

# NIHR Leeds In Vitro Diagnostics Co-operative **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 working with the NIHR Leeds In Vitro Diagnostics Co-operative to plan their Patient and Public Involvement and Engagement (PPIE) activities.

## The NIHR Leeds In Vitro Diagnostics Co-operative's Policy for Patient Involvement

We put patient involvement at the heart of our research programmes, as public input is crucial to the development of our proposals. This ensures research benefits are clear from the outset and that our projects address an unmet clinical, patient-led need.

## What is Patient and Public Involvement?

'Patient and Public involvement' means research is conducted '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 research organisations.

## What is Patient and Public Engagement?

Public engagement is where information and knowledge about research is provided and disseminated to enable feedback and make improvements.

## 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 develop new solutions, improving the design and delivery of research.
- PPI can ensure research is focused on delivering 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 asked of patients.
- It builds a sense of community through shared experience, and challenges the traditional power balance between health professionals and patients.
- Involving patients and the public strengthens 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 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 – making 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.

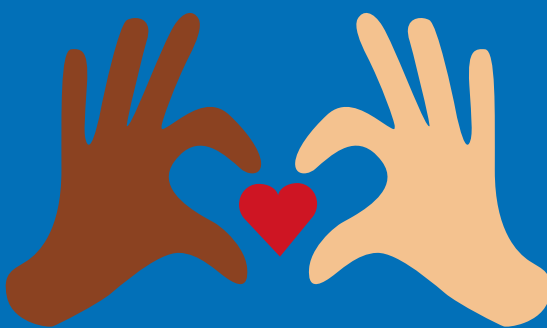
## UK Standards for Public Involvement in Research

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

Researchers can use these 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 at NIHR Leeds In Vitro Diagnostics Co-operative

Here at the NIHR Leeds In Vitro Diagnostics Co-operative 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 NIHR Leeds In Vitro Diagnostics Co-operative team.

## Patient and Public Involvement Core Steering Group

The vision of the PPI Core Steering Group is 'to make sure the views and experience of patients and the wider public are represented in the development and delivery of better care pathways, leading

to improved patient health'. The group meets every three months and works with the NIHR Leeds In Vitro Diagnostics Co-operative to support researchers and ensure they focus 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 300 patients and members of the public who have an active interest in research that takes place across the NIHR network. They may be living with a medical condition themselves, going through diagnosis or provide support/care to someone who is living with a condition. All involvement/engagement opportunities can be disseminated through the PPIE network.

## **Reviewing Grants and Planning Research**

PPI review is essential for particular grant schemes, and the NIHR Leeds In Vitro Diagnostic Co-operative is actively involved in this process. This may be achieved via email or through a focus group facilitated by a researcher.

Researchers may consider setting up an 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 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 our 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 outcomes of research.

## **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 of the study. It is suggested that where PPIE representation is required, two PPIE representatives are recruited.

## Communicating Research to the Public

PPIE networks ensure 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:

- Guidance about how to provide feedback in Plain English to participants of the study regarding the outcome of the research.
- Co-presenting or providing guidance on how to give updates at NIHR network meetings such as “Ask the Researcher”.

- Presenting outcomes to the general public, either through the local media, or the NIHR Leeds In Vitro Diagnostics Co-operative’s website.

## PPI Members Delivering Training

PPI 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. Our team are here to help you design PPI activities that make the most meaningful impact to your research.





# Engagement opportunities through the NIHR network

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

The Ask the Researcher events are still running, but since the pandemic they have been taking place online using Zoom. We recommend your event lasts for a maximum of an hour and a half and includes the chance for PPIE members to ask questions. This will be supported and chaired by a PPIE Manager to make delivery as easy as possible. The NIHR Leeds In Vitro Diagnostics Co-operative team will link you to the organisers of these events so they support you.

They are an opportunity for researchers (alongside relevant colleagues) to present a theme and inform patients/ public of their work. If you have an idea for an Ask the Researcher event please contact our team who will organise the logistics.

## Be Part of Research event

Every year there is a celebration for International Clinical Trials Day in May. Due to COVID-19, this has been on hold, instead focusing on participating in online activities. Prior to the pandemic, members of PPIE groups across the NIHR network played a crucial role in developing these events, and on the day in terms of showing attendees around, signing them up to activities and providing general support.

Research teams had stalls and activities to showcase their work to the public.

### **Bespoke events**

The NIHR Leeds In Vitro Diagnostics Co-operative can develop a range of bespoke events and outreach activities tailored to your needs. 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 NIHR Leeds In Vitro Diagnostics Co-operative team as early as possible in the planning stage.

### **NIHR Leeds In Vitro Diagnostic Co-operative website, Twitter and LinkedIn**

We can share news and information about your research through the NIHR Leeds In Vitro Diagnostic Co-operative:



#### **Website:**

[leedsmic.nihr.ac.uk/](https://leedsmic.nihr.ac.uk/)



#### **Twitter:**

[@NIHRLeedsMIC](https://twitter.com/NIHRLeedsMIC)



#### **LinkedIn:**

[/nihr-leeds-in-vitro-diagnostic-co-operative](https://www.linkedin.com/company/nihr-leeds-in-vitro-diagnostic-co-operative)

# 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: we suggest at least three weeks.

## Arranging activities

The NIHR Leeds In Vitro Diagnostics Co-operative team will work with you to arrange an appropriate time for your

activity, they will organise this using their Zoom account and send out the invites etc.

Alternatively, now we have returned to in-person activity, they will book a Board or Seminar Room depending on your needs. These rooms get booked up in advance, so it is always worthwhile having a couple of dates in mind when planning your activity.

We will arrange for the necessary refreshments to be provided, and this can be discussed in advance.

## Timings of activities

We ask you to run PPIE activities at times convenient for PPIE network members, starting after 10:30am, and providing breaks for activities held longer than 1.5 hours. We ask that no PPI activity starts before 10.30am.

## Considerations for online activities

Discussions in online large group meetings can be hard to manage and hard for people to participate, so please fully discuss your activity with the NIHR Leeds In Vitro Diagnostics Co-operative team who will advise you on how best to run the activity and if breakout rooms are needed. They will provide housekeeping and an introduction for your activity and Chair the discussion.

**Consent will be sought to record the activity, so you can focus on the questions and discussion.**

The time when members will be travelling will need to be considered. Allow time before the activity to set-up the room. It is worthwhile factoring in time at the end of the activity for questions, bearing in mind that PPIE members will have planned their travel/parking around the times 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 NIHR Leeds In Vitro Diagnostics Co-operative team will ask about access and dietary needs; these will be relayed to you. If you are recruiting for yourself, we ask you do the same, discussing any access and dietary needs with the NIHR Leeds In Vitro Diagnostics Co-operative team.



During this time it is important to minimise digital exclusion as much as possible, so some PPIE members may prefer a phone call, one-to one discussion or to receive information via post. It is always best to ask what their access needs are and how you can support their involvement.

### **Feedback following PPI activities**

Feedback is crucial to good involvement. On completion of your activity, please provide a short summary to the NIHR Leeds In Vitro Diagnostics Co-operative 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.

## 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 NIHR Leeds In Vitro Diagnostics Co-operative team who can support you with strategies to deal with problems and put in place strategies to prevent future issues.
- If you receive negative feedback via email, this can be discussed with the NIHR Leeds In Vitro Diagnostics Co-operative team. You may also wish to discuss it with your supervisor. If appropriate, a meeting can be arranged by the NIHR Leeds In Vitro Diagnostics Co-operative 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 available on the NIHR website, and the NIHR Leeds In Vitro Diagnostics Co-operative team can support you with this.



<https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392>

Please contact the NIHR Leeds In Vitro Diagnostics Co-operative team to help you appropriately cost your activities.

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
- Additional costs to support inclusion and access e.g. carer/ child care/ interpreter
- Other expenses e.g. parking
- Recognition payments
- PPIE staff time



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

- Facilities hire
- Catering
- Travel for speakers
- Travel and recognition payments for patient/public 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. patient/public 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). Our team can signpost you to the latest guidance. Recognition payments and some expenses can have an impact on tax and benefits and we advise that you speak to us when costing for PPI expenses/ recognition payments to ensure costs are in line with NIHR 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 their research. It is the responsibility of the researcher to ensure technical and scientific excellence and to ensure 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 NIHR Leeds In Vitro Diagnostics Co-operative 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 a timely fashion. We ask you to provide clear information at least three weeks in advance of holding PPI activities. The PPIE network members need 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 time to listen, 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 in knowing if you have been successful in grant applications and if your research resulted in the outcomes you were hoping for.

You can provide feedback through the NIHR Leeds In Vitro Diagnostics Co-operative team who will keep a record of the people you have involved and can advise on how to give feedback.

## Evaluating the impact of PPI activities

The Leeds NIHR network is developing a set of tools to evaluate the impact of PPI activities. You will be asked for feedback when you conduct PPI, this is essential in the improvement of PPI activities. We also ask PPIE members to provide feedback following their involvement, and we can share key findings to help you reflect on the experience of PPIE members in your 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 conditions related to musculoskeletal, kidney or infectious diseases or cancer. All our PPIE network members have either lived experience, or care for somebody who does.

Prior to the involvement activity taking place, the PPIE team goes through the Ground Rules. This was agreed by the NIHR Leeds In Vitro Diagnostics Co-operative core group and covers the following areas:

### Confidentiality and Conflicts of Interest

The information shared in and around activities is confidential. This covers the details of the research, as well as the information that other participants share about their

own experiences. PPI members may be asked to sign a 'confidentiality agreement' by the researcher or the PPI team. Please also declare any conflicts of interest that you may have.

### Listening

You have been selected as part of the focus group because of your lived experience based upon the condition area. You have the right to speak and be listened to by our staff and by each other. Please remember that this isn't a forum to share issues with your care or complaints. We ask that feedback is constructive and conducive to improving the quality of our research.

### Equality

We are strongly committed to the promotion of equality and diversity for PPI members and staff. We expect the behaviour and attitudes

of PPI members and staff to be consistent with this. We will not tolerate behaviour that goes against these principles and will ask anyone who doesn't adhere to these principles to leave the activity.

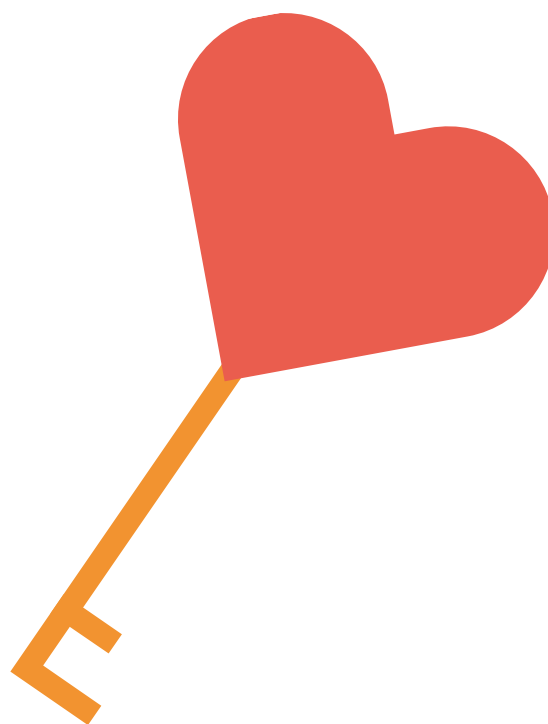
### Accessibility

We will provide you with the information that you need to be prepared for the activity. The accessibility of information and the activity itself are important, and we want to make sure your needs are met. Ahead of the activity if you have any access requirements please do inform the PPI team.

### Respect

It is important that everyone who attends our activities are treated with respect and courtesy. This includes all staff and PPI members listening to and valuing each other's contributions, and not speaking over them. We ask that you

respect the time of others by preparing for the activity and reading through information provided to you. We ask researchers to ensure activities run to time and that all members are given an opportunity to contribute.



## Useful resources and contacts

The NIHR Centre for Engagement and Dissemination took over from INVOLVE in April 2020. As a result of this, they have retired the INVOLVE website and added updated resources to the NIHR website:

**Make a strong application, section on involving patients, carers and the public:**

<https://www.nihr.ac.uk/researchers/apply-for-funding/how-to-apply-for-project-funding/make-a-strong-application.htm>

**Briefing notes for researchers – public involvement in NHS, health and social care research:**  
<https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371>

**Guidance for writing Plain English summaries:**

<https://www.nihr.ac.uk/documents/plain-english-summaries/27363>

**Payment guidance for researchers and professionals:**  
<https://www.nihr.ac.uk/documents/payment-guidancefor-researchers-andprofessionals/27392>

**Different experiences: a framework for considering who might be involved in research:**  
<https://www.nihr.ac.uk/documents/different-experiences-aframework-for-consideringwho-might-be-involved-inresearch/27387>

**Being inclusive in public involvement in health and care research:**

<https://www.nihr.ac.uk/documents/being-inclusive-in-publicinvolvement-in-health-andcare-research/27365>

**INCLUDE Framework – inclusion of under-served groups in your research:**

<https://www.trialforge.org/trial-forge-centre/include/>



## How can the NIHR Leeds In Vitro Diagnostics Co-operative team help?

The NIHR Leeds In Vitro Diagnostic Co-operative team can support you to design, develop and cost your PPI activities.

### Providing feedback following your grant submission:

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

The NIHR Leeds In Vitro Diagnostic Co-operative team can support you with providing feedback when you have not received funding.

### Contact for PPIE activities:

you can call email the NIHR Leeds In Vitro Diagnostic Co-operative team at any time to discuss PPI activities or engagement opportunities:

Email us at:

[nihrleedsmic@leeds.ac.uk](mailto:nihrleedsmic@leeds.ac.uk)





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