Reviewer Recommendations

How to plan, do and report patient and public involvement in research

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"Nothing about us without us"
Attributed to Masutha and Rowland [1].

All health research ultimately aims to help the recipients of healthcare: patients, carers and the public. To maintain focus on meeting this aim, these parties should be represented throughout the research process. Patient and public involvement (PPI) is distinct from engagement or participation (Box 1) [2]; it refers to working in partnership with patients and members of the public to conceive, plan, design, manage, conduct and report research. A summary definition proposed by the National Institute for Health and Care Research (NIHR) states that PPI is "*research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them*" [3]. Within this context, the contribution of patients, carers and the public are equal in value to those of clinicians and researchers.

As part of the 'Reviewer Recommendations' series, we draw on our experiences of research – as patient and public representatives (AP and JH) and clinician-researchers (LS and CS) – to suggest how to make PPI meaningful, authentic and beneficial to all parties. We will discuss how to describe PPI in research papers, and direct readers to resources designed to optimise the conduct and reporting of this important element of healthcare research.

Why involve patients and the public in research?

Fundamentally, PPI is important because it makes research better! We consider this to be for two main reasons: first, it helps to ensure that the work focuses on issues that matter to the 'end users' of research [4]; and second, it helps to ensure that the work isn't problematic or burdensome for participants [5]. Lived experience can have an important role in PPI, as many researchers will not have direct experience of the topic of interest. Although researchers may be experts on their scientific specialism, without lived experience they cannot be fully aware of the context in which their proposed research will be conducted from the perspective of potential participants. Patient and public involvement helps to fill this gap in awareness. Beyond the direct benefits to the research project, there is also potential for PPI to benefit patient and public representatives themselves, for example through empowerment, recognition of expertise and the opportunity to form links with people who have undergone similar experiences [6].

What do patient and public representatives do in research?

The contributions of PPI representatives in research include (but are not limited to): generating research questions; providing feedback on the acceptability of proposed research; study co-design; producing or editing patient-facing materials and plain language summaries; representing patients and the public in research management and governance; collecting and analysing data; and contributing to dissemination, particularly when targeted at patients and the public (Fig. 1). Whilst some of these roles do not require specialised training or knowledge, this can be beneficial for more technical tasks. There are two potential approaches to this: one is to provide training to develop the required skills; the other is to recruit PPI representatives who have prior relevant experience (e.g. someone with previous experience of communications may be ideally suited to a role as a PPI representative in dissemination). Both approaches are acceptable but researchers should be mindful of the potential to reinforce existing hierarchies and health inequalities if only prior experience is relied upon, and training should be provided where needed. The Learning for Involvement website (https://www.learningforinvolvement.org.uk) is a useful resource which provides links to relevant online courses for PPI.

When and how should patients and the public be involved in research?

In recent years there have been concerted efforts to move PPI from what Jackson et al. describe as "*tokenistic box ticking*" (perhaps motivated by a desire to appease funders and ethics committees), towards "*valued team member(ship)*" [7,8]. Achieving this requires working in partnership with patients and the public, rather than simply consulting them when it suits the researchers. One way to achieve this is to integrate patient or public co-investigators as part of the research team from the earliest possible opportunity [9,10]. However, public or patient co-investigators are unlikely to be able to represent a fully diverse range of experiences and viewpoints, so they are often supported by a broader PPI group convened for the purpose of the project. Patient and public co-investigators may be recruited by the study team or be the (co)originators of the research idea. Sharing the 'ownership' of research between researchers and patients and/or members of the public – from start to finish – is known as co-production and is characterised by a flattening of the traditional research hierarchy [11].

Seeking broad patient and public opinions can be challenging at the very earliest stages of a project, (i.e. before a patient co-investigator or PPI group have been recruited). There is a valuable role here for 'standing' PPI groups that can provide feedback on research ideas, such as the National Institute for Academic Anaesthesia - Health Services Research Centre Patient, Carer and Public Involvement and Engagement (PCPIE) group in the UK (https://www.niaa-hsrc.org.uk/PCPIE). Some research funders provide financial support for convening temporary PPI groups to comment on proposed applications to their programmes. The NIHR Research Design Service in the UK is an example of where this can happen. When developing a research question, researchers should make themselves aware of wider research priorities developed from the perspectives of patients, carers, the public and clinicians, such as those produced in partnership with the James Lind Alliance (https://www.jla.nihr.ac.uk).

When researchers seek to obtain data from participants who are patients, carers or members of the public [2], participant-facing materials including consent forms, participant information sheets and surveys should be reviewed by PPI groups. This can help to optimise the phrasing and presentation of such documents to make sure that they are accessible to the intended study population. The timing, conduct and content of participant contacts such as gaining consent or interviewing, should also be considered in partnership with PPI groups to promote acceptability. This is arguably of particular importance for clinical research in anaesthesia, critical care and peri-operative medicine which all take place around the time of major life events for patients. A recent example of this approach was reported in the study by Ratcliffe et al. of recovery from surgery, where data were obtained using wrist-worn accelerometers [12]. A PPI group was surveyed to determine the preferred type of accelerometer device, as well as the acceptability of study contacts and likely familiarity with similar technologies.

Many major research funders now expect evidence of robust PPI in funding applications and will usually include an area to describe the role of PPI (or justification of the lack thereof) on application forms. This should describe how patients, carers and the public have shaped the proposed project to date and explain how PPI will continue should the research receive funding. Although it is not usually required that investigators work with patient or public co-applicants when applying for funding, this is likely to benefit the application, particularly when specific roles and responsibilities relevant to the patient or public co-applicants’ expertise are defined clearly [10].

Patients and the public may be involved in the management and/or oversight of research and the generation and analysis of data. This may be particularly valuable in qualitative or mixed-methods research, where the perspective of the researcher is integral to the analytical process [13]. Including a patient or public perspective may expand the scope of the analysis, as in the ethnographic study of decision-making around admission to intensive care by Griffiths et al.. In this work, members of a patient and public advisory group, some of whom had lived experience of critical illness, helped to develop the analysis of interview transcripts [14].

Dissemination is aided by PPI, particularly when producing materials intended for a patient or public audience. Patient or public co-authors can enhance both the credibility and accessibility of resources. Patient and public co-investigators and collaborators should be afforded the same opportunities to be recognised as co-authors of academic reports as any other colleague, as per the International Committee of Medical Journal Editors guidance [15]. Where authorship is not appropriate or not desired, contributions should be acknowledged as per journal guidelines [16,17].

How to recruit patients and the public for involvement in research

The approach to recruitment in PPI should be inclusive and informed by the task at hand. For example, if a research project intends to investigate the effect of ethnicity on access to obstetric anaesthesia clinics, specific attention should be paid to recruiting individuals with lived experience of maternity care and promoting ethnic diversity among the PPI group. More broadly, measures should be taken to ensure that PPI is inclusive and representative [18]. This may involve, for example, arranging reimbursement for out-of-pocket expenses and time; in the UK there are standard rates specified by the NIHR [19]. A broad range of media can be used to advertise opportunities for PPI, although there is an inherent risk of digital exclusion which must be considered. Where there are challenges in recruitment, it can be beneficial to work with relevant charities or community groups. Whilst directly approaching patients can be successful, researchers should be mindful of the risk of coercion or exploitation. The recording and reporting of characteristics such as sex, age, ethnicity and socio-economic factors among PPI groups (with appropriate data protection in place) may promote accountability among the study team and provide a basis for representative recruitment [18,20].

How to support patient and public involvement

Sustaining meaningful PPI within a project requires the provision of an appropriate level of support to ensure that participation is not burdensome or exploitative. The precise level of support should be tailored to both the individual and the project. Research teams should plan to invest time in nurturing relationships giving the correct level of support. Recruiting the right PPI members can be a time-intensive process, particularly when this involves engaging with underserved or seldom-heard groups [21].

Perhaps the most basic support measure is to ensure that PPI participants have the time to undertake their work and are not financially disadvantaged by doing so. To this end, the time spent on PPI should be considered in advance and reimbursements costed into the research funding proposal [19]. This should include preparatory work (e.g. reading papers) as well as attending meetings or undertaking research tasks. The location and timing of meetings should be planned to accommodate any other commitments of PPI group members, for example employment or childcare duties. Online meetings may be a helpful approach, but appropriate resources and internet access should be provided if required.

Research teams should foster a supportive working environment, and PPI members of the research team need to feel not only comfortable but empowered to speak about their experience and/or views. Measures to enable this may include: providing training on relevant aspects of the research topic or methods; ensuring that concepts are clearly presented to PPI representatives using appropriate language; and assigning a lead individual to act as an advocate for members of PPI groups. These provisions may help to mitigate the hierarchies inherent in academic work.

How to describe PPI in a research report

Whilst the author guidelines of some journals prompt authors to describe how patients or members of the public were involved in the production of an article, this is not universal. However, as with any other aspect of scientific reporting, the aim should be for readers to be able to understand what was done and why, gaining a clear understanding of the results and their interpretation. This includes how PPI influenced the study [11,6] and how involvement in the study impacted on the PPI group [6]. This may be integrated into the methods, results or discussion as appropriate.

The revised Guidelines for Reporting the Involvement of Patients and the Public (GRIPP2) checklists provide advice for the comprehensive reporting of PPI [22]. The long form of GRIPP2 is intended for use when PPI is the main subject of an article; the short form is used for reporting PPI as one component of a broader study. The components of the short form are shown in Table 1.

Social, online, print and other media have an increasingly prominent role in research dissemination and impact. Reporting PPI is just as important in these outputs as in traditional journal articles. However, because brevity is usually a requirement in such media, descriptions of PPI will be necessarily concise. Here, input from the PPI group is invaluable in gauging what are the most important aspects of the PPI process to report.

In conclusion, patient and public involvement have an important and increasing role in all aspects of research from conception to dissemination. The PPI groups should be inclusive and representative, with clearly defined and focused roles alongside measures to ensure that the voices of PPI participants are heard in the research process. Patients and the public possess a type of expertise not readily accessible to clinicians and researchers. A positive PPI process makes the best of this valuable resource and is beneficial for all involved.

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Box 1. Definitions of involvement, engagement, and participation (adapted from [2]).

Involvement

'Where members of the public are actively involved in research projects and in research organisations', e.g. as research co-applicants.

Engagement

'Where information and knowledge about research is provided and disseminated [to the public]', e.g. through television programmes, newspapers or social media

Participation

'Where people take part in a research study', e.g. by being recruited to a study to take part in the research.

Table 1. The short form of the revised Guidelines for Reporting the Involvement of Patients and the Public (GRIPP2) (adapted from [22]).

Component	**Description**
Aim	State the aims of PPI in the study
Methods	Describe the methods used for PPI in the study
Results/outcomes	Present the results of PPI in the study, including both positive and negative outcomes
Discussion and conclusions	Comment on the extent to which PPI influenced the study overall, including positive and negative effects
Reflections/critical perspective	Comment critically on the PPI for the study, reflecting on things that went well and those that did not, so others can learn from this experience

PPI, patient and public involvement.

Figure Legend.

Figure 1. Key roles for patient and public involvement in the research process. PPI, patient and public involvement; PSP, priority setting partnership.