

DEMOS

THE COSTS OF ATOPIC DERMATITIS

ALICE DAWSON

APRIL 2023

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Alice Dawson
April 2023

EXECUTIVE SUMMARY

Atopic dermatitis (AD) is the most common form of eczema in the UK affecting 5-10% of all adults. There isn't one single cause of AD but it is thought to be down to a combination of immune system problems and genetics, and can be triggered by factors like stress, irritants and the environment, leading patients to develop patches of itchy, cracked, dry and sore skin. From the financial costs of medications to an increased risk of developing depression, the costs of AD to many patients are wide-ranging and detrimental to their quality of life, particularly for patients from lower socioeconomic backgrounds. This report aims to investigate and raise awareness of these costs, and set out recommendations on how to improve patient care in order to help reduce these costs.

For many AD patients, the impact this disease has on their lives is exhausting and debilitating. Whether it is the costs of medication, special clothing or travel to appointments, the financial costs patients face to manage their AD are wide-ranging and especially burdensome for those who are financially less well-off. Patients also go through tireless efforts to self-manage their AD, often taking hours out of their day to apply treatments and avoiding things they enjoy doing because it might trigger their AD and make it worse. Along with the physical discomfort AD causes, this can take a psychological toll and puts patients at risk of developing illnesses like depression and anxiety. These costs are not inevitable; timely, high-quality care can help reduce them. However, this report shows that the care available to AD patients is often inadequate and disappointing.

When it comes to accessing high-quality care, systematic failures and stigmatising attitudes towards AD means patients are at a disadvantage right from the start. There is no compulsory requirement for dermatology training in undergraduate or postgraduate medical programmes, leaving primary

healthcare professionals insufficiently trained to provide AD patients with adequate care and failing to get treatment right the first time. Some patients also have to deal with dismissive attitudes from some of the healthcare professionals they see that downplay the seriousness of AD, as well as insensitive and sometimes hostile reactions to their AD from members of the public. It's no surprise then that many patients feel like they face a "battle" to be taken seriously by some healthcare professionals and society as a whole. This is depriving patients of the emotional support that their healthcare professionals, family and peers could provide them. Better emotional support and accurate treatment early on are basic things that can go a long way to reducing the financial costs patients face. To improve patient care and reduce the costs of AD, these systematic failures and insensitive attitudes need to change.

AD HAS SIGNIFICANT FINANCIAL AND NON-FINANCIAL COSTS

AD patients, defined in this report as adults who have been diagnosed with AD at some point in their lives (in childhood or as an adult) and still currently suffer from the condition, bear significant direct and indirect financial costs because of their condition. In the light of the current cost of living crisis in the UK, with high inflation and rising costs of essentials like food and energy, these costs may be putting even greater pressure on AD patients at the moment. Several recent studies have examined the financial costs of AD to both individuals and society as a whole, and have estimated that:

- In the UK, the indirect costs of work impairment to the economy for adult patients with moderate-to-severe AD is estimated to be between £6,741-£14,166 per patient per year, increasing with AD severity.¹ Work impairment includes both having

to take time off work and loss of productivity while at work.

- A total of 1,011 AD patients in a recent study (85%) reported having to spend a mean of 18% extra on personal hygiene, 670 (58%) reported spending 9% extra on washing powder and 654 (55%) reported spending 8% extra on clothing, than people without AD.²
- Patients spend on average an extra £4.89 (€5.69) a month on travel expenses than those without AD, which could at least in part be because of travel to healthcare appointments.²

The impact AD has is not restricted to patients' finances, because AD also has serious intangible costs. Some patients have to deal with sleep issues,

or difficulties forming relationships. The negative impact AD can have on people's quality of life can also lead to poor mental health, which in turn may contribute to diagnosable mental health conditions such as depression.

IMPROVEMENTS TO PATIENT CARE ARE NEEDED

Despite these financial and non-financial costs for AD patients, high-quality care from the NHS is in seriously short supply. As shown in the table below, primary care in particular, where the majority of AD patients will receive all of their treatment, is in serious need of improvement. If left in its current state, it will fail to meet patients' needs.

PROBLEM	RECOMMENDATION
<p>There is insufficient dermatology training and education among primary healthcare professionals.</p>	<ul style="list-style-type: none"> • All universities should make dermatology a compulsory part of all their undergraduate and non-specialist postgraduate medical programmes, reflecting the prevalence of AD and other skin conditions. • To tackle the problem in the short-term, NHS England should aim to increase the number of GPs with extended roles (GPwERs) in dermatology. These are GPs who receive formal training and accreditation giving them additional skills and knowledge in dermatology which other GPs lack. • NHS England should introduce compulsory dermatology training for all healthcare professionals working in primary care.
<p>Patients are not always given enough information, leaving them poorly equipped to self-manage their AD.</p>	<ul style="list-style-type: none"> • The Department of Health and Social Care (DHSC) should work with NHS England to develop a long-term NHS workforce strategy that will address the NHS's severe overall staff shortage and provide sufficient funding for recruitment.
<p>Nurses are able to spend more time with patients meaning they can be in a better position than GPs to provide patients with initial and ongoing education on how to manage their AD. However, there are far too few nurses working in primary care.</p>	<ul style="list-style-type: none"> • NHS England should set up a working group composed of student nurses, existing practice nurses and secondary care nurses to better understand the attitudes nurses have towards working in GP settings, how these attitudes may act as a barrier to recruiting more nurses in GP practices and how this specific barrier can be overcome.

PROBLEM	RECOMMENDATION
<p>Patients who do need to see a specialist face long waits. As of 2021, there were just 508 Whole Time Equivalent (WTE) trained NHS dermatologists in England with 159 WTE vacant posts. ³</p>	<ul style="list-style-type: none"> • Clear tools for healthcare professionals to more accurately identify AD severity, and thus make referrals when needed, should be an essential part of the new compulsory dermatology training NHS England provides to primary care practitioners. • To increase the capacity of dermatology services, the DHSC should work with NHS England and Integrated Care Systems (ICSs) to find ways to increase the number of people training in dermatology, focusing on the regions and local areas where there are particularly severe shortages.
<p>The psychological and emotional support AD patients get is insufficient.</p>	<ul style="list-style-type: none"> • DHSC should provide NHS England with funding to commission more psychosocial services in community settings. • ICSs should aim to ensure that all dermatology services they commission have a mental health provision element. • NHS England, ICSs and primary care healthcare professionals, in partnership with patient groups, should encourage people to join peer support groups, which have been found to improve the quality of life of patients dealing with a variety of illnesses, where appropriate.
<p>Health inequalities exist between AD patients with regard to severity of the condition and access to timely treatment.</p>	<ul style="list-style-type: none"> • All ICSs should have a strategic aim to improve dermatology care, with a key focus on tackling health inequalities between AD patients.
<p>Misinformation and disinformation spread online is harming patients and impacting patient care.</p>	<ul style="list-style-type: none"> • NHS England should make digital resources available to patients to show them how to self-manage their AD effectively and ensure that all primary healthcare professionals as well as dermatology specialists are made aware of these digital resources in order to direct patients to them. • These resources should also be made available to moderators of online support groups and community forums, reflecting the use of these online spaces by patients to seek information on self-management.
<p>An up-to-date assessment of the financial costs of AD to patients in the UK is urgently needed.</p>	<ul style="list-style-type: none"> • Health researchers, particularly health economists, should seek to undertake new studies assessing the current financial costs of AD to patients in the UK, including assessments on the costs to patients with lower socioeconomic status. The National Institute for Health and Care Research or NHS England could be important sources of funding for this research.

INTRODUCTION

The aim of this report is to examine the costs of atopic dermatitis (AD), going beyond the financial costs to the NHS or society as a whole to understand the wide-ranging personal, social and health costs to the individuals who experience the impacts of AD on a daily basis. AD is the most common form of eczema in the UK, affecting 5-10% of all adults.⁴ With the prevalence of AD in adults rising, particularly in adults aged above 75, now is a crucial time for policymakers and the NHS to be considering how the care of AD patients can be improved, and how the costs to both patients and the NHS can be reduced.⁵

The costs this report looks at include direct financial costs, indirect financial costs (such as the impact AD has on patients' work lives), and intangible costs related to lower quality of life and mental health. These costs are not inevitable; if timely, high-quality care is provided, the costs can be significantly reduced. Exploring both the financial and intangible costs of AD allows us to get a comprehensive understanding of the way AD impacts all aspects of patients' lives and consider how the care AD patients receive can be improved to help reduce these costs.

The primary focus of this report is on adult patients. As many of the healthcare professionals we spoke to told us, AD is often incorrectly understood to be a childhood disease, with there being no standardised guidelines in the healthcare system for adults with AD. While a higher proportion of children in the UK have AD compared to adults, this does not mean that the impacts the disease has on adults are any less concerning, nor is providing high-quality care any less important. So while we recognise that AD impacts children, as well as parents and caregivers of children with AD, this report focuses on adults to raise awareness of the costs they face. Geographically, the report focuses on the healthcare context within England, although we have also reviewed UK-wide and international evidence.

This report considers the costs to patients with all severity levels of AD, which can be broadly categorised as mild, moderate and severe. All adults,

regardless of how severe their AD is, will experience the costs of AD to some extent, which is why all severity levels should be considered. However, it is important to distinguish between AD severity levels as the severity can make the costs worse. For this reason, analysis of the impact of severity is included in this report as appropriate. Some of the studies referenced focus on specific severity levels, and this is explicitly stated where relevant.

Methodologically, this report draws on an evidence review of UK and international literature, interviews with healthcare professionals in England and interviews with AD patients to examine the costs of AD, the current state of patient care and how patient care can be improved.

The first three sections of this report look at the costs to patients: direct financial costs, indirect financial costs and intangible costs. The fourth section looks at the costs to the NHS. Section five looks at the current state of patient care, while section six considers how to improve patient care for adults with AD.

SECTION 1

DIRECT FINANCIAL COSTS

This section examines the direct financial costs that AD patients face. Direct costs are the direct transactions AD patients make for both medical and non-medical items. Medical costs include items like prescriptions and over-the-counter medications, while non-medical costs include spending on items like special hygiene products, or types of clothing and bedding which are less likely to make AD symptoms worse.

MEDICATION COSTS MAKE UP THE BULK OF AD PATIENTS' MEDICAL COSTS, PARTICULARLY FOR THOSE WITH COMORBIDITIES

Some AD patients are eligible for free prescriptions as some groups are exempt from paying prescription charges in England. This includes people under age 16, people over age 60 and those on low incomes. However, around 40% of the population in England are liable to pay for their prescriptions, currently charged at £9.35 per item.⁶ Many AD patients also purchase over-the-counter medications, in addition to medications they receive via prescriptions, which is an additional financial cost.

A study of AD patients in several European countries, including the UK, found that AD patients had to spend on average an additional £24.45 (€27.63) on emollients and moisturisers and £15.70 (€17.74) a month on medication, and these expenses were much higher for AD than other chronic illnesses.² These costs are patients' out-of-pocket expenses which are not "reimbursed by a health insurer or national health service", therefore including prescription and over-the-counter medications.²

AD patients have an increased likelihood of developing comorbidities, particularly asthma, allergic rhinitis, food allergies and mental health disorders.^{7,8,9} For example, a 2021 UK study comparing child and adult patients with mild-to-moderate AD to people without AD found that 11% of AD patients had asthma in comparison to just 5% of those without AD. Further, 3.2% of AD patients had depression in comparison to 1.7% of those without AD.¹⁰ AD does not necessarily cause patients to develop these illnesses - asthma has only been found to be associated with AD rather than caused by it, for example.^{11,12} However, the prevalence of these comorbidities does have financial implications with many AD patients with these comorbidities having to pay for multiple prescriptions and over-the-counter medications, increasing the burden of these costs. Most of the healthcare professionals we spoke to cited both NHS prescription costs and over-the-counter medications as being the most significant medical costs adult AD patients face regardless of AD severity, particularly for patients with comorbidities like asthma.

Further, as will be discussed in more detail in section six of this report, misinformation and disinformation on how to self-manage AD is being spread online. Online fraudsters have been found selling fake treatments, medicines or 'cures' for AD with one website promising that their digital program, costing £49, cures AD.¹³ Given the impact AD has on patients quality of life, which will also be discussed in more detail later, many patients may feel like they are in a desperate situation and as a result be more susceptible to this disinformation, causing them to incur unnecessary costs on 'quack' cures.¹³

HOWEVER, AD PATIENTS TYPICALLY FACE MORE NON-MEDICAL EXPENSES THAN MEDICAL

In light of access to healthcare free at the point of use via the NHS, AD patients in England will typically incur more non-medical than medical expenses. In particular, AD patients need to spend more on everyday necessities in order to manage the symptoms of AD. A total of 1,011 AD patients in a recent study (85%) reported having to spend a mean of 18% extra on personal hygiene, 670 (58%) reported spending 9% extra on washing powder and 654 (55%) reported spending 8% extra on clothing, than people without AD.² This suggests that the self-management of AD is a particularly significant source of AD patients' financial burden. One interviewee described spending more on clothes for example:

A lot of it is to do with clothing, because first of all I can't touch a lot of fabrics, and the fabrics I can touch tend to be more expensive, and I wear through them a lot because I kind of rub at my skin like that, so you get holes in clothes... that is a huge additional cost.

- Patient interviewee

However, self-management is not the only source of these non-medical costs. Healthcare professionals we interviewed also said transportation costs to and from GP and hospital appointments are an additional non-medical expense AD patients face. Patients we spoke to said that travel costs to hospital as well as "extortionate" hospital parking charges were one of the main financial costs they incurred as a result of their AD. Indeed, research has found that AD patients spend on average £5.04 (£5.69) more per month on travel expenses than those without AD.² So while patients in the UK may not have to pay for NHS GP consultations or hospital appointments, they do face 'hidden' costs as a result of having to travel to receive their care.

Financially, I'd say, I think most of the costs will be if I go to the hospital... I travel there myself so I have to pay for the parking, I pay for my petrol. Even if it was just to do a blood test, unfortunately at hospitals you have to pay for parking, and you never know if you're going to wait there for 2 hours, 1 hour or 10 minutes, and that's where the costs come.

- Patient interviewee

THESE COSTS PUT A PARTICULAR STRAIN ON THE FINANCES OF PATIENTS WITH A LOWER SOCIO-ECONOMIC STATUS

While the economic burden of medical and non-medical costs impacts all adult AD patients to at least some extent, there is evidence that some of these costs may increase with AD severity and in turn disproportionately impact patients with lower socio-economic status (LSES). A systematic review of studies on the economic burden of mild-to-moderate AD, including in the UK, found that the economic burden of costs like transportation, medication expenses and out-of-pocket expenses increased as the severity of AD worsened.¹⁴ Healthcare professionals we interviewed said that people with more severe AD will typically have to visit their GP more often, which explains why transportation costs increase with AD severity for example.

Financial costs will put more strain on AD patients with LSES. While there has not been any research done to assess the costs of AD for people from lower socioeconomic groups in the UK, research on AD patients in the US has found that patients with LSES particularly struggle to pay for over-the-counter products and forgo appointments due to travel costs.¹⁵ One healthcare professional we spoke to said that sometimes patients with LSES have to make a choice between paying for medication or buying food, indicating similar problems for LSES patients in the UK.

However, the evidence suggesting that the costs increase as severity worsens is particularly concerning as people with LSES may be more likely to suffer from more severe forms of AD. According to a systematic review by researchers from Betsi Cadwaladr University Health Board, LSES is linked with more severe skin disease.¹⁶ Low-income households, a lower level of paternal or maternal education and dilapidated housing were consistently linked to an increase in the severity of common skin conditions, including AD.¹⁶ This means that the higher costs stemming from greater AD severity will disproportionately impact people with LSES, putting an even greater strain on patients' financial situation.

SECTION 2

INDIRECT COSTS

This section examines the indirect costs of AD. Indirect costs include the lost earnings AD patients face as a result of having to take time off work, and loss of productivity while at work due to AD.

AD HAS AN ADVERSE IMPACT ON THE WORK LIVES OF MANY ADULT PATIENTS

Many AD patients have to take time off work due to GP visits (or other medical appointments), as well as the pain and itching caused by AD. A survey from 2017 of adults with moderate-to-severe AD from Allergy UK found that over 46% of respondents had been forced to take days off 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.¹⁷

As well as having to take time off, symptoms like itchy and painful skin can cause productivity loss while at work. In a study of AD patients in the US and Europe (including the UK), 4–49% reported impairment due to AD while at work (presenteeism). The researchers estimated that this resulted in 1.6–19.7 hours per week being unproductive or ineffective while at work, depending on the severity of an individual's condition.¹⁸ Similarly, one healthcare professional we spoke to said that AD has a "sequence" of effects that can all impact patients' productivity at work: itchy and bleeding skin can lead to sleep disturbances which leads to tiredness which can then in turn lead to patients having difficulties at work.

THE NEGATIVE IMPACT OF AD ON PEOPLE'S WORK HAS FINANCIAL CONSEQUENCES

The impact AD has on patients' work lives has economic costs for both AD patients and society as whole. A 2020 study found that in the UK the indirect

costs of work impairment, defined as a combination of absence from work and loss of productivity while at work, to the economy for adult patients with moderate-to-severe AD were between £6,741 and £14,166 (€7685–€16150) per patient per year.¹

Whether patients suffer a financial loss themselves or not depends a lot on how supportive their employer is, particularly in terms of providing paid sick leave. One patient we spoke to said that while she had taken time off work due to AD, she did not think she suffered financially because she had always been with an employer that provided paid sick leave. Another patient said they had not always received paid sick leave when they have had to take time off, while one said they had to take unpaid leave for hospital visits. One patient said they believe they were made redundant due to taking time off work because of AD.

I've had time off sick in the past - obviously that's a huge financial cost, having to take weeks at a time off because of serious infections, and then to a point where they got incredibly bad and I couldn't do my job at all, and I would say I got made redundant due to my sickness and health.

- Patient interviewee

I started a job that didn't have any sick pay for the first 6 months, and I had a few days that I needed to take off because of the pain I was in, and I didn't get paid for those days, which... I understand why they do it, but for someone with a chronic illness, it feels very unfair, because no one can help getting sick.

- Patient interviewee

THESE INDIRECT COSTS INCREASE WITH AD SEVERITY

Greater severity of AD leads to higher indirect costs. For example, the 1996 study found that in the case of severe disease, absence from work rose to 14.9 days per year per patient.¹⁹ A 2019 study on AD patients in the US and European countries, including in the UK, found that across both Europe and the US, higher AD severity was associated with a greater negative impact on work productivity.¹⁸

As has been discussed, people with LSES may experience more severe AD than those from more affluent backgrounds. People with LSES may therefore experience higher indirect financial costs, alongside higher direct financial costs.

In light of how prevalent AD is among adults in the UK, it is surprising that the most recent cost-of-illness assessment for the UK which included adult patients is from a paper published in 1996. Not only is this assessment out of date, but it is based on self-reported data from only a small sample of 155 people.¹⁹ According to a systematic review of economic evidence regarding the costs of AD published in 2019, “these old estimates require updating, with analysis using real-world observational data and methods to better inform current policies for eczema in the UK.”²⁰ This is a clear evidence gap which should be addressed. Having a comprehensive and up-to-date understanding of the financial burden AD patients face, including the impact AD severity and socioeconomic status has on these costs, will make it easier to find the most effective ways to mitigate these costs.

SECTION 3

INTANGIBLE COSTS

This section examines the intangible costs of AD. Intangible costs are the non-quantifiable costs associated with AD, like disruption to people's daily lives and poor mental health, that can impact patients' overall quality of life.

AD CAN ADVERSELY IMPACT PATIENTS' QUALITY OF LIFE

There's not a thing I do from waking up to going to sleep that is not impacted by it [AD] in some way shape or form, whether that is the time I get up, whether that is the clothes I wear, even the food I eat... I can't think of a single thing I do that is not impacted by my eczema in one way or another.

- Patient interviewee

Even things like getting up in the morning and getting ready for work, or if you're running late - you can't just throw on your clothes and scrag your hair back and go. I have to put cream on every morning, and every evening before bed religiously, otherwise I feel uncomfortable and obviously, my skin would suffer.

- Patient interviewee

One way AD may reduce patients' quality of life is through the disruption it causes to people's daily activities. For example, in a 2017 survey of AD patients with severe eczema conducted by Allergy UK, the majority of patients who responded to the survey (86%) said that the management of their condition, such as applying creams, impacted

on their day-to-day activities. Nearly 10% of respondents reported spending more than two hours a day managing their condition, which "represents over 30 days a year spent by patients applying creams to manage severe eczema."¹⁷ A more recent survey from Allergy UK of patients with moderate-to-severe AD found that 32% of patients spent over an hour each day managing their AD.²¹ While these studies focus on more severe forms of AD, people with mild AD will have to apply treatments as well, meaning that all adult AD patients will have their daily lives disrupted to some extent.

The patients we spoke to also told us of the severe disruption AD has on their day-to-day activities. One patient told us that they can't go out in the sun too much because this would make their AD worse, suggesting that the need to avoid triggers is also very disruptive for patients. Another said that sometimes they have to "say no" to going to social events after work because of the time they need to take self-managing their AD. They felt they had missed opportunities to make new friends as a result. Self-management of AD is evidently a significant source of the disruption patients face in their lives, which can impact their social lives and play a role in reducing patients' overall quality of life.

As well as disruption to their daily lives, AD patients typically report dealing with poor mental wellbeing due to their AD. For example, patients we spoke to commonly said that the pain caused by their AD has an adverse impact on their mental health.

You're just trying to get through each day, and you're in pain, everywhere is hurting all over your body, so that's a huge mental cost.

- Patient interviewee

When you're in pain, it's so easy to become depressed, it's so easy to get really wrapped up in that depression.

- Patient interviewee

In a survey by Allergy UK of 237 patients with moderate-to-severe AD, 78% of respondents reported that their social and psychological health had been impacted by their AD. Particular problems patients reported included low self-esteem (70%), their mood (62%), feelings of anxiety (46%) and reluctance to take part in social occasions (44%).²¹ Given the reports of low self-esteem and reluctance to take part in social occasions, it is likely that patients' self-consciousness surrounding their appearance impacts their relationships with others and plays a substantial role in reducing patients' psychological health. One patient we spoke to said they tended to avoid mirrors because seeing a reflection of themselves made them "want to cry".

According to ONS analysis, an individual's self-reported health has the strongest association of any factor with overall wellbeing (as measured by self-reported life satisfaction).²² This fits with the evidence that illnesses such as AD reduce patients' general wellbeing and quality of life.

THE IMPACT AD HAS ON PATIENTS' LIVES CAN LEAD TO MENTAL HEALTH COMORBIDITIES

As well as impacting patients' mental wellbeing, having AD can also lead to diagnosable mental health conditions. Several studies have shown that AD patients have a significant comorbidity burden which includes mental health disorders, particularly depression, anxiety and sleep disorders.^{10,23,24}

While the reasons for this are complex, there is evidence suggesting that AD and the impacts of the illness could be a cause of patients developing such disorders. For instance, a study of adult AD patients in the UK found that there was a causal association between having AD and developing newly diagnosed depression.²³ Similarly, a systematic review showing an association between AD and suicidality (the risk of suicide as indicated by the presence of suicidal thoughts and feelings) found that the physical and psychosocial burden of AD may contribute to this increased risk of suicidality.²⁵

One healthcare professional we interviewed said that negative impacts such as disturbed sleep and disruption to people's work and family lives caused

by their AD can lead to poor mental health, which can then lead to mental health conditions such as anxiety and depression. This supports the evidence that the various impacts AD has on patients' overall wellbeing can lead to patients having more complex and diagnosable mental health disorders.

INTANGIBLE COSTS CAN LEAD TO WORSE INDIRECT FINANCIAL COSTS

Poor mental wellbeing, caused by issues like embarrassment and low-self-esteem, can have an adverse impact on AD patients' work lives, increasing the indirect financial costs to patients. One healthcare professional told us that, due to embarrassment and low self-esteem caused by the impact AD may have on patients' appearance, patients may choose jobs where they don't have to be face to face with people. In some cases, this could have financial implications if this means people with AD have lower-paying jobs or do not progress in their careers, although there is a lack of quantified evidence on this.

Further, a study of countries in Europe including the UK, found that AD comorbidities, including anxiety and depression, significantly exacerbated the indirect cost burden of AD and this was more significant than the impact these comorbidities had on patients' direct financial costs.¹ For example, patients with anxiety reported significantly greater overall work impairment compared to patients without anxiety, and the same was true of patients who reported moderate or severe difficulties with sleep.¹ One healthcare professional we spoke to said that having comorbidities like mental health issues can make it more difficult not only for patients to work consistently, but also to manage their symptoms, which may explain why the intangible costs of AD can lead to worse indirect costs.

SOCIETAL ATTITUDES ARE MAKING INTANGIBLE COSTS WORSE

Ill-informed and even hostile attitudes from society towards AD can adversely impact patients' mental wellbeing. A common issue patients we spoke to complained of was the reaction they received from friends, and sometimes strangers, related to the impact AD has on their appearance. These comments ranged from thoughtless but not necessarily ill-intended remarks to malicious bullying and abuse. For example, one patient told us that people had mistakenly thought they were "sunburnt" when their skin was red because of their AD. Another said that people had come up to them and felt the need to point out that their skin had

“gone red”, leaving them feeling frustrated and hesitant to socialise with people when their AD was particularly bad or visible.

Bullying because of the stigma surrounding the way AD affects patients’ appearance also adversely impacts many patients’ mental wellbeing. Many children with AD experience bullying at school, which can lead to low self-esteem, lack of confidence and anxiety issues.²⁶ A survey from the National Eczema Association in the US found that 20% of parents of children with eczema (including AD) said their child had been bullied at school because of their eczema and 75% of those parents said their child experienced lower self-esteem as a result.²⁷ Experiences of bullying are not however limited to children, and even if most of this bullying does occur during childhood, the trauma from this bullying can impact patients’ mental wellbeing and relationships with others well into adulthood:

I would have adults in the street shouting abuse at me because of how I looked as a teenager, and that sticks with you. My trust in other people, despite all the work that I’ve done and I’m much better than I was, but I do have a fundamental lack of trust in people, because I’ve seen how people respond when you don’t look right.

- **Patient interviewee**

Problematic societal attitudes are not just limited to the visual stigma surrounding AD. Lack of general understanding from friends and family towards the way AD affects patients’ daily lives also has an impact on some patients’ social lives and relationships. One patient told us that sometimes they felt their friends would not understand that they can’t do certain things because of their AD, like “go sunbathing or sit outside”, and this generally has a negative impact on their social life.

Patients’ experiences show that it is not just AD itself that can impact their mental wellbeing, but also the negative and ill-informed attitudes among the general public towards it. Reducing the visual stigma surrounding AD and ensuring patients are surrounded by people who show a level of understanding, sensitivity and empathy towards them would go a long way in mitigating the intangible costs patients face.

SECTION 4

COSTS TO THE NHS

The costs of AD are not limited to patients but also extend to the NHS: this section examines the healthcare costs of AD.

FOR THE NHS, SPENDING ON GP CONSULTATIONS AND PRESCRIPTIONS IS A SIGNIFICANT COST

There are a range of different types of cost for the NHS in treating adult patients with AD. This includes the costs of prescriptions; GP appointments; consultant appointments and hospital appointments in secondary care; specialist staff including dermatologists and nurses; and the cost of related comorbidities such as mental health conditions, as described in the previous section.

A cost-of-illness model created by Toron et al. estimated the additional costs among a group with mild-to-moderate AD compared to a matched control group. They estimated that the excess (additional) costs for mild-to-moderate AD (in both children and adults) for the NHS would be £81.95m (£92.60m) per year.¹⁰ The costs included in this figure are healthcare resource use and drugs, including GP appointments for mild-to-moderate AD patients, referrals to dermatology services and prescriptions for medications like emollients and topical corticosteroids.¹⁰

GP consultations are likely to be the most significant AD-related cost for the NHS. In Toron et al.'s cost of illness study, GP visits for mild-to-moderate AD patients were estimated to cost the NHS £179.09m (£202.37m) in 2020 and make up by far the largest proportion of costs.¹⁰ (It should be noted that this figure excludes patients with more severe AD, so total costs for AD will be higher).

TABLE 1
ESTIMATED DIRECT COSTS OF PATIENTS WITH MILD-TO-MODERATE AD FOR THE NHS IN 2020¹⁰

TYPE OF COSTS	COSTS IN 2020 (£)
GP visits	£179.09m
Referrals	£71.76m
Prescriptions	£7.12m

Most of the healthcare professionals we interviewed cited the amount of GP consultations with AD patients, regardless of severity, as being one of the biggest pressures AD is putting on the NHS. Given that 15-20% of GP workload is estimated to involve skin disease, this is unsurprising.¹⁷ This means that AD in adults is contributing to the severe pressure currently on primary care in England, where there is a shortage of primary care staff, increased workloads and a growing trend for GPs to work part-time.²⁸ However, healthcare professionals told us that the fact that AD in adults is an important cause of demand in primary care is not always recognised by healthcare professionals and managers within the NHS.

Unsurprisingly, severity of AD makes this burden worse. Toron et al.'s cost-of-illness model for mild-to-moderate patients found that the healthcare resource use and drug costs decreased after excluding patients on very potent topical corticosteroids.¹⁰ These patients have at least a moderate form of AD if not more severe, suggesting that costs increase with disease severity. The healthcare professionals we interviewed told us that people with more severe eczema will typically need to visit their GP

more often, partly explaining why costs to the NHS increase with AD severity. This emphasises the need to give patients the most appropriate treatment right from the start to prevent patients' AD increasing in severity.

Prescription costs also contribute to NHS spending on AD. Overall, Toron et al. estimated that the drug costs for mild-to-moderate patients in 2020 were £7.12m (£8.04).¹⁰ However, this excludes patients with more severe AD who require more expensive medications. One healthcare professional we interviewed said the use of some medications for AD patients are particularly expensive for the NHS and as a result, some GPs may be avoiding giving large enough doses to patients or even avoiding prescribing these medications at all, in order to limit costs.

However, while spending on medications may be costly for the NHS in the short-term, as long as the medications are effective that should not be seen as a problem. As one healthcare professional we spoke to put it, while some AD medications are particularly expensive, they can still be cost-effective in the long run. This is because effective medication helps to reduce AD severity and in turn prevents the need for frequent GP visits or referrals to secondary care. Similarly, a study using a matched control group examined the cost-effectiveness of emollient prescriptions for AD: it found that while emollient prescriptions required an extra cost for the NHS, patients using emollients had fewer primary care visits and a reduced need for more expensive prescriptions than those not using emollients - making them cost-effective.²⁹ So, while it is important to be aware of the cost-effectiveness of specific medications, reducing spending on prescriptions should not be a priority for the NHS.

As can be seen in Table 1, Toron et al.'s cost-of-illness model found that the costs of referrals to dermatology services were £71.76m in 2020, less than GP visits but more than prescription costs.¹⁰ While most AD patients will predominantly be cared for in primary care and not by specialist dermatology services, the cost of referrals is still putting pressure on the NHS to at least some extent. One healthcare professional told us that many GPs are failing to refer patients to secondary care when they need to be, partly because of concerns surrounding the costs of referrals and the capacity of dermatology services. Like failures to prescribe appropriate medications due to cost concerns, it makes logical sense that unwillingness to refer AD patients to secondary care when needed is likely to increase the costs to the NHS in the long-term as it increases the risk of AD severity worsening. Getting AD treatment right as

quickly as possible can therefore reduce the need for referral to secondary care later, and in turn reduce financial pressure on the NHS.

SECTION 5

THE CURRENT STATE OF PATIENT CARE

This section examines the current state of AD patient care in the NHS and the implications this has for the costs patients face.

THERE IS INSUFFICIENT DERMATOLOGY EDUCATION AND TRAINING AMONG PRIMARY HEALTHCARE PROFESSIONALS

There is a concerning lack of dermatology training among primary care professionals, like GPs, pharmacists and nurses who work in primary care, who spend a significant amount of time caring for and providing medical advice to AD patients. The majority of AD patients will never see a specialist in secondary care, while dermatology cases make up 15-20% of a GP's workload.²¹ One healthcare professional we spoke to said that pharmacists, who can provide over-the-counter medication without a prescription, are increasingly becoming the first point of contact for AD patients seeking advice or support. This means it is crucial for those working in primary care to have the right training so that they know how to advise patients and prescribe appropriate treatments for dermatological conditions, of which AD is one of the most common.⁴

Despite this, there is no compulsory requirement for dermatology training in undergraduate or postgraduate medical programmes of study in the UK.³⁰ While there are resources for primary care professionals to expand their knowledge, like educational events for primary care professionals run by the Primary Care Dermatology Society (PCDS).³¹ However, as one practitioner we interviewed acknowledged, these are typically optional and will not be used by all healthcare professionals. Given the amount of time AD patients will spend with practitioners working in primary care, it is hard to justify the lack of dermatological training these

practitioners receive.

This lack of education can have detrimental consequences for the quality of care AD patients receive. For example, some of the healthcare professionals we spoke to working in more specialist settings said they had encountered many AD patients who had not been prescribed the most suitable medication or the correct dose of medication by their GP, and that this was in part because GPs are not sufficiently well-informed to make these decisions accurately first time. A qualitative study of GPs' experiences of treating children with AD in the UK confirms that GPs themselves recognise these problems: the study found that "GPs described a paucity of dermatology training" and that "[GPs] reported using a trial-and-error approach to prescribing emollients, and were uncertain about quantities of topical treatments to issue."³²

Patients we spoke to expressed similar concerns about the lack of dermatology knowledge primary care professionals have. In particular, patients cited the insufficient knowledge among GPs as being a serious problem:

She [the GP] said "Well why do you need that emollient because you've got the steroid, you don't need two." And I just looked at her and went... I don't know what I said, I can't remember, but you know flabbergasted that she didn't realise that emollients are the basic first-line treatment for eczema.

- Patient interviewee

I've found that GPs don't know what to do with skin as severe as mine, they don't like that I have all the steroid creams that I have, so I find it a bit of a battle, to be honest, to be taken seriously by GPs.

- Patient interviewee

The healthcare professionals we interviewed also told us that some AD patients have similar experiences with some of the pharmacists they see, who also may not provide patients with the correct advice or medication. All this risks delaying finding the right treatment for patients, potentially worsening the costs for both patients and the NHS alike.

PATIENTS ARE LEFT POORLY EQUIPPED TO SELF-MANAGE THEIR AD

Many AD patients do not receive sufficient information to self-manage their AD. This is particularly the case when it comes to applying medical treatments. For example, many of the healthcare professionals we spoke to said that patients did not know how to properly apply treatments like creams and emollients by themselves, which risks making these treatments less effective. Beyond medical treatments, patients may lack sufficient knowledge of the importance of non-medical methods for managing their AD like eating healthily and managing their stress levels which, if not done, may make their AD deteriorate further.³⁰

Time is one of the main problems here. A 2017 study found that GP appointments in the UK are on average only 9.22 minutes long, which most of the healthcare professionals we spoke to said was not long enough to properly teach a patient how to apply treatments or give them sufficient information on how to self-manage their AD.³³ One healthcare professional who also worked privately explained that in their view, the care they provided to patients with moderate to severe eczema within the NHS was of lower quality compared to the care they provided in private practice, due to this time constraint. According to our interviewee, longer consultations in a private practice allowed more opportunity to give information, advice and guidance, which can be particularly important when prescribing a new medication for example.

NURSES ARE ABLE TO SPEND MORE TIME WITH PATIENTS, HELPING THEM TO BUILD STRONG RELATIONSHIPS

Nurses currently play a valuable role in the care of AD patients. All the healthcare professionals we spoke to told us that the care that specialist dermatology nurses provide to patients is particularly valuable because nurses, unlike GPs, are able to spend more time with patients to provide them with adequate self-management education. Similarly, a paper on the role of dermatology nurses in the care of AD patients across Europe found that specialist nurses play a unique role in both primary and secondary care because they typically spend more time with patients than other healthcare professionals do.³⁴ As a result, they are able to develop strong relationships with patients built on trust. This can increase the effectiveness of self-management education and adherence to treatment while enhancing emotional support to patients. All this can potentially reduce AD severity and improve patients' quality of life.³⁴

However, despite the effective care they provide, there is a shortage of nurses available to care for AD patients. One healthcare professional described specialist dermatology nurses as being like "gold dust" in the NHS due to lack of funding for them, while another suggested that nurses were underused in the care of AD patients. As the majority of AD patients will only ever be treated in primary care, the lack of nurses, both specialist and general nurses, in primary care settings is particularly concerning. Research shows that only 5% of NHS nurses overall are working in primary care and that this is not enough to meet demand.³⁵ Most newly qualified nurses typically opt to work in secondary care, with some believing that primary care is "slower-paced" and might "deskill" them. This problem is exacerbated by the amount of current general practice nurses retiring: in 2015 it was predicted that 33% of existing practice nurses were due to retire by 2020, meaning GP practices will struggle to meet demand if not enough newly qualified nurses are opting to go straight into primary care.²⁴ This has consequences for AD patients, as it means there are not enough opportunities for patients to receive sufficient education on self-management from nurses as soon as possible after symptoms of AD appear, which could in turn prevent their AD from worsening.

PATIENTS NEEDING TO SEE A SPECIALIST FACE LONG WAITS

While the majority of AD patients will never need to see a specialist in secondary care, those that do face long waits to be referred. An Allergy UK survey of AD patients found that the average wait for specialist referral after being diagnosed was 3 months, with 27% waiting over a year for referral.²¹ One healthcare professional we interviewed highlighted that long waits for specialist AD treatment are worse now after the pandemic, reflecting the wider context of the pressure NHS England is currently facing with long waiting lists and high demand for emergency services.³⁶

Problems in assessing the severity of patients' AD appears to be a key problem here. In the same Allergy UK study, the majority of healthcare professionals surveyed said they lacked clear guidelines and did not use a scoring system for assessing the severity of a patient's AD.²¹ Similarly, some healthcare professionals we spoke to said that insufficient knowledge among GPs led to inaccurate assessments of patients' AD severity and delays in referring patients to secondary care. This emphasises further how detrimental GPs' lack of education can be to the provision of appropriate, high-quality care.

When patients are referred, they still face long waits due to the insufficient capacity of NHS dermatology services. Patients we spoke to expressed frustration about how long they had to wait to both get referred to a specialist and to see a specialist dermatologist after being referred: one patient we spoke to said it was a "fight" to get their GP to refer them to a dermatologist and when he was referred he had to wait around "2 or 3 months". This wait made both the intangible and financial costs caused by their AD worse.

You're just trying to get through each day, and you're in pain, everywhere is hurting all over your body, so that's a huge mental cost. Financial cost, you know recurring infections that get you signed off sick, and you're only getting your sick pay and not getting your full wage, that's a huge financial cost. And then socially it costs you, because you're too unwell to go out.

- Patient interviewee

Long waits to see a dermatologist are largely explained by a shortage of dermatologists working in the NHS. A 2021 report on dermatology care by the NHS found that there was a serious shortage of dermatology staff, with there being 659 consultant

dermatologists working in the NHS in England, with 159 whole time equivalent (WTE) consultant vacancies and more than 140 locums (temporary doctors). This is not enough to meet demand.³ The dermatology report stated: "Shortages in the dermatology medical workforce are having a serious impact on the efficient functioning of nearly all units. These shortages dominated discussions in all but a tiny handful of visits."³

There are also regional disparities in waiting times to access dermatology services, exacerbating health inequalities between AD patients further. For example, the average number of wait days for NHS dermatology services in Brighton and Hove is 240, while in Bradford and Crave that number is 17 days.³⁷ One patient we spoke to said that while she found it fairly easy to access dermatology care when she lived in Scotland, she hasn't been able to see a dermatologist since moving to England because of the waiting times:

I would love to see a dermatologist but I think there's an 18 month waiting list where I live, and there's no point frankly, in my opinion.

- Patient interviewee

GIVEN THE ADVERSE IMPACT AD HAS ON PATIENTS' WELLBEING, THE PSYCHOLOGICAL SUPPORT AVAILABLE IS INSUFFICIENT

As has been discussed, AD can have a serious impact on patients' mental health. Despite this, there is a severe lack of specialist psychodermatology services provided by the NHS. Psychodermatology services are typically provided by specialists, including dermatologists and psychologists, who have a strong understanding of the interconnectedness of skin diseases and mental health. Skin diseases can lead to poor mental wellbeing and disorders, and poor mental health can contribute to the development of skin diseases or trigger a worsening of symptoms.³⁸ However, a survey of dermatologists who are members of the British Association of Dermatologists (BAD) and Psychodermatology UK in 2019 found that less than a quarter (24%) of the respondents have access to a nearby dedicated psychodermatology service, which is insufficient to meet patient needs.³⁹ The healthcare professionals we spoke to also highlighted the context of long waiting times for mental health services from NHS England in general, across different categories of care, stating that the lack of access to psychodermatology services was part of this much wider problem.

Beyond the lack of specialist care, there are also barriers to building the strong relationships between AD patients and healthcare professionals that are needed for proper emotional and psychological support. In Demos's work on relational public services, we argue that a strong relationship between the professional and the service user is crucial to providing people with personalised and preventative support.⁴⁰ As discussed, GP consultations are only 10-15 minutes long. Not only is this often too short for a GP to properly support patient self-management, but it is also often too short to gauge the impact of AD on an individual's quality of life or mental health, and in turn provide or refer them to the support they might need.

There is also a problem with many healthcare professionals having a lack of appreciation of the seriousness of AD and the impact it has on patients' lives. Patients themselves have complained about healthcare professionals not taking their condition seriously. For example, in a study of AD patients in the UK, many patients said that the healthcare professionals they saw tended to make dismissive remarks like "oh, it's just eczema", which patients felt trivialised the impact AD had on their lives.⁴¹ One patient we spoke to said she felt like the GPs and practice nurses she sees have "no empathy whatsoever" and tend to dismiss AD as a "skin thing". This patient also expressed frustration about one healthcare professional who had told her to do some exercise to improve her mental wellbeing, without understanding that exercise makes her skin worse. The patient felt that experiences like this had an adverse impact on her ability to trust GPs to support her.

I just don't trust going to a GP. I do it, but I don't trust it, because almost every experience I have is them basically gaslighting me about my skin and about what I do to look after myself... you can have trauma related to speaking to GPs, which is really difficult, I find.

- Patient interviewee

Similarly, one of the healthcare professionals we interviewed said there was a problem with healthcare professionals, mainly those who are not dermatology specialists, failing to understand how detrimental AD can be to patients' lives. They told us that this can lead to a lack of empathy and impede the ability of many healthcare professionals to provide adequate emotional support or recognise when this support is needed.

Fortunately, some AD patients have had far more positive experiences with some of the healthcare professionals they have seen. Patients we spoke to said specialist dermatologists and dermatology nurses had generally shown more empathy and understanding towards the impact AD has on their lives. One patient said a psychologist she saw to help deal with the impacts AD has on her mental health had been "life-changing" because of the empathy and understanding the psychologist had shown. This shows that healthcare professionals who have the ability to empathise with the wide-ranging impacts AD has on patients' lives are a valuable source of emotional support for patients.

MISINFORMATION AND DISINFORMATION ONLINE IS IMPACTING PATIENT CARE

Misinformation and disinformation surrounding AD also impairs patients' ability to self-manage their AD and receive appropriate care. A study of online misinformation and disinformation related to AD found that key areas of false information included things like 'simple cures', dietary changes, vaccines as a cause of AD and alternative therapies. One website claimed that emollients induce AD and promised that their digital program costing £49 cures AD.¹³ One healthcare professional told us that a patient delayed seeking professional help because they had tried cutting out dairy from their diet, incorrectly believing that this would help their AD.

Demos has highlighted the dangers that online disinformation and misinformation pose to social cohesion, the integrity of political processes, national security and public health. For AD, this online misinformation is just as concerning. Online spaces are a key source of information for AD patients seeking information on self-management: one study found that tips on how to manage AD and personal hygiene are some of the most commonly discussed topics on relevant internet forums for those affected by AD.⁴² If patients are seeking this kind of information online, then the presence of misinformation seriously risks impairing patients' self-management knowledge. This risks patients delaying appropriate care, avoiding certain treatments that might help them, doing things that might harm them (like implementing severe dietary restrictions) and potentially wasting money on alternative therapies and fraudulent programs that won't help.

SECTION 6

IMPROVING PATIENT CARE

The final section of this report lays out a set of recommendations on how to improve care for AD patients, looking at the role NHS England, Integrated Care Systems, the government and universities can play in improving care and reducing the costs of AD to patients, the NHS and society as a whole.

MORE DERMATOLOGY TRAINING IS NEEDED TO BETTER EQUIP PRIMARY HEALTHCARE PROFESSIONALS WITH THE KNOWLEDGE THEY NEED TO SUFFICIENTLY CARE FOR AND SUPPORT AD PATIENTS

For universities

All universities in England should introduce compulsory dermatology training in all undergraduate medicine, nursing and pharmaceutical programmes as well as non-specialist postgraduate medicine and pharmaceutical programmes. These programmes should include an element of 'awareness raising' on the impact AD has on patients' quality of life to enhance empathy and understanding among all healthcare professionals. This is important because, as noted above, dermatology cases are particularly common in primary care, making up an estimated 15-20% of GPs' appointments.¹⁷ AD patients we interviewed also cited more training and education for primary care professionals, particularly GPs and GP practice nurses, as one of their top priorities for improving patient care. This recommendation matches that made in the Getting It Right First Time report on dermatology.³

For NHS England

To tackle the problem in the shorter term, NHS England should aim to increase the number of GPs with extended roles (GPwERs) in dermatology. GPwERs in dermatology receive training and accreditation from the Royal College of General Practitioners (RCGP) and the British Association of Dermatologists (BAD), giving them more skills and knowledge in dermatology than GPs without this training.⁴³ To increase the number of these GPwERs, NHS England should work with the RCGP, BAD, the PCDS and existing dermatology GPwERs to find ways of making gaining this accreditation more appealing to GPs and encourage more of them to take it up.

There also needs to be more basic compulsory dermatology training for existing primary care practitioners - particularly for GPs, nurses and pharmacists. This training should be mandatory to ensure that all primary care practitioners have the knowledge and skills needed to provide good quality care to AD patients. If this training is optional, it is likely that only practitioners with a pre-existing interest in dermatology will take it up, which would risk some AD patients receiving better care than others depending on whether or not they end up seeing a GP (or other primary care professional) who has done the training. Given that most AD patients will only ever be seen by primary care professionals, and with AD patients being affected by health inequalities, it is crucial that all AD patients are able to receive care from adequately trained healthcare professionals.

NHS England should partner with educational providers to develop and deliver this training. They should also ensure that existing dermatology specialists, who have both the expertise and practical experience in caring for AD patients, are utilised in the design of this training and as teachers in its delivery. Like university education, this training should also include an 'awareness raising' element on the impact AD has on patients' quality of life to enhance empathy and understanding among practitioners. It should also provide clear tools for healthcare professionals to more accurately identify AD severity.

GREATER USE OF DIGITAL RESOURCES TO PROVIDE PATIENTS WITH THE KNOWLEDGE THEY NEED TO SELF-MANAGE THEIR AD AND TO COMBAT MISINFORMATION

For NHS England

NHS England should make videos and other digital resources about AD available, in particular to show people how to self-manage effectively, which was raised as a key point by the healthcare professionals we interviewed. These resources should be made available on a wide range of platforms including NHS England's website as well as social media and relevant internet forums, where appropriate. NHS England should work to ensure that all primary healthcare professionals and dermatology specialists are made aware of these digital resources in order to direct patients to them.

MORE SPECIALIST DERMATOLOGY NURSES ARE NEEDED IN COMMUNITY CARE SETTINGS

For the Department of Health and Social Care

The Department of Health and Social Care (DHSC) should work with NHS England to develop an NHS workforce strategy that will meet the needs of all patients, not just those with AD. As part of this strategy, the DHSC must ensure that NHS England receives sufficient funding to recruit enough healthcare professionals to deal with the NHS's overall workforce shortage. At present, the NHS is short of 110,000 staff and one in ten nursing posts are empty.⁴⁴ While impacting the NHS's ability to meet overall demand, this shortage also acts as a barrier to recruiting the dermatology specialist nurses required to meet the needs of AD patients.

More specialist nurses in community settings will ensure AD patients can receive timely and accessible specialist care in the community without having to be referred to secondary care. The ability of nurses to spend more time with patients and build relationships will also ensure patients receive sufficient self-management education and help tackle beliefs about AD self-management and treatment which are not supported by evidence.

MORE GENERAL NURSES ARE NEEDED IN GP PRACTICES

For the Department of Health and Social Care

Having more nurses in GP practices ensures that enough time can be spent with AD patients to teach them how to apply treatments correctly the 'first time' and sufficiently self-manage their AD earlier on. This is why it is important for the DHSC and NHS England to develop a workforce strategy with the required funding to address workforce shortages - more funding will help the NHS to meet the needs of AD patients specifically, as well as meet overall demand.

For NHS England

NHS England should set up a working group composed of student nurses, existing practice nurses and secondary care nurses to better understand the attitudes nurses have towards working in GP settings, how these attitudes may act as a barrier to recruiting more nurses in GP practices and how this can be overcome. This working group should also be involved in the development of existing and new initiatives to recruit more newly graduated nurses into GP practices.

IMPROVING DERMATOLOGY CARE SHOULD BE A STRATEGIC AIM FOR INTEGRATED CARE SYSTEMS, IN ORDER TO IMPROVE CARE AND REDUCE HEALTH INEQUALITIES

For Integrated Care Systems

Integrated Care Systems (ICSs) are currently being established across England, with the aim of bringing together stakeholders at a regional level to strengthen collaboration, improve outcomes and reduce inequalities. All Integrated Care Systems should have a strategic aim to improve overall dermatology care. Greater collaboration between NHS services, local councils, social care services and community groups will help to create a better

understanding of the needs of AD patients in local areas, and the barriers AD patients face to receiving high-quality care. The aim should be to ensure that AD patients are given appropriate advice, medication or referral 'first time', whether in a social care setting, at a GP appointment or at a pharmacy. There should also be a focus on any socioeconomic disparities that exist (such as greater severity in patients with lower socioeconomic status), why these disparities exist and how stakeholders can work together to address them.

THE CAPACITY OF DERMATOLOGY SERVICES NEEDS TO BE INCREASED TO REDUCE WAITING TIMES

For the Department of Health and Social Care

The DHSC should work with NHS England and ICSs to find ways to increase the number of people training in dermatology, focusing on the regions and local areas where there are particularly severe shortages. Increasing the number of trained dermatologists in areas where there are severe shortages will ensure there are a sufficient number of dermatologists to meet demand, help to reduce waiting times for patients in those areas and reduce inequalities in waiting times between patients.

MORE DERMATOLOGY SERVICES WITH INTEGRATED PSYCHOSOCIAL SUPPORT ARE NEEDED TO PROVIDE BETTER SUPPORT TO PATIENTS STRUGGLING WITH THE INTANGIBLE COSTS OF AD

For the Department of Health and Social Care

The DHSC should provide NHS England with funding to commission more psychosocial services in community settings. This will enable patients to be provided with psychosocial support at an earlier stage, helping to prevent some of the intangible costs of AD, like low mood, low self-esteem and difficulties forming relationships, developing into more complex issues, reducing the need for referrals to specialists and reducing demand for specialist services. Having this care within the community will also ensure patients will not need to leave their local area and travel long distances to receive such care.

Community dermatology nurses working within these services can spend more time with patients to build relationships and provide emotional support. This may also help them to accurately identify when referral for more serious psychological support is

needed.

For Integrated Care Systems

ICSs should aim to ensure that all dermatology services they commission have a mental health provision element. The collaboration between services within ICSs will ensure that the mental health needs of AD patients can be accurately identified and referrals for support can be made the 'first time'. This will enable patients to receive accessible psychosocial support in their local area at an earlier stage.

NHS ENGLAND AND INTEGRATED CARE SYSTEMS, IN PARTNERSHIP WITH PATIENT GROUPS, SHOULD ENCOURAGE PEOPLE TO JOIN PEER SUPPORT GROUPS WHERE APPROPRIATE

For NHS England and Integrated Care Systems

Peer support groups have been found to be an effective way to help improve the quality of life of patients dealing with a variety of illnesses from cancer to mental health conditions.⁴⁵ Demos's own research found that online peer support was particularly important for people coming to the end of their life, as they were able to seek comfort and advice from people with similar experiences when they could not get this support from other sources.⁴⁶ Given the impact AD has on patients' quality of life and the prevalence of mental health comorbidities among AD patients, healthcare professionals should signpost AD patients to relevant support groups, and encourage them to join where appropriate. Recent qualitative research with AD patients in the Netherlands reported: "Patients often reported positive experiences with support from patient associations and peer contact. As such, they felt it would be useful to provide extra information about these associations in hospitals and other healthcare institutions since many patients might not be aware of the existence of these groups."⁴⁷ Patients we spoke to said that being able to meet and speak to other patients with similar experiences would help them to feel less lonely and would provide them with the kind of understanding they might not get from friends and family.

NHS England should work in partnership with existing patient groups to help build peer-to-peer networks. These networks would provide patients with a way to build relationships with other patients experiencing similar difficulties, which AD patients can use as a source of emotional support to help

reduce the impact of AD on quality of life. By connecting citizens and building relationships, peer support groups can strengthen social capital and give people a source of mutual aid which, as Demos has argued, can have a wide range of individual and societal benefits.⁴⁰ NHS England should also consider funding a research evaluation of peer groups for adults with moderate-to-severe AD to understand participants' perspectives and the potential benefits of the groups for AD.

MORE EFFORTS NEED TO BE MADE TO IMPROVE UNDERSTANDING OF AD AMONG THE GENERAL PUBLIC

For NHS England

NHS England should make resources targeted towards AD patients' friends and family members. These resources should include guidance on how to support a friend or family member with AD as well as a comprehensive 'awareness raising' element on the wide-ranging impacts AD has on patients. These resources should be made in both digital and print formats. Healthcare professionals should help to share these resources either by providing them directly to patients' friends and family members who accompany them to appointments, or by encouraging patients themselves to share them with friends and family.

Improving friends and family members' understanding of AD will help to enhance the 'informal' peer support patients have access to. Patients we spoke to said that 'informal' sources of support from friends and family, both with and without AD, had been useful to them in terms of providing both emotional and practical support. However, the lack of understanding surrounding AD means that currently this informal peer support is limited. This is why it is important for the general public as well as healthcare professionals to be aware of and sympathetic towards the impacts AD has on patients' lives.

For charities

Relevant charities should aim to do more 'awareness raising' campaigns focused on tackling the visual stigma surrounding AD among the wider general public, and raise awareness of the impacts AD-related bullying has on adults.

AN UP-TO-DATE ASSESSMENT OF THE FINANCIAL COSTS OF AD TO PATIENTS IN THE UK IS NEEDED

For researchers

Relevant researchers, particularly health economists, should seek to undertake new studies assessing the current financial costs of AD to patients in the UK, including assessments on the costs to patients with lower socioeconomic status. The National Institute for Health and Care Research or NHS England could be an important source of funding for this research.

It is essential that opportunities to improve patient care and reduce costs for patients are not missed. Having a comprehensive and up-to-date understanding of the financial burden AD patients face will ensure that the DHSC, NHS England and ICSs can take the most appropriate steps to mitigate these costs by improving patient care and reducing health inequalities between patients.

ANNEX 1

EXCHANGE RATES

USED

Where sources cited give figures in Euros, we have converted these to GBP. We have done this on the following basis:

- Reference 1: £1 = €1.14. (The average exchange rate in 2017, when the data was collected)⁴⁸
- Reference 22: £1 = €1.13 (the average exchange rate on 5 February 2018, the same used by Zink et al. in their paper)⁴⁹
- Reference 10: £1 = €1.13 (the average conversion rate for 2018, as cited in reference 10, p. 913)¹⁰

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