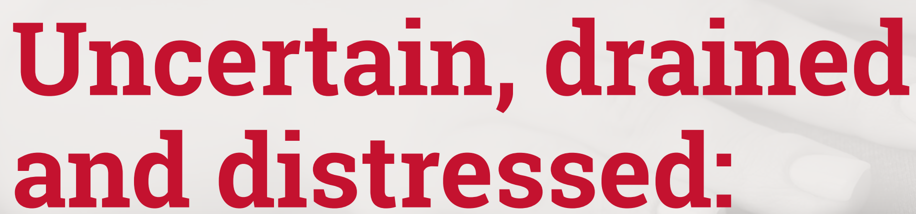

Uncertain, drained and distressed:

delays in care for patients with Alopecia Areata and Atopic Dermatitis lead to significant patient burden

White paper – March 2026

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Abbreviations

ABB	DEFINITION
AA	Alopecia Areata
AD	Atopic Dermatitis
BAD	British Association of Dermatologists
BDNG	British Dermatological Nursing Group
BHNS	British Hair and Nail Society
DLQI	Dermatology Life Quality Index
EOS	Eczema Outreach Support
GP	General Practitioner
HCP	Healthcare Professional
NHS	National Health Service
PAG	Patient Advocacy Group

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Executive summary

Key problems identified

Care is inconsistent

- Regional variations in access to healthcare and expertise for Alopecia Areata (AA) and Atopic Dermatitis (AD) – a postcode lottery depending on where the patient lives

Waiting times are often long

- Patients are frequently left in limbo, with no single healthcare professional (HCP) having responsibility for their care while they are waiting
- Variable waiting times from general practitioner (GP) referral – from 3 months to 3 years to see a dermatologist

Patients can arrive in secondary care misdiagnosed and/or suboptimally managed

- Often need to start their management in secondary care with basic optimisation of treatments that could have been provided in primary care – can leave patients frustrated, particularly if their wait to be seen in secondary care has been significant

HCP education needed to highlight management options available, particularly in primary care

- Initial management (of AD in particular) can be provided in primary care; however, many providers lack training on what management options are available to them and do not have resources to support their patients

Significant psychosocial burden is largely unaddressed

- Mental health impact of AA and AD often overlooked
- Psychosocial support is generally not available – even within specialist dermatology services
- Most patients rely on psychosocial support from charities rather than their healthcare service

Key opportunities to improve care

Cooperation across all levels of healthcare

- It is crucial that primary and secondary care in particular engage in open communication, as well as with their patients, to support better patient management during the referral waiting period

Agree basic standards of care for AA and AD

- Include any relevant tests or questionnaires (e.g., Dermatology Life Quality Index [DLQI]) to be completed at each level of care to ensure consistency, regardless of geographic location
- Ensure patients arrive in secondary or tertiary care with treatment optimised to the best of the previous team's ability

Targeted educational interventions for HCPs in primary and secondary care are highly recommended

- Signpost to existing resources, guidelines and patient materials
- Develop any new educational materials with specific audience type in mind (i.e., targeting specific job roles to ensure relevance) – avoid one-size-fits-all approaches

Address the psychosocial burden of dermatological conditions

- Acknowledge with the patient that the burden of AA and AD often goes beyond cosmetic and validate their feelings
- In the absence of funding for widespread psychodermatology resources:
  - More timely care – reducing waiting period to improve overall patient health
  - Provide clear management plans – having transparent next steps and pathways for escalation should treatment be suboptimal, which will help reassure patients

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Introduction

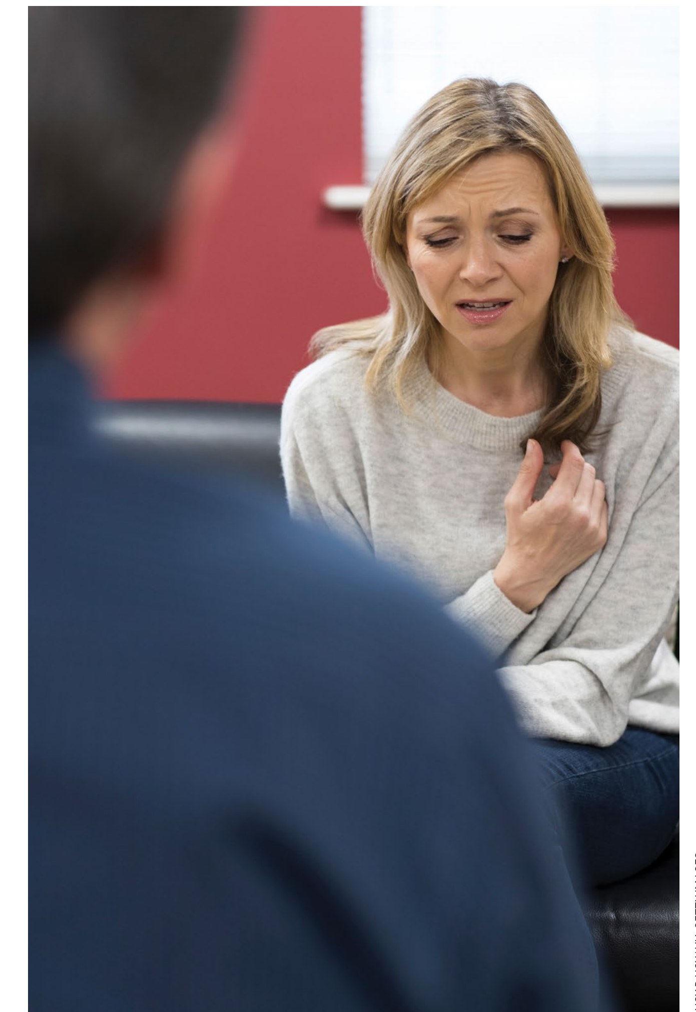
Alopecia Areata (AA) and Atopic Dermatitis (AD) are chronic, immune-mediated inflammatory conditions that extend far beyond their visible symptoms,[1–4] with prevalences of between 0.58% and 2% for AA,[1,5] and 2-10% for AD.[6-8] The impact of both conditions is often vastly underestimated, with a clear lack of recognition for the substantial physical and economic burdens these diseases cause,[6,9,10] requiring ongoing management, frequent healthcare visits, and, in many cases, time away from work or school. Patients with AA and AD face a clear psychosocial burden, experiencing anxiety, depression, social withdrawal and stigma, among others, which can also deeply affect their families and caregivers.[1–4]

The current management of AA and AD in the UK is highly variable despite roughly 24% of the population visiting their general practitioner (GP) each year with skin conditions.[11] Primary care practitioners and other frontline healthcare professionals (HCPs) are often the first point of contact, yet they may lack the time, resources,[12] or dermatology-specific training[13] to confidently diagnose, assess and manage both conditions. These issues are compounded by a lack of standardisation across regions, resulting in a "postcode lottery" of care, where patients' access to timely, effective and appropriate support and treatment depends largely on where they live.[14,15]

This white paper aims to define the key issues that patients with AA and AD face when seeking care for their conditions, as well as provide some potential solutions to alleviate these problems.

A summary of the peer-review paper methodology

A Delphi research study was developed using a mixed-methods approach, combining qualitative and quantitative insights. Data were collected in 3 stages: an initial scoping landscape assessment, a Delphi HCP consensus survey[16] and an expert advisory board meeting, with each stage building the foundation for the next.



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Challenges in care for patients with AA and AD

> "It was affecting every aspect of my life" – A patient with AD discussing emotional burden of living with AD.

> "[There is a] need for education and understanding of the impact of AA on patient's lives [in secondary care] … it is more than just hair!" – Quote from a HCP on secondary care for patients with AA.

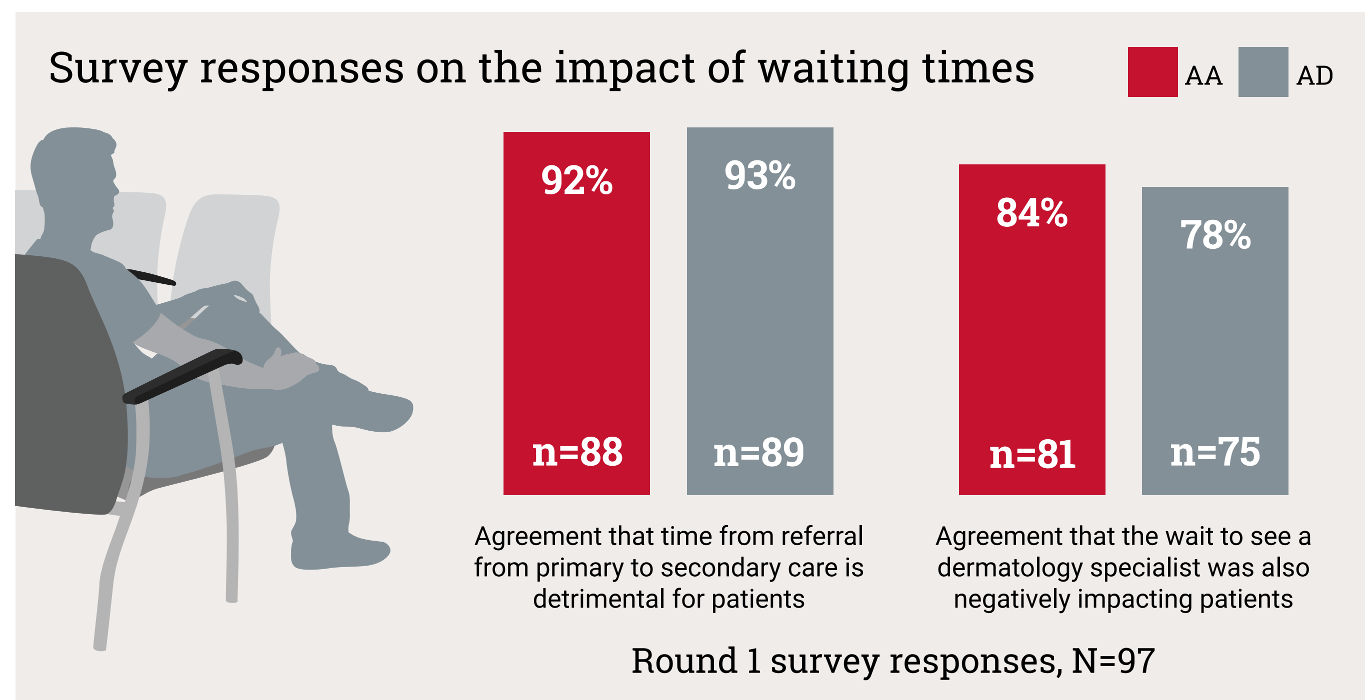
The waiting times for referrals significantly impacts patients

The waiting period between primary and secondary care, and between secondary and targeted specialist (i.e., tertiary) care has been described as purgatory for patients: a time during which no HCP holds responsibility for the patient's wellbeing and patients frequently can feel lost. At the advisory board meeting, it was highlighted that long waiting times could cause patient disengagement.

Referral from primary care to secondary care, and its associated wait times, was identified as a clear barrier to care for patients with AA and AD by Delphi respondents (Figure 1) and HCP interviewees alike, with waiting times to be seen in secondary care varying from 3 months to 3 years in some cases, as reported by the HCPs.[17] This aligns with published literature, which identifies referral from primary care to be a significant bottleneck and point of attrition for patients, with the proportion of patients waiting more than 28 weeks considered substantial.[18]

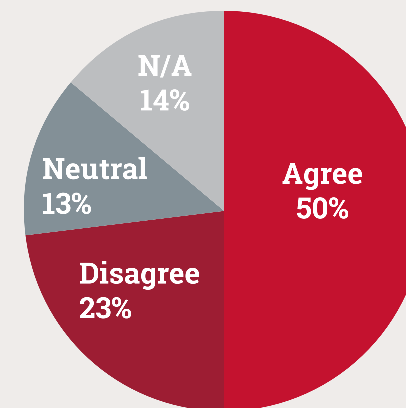
Interviewed patients (5/5) and HCPs (7/7) noted the significant negative impact of long waiting periods following referral on patient mental health. These delays in access to secondary care (both general and specialist dermatology) and uncertainty regarding treatment options were thought by interviewed HCPs to further exacerbate patient distress.

Figure 1: Delphi HCP survey responses showing consensus on the negative impact of waiting times on patients with AA and AD. Results from Gallard *et al.* adapted into a figure observed in round 1 of the survey.[17]



Survey and interview responses on the awareness of AA

2/3 patients disagreed



Round 3 survey responses, N=44

> "There is a high level of awareness and knowledge among general dermatologists (e.g., non-tertiary hair specialists) around all approved medications and their appropriate use in patients with AA"

Figure 2: The agreement between patients and Delphi respondents in the awareness of AA in secondary care. Where participants are in the N/A category, this was not found to be applicable in their practice. Results from Gallard *et al.* adapted into a figure. Result from round 3 (R3) of the survey.[17]

Once in secondary care, it was also felt that the wait to see a dermatology specialist was also negatively impacting patients with AA and AD (Figure 1), with no consensus as to whether there was timely and widespread access to specialist expertise for either condition (18% and 27% agreement, respectively).[17] This echoed a report by the Association of British Pharmaceutical Industry (ABPI) dermatology initiative, which noted cases where specialist dermatology waitlists have been closed to referrals.[19]

HCPs noted significant variation in waiting times and access to speciality clinics compared with general dermatology clinics depending on UK geographic location. For example, there is significant regional variation in access to specialist dermatology care in Scotland, with waiting times "in Edinburgh [taking] up to 3 years [but] over the Firth of Forth in Fife it is only 4 months" – HCP quote.

The education around AA and AD could be improved in both primary and secondary care

The level of education surrounding AA provided to primary care doctors is low, with all patient interviewees and most HCP interviewees in our research reporting that current education is insufficient. This was supported by the Delphi consensus survey results, which found no consensus on the level of awareness primary care providers have about AA or their awareness of the signs and symptoms. For AD, it was agreed that GPs were aware of the signs and symptoms of AD, however interviewed HCPs (5/7) and patients with AD (2/2) stated that GPs could do more to support their patients. The lack of education of GPs in dermatology was reflected in the NHS England Getting it Right First Time (GIRFT) report, wherein it was stated that during their 5-year education, only 1-2 weeks of formal dermatology training would be provided, and in some cases removed from the curriculum completely.[13]

> “After 18 months, to get to the specialists and be told there's nothing to be done was gutting” – Quote from a patient with AA.

Management at the secondary care level also requires improvement. For AA, the expert views on education were more positive in secondary care than primary care, but concerns remained, with 2/3 patients reporting awareness of AA being insufficient and no consensus from survey respondents on the level of understanding of management strategies available (Figure 2). For AD, there was consensus that secondary care providers had a high level of understanding of AD management strategies (73%), but no consensus on whether knowledge surrounding all medications and their appropriate use or the level of education available were sufficient. This could be attributed to the clear changes in requirements from secondary care providers, as well as specialists from 1990 to the 2020s, with the increasing complexity of not only medications themselves but with treatment plans and investigations. The challenge of remaining competent across all areas is ever increasing.[13,20] Furthermore, staffing issues have been identified as a clear issue within dermatology, with shortages not only limiting patient access, but increasing workload of neighbouring trusts,[13] and potentially impacting the training within these departments.

Patient education should also be considered, especially with the rise of misinformation online, which can have dire consequences.[21]

SDI PRODUCTIONS VIA GETTY IMAGES

There is clear evidence of inconsistent care across the healthcare system

It was noted by HCPs and patient advocacy group (PAG) representatives at the advisory board that inconsistent care and lack of clear next management steps can cause patients to disengage from their treatment. Patients specifically mentioned the lack of clear direction, guidance, next management steps or treatment, with no specific healthcare provider officially responsible for their care to be distressing, leaving them feeling adrift. Patients felt unable to return to primary care to seek additional support as they felt there was nothing else that could be done by their GP.

Interviewed HCPs (6/7) reported that AA and AD patients routinely arrived in secondary care undertreated. Reluctance from primary care providers to prescribe potent topical steroids was highlighted by HCP interviewees as a possible cause of the poor health condition of many AD patients arriving in secondary care.

> “If you want [GPs] to refer with better information … GPs need to have a minimum data set of information that they should send with any referral and that isn't the case …” – Quote from an AA HCP describing how to better manage AA in primary care.

> “As a patient living with AA, who may be interested in new treatment options …It is daunting to think about going back into a system that has failed you” – An AA patient discussing how their experience has made them feel about re-entering the healthcare system.

There is a clear mental health burden on patients, but the support provided is limited

Interviews highlighted a disconnect between treatment of visible symptoms of AA and AD, and emotional wellbeing of patients; particularly for those with AD who reported being given treatments to make their condition look better, but these treatments did not address the impact their AD was having on all other aspects of their lives.

The interviewed HCPs (7/7) reported the important role psychosocial support can play for patients living with AA and AD; in particular, the value of targeted psychodermatology services. HCPs reported a strong preference for treatment by providers with expertise in AA and AD psychodermatology who understood the specific burdens associated with conditions that can sometimes be considered “cosmetic” in nature, as generalist psychodermatologists can fail to recognise the profound impact of dermatological conditions beyond the skin. Despite this, interviewed patients were advised to seek psychosocial support through charities rather than the health service (3/3 AA patients and 2/2 AD patients), with the HCPs (6/7) reporting that NHS support was often only accessible for those in crisis. The GIRFT report showed that access to psychodermatology services varied widely across trusts, with only 11 dermatologists running a service within 9 trusts in England.[13] Regions where there were fewer psychodermatologists were referring patients significant geographical distances away, with referrals of patients from north Lancashire to a service in Birmingham. There was a clear indication that psychosocial support is an unmet need within the survey for patients with AA (73%) and AD (68%), with extended waits for specialist support, such as psychodermatology, negatively impacting patients (84% and 78%, respectively).

Potential solutions

The key theme that emerged was the need for cooperation between care providers across all levels (primary/secondary/tertiary care) to enable patients to "wait well" and optimise the management patients receive while waiting on specialist consultations. The gathered data suggest that this may be best achieved by targeting treatment pathways and improving consistency in care, promoting education for HCPs and patients, and addressing the psychosocial burden of dermatological conditions.

Targeting treatment pathways and improving consistency in care

An important next step is to **examine the waiting period between a patient's referral from primary care to their first appointment in secondary care**. In 2023, the average waiting time for first appointments with dermatology were 12% higher than the NHS average (16.9 versus 15.0 weeks, respectively).[22] This interval often represents a critical point of patient disengagement and presents a significant opportunity for targeted intervention.

To address this, efforts should be made to **optimise basic care and support within primary care settings**, ensuring that this waiting period is used productively to stabilise and improve the patient's condition. This includes empowering primary care providers with the tools, resources and guidance necessary to deliver effective initial disease management.

In parallel, it is essential to **establish clear and consistent standards for AA and AD management** within primary and secondary care, including **well-defined escalation plans**. These standards will help ensure uniformity in patient care and provide a more seamless transition across the various care settings and pathways, reducing variability and supporting better outcomes in both primary and secondary care environments.

ALEX PAPP/ VIA GETTY IMAGES

Promoting an educational campaign for HCPs and patients

Education at both the primary and secondary care levels is essential to improve patient outcomes; however, any educational strategy must be grounded in the realities of clinical practice. Primary care HCPs often face significant time and resource constraints that limit their ability to engage with lengthy educational programmes. To address this, **brief, practical and targeted educational materials should be developed or promoted that can be easily accessed and applied in daily clinical practice**, for example:

- **Myth-busting guides**
- **Treatment quick-reference tools**
- **Structured checklists**

Resources should be inclusive, targeting a broad range of practitioners with role-specific guidance, including primary care physicians, advanced nurse practitioners and pharmacists.

Clear referral pathways and minimum standards will support better AA and AD care, both through building HCP confidence and ongoing patient engagement via optimisation of currently available therapies or lifestyle changes. By actively using the waiting period and providing all relevant information for specialist review, a timely, accurate diagnosis and immediate start of new therapies on arrival in secondary care can be executed.

It is vital that secondary care providers use their knowledge and expertise to guide their primary care colleagues to support the delivery of optimal treatment, allowing for better use of the waiting period.

At the secondary care level, more tailored educational initiatives should be directed at general dermatologists, nurses and pharmacists with a specialist interest in AA and AD to **deepen their expertise and remain abreast of developments in available management options**.

To maximise reach and credibility, it is also critical to collaborate with well-respected organisations such as the BAD, the British Hair and Nail Society (BHNS), Alopecia UK, and Eczema Outreach Support (EOS). These **partnerships can help amplify the availability of high-quality resources and advocacy**, while fostering engagement across the care continuum.

FATCAMERA/ VIA GETTY IMAGES

In addition, patient education must not be overlooked. The proliferation of social media misinformation about healthcare has been dramatic and can be detrimental to patient care.[21] Having **clear credible supporting information, amplified by reputable organisations, presented in a way that patients can understand could enable them to be part of meaningful discussions about their condition with HCPs**, giving them confidence in the management of their condition and clarity on next steps. One key source of palatable and reliable information for patients is PAGs, such as Alopecia UK and Eczema Outreach Support. Signposting patients to these organisations could reduce reliance of people with AA and AD on social media for answers about their conditions.

Addressing the psychosocial burden of dermatological conditions

It is essential to **acknowledge with patients that the burden of AA and AD often extends far beyond visible symptoms**. These conditions can profoundly affect self-esteem, emotional wellbeing and daily life. Validating a patient's feelings and experiences is a crucial part of holistic care and can significantly improve the relationship with their HCP.

However, in the current landscape, access to specialist psychodermatology services remains limited for several reasons, including funding constraints and lack of sufficient staff. Therefore, a more practical approach is needed. **Providing more timely access to care can help alleviate some of the psychological and physical burdens** patients face, while ensuring that clear, structured management plans are in place from the outset. **Transparent next steps and defined escalation pathways**, particularly when treatment proves suboptimal, not only support clinical decision-making but also offer reassurance to patients, helping them **feel more supported and in control of their condition**.

In the absence of dedicated psychodermatology support, credible **self-support resources, like those from Alopecia UK and EOS, should be made available early to validate patient experience and raise awareness of the burdens they may face,** such as:

- **Webinars**
- **Patient testimonial videos**
- **Treatment pathway outlines and escalation plans, provided in lay terminology**

Conclusion

Patients living with AA and AD in the UK can feel sidelined by the current healthcare system. Their conditions are not life-threatening; however, they are life limiting and inhibiting. The impact of AA and AD on every aspect of day-to-day life should not be underestimated, and attention should be given to improving the standard of care that these patients receive. Several factors contributed to this assessment, including the reported long wait times for dermatology appointments, limited HCP knowledge of or insufficient training on these conditions, paucity of psychosocial support, and inconsistent treatment pathways. From this research, several key areas have been identified to target to improve the patient experience for those with AA and AD. These include an educational campaign for patients and primary care providers, optimising primary care management to help ensure that patients have access to treatments sooner, especially those for whom treatment escalation is required, and ensuring that psychosocial support is offered to these patients. Together these targeted strategies aim to improve the quality of life of patients with AA and AD in the UK.

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