



All-Party Parliamentary Group on Skin



MENTAL HEALTH AND SKIN DISEASE

A REPORT OF THE
ALL-PARTY PARLIAMENTARY GROUP ON SKIN

London 2020



The views expressed in this report are those of the All-Party Parliamentary Group on Skin which is an informal group of Members of both Houses of Parliament with a common interest in skin disease. This report is not an official publication of the House of Commons or the House of Lords and has not been approved as such by either House or its formal committees.

This report was prepared by a panel of independent experts in skin disease on behalf of the Officers of the All-Party Parliamentary Group on Skin (APPGS). Both the Officers and expert group are listed at the back of the report.

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FOREWORD

“When I turned 19 it [the eczema] became so bad that I couldn’t participate in normal life anymore due to the pain... I had to give up my job as I am always too unwell.

My skin is often too painful to have intimate relations or with to even hug or kiss my partner. I had to postpone my wedding as I can’t cope with the idea of a flare up on my wedding day.

My eczema has caused me to develop anxiety and depression. I have been in hospital twice for a week because of my eczema and in 2019 I had to visit A&E 6 times as a result of a facial eczema outbreak. I have had 36 courses of antibiotics for my skin in the last 2 years. My eczema has ruined my life.”

~ Survey respondent with eczema

I am delighted to introduce the All-Party Parliamentary Group on Skin’s report on the mental health impact of skin disease. As demonstrated by the above evidence provided by a young woman from Edinburgh, skin conditions can have a devastating impact on a person’s life. Our inquiry heard from many people with a skin condition who have experienced social isolation, stigmatisation, depression, anxiety and even, in some, suicidal thoughts.

We also heard that, all too often, children with psychological distress connected to their skin condition suffer without support. This is greatly concerning as without appropriate mental health support provided in childhood, a person’s life course and long-term wellbeing can be severely impaired.

Despite the evident need and growing demand for psychodermatology services, there is an alarming lack of psychological support available to people living with a skin condition. I hope that our report will change this. It provides national policymakers, commissioners and local service providers with an expert consensus on how mental health support for people with a skin condition should be structured in a range of clinical settings. This can often be delivered cost-effectively.

It also outlines the urgent clinical need for healthcare professionals to be equipped with the necessary skills and resources to provide the holistic care that patients need. This must include patient assessments and care that treats the mind and skin together, otherwise you will not break the vicious circle, in which skin problems create psychological problems that in turn exacerbate the skin condition.

We ultimately hope that through the publication of this report, the need for action will be made clear to policymakers and service commissioners working in the Government and the NHS.



SIR EDWARD LEIGH MP
Chair of All-Party Parliamentary Group on Skin
Member of Parliament for Gainsborough
HOUSE OF COMMONS

EXECUTIVE SUMMARY

Key messages

- The APPG on Skin (APPGS) is concerned that access to specialist mental health support for people with skin disease is limited throughout the UK, despite a growing need for such services. This is particularly worrying since the COVID-19 pandemic has exacerbated mental health distress in a skin community that was known to already experience significant appearance-related distress.
- New mental health funding promised to Clinical Commissioning Groups (CCGs) must urgently be used to invest in and improve mental health services that are dedicated to dermatology patients.
- This clinical need is supported by survey data that demonstrated that 98% of skin disease patients report that their condition affects their emotional and psychological wellbeing, yet only 18% have received some form of psychological support. Furthermore, over 5% (N=29) of our survey respondents had suicidal thoughts linked to the impact of their skin condition.

Further messages

- Skin disease can adversely impact on all aspects of people's lives from schooling, relationships, self-esteem, and career choices to social, sexual and leisure activities.
- Experiences of isolation, embarrassment, shame, depression, and anxiety are common. Stigmatisation, discrimination and a lack of social acceptance and understanding is experienced daily for some.
- Children with skin disease are usually not offered support services, which has a profound impact on their long-term mental health, life course and wellbeing into adulthood.
- Psychological interventions can be helpful in both treating and coping with many skin conditions. Yet many individuals with skin disease are desperate and frustrated at being unable to receive the psychological support need.
- Evidence has shown that the psycho-social impact of skin disease on patients has been chronically underestimated by health care professionals.
- Many primary care practitioners do not have access to training in dermatology or the assessment and treatment of patients with skin disease and psychological distress. Fewer have had training in psychodermatology.
- Growing evidence indicates that managing patients holistically from the start of their illness reduces the physical and psycho-social disease volume in the long-term.

SUMMARY OF RECOMMENDATIONS

Care for children with a skin condition

- All children and young people experiencing mental health distress associated with their skin condition must have access to appropriate psychological support.
- Training must be provided to healthcare practitioners to facilitate the identification and management of the psychological aspects of childhood skin disease
- All doctors and allied health care professionals must conduct holistic assessments to ascertain the psychological impact of skin conditions on children and their families.
- It is imperative that, across the UK, there is at least regional access to paediatric psychodermatology clinics.
- There should be clear and appropriately resourced regional pathways established to enable referrals into paediatric psychology services.

Commissioning services

- Commissioners need to understand that psychodermatology clinics are cost effective to run when compared to managing skin patients with psychological distress in more generalist healthcare settings.
- The stepped model of care (Figure 1 & 11), which matches clinical services and inputs to an individual's disease burden, can create savings and improve value for money.
- All regions should have at least one dedicated Psychodermatology service or pathway with a trained specialist psychodermatologist, dedicated liaison psychiatrist input, a multidisciplinary team approach and stepped-care psychological support.
- A sizeable proportion of new funding available to Clinical Commissioning Groups (CCGs) for mental health services must be spent on services available for dermatology patients.
- Each new Integrated Care System must review its regional service provision in dermatology and psychodermatology.
- All commissioners should carry out a regular audit of existing psychodermatology service provision and need within a local area. The findings should be used to inform future investments in resources, which must match the psychosocial needs of the area.

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- Comprehensive multidisciplinary psychodermatology teams providing care to patients with all facets of psychodermatology must be commissioned across the country in proportion to patient populations, and there must be comprehensive psychodermatology services available at least regionally across the UK.
- All patients with a chronic skin condition should receive an annual medicine review, which includes an assessment of the psychological impact of their condition, via a validated psychological health-screening questionnaire.
- Specialist psychodermatology units should use psychiatry business case tariffs rather than dermatology tariffs.
- There should be annual audits of psychodermatology units and quarterly meetings to review activity and outcomes.
- All psychodermatology clinics in departments and regional joint clinic should keep a database of all patients according to nationally agreed template for the purposes of research and audit. Locally gathered audit data should inform business case planning.
- NHS England should create a National Clinical Director for skin to provide the NHS with clinical leadership, advice, and support on dermatology care.

Training

- There should be a programme of reviewing primary care practitioners' skills, training in psychodermatology, and the assessment of psychological distress in long-term conditions. The APPGS recommends that primary care training in dermatology and psychodermatology is mandatory.
- Training Authorities (e.g. Royal Colleges and Universities) should also work with the RCGP, RCN and RPS to ensure that urgent priority is given to the provision of psychodermatological training for all GPs, nurses, and pharmacists.
- Training for nurses must include the training in the basic assessment and support for psychosocial comorbidities of skin disease. Nurses must be able to assess and signpost to available mental health services.
- The continuing professional development of all healthcare professionals should include the mental health impact of skin disease. This could be achieved through annual appraisal and/or other cyclical mandatory training.
- Commissioners and providers must ensure that healthcare professionals, including nurses, pharmacists, and psychological practitioners are given greater opportunities to specialise in psychodermatology.

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- Psychodermatology should be included within the training of Liaison Psychiatrists. The Royal College of Psychiatrists should lead and facilitate this.
- There must be specific intervention training for all staff likely to be involved in providing treatment of psychological impact associated with skin conditions and use of the existing NHS e-learning materials (e-LfH) should be required for anyone working in this area.
- All trainees in dermatology and psychiatry should have an attachment (the APPGS recommends at least 4-6 months) in psychodermatology during their training with specific training curriculum agendas and measurable training outcomes.
- Additional psychodermatology training resources should be developed as part of the existing BAD/Psychodermatology UK and e-LfH modules.
- Commissioners and providers should ensure that comprehensive psychodermatology multidisciplinary team (MDTs) are developed at least regionally. These MDTs should consist of a dermatologists, liaison psychiatrists, psychologists, and specialist dermatology nurses.
- Efforts should be made to establish and propagate national and international networks to support practitioners, share best practice and champion the clinic-academic priorities of all patient groups including children and young people.

Staffing

- All dermatology departments must have at least one dermatologist trained in psychodermatology, specialist psychology input and access to liaison psychiatry advice.
- All local dermatology units must have regional access to psychodermatology services.
- All local dermatology services must have a named lead in psychodermatology services able to provide basic psychodermatological care of patients with skin disease
- Dermatology consultant trainee posts must be increased, and hospital placements should be adequately funded.
- Psychodermatology specialist clinics should routinely provide 45 minutes for new patients and 30 minutes for follow-up appointments. General dermatology clinics should allow at least 15 minutes.

Research

- Research funding for psychodermatology should be prioritised. This should focus on the development, evaluation, and implementation of a range of psychological and educational interventions for patients with skin conditions.
- There should be concerted efforts towards the creation of research networks between psychology, psychiatry, and dermatology.
- Supportive and supervisory networks of healthcare professionals should be established to provide pastoral care.

Patient support and advocacy

- CCGs should distribute to Primary Care Networks an up-to-date directory of dermatology patient support services.
- Consideration should be given to ensuring patient support organisations lead or support service innovation projects.
- Patient support organisations providing psychological support services should ensure that staff are appropriately trained and supported with basic psychological training or toolkits.
- The inclusion of patient support organisations in a review of services and pathway is critical to amplify patient voice and build in the community services provided by that patient support organisation.

INTRODUCTION

Mental and physical health are intrinsically linked. There is a wealth of evidence demonstrating that people are at increased risk of having poor mental health when they live with a chronic skin condition.¹ Appearance-related distress, social anxiety and depression are potential impacts.

The mental health impact of skin disease is becoming increasingly recognised by doctors and patients. For example, since the APPG on Skin last reported on the subject in 2013, there has been a proliferation of social media users. Unfortunately, social media can create unrealistic expectations about appearance, and can lead to distorted or frankly incorrect information.

More recently, the COVID-19 pandemic has increased exposure to stressors and exacerbated mental health distress in a skin community that already suffers significant emotional and psychological distress.

Psychodermatology is a discipline and sub-speciality of dermatology that acknowledges the link between the skin and the mind. Psychological interventions, either alone or adjunctive to conventional dermatology treatments, can be helpful in both with coping and treating many skin conditions.

Skin disease is extremely common. Approximately a quarter of the UK population consult a GP each year due to a skin complaint. However, the APPGS is concerned that access to specialist mental health support for people with skin disease is limited throughout the UK, despite a growing demand and subsequent need for such services. In addition two previous APPGS reports (2003 and 2013^{2,3}) have made recommendations which have not been implemented. For example, the APPGS report 2013 indicated that psychodermatology services should be expanded to cover the entire UK. In reality there remains very scant provision of psychodermatology services across the UK, despite evidence that providing such services is both cost and clinically effective.

Therefore, the APPGS launched its largest Inquiry to date, to comprehensively analyse the state of services that support patients with skin conditions with their mental health. Evidence

has been received from more than 500 patients with skin conditions, over a 100 clinicians, and a number of patient groups. The evidence has been reviewed by health care professionals and patients as identified in the scientific literature.⁴

This report has been produced in collaboration with leading specialists within dermatology and mental health together with patients and their advocates, and the contents herein provides politicians, commissioners, and NHS providers with an expert consensus on recommended service changes. It outlines the ways in which mental health services for people with skin conditions should be developed throughout the entire clinical pathway.

Given the national directive in England towards creating Integrated Care Systems (a regional partnership of NHS organisations, local councils and others which manage local resources), there is an opportunity for local service providers and commissioners to review service provision in dermatology. The recommendations in this report provide evidence based, practical, and implementable strategies that inform the future planning and delivery of care for people with skin conditions. Where possible, the recommended service changes aim to be broadly cost-saving or cost-neutral.

The Group also aims to convey, through its evidence, the substantial psychological and emotional impact of skin disease experienced by millions of UK citizens. This report alters the perceptions, behaviours, and decisions of not only policymakers, but also healthcare professionals and the wider public.

The report is divided into chapters that aim to cover every aspect of mental health and skin disease, ranging from the design and commissioning of services to healthcare professional training, research priorities and patient advocacy.

POLICY BACKGROUND

In 2003 and 2013 the APPGS published two major reports on the psychological impact of skin disease.^{2,3} Both reports highlighted the extensive impact skin diseases have on all aspects of people's lives, poor patient access to specialist mental health care within dermatology, and the lack of investment in psychodermatology. Few recommendations from the reports have been adopted by policy makers and service commissioners working in Government and the NHS to date.

The British Association of Dermatologists (BAD), the professional body for Dermatologists, has reported (despite the two previous APPGS reports) a chronic shortage of psychodermatology service provision in the UK⁵, whilst Getting It Right First Time for Dermatology⁶ has highlighted wide geographical variation in access to psychodermatology in England. The BAD's consensus statement outlines the minimum standards required to support psychodermatology service provision in the UK.⁷

Some improvements have been made since the APPGS's 2013 publication, partly due to the increased public awareness of the necessity to support people with mental health conditions. However, most patients with skin conditions and poor mental health are still unable to access specialist psychodermatology support required.

Recent policy announcements indicate that future investments in wider mental health services are planned. The NHS Long Term Plan commits to improving mental health services in England, both for adults and children, over a ten-year period.⁸ National growth in mental health funding is set to outstrip total NHS spending growth until at least 2023/24. In England, the number of people treated under the Improving Access to Psychological Therapies (IAPT) programme will increase to 1.9 million by 2023/24.⁸ There is also a requirement for all local areas to commission IAPT services for longer-term conditions.

The Government has also acknowledged that early psychological intervention can limit the escalation of problems in children and young people, and has major societal benefits.⁹ It has committed to providing services that ensures that "children and young people showing early signs of distress are always able to access the right help, in the right setting, when they need it".⁹

The NHS Mental Health Implementation Plan 2019/20 – 2023/24 sets out plans to improve dedicated provision for groups with specific needs.¹⁰ The funding available to Clinical Commissioning Groups (CCGs) for mental health services is set to increase from £596 million in 2019/20 to an indicative figure of £1,921 million in 2023/24.¹⁰ This will involve sustaining and commissioning IAPT services, including for long-term conditions (LTCs).

However, beyond commitments to LTCs, it is unclear whether any of the other funding commitments will result in direct investments and improvements in mental health services dedicated to dermatology patients. Therefore, it is essential that any increased overall funding in mental health translates into future investment in services and care for dermatology patients. This report aims to make a clinical and business case to support the development of these services.

CLINICAL BACKGROUND

3.0 Background

Dermatological conditions are among the most common reasons for seeking medical advice. In any given year, over half of the UK population experiences a skin condition¹¹ and approximately a quarter will visit a GP about a skin condition.¹² There are an estimated 2,000 possible skin diagnoses, with presentations ranging from mild through severe to life-limiting.¹¹ The most common skin diseases are inflammatory skin diseases such as eczema, psoriasis, and acne.¹³

3.1 What do we mean by mental health and skin?

There are several interrelated terms used by clinicians and academics to refer to the mental health of a patient, this includes 'psychological', 'psychiatric', 'psychosocial', 'psycho-cutaneous', and 'emotional wellbeing'. Each term emphasises a slightly different facet of health; however, for the purposes of clarity and consistency this report mainly utilises the overarching term, 'mental health', unless a more specific term is required.

Published literature demonstrates a significant mental health burden of living with a skin condition.^{1,14,15} Psychological comorbidities decrease quality of life and can be at least as severe as those experienced by people living with other serious diseases such as cancer and kidney failure.¹⁶

There are a wealth of studies demonstrating the negative emotional impact of skin disease. It can impact self-esteem, mood, body image, and confidence.¹⁵⁻¹⁹ Patients with skin conditions may also experience isolation, embarrassment, shame, depression, anxiety, and suicidal thoughts.²⁰⁻²⁶

Patients with skin conditions may perceive stigmatisation related to their appearance and a lack of social acceptance.^{27,28} Individuals with a noticeable visible difference frequently experience discrimination, rejection and negative reactions from others.^{28,29,30} Avoidance and concealment are common coping strategies to manage such negative experiences, which may perpetuate mental health distress.^{19,25-31}

The experience of mental health problems is not correlated with the severity of the organic skin disease.³² A condition that is classified as ‘mild’ or ‘moderate’ in terms of physical symptoms can result in severe and wide-ranging mental health distress.

Mental health distress can influence and exacerbate the course of skin disease (e.g. stress causing a flare-up), as well as the adherence to treatment and treatment outcome.^{7,15,33} Therefore, a holistic treatment is essential to treat physical symptoms.

The physical and mental health impact of skin disease on the quality of life of a patient can be extensive. The Inquiry’s findings in Chapter 4 explores in depth the link between skin disease and mental health distress in the UK population.

3.2 Care and treatment

Psychodermatology involves a multi-disciplinary interplay between dermatology, psychiatry and psychology. Dermatology predominantly focuses on managing the underlying disease, whilst psychiatry and psychology target associated mental health issues.⁷

Most patients with a mental health component of their skin condition fall into the following broad overlapping categories:^{34,35}

1. Patients who present with a **primary skin disease such as psoriasis accompanied by secondary psychological distress.**
2. Patients with **chronic skin diseases that are exacerbated by stress, anxiety, or low mood** such as eczema or psoriasis.
3. Patients with a **primary condition affecting the skin that cause a change in appearance**, such as a port wine stain, and may **have a psychosocial impact.**
4. Patients with a **primary psychiatric or psychological condition**, such as delusional infestation or body dysmorphic disorder **who present to health care professionals.**

Psychological and educational interventions, typically target behaviour, thoughts, and emotions that in turn influence skin disorder severity and overall patient wellbeing.^{1,36} Psychological intervention as an adjunct to medical treatment can reduce the severity of

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physical symptoms and improve mental health wellbeing, relative to medical treatment alone.^{1,36}

Examples of psychodermatology techniques and resources that might be appropriate for patients in a stepped provision of support includes: peer support, either online via patient advocacy and other communities or in person; mindfulness, aimed at reducing stress; habit reversal, to reduce or break harmful repetitive behaviours such as picking or scratching; and cognitive behavioural therapy (CBT), to alter behaviours, thoughts and feelings, for example reducing avoidance behaviour.¹

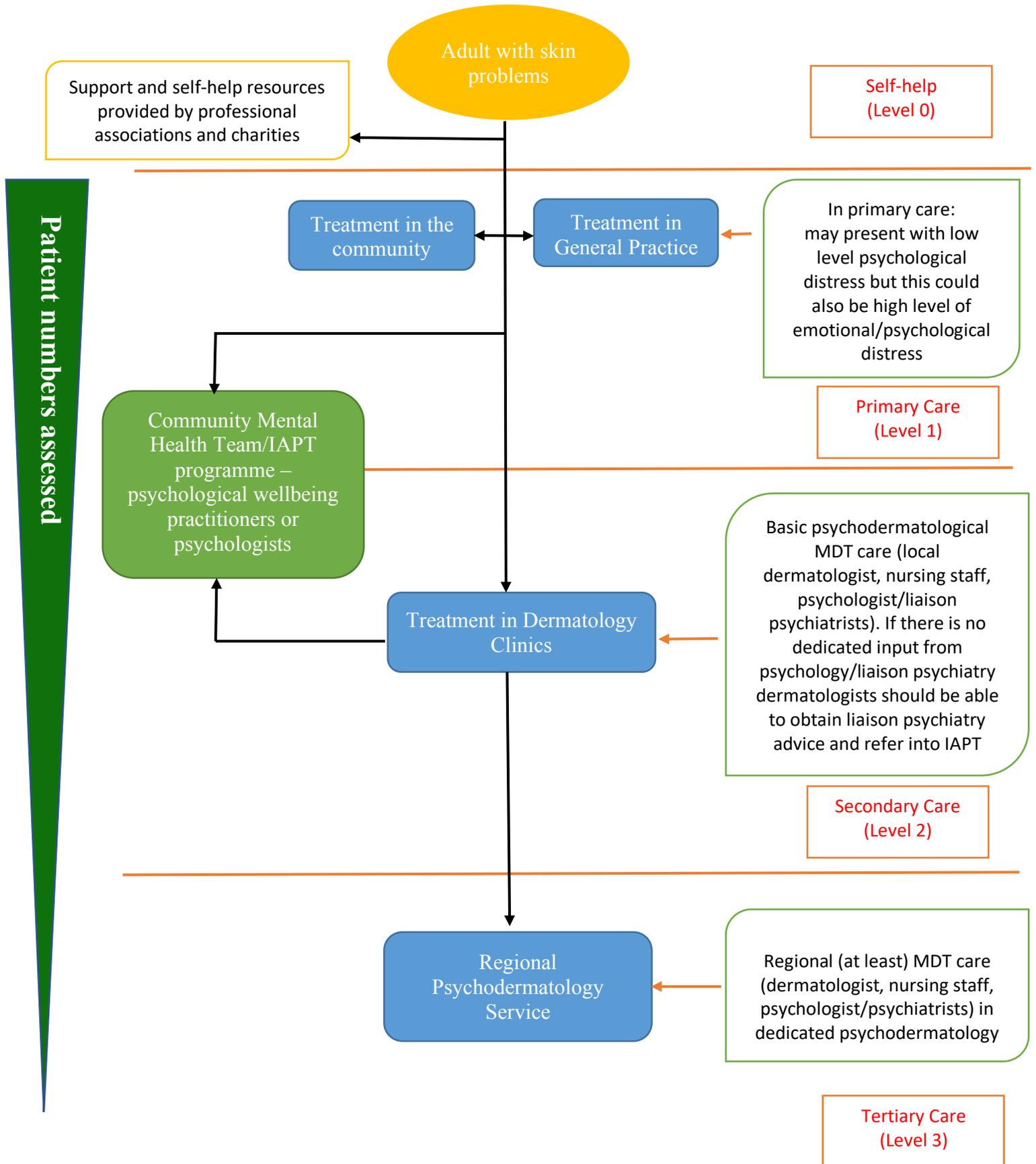
Some patients with skin conditions can benefit from education in self-management strategies, including learning about triggers and self-management interventions and coping strategies.^{17,36,37}

Access to effective physical treatments that improve the symptoms of living with a chronic skin condition can also play a critical part in improving the mental health of an individual.

3.3 Stepped provision of support

Patients with skin conditions and mental health distress can be seen by a range of healthcare practitioners within a range of different locations, depending upon the severity of their condition and service availability (figure 1). There are also some support and self-help resources provided by professional associations and charities, that patients may access prior to or as well as accessing formal services.³⁸ For example, the British Association of Dermatologists recently developed online support webpages for people living with a skin condition that contains a number of brief stand-alone self-help resources³⁹, whilst Changing Faces provides a number of support services including a skin camouflage service.⁴⁰

Figure 1: Stepped provision of support to adult patients with a skin condition and psychological or psychiatric distress



3.31 Primary care

Most of the UK population with a skin condition and mental health distress will be seen in primary care (Level 1). Limited psychodermatology support can be provided within primary care via GPs, nurse practitioners, counsellors, and other accredited practitioners. However, most do not have psychodermatology training and may not understand the mental health impact of chronic skin conditions.^{13,36} Many report not being either confident - or skilled - enough to address psychological aspects of some skin conditions.^{42,43}

Primary care practitioners act as gatekeepers. If they lack the skills to make a psychological assessment, they will frequently miss key signs of distress, and therefore patients with skin conditions may not be referred to appropriate support services.

Moreover, primary care practitioners are often time-limited and may only be able to focus on one issue per appointment (e.g. the physical symptoms). Despite these challenges, primary care practitioners often wish to upskill and provide holistic treatments for patients.

In some cases, primary care is unable to refer directly patients with skin conditions deemed to have low or moderate physical and/or psychological symptoms to specialist care (i.e. Level 2 & 3) due to long waiting lists. Therefore, for most patients with skin conditions, the level of mental health support depends on available referral pathways and the willingness and confidence of primary care to assess adequately and engage with psychological issues.

3.32 Secondary care

Psychodermatological care can be provided in a dermatology department in secondary care (Level 2). However, many dermatologists, psychiatrists, and psychological practitioners have not had specific psychodermatology training and may lack confidence to diagnose and treat patients with skin conditions and mental health symptoms.⁴⁴ Furthermore, in most areas, specialist mental health interventions are only accessible by referral to an outside service not integrated within a dermatology department.⁴⁵

Some patients with anxiety disorders or depression linked to their skin condition can be referred by a GP, or in some areas self-refer, to Improving Access to Psychological Therapies (IAPT) services for people with long-term physical health conditions (LTCs), but again only where IAPT services exist. Psychological well-being practitioners and high-intensity

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therapists such as practitioner psychologists and cognitive behavioural therapists can provide appropriate evidence-based interventions that may help patients with skin conditions and mental health distress. IAPT training is usually generalist; at present there is one dermatology specific pathway within IAPT in Sheffield (see figure 8). Where there is a moderately severe psychiatric disorder, GPs can also refer to Community Mental Health Teams (CMHTs) within which there is access to psychiatry assessment and secondary care psychology input, as well as occupational therapy and social work input. However, at present CMHTs are under-resourced and are therefore forced to focus on patients with severe mental illness (SMI) and those at high risk of harm to self or others.

3.33 Tertiary care

There is a small number of specialist psychodermatology services in the UK. There are 10 formal dedicated psychodermatology clinics in England and just 3 in the devolved nations (2 in Scotland, 1 in Northern Ireland and 0 in Wales).⁵ Many of these services are dedicated to a specific disease (for example psoriasis) and so are not general psychodermatology services. And services are not uniformly distributed, with some areas entirely without any service at all, for example Wales. And, only around a quarter of UK dermatology consultants have access to some sort of psychodermatology service.⁵ Therefore, UK service provision is insufficient to meet national demand.⁵

Most patients seen by healthcare professionals have a primary skin condition with psychological comorbidities. A minority of patients have a primary psychiatric or psychological conditions (e.g. delusional infestation, skin-picking disorder, hair-pulling disorder, dermatitis artefacta and body dysmorphic disorder), requiring specialist psychodermatology services.⁷ These patients can often be unwilling to accept the psychiatric nature of their disorder and unaware of the circumstances that trigger the physical and psychological manifestations.⁴⁶ Therefore, they are suitable for treatment within a dermatology clinic by a multidisciplinary team. A dermatologist diagnoses and excludes organic disease, a psychiatrist provides medications to manage the concomitant psychiatric presentation, and a practitioner psychologist provides psychological therapy to resolve the precipitant.⁴⁶

INQUIRY FINDINGS

“I got eczema at 35, it hit like a train and ripped my life apart. I distanced myself from friends until no one called. So all my life was work, deal with eczema at home, try to sleep for a few hours and go to work exhausted looking like a blotchy, itchy mess.

The main thing is I can't have a girlfriend or wife as I don't want that person to feel emotionally awful due to seeing me when I am in a bad way... Thus, no kids as they would get it and I will not allow that.”

4.0 Background

The APPGS Inquiry collected evidence from patients, professional medical bodies, patient support groups and pharmaceutical companies through a parliamentary evidence session (APPGS, 2020) and two separate surveys, one for patients with skin conditions and the other for organisations with an interest in dermatology [appendix D and E]. Patient witnesses provided oral evidence, and 544 individuals and 16 organisations responded to the two respective surveys.

4.10 Patient survey

Our patient survey was conducted in order to (1) identify and describe the nature of psychological impacts typically experienced by people living with skin conditions in the community in the UK, and (2) to describe their experience of seeking support for these issues.

4.11 Methodology

The patient survey consisted of a 22-item questionnaire for participants (see Appendix D). We received responses from 544 individuals who have been diagnosed with a skin condition at some time (see Appendix D for full demographics of participants).

The methodology of a thematic analysis was selected as it best suited the explorative nature of this research, allowing flexibility in exploratively interpreting the data, whilst also allowing a large amount of data to be divided into broad themes. Interrater reliability of our codes was calculated using a Cohen's Kappa.

4.12 Findings

All questions were found to have adequate rates of interrater reliability. This implied the efficacy of the developed codes - and as such this coding framework - was developed into more general themes.

Analysis of the participants' qualitative responses revealed 5 super-ordinate themes and 12 subthemes (figure 2). Each theme is supported by illustrative quotes.

Figure 2: Survey Themes

Themes	Sub themes
The adverse psychological impact of skin conditions throughout life	<ul style="list-style-type: none"> • <i>Negative wellbeing and distress</i> • <i>Negative perceptions of self and impact of self-worth</i> • <i>Untreated distress in children creates a lifelong mental health burden</i>
An obstacle to social and peer group acceptance and an impact on emotional and physical intimacy	<ul style="list-style-type: none"> • <i>Negative impacts on relationships and intimacy with others and restricting intimate relationships and romantic connections</i> • <i>Implications on social connections and friendships</i>
A barrier to everyday living, work, and education	<ul style="list-style-type: none"> • <i>Barriers to normal living, leading to self-management and changing lifestyles</i> • <i>Difficulty in reaching full potential in academia and career</i> • <i>Barriers to meeting the parenting role</i> • <i>Physical and emotional impact of skin conditions</i>
A lack of recognition, understanding and acceptance	<ul style="list-style-type: none"> • <i>Lack of understanding and acceptance from society</i>
A demand for the clinical recognition of the psychological impact and the lack of available and appropriate psychological support	<ul style="list-style-type: none"> • <i>No support available: patient demand for recognition of psychological effects</i> • <i>When support is available, there is a lack of specialist, supportive, bespoke, adaptive services</i> • <i>With correct psychological and social support, the effects of skin conditions can be minimised</i> • <i>Lack of specialist paediatric support</i>

The adverse psychological impact of skin conditions throughout life

When asked, 98% of respondents reported that their skin condition had affected their emotional wellbeing. Furthermore, 93% of respondents reported that their skin condition had affected their self-esteem. Throughout the survey, respondents’ qualitative responses indicated the psychological impact of their skin condition was extremely significant:

“it’s honestly soul destroying; it destroys every part of you physically and mental”

~ Respondent with atopic dermatitis

“The feeling of helplessness and frustration is indescribable, when the skin is slowly getting worse, almost like a parasite is taking over your body, and all the treatments aren’t helping”

~ Respondent with psoriasis

The chronic nature of many of the respondents’ skin conditions appeared to exacerbate the impact:

“I do not go a day without thinking or worrying about my skin conditions”

~ Respondent with eczema, hidradenitis suppurativa and seborrheic dermatitis

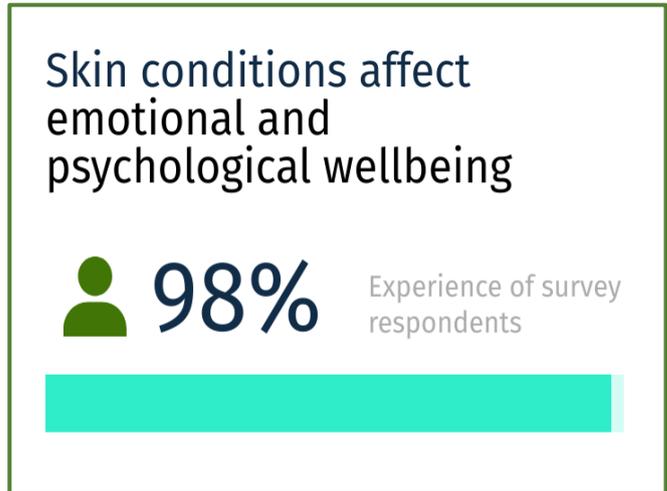


Figure 3: Psychological and emotional impact

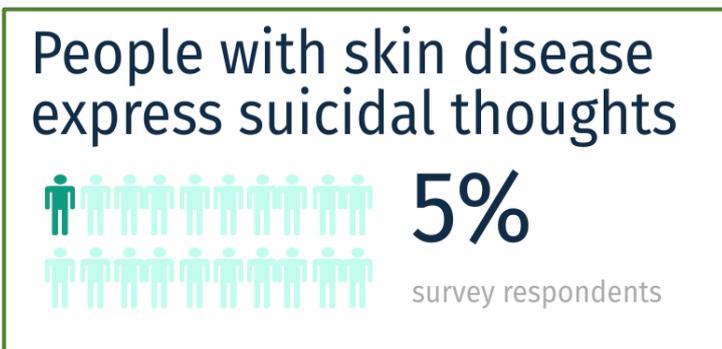


Figure 4: Suicidal thoughts in people with skin disease

Indeed, the impact was such that some respondents spontaneously described having thoughts of hopelessness and/or suicidal ideation. 5.33% (N=29) explicitly mentioned suicidal ideation, despite this not being specifically asked about in the survey.

“I sometimes think what is the point of living. The condition exhausts me”

~ Respondent with eczema

“Absolutely devastating. Psychologically destroying and sometimes I just want to die”

~ Respondent with lichen sclerosus and rosacea

Others reflected on their view of themselves and how living with a condition affected their self-worth and body-image:

“I feel so embarrassed to even go out, I feel I’m the ugliest”

~ Respondent with psoriasis

“This small box cannot begin to describe the sheer living hell of attempting to tear your own skin off”

~ Respondent with atopic dermatitis

In conjunction with negative views about themselves, respondents frequently reflected on how they believed others viewed them and expressed concern for how this had impacted on their opportunity for, or actual, relationships; this is described in more detail in the second superordinate theme.

An obstacle to social and peer group acceptance and an impact on emotional and physical intimacy

Skin disease can significantly hamper a person’s ability to socialise and interact with other people. Experiences of stigmatization and intrusive reactions from others can contribute to avoidance behaviour and feelings of isolation:

“The first time I realized I was different was when a young child approached me in the playground at school. He went to put his hand out to touch me and jumped back and said, ‘I am not going to touch you because I think your skin is contagious’.”

~ Respondent with vitiligo

“I can’t look people in the eye. Every interaction I have with people, I can feel them staring and looking in disgust at the skin on my face. No amount of make-up, skin products or medications improved the conditions, but I constantly get unsolicited ‘advice’ about how to improve it from those without the conditions.”

~ Respondent with acne and rosacea

73% of respondents reported that their condition had negatively affected intimate relationships. This includes respondents actively avoiding relationships themselves as well as respondents feeling that others avoided interaction and intimacy with them because of their condition. Some respondents expressed that they avoided relationships for fear of either being rejected or because of having lowered sense of confidence in their bodies.

“I don’t like to be touched as I feel they will be grossed out”

~ Respondent with psoriasis

Inquiry findings

"It's hard to let anyone love you, look at you, kiss you, etc, when you feel and look disgusting"

~ Respondent with acne and rosacea

"Just the look of my skin is repulsive. I have been single for 5 years"

~ Respondent with cutaneous & systemic mastocytosis

Indeed, some respondents described having had experience of being rejected when they had attempted to pursue intimate relationships.

"any man I dated were turned off by my psoriasis"

~ Respondent with psoriasis

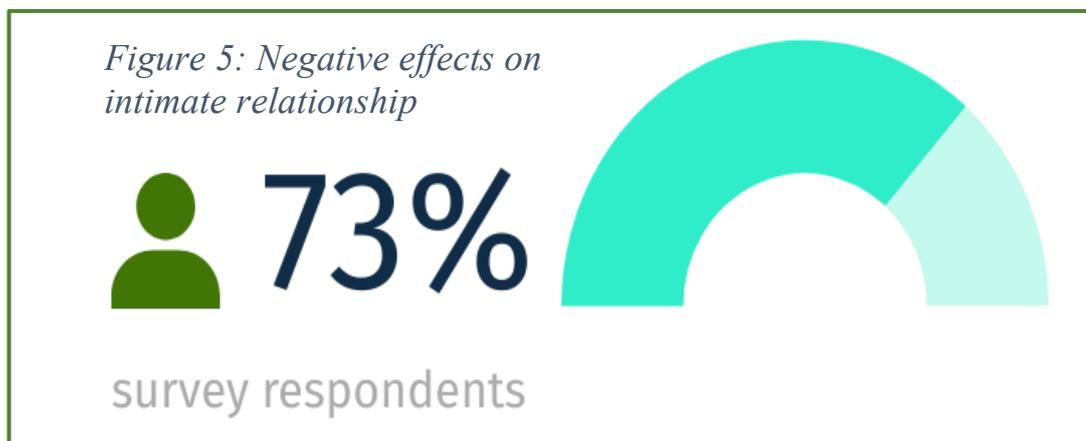
"saying they wouldn't want children with me because they might have it"

~ Respondent with atopic dermatitis

Some respondents reported having supportive relationships, nevertheless there was a sense of the fragility of this support for some or a sense that they were 'lucky'.

"I'm lucky now that I have a supportive and accepting partner"

~ Respondent with psoriasis



Finally, some respondents indicated that their condition affected the quality of intimate contact via intimacy triggering pain or irritation.

"the last thing that you want is to be touched as this just irritates the skin,...especially when I was younger [it] was impossible"

~ Respondent with atopic dermatitis

"It has destroyed my intimate relationship with my husband due to the pain"

~ Respondent with lichen sclerosis

A barrier to everyday living, work, and education

Perhaps in part due the psychological impact of their skin conditions, 87% of respondents reported that their condition had directly affected their social life and leisure activities; and 69% reported that it had affected work or education. In addition, 83% of respondents stated that it had affected their sleep.

The impact on quality of life was via avoidant coping, discrimination, or direct physical limitation:

“When it's bad, I just want to hide as I feel everyone's staring”
 ~ Respondent with atopic dermatitis

“Constant fatigue makes productivity difficult, being unable to stop scratching long enough to actually perform a task”
 ~ Respondent with atopic dermatitis

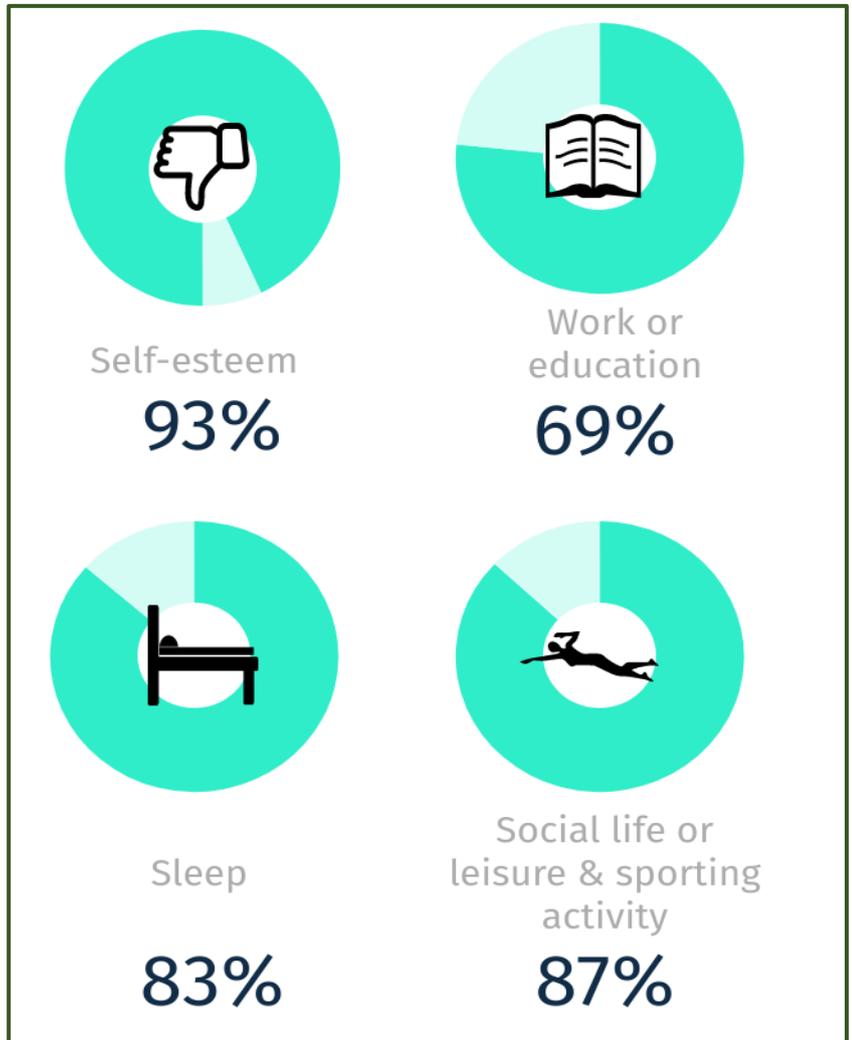


Figure 6: Negative effects for survey respondents

The chronic nature of many skin conditions can be debilitating and cause constant pain, discomfort, fatigue and itch.

“Life is a never-ending catalogue of pain, discomfort, irritation and shame. It is very difficult to relax and enjoy life when you are constantly distracted by the symptoms of psoriasis.”

~ Respondent with rosacea

These barriers were reported as preventing some respondents in achieving their full educational potential or adversely affecting their career:

Inquiry findings

"I found job interviews quite hard because if I put my hand out to shake a potential employer's hand, the first thing they would think of is why was my hand white".

~ Respondent with vitiligo

"I was always in hospital as I child and missed a lot of school. I'm now in work but was unable to make grades to go to university"

~ Respondent with atopic dermatitis

"I have been laid off work due to health issues and do not have the confidence to discuss issues in interviews as it results in discrimination"

~ Respondent with psoriasis and hives (urticaria)

Even everyday activities can become impossible for some people with skin conditions:

"I found it hard to learn to write at school, I couldn't hold a pen properly. I also had psoriatic arthritis so I couldn't straighten my fingers"

~ Respondent with psoriasis

In response to barriers some change their lifestyle and develop 'self-management strategies' to try and mitigate these difficulties:

"Changes what you do, who you meet, opportunities you take, clothes you wear, you can never do anything spontaneously"

~ Respondent with psoriasis

"I would have swimming lessons and often I would forge sickness notes from my mum because I did not want to go swimming and wear a swimsuit"

~ Respondent with vitiligo

"My daily skin routine took 3 or 4 hours each day, just to make my life bearable - soaking in a bath, cleaning the skin, creaming, bandaging"

~ Respondent with psoriasis

A lack of recognition, understanding and acceptance

People with skin conditions can experience rejection from others including a general misconception about the nature of skin conditions and a lack of understanding in relation to their associated physical and psychological impact. Survey respondents also demonstrated that they had internalised dominant stereotypes concerning attractiveness:

"You are not what is categorised as being 'beautiful'"

~ Respondent with psoriasis and urticaria pigmentosa

However, this was not simply a matter of belief. Respondents described numerous examples of having been subject to actual episodes of bullying and in some cases discrimination, which was unsurprisingly associated with the development of negative beliefs about the self:

“Exposed to high levels of abuse as a child, I wish this was just from other children, but schoolteachers contributed too. I spent a long time thinking I was dirty, ugly and unlovable.”

~ Respondent with atopic dermatitis and shingles (herpes zoster)

This ‘judgement from others’ was often hypothesised by respondents to be a result of the lack of education or understanding about skin conditions:

“The misinformation that acne is caused by being dirty fuelled the unsolicited advice I received that implied I had acne due to poor hygiene ...fuelled the ‘blame’ culture of acne further and made me feel like it was my fault.”

~ Respondent with acne

Respondents particularly reflected upon this judgement in relation to the experience of prejudice during school but was also highlighted to carry on into adult life, affecting acceptance and support at work, romantic relationships, and social connections. The following quote indicates how skin conditions are also mistakenly linked to other stigmatising conditions:

“Any man I dated was turned off by my psoriasis....A couple of men even asked me (seriously) if I had AIDS when they saw my skin”

~ Respondent with psoriasis

Even when others were noted as being accepting of respondents’ skin condition, many were usually described as failing fully to empathise with the depth of the impact:

“Other people say “it’s not that bad, nobody will notice”. [However] People do notice and stare.”

~ Respondent with cutaneous mastocytosis

“Although people want to be sympathetic, they really don’t understand the impact”

~ Respondent with atopic dermatitis, contact dermatitis and psoriasis

This lack of understanding was not only reflected on in terms of peers and members of the public but was also frequently reported during encounters with medical professionals as described more fully in the fifth theme.

A demand for the clinical recognition of the psychological impact and the lack of available and appropriate psychological support

Despite 98% of survey respondents stating that skin disease had affected their emotional or psychological wellbeing, only 18% had sought help. This is largely down to a lack of awareness that limited services are available – over half (54%) were unaware that they could seek help – as well as poor diagnosis, signposting, and triaging.

Figure 7: Sought help in connection with their psychological or emotional wellbeing associated with their skin condition



“I have not been made aware of any psychological support by [my] NHS dermatologist. I have broken down in tears at so many of my appointments. I wonder why they are not offering this support.”

~ Respondent with psoriasis

The need to upskill healthcare professionals is evident in the data. It highlights some healthcare professionals’ lack of understanding, support, and recognition, particularly in relation to the severity of psychological impacts from skin conditions:

“I’ve never felt properly supported by dermatologists, as they’re only interested in treating physical symptoms, and not the emotional difficulties attached.”

~ Respondent with psoriasis

“GP totally lacks empathy regarding this condition and require training on its impact on one’s self esteem”

~ Respondent with rosacea

Evidence also suggests that skin conditions are often trivialised, so some patients struggle to receive support or do not ask for help as they feel their mental health it is important enough to mention.

“You often feel that you are troubling the doctor when you visit that you should just suck it and keep applying the moisturiser... As it's not life limiting it isn't seen as important.”

~ Respondent with eczema

“I would be too self-conscious to ask for support having had doctors dismiss my condition in the past. I always feel that I am wasting GPs and consultants time if I have to go as there are people with serious illnesses and not just sore skin.”

~ Respondent with eczema

Mental health services are not available in many areas of the country, so when patients do request psychological or conventional therapies, some feel that their preferences are not respected by clinicians.

"I spoke to my GP about this about 12 months ago and asked for psychologist support, but have [had] no support."

~ Respondent with eczema and psoriasis

Patients reported never being asked how their skin condition impacts their daily life and having their ailments largely ignored. Many were critical of the lack of primary care understanding of the debilitating impact of skin disease.

"I feel that, unfortunately, many GPs have not been given sufficient training in dermatology and it has always seemed to me to be regarded as a "Cinderella" condition"

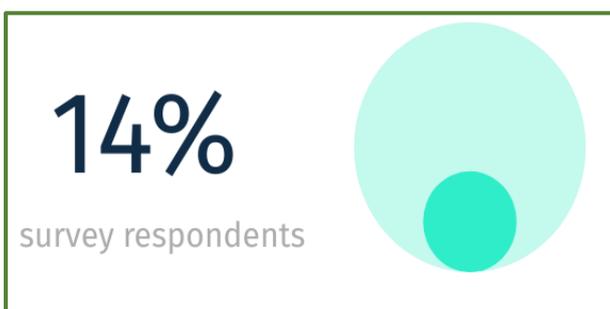
~ Respondent with psoriasis

"I wish that doctors and nurses were trained to recognise lichen sclerosus. It is woefully unrecognised. I feel neglected by the medical profession."

~ Respondent with lichen sclerosus

Some healthcare professionals want to offer mental health support, but can be reluctant to ask questions, such as 'have you felt suicidal?', because they lack the skills, resources or time to manage patients with both skin conditions and mental health issues.

Figure 8: Awareness that in some areas of the UK there are NHS psychological services for people with skin conditions



Only 14% of respondents were aware that the NHS has some limited mental health support services for patients with skin conditions. Many felt compelled to seek private care. However, this is expensive, and many cannot afford it or, if they can, only short-term.

"The system seems broken to me, if you can't afford to fund mental health privately you won't get it."

~ Respondent with psoriasis

"Only able to have 4 sessions as was private but helped with managing other people's comments."

~ Respondent with nodular prurigo and eczema

Some individuals that did successfully seek mental health support, reported a life-changing impact:

“My psychologist was amazingly understanding, where I felt I was drowning she offered me a window of hope, a small solution to each aspect that was affecting me and showed me a way out. Through changing my way of thought and teaching me coping mechanisms I found a way to start functioning again”.

~ Respondent with psoriasis

“Non-judgemental workers. Was set at ease. Didn’t realise from the offset that how I was feeling emotionally was connected to my eczema, as I have experienced mental health issues previously.”

~ Respondent with eczema

4.2 Treatments

Counselling, cognitive behavioural therapy (CBT) and mindfulness are the most common psychological therapies provided to inquiry respondents. Approximately a fifth received medications, such as anti-depressants (figure 9).

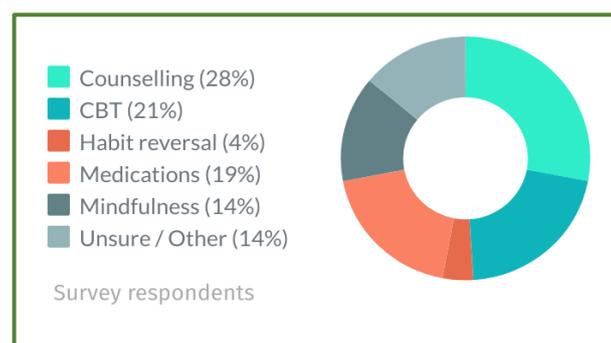
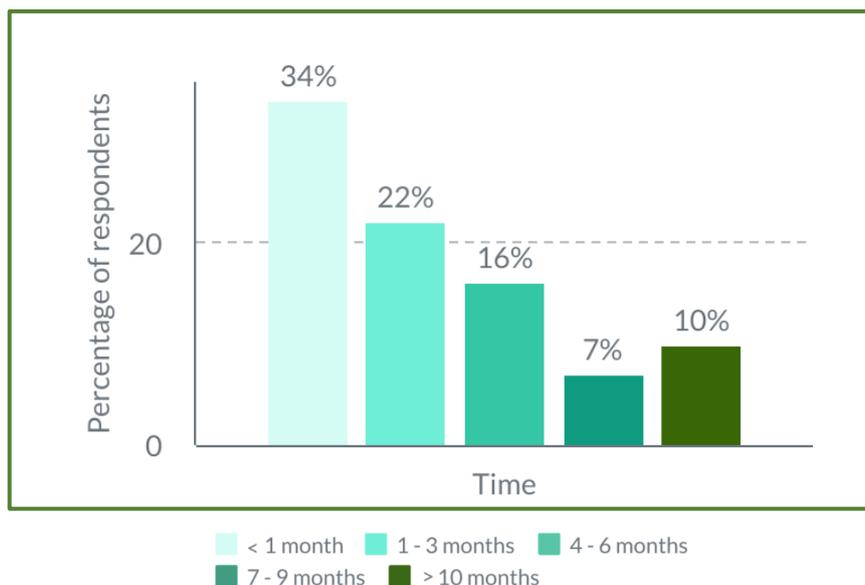


Figure 9: Treatments received by respondents

4.3 Waiting times

Of the 18% of survey respondents who have received mental health therapy, a third received treatment within a month of being referred, and over a half received it within three months. Approximately a quarter of respondents might have waited longer than the NHS’ 18-week target for the time between a patient referral and the start of specialist treatment. Several respondents had to wait over a year and, in one case, it was five years.

Figure 10: Waiting times for mental health support



Survey responses indicate that some patients have been referred by their GPs for mental health support but were never provided with specialist care. These respondents were not included within the waiting times since they were never seen. The results also belie the fact that many patients with skin conditions spoke of a desire to access mental health support but were never been referred by their GP. For example, one individual suffered for years with largely untreated severe symptoms, and only when seeing a GP with an Extended Role in dermatology (GPwER) did a doctor acknowledge the urgent need for the patient to receive specialist secondary care. Others seek and wait for support indefinitely. Therefore, actual waiting times are far worse than reported in figure 10.

4.4 Experiences of organisations

16 skin organisations provided evidence to the inquiry: 4 medical professional organisations, 9 patient groups or charities, and 3 pharmaceutical companies. All organisations that provided a response to the survey question on ‘current NHS service provision for people in psychological distress due to skin conditions’, responded that NHS service provision is either ‘poor’ [80%] or ‘very poor’ [20%].

Organisations report that some patients who are not having their mental health needs addressed, are becoming disillusioned with their care and, as a result, their treatment plan, making them less likely to adhere to their treatments. In some cases, patients are giving up on their care and dropping out of the system altogether. This can result in patients’

symptoms becoming uncontrolled and more severe, requiring more specialist and costly treatment in the future.

Most of the organisations that provide resources and psychological wellbeing services to patients with skin conditions agree that the wider benefits to the NHS of a better mental health service provision would be significant. It would improve patient quality of life and lead to patients being able to self-manage their condition. This can have a beneficial financial knock-on effect, as it should reduce patient reliance on a range of support services. Well treated patients are also more likely to work and contribute to the wider economy, both in terms of securing and maintaining employment, but also in amount of time off from work due to flare ups or appointments. There would also be a significant corresponding benefit for the families and carers of those affected.⁴⁷

PAEDIATRICS

5.0 Background

Several skin conditions such as eczema, psoriasis, and acne are common in childhood and adolescence. For example, eczema affects over 20% of children under 5 and is the most common reason for accessing NHS care for children under 10, whilst acne is the most common reason for those aged between 10 and 18. Less commonly, children can also have life threatening skin diseases, such as toxic epidermal necrolysis, as well as life limiting conditions, such as epidermolysis bullosa.⁴⁷

5.1 Physical impact for children

For some children and young people, the severity of physical symptoms related to the skin can be great, and lead to pain and feelings of desperation:

“pain: feels like being stabbed with needles or in a hail storm”.

~ Child respondent with mastocytosis (‘very itchy skin condition’)

“I feel as if I am drowning in the feeling of an unbearable itch and burn, it feels never ending and it’s honestly soul destroying, it destroys every part of you physically and mentally. It is so unbelievably painful there are no words that can make you imagine the feeling”.

~ Child respondent with eczema

5.2 Psychological impact for children

Skin conditions can carry a psychological burden for many children, young people, and families.^{47,48} Of the 27 paediatric (< 18 years) respondents to the APPGS survey, 100% indicated that their skin condition affected their psychological wellbeing and a majority (85%) had low self-esteem, particularly in relation to engaging with peers at school.

The visibility of many skin conditions can impact upon a young person’s emerging body image and negatively impact upon psychological wellbeing and self-esteem:

“I feel uncomfortable and dislike looking different as a teenager”.

“I self-harm & have suicidal thoughts”

~ Child respondent with eczema

Young people with skin conditions can experience stigmatisation and negative treatment from peers and a general lack of understanding about their condition:

"I've been bullied. I find it hard to make friends. I feel bad about myself."

~ Child respondent with hives (urticaria) and eczema

"no one would come near me in case I was contagious, which also gave me trust issue".

~ Child respondent with eczema and psoriasis

Intrusive or inquisitive comments and reactions of people can make young people feel different and alienated:

"Children in my school ask questions"

"I hate feeling like I am different, I want to be like everyone else and not be stared at"

~ Child respondent with haemangioma

Depression, anxiety, and suicidal thoughts were expressed by some youths.

"I was so depressed. I felt like I was rotting away inside an alien growth on my face. I didn't wanna exist like that. I wanted to chop my own head off".

~ Child respondent with cystic acne

5.3 Disruption to 'normal' life

The social-life, leisure and sporting activity of young people with skin disease can be adversely affected. Many avoid certain activities that require skin contact e.g. sports, and some try to avoid all social and public interactions.

Young people often reported being behind at school because of their visible skin condition and also as a result of missing out on education due to ill-health and medical appointments. Many struggle to concentrate on school work due to the poor sleep patterns due to the severity of their physical symptoms, such as sore, painful, itchy skin.

5.4 Impact on families

Parents may also struggle with aspects of the physical management of the skin condition and take on associated stresses. For example, it can lead to parental and sibling sleep disturbance, anxiety and distress caused by an upheaval of 'normal' family life.⁴⁴ The parental psychological burden can be even greater than the psychological distress experienced by the child.^{47,49}

*"I have been diagnosed with generalised anxiety, partly as a result of a lack of sleep."
~ Parent of two children with eczema*

Therefore, it is essential that doctors conduct holistic assessments to ascertain the mental health impact of skin conditions on not only children and young people, but also the families. Parents/carers and siblings should be offered appropriate psychological support if required.

Doctors must also ensure that parents/carers are adequately educated about the treatment and management of their child's condition and GPs must prescribe adequate amounts of the topical treatments required.

5.5 Mental health services for children and young people

Most presenting with psychological distress associated with their skin disease will be seen in primary care, if they seek healthcare services. However, if primary care practitioners lack the confidence or skills in dermatology or the psychological aspects of chronic conditions, then they may go untreated.

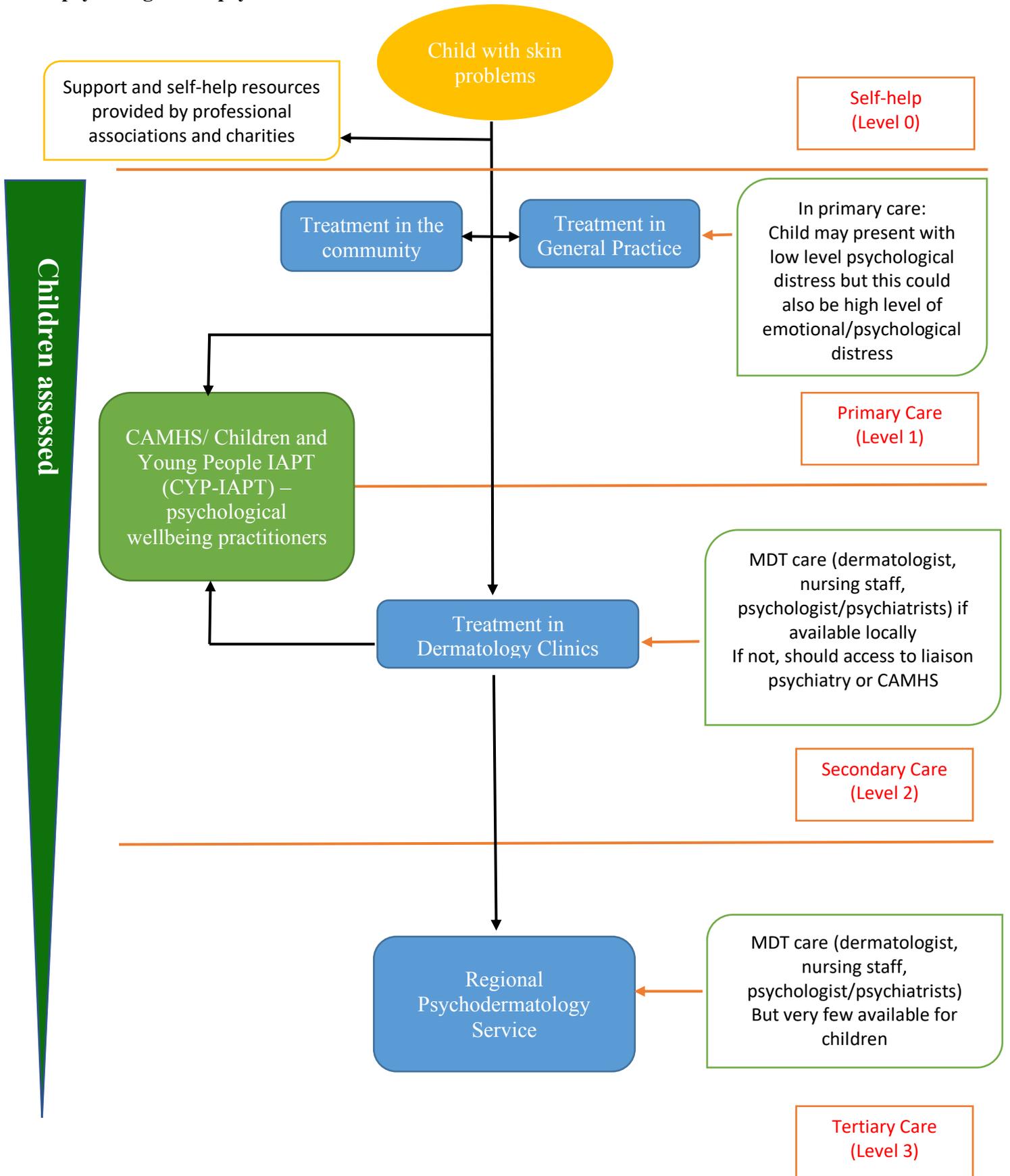
The majority of those with psychological distress linked to their skin condition are unable to access any specialist mental health support within dermatology, despite there being evidence that effective educational and psychological interventions exist.³⁶ Fewer than 5% of dermatology clinics across the UK provide some level of paediatric psychodermatology and there is only one dedicated paediatric psychodermatology service.⁵

These services are predominately concentrated around London, meaning that in large areas of the UK children and young people are unable to receive specialist paediatric psychodermatology care.

There is similarly a lack of generalist psychological therapies available to children suffering from any mental health condition.⁵ Child and Adolescent Mental Health Services (CAMHS) and the Children and Young People's Improving Access to Psychological Therapies project (CYP-IAPT) aim to provide mental health interventions for children and young people. However, both services are overstretched and unable to treat all children and young people experiencing psychological distress⁵.

Figure 11 presents an ideal referral pathway for children with skin conditions and psychological or psychiatric distress. Commissioners and local providers should aim to provide this stepped provision of support.

Figure 11: Stepped provision of support to child patients with a skin condition and psychological or psychiatric distress



5.6 Improving paediatric psychodermatology services

Our Inquiry found that skin disease can affect every facet of a young person's life, from relationships ("I feel like no boys would want me"), schooling ("I dropped out of school as I was so unhappy"), and sleep ("itching at night is lonely and distressing") to self-esteem ("I feel ugly and constantly low") and psychological wellbeing ("I cry a lot when my skin gets infected"). It can dominate and take over the entire life of a child and the family.

We know that adult patients with chronic skin disease have significant psychological needs and therefore it is imperative to build resilience and coping strategies in children and young people as this may prevent long-term mental health burden e.g. anxiety and depression.

Therefore, it is essential that there is greater training provided to healthcare practitioners -in identifying and managing the psychological aspects of childhood skin disease and that clear and appropriately resourced pathways are established to allow timely referrals into paediatric psychology services

Key recommendations

- **All children and young people experiencing mental health distress associated with their skin condition must have access to appropriate psychological support.**
- **Training must be provided to healthcare practitioners to facilitate the identification and management of the psychological aspects of childhood skin disease.**
- **All doctors and allied health care professionals must conduct holistic assessments to ascertain the psychological impact of skin conditions on children and their families**
- **It is imperative that there is at least regional access to paediatric psychodermatology clinics throughout the UK.**
- **There should be clear and appropriately resourced regional pathways established to enable referrals into paediatric psychology services.**

HEALTHCARE PROFESSIONAL TRAINING

“In the main we are finding that people with psoriasis are not getting access to specialist psychological services through the NHS. Instead, it is GPs and/or dermatologists and specialist nurses who are having to try and provide some level of psychological support during their consultations, often without having had any specialist training in this area. The level of psychological support that patients are offered therefore depends on the willingness/confidence of GPs and dermatology specialists to engage with them about psychological issues. This is far from an ideal situation for the healthcare professionals or the patients.” – evidence submitted by the Psoriasis Association

6.0 Background

The APPG on Skin has consistently said that education and training for primary care in dermatology is insufficient.⁵⁰ Given that approximately a quarter of the UK population consult a GP each year because of a skin complaint, there is an acute need for improved training within dermatology to support the high population need.

6.1 Undergraduate training

Training for all healthcare professionals must be tailored to respond to patient need. However, at some medical schools (15%) it is possible to complete undergraduate education without ever completing any formal dermatology focused education.⁵¹ The longest period of training is six weeks – in just one case.⁵¹ The average is about one week.⁵¹

Undergraduate training in psychodermatology is often purely opportunistic. The only occasion for learning may be provided by watching and learning within a clinical setting. Moreover, there is even less opportunity for paediatric psychodermatology training.

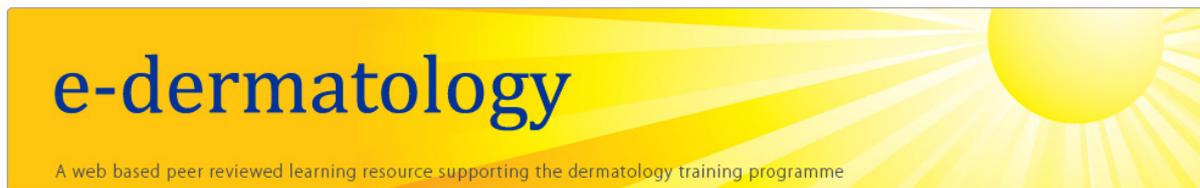
Whilst there is little published evidence for a lack of dermatology training in undergraduate nursing programmes or in postgraduate practitioner psychology training programmes, anecdotal evidence reports a similar situation to that of doctors. Many nurses may lack knowledge in dermatology, which means they are unable to give basic advice and support in skin care.

6.2 Primary care practitioner training

Evidence submitted to this Inquiry indicates that many patients feel let down by the level of knowledge of their GP. GPs are reported to misdiagnose, offer unhelpful and insensitive comments, lack support and trivialise the severity of symptoms. This may have severe impact on young people, who can be at a vulnerable developmental stage and consequently may inhibit them from seeking medical and/or psychological help from health care professionals in the future.

Therefore, formal dermatology training modules, learning resources and educational events for primary care practitioners must be accessible and promoted by Primary Care Networks (PCNs). General Practitioners can already access the psychodermatology NHS e-LfH British Association of Dermatologist module⁵² (see Figure 11), which is hosted on the NHS e-learning suite of resources and available free to all NHS healthcare practitioners. However, it needs to be better promoted by PCNs.

Figure 11: NHS e-dermatology training module



The GPwER in dermatology should be developed and supported in secondary care to ensure that GPs interested in dermatology can receive access to mentoring and shadow clinics.

Primary and Community Care Training Hubs provide education and workforce training for a local area. Their education programmes respond to local needs and can act as a catalyst for the adoption of best practice. They can play a huge role in meeting the dermatological educational needs of multi-disciplinary primary care and community team, including GPs, nurses and other healthcare professionals. All Integrated Care Systems (ICSs) and Sustainability and Transformation Partnerships (STPs) should belong to and work closely with a Training Hub.

The Primary Care Dermatology Society (PCDS) delivers education on a national level and addresses the issue of skin disease and mental health in all its presentations. Local providers should ensure staff have access to PCDS's high quality educational training and events.

6.3 Reviewing primary care practitioner training

Given the lack of available training, the APPG on Skin believe that there is an urgent need for an inquiry to review GP knowledge and training. It should evaluate knowledge and training based upon population need, of which dermatology is one with a high need. In England, Health Education England (HEE) and the medical Royal Colleges and Faculties should lead this inquiry. The respective education and training bodies in Wales, Scotland and Northern Ireland should likewise conduct a formal review into GP knowledge and training.

Health Education England (HEE) should also work with the Royal College of General Practitioners (RCGP), Royal College of Nursing (RCN) and Royal Pharmaceutical Society (RPS) to ensure that urgent priority is given to the provision of proper dermatological training for all GPs, nurses and pharmacists. Training must emphasise that many skin diseases are long-term conditions that require ongoing care. Similarly, the psycho-social effects of skin disease should be incorporated into the teaching and examination of training courses for GPs, nurses and pharmacists.

GP trainers should be evaluated for their dermatology knowledge, skills in discussing visible differences and how they incorporate dermatology teaching into training their trainees. Appraisers should emphasise the importance of covering all aspects of general practice in the annual appraisal, dermatology included. At revalidation, Responsible Officers could pay attention to sufficient evidence of learning and demonstrating competencies in the main dermatological conditions.

All institutions providing nurse education training must ensure the teaching of undergraduate nurses includes the impact that skin disease has on mental health.

The APPG believes that part of the training for mental healthcare practitioners such as clinical psychology trainees and IAPT psychological wellbeing practitioners and high intensity therapists must include training in the basic assessment and support of psychosocial comorbidities of skin disease. At the very least, mental health care professionals must be

able to assess and know how to modify psychological therapies for use with patients living with skin conditions.

The continuing professional development of all healthcare professionals should also include the mental health impact of skin disease. Some training resources have been developed within the third sector (for example, The Psoriasis Association's 'PsoWell' training programme for dermatology specialists and psychologists⁵³) and there are also some limited modules available to General Practitioners on specific skin diseases such as alopecia.⁷³ In addition, the online NHS e-learning suite of resources is a valuable resource and includes a module on psychodermatology. However, the use of such modules is not built into training appraisals and continuing professional development could be achieved through including the monitoring of completion of such training through the annual appraisal system and/or linked into cyclical mandatory training.

6.3 Psychodermatology training within Dermatology

There is an appetite amongst dermatology specialist staff to learn new skills to empower their patients to live better lives. Our Inquiry found that few healthcare professionals have any formal training within psychodermatology.

Despite the combined British Association of Dermatologists and Psychodermatology UK Training School in Psychodermatology which has been running for more than 12 years, there is a clear demand for training amongst specialist groups. Advanced schools in psychodermatology for senior practitioners (dermatologists, nurses, psychiatrists, psychologists) are needed to maintain, develop and supervise basic psychodermatology skills.

Commissioners must ensure that healthcare professionals, including nurses and pharmacists, are given greater opportunities to increase their knowledge in the psychological needs of dermatology patients.

Service leads should ensure that staff make use of the existing e-LfH resources. For example, the APPGS believes that the introductory psychodermatology NHS and the British Association of Dermatologists approved e-LfH module should be completed as standard by all dermatology professionals. There should also be specific intervention training in evidence

based brief interventions¹, such as habit reversal and stress reduction provided for a group of dermatology staff within each service who are likely to be involved in providing treatment of psychological impact. Such training should be available to nurses working in dermatology clinics, who have access to supervision or consultation with a registered psychological practitioner.

Access to additional psychodermatology training must be given a priority so that doctors and nurses can have paid for time off work to develop the necessary skills to ensure evidence based effective care. Moreover, NHS services should support the educational development of its employees and routinely fund the provision of specific psychodermatology training as recommended by regional psychodermatology leads. This has been shown to be cost-effective by ensuring that the psychological as well as physical needs of patients are met in the correct clinical environment.

More broadly, to enable healthcare professionals to upskill in basic psychological techniques, funding should be provided to further develop and add to the existing e-LfH NHS psychodermatology e-resources.

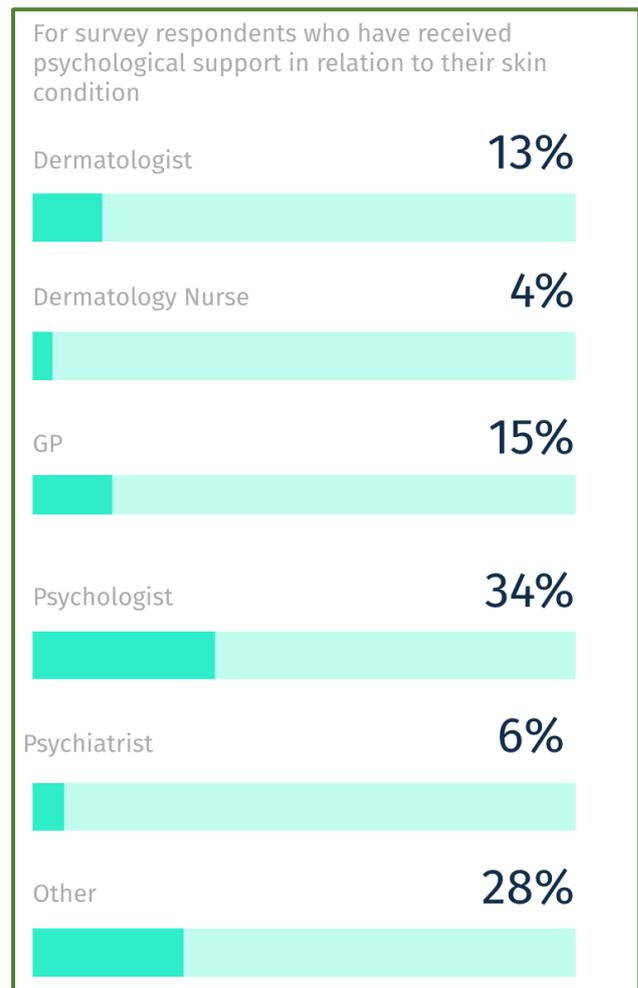
6.4 Dermatologists

The introductory NHS e-LfH psychodermatology module (figure 11) forms part of the dermatology curriculum, and this existing training includes measuring psychological impact and the use of relevant scales and questionnaires. However, there is a need to further develop this to support training in diagnosing and treating psychological comorbidities for consultant dermatologists.

Additional psychodermatology e-learning modules should be developed on the e-LfH platform and a working group should look to work to further develop the Dermatology Higher Specialist Training curricula that would guide this process.

Despite the combined British Association of Dermatologists and Psychodermatology UK Training School in Psychodermatology, there is an urgent need to develop specialist training within psychodermatology. It should be developed via accreditation and collaboration between the British Association of Dermatologist, Psychodermatology UK, Royal College of Psychiatrists, and British Psychological Society, with input from patient organisations and charities. Advanced schools in psychodermatology for senior practitioners (dermatologists, nurses, psychiatrists, psychologists) are needed to maintain, develop and supervise basic psychodermatology skills. Disease speciality groups should also increase healthcare exposure to psychodermatology, so that the likelihood of trainees choosing it as a subspecialty in the future increases.

Figure 12: Healthcare professionals treating skin patients



6.5 Nurses

Psychodermatology is an important component of nursing and multi-disciplinary patient care. Highly trained consultant nurses, advanced nurse practitioners and dermatology specialist nurses can explicitly implement and support the delivery of psychological interventions.⁴⁹ Nurses can access the e-LfH psychodermatology modules. However, the APPG on Skin is aware of only a few additional training opportunities for nurses in psychodermatology [see appendix F]. Therefore, like other HCPs, nurses must have access to new and additional psychodermatology education.

6.6 Psychologists and psychological practitioners

Doctorate courses that are Health & Care Professions Council (HCPC) and British Psychological Society (BPS) accredited should include teaching on the psychological impact

of skin disease across the lifespan as part of competency development in the application of psychological interventions to long-term conditions in adults and children. Training should also consider how to assess and intervene across different developmental stages and cognitive needs. This should include both direct provision of evidence based psychological therapies for patients and their families, as well as considering not only individual but also systemic interventions (e.g. joint care across health, social work, and education settings). Psychologists are also well placed to support other healthcare professionals in developing psychological skills such as habit reversal or relaxation techniques.

Trainee clinical psychologists and other NHS psychological practitioners such as trainee psychological wellbeing practitioners can access the e-LfH psychodermatology module and should be signposted to this resource. This should include both direct provision of evidence based psychological therapies to patients, and for psychological practitioners should also include the development of competencies to support other professionals who might provide low-intensity psychological techniques, such as habit reversal and evidence-based stress reduction and relaxation techniques.

In order to facilitate this, the British Psychological Society's Faculty of Clinical Health Psychology and Paediatric Psychology Network should ensure that it has an active network of practitioner psychologists with expertise/interest in developing and promoting the provision of psychological services to people living with skin conditions.

6.7 Psychiatrists

In a regional paediatric psychodermatology service there must be access to a Paediatric Liaison Psychiatry service.

In an adult psychodermatology service there should be input from a liaison psychiatry Consultant. Currently it is unusual for liaison psychiatrists to receive training in psychodermatology as there are so few services. There should be experience and training in psychodermatology provided within the training of all trainee psychiatrists and particularly for liaison psychiatrists.

6.8 Multidisciplinary Teams (MDT)

The APPGS recommends the development of a psychodermatology multidisciplinary team (MDTs) at least regionally consisting of dermatology, psychiatry and psychology input. The evidence that MDTs are cost and clinically effective^{46,55,56} is mounting, and it is believed commissioners and providers should be setting up and maintaining MDT psychodermatology services across all devolved nations for adult and paediatric dermatology services.

6.9 Networks

Practicing psychodermatology is demanding.^{57,58} Networks for all psychodermatology HCPs provide a structure for support and sharing of best practice. Psychodermatology UK was established at the end of the 20th century and is now developing a network within the UK and internationally. The European Society for Dermatology and Psychiatry (ESDaP), established in 1975, is expanding to be more global, than strictly European, network, it similarly champions clinic-academic excellence in psychodermatology. A network of psychologists with an interest and/or expertise in working within dermatology is also being developed by The British Psychological Society's Faculty of Clinical Health Psychology. The APPGS actively encourages the establishment and propagation of national and international networks to support practitioners, share best practice and champion the clinic-academic priorities of patients.

Key recommendations

- **There should be a programme of reviewing primary care practitioners' skills, training in psychodermatology, and the assessment of psychological distress in long-term conditions. The APPGS recommends that primary care training in dermatology and psychodermatology is mandatory.**
- **Health Education England (HEE) should work with the RCGP, RCN and RPS to ensure that urgent priority is given to the provision of psychodermatological training for all GPs, nurses, and pharmacists.**
- **Training for nurses must include the training in the basic assessment and support for psychosocial comorbidities of skin disease. Nurses must be able to assess and signpost to available mental health services.**

- **The continuing professional development of all healthcare professionals should also include the mental health impact of skin disease. This could be achieved through the annual appraisal and/or other cyclical mandatory training.**
- **Commissioners and providers must ensure that healthcare professionals, including nurses, pharmacists, and psychological practitioners are given greater opportunities to specialise in psychodermatology.**
- **Psychodermatology should be included within the training of liaison psychiatrists. The Royal College of Psychiatrists should lead and facilitate this.**
- **All trainees in dermatology and psychiatry should have an attachment (the APPGS recommends at least 4-6 months) in psychodermatology during their training with specific training curriculum agendas and measurable training outcomes.**
- **There must be specific intervention training for all staff likely to be involved in providing treatment of psychological impact associated with skin conditions and use of the existing NHS e-learning materials (e-LfH) should be required for anyone working in this area.**
- **Additional psychodermatology training resources should be developed as part of the existing BAD/Psychodermatology UK and e-LfH modules.**
- **Commissioners and providers should ensure that comprehensive psychodermatology multidisciplinary team (MDTs) are developed at least regionally. These MDTs should consist of a Dermatologists, Liaison Psychiatrists, Psychologists, and specialist dermatology nurses.**
- **Efforts should be made to establish and propagate national and international networks to support practitioners, share best practice and champion the clinic-academic priorities of all patient groups including children and young people.**

STAFFING

7.0 Staffing numbers

Rising referral rates from primary care to secondary care within dermatology is putting pressure on the speciality. Many dermatology departments are over-subscribed and have long waiting lists. In addition, the COVID-19 pandemic has added a huge burden of dermatological disease, which has meant that dermatologists are now working differently using virtual consultation formats (which carries resource implications), and that work which had otherwise been scheduled was delayed.

There are currently insufficient numbers of consultant dermatologists nationally to meet the demands of the population. An APPG on Skin audit (2019) revealed that each whole-time equivalent (WTE) doctor working in dermatology in the UK is responsible for over 80,000 people, which is 17,500 above the baseline target ratio based on recommendations from the Royal College of Physicians.⁵⁹

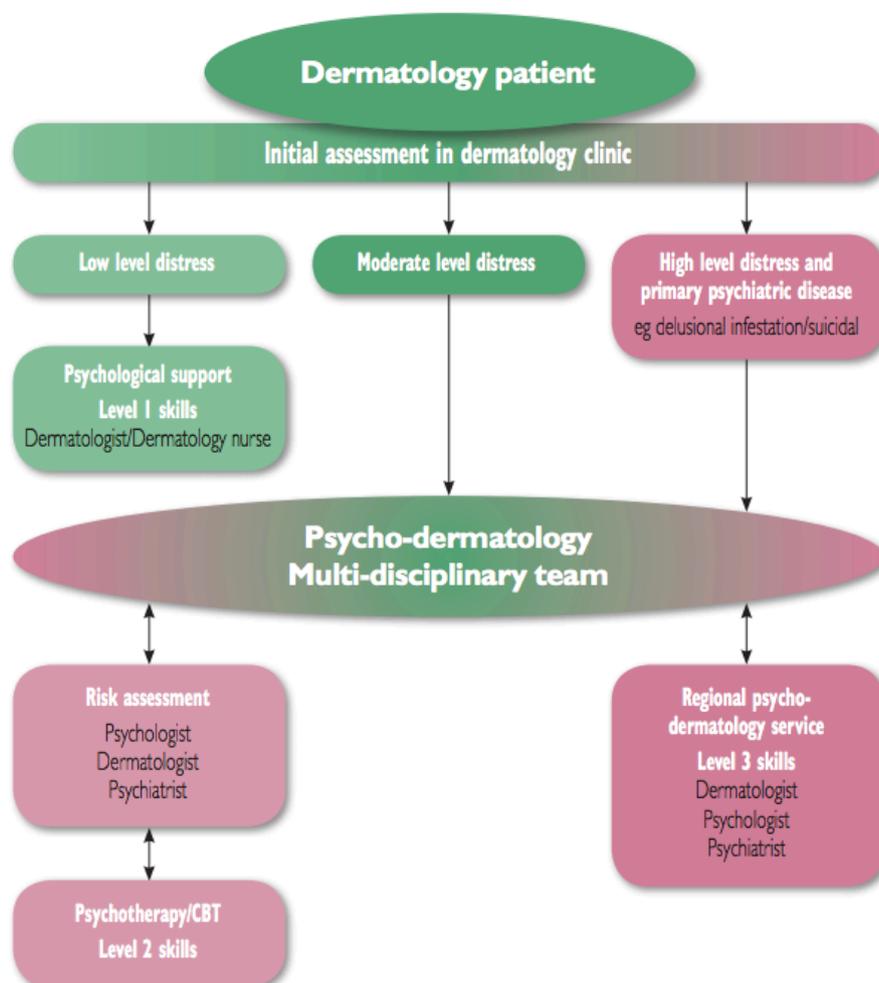
There is similarly a lack of practitioner psychologists, psychiatrists and nurses specialising in dermatology dedicated to dermatology departments. The APPG on Skin audited some NHS England psychology services in dermatology departments and found a lack of WTE psychologists.⁶⁰ The initial funding for psychologist posts in dermatology departments was found often to be reliant on charities or pharmaceutical companies, with local business planning subsequently securing a permanent role.⁶⁰ The APPGS suggests that the evidence presented in this report (see chapters 8 & 9) provides evidence to ensure that the future business planning of commissioners includes the provision of psychology expertise in all dermatology departments, and which is not reliant on external funding. There should similarly be dedicated funding for liaison psychiatry posts to provide psychodermatology input.

There is an urgent need to increase the number of specialists to reduce the time taken for patients to access the care they need and support healthcare professionals in primary care. It is therefore imperative that more dermatology consultant and mental health speciality posts are funded and training numbers are increased.

7.1 Support teams

The recognition and management of patients with skin conditions with mental health distress requires specific skills from clinicians with experience and expertise.⁷ The BAD working party report on minimum standards for psychodermatology services outlines different levels of minimum competencies for clinicians depending upon the severity of mental health distress experienced of patients they treat.⁷ This stepped model of care approach therefore matches healthcare professional expertise to clinical need (Figure 13).

Figure 13: The stepped-care provision of psychodermatology services (Reprinted from Turner et al. 2015)⁶¹



Patients with low level distress can be managed by dermatologists and allied health professional staff, whilst those with moderate or high distress levels should be seen by a multi-disciplinary team of psycho-dermatology specialists.⁷ A combination of dermatologists, psychologists, psychiatrists and specialist nurses should provide this holistic support.

The APPG on Skin is calling for all dermatology departments to have a dermatologist trained in some psychodermatology, specialist psychology input and access to liaison psychiatry advice.

Each department should also have a clinical nurse specialist with training in habit-reversal and other behaviour-change techniques. Nurses specialising in dermatology should have access to regular training and supervision with a practitioner psychologist. They should also have access to liaison psychiatry advice and assessment of the patient where required.

Hospital managers must ensure that staffing is configured in a way that optimises multidisciplinary care and patient preference in the dermatology department.

For patients for whom the primary skin condition has a high psychological burden, a psychodermatologist should work with a clinical, health, or counselling psychologist that is Health and Care Professions Council (HCPC) registered. For patients with psychiatric diseases, the presence of a psychiatrist within the primary consultation is recommended.

In addition to routine psychodermatology expertise within dermatology departments, there should be at least regional access to tertiary psychodermatology clinics. These clinics should consist of a multidisciplinary team (dermatologist, psychiatrist, psychologist, nurses specialising in dermatology) to support local dermatology clinics and to treat the most complex cases.

7.2 Resources to provide psychodermatology care

Dermatologists need adequate consultation times to allow exploration of patients' feelings. The APPG on Skin recommends 45 minutes for each new patient and 30 minutes for follow-up appointments in psychodermatology specialist clinics. General dermatology clinics should allow at least 15 minutes.

Commissioners and NHS service providers must ensure that patients accessing dermatology care have greater access to psychological therapies and make available online consultation platforms.

Key recommendations

- **All dermatology departments must have a dermatologist trained in psychodermatology, have specialist psychology input and have access to psychodermatology-dedicated liaison psychiatry advice.**
- **All local dermatology units must have regional access to psychodermatology services.**
- **All local dermatology services must have a named lead in psychodermatology services able to provide basic psychodermatological care of patients with skin disease**
- **Training numbers for dermatology consultant posts must be increased and hospital placements must be adequately funded.**
- **Psychodermatology specialist clinics should routinely provide 45 minutes for new patients and 30 minutes for follow-up appointments. General dermatology clinics should allow at least 15 minutes.**

ESTABLISHING PSYCHODERMATOLOGY SERVICES

8.0 Background

Commissioners may erroneously perceive psychodermatology services as costly and therefore reluctant to fund them. This chapter identifies examples of best practice within the current provision of psychodermatology services in the UK that could be rolled-out more widely. It aims to demonstrate how NHS service providers can configure their services to be resource efficient and clinically efficacious.

As earlier highlighted, primary and secondary care practitioners need to be supported with adequate training in dermatology, input from specialist mental health practitioners, and available referral pathways. To establish effective psychodermatology services these factors need to be addressed at the onset.

8.1 Asking the right questions in primary care

The psychological component of a patient's illness can be missed when healthcare professionals fail to monitor and screen for depression or psychological distress.

Therefore, there should be an annual medical review of all patients with a chronic skin condition, which includes an assessment of the psychological impact of the condition, via a validated psychological health-screening questionnaire. An annual medicine review already exists in Scotland for psoriasis and psoriatic arthritis⁶²; this should be duplicated for all UK patients with a chronic skin condition. The Dermatology Life Quality Index (DLQI), or the patient health questionnaire depression scale (PHQ- 9) and the generalised anxiety disorder scale (GAD-7) are among suitable options that can be freely used. PHQ-9 and GAD-7 are also available to use as minimum screeners.

HCPs in primary care should also routinely ask all dermatology patients after an acute presentation (e.g. a flare):

1. During the past month have you often been bothered by feeling down, depressed, or hopeless?

2. During the past month have you often been bothered by little interest or pleasure in doing things?

Findings from the informal questioning or the health-screening questionnaires should enable the healthcare professional to decide whether the patient might require further support.

8.2 Primary care psychology service

Many people with skin disease (54% of survey respondents) are not aware that there are limited psychological services available for patients with skin conditions. The NHS, HCPs, medical speciality groups and advocacy groups must focus on improving the signposting of, and access to, such services and resources.

All primary care HCPs should have sufficient time and training to be able to provide self-help advice to patients with mild psychosocial distress, including triggers and coping strategies. Some patients will need support in accessing self-help materials and external support services.

“My GP gave me a telephone number to call to book myself in to see an NHS therapy, but I was housebound and felt too embarrassed to call.”

~ Respondent with eczema

GPs should consider referring individuals with more moderate psychological distress, including anxiety and depression, to the Improving Access to Psychological Therapies (‘IAPT’) programme. In some regions self-referrals can also be made.

IAPT therapies, where they exist, can provide vital psychological support for many patients with skin conditions that use the services. However, the APPGS is concerned that the majority of IAPT services are generalist services and, therefore, HCPs might not have the knowledge or skills to provide support that accounts for the precipitant of the distress.

“I spoke to my GP and they referred me to my local NHS well-being service, however this was very generic and did not specialise in skin, so it was mostly irrelevant and did not help me.”

~ Respondent with eczema

Therefore, commissioners should, at a minimum, invest in services that focus on providing evidence-based psychological therapies to people with long-term conditions (LTCs). IAPT services that are tailored to patients with skin conditions are preferable (Figure 8).

Figure 8: Providing specialist IAPT services for people with skin disease

In line with the expansion of Improving Access to Psychological Therapy (IAPT) services outlined in the Five Year Forward View for Mental Health (2017), Sheffield IAPT has developed a 'Health and Wellbeing Service'. This innovative service provides people living with a range of long-term conditions (LTCs) and persistent physical symptoms (PPS) access to evidenced-based psychological therapies to help overcome stress, anxiety and low mood associated with living with the health conditions. This service accepts not only referrals from clinical staff but actively encourages self-referral. The Sheffield service is unique amongst the IAPT-LTC services in that it has developed a dedicated pathway for people living with skin conditions.⁶ The service is referred to as: 'The Living Well with Skin Condition' pathway and was developed as a collaboration with Sheffield primary care services as well as the dermatology department at the local acute hospital.

The service developed and integrated psychodermatology training for trainee psychological wellbeing practitioners (PWPs) into the standard NHS IAPT training programme ran at The University of Sheffield. Dermatologists and other healthcare professionals were also provided with training.

Dermatologists have access to a 'prescription pad' with brief psychological questionnaires and they can use this to refer patients into the service. A psychological wellbeing practitioner also attends some clinics. Patients can also self-refer after finding information about the service in their GP practice (where extensive posters and leaflets have been distributed) or by reading about the service themselves on the IAPT Health and Wellbeing website. The website provides access to some standalone self-help materials and signposts people to other sources of support as well as providing a mechanism for people to request an appointment.

People accessing the service are initially assessed by a PWP and then provided access to a number of services including a dedicated group tailored specifically for individuals with a skin condition. This unique psychoeducational course uses cognitive behavioural therapy (CBT) techniques to assist people in overcoming skin related stress, anxiety, and low mood, and to learn how to manage specific issues such as itch and scratching behaviour and sleep disturbance.

Patients may also be provided with access to online CBT interventions, and patients with higher levels of psychological distress can be 'stepped-up' to a CBT therapist or clinical psychologist.

Key components of the programme:

- Stepped-care model of support
- Self-referral possible
- In-clinic clinician screening tools available
- Access to a dedicated course with a workbook
- Access to online long-term condition CBT
- Access to counselling or clinical psychology intervention if needed
- Advice available to dermatology staff
- Routine collection of outcome data to guide individual clinical care and evaluation of the service.
- Training integrated into standard IAPT training & service specific training available

The Sheffield IAPT service is limited to only people living, working, or studying in Sheffield. The Sheffield Health and Wellbeing IAPT service is likely to provide a model for other regions, and the APPGS would wish to see dermatology patients being able to access this sort of service in other cities.

Other regions should look to Sheffield's IAPT for patients with skin conditions as a model to adopt locally. The APPGS would like each CCG to implement a skin-focused programme in their local IAPT service where that service exists.

8.3 Screening for mental health distress in secondary & tertiary care

Service development in secondary and tertiary care needs to reflect the psychological needs of patients. Like primary care, hospital managers should build the routine screening and collection of patient-reported psychological distress into their services. Figure 9 provides an example of best practice that can be duplicated in further hospital settings.

Figure 9: Bridging the gap between mental & physical healthcare in secondary care

IMPARTS ('Integrating Mental and Physical Healthcare: Research Training and Services') is a programme running in general hospital settings that screens for depression and anxiety in patients with long-term physical health conditions.

One example is its use in a tertiary outpatient dermatology service where patients with psoriasis complete the PHQ-9, GAD-7 and DLQI on an electronic tablet, while waiting for their appointment. The treating dermatologist receives the results prior to the consultation, as well as an automatic suggestion on the type of support that might be most appropriate based on the screening scores and stepped-care.²³

Patients with higher levels of psychological distress are referred to a clinical psychologist dedicated to the dermatology department (when the distress interacts with their skin condition or its treatment) or to the hospital liaison psychiatry service. Patients with lower levels of distress are advised to self-refer into their local primary care psychology service (Improving Access to Psychological Therapies, IAPT) alongside the clinician alerting the GP.

Key components of the programme:

- Routine screening and collection of patient-reported distress in all dermatology appointments.
- Early identification and management of mental health disorders and their impact on physical health
- Stepped-care model of support
- A clear referral pathway
- Technology used to support and inform doctors
- Teams are offered training by the IMPARTS team and clinical psychologist in dermatology to support their ongoing use of this collaboration, in topics such as: “eliciting concerns and listening”, and “discussing and managing psychological distress”.

The model in Figure 9 will only work if there is access to liaison psychiatry assessment as the screening may reveal suicidal thoughts and create need for urgent liaison psychiatry advice and assessment. Many hospitals do not currently have outpatient liaison psychiatry services, although almost all have access to urgent liaison psychiatry advice.

8.3 Specialist psychodermatology services

As earlier highlighted, the provision of psychodermatology services across the UK is extremely limited and insufficient to meet patient need. It is imperative that all regions in the UK have at least one dedicated Psychodermatology service or pathway with a trained specialist psychodermatologist, consultant liaison psychiatrist with psychodermatology expertise, multidisciplinary team (MDT) approach and stepped-care psychological support. In England, this would include at least one service in London, South West, South East, East of England, West Midlands, East Midlands, Yorkshire and the Humber, North East, and North West.

The type of service will depend on the type of patients seen in the unit.³⁴ The core team should include a psychodermatologist and a psychologist, whilst access to a liaison psychiatrist is essential when treating patients with psychiatric problems.³⁴

Commissioners looking to set up or maintain a service should follow the advice from the ‘*Working party report on minimum standards for psychodermatology services 2012*’⁷ produced by Psychodermatology UK and BAD.

To ensure the effectiveness of psychodermatology units, there should be annual audits and quarterly meetings to review activity and outcomes. Evidence must be collected on changes in affect or distress in patients, and not solely on quality of life, which is a broad measure that may miss significant distress.

All psychodermatology clinics in departments and regional joint clinic should keep a database of all patients according to a nationally agreed template for the purposes of research auditing. Locally gathered audit data should also inform business case planning.

Departments offering psychodermatology care should follow NHS England’s 18-week target from referral to treatment. The Inquiry heard that currently adult patients with primary psychiatric disease are often waiting longer than 18 weeks, as there are so few centres offering this service, whilst the situation in paediatrics is even worse.

HCPs treating patients with primary psychiatric disease, including delusional infestation (DI), are at increased risk of receiving complaints and abuse from patients.⁵⁷ Therefore, when setting up a psychodermatology service, it is important to provide support services for HCPs and have procedures in place to minimise risk to both service users and staff.

8.4 Making a business case

A growing body of research shows that multidisciplinary psychodermatology services have the potential to be cost-effective in their use of healthcare resources.^{43,50,56,65}

The direct healthcare costs associated with caring for a patient with typical psychocutaneous (a skin condition that has a psychological cause) problems outside of specialist multidisciplinary services can be great.⁵⁶ This includes the cost of general practitioner appointments, dermatology outpatient appointments, outpatient appointments for other specialities, A&E attendance, and biopsies.

For example, Goulding *et al.*⁵⁶ outline a patient with intractable eczema and extensive scratching habits. Prior to referral, £9,222 was spent on her care. After receiving referral for psychodermatology care, the cost of input – namely habit reversal therapy – was only £382, and led to a resolution of her eczema.

When making a business case to set up a psychodermatology service, commissioners must be provided with the evidence that demonstrates dedicated psychodermatology services are cost-effective. Furthermore, specialist services business case tariffs rather than dermatology tariffs are more appropriate for use.

8.5 Remote consultations

At the time of writing, many healthcare professionals are engaging in remote appointments owing to COVID-19 safety precautions. The APPG on Skin encourages NHS service providers to maintain the option for remote appointments as part of a menu of service options post-COVID-19. Investments could also be made in furthering the use of tele-dermatology and dialogue between primary and secondary care, but not at the expense of losing resources for face-to-face consultation. Remote care within psychodermatology should never be the norm. The APPG on Skin has concerns that clinical care could be adversely affected, and multi-disciplinary teamwork hampered or curtailed.

However, the Inquiry heard that many children and their families, in particular, favour remote consultations, due to the time taken to travel to appointments. Therefore, the APPGS recommends that flexible working patterns are adopted. Virtual / remote consultations should be available for all patients (including psychodermatology patients) where this is preferable (either by the patient or the HCP), together with face-to-face consultations where this is preferable (either by the patient or the HCP).

Face-to-face consultations are particularly crucial in psychodermatology as clinical information obtained is much more reliable and comprehensive when face-to-face consultations are used effected. Many non-verbal cues to psychological distress can be missed on the telephone and in complex cases the process of developing trust and engagement and involving other family members is hampered if only telephone contact is available.

Key recommendations

- **All patients with a chronic skin condition should receive an annual medicines review, which includes an assessment of the psychological impact of the condition, via a validated psychological health-screening questionnaire.**
- **Specialist psychodermatology units should charge psychiatry tariffs rather than dermatology tariffs.**
- **All regions should have at least one dedicated comprehensive Psychodermatology service with a trained specialist psychodermatologist, dedicated liaison psychiatrist input, a multidisciplinary team approach and stepped-care psychological support.**
- **There should be annual audits of psychodermatology units and quarterly meetings to review activity and outcomes.**
- **All psychodermatology clinics in departments and regional joint clinic should keep a database of all patients according to nationally agreed template for the purposes of research and audit. Locally gathered audit data should inform business case planning.**

COMMISSIONING

9.0 Background

The Inquiry heard from numerous healthcare professionals, organisations and patients who called for a reform of the way services were commissioned for people with skin disease and mental health distress.

The APPG on Skin is cognisant that the budgets of commissioners are likely to be increasingly squeezed in the aftermath of COVID-19, therefore where possible, our recommendations aim to be largely cost-saving or cost-neutral in the long run. They aim to be evidenced based, practical and have implementable strategies for improving the healthcare of patients with skin conditions.

9.1 Cost of maintaining the status quo

Commissioners may be reluctant to fund multidisciplinary psychodermatology services, perceiving them to be costly.⁵¹ However, the NHS Long Term Plan outlines how “the cost of poor mental health to the economy as a whole is estimated to be far in excess of what the country gives the NHS to spend on mental health”.⁸ Treating the mental health needs of a local area’s population will boost productivity and income, and can reduce the pressure on other local services (e.g. social care).

The cost to the economy through lost working and educating days due to skin disease related absenteeism is substantial. The UK Government paid £61 million in work benefits where the main condition was a skin disease in 2012/13.⁶⁶

This was reflected in the Inquiry’s evidence, which found that a number of patients with depression, anxiety or mental health distress who stated that their wellbeing had a disruptive effect on them being able to work, complete education or function fully in society. The APPG on Skin believes that if they were given access to specialist mental health support, they would be empowered to better cope with the impact of their condition and therefore be more able to attend education and work, and be more productive when at work. This will have a positive impact on workplace productivity and public finances.

Early psychological interventions in children and young people with skin conditions can limit the duration of physical and psychological problems. Psychological interventions in this group can be cost-effective as they can build resilience and prevent the long-term escalation of psychological and psychiatric morbidity that can carry into adulthood.

Many skin conditions are associated with comorbidities that are costly to manage. Psoriasis is a case in point, with psoriatic arthritis and Crohn's disease representing just a couple of the common comorbidities. Either through modifying the behaviour of a patient with a skin condition and / or providing psychodermatology care, many comorbidities can be reduced in their severity and prevalence.⁶⁷ Therefore, early interventions can be cost-saving over a period of time.

The APPGS believes that it is imperative that future funding available to CCGs for mental health services must include some services available for dermatology patients.

9.2 Cost of not being seen by a specialist

It is the responsibility of NHS service providers to have staffing arrangements in place that deliver safe and effective care. Each must ensure that they have sufficient expertise in each area. There must be a critical mass of HCPs that ensure that the NHS England's 18-week target from referral to treatment is consistently met.

HCPs can spend a disproportionate amount of time attempting to deal with patients with skin conditions and mental health distress if they are not seen in a specialist setting.⁴⁷ Not only does this have associated resource costs, but a longer duration of untreated mental health distress has been shown to lead to significantly less favourable clinical outcomes.⁶⁸

Hospital managers and commissioners may have mistakenly believed that psychodermatology clinics are more expensive if they involve multiple healthcare professionals and longer consultation times.³⁴ However, as earlier highlighted, there are a wealth of studies demonstrating that it is more cost effective to run these clinics than manage patients with skin conditions and psychological distress in more generalist healthcare settings. One study into the cost of treating delusional infestation found that "the average cost prior to attending a dedicated psychodermatology clinic was £85,478 per patient per

year, while the average cost of management in the psychodermatology clinic was £35,912 per patient per year”.⁴⁶

There are hidden cost layers in a non-specialist setting, for example, the cost of managing ‘doctor shoppers’ that repeatedly attend consultations in primary and secondary care, as they believe their disease is not being acknowledged.⁶⁹ Furthermore, for some conditions, such as dermatitis artefacta, the manifestation of the psychological problem is unlikely to be resolved by a dermatologist, psychiatrist or psychologist in isolation.⁴⁶ Therefore a multidisciplinary approach in a specialist service is needed to resolve the condition and reduce the burden on the NHS of managing the patient.

9.3 Dermatology lead in NHS England

At the time of writing, there are 26 clinical areas that have a National Clinical Director (NCD) or National Specialty Adviser to NHS England. This ranges from tobacco addiction to sepsis and respiratory disease. But there is not such a NCD for skin disease. There is, however, an acute need for leadership within dermatology given the wide variation in the delivery and quality of psychodermatology care throughout England. The APPG is calling for the creation of a NCD for Skin to provide the NHS with clinical leadership, advice and support on dermatology care.

9.4 Local commissioning planning

To deliver well-planned psychodermatology care, commissioners should invest in necessary resources to match the psychosocial needs of the area. The stepped model of care, which matches clinical input and services to an individual’s disease burden, can create saving by improving value for money. The exact configuration of a local multidisciplinary team will, to some extent, be determined by local expertise.

Commissioners should arrange for primary and secondary care professionals to have access to a range of supportive services including psychological support, access to medical social workers, camouflage services and occupational therapy.

NHS England and the Department of Health and Social Care has made substantial efforts to improve the national delivery of mental health care, including through the publication of the NHS Long Term Plan. Commissioners should evaluate whether these national priorities for

mental health provision are reflected in the delivery of local services for people with skin disease.

Each CCG in England should carry out an audit of existing service provision and need within the local area. It must compare available resources (e.g. facilities, services, healthcare professional numbers) with the level of current and future service demand. The audit should review the quantity of unnecessary investigations and referrals conducted for patients with psychocutaneous disease. It should also seek patient feedback, include a review of waiting list data and monitor workforce training needs.

Depending upon the findings of the audit, commissioners might need to resign current services, commission new specialist services, recruit further HCPs, fund training for HCPs and make investments to raise public awareness on available support services.

Integrated care systems should also evaluate the distance and availability of referral to psychodermatology clinics. As a minimum standard, if there is no access to regional psychodermatology clinics, then NHS organisations and local councils should join forces to coordinate the creation of a regional service.

9.5 Workforce planning

The NHS People Plan 2020/21 commits to invest in training the future mental health workforce.⁷⁰ This is welcome as there is currently a chronic shortage of training opportunities in psychodermatology. Therefore, it is imperative that investments in the NHS' mental health workforce includes HCPs that are dedicated to dermatology departments.

Consultant dermatologists should also be prioritised as one of the specialities with a critical shortage of specialists and correspondingly receive an increase in Foundation Year 2 posts.

At a local level, individual health providers must ensure that they have a sufficient staffing arrangement in place to deliver safe and effective care for dermatology patients with mental health distress. There must be a critical mass of HCPs that ensure that the NHS' 18 week target from referral to treatment is consistently met.

Key recommendations

- **A sizeable proportion of new funding available to Clinical Commissioning Groups (CCGs) for mental health services must be spent on services available for dermatology patients.**
- **Commissioners need to understand that psychodermatology clinics are cost effective to run when compared to managing skin patients with psychological distress in more generalist healthcare settings.**
- **Each new Integrated Care System must review its regional service provision in dermatology and psychodermatology.**
- **All commissioners should carry out a regular audit of existing service provision and need within the local area. The findings should be used to inform future investments in resources, which must match the psychosocial needs of the area.**
- **Comprehensive multidisciplinary psychodermatology teams providing care to patients with all facets of psychodermatology must be commissioned across the country in proportion to patient populations, and there must be comprehensive psychodermatology services available at least regionally across the UK.**
- **NHS England should create a National Clinical Director for Skin to provide the NHS with clinical leadership, advice, and support on dermatology care.**

RESEARCH

10.0 Background

Research and development (R&D) investment in skin disease in the UK is insufficient to treat its underlying burden of disease. Research indicates that skin disease is the fourth most underfunded disease area relative to disease burden, as measured by disability-adjusted life years (DALYs).⁷¹ Unlike some diseases that are well-funded to meet the burden of disease, including cancer and diabetes, skin is reported to be underfunded by £154.6 million in the UK.⁷¹

The under-investment in R&D could be linked to the trivialisation of skin disease as Research Councils and non-skin dedicated charities choose to instead focus their investments on diseases with greater mortality and public profile. Pharmaceutical companies could also be hesitant to invest in R&D within dermatology due to a belief that there is chronic underfunding for skin treatments, and they will not receive equitable reimbursement, even if patients could benefit.

10.1 Future research

The APPG on Skin recommends that the funding for future research centres on the overall management and treatment of psychodermatology patients and the establishment of national guidelines. There is currently a lack of large scale, well designed clinical trials that evaluate interventions to address psychological difficulties experienced by people with a variety of skin conditions.^{1,37} Programmatic research is required to build and test sustainable psychological interventions. Future research should attempt to demonstrate effectiveness and cost-effectiveness in a range of evidence-based medicines and interventions.

The APPG on Skin has contributed to a review of priority setting partnerships (PSPs) within dermatology (see Thompson *et al.*⁴). The paper highlights that some PSPs already direct stakeholders towards investing in research studying the psychological aspects of skin disease. However, it is believed that all PSPs within dermatology should actively include identification of priorities focusing on the psychological aspects of the condition. Future consideration should also be given to establishing a specific psychodermatology PSP. This

would facilitate more comprehensive research questions on the psychological aspects of skin disease and treatments.

Greater funding within dermatology must be prioritised for psychodermatology research, both commercially and non-commercially. Currently research projects within dermatology may be less likely to be funded if they are to study the psycho-social aspects of skin disease or if they are aimed at primary psychiatric disease presenting to dermatology HCPs. The APPGS recommends that:

Research funding should be provided for pre-trial and trial work on the development, evaluation, and implementation of complex psychological interventions to improve health. Consistent with the Medical Research Council framework for complex interventions this should include developing and testing interventions across the stepped care model, including face-to-face groups and one-to-one therapy.

The National Institute for Health Research (NIHR) and other research funders with an interest in skin conditions should prioritise funding for trials that will help to develop evidence based psychodermatology interventions. Funding is required to develop both psychological and educational interventions across all the ages.

There must also be greater collaboration with the National Institute of Health Research. The APPGS recommends that all studies in psychodermatology are placed on the NIHR dermatology research portfolio.

10.2 Collaboration within psychodermatology

Psychodermatology involves a multi-disciplinary interplay of medical specialties. However, there is currently a lack of multi-disciplinary coordination in the development of research within the area. Therefore, there should be concerted efforts towards the creation of research networks between psychology, psychiatry, and dermatology.

Working in psychodermatology can expose HCPs to vulnerable patients with complex needs. Research has demonstrated that HCPs working in psychodermatology are at risk of experiencing complaints, abuse, and burnout.^{57,58} Therefore, the establishment of supportive and supervisory networks is crucial.

Key recommendations

- **Research funding for psychodermatology should be prioritised. This should focus on the development, evaluation, and implementation of a range of psychological and educational interventions for patients with skin conditions.**
- **There should be concerted efforts towards the creation of research networks between psychology, psychiatry, and dermatology.**
- **Supportive and supervisory networks of HCPs should be established to provide pastoral care.**

PATIENT SUPPORT & ADVOCACY

11.0 The value of patient support organisations

Patients with skin disease rightly expect to be provided with adequate and appropriate support to manage, control, and live with their condition. Patient support organisations play an important role in helping patients cope with the psychosocial effects of skin disease, often stepping in when healthcare professionals are prevented from being able to give patients comprehensive psychosocial support they need for any given dermatological condition.

Patient support organisations are therefore a critical part of the healthcare community and can support awareness raising and the development of services, in a variety of ways:

Campaigning and advocacy

Organisations such as the National Eczema Society, The Psoriasis Association, and Changing Faces have an important campaigning and advocacy role, bearing witness to the experiences and needs of those with chronic skin conditions, building campaigns to highlight this, and working with and lobbying Government and key policy-makers within the NHS, to improve service provision.^{18,28,35}

Support

Many patient support organisations also provide direct support to individuals and patient groups, often at a community and primary care level. This support is often on a tiered intervention model, it encompasses the following: helpline services - where they provide information, emotional support and advice, peer support - either via online communities or in person, education and training - to schools, corporates and healthcare professionals highlighting the patient voice and the challenges they face in everyday life, short term counselling support.

Some examples:

I have had to find out with the help of The National Eczema Society about food allergies and carefully worked out what caused my eczema and now it is finally under control.

~ Respondent with eczema

"I have not been provided with professional support, but I have used online communities, connected to other people with psoriasis and contacted the Psoriasis Association. This has helped my confidence and self-esteem – I used to sometimes struggle to look in the mirror."

~ Respondent with psoriasis

The information that patient support organisations provide on treatment options can empower patients to demand a change of treatment from a doctor and articulate their psychological distress.

"Personal contact and shared experience of psoriasis has helped more than all the topical treatments".

~ Respondent with psoriasis

Sharing tips for coping through social media channels and provide forums for peer-to-peer support and shared learning are key.²⁰ These interactions can cultivate feelings of belonging and acceptance, and as such can be important in maintaining psychological wellbeing.⁷²

11.1 Working with our patient support organisations

Patient support organisations, therefore, hold a unique space in the healthcare community, often being a position to convene disparate organisations to highlight a need and campaign effectively for resolution. They are able to access funding from different sources that can be used for advocacy, or drive research and service innovation for the benefit of the service user that can result in mainstream adoption.

Our Inquiry found that whilst some primary care practitioners routinely direct patients with mild psychosocial distress to services and resources provided by patient support organisations, unfortunately, this does not occur often enough, and patients tend to have to find their own way to support services.

There is a need to develop clear referral pathways, incorporating patient support organisations services at the appropriate level. CCGs should have an up-to-date directory of dermatology patient support services that is distributed to Primary Care Networks. This will ensure that GPs/HCPs routinely signpost relevant psychosocial resources to patients. CCGs should also ensure that they establish direct local links with these patient support groups, as part of their commissioning arrangements.

Our Inquiry also heard that most patient support organisation staff are volunteers and not trained in providing psychological support. Organisations providing such services should ensure that staff or volunteers are appropriately trained and supported with basic psychological training or toolkits.

Key recommendations

- **CCGs should distribute to Primary Care Networks an up-to-date directory of dermatology patient support services.**
- **Consideration should be given to ensuring patient support organisations lead or support service innovation projects.**
- **Patient support organisations providing psychological support services should ensure that staff are appropriately trained and supported with basic psychological training or toolkits.**
- **The inclusion of patient support organisations in a review of services and pathway is critical, to amplify patient voice and build in the community services that patient support organisations provide.**

CONCLUSION

The evidence received in our Inquiry highlights the extensive impact skin diseases can have on all aspects of people's lives from schooling, relationships, self-esteem, and career choices to social, sexual and leisure activities. Indeed, millions of UK citizens with skin disease are likely to experience some degree of psychological and emotional distress.

There was a clear sense of frustration from those working in dermatology and dermatologists in their inability to access the appropriate psychological support that they, and their patients, need. Government health policy that focuses on investing in, and expanding, specialist mental health support for people with skin disease is urgently required.

The education and training of HCPs that treat people with a skin condition must improve. It was found that, despite many HCPs desiring training and upskilling, many lack knowledge in dermatology and in the assessment and treatment of patients with psychological distress. Therefore, it is essential that robust education and training frameworks in dermatology and psychodermatology are developed and expanded.

At a national level, skin disease remains a chronically underfunded and undervalued disease area. There must be a National Clinical Director for skin at NHS England to champion the speciality and advocate for increased funding, training of specialists and improvements in undergraduate training of HCPs.

At a local level, commissioners must invest the necessary resources to provide appropriate psychological care for the local population with a skin condition. The stepped model of care, which matches clinical input and services to an individual's disease burden, can create savings by improving value for money.

Psychological interventions must also be provided to children and young people when the needs present. When children and young people are not offered support services, their long-term mental health can be severely affected.

Ultimately patients with a skin condition should reasonably to be provided with excellent and appropriate support to manage, control, and help them to live with their condition.

APPENDICES

APPENDIX A

Officers of the APPGS

- Sir Edward Leigh MP (Chair)
- Mary Glendon MP (Secretary)
- Rt Hon Dame Cheryl Gillan MP (Vice Chair)
- Baroness Finlay of Llandaff (Vice Chair)
- Baroness Masham of Ilton (Vice Chair)

Clinical and NHS Advisors of the APPGS

- Dr Anthony Bewley (Consultant Dermatologist & former Chair of Psychodermatology UK)
- Nick Evans (Chair of Psoriasis Association)
- Dr Tanya Bleiker (President of British Association of Dermatologists)
- Rebecca Penzer-Hick (President of British Dermatological Nursing Group)
- Dr Angelika Razzaque (Executive Chair of Primary Care Dermatology Society)
- Professor Andrew Thompson (Consultant Clinical/Health Psychologist & Professor of Clinical Psychology)

APPENDIX B

Membership of the Working Group that led the inquiry

- Chair, Dr Anthony Bewley (Consultant Dermatologist)
- Dr Rukshana Ali (Clinical Psychologist)
- Mandy Aldwin-Easton (Director, Ichthyosis Support Group)
- Dr Alia Ahmed (Consultant Dermatologist)
- Dr Iyas Assalman (Consultant Psychiatrist)
- Dr Susannah Baron (Consultant Dermatologist)
- Marilyn Benham (Chief Executive Officer, British Association of Dermatologists)
- Lisa Bickerstaffe (Communications Manager, British Skin Foundation)
- Prof Christine Bundy (Professor of Behavioural Medicine)
- Pippa Donovan (former Director, Changing Faces)
- Nick Evans (Chair, Psoriasis Association)
- Nina Goad (Head of Communications, British Association of Dermatologists)
- Berkeley Greenwood (APPGS Secretariat)
- Sebastian Guterres (APPGS Secretariat)

- Lucy Moorhead (Consultant nurse)
- Professor Celia Moss (Consultant Paediatric Dermatologist)
- Rebecca Penzer-Hick (Dermatology nurse specialist & President of British Dermatological Nursing Group)
- Andrew Proctor (Chief Executive, National Eczema Society)
- Eyal Raveh (Ex-Trustee, Vitiligo Society)
- Dr Angelika Razzaque (General Practitioner & Executive Chair of Primary Care Dermatology Society)
- Dr Julia Schofield (Consultant Dermatologist)
- Dr Reena Shah (Chartered Clinical Psychologist)
- Prof Andrew Thompson (Consultant Clinical/Health Psychologist & Professor of Clinical Psychology)
- Dr Ruth Taylor (Consultant Psychiatrist)
- Dr Mark Turner (Clinical Psychologist)
- Dominic Urmston (Patient Advocacy and Communications Manager, Psoriasis Association)
- Mary-Jane Wheeler (Trainee Clinical Psychologist)

APPENDIX C

Witnesses Providing Oral Evidence

- Dr Alia Ahmed (Consultant Dermatologist)
- Natalie Ambersley (Changing Faces Ambassador)
- Shal Henry-Treloar (nominated by National Eczema Society)
- Jess Gudenus (nominated by Psoriasis Association)

APPENDIX D

Patient survey on the psychological and emotional impact of skin conditions

1. Which skin condition(s) do you have?
2. Please describe the physical symptoms of your skin condition(s)
3. It is hard for people that have not had a skin condition to understand the effect of these symptoms, please in your own words describe your symptoms and their impact.
4. Has your condition(s) affected your emotional or psychological wellbeing?
5. Has your condition(s) affected your self-esteem?
6. Has your condition(s) negatively affected your intimate relationships?
7. Has your condition(s) affected your social-life or leisure and sporting activity?
8. Has your condition(s) affected your work or education?
9. Has your condition(s) affected your sleep?

10. Please list any other aspects of your life that your skin condition affects
11. Did you know that in some areas of the UK there are NHS psychological services for people with skin conditions?
12. Have you sought help in connection with your psychological or emotional wellbeing associated with your skin condition(s)?
13. If you have received psychological support in relation to your skin condition, who made the referral?
14. If you have received psychological support in relation to your skin condition, who treated you?
15. How long did you wait before you were seen for psychological and emotional support?
16. What treatment(s) did you receive?
17. Did you find the support / psychological treatment you received helpful in managing the impact of your skin condition(s)?
18. Please provide any further comments on your experiences
19. What is your gender?
20. What is your age?
21. Where do you live?
22. If you have any further comments, then please provide them

Demographics of survey participants

Characteristic	Frequency	Percentage of sample who answered this question
Gender		
Male	73	13.85%
Female	443	84.06%
Prefer not to say	8	1.52%
Other	3	0.57%
Skipped Question	17	-
Age		
Under 18	27	5.11%
18-24	76	14.39%
25-44	243	46.02%
45-64	153	28.98%
65+	26	4.92%
Prefer not to say	3	0.57%
Skipped Question	16	-
Area of residency		
Scotland	55	10.48%
Northern Ireland	14	2.67%
Wales	23	4.38%
North East	18	3.43%
North West	53	10.10%
Yorkshire and the Humber	39	7.43%
West Midlands	44	8.38%
East Midlands	28	5.33%
South West	61	11.62%
South East	77	14.67%
East of England	28	5.33%
Greater London	54	10.29%
Prefer not to say	17	3.24%
Skipped question	19	-

Patient demographics (N=544)

Characteristic	Frequency	Percentage of sample who answered this question
Skin condition		
Acne	35	6.45%
Alopecia	6	1.10%
Atopic dermatitis (Eczema)	236	43.46%
Contact Dermatitis	38	7.00%
Hidradenitis Suppurativa (HS)	8	1.47%
Hives (Urticaria)	38	7.00%
Ichthyosis	17	3.13%
Lichen Sclerosus	51	9.39%
Lipoedema	1	0.18%
Lupus	2	0.37%
Melanoma	3	0.55%
Non-melanoma Skin Cancer (including Squamous Cell Carcinoma & Basal Cell Carcinoma)	10	1.84%
Psoriasis	177	32.60%
Rosacea	27	4.97%
Shingles (Herpes Zoster)	4	0.74%
Vitiligo	18	3.31%
Unsure/Undiagnosed	3	0.55%
Other	56	6.45%

Patient demographics continued (N=544)

APPENDIX E

Survey for organisations on the psychological and emotional impact of skin disease

1. What is the name of your organisation, charity, or patient group?
2. What is your role (e.g. psychological support lead, charity manager etc.
3. What condition(s) are the focus of your organisation, charity, or patient group?
4. Please outline the psychosocial burdens or impacts that are expressed by people who interact with your organisation?
5. What support and psychological wellbeing services (if any) does your organisation provide?
6. Do you feel that current NHS service provision for people in psychological distress due to skin conditions is: Very poor, Poor, Sufficient, Good, Excellent, Not sure, Prefer not to say.
7. If you feel that services could be improved, please explain what your key changes would be.
8. What does your organisation view as the wider benefits to the NHS of better psychosocial service provision?
9. Finally, do you have any policy recommendations for the Group to focus upon?

APPENDIX F

Psychodermatology training & learning opportunities for nurses

1. “The mind and the skin” module as part of the MSc module at Hertfordshire University.
2. PsoWell Training Programme.
3. Scottish Dermatological Nursing Society psychosocial aspects of care course.
4. Changing Faces training course for health and social care professionals.
5. St John’s Derm Academy training events.
6. NHS E-learning for Health provides psychodermatology modules which form part of the British Association of Dermatologists training curriculum. These modules are open to all NHS personnel see <https://www.e-lfh.org.uk/programmes/dermatology/>.
7. Royal College of General Practitioners elearning module on alopecia see <https://elearning.rcgp.org.uk/course/info.php?id=283>.

APPENDIX G

Psychodermatology support and self-help resources provided by professional associations & charities includes;

1. Most patient support groups offer information, booklets or factsheets on the management and treatment for the respective skin condition, including its psychological components. A list of patient support groups can be found here: <https://www.bad.org.uk/patient-support-groups>.
2. A number of patient support groups offer helplines that provides support and information to people living with a skin condition, this includes, but is not limited to: Changing Faces, Psoriasis Association, Herpes Viruses Association, National Eczema Society, Behcet’s UK, Scleroderma & Raynaud’s UK, British Porphyria Association, Anaphylaxis Campaign, Allergy UK, and Alopecia UK.
3. The Skin Support website <http://www.skinsupport.org.uk/> (developed by the British Association of Dermatologists) provides information to support people in psychological distress due to skin conditions (e.g. information on Anxiety, Stress & Depression; Meditation & Mindfulness; Living with a Skin Condition).
4. Changing Faces, offers a free skin camouflage consultation service (<https://www.changingfaces.org.uk/skin-camouflage>) and one-to-one sessions with a Wellbeing Practitioner for children and adults in the UK who have a condition, mark or scar that affects their appearance (<https://www.changingfaces.org.uk/adviceandsupport/adults>).
5. Vitiligo Society is producing a new guided meditation mobile app for those dealing with skin conditions: <https://vitigosociety.org/skindeep/>.
6. Psoriasis Association has a hints and tips resource for people living with psoriasis and psoriatic arthritis on coping well with the COVID-19 pandemic: <https://www.psoriasis-association.org.uk/news/hints-and-tips-coping-with-covid-19>.
7. British Skin Foundation have run online clinics which provide an opportunity for the public to ask doctors questions regarding mental health and skin conditions: <https://www.talkhealthpartnership.com/clinics/ask-expert-bsf-mental-health-and-skin-conditions>.

8. National Eczema Society provides information, advice and emotional support for people living with eczema and their families through their free, confidential, nurse-supported Helpline (eczema.org/helpline/).
9. Alopecia UK has support group meetings that are led by people with personal experiences of living with alopecia: <https://www alopecia.org.uk/Pages/Category/find-a-support-group>
10. Eczema Outreach Support offers one-to-one emotional support to families raising a child with eczema: <https://www.eos.org.uk/#>.

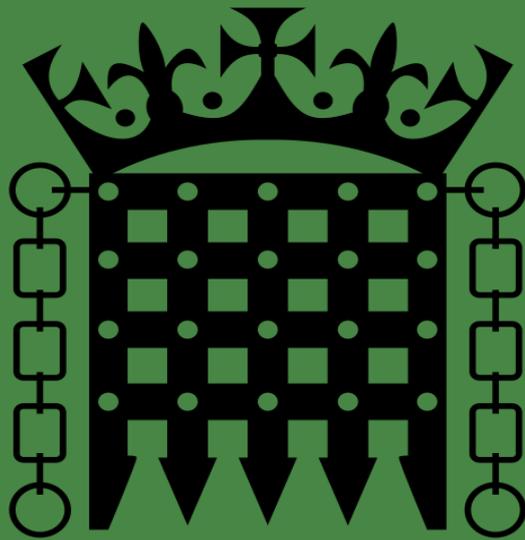
BIBLIOGRAPHY

1. Lavda AC, Webb TL and Thompson AR (2012) A meta-analysis of the effectiveness of psychological interventions for adults with skin conditions. *British Journal of Dermatology*, 167(5), pp.970-979.
2. All Party Parliamentary Group on Skin (2003) Report on the enquiry into the impact of skin diseases on people's lives. <<https://www.appgs.co.uk/wp-content/uploads/2012/06/ENQUIRY-INTO-THE-IMPACT-OF-SKIN-DISEASES-ON-PEOPLE%E2%80%99S-LIVES-2003.pdf>>.
3. All Party Parliamentary Group on Skin (2013) The psychological and social impact of skin diseases on people's lives. <<https://www.appgs.co.uk/publication/view/the-psychological-and-social-impact-of-skin-diseases-on-peoples-lives-final-report-2013/>>.
4. Thompson AR, Guterres S and Bewley AP (in press) Psychodermatological research priorities identified by Priority Setting Partnerships. *Clinical and Experimental Dermatology*.
5. Massoud S, Assaf J and Bewley, AP (in press) Psychodermatology Services in the United Kingdom: the results of the 2019 survey. *British Journal of Dermatology*.
6. Getting It Right First Time (2020) Dermatology (in press).
7. Bewley AP, Affleck A, Bundy C, Higgins, E, McBride S, Millard L and Taylor R (2012) Working party report on minimum standards for psycho-dermatology services. British Association of Dermatologists, London.
8. NHS England (2019) The NHS long term plan. NHS England.
9. Department of Health and Social Care and Department for Education (2017) Transforming children and young people's mental health provision: A Green Paper.
10. NHS England (2019) NHS Mental Health Implementation Plan 2019/20 – 2023/24. NHS England.
11. Schofield J, Grindlay D and Williams H (2009) Skin conditions in the UK: a health needs assessment. Centre of Evidence Based Dermatology, University of Nottingham.
12. ABPI Dermatology Initiative (2018) Making real our shared vision for the NHS: optimising the treatment and care of people with long-term skin conditions in England.
13. The King's Fund (2014) How can dermatology services meet current and future patient needs, while ensuring quality of care is not compromised and access is equitable across the UK?
14. Chernyshov PV, Zouboulis CC, Tomas-Aragones L, Jemec GB, Svensson A, Manolache L., Tzellos T, Sampogna F, Pustisek N, van der Zee HH and Marron SE (2019) Quality of life measurement in hidradenitis suppurativa: position statement of the European Academy of Dermatology and Venereology task forces on Quality of Life and Patient-Oriented Outcomes and Acne, Rosacea and Hidradenitis Suppurativa. *Journal of the European Academy of Dermatology and Venereology*, 33(9), pp.1633-1643.
15. Dalgard FJ, Gieler U, Tomas-Aragones L, Lien L, Poot F, Jemec GB, Misery L, Szabo C, Linder D, Sampogna F and Evers AW (2015) The psychological burden of skin diseases: a cross-sectional multicenter study among dermatological out-patients in 13 European countries. *Journal of Investigative Dermatology*, 135(4), pp.984-991.
16. Psoriasis Association and LEO Pharma (2019) Wake up to psoriasis.
17. Ahmed A, Steed L, Burden-Teh E, Shah R, Sanyal S, Tour S, Dowe S, Whitton M, Batchelor JM and Bewley AP (2018) Identifying key components for a psychological intervention for people with vitiligo—a quantitative and qualitative study in the United Kingdom using web-based questionnaires of people with vitiligo and healthcare professionals. *Journal of the European Academy of Dermatology and Venereology*, 32(12), pp.2275-2283.
18. Happiness Research Institute and LEO Innovation Lab (2018) Eczema Happiness Study 2018.
19. Johnston SA, Krasuska M, Millings A, Lavda AC and Thompson AR (2018) Experiences of rosacea and its treatment: an interpretative phenomenological analysis. *British Journal of Dermatology*, 178(1), pp.154-160.
20. Kanji A (2019) Perspective on Living With a Skin Condition and its Psychological Impact: A Survey. *Journal of Patient Experience*, 6(1), pp.68-71.
21. Theodosiou G, Montgomery S, Metsini A, Dalgard FJ, Svensson Å and Von Kobyletzki L (2019) Burden of Atopic Dermatitis in Swedish Adults: A Population-based Study. *Acta dermato-venereologica*, 99(11-12), pp.964-970.

22. Ra A, Bickerstaffe L and Bewley AP (in press). More than skin deep: Acne vulgaris and its impact on the psyche.
23. Lamb RC, Matcham F, Turner MA, Rayner L, Simpson A, Hotopf M, Barker JNWN, Jackson K and Smith CH (2017) Screening for anxiety and depression in people with psoriasis: a cross-sectional study in a tertiary referral setting. *British Journal of Dermatology*, 176(4), pp.1028-1034.
24. Titeca G, Goudetsidis L, Francq B, Sampogna F, Gieler U, Tomas-Aragones L, Lien L, Jemec GB, Misery L, Szabo C and Linder D (2019) 'The psychosocial burden of alopecia areata and androgenetica': a cross-sectional multicentre study among dermatological out-patients in 13 European countries. *Journal of the European Academy of Dermatology and Venereology*.
25. Thompson AR, Kent G and Smith JA (2002) Living with vitiligo: Dealing with difference. *British Journal of Health Psychology*, 7, 213-225.
26. Clarke E, Thompson AR and Norman P (2020). Depression in People with Skin Conditions: The Effects of Disgust and Self-Compassion. *British Journal of Health Psychology*.
27. Dalgard FJ, Bewley AP, Evers AW, Gieler U, Lien L, Sampogna F, Ständer S, Tomas-Aragones L, Vulink N and Kupfer J (2018) Stigmatisation and body image impairment in dermatological patients: protocol for an observational multicentre study in 16 European countries. *BMJ open*, 8(12).
28. Thompson A and Kent G (2001) Adjusting to disfigurement: processes involved in dealing with being visibly different. *Clinical psychology review*, 21(5), pp.663-682.
29. Changing Faces (2017) Disfigurement in the UK.
30. Grandfield TA, Thompson AR and Turpin G (2005) An attitudinal study of responses to a range of dermatological conditions using the implicit association test. *Journal of Health Psychology*, 10(6), pp.821-829.
31. Montgomery K, Norman P, Messenger A and Thompson AR (2016). The importance of mindfulness in psychosocial distress and quality of life in dermatology patients. *British Journal of Dermatology*, 175, 930-936. DOI: 10.1111/bjd.14719.
32. Augustin M (2013) Cumulative life course impairment: identifying patients at risk. In *Dermatological Diseases and Cumulative Life Course Impairment*. Karger Publishers. 44, pp.74-81.
33. Fortune DG, Richards HL, Kirby B, McElhone K, Markham T, Rogers S, Main CJ, Griffiths CEM (2003) Psychological distress impairs clearance of psoriasis in patients treated with photochemotherapy. *Arch Dermatol* 139(6): 752-756.
34. Aguilar-Duran S, Ahmed A, Taylor R and Bewley AP (2014) How to set up a psychodermatology clinic. *Clinical and experimental dermatology*, 39(5), pp.577-582.
35. Marshall C, Taylor R and Bewley AP (2016) Psychodermatology in clinical practice: main principles. *Acta dermato-venereologica*, 96(217), pp.30-34.
36. Ersser SJ, Cowdell F, Latter S, Gardiner E, Flohr C, Thompson AR, Jackson K, Farasat H, Ware F and Drury (2014) Psychological and educational interventions for atopic eczema in children. *Cochrane Database of Systematic Reviews*. Issue 1.
37. Shah R, Hunt J, Webb T and Thompson A (2014). Starting to develop self-help for social anxiety associated with vitiligo: Using clinical significance to measure the potential effectiveness of enhanced psychological self-help. *British Journal of Dermatology*, 171, 332-337.
38. Heapy C, Montgomery K, Ersser S, Gass M, Goad N, Thompson AR (2020) A Psychosocial Support Website From the British Association of Dermatologists for People Living With a Skin Condition: Mixed Methods Evaluation. *JMIR Dermatology*. 2020;3(1):e17052.
39. Skin Support (2020) Help & Support. <www.skinsupport.org.uk>.
40. Changing Faces (2020) What is the Skin Camouflage Service. <<https://www.changingfaces.org.uk/skin-camouflage/what-is-the-skin-camouflage-service>>
41. Bundy C, Borthwick M, McAteer H, Cordingley L, Howells L, Bristow P and McBride, S (2014) Psoriasis: snapshots of the unspoken: using novel methods to explore patients' personal models of psoriasis and the impact on well-being. *British Journal of Dermatology*, 171(4), pp.825-831.
42. Chisholm A, Nelson PA, Pearce CJ, Littlewood AJ, Kane K, Henry AL, Thorneloe R, Hamilton MP, Lavallee J, Lunt M, Griffiths CEM, Cordingley L, Bundy C (2017) Motivational interviewing-based training enhances clinicians' skills and knowledge in psoriasis: findings from the Pso Well study. *British Journal of Dermatology*, 176, (3), pp.677-686.
43. Nelson PA, Cordingley L, Keyworth C, Chisholm A, Pearce CJ, Griffiths CEM, Bundy C (2014) 'In someone's clinic but not in mine' – practitioners' views of supporting lifestyle behaviour change with patients with psoriasis: a qualitative interview study. *British Journal of Dermatology*, 171(5), pp.1116–1122.
44. Muralidharan V, Zahedi D, Kaur B and Goulding JMR (2019) Diagnosis and management of psychodermatological problems: confidence levels among dermatologists and psychiatrists. *Clinical and Experimental Dermatology*.
45. Lowry CL, Shah R, Fleming C, Taylor R and Bewley AP (2014) A study of service provision in psychocutaneous medicine. *Clinical and experimental dermatology*, 39(1), pp.13-18.

46. Mohandas P, Bewley AP and Taylor R (2013) Dermatitis artefacta and artefactual skin disease: the need for a psychodermatology multidisciplinary team to treat a difficult condition. *British Journal of Dermatology*, 169(3), pp.600-606.
47. Ablett K and Thompson AR (2016) Parental, child, and adolescent experience of chronic skin conditions: A meta-ethnography and review of the qualitative literature. *Body image*, 19, pp.175-185.
48. Vallerand IA, Lewinson RT, Parsons LM, Lowerison MW, Frolkis AD, Kaplan GG, Barnabe C, Bulloch AG and Patten SB (2018) Risk of depression among patients with acne in the UK: a population-based cohort study. *The British Journal of Dermatology*, 178(3):e194.
49. Moss K, Johnston SA and Thompson AR (2020) The parent and child experience of childhood vitiligo: An interpretative phenomenological analysis. *Clinical Child Psychology and Psychiatry*, pp1-14.
50. All Party Parliamentary Group on Skin (2017) Interim Results 2017 Audit of Dermatology Services. <http://www.appgs.co.uk/wp-content/uploads/2017/10/APPGS_FOI_Report17Audit2.pdf>.
51. Dermatology Council for England (2017) 2017 Audit of Undergraduate Education. <<https://www.appgs.co.uk/publication/view/2017-audit-of-undergraduate-education/>>.
52. e-LfH (2020) E-dermatology. <<https://www.e-lfh.org.uk/programmes/dermatology/>>.
53. Psoriasis Association, 2020. PsoWell Training Course. <<https://www.psoriasis-association.org.uk/awareness/psowell>>.
54. British Dermatological Nursing Group. and British Association of Dermatologists, 2020. Role descriptors for Clinical Dermatology Nurses. <bad.org.uk/shared/get-file.ashx?itemtype=document&id=6549>.
55. Altaf K, Mohandas P, Marshall C, Taylor R and Bewley AP, 2017. Managing patients with delusional infestations in an integrated psychodermatology clinic is much more cost-effective than a general dermatology or primary care setting. *British Journal of Dermatology*, 177(2), pp.544-545.
56. Goulding JM, Harper N, Kennedy L and Martin KR (2017) Cost-effectiveness in Psychodermatology: a case series. *Acta dermato-venereologica*, 97(5), pp.663-664.
57. Gkini MA, Dimitrov D, Tanev T, Chan Y, Taylor R and Bewley AP (2018). Are dermatologists who treat patients with delusional infestation at risk of major complaints and being stalked?. *Journal of the European Academy of Dermatology and Venereology*, 32(10), pp.379-381.
58. Gkini MA, Hussain K, Taylor R, Bewley AP (2020) Burnout in psychodermatology: results from a European survey. *British Journal of Dermatology*.
59. All Party Parliamentary Group on Skin (2019) 2019 Audit of UK Dermatology Coverage. <http://www.appgs.co.uk/wp-content/uploads/2019/05/APPGSDCE_Audit_of_Dermatology_Coverage2019.pdf>.
60. All Party Parliamentary Group on Skin (2020) All Party Parliamentary Group on Skin survey on existing psychology services in dermatology. Unpublished raw data.
61. Turner MA, Moorhead L, Simpson A and Jackson K (2015) Progress in developing and implementing stepped-care psychological support for people with psoriasis. *Dermatological Nursing*, 14(2), pp.22-30.
62. Scottish Intercollegiate Guidelines Network (2010) Diagnosis and management of psoriasis and psoriatic arthritis in adults.
63. Sheffield Health and Social Care NHS Foundation Trust (2020) Sheffield IAPT <<https://iaptsheffield.shsc.nhs.uk/living-well-with-a-skin-condition/>>.
64. IMPARTS (2020) Resources & Self-Help. Integrating Mental & Physical Healthcare: Research, Training & Services: King's Health Partners. <<https://www.kingshealthpartners.org/resources/case-studies/754-imparts-delivering-integrated-care-for-better-wellbeing>>.
65. Atkar R, Bewley AP and Taylor R (2012) The cost effectiveness of a dedicated psychodermatology service in managing patients with dermatitis artefacta. *British Journal of Dermatology*, 167, pp.48.
66. The Work Foundation (2016) The impact of long term conditions on employment and the wider UK economy.
67. Ni, C and Chiu MW (2014) Psoriasis and comorbidities: links and risks. *Clinical, cosmetic and investigational dermatology*, 7, pp.119.
68. Romanov DV, Lepping P, Bewley AP, Huber M, Freudenmann RW, Lvov A, Squire SB and Noorthoorn EO (2018) Longer duration of untreated psychosis is associated with poorer outcomes for patients with delusional infestation. *Acta dermato-venereologica*, 98(9-10), pp.848-854.
69. Bewley AP, Affleck A, Bundy C, Higgins E and McBride S (2013) Psychodermatology services guidance: the report of the British Association of Dermatologists' Psychodermatology Working Party. *British Journal of Dermatology*, 168(6), pp.1149-1150.
70. NHS England (2020). We are the NHS: People Plan for 2020/2021 – action for us all.
71. Richardson B and Bentley S (2020) R&D investment in Life Sciences: Where are the gaps? Carnall Farrar. <<https://www.carnallfarrar.com/life-sciences/insights/rd-investment-in-life-sciences-where-are-the-gaps/>>.
72. Iliffe LL and Thompson AR (2019) Investigating the beneficial experiences of online peer support for those affected by alopecia: an interpretative phenomenological analysis using online interviews. *British Journal of Dermatology*, 181(5), pp.992-998.
73. Royal College of General Practitioners (2020) Alopecia eLearning course. <<https://elearning.rcgp.org.uk/course/view.php?id=283>>.

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