



Patient Panel Newsletter

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Public Contributor Day for NETSCC— Amanda Roberts

Did you know that a dog who had detected a cancerous growth on its owner, started our wonderful Hywel Williams on his journey of involving patients, carers and the public in his research plans? On a Monday in October I was at a Public Contributor Day for [NETSCC](http://www.netsc.ac.uk) and Hywel opened his talk to us with this canine fact.

The NIHR, Evaluation, Trials and Studies (NETS) programmes, fund valuable independent research for health and social care decision makers. They are managed by the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC). [The NIHR \(National Institute of Health Research\)](http://www.netsc.ac.uk) is funded solely by the NHS and is effectively the research division of the NHS. NETS are not the only funding streams to originate in the NIHR, but are a significant one.

Public Contributor Days happen maybe once a year, and I thought this was mainly for public contributors recently appointed to roles on funding committees, or maybe as reviewers of funding applications. Spaces were limited and there were only just under 60 attendees, and some of the people there were old friends who already have lots of experience of standing up for patients in research settings. The main purpose of the day was to provide some training and critical appraisal skills, but also to see how patient involvement could undergo a step change throughout NHS research.

I was typical of the demographics of the meeting. White,

female and on the wrinkly side of middle age. As the advert says, there are other types available! This is worth thinking about and was covered at the meeting. In PPI (patient and public involvement – what we all do in the CEBD patient panel), we do not necessarily tap into children's voices in the same way we do for adults and carers. Migrants, travellers, comorbid mental health issues, prisoner populations and those affected by autism (dermatology is so sensory) etc are also important. We then have to think about how we try to best include these groups in research as co-producers of research. Sometimes that means not just convening meetings in the daytime but a whole range of ways of engaging people and out of hours. Doing this is challenging, but nevertheless looking at working with under-represented groups was a point that came through.

Another message from the day was that within any large project grant team, a person should be nominated as the PPI lead to support the PPI collaborators and 'look after them properly'. PPI after all is all about relationships and genuine commitments from the top. There is no doubt that Hywel was a star speaker and because of my connection with Nottingham, people commented to me how impressive they found that the CEBD has a patient panel, wishing that they could connect in to something similar for their condition or their area.



Cochrane Crowd

[Cochrane Crowd](http://www.cochrane.org/crowd) is a new initiative that will enable anyone to get involved with [Cochrane](http://www.cochrane.org) and help identify the evidence needed to make informed healthcare decisions. This is a great way to get experience in searching and screening for studies, which then go into the [Cochrane Central Register of Controlled Trials, CENTRAL](http://www.cochrane.org/central).

CEBD 2015-16 Impact Review Coming Soon

The CEBD 2015-16 Impact Review will be available in the New Year. If you would like to be added to the mailing list for this publication, which summarises key CEBD activities over the past two years, please contact [Carron Layfield](mailto:c.layfield@nottingham.ac.uk). You can find previous reports on the [CEBD website](http://www.nottingham.ac.uk/dermatology).

On-line Training Opportunity from CEBD

CEBD has a 5-year plan to develop teaching material for healthcare professionals and students with an interest in evidence-based dermatology. As the first stage in this process we are pleased to announce the launch of a short online e-learning package on **how to conduct critical appraisal of a scientific paper in the field of dermatology**. This new resource, which is free of charge and available for use across the world, can be accessed at http://www.nottingham.ac.uk/toolkits/play_15277. Please do take a look at this course as, although it is primarily aimed at healthcare professionals, we feel it will be a good learning opportunity for our patient panel members too.

Study and Funding Update

A quick update on some CEBD-related studies which have had various level of input from the Patient Panel over the past few years—many thanks to all those who have contributed.

BATHE—the bath emollients for eczema study has now completed recruitment and study results should be available by the end of 2017.

Hi-Light—recruitment is almost complete for this study investigating the use of hand held UVB devices to treat vitiligo. Due to the length of the treatment and follow up period, study results will not be available until towards the end of 2018.

TREAT—the health economics study has now been funded for this trial, which is investigating the use of systemic treatments for severe paediatric eczema.

BEE—this study, comparing the use of the four most commonly prescribed emollients in primary care for the treatment of eczema, has now been funded by the [NIHR HTA](#) and should start recruiting patients in the next 6-12 months.

Eczema and Anaemia study—we are really sorry to have to let you know that the funding application to [Action Medical Research](#) for this database study investigating links between eczema and anaemia was not successful. The study was rated as being of both high quality and importance, but the funding body unfortunately did not have sufficient funds available to meet demand. The study team are now investigating alternative funding sources for this work.

Priority Setting Partnerships

The second stage survey for the [cellulitis priority setting partnership](#) will be live from the end of December 2017 for 6 weeks. Please circulate this link, when we send it out to you, to anyone you know who has been affected by [cellulitis](#), so they can have their say in helping to set future research priorities in this area.

We are really pleased to be able to let you know that we have obtained funding from the [British Society for the Study of Vulval Disease](#) to undertake a priority setting partnership in [Lichen Sclerosus](#). If you are aware of anyone affected by this condition who might be interested in getting involved, then please encourage them to contact [Dr Rosalind Simpson](#), who is leading this project.

Meet a Member of CEBD Staff Laura Prescott

Laura will soon be the Managing Editor of [Cochrane Skin](#), having started as Editorial Assistant for the Group in 2009! She works full time and oversees editorial process activities to ensure that protocols and reviews are successfully prepared for publication. One of her main roles is to ensure that submissions meet quality standards, which involves checking them against the mandatory Cochrane standards (known as 'MECIR': Methodological standards for the conduct of new Cochrane Intervention Reviews). She works with her colleagues to provide specialist advice to international

review teams, in order to encourage progress and remove barriers to facilitate completion of their work. Another important aspect of the latter is the management of timelines and prioritisation of the Group's work load. Ensuring that working practices remain highly efficient is another aspect of the Managing Editor role. Laura is also a qualified Cochrane copy-editor.

In her spare time, Laura likes going out for meals, going to weekly exercise classes to counter going for the meals, seeing her Grandad's dog, listening to comedy podcasts, and eating Lindt chocolate.

