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

July 2019

PARLIAMENTARIAN ATTENDEES

Sir David Amess MP
Sir Paul Beresford MP
Sir Graham Brady MP
David Davies MP
Baroness Masham of Ilton
Mary Robinson MP
Angela Smith MP
Virendra Sharma MP
Parliamentary assistant to Mark Prisk MP
Parliamentary assistant to Paul Bloomfield MP
Parliamentary assistant to Michael Fallon MP
Parliamentary assistant to N/A

SPEAKERS

Dr Karen Gibbon, Honorary Secretary, British Association of Dermatologists
Helen McAteer, Chief Executive, Psoriasis Association
Dr Angelika Razaque, Executive Chair, Primary Care Dermatology Society
Andrew Proctor, Chief Executive, National Eczema Society
Lucy Moorhead, Secretary Elect, British Dermatological Nursing Group

Presentation: Dr Karen Gibbon (British Association of Dermatologists)

- Dr Karen Gibbon (KG) thanked Sir Paul Beresford for his service as Chair of the APPG.
- KG provided a clinical background to inflammatory skin conditions. She revealed that there is strong evidence showing that skin diseases can negatively impact on quality of life (QoL).
- KG stated that the size of surface area affected by a skin condition does not correlate with the impact of the condition on QoL. She also said that some chronic skin conditions can impact QoL more than for non-dermatological life threatening diseases, such as cancer.
- She discussed NHS England's two pieces of guidance to Clinical Commissioning Groups (CCGs) on items which should not routinely be prescribed in primary care. KG suggested that the guidance had been misinterpreted by many CCGs.
- Many CCGs are not offering patient choice on emollients, which is contrary to the advice of NICE, according to KG.
- She stated that emollients are essential for the management of dry, scaly skin conditions. They maintain and help repair skin barrier function, as well as providing relief of itching.

- KG presented pictures on a variety of inflammatory skin conditions to illustrate their severity and potential impact on QoL.

Presentation: Helen McAteer (Chief Executive, Psoriasis Association)

- Helen McAteer (HM) revealed that 1–2 % of the population have psoriasis and there is an equal gender balance.
- HM outlined how psoriasis is a lifetime condition and requires extensive management. For example, it requires on average two hours a day to self-manage mild psoriasis.
- HM said that the extent of the body area covered with psoriasis does not equal the severity of the condition. Therefore, treating a small patch of psoriasis can significantly improve a patient's QoL.
- HM argued that emollients are important and patients require their use in large volumes. She estimated that a large tub of emollient can cost £10. The burden of cost increases when a person needs to frequently buy tubs throughout a lifetime.
- HM is greatly concerned by the growing trend of patients being denied emollients.
- She stated that emollients can prevent or limit the progression of psoriasis, which staves off the need for other harsher, more expensive treatments.
- Another area of concern for HM, is the lack of access to secondary care services for patients with inflammatory skin conditions. The two week cancer referral pathway for cancer has negatively impacted patients with long-term inflammatory skin conditions. Patients with inflammatory skin conditions have to wait 9 months on average for a referral. This is far too slow for specialist care, according to HM.
- HM is disheartened by how the skin community has engaged in considerable work into national and NICE expert guidance, which is being disregarded at local levels.

Presentation: Dr Angelika Razzaque (Chair, Primary Care Dermatology Society)

- Dr Angelika Razzaque (AR) thanked Sir Paul for his contributions as Chair.
- AR said that clinicians in Primary Care need to be supported so that they prescribe what is most suitable for the person in front of them rather than what guidelines or formularies suggest.
- According to AR, patients are experts in their own right. She has heard patient stories and experiences resonating this view, but it is difficult to get the message through to policymakers.
- AR said that getting the right emollient and the correct quantities remains a persistent battle that patients face. The recent NHS over-the-counter guidance consultation has, sadly, not resulted in PCDS's and the skin community's concerns being taken seriously. She believes that we need to continue conversations with NHS England in order to get the message through.
- AR stated that a lack of dermatology training remains unaddressed by Health Education England, however, there are opportunities through the PCDS, which has recently opened up their membership to the wider primary care team attracting nurses, pharmacists and podiatrists. There is more emphasis on community service provision and patients being increasingly asked to self-care. AR believes that multiprofessional learning is important to relay consistent messages to patients.
- AR said that closer working with secondary care is an important part of multiprofessional learning and the PCDS will continue to engage with consultant colleagues and the BAD to deliver this.
- AR revealed that GPs are under pressure and timely access for patients remains a problem. We need to utilise expertise within primary care and ensure that patients with skin conditions are seen at the right time, by the right person, in the right place.

- According to AR, Primary Care Networks are expected to deliver services at scale for populations between 30-50,000, and in this may lie an opportunity to redevelop patient pathways in the community, including for dermatology. AR believes that patients are paramount in the co-design and co-production of such services.

Presentation: Andrew Proctor (Chief Executive, National Eczema Society)

- Andrew Proctor (AP) stated that over 6 million children and adults are affected by eczema, equivalent to around 10,000 people in the average constituency.
- AP revealed that people with eczema experience a range of difficult and distressing symptoms – including red, sore and painful skin, constant itchiness and huge discomfort. The relentless regime needed to manage inflamed skin – the regular moisturising several times a day, avoiding triggers, managing flare-ups, applying medications takes a lot of time and commitment.
- AP suggested that for parents especially, it can place a huge strain on family life.
- AP said that the constant itchiness and the involuntary desire to scratch the skin is one of the most challenging aspects of eczema.
- AP is deeply frustrated that eczema is regarded by some as a minor skin complaint, when nothing could be further from the truth.
- He stated that the emotional and psychological impact of eczema is often not acknowledged, even by healthcare professionals, but time and time again National Eczema Society hears of the mental health challenges people face and the lack of support in this area.
- According to AP, regular use of emollient is essential for the effective management of all types of eczema. The recommended amount of emollient to use is 500g per week for older children and adults, and 250g per week for younger children. Those people with more severe eczema will need larger quantities.
- However, NHS emollient rationing is now affecting many people with eczema and eroding their QoL.
- AP revealed rationing hits the poorest in society the hardest, especially parents of young children with eczema who cope on low incomes, and the elderly who depend on their pensions. Many struggle to afford sufficient emollients and without these products on prescription, they can't keep their eczema under control.
- The National Eczema Society has heard of patients having their emollient products changed unexpectedly to cheaper and less effective brands (script switching), not being prescribed sufficient quantities of emollient, and some being denied emollient on prescription altogether.
- AP stated that the National Eczema Society has produced guidance for patients, setting out the research and clinical evidence, for people to use with their GP when making the case for having emollients on prescription.
- A survey conducted by BDNG in association with National Eczema Society earlier this year revealed that 71% of front-line dermatology nurses who responded said they believed people with eczema have been adversely affected by NHS emollient rationing.
- AP argued that preventative treatments, such as emollients, are essential for many to be able to manage their eczema, to have better health and quality of life, and reduce the need for frequent medical consultations and more drug treatments.
- AP is frustrated that people with skin conditions like eczema are being stigmatised and discriminated against by NHS Commissioners, simply because the products they rely on to manage their medical condition are available over-the-counter.
- AP said that NHS England guidance recommends that GPs stop prescribing emollients for mild dry skin and mild irritant dermatitis. There are general exceptions in the existing prescribing guidelines, including allowing for the treatment of people with long-term conditions including eczema, but these general exceptions are either not being considered,

misinterpreted or ignored by local commissioners when it comes to people with long-term skin conditions.

- AP believes that part of the problem is terminology, and how guidance is interpreted by CCGs. He believes NHS England must do much more to make clear when emollients can be prescribed, so there is no room for confusion by CCGs and individual prescribers.
- AP would like to see some effort to model the cost implications of emollient rationing across the health economy, to surface the false economy of emollient rationing.
- AP also raised the issue of a chronic shortages of dermatologists and competing pressures on their time, leading to unacceptably long waits for appointments for people with inflammatory skin conditions like eczema. He asked whether this would be seen as acceptable in diabetes care, or arthritis care, for example.

Presentation: Lucy Moorhead (Secretary Elect, British Dermatological Nursing Group)

- Lucy Moorhead (LM) outlined how the British Dermatological Nursing Group (BDNG) is an independent speciality group of nurses and healthcare professionals with an interest in dermatology nursing, and the second largest in the world.
- LM revealed that nurses can provide holistic dermatological care in primary, secondary and tertiary care.
- LM informed the audience that nursing will soon become a degree entry profession and that the scope of practice for nurses has expanded over the past 20 years.
- She outlined how nurses, crucially, provide compassionate care for patients with skin conditions, often autonomously.
- LM spoke of the BDNG's concern over the rationing of treatments. If patients with inflammatory skin conditions do not receive early appropriate treatments, then their condition can worsen and they could require systemic and high cost treatments. Therefore, LM argued that it is essential to receive the appropriate quantity and type of treatment.
- LM discussed the psychological impact of skin disease, highlighting a recent example from her own practice of a patient severely adversely affected by inappropriate prescribing.
- LM concluded that the BDNG are happy to work with and support all the organisations gathered at the meeting in order to improve care and increase the awareness.

Group discussion

- David Davies MP thanked attendees and introduced his interest in dermatology.
- Baroness Masham inquired as to why some skin treatments, including emollients, are not free on the NHS. She recommended that everybody struggling to receive treatments should go to their MP to complain, and if your MP is not helpful then you can contact a member of the House of Lords.
- Baroness Masham argued that schools need to be better informed in how to look after children with inflammatory skin conditions. Elizabeth Allen (British Association of Skin Camouflage) stated that teachers need re-educating since many are worried of being accused of inappropriate touching if they apply creams for children.
- Nigel Scott (Herpes Viruses Association) asked whether the issue of treatment rationing was suitable for a petition. David Davies said that his preference would be to raise the issue individually with more MPs.
- David Davies MP advised attendees and patients affiliated to patient groups to attend MP surgeries and raise the issue of treatment rationing.
- Virendra Sharma MP suggested that MPs apply for a Westminster Hall debate to challenge the Department of Health and Social Care on the issue of emollient rationing and CCG guidance being misinterpreted. The present MPs agreed to support the debate.
- Angela Smith MP revealed how she had suffered greatly from eczema as a child. She stated that eczema brings a raft of psychological issues. Angela Smith discussed how she

was never given advise on management of her skin condition. She would like the NHS to involve patients more in the management of their own condition.

- Angela Smith MP praised the work of skin groups in raising awareness within schools.
- A number of attendees provided patient experiences of living with an inflammatory skin condition. Issues included a lack of support from GPs, not being referred to a dermatologist, and not being informed by healthcare professionals of the importance of the regular use of emollients.
- Representatives from Lipoedema UK spoke of lipoedema as a chronic condition that leads to the accumulation of fat below the waist. They remarked on how people with lipoedema can be ostracised for their appearance as members of the public do not understand its causes.
- A patient commented on how she was pushed between systems and how she would like a joined up system of thinking, including an improvement in the knowledge of GPs.
- David Davies remarked that living with a chronic skin condition is a form of disability and it has not been recognised as such.

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