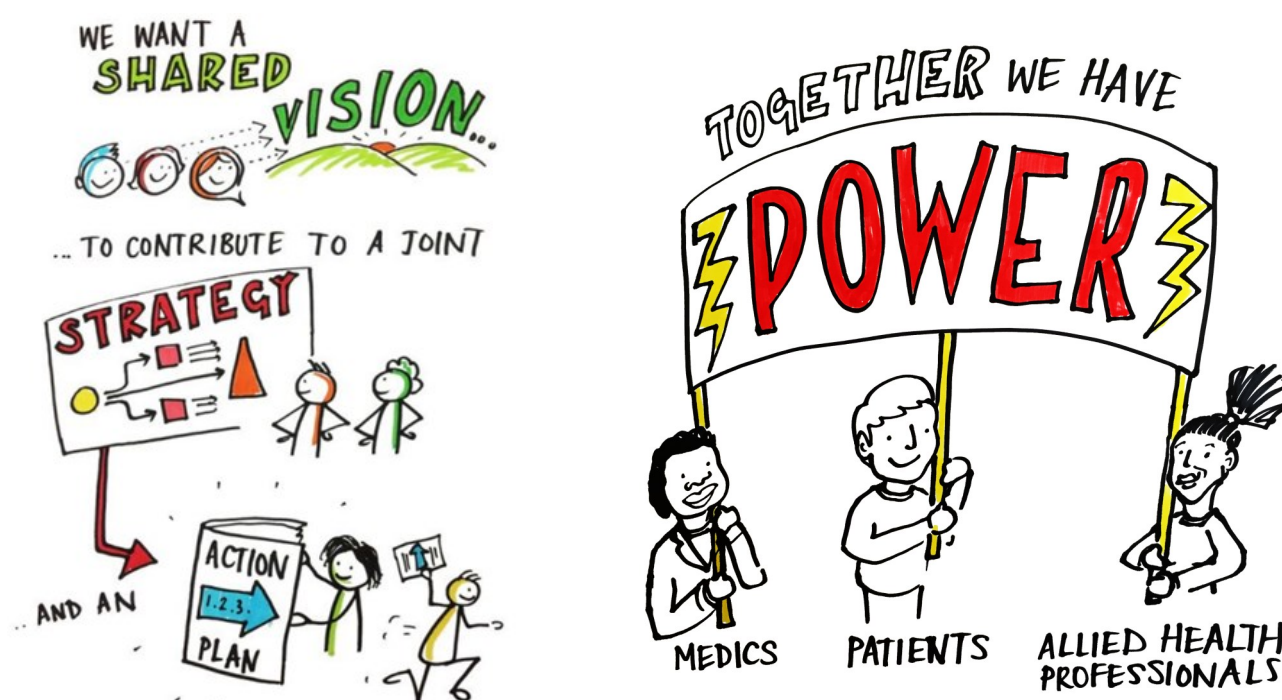


Patient and Public Involvement and Engagement (PPIE) Strategy

2017-2022



Leeds Biomedical Research Centre (BRC)
Leeds Clinical Research Facility (CRF)

1. Vision

Our vision is that Patient and Public Involvement and Engagement (PPIE) will be integral to everything we do and that Patient and Public Involvement (PPI) members will be our partners and reflective of our communities of interest.

2. Ambition

Our ambition is to be an international exemplar of meaningful and productive patient and researcher partnership in the planning, conduct, prioritisation and communication of research. This strategy outlines how we will make the transition from where we are now to our planned way forward.

3. Mission

We will provide and develop a broad range of engagement and involvement opportunities that will reach a wide audience and demonstrate excellence in PPIE activity. PPIE will be an activity across all research areas and we will work towards consistent best practice. We will work towards patients being actively involved in shaping research questions, ensuring that all research reflects the highest priorities for patients.

4. Scope

This strategy has been coproduced by NIHR Leeds Biomedical Research Centre (BRC) and NIHR Leeds Clinical Research Facility (CRF) PPI members and staff and refers to all PPIE activities conducted by these organisations.



'Working with researchers has given me the privileged opportunity to put my views across as a patient as well as being a voice for the wider public. Being part of a group and working closely with other PPI groups and staff has enabled us to develop all our ideas, and inspirations, which enabled us to produce a strategy of great strength and quality.' Lynne Lister, PPI Representative on the Strategy Development Group

5. Reasons for Involving Patients and the Public and reasons why Patients and the Public become involved

There are many reasons why we involve patients - here are just a few:



- Patients and lay representatives offer different viewpoints to research teams and can help to develop new solutions, improving the design and delivery of research.
- PPI can ensure patient focussed outcomes which meet the needs and aspirations of future patients - keeping research grounded in what matters to patients.
- Without patient participation there would be no research – PPI allows the patient's voice to be heard in the design and conduct of research as well as through direct participation.
- It builds the knowledge and confidence of people who take part, contributing to wider health and social care outcomes.
- It builds a sense of community through shared experience and challenges the traditional power balance between medical and lay people.
- Involving patients and the public strengthens researcher's applications for research funding.

There are also many different reasons why patients and the public become involved:

- To improve health and social care outcomes.
- To make a difference to the lives of others.
- To give back to the future of healthcare as a result of receiving good care.
- To develop skills and learn more about research.
- Personal experience of or loved one's experience of a condition.
- Through personal or professional recommendation.
- To work with inspiring teams and to connect with people with similar experiences.

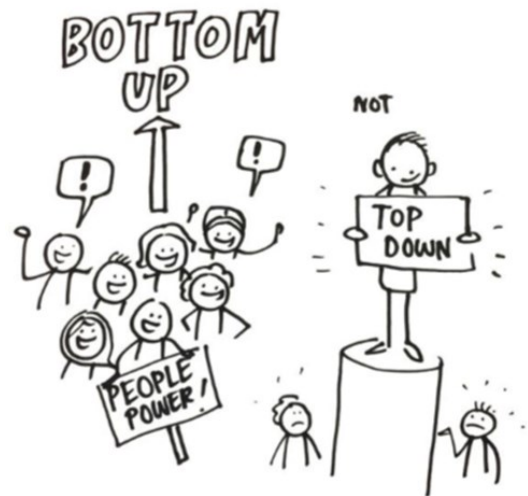


6. Definitions

This strategy refers to our 'Public Involvement' and 'Public Engagement' activities.

Public Involvement

INVOLVE, the national advisory group for Patient and Public Involvement, defines '**public involvement**' in research as 'research being carried out 'with' or 'by' members of the public rather than 'to' 'about' or 'for' them. It is where members of the public are actively involved in research projects and in research organisations. This includes, for example, working with research funders to prioritise research, offering advice as a member of a project steering group, commenting on and developing research materials, undertaking interviews with research participants.



Public Engagement

'**Public engagement**' is where information and knowledge about research is provided and disseminated. This can be through events, media coverage, social media and newsletters.

For definitions of the terms, abbreviations and organisations referenced in this document please refer to our Jargon Buster in Appendix One.

7. Strategy

Building on our strengths - Both the CRF and BRC have well established PPIE activities. We want to build on these - learning from what we do well and what we could improve. We are committed to co-production and will continue to co-design our engagement and involvement programme with our PPI members.

Developing new ways of engagement - We are aware that digital technology presents an opportunity for us to expand our conversations beyond our local area and engage further with working age people. We are also aware that we need to develop innovative approaches to reach seldom heard groups and to expand the impact and reach of our PPIE activity.

PPIE Excellence - Our PPIE activities will be led by national best practice, whilst responding to local priorities. We will review our PPIE activity against the INVOLVE Standards for PPIE, identifying where activity has a high impact and demonstrating flexibility to ensure we achieve PPIE excellence.

Valuing Patients and the Public - We will ensure that our environment and approach to patient involvement and engagement is conducive to delivering a safe, supportive and caring experience, valuing the contribution PPI members make to future healthcare innovation.

8. Implementation

We have aligned our objectives with INVOLVE Standards for PPIE. Through co-production workshops and surveys we have identified how these can be implemented at a local level. The programme of activities through which we plan to achieve these objectives is detailed in the PPIE action plan 2017-22 (available on BRC and CRF websites).



Goal:

We will strive for research to be informed by a diverse group of patient, carer and public representatives.

Objectives:

- To develop a programme of outreach where seldom heard groups as appropriate to our research are heard.
- To develop a programme of activity that engages young people in our work
- To draw on digital technologies to engage new audiences
- To work towards a shared approach to diversity, equality and inclusion across Yorkshire & Humber



Goal:

We will offer support and learning that builds confidence and skills for PPI involvement in research.

Objectives:

- To build expertise and capacity of researchers across the CRF/ BRC in PPI
- To build the expertise and increase the engagement of PPI members across the BRC / CRF



Goal:

We will capture the difference PPIE activities make.

Objectives

- To establish monitoring, evaluation and review processes for PPI/E activities
- To communicate the impact of PPIE activities externally

Goal: We will develop and maintain effective relationships and partnerships to increase the impact of PPIE activity and demonstrate an efficient and coordinated approach.



Objectives:

- To build upon and develop partnerships to share good practice, reduce duplication and to draw on the strengths of partnerships to improve PPIE activity
- To identify and develop opportunities for shared working across the Northern BRCs / CRFs and across the Yorkshire PPI Network
- To build upon our opportunities for patients to frame research questions and focus
- To develop new ways of PPI e.g. research priority setting, coproduction of research, patients as researchers etc
- To raise our profile and share learning nationally and internationally.

Goal: We will ensure that people are better connected with our research and PPIE activities.



Objectives

- To develop a communications strategy
- To build upon our website engagement
- To use social media platforms more effectively
- To provide effective information, guidance and support for PPI members
- To maintain and update a regular PPIE Newsletter
- Develop research dissemination strategies to improve public awareness and knowledge transfer

Goal: We will involve the public in the governance and leadership of the CRF and BRC providing visible leadership and clear lines of responsibility



Objectives

- To ensure patient voice is represented at a strategic level
- To enable PPI members to shape future research priorities
- To represent patient voice at a national level

9. Strategic Context

National

“Going the Extra Mile” outlines the National Institute for Health Research’s (the research arm of the NHS) commitment to and vision for Patient and Public Involvement in the field of research:

‘Public involvement should be so embedded in the culture of NIHR that new staff or new researchers coming into the field would naturally take on the values and practices of effective public involvement.’ Going the Extra Mile

INVOLVE has conducted a nationwide consultation to identify six standards which should underpin good quality PPI: Inclusive opportunities, working together, support and learning, communications, impact and governance. We have aligned our objectives to these standards and explored through coproduction events how we will achieve these locally.



The UK Policy Framework for Health and Social Care Research 2017 sets out principles of good practice in the management and conduct of health and social care research in the UK. Principle 4 states that ‘Patient, Service User and Public Involvement members are involved in the design, management, conduct and dissemination of research, unless otherwise justified.’

Regional and Local

Leeds Teaching Hospitals NHS Trust (LTHT) has an ambitious strategy over the next 6 years to use the outcomes of research to develop world class care, by becoming a global leader in clinical research and innovation, in direct partnership with the University of Leeds and other national and international collaborators. It values and supports public involvement in shaping research awareness initiatives and facilitates opportunities for patients to participate in research through the national Patient Research Ambassador Programme (PRA).

The University of Leeds (UOL) Faculty of Medicine and Health has strategic plans to facilitate a change over the next five years in the quality, volume and impact of world-leading research carried out in Leeds, building on existing strengths and a commitment to interdisciplinary working, new technology platforms and focus on the quality of care. This strategy aligns with the University of Leeds Strategic plan for Public Engagement with Research at the University of Leeds until 2020 which sets out the vision *that ‘By 2020 all research projects at the University of Leeds will include an appropriate engagement activity.’* The University has a senior champion for Patient Engagement and a Manifesto for Patient Engagement which is signed by Sir Alan Langlands, Vice-Chancellor.

Regionally and locally we have a strategic commitment to work in partnership with other NIHR funded research organisations. We are members of the NIHR Voices Regional Forum. We are working closely with the NIHR Leeds In-vitro Diagnostics Co-operative and the NIHR Leeds Surgical MedTech Co-operative (NIHR Leeds MICs) to reduce duplication and work more efficiently and effectively together to improve PPIE excellence.

The CRF and BRC are integral components of these plans, and our success and growth as a UK Network Clinical Research Facility and Biomedical Research Centre will be fundamental.

10. Leeds Clinical Research Facility and Leeds Biomedical Research Centre

Leeds Clinical Research Facility (CRF) Leeds CRF is hosted by and operates from four integrated geographical sites within Leeds Teaching Hospitals NHS Trust, supported by a central senior management operational delivery (hub) team. Leeds CRF provides the necessary research specific infrastructure and space to capitalise on areas of significant research strength in Leeds and expand our capacity and capability to conduct high quality, experimental medicine research within a safe environment for the benefit of patients. Our CRFs are located at:

Chapel Allerton Hospital – Focus on musculoskeletal diseases and aligned with the NIHR Leeds Biomedical Research Centre (BRC) <http://leedsbrc.nihr.ac.uk>

Leeds General Infirmary – Focus on Adult and Paediatric research

St James's University Hospital – Focus on experimental medicine, early phase trial conduct and first in human studies

University of Leeds DentCRU - Translational (research which turns scientific discoveries into patient benefit) and clinical research within dentistry, with outreach activities across several specialties <http://leedscrf.nihr.ac.uk/>

The CRF supports several PPIE groups, internal researcher engagement and involvement events, external outreach with third sector organisations to promote research and raise awareness, alongside facilitating direct PPI involvement in study specific project teams, CRF developments and governance.

Leeds Biomedical Research Centre (BRC) Leeds BRC is a world leading centre for translational research into therapies across musculoskeletal diseases. The centre brings together two leading University of Leeds research institutes, the Leeds Institute of Rheumatic and Musculoskeletal Medicine (LIRMM) and the Institute of Medical and Biological Engineering (iMBE) with Leeds Teaching Hospitals NHS Trust (LTH). In April 2017 Leeds BRC became the only dedicated musculoskeletal Biomedical Research Centre in the UK having been awarded £7 million funding to continue this work from 2017 to 2022. Leeds BRC currently has an active PPIE programme for musculoskeletal research. This includes a PPI Steering group, “Ask the Researcher” regular engagement events, a newsletter, patients on research study management groups and strategic boards and regular focus groups and surveys which influence individual research projects.



11. Resources and expenses

The BRC is funded by NIHR and has committed a dedicated PPIE Manager Post. There is a budget attached to PPIE. All pre grant activity will be funded through the BRC and all post grant PPIE activities will be costed into Researcher's bids. It is recognised that to achieve this vision additional capacity needs to be identified. The CRF has had a mixed funding model to date, including charity, network and NIHR is utilised in support of PPI panel meeting support, subsistence and travel costs and wider PPI activities. Going forward a renewed and sustainable financial plan will be implemented to ensure our PPI activity remains vibrant, inclusive and effective and our PPI members feel supported, valued and empowered.

No PPI member will be out of pocket as a result of their involvement and costs incurred for involvement will be paid.

12. Reporting, Monitoring and Review of the Strategy and Action Plan

Internal

The BRC/CRF PPIE Strategy Working Group will steer and oversee the activity in the supporting action plan, meeting on a quarterly basis. Progress against the strategy will be reported at the BRC Board and CRF Executive Meeting on a quarterly basis.

External

The BRC/CRF will report the outcomes of this strategy annually to the NIHR / The Department of Health and Social Care (DHSC). Additionally, we will develop an annual process of reporting to PPI members the impact of their involvement to ensure we remain accountable and transparent. Our strategy will be made available on our respective websites PPIE pages.

Review

The action plan and strategy are living documents and will be reviewed by the **30th April** each year to reflect lessons learnt through self-assessment and changes in priorities / legislation.



“Usually we get involved as PRAs in the implementation phase of a research study, so it is great to have a say in a strategy that will influence how research needs are identified and studies are designed for maximum benefit to patients.”

Peter Webster, Patient Research Ambassador

13. Acknowledgements

This strategy has been developed in partnership between the BRC and CRF in order to streamline and build upon our activities, efforts and resources. A series of coproduction meetings, surveys and scoping of national best practice have informed the content. We would like to thank and acknowledge the people who have coproduced this strategy: BRC PPIE Group, CRF groups, Patient Research Ambassadors and the staff at the BRC, CRF, NIHR Leeds In-vitro Diagnostics Co-operative and the NIHR Leeds Surgical MedTech Co-operative. NIHR Leeds MICs). Additionally thanks to Tom Bailey for the visual images which feature in this document and are a graphic record of the coproduction meetings we held to develop this strategy.

14. References

1. NIHR (2015) **Going the extra mile: Improving the nation's health and wellbeing through public involvement in research.** <https://www.nihr.ac.uk/patients-and-public/documents/Going-the-Extra-Mile.pdf>
2. Health Research Authority (2017) **UK Policy Framework for Health and Social Care Research** <https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/>

Appendix One: Jargon Buster

Terms, Organisations and Abbreviation	Explanation
Department of Health and Social Care (DHSC)	Ministerial department responsible for creating health and social care national policies and legislation
The Institute of Medical and Biological Engineering (iMBE)	A leading global centre of excellence in medical and biological engineering based at the University of Leeds.
INVOLVE	INVOLVE was established in 1996 and is part of, and funded by, the National Institute for Health Research, to support active public involvement in NHS, public health and social care research. It is one of the few government funded programmes of its kind in the world.
Leeds Biomedical Research Centre (BRC)	A world leading centre for translational research into therapies across musculoskeletal diseases based at Chapel Allerton Hospital
Leeds Clinical Research Facility (CRF)	Provides the necessary research specific infrastructure and space to capitalise on areas of significant research strength in Leeds and expand our capacity and capability to conduct high quality, experimental medicine research within a safe environment for the benefit of patients.
Leeds In Vitro Diagnostics Co-operative	Supports diagnostics developers in the design and validation of new diagnostic tests focussing on the following clinical themes: oncology, musculoskeletal disease, renal medicine and infection diagnostics.
Leeds Surgical Med Tech Cooperative	The Surgical MedTech Co-operative undertake a variety of activities to identify new areas in need of innovation, support research to address clinical problems, and provide a resource for evaluating new surgical technologies of the NHS.

Terms, Organisations and Abbreviation	Explanation
Leeds Institute for Rheumatic and Musculoskeletal Medicine (LIRMM)	Based in the Faculty of Medicine and Health at the University of Leeds LIRMM deliver a dynamic portfolio of research and education, including wide-ranging clinical, translational and basic research with a focus on: Clinical musculoskeletal medicine, Experimental musculoskeletal medicine, Clinical biomechanics and physical medicine, Orthopaedics and Rehabilitation medicine.
Leeds Teaching Hospitals NHS Trust (LTHT)	Leeds Teaching Hospitals NHS Trust is one of the largest and busiest acute hospital trusts in the UK.
National Institute for Health Research (NIHR)	The research arm of the NHS.
Participation	Taking part in a research study, for example people being recruited to take part in a clinical trial.
Patient and Public Engagement (PPE)	Where information and knowledge about research is provided and disseminated, for example through events and science fairs.
Patient and Public Involvement (PPI)	Public involvement' in research is research being carried out 'with' or 'by' members of the public rather than 'to' 'about' or 'for' them. It is where members of the public are actively involved in research projects and in research organisations. This includes, for example, working with research funders to prioritise research, offering advice as a member of a project steering group, commenting on and developing research materials, undertaking interviews with research participants.
Patient Research Ambassador (PRA)	Someone who promotes health research from a patient point of view. They could be a patient, service user, carer or lay person who is enthusiastic about health research and is willing to communicate that to other patients, the public, as well as other healthcare professionals.