- **58%** said that it impacts on their personal relationships
- **7 in 10** respondents said that their sleeping habits were affected by the condition
- **73%** of respondents stated that their social life is impacted by the condition, with **6 in 10** stating that it made them want to stay indoors
- **One third** of respondents said that their eczema makes them eat unhealthy food options, whilst **one in ten** said it made them consume more alcohol

\*Allergy UK ran this survey of patients with severe eczema from 15th November 2016 until Friday 9th December 2016. The number of respondents to the survey was 305. The project was funded by Sanofi Genzyme, who had no editorial control over the content or the outputs from the survey.

“ My eczema is all over my body but mainly my face which flares often. I don't like going anywhere or being around people who don't know why my face is bright red and scabby. I have no self-esteem or confidence. It affects my relationship as I feel I'm not good enough even though we've been together 10 years. ”

Patient with severe eczema<sup>1</sup>

The process of managing severe eczema can also have an impact on a person's day-to-day life. Some patients need to have a number of eczema-related hospital and GP appointments, which can be inconvenient.

- 86% of respondents to Allergy UK's patient survey stated that the management of the condition impacts on their day-to-day activities.<sup>1</sup>
- Nearly 10% of respondents reported spending more than two hours a day managing their condition, such as applying cream. That represents over 30 days a year spent by patients applying creams to manage severe eczema.<sup>1</sup>

“ I have had significant bouts of depression ”

Patient with severe eczema<sup>1</sup>

## THE BURDEN ON THE NHS

**Severe eczema places additional financial burden on the NHS: the cost to the NHS in England and Wales in 2005/6 was £1.8 billion.<sup>17</sup>**

Skin diseases are some of the most common conditions that primary healthcare professionals manage, accounting for around 13 million GP consultations a year<sup>6</sup>. This is estimated to cost the NHS up to £585 million per year in appointments alone<sup>18</sup>. It is estimated that 15-20% of GP workload involves skin disease and, at any time, 23%-33% of the population are affected by skin diseases that would benefit from medical care.<sup>6,19</sup>



There are 717,000 new referrals to secondary care for skin conditions each year.<sup>7</sup> More people are referred to specialists for skin conditions than heart disease, yet 21% of referrals to secondary care could have been treated in a primary care setting, which could be needlessly costing the NHS up to £29 million a year.<sup>20</sup>

Only **14%** CCGs have information on the prevalence of atopic dermatitis in their respective areas<sup>4</sup>

“ It makes me feel very low and the pain can become so bad it makes me cry ”

Patient with severe eczema<sup>1</sup>



Research has found that most NHS Trusts in England do not monitor or track data on outpatient appointments for adult patients with diagnosed or suspected Atopic Dermatitis.<sup>4</sup> Whilst some Trusts do collect outpatient appointment data for skin conditions, it is not collected in a way in which it can be broken down further by individual skin condition.<sup>4</sup> This makes it difficult to understand the true burden of severe eczema on secondary care services. Without an understanding of the true burden, it could mean that appropriate services are not being commissioned.

The majority of eczema patients see healthcare professionals regularly regarding their eczema. Nearly 70% visit their GP, practice nurse, allergy or dermatology team more than twice a year, whilst more than 40% do so more than four times per year.<sup>1</sup> For some patients, appointments are a particularly frequent occurrence, with around one in five reporting that they see a health professional more than nine times each year about their eczema.<sup>1</sup>

“ It is so, so much better now that I have regular contact with a dermatologist - before I felt so alone with it. ”

Patient with severe eczema<sup>1</sup>

“ Everything I do is an extra struggle. I get very down and feel nobody understands at all. My relationship with my husband has massively suffered and whilst I haven't taken many days off sick I often struggle with doing my work ”

Patient with severe eczema<sup>1</sup>

## THE BURDEN ON THE WIDER ECONOMY

Long term skin conditions also have an impact on the wider UK economy. This is particularly the case in the employment of people with severe eczema, both in terms of securing and maintaining employment, but also in the time off work due to flare ups or appointments. Chronic skin conditions can influence people's life choices, as well as negatively impacting their employment opportunities.<sup>6,21</sup>



Sickness absence costs UK taxpayers and employers an estimated £22 billion per year,<sup>22</sup> with around 300,000 people each year becoming the recipients of health-related benefits. Allergy UK's survey of people with severe eczema found that over 46% of respondents had taken days off of work in the last year due to their eczema.<sup>1</sup>

Whilst the average number of sick days taken per employee per year in the UK is 6.5 days,<sup>23</sup> the patient survey found that more than 24% of respondents reported missing six or more days a year of work just as a result of their eczema.<sup>1</sup> Moreover, nearly 15% had missed sixteen or more days of work due to their condition.<sup>1</sup>

“ It impacts my ability to move, go out, dress in ordinary clothes...I struggle to move/bend if it is really bad. At work I am constantly moisturising. It makes a mess of my clothes, my desk, my notebooks. Everything. ”

Patient with severe eczema<sup>1</sup>

## NEED TO PRIORITISE SEVERE ECZEMA

Despite its prevalence, its impact on the lives of adults who live with this chronic skin condition, and its cost to the NHS and the wider economy, severe eczema is seen as a low priority health issue. Therefore it is of vital importance that this condition receives appropriate prioritisation, to ensure people affected receive the best care possible and to reduce the financial burden on local health services and the wider economy.



### UNDER PRIORITISATION OF SKIN CONDITIONS BY POLICY MAKERS AND HEALTHCARE PROFESSIONALS

“ Dermatology represents an important part of NHS provision...and yet this important area is poorly understood and has received comparatively little attention. Commissioning has often been poor. Inadequate planning has left gaps in the workforce. The 40,000 GPs managing this workload have received little training in dermatology and there are only 650 consultants to advise them and provide the more specialist care. ”

The King's Fund, 2014<sup>7</sup>

Despite the millions of primary care appointments and hospital referrals for skin diseases that take place every year in the UK, dermatology is not prioritised by policy-makers. At present, there are no specific indicators or incentives for dermatology, which makes prioritisation by healthcare professionals and commissioners a challenge. Research in 2016 found that 87% of CCGs do not have a commissioning policy on dermatology.<sup>4</sup>

The Dermatology Council for England (DCE) published a report in 2015 which found that commissioners were aware of the pressure being placed on dermatology services, with 55% of CCGs confirming that they had been informed of workforce capacity issues. Despite this, only 37% of the CCGs had actively reviewed their dermatology service provision since the formation of the CCG<sup>24</sup>. Such reviews are a vital part of ensuring services reaches the required standards identified in the Health Needs Assessment.<sup>25</sup> As a result of this pressure, many dermatology appointments last only eight minutes, which many believe is not sufficient for proper diagnosis.<sup>26</sup>

Whilst there are pockets of excellence in the management of dermatology, clear national leadership is needed to improve outcomes for patients.

“ I can't put makeup on my face, I'm itching everywhere every day I can't go to the gym because I sweat and it flares my skin up. ”

Patient with severe eczema<sup>1</sup>

## LACK OF NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE (NICE) GUIDELINES ON THE MANAGEMENT AND TREATMENT OF ADULTS WITH SEVERE ECZEMA

There are currently no national guidelines or quality standards in England and Wales on the diagnosis, treatment and management of severe eczema in adults. In Scotland there is a national clinical guideline on the management and treatment of children and adults with atopic eczema in primary care, which was published in March 2011 by the Scottish Intercollegiate Guidelines Network (SIGN).<sup>5</sup> Current NICE guidelines focus on severe eczema in children under 12 years old only.<sup>27</sup>

Without a national standard of care for adults with the disease, patients may not be routinely receiving optimal care. As a disease that affects both physical and mental health, it is vital that policy-makers produce guidelines on the management of adult severe eczema to ensure that healthcare professionals are supported to provide optimal care for their patients.

“ It keeps me awake at night. I refuse to have a partner because of it. ”

Research found that in 2016, only 3% of CCGs had a commissioning policy on adult atopic dermatitis, whilst only 15% of Trusts produced local guidelines on adult atopic dermatitis.<sup>4</sup>

Only **3%** of CCGs had a commissioning policy on atopic dermatitis in 2016.<sup>4</sup>

“ I’ve had to change my job due to my eczema worsening – I was working in A&E and was going to train to be a nurse, but I can’t now because of my skin as it’s an infection risk. ”

Patient with severe eczema<sup>1</sup>

## WHAT THIS MEANS FOR THE TREATMENT AND MANAGEMENT OF SEVERE ECZEMA

### CURRENT TREATMENT OPTIONS

Whilst there is currently no cure for severe eczema, there are a number of treatments available that people can use to manage their symptoms. Current treatment options for adults with severe eczema include: emollients; topical corticosteroids; anti-histamines; oral corticosteroids; phototherapy; and systemic treatments.<sup>28</sup> Patients with severe eczema often try multiple treatment options to manage their condition, with systemic treatments available to those who are troubled with repeated, widespread flare ups of the disease, or who have severe eczema that is hard to control with topical treatments alone.

“ It has ruined my career in the army. It gives me a very low mood.  
Patient with severe eczema <sup>1</sup> ”

## VARIABLE KNOWLEDGE ON SKIN CONDITIONS IN PRIMARY CARE

Dermatology services across the country are over-stretched and understaffed, which means that there is pressure on GPs to try to treat and manage patients who may need specialist care. It is widely acknowledged that there is a lack of knowledge about skin disease in general practice due to poor undergraduate and postgraduate training.<sup>19</sup> Furthermore, few GPs have a developed specialist interest in dermatology. With the workload pressure on general practice all too well known and up to a quarter of GP workload involving skin disease, there is a clear need for better support for GPs to appropriately manage dermatological issues and address the unmet patient need.



## REGIONAL VARIATIONS IN ACCESS TO DERMATOLOGY SPECIALISTS

The challenges faced in primary care for severe eczema patients are exacerbated by the under-provision of consultant dermatologists in the UK.

### Snapshot: Dermatology Services at a Glance

- There is just **one consultant to every 130,000 people** in the UK. Currently no region in the UK meets the Royal College of Physicians' recommendation of **one consultant for every 62,500 people**.<sup>6,19</sup>
- In 2012 there were **813 dermatology specialists** in the UK, which is an estimated 250 specialists under the number recommended by the Royal College of Physicians.<sup>19</sup>
- In 2014, it was estimated that **20% of consultant dermatologist posts in England were unfilled**.<sup>26</sup>
- In 2015 over **two thirds of NHS Trusts operated with consultant level vacancies**, nearly half did not have fully staffed specialist secondary care services and nearly three quarters were employing locums to fill the gaps.<sup>24</sup>

“ When it is particularly bad it is horrendous with unsuccessful doctors' visits, spending unnecessary money on creams, which make it worse and clothes and washing powder that makes it worse also.  
Patient with severe eczema <sup>1</sup> ”



At present, many patients are either not being referred to specialists when necessary or are referred when they could be better managed in primary care. This creates additional pressures on primary and secondary care and also means that many patients across the country may not be receiving the most appropriate treatment for their condition. This can result in people attending more appointments than necessary, which overloads the health system, can be inconvenient for patient and results in significant costs to the NHS.

## DELAYED DIAGNOSIS

Timely diagnosis of severe eczema and appropriate referral to specialists is vital for optimal patient care. However, evidence suggests that this is not routinely managed across the country. Almost half of patients are required to see their GP or nurse between two to four times before they receive a diagnosis of eczema. Worryingly, almost one in ten people with severe eczema who responded to the patient survey stated that they were forced to attend more than ten primary care appointments before being diagnosed.<sup>1</sup>

“ I cannot wear white clothing because as soon as I itch I bleed which then stains my clothes. I have dirty looks from customers at work when they see my eczema and I constantly have to stop what I am doing to ‘sooth’ an itch. ”

Patient with severe eczema<sup>1</sup>

## NATIONAL GUIDELINES AND SCORING TOOLS

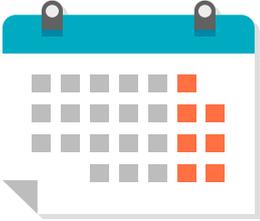
Delayed diagnosis may be in part due to the lack of NICE clinical guidelines for adult severe eczema to ensure that people receive optimal treatment and management of the disease. Whilst there are currently no adult severe eczema specific national guidelines in England and Wales, the Primary Care Dermatology Society (PCDS) and British Association of Dermatologists (BAD) produced a guideline in 2005<sup>29</sup>. As it is not nationally recognised and implemented, the guideline is not routinely adhered to by healthcare professionals and commissioners. With a significant lack in local guidelines and understanding about atopic dermatitis - only 3% of CCGs had a commissioning policy on adult atopic dermatitis in 2016, whilst only 15% of Trusts produced local guidelines on the disease<sup>4</sup> – it is therefore vital that a national guideline for adult atopic dermatitis is agreed to ensure the appropriate management and treatment of patients.

In order to obtain an accurate diagnosis for eczema and understand the most appropriate treatment option, the severity of the disease should be scored; however, whilst scoring tools exist, there is currently no nationally recognised scoring system in the UK. This can exacerbate delays to treatment and result in unnecessary additional appointments.

The Eczema Area and Severity Index (EASI) is an accepted and validated scoring tool used to measure the severity of the disease. However, it is not well-known or used widely in clinical practice. In order to ensure that all healthcare professionals are supported to appropriately diagnose and manage the disease, the EASI tool or a similar scoring tool should be rolled out nationally. This may help to alleviate many of the current challenges in the patient pathway.

“ I was told I hadn’t visited the GP often enough [to be referred], despite having it all my life and having had a record of visiting. ”

Patient with severe eczema<sup>1</sup>



## LENGTHY WAITING TIMES

Research found that more than 60% of patients who responded were forced to wait between one and three months for a secondary care appointment after being referred. Almost 30% of respondents waited between four and seven months before being seen in secondary care, and one in ten had to wait eight months or more.<sup>1</sup>

Research also found that the average waiting time to treatment from referral for adults with atopic dermatitis was between 11-15 weeks.<sup>4</sup> This will be of concern to many patients, given the significant impact the disease can have their lives, but also as severe eczema tends to appear in flares meaning it can worsen suddenly and disappear just as quickly.

“ Time applying creams interferes with my daily routine as well as work as I have to find the time to apply creams during my shift. ”

Patient with severe eczema<sup>1</sup>

## VARIABLE ACCESS TO PSYCHOLOGICAL CARE AND SUPPORT

As a disease that can have a significant impact on a person's mental health and wellbeing, it is crucial that people have access to appropriate information and support to manage all symptoms of the disease. Evidence suggests that people with the disease are not routinely provided with the necessary advice and support for the psychological impact of severe eczema.

There is currently limited access to relevant practitioners, such as psychologists, psychiatrists and counsellors as part of dermatology services. In 2013 it was estimated that only three out of 127 hospitals surveyed had a dedicated psychodermatology service, a reduction since 2004.<sup>6</sup> Research in 2016 found that only 17% of NHS Trusts support healthcare professionals to deliver psychodermatological care with standards or through the use of national guidelines.<sup>4</sup>

**17%** of NHS Trusts support healthcare professionals to deliver psycho-dermatological care<sup>4</sup>

Evidence shows that the psychological impact of atopic dermatitis is not recognised and data on referrals is not routinely recorded by NHS Trusts.<sup>4</sup> As such, many adult patients may not be receiving appropriate care to manage their full range of symptoms. Indeed, 85% of dermatology patients suffer psychological effects of their condition, despite this 58% of secondary units do not provide any psychological services for dermatology patients.<sup>20</sup> It has been suggested that an increased understanding of the psychiatric comorbidity associated with skin disease and a joined up approach between biological, psychological and social factors to management will ultimately improve patients' lives.

“ I have throughout my life lost huge amounts of time due to my eczema... even now I lose something like two hours a day to putting creams on and waiting for them to go in. ”

Patient with severe eczema<sup>1</sup>

# CALLS TO ACTION

---

Across all stages of a patient journey – from diagnosis to referral to treatment – there are many opportunities to improve outcomes for those with severe eczema. Indeed, a number of steps could be taken by policy makers and healthcare professionals across the patient pathway to support optimal management of the disease and reduce regional variation. The key calls to action are detailed below.



**Urgently** address the delay in recognition, diagnosis and management of severe eczema in adults by improving the education and training of front line healthcare professionals.



**Establish** guidelines across the UK for the diagnosis, management and treatment of severe eczema in adults, including a nationally standardised scoring tool.



**Facilitate** a care pathway with appropriate coding and funding for people with adult severe eczema to get the appropriate treatment and care through policy changes.

# REFERENCES

- <sup>1</sup> Allergy UK, Survey of patients with severe eczema (November 2016 – December 2016).
- <sup>2</sup> S. Nutten, *Annals of Nutrition and Metabolism*, 'Atopic Dermatitis: Global Epidemiology and Risk Factors' (2015). Available at: <http://www.karger.com/Article/PDF/370220> (Accessed: March 2017).
- <sup>3</sup> Office for National Statistics. 2014 UK mid-year population estimate. Available at: <http://www.ons.gov.uk/generator?uri=/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/february2016/ff1144ea&format=xls> (Accessed: March 2017)
- <sup>4</sup> Sanofi Genzyme, Freedom of Information request. Data on file. 2016.
- <sup>5</sup> Scottish Intercollegiate Guidelines Network, 'Management of atopic eczema in primary care' (2011). Available at: <http://www.sign.ac.uk/pdf/sign125.pdf> (Accessed: March 2017).
- <sup>6</sup> All-Party Parliamentary Group on Skin, 'The psychological and social impact of skin diseases on people's lives' (2013). Available at: <http://www.appgs.co.uk/publication/view/the-psychological-and-social-impact-of-skin-diseases-on-peoples-lives-final-report-2013/> (Accessed: March 2017).
- <sup>7</sup> The King's Fund, 'How can dermatology services meet current and future patient needs, while ensuring quality of care is not compromised and access is equitable across the UK' (2015). Available at: <http://www.bad.org.uk/shared/get-file.ashx?id=2348&itemtype=document> (Accessed: March 2017).
- <sup>8</sup> National Eczema Association, 'Atopic Dermatitis found to be an immune-drive disease'. Available at: <http://www.mountsinai.org/about-us/newsroom/press-releases/atopic-dermatitis-found-to-be-an-immune-driven-disease> (Accessed: March 2017).
- <sup>9</sup> A. Worth, A. Sheikh, *Current Opinion in Allergy and Clinical Immunology*, 'Food allergy and atopic eczema' (2010). Available at: <https://www.ncbi.nlm.nih.gov/pubmed/20375880> (Accessed: March 2017).
- <sup>10</sup> Brandpoint, 'Atopic Dermatitis: Understanding what makes people 'itch'' (2015). Available at: <http://www.brandpointcontent.com/printsite/health-fall-/atopic-dermatitis-understanding-what-makes-people-itch-,22473> (Accessed: March 2017).
- <sup>11</sup> British Skin Foundation, 'Skin information: Eczema (Atopic Eczema)'. Available at: <http://www.britishskinfoundation.org.uk/SkinInformation/AtoZofSkindisease/Eczema.aspx> (Accessed: August 2016).
- <sup>12</sup> Swen Malte John, Adjacent Government, 'Highlighting eczema in the workplace' (2015). Available at: <http://www.adjacentgovernment.co.uk/lg-edition-008/highlighting-eczema-workplace-2/22310/> (Accessed: August 2016).
- <sup>13</sup> Allergy UK, 'Atopic Dermatitis/Eczema in Children' (2013). Available at: <http://www.allergyuk.org/atopic-dermatitis-and-eczema-in-children/atopic-dermatitis-eczema-in-children> (Accessed: March 2017).
- <sup>14</sup> J. Silverberg, N. Garg, A. Paller, A. Fishbein, P. Zee, *Journal of Investigative Dermatology*, 'Sleep disturbances in adults with eczema are associated with impaired overall health: a US population-based study' (2015). Available at: <http://www.ncbi.nlm.nih.gov/pubmed/25078665> (Accessed: March 2017).
- <sup>15</sup> NHS Choices, 'Atopic eczema – Symptoms'. Available at: [http://www.nhs.uk/Conditions/Eczema-\(atopic\)/Pages/Symptoms.aspx](http://www.nhs.uk/Conditions/Eczema-(atopic)/Pages/Symptoms.aspx) (Accessed: March 2017).
- <sup>16</sup> R.T. Anderson, R. Rajagopalan, *Current Allergy and Asthma Reports*, 'Effects of allergic dermatitis on health-related quality of life' (2001). Available at: <http://www.ncbi.nlm.nih.gov/pubmed/11892052> (Accessed: March 2017).
- <sup>17</sup> J. Schofield, D. Grindlay, H. Williams, Centre of Evidence Based Dermatology, University of Nottingham, 'Skin Conditions in the UK: A health care needs assessment' (2009). Available at: <https://www.nottingham.ac.uk/research/groups/cebcd/documents/hcnaskinconditionsuk2009.pdf> (Accessed: March 2017).
- <sup>18</sup> Personal Social Services Resource Unit, 'Unit Costs of Health and Social Care 2015' (2015). Available at: <http://www.pssru.ac.uk/project-pages/unit-costs/2015/index.php?file=full> (Accessed: March 2017).
- <sup>19</sup> D. Eedy, *British Medical Journal Careers*, 'The Crisis in Dermatology' (2015). Available at: [http://careers.bmj.com/careers/advice/The\\_crisis\\_in\\_dermatology](http://careers.bmj.com/careers/advice/The_crisis_in_dermatology) (Accessed: March 2017).
- <sup>20</sup> British Association of Dermatologists, 'King's Fund report into dermatology services in the UK' infographic (2015). Available at: <http://www.bad.org.uk/official-responses/kings-fund-report-into-dermatology-services-in-the-uk> (Accessed: March 2017).
- <sup>21</sup> Z. Bhatti, S. Salek, C. Bolton, L. George, J. Halcox, S. Jones, I. Ketchell, R. Moore, R. Sabit, V. Piguet, A. Finlay, *Health and Quality of Life Outcomes*, 'The development and validation of the major life changing decision profile' (2013). Available at: <http://hqlo.biomedcentral.com/articles/10.1186/1477-7525-11-78> (Accessed: March 2017).
- <sup>22</sup> NHS, 'Five Year Forward View' (2014). Available at: <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf> (Accessed: March 2017).
- <sup>23</sup> Personnel Today, 'Sickness absence rates and costs revealed in UK's largest survey' (2015). Available at: <http://www.personneltoday.com/hr/sickness-absence-rates-and-costs-revealed-in-uks-largest-survey/> (Accessed: March 2017).
- <sup>24</sup> The Dermatology Council for England, 'An Audit of Dermatological Commissioning and Workforce Capability: Interim Report' (2015). Available at: <http://www.appgs.co.uk/wp-content/uploads/2015/07/DCE-FOI-Report-2015-Final.pdf> (Accessed: March 2017).
- <sup>25</sup> British Association of Dermatologists, 'Lessons for the NHS: Commissioning a Dermatology Service' (2013). Available at: <https://www.bad.org.uk/shared/get-file.ashx?itemtype=document&id=1009> (Accessed: March 2017).
- <sup>26</sup> All-Party Parliamentary Group on Skin, 'All-Party Parliamentary Group on Skin Event: A Crisis in Dermatological Education and Workforce', Minutes (2014). Available at: [http://www.appgs.co.uk/wp-content/uploads/2015/01/APPGS\\_Minutes2ndDec14final.pdf](http://www.appgs.co.uk/wp-content/uploads/2015/01/APPGS_Minutes2ndDec14final.pdf) (Accessed: March 2017).
- <sup>27</sup> National Institute for Health and Care Excellence, 'Atopic eczema in under 12s: diagnosis and management' (2007). Available at: <https://www.nice.org.uk/guidance/cg57> (Accessed: March 2017).
- <sup>28</sup> NHS Choices, 'Atopic eczema – Treatment'. Available at: [http://www.nhs.uk/Conditions/Eczema-\(atopic\)/Pages/Treatment.aspx](http://www.nhs.uk/Conditions/Eczema-(atopic)/Pages/Treatment.aspx) (Accessed: March 2017)
- <sup>29</sup> The Primary Care Dermatology Society and British Association of Dermatologists, 'Guidelines for the management of atopic eczema' (2006). Available at: <http://www.pcds.org.uk/images/stories/pcdsbad-eczema.pdf> (Accessed: March 2017)



This report was written and funded by Sanofi Genzyme, working in collaboration with Allergy UK. The content was approved by Allergy UK and reviewed by Sanofi Genzyme to ensure compliance with the ABPI Code of Practice.

Date of preparation:  
April 2017  
Job Bag Code:  
SAGB.SA.17.04.0413