Patient and Public Involvement section – ResearchFish reporting questions

Section Guidance Text

Patient and public involvement (PPI) is where research is carried out 'with' or 'by' members of the public, rather than 'to', 'about' or 'for' them. When patients and members of the public get involved in research, they are partners alongside researchers, shaping what research takes place, how it is carried out, and how the results are shared and applied in practice.

PPI is important and possible in all research. This includes research in laboratories, communities and research into health and social care. Excellent involvement is inclusive, values all contributions, ensures people have a meaningful say in what happens and influences outcomes. This is set out in detail in the UK Standards for Public Involvement.

PPI is different from:

- **Engagement**, where research and people connect, breaking down barriers and sharing information, for example, through open days or sharing a blog on social media.
- **Participation**, where people take part in a study as participants, for example, completing a survey or being part of a clinical trial.

In this section, we would like you to share information on your PPI for this research award, how people have been involved (if they have), the challenges, and the impact this has had on your research.

As an organisation that funds and/or manages research, we are committed to improving the extent and quality of public involvement across the sector so that it is consistently excellent. As such, we would like to understand and report on the impact that involving people with lived experience has on our research. It is well documented that research involving individuals with relevant lived experience will be more relevant, acceptable and better communicated (Health Research Authority – Impact of Public Involvement). We want to continue to build the evidence base for PPI, showing it as a key element to any research project, and to creating equitable and impactful real-world changes through research.

We will use your answers to this section to help us tell this story and share best practice examples. We will also use this to build a picture of the barriers and challenges you collectively face and to explore the role research funding and management organisations play in addressing those.

In addition, these questions provide you and the people you've worked with a space for reflection, to think about and capture the impact of involvement in your work, and an opportunity to go on to strengthen and improve it.

Questions

Q1: Have you actively involved patients and/or members of the public in your research?

A1: Mandatory, single selection

- *Yes
- **No

**Q2 [Only for those answering No to Q1] Please explain why you have not actively involved patients and/or members of the public in your research?

A2: Mandatory, single selection

- The funder has agreed that PPI is not required for this award
- The funding is for non-PPI-related research support, e.g., office or equipment costs.
- PPI has not yet started, or is scheduled for later in the award
- Efforts to engage patients and/or members of the public have been unsuccessful so far
- I/we didn't have the time, skills, or money to involve the public
- Other [free text]

*Q3 [Only for those answering Yes to Q1]: How have patients and the public been actively involved in your research? (Please indicate all that apply)

A3: Mandatory, multiple selection, checklist

- Identifying and prioritising the research question(s), e.g., talking to patients and the public to explore issues/needs and developing a research question together around that topic
- Developing an application for funding or ethics review, e.g., having a PPI member as a co-applicant and contributing to a review panel or agreeing on the PPI plan for the future
- Design of the research, e.g., defining the outcome measures or agreeing on a recruitment strategy
- Management of the research, e.g., part of a committee that makes key decisions
- Undertaking the research, e.g., carrying out interviews or co-facilitating groups
- Analysing and interpreting the data, e.g., reviewing the data, helping identify conclusions
- Writing up of the research, e.g., co-authoring papers or helping with lay summaries
- Dissemination of outputs, including research findings, e.g., co-presenting or designing the communications plan

- Implementing research findings or recommendations to change policy and practice, e.g., sharing and advocating for findings with key stakeholders, or sharing involvement practice
- Developing future applications or research

Q4: What have been the most significant challenges of involving patients and the public in your research? (Please indicate all that apply)

A4: Mandatory, multiple selection, checklist

- No challenges
- Maintaining relationships and continuity over time
- Building on initial engagements and progressing this to involvement
- I/we do not have the skills or training to work with patients and the public
- I/we do not have the knowledge of the condition and its impact to enable us to build flexible and inclusive opportunities to get involved
- The nature of the condition can affect people's ability to be involved
- Training and support for patients and the public
- Time constraints
- Lack of financial resources
- Accessing enough people who reflect the group that may benefit from the research
- Practical and logistical, e.g., venue, accessibility, or meeting times

Q5: What kind of impact has patient and public involvement made to your research?

A5: Mandatory, multiple selection

- ***It has had a positive impact on my research (please explain more below)
- It has had no impact on my research (please explain more below)
- It has had a negative impact on my research (please explain more below)

Q6. ***[Only for those answering positive to Q5] What positive impact has patient and public involvement made to date? (Please indicate all that apply)

A6: Mandatory, multiple selection, checklist

- Our team's knowledge of needs, barriers and challenges has increased
- It has been rewarding and motivating for the team
- Our research is more focused on actual needs and experiences

- We have been more effective in recruiting participants for research (as opposed to involving people)
- We have better relationships with communities/groups we struggled to engage with or recruit from
- Research results and outcomes are more relevant and meaningful
- Our communications have improved
- We have been better able to influence policy and practice
- Successfully being awarded relevant follow-up funding

Q7: Please summarise, in under 500 words, how patients and the public have been involved, the challenges, and the impact this has had on your research.

A7: Mandatory, Free text