

NIHR Leeds Biomedical Research Centre

Patient and Public Involvement, Engagement and Participation Spring Newsletter 2025

News and updates



Updates from the NIHR Leeds BRC

Spring 2025

Welcome!

Welcome to the Spring 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 trying out a new format this year, so let us know what you think of our simplified design and stories!



This editions stories include:

Annual Report

Our 2024-2025 Annual Report is ready to share, highlighting how we have worked with **193** of you over the last year to improve health research.

Spotlight on PMR

We supported Dr Sarah Mackie and her team in 11 PPIEP activities, feedback from patients gathering on what matters to them most in their PMR treatment.

Involvement Opportunities

A list of upcoming Involvement opportunities, Including a study on UTI Infections, and xxx

Event Highlight

International Clinical Trials Day
20th May 2025

Our biggest in-person event of the year, hosted at the Leeds BRC and involving 12 research teams, 3 charities, and over 50 guests!



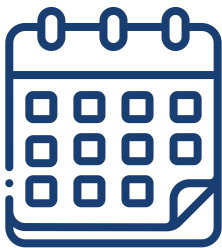
Leeds BRC Annual Report Highlights 2025

The BRC 2024-2025 Annual report has now been completed, summerising our work over the last year. If you would like to recieve the full report please email us at PPIBRC@leeds.ac.uk. Please enjoy some of the hilights from this years report:

Community Engagement Highlight: Lunch and Learn

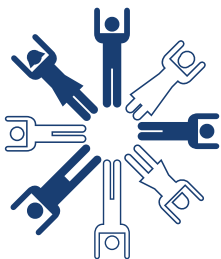


- 4 events in local community locations
- 12 researchers involved.
- 86 participants.



We ran **14** PPIE Activities
175 people got involved

We attended **7** community events



We engaged with **193**
patients and public members

We supported **48** research
meetings



Pathology Theme

Annual PPI activity report

The Leeds BRC Pathology team have been incredibly active this year, taking part in a range of patient engagement activities and meeting with people from across Leeds and Yorkshire, including one of our previously shared Lunch and Learn events!

If you would like the full activity report, give us an email at PPIBRC@leeds.ac.uk. Otherwise, please enjoy the photo gallery highlighting some of the activity the team got up to this year.

Be Curious

Saturday 18th May 2024



Left to Right; Leanne Galvin, Dr Susan Richman, Dan Bottomley and Gemma Hemmings at the University of Leeds 'Be Curious' event, 18th May 2024.



Katrina setting up one of our microscopes. Leanne and Eleanor viewing the slides and two visitors also having a look (photos taken with consent of visitors).



Above: Dr Caroline Cartlidge deep in discussions with patient rep Kate. Right: (L to R) Hannah Rossington YCRBCIP manager, Patient Rep Kate, Dr Susan Richman.

YCR staff, Patient Rep and BriteVox staff laboratory visit

May 2024

We hosted employees from BriteVox, the fundraising partner of Yorkshire Cancer Research, along with staff members from the charity, and one of our patient representatives. The visitors learned about the work we have undertaken using large Programme grants awarded to our department by Yorkshire Cancer Research.



Prof Phil Quirke (above) and Prof David Sebag-Montefiore (left) introducing our visitors to the work made possible by funding from Yorkshire Cancer Research.



Clockwise from top left; Gemma, Subaa, Hayley and Mike showing our visitors tissue fixation, FFPE block sectioning, H&E staining, super-res microscopy, and slide digitization respectively.

CRUK Staff and Fundraisers laboratory visit

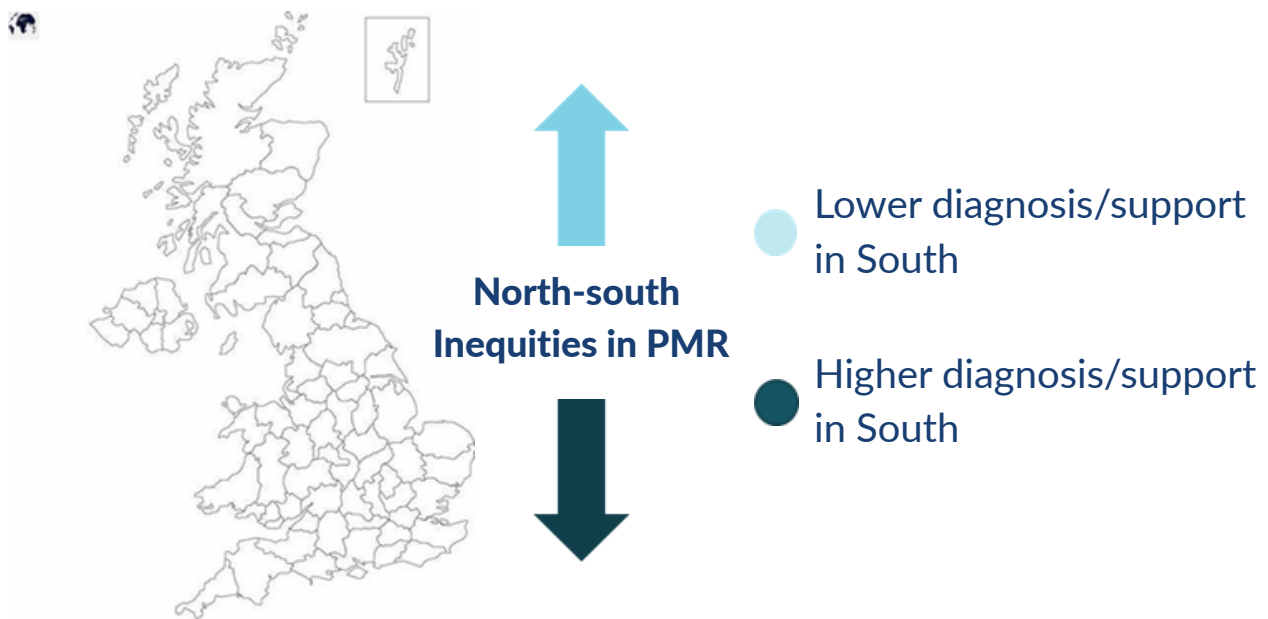
November 2024

We hosted members of staff from Cancer Research UK, employees from Barrett Steel and several very committed charity fundraisers. Among other things attendees tried their hands at pipetting, while learning about the sample processing pipelines in the labrotory.



Spotlight on Polymyalgia Rheumatica: PMR paradox

Dr Sarah Mackie and her team have recently completed a PPIEP research project funded by the NIHR, looking at identifying barriers for PMR patients, sharing patient stories, and improving their access to healthcare and research. The grant focused on the North-South divide of PMR, and addressing issues faced by patients in the North.



You can read the full grant award here:

[The Polymyalgia Paradox](https://fundingawards.nihr.ac.uk/award/NIHR205184)

<https://fundingawards.nihr.ac.uk/award/NIHR205184>

The large-scale project worked with 41 different patients and members of the public across 11 different meetings to map what were the most important aspects of their PMR journey, and what researchers should be focusing on when it comes to PMR research.

Sarah and her team are now working on sharing the outcomes of the project, and taking forward the next steps in their PMT research. Keep an eye on the NIHR Leeds BRC website for more updates in the near future!

INCLUDE disability project

Anna Anderson, one of our incredible researchers here at the BRC, has been working on a research project following our Community Conversations work focusing on improving accessibility in health research.

Working with Leeds and Yorkshire charities including DEAFForum, Leeds Involving People, and Together we Can, Anna worked with local people to discuss the barriers they face in healthcare and health research.

One of the issues highlighted was access to regular health research projects. Projects that focus on disability may include disabled people, but often disabled people are not part of 'normal' research projects – disabled people still have views to share about research that is not focused on their disability.

Following this project, Anna will be teaming up with the PPIEP team to look at next steps for addressing the concerns raised, including:

- Development of INCLUDE disability resources for researchers.
- Supporting patients in co-producing resources, and offering training in areas such as 'Introduction to research'.
- Continued community engagement, including bringing researchers into community spaces.

Anna received some great feedback from our community partner Healthwatch on how we can better work with their team going forward:

'I think our experience of working with you have been very positive, in particular we appreciate the flexibility in using the budgets, as it allows us to tailor activities in a way that best fits the needs of the community groups we work with. This approach has been really helpful in making engagement more meaningful and effective.'

We Look forward to supporting Anna in her next steps with her inclusion work, and if you would like to find out more about the work she has done, please give us an email at PPIBRC@leeds.ac.uk.



Leeds SpA Team PPIEP Event

In march the Spondyloarthritis (SpA) Patient Event took place, bringing together patients, researchers, and the PPI team to discuss ongoing SpA research.

As part of the day the team heard from both researchers and PHD students, with topics including:

- Research project investigating non-drug therapy for Psoriatic Arthritis.
- PHD project on bowel inflammation in newly diagnosed Axial Spondyloarthritis (axSpA).
- PHD project on genetics research to improve the care of patients with SpA.

The patients were able to offer feedback to the researchers and students, and continue their discussions over a shared lunch in the afternoon.



(Above) SpA group meeting hosted at the Leeds BRC Meeting room, Chapel Allerton Hospital



(Right) The SpA team posing with the SpA banner.

Owls on Tour:

Children and Young People's Involvement in Health and Social Care Research: Making Connections

The Leeds Young Research Owls group formed in October 2019, and now consists of over 20 members, all young people that are patients, or aspiring healthcare professionals and scientists who are passionate about being involved in and supporting research.

In February the group had the opportunity to attend the Making Connections National Meeting in Birmingham. 5 group members, alongside their research leader Heather Rostron, made the journey to join like-minded young people from across the country in discussing the importance of involving young people in health research.

The topics covered included:

- The Importance of Involving Young People.
- Trauma informed approaches to children's mental health research.
- Involvement at every stage.

You can find out more about the Leeds Owls on their website here:

<https://generationr.org.uk/leeds-young-research-owls/>



Attendees at the Children and Young People's Involvement in Health and Social Care Research: Making Connections meeting 2025.

The NIHR Leeds BRC News and Stories

Patient views on the use of AI in healthcare

The Leeds Teaching Hospital Trust Research and Innovation department has worked with a group of patients to gather their thoughts on the use of AI in our healthcare services. From these discussions the team have developed a short video summarising everyone's thoughts, and helping explain how AI is currently used in our research pathway.

You can watch this video now on the LTHT Youtube channel, or by following the link here to the right.

Watch Now: The use of AI in healthcare - Patient's views



Video Link:

<https://youtu.be/GzhmOVQ1ttY?si=WZga4P9EGmlhb00m>

Lunch and Learn

We have continued our Lunch and Learn Programme of events, running sessions once again with Burley lodge, and joining the Sikh Elders group for a couple of sessions discussing diabetes, Obesity, and foot health.

Following the summer we look forward to running more events with other Leeds community groups.



Involvement Opportunities

Do you or someone you care for suffer from UTI's?

We are looking for women who experience Urinary Tract Infections (UTI's), to help us plan some research that aims to improve the diagnostic process and future treatment of UTI's.

Whats Involved?

- Review our study materials.
- Feedback on sample collection methods.
- Help make the research inclusive and accessible.
- Help plan how to share our results with people once the study is complete.

We can support you to get involved in a way that works for you, including 1 on 1, joining a focus group, or sending you printed documents to review

A recognition payment is available to thank you for your involvement.

Want to find out more? get in touch!

Email Us: **PPIBRC@Leeds.ac.uk**

Text or Call Us: **07935341885**



Do you have Scleroderma?

scleroderma



We are currently undertaking research activity relating to the prevention and better management of Scleroderma and are seeking people with lived experience of the condition.

This can either be as a patient, care giver or someone who is undergoing investigations.

If you're interested in finding out more, please register your interest by emailing us on PPIBRC@leeds.ac.uk
Or text/Call Us: **07935341885**

NATIONAL EVALUATION OF WEIGHT-MEDICATION ACCESS

Help shape our research by sharing your experiences with weight management support

JOIN US IN
UNDERSTANDING
MORE ABOUT
ACCESS TO
WEIGHT
MEDICATION



Photo credit: ECPO Media

We are seeking to recruit an advisory group of seven people to support our research study

We'll pay for your time and cover travel costs for in-person meetings. Support is available for online participation.

You must be 18+ and willing to attend monthly meetings as part of our Patient and Public Involvement and Engagement (PPIE) group.

We welcome people from all backgrounds and communities to ensure our research is accessible to everyone.

CONTACT INFORMATION:

If you are interested in this opportunity, please tell us in a couple of sentences about you and why you are interested (only disclose information you are comfortable with sharing).



info-newa-study@**bristol**.ac.uk



0117 455 7944



Thank you!

Thank you for taking the time to read our Spring Newsletter, we hope you have some lovely plans for the warmer weather, and we look forward to sharing more with you in our Summer Newsletter later this year.

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.

