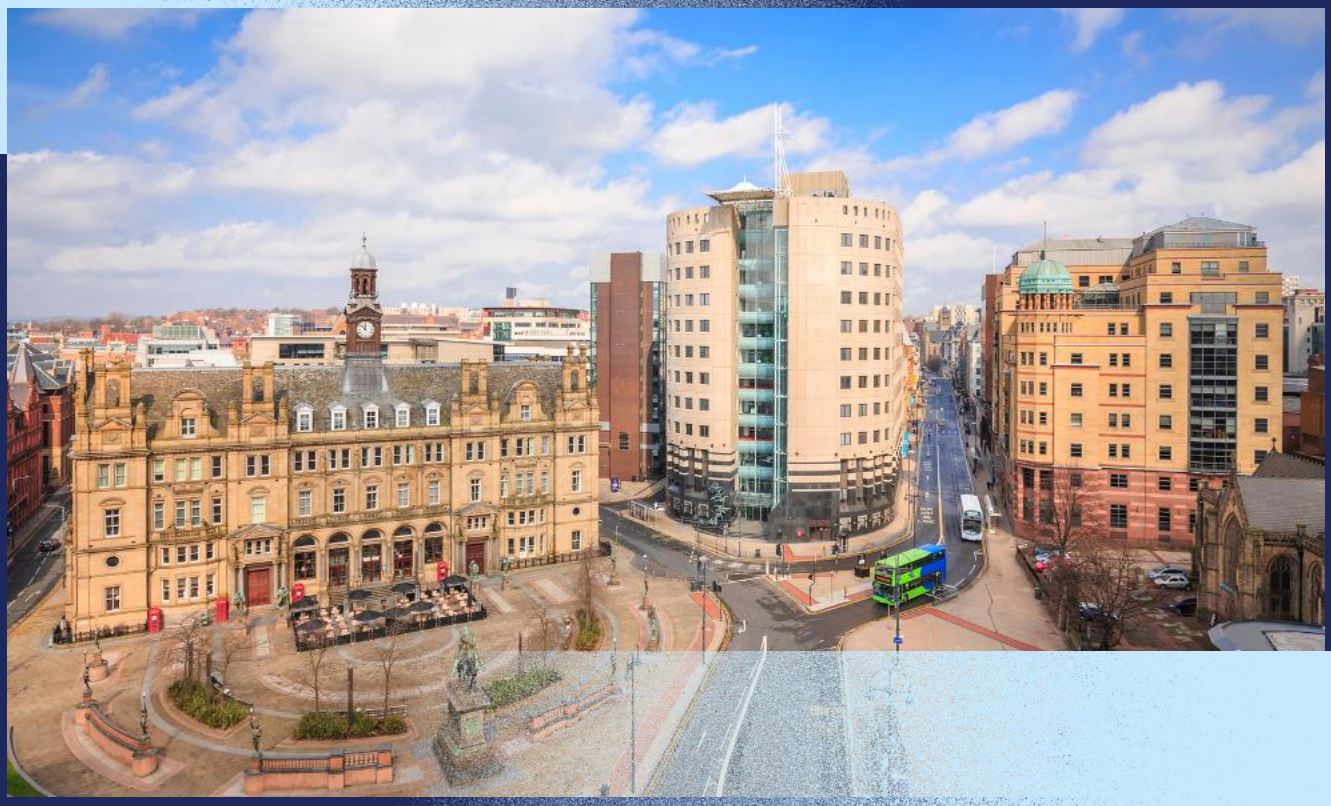
NIHR | Biomedical Research Centre

Patient and Public Involvement, Engagement and Participation in Leeds

Spring Newsletter 2026



The Leeds Teaching Hospitals NHS Trust

University of York

University of Leeds

Updates from PPIEP in Leeds

Spring 2026

Welcome!

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

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

2026 has got off to an exciting start, with many new projects coming to the NIHR Leeds Biomedical Research Centre (BRC). As the warmer weather returns, we hope to see you at one of our many upcoming activities soon!

This edition's stories include:

National News

The NIHR Leeds BRC PMR paradox work is making national headlines, with the BBC spotlighting our work looking at the 'divide' in treatment.

Hello Hearts

Our teams have been out in the community sharing the CRF Hello Hearts programme, and encouraging our local communities to learn more about their heart health.

Diabetes Day

The PPI team ran our first big event of the year; Diabetes Information and Research Day, where over 50 people attended to present and learn about diabeties.

Event Highlight

International Clinical Trials Day

20th May 2026 - Leeds BRC, Chapel Allerton

Returning for its second year, we will be hosting an International Clinical Trials Day event at the NIHR Leeds BRC, looking at the last 20 years of health research in the UK.

Keep an eye on your emails for more details!

Project Spotlight:
Lunch and Learn & Hello Hearts

NIHR
Clinical Research Facility

At the start of this year we ran another Lunch and Learn event in collaboration with the Hello Hearts work being led by Julie in the CRF team. The event was hosted at the Cardigan Community Centre, where participants learned how different conditions like diabetes could affect their heart, and what lifestyle changes could be made to help keep their heart healthy.

After the talks participants were able to get their BMI (Body Mass Index) and heart rhythm checked by the clinical team, and receive personalised advice.

The event was another great success, and we look forward to continuing to run Lunch and Learn sessions in 2026.

If you have a community group who would be interested in a visit from our team, please email us at **PPIBRC@leeds.ac.uk**

Event Spotlight:
Diabetes Research and Infromation Day

Over the last couple of years, we have been out and about in different communities to talk about research and increase involvement from groups that don't usually get involved. As part of our commitment to giving something back to people we asked them what they would like more information about and diabetes was one of the conditions that was mentioned by most groups.

As a direct response to our community feedback, we organised a diabetes information and research event on 17th March at St Georges Centre in Leeds and invited all our community partners to attend, as well as existing PPI members.

On the day we had presentations from Dr Nina Davies, the clinical lead at Leeds Community Healthcare NHS Trust around the diabetes prevention programme and Professor Ramzi Ajjan about diabetes as a disease and research taking place in this area.

There were also workshops on different diabetes research including eye health and diet, foot health and weight management and the path to remission programme. The day ended with a marketplace event with stalls from diabetes researchers, The Obesity Institute, Healthwatch Leeds, blood pressure checks, Diabetes UK, heart health and diabetes, orthopaedic supports and diabetes foot health.

Diabetes Research and Infromation Day

"The day was an important reminder that diabetes affects people in many different ways, and not everyone finds it easy to get the care they are entitled to. We also talked about how research needs to include people from under represented communities so the care we offer is fair and reflects everyone's needs. Listening to people's experiences helps us make services better for all our communities".
-Nina Davies

The day was attended by over 50 people with positive feedback received around the information and advice provided and the overall format of the day. It was a great opportunity to showcase the diabetes research taking place, provide information for participants and increase interest and involvement in PPI and research.

"It has been a good event to gain knowledge & awareness about DT1 & DT2, Good discussions and workshops" -Participant

In memory of Yolande Sowerby

Yolande Sowerby 1935 – 2026

We are sorry to share the news of the passing of Yolande Sowerby, one of the NIHR Leeds BRC's founding PPIEP members. Since 2012, Yolande has been integral in embedding patients in the heart of our research. Her passion, enthusiasm and common sense shaped much of our thinking and actions in how we meaningfully work with patients as partners and for that, we at the BRC, are truly grateful.

Her input into our initial strategy paved the way for how we deliver PPIEP activity and communicate with patients and members of the public about getting involved. She always advocated for inclusion, long before it became the important area it is now. Anyone who met her will know what a bright and warm person she was, with a true zest for life which she brought to everything she did.

Yolande worked on the guidance we provide for researchers, as well as speaking at events and training sessions explaining the importance of PPIEP in research. Her contributions were always insightful and well-received with a pertinent question or two added into the mix.

If you can cast your mind back far enough, you may remember Yolande delivering Tai Chi sessions at 'Ok to Ask' events in the early years of PPIEP. Everyone always enjoyed the sessions and commented on how lovely Yolande was and several were inspired to take up Tai Chi afterwards, even inviting Yolande to deliver a session at their place of work as part of a wellbeing event.

We are grateful for everything Yolande has shared with us and contributed over the last 14 years, and she will be sadly missed by us all.

Your healthwatch Leeds

Partnership Working

Over the last few months, we have worked in collaboration with our community partner Healthwatch Leeds to support our PPI activities. They have supported with recruitment to a range of activities and focus groups for studies around physiotherapy and drug allergies.

This partnership allows us to build on our inclusive approach to PPI and increase diversity in our membership by engaging with groups and communities that do not usually get involved. Healthwatch have attended clinics and promoted the activities among their community contacts to bring in a diverse lived experience voice. This partnership has also enabled us to better meet the ever increasing demand for PPI support and activities.

Visit the HealthWatch website to find out more about them and the amazing work that they do: **https://healthwatchleeds.co.uk**

United by Ribbons Cancer Support Group

One of our PPIEP members has started a new cancer support group: United by Ribbons. take a moment to read Linda's story here:

"I'm Linda. I was diagnosed with Non Hodgkins Follicular Lymphoma in 2024.

Though I was coming to terms with my diagnosis, I wanted to learn more about my condition and what the future may hold regarding the long term effects. I was eager to connect with others who were in a similar circumstance to myself.

I struggled to find a face-to-face group which took place in the evening, I needed somewhere I could attend without disrupting day-to-day life. When I was able to attend support groups, I found being able to talk to other people who were also on their own cancer journey was really beneficial and comforting, they understood me and what I was going through, this helped me gain so much knowledge on the affects cancer has.

We are strong and resilient, something we should all be proud of.

Due to the struggles I experienced, I decided to set up this group to make it easier for anyone who may be seeking community and support, whether that be for themselves, a family member or a friend. Helping others is something I am passionate about and I hope this group will provide knowledge, strength and positivity.

The ribbons represent all types of cancer! This group is not aimed at one in particular. Together we unite, we fight! Community is everything ❤️.

Thank you for reading and Welcome to United by Ribbons Cancer Support Group ❤️"

UNITED BY RIBBONS
PEER CANCER SUPPORT

First Tuesday Of The Month
18:00 - 20:00

Held upstairs in The Loft at Nyla's.

Whether you are living with cancer, supporting a loved one or coping with a loss this group offers the chance to connect, talk and feel understood with others going through a similar experience.

For more information please contact Linda on:
lindaswellness101@gmail.com

nyla's

Nyla's, 156 Briggate, Leeds LS1 6LY

nyla's

Funded by:
NIHR
National Institute for Health and Care Research

The Hidden Cost of Steroids

A team of researchers from across the University of Leeds, University of West England, Bristol and Vasculitis UK have been awarded funding to improve existing Patient-Reported Outcome Measures (PROMs) for steroid side-effects in patients who have immune-mediated inflammatory diseases (IMID) such as Rheumatoid Arthritis, Lupus and Polymyalgia Rheumatica (PMR).

Steroids work quickly by controlling active inflammation and improving symptoms, but they often have side effects. Newer treatments are available, but they are usually more expensive than steroids, however, currently only some of the costs of steroid treatment are being considered, mostly the ones directly linked to health care. Steroids can affect many parts of life, not just health care. so the team want to understand the full impact of steroid use - including the wider costs to patients, families and society, as well as how steroids affect people's day to day wellbeing and quality of life.

The project will include focus groups, and examples of patient questionnaires will be used to get peoples' feedback. The team includes:

- Amy Rebane - PPIEP Lead at the NIHR Leeds BRC.
- Professor Ann Morgan – MSK theme lead for the NIHR Leeds BRC.
- Miao Young – health economist from the University of Leeds.
- Zoi Anastasa – Director of Operations Vasculitis UK.
- Jo Robson -Professor of Rheumatology at the University of West England, Bristol.
- Dr Clare Pain- Paediatric Rheumatologist, Alder Hay Children's Hospital.

Arthritis UK

Recruitment for related PPIEP activities will begin soon, but in the meantime you can email **PPIBRC@Leeds.ac.uk** with any questions.

PMR PARADOX:
BBC Spotlights Leeds PMR research

The PMR (Polymyalgia Rheumatica) Paradox team are excited to share some media news followed by plans for publication of their PMR PARADOX project. The team's hard work has been recognised by the BBC: **Study finds 'north-south divide' in muscle condition treatment - BBC News**, and the Yorkshire evening post: **Leeds researchers champion creative approach to address North-South divide**. If PMR is of interest to you, we invite you to take the time to read the articles, and please feel free to share this with anyone you may know who is also interested in PMR.

You can reach the articles by following the links above or scanning the QR codes bellow:

Read the BBC Article here:

And the Yorkshire evening post article here:

"We are truly grateful to everyone involved in PARADOX and for the work completed in this project!"

The research team are beginning to draft two papers relating to the PMR PARADOX study. The first will be focussed on the methods and the second will be about the overall project findings. We will be aiming for submission around September this year.

NIHR Leeds Snapshots

Living well with Diabetes event

On Sunday 8th March the CRF team, including Julie, the Equality, Diversity, and Inclusion (EDI) lead, and Shind, attended the 'Living Well with Diabetes' event. The event was organised by Sikh Wellbeing, and was held at the Sikh Gurdwara - Guru Nanak Nishkam Sewak Jatha (GNSSJ) Leeds building.

The event included health checks, including blood pressure checks, and featured talks on the links of diabetes through mind, body and spirit. Dr Sunil Daga the BRC's EDI co-lead also spoke at the event.

HM Treasury visit to Leeds

NIHR Leeds BRC together with city and regional leaders, recently welcomed HM Treasury to showcase our work in Leeds.

The visit shone a light on the BRC as an international centre of excellence, supporting translational research across antimicrobial resistance & infection, cardiometabolic disease, haematology, musculoskeletal disease, pathology and surgical technologies.

Visit our website to read the full article:

Scan to read the article:

https://leedsbrc.nihr.ac.uk/2026/02/19/nihr-leeds-biomedical-research-centre-showcases-collaboration-and-impact/

NIHR Leeds Snapshots

Staff Updates

NIHR Leeds BRC has appointed new co-leads to its musculoskeletal theme workstreams and in our EDI (Equality, Diversity and Inclusion) and Research Culture areas.
We are excited to welcome Professor Heidi Siddle (left) as co-lead to workstream seven of the Musculoskeletal Disease theme, and Dr Sunil Daga (right) as our new co-lead for EDI and Research Culture.

Embodying Fatigue Article

Scan to read the article:

https://journals.sagepub.com/doi/10.1177/09593535261429140

Following the Embodying Fatigue work last year which focused on creative ways to express fatigue symptoms, Lucy and her colleague Ellie have co-authored a paper for a special issue of Feminism and Psychology. The paper, *Creative exploration kits for embodying long-term fatigue: Developing a novel qualitative method through academic–artist collaboration and feminist praxis*, is open access and available online now.

Lucy has also begun the next funding bid to continue the Embodying Fatigue project, and we hope to update you on the progress later in the year.

NIHR Leeds Snapshots

NIHR Rebrand

As you may have noticed, the National Institute for Health and Care Research is introducing some new branding, including new fonts, colours, and logos!

Over the next few months you will see all NIHR infrastructure change over to the new branding, with a focus on “One NIHR” and the collaboration between all the different teams that sit under the NIHR umbrella.

NIHR | National Institute for Health and Care Research

NIHR | Biomedical Research Centre

NIHR | HealthTech Research Centre

NIHR | Clinical Research Facility

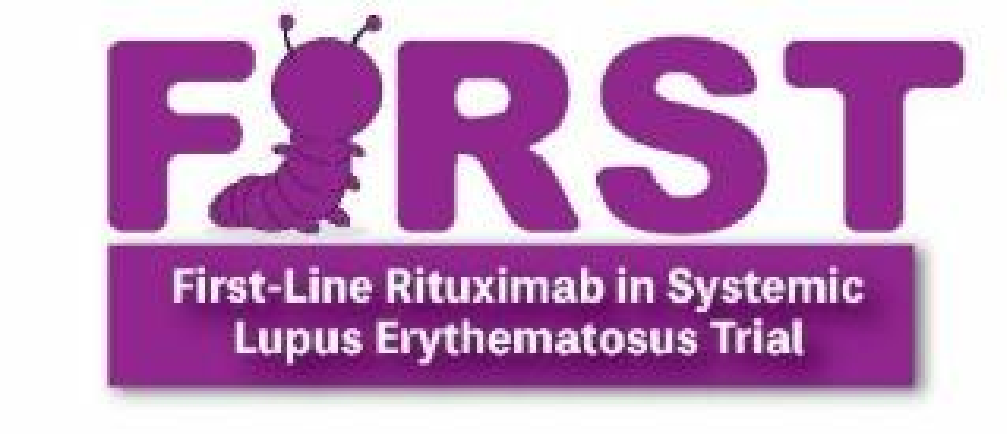
Event Recordings

The NIHR Leeds BRC YouTube channel continues to be updated with our Ask the Researcher recordings, with the recent addition of *Understanding the risk of heart disease in people with PMR and GCA* with Dr Katrina Freimane.

Visit the YouTube channel to find our Ask the Researcher playlist, alongside informative videos from other teams across the NIHR Leeds BRC. If there is something you would like to see on our YouTube Chanel, or something you have produced with BRC support that you would like including, please contact us at **PPIEBRC@leeds.ac.uk.**

Scan the QR Code to visit the NIHR Leeds BRC YouTube channel and see Dr Fremane’s AtR talk.

Opportunities



Do you have Lupus, or care for someone who has Lupus?

If so, we will be holding a full-day workshop session in May/June to discuss our planned research in this area. The workshop will be hybrid, so you will have the option to join either online or in-person at the NIHR Leeds BRC at Chapel Allerton Hospital.

In the morning session, Prof Ed Vital and members of his research team will introduce the NIHR-funded 'FIRST' study. The study wants to find out if it's better to use rituximab right after diagnosis—instead of waiting—as this is often the time when the disease is most challenging to manage. This could lead to better treatment, fewer side effects, and a better life for people with lupus-especially early on.

You won't be taking part in the study, the team is creating a video to help get people involved, and we would like your input into how we explain the research and promote it to people.

In the afternoon session, we will be discussing how Lupus impacts on people's lives more generally and the effect of symptoms, in a focus group session with members of Prof Vitals' team.

If you have Lupus or care for someone who does and are interested in getting involved, please contact us on PPIBRC@leeds.ac.uk for more information.

Opportunities

Harmony in Motion is an artist-led organisation bringing movement, sound, art and care into the same room.

We create safe, innovative, and inspiring spaces where people with Parkinson's and their loved ones and/or carers can connect with themselves and each other through the joy of moving and listening differently.

We are in the process of setting up a regular session in Leeds/Bradford.

If this is something that interests you, or you would like to keep in contact with us then join the Harmony in Motion mailing list:
http://eepurl.com/jxayLM

Gentle updates, news of upcoming projects, and ways to move, connect, and create together.

Scan to sign up to the mailing list:
http://eepurl.com/jxayLM

Volunteers Needed

We're looking for local voices; if you've used Leeds Teaching Hospitals, you can help guide our grant funding and research decisions. Join our Community Voices group and share what matters most to you and your community.

Community Voices Volunteer (PPIEP) | Leeds Hospitals Charity Volunteering:
https://volunteers.leedshospitalscharity.org.uk/

Opportunities

Patient Stories

20 Years

Powering life-changing research

As part of celebrating 20 years of the National Institute for Health and care research, the Leeds Biomedical Research Centre is looking for patients who would like to share their health research stories.

Over the next wear we want to share your stories to help show the real world impact of health research in the UK, and to demonstrate how working in partnership with patients and the public strengthens research and ensures it remains relevant to the communities we serve.

If you would like to find out more, please contact our team at **PPIBRC@Leeds.ac.uk.**

You can also find out more about NIHR20 and somilar success stories by visiting the NIHR website: **https://www.nihr.ac.uk/nihr20**

Scan to visit the NIHR20 website

Thank you!

Thank you for taking the time to read our Spring 2026 Newsletter, we have some exciting activities coming up over the next 3 months, and we look forward to sharing these with you in the Summer 2026 Newsletter.

Want to help us continue to improve the work that we do?

Have some ideas that you would like to share?

Please complete our Feedback form:

https://forms.office.com/e/DCucaCNsv7