



All Party Parliamentary Group on Skin



# **THE PSYCHOLOGICAL AND SOCIAL IMPACT OF SKIN DISEASES ON PEOPLE'S LIVES**

A REPORT OF THE  
ALL PARTY PARLIAMENTARY GROUP ON SKIN

London 2013

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Updated 2013 Edition



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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. The APPGS is supported by grants from the British Association of Dermatologists, the Primary Care Dermatology Society, the British Dermatological Nursing Group and by subscriptions from external members of the Group (this includes industry members). These funding sources support the APPGS' Secretariat, which provided administrative assistance in the preparation and publication of this report.

# **THE PSYCHOLOGICAL AND SOCIAL IMPACT OF SKIN DISEASES ON PEOPLE'S LIVES**

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## EXECUTIVE SUMMARY

Skin disease can have a devastating effect on a person's physical and psychological wellbeing.

As with our 2003 enquiry, the evidence received by this enquiry highlighted the extensive impact skin diseases have on all aspects of people's lives from schooling, relationships, self-esteem and career choices to social, sexual and leisure activities. There was clear sense of desperation, frustration and, in many cases, isolation.

Although research into this area has developed in recent years, there remains a lack of dedicated services to tackle the psychological needs of patients with skin disease. The benefits of psychological interventions continue to go largely unrecognised and the trivialisation of skin disease in general threatens to derail years of progress in patient care.

Whilst there have been some advances in terms of available treatments and diagnostic tools, dermatology is still rarely, if ever, considered a core module in university medical and nursing courses. As a result, interest in the field is not widespread and we are now burdened with a severe shortage of dermatologists in the UK. Until dermatology has been recognised as one of the core fields of primary care, variation in the standard of provision is only likely to get worse.

The NHS is undergoing its most radical overhaul since its creation; it is vital therefore that patients with skin disease do not lose out as a result of the changes. Relatively few skin diseases are life threatening – although some are - but it is essential that they are not allowed to be marginalised or under-prioritised as a result.

Ultimately patients with skin disease rightly expect to be provided with adequate and appropriate support to manage, control and live with their condition.

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

**Sir Paul Beresford  
Chair, All Party Parliamentary Group on Skin  
Member of Parliament for Mole Valley**

## **Summary of Recommendations**

### **Impact of Skin Disease on People's Lives**

- When a patient with a skin disease may be expected to benefit from a licensed treatment, Clinical Commissioning Groups should ensure that that treatment is made available to the patient as soon as possible.
- When giving advice to patients on how to manage their condition, health professionals should recognise the burden of the treatment itself in addition to the physical symptoms. Medical and nursing training programmes should reflect this.
- The Medical Research Council should encourage the pharmaceutical industry to conduct research into treatments that do not place additional burdens on patients.
- The Health and Safety Executive should ensure that employers are educated about the realities of skin disease. Guidelines on managing skin conditions in the workplace should be made more widely available.
- When assessing a patient's condition, health professionals need to understand how that condition might be affecting their psychological health and day-to-day routine.

### **Support Services for Patients**

- The Department of Health and/or the NHS England should alert commissioners to the potential financial benefits of psychological interventions so that they can manage joint budgets appropriately.
- Clinical Commissioning Groups 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.
- The Medical Research Council should coordinate research to establish the clinical and cost-effectiveness of psychodermatology services.
- Clinical Commissioning Groups should ensure that they establish links with patient support groups. Health professionals should be made aware of these and should direct patients to the appropriate group for additional support if it is needed.

## **The Cost of Skin Disease**

- The Medical Research Council should coordinate research to establish the true cost of skin disease to the NHS and to society.
- The Government should closely monitor access to the PIP scheme upon its introduction to ensure that the recent revision to the regulations meets the needs of those with fluctuating conditions.

## **The Need for Action**

- At the time of writing, there is no dedicated lead within the NHS England for dermatology. Although commissioning for dermatology services is a local matter, a dedicated individual at a national level should provide oversight. For this reason the APPGS recommends the creation of the role of National Clinical Director for Dermatology.
- Robust monitoring of community dermatology services should be maintained and health professionals working within these services need to be suitably trained and accredited (see section 8).

## **Educating Health Professionals**

- The General Medical Council working with the Royal College of GPs, Royal College of Nursing and Royal Pharmaceutical Society, should ensure that urgent priority is given to the provision of proper dermatological training for all GPs, nurses and pharmacists. The training should emphasise that most inflammatory skin diseases are long-term conditions and are likely to need on-going care, often throughout a patient's life. Similarly the psychosocial effects of skin disease should be considered an integral part of any dermatological training course.
- Clinical Commissioning Groups should ensure that nurses and pharmacists be given greater opportunities to specialise in dermatology and psychodermatology.

## **Measuring Quality of Life**

- The APPGS welcomes the publication of the 2012 NICE guideline on psoriasis and recommends that NICE consider the use of dermatology-specific and disease-specific quality of life measures in future skin-related NICE guidelines.
- Further research is needed to assess uptake of HRQoL measures. The APPGS recommends that NICE consider the creation of a Quality and Outcomes Framework indicator to incentivise uptake of dermatology-specific QoL measures.
- Funding should be made available for research into the creation and use of methodology to measure the impact of skin diseases on individuals.
- Funding should be made available for research on the psychological and social impact of rare skin diseases, which are often overlooked in favour of more prevalent conditions.

## **1. Background**

- 1.0** Skin diseases can have profound physical, psychological and social consequences for those who live with them, for carers and for family members. Whilst the physical symptoms are diverse in nature, all have the potential to impact on one's mental wellbeing.
- 1.1** Those not directly affected by skin disease tend to trivialise them. Some even find them repellent; their indifference or distaste is often exacerbated by the misplaced assumption that skin diseases are contagious or that they are caused by poor hygiene. There may even be a doubt in the public mind that skin diseases count as sickness in the ordinary sense of the word. Such views are reflected in the relative lack of importance attached to skin diseases by the Government, health service managers and health professionals not directly concerned with dermatology, as well as by the public.
- 1.2** It is for this reason that in 2003, the All Party Parliamentary Group on Skin (APPGS) decided to conduct an enquiry into the psychological and social effects of skin diseases. In addition to assessing the extent to which skin diseases affected peoples' daily lives, the enquiry sought to produce a number of recommendations designed to influence the future planning and delivery of care.
- 1.3** In the intervening decade since the report was published a number of changes have taken place both in terms of the way care is delivered and paid for and in terms of the treatment options available to patients. However many of the problems raised in the Group's 2003 report continue to exist and treatment for the psychosocial effects of skin disease is still the exception rather than the norm.
- 1.4** After discussing this lack of progress with its members and other stakeholders working in the field of dermatology, the APPGS decided in 2011 to update the Group's previous report on the subject of psychosocial effects of skin disease.
- 1.5** The aim of this new report was twofold: to update the previous report using new evidence published within the last ten years, and to reemphasise the importance of providing a holistic package of care for those in need.
- 1.6** The conduct of this latest enquiry closely mirrored that of the Group's 2003 enquiry. Evidence was submitted both in writing, through a formal consultation period, and orally at a hearing held in the House of Commons in November 2012 (see Appendix B for a list of witnesses). Submissions were received from patient groups, consultant dermatologists, nurses, GPs, other health professionals and members of the public.
- 1.7** In total, 112 submissions were received, excluding academic research papers submitted to the enquiry from members and partner organisations.

- 1.8** A specialist advisory committee was established to guide the APPGS in its enquiry. Members of the committee are listed in Appendix A.
- 1.9** A Glossary briefly explaining the characteristics of the skin diseases mentioned in the report is set out in Appendix C.

## **2. Summary**

- 2.0** It is estimated that around 54% of the UK population experience a skin condition in any given twelve-month period. The majority of these patients (69%) self-care, with around 14% seeking further medical advice – the most common reasons being skin infection or eczema.
- 2.1** Skin diseases can adversely affect almost every aspect of a person's life. They can also seriously affect the lives of other family members and carers. Common psychological problems associated with skin disease include feelings of stress, anxiety, anger, depression, shame, social isolation, low self-esteem and embarrassment. Skin conditions can also affect one's personal, professional and social life.
- 2.2** Many skin diseases including acne, eczema and psoriasis, can result in disability levels equivalent to those experienced by patients with non-dermatological chronic diseases. The risk of developing mental health problems has been shown to be higher in those with a physical health problem. Some studies have shown a correlation between skin disease and a higher risk of drug and alcohol misuse. There is also evidence to suggest that suicidal ideation is higher amongst those with a skin disease.
- 2.3** The psychological impact of skin disease on an individual is not directly related to the overall area affected or to the objective severity of the condition. However, there is evidence that suggests being affected in visible places such as the face or hands or intimate genital areas causes higher levels of distress as they are less easily covered and/or can precipitate or perpetuate relationship issues.
- 2.4** Opportunities for dermatology training for non-specialist health professionals, especially for pharmacists and for doctors and nurses in primary care are inadequate.
- 2.5** People with skin disease place great value on the information and help provided by patient support groups working within the field of dermatology.
- 2.6** Data on the costs of skin disease is still patchy. Some studies have taken place looking at the costs associated with eczema and psoriasis but more research is needed in this field, particularly in relation to other skin conditions.
- 2.7** The Government's move towards stressing health outcomes and the commitment within the NHS Outcomes Framework to improve the quality of life for people with long term conditions is a welcome step in the right

direction. So is the publication of its mental health strategy, *No Health Without Mental Health*. However there is evidence that suggests skin conditions are still being trivialised by both the public and those working within the health system.

- 2.8** A number of tools designed to assess patients' quality of life (often in the form of a questionnaire) have been produced over the years, however uptake of these is still patchy and there remains confusion as to what to do with the results. Some quality of life measures do not ask about distress and thereby minimise the actual measured impact on psychological wellbeing. The psychosocial impact of skin disease should be taken into account by clinicians and when considering treatment and management options. Quality of life measures should be used and the results incorporated into health-service planning when assessing priorities.
- 2.9** Access to psychologists, psychiatrists and counsellors within dermatology services across the UK (psychodermatology) is lacking. Routine & easy access to psychiatric liaison services is not common. Only 3 out of 127 hospitals have a dedicated psychodermatology service - provision of these services has deteriorated since 2004.

### **3. The Extent of the Problem**

- 3.0** Skin disease accounts for between 15% and 20% of a GP's workload and it is the most frequent reason for patients to visit their GP with a new problem.
- 3.1** Nearly 13 million people (24% of the population) in England and Wales visit their GP with a skin problem each year. Of these, around 0.8 million (6.1%) are referred to secondary care for specialist advice. Most of this specialist work is outpatient-based.
- 3.2** The most common conditions seen by a specialist are eczema, psoriasis and acne.
- 3.3** Atopic eczema is the most common form of eczema. While it can affect people of all ages, it is primarily seen in children, affecting 5-15% of UK children by the age of seven. Most people 'out grow' the condition but a number of adults continue to show symptoms at a later age, some even have the condition for life. Eczema is typically characterised by red, sore and itchy patches of skin.
- 3.4** It is estimated that psoriasis affects between 2-3% of the population (1.8 million). It is an immune condition that triggers excess replacement of skin cells, which can lead to raised plaques on the skin that can be flaky, sore and itchy. Like eczema, it can appear on any part of the body and be subject to flare-ups. Psoriatic arthritis affects 1 in 5 of those with psoriasis; like other forms of arthritis, joints can swell and become inflamed and painful, causing difficulties with general mobility.

- 3.5** Acne is a condition most commonly associated with adolescent teenagers. Whilst the condition is thought to be linked with hormone changes during puberty (around 80% of people between the ages of 11 and 30 will be affected by acne) the condition can affect people well into their adult lives. About 5% of women and 1% of men have acne over the age of 25. Acne arises when glands in the skin begin to produce excessive amounts of an oily substance known as sebum. This blocks small holes in the skin through which hairs grow (hair follicles), causing blackheads and whiteheads.
- 3.6** Other common conditions seen by specialists include vitiligo, urticaria, rosacea, herpes simplex, shingles, vascular lesions, benign skin tumours, benign moles, solar keratosis, viral warts, non-malignant skin cancers and malignant melanomas.
- 3.7** Every skin condition can have an effect on one's psychological wellbeing. It is important to note however that the psychological impact of skin disease on an individual is not directly related to the extent of skin affected or to the extent of the condition. Instead, the psychological and social impact of the condition can depend heavily on the sites and distribution of the symptoms, the attitude of the individual and naturally the social circumstances and reception encountered. Social support, current relationships, coping skills, illness beliefs, symptoms such as sleep loss, social stigma and past experiences with the illness all play a crucial role.
- 3.8** A study conducted in 2011 involving 510 acne patients found that a significant number reported levels of social, psychological and emotional problems that were as great as those reported by patients with long-term conditions such as chronic disabling asthma, epilepsy, diabetes, back pain or arthritis.
- 3.9** Similar studies have demonstrated that patients with psoriasis can experience a reduction in quality of life comparable to that of patients with diabetes, heart disease and cancer.
- 3.10** 57% of 520 vitiligo patients surveyed in 2005 indicated that their condition moderately or severely affected their quality of life.
- 3.11** In 2005, a study comparing impairment of quality of life in children with skin disease and children with other chronic childhood diseases, found that skin diseases can be just as distressing, and in some cases more distressing, than other serious conditions such as cystic fibrosis. This perception was generally shared by parents. Using Health Related Quality of Life (HRQoL) measures, children with psoriasis scored higher than those with epilepsy, enuresis and diabetes; and children with urticaria scored higher than those with asthma.

#### **4. Evidence of the Impact of Skin Disease on People's Lives**

- 4.0** The World Health Organisation defines quality of life (QoL) as "the individuals' perception of their position in life, in the context of the cultural and value system in which they live and in relation to their goals, expectations,

standards and concerns". Whilst QoL measures are used to assess individuals' general wellbeing, health-related quality of life (HRQoL) measures are more commonly used to assess the effects of a particular condition or disease on a person's quality of life.

- 4.1 According to Bath et al. (2007): 'The measurement of HRQoL is becoming increasingly important in patients with skin diseases. Despite the availability of a variety of instruments and new psychometric techniques, there is no consensus as to which HRQoL instruments are to be preferred in dermatology.'
- 4.2 Key quality of life domains for people with skin diseases tend to include any or all of the following: symptoms and diagnosis; treatment; self-esteem and psychological health; life-changing decisions and work; social, sexual and leisure activities; physical functioning; family relationships; sleep disturbance and schooling; ethnic and cultural issues; and environmental issues.

## Symptoms and Diagnosis

- 4.3 The symptoms of skin diseases, which can be very severe, are often underestimated by those not directly affected.

*"I suffer with a high level of sweating from my armpits. This leaves large damp patches on my clothes which I always fear are visible, and often are. This makes all social situations including going out, working and studying difficult as I find myself constantly worrying about the visible sweat on my clothes and the assumptions that those around me will make that I'm smelly and unclean. My case is made worse in situations of heightened emotion, particularly when I'm nervous or excited. The whole situation is exasperated when I become nervous that I am sweating excessively, which results in me sweating more because I am nervous."*

- Evidence submitted by a patient with hyperhydrosis

- 4.4 Evidence submitted to this enquiry indicated that the diagnosis of skin diseases, especially the rarer ones, can be protracted and uncertain. Lack of dermatology training for non-specialist health professionals, particularly those in primary care, frequently causes unnecessary delay in establishing a correct diagnosis.

*"I don't think the GP knows enough about the skin condition. I tried to get referred to a dermatologist for a second opinion and was told I couldn't have one until the cream was being applied four times a day – which is impossible when your son is at school five days a week and wants to go out and play football not be lathered in cream all the time."*

- Evidence submitted by a parent on behalf of her son (complex case of ichthyosis vulgaris and eczema)

## Treatment

- 4.5** Many patients manage their skin condition themselves and for some this is a positive action, being in control of their own condition. Others do it because their experience of the medical profession is poor. As many GPs have little experience of skin conditions they, may exhibit less empathy and confidence when treating skin conditions.
- 4.6** Lack of appropriate dermatological training for non-specialist health professionals, particularly those in primary care can impact upon the choice and effectiveness of the treatment.

*“They [doctors] treat the condition by handing out creams and lotions etc, but never offer advice on how to deal with it.”*

- Evidence submitted by an individual on behalf of a family member with ichthyosis.

*“Many doctors have no understanding whatsoever about the effect of skin disease on patients’ psychological welfare. Treatment is often grossly inadequate for them.”*

- Evidence submitted by a consultant dermatologist.

- 4.7** Moreover, both health professionals and members of the public continue to underestimate the burden of the treatments themselves. Many treatments continue to have a negative impact on daily living and self-esteem and for some, such as psoriasis patients, this can often involve a demanding, time-consuming and repetitive regime.

*“Doctors assume that the treatments they recommend represent solely solutions, whereas they can be highly problematic from a patient’s perspective, within the framework of everyday life.”*

- Evidence submitted by a patient with psoriasis.

*“I have throughout my life lost huge amounts of time due to my eczema... even now I lose something like two hours a day to putting creams on and waiting for them to go in”.*

- Oral evidence submitted by a patient with eczema.

- 4.8** As one of the enquiry’s witnesses pointed out, for many, the total time spent each week applying treatments could equate to nearly half a week’s working hours or up to three hours a day. When added to one’s actual working hours, this represented a substantial figure.
- 4.9** In the case of topical treatments, it is essential that patients be given a choice so that they can find the most appropriate treatment to suit their particular needs.

- 4.10** There continues to be an assumption within the NHS that treatments for skin diseases must necessarily be inexpensive, partly perhaps because skin diseases are seen as ‘minor ailments’ and partly because treatments for them have not generally been costly in the past. Increasingly, this is resulting in new, more effective but more expensive treatments (such as biological treatments) being denied to patients by trusts preoccupied with staying within their prescribing budgets. In 2009, 40% of UK psoriasis services cited funding as a significant obstacle to prescribing biologic drugs. This is despite guidance from the National Institute of Clinical Excellence (NICE) highlighting the potential benefits to a patient’s quality of life in cases of severe psoriasis (severe symptoms only occur in a minority of psoriasis patients).

## **Self-Esteem and Psychological Health**

*“Without using skin camouflage to face (rosacea) and occasionally to backs of hands (psoriasis) I would be frequently asked what my medical conditions are... I do not think it is reasonable to be questioned on my medical history by a complete stranger in the middle of Tescos – but the public feel it is perfectly okay to do so!”.*

- Evidence submitted by a woman with rosacea and psoriasis.

- 4.11** In 2012, the British Skin Foundation conducted a survey in which 729 people were asked a series of questions relating to their skin disease or that of the person they care for. 47% of respondents said that they had been victims of verbal abuse one or more times and a further one in six (16%) people admitting to having self-harmed as a result of their skin disease. Disturbingly, seven out of 729 participants said they had attempted suicide, with another 17% (125 respondents) stating they had contemplated suicide at some stage.
- 4.12** One study found that 20% of patients with psoriasis said that they had been rejected and stigmatised by the public as a result of their condition. Another study found that 20% of those with severe psoriasis were on anti-depressant medication.
- 4.13** Society’s increasing pre-occupation with image creates mounting pressure on people with skin conditions. In 2003, the APPGS received many reports of discrimination and prejudice and our latest findings confirm that this is a continuing theme.
- 4.14** Some skin conditions such as acne occur predominantly in adolescence, a developmental period in which there is considerable focus on appearance. The impact of skin disease on teenagers’ self esteem during this period can be devastating. Evidence submitted to a recent APPG on Body Image enquiry showed appearance was the focus of bullying in 56% of cases. In situations where a child has experienced negative reactions towards their skin, there may be a risk of developing ‘body specific shame proneness that clinical experience suggests may become generalised to long-term appearance sensitivity.’ Recent studies have indicated that the development of acne vulgaris later in life or having the condition continue into early adulthood can be associated in some cases with high levels of distress.

**4.15** This emphasis on appearance has been heightened considerably in recent years by the media and the mis-sold ideal of the perfect body. Professor Nichola Rumsey told the recent APPG on Body Image enquiry that ‘we are increasingly living in an appearance saturated society and that the value individuals place on their appearance is becoming greater and more disproportionate to other aspects of self-concept. By focussing too much attention on appearance, other important attributes such as intelligence, kindness and determination were seen to be becoming less important.’

*“I feel like I am disgusting. I feel unattractive and I have such little confidence in myself as a result of how I look. People stare at my face and it makes me feel completely worthless”*

- Evidence submitted by a woman with severe acne.

**4.16** The medical condition herpes simplex, best known as the cold sore, has a disproportionate stigma attached to it when it occurs on the genitals. According to the Herpes Virus Association, people newly diagnosed often say “*I don’t know anything about it, I just know that it is something terrible.*” Prior to the advent of antiviral drugs, genital herpes was treated as a minor skin condition, occurring on an alternative site to the common cold sore.

**4.17** Hair disorders such as hirsutism (excess hair production) and alopecia (hair loss) also fall under the remit of dermatology. Hair disorders can impact upon a woman’s sense of femininity. Several studies have indicated that women may be more vulnerable to experiencing psychological distress than men. This could be due to cultural factors. However it is important to emphasise that the psychological impact upon men can be just as severe.

## Psychological and social problems related to skin conditions

- |  |   |
|--|---|
| <ul style="list-style-type: none"><li>- Anger.</li><li>- Anxiety.</li><li>- Avoidance.</li><li>- Bullying</li><li>- Depression.</li><li>- Embarrassment.</li><li>- Exhaustion.</li><li>- Frustration.</li><li>- Guilt.</li><li>- Helplessness.</li><li>- Increased alcohol intake.</li><li>- Irritability.</li><li>- Low confidence.</li><li>- Low self-esteem.</li><li>- Performance Issues</li></ul> | <ul style="list-style-type: none"><li>- Poor body image.</li><li>- Relationship issues.</li><li>- Resentment.</li><li>- Secretiveness.</li><li>- Sexual problems.</li><li>- Sleep deprivation/sleeplessness.</li><li>- Social isolation.</li><li>- Stress.</li><li>- Suicidal thoughts.</li><li>- Suicide.</li><li>- Teasing.</li><li>- Withdrawal.</li></ul> |
|--|---|

**Source:** Green. L (2010)

## Life-changing decisions and work

*"In my work place I have become a trainer, in the summer months I try not to accept any requests as this is when I am at my worst, even in the cooler months of the year I ensure I wear layers so as I can take them off and control my temperature, as soon as it rises my hyperhidrosis starts, I then become anxious and it tumbles out of control from there, as you can imagine, if I am standing in front of trainees it can become crushingly embarrassing for me and also for them, my hyperhidrosis is in my head, so beads of perspiration can run off my face and head, my hair becomes soaked and any make up runs. Also if I visit another office for a meeting I will consider what I am to wear before going as if their heating is on in the winter I start getting hot and anxious again. This is a daily concern."*

- Evidence submitted by a woman with hyperhidrosis.

- 4.18** The majority of the work-related evidence received by the enquiry concerned eczema and psoriasis. However many other skin diseases can be similarly damaging, limiting opportunities at and for work, and causing functional and interpersonal difficulties.

*"I feel that in applying for jobs over the last few years, since my Vitiligo has become more extensive, I've possibly been passed over in favour of other, un-disfigured candidates. In addition the process of putting yourself through job interviews is difficult in itself but is an additional strain with the heightened worries about wearing or not wearing camouflage, should you mention the condition, does it make the interviewer feel uncomfortable, do you look significantly less normal/attractive with the condition?"*

-Evidence submitted by a patient with vitiligo

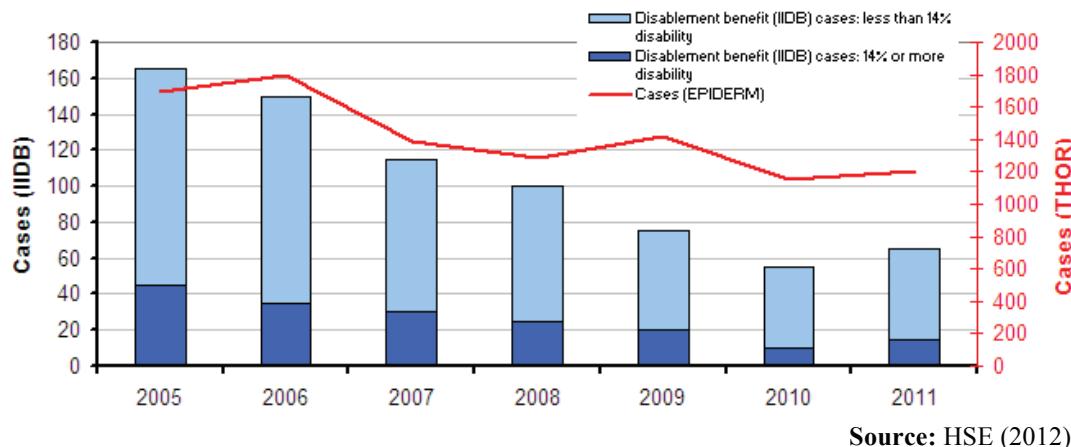
- 4.19** The enquiry was told by Ray Jobling, a patient with psoriasis, that having psoriasis had changed his life as a teenager because he had always wanted to join the Royal Navy but was prevented from doing so by his condition. After a long series of tests designed to determine his suitability for the role, he was rejected at the final hurdle – the medical exam. The Ministry of Defence states on its website that any ‘active skin disease such as eczema or widespread psoriasis’ can prevent someone from starting a military career.

- 4.20** The enquiry also heard from Margaret Cox, a life-long eczema patient. She said that her condition played a part in her decision to stop practising as a commercial lawyer. Despite being a partner in a large firm, the working hours did not work around her treatment routine and the dress code often caused problems. Furthermore, absences from work due to hospital and GP appointments were not understood or appreciated by colleagues.

- 4.21** Many people with skin conditions suffer from flare-ups. Maintaining steady uninterrupted work can be difficult and in some cases impossible. Pemphigus vulgaris (PV) is just one example of a condition that is subject to flaring. The acute phases of the disease can be so debilitating that work is simply out of the question.

- 4.22** When it comes to measuring work-related skin disease, there are a number of different data sources and reporting mechanisms that one can use. The Health and Occupation Network (THOR) provides surveillance mechanisms for dermatologists (EPIDERM scheme), occupational physicians (OPRA scheme), and GPs (THOR-GP). To complement these reporting mechanisms information is also provided by the Self-reported Work-related Illness (SWI) survey - a set of questions included in the annual Labour Force Survey (LFS), and assessments for Industrial Injury and Disablement Benefit (IIDB). The Health and Safety Executive (HSE) combines and analyses these data sets and produces a report on work-related skin disease each year.
- 4.23** Using the latest available data from the HSE (2009-11), there are an estimated 132 new diagnoses of skin disease per 100,000 workers per year based on The Health and Occupation Network (THOR-GP) reporting scheme. This equates to approximately 40,000 new cases of work-related skin disease per year.
- 4.24** The latest EPIDERM data from 2011 indicated that the vast majority of new diagnoses each year were contact dermatitis (77%), a small number were non-cancerous dermatoses (8%), and the remainder were skin cancers (15%). Florists, hairdressers and beauticians were found to have the highest rates of dermatitis. Workers in health and social care and chemical manufacturing plants were also found to be at risk.
- 4.25** Based on the HSE's 2009-11 data, skin disease accounted for around 2% of total days sickness absence certified due to all occupational illnesses.
- 4.26** One study of 369 people found that 59.3% of those with severe psoriasis could lose up to 26 days of work a year because of their psoriasis.

**Figure 1: Occupational contact dermatitis in Great Britain, 2005-2011**



Although there has been a downward trend in terms of claims for disablement benefit due to occupational dermatitis, work-related skin disease continues to be a problem.

## Social, Sexual and Leisure Activities

*“Any activities that need uncovering myself at all, (I live covered from neck to toe, and with makeup on my face) are a no-no as I get stares and people cat calling or moving away from me, thinking I have something catching. This particularly includes swimming, dancing, gym, going to the beach or being out in the sun.”*

- Evidence submitted by a patient with acne

- 4.27** Evidence submitted to this enquiry indicated that skin disease can significantly hamper a person's ability to socialise and interact with other people. Forging personal (friendships and intimate) relationships and maintaining them can also be markedly harder for people with a skin condition.
- 4.28** According to the British Skin Foundation's 2012 survey of people with a skin disease, 29% found that their condition was an active barrier to finding a partner. 20% felt that their skin disease was the driving factor behind the breakdown of their most recent partner relationship or a previous one. When asked to rank what they felt were the top three areas affected by their skin condition, 56% said that making friends was their third biggest concern (behind the fall in confidence and the affect on their working life).
- 4.29** Patients with vitiligo frequently report a negative impact on sexual relationships and cite embarrassment as the primary cause.
- 4.30** Physical pain can also prevent individuals from enjoying an active sexual life – vulvadynia is but one example example, where patients suffer from persistent, unexplained pain of the vulva.
- 4.31** Those severely affected by epidermolysis bullosa (EB) cannot work and often depend on benefits. Consequently socialising is limited by financial constraints. Opportunities for establishing friendships or relationships are reduced by transport difficulties or inability to participate fully and, for those with visual impairment, self-consciousness can inhibit them from joining hobby or interest groups or attending social events.
- 4.32** Avoidance of social situations is often linked very closely with the psychological wellbeing of the individual.

*“My severe acne and scaring on my face has dramatically reduced my confidence and self-esteem. I feel ugly and ashamed, and I don't like people staring at me so I avoid going out of the house as much as I can.”*

- Evidence submitted by a woman with severe acne.

- 4.33** Very often, isolation causes further distress to the individual. As a result they are less likely to want to socialise in the first place. If left unchecked, this downward spiral can wreak havoc on an individual's mental wellbeing.

*"I am 44, divorced and now seeing a new partner. After two years of being together I still can't let him sleep over - if he does he will see my dripping wet hair first thing in the morning and no one wants to stroke their partner's hair romantically in the morning only to find sweaty, wet hair. Neither do I want him to see the saturated wet pillowcase that I wake with every morning...After he leaves (because I won't let him stay) I sit and sob because I feel so ashamed of my body".*

- Evidence submitted by a woman with hyperhidrosis.

- 4.34** Many people with a skin disease avoid leisure and sporting activities. Often this can be down to personal feelings of anxiety, low self-esteem, embarrassment or shame.

*"I always wanted to learn how to swim but I am very aware of my appearance. I feel the need to keep myself covered."*

- Evidence submitted by a man with ichthyosis.

- 4.35** It is recognised that physical activity can lead to enhanced psychological well-being and improved quality of life, in the areas of control and self-esteem, for example, increased confidence, better cognitive functioning, reduced anxiety and stress and decreased depression. However people with skin disease, particularly moderate to severe sufferers, may experience the opposite and therefore approach with caution any physical activity which puts them at risk of exposure.

- 4.36** For some, exercise is not an option due to the physical pain.

*"I would like to exercise on a regular basis but my skin can hinder this as I can't really commit to a regular day each week as my skin may be sore and I won't be able to go."*

- Evidence submitted by a female with Netherton's Syndrome.

## Physical Functioning

- 4.37** Leg ulcers, common in the elderly, can have a devastating affect on a patient's general mobility. It is generally accepted that leg ulcers impact upon one's quality of life, yet too often health professionals focus on treating just the wound, rather than the whole person.

- 4.38** Several skin diseases including post herpetic neuralgia (PHN), can cause intolerable pain. PHN can make undertaking basic tasks, for example, bathing, dressing and eating, extremely difficult.

- 4.39** Impaired physical functioning is common in patients with skin disease. This loss of mobility can in itself contribute towards psychological distress. Those with severe psoriatic arthritis for example, may find it hard attending social gatherings. Enforced isolation, if prolonged, can lead to feelings of depression and loneliness.

## **Family Relationships**

- 4.40** Skin conditions can have a wider impact beyond the individual concerned. The whole family can be affected in one way or another.
- 4.41** Parents caring for a child with eczema may feel distressed about their child's emotional health and their inability to help, because of this, they may also experience feelings of guilt and depression. Siblings may also feel jealous or excluded.
- 4.42** In a 2004 study, 75% of carers felt that being able to achieve control of eczema would be the single most important improvement to their own quality of life or that of their children.
- 4.43** Caring for a child with EB can be very distressing for all the family. Not only are there considerable time implications but psychologically it can be very hard seeing your child in pain on a regular basis. Parents that have a child with EB often have to arrange periods of absence from work in case the school contacts them for help with treating blisters.

*'For the first six weeks of her life Isla was carried around on a padded mattress to avoid tearing her delicate skin. Picking Isla up and giving her a cuddle is no easier now... You can't pick up a child who has EB by gripping their body or by lifting them under their arms – it rips their skin. Goodness knows how we'll lift her as she gets bigger.'*

- DEBRA.org.uk

*'Caring for Rhys is a full time job and Tanya says that she's lucky to have support from her partner and her parents who live down the road.'*

- DEBRA.org.uk

## **Sleep Disturbance and Schooling**

- 4.44** A study conducted in 2009, found that sleep disturbance affected up to 60% of children with eczema, increasing to 83% during exacerbation. The study also found that disturbed sleep in children with eczema is associated with behavioural deficits, potentially impacting on their academic and social development. The child's sleep disturbance often affects other family members and can impact siblings' academic and parental work performance.
- 4.45** The potential knock-on effects of sleep disturbance in children with eczema were recognised by the 2007 NICE guideline on atopic eczema in children. Referral to specialist dermatological advice is recommended if 'the atopic eczema is giving rise to significant social or psychological problems for the child or parent/carer (for example, sleep disturbance, poor school attendance)'.
- 4.46** Although primarily a condition affecting children, sleep disturbance can also affect adults with eczema.

*'I struggled hugely as a youngster... because of the unremitting itch, I slept very poorly and to this day, I have a completely strange sleep pattern.'*

- Oral evidence submitted by a woman with eczema

- 4.47** Aside from issues of attainment and discomfort caused by school uniforms (many of which are woollen or synthetic and can exacerbate the condition), children with skin diseases can be subject to bullying on a regular basis. This can lead to withdrawal and isolation (exacerbating a negative sense of self) – psychologically this can affect an individual well into adult life.
- 4.48** The APPGS' previous enquiry into the psychosocial effects of skin diseases found that schools often found it hard to understand the needs of children with eczema and the strategies for dealing with it. School staff were at times reluctant to supervise or carry out the application of moisturisers and some were afraid of touching children - possibly because of child protection issues. Since then, the National Eczema Society has produced guidance for teachers and school staff. The guidance aims to tackle the stigma associated with eczema and emphasises the fact that some children will need to be absent from school during an intense flare-up. The NES' guidance is hosted on the Department for Education website and available for teachers and school staff to download.

## **Ethical and cultural issues**

- 4.49** Skin diseases have special significance and are associated with various beliefs and taboos in different cultures. In a multi-cultural society such as exists in the UK, it is important for health professionals to acknowledge that some of their patients from ethnic minority groups may have additional or quite different psychological and social needs from those of the majority of the population. Myths and beliefs about skin diseases can have a profound effect on the patient and affect their ability to cope. Understanding the implications of this is crucial to providing effective care for people with skin disease.
- 4.50** Vitiligo is a disease that is more noticeable in people with darker skin or in the summer when people with paler skin types tan. The loss of pigmentation can appear more pronounced in these patients and increased visibility has been linked to higher levels of psychological distress. However other papers have shown that people with fairer skin also exhibit high levels of psychological distress. The condition has been subject to much curiosity across many different cultures. In some cultures, the condition has been confused with leprosy - this has led to an increase in stigmatisation.
- 4.51** Thompson et al. in 2010 reported in a study with British Born South Asian women that vitiligo was related to stigmatisation and this was influenced by, and affected, cultural practices.
- 4.52** The loss of skin colour in patients with vitiligo may also threaten ethnic identity, adding another dimension to their psycho-social distress. It has been

shown that community support can play a huge role in helping patients adjust to their condition.

- 4.53** One aspect that is often not mentioned relates to gender. This may be particularly important in some cultures where a woman's marriage and career prospects may be damaged. Also, women may bear the chief burden for support and treatment of family members with skin disease. In the UK, there is concern about women from different ethnic groups who do not speak English and whose access to satisfactory medical care is frequently compromised by the lack of suitably qualified, sympathetic female interpreters.
- 4.54** More research is needed in this area and on other skin conditions in order fully to understand the impact of cultural beliefs and how they affect patients' ability to cope with their condition.

## Environmental Factors

- 4.55** Atopic eczema is a skin condition that results from a genetic predisposition to allergy. Symptoms often flare up when exposed to environmental factors or allergens. House dust mite droppings are a common allergen, as is pet fur and plant pollen. Eczema is also connected to food allergens, patients may therefore have to avoid common staples such as cows milk, wheat or eggs. Having a food allergy increases the likelihood of your atopic eczema being severe.
- 4.56** Temperature and textures also impact upon the severity of certain skin diseases. Carpets may have to be changed, special bed linen may have to be bought, clothes may need to be washed in a certain way – a person's home may need to be customised to help them manage their condition. Outside of the home, these factors are harder to control. A person's workplace could harbour a number of allergens and for those working outside, exposed to the elements, there is little they can do to protect their skin. All of these factors should be taken into account when assessing a patient's ability to manage their condition.
- 4.57** Some conditions such as Lupus and XP that cause extreme photosensitivity may require investment in light exclusion equipment and clothing. The management of Ehlers-Danlos Syndrome (EDS) or Epidermolysis Bullosa (EB) often demands modifications to accommodation.

*'The family home in Bolton has been extended with a wet room and extra bedroom to make it easier to clean Rhys's blistered skin and then apply fresh dressings.'*

- DEBRA.org.

## Recommendations

- When a patient with a skin disease may be expected to benefit from a licensed treatment, Clinical Commissioning Groups should ensure that that treatment is made available to the patient as soon as possible.
- When giving advice to patients on how to manage their condition, health professionals should recognise the burden of the treatment itself in addition to the physical symptoms. Medical and nursing training programmes should reflect this.
- The Medical Research Council should encourage the pharmaceutical industry to conduct research into treatments that do not place additional burdens on patients.
- The Health and Safety Executive should ensure that employers are educated about the realities of skin disease. Guidelines on managing skin conditions in the workplace should be made more widely available.
- When assessing a patient's condition, health professionals need to understand how that condition might be affecting their psychological health and day-to-day routine.

## 5. Support Services for Patients

- 5.0** Significant advances have been made in the field of medicine since the APPGS' 2003 report. Surgical techniques are continually being refined and the removal of skin tumours is becoming ever safer. Unfortunately however, there remain many inflammatory skin diseases that have no cure. They can only be managed effectively with appropriate treatments (medical and psychological).
- 5.1** In the absence of a cure, patients wish to minimise the impact of the disease on their daily lives. Yet many treatments are in themselves burdensome. Some treatments for vitiligo may require frequent visits to hospitals for light therapy. Topical preparations for psoriasis and eczema are often messy, requiring a significant time commitment, thus adding to the stress of coping with the psychological symptoms. For this reason it is vital that health professionals are knowledgeable of, and sympathetic to, the patient's physical and mental needs. These needs should be provided for efficiently with appropriate speed in a pleasant environment with privacy. Patients should feel able to express their concerns and have their worries allayed. Unfortunately, at present, this is not always possible.

*'Several of my patients have major issues with their skin condition and how it affects their life. I spend a lot of time talking to patients when they attend for treatment. Sadly my allocated time is 15 minutes per treatment and if someone has an issue my time is so limited and discussions are often cut short. The room I work in is totally inadequate for the purpose and again sadly I have no private area to speak with patients in order to enable patients to speak freely.'*

- Evidence submitted by a specialist nurse

- 5.2** This enquiry received a great number of submissions from health professionals working within the field of dermatology. There was broad agreement that services could be improved in two ways (i) by improving education across the board (this issue is addressed in section 8); and (ii) by integrating or providing easy access to psychological support services.

*'The appointment of a psychologist within each dermatology department/area would be extremely beneficial for patient support.'*

- Evidence submitted by a specialist nurse

*'Secondary care services need to be integrated & fully comprehensive, fit for purpose in the long-term management of the disorders & their treatment.'*

- Oral evidence submitted by a patient with psoriasis

*'Psychologists should be routinely available within dermatology units. Conditions such as psoriasis and eczema which have considerable impact should be commissioned with a multi-disciplinary team including a psychologist.'*

- Evidence submitted by a consultant dermatologist

- 5.3** In 2011, Consultant dermatologist, Dr Anthony Bewley, conducted a survey of 127 hospitals across the UK. He found that only one hospital had a dedicated dermatology/psychiatric clinic, 7 out of the 127 had a psychodermatology service and one hospital had a children and adolescent psychodermatology service. These findings demonstrate a significant gap in psychodermatology services across the UK. A recent survey by Dr Shah (Chartered Clinical Psychologist) and Dr Bewley (2012) indicated that, out of the 7 psychodermatology services, only 3 had a dedicated psychologist, suggesting that psychological services had further reduced.

- 5.4** In theory, provision for those seeking help with the psychosocial effects of skin disease should have improved within the last ten years. In practice, however, progress has been small in some areas and non-existent in others.

- 5.5** The Increasing Access to Psychological Therapies (IAPT) programme was initiated in 2011. The programme's four year plan proposed to initiate: a nation-wide roll-out of psychological therapy services for adults with mental health problems; a standalone programme for children and young adults; and, models of care for people with long term physical conditions, medically unexplained symptoms or severe mental illness. Despite the introduction of the

IAPT programme, this enquiry found that many health professionals, far from being liberated, felt constrained by a system that did not allow for appropriate referrals.

*'If I assess my client as having high DLQI scores and PHQ-2/9 scores I am very limited in referral onward pathway. I am limited to referral back to GPs who in my experience, do not prioritise any concerns re psychosocial aspects of the skin disease in their future care pathway.'*

- Evidence submitted by a specialist dermatology nurse

*'We cannot refer directly to a consultant psychologist. Referrals are through a triage system to which we have no influence. We have requested psychological support with each new appointment but it fell on deaf ears.'*

- Evidence taken from Bewley. A et al (2011)

- 5.6** Recognition of mental health needs has increased in recent years but it is still viewed as largely separate to that of physical need. Evidence submitted indicated that the system is failing to manage psychosocial needs appropriately because of a lack of conceptual and budgetary integration.

*'The Increasing Access to Psychological Therapies strategy post-Layard Report is a great opportunity to address the psychological aspects of all long-term conditions and psoriasis could benefit from this. However, as services have been polarised into mental health and physical health the budget for mental health services prioritises serious mental health issues (suggesting suicidal thoughts is not serious enough) and patients with a primary medical condition once again are ignored.'*

- Evidence submitted by a professional psychologist

- 5.7** This lack of joined-up thinking may be due to a lack of awareness of psychosocial interventions. Often misunderstood and viewed as an unaffordable add-on or luxury, the benefits of such interventions can in fact be huge for patients with skin disease. Indeed, several studies have shown that these interventions can have a significant impact on both the physical symptoms of skin disease and on patients' quality of life.
- 5.8** There are several different interventions that can be used for treating patients with a skin disease and a recent systematic review carried out by Lavda, Webb, and Thompson (2012) found good evidence for a range of techniques being effective in reducing distress. However, the authors concluded that further research is needed to extend the variety and focus of the psychological interventions that are available.

## **Behavioural Therapy**

- 5.9** Common behavioural interventions include assertiveness and social skills training, behaviour analysis sessions, relaxation training, habit reversal training and imagery to help treat associated feelings of anxiety and depression to name a few.

## **Cognitive Behavioural Therapy (CBT)**

- 5.10** With everything that we do, our behaviours are linked to our thoughts, physical feelings and emotions. The idea behind CBT is to try and challenge and change negative and/or irrational thoughts that the patient may have, as well as helping them to increase positive coping strategies and balance their activity (work/play). This approach takes the view that it is not necessarily the situations that are stressful, but the patient's perceptions of them that make them so. Skin disease can increase the likelihood of these 'cognitive errors' taking place. By exposing the rationale behind these negative perceptions, CBT aims to empower the patient and improve their general outlook on their daily lives. There is evidence to suggest that CBT is effective for those with psoriasis, eczema and other skin disorders. However more research is warranted.
- 5.11** Of course in many cases, negative situations are in fact caused by external factors (stigma, public discrimination etc.) and not by patients themselves. CBT aims only to address those circumstances in which a patients' perception *may* have been influenced by irrational internal thought processes.
- 5.12** CBT in its most intense forms is a form of psychotherapy, however, elements of the approach can be used in guided self-help, and it is this later form of CBT that has been most evaluated within this context. Lavda et al. (2012) found that studies that had evaluated CBT-informed techniques reported a medium-large effect size, and whilst being lower than the effect size for habit reversal, this difference was not statistically significant.

## **Group Therapy**

- 5.13** Group therapy can be used in conjunction with a variety of different psychological therapies. It is designed to help people tackle feelings of loneliness and isolation and can help encourage the development of reasoning and social skills. Confidence is often boosted as a result and mutual bonds of trust can form with other group members; all of which help alleviate the psychological symptoms of an individual's condition. It is a cost-effective approach that warrants further investigation.
- 5.14** Group therapy also encourages positive action in the form of self-help and mutual aid; this in turn, can lead to collective campaigning in the form of patient advocacy groups. It should be noted that the above benefits can be achieved with non-group based therapies, however some patients may respond better to this method of intervention.

## **How can therapy help in the treatment and management of dermatology patients?**

Therapy such as CBT can help dermatology patients to:

- come to terms with their conditions;
- explore treatment options and facilitate decision-making;
- examine difficulties they are experiencing with their condition and gain insight into what factors maintain those difficulties;
- explore and challenge dysfunctional appraisals, beliefs and assumptions;
- identify useful coping strategies;
- facilitate social interaction skills;
- examine issues that may be indirectly linked to the skin condition;
- challenge and cope with anticipatory anxiety and depression.

Group therapy, especially social and assertiveness skills training can help dermatology patients:

- encounter difficulties in social situations;
- discuss their problems with others who can empathise;
- develop a better understanding through the others' experiences of their condition;
- allow members to acquire and develop a variety of skills and put them in practice with other members;
- serve as a means of emotional and social support for skin patients.

**Source:** Papadopoulos. L, Walker, C. (2005)

### **Psychoanalytic psychotherapy and hypnosis**

**5.15** Psychotherapy and hypnosis are techniques used to try and expose unconscious processes, in the words of Dr Linda Papadopoulos, 'to create meaning where there is anxiety or confusion'.

**5.16** All of these interventions can have an impact. Although the research evidence is largely based on CBT, there are a plethora of therapies (some not mentioned here) that psychologists can use to help people with skin disorders. It is important to remember that some interventions may be more appropriate than others depending on the individual. Health professionals should familiarise themselves with the different interventions available in order better to meet the needs of the individual concerned.

### **Patient support organisations**

**5.17** Patient support organisations play a huge role in helping patients cope with the psychosocial effects of skin disease. Shortages of resources, training, specialists and support for doctors frequently prevents health professionals

from being able to give patients comprehensive advice on any given dermatological condition – patient support groups often fill this gap and they are highly valued for doing so. Moreover, patient support organisations often provide patients with a means of contacting other individuals with the same condition. This can help foster friendships, encourage an exchange of experiences, normalise the condition and alleviate feelings of loneliness and isolation.

- 5.18** Patient support organisations are especially important for the rarer skin diseases that typically receive little attention. The Ichthyosis Support Group, the Pemphigus Vulgaris Network and DEBRA are prime examples. However a great number of others exist offering excellent support and advice.
- 5.19** In addition to acting in an advisory capacity, a number of patient organisations such as the National Eczema Society and the Psoriasis Association, also play an important advocacy role, lobbying Government and key policy-makers within the NHS. They commonly liaise with industry, spearhead educational programmes, and seek to actively engage the public. The value of their work and their future potential should not by any means be underestimated.
- 5.20** Unfortunately, many of these organisations are unable to do more for their members due to a lack of funds. Many struggle to survive and some have been forced to dissolve their membership altogether - the Acne Support Group is but one example.

### **Camouflage services**

- 5.21** Changing Faces, an organisation dedicated to helping people and families whose lives are affected by conditions, marks or scars that alter their appearance, provides a comprehensive skin camouflage service. Self-referral to this service has been suspended in some areas due to high demand, however access can still be obtained through a referral from a GP or dermatologist. All practitioners are volunteers and the cost of training is high, consequently these organisations typically struggle to secure enough funding. Further information regarding this service can be obtained via the Changing Faces website.
- 5.22** Founded in 1985, the British Association of Skin Camouflage (BASC) is a charity which promotes, supports and furthers the techniques of skin camouflage to help alleviate the psychological, physical and social effects that an altered image can have on people's lives by the simple application of specialised products. BASC does not sell or endorse any brand and most of the products used are currently refundable on Form FP10. BASC is recognised as a leading authority on the training of professionals within the field of skin camouflage, providing the necessary skills to undertake ward and clinic consultations. A fee may be charged for private practice, however this does not apply for BASC consultations within the NHS. Information and advice is free of charge from their Head Office, where a range of literature and useful contact points is available for anyone seeking advice on skin camouflage.

## **Recommendations**

- The Department of Health and/or the NHS England should alert commissioners to the potential financial benefits of psychological interventions so that they can manage joint budgets appropriately.
- Clinical Commissioning Groups 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.
- The Medical Research Council should coordinate research to establish the clinical and cost-effectiveness of psychodermatology services.
- Clinical Commissioning Groups should ensure that they establish links with patient support groups. Health professionals should be made aware of these and should direct patients to the appropriate group for additional support if it is needed.

## **6. The Cost of Skin Disease**

- 6.0** Ten years ago the APPGS found that the data on the cost of skin disease was patchy. A decade on, this is still the case. Some studies have been conducted on the costs of eczema and psoriasis, but the overall costs of skin disease remain difficult to quantify.
- 6.1** In terms of sales of over-the-counter (OTC) skin treatments, the number has increased dramatically in the last decade, now totalling approximately £400 million a year, this equates to 17% of total OTC sales (2011).
- 6.2** A study conducted in 2009 found that prescribing costs for skin disease in England had remained fairly static around £237.7 million (2.85% of the total prescribing budget). The same study estimated that the total cost of skin disease to the NHS was around £1,819 million (2005/06 figures).
- 6.3** Almost all skin diseases impose additional costs on those affected by them. People with skin disease requiring financial assistance by way of Government benefits, have in the past been denied access to the Disability Living Allowance (DLA) because their condition has failed to meet certain criteria, such as the mobility test. The assessment process for DLA has historically failed to take into account fluctuation in the severity of symptoms and many

feared that its replacement scheme, the Personal Independence Payment (PIP) would do the same when it is introduced in April 2013.

- 6.4** After intense lobbying from patient groups, most notably the Multiple Sclerosis Society, the Government recently amended the PIP regulations. Assessors will now be required to consider whether claimants can perform activities ‘to an acceptable standard, safely, repeatedly, and in a reasonable time period’ – this is designed to recognise the difficulties faced by those with fluctuating conditions. At the time of writing, the regulations are still being finalised.

## Recommendations

- The Medical Research Council should coordinate research to establish the true cost of skin disease to the NHS and to society.
- The Government should closely monitor access to the PIP scheme upon its introduction to ensure that the recent revision to the regulations meets the needs of those with fluctuating conditions.

## 7. The Need for Action

- 7.0** Despite skin problems being one of the most common reasons a person visits their GP, dermatology has for many years been trivialised and marginalised throughout medical and health professional education and training.
- 7.1** With the Government’s NHS reforms in full swing, there is a risk that dermatology services could become even more marginalised as a result of the changes to the commissioning system. Careful planning is required in order to ensure patients do not further lose out as a result of the reforms.
- 7.2** Ever since the previous Government published 'Shifting Care Closer to Home' (2007), there has been a clear move towards community/primary care and a move away from secondary care. Local district hospitals are struggling to cope with the demand that is being placed on them on a day-to-day basis. Coupled with the need for the NHS to find £20 billion in efficiency savings by 2015, it seems logical to shift certain services into the community setting where in many cases, a patient's condition can be managed perfectly well. For dermatology services, this brings a number of *potential* advantages such as increased access and shorter waiting times, both of which benefit the patient. On the other hand, for this system to work safely and effectively, health

professionals (GPs and counsellors/psychologists working in primary care) need to be adequately trained (and accredited) to deal with the vast array of conditions that come their way.

- 7.3 The extension of care into the community will require close monitoring. Dermatology services have been identified as services that could potentially benefit from the new Any Qualified Provider (AQP) scheme and as a result a number of independent providers are setting up and bidding to win a community dermatology service. Again, this *could* increase access and dramatically reduce waiting times for patients, but it is important to emphasise that access does not necessarily correlate directly with the quality of care received.
- 7.4 From a dermatology patient viewpoint ‘shifting care’ to the community will not automatically give patients access to a high standard of care unless there are robust competency-based education and training programmes and dermatological and psychological clinical experience which equates with the criteria set for community dermatology services. Once established these services will require ongoing assessment and evidence of competency to continue to practice in the management of dermatological disease and integration between community and secondary care services; any less of an approach would ultimately impact on the patients’ experience and outcomes.

## Recommendations

- At the time of writing, there is no dedicated lead within the NHS England for dermatology. Although commissioning for dermatology services is a local matter, a dedicated individual at a national level should provide oversight. For this reason the APPGS recommends the creation of the role of National Clinical Director for Dermatology.
- Robust monitoring of community dermatology services should be maintained and health professionals working within these services need to be suitably trained and accredited (see section 8).

## **8. Educating Health Professionals**

*'From the undergraduate medical programme through to Medical Research Council GP exam there is room for improvement. Given that one third of all GP consultations will be for skin conditions it deserves more space in the training programme.'*

- Evidence submitted by a consultant dermatologist.

- 8.0** The All Party Parliamentary Group on Skin and its partner organisations have consistently said that education and training in the field of dermatology is insufficient and given that dermatology services have been identified in several areas as AQP priorities, the need for appropriate training is now more acute than ever.
- 8.1** Unfortunately, since the publication of the APPGS' first report on the issue of education (1998), the situation has improved only fractionally. A 2008 survey of UK final year medical students found that 56% of the 449 respondents regarded the level of education in dermatology as sufficient, but despite this, only 65% felt that they had adequate skills to assess patients with skin disease while only 52% felt they had adequate skills to manage them.
- 8.2** We understand that training for consultants is, on the whole, satisfactory, but little progress has been made on the undergraduate curriculum and the level of training in dermatology (and especially psychodermatology) continues to vary widely across the country. By failing to provide adequate education in this field of medicine, we are failing to meet the needs of patients.
- 8.3** Skin disease is the most common reason patients visit their GP with a new problem, yet strangely, despite this demand, or maybe even because of it, skin diseases have been increasingly trivialised to the extent that they are now widely considered to be 'minor ailments'. Consequently, the importance of dermatology and psychodermatology has been undermined and underestimated.
- 8.4** Evidence submitted to this enquiry and previous inquiries indicates that many patients feel let down by the level of knowledge of their GP. Between a third and a half of all referrals are due to an uncertain diagnosis.
- 8.5** Conversely, as gatekeepers to specialists, GPs are responsible for assessing whether a patient's condition warrants further investigation and referral to secondary care. If a patient's condition is misdiagnosed or fails to respond to prescribed treatments this will result in multiple appointments in primary care before referral is made, thereby costing the NHS far more in the long term. With cases of skin cancer on the rise, correct and early diagnosis is essential, especially given the high levels of psychological distress associated with this group of patients.
- 8.6** If GPs were on the whole more knowledgeable of skin conditions and their psychological impact, this would simultaneously help to tackle inappropriate referrals and the number of incorrect diagnoses.

- 8.7** In 2007, the Royal College of General Practitioners (RCGP) produced a curriculum statement on the 'Care of People with Skin Problems' (updated in 2012). This statement went a long way in recognising dermatology as a key component of a GP's training. It set out a number of expected key competencies within the field and crucially it recognised the importance of the psychological and social effects of skin diseases. Unfortunately however, this is still an optional component.
- 8.8** For undergraduates, the BAD recommends a two-week full-time attachment to a dermatology unit, with a realistic assessment at the end of the course. Dermatology should also be taught when undergraduates work with general practitioners in the community. For GP trainees undertaking their two year hospital placements, a six month post in dermatology alone or in a combined post (such as dermatology/general medicine or a combined minor specialty rotation) would go a long way in helping trainee GPs take a special interest in dermatology. Crucially however, this interest is unlikely to arise in the first place if it is not covered at an undergraduate level.
- 8.9** There is an alarming under-provision of consultant dermatologists in the UK. Compared with mainland Europe, the ratio of consultant dermatologists to the general population remains low in the UK - one consultant to every 130,000 people. This may well be in part due to a lack of exposure to dermatology at an undergraduate and postgraduate level, but it may well be due also to the lack of training posts available.
- 8.10** As a result of this shortage, other healthcare professionals are often greatly involved in the provision of dermatological care. The APPGS and its partner organisations have consistently stated that education and training for all health professionals working within the field of dermatology is insufficient.
- 8.11** As with GPs, both undergraduate and post-graduate nurse training programmes contain little dermatology, despite the fact that nurses often play a leading role in the management of skin diseases. Similarly pharmacists are often the first point of contact for advice on skin problems and are an integral part of dermatology services. Like nurses, pharmacists do undertake some dermatological training but the extent to which dermatology is covered could be significantly improved upon, as could the promotion of specialisation through further training.
- 'The education & training of health care practitioners needs more & better coverage of dermatological problems and care as a priority. It could also benefit from the explicit inclusion of patient experience & perspectives. Dermatologists need to bring psychosocial concerns to the forefront rather than the margins of their practise.'*
- Oral evidence submitted by a patient with psoriasis
- 8.12** The psychological and social effects of skin disease should be considered an integral part of any dermatological training course. The course should involve specialist psychologists and psychiatrists to inform the teaching.

## **Recommendations**

- The General Medical Council working with the Royal College of GPs, Royal College of Nursing and Royal Pharmaceutical Society, should ensure that urgent priority is given to the provision of proper dermatological training for all GPs, nurses and pharmacists. The training should emphasise that most inflammatory skin diseases are long-term conditions and are likely to need on-going care, often throughout a patient's life. Similarly the psychosocial effects of skin disease should be considered an integral part of any dermatological training course.
- Clinical Commissioning Groups should ensure that nurses and pharmacists be given greater opportunities to specialise in dermatology and psycho-dermatology.

## **9. Measuring Quality of Life**

- 9.0** Dermatologists and others caring for people with skin disease have probably always been aware of the potential for impairment of life quality caused by skin disease. This area has been described in dermatology literature many times over the last century. However formal research, involving the creation and use of methodology to measure impact, is a relatively recent development.
- 9.1** Measuring HRQoL is an important aspect of dermatological care. HRQoL assessments allow patients to express their opinions about the value they place on health and how their condition and its treatment affect their quality of life. Crucially HRQoL also allows health practitioners to assess changes in a patient's well-being throughout the course of the disease.
- 9.2** There are several different ways in which HRQoL can be measured. One uses standardised, fixed repeatable questionnaires, which are scored. A second approach uses questionnaires that allow a variable response, taking into account the particular issues that matter to the individual. Another method is to assess the value that people place on the presence or absence of disease states – the utility approach.
- 9.3** Some techniques are designed to be used across all disease states, some for use across a range of skin diseases and some for use in specific diseases. In many investigations, both a generic measure and a dermatology-specific measure have been used together.
- 9.4** Most questionnaires are for use with adults but there have been methods used for measuring HRQoL in children with skin disease, and infants with atopic

dermatitis. A study published in 2006 found that by using HRQoL measures, the impact of atopic dermatitis on children could be likened to that of other debilitating diseases such as diabetes and asthma – in some cases it was found to be greater.

### **Dermatology Specific Measures**

- 9.5** Dermatology specific measures are used to compare the impact of different skin diseases, or to measure change before and after intervention. Having a single simple measure that can be used across all skin disease is advantageous in a busy clinical setting. The dermatology-specific measures that have been used the most widely include the Dermatological Life Quality Index (DLQI) and Skindex. Other measures include the Dermatology Quality of Life Scales and the Dermatology-specific Quality of Life instrument. There is one general dermatology measure specifically for children and that is the Children's Dermatology Life Quality Index (CDLQI).
- 9.6** The DLQI consists of 10 questions covering a wide range of ways in which patients' lives are affected by skin disease. These include symptoms, embarrassment, interference with shopping or housework, clothes, social or leisure activities, sport, work or studying, personal and sexual relationships and the effects of the treatment itself. The questions are answered by a simple tick-box method and each score 0-3. The DLQI together with its US counterpart, Skindex, has been found to be useful tool in assessing the psychosocial impact of skin disease on patients.
- 9.7** The CDLQI is for children from 4 to 15 years old. It has 10 questions and can be completed by older children unaided, but younger children need help (an illustrated cartoon version of the CDLQI has been produced to help young children understand the nature of the questions). The CDLQI has been used to great effect in measuring the impact of atopic dermatitis.

### **Disease Specific Measures for Quality of Life and Physical Severity**

- 9.8** The questions in disease-specific measures reflect as closely as possible the problems encountered by people with that condition. These questionnaires are particularly suitable for comparison with same disease patients. In many skin diseases, however, people's lives are affected in similar ways, and so dermatology-specific measures can be used. There is no need for all skin diseases to have their own disease-specific measure. However, as well as those listed below, they are available for ulcers, urticaria, pemphigus, excessive axillary sweating, scalp dermatitis and for women with androgenetic alopecia.

### **Psoriasis**

- 9.9** The most commonly used quality of life measure for patients with psoriasis is the DLQI. However, clinicians can use the Psoriasis Area Severity Index (PASI) to measure the physical severity of the disease. The PASI combines the assessment of the severity of lesions and the area affected (head, upper limbs,

trunk, lower limbs) into a single score. Sometimes used in conjunction with other disease-specific measures such as the Psoriasis Disability Index, the Psoriasis Index of Quality of Life (PSORIQol), and the Psoriasis Life Stress Inventory (PLSI). Non-disease specific measures used for psoriasis also include, the Body Surface Area (BSA) and the Physician Global Assessment (PGA). The PASI remains the most extensively used and validated tool for measuring the severity of psoriasis.

- 9.10** The 2012 NICE guideline on psoriasis recommends that the severity of the disease is assessed regularly using quality of life tools. It also recommends the provision of advice and follow up for new treatments and a review should be undertaken after four weeks of starting a new topical treatment. This is a welcome development but more needs to be done to increase the uptake of dermatology-specific HRQoL tools.

### **Atopic Dermatitis**

- 9.11** The DLQI and CDLQI are commonly used for measuring the impact of atopic dermatitis (they are however typically used for a wide range of skin diseases). Specific measures also exist for measuring the impact of atopic dermatitis in infants and on their families, these include the Infants Dermatitis Quality of Life questionnaire (IDQoL) and the Dermatitis Family Impact (DFI) questionnaire.

### **Acne**

- 9.12** The simple five-question Cardiff Acne Disability Index (CADI) has demonstrated good reliability and validity. The Assessments of the Psychological and Social Effects of Acne (APSEA) questionnaire has 15 questions some of which relate to the overall impact of and some to the recent past. A nine-item Acne-specific Quality of Life Questionnaire (Acne-QoL), which has 19 questions, has been validated but uptake of the tool has been mixed. Other tools include: the Acne Disability Index (ADI) and the Acne Quality of Life Scale (AQOL).

### **Vitiligo**

- 9.13** There is currently a lack of consensus amongst the medical community as to how best to measure quality of life in patients with Vitiligo. Where a tool is used, it is often the DLQI – there is currently no universal tool for the measurement of quality of life in patients with vitiligo. Having said that, a study published last year (Lily et al, 2012) attempted to establish a new measurement tool, the VitQoL.

### **Uptake and Use of Quality of Life Indices**

- 9.14** HRQoL methodology is still developing, with less than 30 years of experience of its use. Consideration should be given to developing techniques whereby the problems experienced by patients are reflected better than they are now, but that retain simplicity to allow routine use. The areas of infancy, adolescence

and the elderly require special attention, and there is also a need to develop methods that are less reliant on language than at present, so that they can be understood across ethnic and language barriers.

- 9.15** Some of the health professionals that submitted evidence to this enquiry said that the current questionnaires in use were not tailored enough to suit the individual needs of the patient:

*'They [QoL questionnaires] do not give sufficient information to allow staff to manage a problem precisely, by default it becomes a general intervention and on the whole this is less effective than a targeted and tailored one'*

- Evidence submitted by a psychologist.

Furthermore, there is the very real question of how much GPs and consultants can realistically fit into a short patient consultation:

*'I am aware of DLQI and a vague knowledge of a few other quality assessments. It is difficult in the clinic to give more than a cursory review of the DLQI with limited time.'*

- Evidence submitted by a consultant dermatologist.

- 9.16** The need for a more tailored set of measurement tools is crucial if the psychological needs of patients are to be assessed efficiently within a very short period of time. From the affected person's point of view, the score for a predetermined set of questions may not reflect what is of importance to that individual person. Methods that take account of individual variation in importance are therefore desirable, provided they remain simple.

- 9.17** The secondary impact of skin disease on partners and families of those affected is a largely hidden burden of disease; some important research has been carried out in this area however further research and techniques are required to measure these areas. Virtually all methods of measuring quality of life relate to the current impact of skin disease on patients' lives. However, skin disease may have profound long-term consequences on major life decisions and so influence the long-term development and quality of life of individuals.

- 9.18** It is essential that people with a skin disease are integrally involved in the development of new psychological and quality of life measures.

- 9.19** Whilst it is important to emphasise the need for more research in this area, it is of equal importance to encourage the proper use of existing HRQoL measures. Existing measures may have their drawbacks but they still represent some of the best tools available for health professionals to measure the psychological and social effects of skin disease over time.

- 9.20** Evidence submitted to this enquiry suggested that health professionals are not always sure as to what to do with the results of a questionnaire. Proper training is required in this area to ensure that health professionals interpret the results of questionnaires correctly. Ideally the use of such tools should be taught, or at the very least introduced, at an undergraduate level.

## **Recommendations**

- The APPGS welcomes the publication of the 2012 NICE guideline on psoriasis and recommends that NICE consider the use of dermatology-specific and disease-specific quality of life measures in future skin-related NICE guidelines.
- Further research is needed to assess uptake of HRQoL measures. The APPGS recommends that NICE consider the creation of a Quality and Outcomes Framework indicator to incentivise uptake of dermatology-specific QoL measures.
- Funding should be made available for research into the creation and use of methodology to measure the impact of skin diseases on individuals.
- Funding should be made available for research on the psychological and social impact of rare skin diseases, which are often overlooked in favour of more prevalent conditions.

## **10. Conclusions**

- 10.1** As with our 2003 enquiry, the evidence received by this enquiry highlighted the extensive impact skin diseases have on all aspects of people's lives from schooling, relationships, self-esteem and career choices to social, sexual and leisure activities. There was a clear sense of desperation, frustration and, in many cases, isolation.
- 10.2** Although research into this area has developed in recent years, there remains a lack of dedicated services to tackle the psychological needs of patients with skin disease. Investment should continue with the aim of developing evidence based psychological interventions capable of addressing differing levels of need. There is a need for further access to self-help/management tools as well as to psychological therapy.
- 10.3** It is clear that the impact of skin diseases on people's lives is not often appropriately considered in their treatment. Furthermore, the increasing trivialisation of skin diseases is putting dermatological services at risk. The less importance the Government and the public attach to skin diseases, the less likely it is that dermatology services will be invested in. As a consequence existing QoL measures should be integrated into the assessment of treatment and management options for patients.

- 10.4** The NHS in England is undergoing its most radical overhaul since its creation; it is vital therefore that patients with skin disease do not lose out as a result of the changes. Relatively few skin diseases are life threatening (in the immediate sense) but it is essential that they are not allowed to be marginalised or reprioritised as a result. Demand is unlikely to drop suddenly, so there continues to be a very real need to provide robust education and training frameworks for health professionals working within the field.
- 10.5** In order to meet the challenges of tomorrow (and today), dermatology (together with psychodermatology) needs to be accorded the central place it deserves in undergraduate and post-graduate medical and nursing education. Until dermatology is recognised as one of the core fields of primary care and a valued specialism (reflecting actual demand), variation in the standard of provision is only likely to get worse.
- 10.6** Ultimately patients with skin disease deserve the right to be provided with excellent and appropriate support to manage, control and live with their condition.

## **Appendix A**

### **Membership of the Working Group that led the enquiry**

Dr Anthony Bewley (Consultant Dermatologist) – Chair  
Mandy Aldwin (Patient Representative)  
Dr Susannah Baron (Consultant Dermatologist)  
Dr Christine Bundy (Senior Lecturer in Health Psychology/Behavioural Medicine, University of Manchester)  
Ivon van Heugton (healthcare Policy Advisor, Changing Faces)  
Mark Johnson (Administrative Secretary, APPGS Secretariat)  
Dr Stephen Kownacki (Chair, Primary Care Dermatology Society)  
Helen McAteer (Chief Executive, Psoriasis Association)  
Dr Reena Shah (Chartered Clinical Psychologist)  
Claire Strudwicke (Patient Representative)  
Henrietta Spalding (Head of Policy and Practice, Changing Faces) – substitute for IvH  
Barbara Page (Nurse Representative)

### **Also consulted:**

Prof. Andrew Finlay (Professor of dermatology - retired)  
Dr Andrew R. Thompson (Reader in Clinical Psychology, University of Sheffield)

## **Appendix B**

### **Officers of the APPGS**

- Sir Paul Beresford MP (Chair)
- Baroness Finlay of Llandaff (Vice-Chair)
- Baroness Masham of Ilton (Vice-Chair)
- Rosie Cooper MP (Treasurer)
- Sir Peter Bottomley (Secretary)

### **Special Advisors of the APPGS**

- Ray Jobling (Patient Advisor)
- Dr Julia Schofield (Clinical Advisor)
- Nick Evans (Patient/NHS Advisor)

### **Membership of the APPG Advisory Group**

- Peter Lapsley (Patient Chair)
- Prof. Christopher Bunker (President, British Association of Dermatologists)
- Berkeley Greenwood (Co-Administrative Secretary, APPGS Secretariat)
- Mark Johnson (Co-Administrative Secretary, APPGS Secretariat)
- Dr Stephen Kownacki (Chair, Primary Care Dermatology Society)
- Helen McAteer (Chief Executive, Psoriasis Association)
- Elizabeth Parrish (Nurse Representative and Chair, Dermatology Council for England)
- Dr Amanda Platts (GP)
- Dr Julia Schofield (Clinical Advisor)
- Nigel Scott (Patient Representative)
- Julie Van Onselen (Nurse Representative)
- Michael Yarrow (Industry Representative)

## **Appendix C**

### **Witnesses Providing Oral Evidence**

- Mandy Aldwin (Trustee, Ichthyosis Support Group; ichthyosis Patient)
- Margaret Cox (Chief Executive, National Eczema Society)
- Ray Jobling (Chair, Psoriasis Association; psoriasis patient)
- Maxine Whitton MBE (Patron, Vitiligo Society; vitiligo patient)

## **Appendix D**

**NOTE:** Links to patient organisation websites can be found via: [www.appgs.co.uk](http://www.appgs.co.uk)

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