



Patient Panel Newsletter

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CEBD Updates

- **Baby news:** we're delighted to let you know that CEBD Senior Research Fellow Laura Howells has had her baby. Robin arrived into the world on 15th Jan weighing in at 9lb 2oz and we're sure you'll join us in wishing Laura huge congratulations on the safe arrival of her son.
- **Outreach event:** CEBD are taking part in the [Nottingham Festival of Science and Curiosity](#) this year. We're having a stand at [Strelley Road Library, Nottingham](#) on Wednesday 14th February with activities including making a model of your skin from craft materials and a game involving designing a sun hat which aims to explain the principles of being randomised into a clinical trial. If you're local, come along and say hello and have a go at the activities or take a look at some of the other exciting things happening across Nottinghamshire 5th-16th February as part of this event.
- **Study update:** we're really pleased to let you know that after a long set-up period, the [BEACON study](#) has now recruited its first patients from Guys and St Thomas, London. The study aims to provide the first ever comprehensive evidence on the comparative effectiveness, tolerability and cost-effectiveness of ciclosporin, methotrexate and dupilumab in the treatment of moderate to severe adult eczema. Additional sites will now be opened across the UK with over 30 hospitals eventually involved. The study aims to recruit 402 participants and is being set up as a multi-arm, multi-stage platform trial capable of adding new arms as novel treatments emerge (similar to the RECOVERY trial in COVID). The qualitative research elements of this large clinical trial are being led from CEBD and many thanks to all the CEBD Patient Panel members who have supported the development of the study over the past few years.
- **2024-2025 CEBD Patient Panel meetings:** to try and make travelling to Nottingham a bit more appealing, we're shaking things up a bit with timings for the CEBD Patient Panel meetings and are going to try having our face to face meeting in the Spring (rather than October when we've tended to have previous meetings). To help with planning, this means our next face to face meeting will be in Spring 2025 and we're aiming to have two online meetings this year. There will be one towards the end of 2024 and one in early summer which will have a focus on providing input into studies being developed by dermatology trainees via the [UK Dermatology Clinical Trials Network \(UK DCTN\) Trainee Groups programme](#).

Welcome to new member of CEBD staff Emma Campbell

I've worked at the University of Nottingham for over 10 years. I have a PhD in Molecular Biology (from far too long ago!) and over 20 years' experience in science communication and research project management.

Within CEBD, I'll be working as a Research Fellow with the RAPID Eczema Trials team. I'll mainly be focusing on knowledge mobilisation (getting the results of research to people that need it) and process evaluation (looking at

how we've done what we've done, if we've done what we said we'd do and how people involved feel about it).

Outside of CEBD, I definitely 'work' as a taxi driver for my two children! When I'm not doing that, I'm usually trying to stop our new puppy from eating all of our shoes. I love being outdoors in the countryside and going to the theatre, but definitely need more hours in the day for this 'me time'



[Rapid Eczema Trials](#)—lots to celebrate!

This five-year research programme is investigating new approaches to undertaking studies in mild to moderate eczema including co-production of trials with patients and online methodology for delivering the prioritised trials quickly and efficiently. We're delighted to let you know that the first study to evolve from Rapid, which is investigating the effects of bathing frequency on eczema management, has recently opened to recruitment.

[The Eczema Bathing Study](#) is open to people with eczema over 1 year old and aims to recruit 390 participants who will be randomly allocated to take a bath or shower either at least 6 times a week or no more than twice a week. Please let everyone you know affected by eczema about this study and help us answer this important question. The great thing about Rapid studies is that there is no

need to visit a healthcare setting to take part—you simply self-refer via an online portal.



The programme aims to deliver three online studies in total, and following prioritisation activities with the eczema community, the focus for the next studies will be 'Best way to keep control of eczema between flare-ups' and 'Psychological interventions to influence how people respond to stress'.

In addition to the first study opening to recruitment, we're also celebrating the fact that the citizen scientist community for [Rapid Eczema Trials](#) has now grown to over 500 people. This illustrates the enthusiasm of those living with eczema to help shape research to support themselves and others manage their condition better. If you're affected by eczema, then [what's stopping you getting involved?](#)

Updates from the National Institute for Health and Care Research (NIHR)

- The revamped [Learning for Involvement](#) website is now live. This NIHR site aims to bring information about public involvement, resources (such as guidance, websites, videos, articles and blogs) and training together in one place. The content is suitable for people with different levels of experience in patient and public involvement, and you should be able to find something that can help you develop your skills.
- The [SAFA acne study](#) (spironolactone for adult female acne) was recently highlighted in the NIHR public involvement newsletter. It's great to see studies like this raising the profile of dermatology research.
- If you're interested in taking part in studies as a participant, why not sign up for the new ['Be Part of Research' matchmaking service](#)? Once registered, information on suitable studies will be sent direct to your inbox and over 400,00 people have registered to date.

Developing VLS patient information resources

A collaborative working group of researchers, patients and doctors has raised £40 000 in funding to create a new patient resource for patients with lichen sclerosus! Led by Sophie Rees at the University of Bristol, the project also involves Rosalind Simpson from CEBD and four active patient representatives from the new vulval skin disease patient panel.

Vulval lichen sclerosus (VLS) is a distressing skin condition requiring lifelong management. Long-term consequences include anatomical changes and possibility of cancer development. Information for VLS can be limited in scope, inconsistent, and patients report conflicting advice from healthcare professionals, often seeking information from peers or online. The aim of the project is to develop a comprehensive, reliable, and accessible information

resource for patients living with VLS. In turn this should empower patients to support their own management using reliable information, as well as guide healthcare professionals to provide consistent information.

The resource will be co-developed at a patient workshop, and a specialist company will be employed to create a contemporary 'look' and multimedia content. It will include optional downloadable content for patients to add their diagnosis and treatment plan, including a personalisable diagram to aid topical steroid application. It will also be inclusive, with easy-read content for people with low literacy or learning disabilities, representative of people of colour, using gender-affirming language, and available in different languages.

The project has been co-funded through grants from the British Society for the Study of Vulval Disease (BSSVD), Wellbeing of Women (WoW) and the British Association of Dermatologists (BAD). Watch this space for updates!

Interesting updates from CEBD student projects

You hear lots from us about the clinical trials and larger research studies going on at CEBD, but there are also a wide range of interesting smaller research projects happening. These are often undertaken by University of Nottingham medical or masters students working with us for short periods of time and sometimes help to feed into and support the bigger projects. We hope you enjoy reading about some of these projects.

How do healthcare professionals assess acne severity? A medical student has been investigating how health care professionals (HCPs) assess acne severity in their clinical practice. The student sent an online survey to health professionals on the UK Dermatology Clinical Trials Network and the British Dermatological Nursing Group's mailing list, to ask what they look for when assessing acne to decide if it is mild, moderate or severe. In the survey they also asked HCPs what they found difficult, including in skin of colour, and how this can be improved. The survey was answered by 36 people from across the UK and from different professions. The student found that the main way health professionals assess acne severity is through assessing active acne. This involves lesion (spot) counting and determining the specific clinical subtype of lesions. Assessment of previously affected areas (clinically termed negative sequelae) and the location of the acne on the body are also important. This project will help with a large new acne trial called Acne-ID being led from CEBD.

Does anti-diabetic medication affect skin cancer risk? Around 46 new skin cancer cases are identified every day in the UK, and this is expected to increase in the coming years. Skin cancer is typically caused by too much damage caused by sunlight on skin types and some medications (eg blood pressure medications) appear to increase the likelihood of developing skin cancer. However, it is not clear whether anti-diabetic medication increases or decreases the risk of developing skin cancer. Anti-diabetic medication is commonly used for individuals with type 2 diabetes (T2D) to control blood glucose (sugar) levels.

This research (carried out by a masters student) aimed to summarise and combine the results from previous studies that examined the link between anti-diabetic medication and skin cancer risk. We searched scientific databases to identify all relevant studies. The most common types of skin cancer were included (basal cell carcinoma, cutaneous squamous cell carcinoma and melanoma). Only oral anti-diabetic medication used to treat T2D was examined. Overall, anti-diabetic medication use was associated with a slightly decreased risk of skin cancer. A greater dose of anti-diabetic medication reduced the risk of skin cancer more greatly compared to a low dose. We also observed that the risk of basal cell carcinoma and cutaneous squamous cell carcinoma was reduced following anti-diabetic medication use, compared to non-users. Anti-diabetic medication use was not shown to increase the risk of skin cancer, it means that they are safe to use, particularly in patients who are at the greatest risk of skin cancer. It also shows that anti-diabetic medication has properties that reduce skin cancer risk, but more research is needed to confirm this.

Vulval Lichen Sclerosus (VLS) primary care survey study: VLS is a frequently misdiagnosed and under-recognised disease predominantly affecting post-menopausal women. Previous research has focused on the perceptions of women with the disease. In these studies, women have reported persistently negative interactions with health care professionals (HCPs) when seeking diagnosis and treatment. This study (led by a medical student) sought to investigate the views and experiences of VLS from HCPs in primary care.

Over 120 HCPs completed online and paper surveys, mainly GPs and GP trainees. The results from the surveys showed that confidence levels in the identification and management of vulval disease and VLS correlated with experience, exposure, and gender, with the female HCPs in general showing greater confidence. The level of education participants had received on VLS was low, with 41% having neither received organised teaching nor participated in self-directed learning. The most frequently identified barriers to diagnosis were patient embarrassment, lack of knowledge, time and absence of clear diagnostic criteria. Additionally, 97% of HCPs said they would find diagnostic criteria helpful.

Based on the findings of this study, important recommendations include integrating education on VLS into GP training to bridge knowledge gaps, further research investigating these barriers with a view to overcoming them and development of a diagnostic tool to simplify the VLS diagnostic process.