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*This paper was prepared by the Group's secretariat Decideum Ltd**

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INTRODUCTION AND AGM:

The APPG on Skin reformed with the following Officers elected: Sir Edward Leigh MP (Chair), Mary Glendon MP (Secretary), Baroness Masham of Ilton (Vice Chair), Baroness Finlay of Llandaff (Vice Chair) and Dame Cheryl Gillan MP (Vice Chair).

Sir Edward noted the passing of Professor Ronald Marks and read a eulogy.

Sir Edward said the APPG aims to raise the profile of dermatology in Parliament. He believes that the Group has made a difference over the years by increasing funding and interest in dermatology. As Chair, he will try to make Ministers devote more resources to dermatology. He outlined that the meeting would hear oral evidence to support the production of the Group's major new report on ‘Mental Health and Skin Disease’.

1ST SPEAKER - DR ALIA AHMED, CONSULTANT DERMATOLOGIST

Dr Ahmed has a specialist interest in psychodermatology, is on the Executive Committee for Psychodermatology UK, and is an advisor for the APPG on Skin's ‘Mental Health & Skin Disease’ report.

Psychodermatology considers the skin and mind together by treating both the skin and any psychological issues at the same time. People at are increased risk of having poor psychological health if they have a chronic skin condition. My patients have issues with embarrassment, body image, and feel socially isolated.

There are three types of patients I see: those that have skin disease that is made worse by stress (e.g. rosacea, hives), chronic skin conditions that have a large psychological impact (e.g. acne, eczema, psoriasis, vitiligo), and primary psychiatric disease (e.g. body dysmorphic disorder, skin picking disorder). Patients should, ideally, see one or more of a number of experts, including a dermatologist, a psychiatrist, a psychologist and dermatology specialist nurses.

Departments that offer psychodermatology care are oversubscribed and have extremely long waiting lists. There is a lack of specialists, and of any effort to retain people who have expertise in psychodermatology. For example, a junior doctor was working in my psychodermatology clinic, but now she is a Consultant wanting to work with us, but we are told that there is no funding for the post. We are paid a high tariff per patient in the clinic. So, technically the money should be available. There is a lack of psychologists, mainly due to funding. Hospitals often rely on drug companies to fund psychologists, but it is often for only up to a year, which makes the post precarious.

There is no formal training programme in psychodermatology. The report should explore how to train more experts in the field.

There is a high prevalence of psychological disorders in skin patients. “85% of dermatology patients feel that the psychological impact of their skin condition is a major component of their illness”. Psychological issues can also create a vicious cycle by making your skin worse.

“17% of patients say that they need psychological support to cope with their diagnosis”. This is probably underreported as many do not know that they can ask for help. Skin conditions are often trivialized, so patients do not think it is important enough to mention their psychological health.

A 2019 survey found 75% of dermatologist do not have easy access to a dedicated psychodermatology services, and there are none in Wales. There is also a lack of paediatrics psychodermatology clinics. 45% said that the nearest psychodermatology clinic was outside of their region. My clinic in London has people travelling from Dumfries in Scotland. I also have a patient from Cornwall who routinely spends £300 on a roundtrip taxi.

There is a massive disparity in what services are available and what patients need. In the new report we want to suggest solutions. Likely recommendations include improving and increasing dermatology training for doctors and nurses, at least regional coverage of adult and paediatric dermatology services, and research priorities showing what services work and why they should be available more widely.

2ND SPEAKER – NATALIE AMBERSLEY, CHANGING FACES AMBASSADOR

As a child, vitiligo spread to my arms, legs and face. My GP was unable to diagnose the condition. “In the 1980s the conversation was all about getting rid of it, there were no conversation about how to manage it”. “I became like a human guinea pig. I was in and out of hospital.”

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

As a teenager I became really self-conscious. I became anxious, shy and I was vulnerable. “I felt like my skin controlled every part of my life.”

“I would have swimming lessons and often I would forge sickness notes from my mum because I did not want to go swimming and wear a swimsuit. If I did have to go swimming then I would run to the changing rooms five minutes before the bell went at play time, so that I could grab one of the cubicles and get changed. I remember standing in the cubicle and trying to have that internal conversation with myself, trying to get myself to go outside in front of all my school friends and go forward with the swim class”.

“I found it really hard to enjoy summer because I could not wear shorts and t-shirts, I wanted to really cover up my skin. I did not want people to see it because I felt like I was being judged”.

“I went through a period of wearing camouflage makeup, but it was really hard to match my skin because I was slightly darker, so I often had to mix two or three pots of cream. It would take 30 minutes to put this camouflage makeup on”. “It was not worth the hassle”.

“I found dating quite hard. I found it hard to make new friends because I felt like I had to explain what was on my skin”.

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

Within three months of light therapy, the patches of original colour started to reappear. “I felt like I had been reborn”. “I had a new chance to be myself and not feel anxious about my skin”. “I bought my first swimsuit when I was 26 years old, as I felt so much more conformable in my skin”.

Social media has allowed me to connect with people with vitiligo and other visible differences. Changing Faces has allowed us to connect, talk and support each other. Campaigning has empowered me to feel more confident in my skin.

“Thousands and thousands of people are still hiding behind closed doors, scared to go out their house due to a fear of being judged.”

3RD SPEAKER - SHAL HENRY-TRELOAR

I have two children with atopic eczema. I have been a school nurse for 13 years.

My eldest son is gifted, but the eczema got to a stage where he was academically falling behind. “He was refusing to write”. “He couldn’t hold his pen properly because it was greasy”.

We had problems accessing his creams at school. “The school did not have a care plan for eczema”. They now use a care plan I helped to develop at a previous school I worked at.

Eczema impacted the sleep of my youngest child. “He would have emotional outburst, he wouldn’t want to wear shorts in the summer. Swimming lessons were suspended because of his flare ups.”

“The GP just said ‘no keep on with same medication [hydrocortisone]’. I was arguing that he needed something more. I felt that within the consultation I was not respected as a healthcare professional, as well as a mother. My views were disregarded.”

“I was having to Hoover his bed each night as his skin was coming off”. “We had to bath him at night as he was in so much discomfort, he would be screaming”. “The uniform was an issue because it was synthetic material. We asked the school for a special non-logged uniform.”

“Finally, we saw a GP with a special interest in dermatology, he shook his head and asked why he isn’t in secondary care”. After a year of asking for a referral he was finally referred to a specialist.

After undergoing light therapy, “my son has now got his life back. The spark, the bubbles, the confidence, the swagger. You can’t keep clothes on him now”.

I have been diagnosed with generalised anxiety, partly as a result of a lack of sleep.

We have had issues with CCGs not prescribing creams as they were not on the formulary list.

“People don’t see it as being serious because it isn’t life threatening, but it actually it is. It is life limiting in the sense that you aren’t living your full potential.”

4TH SPEAKER - JESS GUDENUS

I grew up with psoriasis and felt isolated. "I didn't know anyone else with psoriasis, I didn't understand the things I was experiencing were shared by other people".

"As a young child it's a very hard thing to go through". The skin loses all its elasticity so it can crack, bleed and be extremely painful.

"I went through all the treatments I was offered through the years, several times over". Some worked a bit, but the psoriasis always came back. "When I was covered at my worst it covered my face, hands, feet, chest, back, legs and scalp".

"So, I found it hard to learn to write at school, I couldn't hold a pen properly. I also had psoriatic arthritis so I couldn't straighten my fingers". "I had to wear white socks at school and my mum had to peel my bloody socks off my feet really carefully, trying not to cause any more damage".

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

"People's reactions affected me a lot. I have a really bad memory of getting kicked out of the hairdresser aged 6 because she thought my psoriasis flakes were headlice".

As a teenager, "being covered in flaky red skin is not particularly attractive to the opposite sex".

"These experiences stuck with me and built up over the years. They were weighing on me, but I wasn't particularly aware of it. When people asked me how I was feeling about it, I would always say I was fine. Everyone would say I was so strong. I wasn't really fine, I just didn't have a way of expressing it. I didn't know I could get help for it".

Psoriasis always comes back, sometimes due to stress. "I can never help thinking it's my fault because I haven't eaten healthily enough or because I have not been applying the right creams".

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

I have been unable to do my NHS work when my hands were covered in psoriasis and did not comply with infection control protocol. I could no longer exercise - swim because of the chlorine, run because of my feet bleeding, yoga because my hands, feet, knees and elbows were covered. "It became overwhelming, it affected everything I did, so I developed avoidance behaviours. I would awkwardly avoid shaking hands". "It affected my relationships, my sex life, it affected my work - it became this thing that took over my life completely".

A nurse at work recommended I seek psychological help. "This felt like the permission I needed". "It isn't life threatening, so you feel silly for making a fuss, like your problems are not serious enough for getting psychological help". There is a certain amount of shame.

Psychotherapy enabled me to explore my emotional triggers and stresses. It enabled me to be more honest and open about how it was impacting me. After a year of psychotherapy, I have stopped using all topical

treatments and my psoriasis has not got worse. This is good anecdotal evidence of the strong link between skin conditions and mental health.

“It makes me sad thinking about the little girl I was and all the years that I suffered without help. We have to do better, we have to consider providing better services. To support people to live normal, fulfilled, happy lives”.

FLOOR DISCUSSION

Sebastian Guterres, Secretariat of APPG on Skin, thanked the speakers and asked the audience whether they had comments or recommendations for the report.

Dr Julia Schofield, a Dermatologist in Lincolnshire, said she runs an educational master’s programme in dermatology for nurses and doctors at the University of Hertfordshire. She offers a ‘Mind and Skin’ 30 credit master’s module. The module is expensive. “You need to acknowledge in the report the issue of financing nursing education - it is currently absolutely dreadful. Lots of nursing students pay for the module themselves”.

In Lincolnshire there are no psychodermatology services. There is a shortage of psychologists. “We will never get psychologists to support us because of cost and availability. We may be able to join-up with a psychiatrist.”

Lucy Moorhead, from the British Dermatological Nursing Group, said “lots of nurses offer psychological help intuitively, but they do not have the tools and are scared to ask the big questions, like are patients suicidal”.

“It is important to note that, when patient’s skin is clear it doesn’t mean that their mental health needs are met”.

Danielle Frewin, from AbbVie, asked about evaluating the existing psychodermatology services for cost-effectiveness and patient outcomes. **Dr Ahmed** replied that there is literature, which will be referred to in the report, that shows that dedicated psychodermatology services are cost-effective. Long-term skin conditions can massively impact you as an adult, and lead to changes in behaviour that become irreversible. If people were treated better as children then they would not develop personality disorders and the health and social care system would not have the associated economic burden.

Dr Schofield believes the reason psychodermatology services are so overstretched is because “the pyramid isn’t working. Psychodermatologists should only be seeing the really serious and complicated patients. We need these services available in every region. We need a pyramid of upskilling along the way.”

Dr Ahmed said that she has never met the eczema nurse in her Trust. Therefore, she believes increasing communication between local networks and teams should be a priority.

Kate Forster, from Lipoedema UK, believes “education is key as it goes hand in hand with early diagnosis”. It often takes 20 years to get diagnosed with lipoedema, at which times there has been a host of inappropriate referrals to different parts of the NHS. The challenge for education is where the responsibility sits; Lipoedema UK have done work with the RCGP to develop a lipoedema module for GPs, but it cost Lipoedema UK £5,000.

Kate also highlighted the need for there to be referral routes available. Currently few dermatology services will take lipoedema patients.

Andrew Proctor, from the National Eczema Society, said most patients with eczema see GPs and do not get access to secondary care or tertiary care - where there might be psychological expertise offered and available. There is very limited psychological care in primary care, not even easy access to counselling. He would like the report to also focus on strategies to improve access to emotional and psychological services in primary care, for the many people with eczema who are having to cope without any help at the moment.

Dr Schofield believes GPs are good at dealing with just mental health problems. However, they tend to “medicalize the skin condition and do not treat the mental health issue”.

Dr Schofield advised that the report should signpost people with long-term conditions to services. **Dr Ahmed** highlighted that primary care professional can refer patients to talking therapies, and in some areas you can self-refer. However, she noted that people with skin conditions are not good at verbalising how they feel to GPs. She would like more self-referral options, and better advertisement of them.

Kate Forster said that Diabetes UK produced a report on the psychological impact of the disease. **Dr Schofield** advised that the report draws from other models for psychological support for other long-term conditions.

Dr Celia Moss, Consultant Dermatologist at Birmingham Children’s Hospital and Trustee of National Eczema Society, said that we are unlikely to get new dedicated psychodermatology clinics, so we need to focus on encouraging healthcare professionals to develop an interest in the field.

She stated that patient support groups ensure people do not feel isolated. She believes their services need to be built more formally as a resource into the health system.

Dr Schofield revealed that the Psoriasis Association is supporting a project teaching clinicians about motivational interviewing techniques. She believes webinars are also very useful for empowering patients. **Dr Ahmed** agreed. She highlighted the need for clinicians to remember to flag these resources to patients.

Natalie would like resources to be developed and promoted that teaches children how to treat other children with visible differences.

Sir Edward thanked all attendees. He looks forward to supporting the report. In the future, he would also like the APPG to focus on a lack of available referrals for skin patients and dermatology medicines not being on local formularies.