



# Patient Panel Newsletter

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## Updates from CEBD

- We're really pleased to be able to let you know that research at CEBD related to women's health and dermatology is going from strength to strength. The [PEARLS study](#), investigating treatment options for the vulval skin condition lichen sclerosus has reached the end of its 6 month pilot phase having recruited 67 patients to date. The [SHELLS study](#) is investigating better diagnosis of this condition and has now opened to recruitment at 5 sites across the UK with more to come on board over the next few months. Due to the sensitivities involved in this research, the team have set up a separate patient panel to support this work, including representatives from the [Lichen Sclerosus and Vulval Cancer UK awareness group](#). This has been a really neglected area and it's heartening to see such progress being made to get better diagnosis and treatments for those affected.
- The [Rapid Eczema Trials](#) research programme was recently awarded runner-up for 'Innovation in Patient and Public Involvement' at the recently held [International Clinical Trials Methodology Conference](#) in Edinburgh. Congratulations to the team, and in particular CEBD Patient Panel member Amanda Roberts who stepped in at the last moment to deliver the presentation linked to this award.
- The full stage application for the THESEUS II study has now been submitted to the National Institute for Health and Care Research ([NIHR](#)) for funding. Led by Dr John Ingram, a Consultant Dermatologist in Cardiff, CEBD are key collaborators in this important study which is investigating the role of laser hair removal combined with adalimumab biosimilar therapy in the treatment of the skin condition Hidradenitis Suppurativa (HS).

## Patient Panel Meeting Saturday 9th November 'CEBD research - behind the scenes and the reality of how it all comes together'

Many thanks to the ten panel members who have already let us know that they'd like to attend this online meeting which is taking place via MS Teams 10.00am-12.30pm on Saturday 9th November. We're aiming to show the challenges and realities we face at CEBD in keeping a research pipeline going, how we address research gaps and why input from patients and carers like yourselves is so important. (The 'Cash for Questions' article over the page aims to give you some background information to the funding side of things). Most sessions will be short interactive presentations with an educational theme, and all are being led by staff from CEBD. There will also be the opportunity for you to provide feedback on an activity we're planning about getting information out into the community related to research and eczema which will be presented by Kim Thomas.

The programme for the meeting is outlined below—[please just get in touch and let us know if you'd like to attend if you haven't done so already](#). Although we are unable to provide direct payment for attending, all those who do join us will receive a £30 Love to Shop voucher after the meeting as a token of appreciation for taking part.

Session	Presenter
Welcome and introductions	Kim Thomas
Setting the scene—the research lifecycle and Patient and Public Involvement	Carron Layfield
Getting a research priority setting partnership (PSP) off the ground—Skin of Colour PSP	Paul Leighton
It's taking how long to get funding? <a href="#">Eczema Care Online</a> Community Pharmacy project	Jane Harvey
Comfort break (approx. 11.20am)	
What happens when a project comes to an end? <a href="#">DIPSOC</a> psoriasis study	Esther Burden-Teh
Getting your input into a dissemination activity— <a href="#">Rapid Eczema Trials</a>	Kim Thomas

## Cash for questions... where does the money come from?

Doing research costs money! In fact, it costs quite a lot of money to do research well!

Research groups like CEBD face the constant challenge of not only doing research, but at the same time they need to be looking for the funding that will support the next study, then the next, and so-on. Knowing where to look for this money and how to get it is as much part of our world as knowing about statistics, trial design and how to do a research interview. The National Institute for Health and Care Research (NIHR) is a key funder of clinical research in the UK, and it is where CEBD most often look for grants and awards to support our research.

### How does the NIHR allocate it's money (approx. £460M in 2023-4)?

The NIHR operates 12 funding competitions, each having the broad purpose of improving patient outcomes and/or improving how the NHS works. They work independently of each other, but are organised in similar ways.

Each competition has a panel of experts that consider applications and make decisions about which research should be funded, and which rejected. Kim Thomas, Sonia Ratib and Paul Leighton have all sat on this type of panel and Hywel Williams was Director of the NIHR's largest funding competition. All of these panels include members of the public.

Applying to these panels takes place in two-stages. At stage 1 research groups offer a summary of the research that they would like to do, most often focusing upon why

the research is important and the benefits that it might offer. At stage 2 (if invited) research groups offer a fuller description of the research, most often providing detail about the research methods. Depending on the requirements of the competition, and whether it is stage 1 or 2, these funding submissions can range from 10 to 100 pages.

### How do panels make decisions?

Each panel might consider between 15-30 submissions in a day; sometimes panels meet over multiple days due to the number of submissions. For each submission two or three panel members will be asked to introduce the research to the rest of the panel, offering their assessment of what's good about it and where it might be improved.

For stage 2 submissions external reports about the research are also considered. Discussion of the proposed research is then structured around four topics: (1) clinical relevance, (2) research methods, (3) PPIE, and (4) Equality, diversity and inclusion. After this discussion all panels score the submission on a scale of 1 (not fundable) to 6 (definitely fund).

Throughout the process the NIHR is committed to the participation of members of the public – in writing external reports, in introducing research to the rest of the panel, and in discussing the four core topics. You can become an [NIHR reviewer](#) or get involved in an [NIHR panel/committee](#) and you'll hopefully find your experience with CEBD helpful in this. And why not come along to the panel meeting on Sat 9th Nov (see over) to find out how we try and keep the funding coming in!

## Update on the EXCISE skin cancer surgery study and further opportunities to get involved

We're really pleased to let you know that the EXCISE study has been funded by the National Institute for Health and Care Research (NIHR). This clinical trial, led by Dr Rachel Abbott, a Consultant Dermatologist based in Cardiff, will investigate whether prophylactic antibiotics reduce the risk of wound infection following surgical removal of ulcerated skin cancers. EXCISE was developed with support from the UK Dermatology Clinical Trials Network ([UK DCTN](#)) which is based at CEBD and the study has been presented at a couple of CEBD Patient Panel meetings for feedback which was really helpful in the development process—thanks to all panel members involved.

Now funded has been confirmed, the EXCISE team are looking for patients and carers with lived experience of skin cancer surgery to get involved in a patient reference group to support input into study set-up, delivery and when the

## Other things that caught our eye recently....

- Have you seen this [recent NIHR blog](#) 'reporting in PPI in research publications is the exception not the rule'? It seems that although great improvements have been made in patient and public involvement (PPI) in research, this is not being reported when research studies are published in scientific journals.
- If you're interested in getting involved in systematics review check out this free of charge webinar (organised by the Primary Care Research team at Oxford University) taking place Tues 3rd Dec 10am-11.30am. It will cover things such as how and why reviews are conducted, what sort of analysis is used and how to involve patients and carers. You can register [here](#) or contact the Oxford team for further information [here](#).
- Check out this [video from Equality Health](#) who are working with a number of charities to help improve diversity in research involvement.