

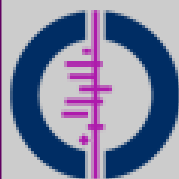
Patient Panel Newsletter

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CEBD news and updates

Three months have passed since the last newsletter and there has been quite a bit of activity across CEBD. We're all still working from home as we can deliver the sort of research we do remotely and suspect we'll be continuing from our dining room tables and spare rooms for a while longer. Some key things to mention are:

- The full application for the BEACON study comparing dupilimab, a new biological treatment for eczema, with two other treatments (methotrexate and ciclosporin) has now been submitted to the National Institute for Health Research (NIHR). Led by a team in London, this study has been developed with support of the UK Dermatology Clinical Trials Network ([UK DCTN](#)) and patient panel member Tim Burton is part of the study team. It's been a busy time for the UK DCTN team as a further NIHR application (at outline stage) has also been submitted for the COUNT study, investigating the chemoprevention of skin cancer using nicotinamide in organ transplant recipients.
- The first round of the [Blistering Skin Diseases Priority Setting Partnership](#) saw almost 1,000 questions submitted with over 650 of these coming from patients and carers. The team are now working hard on putting these into categories for the next survey and looking at potential options if the final workshop needs to be held remotely.
- The review of CEBD Patient Panel activities against the [UK Standards for Patient and Public Involvement in Research](#) continues and we now have more information about the panel on the [CEBD website](#) including a [purpose statement](#) for the group. Many thanks to panel members Anjna Rani, Amanda Roberts, Irene Soulsby and Colette O'Sullivan for their efforts in this continued piece of work.
- Some CEBD linked studies are starting to re-open to recruitment including the [two studies](#) linked to the [Eczema Care Online \(ECO\)](#) project and [SAFA](#) (a clinical trial investigating the use of spiranolactone for adult female acne).
- Congratulations to Dr Esther Burden-Teh (pictured right) who passed her PhD exam last week. Esther is a trainee dermatologist and has been working with us for a number of years now on her NIHR Clinical Fellowship and PhD on diagnostic criteria for childhood psoriasis and the resulting [DIPSOC study](#).



Cochrane COVID-19 consumer rapid response group

In April 2020, Cochrane launched the [COVID-19 consumer rapid response group](#). Currently, nearly 100 people with lived experience related to COVID-19 have joined the group, signing up to offer their time, skills, and experience to get involved with Cochrane's work on COVID-19 rapid reviews and accommodate limited timelines. So far, 16 consumers have been connected with research teams for 13 [COVID-19 rapid reviews](#), either as members of author teams or as peer reviewers. Interested consumers can still become involved in the COVID-19 consumer rapid response group; [find out more and sign up](#).

CEBD Patient Panel event—October event now a shorter remote meeting with the annual event postponed to March 2021

In the face of such uncertain times, we have taken the decision to postpone our annual CEBD Patient Panel event until next year. The new date for this one day meeting is Saturday 6th March 2021 and as originally planned, this will be taking place at the [Orchards Hotel, Nottingham](#). Please do let [Carron Layfield](#) know if you'd like to attend and add the date to your diaries—further details will follow in due course and if you have any suggestions to make for the event please [get in touch](#).

As previously communicated, we are now planning a shorter online meeting on Saturday 10th October so that we can keep in touch with each other in the meantime. The exact format hasn't been finalised as yet, but we are

trying to take your feedback on board with regards to timings, meeting platforms and content and will aim to make it as straightforward to get involved as we can.

This remote meeting will involve an update on CEBD activities over the past 12 months along with the chance to contribute to CEBD related research projects, including how to best communicate the results of the [BEE eczema study](#). Many thanks to those of you who have already expressed an interest in joining us in October. It has been really encouraging to see people get in touch who haven't been able to take part in these events before so hopefully more frequent remote meetings (in addition to the much valued annual face to face event) will be an improved way of working for us in the future. It would be great to see as many of you get involved in this remote meeting as possible, again just make the [panel co-ordinator](#) aware if you'd like to join us on the day.

Informing the development clinical trials in blistering diseases—Monica Persson

Last month marked one year since I joined CEBD and delved into the world of blistering skin diseases research. As we slowly begin to tie up loose ends in this project, now feels like a good time to provide an update of our journey so far. With help from a panel of patients and public (including patient panel member Ingrid Thompson, who is affected by the blistering condition bullous pemphigoid) the idea of using routinely collected healthcare data to inform future trials in blistering diseases evolved into the job I do today. When I say routinely collected healthcare data I mean the information that your GP types in to the computer during consultations, the information about the prescriptions that you are given, and details of any hospitalisations that you have had. These are available for a portion of GPs in the UK and are all anonymised, of course.

Our first step was to determine if we could accurately identify people with [bullous pemphigoid](#) and [pemphigus vulgaris](#) using this information. We were reassured that we could identify people with bullous pemphigoid, but unfortunately the information was not good enough to identify those with pemphigus vulgaris. Conversations with our patient and public steering committee helped hammer home the impact of this. We would not be able to use this

information to conduct much needed research for people with a debilitating disease and this led to our consequent call for improved disease recording in GP databases. These important conclusions have been accepted for publication in the journal BMJ Open.

Our next step was to look at the number of people with bullous pemphigoid in the UK. Although the number of new people being diagnosed each year has remained relatively stable, with only a small increase every year, people with bullous pemphigoid are still more likely to die early than their peers. Researchers, clinicians, and patients alike felt this was an important message and one we made in a publication that is now available in the [British Journal of Dermatology](#).

We've accomplished a lot in the last year, but we've still got more up our sleeve. Over the coming months, we plan to describe the pre-existing diseases that people with bullous pemphigoid have in order to see how many might be eligible for future trials. Finally, we want to give a better picture of how many are being treated with steroid tablets and what this treatment looks like. So as they say, watch this space...



A glimpse into national research funding during the pandemic from Hywel Williams

I hope that you – our valued patient panel colleagues are well. It has certainly been a strange and challenging time for us all, and easing restrictions and trying to work out how to get back to some sense of normality is turning out to be a lot less straightforward than imposing a lockdown.

As many of you know, in addition to my role in researching skin conditions, I also work for the Department of Health and Social Care, directing the [National Institute of Health Research Health Technology Assessment Programme \(NIHR HTA\)](#). The HTA Programme supports over 400 national studies (mainly clinical trials) into all health and care studies such as cancer, surgery, mental health, maternal and child health and all of the specialties including dermatology of course. Some of those studies requiring face to face recruitment had to be completely paused during the lockdown, most were slowed down considerably and some carried on as normal if they were collecting data remotely.

During the lockdown, most of the [NIHR efforts](#) have been channelled into funding and supporting urgent research into the prevention and treatment of COVID-19. Many major studies have been set up including the large trials of different medicines to try and prevent and treat COVID-19 patients as well as the vaccine trials that are about to start. The national capacity to deliver these trials through the clinical research network is limited, so all new studies (including industry ones) have to be prioritised by a single national group called the [Urgent Public Health Group](#). Lots of other groups have been set up by the Chief Medical Officer such as the [rapid research panel](#) (a new joint funding panel with the Medical Research Council), the Therapeutics taskforce, the Diagnostic Test taskforce, the Vaccines taskforce and more. At times, the work has been chaotic and some overlap has happened, but these are settling and the research effort is a lot clearer and more stable now.

I am involved with several COVID-19 research groups including the Urgent Public Health oversight group, the rapid review panel and something called [RAPID-19](#) which



has been a real good news story. The idea behind RAPID-19 was to bring NICE, drug regulators (MHRA), NIHR and NHS England together to speed up the assessment and approval of medicines that appear to be helpful for the treatment or prevention of COVID-19. Instead of taking several weeks, our process is just 10 days, and we managed to get the first doses of a drug called [remdesivir](#) to NHS patients within 2 days once it was approved. The NIHR has also just announced a new funding scheme called Recovery and Learning, to bridge the gap between urgent public health research and business as usual. The scheme is all about research into how best to help people recover from the virus including mental health aspects and rehabilitation.

As restrictions are cautiously lifted, the HTA programme is now preparing for a [cautious restart](#) of our non-COVID-19 research that has been paused. Whilst COVID-19 research has clearly been the priority over the last few months, there is still a need for research into other important conditions such as cancer and heart disease (and dermatology!). So the clinical research network and study teams are now working out ways on how to restart their projects.

Thankfully, very little of our current research at the CEBD has been halted due to the pandemic – mainly because most of our major trials have just completed or are using remote methods such as text and online materials to collect outcomes. The pandemic has allowed us to do some thinking about new research, and we look forward to working with you again soon.

New NIHR Centre for Engagement and Dissemination and NHS Evidence website

The National Institute for Health Research (NIHR) have recently launched their new [Centre for Engagement and Dissemination](#). This aims to bring together patient and public involvement (PPI), engagement, participation and dissemination under one umbrella to make research more representative, relevant and ready to use. The initiative is being led by the new NIHR Director of Public Voice [Jeremy Taylor](#) (the link will take you to a recent blog) and currently encompasses [NIHR Involve](#). Key areas of focus will be learning and capacity development, building an evidence user-community, production of targeted evidence resources and innovation projects to harness and share ideas in these areas. Activities to date include the new [NIHR Evidence website](#) with three types of evidence resource targeted at different audiences as follows:

Alerts	Short summaries of the latest health research in plain English to promote the use of research by all members of society
Collections	Overviews of recent topics or themes highlighted as of interest by the community
Themed Reviews	Specially created reviews of recent research on topics of strategic importance for the UK health and social care system

The NIHR are looking for [patients, carers and the public to register as reviewers](#) to help determine what research should be promoted on the NIHR Evidence website. Reviewers will be asked to read the abstract of a published paper in a research area of their interest before answering questions related to the importance of the paper's findings. A reviewing task should take between 20 and 30 minutes and NIHR will be offering a payment of £12.50 for each completed review. Please do consider this opportunity to help ensure that research about skin conditions is considered and reviewed appropriately for this important channel of communication.

People in Research

We often get asked how you can get more widely involved in research that's taking place outside CEBD. A good place to start is the [People in Research](#) website which aims to collate involvement opportunities in NHS, public health and social care research from across the UK. Take a look to see the projects currently asking for input and if you'd like to hear about the latest opportunities you can sign up for email reminders.

And finally.....other NIHR PPI related updates



- The [NIHR Annual Report 2018/2019](#) is now available and features over 100 NIHR major research achievements, with [chapter 2](#) dedicated to the valuable role that members of the public and patients play in this (pages 12-18).
- A [communication](#) indicating NIHR commitment to diversity in patient and public involvement and engagement.
- A [report](#) outlining the experiences of a number of sites that have been testing the [UK Standards for Patient and Public Involvement in Research](#) over the past couple of years.
- Updates to the [NIHR Involve Learning for Involvement](#) website which aims to bring information about patient and public involvement resources and training together in one place.

Don't forget, you can [sign up](#) to receive direct updates from the NIHR on a range of activities including PPI and NHS Evidence.