



# Patient Panel Newsletter

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## Research Priorities in Community Pharmacy—Online Workshop Monday 9th May

We have obtained funding from the [NIHR School of Primary Care](#) to identify dermatology research priorities in community pharmacy. Pharmacists working in the community (in retail and high street settings such as Boots) see people with skin rashes, allergies, acne and eczema almost every day. Research in this area could help pharmacists to manage enquiries about skin conditions. It might also help produce resources that pharmacists use in consultations or result in new pathways which connect pharmacists and GPs in the management of skin conditions. The project is being led at CEBD by [Paul Leighton](#) and [Jane Harvey](#) and they have

been working with pharmacists to identify a list of research priorities. We now need patient/carer input into this to establish the most important questions to move forwards.

If you would like to get involved in this, there is an online workshop taking place Monday 9<sup>th</sup> May 2022, 7-9pm. The workshop will have 8-10 participants (all people affected by a skin condition or carers of these) and you will be asked to provide feedback on the research topics identified in a group discussion. A £25 voucher will be given to workshop participants as a thank you for their time. The sign up link is [here](#)— please get in touch with [Jane](#) if you would like more information.



## Meet a panel member—Simon Leng

I'm Simon Leng and I live in Leicestershire with my wife and two teenage daughters. I very recently joined the CEBD Patient Panel through my eldest daughter's treatment for severe facial acne. My own experience of skin disease has been much less dramatic, having developed asthma-related eczema in my joints throughout most of my early childhood. Most prescribed treatments failed to make any noticeable improvements back in the '70s, but thankfully for me, both asthma and eczema disappeared almost completely with the onset of puberty (such glorious times!).

Skip forwards four decades and in contrast to my own experience, my daughter's acne **started** with the onset of puberty. Until this point, I don't think I'd ever truly understood how cruel, debilitating and painful acne could be, especially for young adults. Having exhausted most over-the-counter and prescribed remedies over a period of 2 years, our family GP suggested a referral for

Isotretinoin treatment. Despite the poor media image of Isotretinoin, my daughter reluctantly accepted the referral, under the careful stewardship of the Nottingham QMC Paediatric Dermatology dept. The results in just a few short months were transformational, both in skin quality and self-esteem.



This stark contrast of caring, effective treatment versus the damaging backdrop of poor social media coverage for Isotretinoin fascinates me, so I jumped at the opportunity to participate as a CEBD panel member and PPI Co-Applicant for a low-dosage Isotretinoin research study. It's been extremely gratifying to be welcomed into the team, and to share the collective and varied lived-experience of other CEBD panel members. I'm also rather enjoying discovering the clinical research process, whilst hopefully making a useful contribution to making Isotretinoin safer and more widely accepted as an efficient treatment for acne.

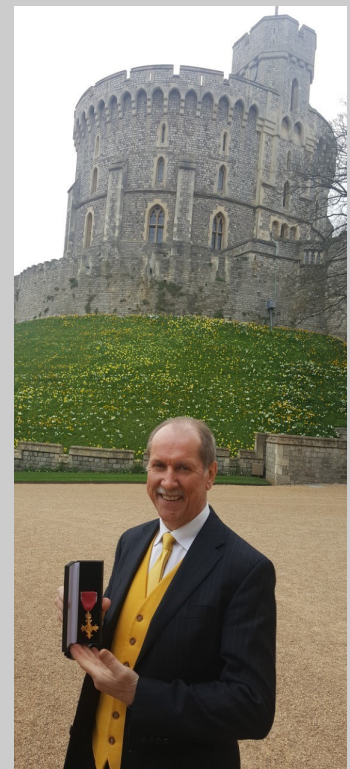
## CEBD Patient Panel Online Meeting Saturday 12th March

Many thanks to the fourteen panel members who gave up their Saturday morning to come to the online panel meeting on 12th March. Feedback from those present on the three studies discussed (remote consultations for paediatric eczema, lower dose isotretinoin for acne and the use of antibiotics following the surgical removal of ulcerated skin cancers) has been invaluable. For example, the study team led by Dr Rachel Abbott in Cardiff developing a study on the use of antibiotics following the surgical removal of ulcerated skin cancers, are completely changing the design of their study following input from the panel members at this meeting. They were originally planning a 3-arm study but are now revising their study design to a 2-arm study and are delaying their application make the changes needed. Full feedback from study teams has been provided to those who attended and shows that input from panel members really does make a difference.

We also heard about a new initiative from CEBD member of staff Stephanie Lax and panel member Amanda Roberts on the [NHS green agenda](#) from a dermatology perspective. If you weren't at the meeting and would like to find out more and potentially get involved please [get in touch](#).

## Updates from CEBD

- Funding has now been confirmed for the RAPID study. This National Institute for Health Research (NIHR) funded project is a five year programme grant investigating new approaches to undertaking studies in people affected by mild to moderate eczema. Workstreams include efficient online trials in the NHS, an online platform to allow patient led trials and implementation and process evaluation including work with seldom heard groups. The project will start in September and is being led from CEBD by Kim Thomas with Patient Panel member Amanda Roberts as a co-applicant. Many thanks to all those panel members who have contributed to the development of RAPID over the past couple of years.
- Listen to this British Journal of Dermatology (BJD) [podcast](#) featuring CEBD Patient Panel co-ordinator Carron Layfield talking about patient involvement in dermatology research with BJD Patient Associate Editor [Bernd Arents](#) and Jonny Guckian, a clinician with a special interest in the lived experience of dermatology patients.
- We are delighted to welcome two new members of staff to CEBD. Bridget Candy has joined the Cochrane systematic review team working on a [large meta-analysis review of topical anti-inflammatory treatments for eczema](#) and Mikolaj Swiderski is working on a project investigating routinely collected medical data to investigate causes of the rare skin disease bullous pemphigoid (see overleaf for more on Mikolaj and this project).
- Did you realise that the [UK Dermatology Clinical Trials Network](#) is celebrating it's 20th birthday this year? Please keep an eye out for activities to help celebrate this including a series of blogs which will include experiences from past and present patient representatives on network committees.
- It's great to see the CEBD Patient Panel and a number of our studies getting quite a few mentions in this [recently published review](#) of Patient and Public Involvement in Dermatology Research (if you can't access the article via this link [please get in touch](#) and we'll send you a copy).
- And finally, CEBD Co-Director Hywel Williams (pictured right) had a very special visit to Windsor Castle at the end of March to receive his OBE from The Princess Royal.



## Meet a member of staff - Mikolaj Swiderski

[Mikolaj](#) joined CEBD in March 2022 as a Research Associate. He works on an NIHR funded project which aims to determine the risks associated with prescribed medicines/vaccines and the skin condition [bullous pemphigoid](#) (BP) in the UK using anonymous patient datasets from the Clinical Practice Research Datalink ([CPRD](#)) service. BP is a painful, blistering skin condition that occurs most commonly in older people. It is an autoimmunological disease with an unknown cause. Previous studies link some medicines with BP, but the findings are based on very small numbers of patients and come from small specialist hospitals. As this project is using a data approach, much larger numbers of patients can be considered from different care settings to investigate these links further. The project's primary goal is to inform about optimal treatments for patients to reduce the risk of BP and raise awareness about it to improve earlier diagnosis and wellbeing.



Mikolaj is a final year PhD student in mathematics at the University of Nottingham's School of Mathematical Sciences. He has a background in mathematical modelling of gene regulatory networks in plants, bioinformatics, climate science and environmental engineering. He has experience in the management and analysis of various types of data. Outside of work, Mikolaj enjoys reading books (sci-fi, adventure, history), listening to music and playing video games.

## NIHR updates

- The NIHR have changed their name to the [National Institute for Health and Care Research](#) to emphasise their long term commitment to social care research. The NIHR acronym will remain unchanged.
- The NIHR 20-21 [annual report](#) is now available.
- The NIHR have signed up to a commitment, along with a host of other organisations including Cancer Research UK, Universities UK and the Association of Medical Research Charities to improve public involvement in research. This [shared commitment](#) aims to improve the extent and quality of public involvement across the research sector so that it is consistently excellent.
- Take a look at the very recently published [NIHR framework](#) to promote race equality in public involvement in research.
- Don't forget about the [NIHR Learning for Involvement site](#) which hosts Patient and Public Involvement training resources.

## CEBD Patient Panel Journal Club

Six panel members joined our first CEBD Patient Panel online journal club on Friday 25th April. This one hour session involved reviewing a research publication (the results of the [HI-LIGHT vitiligo study](#)) and discussing as a group what we liked and didn't like about the study/publication and aspects we'd like to know more about.

There were some great discussions and lots of points raised such as why patient and public involvement was only briefly mentioned in the publication (even though lots was done), how the study results were presented and how people interpreted these results. Based on feedback from those who attended, we'll definitely be running more sessions like this and will aim to host one every 2-3 months. The next one will be on **Friday 10th June 12-1pm** and we'll be looking at a qualitative research publication rather than a clinical trial—please do [let us know](#) if you'd like to attend. The aim of these sessions is to provide an interactive and informal environment where panel members will hopefully learn more about dermatology research and the methods used.

