



Patient Panel Newsletter

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Scoping Systematic Review on Treatments for Eczema Published

We are delighted to let you know that the scoping systematic review of treatments for eczema has now been published and can be accessed at <http://www.journalslibrary.nihr.ac.uk/pgfar/volume-4/issue-7#abstract> All journals published by the National Institute for Health Research (NIHR) Journals Library are open access and are free to view and download online. The review covers the period Jan 2001 to Aug 2013 and was conducted with the aim of informing health-care professionals, commissioners and patients and their carers about key treatment developments and research gaps.

The review identified 287 new trials encompassing 92 treatments with areas for further research identified including the optimum use of emollients, bathing frequency, wash products, allergy testing and antiseptic treatments. The greatest benefit identified is the use of twice weekly anti-inflammatory treatment to maintain disease remission.

Thank you....

Many thanks to the ten panel members who attended the most recent patient panel training day in Nottingham. A number of study ideas were discussed and feedback from the relevant study teams is summarised on the final page of this newsletter. Attendance at these annual meetings is open to all panel members (all expenses are paid) with the days being structured around training sessions in the morning and workshops offering an opportunity to contribute to research projects in the afternoon.



Meet a Panel Member—Carolyn Hughes

I'm Carolyn. I've had psoriasis since childhood and recently developed psoriatic arthritis as well. I joined the Patient Panel when it was first set up in 2009, after reading about it in the Psoriasis Association's newsletter. Living with a skin condition is difficult and looking after my skin is hard work. I wanted to find out what, if anything, I could do that might help others facing the same challenges. At the first Patient Panel meeting in Nottingham I found that there were lots of different and practical ways that I could get involved in research, even though I don't live near to the CEBD. Hearing about the achievements and experiences of the other members of the Panel was inspiring, and still is.

I joined the Cochrane Skin Group as a 'Consumer

Referee' and was asked to read and give my comments on several Cochrane reviews related to psoriasis. I have also become involved as a 'Consumer Author' on three Cochrane reviews on psoriasis therapies. I have attended several Patient Panel meetings/training days over the years, all of which have helped me to learn more about research and clinical trials and even health economics, and have allowed me to contribute to research projects in other skin diseases. Most recently I have been helping Esther Burden-Teh with her research development and grant applications to develop a diagnostic tool to help doctors to diagnose psoriasis and psoriatic arthritis in children.



Update on On-Going Trials



We are really pleased to be able to let you know that the [BEEP study](#) has successfully recruited to target. This milestone was achieved over 4 months ahead of schedule, which is truly an impressive feat. BEEP is an NIHR funded, randomised controlled trial to investigate whether applying emollients for the first year of life can prevent eczema in a high risk population. Just under 1300 newborn babies with a family history of eczema, asthma or hay-fever have now been recruited from 15 recruiting centres across the UK. The primary outcome is the proportion of infants with an assessor blinded diagnosis of eczema at 2 years of age. We have now halted recruitment into the study but may open it up again later in the year depending on factors such as follow up rates for those already recruited.



There is also good news to report about the [Hi-Light study](#) as this trial has now recruited over half it's recruitment target. This randomised controlled trial is assessing hand-held narrowband UV devices, alone and in combination with topical steroid, for early focal vitiligo. The trial, funded by the NIHR HTA, is aiming to recruit 440 participants, aged 5 years and above, with limited non-segmental vitiligo (affecting <10% of body surface area) which is of recent onset or actively spreading. The trial is recruiting at 16 sites across the UK with individual participation lasting 21 months (9 months of treatment and 12 months of follow-up).

Opportunity to Get Involved— Discussion Group on 'Long-Term Control' of Eczema

If you have eczema or care for a child with eczema, we are interested in your opinions. We would like you to take part in an online discussion group (approximately 60-90 minutes) to discuss your experiences of long-term management of eczema.

For more information please email: eczema@nottingham.ac.uk or telephone: 0115 8468634

Recognition for the BLISTER study at BAD Annual meeting



A presentation given by Prof Hywel Williams on the [BLISTER trial](#) (doxycycline versus prednisolone for initial treatment of bullous pemphigoid) on behalf of the BLISTER Study Team has been awarded the CDA Trophy for Best Scientific Session paper at the 96th [Annual Meeting](#) of the British Association of Dermatologists (BAD), which was held in Birmingham on 5th - 7th July 2016. We are really proud of this achievement as it is a real testament to the dedication of the study team and all the recruiting centres and patients involved.

Meet a Member of CEBD Staff—Esther Burden-Teh

Esther joined the CEBD in August 2014 as a Clinical Research Fellow. She is a Dermatology Registrar and is taking time out of her clinical training to undertake a PhD and specific research training. Over the past 2 years Esther has been a UK Dermatology Clinical Trials Network (UKDCTN) registrar fellow and is now part of the UKDCTN Trial Prioritisation and Generation Group.

Esther's research interest is in psoriasis and psoriatic arthritis in children. Her PhD is focused on developing diagnostic criteria to help improve the early recognition of psoriasis in children and also improve the quality of research studies in this area. As part of her PhD, Esther has also interviewed dermatologists and rheumatologists, and undertaken a review mapping epidemiological studies in childhood psoriasis.

Esther is also involved in other research projects such as designing a randomised controlled trial to investigate psychological interventions in vitiligo. She is interested in engaging children about research and skin disease, and with Carron Layfield has had the opportunity to be a part of University of Nottingham outreach events and National Science Week at a local primary school.

In her spare time Esther enjoys travel, good food and walking in the Lake District.



Feedback on Projects from CEBD Patient Panel Training Event Saturday 11th June

Knowledge Mobilisation in Eczema: Getting Research into Practice

This NIHR funded study was presented by Dr Fiona Cowdell, a nurse and researcher from the University of Hull who is interested in finding new and creative ways to ensure that people with eczema and people who provide eczema care have easy access to understandable, up-to-date evidence on the best treatments for eczema. The first part of the study involves observing eczema consultations in general practice, interviewing health care practitioners and reviewing the available evidence. Fiona found coming to the day particularly helpful as it:

- Gave her an opportunity to hear patient and carer perspectives which are often significantly different from those of care providers.
- Put her in touch with members who were interested in becoming more involved in the project.
- Helped inform completion of the Research Ethics application which was well received.

Eczema Health Economics Study

This NIHR funded study was presented by Emma MacManus, a research assistant in health economics from Norwich. The project is addressing how to prioritise the available research funding across the different treatment uncertainties identified by the Priority Setting Partnership on treatments for Eczema. Emma commented:

- The resulting discussion was very useful, as it identified that the 'step up' approach used in children was not often applied in adults - with initial treatments more likely to be the strongest medication available to 'nip it in the bud,' (as opposed to trying a lower potency first).
- Panel members helpfully reminded her that guidelines and what occur in practice are often very different! And this is something they need to take on board when progressing this work.
- It was very informative to find out about the online communities they were a part of, as it gave her ideas of how they might be able to reach additional patients for future work.

Eczema NIHR Programme Grant Application—Supporting self-care for eczema

The aims of this work are to develop interventions to support eczema self-care, to provide better evidence to address the safety concerns around the use of topical corticosteroids in eczema and to explore how to embed interventions for eczema within existing clinical care pathways. Prof Kim Thomas reported back that discussions with the panel:

- Confirmed that young adults may have very different eczema support needs compared to older adults with eczema in particular-
 - i. Young people are more likely to be still hoping that the eczema will get better and be less focussed and committed to using their treatments effectively (more distracted by life).
 - ii. They are more likely to be exposed to trigger factors (eg swimming, music festivals).
 - iii. Late teens / early 20s can be a particularly difficult time for people (lots of changes in their lives, usual support mechanisms not so available, more time consuming to treat as larger areas affected as they grow up, peer pressure particularly important, eg impact of grease on clothes).
- Highlighted issues around access and acceptability of a website versus apps / videos etc.—need to work more on making the intervention attractive and inviting to users, as well as being easy to access on multiple platforms (especially if targeting teenagers and young adults) ie tailoring of the intervention is likely to be really important.
- Showed the need to adopt a marketing approach.
- Indicated that it would be useful to get a sense of how committed people are to their treatments at the start of the trial as this will affect their attitudes and interaction with the website.
- Showed a universal dislike for the term “emerging adults” – so this term will not be used in any materials aimed at participants.

Long-Term Control– What Does This Mean to Eczema Patients and Carers

Laura Howells, a British Skin Foundation funded PhD student at CEBD, discussed how the terms used to describe “long-term control” of eczema are variable and that their meaning is not always easily understood. Laura presented some data from an online survey that illustrated what were people’s preferred terms. She’s stated that feedback from the panel was really useful in:

- Helping to gain an understanding into why people with eczema and carers preferred using certain terms to describe their eczema over other words.
- Identifying panel members to help further with this research by providing feedback on the questions she hopes to use in online discussion groups to discuss the long-term management of eczema with adults with eczema and carers with eczema. These comments have been really useful and insightful and will hopefully have a big impact on ensuring the discussion groups are successful. Please see page 2 if you’d like to take part!