



Patient Panel Newsletter

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Updates from CEBD

- We're really pleased to let you know about the launch of a new resource for patients affected by the vulval skin condition lichen sclerosus. The [Lichen Sclerosus Guide](#) has been developed by a team of healthcare professionals, researchers and patients including staff at CEBD. Including sections on causes, symptoms and signs; treatment; everyday life with LS and information for healthcare professionals this is a wonderful resource for those living with LS and those supporting them. Funded by [Wellbeing of Women](#), the [British Association of Dermatologists](#) and the [British Society for the Study of Vulval Disease](#), the site aims to empower those affected to learn about the condition, access the right treatment and live more comfortably.
- Dr Jane Harvey and Dr Paul Leighton have been successful in securing funding from the [National Institute for Health and Care Research \(NIHR\)](#) to look at how to implement [Eczema Care Online \(ECO\)](#) in community pharmacies. Many thanks to all the patient panel members who have helped support the development of this project.
- The UK Dermatology Clinical Trials Network (UK DCTN) [annual report is now available](#). Highlights from the past 12 months include studies on acne and skin cancer opening to recruitment and funding for new studies on skin cancer surgery and skin cancer prevention.
- CEBD staff recently supported the [2025 Nottingham Festival of Science and Curiosity](#) with a stand at Hyson Green library. Over 80 children and their families came along and activities included making a model of skin out of craft materials and a colouring activity to help show the different functions of the skin.
- Did you see this [recent article in the Guardian](#) about lip balm? Dr Rosalind Simpson (Clinical Associate Professor at CEBD) dispels the myth that using lip balm is addictive.
- The 2023-2024 CEBD Impact report, which summarises key research activities over the past couple of years, will be available soon. Please [let us know](#) if you'd like a copy of this emailing to you, past copies can be found on the [CEBD website](#).

Carbon footprinting clinical trials—are online trials better for the environment?

We are carbon footprinting the online clinical trials taking place as part of the [Rapid Eczema Trials](#) research programme to see if they have a lower carbon footprint than clinical trials which take place in a more traditional healthcare setting.

Carbon footprinting for the [Eczema Bathing Study](#) has now been completed. This work was undertaken by a third year medical student, Vaibhav Chaganti, who some of you may remember from the June 24 patient panel meeting when he presented his plans for this work.

The results show that the carbon footprint of the study was 10.47 tonnes. This compares favourably to the

carbon footprint of 12 trials conducted in a healthcare setting which averaged at 74 tonnes. One of these (the [CRASH study](#)) had a carbon footprint of 126 tonnes which is the equivalent of 200 flights from London to New York!

Main factors for carbon emissions for the online Eczema Bathing Study were staff commuting, office heating and lighting and energy consumption for home working.

This study is contributing important data for the [Greener Trials initiative](#) and carbon footprinting will be repeated for all studies associated with Rapid Eczema Trials.



Sharing experiences of attending a Society for Academic Primary Care Dermatology Special Interest Group meeting - Tracy Owen and Goldie Putrym

From feedback at CEBD Patient Panel events, we know you're always keen to hear what fellow CEBD patient panel members and others involved in dermatology patient and public involvement are getting up to. We hope you enjoy reading about Tracy and Goldie's (pictured right) experiences of attending a recent dermatology research meeting.

The bosses gave me the day off to wear my other hat up in London at the BAD offices ([British Association of Dermatologists](#)). It's not as 'BAD' as it sounds. An invitation from the superb [Rapid Eczema Trials](#) to participate as a PPI (Public Patient Involvement) within the 13th [Society for Academic Primary Care \(SAPC\)](#), [Dermatology Research Specialist Interest Group \(SIG\)](#) meeting. Such a privilege to be part of research. The day included research concepts related to all things dermatology from using AI technology for Eczema, Acne Care Online, to Hidradenitis Suppurativa.

Having listened to, and discussed the innovative aspects that our dermatology leads are instigating, it was so evident, that the group are so willing to share, and work together to enable the best outcomes for the various research projects. In a world where many are afraid to share their ideas for fear of it being used elsewhere, this expert group communicate and support each other as a unit to share their experience and knowledge for the future better of the patient experience. **Tracy Owen**

It was a chilly February morning. The sun was shining and I was beaming. It was my first visit to the BAD building, and the first time in a very long time amid the history and architecture of Fitzrovia. I had been invited along to the SAPC skin interest group meeting as a patient contributor on Rapid Eczema Trials and

couldn't wait to hear about current and upcoming research in dermatology.

The projects that were presented over the day spanned the body as well as the mind. We discussed different

treatment options for acne, the promise (and pitfalls) of AI in diagnosis, and conditions I had never heard of before like vulval lichen sclerosus and hidradenitis suppurativa. Above all we spoke about eczema which was unsurprising seeing as so many of us struggle with it in so many different ways. But despite the variety in the conditions and approaches, I noticed a clear common theme that ran through every single project - the focus on the patient experience and how to improve it.

Perhaps you find this as striking as I did. We often think of research being done by academics and clinicians conjecturing and hypothesising in their ivory towers, far removed from the day-to-day realities of the conditions they are studying. I'm not sure where this idea comes from - perhaps the media, perhaps misinformation or perhaps the reality of the past.

Whatever the origin, it looks the patient-centred approach to research is now becoming the norm. Yes, there's a push from above (the NIHR) but also a pull from within. Many of the researchers who spoke - doctors, nurses, psychologists - seemed to have been touched so deeply by a conversation with a patient that they were determined to make a change.

I left the meeting that day inspired that we, as patients, can be part of that change. How we feel and what we think can shape what gets studied and how that research is designed. **Goldie Putrym**





Update on UK Dermatology Clinical Trials Network (UK DCTN) Trainee Group projects

We wanted to take this opportunity to highlight how the [2024 UK DCTN Trainee Group projects](#) are progressing, as many of you contributed to these when the groups presented their research ideas at the CEBD Patient Panel meeting last June.

- **Feasibility study for spironolactone for the treatment of HS in adult females.** Service evaluation and a clinician survey to inform current clinical practice has been completed. They are now planning further feasibility work (including with patients) and are seeking funding for this.
- **Is oral spironolactone effective and safe in treating acne vulgaris in the female adolescent population (12-17 years old)?** This team have completed a clinician survey and have secured £10,000 funding to complete further feasibility work. This will include seeking patients input and they are going to be using a novel approach to analysing social media data as part of this.
- **Are clean non-sterile medical examination gloves non-inferior to sterile gloves in preventing postoperative infections in minor skin surgical procedures?** A clinician survey has been completed and a patient survey is underway. The team are seeking funding from the British Society for Dermatological Surgery for a small feasibility study to test if a full study is possible.
- **Is metformin MR (1500mg once daily) and doxycycline (100mg twice daily) more effective than doxycycline (100mg twice daily) monotherapy in reducing the severity of HS in adults?** This team have completed a clinician survey and are hoping to move forwards with more feasibility work.

Many thanks again to all the patient panel members who helped introduce these teams to patient and public involvement work early in their research careers.

Welcoming a new Masters Research student to CEBD—Yasaman Hashtrodyar

I am excited to join the CEBD team as an MRes student, working on a research project exploring the possible association between bullous pemphigoid and antibiotic use in older people using the Clinical Practice Research Datalink. As a pharmacist, I have gained experience in various fields, including community pharmacy, medical content writing, nanodrug delivery, and pharmacovigilance. Over time, I developed a strong interest in pharmacoepidemiology and pharmaceutical clinical trials, as they allow me to contribute to evidence-based decision-making and improve patient outcomes by assessing the safety and effectiveness of medications.

Eager to take on a research project of my own, step outside my comfort zone, and develop new skills, I joined CEBD to work in a multidisciplinary environment that produces impactful research.

Having recently moved from Iran, I also see this as a valuable opportunity to learn more about the UK healthcare system and advancements in

epidemiological studies. One of the most inspiring aspects of joining this team has been its strong emphasis on public and patient involvement in research, as their perspectives ensure that studies address issues that truly matter to patients, not just healthcare professionals. As a result, this approach leads to more meaningful and applicable research outcomes.

Outside of work, I love hiking and exploring nature, as it helps me unwind and stay active. Traveling is another passion of mine, as I enjoy familiarizing myself with different cultures and cuisines. Though I am not a professional singer, I also enjoy singing in my free time!

