

# **NIHR Lancashire Clinical Research Facility**

## **Patient and Public Involvement and Engagement Strategy (PPIE)**

**2022 – 2027**

***Enhancing Healthcare by Involving Patients & the Public in Research***

### **Context and Introduction**

Patients are at the heart of the NIHR Lancashire Clinical Research Facility (LCRF) and one of our main priorities is to ensure that patients and the local and wider community are involved in all aspects of work undertaken at the facility.

The NIHR LCRF is the only centre in Lancashire and South Cumbria delivering early phase experimental research. Patient and Public Involvement and Engagement (PPIE) will enhance how we deliver and communicate the research and innovation we offer to our patients and the wider public. The following document sets out the aim of the LCRF in supporting and delivering patient and public involvement and engagement.

PPIE is essential to the work of the NIHR Lancashire Clinical Research Facility and is key to us achieving our aims of being a sustainable hub for the delivery of Experiment Medicine trials in Lancashire & South Cumbria.

### **Definition of PPIE**

The NIHR define public involvement in research as “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them”. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials and undertaking interviews with research participants.

The NIHR use the term ‘public’ to include patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services. Whilst we are all actual, former, or indeed potential users of health and social care services, there is an important distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services.

The NIHR define public engagement as people sharing knowledge and information. For example, an open day at a research centre where members of the public are invited to find out about research.

### **Lay Research Group (LRG)**

LCRF PPIE activities are directed by the Lancashire Teaching Hospitals NHS Foundation Trust Lay Research Group (LRG). Their aim is to facilitate and deliver research PPIE activities across the whole Lancashire Teaching Hospitals NHS Foundation Trust (LTHTr) organisation, including clinical and academic research. Working alongside health professionals the Lay Research Group

get involved in many aspects of research, including what new studies to do and how best to do them. They input on ethic and funding applications, provide a public. and patient perspective on using patient data for research.

### **Operations group**

The LCRF Operational Management Group is a functioning group comprising of LCRF medical director, manager, lead research nurse(s), finance analyst(s), clinical fellow(s), lay representatives, and other team representatives as required. Its primary purpose is to design and implement effective operating systems and procedures to ensure the safe and efficient running of the Lancashire Clinical Research Facility. At Operations group reports outcomes to the Partners group.

### **Partners group**

The NIHR LCRF Partners group comprises of representatives of four partner organisations: Lancashire Teaching Hospital Foundation Trust (LTHTr), Lancashire and South Cumbria Foundation Trust (LCSFT), University of Central Lancashire (UCLAN), and Lancaster university (LU). The group approves the NIHR LCRF Strategy including the EDI, PPIE and IP policies and assists and directs the Operations Group to achieve the outcomes laid down in these policies. In addition, the partner's group monitors compliance with NIHR Award 2022-27 objectives and contract.

## **Research impact**

Research Impact encompasses the diverse ways that research benefits individuals, organisations and nations through increasing effectiveness of public services and policy, improving quality of life and health, or economic benefits. The LTHTR LRG have conducted an Impact assessment (referenced below), to ascertain how LTHTR research is practically applied to benefit the public and patients.

The aim of the project was to establish the impact of LTHTR research, whether it is tracked and measured, the current challenges and opportunities to improve research impact. The involvement of public and patients to help improve research impact was also an important consideration.

Three main categories of health research impact were found; personal impact, professional impact and healthcare practice impact. Challenges and opportunities for improving impact were discussed, with five key areas identified for action to help improve health research impact at LTHTR; Organisational support to embed research and innovation culture; Start by considering impact; Effective and representative public patient involvement and engagement; Streamlining working practice, improving network and collaboration opportunities; Promotion of research to deliver health care improvement

## **Vision**

*To build an informed, engaged, and diverse patient and public membership and to embed members in committees and research teams to advise on how research is planned, conducted, and communicated both internally and to the wider community.*

This is a vision which seeks to embed PPIE into the core business of LCRF activities. Public members will be essential to the LCRF team to build an actively engaged group within Lancashire and South Cumbria so we can promote excellence in clinical care and organisational governance. We will widely share the opportunities that the LCRF offers to prospective commercial and educational collaborators.

**We will achieve our vision by:**

- Supporting current research themes - Cancer, Neurosciences and Mental health plus all other areas of health research supported by the LCRF
- Engaging patients and the public in building quality clinical trial delivery within the LCRF
- Enabling continuous quality improvement through patient and public feedback.
- Involving patients and the public at all levels of research planning and execution
- Widely sharing LCRF activities, opportunities, and achievements
- Establishing links and sharing practice within the national CRF network
- Creating practical and achievable patient and public involvement projects that allow us to achieve, measure, and share our vision.

**Objectives**

**The objectives will be aligned to the six standards set out in the UK Standards for Public Involvement which are ‘designed to improve the quality and consistency of public involvement in research.’**

The six standards are:

- **Working Together** - *Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.*
- **Communications** - *Use plain language for well-timed and relevant communications, as part of involvement plans and activities.*
- **Inclusive Opportunities** - *Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.*
- **Governance** - *Involve the public in research management, regulation, leadership and decision making.*
- **Impact** - *Seek improvement by identifying and sharing the difference that public involvement makes to research.*
- **Support and Learning** - *Offer and promote support and learning that builds confidence and skills for public involvement in research.*

**Working Together.**

*Short Term Strategic Goals (1-2 years):*

- Within the first six months, the Head of Clinical Research Operations/NIHR Lancashire CRF (LCRF) Lead will be an active member within the Lay Research Group (LRG). This is vital to direct the PPIE activities in the LCRF so they align with the expectations of the public members and to ensure the LCRF is accountable to the LRG.
- The LCRF will be an active member of the PPIE infrastructure in the Manchester Biomedical Research Centre (MBRC) to share knowledge, build capacity and ensure Lancashire and South Cumbria is actively involved in all strategic discussions related to the MBRC, This includes working with the VOCAL ( <https://wearevocal.org/> ) Director and for the LCRF Lead to be part of the Inclusive Research and Oversight Board (IROB).
- We will arrange for the Director of VOCAL and the Chair of the IROB to visit the LCRF and engage with the LRG members to discuss collaborations and advise on joint PPIE activities.
- We will engage with Lancashire Teaching Hospitals NHS Foundation Trust Patient Experience Lead to promote research to improve patient experience. This includes involving the LTHTr Patient Experience Lead in the LCRF meetings and for the LCRF Lead to be an active member of the Trust Patient Experience Group.
- We will focus on involving the public members further ensuring they are actively participating in meaningful projects. Within the first two years, we will create the processes to ensure thorough public involvement has been undertaken by all Sponsors and taking every opportunity to ensure all studies delivered in the LCRF have been reviewed by public members.
- We will actively reach out to other patient and public groups in the locality (e.g. Lancashire Teaching Hospitals NHS Foundation Trust; Lancashire and South Cumbria Foundation Trust; Lancaster University and University of Central Lancashire) to create awareness of the LCRF research activities, explore input into LCRF PPIE activities, and to receive specialist feedback where necessary.

### *Medium Term Strategic Goals 3-5 years*

- We will continue to be involved, and take opportunities, to input into regional home-grown research ensuring all research being developed by the MBRC, that will be delivered within the LCRF, has included public involvement from Lancashire and South Cumbria.

### **Communications**

#### *Short Term Strategic Goals 1-2 years:*

- In conjunction with the LRG members, we will create a library of communications within Lancashire Teaching Hospitals NHS Foundation Trust for staff and patients to increase awareness of current research delivery and the impact of research. This includes:
  - Designing posters to demonstrate the research work being delivered within the Trust.



- Updating public involvement in research promotional literature and providing lay content for LCRF, and LCRF partners, webpages.
- We will ensure all communications are written using language that is appropriate and sensitive to all communities and therefore inclusive to all.
- We will include public members in two research huddles per year to share information and demonstrate the outcome of public involvement into research.

#### Medium Term Strategic Goals 3-5 years:

- We will continue to develop methods to promote the work of the LCRF to the public. As above this includes poster and leaflet campaigns as well as open days.
- We will ensure public members co-create digital awareness activities, such as being part of a video to educate staff, patients, and visitors; podcasts/bulletins/social media.

#### **Inclusive Opportunities**

##### *Short Term Strategic Goals 1-2 years:*

- We will ensure public members are included digitally by offering PPIE activities virtually and offering a hybrid model of engagement (virtual and in person).

- We will ensure public members are given the resources and equipment to be involved in PPIE activities.
- Identify successful PPIE Inclusivity strategies employed by other local public involvement groups and seek to replicate them locally where possible.

### *Medium Term Strategic Goals 3-5 years*

- We will widen the involvement in under-served communities by building relationships with different communities within the region the LCRF serves. We will conduct a project to identify groups within the Trust, and region, and understand how we can build relationships with these communities.
- Once we have developed the opportunities for PPIE involvement, we will engage with the local communities to increase the public members involved in LCRF activities and ensure the group represents the local community which the LCRF serves. To encourage diversity, we aim to make the group representative of all sections of the community which LTHTr covers and for each group member to feel recognised, valued and respected.

### **Governance**

#### *Short Term Strategic Goals 1-2 years:*

- Patient and public groups play a vital part in the planning and implementation of the operational activities of the LCRF. Public members will continue to be a core member of the LCRF Operational and Partners Groups.

- Public members will be an active member of the LCRF Study Review Group, reviewing new studies and being part of the decision-making process.

#### *Medium Term Strategic Goals 3-5 years*

- We will welcome a diverse group of public members onto our Operational and Partners Groups to include representatives from a variety of communities and cultures. This will be achieved via the LCRF Lead work on the Inclusive Research and Oversight Board (IROB).

#### *Long Term Strategic Goals 5+ years:*

- Through engagement with communities and public members, the LCRF study portfolio will be fully shaped by the needs of, and the health conditions prevalent in, the people living in Lancashire and South Cumbria so that they have access to early phase experimental medicine studies that will support better health.

### **Support and Training**

#### *Short Term Strategic Goals 1-2 years:*

- The Head of Clinical Research Operations/LCRF Lead will continue to be an active member of the UKCRF Network PPIE Group. They will share learning, training, and tools to our public members.
- Within the first 12 months we will employ a PPIE coordinator (0.2wte) to provide training and education to our public members and LCRF team. Their role will be to implement, and update, this strategy to ensure the LCRF is finding all opportunities to deliver meaningful PPIE activities.
- We will be involved in all PPIE training offered by the NIHR, UKCRF Network and charities and offer these to our public members.
- We will attend and integrate all support and learning offered by the MBRC to ensure all PPIE activities are meaningful.
- The LRG members will be offered the opportunity to complete the NIHR Good Clinical Practice (GCP) course where relevant, or alternatively similar qualifications including “Improving Healthcare through Clinical Research” (<https://www.futurelearn.com/courses/clinical-research>) and “What is Health Research” (<https://www.futurelearn.com/courses/what-is-health-research>).

*Medium Term Strategic Goals 3-5 years:*

- We will increase the PPIE coordinator role to 1wte to further develop the PPIE activities so that public members are further embedded into the activities of the LCRF.
- We will seek opportunities within the Trust, and region, for public members to provide coaching/ mentoring to health research professionals, highlighting the opportunities and benefits of lay research involvement in their research projects.

## **Impact**

### *Short Term Strategic Goals 1-2 years:*

- Integrating the Impact Project already undertaken, we will work with the LRG and other patient groups within the Trust to understand what impact means to them (and how this may be measured) so that our PPIE activities reflect this common meaning.
- The LCRF Lead will work with the NIHR and attend meetings related to PPIE so that we can ensure national PPIE objectives are incorporated and embedded in the LCRF activities. Being involved will allow us to learn and share our activities with a wider audience.

### *Medium Term Strategic Goals 3-5 years:*

- In relation to the awareness campaign, we will survey if the materials had any impact on the patients involved in research studies in the LCRF.
- We will review all LCRF studies where public members were involved in the planning and writing of key research studies to assess the impact their involvement had on the patients, the trial, and the wider patient community.

## **Ongoing monitoring**

On at least a yearly basis, the Operations group will review the progress of the LCRF in accordance with the above goals, with a formal report prepared for discussion at the Partners Group. Achievements will be celebrated and any modifications to the policy will be agreed upon by the LCRF prior to implementation.

Authors: J.Bramley (Head of Clinical Research Operations/NIHR Lancashire Clinical Research Facility Lead), P.Brown (Deputy Director of Research & Innovation), D.Cameron (LCRF Clinical Fellow), J.Watson (Lay Research Group Representative), D.Hadjjiannakis (LCRF Medical Director).

## Appendix 1: SMART Objectives

<b>Overall goal</b>	<b>What is the Specific aim?</b>	<b>How will this be Measured?</b>	<b>Is this goal Achievable?</b>	<b>Is this goal Relevant to the overall strategy?</b>	<b>Over what Timescale will this be performed?</b>	<b>Responsible individual/Team</b>
<b>Head of Clinical Research to be an active member within the LRG</b>	<b>LCRF Lead to attend LRG meetings and facilitate input to operations group</b>	<b>Minutes of LRG meetings describing the input of LCRF Lead</b>	<b>Y</b>	<b>Y</b>	<b>Sep 2023</b>	<b>LCRF Lead</b>
<b>Ensure public members are included digitally</b>	<b>Offer hybrid attendance at LRG and Partners forums</b>	<b>Invitations to discussion forums to include Microsoft Teams links (or other suitable digital attendance opportunity)</b>	<b>Y</b>	<b>Y</b>	<b>Sep 2023</b>	<b>LRG Forum coordinator, Partners meeting coordinator</b>
<b>Public members will be active members of the LCRF Study Review Group</b>	<b>Lay representatives to attend LCRF SRG</b>	<b>Minutes of SRG describing the attendance and input</b>	<b>Y</b>	<b>Y</b>	<b>Sep 2023</b>	<b>LCRF Lead</b>
<b>We will employ a PPIE coordinator (0.2wte)</b>	<b>Employment of PPIE coordinator</b>	<b>Presence of PPIE coordinator within the department</b>	<b>Y</b>	<b>Y</b>	<b>Sep 2023</b>	<b>LCRF Lead</b>

	<b>within the department</b>					
<b>LCRF to be an active member of the PPIE infrastructure in the Manchester Biomedical Research Centre (MBRC)</b>	<b>LCRF Lead to attend Inclusive Research and Oversight Board (IROB).</b>	<b>Minutes of IROB meetings describing input of LCRF Lead.</b>	<b>Y</b>	<b>Y</b>	<b>Mar 2024</b>	<b>LCRF Lead</b>
<b>Director of VOCAL and the Chair of the IROB to visit the LCRF</b>	<b>Director of VOCAL and the Chair of the IROB to visit the LCRF</b>	<b>Feedback within IROB meeting minutes.  Article for LCRF website to commemorate the visit.</b>	<b>Y</b>	<b>Y</b>	<b>Mar 2024</b>	<b>LCRF Lead/IROB representative/Director of VOCAL.</b>
<b>Public members will continue to be a core member of the LCRF Operational and Partners Groups.</b>	<b>Public representatives (including those identified through LRG) to be invited to Operations and Partners groups</b>	<b>Minutes of these minutes describing the attendance and input of members of the public</b>	<b>Y</b>	<b>Y</b>	<b>Mar 2024</b>	<b>LCRF Lead</b>
<b>Promote research to improve patient experience</b>	<b>Involve the LTHTr Patient Experience Lead in the LCRF meetings and for the LCRF Lead to be an active member of the Trust Patient Experience Group.</b>	<b>LCRF Operations group minutes demonstrating input from LTHTr Patient Experience Lead.  Trust Patient Experience Group meeting minutes describing the input of LCRF Lead</b>	<b>Y</b>	<b>Y</b>	<b>Sep 2024</b>	<b>LCRF Lead</b>
<b>Create the processes to ensure thorough public involvement</b>	<b>Provide all upcoming studies to LRG members</b>	<b>Minutes of LRG and SRG forum describing discussion of</b>	<b>Y</b>	<b>Y</b>	<b>Sep 2024</b>	<b>LCRF Lead/LRG Forum</b>



	(or representative) for review	upcoming studies and feedback received.				
Actively reach out to other patient and public groups from the locality	LCRF Lead to make initial contact with known PPIE contacts within the locality	Attendance at LRG of visiting PPIE representatives	Y	Y	Sep 2024	LCRF Lead/LRG
Create a library of communications	Update public involvement with posters, and promotional literature displayed on LCRF website	Lay promotional literature available via LCRF website	Y	Y	Sep 2024/Ongoing	LCRF/LCRF Website team
Ensure all communications are written using language that is appropriate and sensitive	Communications produced to be presented to LRG +/- Patient Experience Forum	LRG meeting minutes/Affirmation on literature that it has been reviewed by lay representatives	Y	Y	Sep 2024	LCRF Lead
Ensure public members are given the resources and equipment to be involved in PPIE activities.	For LRG members to be given appropriate confidentiality training and contracts to allow them to review confidential study paperwork	Appropriate contract to exist between LTHTr and LRG group	Y	Y	Sep 2024	LCRF Lead
Head of Clinical Research Operations/LCRF Lead will continue to be an active member of the UKCRF Network PPIE Group	LCRF Lead to attend UKCRF PPIE	Minutes of meetings showing attendance. Minutes of LRG group displaying subsequent learning and information passed on.	Y	Y	Sep 2024	LCRF Lead

<b>LCRF Lead will work with the NIHR and attend meetings related to PPIE</b>	<b>LCRF Lead will to attend PPIE meetings at a National Level</b>	<b>Minutes of these meetings to be recorded</b>	<b>Y</b>	<b>Y</b>	<b>Sep 2024</b>	<b>LCRF Lead</b>
<b>Include public members in two research huddles per year</b>	<b>LRG members to be invited to team huddles on a 6 monthly basis</b>	<b>Staff feedback from LRG attendance at huddle</b>	<b>Y</b>	<b>Y</b>	<b>Sep 2025</b>	<b>LCRF Lead</b>
<b>Engage with the local communities to increase the public members involved in LCRF activities</b>	<b>Expand the membership of the LRG forum open to interested parties.</b>	<b>Minutes of LRG documenting new membership</b>	<b>Y</b>	<b>Y</b>	<b>Sep 2025</b>	<b>LRG Lead</b>
<b>Develop methods to promote the work of the LCRF to the public</b>	<b>Annual open days for the LCRF</b>	<b>Publication of promotional material from the open days to LCRF website</b>	<b>Y</b>	<b>Y</b>	<b>Sep 2026</b>	<b>LCRF Lead</b>
<b>Identify successful PPIE Inclusivity strategies employed by other local public involvement groups (including to represent under-served communities) and seek to replicate them locally where possible.</b>	<b>LCRF and LRG Lead to review local inclusivity strategies as part of outreach as described.</b>	<b>Minutes of LRG forum describing reviewed strategies</b>	<b>Y</b>	<b>Y</b>	<b>Sep 2026</b>	<b>LCRF Lead/LRG</b>
<b>LRG members will be offered the opportunity to complete the NIHR Good Clinical Practice (GCP) course where relevant</b>	<b>LRG members to be signposted to self directed learning for GCP qualification</b>	<b>Record of GCP certification to be centralised</b>	<b>Y</b>	<b>Y</b>	<b>Sep 2026</b>	<b>LCRF Lead/LRG group</b>
<b>We will survey if the Awareness Campaign had any impact on the patients</b>	<b>Encourage patents to take part in research</b>	<b>Audit of number of patients involved in Research an membership of the LRG</b>	<b>Y</b>	<b>Y</b>	<b>Sep 2026</b>	<b>LCRF Lead/LRG Lead</b>

<b>We will review all LCRF studies where public members were involved in the planning and writing of these studies to assess the impact their involvement had on the patients, the trial, and the wider patient community.</b>	<b>Make research studies relevant to the patients and increase patient involvement</b>	<b>Audit a random selection (10%+) of trials for the above impact</b>	<b>Y</b>	<b>Y</b>	<b>Mar 2027</b>	<b>LCRF Lead</b>
<b>Ensure public members co-create digital awareness activities</b>	<b>LRG members to help produce promotional videos for the LCRF department</b>	<b>Publication of promotional material on LCRF website</b>	<b>Y</b>	<b>Y</b>	<b>Sep 2027</b>	<b>LCRF Lead</b>
<b>LCRF study portfolio will be shaped by the needs of, and the health conditions prevalent in, the people living in Lancashire and South Cumbria</b>	<b>In conjunction with EDI Forum, LCRF to review audit of current patient cohorts</b>	<b>Ongoing audit of patient health conditions</b>	<b>Y</b>	<b>Y</b>	<b>Sep 2027</b>	<b>LCRF Lead/EDI Forum</b>
<b>Be involved in PPIE training offered by the NIHR, UKCRF Network and charities</b>	<b>Attendance of LCRF members and lay members at NIHR training events</b>	<b>Certificates of attendance to be centralised</b>	<b>Y</b>	<b>Y</b>	<b>Sep 2027</b>	<b>LCRF Lead</b>
<b>Attend and integrate support and learning offered by the MBRC</b>	<b>Attendance of LCRF members and lay members at MBRC training events</b>	<b>Certificates of attendance to be centralised</b>	<b>Y</b>	<b>Y</b>	<b>Sep 2027</b>	<b>LCRF Lead</b>
<b>We will increase the PPIE coordinator role to 1wte</b>	<b>Employment of PPIE coordinator within the department</b>	<b>Presence of PPIE coordinator within the department</b>	<b>Y</b>	<b>Y</b>	<b>Sep 2027</b>	<b>LCRF Lead</b>

