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

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AGENDA

Time	Speakers
17:00	Sir Paul Beresford MP, Chair, APPG on Skin
17:05	Dr Karen Gibbon, Honorary Secretary, British Association of Dermatologists
17:12	Andrew Proctor, Chief Executive, National Eczema Society
17:19	Helen McAteer, Chief Executive, Psoriasis Association
17:25	Dr Angelika Razzaque, Executive Chair, Primary Care Dermatology Society
17.32	Harry Thurston-Smith (Sanofi) & Jonathan Fox (LEO Pharma), Industry Dermatology Initiative
17:50	Group discussion

PARLIAMENTARIAN ATTENDEES

- Sir Paul Beresford MP
- Mary Glendon MP
- Baroness Finlay of Llandaff

NOTES

Introduction and AGM: Sir Paul Beresford MP (Chair of the APPG on Skin)

- Sir Paul conducted the AGM to confirm the Officers for the next year. Baroness Masham of Ilton and Rt Hon Dame Cheryl Gillan MP sent their apologies for missing the meeting.
- Sir Paul welcomed attendees and introduced the first speaker.

Presentation: Dr Karen Gibbon (Honorary Secretary, British Association of Dermatologists)

- Dr Karen Gibbon (KG) discussed the clinical treatment guidelines in dermatology.
- KG presented pictures of a variety of dry and itchy skin conditions, which highlighted how they can be severe, serious and chronic. Therefore, KG emphasised the need to get the correct diagnosis and recommend essential emollient treatment.
- She said that anecdotally the British Association of Dermatologists (BAD) has heard that some CCG prescribing practices do not follow the appropriate clinical guidelines regarding emollients and patient choice.
- KG explained how emollients contain lots of additives that can cause further health issues if the correct one is not prescribed. An incorrect prescription can cause a cascading inflammatory process and may lead to worsening allergic or irritant contact dermatitis.
- She said that some emollients sting or burn if applied to the wrong body site, which can mean people do not take the treatment and their condition can deteriorate.
- KG highlighted how patient choice is valued in NICE recommendations eg for eczema and psoriasis.
- KG said GPs are struggling to understand the many different emollient preparations and therefore recommendations when given by them in secondary care need to be followed.
- It was revealed how the BAD have met with NHS England (NHSE), and the BAD reiterated their disagreement with the conclusions NHSE had drawn from the BATHE study. She discussed how the BAD believe NHSE's consulted recommendations to remove bath and shower preparations from routine funding was a false economy, based on the misinterpretation of one clinical study.
- KG said the step-wise approach for the management of eczema in NICE guideline CG57 involves emollients, then topical steroids, followed by topical calcineurin inhibitors, and finally systemics (including biologics such as dupilumab). The cost of managing eczema is much lower at the bottom rung of the treatment ladder and it is imperative that eczema is controlled appropriately at this level.

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

- Andrew Proctor (AP) stated that emollient rationing threatens the health and well-being of millions of people with eczema.
- AP outlined how atopic eczema is a long-term inflammatory skin condition that can be miserable to live with, including: painful skin, constant discomfort, lack of sleep and self-consciousness with your appearance.
- AP argued that it is wrong of the NHS to characterise eczema as 'mild dry skin' or a 'minor skin complaint' in the context of prescribing priorities.
- He outlined the necessity for people with eczema to use plenty of emollients to keep their skin protected and restore the skin barrier. He said there are a range of emollient formulations and properties, although usually only a few product options are available on local formularies.
- AP argued that emollient rationing is occurring and affecting many people. It penalises and erodes the quality of life of those with the greatest health need and disease burden, according to AP.
- AP stated that rationing hits the poorest in society the hardest, especially parents of young children with eczema and the elderly who depend on their pensions, as they are unable to afford products to keep their eczema under control.
- AP said his charity have been increasingly hearing from people who say that their emollient products are being changed unexpectedly to cheaper and less effective brands (script switching), not being prescribed in sufficient quantities, and some being denied 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. The British Dermatological Nursing Group is also preparing similar guidance for nurses to support patients.
- AP outlined his strong concerns over the tendency of the NHS to remove access to emollient treatments for patients whose conditions have improved because of taking treatments.
- He argued that NHS commissioners are discriminating against skin conditions because they are available over-the-counter (OTC).
- He said these preventative treatments 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 said the CCG guidance which recommended that GPs stop prescribing emollients for mild dry skin and mild irritant dermatitis has been interpreted incorrectly by some commissioners to mean they should stop prescribing all emollients for eczema.
- AP wants much more done by NHS commissioners to improve the use of terminology and make it clear when emollients should or should not be prescribed.
- He said the general exceptions in guidance, including for long-term conditions, are often either not being considered, misinterpreted or ignored by local commissioners.
- AP wants to see modelling done on the cost implications of emollient rationing across the health economy since poorly controlled eczema results in more consulting time and drug treatments. He questions why NHS Clinical Commissioners have a short-sighted approach and are only considering the prescription costs when evaluating costs, without giving due consideration to the cost implications across the wider health economy.

Presentation: Helen McAteer (Chief Executive, Psoriasis Association)

- Helen McAteer (HM) argued that clinical dermatology knowledge is not being transferred into practice in many places.
- HM said psoriasis is not “just a skin condition” but a complex immune mediated inflammatory disease resulting in increased risk of high blood pressure, obesity, high cholesterol, diabetes and heart disease, not to mention depression, anxiety and suicidality.
- HM revealed that cost-saving measures can lead to under-treating patients from the point of diagnosis. This means the raft of additional health needs are then also not addressed, which leads to greater costs elsewhere.
- HM quoted Professor Catherine Smith, “if the existing guidelines were used and implemented, patients would be better treated”. However, HM revealed that national guidelines set either by NICE or the BAD are routinely ignored at a local level.
- She said continually purchasing emollients becomes expensive over time and if you cannot afford them then your skin goes untreated. As a result your skin inevitably gets worse and ultimately leads to more expensive treatment than the one originally denied.
- HM highlighted how there is a postcode lottery for access to some skin treatments.
- She raised scalp psoriasis as an example of where clinicians are being forced at a local level into prescribing sub-optimal treatments and patients are self-medicating on ineffective therapies.
- HM appreciates the need for the NHS to achieve value for money, however, she argued that value for money does not always mean the cheapest option.
- HM outlined how treatments can fail for some patients, which means they need further options. She said this can be for a number of reasons, but research shows in half the number of patients it has failed simply because they do not have enough of the drug in their body, and for 40% of those who respond well, the dose could be reduced.

- HM raised concern over Hospital Pharmacy departments simply informing patients of treatment switches, including for biosimilars, when there are letter templates agreed by NHSE and patient groups. She stated that this is undermining the clinicians.
- HM highlighted concern over clinicians being forced at a local level into prescribing a treatment that may not ordinarily have been their first choice. This can remove alternatives which is worrying as they can be necessary if response to a particular treatment decreases over time.
- In HM's concluding remarks she said "skin conditions need to be treated with respect". She believes the power is at a local level, yet it is at national level where guidelines are set.

Presentation: Dr Angelika Razzaque, Executive Chair, Primary Care Dermatology Society

- Dr Angelika Razzaque (AR) revealed how the recent NHSE consultation on the prescribing of OTC products has been met with much criticism with regard to the prescribing of bath additives. She said this has been widely understood as a misinterpretation of the findings from the BATHE trial.
- AR stated that dermatology has been historically marginalised because access to common treatments is available OTC. However, emollients including bath additives and soap substitutes form an important part of treatment for many skin conditions.
- AR argued that we need to look at emollients as medicines and not just as moisturisers.
- She outlined how GPs have been asked to rationalise prescribing of emollients, soap substitutes and bath additives as a result of CCG pressure to achieve cost savings and cost effectiveness.
- AR discussed how a blanket approach to prescription can occur which neglects the fact that there are varying degrees of severity and needs for people.
- AR stated that there is a variation in the understanding of patient need due to the lack of training amongst GPs.
- AR said guidelines aim to standardise care, but GPs often use them only as guidance and deviate from them if a particular case allows so.
- According to AR, the volume of guidances and guidelines given to a GP makes it very difficult to prioritise advice.
- AR revealed how the Quality and Outcome Framework (QOF), to which GPs are working to, has set the scene for prioritisation, but dermatology does not feature. She argued that conditions such as psoriasis should be added to the framework as we now know about the long term implications with regards to co-morbidities.
- AR stated that approximately 25% of consultations in GP are related to a skin complaint. Yet, she believes GP education is not fit for purpose to match this need and patients are suffering.
- Guidelines and guidances are necessary according to AR, however the implementation is variable and the interpretation even more so. She wants a standardised approach to reduce the variation of care and health inequalities.
- AR called for research to be accepted and not subject to interpretation by non-specialists. She also said clinicians needs to be involved in consultation processes.
- AR also argued GP education and medical school education in dermatology needs to have a higher priority to improve overall patient experiences. This included revising the curricula to match the increased demand.

Presentation: Harry Thurston-Smith (Sanofi, Co-Chair Association of the British Pharmaceutical Industry Dermatology Initiative)

- Harry Thurston-Smith (HTS) introduced the Association of the British Pharmaceutical Industry Dermatology Initiative's (ABPI DI) report on '*Making real our shared vision for the*

NHS: optimising the treatment and care of people with long-term skin conditions in England'. He handed out copies and said it was [available online](#).

- HTS spoke on the desire within Industry and the ABPI DI to get dermatology on the NHS and political agenda.
- He revealed the project had identified a data gap - the burden on the NHS of treating, or not treating, dermatology. They commissioned an independent service evaluation by Dr Julia Schofield to look at the burden of dermatological conditions on primary care between the years of 2006 and 2016.
- He mentioned how the report focuses on the long-term skin conditions: psoriasis, atopic eczema, urticaria, rosacea and acne.
- HTS disclosed the report's findings that each year in England, 24% of the population visit a GP with a skin problem and 54% of the population is affected by a skin disease.
- He raised the concern over the fact that despite prevalence of skin conditions going up, consultations per patient have reduced compared to previous study findings. The author has deduced that skin patients are becoming more reluctant to return to a GP for a follow-up.
- HTS also revealed that approximately 3 million hours were spent by GPs on skin conditions in 2016.

Presentation: Jonathan Fox (LEO Pharma, Association of the British Pharmaceutical Industry Dermatology Initiative)

- Jonathan Fox (JF) revealed the three priority areas outlined in the report where it was felt that urgent action is required to free up resource in the system to improve care for people with long term skin conditions. The first is to optimise self-management of skin conditions. JF said this includes empowering patients via patient education programmes and improving access to high quality education materials.
- JF outlined the second approach which is to use technology and innovation to streamline the patient pathway. This includes commissioning new patient pathways, such as the use of teledermatology and other technologies as a means of freeing up capacity for inflammatory skin conditions. Lincolnshire and Devon teledermatology services are included in the report as practical examples of good practice.
- The third approach revealed by JF is to maximise the use of available resource, skill and experience. He emphasised the importance of GPs with extended roles to support the expansion of intermediate dermatology services. The ABPI DI report also recommends developing local champions to provide leadership and drive integration of localised dermatology care. Finally, the report set out ambitions to make dermatology a national focus and this has now been seen with dermatology recognised as an area of focus within the Elective Care Transformation Programme (ECTP) recently rolled out by NHS England and in Dr Nick Levell's work on the Get It Right First Time programme. Also, of note is the fact that the ABPI DI report is referenced within the ECTP handbook which is recognition of the quality of the work. JF believes the recommendations in the report to be pragmatic, achievable and, perhaps most importantly, to make best use of the resources available to the NHS today.
- JF provided the meeting with an update on the plans of the Industry Dermatology Initiative (IDI). Currently LEO, Sanofi, Celgene and Novartis are members, however, two more Industry members will be joining over the coming weeks.
- JF revealed their desire to take forward the recommendations of the report in 2019. This includes engaging with national stakeholders; including the Elective Care Transformation Programme and Getting It Right First Time (GIRFT) team at NHS England; and local Sustainability and Transformation Partnerships (STPs) or Integrated Care Systems (ICS) to prioritise dermatology pathway redesign.
- JF said that they are eager to work with STPs with an appetite to redesign dermatology services and have started to engage with Lincolnshire STP. JF said they aim to convene a

roundtable/workshop to look at implementing the report recommendations and will be pulling in expertise from the Expert Working Group and sharing practical examples of good practice with the STP to help them with pathway redesign.

- JF said that the group anticipate developing an implementation plan for STPs that could be rolled out more widely.

Group Discussion

- Sir Paul said the Secretary of State for Health and Social Care, Matt Hancock, has a focus on increasing prevention. However, he believes there are two 'Cinderella' services - children's dentistry and dermatology. According to Sir Paul, it is imperative to 'wake up' the Department and get them to realise that prevention is the way forward for improving skin outcomes.
- Sir Paul said he wants the Secretary of State to realise that we need to 'put the skin on the body'.
- Sir Paul asked all skin stakeholders to send thoughts, information and suggestion to the APPGS Secretariat.
- He would like to start political engagement on the issue of skin patients being refused access to treatments. This will start with MPs sending written questions to the relevant Health Ministers so that they realise people are interested in the issue. This could be then followed by a focused debate, and lots of pictures would be shown to the Junior Minister. If momentum is created behind this issue then Sir Paul said he would like to have a meeting alongside the APPGS Secretary, Mary Glindon MP, with Matt Hancock to seek change.
- Mary Glindon MP said she was shocked by the inadequate skin care provided to people.
- Mary Glindon revealed how she has never been made aware of these issues by any constituent and asked why. She also asked whether the group could encourage MPs to write in local newspapers to tell their constituents about their options and said she would.
- Andrew Proctor replied by stating that many patients feel demoralised, pushed around and like they do not have a voice.
- Elizabeth Allen, British Association of Skin Camouflage, agreed and said we need to 'wake patients up' and create a campaign.
- Jess Hobart, Mastocytosis Support Group, revealed how a patient with mastocytosis had waited a year to get a referral to secondary care.
- Dr Karen Gibbon argued that the skin cancer referral pathway is putting too much pressure on secondary care and the fact it is moving from two weeks to one is going to compound the issues of patients with chronic dry, itchy skin conditions not being seen quickly enough.
- Sir Paul stated that he would appreciate if patient groups could write to their members with requests for individuals to write to their local MP. Sir Paul hopes this would induce MPs to ask questions of the Government and get involved in any debate.
- Sir Paul's request was agreed by the group.

END