

# Patient Panel Newsletter

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## CEBD Patient Panel Online Meeting Saturday 12th March

Our next CEBD Patient Panel meeting will be taking place online (using Microsoft Teams) on the morning of Saturday 12th March 10am-12.30pm. The programme for this meeting will include the opportunity to contribute to three studies; a smaller feasibility study on service delivery (remote paediatric eczema consultations), a full stage funding application for a clinical trial on the treatment of acne and an earlier stage funding application for a study investigating the use of antibiotics after skin surgery (so lots of variety!). Please remember that you don't need to be affected by a particular condition to be

able to make a valuable contribution, general perspectives are really so helpful and valued. There will also be an update of recent CEBD activities along with an optional networking session after the meeting 'officially' finishes when we'll hear about some new developments including a CEBD Patient Panel Journal Club which we're hoping to trial before Easter.

If you'd like to attend [please let us know](#) and we'll make sure you receive all the relevant pre-meeting information and of course the all important link to join! If you have any queries at all about this meeting or haven't attended a panel meeting before and are a little unsure of what is involved then do [get in touch](#) so we can go through what to expect.

## A few updates from CEBD

- It really has been all systems go recently as we moved to a new office in January!! Please note our new postal address is Applied Health Services Research Building (building number 42), University of Nottingham, University Park Campus, Nottingham NG7 2RD.
- We're really pleased to let you know that the outline application to the [National Institute for Health Research \(NIHR\)](#) for the clinical trial on lower dose isotretinoin for the treatment of acne (led by Esther Burden-Teh and Kim Thomas) that was discussed at the October panel meeting has been successful and we'll be looking at the next stage of the application at our meeting in March.
- NIHR funding has now been confirmed for two studies that CEBD is collaborating on and that have been developed with support from the patient panel. The acne programme grant (led by Miriam Santer, Southampton) aims to improve outcomes for mild/moderate acne by promoting the use of effective treatments and reducing overuse of long-term oral antibiotics through an online intervention to support acne self-management. The TIGER study (led by Matt Ridd, Bristol) will investigate the usefulness of allergy testing in paediatric eczema.
- Don't forget that you can keep up to date with CEBD activities by following us on Twitter @CebdNottm. Some studies such as [Eczema Care Online \(ECO\)](#) also have [great blogs](#) with more in depth updates and information.

## What's happening at Cochrane Skin???

In August 2021, all [Cochrane](#) Review Groups in the UK received confirmation from the NIHR that infrastructure funding for groups would not be renewed beyond March 2023. Cochrane is also reviewing their current structure, so very sadly the future of Cochrane Skin is currently unclear. However, they are still committed to supporting current author teams to complete their reviews and we will keep you posted about future ways that patients and carers can be involved with Cochrane to maintain a sense of community. You can read more on the [Cochrane Skin website](#).

This is starting to impact on the team and Laura Prescott, Managing Editor of Cochrane Skin, left her role at the end

of January for pastures new. She started as an Editorial Assistant in 2009 and became Managing Editor in 2016. You may have encountered her bubbly personality, kindness and love of memes, cakes and dogs. She was also incredibly hard working and collaborative, and her knowledge of all things Cochrane was immense. Laura will leave a huge gap in Cochrane Skin, in CEBD, and also in the wider Cochrane community. We wish her well in her new editor role with a group of dermatology journals at the British Association of Dermatologists. Helen Scott remains as Assistant Managing Editor so please [do get in touch with Helen](#) with your Cochrane Skin queries.



## MHRA public consultation on proposals for legislative changes for clinical trials

The [Medicine and Healthcare products Regulatory Agency \(MHRA\)](#) have recently launched an 8-week consultation on proposals for legislative changes for clinical trials. They are looking to streamline clinical trial approvals, enable innovation, enhance clinical trials transparency, enable greater risk proportionality, and promote patient and public involvement in clinical trials.

They would like to hear from the public and patients, clinical trial participants, researchers, developers, manufacturers, sponsors, investigators and healthcare professionals to help shape improvements to the legislation for clinical trials so please do engage with this process if you can. The closing date for taking part is Monday 14th March and further information can be found [here](#).

## Update on skin cancer surgery Priority Setting Partnership

There has been great interest in the [skin cancer surgery Priority Setting Partnership](#) with over 1100 research suggestions put forward in the first stage survey. The data generated has now been sorted and 38 summary questions not already answered by research have been identified for ranking in the second stage survey.

We are asking for your help to prioritise this list—please take part in this survey <https://www.surveymonkey.co.uk/r/pspskin> if you have had surgery for skin cancer or are a carer /family member of someone who has. If not, you can still get involved by circulating the survey link to friends, family and your personal/professional networks to help ensure a good response from the patient community. CEBD Patient Panel member Pat Fairbrother is on the Steering Committee for this project and it was funded by the 2019 [UK Dermatology Clinical Trials Network](#) Themed Call.

If you'd like to know more about Priority Setting Partnerships (PSPs) the [James Lind Alliance website](#) is a good place to start, over ten have been completed to date in dermatology including in [acne](#), [psoriasis](#), [vitiligo](#), [eczema](#) and [cellulitis](#).



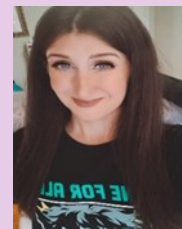
## CORALS completes first stage of a core outcome set for lichen sclerosis

We are delighted to announce that the [CORALS](#) (Core Outcomes for Research in Lichen Sclerosus) initiative has finished its first stage! Lichen sclerosis (LS) is a long-term condition that causes inflammation in the genital area. It mainly affects women but can also affect men and children. Symptoms can be distressing and impact hugely on quality of life and everyday function. It can lead to scarring, which causes difficulty passing urine and can make having sex impossible.

LS has traditionally been a 'taboo' topic and has been under researched. Following completion of the [Lichen Sclerosus Priority Setting Partnership](#) in 2018, we are delighted that with a small grant from the UK Dermatology Clinical Trials Network, we have been able to move one of the 'top 10' research priority areas for LS forward. Agreeing core outcomes for LS clinical studies is important to enable the results from multiple clinical trials to be

compared and combined. It will give a better overall understanding of the existing evidence and how effective treatments are. CORALS has received input from patients – 77 patients in 3 rounds of an electronic (online) delphi survey and 15 patients who took part in virtual consensus meetings. Results will be released soon!

We also have a new patient rep on the CORALS steering group, Jaclyn Lanthier. Jaclyn is the face behind The Lost Labia Chronicles, which includes a blog, a YouTube channel, as well as an eBook centering around vulvar Lichen Sclerosus. Jaclyn is passionate about disseminating evidence-based information and addressing mental and sexual health with Lichen Sclerosus. She is on the executive board of [Lichen Sclerosus Support Network](#) and spends a lot of time in the LS online communities helping to provide support to folks with LS. Jaclyn is 34 years old and was diagnosed at 31 (but symptomatic since she was 20) with vulvar Lichen Sclerosus. She works full-time as a data consultant and social media manager in Toronto, Canada.



## NIHR next steps on working with patients and the public

The NIHR have recently [published their key areas of focus for working with patients and the public](#). Five areas have been identified as priorities: equality, diversion and inclusion; standards, processes and incentives; digital engagement; capacity building and finally impact and learning. There is a series of targeted actions for each priority area planned and the NIHR are keen to hear examples of good practice and CEBD will feed into these where we can. You can keep directly updated of NIHR patient and public involvement activities by signing up for their [quarterly newsletter](#).

## Sometimes it is best to halt research if someone else has done something similar well: an interesting tale to share with the CEBD patient panel.

Laura Howells and Hywel Williams

You might have heard CEBD colleagues going on about reducing research waste – by that we mean needlessly repeating research that has been done by others with dubious added value. Sometimes repeating a piece of research (called *replication*) is really important especially for genetic studies or those that make worrying claims such as eating a certain type of food causes cancer. One study is rarely enough, so some degree of replication is good e.g., by testing the same study hypothesis in people from a range of ages and ethnicities and in different places from over the world.

Yet as pointed out as far back as 1999<sup>1</sup>, avoidable research waste is rife in medicine. Patients are often not involved at all in prioritising research questions with doctors. Checking to see if anyone else has already done the research or is about to do it is often not done at all. Then the outcomes used in research may not be the most relevant ones to patients. Worse still, the final results are not published at all about half of the time, especially if they do not look good. Despite this scandal, there has not been a lot of progress in reducing avoidable research waste, and dermatology is not immune to the problem<sup>2</sup>.

When Douglas Grindlay (who has since sadly left the CEBD) collected systematic reviews of [psoriasis treatments](#) (given by mouth or injection), we noticed there were quite a lot, and over 20 reviews used a special approach called network meta-analysis (NMA). NMAs use a special technique that allows us to compare across a wide range of studies to get a more complete picture of how well different drugs perform against each other rather than just placebos, in a field like psoriasis with so many drugs available, NMAs can be a really useful tool, and we might have anticipated 3 or 4 publications to update an NMA, or to do important replication work over a 20 year period. But 20+ *sounds* wasteful. In fact, the publication of systematic reviews in dermatology seems to have spun completely out of control<sup>3</sup>, with teams churning them out like sausages, and over 90% being of poor quality<sup>4</sup>.

So we wanted to take a closer look at the NMAs of psoriasis treatments to try and see how many demonstrated awareness of previous work, and what they added to the existing body of evidence. We came across a nice framework in the British Medical Journal with guidance on when it makes sense to try and replicate a systematic review<sup>5</sup>, so we contacted that team and set about working with them to apply their checklist to our

psoriasis NMAs. We did a protocol and started piloting the checklist on a few studies. It was not as straightforward as we thought, but we were getting there.

Then, just as we were checking for any related publications, we saw that a very similar study had just come out in the *British Journal of Dermatology* which was written by a very good team linked to Cochrane Skin<sup>6</sup>. They did a very thorough search and found an incredible 47 such redundant NMAs. Confidence in the results was low in 83% of such studies, and only 23% registered a protocol - meaning that we will never know if the results presented were the ones that they planned to look at. Over half received funding from Pharma.

When we read this review, we were initially deflated because the overlap with what we had started doing was huge. But after some reflection, we came to the conclusion that the new article had done a really good job of shining a light on redundant NMAs in psoriasis. We made the difficult decision to “practice what we preach” by not repeating a lot of the work. Instead, we sent in a rapid response (which has just been accepted) agreeing with the study conclusions, and adding in the framework that we were about to test as others might find it useful before rushing into doing another NMA<sup>7</sup>.

Sometimes it is difficult to stop a piece of research when you have put some effort into planning and piloting it, but it is important to do so if the extra effort (which could be spent on something else more useful) is just not worth it. Our aborted study will paradoxically be remembered by us as an example of not wasting research time. We hope that other researchers will follow suit by checking what others are doing before rushing ahead with new research.

### References:

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