



# Patient Panel Newsletter

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## Reflections from the Involve national meeting 28th November, London

CEBD Patient Panel members Amanda Roberts and Amina Ahmed (pictured right) both recently attended the Involve meeting and share their experiences of this below.

### Amanda Roberts comments

“INVOLVE conferences can be measured in hugs’, is a quote from the INVOLVE conference which ran at Nottingham seven years ago. It was made by Sally Crowe who helped the Centre for Evidence Based Dermatology carry out their Eczema Treatments Priority Setting Partnership. And I know what she means: it is the only conference I have been to where so many delegates seem to be hugging and greeting.

[INVOLVE](#) is funded by the NHS via the [National Institute for Health Research](#) and is to support patients, carer and members of the public to get involved in helping shape research. They hold a conference every two years normally, but we had to wait three years for this one. They are 21 years old this year and during that time the patient and public involvement (PPI) scenery has blossomed. But there is still a long way to go.

This was my third conference and for me it is like a pre-Christmas party which someone else has organised for me and my friends. There are so many people there who I have met through the research funding panels or other PPI work I have the luck to be caught up with. This year’s event was smaller and just one day, whereas previous conferences were two day and had up to ten workshop running in parallel. INVOLVE’s ground breaking paper [“Going the extra mile”](#), which was published three years ago, marked changes within INVOLVE and the reduced conference was an indication of this. This year INVOLVE were seeking feedback on their

### [Standards for Public Involvement](#)

, which are a work in progress but long overdue. So exciting times ahead and if you get the chance to go to a future INVOLVE conference, you know you will be amongst friends.”

### Amina Ahmed says

“This was the first time I have attended an Involve Conference and I thank CEBD for recommending this to me and funding the fees for my attendance!

Having never explored research beyond eczema and the Nottingham area, the event was an eye opener in relation to the number of people and organisations that attend. It was wonderful to see so many patients, representatives and researchers under one roof (the venue itself being stunning, set next to Westminster Abbey!)

The opening presentations from patients on how their life experiences have helped them shape and create charities and research was very impressive and humbling. The breakout areas on research completed, or in progress, showed a great variety of style and content which provided ideas and contacts in relation to some of the projects I am involved in.

The parallel sessions during the day were a really good idea, so you could pick and choose the most relevant sessions to attend based on your experience and interest. I met some amazing people and widened my understanding of how Involve promotes and connects so many people and organisations. The opportunity to pick up more information on what it means to be a patient representative from others was invaluable, and quite reassuring to see so many people from different backgrounds.”



## Letters of thanks/support for your employers

We’re aware that some of you are very kindly given time off work by your employers to enable you to take part in CEBD related research activities. Please do get in touch if you would like us to send a letter of thanks to your employer and to make them aware of how important your contributions are. We’re also more than happy to send letters of support that might help strengthen such requests moving forwards—please get in touch with [Carron Layfield](#) to get this sorted out.

## 'Patients Included' with Cochrane

Each year, the [Cochrane Collaboration](#) holds an international conference in a different location. The [2018 conference](#) is planned for 16 – 18 September 2018 in Edinburgh. Most importantly from the point of view of patient representatives, such as those linked to Cochrane through CEBD, the strapline for the conference is 'Cochrane for all: making our conference a 'Patients Included' event'. '[Patients Included](#)' is an international initiative to encourage the inclusion of patient representatives in conferences and research programmes. The planning for the Edinburgh event has started and during October two meetings were held, in Oxford and Edinburgh, to examine how best this 'patients included' approach will be successful. Peter Smart, a member of the CEBD patient panel, attended the Edinburgh meeting and reports below on his experiences.

"The meeting consisted of ten researchers, academics and patient representatives, as well as representatives of Cochrane. After general introductions and statements of our interest in helping with this initial planning stage, we discussed two questions in depth: what will make the conference appealing and what will make it easy for people to participate? There was a real buzz. We were particularly concerned that patients attending the conference did not feel overwhelmed by academics and practitioners (what one person summed up as 'evidence not eminence'). We looked at ways in which all those there could feel that they were being treated on an equal footing. We also discussed how potential delegates could tap into the conference remotely: what Cochrane calls 'Beyond the room'.



There were some potentially radical ideas to ensure patient inclusion. To dispense with titles in

name badges; to make an early call for topics for plenary or group sessions, and then identify an appropriate researcher/academic/practitioner and a patient representative who would jointly prepare and present the session; to ensure sessions had 'real world relevance' and, where a session might raise more questions than answers, for the presenters to anticipate this and use discussion for pointers to new research.

To meet the requirements of special needs groups who might find the conference overwhelming, and of those who are unable to attend in person for any reason, we agreed that video streaming and other ICT solutions would take the conference 'beyond the room', ideally on a two-way basis. We felt that the structure of the conference could move away from the traditional 'four streams/four sessions a day' to something more flexible, to encourage networking, whilst recognising that it also needed to be manageable. We also suggested ways in which patient reps could be made to feel welcome in a large conference (about 1200 people are expected), noting that some may not have English as their first language and some might be coming from totally different cultures.'

Peter adds, "If any members of the patient panel have ideas for a session, I'm sure Kim, Carron and Jo would be pleased to hear from you. I understand there will be a number of bursaries available to enable patient reps to attend the conference. I'll try to keep you updated."

If you're interested in finding out more then the [conference website](#) is now live and the [first conference newsletter](#) to be issued after the recent meetings is available with information also on the interesting and informative blog [Evidently Cochrane](#).



## INVOLVE learning and development update

For the past 12 months [INVOLVE](#) have been co-ordinating a learning and development group to enhance the resources available for providing training and support for all involved in patient and public involvement in research. As part of this a 'Find and Share' website will be made available in 2018 providing access to information about training courses, learning and development opportunities and other resources. A [test page](#) is currently available and we will of course keep you informed - you can also [sign up](#) for relevant updates via their e-newsletter.