



Patient Panel Newsletter

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Studies in development

We're sorry to have to let you know that the full stage application to the [National Institute for Health Research](http://www.nihr.ac.uk) (NIHR) for a study investigating the implementation of a care package to improve incontinence-associated atopic dermatitis in adults was not successful. Feedback from the NIHR was that the application was fundable but that another team with more experience in this area of research were successful in obtaining the funding to deliver this project. Many thanks to those of you that provided support to help with the development of this work—it's hard when things don't get funded, but it is an unavoidable part of the research process at times.

An outline application has been submitted to the NIHR for a study comparing the effectiveness and safety of oral ciclosporin, subcutaneous methotrexate and subcutaneous dupilumab for the treatment of moderate to severe atopic dermatitis in adults. This is being developed by a study team in London with support from the [UK Dermatology Clinical Trials Network](http://www.ukdermatologyclinicaltrialsnetwork.org), which is based at CEBD. We'll be doing a workshop on this at the panel event on 12th October which will be delivered by Jo Chalmers, a Senior Research Fellow at CEBD, and Tim Burton, a member of the CEBD Patient Panel and member of the study team.

Finally, a big thank you to those of you that responded to a request from a study team based in Bristol who are working on an application to the NIHR for a study on the use of amitriptyline for prevention of pain in shingles. The study team received a great response with over 46 questionnaires completed. They are currently working on the application, building your opinions into their proposal, and full feedback will be provided to those that took part in this once the application has been submitted in early December.

Meet a Panel Member—Anjna Rani

I have been a member of the CEBD Patient Panel for almost ten years now. It has been amazing to meet so many people who are passionate about research in so many different skin conditions, and I don't just mean the clinicians!

I have always been curious about eczema (which I have had pretty much all my life, and never without respite), the vast array of treatments available and how one thing never seemed to work forever. Personally, I wanted to understand how newer treatments became available and actually what research was taking place to select these treatments as suitable for eczema. Over the years this has become a lot clearer than when I was a teenager, when I had all these questions literally burning inside of me.

I have been fortunate to have been actively involved in a number of projects as a result of being on the Patient Panel. One key project was a Priority Setting Partnership in collaboration with the James Lind Alliance to identify uncertainties in eczema treatments. It was so important that

this was conducted, especially as the incidence of having eczema is on the increase. Filtering through the questions raised by everybody that had chosen to participate in the survey, it was poignant to see that there was no clear guidance on the best way to use steroidal creams—one of the key fundamental management treatments readily available, and yet no studies available on how best to apply these!

Being on the Patient Panel and attending the annual Patient Panel days, it is great meeting researchers and especially those wanting to understand the personal impact on people. Sometimes just an *ad hoc* conversation can lead to researchers considering how the outcomes of their research needs to be relevant to everyday people. This has improved remarkably over the years, and it is great to see this, especially with newer treatments becoming available!!



Update on CEBD Patient Panel Action Plan

At the last CEBD Patient Panel event we undertook a review of the Patient Panel and related activities against the [new national standards for public involvement](#). The aim of this was to try and ensure that CEBD patient and public involvement activities reflect up to date practice in this field and to make sure CEBD are supporting Panel members in the best way we can.

A working group, comprised of three members of CEBD staff (Carron Layfield, Paul Leighton and Stephanie Lax) and three members of the Patient Panel (Amanda Roberts, Anjna Rani and Irene Soulsby), reviewed the feedback from this session and developed an action plan to address priority areas. These included:

- Supporting new/less experienced Panel members better
- Making changes to the annual events
- Investigating ways to increase the breadth and reach of our public involvement work
- Improving communications between Panel members outside annual events
- Developing a code of conduct for Panel-related activities

We are now working on delivering activities to support this action plan, and to date we have:

- Developed an induction pack and mentor list for new Panel members
- Formulated a code of conduct for all involved (CEBD staff, research collaborators and Panel members) in Panel-related activities
- Involved Panel members in planning the programme for the annual event and introduced shared learning sessions as part of the activities
- Started mapping other relevant groups to see how we can work better with stakeholders such as young people and those from under-represented communities
- Joined our local [Sharebank](#) to investigate wider training opportunities

Future work will hopefully focus on communications and investigating how we can involve Panel members earlier in the development of research ideas.

If you would like to get involved in this work (or would like to see a copy of the Action Plan or would find a copy of the induction document useful) please contact panel co-ordinator [Carron Layfield](#) for further information.

New NIHR Website—Be Part of Research

[Be Part of Research](#) is the new NIHR website to help make it easier to find clinical trials (replacing the Clinical Trials Gateway site) and studies to take part in as a participant. You'll also find lots of useful videos there of people speaking about their experiences of taking part in research, and a link to the really useful, free on-line course '[Improving Healthcare Through Clinical Research](#)'. The next four week course starts on 7th October, so sign up quickly if you'd like to take part.

Meet a Member of CEBD Staff — Monica Persson

Monica joined the CEBD team in May 2019 as a Research Fellow. Her work involves using routinely collected data from GP surgeries and hospitals to inform the development of clinical trials in blistering skin diseases. The aims of the work are to determine how many people in the UK have these rare blistering skin diseases, whether the number of people is changing over time or varies by age, gender, and other features, how many would be able to take part in future trials, and how people are currently being treated.

Monica has a degree in Medicine and a PhD in Rheumatology from the University of Nottingham. She has a background in evaluating and combining research evidence to improve the treatment of painful osteoarthritis.

In her spare time, Monica can either be found at the local climbing wall, competing in sports tournaments (Softball or Ultimate Frisbee), or crafting away at home.

