



Patient Panel Newsletter

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CEBD news and updates

- We are absolutely delighted to let you know that CEBD Co-director Prof Hywel Williams (pictured here) has been awarded an OBE in the recent [Queen's birthday honours list](#). Congratulations Hywel and very well deserved indeed!!
- The RAPID programme grant exploring a 'citizen science' approach to studies investigating the management of eczema has progressed to full stage application with the National Institute for Health Research (NIHR).
- Dr Roz Simpson has been successful in her application for an Advanced NIHR Clinical Fellowship to undertake further research in the field of vulval dermatology. These funding awards are extremely competitive and highly prestigious so very well done indeed to Roz on securing this Fellowship which will commence in September for a period of six years.
- We have had over 750 responses to date to the CEBD skin tone survey. If you haven't completed it yet please do so at <https://forms.office.com/r/VGaDiN8ibz>. We'd also be really grateful if you could forward this on to your friends, family, colleagues and any other networks you may have—it only takes 5 mins to complete and the more responses we get the better. This recent [article on the BBC news website](#) highlights why this is so important.
- We are keen to improve the diversity of the CEBD Patient Panel—please see some of the work we are doing with the [Black Skin Directory](#) to help with this. If you know anyone who would be keen to get involved in panel activities please do encourage them to get in touch.
- We said goodbye last month to CEBD Senior Research Fellow Dr Joanne Chalmers who has left CEBD to undertake a role in Notts Clinical Commissioning Group where she will support the implementation of evidence based practice.
- Please don't forget to [let us know](#) if you'd like to attend the next CEBD Patient Panel event which we are aiming to hold as a face to face meeting on Saturday 9th October at [The Orchard Hotel, Nottingham](#). For those new to the group, this is an excellent way to step into getting involved and meet other panel members and CEBD staff—all are welcome and travel expenses are paid.



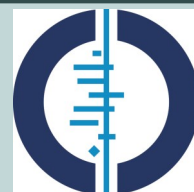
Guest article by CEBD Co-Director Prof Hywel Williams: key opinion leaders

Have you ever heard of key opinion leaders (KOLs) in medicine? KOLs are senior clinical/academic influencers who are paid by the pharmaceutical industry to influence clinician prescribing of their new product by clinicians at sponsored symposia, through writing articles in journals and online "educational" sessions. A LOT of this sort of activity goes on at our meetings and in online contacts. [This](#) is the best article I have ever read on the phenomenon of key opinion leaders (KOLs) – it is open access and very nicely written in an accessible and understandable way.

The depth of analysis and thought in this article is impressive – covering the history of KOLs and why they have expanded in recent times. But the article does not simply say that the emergence of KOLs is a bad thing in the long run, but instead suggests that a new principled system offers opportunities to rebalance academia-industry partnerships away from KOL prescribing influencers at sponsored symposia to innovation and knowledge leaders whose aim is knowledge gain and innovation at public meetings. The aim of innovation and knowledge leaders (IKLs) is science and innovation rather than marketing and influence. It is a controversial area that might cause offence to some colleagues who receive funds from industry, but this article opened out the topic in a non-judgmental and helpful way. It is a fresh perspective that offers a sustainable way forward.

Article reference: Scher JU, Schett G. Key opinion leaders - a critical perspective. Nat Rev Rheumatol. 2021 Feb;17(2):119-124. doi: 10.1038/s41584-020-00539-1. Epub 2020 Nov 30. PMID: 33257869; PMCID: PMC7703499.

What's happening at Cochrane Skin???



- If you are affected by eczema (either as a patient or carer) and free on the afternoon of Mon 28th June then please join us for an online meeting to help inform a new, large Cochrane systematic review about topical treatments for eczema. Please [get in touch](#) to find out more or to find out how to contribute without joining the meeting if you are busy then.
- Cochrane blogshots are an excellent way to keep up to date with Cochrane reviews. These bite-sized summaries contain key information about recently published reviews and can be found on the [Cochrane Skin website](#).
- Keep even more up to date by following Cochrane Skin on Twitter—they now have their own account at <https://twitter.com/CochraneSkin>—an Instagram account will follow soon!
- The [Cochrane Consumer Network](#) are supporting a wider Cochrane initiative to look at how to best engage patients and carers (and other stakeholders) in the development of [health guidelines](#). You can find out more [here](#) and can take [part in a survey](#) (which takes in the region of 45 mins) to provide your feedback on this topic (deadline 8th July).

The Dragon In My Skin – book, animation, and resources for schools

We are pleased to update you on the school-based outreach collaboration between Stephanie Lax from CEBD, Fiona Cowdell from Birmingham City University (BCU), and [Sinfonia Viva](#). It aimed to communicate 5 key messages about eczema self-care derived from Fiona's *mindlines* work, and to raise awareness about the condition.

Writer Hazel Gould was commissioned to write a story and came up with the brilliant dragon concept, which was then beautifully illustrated by Jay Nolan-Latchford. We were set to run in-person classroom workshops based on the book when COVID-19 arrived. But, we made this a positive; the outcome was no longer an event for select schools, but an animation that could be shared internationally!

The soundtrack was written through Zoom songwriting workshops with children with eczema and their families; they created lyrics, melodies, and effects. They then recorded themselves on whatever devices they had and emailed their contributions to be layered over the orchestra. Local animators used Jay's images to produce the film, and the result premiered on Zoom on 27th March 2021. It's doing well on [YouTube](#) and French and Portuguese translations have been requested.

BCU's School of Education then took the project to a new

level in producing a flexible, cross-curricular resource pack to accompany the animation, now being piloted by a cohort of 300 teaching students. We took on board your feedback to 'educate the educators' and to make it relevant to the whole class without the need to single out individual children.

We continue to advertise and disseminate the resources and are excited to see how people use them. Links to the digital book, resources, and further information about the project are on the [CEBD website](#). Feedback is now coming through and we will keep you updated on Twitter ([#DragonInMySkin](#)). If you have any ideas how we can more widely share this, or if you'd like a hard copy of the book for a school, please [get in touch](#).



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Sinfonia Viva is supported using public funding by Arts Council England.

National Institute for Health Research (NIHR) Updates

- Please remember that the Involve website (which previously hosted information about patient and public involvement in research) is in the process of being mothballed. You will now find updated information on the [NIHR website](#) with learning resources on the [Learning for Involvement](#) website.
- The NIHR celebrated International Clinical Trials day with a [survey on public attitude to health research following COVID-19](#). It's amazing to see that there have been over 1.1 million participants in 190+ NIHR funded COVID-19 studies since the start of the pandemic. There is also a new [two-week online course](#) you can take part in to enable you to better understand how the research community has responded to COVID-19.
- There are some great videos on the [NIHR Youtube channel](#) NIHRtv. Most of them are short bite-sized chunks of information and recent additions include 'Why inclusion matters in clinical research' and information about the new, national 'Patient Recruitment Centres'.
- Check out these [co-production podcasts](#)—some really interesting perspectives on co-producing research.