NIHR Oxford Health Biomedical Research Centre
& Oxford cognitive health Clinical Research Facility

# Introduction to Patient and Public Involvement

*For research staff, September 2018*

This document provides a short introduction to Patient and Public Involvement (PPI) for research staff, and signposts to useful sources of information.

It also outlines the support the Oxford Health Biomedical Research Centre (OH BRC) can offer to help your PPI activities.

Sections cover:

Please get in touch with the PPI Manager, Claire Murray, if you require any support in your involvement work: claire.murray@oxfordhealth.nhs.uk. Or visit the OH BRC website.

## What is Patient and Public Involvement (PPI)?

- PPI is about actively involving patients, carers and the public in the design and delivery of research and the wider work of research organisations.

- The term ‘patients and public’ includes patients, potential patients, carers and people who use health and social care services, as well as people from organisations that represent people who use services.

- INVOLVE, the NIHR national advisory group for PPI, defines public involvement in research as research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.

- Involvement in research is distinct from ‘engagement’ (where information and knowledge about research is disseminated) and ‘participation’ (where people take part in a research study).

- You can find out more about PPI at the INVOLVE website.

## Why involve patients and public in research?

The OH BRC is committed to ensuring our patients inform our research at each key step. Our vision is for PPIE to be embedded within the research themes and influence the activity of the OH BRC.

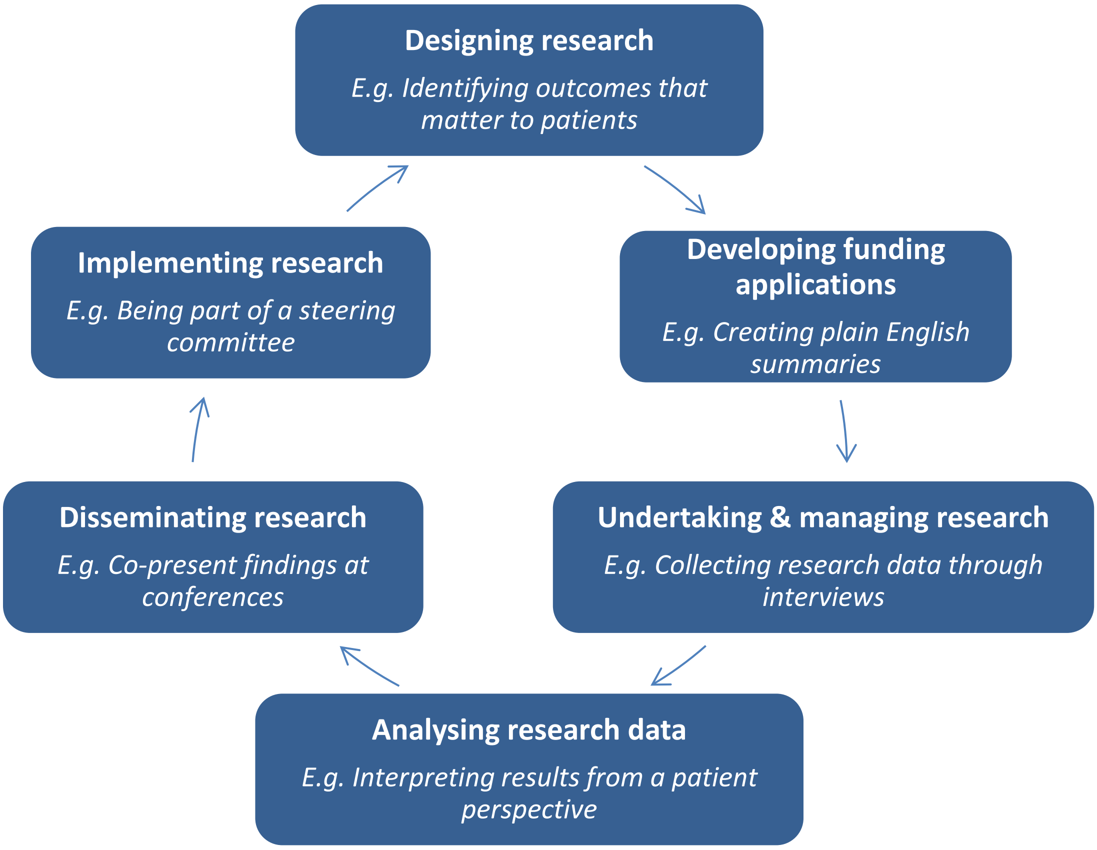
The benefits of involving patients and the public in research have been identified as including:

- Stimulate new ideas
- Fill gaps in researcher knowledge
- Challenge assumptions and help researchers reconsider what is important
- Identify and avoid potential problems in research studies
- Improve communication with participants of research studies
- Make research findings more accessible
- Enhance public knowledge about research and understanding of science
- Increase influence of research

You can find out more about the potential benefits of PPI at the INVOLVE website and in Changing what researchers ‘think and do’ *(Staley K. 2017)*

## When and how to involve patients and public in research?

PPI can take place right across the research cycle, and it is best practice to involve people as early as possible when developing research projects - so that involvement can genuinely influence the design and delivery of research.



**Designing research**

*E.g. Identifying outcomes that matter to patients*

**Developing funding applications**

*E.g. Creating plain English summaries*

**Undertaking & managing research**

*E.g. Collecting research data through interviews*

**Analysing research data**

*E.g. Interpreting results from a patient perspective*

**Disseminating research**

*E.g. Co-present findings at conferences*

**Implementing research**

*E.g. Being part of a steering committee*

Patient and Public Involvement can include a whole range of activities, and will look different depending on what is most appropriate for the individual research project.

For example, patients, carers and members of the public may work with researchers to:

- Help select research that is important
- Devise relevant research questions
- Identify outcomes that matter most to patients
- Design studies so they are easier to take part in
- Develop clear information about research studies
- Help create plain English summaries of studies

- Co-produce consent forms
- Make sure communication is sensitive and appropriate for participants
- Help collect research data, for example through interviews
- Analyse research findings from a patient perspective
- Raise awareness amongst the public of what research is taking place
- Share findings of important research
- Help make sure research is reported in understandable ways
- Be part of a research project steering group

Co-producing a research project is an approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge.

## Best practice in PPI

There are shared principles for what makes good quality PPI, and the NIHR have published National Standards for Involvement. These six standards describe what good public involvement looks like:

1. Inclusive opportunities that are accessible to your target community
2. Working together in a way that values all contributions
3. Support and learning that builds confidence and skills for public involvement
4. Plain language and two-way communication
5. Capture and share the impact of public involvement on research
6. Involve the public in leadership and governance of research organisations

## Ten tips to get you started

**1) Start early:** Give yourself time to plan properly. The most successful PPI projects are well thought through, and consider from the outset how PPI can influence your research at different stages of the research cycle, and who you might need to work with to make your PPI a success.

**2) Identify your purpose:** Start with thinking about why you are carrying out PPI, what will patients and public contributors bring to your research? Identify what difference they can make, and how they might benefit from involvement.

**3) Who are you looking for:** What experience or skills are you looking for, be specific. Think through the purpose for the PPI opportunity and what that tells you about the PPI contributors who can make the biggest difference to your research.

**4) Find your contributors:** Where are the people you are looking for spending their time? Which organisations or services are they in contact with, what activities do they take part in, or what websites do they visit? How will you communicate your involvement opportunity to encourage people to work with you?

**5) Chose the most appropriate method:** Which method is best will depend upon the point in the research cycle, the purpose of the involvement, and the group or community you are working with. Consider how to ensure your contributors are safe and supported. Often PPI is based around a focus group or research advisory group, but CLAHRC Oxford have developed a guide to Inventive Involvement which shares a wider range of tools.

**6) Think about practicalities and support:** When and where will you run your involvement? What timing and location will be most convenient for your contributors? What support or information will your contributors need to enable them to participate? How will you refund expenses and make payment for your contributor’s time? What resources or extra help will you need to deliver the PPI activities well?

**7) Communicate clearly:** Make sure you use plain language and avoid jargon when communicating with potential patient and public contributors. (The Plain English Campaign have some useful guidance.) Make sure your communication format and design is appropriate for your target audience.

**8) Keep in touch:** Feedback to your PPI contributors on how their involvement has influenced your research project. Ask whether they would be interested in hearing how the project develops and about future opportunities for involvement.

**9) Make it a two-way process:** Can you work with PPI contributors to design the involvement from the outset? Working together to develop opportunities can help build positive relationships and improve the experience of involvement.

**10) Make time to evaluate:** After your PPI activities are complete, reflect on how well they delivered on the purpose you identified. What went well and what could have been improved? Ask your contributors about their experiences of being involved.

## How can OH BRC and CRF support your PPI?

- Claire Murray is the Patient and Public Involvement Manager for the OH BRC and CRF. She can advise on the design of PPI activities, support their delivery and help you share your PPI opportunity with potential contributors. She manages the Patients and Research Group, and supports a network of patients, carers and the public who are interested in PPI in mental health and dementia research. Claire.murray@oxfordhealth.nhs.uk

- The PPI pages of the OH BRC website list some useful resources for researchers.

- The OH BRC has published a Patient and Public Involvement and Engagement Strategy, which sets out our vision to embed PPI into BRC research and future development.

- We have also produced a short animated film to outline what PPI is, and why patient, carer and public involvement in mental health and dementia research is important.

- Oxford Health BRC partners with the Oxford BRC, South Central Research Design Service and Oxford CLAHRC to deliver monthly PPI Q&A sessions. Information on dates and venues are posted on the OH BRC website .

If there are other resources or support that would be helpful please let us know by emailing Claire.murray@oxfordhealth.nhs.uk .

## OH BRC and CRF Payment Policy

- Patients, carers and members of the public should never be out of pocket as a result of being involved in research, and expenses should always be reimbursed.

- Just as the researchers, doctors or other professionals who work here are paid, so we offer involved patients, carers and members of the public payment for their time spent on these tasks. This is distinct from reimbursement of expenses. Not all PPI contributors wish to accept payment for PPI, but the offer should always be made. We encourage you to budget for this as soon as possible.

- A payment policy has been developed and published on the website, to guide the remuneration of PPI at the Oxford Health BRC and Oxford cognitive health CRF, in keeping with INVOLVE guidance.

## Useful Links

- **INVOLVE Briefing notes**
  Ten briefing notes for researchers giving information on how to involve members of the public in research. www.invo.org.uk

- **NIHR Research Design Service**
  The Research Design Service publish a useful Patient and Public Involvement Handbook. www.nihr.ac.uk

- **CLAHRC Oxford PPI Resources**
  CLAHRC have a great range of resources including a PPI Guide (which includes templates for advertising PPI opportunities, role descriptions and more) and an Inventive Involvement guide with information on lots of different methods for involvement. www.clahrc-oxford.nihr.ac.uk

- **NIHR Imperial Biomedical Research Centre PPI Hub**
  Imperial BRC have developed an online collection of PPI resources, structured around the key steps in patient and public involvement. www.imperial.ac.uk

- **INVOLVE Guidance on co-producing a research project**
  This guide explains key principles and features of co-producing a research project. www.invo.org.uk

*Thank you to the members of the* OH BRC Patient and Research Group *and the research staff who contributed to the development of this resource.*