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Patient and Public Involvement (PPI) in Research

A Guide for Researchers at LSHTM



Improving Health Worldwide

What is PPI?

PPI stands for Patient and Public Involvement. It may also be referred to as Patient and Public Involvement & Engagement (PPIE) or even as just Public Involvement (PI). This guide provides an introduction to what PPI is and where to start when planning how to involve patients and/or the public with your research.

INVOLVE, a national advisory group supporting active public involvement, defines PPI as “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.”

Involvement is different from participation in research and different from public engagement. Though these areas often overlap and can be linked, it is important to distinguish between them.

Below is a table with some example activities which can be classified as involvement, engagement, or participation.

Involvement	Engagement	Participation
<ul style="list-style-type: none"> • Hold a focus group with patients to set research priorities. • Have a member of the public on a grant advisory panel or steering group. • Seek feedback on a grant application or survey design from patients or the public. • Co-present a talk with a member of the public or patient to an academic or non-specialist audience. • Co-write the lay summary of a grant proposal with public and patient groups. • Develop patient information leaflets with input from public and patient groups. 	<ul style="list-style-type: none"> • Discuss research at a booth at a science festival. • Share research findings in a public talk. • Collaborate with artists and the public to create a visual representation of research. • Contribute to a public Q&A discussion session. • Work with a museum curator and the public to develop an exhibition. • Hold an interactive workshop in a school or at an after school science club. • Co-create a film about lived experiences of patients or the public. 	<ul style="list-style-type: none"> • Recruit participants into a clinical trial or research study as a subject. • Interview individuals as part of a research project. • Conduct a survey to answer a research question.

Why is PPI important?

Funding:

NIHR’s strategic goals for 2025 include making public involvement a required part of high quality research. Many funders and ethics boards will have patient/public representatives on their review panels, and expect to see PPI as part of a well-considered research project.

Better research:

With patient and/or public input, research can be more relevant, user-focused, and more likely to be taken up in practice. E.g. individuals with a lived experience can bring in new perspectives or ensure your trial methods are suitable.

Ethics:

Members of the public should be able to inform research that affects them and that is funded through public money.

Who do we involve with our research?

According to INVOLVE, relevant individuals to involve in our research can include: “patients, potential patients, carers and people who use health and social care services (service users), as well as people from organisations that represent people who use health services”.

The people you involve will be specific to your research, e.g. you may seek individuals who have had a certain experience or a particular condition, people of a particular age, individuals who have used a particular service, etc. Depending on your project and the depth of involvement or collaboration that you are aiming for, you may be hoping to involve a single ‘patient expert’ with previous experience working with researchers, or perhaps a larger group of people who have never been involved with a research project before.

It is important to distinguish between someone who may use health services and someone who works professionally within these services, e.g. doctors and nurses. Professionals in the health care sector are not the main focus of PPI activities (even though they are sometimes patients and are members of the public). This is because they are most often involved in the delivery of services and treatments. However, some studies also include ‘practitioner’ involvement or engagement.

It is important to consider how patients and public involved in your research want to be referred to. People may prefer to be called public representatives, a contributor, a public expert or a patient, as a few examples. An individual’s preference may change as their involvement evolves and/or their personal situation changes. For example, someone may identify as a patient at the start of their involvement with research and then go on to recover, and prefer to be referred to differently. You would generally avoid calling ‘involved’ patients and public a ‘research participant’ – as a participant is someone who takes part in the actual research study (e.g. interviewed for research, participating in a clinical trial), whereas an ‘involved’ member of the public is working with researchers to support the design and/or conduct of the research.

TOP TIP: Manage expectations

An agreement should be reached early on about what members of the public are able to be involved in, in relation to the research, and the time commitment they are able to give to the project. This should be clearly communicated and agreed so that there is mutual understanding amongst all parties.



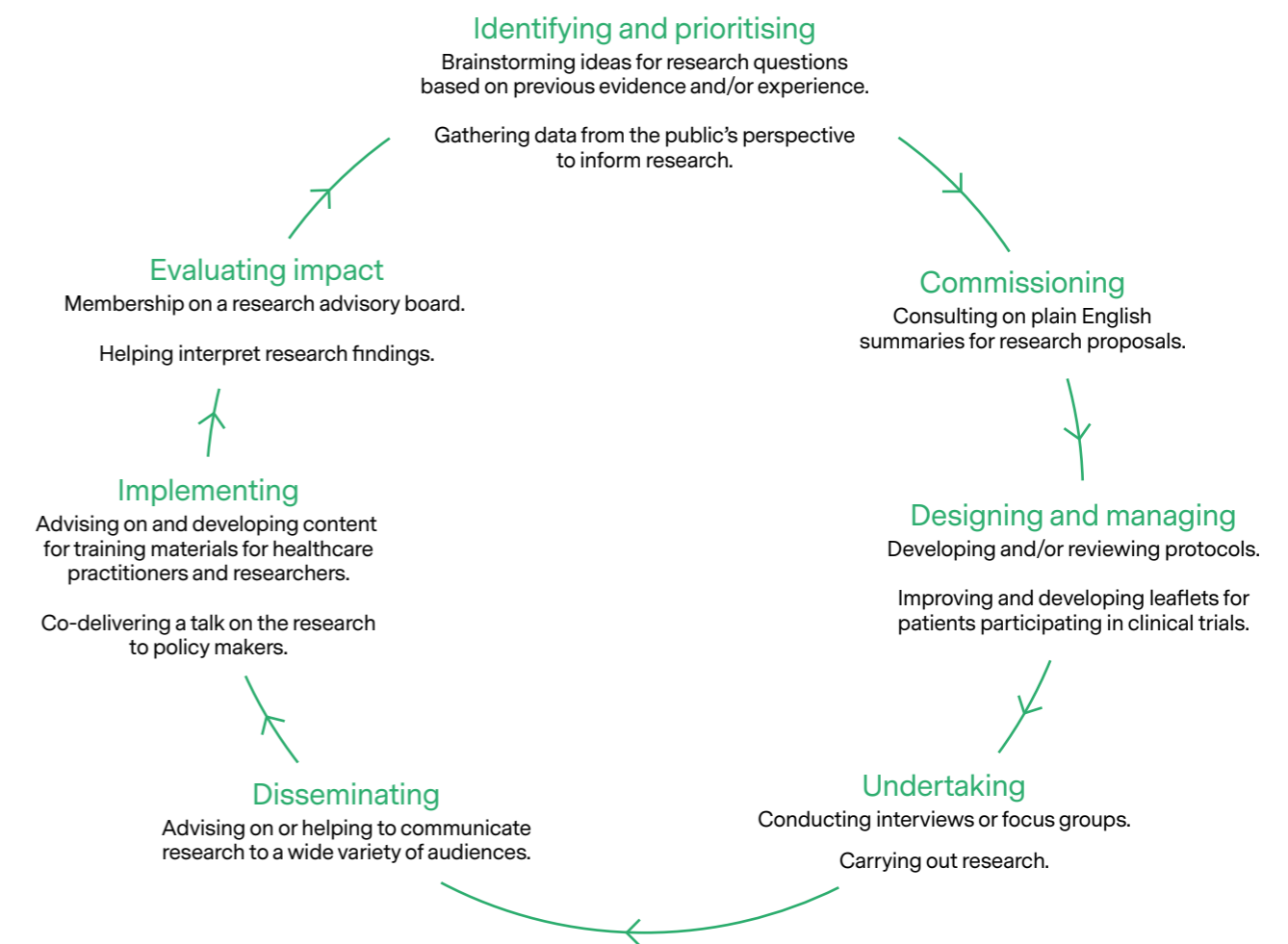


When should PPI take place?

Involvement can happen throughout the research cycle, from identifying research priorities before a grant has been submitted through to co-presenting the results and visioning ideas for follow-on research.

It is best practice to create opportunities for involvement as early as possible in the research cycle. Involving patient/public representatives at an early stage can be particularly relevant, e.g. they may be able to advise on how best to recruit patients.

Below are the stages in research where involvement can be incorporated, extracted from INVOLVE⁵ and NIHR⁶ resources.



How to find people?

There are multiple ways to advertise involvement opportunities. These could include:



Connecting to a group through an existing network that you, or a colleague, are already involved in. Depending on your area of research, there may already be an existing group of patient/public representatives willing to get involved or a network you can reach out through.



Establishing and fostering links with patient organisations and charities in your respective research area. Not only can this assist with the recruitment of patient/public representatives but may also be more widely relevant when it comes to disseminating your research.



Look for organisations that are invested in involvement more generally to see if you are able to advertise through them. Some examples of organisations include: *People in Research*¹, *Involving London*², *Research Design Service London*³, and *North West People in Research Forum*⁴.



Engage with representatives at local community centres and/or local surgeries to put up posters or hand out information.



Advertise in the local newspaper or through promoted ads on social media.



Reach out to patient associations at large hospital trusts or Patient Advice and Liaison Service Officers based at NHS Trusts.



If you work with national audit data, many of the audits have active links to patient organisations which you may be able to work with.

Ensure that you consider and adapt your methods of advertising or contacting individuals or groups depending on who you are trying to reach. For example, some patient groups may be more accustomed to using social media to engage with one another or with external organisations.

Once you have built up a relationship with patient/public representatives they could be involved in future projects, where appropriate, if they have agreed that you can contact them in the future.

TOP TIP: Training

Similar to providing members of your research team with opportunities for personal development, are there training courses or conferences applicable to your patient/public representative that would enable them to more effectively carry out their role in the project? This is most relevant if you are working with these individuals for a longer period of time.

TOP TIP: Involvement is always possible

It is never too late to start incorporating involvement into your project. For example, if the grant is already funded, it is still possible to gather feedback to shape the remaining study or to work with patient/public representatives to undertake the research itself.

Different types of PPI

Public involvement can take many forms. The method you use will depend on the research being done, the stage of research where PPI is implemented, your reasons for doing PPI, and the preferences of your patient/public representatives.

Consultation

This type of involvement includes asking patient/public representatives for their views and advice, and incorporating these into research. This could occur as a one-off consultation or more regularly throughout the research project.

Consultation can be particularly useful in preparing grant applications (e.g. seeking input on the design of research). However, as patient/public representatives are most often contacted and recruited at this stage of research, be aware of 'consultation fatigue' and making the consultation look exploitative or tokenistic. Ensure you build in enough time and create a space where representatives feel they are able to respond. Always provide feedback on how their comments will be used. Consultation at the beginning of a research project can also be a tool for developing relationships for future involvement at different stages in research.

Examples:



Focus group – hosting a focus group(s) with patient/public representatives to seek input on the key research questions, methodology, research participant recruitment and/or project communication and dissemination. Consider whether the use of an external facilitator would enhance the consultation.



Research Advisory Board member – Having a patient/public representative regularly attend and fully participate in your project's Research Advisory Board.

TOP TIP: Provide relevant information

Ensure that your patient/public representatives have access to the tools to enable them to have meaningful involvement, such as providing relevant background information.

As not all patient/public representatives will understand research terminology, consider how you can ensure that materials and conversations which include them are made accessible. For example, you could include a glossary of terms for scientific or technical language and ensure that language used at meetings is accessible and understandable for all attendees.

Collaboration

This type of involvement can also be known as partnership or co-production, where responsibility is shared and decisions are jointly made by researchers and patient/public representatives.

It can include co-developing a grant application or forming a study steering group to identify research priorities. The patient/public representative may also be involved in undertaking, analysing and reporting on part of the research. This sort of involvement can lead to a richer study but often is more expensive, requires more time and may require additional training/support for both the researchers and the patient/public representatives involved.

Example:



Co-developing a talk – A researcher and patient/public representative co-prepare and deliver a talk about the research together. This could occur in a public forum, to policy makers or at an academic conference.

User-led

This can also be known as user-controlled research, where patient/public representatives control and undertake the research project themselves. Researchers may provide training or support to the project, or be consulted at relevant points for their expertise. They may also be approached by a group to carry out the research on behalf of the users.

Example:



Service user-led research project – Service users lead a research project on their self-identified needs. They set the research questions, plan the study design, analyse and write up results, getting support from researchers when needed.

Budgeting for PPI

Recruiting and training patient/public representatives, holding meetings and reporting back all take time and resources and it is important to build this into funding applications and project planning. Funding bodies will expect that you have costed these activities in appropriately.

Some common costs to consider for PPI can include:

- Patient/public representative recruitment, expenses (travel, food, etc.) and payment.
- Venue hire and refreshments.
- Training for researchers and/or patient/public representatives.
- Additional support for patient/public representatives (e.g. transport challenges or resources provided in alternative formats such as translated, large print, braille, etc.).
- External professionals (e.g. facilitator).

There are many online resources on how to budget for PPI. For example, INVOLVE provides practical advice on [budgeting for involvement](#)⁷ and an [online cost calculator](#)⁸ for estimating costs depending on the type of involvement activity.

Expenses and payment

You should strongly consider how patient/public representatives can be compensated for their time. Some grant panels may object to proposals that have not properly budgeted for this. It is a good idea to find out what the funder's expectations are in regards to this.

When offering payment to patient/public representatives, it can be valuable to let payment be optional or let people donate their payment to a charity if they want to and/or are able to, so as not to exclude people who just want to volunteer, or people who could not participate if they were compensated.

Payment can occur directly as an honorarium, be an agreed upon amount or can be provided through other avenues such as training and/or travel and participation in conferences.

Any expenses that patient/public representatives incur through being involved with your project should also be covered. Possible expenses include: travel, childcare, subsistence and accommodation. Consider covering expenses in advance if you cannot guarantee timely reimbursement. For information on how to do this at LSHTM, contact the Finance Office.

TOP TIP: Involvement and state benefits

If individuals planning to become involved in your work are receiving state benefits they need to be appropriately advised prior to getting involved. This is because any form of payment, even reimbursements, can be treated as earnings, which can affect their ability to receive benefits. It is best to let people know this before starting as, even if the person is not being paid, it may impact their status.

NIHR offer a confidential service which advises on this and can provide a letter that states participation is not work. It is best practice as a researcher not to give advice regarding benefits, but to direct patient/public representatives to this service.

Credit or acknowledgement for an individual's time is also best practice, e.g. contribution acknowledged in research papers and/or reports, sending a thank you card, informing them after the fact of how their involvement contributed to research.

TOP TIP: Monitoring and evaluation

Similar to research activities and outcomes, it is important to track involvement activities and outcomes, using both quantitative and qualitative tools. This is particularly important if you need to report on your PPI activities to funders or others.

Other resources

This guide was made by researching and compiling information from the following organisations and guides. Visit their websites for more information and to check out their best practice guides.

- INVOLVE
- National Institute for Health Research (NIHR)
- Research Design Service London
- Generation R – Young People improving Research
- Parkinson's UK
- University of Plymouth 'Working Together Guide: An essential guide for healthcare practitioners, researchers, educators and regulators looking to work with service users, patients, carers and members of the public'



If you would like to discuss your proposed PPI plans while they are in development, including PPI sections of funding applications, please contact the Public Engagement Team on: publicengagement@lshtm.ac.uk.

TOP TIP: Staying in touch

Ask if patient/public representatives consent to be contacted in the future, and ensure that you provide them with feedback and updates on the research project, even if the feedback is that the grant was not funded. Knowing how they contributed to the research can contribute to making them feel valued and can build relationships for future PPI.





Ask patient/public representatives how they wish to be contacted. Be aware that email may not be the best form of contact for everyone.

Resources:

1. People in research:
www.peopleinresearch.org
2. Involving London:
www.involvinglondon.co.uk
3. Research Design Service London:
www.rds-london.nihr.ac.uk
4. North West People in Research Forum:
www.northwestpeopleinresearchforum.org
5. Stages of research – INVOLVE:
www.invo.org.uk/posttypereource/where-and-how-to-involve-in-the-research-cycle
6. Stages of research – NIHR:
www.nihr.ac.uk
7. Budgeting for involvement:
www.invo.org.uk/posttypepublication/budgeting-for-involvement
8. Online involvement cost calculator:
www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator

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