

NIHR Leeds Biomedical Research Centre

Patient and Public Involvement, Engagement and Participation

Winter Newsletter 2025

News and updates



Updates from the NIHR Leeds BRC

Winter 2025

Seasons Greetings

Welcome to the Winter 2025 edition of our Patient and Public Involvement, Engagement and Participation (PPIEP) Newsletter.

If you would like to receive this by post, please email Libby on ppibrc@leeds.ac.uk with your name and address.

We are excited to share our seasonal wrap-up with you, along with some of what we have in store for 2026.

This editions stories include:

Pain and the Brain Workshop

The start of an innovative project looking at how audio stimulation can help people with chronic pain.,

ICTD Roundup

A round up of the amazing International Clinical Trials Day which took place on the 20th of May and saw over 50 people visiting the BRC for a day of activities and talks.

Be Part of Research

Sign up to Be Part of research to find out about health and social care research taking place in England, Northern Ireland, Scotland and Wales.



Event Highlight

Iconic Fatigue

Running until 24th December 2025

An art exhibition at Suny Bank Mills highlighting peoples lived experience with chronic fatigue.

**ICONIC
FATIGUE**

Part of the 'Broken/Makeshift' Exhibition:
11th Oct - 24th Dec
Sunny Bank Mills

Project Spotlight: Remote Peer Mentorship in Osteoarthritis

The project 'Remote Peer Mentorship in Osteoarthritis' (RaMlgO), was shortlisted for the Arthritis UK Research Highlight of the Year.

You can find out about all six shortlisted projects on the [Arthritis UK website](#), including a news story on the winning paper, '[Exploring the genetics of osteoarthritis](#)'.

The team have developed a remote support programme to help people with osteoarthritis facing 'socioeconomic disadvantage' – barriers linked to factors such as education, income or housing. Over six remote sessions, a trained volunteer gives guided support to someone else with the same condition, a process known as 'peer mentoring'.



Anna Anderson and a patient representative, working on RaMlgO.

The findings suggest the programme could benefit people delivering and receiving it and so help create a fairer future. The project was led by Prof Gretl McHugh from the University of Leeds working with first author Dr Anna Anderson, the wider research team, public co-applicants, and peer mentors.



Visit the Arthritis UK website by scanning the QR code, or following the link:
<https://www.arthritis-uk.org/our-research/research-we-fund/research-highlight-of-the-year/>

Project Spotlight: Iconic Fatigue

Following the fatigue workshop run by Lucy Prodger's and supported by our PPIEP team, we are happy to share with you the connected project , 'Iconic Fatigue' now exhibiting in Sunny Bank Mills in Farsley until **24th of December**.

Iconic Fatigue is a new project by award winning duo disabled artist Ellie Harrison and designer Bethany Wells in collaboration with print designers Hester Simpson and Charlotte Raffo. They interviewed people with energy limiting conditions to hear about their experiences, then interpreted their words through print design to boldly occupy a space in contemporary society that people with chronic illness are often excluded from. These print designs are then made up into bedding sets. Bed linen and audio interviews combine to make an Immersive installation at the Sunny Bank Mills galleries.

Iconic Fatigue is led by and works with people with lived experience of Chronic Fatigue, Long Covid and other energy limiting conditions. It is underpinned by academic research, and developed in collaboration with Dr. Lucy Prodgers from the School of Medicine at University of Leeds, supported by Leeds Cultural Institute.

If you have the time, we highly recommend a visit to see the fantastic art on display, and see some of the different ways the PPIEP work you do can impact areas outside of research.



Project spotlight: Pain and the Brain workshop

The Audio closed loop alpha neuromodulation for pain workshop was run at the NIHR Leeds BRC to trial how audio stimulation might work in helping participants with their pain management. The team consisted of Steve Halpin, Sol Harter, and James McLaughlan, with assistance from Libby in the PPIEP team.

Participants tried pre-recorded versions of 5 different types of audio stimulation options and gave their thoughts on how they felt to use. They then provided feedback on the study design proposal: where participants will be asked to attend the research lab to try different audio stimulations while their brain response is monitored.



Left: The Research team and the PPIEP group participants. Right: a group participant trialing the EEG cap.

The group identified key design considerations, including comfort, control and compatibility, so that future users will be able to get the most out of the device.

The session ended with a demonstration of the Closed Loop technology. One of the PPIEP members had an EEG cap applied, and participants were able to see in real time as the device monitored the brainwave activity of the volunteer. The participant commented that they found it very relaxing, and that “*it was like it was putting my brain to sleep*”.

If you would like to hear more about this project, or if you would like to be kept up to date as it progresses, please let us know by emailing **PPIEP@leeds.ac.uk**

The NIHR Leeds BRC News and Stories

PMR Paradox

Led by Dr Sarah Mackie, In partnership with the charity PMRGCAuk and sponsored by the National Institute for Health and Care research (NIHR), the Polymyalgia Paradox project has highlighted significant health inequalities, especially in the North of England, where patients are less likely to be diagnosed, referred, or supported.

[Read the full Writeup on our website HERE.](#)



Scan to visit the BRC Website

Ask the Researcher

We ran another Ask the Researcher event in July with Dr Katrina Freimane, where she shared her work in understanding the risk of heart disease in people with Polymyalgia Rheumatica (PMR) and Giant Cell Arteritis (GCA).

The Hybrid event went really well, and we received some great feedback from attendees, along with requests for future talk topics. You can watch the edited recording of Katrina's talk on our YouTube Channel.



Scan to visit our YouTube channel:

<https://www.youtube.com/@nihrleedsbiomedicalresearch4165>

Festive Celebration

We hosted a small festive celebration for our PPIEP contributors, where our team lead Amy Rebane, and the director of the BRC Philip Conaghan. Philip shared feedback from the scientific advisory board review, who noted “*better and earlier diagnosis, prevention and ... personalisation has already been realised ... across all 6 research themes*”.

Attendees took part in a festive quiz, and shared lunch with the BRC team to round off the day. Thank you to everyone who attended, and we look forward to another year of amazing PPIEP work in 2026.



‘Embodying Fatigue’ Podcast

Following the success of Lucy Prodger's Fatigue workshop, She has worked again with artist Ellie Harrison to produce a podcast: ‘Embodying Fatigue’.

The podcast features conversations, reflections, and creative projects that aim to amplify underrepresented voices and reimagine how we understand and communicate lived experiences of fatigue.



[Scan the QR code or listen here:
https://embodyingfatigue.podbean.com/](https://embodyingfatigue.podbean.com/)

Lunch and Learn

In October we hosted another Lunch and Learn Session with the Leeds Hamwattan group. We had over 30 attendees come and learn about Bowel Cancer Screenings and improving recovery with Physiotherapy. We are really pleased with how well our lunch and learn programme of events have been received, and we look forward to running more in 2026.

If you have a community group that might enjoy a Lunch and Learn session, please get in touch with our PPI team on PPIBRC@leeds.ac.uk

International Clinical Trials Day

Our International Clinical Trials Day (ICTD) event, hosted on the 20th of May 2025, was a great success.

The event had over 50 attendees and 12 stalls including the charities Healthwatch and Yorkshire Cancer Community.

Attendees were able to meet directly with research teams at their stalls, and listen to talks from researchers across the BRC detailing their current research projects.

Attendees were taken on facility tours to see the NIHR Leeds BRC Ultrasound and MRI departments in action, and took part in mini workshops to share their thoughts on clinical research.

We received some lovely feedback from both researchers and PPIEP members, and we hope we can host a similar event in 2026.

“Learnt something useful from every talk, met so many interesting people - Thank you”

“Wow Leeds - very informative, lets have another please”

“The entire day was inspiring, innovative and exciting!”



Pictures from the 2025 ICTD Event.

FIG Meeting

This September we ran our last Fighting Infection Group (FIG) meeting of the year, with participants joining both online and in person to hear from the different research teams.

Topics included:

- Raising antimicrobial resistance (AMR) awareness.
- Protecting patients from C difficile infections.
- Steriwave: a nasal decolonisation tool.
- Portable antibiotic pumps for hospital patients.
- The allergy antibiotics and microbial resistance (ALABAMA) trial.

We are so pleased with how successful this group has been, and we are looking forward to running more meetings in the new year to bring even more AMR and Infection research to our PPIEP members.



AIMTECH workshop - Digital monitoring for Raynauds

We ran a focus group at the NIHR Leeds BRC to look at the use of a digital monitoring tool in managing a patient's care for Raynauds.

The research team received some great insights from the attendees, and are hoping to bring more updates and next steps in 2026.



Shaping how research findings are shared

In July PhD student, Fern Harvey held a meeting with 12 public contributors to talk about how research findings are shared. The main points are shown in this infographic.

Public contributors described very different experiences of hearing about study results they were involved in. Some said they never received any feedback when a study ended, which left them feeling disappointed and less willing to take part in future research. Contributors also stressed that researchers should consider how they share their findings, making sure documents are easy to read, with clear language and a suitable font size.

Overall, the group agreed this is an important issue that needs more discussion to improve how research results are shared.

Please contact the BRC team for the full-sized, more detailed Infographic on
PPIBRC@leeds.ac.uk

Sharing research findings - public contributor summary

" Make research findings transparent, appropriate to the audience, and think about the timeframe for when findings will be shared".

Public contributors often do not receive feedback



Researchers need to make what they share accessible



Researchers need to share negative findings



A challenge with budget and time

Rare Disease Podcast

As a part of the 'Keep It Science' Podcast, Prof. Francesco Del Galdo and Dr Elisabeth Kugler join Dr Nick Gaunt to discuss their work on Scleroderma.

The podcast has been selected as one of the top 5 BBC Radio uploads in 2025, and the team will be fetured on the BBC Radio Christmas special on the 27th of December. You can listen to this episode live on the BBC website: <https://www.bbc.co.uk/programmes/p0gp61hk>

The podcast is available on the Zeeks- Art for Geeks Ltd YouTube channel, along with their full catalogue of informative podcasts.

Listen now: <https://youtu.be/FCg3vT7MOco>



Scan to Listen
to the podcast
on YouTube

Disability inclusion blog

Dr Anna Anderson has recently published a blog post detailing her work into disability inclusion as part of the BRC Qualitative Social and Behavioural Research Network. The article highlights why it is so important for researchers and healthcare workers to consider disability inclusion.

Nearly one in four people in the UK is disabled, making disability inclusion a priority for all health research areas – not just those focused on disability.

To read the full article, visit the NIHR Bristol BRC Website:

<https://www.bristolbrc.nihr.ac.uk/news/improving-disability-inclusion-in-qualitative-health-research-why-and-how/>



Scan the QR Code to read
the full article online.

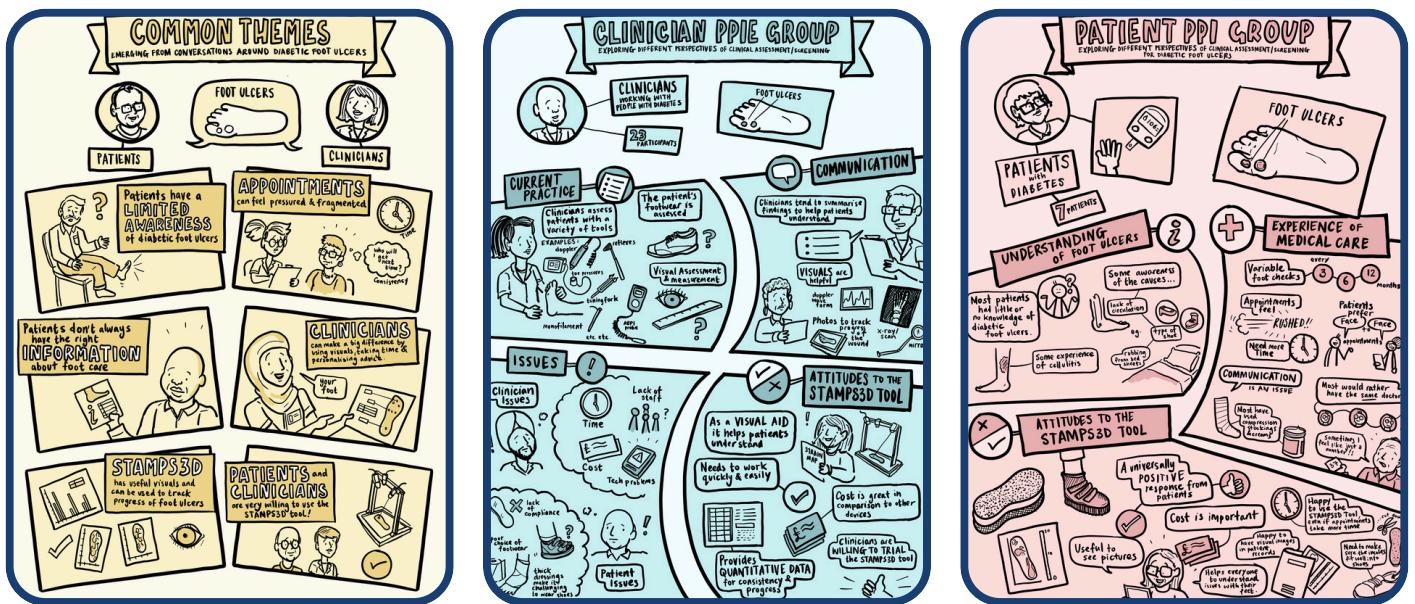
NIHR | Bristol Biomedical
Research Centre

Diabetic Foot Ulcers: Exploring different perspectives of clinical risk assessment/screening

A team of researchers at the NIHR Leeds BRC ran a focus group to look at peoples understandings around diabetic foot ulcers, and to gather patients thoughts on their research method: STAMPS3D. This method uses Digital Image Correlation (DIC) to measure the strain captured by an insole placed in a patients shoe. in particular they were looking at:

- Awareness and knowledge of diabetic foot health and ulceration risk.
- Peoples perceptions of current assessment methods.
- Acceptance and attitudes towards STAMPS3D and potential impacts.

The team heard from both clinicians and Patients, and produced some info graphics to demonstrate their findings. Please contact the PPI team at PPIBRC@leeds.ac.uk if you would like full scale copies of these graphics.



Graphics developed as part of the Diabetic Foot Ulcers project

Involvement Opportunities

Be Part of Research



Be Part of Research:
Small actions can lead to big discoveries. Sign up today!

Register Now



Visit the Be Part of Research website here to find out more and to register: <https://bepartofresearch.nihr.ac.uk/>

Involvement Opportunities

Remission in Psoriatic Arthritis (PsA)

**Do you have Psoriatic Arthritis?
Would you like to provide some research feedback?**

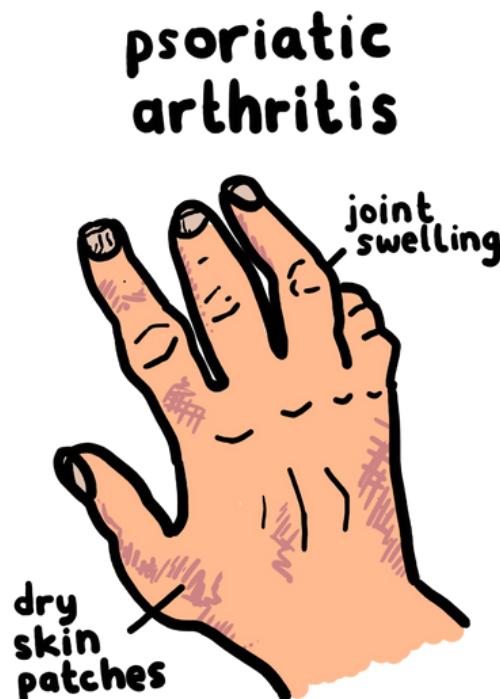
In early 2026 we will be running a focus group to gather feedback on a project looking at remission in Psoriatic Arthritis (PsA).

We need people with lived experience in this area to help Gabriele and his team shape this research project.

If you think this might be relevant to you, or if you would like to find out more about this project please get in contact with our team.

Email Us: PPIBRC@Leeds.ac.uk

Text or Call Us: 07935341885



Thank you!

Thank you for taking the time to read our Winter Newsletter, we hope you have a lovely festive season, and a happy new year. We look forward to working with you all in 2026.

If you have any feedback, please contact Libby at ppibrc@leeds.ac.uk

Feel like we're missing something?

Have some exciting PPIEP work to share?

Want something included in a future newsletter?

Please email us at ppibrc@leeds.ac.uk

