



Not Just Skin Deep

Getting under the skin of eczema

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Foreword: Allergy UK

In the four years since we worked with Sanofi, in 2017, to produce the Seeing Red: Getting Under the Skin of Adult Severe Eczema report, we have seen many changes within the NHS, with the COVID-19 pandemic continuing to have such a huge impact. Nevertheless, I am struck by the many similarities I have seen in the patient case studies and testimonies in this new report.

The impact that severe eczema continues to have on people's lives is laid out here in stark terms; lengthy waiting times, negative impact on mental health, disruption to work, disruption to personal lives. Yet still, a very small percentage of Integrated Care Systems (ICS) and their predecessors, Clinical Commissioning Groups (CCGs) have an eczema commissioning policy in place. And there is still no NICE adult guideline for eczema to help reduce unwarranted variation in care.

It is clear that getting back to where we were pre-pandemic is not enough, given the gaps in care that already existed; we do need to make services better than before.

Of course, we understand that COVID-19 has had an enormous impact, and we fully recognise this. But as consideration is being given to what good post-pandemic services will look like, there is an opportunity to ensure that we make patient centricity fundamental to our approach. Any redesigned or restored services post-pandemic must be led by the needs of the patients if we want to move forward positively.

As this report demonstrates, severe eczema continues to be a source of considerable and relentless distress to those who live with the condition; distress that is both physical and psychological. And it is this continuing burden for people with severe eczema that motivated us to once again partner in producing this report.

As the UK's leading patient organisation providing support services across the breadth of allergic disease, we look forward to working with all stakeholders to help drive forward the work required to improve services for people living with this distressing skin condition.

Because quite simply, there has not been enough improvement in quality of life for people living with severe eczema in the four years since our last report. Hopefully the experiences of patients presented here will help to inform and drive the necessary change that we and everyone with severe eczema wants to see. - Carla Jones, CEO, Allergy UK

Executive Summary

Not Just Skin Deep: Getting under the skin of eczema, aims to highlight the psychological, social and physical effects of moderate-to-severe eczema on those who have to live with the condition.

The COVID-19 pandemic has had an adverse impact on all health conditions, including eczema. But for those living with eczema, many of these issues existed long before the pandemic.

In 2021, Allergy UK along with Sanofi surveyed 30 healthcare professionals, 268 moderate-to-severe eczema patients, and received Freedom of Information responses from 99 of the remaining CCGs within 42 Integrated Care Systems, to produce this report and explore the long-term impacts of a life with eczema. The headline findings from our research are outlined below.

Our Findings:

Experience of care

Almost half of HCPs felt they didn't have clear guidance

and support around when to **diagnose and refer patients** with atopic dermatitis.⁵

Over a quarter of patients waited over one year

for a **referral to specialist care** for their treatment.⁶



50% of 179 waited more than a year for a treatment regime that made their eczema manageable.⁶



Only 3% of CCGs

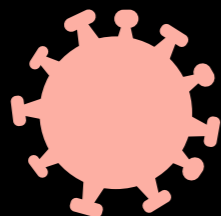
had an **adult eczema commissioning policy** in 2021.¹⁸

CCGs that did not have a commissioning policy had **no plans to put a policy in place** within the next 2 years.¹⁸

Covid-19 and eczema

26 out of 30 HCPs

said COVID-19 had made it moderately to extremely **difficult to diagnose patients**.⁵



Almost 1/2 of 196 patients

said COVID-19 had made it more **difficult to access services and treatments**.⁶



Quality of life

~1/3 of 206 patients spent over an hour each day

managing their eczema.⁶

78% of 237 patients admitted eczema had

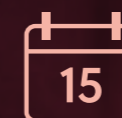
negatively impacted their mental health.⁶



23% of 92 patients

took more than 15 days off work

due to their eczema.⁶



~1/3

of patients had experienced **depression** due to their eczema.⁶



90% of 264

patients with eczema have an additional allergic condition and

a 1/4 have 3+ allergies.⁶

93% of 237 patients are not aware of any mental health support.⁶

30 out of 30 healthcare professionals felt there was not adequate mental health support provided for patients with eczema.⁵



Introduction

Since our first report on severe eczema Seeing Red¹ in 2017, the healthcare system has faced major challenges, none more severe than the COVID-19 pandemic, which forced clinicians to suspend face-to-face consultations^{2,3} and led to a backlog in the identification, diagnosis and treatment of patients.⁴

Of the healthcare professionals surveyed in this report alone, the majority said the pandemic has made it difficult to both identify and diagnose patients,⁵ and patients themselves have struggled with the lack of face-to-face appointments for skin conditions.⁶

As we reset from the pandemic, the reconfiguration of the healthcare system from Clinical Commissioning Groups (CCG) to new Integrated Care Systems (ICS), provides an opportunity to not only recover services but to improve them. As part of this change, Primary Care Networks (PCNs) will become the centre of service delivery and assessing local population health. Therefore, it is critical PCNs take a leadership role in supporting patients with skin conditions, especially as the burden of presentations and management occurs in primary care.⁷

This report aims to provide an insight into the lived experiences of patients with moderate-to-severe eczema and highlight the significant impact on day-to-day life. Crucially, it will present actionable healthcare solutions to address the issues faced by patients, reform the patient pathway, and improve lives.

“It’s a demoralising and miserable condition to live with and it is often hard to find anything that really makes a difference.”⁶

Methodology

In 2021, to assess the impact of moderate-to-severe eczema on patients we developed a methodology that encompasses both qualitative and quantitative research. This has included: a survey conducted by Allergy UK in which 268 patients shared insights on their lived experience with moderate-to-severe eczema, interviews with people living with the condition, and a survey conducted by Allergy UK of 30 healthcare professionals (HCPs). We also received Freedom of Information responses from 99 of the remaining CCGs, as they stood in 2021, within 42 ICS’ about their eczema commissioning policies. This report will refer to the primary research we have conducted throughout, notably in reference to the statistics, quotes, and case studies herein. We have also identified the sample sizes throughout, based on the total number of respondents who provided an answer for the question.

What is eczema?

Moderate-to-severe eczema, clinically known as atopic dermatitis, is a chronic inflammatory autoimmune disease that causes the skin barrier to become defective, leading to a loss of function which means that allergens can sensitise through the skin. It is normally characterised by itchy, non-contagious, inflamed skin that can be present on any part of the body.⁸

“I’ve got eczema that causes blisters, so when they itch then burst, [it makes] skin terribly sore.”⁶

Section one: COVID-19 and eczema

The challenges faced by the NHS due to the COVID-19 pandemic are well known⁹ and for patients living with moderate-to-severe eczema, those challenges have been particularly acute, with specific issues identified in diagnosing and referring patients, as well as in access to services.^{5,6}

“It’s been so awkward because you can’t have face to face appointments. You have to take a photo of the problem and the eczema made me feel so bad about myself, the last thing I wanted to do was take pictures.”⁶

While there is recognition that healthcare professionals delivering services have been doing their best in very difficult circumstances, the limitations of sustained interaction by phone have become apparent. One of the reasons for this may be the difficulty in assessing a very visual disease remotely. This hints at the limitations of digital consultation which may not be suitable as a long-term solution.

“Not been able to attend hospital appointments in person - (it) is no good for skin conditions.”⁶

Additionally, there have been difficulties faced during the pandemic, where some services (those deemed acute, or essential like cancer and emergency services) were prioritised above others.¹⁰ This has had a knock-on effect on eczema patients and the service that they have received, with just under half of patients surveyed saying that the pandemic has made it more difficult to access services and treatments.⁶ While it is testament to the efforts of the healthcare professionals that run moderate-to-severe eczema services, and their extraordinary efforts during the pandemic, that this number is not greater; a large proportion of people have faced disruption and difficulty in accessing the services upon which they rely.

26/30 HCPs we surveyed said COVID-19 has made it moderately to extremely difficult to identify patients.⁵

One third of HCPs indicated that it has been much harder to diagnose patients with moderate-to-severe eczema.⁵

25/30 HCPs said COVID-19 has made it moderately to extremely difficult to refer patients with eczema.⁵

“Appointment has been cancelled multiple times. Stress has made my eczema flare.”⁶

Evidence shows there has been a significant impact upon both the delivery of eczema services, and the impact felt by individual service users. A particular difficulty with moderate-to-severe eczema is that as well as leaving service users feeling that their clinicians have struggled to assess their conditions via remote digital methods, the stress of using a service under COVID-19 restrictions could also have exacerbated some people’s eczema.⁶

“I have had good GP and hospital service throughout COVID-19, but a lot of contact has been by phone. It’s very hard to feel understood or properly assessed by phone.”⁶

COVID-19 has also resulted in other lesser examined consequences for people. The practice of frequent handwashing and using alcohol-based hand gels can cause problems such as dry hands and hand eczema.¹¹ Moreover, recent studies have indicated that the pandemic has led to increased instances of skin irritation and disease, especially among health workers who are required to wear personal protective equipment.¹²

This could mean that as the UK gradually reopens, a new spike in the number of moderate-to-severe eczema cases may emerge.



Recommendations

- The option for in-person consultations should be returned to ensure skin conditions can be appropriately diagnosed and managed. The NHS Long Term plan highlighted a drive for some specialist referrals for dermatology to take place with pictures and questionnaires¹³ this should be part of the shared decision-making between patients and their clinical teams.

Patient case study

“I refuse to use hand sanitiser.

If it's offered, I'm happy to go and wash my hands with soap and water. I will happily do that; I'm not going to refuse, but I am not using gel because if I have cuts in my hand, it's just so painful. On face masks, I mainly suffer with facial eczema and it's mainly across my top lip here, so I've had to find face masks that are lifted off my face so they're not resting on it so that it doesn't create a flare up. That's OK in the winter and sometimes they actually help because I'm able to maintain a consistent skin temperature, so it doesn't dry out as much, whereas in the summer obviously it's like baking underneath which is not what you want.” – **Anonymous patient**

“When the pandemic began, I was quite new to taking the immune suppressant drugs, and I found it very difficult to have any sort of advice on how long I needed to be taking these for, what would happen if I stopped taking them etc. So, there was a period of quite a few months where I was kind of a left in limbo. And having treatment such as that to make it work safely you need to have regular blood tests, so COVID-19 really did make me worry about the treatment I was on at the time, because I didn't feel like it was being monitored to the extent of what I knew it had to be. I couldn't have the face-to-face discussions with the specialist so I ended up writing a letter to one of the doctors because I had some real concerns about the medication.

The medication made me have to shield. I live on my own, so I had to work from home for about four months, not see anyone, and that did negatively affect me mentally. I felt isolated and, you know ... I couldn't even go back into work when we were allowed. I was in sort of a long-distance relationship, my girlfriend lived fifty miles away, and it meant that I couldn't see her. That put a massive strain on our relationship. I think the shielding and not being able to spend that time together had such a detrimental effect that we eventually split up.” – **Stephen**

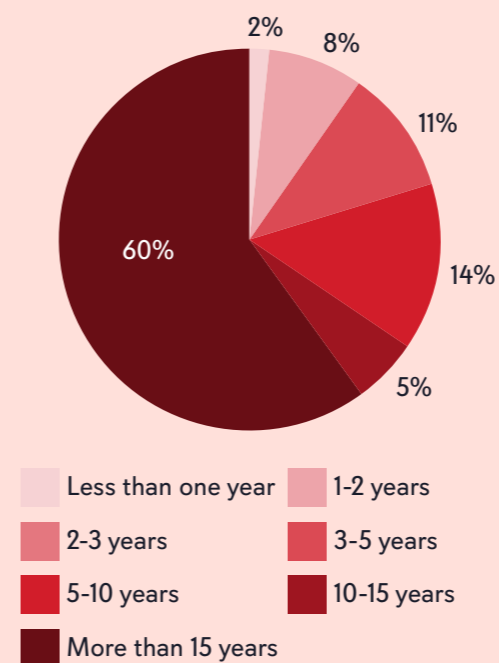
Section two: Experience of care

History and childhood transition

Patients with moderate-to-severe eczema have been affected by the condition for many years and have had varied experiences of care as they transitioned into adult services.

Of the patients surveyed, many found they received better support in childhood services, and that this was recognised by their own clinicians. Patients were often told in their childhood they would “grow out” of the condition and have not, and those who continued to receive long-term support are prescribed stronger treatments in adulthood.⁶

How long have patients lived with eczema?⁶



“My dermatologist has explained that children’s services are better than adult services.”⁶



Two thirds (60%) of 265 patients surveyed have lived with moderate-to-severe eczema for over 15 years.⁶

76% of 264 patients have experienced moderate-to-severe eczema throughout their childhood.⁶

Recommendation

- Each ICS / PCN should improve the transition of childhood to adult care settings.

Diagnosis

Waiting times

Diagnosis is the initial stage for patients to access appropriate treatments and start to be able to manage their eczema effectively. However, we found that there is likely to be significant variation in time to diagnose moderate-to-severe eczema patients. Just over one in three (37%) patients surveyed were seen within a month of noticing their first symptoms, while one in five (20%) waited over one year for an eczema diagnosis.⁶

Guidance and support for healthcare professionals

We found the majority (23 in 30) of healthcare professionals thought there was not a good awareness of how to manage and treat moderate-to-severe eczema amongst GPs,⁵ which could be one reason diagnosis of eczema patients can sometimes be poor. Indeed, they mentioned that there was variation in many areas related to the diagnosis of the disease, including knowledge of eczema and treatments, as well as degree of priority and follow-up support.⁵

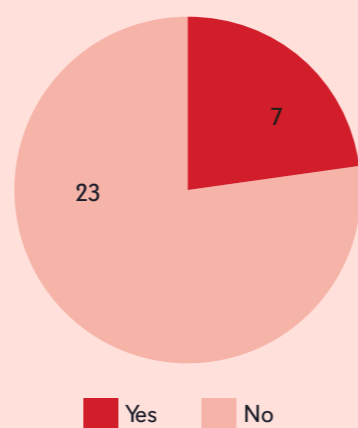
“It is variable. Some have understanding of the need for the right amount of emollients and other topical ointments or cream to be dispensed. Some do not consider it (eczema) a significant problem.”⁵

Of the 13 healthcare professionals who did not think they had clear guidance, 12 HCPs agreed they would benefit from clearer guidelines to help diagnose and treat patients with moderate-to-severe eczema.⁵

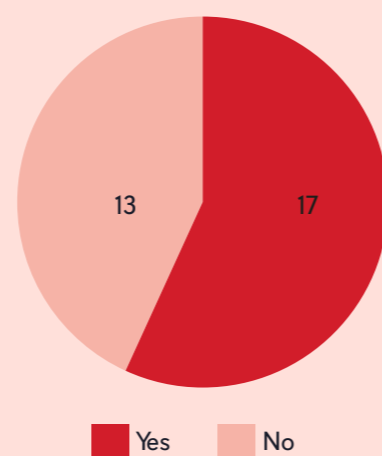
Healthcare professionals highlighted the importance of clear guidelines, noting that there is currently a lack of consensus at all stages - from naming the disease, through diagnosis to treatment. Clear guidelines were also deemed “essential” to support understanding of the disease and treatments to the patient.⁵

For those who did not have an issue with guidelines, one healthcare professional had written guidance for their own department which had been effective and supported prescribing decisions, and another regularly managed eczema.⁵ This still indicates that clinicians either need experience in the area or require clearer, updated guidance.

Did HCPs think there was good awareness of how to manage and treat eczema amongst GPs?⁵



Did HCPs think there was clear guidance and support to diagnose and refer patients?⁵



Tools to identify severity of eczema

Only 13 out of 30 healthcare professionals surveyed currently use tools such as scoring systems to identify, diagnose and refer people with eczema; and even then, these are generally used in an inconsistent way.⁵

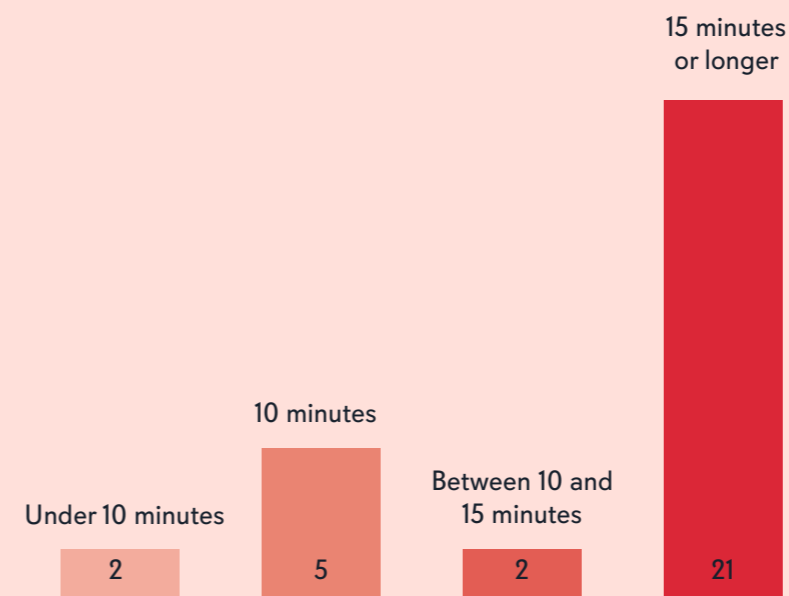
25 out of 30 HCPs agreed the following elements should be included in the national scoring system⁵:

- Total body surface affected
- Severity of dry skin and redness
- Pruritus (itch)
- Psychological impact as reported by the patient (e.g., loss of sleep, mental health impact)

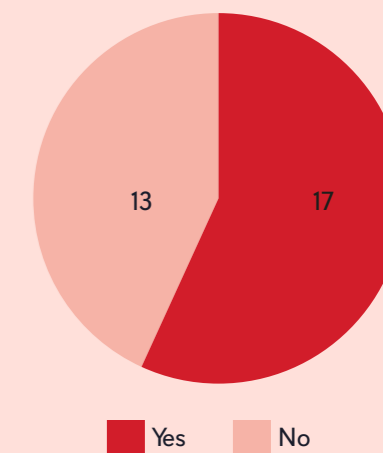
Additional elements were also suggested such as impact on school or work, adequate access to treatments, triggers, skin pain, area affected, presence of chronic changes such as lichenification and prurigo, infections, and taking into consideration people with darker pigmentation i.e., terms such as “redness” are not beneficial.⁵

A clearer and more consistent use of scoring systems and guidelines could help reduce consultation times, as we found that eczema consultations took up a significant amount of time for healthcare professionals, with the majority (21 in 30) lasting 15 minutes or longer.⁵

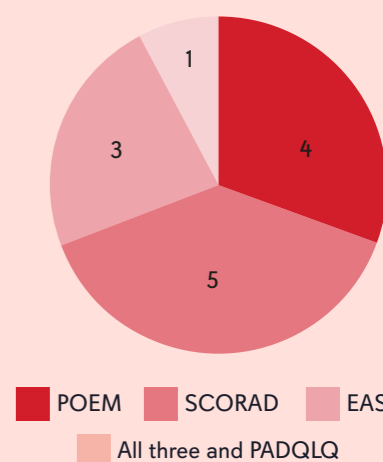
How long do HCPs spend in a typical consultation with patients?⁵



Did HCPs currently use an eczema scoring system?⁵



The 13 HCPs that did use an eczema scoring system, used the following:⁵



Recommendation

NICE should prioritise development of an adolescent and adult guideline for atopic eczema, for those aged 12 and over, to address unwarranted variation, which all ICS / PCNs should use to reduce the ‘postcode lottery’. This should include a policy around steroid use for eczema to address overuse and a national scoring system for atopic eczema. It should be circulated amongst healthcare professionals to ensure consistency of use.

Referral

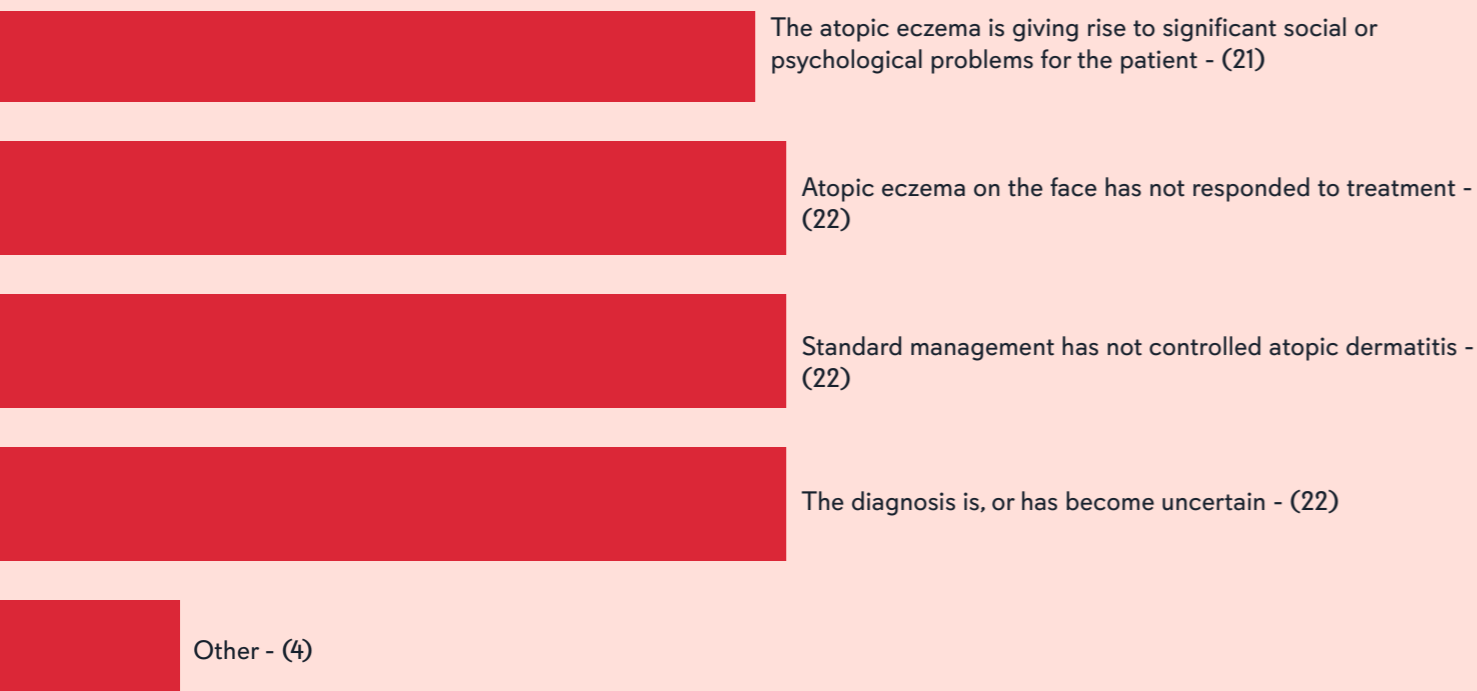
Specialist care

Once people are diagnosed, those with moderate-to-severe eczema may need to be referred to specialist care. We found significant variation in waiting times for a specialist referral, with the average¹⁴ wait being over three months.⁶

The exact reasons for this variation in specialist referral are unknown, however healthcare professionals do trigger referrals for a multitude of reasons at their discretion. Beyond the main reasons identified in our survey, other reasons for referral specified included age and aesthetics, the need for secondary care or advanced therapy, parental request, or that a patient previously had PUVA and requested the same.⁵

“It took several years to be taken seriously and be referred to specialists. So, by the point I received treatment that worked, my skin was so unmanageable that it has taken years to try and recover it to a more manageable state.”⁶

What symptoms or context might trigger a referral to a dermatology specialist by HCPs?⁵



Appropriate treatment

The amount of time patients wait for a referral can hinder their ability to appropriately manage their eczema, becoming a long-term issue for many which affects their quality of life. Patients had varied experiences accessing appropriate treatments. Some people also suffered from steroid withdrawal reactions, after being prescribed steroids for a long period of time,⁶ which are known to be associated with topical creams.¹⁵ Patients noted that they often managed their treatment at home, by themselves without input from clinicians, and this can sometimes have a financial burden on patients.¹⁶

“I have had to shop around for the last 10 years or so when it comes to finding a GP who is interested in helping to solve the problem as many (in my opinion) rush to prescribing steroid creams and don’t understand the impact of eczema on day to day life.”⁶

“A lot of creams didn’t work but I have now found one that does. It has been expensive.”⁶



Half of patients (50% of 179) wait more than a year for a treatment regime that makes them feel their eczema is manageable.⁶



73% of 154 patients were referred to specialist care within one month to one year after their diagnosis.⁶



27% of 154 patients waited over a year for a referral to specialist care.

Of those who waited at least one year for a referral, nearly two thirds (63%) ended up waiting over two years.⁶

Pathway improvement

In addition to improving the scoring system itself, healthcare professionals were keen to see the overall pathway improve for patients.

HCPs suggested the following to improve the overall patient pathway:⁵

- More specific national guidelines for primary care
- Quicker access to specialise dermatology clinics
- Improved availability of contact allergy testing
- Improved teaching about steroid potency and maintenance regimes

Parliamentarians have previously called for the creation of national clinical guidelines for the management of moderate-to-severe eczema in adults and adolescents. Ministers from the Department for Health and Social Care have confirmed that there is a commitment for NICE to develop a guideline for adult moderate-to-severe eczema,¹⁷ however no significant progress on this has been made since our first report, Seeing Red,¹ in 2017.

The East of England is the only English region which has CCGs with adult eczema commissioning policies,¹⁸ indicating there is a ‘postcode lottery’ for patients when it comes to standardised care.

Current commissioning policy

None of the CCGs that did not already have a commissioning policy had plans to put one in place within the next 2 years.¹⁸

However, some CCGs tend to follow the NICE technology appraisals for eczema, and have created guidance on treatment prescription based on these,¹⁸ or have created their own internal triaging system.¹⁸ This shows there is a need for standardised guidance of care, as there seems to be reliance on the NICE technology appraisals which do not provide a holistic view of care across the patient pathway.

Only 3% of CCGs had an adult eczema commissioning policy in 2021.¹⁸

This is compared to 3% in 2017¹ showing not much has changed since our initial report¹ in terms of creating and implementing policies.



Patient case study

“I’ve actually been at the same GP all of my life, but I was never ever referred to a dermatology unit or moved from paediatrics to adult care purely because I wasn’t perceived to have severe enough eczema.

My general experience is trying to explain to GPs what you’re feeling, and they’ve got a tick box in front of them. GPs obviously have a surface level understanding of so many illnesses because that’s their job. They signpost you to a specialist, but they don’t necessarily signpost you early enough. Or if you’re perceived to be coping, it’s easier for them to give you a steroid cream rather than dig into the deeper problem, - they’re just putting a plaster on the wound rather than stopping you fall over.

From my experience they only refer you if it starts affecting your quality of life. I haven’t experienced it, but I know of other people that suffer from eczema, when they arrive at a GP or the dermatologist, they’re given a form about rating their quality of life and how much their condition is affecting it. I think that’s starting to come into it. I personally was referred to allergy testing when I was because it was affecting my quality of life so much that I had zero social life and I think that’s partly why I think I got that referral.” - **Anonymous patient**

“If I was able to control my journey in a more positive way, I would say that I would ideally have been diagnosed earlier. I would have talked to the right people at the point of first getting symptoms, and not having 2 or more years of worrying and not knowing what was going on. And I could have just been given the best treatment for me at the time. And that is a selfish perspective, that’s me just saying, ‘God, I wish I hadn’t had to go through those years of turmoil to get to where I am now’, but I also think of it as being an economic benefit as well. I think that by lots of trial and error, and consultation after consultation, and going A to B to C and back to A again, it can cost the NHS a heck of a lot of money. If I could be seen by the right person at the outset, then me and the NHS could have avoided all that expense, as well as the heartache.” - **Stephen**

Recommendations

- Each ICS / PCN should have a commissioning policy for dermatology to ensure there is a standardised pathway and access to care for people with eczema, irrespective of where they live.
- Each ICS / PCN should have a dedicated dermatology lead who acts as the key liaison with secondary and specialist care dermatology departments.

Section three: Quality of life

Daily life

Living with a long-term skin condition can take a toll on patients' lives, and management of symptoms often takes up a significant portion of time.

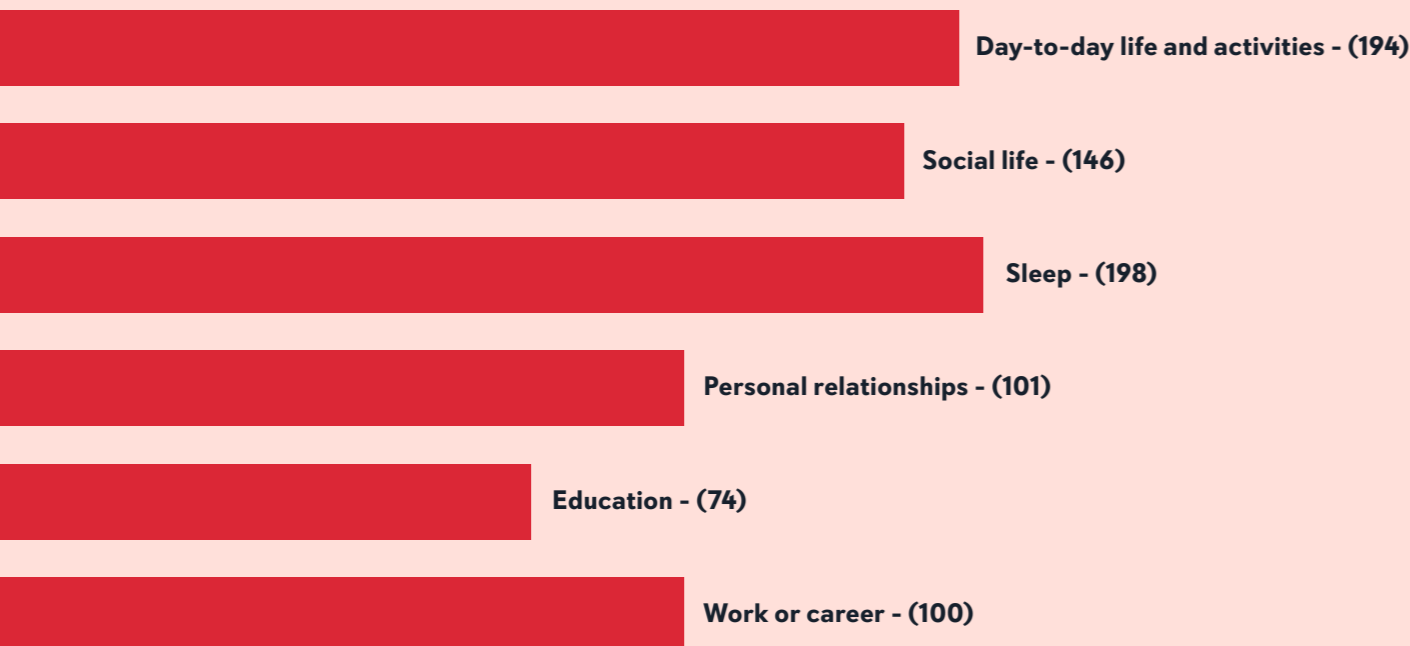
“I have had to learn to live with it by accepting the need to apply up to six different creams daily and ensuring that I faithfully do this to manage the condition.”⁶

Notably, almost a quarter (23%) of the 92 patients who had to take time off work ended up missing more than 15 days of work because of their condition⁶ which indicates a severe impact.

The UK workforce already experiences a high level of sickness absences; in 2020 it was reported that 118.6 million workdays were lost, equating to 3.6 days lost per worker.¹⁹ Our data⁶ reflects that moderate-to-severe eczema patients experience higher than average levels of sick days compared to the average UK worker, revealing a potentially detrimental impact on finances and employability for this population of patients.

The impact of living with eczema on patients daily life⁶

Aspect of daily life which have been disrupted



Around a third (32% of 206) of patients spent over an hour each day managing their eczema, i.e., through applying creams.⁶

Psychological Health

The psychological health impact on people with moderate-to-severe eczema is extensive, indicating that skin conditions have a far deeper reach into the social and psychological health of patients beyond just physical debilitation and time spent on disease management. Indeed, it has been found that depression, anxiety, and suicidal ideation are more common amongst people with moderate-to-severe eczema.²⁰ These damaging social and psychological impacts of the condition need to be addressed and supported appropriately.

More than three quarters (78%) of 237 patients were affected by social or psychological health issues.⁶

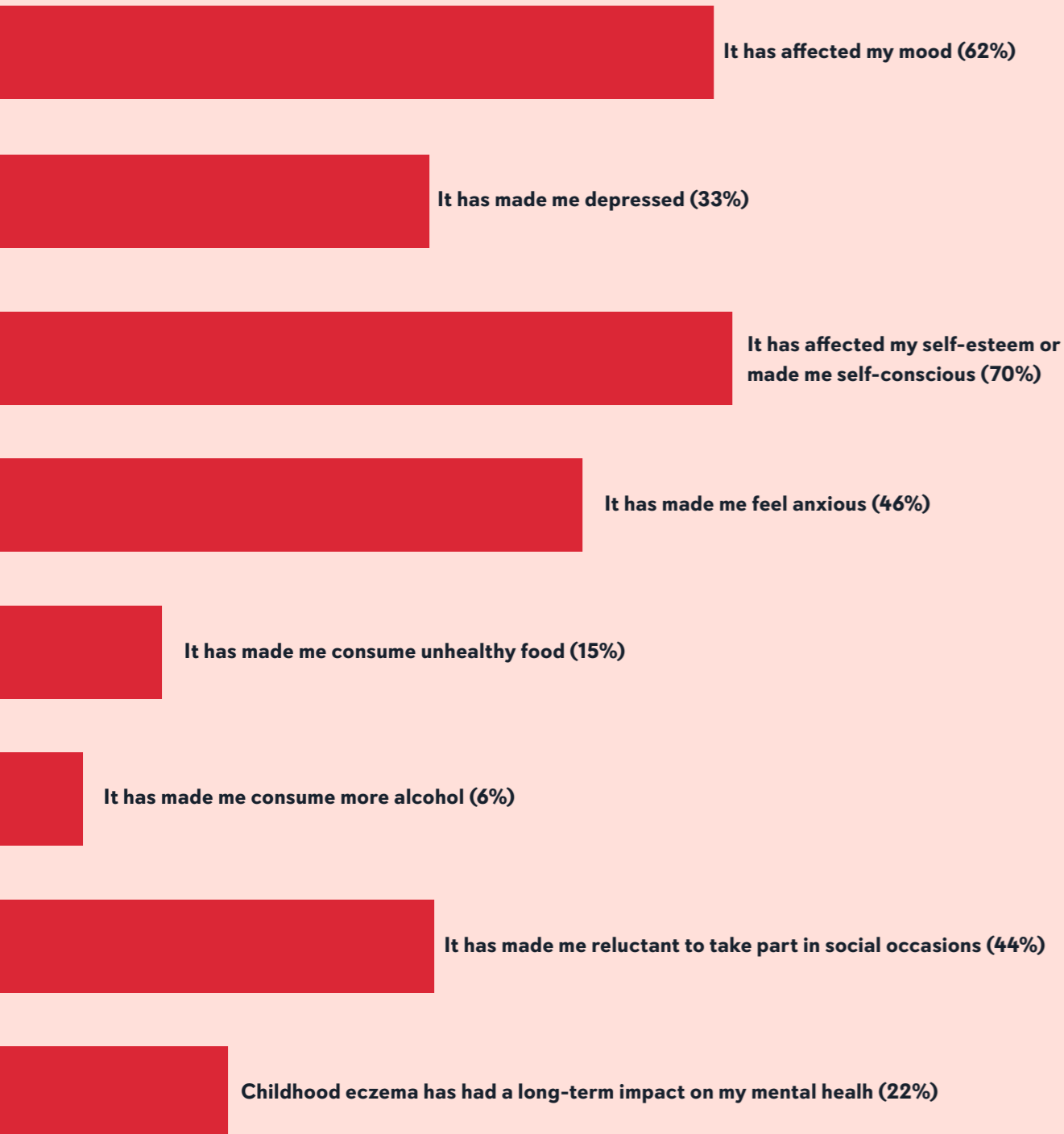
“I have had eczema for my whole life - it has been horrendous. It has been dreadful, wrecking many hopes and dreams.”⁶



The number of different social or psychological effects people living with eczema suffer from⁶:

0	27%
1	10.5%
2	10.9%
3	15.4%
4	12.7%
5	10.9%
6	9%
7	2.2%
8	1.5%

Patients who experienced social and psychological effects from living with eczema said they had been impacted in the following ways:⁶



Evidently, the wide-ranging burden of moderate-to-severe eczema needs to be considered when diagnosing and treating patients, to provide a holistic care pathway that considers the social and psychological needs in addition to the physical. However, patients currently are unaware of the existence of patient support groups or of psychological support they could be referred to.⁶ There was also a clear consensus amongst healthcare professionals that psychological support for patients was poor.⁵

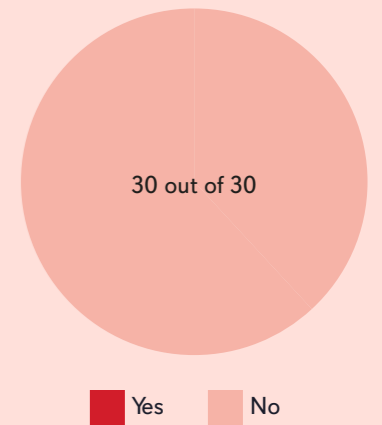
98.5% of 201 patients said they had never been advised to access a support group.⁶

93% of 237 patients were unaware of the existence of psychological support.⁶

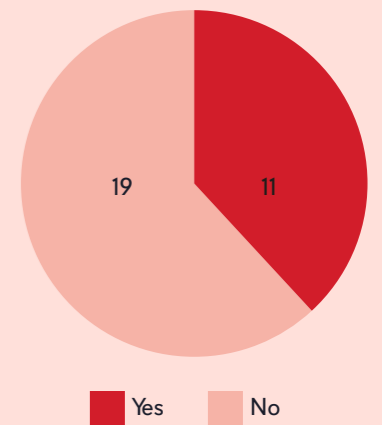
Only 6% of 106 patients had been offered any psychological support by their clinician.⁶

The three patients who said they had been told of a patient group had been signposted to the National Eczema Association, Allergy UK and Allergy Card respectively.⁶

Did HCPs think there was adequate mental health support for patients?⁵



Did HCPs refer patients for psychological support?⁵



Physical health

Notably, the patients we surveyed were found to have a range of other allergies alongside their eczema diagnosis, which could indicate a common underlying trigger for these conditions.

“Combine eczema with asthma and twice a year I get a major episode that requires steroid treatment.”⁶

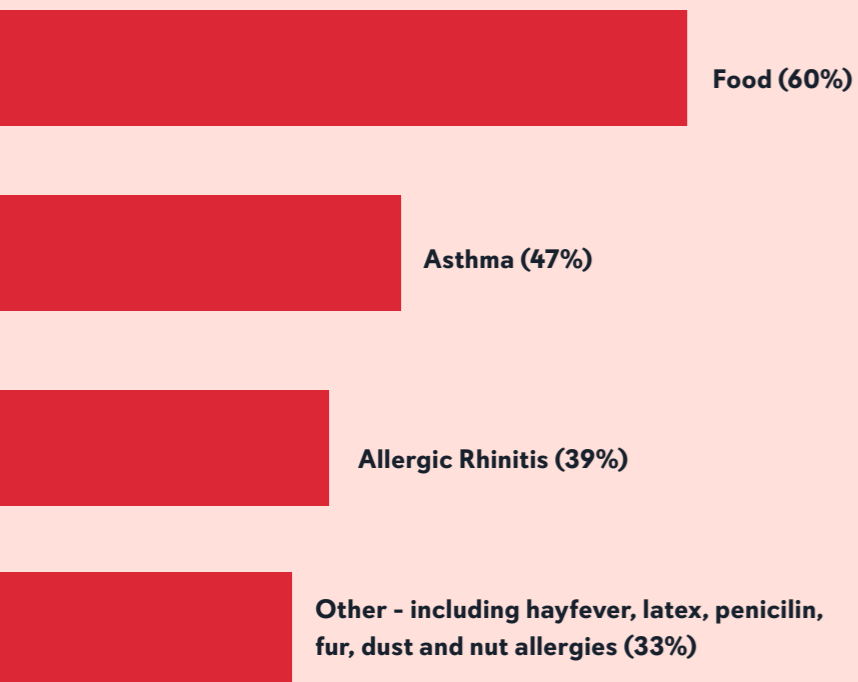
In 90% of 264 patients, moderate-to-severe eczema was one of at least two co-existing conditions.⁶

A quarter of 264 patients had three or more additional allergies.⁶

The patients who suffered from co-existing allergies found that there is little joined up care across services to address all these issues efficiently and effectively due to the lack of knowledge by clinicians or simply a lack of communication across clinics.⁶



Percentage of people that suffered additional allergies alongside their eczema⁶
Type of allergy



Recommendations

- Each ICS / PCN needs to ensure psycho-dermatological support, such as counselling, is commissioned as part of the patient pathway, to improve access to psychological support.
- Education and training of healthcare professionals in primary care on the availability and range of support services available, including patient advisory groups, should be improved so that they can signpost patients to support.
- Each ICS / PCN requires greater collaboration between dermatology, allergy, and respiratory departments to ensure an integrated and personalised approach to patient care.

Patient case study

“I never relax.

I used to relax with a bath, but going in a bath now is just a nightmare, and the shower - that feels like needles, the force of the water. I can't stop scratching and I scratch all night in my sleep. I wondered if some CBT might help me with thinking about how to stop myself scratching. The clinical team agreed but the waiting list was so long that I never got any, so I didn't really get any help with anything. I was once given a Quality of Life questionnaire, to fill in with scores of 1 to 10 for things like how much it impacts on relationships, work, social life, all those sort of things. Well, 10 was the most negative score, and I put 10 for them all, and some of them I put 10+++. When I saw the consultant I said “If you look through my notes you should find a piece of paper with my Quality of Life questionnaire on there... it might help if you looked at that to understand what I'm going through”. Nobody addressed that questionnaire, they did nothing with it.” - Sarah

“My normal was probably quite a high level of discomfort compared to the average person but that's just what I thought everybody was living with, so I was like “OK this is what we have to deal with”. From the age of 4 to 12 I would go to bed quite early because I'd had enough of trying to cope with what I was coping with in the day. I would sit on my parents' bed and watch TV or something to distract me. There's a lot of adjustments that are done every day and in family life that we didn't realise we had made. We wouldn't travel further than France just in case. Obviously because evenings were just a struggle to get to bed there was no kind of “let's go out and do this” and if someone had pointed that out it would have been apparent to us. But even my parents admit that we just became accustomed to what we were doing and it's only when we would stay with family, they would see our evening routine was not normal, and that struck a chord.” - **Anonymous patient**

“I was invited by a friend to go to a wedding in Thailand, and the whole thing was very, very painful and very, very unpleasant for me. Travelling on planes was very uncomfortable but when I got to the airport, one of our flights was cancelled so we had to try and get another plane, and the guy checking us in looked at me in horror and said, ‘Are you okay? Are you sure you're okay to fly?’ Because my skin was that bad. What he could see around my neck and shoulders was so red and inflamed, and I was so physically in discomfort, that I think it kind of broke his heart. He didn't think it was a good idea for me to get on the plane. On the actual day of the wedding itself I ate some food that basically made me have such a bad reaction that I ended up hospitalised.” - **Stephen**

Recommendations

We are calling for the following recommendations, summarised from the report, to be implemented to improve the patient pathway, access to care, and ultimately the lives of those living with eczema.

1. Develop standardised NICE adult & adolescent guidelines

NICE should prioritise development of adult and adolescent guidelines for atopic eczema, to address unwarranted variation which all ICS' / PCNs should use to reduce the 'postcode lottery'. This should include a policy around steroid use for eczema to address overuse and a national scoring system for atopic eczema. It should be circulated amongst healthcare professionals to ensure consistency of use.

2. Ensure all ICS' have an eczema commissioning policy

Each ICS / PCN should have a commissioning policy for dermatology to ensure there is a standardised pathway and access to care for people with eczema, irrespective of where they live.

3. Improve psychological support and access

Each ICS / PCN needs to ensure psycho-dermatological support is commissioned as part of the patient pathway, to improve access to psychological support. Education and training of healthcare professionals in primary care on the availability and range of support services available, including patient advisory groups, should be improved so that they can signpost patients to support.

4. Prioritise and integrate eczema across settings

Each ICS / PCN should ensure the patient pathway is integrated across different settings in which eczema patients present. This includes:

- Improving the transition of childhood to adult care settings
- Require a dedicated dermatology lead who acts as the key liaison with secondary and specialist care dermatology departments
- Greater collaboration between dermatology, allergy, and respiratory settings to ensure an integrated and personalised approach to patient care.

5. Ensure in person appointments are maintained for skin conditions

The option for in-person consultations should be returned to ensure skin conditions can be appropriately diagnosed and managed. The NHS Long Term plan highlighted a drive for some specialist referrals for dermatology to take place with pictures and questionnaires,¹³ this should be part of the shared decision-making between patients and their clinical teams.

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