



Patient Panel Newsletter

Feedback from Training Event Sat 9th Sept 2017

Many thanks to the nine patient panel members who attended the CEBD Patient Panel training day on Sat 9th Sept at the University of Nottingham. Sessions in the morning included an update on CEBD activities over the past 12 months and a presentation from guest speaker Rod Tucker, a pharmacist from Hull who gave a really interesting presentation on a study he'd conducted investigating how pharmacists can better support psoriasis patients – something he wishes to replicate for other skin conditions in the future. A training session of the research lifecycle and a workshop to help develop a template for requesting input from panel members into studies followed. We are now working on developing this template further and hope that it will make it easier for you to understand what is needed when we're asking for feedback and for you to get involved in projects.



The afternoon involved workshops on the newly funded [National Institute for Health Research \(NIHR\) Programme Grant involving a self-care programme for eczema](#). These sessions were led by Kim Thomas (Nottingham) and Miriam Santer (Southampton) who are the project leads. This included reviewing current patient decision making tools to help with initial ideas on how on-line resources linked to this programme will be formatted. A session was also held focussing on the attitudes and feelings of eczema patients towards the use of topical corticosteroids as this area is another workstream of the project. Feedback from both session leads has been very positive with Miriam commenting that the session on topical corticosteroids opened a really important and much needed debate. The day finished with a review of a number of health economics projects from Tracey Sachs and Emma McManus (Norwich).

We were really pleased to be joined on the day by Sandra Lawton, a dermatology nurse consultant who has written an inspiring blog about the day for [Nursing in Practice](#) with contributions from panel members Tim Burton and Amanda Roberts. Please do let us know your ideas for future meetings then we can try to ensure we meet your training needs.

Meet a member of the CEBD Patient Panel — Patricia Fairbrother

My working background has always been in healthcare, mostly managing surgical practices. I have a history of skin cancers, primarily basal cell carcinomas (BCCs) all having required surgery, over several years, I also have a history of breast cancer and it was following that particular diagnosis that I originally became an enthusiast in the developing role of patients in advocacy.

I joined a national cancer charity as a member of their newly formed advocacy steering group. Subsequently, after having two more BCCs I looked for areas I could use my advocacy skills in skin. I felt I had a lot to bring to skin as breast cancer has a very strong patient representative focus. I have been a patient representative for the past four years on the regional clinical advisory group for skin cancer, managed through the East Midlands Clinical Network, plus a consumer representative for the clinical studies group for Skin at the [National Cancer Research Institute](#). This role has given me a chance to become involved in the management of a number of skin cancer

clinical trials.

I am a trustee of the patient led cancer charity, [Independent Cancer Patients Voice](#), specialising in patients partnering with researchers, providing comment and opinion on study applications. This charity has a unique focus in that it provides patient experience in an unfiltered way and offers regular training opportunities. Most members are involved with the designing and running of at least one clinical trial.



I am also involved in skin cancer guidelines for the British Association of Dermatologists, and have just taken on a patient representative role on the steering group of the [UK Dermatology Clinical Trials Network](#). I joined the CEBD Patient Panel approximately two years ago, and attended my first panel meeting on 9th September this year and found the people I met quite inspirational and hugely knowledgeable. I look forward to a long association with the group.



Cochrane Skin celebrates 20 years—are you interested in getting involved in new priority systematic reviews?

[Cochrane Skin](#) is a network of people from around the world committed to producing and updating systematic reviews relating to skin conditions to help provide better evidence on healthcare interventions. With its editorial base at CEBD, the group has recently celebrated its 20th birthday and part of the celebrations included undertaking a programme of work to identify a number of priority new review titles listed below:

- Interventions for pruritus of unknown cause
- Network meta-analysis of topical eczema treatments
- Network meta-analysis of systemic eczema treatments
- Interventions for folliculitis and boils

The input of patients and carers into these reviews is vital so if you would like to get involved please let us know by contacting CEBD Patient Panel Co-ordinator [Carron Layfield](#). You can contribute in lots of ways – for example reviewing and contributing to lay (Plain English) summaries of reviews and help and support is available from the [Cochrane Consumer Network](#).

NIHR Signal highlights eczema research

[The National Institute for Health Research \(NIHR\) Dissemination Centre](#) aims to put good research evidence at the heart of decision making in the NHS, social care and public health.

Linked to National Eczema week (16th-24th Sept) there has been a recent highlight from this dissemination centre focussing on the impact of [NIHR funded eczema research](#) which includes a number of CEBD studies. The highlight includes a summary of the research, the implications for clinical practice and guidelines and a number of blogs from patients and carers (including some panel members) along with signposts for more information.

Update on Priority Setting Partnerships (PSPs)

There are two on-going [priority setting partnerships](#) on skin disorders being conducted at the moment; the psoriasis PSP (funded by the [Psoriasis Association](#)) and a PSP on lichen sclerosus (a long-term skin condition mainly affecting the genitals, funded by the [British Society of Vulval Disease](#)).

The [Psoriasis PSP](#) will be collecting research uncertainties until the end of October 2017 so please do take part if you are affected by this condition. The [Lichen Sclerosus PSP](#) is at a similar stage but with over 1800 uncertainties submitted to date the first stage of the process will close shortly.

A PSP on [hyperhidrosis](#) is at the planning stage and should be launched early next year—please do let us know if you (or someone you know) is affected by this condition and would like to get involved in the project.

BBC3 programme featuring vitiligo

Dr Jonathan Batchelor, a Consultant Dermatologist based in Derby and honorary researcher at CEBD, has recently contributed to a [BBC3 programme on vitiligo](#). The film is about living with vitiligo and the profound psychological effect it can have on affected individuals. It also looks at ways in which people with vitiligo can live positively with the condition, embracing the way in which it makes them stand out from the crowd and is a thought-provoking look at how to live positively with a long-term, visible skin condition.

Meet a member of CEBD staff—Natasha Rogers

Graduating from the University of Nottingham in 2009 with a Masters degree in Biochemistry and Biological Chemistry, Natasha went on to attain a PhD for her work in Respiratory Medicine. She joined the Centre of Evidence Based Dermatology in 2013 and is now the lead for our research impact and communications.

Natasha's core activities facilitate the communication of research; she designs and produces many of the graphics, flyers and newsletters used to disseminate and promote CEBD research and resources. She was responsible for the redesign of the CEBD website in 2016,

the production of the [first CEBD online course](#) and currently manages and maintains the eczema [GREAT database](#). Natasha also ensures that the impact of the centres research is captured and is

responsible for our engaging [Twitter account](#) which now has over 1,500 followers. Natasha has recently developed an interest in wildlife photography, and so often spends her lunch break walking around our leafy King's Meadow Campus. Here's one of her photos, taken just outside the CEBD office of a kestrel.

