



Patient Panel Newsletter

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Reflections on the CEBD Patient Panel Event, Saturday 12th October

Panel member Kate Sykes writes below about her experiences of attending the recent event.

I attended the Patient Panel event, having missed out on last year's I was looking forward to catching up with members new and old! It was an interesting day and I'd like to share some of the highlights that I took away from it.

To start, we had updates from other Panel members. This was a great opportunity to hear what they have been up to and it gave me a true window to their Patient and Public Involvement (PPI) activity, something you don't always see throughout the year.

Hearing from Adele Horobin, a PPI manager and one of the PPI panel members from the [Nottingham Biomedical Research Centre](http://www.nottingham.ac.uk/dermatology), was next. As my PPI involvement is focused on eczema, it was insightful to learn how PPI is used in other areas of research. I found it helpful to hear of how they collaborate as a team. They offered some really useful information and by sharing some of these best practices, it could make our CEBD PPI work even stronger.

After lunch, we held a workshop session where we broke off into separate groups to discuss studies that need PPI

input. It invoked some passionate discussion and it certainly made me think from a different perspective.

The day was finished off by a brilliant presentation from Hywel Williams who was talking about dermatology research over the past 10 years, including PPI and how imperative it is to successful research. His talk was so engaging and inspirational. A great end to a very well organised day. Can't wait for next year!



Message from panel co-ordinator Carron Layfield: It was great to see so many panel members at the event—14 of you attended and we got some great feedback about the day. We're now looking for ideas to help us plan the 2020 meeting so please [do let me know](#) what you'd like to see happening.

CEBD News and Updates

- We're really pleased to be able to let you know that the BEE study, investigating the best emollient for childhood eczema, has recruited to target and recruited 550 participants. Due to the 12 month follow up period, the study results aren't anticipated until Spring 2021—please see the [study website](#) for further information.
- The first round survey for the blistering skin disorders Priority Setting Partnership (PSP) is now live. This PSP will identify future research priorities for treatments of bullous pemphigoid, pemphigus vulgaris and mucous membrane pemphigoid. If you, or any family or friends are affected by these conditions, please share your treatment uncertainties for these diseases by [taking part](#) in the questionnaire. The PSP is supported by the patient support group [Pemfriends](#), with Panel member Ingrid Thompson on the Steering Committee.
- The successful application for the 2019 UK DCTN Themed Call on Dermatological Surgery was for a Priority Setting Partnership in skin cancer surgery and Panel member Pat Fairbrother has joined the project team.
- We're really pleased to let you know that long-standing panel member Amanda Roberts, who also runs the [Nottingham Support Group for Carers of Children with Eczema](#), has been short-listed for the [NIHR School for Primary Care Research](#) Exceptional Contribution to Patient and Public Involvement Prize. The prize will be announced at an upcoming event on 26th November—well done, well deserved and good luck Amanda!!!

To Boldly Go ... to the Cochrane Colloquium that sadly never was

Panel member Peter Smart writes below about his recent experiences traveling to Chile (an eventful trip!!).

Those who were at the CEBD Patient Panel annual meeting on 12 October will recall my enthusiastic presentation, that I had been selected to present a paper to the annual [Cochrane Colloquium](#) in Santiago de Chile on 22 October. Sadly, the Colloquium never took place. Here's my journal.

Saturday 19 October. My darling wife gets up at 03.00 to drive me to Aberdeen airport to catch the 06.00 flight to Amsterdam.

Sunday 20 October. After three flights, I arrive Santiago at 03.15 local time. Walk across the forecourt to the airport Holiday Inn, where my head hit the pillow and I slept till 10.00. Take my pre-booked taxi to the conference hotel where I was expecting to meet others from the [Cochrane Skin Group](#) the following day. **But!** Shortly before my flight left Amsterdam for Panama, I received a WhatsApp from my son, 'Be careful in Chile. Lots of demonstrations in capital.' Then I caught sight of a headline on MSN, about the increasing level of civil unrest in Santiago. Whoops! What had started as a student protest against increased metro fares was turning nasty and apparently bringing every disaffected group onto the streets.

Sunday afternoon Now at the Novotel in Vitacura, one of the most peaceful and pleasant suburbs in the world (pictured above right). Then the WhatsApp messages started to arrive. First, to say that the Cochrane Board were holding an extraordinary meeting to decide whether the Colloquium could go ahead, in view of night-time curfews and minimal public transport services. Then, to say that the Colloquium was cancelled in its entirety as a precautionary measure, in case the volatile situation got worse with hundreds of delegates in town. Then, another to say that a gathering of those known to have arrived would be held at the Hyatt Place hotel at 17.30 but that the curfew that evening would start at 19.00.

I went to the gathering for a while, but knew I had to walk



back the short distance to my hotel by 19.00. Didn't want to be arrested as a curfew breaker! Sat watching local news whilst I had dinner: a supermarket totally destroyed by fire, other buildings being torched, 5 dead in one incident, 2 in another, military on the streets down-town. Vigilante groups being set up in middle class housing areas to protect their properties. All at least several miles from my hotel. But who could tell what the morrow might bring?

I soon realised there was little point in staying in Santiago for the next eight nights, although in beautiful Vitacura I never felt threatened. I phoned KLM and they kindly found me a seat on Monday's flight back to Amsterdam and on to Aberdeen.

Monday 21 October. Back out to Santiago airport. Flight departs 11.45, for the quick trip over the Andes to Buenos Aires, refuelling stop, then up and away for another 13 hours overnight.

Tuesday 22 October. Quick change of planes in Amsterdam and on home soil at 12.10. Long suffering wife waiting for me. Only 'glitch': for some reason, Customs at Aberdeen must think I look suspicious, sideline me into their interrogation chamber, ask a few questions, scan my bags and then let me go! Perhaps it was my false beard, shades and baseball cap! 27593 kilometres. Nearly 40 hours on planes. All in the space of 78 hours. Good job I'm a seasoned flyer and a self-declared 'aviation anorak'.

About a week later Receive a request to put my presentation into a video with voice over (10 minutes maximum) as there will now be a virtual Colloquium (see below). The video can be viewed [here](#).

Virtual Cochrane Colloquium—every cloud.....

It's really great to see that Cochrane have turned having to cancel the Colloquium that Peter so valiantly attempted to attend into something positive by hosting a virtual event on-line. This will take place 2nd-6th December and will highlight the theme of 'Embracing Diversity'. It will be open to all Cochrane members and supporters and full details of how to sign in and what's taking place can be found on the [website](#). If you're not already part of Cochrane you can find out more and how to get involved [here](#).