



Patient Panel Newsletter

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Updates from CEBD

- We're delighted to let you know that CEBD Co-Director Prof Hywel Williams has returned to work one day a week following his recent serious illness. I'm sure you'll all join us in warmly welcoming him back and agree he's looking well.
- Congratulations to all involved in the [BEE \(Best Emollient for Eczema\)](#) study which has just been awarded the Royal College of GPs Research Paper of the Year Award. The award was made as the [trial results](#) are so relevant to children with eczema, their families and for primary care clinicians in making decisions with parents about management of a child's eczema. This is a really prestigious award which will help to raise the profile of dermatology research and the impact of living with eczema and shows how important it is to get involved and support good quality research.
- The kick-off meeting for the Acne-ID study has now been held. Funded by the National Institute for Health and Care Research ([NIHR](#)), this study will investigate lower daily dose isotretinoin for the treatment of acne in young people aged 12-24.
- We were sad to say goodbye to Dr Sophie LeDucq this month (pictured above with Hywel—though to be honest they don't look very sad!). Sophie has worked with us on a range of research methodology projects for the past 12 months and has now returned to her clinical post at Tours University Hospital in France.



CEBD Patient Panel Day Saturday 7th October

Many thanks to the ten patient panel members who gave up a large part of their weekend to attend the CEBD Patient Panel day on Saturday 7th November at Jubilee Conference Centre in Nottingham. We had attendees from all over the country in addition to more locally based panel members (pictured below with some CEBD staff members).

The day started with an update on CEBD activities (delivered remotely as CEBD co-director Kim Thomas was poorly!) and two linked sessions on [systematic reviews](#) followed. The team got some really helpful feedback on



how to best communicate results from this sort of research—'one size doesn't fit all' and involving the target audience is key.

After a learning session that focussed on [research impact](#), we then split into two workshops to consider different projects. One group looked at potential future studies in primary care with the group feeling a focus on the delivery of dermatology services may be a good useful area to explore. The other workshop looked at patient facing materials for an acne study including a [patient reported outcome measure](#) on how to record changes in acne severity from a patient perspective.

The day finished with a session on the [Include Ethnicity Framework](#). This is a tool that has been developed to help ensure that research studies are accessible to all participants that the study results would be applicable to and with the aim of encouraging more diversity in those taking part in research studies.

We got some great feedback from those attending, with many indicating they got a lot more out of the meetings than just learning about research. Our next CEBD Patient Panel meeting will be a shorter online meeting in Spring 2024—please do [get in touch](#) and let us know if there are any topics you'd like to see covered.

TREAT study results published

The TREAT study investigated the use of ciclosporin and methotrexate to treat severe eczema in children. Led by [Carsten Flohr](#), the results of this clinical trial have just been [published in the British Journal of Dermatology](#). Over 100 children aged 2-16 years old (who didn't respond to potent topical treatments for their eczema) took part in this study which recruited from 13 hospitals across the UK and Ireland.

The study showed that both ciclosporin and methotrexate are effective treatments for severe childhood eczema over

a period of 36 weeks. The results demonstrated that although ciclosporin

works more quickly initially, a more sustained treatment response is seen with methotrexate, even after treatment is stopped. Please see [this video](#) which summarises the study results really nicely.

Many thanks to all the CEBD Patient Panel members who have supported this study over the years, with particular thanks to Amina Ahmed and her family and Tim Burton.



Rapid Eczema Trials Community Q&A Session: Eczema is Different

Some of the citizen scientists involved in the [Rapid Eczema Trials](#) research programme delivered a Community Q&A session at the end of September on the theme of '[Eczema is Different](#)'. The aim of the session was to generate a sense of community and encourage open and honest questions about living with eczema. You'll find a series of videos from the session on different themes including [socialising with eczema](#), [holistic approaches to managing eczema](#), [how eczema can affect relationships](#) and [initial confusion about what eczema is](#).

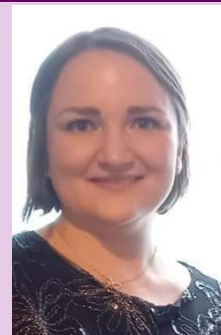
Meet the CEBD Team—Dr Louise Clarke

Louise joined us as an Academic Clinical Fellow in April 2023 and is working with Dr Rosalind Simpson on vulval lichen sclerosus (VLS) research. VLS is a skin condition of the outer female genitalia which affects all age groups but primarily post-menopausal women. It is often misdiagnosed and/or there is a delay in diagnosis which can lead to further problems and complications.

Most cases of VLS in the UK are diagnosed in primary care and Louise will be working on a number of primary care based projects as follows:

- A survey of professionals in primary care about diagnosing and treating VLS.

- An interview study of professional in primary care to identify barriers to diagnosis and treatment.
- A review of existing studies to identify problems leading to misdiagnosis and delayed diagnosis of VLS.



Louise has been a doctor in the NHS for 11 years and in addition to her research work at CEBD is currently working as a GP trainee in North Nottinghamshire. She has a specialist clinical interest in women's health which led to her working with us. Outside of work, she enjoys spending time with her 2 children, Belle the dog and singing in a choir.

Other Useful Updates

- We keep hearing a lot about 'AI' in the news—take a look at this useful update from the NIHR on 10 [promising AI interventions for healthcare](#).
- Have you seen the results of this recent NIHR survey about [research participants experiences of taking part in research studies](#) ?
- The NHS Health Research Authority (HRA) have just launched new principles for '[People-Centred Research](#)' which aim to encourage researchers to focus research on what matters most to the people it is for and about. You can sign up for monthly email updates from the HRA [here](#).