

Patient Panel Newsletter

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Updates from CEBD

- We're sad to say goodbye to Barbara Maston (pictured here) who left her role as a Research Administrator with us last month after 14 years of working at CEBD. We know she helped many of you with travel bookings and expense claims and I'm sure you'll join us in wishing Barbara well in her retirement. Please email cebd@nottingham.ac.uk for future support.
- Did you know that the [Eczema Care Online \(ECO\) website](#) has received over 100,000 visits since it's launch in 2022? This independent, evidence-based online resource is aimed at supporting the self-management of eczema. Please do share this website with anyone you know who is affected by eczema—as you'll see from [this publication in the BMJ](#), it does make a difference.
- We're pleased to let you know that the [Acne-ID study](#), which is investigating using lower doses of the medication isotretinoin for severe acne in young people, has successfully reached it's internal pilot recruitment target. Well done to all the team including the patient panel members involved!!
- We're also pleased to let you know about some successes for the [Rapid Eczema Trials](#) research programme, which is all about doing eczema clinical trials 'differently' including co-designing trials with patients and running these trials online rather than in a healthcare setting. Results from the Eczema Bathing Study (which investigated the effect of bathing frequency on eczema severity) have now been published in the [British Journal of Dermatology](#) and the study has been featured by the [NIHR 'Be Part of Research' initiative](#). Recruitment is going well for the second online study in the research programme the 'Keep Control Study' with over 280 people with eczema recruited so far.
- Winners for our eczema summer art competition have now been announced. Please take a few minutes to [look at some of the artwork, poetry and videos we received](#). Be warned, it's an emotional rollercoaster.



CEBD Patient Panel Meetings—next one Sat 16th May 2026

Many thanks to the 15 CEBD Patient Panel members who gave up their Saturday morning on 1st November to join us for an online CEBD Patient Panel meeting. After a brief update on CEBD activities from [Carron Layfield](#) (who co-ordinates this group) panel members contributed to a group discussion on a study in development on the skin condition Hidradenitis Suppurativa (HS). Led by [Laura Howells](#), a Senior Research Fellow at CEBD, this project which will investigate how the management of HS in primary care can be improved. The meeting finished with a presentation from CEBD Co-Director [Hywel Williams](#) on 'research wastage' which is the practices within research that are inefficient, unnecessary, or fail to deliver reliable results. Hywel's session was a highlight for many attendees with feedback comments including 'Eye-opening and gave me an insight into something I hadn't considered before. So full of common sense.' Catching up with people was a further highlight with a lack of time being one of the main negative things about the meeting.

Our next face to face CEBD Patient Panel meeting will take place Saturday 16th May 2026 at Jubilee Conference Centre. This full day meeting is an excellent opportunity to find out more about what's happening at CEBD, network with other panel members and CEBD staff, contribute to CEBD studies and undertake some learning opportunities. Don't forget travel costs are covered—please [get in touch](#) if you'd like to attend, have any questions and have any suggestions for topics you'd like to see covered at the meeting. Current ideas include a session on the National Institute for Health and Care Research (NIHR) and their different funding streams and a workshop on environmental sustainability in dermatology.

Success for LS Guide team at 2025 Picker Experience Network Awards

[Rheanne Leatherland](#), Research Assistant, CEBD and member of the [LS Guide](#) team

The Picker Experience Network (PEN) is an independent, 'not for profit', service provider and membership-based network. It was previously known as the Patient Experience Network, but changed its name when it was taken over by the Picker group in 2024. PEN is founded upon an understanding of the importance of a great experience – whether this is for patients, carers or staff. The PEN Awards are the first and only awards programme to recognise best practice in patient experience across all facets of health and social care in the UK and beyond.

The PEN 2025 Awards event, held at the Aston Webb Great Hall at Birmingham University, celebrated the achievements of healthcare leaders, innovators, and patient experience champions. There are a number of categories for which projects can be nominated. Following review by an independent panel of judges, entries are shortlisted and finalists are invited to attend the award giving ceremony.

The main event was hosted by Ruth Evans, Founder and Managing Director of PEN, who provided a lively introduction and background to the awards. This was accompanied by British Sign Language interpreters who continued to translate throughout the whole day, providing a real inclusive feel for everyone present. The keynote talk was delivered by Freya Williams (pictured second left above presenting the LS guide team their award), a recently qualified paediatric nurse who has overcome significant health battles with a rare genetic condition, Ehlers Danlos Syndrome, to complete her degree and start work. Her account of being a patient and needing to take time off studies, the psychological lows that came with it, and the health professionals who pulled her through, was truly humbling. Freya's key message was that small differences can make a huge impact to the patient in front of you.

Moving on, with an 'Oscars' style vibe, the individual award categories were introduced and presented by a different patient experience champion. Finalists in the category were invited onto the stage. With music, drum rolls and energy, golden envelopes were opened to reveal the runners up and winners, followed by photo opportunities as the finalists moved off the stage.



LS Guide team members pictured above (L-R): Sophie Rees, Rosalind Simpson (centre) Rheanne Leatherland and Zoe Breen. Not present: Lisa Kirby, Caroline Owen and Claire Baumhauer.

We were delighted, albeit somewhat surprised, when the [Lichen Sclerosus Guide](#) was announced as winner in the 'Communicating Effectively with Patients and Families' category. One of the patient co-producers, [Claire Baumhauer](#), was also individually awarded the 'Individual Patient Contribution' prize!

The LS Guide is a free, co-produced online resource supporting people with vulval lichen sclerosus (VLS), a chronic and often misunderstood skin condition. The guide combines clinical expertise with lived experience, offering clear, accessible information through written content, videos, animations, and downloadable tools. The guide was praised for its inclusive, evidence-based approach to tackling stigma and improving health literacy. It was noted to empower patients, support clinicians, and bridge gaps in care - making it a model for effective communication and partnership in healthcare.

The Southern Health and Social Care Trust's project '[Seasons of Life](#)' was recognized as the overall winner of the 2025 Awards for their pioneering bereavement and loss support programme delivered in schools across Northern Ireland. Recognising that grief extends beyond bereavement to include experiences such as parental separation, care placement, refugee status, and family imprisonment, the initiative offers inclusive, trauma-informed workshops for children and young people. It fills a critical gap in support for young people experiencing loss and is ready for wider rollout - offering a scalable, compassionate model for partnership-driven care – a truly worthy overall winner!

The day had a strong sense of inclusivity, celebration and innovation and we encourage everyone to take a look at the [PEN website](#) to see how their work might fit in with projects you're involved in.



Thinking about how we wash our clothes

Irene Soulsby, CEBD Patient Panel Member

Sometimes we fly with just a “carry on” bag and don’t check anything into the hold (saves waiting around for bags and the fear of them not being there upon arrival!). We occasionally stay in accommodation which has a washer, and I wondered if there were any new laundry products that might go into our bags. (I’m never sure if there might be a hold up when going through airport security with liquids and powders!) It would also save buying washing products when we got to our accommodation.

I came across Laundry Detergent Sheets/Leaves. I thought that they might be ideal for travel! I decided to try them out at home first and really liked them! There wasn’t the heavily perfumed scent (the brand that I tried) -supermarkets send my nose twitching like mad! They didn’t take up much space – a very small packet which went on top of our washer, compared to the huge box of washing powder. Clothes seemed to wash well. As far as I’m aware, sheets are also suitable for hand washing clothes. I would add that I don’t have any skin problems, my husband has psoriasis, he was fine as well. I’d be interested to know if anyone else had tried them and what you thought—[let us know](#).

At the same time, I had picked up an Ecoegg (Laundry

egg) which is a “complete replacement for laundry detergent and fabric conditioner and can be used for 70



washes” (according to info on the box). You fill the “Egg” with mineral pellets (supplied). I have been trying these for a few weeks and like these also. Neither of us have had any problems with our skin.

I appreciate that others might experience a reaction with these new products.

Another thing I noticed was that there wasn’t the smattering/mountain of powder on the garage floor and also the dosage (sheet or egg) seemed to be sufficient. I’m hoping that they would be cost effective (the ones I bought were very reasonable) as well as kinder to the planet. The only thing that I would add is that if the dosing egg is in the washer drum, it can sound a bit clunky if you’re only washing a few items. PLEASE remember to follow the instructions though and be sure to remove the plastic egg from the washer when you’ve finished (just in case it may melt in a tumble drier!!).

There are so many innovative products on the market now and I’m glad that I decided to try some of the new ones.

These are my personal thoughts as a member of the CEBD Panel and not official recommendations.

And finally...other interesting things that caught our eye

- Did you know that [new clinical trials regulations](#) are coming into force in the UK from April 2026? Patients and the public have been instrumental in helping to develop these changes with one key change being that all trials will be required to publicly register and publish their results, including easy-to-read summaries for participants (something CEBD have always done of course!).
- Have you seen this interesting [book](#) aimed at children which is all about getting involved in research? Produced in collaboration with the National Institute for Health and Care Research (NIHR) there is also [a video](#) available of the author reading the book which aims to give children and younger people a greater understanding of what research is and why it’s important. Please think about sharing this with young people you know and using it as a tool to talk to them about projects you’re involved with at CEBD.
- Have you heard about the [#Step Forward](#) campaign? The [NHS Health Research Authority](#) are looking for more members of the public to get involved in joining their [Research Ethics Committees](#) which review applications for research approval.
- Check out this interesting [NIHR blog](#) which focusses on inclusion in research.