



GUIDE TO

PATIENT AND PUBLIC INVOLVEMENT IN HSE RESEARCH



Knowledge Translation, Dissemination, and Impact

A Practical Guide for Researchers

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This guide is part of the series of guides about the translation, dissemination, and impact of research. It aims to help researchers think about the opportunities to involve patients, service users, carers, families using health and social care services, people with lived experience of health conditions (who may or may not be current patients), patient advocacy organisations, and members of the public in their research.

The guide explains what patient and public involvement (PPI) is, what it involves, and gives suggestions about how to involve contributors in all parts of the research cycle and knowledge translation. It also explains the importance of recognising and valuing PPI and gives examples of good practice. Users of the guide will be able to:

- Understand the value of PPI.
- Use different methods of involvement appropriate to their study.
- Demonstrate good practice in PPI.

1. What is patient and public involvement in research?

Definitions

When we use the term **Patient and Public Involvement** (PPI) it refers to patients, service users, carers, families using health and social care services, people with lived experience of health conditions (who may or may not be current patients), patient advocacy organisations, and members of the public¹.

The widely used definition of **Patient and Public Involvement in research** is:

'--- research carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them'.

It means working in collaboration or **partnership** with patients, carers, service users, families, people with lived experience, or the public, in planning, designing, managing, conducting, dissemination and translation of research.

2. What is the difference between patient and public involvement, engagement, participation?

The terms involvement, engagement, and participation in research are often used interchangeably but in health research they have different meanings and cover different activities.

As described above, **involvement** in research refers to research carried out 'with' or 'by' patients, service users, carers, families using health and social care services, people with lived experience of health conditions (who may or may not be current patients), patient advocacy organisations, and members of the public. Involvement can include people getting involved in these ways:



- Setting research priorities
- Co-applicants for funding for a research project
- Members of a project steering, management, or advisory group
- Advising and developing patient information leaflets
- Co-researchers e.g. carrying out interviews with research participants
- Carrying out user led research.

Engagement is about awareness raising, sharing, disseminating knowledge about research, and engaging patients, service users, carers, families using health and social care services, people with lived experience of health conditions (who may or may not be current patients), patient advocacy organisations, and members of the public in a conversation about research. This might be through:



- Research open days or dissemination events
- Through the media and social media
- Science festivals.

¹ The inclusion criteria may differ in other organisations, but this is intended to be inclusive of the different people served by HSE.



Participation is when people take part in a research study as participants. This might be a clinical trial, taking part in an interview or focus group or online activity. Usually it involves people consenting to take part and have their data collected so that researchers can answer a particular research question.

3. What is community based participatory research?

Community Based Participatory Research (CBPR) is a:

"Collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community, has the aim of combining knowledge with action and achieving social change." (Arbor et al 2003).

CBPR involves partnering, or co-producing, research with a community organisation or group to develop, deliver and manage a research project. This type of involvement differs from other PPI in that the community organisation is representing a community whereas individual PPI contributors are usually bringing an individual perspective. CBPR is an opportunity to reflect the diversity of the community by recruiting a range of people from different genders, ethnicity, disabilities and abilities, and backgrounds. In this type of involvement it is helpful to have a partnership agreement between the community organisation, health, and academic partners to cover the following:

- Project management
- Rights and responsibilities
- Ethical issues
- Partner's expectations
- Roles and relationships
- Community training and participation
- Data ownership and Intellectual Property (IP)²
- Data storage and access
- Decision making processes
- Practical matters
- Reward and recognition
- Feedback and review at the end of the project



² Intellectual property describes ideas and 'know how' that are created in someone's mind. Sometimes during research, ideas and concepts are developed with practical application or commercial potential. Examples of this might be a new device, software, an educational programme, or a pharmaceutical product.

4. Why do we need patient and public involvement in research?

PPI is important for three main reasons:



To improve the **quality** of our research



To improve the **value** of our research



To increase the **impact** of our research

PPI can improve the quality and relevance of research. If contributors are involved in prioritisation of topics, it can highlight issues that are important to patients, service users, carers, families using health and social care services, people with lived experience of health, patient advocacy organisations, and members of the public. It can result in better research studies as PPI representatives bring a different perspective to the study and can help prevent poor research questions by focusing on areas that patients consider to be important. Even if you are involved in lab based research, having the PPI context can help you to see the wider context of your research, and how it will impact on people in the longer term.

Asking the research questions that patients see as important, and designing and using the methodologies that participants are more likely to engage with, can help reduce research being wasted. During analysis of data, PPI contributors can highlight the findings that are relevant to the population studied, identify new themes, and help researchers in their interpretation of the findings.



People with real lived experience can help to communicate your work and explain its importance to patient, service user, carer, family, and advocacy groups and organisations. Knowing that there has been a PPI perspective in the research can make the research more meaningful to those who might benefit. Lay reviews are an important part of preparing proposals and bids for funding. PPI contributors can play a key role in improving the readability of research proposals and findings and help with sharing the findings with lay audiences.

PPI representatives can inform all parts of the research cycle to help improve the outcomes from the research study and ensure they are relevant to those patients, families, and members of the public who may benefit.

PPI is the right thing to do. A significant amount of health research is publicly funded and therefore researchers should be accountable for their use of that funding.

Benefits of involvement for PPI contributors



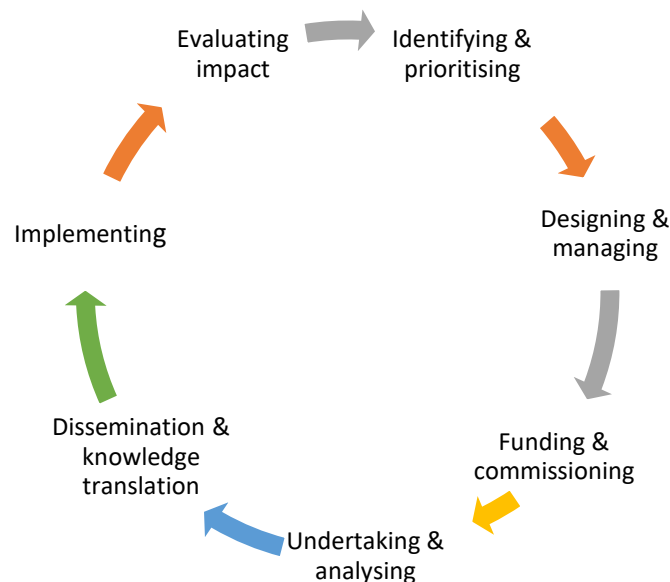
PPI can also bring benefits for the PPI contributors and the evidence from research shows that they can:

- Gain new knowledge and skills
- Learn more about health services and treatments.
- Share expertise and experience.
- Increase their confidence and wellbeing.
- Feel empowered and valued for their contribution.
- Access training opportunities.
- Meet others involved in PPI and form networks and supportive relationships.

5. What does patient and public involvement in research involve?

PPI contributors can get involved at all the different stages of the research cycle (see figure 1).

Figure 1 – the research cycle



This might include:

- Taking part in priority setting exercises to identify areas of importance or unanswered research questions, helping to set research questions.
- Being part of the team developing the design and methodology for a study, preparing a funding application, developing information materials and research tools such as interview or focus group schedules.

- Being a member of a commissioning or funding panel making decisions about the award of funding to studies.
- As a co-researcher being part of the research team carrying out interviews, focus groups, or other forms of data collection, analysing the data and giving a PPI perspective on the interpretation of the data.
- Developing a dissemination and knowledge translation plan to share the findings from the research, advising on how to share findings with patients, service user, carer, family, groups, or organisations, being a co-author of a report or paper, co-presenter of the findings.
- Playing an active role in working with patient, service user, carer or family groups or organisations to implement the research findings.
- With the research team, evaluating the impact of the research and the PPI part of the study and the difference that made.
- Leading their own research, and taking responsibility for all stages of the study, or commissioning research from others.

PPI roles

PPI contributors can also undertake a number of different roles, for example being a co-applicant, a co-researcher, a member of a steering or project management group, a member of a PPI reference or advisory group, or leading research.



Co-applicant in a research funding application

Being a co-applicant involves being part of a partnership or consortium developing a funding application. This might involve identifying a research question, co-writing a lay summary, bringing the lived experience of a patient, service user, carer, identifying any ethical issues, and agreeing the proposal with the rest of the team. If funding is agreed, the co-applicants may then become the research team responsible for the delivery, management, and conduct of the project.

Co-researcher

A co-researcher will take an active role in one or more aspects of a study e.g. developing research tools, data collection (interviewing, focus groups), recruitment of participants, analysis, interpretation of results, report writing, dissemination. They will attend regular research team meetings and bring the perspective of the lived experience.

Member of a project steering or management group

Patients, service users and carers may take part in a study as part of the core project management team, as members of a steering group, a review group or panel, or on an advisory panel or similar. Before funding is awarded, they might advise on the design of the study, the relevance of a research question, recruitment of participants, review the project proposal, advise on the PPI perspective and how PPI should be included in the project. After the award of funding, the project steering group will support the research team. They could review documentation including information sheets and consent forms, comment on the analysis, advise at different stages of the project including

dissemination. PPI contributors may specifically assist with the recruitment of participants and bring the perspective of the lived experience.

Member of a PPI reference or advisory group

PPI contributors may be part of a project steering group or there may be a separate reference or advisory group formed to provide the PPI perspective. The group or team might help prepare patient information sheets, lay summaries, and advise on different stages of the research project.

User led research

Patients, service users, carers or families may undertake, or commission, research based on priorities and questions they have identified.

6. How do I find and involve patient, service user, carer, families, people with lived experience, or public contributors in my research study?



The first stage in thinking about finding and involving PPI contributors in your study is to decide what it is you want them to do. Writing a role outline or description is a good starting point as this will help people who might be interested in working with you in knowing what they are being asked to do.

Writing a role outline

The following are some ideas of what you might include in developing a role outline or description to recruit PPI contributors.

- a. **Title: role of (*insert name*)**
- b. **Background:**
 - What the project is about
 - The aims and objectives of the project
 - The role and its purpose
- c. **Responsibilities:**
 - What the PPI contributor is expected to do e.g. attend meetings, contribute to a funding proposal, carry out interviews
 - How many meetings they will be expected to attend and the likely length of the meetings, whether they will be in person or online
 - Any work that is expected between meetings
 - Expectations in terms of confidentiality and data protection
- d. **Support offered:**
 - The support the PPI contributor will be offered e.g. training, support before and after meetings
 - The name of the main contact person
- e. **Duration of the role:**
 - How long the role is expected to last
 - What will happen if the project is terminated early
- f. **Payments and expenses:**
 - Details of whether contributors will be paid for their involvement
 - If payments are available, how much will be paid for the activities they undertake
 - Whether travel and expenses will be paid

- The procedure for claiming payments and expenses
- g. Person specification including:
 - What experience, knowledge, skills, and personal attributes are needed for the role and whether they are essential or desirable criteria
- h. Contact details:
 - Name, email, telephone number for the main contact person who can answer any queries about the role
 - Web page or other source of information where relevant
- i. Details of the recruitment process e.g. shortlisting, interviews, informal discussion
- j. Closing date for expressions of interest.

Next you will want to find potential PPI contributors and need to think about who you want to involve. Is it patients, service users, carers, families using health and social care services, people with lived experience of health conditions, patient advocacy organisations, or members of the public? The following considerations can be helpful:

- Do you need people with direct lived experience or knowledge of your topic area?
- Do you want people with direct experience who have contact with patient, carer or family organisations and are able to share the research with those organisations and improve dissemination?
- Involving people from diverse communities by recruiting a range of people from different genders, ethnicity, disabilities and abilities, and backgrounds.
- Is your research a public health issue that would benefit from the public perspective and help in getting the right messages to the public.



You may already have contact with some PPI contributors who can advise you and suggest people who might be interested in your study. There may be established PPI groups in your topic area or charities, advocacy, or support groups who can advise you on recruiting people or help to connect you with them. If you are not aware of any groups, an internet search may help.

Experts by experience can be recruited through patient groups, advocacy groups, charities, or through health and social care professionals. Similarly, carers can be located through carer groups, charities, advocacy groups and health and social care professionals. Community groups can be found in local communities, town or city web sites often highlight local groups. The charity register will also list groups.

You could also advertise on social media using platforms that the people you are targeting are likely to use, through GP practices, outpatient departments or local libraries. If you are not able to find a

patient, carer, family, or advocacy organisation to help you could seek help from clinicians or community workers in your topic area or look more broadly at other local or national organisations not necessarily related to your specialist area. This can be helpful in trying to find a more diverse group of people who might be interested. It is important to consider how to involve people from seldom heard groups and to reach out to community groups who may support or offer services to them.

When recruiting people for involvement think about the different platforms for engagement that you might use e.g. emails, online meetings, face to face meetings, focus groups, social media groups. Consider whether any of those platforms might exclude those you want to involve. For example, face to face meetings might be difficult for those with mobility issues; online meetings might not be possible for those who do not have access to technology.

7. Including Patient and Public Involvement in your application for research funding



Many research funders require evidence of PPI in an application for research funding. They will expect the applicant to indicate where and how PPI will be part of the research study and also whether it has been part of the development of the funding application. PPI contributors may be co-applicants to the funding application or may have been involved in the generation of the research question or design of the study and the application process. There are some general points to consider when writing a funding application and including PPI:

- Make sure you say who you are involving and why.
- Outline how they will be involved.
- Describe how their involvement will improve the study and make it more relevant.
- Outline how the PPI contributors will be kept informed about the study particularly the results and how they might be involved in communicating the outcomes.

Remember to cost any PPI into the funding application.

8. Ethical issues

Ethical approval is not usually needed to involve patients, service users, carers, families, those with lived experience, patient, or family organisations in PPI activity. They are not being recruited as research participants so do not need to give formal written consent for their involvement. PPI is voluntary and it is important that contributors give their agreement to being involved and it is good practice to have a partnership agreement setting out everyone's expectations.



Safeguarding PPI contributors' health and wellbeing is the responsibility of the research team. Researchers should ensure they are aware of their organisations safeguarding policy, particularly if they are involving anyone from a vulnerable group including those with impairments, disabilities including intellectual disabilities, mental ill health, children, and young people.

PPI contributors should be made aware of the nature of their involvement, their right to withdraw when they wish, any implications and risks of being involved.

9. Value and reward



It is important to recognise that PPI contributors have contributed time, skills, experience, and expertise through their involvement. This should be **recognised**, **valued**, and, where possible, **rewarded**.

Forms of recognition include:

- **Thanking** contributors for the contribution they have made. **Celebrating** any successes.
- Keeping contributors updated about the research and giving **feedback** on how their contributions have made a difference to the project.
- Keeping people **informed** about other opportunities to contribute that might arise.
- **Including** contributors in reports, publications, and presentations and making sure their contributions are **acknowledged**.
- Offering learning **opportunities** to contributors and other events such as conferences and seminars.
- Providing vouchers or tokens.
- Payments and expenses.
- Donations or resources for community groups or charities.



Principles to consider when deciding on any form of recognition and reward, particularly payments and expenses:

- PPI contributors should always be offered a choice about whether they accept the recognition or reward they are offered. They may choose to be volunteers rather than accept payments or expenses. For some contributors, accepting payments may affect their social security payments or benefits. There may also be an impact on tax payments. Contributors should be advised to check any implications payments and expenses may have.
- Payments and expenses should be fair and proportionate to the activity being undertaken.
- If possible, pay expenses in advance but if not ensure prompt payment after the activity.
- Always check whether your organisation has a system and/or policy for making payments and paying expenses before offering payments. If it does not have a process be transparent with PPI contributors so they can make an informed choice about whether to get involved in your project or not.
- Where you are able to pay expenses and other payments, develop your policy and system for this at the beginning of the project.
- Cost PPI resources and expenditure into any funding proposal.

Useful information about payments and recognition of PPI can be found at:

<https://www.nihr.ac.uk/documents/centre-for-engagement-and-dissemination-recognition-payments-for-public-contributors/24979>

Costing PPI in funding proposals

Wherever possible resources for PPI should be costed and included in any funding proposals. This could include:

- The cost of support and training to enable involvement.
- Time for reading papers and documents, preparing documentation, attending meetings, working from home.
- Childcare or carer costs.
- A co-researcher undertaking interviews or focus groups.
- Attending conferences and presentations.
- Accommodation for overnight stays.
- Payments and expenses for specific activities; subsistence.
- Vouchers and tokens.
- Donations or payments to community groups or charities.



10. How do I know patient and public involvement in my research study has made a difference?

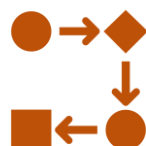
It is essential that we evaluate PPI contributions to our research to enable us to improve the quality and value of PPI and the quality of research. It is also important that we are able to feedback to contributors on the impact of their involvement. Most PPI contributors get involved because they want to make a difference and feeling valued in the process is important. We also want to avoid doing anything that may have a negative impact on PPI contributors or is potentially harmful. Evaluation might focus on the quality of the PPI, the relationships created in the research team, the process that has taken place and whether or where the PPI contribution had most impact. It might also focus on the outcomes and what difference the PPI contribution made.

You need to plan how to evaluate your PPI at the start of your project and consider how you are going to assess whether it has made a difference and what the impact has been. PPI contributors should be part of this conversation, and decisions about how success is defined, and how they would like to report on their involvement in the project.

Points to consider

Will you be trying to determine whether PPI has:

- Impacted on the research and/or the people involved.
- Improved the research process and/or the conduct of the research.
- Impacted on the outcomes of the research.
- Had short term impacts e.g. on documentation or long term impacts.
- Had positive or negative impacts or unintended impacts.



Process



Outcomes

Will the evaluation be from the perspective of the PPI contributor(s) or the research team, or look at the project as a whole?



Guide No 5: How to achieve impact with your research: planning for impact contains some useful templates for planning the impacts you are hoping to achieve.

Approaches to evaluating PPI

There are different approaches to evaluating PPI in research including:

- Pre and post project evaluation tools/questionnaires.
- Ongoing feedback/reflection after each meeting or activity.
- PPI contributor diaries and narratives of their experiences.
- Process and outcome evaluations – tools might include the use of impact logs.
- Realist evaluation – focuses on the context, mechanism, and outcome i.e. what works for whom, in what context, and how?

Decide how you and your PPI contributors will record the PPI experience. Useful tools include the Public Involvement Impact Assessment Framework (PiiAF) which is available on: www.piaf.org.uk. Stakeholder feedback is a useful tool in gathering evidence of impact and HSE Research and Development recommends the use of the VICTOR impact tool (making Visible the ImpaCT Of Research). The VICTOR pack has some useful stakeholder questionnaires that can be used to seek feedback and can be used in conjunction with this guide. You might also want to ask stakeholders for testimonials describing how they used the research, what difference PPI contributors made, and what changes took place.

Key evaluation questions to consider are:

Has our PPI achieved what we said it would achieve?
 Did PPI make a difference?
 What has worked well?
 What did not work so well?



Has the PPI led to changes in:

- the research question or methodology,
- informed or shaped the analysis,
- increased recruitment?

Was our approach to PPI the right one?
 What lessons have we learned about our approach to PPI?
 What learning has taken place as a result of the PPI contribution?
 Have we used our resources in the most effective way?
 Have there been any negative impacts for the PPI contributors, the researchers, the project?



Reporting on the impact of PPI

Having collected information on the difference or impact PPI made to the project, consideration has to be given to how that learning will be used and reported. It might be How will included in a project report, a conference presentation, or in a blog. If you are publishing a paper, you will want to think about how to include the PPI perspective. There is guidance for reporting PPI and the GRIPP2 ‘Guidance for Reporting Involvement of Patients and the Public’, a reporting tool, has been developed

to ensure consistency and quality in reporting PPI in publications (see [GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research | Research Involvement and Engagement | Full Text \(biomedcentral.com\)](#)).

Two other guides in this series contain useful information and templates:



Guide No 5: How to achieve impact with your research: planning for impact gives a useful overview of how to plan for impact and



Guide No 6: Evaluating your knowledge translation provides advice on evaluating impact.

Impact is the difference research and new knowledge makes to health care, policy, society, the economy, the environment, technology, or to education and training. It is when knowledge benefits or influences others, and we can demonstrate that has happened.

11. Good practice in PPI

There is a lot of advice available about good PPI, here are some pointers to ensure that PPI contributors have a good experience of involvement:

- Keep respect for the individual, listening, transparency and openness at the centre of involvement.
- Find out whether PPI contributors have any specific needs or circumstances to take into account to enable them to contribute.
 - Ensuring early and ongoing advice, support and training for PPI contributors where required. These needs should be assessed before and during the study and reflected upon at the end.
 - Give feedback to PPI contributors on a regular basis to ensure they feel involved and valued for their contribution.
- Make sure all written communications are in plain English.
- Provide a role description or outline for the PPI contributors or a partnership agreement for CBPR. Manage people's expectations and ensure they understand their role and how they will be asked to contribute.
 - Excellent communication is critical. As with any project communication is key and the research team and PPI contributors should agree from the outset how best to ensure this occurs.
 - Ensuring contact details are made clear and are available to PPI contributors so that if they do not feel able to discharge their roles and responsibilities, they have someone to discuss this with.
- Preparation and making sure you have the resources for any PPI is essential. Give plenty of notice of meetings and send the papers and agenda at least a week in advance. Keep copies of any papers as not everyone may have been able to print or download copies. Provide contact details so the PPI contributor can get in touch if they need to.
- Consider the times and venues for meetings and make sure they are convenient for PPI contributors. Ensure rooms are accessible for



anyone who might have access difficulties. Keep meetings to a reasonable length and have comfort breaks.

- Hold induction sessions for PPI contributors to meet the research team and other people such as fellow project team members. This is an opportunity to build confidence and relationships. Consider creating a buddying system pairing a PPI contributor with another member of the team.
- Process any payments and expenses promptly.
- Ensuring other training needs that would otherwise be provided to research staff are identified for the PPI contributors engaged in similar roles, and that they are enabled to access this training as necessary with similar support.
- Ensuring training for research leads about enabling PPI involvement.



12. Sources of information



PPI IGNITE NETWORK *PPI Ignite Network Ireland* – the PPI Ignite network is funded by the Health Research Board and Irish Research Council and aims to promote excellence and innovation in PPI. It is a partnership between 7 lead universities and national partners including IPPOSI, Research Charities, and HSE. It has a repository of information and resources. <https://ppinetwork.ie>

IPPOSI *IPPOSI* - the Irish Platform for Patient Organisations, Science, and Industry. It has a repository of resources relating to PPI in research. <https://www.ipposi.ie>



EUPATI – European Patients Academy on Therapeutic Innovation. It provides training for patients and patient representatives on the process of medicines research and development. <https://eupati.eu/>

Useful references

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