Issue 2
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CENTRE OF EVIDENCE BASED DERMATOLOGY (CEBD)

Patient Panel Newsletter

www.nottingham.ac.uk/dermatology

Training Day—Sat 11th June

Many thanks to all those Patient Panel members who have confirmed their attendance at the next Patient Panel Training Day which is taking place at the Hemsley Building, University of Nottingham on Saturday 11th June. As previously communicated, we'll be running training sessions on taking part effectively in teleconferences and the use of big datasets in clinical research. Workshops will cover a number of on-going studies and studies in development including one on how to best get evidence from eczema research studies to those that need it and we really look forward to getting your input into these projects.

Places are still available and the meetings are a great place to catch up with CEBD staff you've been working with remotely, to find out more about research and to get to know your fellow panel members. All relevant travel expenses are covered so if you'd like to attend please just let Carron Layfield know.

Improving Healthcare Through Research Free On-line Course June 2016

Following on from the success of the course held in November 2015, the National Institute for Health Research Clinical Research Network (NIHR CRN) have announced that they are running another free on-line course in June this year. Launching on 6th June, 'Improving Healthcare Through Clinical Research' is a 4 week on-line course which is available free of charge to all. It illustrates how medical treatments are discovered, tested and evaluated and is a great introduction to clinical research.

To find out more about the training and to register please click here.

Friends of CEBD Newsletter

If you'd be interested in getting a more in-depth monthly newsletter about CEBD which includes a listing of relevant publications from the group then please sign up for our 'Friends of CEBD Newsletter' by e-mailing our information specialist Douglas Grindlay .

Meet a Member of CEBD Staff—Sonia Ratib

Sonia joined the Centre of Evidence Based Dermatology as an Assistant Professor in Medical Statistics in October 2014. She has experience analysing large epidemiological studies, teaching statistics, supervising post-graduate students and providing statistical support to NHS professionals.

Sonia's particular research interests are in designing and conducting dermatological studies using linked datasets of routinely-collected data including the Clinical Practice Research Datalink and Hospital Episode Statistics as these data reflect what is seen in clinical practice. She is currently working on a study looking at the risk of eczema in children and how this varies with social deprivation and ethnicity. She is also planning future studies in the area of vitiligo and associated psychological outcomes. Sonia will be running a training session on the use of large databases and datasets in research for the Patient Panel at the next training event on Sat 11th June.

She is co-supervising two PhD projects: one on the development of diagnostic criteria for children with psoriasis and another on improving the use of an instrument for measuring eczema symptoms. During her spare time, Sonia enjoys travelling and spending time with family and friends.

Involving Patients and Carers More Effectively in HOME

The HOME (Harmonising Outcome Measures for Eczema) initiative was founded in 2008 in response to the use of multiple unvalidated outcome measures in eczema trials. The aim of HOME is to agree a set of core outcome measures which should be included in ALL atopic eczema clinical trials and clinical record keeping to allow efficient comparison of data across multiple trials.

Progress has been made towards this goal with agreement being reached on core outcomes for clinician reported signs (EASI) and patient reported signs (POEM) to date. An initial exercise to find out what the dermatology community felt was important was followed by 4 working meetings; HOME I, II, III and IV . The input of patients and carers into HOME is vital but feedback from those who attended previous meetings indicated that we could do a better job with helping them to understand their role in the HOME meetings and what was happening.

With this in mind and in advance of the HOME IV meeting which took place in April 2015 we looked at ways to involve and engage patients better and took the decision to have a Patient Pre-meeting the day before the main HOME IV meeting started (see photograph below). The objective of this was to introduce the patients and carers to each other, explain what was expected of them at the meeting and go through some of the more technical aspects of what was going to discussed at HOME IV. Fifteen patients and carers attended from across the word—including representatives from Brazil, the Netherlands, USA, France, Canada, Norway and Sweden with two from the UK—Tim Burton and Rosemary Humphreys.

Feedback from those who attended indicated that they really valued this pre-meeting and that it helped them participate in HOME IV more effectively. A number of the patients commented that it was really helpful for them to know who the other patients were.

Rosemary explains further below her role in HOME, how she is involved more widely in outcome measures research and why this is important.

Meet a Member of the CEBD Patient Panel—Rosemary Humphreys

I have eczema, as does my daughter and grandchildren. I joined the National Eczema Society when it began in 1975 and have fulfilled various roles within it. In 1997 when Hywel Williams set up the Cochrane Skin Group he invited skin charities to a meeting to discuss getting consumers involved in its work. Since then I have had a PPI role in many areas of research and healthcare (public research partner is the latest term!) but of course dermatology has always been my main interest.

I had never heard of Core Outcome Sets (COS) until I was invited to join HOME but once it had been explained to me it seemed logical – essential in fact – for patients to be involved in defining a set of outcomes to be measured in all research into their condition. After all, while our health professionals and researchers are experts in their field, we are the ones who live with the condition on a daily basis. All of us patients have found it hard to understand some of the work so the HOME IV patient pre-meeting described above was a great idea. We were all very positive about the experience and it was noticeable how much more we contributed to the subsequent HOME meeting.

As a result of being involved in HOME I was invited to give a talk about our PPI work at a COMET meeting in London and at COMET IV. COMET stands for Core Outcome Measures in Effectiveness Trials and is an international 'umbrella' organisation for researchers working on COS. Its database currently contains references to 745 COS. I am the public co-chair of the COMET PPI working group, PoPPIE (People and Patient Participation, Involvement and Engagement). We aim to raise awareness of COS among patients and patient organisations and to develop resources to support patients and COS developers. We recently held a workshop at the Cochrane UK Symposium to raise awareness amongst systematic reviewers. Like HOME, COMET recognises the importance of patients' experience contributing to Core Outcome Sets.