



# Patient Panel Newsletter

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## Review of CEBD Patient Panel and Public Involvement Activities - Would You Like to Get Involved and Help Shape Future Plans??

We are currently undertaking a review of CEBD Patient and Public Involvement activities (including those of the CEBD Patient Panel) using the [new national public involvement standards for research](#). It's really important that we reflect on what we're doing and try and make sure that such activities remain relevant and fit for purpose, and that all of those involved feel valued and engaged.

Many thanks to those CEBD Patient Panel members who attended the training day in September and provided us with some feedback against these new standards. If you were unable to attend on this day and would like to share your opinions on your experiences of being involved with CEBD research activities to help with this, then please do [get in touch](#) so we can take your comments into account.

We're now working on developing an action plan to help improve how we all do things. It's really important that we do this as a team with input from both CEBD staff and panel members—if this is something you'd like to get involved in moving forwards, then [please let us know](#).

### Meet a Panel Member—Tim Burton

Hi, I'm Tim and I live and work in Nottingham. As a child I had mild eczema, mainly behind my knees. It didn't cause me too many problems, but I do remember it being really itchy and annoying at times. In my early twenties my eczema suddenly got much, much worse, to the point where it was very bad and affected every inch of my skin. I really struggled to cope with it. The constant itching and pain was draining. Steroid creams only helped a bit despite repeated use. After being hospitalised for a few weeks I started a systemic treatment which helped a lot and allowed me to continue my life despite still being affected by eczema symptoms and having to spend a lot of time putting creams on. Since then I have had to continually use one systemic treatment or another to try and keep my eczema under control.



I first became aware of the CEBD Patient Panel through an advert in the [National Eczema Society](#) magazine (Exchange) asking for volunteers to join the panel. I made a phone call, had a nice chat with Carron and was encouraged to attend the next meeting, which I did. That was nine years ago. I have attended nearly every meeting since and have enjoyed every one. It is so great to meet and share ideas and experiences with others whose lives have been affected by skin disease and to learn more about research and patient involvement.

Since joining the CEBD Patient Panel all that time ago, I have been involved with various research projects, mostly eczema-related. Having struggled with eczema for so many years I feel passionate about being involved in research which will help and improve treatments, and therefore the lives of those with skin conditions. I am currently actively involved with several eczema-related research projects ([HOME](#), [TREAT](#) and [A-Star](#)) and hoping to make a difference for the benefit of all. I am also a member of the [UK Dermatology Clinical Trial Network](#) Steering and Executive Committees, and my involvement in all of these is a result of being a CEBD Patient Panel member. I have been lucky over the years to have had a some great care provided by the NHS and giving up some of my time is a way I can give something in return.

## Hyperhidrosis Priority Setting Partnership Top 10 Revealed

We're really pleased to be able to let you know that the [Top 10 research priorities](#) identified by the recent [Priority Setting Partnership](#) on hyperhidrosis (a common skin condition which affects up to 3% of the population and is characterised by excessive and abnormal sweating) have been finalised. This brings the number of completed dermatology Priority Setting Partnerships to eight, more than for any other clinical speciality.

This top ten includes questions such as identifying the most safe and effective permanent solution for hyperhidrosis, and looking at how the condition affects the quality of life of those affected. This project was funded by the [UK Dermatology Clinical Trials Network](#) and we hope that it will lead to a boost in research in hyperhidrosis, as has happened for other skin conditions where such partnerships have provided valuable evidence for research need in often neglected and under-researched areas.

## Ten years of the CEBD Patient Panel

Did you realise that it's ten years since we established the CEBD Patient Panel, which was set up in 2009 as part of a [National Institute for Health Programme Grant](#)?

We'd love to hear your ideas how about how we can best celebrate this milestone at the next CEBD patient Panel Training Event, which will be taking place later this year (date to be confirmed).

Please do [get in touch](#) with some suggestions but bear in mind that two weeks in the Maldives may be out of the question!!

## Meet a Member of CEBD Staff — Paul Leighton

Paul joined the CEBD in June 2018 as an Associate Professor in Applied Health Research. He has a background in the social sciences (an MA in Social Anthropology and PhD in Sociology) and has worked for fifteen years in applied health and social care research. From 2012-2018 Paul was Deputy Director of the [NIHR Research Design Service East Midlands](#), a unit at the University of Nottingham which supports clinicians in designing and setting up research in the NHS.



As a research methodologist Paul has worked across a number of clinical areas, including hand surgery, hearing, child health and ophthalmology. He is currently working on eczema ([ECO](#)), vitiligo ([HI-Light](#)) and hidradenitis suppurativa ([THESEUS](#)) research studies at CEBD. His work often involves capturing the experiences and opinions of patients and healthcare professionals, providing this more personal type of insight to complement the clinical and economic data that is commonly generated in large applied health studies. Paul has an interest in the social and sociological aspects of healthcare, and often finds himself debating the relative merits of sociological and psychological approaches to health and applied health research (Paul's wife is a psychologist—Paul often loses these debates).

Paul often gets lost whilst walking in the countryside, and is a very bad golfer.

## Other things of interest.....

- The website for the [SAFA study](#) (Spiranolactone for Adult Female Acne) is now live. This is the first UK-based independent clinical trial on acne for many years, and has been developed with support from staff at CEBD and the [UK Dermatology Clinical Trials Network](#) and Patient Panel member Irene Soulsby is involved.
- Dr Robert Boyle, Joint Co-ordinating Editor of Cochrane Skin, which is based at CEBD, appeared on Channel 4's Dispatches Programme '[The Great Formula Milk Scandal](#)' on Mon 18th March
- The new British Association of Dermatologists [patient website](#) is now live—many thanks to all the patient panel members who reviewed the preview site. This website aims to provide reliable information and advice for those living with a skin condition.
- We have been invited to write an article about the CEBD Patient Panel for the '[Partnership in Practice](#)' series which is published on-line in [BMJ Opinion](#)—watch this space!!