

CENTRE OF EVIDENCE BASED DERMATOLOGY (CEBD)

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Patient Panel Newsletter

www.nottingham.ac.uk/dermatology

Patient take over edition: Produced by Irene Soulsby, Anjna Rani and Amanda Roberts

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CEBD biennial report



Check out this colourful and interesting report!

<https://www.nottingham.ac.uk/research/groups/cebd/documents/annual-reports/impact-engagement-2324.pdf>

New dermatology treatments



Anjna Rani writes: A quick piece on some new dermatology treatments that have been approved over the last couple of years for awareness. For those with atopic dermatitis (eczema) would have heard the buzz about a biologic treatment being available called Dupilumab. Since then, a number of similar drugs have been approved such as tralokinumab, baricitinib, upadacitinib and abrocitinib. These all work by blocking the activity of naturally occurring chemicals in the body such as interleukins or janus kinases. Great to have so many other options and some available in a tablet form instead of injections, and that they have all been tested alongside using your other standard treatment regimens such as emollients/moisturisers and steroid creams.

A very recent approval has been nemolizumab. This has been approved to treat prurigo nodularis as well as atopic dermatitis (subject to age restrictions). Prurigo nodularis is a chronic skin condition that causes hard, itchy bumps called nodules so it is good news there is another type of treatment to help with this condition, as well another add to eczema treatments.

Chronic hand eczema has always been quite problematic to treat. Another option recently approved is delgocitinib specifically for moderate to severe chronic hand eczema (after steroid creams have been tried or are not suitable to be used).

For psoriasis, a lot of research has been looking at blocking the activity of interleukin-17 (IL-17) in the body. Several treatments blocking this naturally occurring chemical have been approved such as secukinumab, ixekizumab, brodalumab and bimekizumab. Further research looking at other types of interleukin for other skin conditions is being explored (e.g. lebrikizumab blocking interleukin-13 inhibitor for atopic dermatitis).

As a reminder and one that made the news about body image in particular, was the approval of a cream called ruxolitin for the treatment of non-segmental vitiligo in adults and adolescents with facial involvement. It has been incredibly difficult to have a range of treatments for vitiligo approved, so a fantastic win here.

Another reminder of the approval of ritlecitinib for the treatment of severe alopecia areata in patients aged 12 and over.

With all treatments, there is always a risk of side effects. A scheme called yellow card reporting is run by the regulatory authority in the UK, the MHRA who also approve these treatments. This is to report these side effects and can be easily done by following the link:

<https://yellowcard.mhra.gov.uk/>

As well exploring treatments, there is a push to get the waiting lists down of people actually being diagnosed with conditions and having access to care, particularly for detecting those with skin cancer. There is a huge amount of work being done to look at artificial intelligence or AI to support on this, so watch this space.

NIHR strategic commitment to public partnerships



The NIHR has published its first [Strategic Commitments for Public Partnerships](#) to improve how we work with patients, service-users, carers and the public. This is a step change in our ambition to make public partnerships diverse, inclusive and impactful.

Videos that explain research concepts



Irene Soulsby writes: This is a fabulous little clip about the expectations for a co-applicant member of the public. Great Expectations https://youtu.be/iY771_a_L1Q?si=d6piQpkyVgaRI7gZ

I started volunteering for university projects in the North-East. One project required me to take part in testing, sometimes for hours at a time. It was very monotonous, and I had to watch something to keep me awake and engaged in the task. Otherwise, I'd get a bit "groggy". I remembered my childhood love of Tom and Jerry cartoons and chose to watch them. Watching the cartoons worked – most of the time - and I still found it difficult not to laugh!

This brings me back to "what makes a good, or favourite video" and here are a few thoughts from me

- 1 Who is the video for? Is it better to have people talking or an animation? Perhaps it's for children, younger people. A specific group, or topic?
- 2 Is there a story? Often this is a more engaging way to explain research or a condition. I think people like stories, and this makes it more "human".
- 3 Would it be suitable for all to watch? Perhaps it could be translated into different languages?
- 4 Some videos have shapes to represent people: I think is a good idea, to capture our diversity.
- 5 I think it's very effective to have a range of voices, someone who sounds like they are from our community. Someone we could relate to and find trustworthy.
- 6 Background music can be pleasant to listen to, or perhaps it gets in the way and could be a bit distracting?
- 7 I think our attention span can be limited so "short and sweet and to the point".

Nowadays, there are so many great animated films at the cinema, and I still enjoy watching them!

I will keep an eye out for my favourites, and it would be great to hear from any of our readers – do you have any favourite videos? (specifically relating to PPI, or a project that you might have come across or been involved with in some way?)

Deep End GP Practices



The Deep End Movement advocates for staff and patients in GP practices that serve very deprived (lower opportunity) populations. The Nottinghamshire Deep End Group is open to all practices with an IMD of greater than 40. They aim to increase research participation in our most deprived, the **bottom 15 % of all practices**, and underserved populations. There are many barriers for this population engaging in research. Practices have fewer resources (less funding for work done) and patients are less likely to engage in research for multiple reasons (e.g. finances, education, trust, digital poverty, illiteracy, poor English skills etc.). They aim to increase research study engagement and delivery in underserved communities in Nottinghamshire. There are benefits for underserved populations by increasing research participation. Participating in research projects and engaging with research design will impact what research is done, how it is delivered and the results. Research impacts policy and therefore this could lead to better healthcare and health outcomes for underserved populations.

Patient outcomes following facial skin cancer surgery



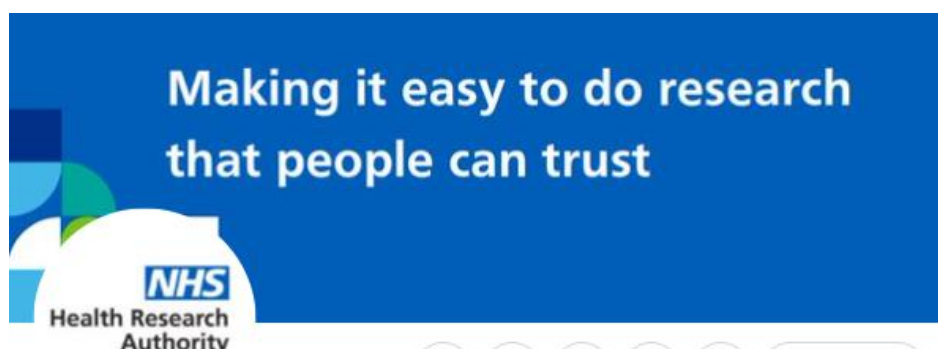
Patricia Fairbrother writes: I have been a non melanoma skin cancer patient on and off for some years. The cancers have all occurred on my limbs, but I am very much aware that skin cancers can also occur on the face. There seems to be very little research up to now as to the psycho/social effects on patients who have undergone such treatments. My own research has shown that as a rule, most patients facing facial surgery be it MOHs (removing the cancer slowly in layers and the layers being examined histologically during surgery until clear) or straightforward standard excision, most just want their cancer “to be gone”. Cosmetic considerations are usually secondary. I have spoken to two such patients who both had two different surgeries for their

facial cancers. The first surgery for both involved MOHs and with both patients the second surgery was with general standard excision. Both patients healed well physically and mostly psychologically, but one patient explained how she has always held a gym membership and wasn’t able to access the gym for some months because of the impact on her face with that type of movement. This impacted her mental state giving her feelings of frustration. With the second surgery she thought about this aspect and found an online standing Yoga exercise that could be executed mainly with her arms! She was happy!

Overall, both patients I talked to were very happy with their surgical teams, the cosmetic outcome of their extensive facial surgery, and now after approximately two years post surgery, their scars have faded to be almost non-existent. Both are now acutely aware of the effects of sun damage, and wear the highest factor sun cream daily throughout the year. Both are concerned that there could be more cancers following on from decades of sun damage.

I feel very strongly that there is a need to raise more awareness of the dangers of skin cancer and the damage both physically and psychologically skin cancer can cause.

New report shows encouraging levels of public involvement in health and social care research in the UK



- Around three quarters of health and social care studies are involving patients and the public in their research according to our latest analysis of data.

- A sample analysis from the nearly 4,000 studies which received a favourable opinion from a Research Ethics Committee (REC) in 2023, showed that overall 74% of studies told us that they had involved patients and the public in their research.
- This approach to public involvement is not consistent across all types of research though.
- The Health Research Authority looked at whether rates changed when research was a clinical trial and whether the sponsor was commercial or non-commercial.
- Just over half (54%) of clinical trials and 53% of commercially sponsored research reported public involvement.
- The figures were significantly higher for non-clinical trials (83%) and non-commercially sponsored research at 89%.
- Throughout the HRA analysis there were great examples of meaningful public involvement where the difference being made was clearly demonstrated.
- However, not all applications provided clear information that would help Research Ethics Committees to understand how people's input is helping to make the study ethically acceptable.
- In addition, there were some applications where public involvement was confused with participation in research or dissemination of research findings.
- 884 members of Research Ethics Committee (REC) volunteered 75,000 hours in 2024

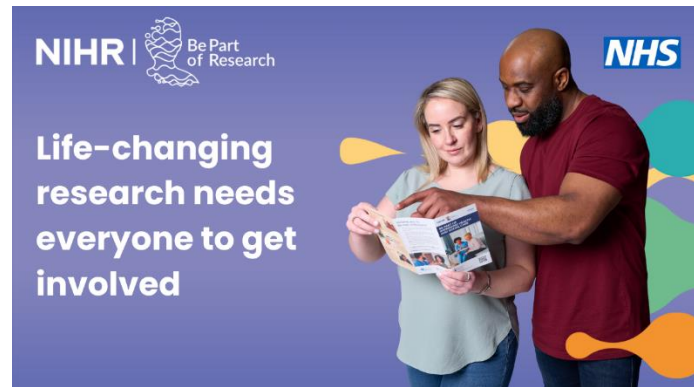
[New report shows encouraging levels of public involvement in health and social care research in the UK - Health Research Authority](#)

Forging a more equitable future through Patient and Public Involvement and Engagement



Another report, this time from the Health Innovation Network, [Forging a more equitable future through Patient and Public Involvement and Engagement](#), sets out recommendations, exploring how patient voices can be embedded in the development of digital technology, the need to move beyond conventional pathways, and how to build trust through local communities.

A new NIHR service makes it easy to take part in health and care research



Be Part of Research makes it easier than ever to find and take part in health and care research. The free online service matches volunteers to health and care studies, based on your interests, taking place online or at locations near you.

Through Be Part of Research, you can find and take part in research into nearly every major health condition - as well as social care research.

Simply sign up online and choose the areas of research you're interested in. You'll be matched to suitable studies and sent clear information about what's involved and how you can take part, if you choose to.

Whatever your state of health, you can help find new and better ways to treat conditions, and improve care. You can even take part as a healthy volunteer. Your family may have been particularly affected by a particular condition, or you may have experienced an illness and want to make life better for others living with it.

Sign up to Be Part of Research today and make a difference to the health and care of tomorrow. With your help, research can go further and faster.

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