



Patient Panel Newsletter

www.nottingham.ac.uk/dermatology

The DIPSOC study

The [DIPSOC study](#) is now open and recruiting! It is a study to develop **D**iagnostic criteria for **P**Soriasis in **C**hildren and will be recruiting 320 children and young people under the age of 18 to take part. The study will be testing how well a list of expert-derived 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. The study will also look to create the best predictive criteria from the items that are tested. Overall, the DIPSOC study aims to improve how health professionals recognise and diagnose psoriasis, and improve the quality of research about psoriasis in children and young people.

Recruitment has started well and 50 participants have been recruited to DIPSOC so far. The study is open at eight sites including Nottingham, London, Middlesbrough, Cambridge, Coventry, Sheffield, Glasgow and Dorchester. DIPSOC is funded through the National Institute for Health Research via a [Clinical Fellowship](#) awarded to Dr Esther Burden Teh a trainee dermatologist and Clinical Fellow based here at CEBD—some of you may have met Esther at previous patient panel meetings.

Young people, parents and members of the CEBD patient panel have already provided important input on the design of the study, application for funding and the patient information sheets. It is really great to see everyone's hard work coming together. Towards the end of 2018, the next step will be to make sure the criteria coming out of the DIPSOC study are easy to understand by all (including patients). So watch this space



The Impact of Priority Setting Partnerships on Dermatology Research

A [Priority Setting Partnership \(PSP\)](#) is a collaboration between healthcare professionals, patients and their carers/relatives to prioritise research questions for a specific condition. The central aim is to encourage research that answers questions that are important to ALL groups. The end point of the priority setting exercise is to produce a final list (often a top 10) of agreed research questions that are then publicised widely and sent to potential funders. The results of PSPs are used by funders, such as the [National Institute for Health \(NIHR\)](#), to prioritise research questions for funding calls and by other groups such as [Cochrane Skin](#) to prioritise and conduct systematic reviews.

There have been six skin-related PSPs completed in the UK since 2010 ([eczema treatments](#), [vitiligo](#), [hidradenitis suppurativa](#), [acne](#), [alopecia](#) and [cellulitis](#)), which is more than in any other clinical specialty. CEBD have been involved in most of these, with CEBD Patient Panel members actively taking part in project steering committees and related workshops. These PSPs have significantly influenced the agenda within the dermatology research community, with a number of funded studies having been instigated by a PSP Top Ten question. For example, the [Hi-Light vitiligo study](#) was developed in

response to an [NIHR commissioned call](#) which followed the vitiligo PSP and the newly funded SAFA study (Spironolactone for Adult Female Acne) resulted from a similar NIHR initiative after the acne PSP.

It is important to remember that it can take 2-3 years for clinical trials such as these to be developed and the funding calls can take time to appear, so it may be some years before a study arises after a PSP. This is well illustrated by the work related to hidradenitis suppurativa (HS). The HS PSP was completed in December 2013, but the NIHR have only recently issued a funding call on this disease as a lot of work needed to be undertaken to be ready for a study in this previously under-researched area. We are currently working with a team in Cardiff on this with support from the [HS Trust](#) (*What are the best management options for hidradenitis suppurativa when first line treatments fail?*) and will know whether this funding application has been successful towards the end of the year.

CEBD continues to be significantly involved in dermatology PSPs and there are three on-going which are expected to finish this year: [Psoriasis](#), [Lichen Sclerosus](#) and [Hyperhidrosis](#). If you or someone you know are affected by any of these conditions please do encourage them to take part— as illustrated above this is a really worthwhile way to effectively contribute to research.

Working with patients to develop research on Blistering Skin Disorders—feedback from a recent visit to CEBD



Isobel Davies and Ingrid Thompson write below about visiting CEBD to discuss some new research projects related to blistering skin disorders, an [area of interest](#) for researchers at CEBD.

They are both involved in a patient support group called [Pem Friends](#) which aims to provide help and support to patients and carers affected by blistering disorders such as [pemphigoid](#) and [pemphigus](#). The Priority Setting Partnership element of this work has been funded by a pump-priming award from [Nottingham University Hospitals Trust](#) and an application is being submitted to the NIHR funding stream [Research for Patient Benefit](#) for the database work.

“The Nottingham based Centre for Evidence Based Dermatology is proposing to conduct research into Pemphigus Vulgaris (PV) and Bullous Pemphigoid (BP) across the UK. In preparation for writing a research funding application, the main researchers wanted to get patient input and, as part of that, invited PEM Friends to collaborate. We went along to hear about it and to represent our initial views.

One aspect of the research is to identify the number of people across the UK who have either PV or BP, and what treatment they are receiving. They will do this via a large national GP database. The other element is the

establishment of a “Priority Setting Partnership”, which involves surveying as many patients (and clinicians) as possible, to establish what the main questions or issues are that people would like to have addressed. These will form the basis of future research priorities.

At the meeting, we discussed a range of issues that affect us as patients and the scope of the first part of the work. We also talked about how the data might be best collected from as many people with PV or BP as possible.

Due to the serious side effects of the steroids which are commonly used to treat the disorders, there is an urgent need to conduct high quality trials to find better treatments. Because these conditions are rare it’s really important to find out how many patients there would be to take part in the trials and how they are currently treated.

We will continue to help support this research by becoming involved as co-applicants and providing input into the planned research on an on-going basis. We will also liaise with members of our PemFriends Facebook group to help provide information.”

Isobel Davies and Ingrid Thompson, PEM Friends

New BAD Acne Support Website

This spring the [British Association of Dermatologists](#) (BAD) will be launching Acne Support (www.acnesupport.org.uk). The public-facing website is a new and exciting digital platform that brings expert acne education to a wide audience (please note that although not currently live the website will be available very shortly). This is a much needed resource as there is currently no official UK based patient support group for those affected by acne. Areas such as acne causes, treatment and prevention are covered in detail. The website also provides advice on acne scarring, myth busting and emotional support. It is the association’s hope that patients, clinicians and the wider public will find the website a valuable resource. Other BAD supported patient resources include [Skin Support](#), a website which aims to provide emotional support for those affected by skin disorders, and a range of [patient information leaflets](#) which are written by experts in the field and regularly updated.

Other things of interest.....

- We are starting to plan for the next CEBD Patient Panel event which will be taking place in the Autumn (date to be confirmed)—please do let [Carron Layfield](#) know if there is anything research related you would like covered at the meeting.
- After a few issues related to the prescribing of the study emollients, the BEE study (Best Emollient for Eczema) is now up and running again and actively recruiting, with 40+ patients recruited to date—please see the [study website](#) for more information.
- More resources are now becoming available on the [INVOLVE learning and development webpages](#)—check out the [top tips](#) and [learning needs tool](#).