

Patient Panel Newsletter

www.nottingham.ac.uk/dermatology

Exciting opportunity to get involved in a new eczema research project—please get in touch to express your interest in this co-production work

We are in the process of developing plans for an ambitious new programme of eczema research that will allow people with eczema to be more involved in designing and conducting high quality trials of non-pharmacological interventions for themselves. Many of the research uncertainties that were identified during our [Eczema Priority Setting Partnership](#) back in 2013 are yet to be addressed – especially those that were identified as being important by patients, such as:

- Which is the best way for people with eczema to wash: frequency of washing, water temperature, bath versus shower?
- What are the best and safest natural products to apply to the skin for eczema?
- How much does avoidance of irritants and allergens help people with eczema?
- What is the role of diet in treating eczema: exclusion diets and nutritional supplements?
- What is the best psychological treatment for itching/

scratching in eczema?

- Which should be applied first when treating eczema, emollients or topical steroids?

The vision is to work in partnership with people with lived experience of eczema, and patient support organisations, to develop an online platform that will allow high quality trials to be delivered rapidly and efficiently, whilst also maintaining methodologically high standards.

We would like to empower patients to lead on the research questions that matter most to them and to enrol large numbers of participants into the trials from varied populations, so that we can be sure the results are relevant to all groups in society. We believe that by establishing standardised methods and novel approaches to recruitment of participants, we will be able to conduct a series of rapid eczema trials, thus transforming how eczema research is conducted.

If any of you are interested in finding out more about this research programme or would like to get more actively involved in helping to lead the work, then please do get in touch with either [Kim Thomas](#) (kim.thomas@nottingham.ac.uk) or [Jo Chalmers](#) (joanne.chalmers@nottingham.ac.uk) who are currently co-ordinating the outline development work around the project.

Useful training resources and links

We're aware there are quite a few new Patient Panel members who might have missed some of the links and information we've circulated previously about relevant websites and online training to help familiarise you with clinical research. Please see some good starting points below, and of course please do contact panel co-ordinator [Carron Layfield](#) for further information and support as needed. If you haven't already, we'd also recommend all panel members signing up for the National Institute for Health Research (NIHR) [Patient and Public Involvement newsletters](#).

- There is an excellent free on-line training course from the NIHR '[What is Health Research?](#)'
- [Learning for Involvement](#) is the new hub from [Involve](#) for training related resources. The [interactive course](#) on reviewing NIHR applications is an excellent introduction to getting involved and is suitable for all, not just those involved in reviewing.
- The language, terminology and acronyms used in clinical research can be confusing—try bookmarking an [on-line jargon buster](#) so you have a resource to hand if you come across things you don't understand.

CEBD Patient Panel Facebook page

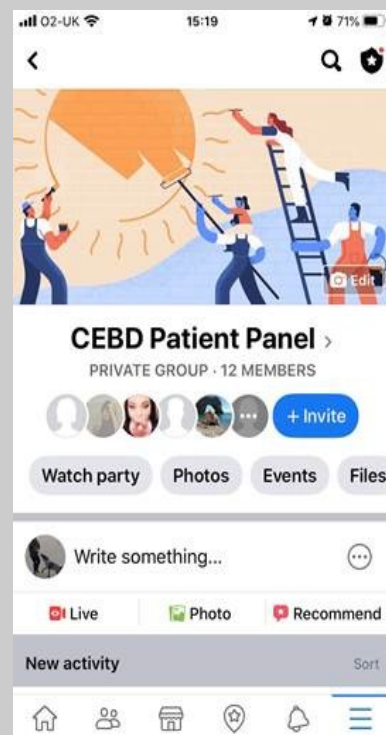
As you may be aware, an ongoing piece of work for the CEBD Patient Panel is around communication: how we communicate outside of the annual event, how we can work together and how we can share our knowledge and experience using the simplest mechanisms possible. This is outside these newsletters and other information we get directly from CEBD (mainly from Carron Layfield who co-ordinates the panel) - it's about panel members independently keeping in touch.

Did you know that the CEBD Patient Panel has its own Facebook page? I didn't until Amanda told me (thanks Amanda!!) and I'm now looking after the page on behalf of the panel. It has been quiet for a while, but we are trying to get it up and running again.

We want the page to be a safe, shared space where any of us can suggest articles and events of interest to our group and swap ideas. The group is set as 'private'; there are three simple questions that need a response and then the admin can give you access.

The Facebook page will better perform its function if all of us input ideas for articles, news or events (if left to my own devices you are going to get A LOT of pictures of my dog). To get something published on this page please email me at contact.colette50@gmail.com

Colette O'Sullivan, CEBD Patient Panel member



Cochrane Skin review prioritisation exercise 2020—please take part

Cochrane Skin are currently reviewing their portfolio of reviews, considering gaps and looking to identify new review priorities to help best inform clinical guidelines, health policy and future research priorities. To help with this they are conducting a survey of relevant stakeholders, including patients and carers, to get initial suggestions. We'd be really grateful if you could take 5-10 minutes to complete this survey at



<https://www.surveymonkey.co.uk/r/VZ7FHMY>. The deadline for taking part is 31st January so please do this sooner rather than later. Please feel free to circulate to others that might be keen to take part. Thank you!!

CEBD news and updates

- We're really pleased to be able to let you know that the [BEEP eczema prevention study](#) results have been accepted for publication in the Lancet. We will of course send you the link when the publication goes live.
- [The BLISTER trial](#) on treatments for bullous pemphigoid was one of five studies shortlisted for the Inspirational Research Stories Competition at the [CRN East Midlands @5](#) celebration event on 11th December. Well done to everyone who contributed!
- CEBD Patient Panel member Anjna Rani was recently featured in a Cochrane news bulletin commenting on a review that she's been involved in, 'Interventions to reduce Staphylococcus aureus in the management of eczema'. Find out what Anjna had to think about the reviewed studies [here](#).
- The BEACON study (a trial comparing the effectiveness and safety of oral ciclosporin, subcutaneous methotrexate and subcutaneous dupilumab for the treatment of moderate to severe atopic dermatitis in adults), which was featured at the most recent panel training day, has been short-listed for full application to the [National Institute for Health Research](#). Many thanks to all who have supported the development of the study by taking part in surveys and sharing their thoughts on the design of the trial during group discussions, and in particular to patient panel Tim Burton, who is a member of the study team. We'll keep you informed of the outcome of the application in due course—fingers crossed.
- Remember we said in the last newsletter that panel member Amanda Roberts had been nominated for a PPI Contributor Award at the [Society for Primary Care Research Annual Meeting](#). We're delighted to be able to let you know that she received a 'Highly Commended Award' which was very well deserved indeed—well done Amanda!!