



# TIME FOR CHANGE IN THE UK

THE TRUE IMPACT OF ECZEMA AND  
THE EXPERIENCES OF CHILDREN,  
YOUNG PEOPLE AND THEIR FAMILIES  
IN MANAGING THE CONDITION

Financial support for the Eczema Outreach Support survey was provided by Sanofi, who had no editorial control over the content or interpretation of the results.

This subsequent report has been written and funded by Sanofi and reviewed by Eczema Outreach Support.

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**sanofi**



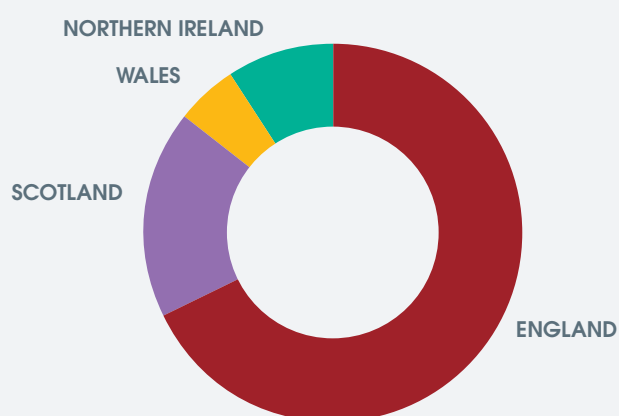


# INTRODUCTION

Between December 2020 and February 2021, the national charity, Eczema Outreach Support (EOS) surveyed children and young people (11-17) with eczema and parents/carers of children aged 0-17 with eczema to find out about the true impact eczema has on their lives and how they are supported to manage it. Financial support for the EOS survey was provided by Sanofi, who had no editorial control over the content or interpretation of results.

This subsequent report has been written and funded by Sanofi in collaboration with EOS. This report highlights the key findings from the survey in terms of the changes needed to improve outcomes for children and young people with eczema, and their families. Please note that all findings from the survey refer to the numbers and percentages of those who have participated in the survey itself, not the wider community. A breakdown of the number of respondents to the survey by age and location is outlined below:

## PARENTS/CARERS OF CHILDREN AND YOUNG PEOPLE (AGED 0-17 YEARS) WITH ECZEMA (3,435 RESPONDENTS)



### LOCATION

**ENGLAND 2,331** respondents

**SCOTLAND 617** respondents

**WALES 176** respondents

**NORTHERN IRELAND 311** respondents

### AGE OF THEIR CHILDREN

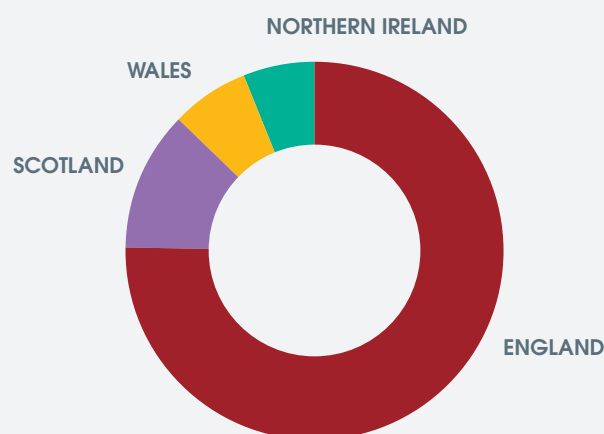
**UNDER 1 YEAR 198** respondents

**1-4 YEARS 1,289** respondents

**5-10 YEARS 1,390** respondents

**11-17 YEARS 558** respondents

## YOUNG PEOPLE WITH ECZEMA (AGED 11-17 YEARS) (510 RESPONDENTS)



### LOCATION

**ENGLAND 385** respondents

**SCOTLAND 60** respondents

**WALES 35** respondents

**NORTHERN IRELAND 30** respondents

### AGE OF YOUNG PERSON RESPONDENTS

**11 YEARS 30** respondents

**12 YEARS 41** respondents

**13 YEARS 65** respondents

**14 YEARS 79** respondents

**15 YEARS 73** respondents

**16 YEARS 52** respondents

**17 YEARS 170** respondents

# FOREWORD



Those who continue to have eczema as teenagers tend to be more severely affected – both physically and in terms of self-confidence.

At Eczema Outreach Support (EOS), we are dedicated and passionate about supporting families and improving eczema services across the UK. EOS exists to help families deal with the practical and emotional aspects of having a child with eczema. We understand the impact the condition can have on the whole family, and we understand how isolating it can feel. We support people with eczema up and down the country and have undertaken this survey to assess the true impact eczema has on children and young people and better understand their experiences of care.

Eczema often starts in childhood: **20%** of children in the UK are affected by eczema at some stage<sup>i</sup> and **5-15%** of young people continue to be affected by eczema (European figures).<sup>ii</sup> Those who continue to have eczema as teenagers tend to be more severely affected – both physically and in terms of self-confidence.<sup>iii</sup> As such, the survey and subsequent report has focused on children, young people and the parents/carers of children with eczema, looking at the impact of eczema, the healthcare experience, the provision of support services, impact on school and current national guidance. In this report, we refer to ‘children’ as 0-10 year-olds and ‘young people’ as 11-17 year-olds.

Overall, the findings from this survey show that for many children, young people and parents/carers of children with eczema, their condition has a negative impact on their day-to-day lives, with only **3%** stating that over the last 6 months, their or their child’s eczema hadn’t become sore, itchy and flared once.<sup>iv</sup> While eczema may be widely regarded as a relatively minor skin condition, it can and does have a major impact on the quality of life of those who suffer from it, and from what we’ve found from our survey results, this impact is sometimes not recognised or often downplayed, and that more could be done by healthcare professionals and schools to limit this impact.

**Magali Redding**

Founder, Eczema Outreach Support



## KEY FINDINGS & CALL FOR ACTION IN 2022

This UK-wide survey has provided us evidence about: the impact of eczema on life, including the effect of COVID-19 on families; which services are already working well; and the most urgent calls for action in order to better care for and support families affected by eczema in the UK.

Our **9 recommendations** are as follows:

### PRIMARY CARE HEALTHCARE PROFESSIONALS SHOULD...

# 1.

#### **Receive significantly more core dermatology training, reflecting their heavy skin disease caseload.**

Eczema is the second most frequent reason for a new dermatological consultation in general practice.<sup>v</sup> Yet studies suggest that eczema is often accorded a low priority in primary care.<sup>v</sup> The survey showed that **more than 1 in 10** parents/carers had seen their GP 6-10 times in the last year for their child's eczema whilst nearly half had been to their GP 2-5 times.<sup>v</sup> This suggests that referrals to a specialist may be necessary in some cases and that GPs must be supported to recognise when a referral is needed. Despite the significant role that primary care plays in eczema, dermatology has not been a compulsory part of GP training,<sup>vi</sup> and the training at undergraduate and postgraduate level in dermatology is viewed as poor.<sup>vii</sup> This is insufficient and can lead to sub-optimal treatment, resulting in the deterioration of people with eczema's skin condition and well-being, leading to referrals to secondary care.

# 2.

#### **Put young people at the centre of their own eczema care**

by discussing directly with them their treatment choices and potential referrals to other services, such as psychological support and peer-groups. The survey found that **68%** of young people would like to be more involved in decisions made about their care.<sup>iv</sup> Yet **more than one in four** young people said their healthcare professional talks mostly to their parent/carer at appointments and **27%** said that they had never had treatments explained to them directly.<sup>iv</sup> Whilst responses showed that the older the young person was, the more likely they were to be involved in their care, less than half of 17-year-olds were spoken to directly.<sup>iv</sup> By involving young people in decisions and conversations about their care, they are more likely to achieve better outcomes.

# 3.

**Prioritise the development of children, young people and their families' self-management skills** so they can better control their eczema at home. Better health outcomes are achieved when people with eczema understand the importance of adhering to treatments and when they play an active role in treatment decisions.<sup>viii</sup> Key to this is providing written treatment plans and their use has been important during the COVID-19 pandemic, allowing the continuation of care throughout challenging times. However, our survey found **three quarters** of parents/carers did not receive a clear treatment plan from their GP to use at home for the management of their child's eczema.<sup>iv</sup> Moreover, only **half** of the young people who received direct information on their treatments from their healthcare professional felt the advice had helped them to manage their eczema.<sup>iv</sup> Clearly, improvements are needed to ensure optimal self-management.

**THE NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE (NICE) AND SCOTTISH INTERCOLLEGIATE GUIDELINES NETWORK (SIGN) SHOULD...**

# 4.

**Develop and maintain up to date national clinical guidelines** for the diagnosis, treatment and management of atopic eczema in young people over 12 years and adolescents to ensure standardised care across the UK. Setting out a specific optimal pathway will support both people with eczema and the healthcare professionals caring for them.

**SCHOOLS AND LOCAL AUTHORITIES SHOULD...**

# 5.

**Be equipped with and use specialist resources** on practical ways to support children and young people with eczema during school hours. Generally, students with better health and wellbeing are likely to achieve more academically than peers who have a poorer level of health and wellbeing.<sup>ix</sup> Students with eczema deserve the same life chances as those without, but we know that eczema can have a significant impact on a pupil's education (for example in terms of concentration, missed days and lack of sleep). Worryingly, our survey found that **over half** of young people's education setting or place of employment do not have the appropriate support structures in place to help with their eczema needs.<sup>iv</sup> Providing schools with the right resources will help to ensure students with eczema are supported.

# 6.

**Deliver eczema awareness workshops and training** for teachers and pupils and share best practice within their networks. This is vital, as our survey showed that **58%** of young people believed their education setting/employer did not understand their eczema needs whilst **70%** stated they had no support provision in place.<sup>iv</sup> Many pupils wanted their teachers, friends and peers to show more awareness and understanding of their eczema needs and further training would go some way to achieving this.

**INTEGRATED CARE SYSTEMS ICSSs (CROSS-SERVICE STATUTORY BODIES) SHOULD...**

# 7.

**Meet the target waiting times** from referral to treatment for dermatology services (current target is **95%** of patients to be seen by a specialist within 18 weeks of referral). Data for 2019/20 showed that only **80%** of dermatology patients were treated within 18 weeks of referral<sup>x</sup> and by January 2021 **14%** of dermatology patients had waited more than six months to be seen by a specialist.<sup>xi</sup> There are also large regional variations in waiting times, with some people in Northern Ireland waiting over 52 weeks for their first consultant-led outpatient appointment.<sup>xii</sup> As the NHS builds back from the COVID-19 pandemic, it is vital that targets for referral to treatment are met.

# 8.

**Increase the provision and improve access to psycho-dermatology provision** across the UK based on a person-centred approach. Currently, access to these services can be difficult, as shown by our survey, which established that many parents/carers found it either **impossible (27%)** or **difficult (19%)** to access mental health support for their child.<sup>iv</sup> Yet demand for the services is strong, with **39%** of young people reporting they would benefit from mental health support.<sup>iv</sup> Support for mental wellbeing can make a significant difference to people with eczema, and **88%** of young people who had accessed this support found it helpful.<sup>iv</sup>

# 9.

**Recognise the value of the third sector** in meeting the unmet practical and emotional support needs of families with eczema by providing funding and working in partnership. A number of respondents to our survey praised the support they have received from charities and the positive impact it had on their lives.





# HEALTHCARE EXPERIENCE AND PROVISION FOR CHILDREN AND YOUNG PEOPLE WITH ECZEMA

## HEALTHCARE PROFESSIONAL AWARENESS AND UNDERSTANDING OF ECZEMA

Living with eczema and managing the associated symptoms of the condition can impact all aspects of someone's life. For children, it can affect their physical and mental health, self-confidence, education, and their social life.<sup>xiii</sup> The wider families of those with eczema are often also affected by the disease as they are a key support network. Supporting children in managing their eczema treatment can also affect carers, in particular, impacting their mental health, work and finances.<sup>xiv</sup> Optimal management of eczema and empowerment of children, young people and their families to understand and be involved in their eczema care is vital in limiting the impact that the disease has on children, young people and their families.

## PHYSICAL IMPACT ON CHILDREN AND YOUNG PEOPLE

The itchy and painful symptoms can, for those with very severe skin reactions, impact everyday tasks, with the pain from their inflamed skin causing discomfort and emotional distress.<sup>xv</sup> This in turn can play a huge role in their quality of life and their overall well-being. In childhood, eczema has been shown to be greater than or equal to other common childhood diseases such as asthma and diabetes in impairing quality of life.<sup>xiv</sup> Furthermore, the negative impact it can have on children's quality of life is not just caused by physical discomfort, but also the time taken in managing symptoms. This is also the case for family members, who may be primary caregivers and therefore responsible for skin management routines and treatment.

Eczema is the most common chronic inflammatory skin disease and accounts for many GP appointments. This was highlighted by the survey, with **19%** of parents and carers

saying they have seen their GP at least six times in the last year in relation to their child's eczema, while **46%** said it has been two to five times.<sup>iv</sup> However, overall, the survey showed that nearly **1 in 4 parents/carers** and nearly **1 in 5 young people** reported feeling that their healthcare professional did not understand the impact eczema can have on their lives.<sup>iv</sup> Given the heavy skin disease caseload faced in primary care, core dermatology training should be prioritised.

### PHYSICAL IMPACT OF ECZEMA

- **52% of young people and parents/carers of children aged 0-17 with eczema reported that itching was an issue 'most days'**<sup>iv</sup>
- **69% of young people with the severest form of eczema (self-reported) said itching is an issue 'most days'**<sup>iv</sup>
- **46% of young people and parents/carers reported that they themselves/their child had at least 26 flare-ups in the past 6 months'**<sup>iv</sup>

**"I just feel embarrassed when I need to like keep itching."**

*(12-year-old with eczema)*

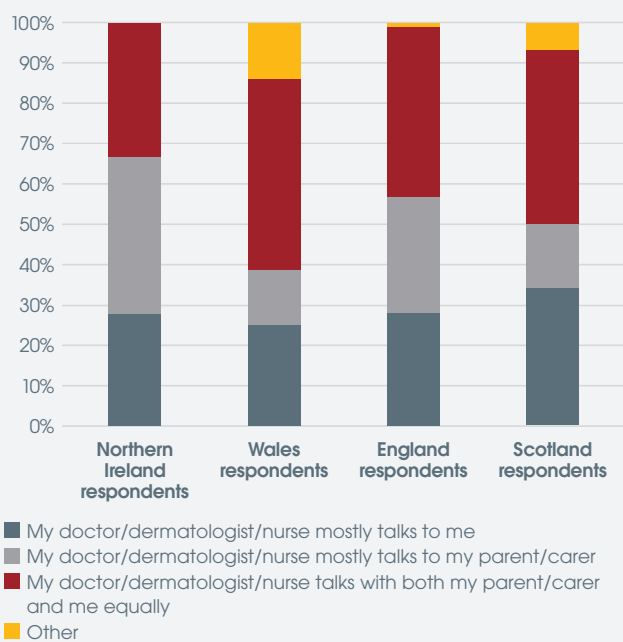
**"Eczema stops me doing every-day activities like holding a pen."**

*(15 year-old with eczema)*

## EMPOWERING CHILDREN AND YOUNG PEOPLE WITH ECZEMA AND THEIR FAMILIES

It is important that young people with eczema, as well as parents/carers of children with eczema, feel engaged and are confident in managing their own care. However, currently, the survey found that only **29%** of parents and carers felt encouraged by their GP to be involved in decisions made about their child's treatment.<sup>iv</sup> For young people particularly, it is important that they are prepared to become responsible for their care by having direct conversations with their healthcare professionals; however, **27%** of the surveyed young people said that their healthcare professional talks mostly to their parent/carer at appointments<sup>iv</sup> and **27%** said that they had never had treatments explained to them directly.<sup>iv</sup> Overall, **62%** said they rarely or never talk to their healthcare professional about their eczema and their views on treatment.<sup>iv</sup> The reasons for this do not seem to be due to young people's apathy; **68%** stated that they want to be more involved in decisions about their treatments.<sup>iv</sup> Research suggests that there was a feeling amongst recently qualified GPs and those with more experience that eczema was generally accorded a low priority in primary care practice and that many GPs provide limited supportive information to patients.<sup>xvii</sup>

### PATIENT INVOLVEMENT IN CONVERSATIONS WITH HEALTHCARE PROFESSIONALS (BY COUNTRY)



**"I want to be involved in the conversation and not just talked at like I'm still a child needing to understand my treatment."**

*(17-year-old with eczema)*

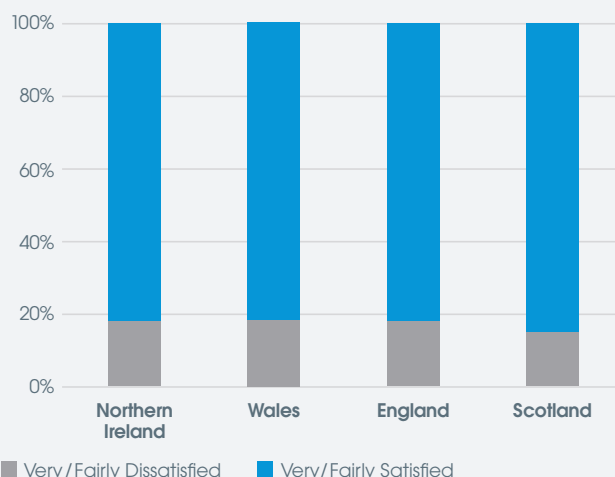
## NEED FOR APPROPRIATE REFERRAL TO SPECIALIST DERMATOLOGY SUPPORT

The majority of parent/carer respondents reported that their child had not been referred to a dermatology specialist in

regards to their child's eczema (**55%**).<sup>iv</sup> There is widespread variation in GP referrals to specialised care, caused by a range of factors, including uncertainty about the diagnosis, perceived seriousness of the skin condition and patient preference.<sup>xvii</sup> As such, it is important to ensure that children and young people are assessed and referred appropriately to reduce variation in care and ensure that they are able to receive the right treatment at the right time. This was notable as, of those parents/carers who had seen a dermatology specialist, **72%** of parents/carers found that their understanding of using the treatments prescribed to them was higher<sup>iv</sup> compared with **56%** of parents/carers who said the same after a GP visit.<sup>iv</sup> For example, when seeing a specialist, parents/carers were much more likely (**67%**) to receive a clear treatment plan to use at home,<sup>iv</sup> helping them to manage their child's eczema. This is significantly different to experiences with GPs where the majority (**76%**) of parents/carers reported not receiving one.<sup>iv</sup> Both before and during the COVID-19 pandemic, the development of an individualised eczema care plan was welcomed, highlighting the positive experience people with eczema feel when care is personalised.<sup>xviii</sup> The use of these care plans, coupled with digital technology, allowed the continuation of care throughout challenging times and facilitated better eczema management.<sup>xix</sup>

Overall, the majority (83%) of parents/carers reported being fairly satisfied or very satisfied with the care provided by their specialist in relation to their child's eczema.<sup>iv</sup> With personalised care being one of the five major practical changes to the NHS that will take place over the next five years, as set out in NHS Long Term Plan, it will be important to expand the use of written care plans for young people with eczema. Other important goals include expanding access to consultant dermatologists and ensuring the target of 95% of patients being seen by a specialist within 18 weeks of referral is met.

### PARENT/CARER SATISFACTION WITH THE CARE PROVIDED BY SPECIALISTS IN RELATION TO THEIR CHILD'S ECZEMA (BY COUNTRY)



**"Most of the time I don't understand the dermatologist, but the written letter sent home explains the treatment plan in detail. This helps a lot."**

*(Parent/carer of children with eczema over 5-years of age)*



# PROVISION OF DERMATOLOGY AND PSYCHODERMATOLOGY SERVICES IN THE UK



The COVID-19 pandemic has added significant pressure on an already limited number of dermatologists. Many planned appointments were cancelled or severely delayed due to the NHS dealing with the pandemic<sup>xx</sup> and these delays in patient's accessing care, and ultimately treatment, will have an impact on those trying to transition through the eczema care pathway. That said, demand for GP services continue to rise<sup>xxi</sup> and so appropriate referrals to specialists are vital to reducing the overall burden of eczema on the health service. By addressing waiting times and facilitating appropriate referrals, children and young people should be able to better manage their eczema.

**66%** of parents/carers and young people said that their care has been impacted by COVID-19.<sup>iv</sup> Some young people have found that the pandemic has led to an increased feeling of stress and anxiousness, which has had a dramatic impact on their flare-ups.

The pandemic has clearly expedited the wide scale roll out of innovation throughout the health system.<sup>xxii</sup> For example the use of tele-dermatology has been expanded during the pandemic and a number of respondents in the survey specifically referenced using these services: "I think all doctors should allow for online consultations or for photos to be sent and reviewed rather than having to come in."

**"Her anxiety has got worse now with everything going on, she is having therapy zoom sessions to try and help her eczema and anxiety."**

*(Parent/carer of a young person with eczema aged 11-17 years)*

**"Flare-ups have been more easily contained and treated in lockdown with time at home - they haven't always been so severe or widespread. We have also had time to experiment a little more with diet."**

*(Parent/carer of a young person with eczema aged 11-17 years)*



## PSYCHODERMATOLOGY

Eczema can have a huge impact on a young person's mental health, with research suggesting there is 'significant association between eczema and suicidal ideation'.<sup>xxiii</sup> Despite this, mental health provision and access to psychodermatology support appears to be lacking.<sup>xxiv</sup> Worryingly, when seeking mental health support for their child, **46%** reported it was 'difficult' or 'impossible' to get the help they asked for.<sup>iv</sup> Recent research illustrates that there is 'significant variability in the national provision of psychodermatology services, despite evidence that these services are highly in demand and highly cost-efficient'.<sup>xxv</sup>

### MENTAL HEALTH

- **52% of parents/carers reported that when their child's eczema was at its worst, it made their mood low<sup>v</sup>**
- **39% of parents/carers reported that their eczema made their child feel less confident<sup>iv</sup>**

Psychodermatology can be helpful in teaching people with eczema, particularly young people, how to optimally manage their condition, including providing various relaxation techniques.<sup>xxvi</sup> This can lessen the severity of symptoms, improve outcomes and reduce the need for medical treatment.<sup>xxvii</sup> Of those parents/carers that were able to access mental well-being support for their child, **50%** found these service's provided 'a little' benefit, while **17%** responded 'a lot', however, **33%** found that it was not at all helpful (although **29%** parents/carers of 11-17 year-olds reported the same).<sup>iv</sup> In contrast, the majority of young people (**88%**) who accessed professional mental well-being support reported that it was helpful.<sup>iv</sup>

**"My daughter feels that people will always see her skin before her. Old teachers have called her moody and one even vocalised 'it's only itching?!' Which she has heard, internalised and I haven't been able to unlock yet for her so am really hoping the counsellor can help when they are involved - the GP has actively supported this referral."**

*(Parent/carer of young person with eczema aged 11-17 years)*

**"I wish there was some support available for both parent and child as it is so stressful and overwhelming."**

*(Parent/carer of young person with eczema aged 11-17 years)*

The British Association of Dermatologists (BAD) recommends that psychodermatology services are "expanded"<sup>xxviii</sup>, and has produced a Working Party Report on Minimum Standards.<sup>xxix</sup> The report provides a set of recommendations on the minimum standards required to support psychodermatology service provision in the UK.<sup>xxx</sup>

Overall, in order to ensure access to mental health support for eczema, psychodermatology services need to be fully integrated into a comprehensive NICE pathway. There are already examples of best practice, such as from the Royal Free London NHS Trust, which provides cognitive behavioural therapy for patients referred by a dermatologist,<sup>xxxi</sup> and recommendations from dermatology groups, such as the BAD, that can be developed and tailored for young people, but further work is needed to ensure care is consistent in supporting children and young people with eczema at a local level.

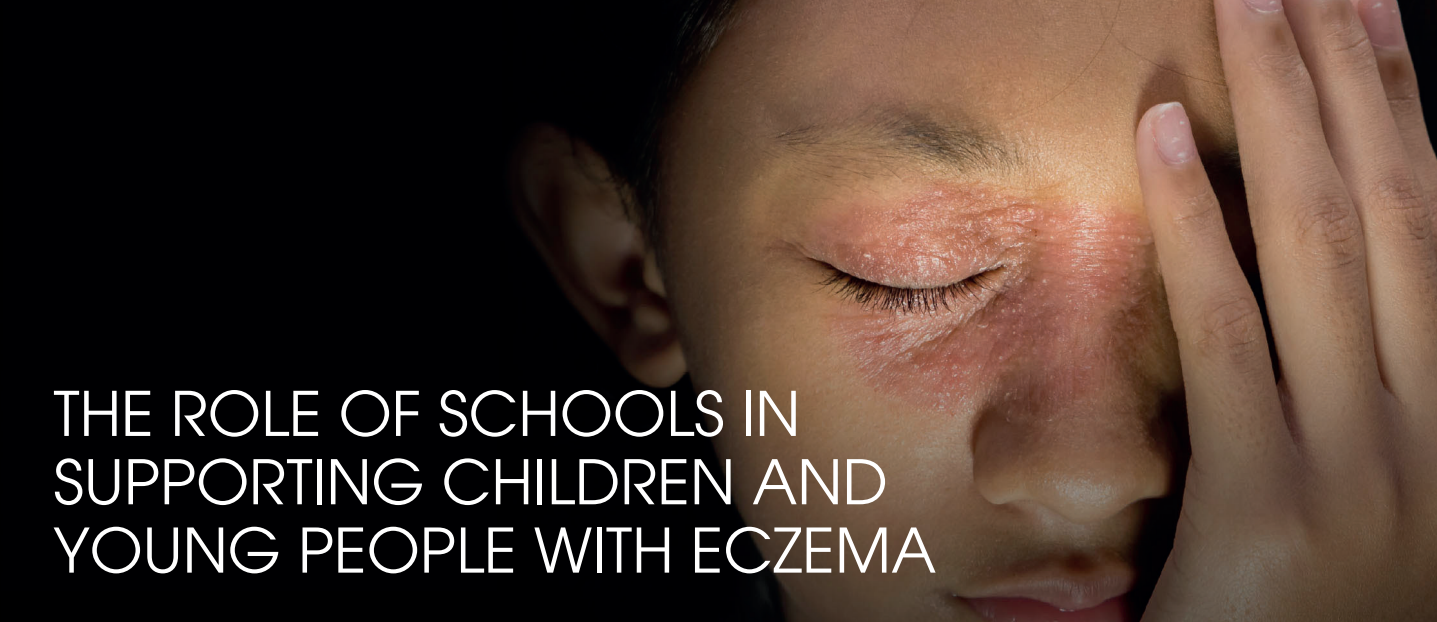
### ROLE OF THE THIRD SECTOR

In the UK, we have excellent patient organisations that work to support and guide people with eczema. This is particularly valuable given the lack of national guidance available, and ICSs should ensure that they collaborate with them to maximise benefit for children and young people with eczema.

Eczema Outreach Support (EOS), for example, provides meaningful support for children and young people with eczema, as well as their parents, carers and educators; including through resources hosted on their website. The support and guidance provided by these organisations can be a great aid for children and young people with eczema and their families, and can offer adolescents a way of sourcing information and advice independently. Other charities highlighted by respondents as having provided valuable information and care include the National Eczema Society (NES); Allergy UK; Mind; and Changing Faces.

**"Until we found the EOS group, (my child) had little support and if we'd met the group earlier, it would've been helpful."**

*(Parent/carer of a young person with eczema aged 11-17 years)*



# THE ROLE OF SCHOOLS IN SUPPORTING CHILDREN AND YOUNG PEOPLE WITH ECZEMA

## IMPACT OF ECZEMA ON PUPILS AND THEIR EXPERIENCES

As a condition that can impact all aspects of a child and young person’s life, including their mental wellbeing, concentration, ability to sleep and physical ability to write and participate in learning and extra-curricular activities, eczema can have a significant effect on their education.<sup>xxxii</sup> Students with eczema deserve the same life chances as those without. To achieve this, it is vital that schools and local authorities recognise the impact eczema has on their pupils and put measures in place to support those with eczema. This includes providing training to staff and all pupils on eczema and utilising specialist resources to encourage staff to adequately support their students with eczema.

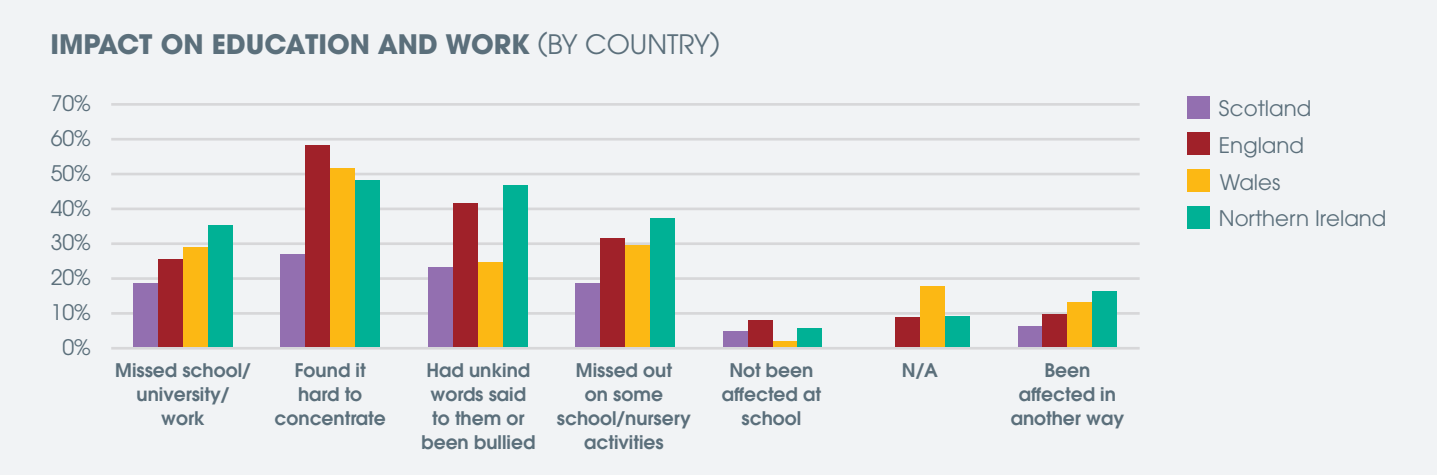
## SLEEP DEPRIVATION AND CONCENTRATION

Good sleep is critical for optimal educational outcomes<sup>xxxiii</sup> and so conditions like eczema, which often affect a child or young person’s sleep, can have a detrimental impact on their education. Sleep deprivation due to eczema symptoms can lead to tiredness, mood changes and

can affect productivity and concentration, all of which influences a child or young person’s ability to perform to the best of their ability at school, university and work.

The survey highlighted that eczema can significantly affect children and young people’s sleep. **62%** of parents and carers of children aged 0-17 years reported their child’s sleep was disrupted by their eczema at least once a week, with nearly one third (**28%**) reporting it was disrupted ‘most days’.<sup>iv</sup> **76%** of those responding about young people (young people themselves and their parents/carers) stated that eczema impacted the young person’s sleep at least once a week.<sup>iv</sup> Interestingly, when looking at results from just young people themselves this dropped to **57%**, with **21%** of young people stating this happens ‘most days’.<sup>iv</sup> The older the adolescent, the more likely they were to report that their eczema disturbs their sleep ‘most days’ or ‘four to five times a week’ (**26%** of 11-14-year-olds reported this vs **36%** of 15-17-year-olds).<sup>iv</sup>

**More than half** of all parents and carers who responded stated that itching had been an issue ‘most days’ for their child.<sup>iv</sup> In terms of eczema’s impact on concentration, older children were more often affected: **46%** of parents and





carers of children aged 0-17 years reported that their child found it hard to concentrate at school due to their eczema<sup>iv</sup> compared to **50%** of respondents answering about young people specifically (themselves and their parent/carer).<sup>iv</sup> Interestingly, fewer young people and their parents/carers in Scotland reported problems with concentration than elsewhere in the UK (**27%** in Scotland compared to between **48%** and **58%** for the other three nations).<sup>iv</sup>

## PARTICIPATION IN ACTIVITIES AND PHYSICAL SIDE EFFECTS

Eczema may also physically affect a child or young person's ability to participate in school activities, attend lessons, wear a uniform comfortably and for some, can even influence their ability to participate fully in exams. In terms of missing days at their educational setting (nursery, school), **29%** of parents/carers responded that their child had missed days due to their eczema.<sup>iv</sup>

Unsurprisingly, those young people who classed their eczema as 'severe' were more likely to report that their eczema had impacted their time at school, university or work in all categories (missed days, concentration, bullying and missing out on activities). However, interestingly **11%** of those who classed their eczema as 'mild' reported that their eczema had still caused them to miss days off of school in the past year.<sup>iv</sup> Geographic location was important for outcomes; data from young people and their parents/carers showed that in Scotland, they were less likely to miss days of school/university/work (**19%**) compared to their counterparts across the UK (**36%** in Northern Ireland, **30%** in Wales and **26%** in England).<sup>iv</sup>

It was highlighted in respondents' comments in the survey the impact their eczema has on their ability to attend lessons, for instance having to leave early to reapply their

creams. School uniform can affect their experience with respondents explaining that the fabrics and requirements exacerbated their symptoms. Worryingly, a number of young people who responded mentioned that they were unable to properly concentrate or write in exams due to the pain. These experiences show that the impact of eczema for pupils can be significant and unfortunately, many don't appear to receive the support they need at school.

## AWARENESS OF ECZEMA IN SCHOOLS

Despite the substantial impact eczema can have on a pupil's experience in education settings, a number of schools do not appear to have the tools to support pupils with eczema. Many students feel they are not supported nor their needs understood.

Whilst the majority of parents/carers of children of all ages (**80%**) stated school/nursery understands their child's eczema needs<sup>iv</sup> and **87%** said the educational setting had been supportive of their child's needs,<sup>iv</sup> young people's responses showed that they do not feel the same way. **56%** of young people stated that their school didn't understand their needs.<sup>iv</sup> It also appears that the older a child gets the less support they are likely to receive. The pie charts on page 12 shows that the older a child gets, the less likely they were to report having a formal or informal support plan in place in their educational or work setting.

Young people in Scotland reported that schools, universities or work understands their needs more than in other parts of the UK - **64%** agreed, compared to between **54%** and **55%** reported across England, Wales and Northern Ireland.<sup>iv</sup> As such, they were more likely to be provided with a formal or informal support plan/agreement: **27%** reported having one in place in Scotland compared to England (**22%**), Wales (**23%**) and Northern Ireland (**27%**).<sup>iv</sup>

## IMPACT ON EXAMS

**"I feel that there should be an option to apply cream in...exam(s) because writing often makes my eczema itchy. Extra time should be allocated to put cream on during the examination if you need to...Otherwise you sit and write in pain which... disrupts your train of thought."**

*(15-year-old respondent)*

**"(I) cannot write in exams because my fingers are impacted a lot by eczema."**

*(17-year-old respondent)*

**"I would get very itchy and bleed before exams."**

*(17-year-old respondent)*

## IMPACT OF UNIFORM

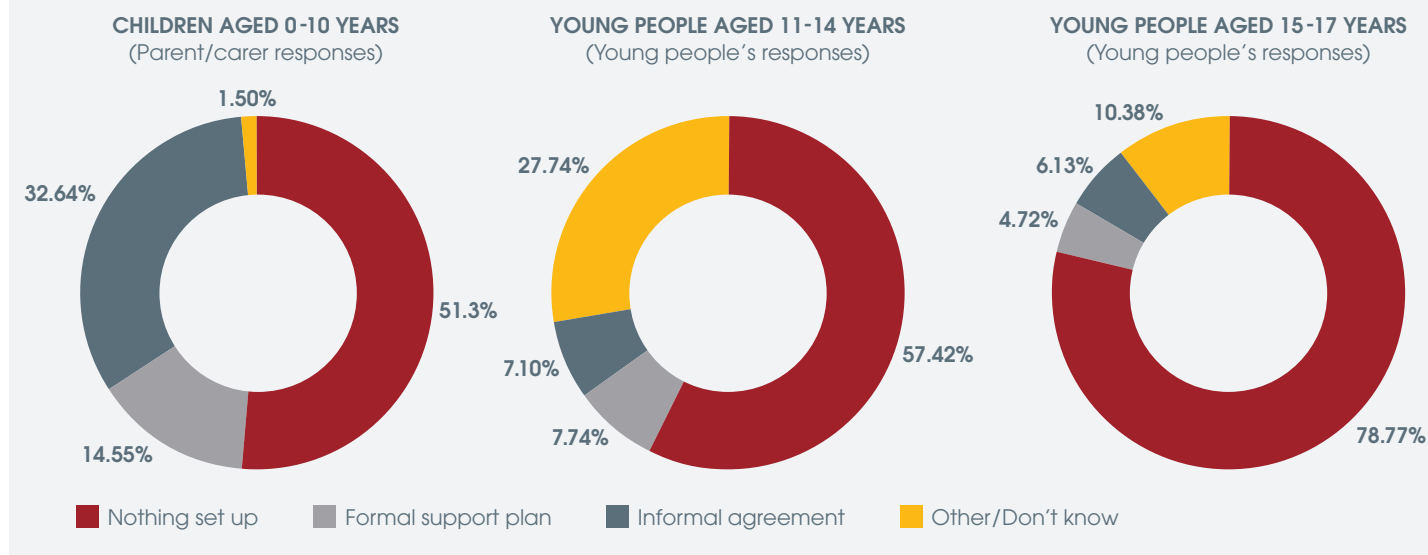
**"I do feel itchy sometimes with my school uniform but I still need to wear it. It's mostly polyester. I hate it."**

*(11-year-old respondent)*

**"School uniform is uncomfortable for someone with eczema so it would be nice if they had alternative materials or allow us to wear something else to let us be comfortable."**

*(16-year-old respondent)*

## FORMAL OR INFORMAL SUPPORT PROVIDED IN EDUCATIONAL SETTING OR WORK (BY AGE)



It is clear that a lack of awareness of the impact of eczema from staff and other pupils also hugely impacts a student's experience in education. Many schools do not educate their students about eczema and as such, those with eczema can face unkind words or bullying. Results from the survey showed this gets worse as pupils get older. For children aged 0-10 years, **22%** of parent/carer respondents said this had happened in their child's education setting.<sup>iv</sup> The figure increases (**32%**) in those responding about young people's experiences.<sup>iv</sup> Interestingly, young people in Scotland (**23%**) and Wales (**25%**) were less likely to experience this than in England (**42%**) and Northern Ireland (**47%**).<sup>iv</sup>

As a result of teachers not understanding eczema needs, many children find their experiences more difficult. Young people reported teachers strictly enforcing uniform policies that exacerbate their eczema or telling them to remove layers (e.g. during PE) leaving their inflamed skin exposed and them feeling vulnerable. When asked about their individual experiences, some issues raised in the open text part of the survey highlighted that young people find it awkward having to explain to teachers why they need to apply cream in the middle of a lesson. Similarly, some young people outlined that their school doesn't have appropriate areas for them to apply their treatment, emphasising the importance of access to a private space. When asked what a school could do to make things better for them, one respondent said: *"Having a time and place where I can do my skin routine. Talking to someone who can help us feel comfortable with our skin, and letting other people know more about our skin so we feel more comfortable."*

**"Bullying can be quite a problem so maybe just teach kids about eczema."**

*(14-year-old respondent)*

**"Including skin conditions in the curriculum would help with bullying. Also, (schools should) take bullying seriously when it relates to skin conditions."**

*(Parent/carer of a young person aged 11-17 years)*

All these issues could easily be addressed by schools making their staff aware of measures that can be put in place to support students with eczema. It is vital that schools and local authorities recognise and implement the measures we've set out in our calls to action.

## LACK OF SUPPORT AT SCHOOL LEADS TO MANY PROBLEMS:

**"I have not been able to...participate in science experiments a few times and the teachers have never been very understanding."**

*(16-year-old respondent)*

**"I have to leave class 5 minutes early to put my cream on in two of my lessons. Sometimes I miss what the homework is."**

*(11-year-old respondent)*

**"(I need) a better place for my treatment. I have to take my clothes off in the toilet in the medical room and do my treatment next to the toilet. There isn't enough time for me to do my treatment twice at school without me missing lessons so I do it once at lunch which isn't enough for my skin and I miss time at lunch."**

*(11-year-old respondent)*

**"I wish that the school educated other students about it, because I feel like it's awkward having to explain to teachers why I need to apply cream on in the middle of a lesson, or if a classmate asks."**

*(14-year-old respondent)*



# NATIONAL GUIDANCE ON ECZEMA



## NATIONAL AND LOCAL GUIDANCE

It is vital that National Institute of Health and Care Excellence (NICE) and Scottish Intercollegiate Guidelines Network (SIGN) urgently develop guidelines for the diagnosis, treatment and management of atopic eczema in young people and adults to ensure standardised care across the UK. We know that there is variation in the care people with eczema receive across the country and national guidelines would help to address this by setting out a specific optimal pathway that can be implemented. It is also important that relevant clinical guidelines on eczema are continually updated in a timely way to reflect new treatment options, pathways and research findings.

Currently, in England and Wales, there is no national guidance from NICE on the diagnosis and management of eczema in people aged 12 years or older. NICE's guideline for under 12-year-olds focuses on the diagnosis and management of eczema including recommendations on treatment and specialist referral.<sup>xxxiv</sup> Meanwhile in Scotland, a national guideline on the management of atopic eczema in primary care was published in 2011 and this recommended a similar approach in adults and children to the management of atopic eczema.<sup>xxxv</sup>

Like Scotland, Northern Ireland has produced specific guidance on managing atopic eczema, which states that whilst NICE's guidelines are for under 12s, they can be used to manage eczema in 'older children and adults'.<sup>xxxvi</sup> While this is certainly welcome, a lack of specific guidance on the management of eczema in people 12 years and older impacts the level of care that people with eczema across the country are receiving. It means that specific consideration to the individual challenges faced by various age groups, including the difficult transition from paediatric to adult services, has not been given.

Worryingly, as well as a lack of national guidance, evidence shows that local commissioning guidance on eczema is very limited. Indeed, a 2016 Freedom of Information request found that the majority of commissioners did not have a local commissioning policy on eczema, with only 3% having guidance at that time.<sup>xxxvii</sup> Areas that provide specific local guidance for the management of eczema appear to be the exception, not the rule, and often guidance is still only focussed on children. For instance, Waltham Forest Clinical Commissioning Group (CCG), which now operates as NHS North East London CCG, published specific guidance on atopic eczema in children in 2017,<sup>xxxviii</sup> however, as with national guidance it does not apply to young people or adults' care. Now that ICSs are becoming established, it is a good opportunity to revisit the need for local guidance to ensure that the care of those with eczema is recognised locally.

As a result of this lack of national or local guidance on how eczema can be optimally managed in young people and adolescents, it is unsurprising that there are many challenges in the way some healthcare professionals manage the condition and the patient experience of care. There is a need to set out the optimal pathway for young people and adolescents with eczema to support not only themselves, but also the healthcare professionals caring for them. Guidance would support healthcare professionals to understand how to best manage the condition in patients aged 12 years and older, recognise when a referral is appropriate to specialist care, be aware of the impact that it has on people living with the condition, and could also support the right conversations with them. The survey showed that many children and young people are not receiving optimal care and highlights the need for greater standardisation of care across the UK, which would come in part through national and local guidance.

# NATIONAL GUIDANCE ON ECZEMA (CONTINUED)

## SUPPORT FOR YOUNG PEOPLE IN THEIR TRANSITION TO ADULT ECZEMA SERVICES

Transitioning to the adult care pathway is the “process of planning, preparing and moving from children’s health care to adult health care.”<sup>xviii</sup> This is an important step that young people with eczema have to take as they become adults in order to ensure continuation in their care. The transition to adulthood generally can be a difficult time for young people, and many aspects can particularly affect young people with eczema, such as progress from school to college, university or work; the pressures that become more apparent in teenage years, such as exam stress; changes in socialising habits and many others. With all of these external changes often exacerbating eczema symptoms, it is crucial that their transition to adult services is managed well. Unfortunately, the transition to adult care is “often associated with deterioration in the health of adolescents with chronic conditions.”<sup>xi</sup> When looking at involvement in care for each age group, as anticipated, older groups have a more direct input than their younger counterparts. For respondents who said they were 15 to 17

years-old, **35%** said their healthcare professional speaks directly to them, compared to **20%** of respondents who are 11 to 14 year-olds.<sup>iv</sup> Remarkably, however, **24%** of 15 to 17 year-olds reported that their healthcare professional still speaks directly to their parent or carer.<sup>iv</sup> This is concerning, as it means that many young people will not be used to taking ownership of conversations around their care and so may feel unprepared for their transition to adult services. At a basic level, young people should be prepared to become responsible for their care by having direct conversations with their healthcare professionals. It is also imperative that they have an opportunity to engage with adult services ahead of time, so that they smoothly progress through the pathway and continue to receive the care and support they need.

A number of resources have been developed for young people transitioning from adolescent to adult care more generally. The NICE guideline ‘*Transition from children’s to adults’ services for young people using health or social care services*’;<sup>xii</sup> is a key example and covers the period before, during and after a young person moves from children’s to adults’ services. As part of this guidance, a set of Quality Standards for the transition from children’s to adults’ services exist. Quality statement five focuses on ‘missed first appointments after transfer to adults’ services’, which includes steps that should be taken if a young person does not attend their first meeting or appointment, and how they should be given further opportunities to engage.<sup>xii</sup> Interventions such as this are particularly important, as falling away from the care pathway can have a detrimental impact on young people’s health.

## TRANSITIONING SUPPORT

**“He is 17 and is hugely struggling with the impact of significant flare-ups and a management plan that works. He definitely would benefit from support but nothing is offered nor is available locally.”**

*(Parent/carer of young person aged 17 with eczema)*

## CONCLUSION

The effect of eczema on the day-to-day lives of children, young people and families appears significant; from lack of sleep and concentration, to missing school and important events, to bullying and a lack of self-esteem. One of key areas that has been prevalent throughout the survey is how many children and young people do not feel heard by their healthcare professional and are ready to be more involved in their own care. It is clear that while the current level of care afforded to children and young people with eczema is of a good standard, there are areas, such as greater involvement in care,

mental health support and general understanding from peers, schools and healthcare professionals, where significant improvements can and need to be made. The adoption of our 9 key recommendations would go some way to improving the day-to-day lives of children, young people and their families. It would also provide healthcare professionals, cross-service statutory bodies, employers and educational facilities with the foundations to effectively support children and young people who have eczema in a more pragmatic way that meets their physical and emotional needs.



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