



# Patient Panel Newsletter

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## CEBD Patient Panel meeting Saturday 24th September

Many thanks to the nine patient panel members who gave up part of their weekend to attend our recent annual panel meeting at Jubilee Conference Centre, Nottingham on Saturday 24th September. We were joined by panel members from across the country, with Tressa Davey from the Isle of Wight getting the award for furthest travelled attendee! If you couldn't make it and would like one of the CEBD baseball caps modelled in the photo below please just [get in touch](#) and we'll post one out for you.

After an update on CEBD activities from CEBD Co-director Kim Thomas we had a (very) informal learning session on 'Demystifying the Language used in Clinical Research' from Paul Leighton based on the quiz show Call My Bluff. This was great fun and for those not present, an [online glossary](#) explaining terms used in clinical trials and other forms of applied research, can be found on the National Institute for Health Research (NIHR) website. CEBD PhD student Arabella Baker and our new intern Natalie Bonsu (also a medical student at Nottingham University) then delivered a really useful session on Social Media and Research. After lunch (and many thanks to the venue for providing such fantastic allergy information) Rosalind Simpson, a clinical academic at CEBD, gave a talk on how non-scientists can get the best out of reading a research paper. The final sessions of the day were workshops looking at how to publicise the [Eczema Care Online](#) website and feedback on the new [RAPID](#) project (see below). Insights from those present were much appreciated indeed by the study teams.

This face to face meeting is an annual event and if you have any ideas for learning sessions for the future [please let us know](#) and we'll do our best to include them next year.



## RAPID Eczema Trials

[RAPID](#) is an NIHR funded Programme Grant with a 'citizen science' approach to clinical trials for eczema. Co-led by Kim Thomas (CEBD Co-director) and Amanda Roberts (CEBD Patient Panel member and eczema patient and carer), the project aims to deliver co-produced studies that will answer questions about eczema care that are important to patients. In addition to the website, you can read more in this [great blog](#) that Amanda has written.

The study ideas will be prioritised by small working groups of patients and carers and to start things off, the first topic RAPID is investigating is [bathing and eczema](#). We are looking for people affected by eczema to get involved in this prioritisation group, so if you feel this is something you could do then please [register your](#)

[interest](#).

Once the patient priorities have been identified, online clinical trials will be developed so the studies can be done in an efficient way without lots of paperwork. RAPID is also aiming to get the results of the research out to the eczema community more quickly and people affected by eczema are also needed to get involved in working out the best ways to do this. Again, if this is something you are interested in getting involved in [please sign up](#).

We really want to engage people who don't normally get involved in research with RAPID, so please do help us spread the word about the project by telling your friends family and colleagues. If you have any links with community groups please do [let us know](#) so that we can get in touch with them.

## **VROOM study results published—effect of stopping low dose methotrexate on response to COVID-19 booster vaccination**

[The Vaccine Response On Off Methotrexate \(VROOM\) trial](#) looked at the impact of interrupting methotrexate treatment for two-weeks after a COVID-19 booster vaccination on vaccine responses in adults with autoimmune inflammatory conditions.

Methotrexate is the most commonly used immune-suppressing drug, with around 1.3 million people in the UK prescribed this medicine for inflammatory conditions such as rheumatoid arthritis, and skin conditions such as psoriasis. While methotrexate is effective at controlling these conditions and has emerged as first line therapy for many illnesses, it reduces the body's ability to fight infections and the ability to generate robust response to flu and other vaccines, including those against COVID-19.

The study, led by Prof Abhishek Abhishek at the

University of Nottingham, (with dermatology input from CEBD Co-director Prof Hywel Williams)



found that by interrupting methotrexate treatment in such patients for two weeks after a COVID-19 booster vaccination, their antibody response to the jab is doubled. The improvement in antibody response was maintained over a 3-month period. There was a short-term increase in risk of flare-up of inflammatory conditions in the patients that stopped methotrexate for 2 weeks but most could be self-managed and there was no adverse impact on their quality of life or general health. The study was funded by the National Institute for Health Research (NIHR) and the full study results are published in [The Lancet Respiratory Medicine](#).

Please note we have included this study as a general interest item. We do not advise or advocate stopping any medications without consulting the GP or dermatologist that prescribed them for you.

## **Vacancy on CEBD Patient Panel Action Plan Review Team**

When the [UK Standards for Public Involvement in Research](#) were published in 2018, we reviewed our CEBD involvement and patient panel activities against them and developed an action plan of areas for improvement. Actions delivered have included an induction pack for new panel members and the panel code of conduct. To help monitor and deliver this plan, we have a small working group comprised of CEBD Patient Panel members and CEBD staff. A vacancy has arisen on the group due to a panel member stepping down. The main commitment for this group is an online meeting (no more than 2 hours) every 2-3 months to review the action plan and CEBD Patient Panel activities which includes things such as helping to plan the programme for our annual meetings.

If this is something you're interested in getting involved in, or would like to find out more then please [get in touch](#) with CEBD Patient Panel Co-ordinator Carron Layfield. Unfortunately, there is no payment associated with this activity.

## **Other Updates from CEBD**

- We're delighted to let you know that NIHR funding has been confirmed for the PEARLS study. Led by Rosalind Simpson, this clinical trial of the vulval skin condition lichen sclerosus will test which is the best treatment approach for the condition: using steroid flare creams twice a week, regardless of whether symptoms are experienced, or using these creams to treat symptoms when they re-appear.
- Don't forget we have a WhatsApp group for patient panel members to keep in touch with each other outside your CEBD activities which is managed by panel member Irene Soulsby. Please [let us know](#) if you'd like to be added to the group.