

NIHR Leeds Biomedical
Research Centre (BRC)

Patient & Public Involvement and Engagement (PPIE)



Guide for Researchers

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An Introduction to Patient and Public Involvement and Engagement

This booklet has been designed to support researchers at NIHR Leeds Biomedical Research Centre (NIHR Leeds BRC) to plan for their Patient and Public Involvement/Engagement (PPIE) activities.

The NIHR Leeds Biomedical Research Centre's Vision for Patient Involvement

Our vision is that, 'Patient and Public Involvement will be integral to everything we do, that patients will be our partners and reflective of our communities of interest'.

What is Patient and Public Involvement?

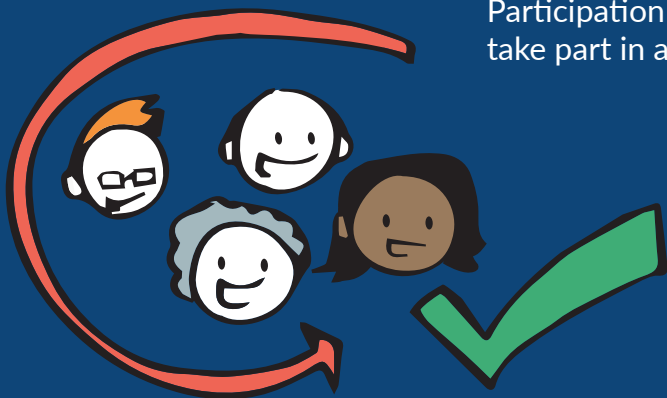
'Patient and Public involvement' in research is research being carried out 'with' or 'by' members of the public rather than 'to' 'about' or 'for' them'. It is where members of the public are actively involved in research projects and in research organisations.

What is Patient and Public Engagement?

Public engagement is where information and knowledge about research is provided and disseminated.

What is Participation?

When working in research, it is important to be clear about the differences between PPIE and participation. Participation is where people take part in a research study.



Why do we involve Patients and the Public?

There are many reasons why we involve patients and the public; here are just a few:

- Patients and the public offer different viewpoints to research teams and can help to develop new solutions, improving the design and delivery of research.
- PPI can ensure research is focused on delivering the outcomes that matter 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.
- PPI members can support you to develop recruitment plans which retain participants and are realistic in the commitment ask of patients.
- It builds a sense of community through shared experience, and challenges the traditional power balance between health professionals and the patient.
- Involving patients and the public strengthens a researcher's applications for research funding.
- PPI members can help ensure materials are written in plain English and in a context by which patients and members of the public can make a truly informed choice as to their participation in the research.
- Most funders acknowledge the value of PPI, so demand that it is meaningful.

Our Approach to PPI

We strive towards an approach of 'co-production' within our research and are informed by the key principles of co-production which are:

- Sharing of power – the research is jointly owned and people work together to achieve a joint understanding.
- Including all perspectives and skills – make sure the research team includes all those who can make a contribution.
- Respecting and valuing the knowledge of all those working together on the research – everyone is of equal importance.
- Reciprocity – everybody benefits from working together.
- Building and maintaining relationships – an emphasis on relationships is key to sharing power. There needs to be joint understanding and consensus and clarity over roles and responsibilities. It is also important to value people and unlock their potential.

UK Standards for Public Involvement in Research

The National Institute for Health Research (NIHR) have published a set of standards which demonstrate effective and good quality public involvement.

Researchers can use the standards to reflect on their plans for public engagement. Information about the standards can be found here:



<https://sites.google.com/nihr.ac.uk/pi-standards/home>



“Patient and Public Involvement is central to how we plan and develop our research, it ensures we keep patients at the heart of everything we do and makes sure our research makes a real difference to people’s lives”

Professor Paul Emery, Director of Leeds BRC



Patient and Public Involvement at the NIHR Leeds BRC

Here at the NIHR Leeds BRC we seek to actively involve patients in all aspects of the research process as early as possible. Researchers have access to the following Patient and Public Involvement/Engagement (PPIE) options via the PPIE Team.

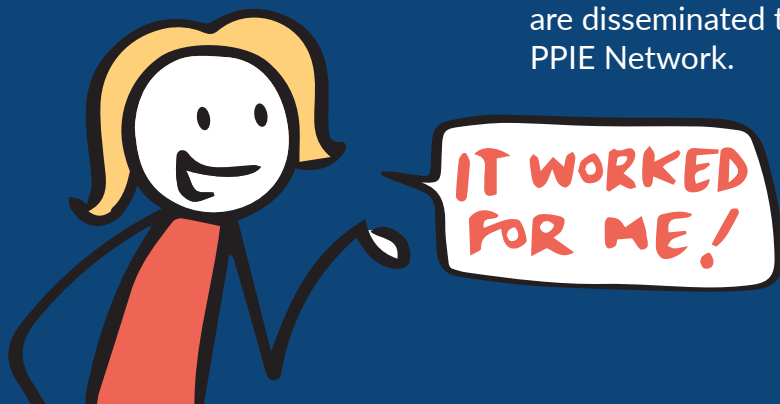
Patient and Public Involvement Core Steering Group:

The vision of the PPI Core Steering Group is: 'To create a community of impassioned, informed and determined people to support and provide advice through involvement in the development and conduct of research at the NIHR Leeds

Biomedical Research Centre.' The group meets every six to eight weeks and works with the NIHR Leeds BRC to support researchers to ensure that they are always focussed on the needs of patients and that the patient voice is at the heart of research.

Patient and Public Involvement/Engagement Network:

This is made up of over 220 patients and members of the public who have an active interest in the musculoskeletal research that takes place here at the NIHR Leeds BRC. They may be living with a musculoskeletal condition themselves, going through diagnosis or provide support/care to someone who is living with a musculoskeletal condition. All involvement/engagement opportunities are disseminated through the PPIE Network.



Reviewing Grants and Planning Research:

PPI review is now considered essential for particular grant schemes and the NIHR Leeds BRC PPIE Network is actively involved in this process. This is often done through a focus group facilitated by one of the researchers.

The researcher may consider setting up a Advisory Group of PPIE Network members. This group can guide the researcher through the entirety of their study, from concept through implementation and dissemination. This is particularly useful, as the Advisory group will have an in-depth understanding of the research and commitment to supporting researchers to address any issues that arise throughout the project.

Reviewing Patient Literature:

It is suggested that all patient or participant-based information is reviewed by PPIE Network members, for clarity, accuracy and appropriateness. The review will be via email with responses collated by the PPIE Team and forwarded to the researcher. Hard copies can be provided to PPIE Network members if requested. PPI members can also help researchers provide summaries in clear and concise language, so non-medical individuals can easily understand the outcome of research studies.

PPI Representatives on Research Steering Groups:

Once grants have been approved and studies are ongoing, the study will be overseen by a Steering Group. PPI representatives often participate in the Steering Group to provide a patient perspective on the management of the study. It is suggested that where PPIE representation is required, two PPIE representatives are recruited.

Communicating Research to the Public:

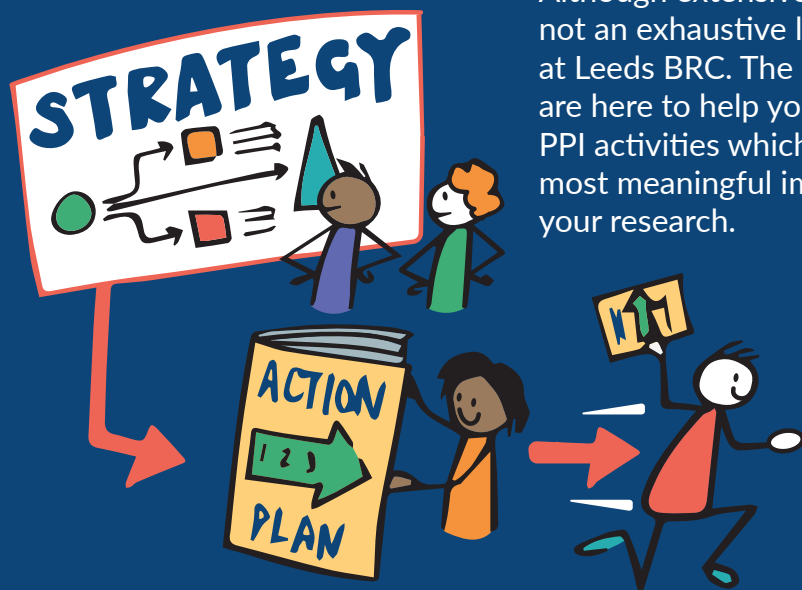
The PPIE Network wants to ensure that the results of research are communicated effectively to members of the public. There are a number of different ways this can be done with support from the PPIE Network:

- a. guidance about how to provide feedback in Plain English to the participants of the study as to the outcome of the research;
- b. co-presenting or providing guidance on how to give updates at NIHR Leeds BRC meetings such as “Ask the Researcher”
- c. presenting the outcomes to the general public, either through the local media, or the NIHR Leeds BRC website.

PPI Members Delivering Training:

Our PPI Core Group members have contributed to both informal and formal training sessions about PPIE in research. Audiences have been representative of researchers and interested patients, with PPI members giving an insight into lived-experiences of their conditions and involvement in research.

Although extensive, this is not an exhaustive list of PPIE at Leeds BRC. The PPIE Team are here to help you design PPI activities which make the most meaningful impact to your research.



Engagement Opportunities at Leeds Biomedical Research Centre

There are a range of opportunities for you to engage the public in your research and communicate the findings of your research to a wider audience. These include:

Ask the Researcher Events

Ask the Researcher events are held approximately six times a year, and last for two hours including 30 minutes for either lunch or supper (depending on the time of day). They are an opportunity for researchers (alongside relevant colleagues) to present on a theme and inform patients/public of their work. We hold a daytime and evening session to encourage a broad range of people to attend. Where possible, the daytime session

is now filmed so we can show your presentation to a wider audience through our website. If you have an idea for an Ask the Researcher please contact the PPIE Team who will organise the logistics of the event.

Be Part of Research Event

Every year we put on a celebration event for International Clinical Trials Day in May. Members of the PPIE Core Group play a crucial role in developing the event, and also on the day in terms of showing attendees around, signing them up to activities and providing general support. We also ask our research teams to hold stalls and activities to showcase their work to the public.



Bespoke Events

The NIHR Leeds BRC also develop a range of bespoke events and outreach activities tailored to the needs of research areas. For example, you may have successfully completed a research study, and want to thank PPIE participants and tell a wider audience about your findings. Additionally, you may want to do some targeted PPIE work with a specific community group.

Please discuss your requirements with the PPIE Team as early as possible in the planning stage.

Patients Matters Newsletter

Our quarterly newsletter is a great opportunity to let patients know about your research. If you have a good news story please let the PPIE Team know.

Leeds Biomedical Research Centre Website, Twitter and Facebook

We can share news and information about your research through the NIHR Leeds Biomedical Research Centre:



Website:

<http://leedsbrc.nihr.ac.uk/>



Twitter account:

@LeedsBRC



Facebook page.



Tips for making your PPIE Activities Meaningful

Research shows that carefully considering the PPIE activities you would like to conduct as early as possible has the maximum impact on research. Here's some tips about how to make your activities meaningful:

Lead-in Time

It is good practice to give patients/members of the public adequate time to make an informed decision about their involvement. At the NIHR Leeds BRC we have defined this as at least three weeks.

Booking of Meeting Rooms

The PPIE Team will book the NIHR Leeds BRC Board Room or Seminar Room for you depending on your needs. These rooms do get booked up in advance, so it is always

worthwhile having a couple of dates in mind when you are planning your activity. The PPIE Team will arrange for the necessary refreshments to be provided, and this can be discussed ahead of the activity.

Timings of Activities

We ask that you run PPI activities at times which are convenient for PPIE Network members, providing breaks for any activity held for longer than 1.5 hours. We ask that no PPI activity starts before 10.30am, and that the time members will be travelling home is also considered. Allow time before the activity to set-up the room, so it is ready for when PPIE Members arrive. It is always worthwhile to factor in time at the end of the activity for questions, bearing in mind that PPI Members will have planned their travel/parking around the times that have been given to them.

Plain English

We ask that as far as possible your activities are delivered in plain English. Provision of a jargon buster or glossary may be required to explain medical terminology in a way that is understandable for a lay person.

Accessibility of PPI activities

It is important to consider accessibility when planning your PPI activities. This could be anything from patients using a wheelchair to needing information provided in a larger font. When recruiting to activities, the PPIE Team will ask about access and dietary needs, these will be relayed to you. If you are doing any recruitment yourself, we ask that you do the same, discussing any access and dietary needs with the PPIE Team.

Feedback Following PPI Activities

Feedback is crucial to good involvement. On completion of your activity, please provide a short summary to the PPIE Team, who will circulate it to the PPIE Network members who took part.

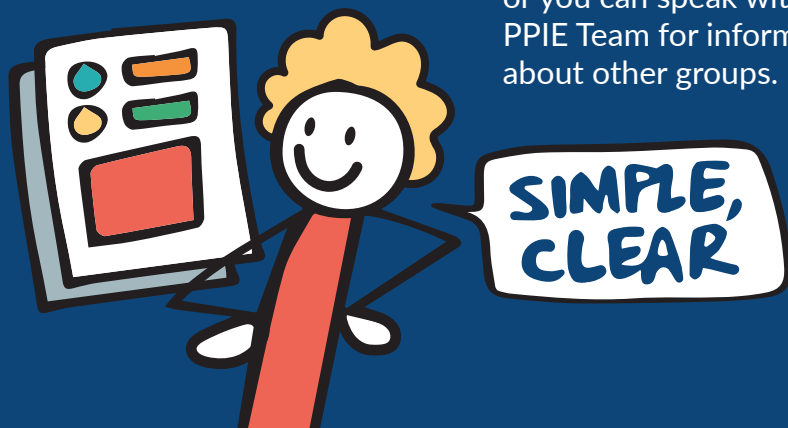
Support for PPI Members

Due to the nature of the discussions you will be having with PPI members there can be times where members become upset or ask for support that cannot be provided in your capacity as a researcher. There is a list of organisation who support people on our website:



<http://leedsbrc.nihr.ac.uk/patient-and-public-involvement/information/>

or you can speak with the PPIE Team for information about other groups.



Dealing with Challenges

On rare occasions you may experience challenges when delivering PPI activities.

There are a number of ways to reduce the chance of this happening:

- Ensure you are clear about the role you would like PPI members to take part in and how they can influence your research.
- Provide easily accessible information in advance of the meeting.
- Ensure members are aware of our Code of Conduct for PPI members and revisit this with the group at the beginning of your activity (or ask the group to make a list of behaviours they expect from everyone in the room e.g. one person speaking at a time, respect each other).
- Ensure you go through house-keeping – introductions, location of toilets, fire assembly points, mobile phones on silent, etc.
- If a member is disruptive, disrespectful of other members or abusive ask them to leave the room with you and explain your concerns.
- Raise concerns with the PPIE Team who can support you with strategies to deal with this and can also put in place strategies to prevent future issues.
- If you receive negative feedback via email, this can also be discussed with the PPIE Team. You may also wish to discuss it with your supervisor. If appropriate a meeting can be arranged by the PPIE Team with the PPIE Network Member.



Budgeting for Patient Involvement

PPIE members should not be out of pocket as a result of their involvement. To budget appropriately, there is guidance and a cost calculator available on the INVOLVE website and the PPIE team can support you to do this.



[www.invo.org.uk/
posttypepublication/
budgeting-for-
involvement/](http://www.invo.org.uk/posttypepublication/budgeting-for-involvement/)

Please contact the PPIE team to help you appropriately cost your activities.

Prior to you receiving funding

The NIHR Leeds BRC will cover the cost of your PPI expenses. This will include up to £50 per patient for travel expenses, refreshments, parking and a meal if the activity takes place over a meal time or for over 4 hours e.g. lunch or dinner time.

Following grant award, PPIE activities must be appropriately budgeted for and costed into grants.

For PPI activities the following costs should be outlined:

- Travel
- Training for staff and PPI members
- Refreshments
- Facilities hire
- Refreshments
- Additional costs to support inclusion and access e.g. carer/ child care/ interpreter
- Expenses
- Recognition payments
- PPIE staff time



For PPE activities (such as dissemination events) the following costs should be outlined:

- Facilities hire
- Catering
- Travel for speakers and recognition payments for PPI speakers
- Resources e.g. posters, leaflets
- Additional costs to support inclusion and access e.g. carer/ child care/ interpreter
- Out of pocket expenses and recognition payments for members playing an active role in your event e.g. speakers or volunteers
- PPIE staff time to organise and manage your event

For engagement activities we do not generally reimburse expenses, however you should be clear with attendees that this is the case.

Claims process for expenses and recognition payments
You must be clear before you organise PPI activities about how you will reimburse PPI members for expenses and recognition payments (where applicable).

Your team may have petty cash or you may need to process this through an expenses claim form.

The PPIE team can advise you on this. Recognition payments and some expenses can have an impact on tax and benefits and we advise that you speak with the PPIE Team when costing for PPI expenses/ recognition payments to ensure the costs are in line with our policy.



Expectations of PPI Members and Researchers

The Role of the Researcher

Researchers are required to consider and develop PPI activities which are meaningful and enhance the quality of their research. In focus groups, the researcher will lead discussions and keep them on track and relevant to the research areas discussed. The researcher will consider feedback and how this impacts on their research. It is the responsibility of the researcher to ensure technical and scientific excellence and to make sure the design and conduct of the research meets legal and regulatory requirements. There may be times where the suggestions of patients cannot be included due to these requirements. If this is the case, the PPIE Team can provide guidance about how to communicate this with PPIE members.

Timely, Jargon-free Information

We aim to ensure PPIE Network members are provided with the information they need to effectively contribute in good time. We ask that you provide clear information at least three weeks in advance of holding PPI activities. The PPI request forms have been designed to capture the information PPIE Network members need in order to have an understanding of the aims of your research, any specific requirements you have for the PPI member, and their role.



Valuing and recognising the contribution of PPIE Members

PPIE Network members are passionate about improving research outcomes, volunteer their spare time and are an essential partner in our research. We ask that you value and recognise their contributions.

Active Listening

PPIE Network members bring a wealth of lived experience to research and can bring a range of different perspectives. We ask that you take the time to listen and consider the range of views you will hear and use this to inform your research.

Feedback

PPIE Network members tell us that one of the best ways to value their involvement is to keep them informed about the progress you make with your grant applications, research and eventually the outcomes of your research. Feedback does not always

have to be positive, PPIE members will be interested to know if you have or have not been successful in grant applications and if your research did not result in the outcome you were hoping for. You can provide feedback through the PPIE Team who will keep a record of the people you have involved and can advise on how to feedback.

Evaluating the Impact of PPI Activities

The NIHR Leeds BRC has developed a set of tools to evaluate the impact of PPI activities. You will be sent the evaluation forms when you conduct PPI activities and we ask that you complete these at set stages of your involvement. The completion of these evaluation forms is essential in the improvement of PPI activities at the NIHR Leeds BRC. We also ask PPIE Members to provide feedback following their involvement, and we can share key findings from this feedback to help you reflect on the experience of PPIE Members in your involvement activities.

The Role of a PPIE Network Member

The role of a PPIE Network member is to provide advice from a patient's perspective to ensure research is relevant to those living with a musculoskeletal condition. All our PPIE Network members have either lived experience of a musculoskeletal condition, or care for somebody who does.

Prior to the involvement activity taking place the PPIE Team will send a copy of the Code of Conduct to participants. This was agreed by the NIHR Leeds BRC PPIE Core Group and covers the following areas;

- **Equality and Diversity** – The NIHR Leeds BRC is strongly committed to the promotion of equality and diversity for PPIE Network members and staff. PPIE Network members' behaviour and attitudes must be consistent with the aims of the BRC PPI Core Group to support inclusion, diversity and equity for all.
- **Respect** - PPIE Network members must treat each other, researchers and others they come into contact with when volunteering in their role with respect and courtesy at all times. PPIE Network members must respect different opinions and experiences - listening to and recognising the value of others' contributions to discussions.

We ask that feedback is constructive and conducive to improving the quality of our research.
- **Confidentiality** - PPIE Network members must respect the status of confidential issues they read and discuss. They are bound to maintain the status of this material and any information shared by researchers or other PPIE Network members.

- **Integrity** - PPIE Network members are required to use their knowledge, expertise and experience to give the best advice they can. PPIE Network members should act in an individual capacity and not as a representative of any group, organisation or individual.

PPIE Network members must not accept gifts or hospitality which are aimed at compromising their neutrality.

- **Commitment** - PPIE Network members should prepare for meetings to ensure they add value to any PPIE activities and should inform the PPIE Team if they are unable to attend.
- **Conflicts of interest** - PPIE Network members should identify and promptly declare any actual, potential or perceived conflicts affecting them. It is requested, that if they

hear something within a focus group which they feel would be a conflict of interest to them, to make the researcher aware.

A conflict of interest could be working for or having involvement in activities, organisations or funders related to the research or being involved as a participant in a research trial directly related to the research being discussed.

PPIE Network members are encouraged to speak to either the PPIE Team or researcher if they are unsure.

- **Openness and accountability** - PPIE Network members must be open, responsive and accountable to each other, members of staff and other stakeholders about their involvement, actions and work, including their use of PPIE Network resources.



Useful Resources and Contacts

INVOLVE was established in 1996 and is part of, and funded by, the National Institute for Health Research, to support active public involvement in the NHS, public health and social care research.

As a national advisory group their role is to bring together expertise, insight and experience in the field of public involvement in research, with the aim of advancing it as an essential part of the process by which research is identified, prioritised, designed, conducted and disseminated. They have a range of useful resources including:

Briefing notes for researchers:

www.invo.org.uk/resource-centre/resource-for-researchers/

Developing training and support for public involvement in research:

www.invo.org.uk/resource-centre/training-resource/

Jargon buster to understand research:

www.invo.org.uk/resource-centre/jargon-buster/

The following resources may also be of use to you:

Plain English guidance:

www.plainenglish.co.uk/files/howto.pdf

Guidance on participant information sheets:

www.hra-decisiontools.org.uk/consent/index.html

Impact of PPI in clinical trials:

www.phc.ox.ac.uk/ppi/impact/ppi-in-clinical-trials

General information on patient involvement in clinical research:

www.nihr.ac.uk/patients-and-public/

How can the PPIE Team help?

The PPIE Team can support you to design, develop and cost your PPI activities. You will be asked to complete a request form for PPI activities, depending upon which type of activity you will be given a form to complete either:

1. Reviewing Grant Applications Guidelines for Researchers

This form is to be completed by researchers who are preparing any grant application which they would like reviewed by members of the PPIE Network. Or...

2. Patient and Public Role Description Template

This form is to be completed by researchers to indicate the commitment needed from PPIE Network members, and the nature of their involvement. This form must be completed for all PPI requests.

To ensure meaningful involvement, forms must be submitted to the PPIE Team at least three weeks prior to the involvement activity taking place. All forms can be requested from the PPIE team or can be accessed on the NIHR Leeds BRC website in the PPI section:



<http://leedsbrc.nihr.ac.uk/>

Providing Feedback Following your Grant Submission:

Feedback is a crucial element for meaningful involvement. It shows respect for the time given by those who have taken part and completes the involvement cycle.

When you have received funding, we ask that you complete the Feedback on Receipt of Grant Form. This gives prompts about how PPI has contributed to the grant award and how you plan to continue with PPI in your study.

The PPIE Team can support you with providing feedback when you haven't received funding.

Outreach and Engagement with External organisations:

The Outreach and Development Manager can support you if you would like to reach a broader and more specific community with your PPI activities and to deliver PPI activities in the community.

Contact for PPIE Activities:

You can call or email the **Patient and Public Involvement/Engagement Team** at any time to discuss PPI activities or engagement opportunities:



Email:
PPIBRC@leeds.ac.uk



Direct number:
0113 3924485





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