



Patient Panel Newsletter

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CEBD Patient Panel Meetings and Citizen Science Project for International Clinical Trials Day

Many thanks to the eleven panel members who joined us on Saturday 6th March for the online meeting, along with Dija Ayedole who joined us as a guest from [The Black Skin Directory](#). We've had some great feedback from those involved - we're all getting more used to this way of working it seems! Projects discussed included the RAPID eczema Programme Grant application which is based around a series of innovative, patient-led studies that aim to answer research questions more quickly than conventional clinical trials and a feasibility application investigating the usefulness of reduced bathing for babies in the prevention of eczema.

Outside these funding applications, a project proposed by the Patient Panel Action Plan Team to help CEBD recognise and celebrate [International Clinical Trials Day](#), which is held on 20th May each year, was reviewed. This is a short, online survey around the [Fitzpatrick scale](#), which is commonly used to classify skin tone in clinical practice and research. The survey will explore how people see their skin tone and how to best describe skin when it is inflamed and sore. We will need this survey to have a very broad reach and will be asking you to help and support us by not only completing it but also sharing with your contacts such as friends, family and other networks you may have so keep an eye out for this!!

If you are interested in further information on any of these projects and/or getting involved in them [please get in touch](#). Don't forget, we are planning to hold our next panel meeting face to face on Saturday 9th October at The [Orchards Hotel, Nottingham](#)—if you would like to attend or suggest items for the programme [do let us know](#).

WANTED! Consumer Reviewers for Cochrane Systematic Reviews

As previously reported, CEBD Patient Panel member Peter Smart has been appointed the first Consumer Editor of the [Cochrane Skin](#) (CS) Editorial Team. Peter is currently on a steep learning curve of the tasks he will be engaged in, working with CS Editor Laura Prescott.

One very important part of the role will be to help identify more patients and carers (termed consumers by Cochrane) who are willing, and able, to act as Consumer Reviewers for upcoming protocols (a plan for carrying out the Cochrane Review) and the Cochrane Reviews themselves. If you are unsure what a Cochrane Review is, you may find this [short video](#) helpful. The main tasks involved are:

- 1) to read through and comment on a protocol/review, from the point of view of clarity, particularly in regard to the use of plain language that patients/carers/the public can understand, and
- 2) to ensure that the correct objectives are specified so that the research reported actually achieves the aims set for it.

Full information about the role is available on the [Cochrane Consumer website](#) and to help with the tasks involved reviewers receive a template against which to give their feedback, which includes guiding questions to help formulate comments. We know that a number of members of the panel are already actively engaged in this and are hoping that some additional members will be willing to

volunteer.

Although we are happy to hear from anyone who would like to get involved, at the moment Consumer Reviewers are urgently required to support reviews in acne and a rare skin condition called Stevens-Johnson syndrome. The acne reviews are at an earlier stage (it is the protocol that needs input) and are linked projects relating to the treatment of the acne: 'Non-systemic pharmacological interventions for acne and its complications: an overview of systematic reviews' and 'Systemic pharmacological treatments for acne: an overview of systematic reviews'. These [overviews](#) are a new initiative for Cochrane and aim to provide user-friendly summaries of the breadth of research without needing to take on board the results of multiple systematic reviews.

The other review is on systemic interventions for the treatment of [Stevens-Johnson syndrome \(SJS\)](#), [toxic necrolysis \(TEN\)](#), and [SJS/TEN overlap syndrome](#). These conditions (which can result from an adverse reaction to medication) are very rare (1-2 people/million) and have a 20% mortality rate. It is unlikely that we can identify a patient who is able to conduct the review and so we would be really grateful if any panel member could step forward to get involved.

If anyone is willing to participate as a Consumer Reviewer for any of these studies or would like further information about what is involved, please contact [Peter](#).



DIPSOC study – a special results update before publication!

Here is a sneak preview of the [DIPSOC study](#) results before they are officially released as a publication in a medical journal. Many of you have contributed to the funding application, study design and patient information leaflets, and it is really good to be able to update everyone who has been involved. For now, please keep them under your hat!

DIPSOC was designed to develop Diagnostic criteria for Psoriasis in Children. These criteria will help how psoriasis is recognised and diagnosed, and also help to improve the quality of future research so children with psoriasis have better treatment in the longer term. The study tested how well a list of expert-agreed diagnostic criteria (skin changes to look for and questions to ask about in the medical history) perform at separating psoriasis from other scaly red rashes. It is a while ago since patients were first recruited to the study (2017) and even longer since the research project started (2015), and so it is with much anticipation that we now have the results

The expert-agreed criteria were able to correctly identify psoriasis in more than eight out of 10 children. However, the list of criteria which needed to be assessed was long (16 items) and potentially off-putting for use and therefore we looked to see if we could identify a shorter list of best predictive criteria. Using statistical techniques, seven

criteria were found that were most useful in identifying psoriasis. These were red flaky patches on the scalp, inside the ear, on the body with clearly defined edges, on the back of the elbow or front of the knee, in the umbilicus (tummy button), in the groin creases where a nappy would be and finally psoriasis in a family member.

Using the statistical technique, the probability or chances of a child having psoriasis can be calculated. Also, if two or more of these seven criteria are found on history and examination, then psoriasis will be correctly identified in close to eight out of ten children (nearly as good as the expert-agreed longer list!)

The DIPSOC study was a tremendous effort from patients and their families, health professional and researchers. Three hundred and thirty children were recruited from 12 dermatology departments across England, Wales and Scotland. Although every study has bumps along the way, everyone involved commented how the study was easy to recruit to, simple and attractive for patients. For this we only have the excellent patient and public involvement to thank from the CEBD Patient Panel and the [Young Person's Advisory Group for Research](#). Thank you.



Cochrane Systematic Review on prevention of eczema and allergy published

A Cochrane Review was published last month (including 33 studies and 25,827 individual participants) which [evaluated the effects of skin care regimens during infancy on the subsequent development of eczema and allergy](#). Key findings were:

- The use of moisturisers does not affect the risk of developing eczema but probably increases the risk of minor skin infections.
- It is unclear whether the use of moisturisers affect the risks of food allergies.
- There was insufficient information about the role of bathing and washing.
- Further research is needed to understand whether different approaches to infant skin care might promote or prevent eczema .

CEBD Patient Panel Facebook page has been closed down

The CEBD Patient Panel Facebook page was established by panel members a couple of years ago as a closed group with the aim of enabling panel members to keep in touch with each other and share information outside CEBD activities. Due to a lack of engagement, the decision has been taken to close this Facebook page. Many thanks to panel member Colette O'Sullivan for her efforts in keeping the page going. If you have any ideas on how panel members can best keep in touch with each other outside of the group please do [share them with us](#) and if you would like to join the existing e-mail distribution list for keeping in touch outside CEBD activities [please let us know](#).

Other CEBD updates

- The [2019-2020 CEBD report](#) is now available on our website. It includes a summary of all CEBD research, highlights of the past couple of years and a focus on the impact of some of the projects you may have been involved in along with a section on patient involvement and public engagement.
- We are sadly saying goodbye to our CEBD Information Specialist, Dr Douglas Grindlay, at the end of this month as the fixed term funding supporting his role has come to an end. Unfortunately, this means there will be changes to some of the resources that CEBD can provide to the dermatology community (such as the monthly e-mail updates and some of the web based resources).