

Patient Panel Newsletter

www.nottingham.ac.uk/dermatology

New National Standards for Public Involvement in Research

Over the last 18 months a [UK wide partnership](#) have been involved in developing a set of standards and indicators for public engagement in research. The objective of the [standards](#) is to improve the quality and consistency of public involvement in research. They aim to do this by providing clear and concise benchmarks for all involved along with indicators against which improvement can be monitored. They are not intended to be used as guidelines but as a framework to encourage effective and meaningful public involvement and to see how it can be bettered.

The standards cover six key themes as follows: [inclusive opportunities](#), [working together](#), [support & learning](#), [communications](#), [impact](#) and [governance](#). The standards are currently being evaluated over the next 12 months at [ten test bed sites](#) across the UK to see how well they work in practice.

We are starting to look at what we do here at CEBD in relation to the standards and hope to get your input into this at the next CEBD patient panel event, which is taking place in Nottingham on Sat 29th September—please let [Carron Layfield](#) know if you'd like to attend.

Meet a Panel Member—Irene Soulsby

I'm Irene and live in Newcastle upon Tyne and have recently joined the group.

My acne started in the late 1960's, when I was about 10 and lasted for the best part of 20 years. In those days, it was suggested that it was "diet", "too much sugar", "part of growing up" but I still remember having a very difficult time, especially in my teenage years. I don't think that it was ever mentioned that it might have been connected to hormones and investigated further. When I was 30 my condition seemed to "mysteriously clear-up" overnight. Although not life-threatening, I do remember having a really grotty time. I think it must be a lot harder now, with social media being everywhere.

I saw that Southampton Uni were looking for a PPI member for a clinical trial for acne and was delighted to be accepted. This is the SAFA study (Spiranolactone for Adult Female Acne) and was developed with support from the [UK Dermatology Clinical Trials Network](#). The tasks involve looking at documents and commenting wherever possible and we also have regular phone calls with a vast team of people. Even though I have just turned 60, I found that the questionnaire about Quality of Life seemed to echo what I was going through all those years ago and that I have not seemed to have forgotten about! It's been really

interesting to find out about how a trial is started and run. It's very complex and complicated, but what is great is that is that researchers are trying to identify a successful treatment and finding out how people feel and their experiences.

I was asked if I would like to come along to the [Annual Evidence Update Meeting](#) in Nottingham last month as it was on acne and hidradenitis suppurativa (HS) and I jumped at the chance. Alison Layton from the SAFA trial was giving a presentation about the study. The presenters (from all over Europe) talked about maintenance of acne treatment, laser therapies and potential new treatments. It was all very interesting and all gave me a greater insight into acne and its complications. It was also the first time that I had heard about the condition HS and Ceri Williams (a HS patient) gave an account of her life after diagnosis, a very moving and honest talk.

It was a great opportunity to visit Nottingham Campus (it's amazing!) and am very proud of my Certificate of Attendance! I left school when I was 16 and amongst my friends that was the norm, however, you are never too old to learn and participate and I love my "University years".

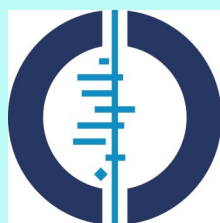


Rosamund Snow Prize to Attend the 2018 Cochrane Colloquium

As reported back in December, the theme for the [2018 Cochrane Colloquium](#) (taking place in Edinburgh 16th-18th Sept) is 'Patients Included'.

The [Rosamund Snow Prize](#) has been established to provide funds to enable two young people (aged under 30 and resident in the UK or Eire) to attend this conference. To be eligible they should have experience of using health services and an interest in health research.

Please do share this with anyone who you think might be interested in applying. The [application process](#) is relatively short and includes a 200 word summary of experiences of using health services and what attendees think they'll get out of going to the meeting. The deadline is **20th June 2018** so you'll need to be quick!!



Summary of feedback from CEBD Patient Panel on the SOFTER participant online questionnaire

We are very grateful for the enthusiastic response from members of the CEBD Patient Panel to our request for feedback on a participant questionnaire for the SOFTER study. The feedback identified errors and inconsistencies in the wording of questions and identified where questions might be interpreted differently by individuals. As a result of this feedback, we have made a number of changes to the wording of the questions and we have even removed some questions altogether. The feedback on practical aspects, such as time taken to complete the questionnaire and problems with receiving the email containing the questionnaire link due to spam filters has helped us to provide more accurate instructions to participants. The questionnaire is now more user-friendly and this will result in higher completion rates and, therefore, more accurate study data. Thank you to all those who helped with this!

Dr Carsten Flohr & Dr Zarif Jabbar-Lopez, Lead Investigators, Softened Water for Eczema Prevention (SOFTER)



General Data Protection Regulation (GDPR)

The new European Union [General Data Protection Regulation \(GDPR\)](#) came into effect on 25th May 2018 and replaces the previous data protection act. In accordance with the GDPR we are issuing this Privacy Notice telling you what information we collect and how it is used. We decided to add it to this newsletter rather than send yet another GDPR related e-mail.....

As part of the CEBD Patient Panel, we collect personal information in the form of names, email and postal addresses, the skin condition (s) you are affected by and a record of your participation in projects/attendance at CEBD Patient Panel events. We use this information to send out these regular newsletters and keep you informed about forthcoming projects to get involved in and relevant training days and meetings. The information is kept in a password protected database which only a very limited number of staff at CEBD can access.

If, at any time, you no longer wish to be a member of the CEBD Patient Panel then please just get in touch with [Carron Layfield](#) and we will remove your details from the database.

Other things of interest.....

- The [BATHE eczema](#) study made quite a splash in the news when the study results were published recently—did you see any of the team on the news? There is a useful [animation](#) summarising the study results which showed that bath emollients do not really help in childhood eczema.
- CEBD Co-Director Prof Hywel Williams will be a guest on The John Holmes Sunday Morning Show, Radio Nottingham on Sunday 17th June. It will be available on [i-player](#) so why not listen in?
- Keep your eyes out for a [new video about the UK DCTN](#) - many thanks to patient panel member Amina Ahmed for giving a patient perspective on clinical research.
- Did anyone else notice the [Skin Deep](#) garden at the RHS Chelsea Flower Show last month? It won a silver gilt medal and aimed to show a variety of skin conditions.
- As the NHS turns 70, the National Institute for Health Research campaign '[I am Research](#)' aims to raise the profile of research and highlight the benefits it can bring. Is there something happening near you that you'd like to tell us about?