

Patient and Public Involvement (PPI)

Quick guide for Researchers and Healthcare Innovators

1 Identify the purpose of PPI

Be clear: why is PPI essential to your research? This shapes the approach and evaluation methods.

Key reasons to involve Patients and the Public may include:

- Improve the relevance of project aims
- Help strengthen applications when seeking funding
- Improve the quality and value of a research study or service design project
- Increase participant recruitment and retention
- Increase the impact of your project
- Deliver real-world impact aligned with real needs

2 Start early in the process

Start PPI activities at the early planning phase, so you can receive meaningful contributions.

Helpful actions to take include:

- Set research questions and objectives with PPI contributors
- Decide what to involve patients/public in and why. e.g. Co-applicants in grant development; Co-design patient facing documents
- Clearly define and share roles, time commitment, and expectations
- Make room for ideas from patients to develop along the way as the team learn together
- Check early whether you need additional ethical approvals, especially if sensitive information is included.

3 Recruit and support PPI contributors

Things to keep in mind:

- See patients' real life experience as valuable expertise
- Approach those who are seldom heard, less reached, or ignored
- Be respectful and inclusive: recognise all voices as valid
- Offer appropriate payment and reimbursement for time and expenses
- Ensure accessibility in meetings, documents, and events (language, format, location, timing)
- Create safe spaces for open discussion and feedback
- Ensure confidentiality and follow your organisations guidelines for safeguarding and privacy



4 Involve throughout the research

Effective involvement means contributing at multiple phases, not just consultation at the beginning.

Where to embed PPI:

- Project start: Discuss project rationale with PPI contributors, they will identify challenges and solutions you haven't thought of
- Protocol and study design
- Data analysis and interpretation
- Sharing results with the public
- Implementation of research findings
- Evaluation of research and PPI

What works well:

- Hold regular meetings or virtual check-ins
- Document contributions to recognise impact

5 Communicate early and consistently

Trust is earned through consistent and open engagement.

Recommended actions:

- Use plain language and avoid technical jargon
- Keep PPI contributors updated on decisions, changes, and progress
- Be open to feedback and explain how patient input shaped the project
- Value time spent understanding one another

6 Monitor and evaluate

Evaluation is essential to understanding the impact and demonstrating the value of PPI.

How to evaluate PPI:

- Use formal tools
- Collect constructive feedback from PPI contributors
- Share what worked and what didn't