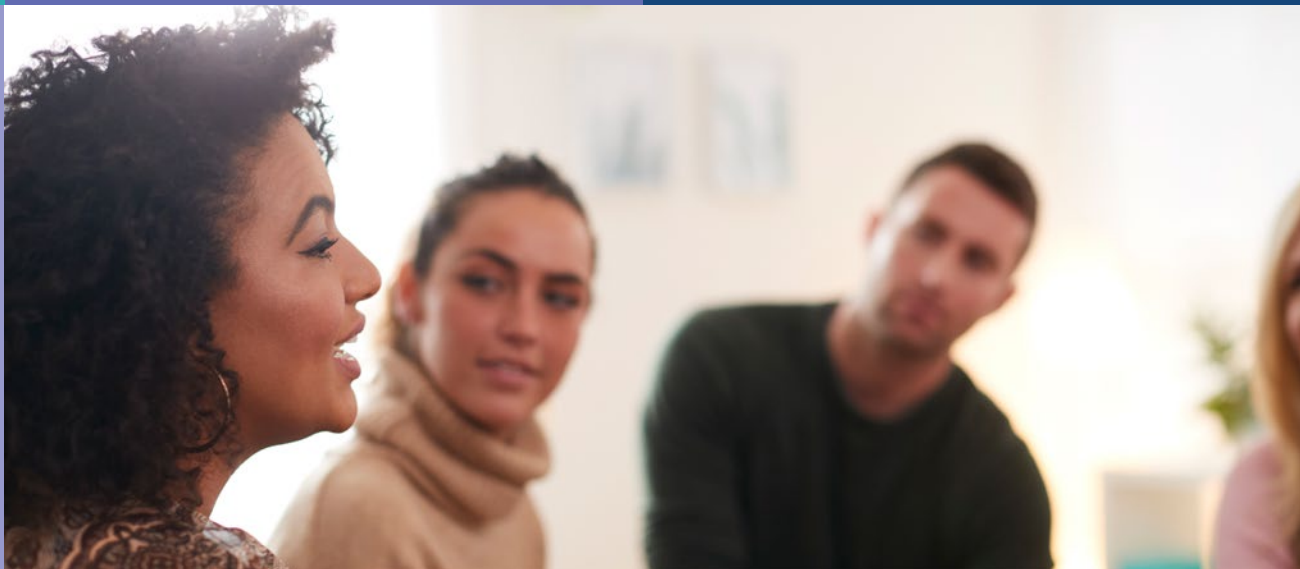
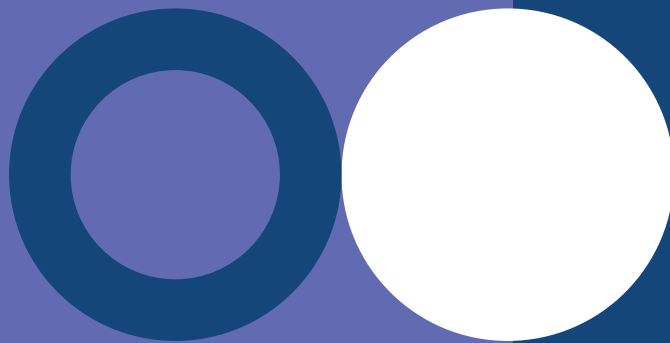


A brief guide to patient and public involvement and qualitative methods within health and social care research



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Introduction

There are similarities in both the ways patient and public involvement (PPI) and qualitative research activities are conducted, and the language used to describe them. Because of this, the distinction between the two can sometimes be blurred. These similarities can cause confusion for those writing grant applications and for those reviewing them.

This guide aims to:

- describe how PPI and qualitative research methods can support the development of health and social care grant applications
- outline some key differences between a qualitative focus group and a PPI workshop, whether delivered face to face or online
- suggest how PPI activities and qualitative research might be written into grant applications to demonstrate embedded PPI and collaborative research

This document does not set out to describe how to 'do' PPI or qualitative research, nor to cover all instances where the public can contribute to research. RDS advisers can provide specific and in-depth support for the development and conduct of PPI and qualitative activities in research applications.

What is Patient and Public Involvement and what is qualitative research?

Patient and Public Involvement (PPI)

PPI is the inclusion of patients and non-patients (potential patients, carers, supporters, people who use health and social care services, the general public) in designing, prioritising, conducting and disseminating health and social care research.

The NIHR defines public involvement in research as “Research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them”

We refer to people in this role as public contributors. They bring their personal knowledge, skills, and life experiences to help develop and support research. Public contributors should be seen as equal partners in any conversations or decision-making around research, bringing their unique experiences and perspectives to complement and enhance academic and clinical expertise. This is a very different role to being a research participant where patients and members of the public provide informed consent to test or trial a new treatment or therapy.

PPI should not be a confirmatory exercise aimed at getting a quote to support a grant application, but an integral part of all NIHR funded research. As such, funding panels expect to see active and meaningful PPI both in the development of almost all grant applications and written into the conduct of that research once funded.

The anticipated benefits of PPI are:

- To make the process and outcomes of research more relevant to the needs and preferences of patients and the public
- To contribute to a reduction in avoidable waste in research – that is, research that does not have a trajectory towards “real world” improvements in disease or health outcomes
- To improve the quality of research, for example, ensuring that the role of those people taking part in the research is clearly explained, the burden for these participants is reasonable, and recruitment strategies are effective
- To ensure research outcomes are accessible, acceptable and appropriate for those intended to benefit from them

Patients and the wider public can be involved – or become involved – at any stage in the research process (see Table 1 for suggestions). Figure 1 provides a more detailed illustration of how research and PPI activities interface throughout the life cycle of a research project.

Table 1: Public involvement in health and social care research

Public involvement in health and social care research
Deciding on and developing research questions that are important to patients and the public
Exploring ethical issues around the proposed research: <ul style="list-style-type: none">- Are the inclusion/exclusion criteria appropriate?- How might prospective participants be approached and recruited?- Is the overall burden of the research appropriate?- Are there aspects of the research that might cause distress and how might these be mitigated?
Contributing to the governance of research (membership of management or steering groups)
Contributing to the writing of any patient facing documentation including information sheets and informed consent forms
Contributing to the development of topic guides or interview schedules for qualitative focus groups or interviews
Contributing to data collection (e.g., co-facilitating qualitative research focus groups)
Contributing a perspective to qualitative data analysis (e.g., development of themes, sense checking, identifying and mitigating research bias)
Helping to develop and plan stakeholder events
Collaborating with researchers to review and disseminate the findings of research to academic and non-academic audiences

Qualitative research in applied health and social care research

In applied health and social care research, it is essential to understand the experiences and beliefs of the patients, carers, the wider public, health professionals and those involved in conducting the study. Broadly, qualitative research refers to a wide range of methodologies which seek to address questions relating to “why?”, “how?” and, “for whom?” Qualitative research aims to “study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them” (Denzin and Lincoln 1994, p2).

Particularly relevant to applied healthcare research, qualitative methods can help to develop a better understanding or explanation of lived experience, perhaps for example, exploring the beliefs, attitudes, or knowledge of patients or health professionals regarding a particular phenomenon or issue. It can be used to explain why or how quantitative investigations may have observed particular findings, for example,

- within clinical trials,
- in process evaluations,
- in intervention development and feasibility studies. Table 2 contains some examples of when and why qualitative research is undertaken.

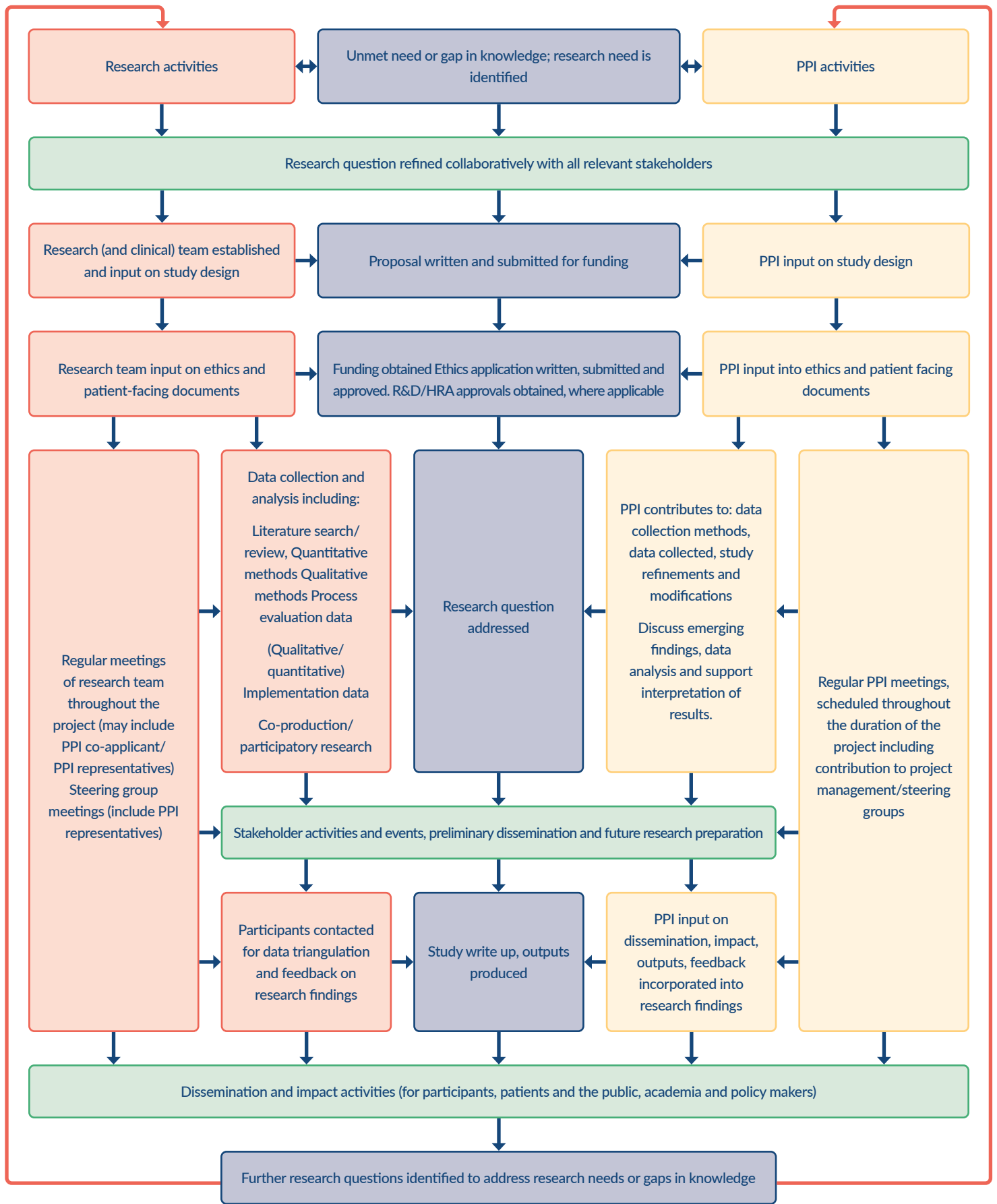


Figure 1: Illustration of how research activities and patient and public involvement (PPI) interface throughout the research process

Table 2: Qualitative methods in health and social care research

Qualitative methods in health and social care research
Understanding patients' lived experience of a particular health condition
Exploring health professionals' views of providing or delivering a treatment (e.g., training needs, challenges, barriers and opportunities to intervention delivery, motivation, opportunity and capability)
Co-design of research, intervention, treatment or service (e.g., Participatory Action Research, consensus-based research activities). Can include co-design of methods and outcomes
Exploring the views of patients and carers (or other service users) of an intervention content and/or its delivery
Developing a clearer, more rounded understanding of trial findings as part of a process evaluation
Understanding patient, public and other stakeholders' experiences of taking part in a clinical trial, including perceptions of being assigned to different treatment groups, and why patients withdraw or discontinue treatment
Exploring health professionals' or researchers' views of being part of a trial, service delivery or other research investigation

Comparing and contrasting PPI and qualitative research activities

There are similarities in the ways some PPI and qualitative research activities are carried out and both aim to develop a fuller understanding of issues relevant to the topic of investigation from a patient or public perspective. However, the intent of these activities is always different.

PPI addresses issues and uncertainties about the research through the involvement of the public. In this way PPI aims to improve the design and conduct of research rather than providing data to answer research questions.

Applied health or social care qualitative research addresses research questions through the collection and formal analysis of non-numerical data from participants using predefined methodology.

In practice, what differentiates a PPI workshop from a qualitative research focus group may sometimes be unclear. Table 3 summarises key characteristics of both activities.

Formal ethical approval is not required for PPI activities as public contributors are actively involved in decision making around research. However, [UK Standards for Public Involvement](#) provide a framework to encourage researchers into approaches and behaviours that reflect good practice in public involvement. On the other hand, all primary research with human participants, whatever the methodological approach, requires formal ethical review and approval.

The outcomes of PPI interactions often contribute to decision making in “real time” as the result of conversations in which researcher, clinician and public perspectives are concurrently and equally considered. Outputs from PPI workshops are usually captured via informal means for example via flip charts or comments written on sticky notes. PPI workshops may be recorded but agreement for this must be obtained from all taking part, ideally **before** arrival at the event. The recording is not transcribed, nor the content formally analysed, but kept only briefly as a reminder of the meeting before being deleted. Quotes from PPI workshops may be used in research applications but only with the permission of the public contributor.

In qualitative research, participants are provided with detailed information about the study and given the opportunity to ask questions about the research and what is involved in taking part. Subsequently, informed consent is obtained, and researchers ensure that participants have a clear understanding of their right to withdraw from the study at any time. Qualitative data are (in the majority of cases) recorded, transcribed verbatim, and analysed systematically, for example using a thematic, phenomenological or grounded theory approach. The method of analysis, along with the sampling strategy (selection of participants), methods of deciding when to cease data collection, data management, processing and synthesis are all described in a research protocol that has been ethically approved.

“Consensus-based” research is often considered a ‘grey’ area where qualitative and PPI activities are often confused. Similarly, qualitative investigations may employ an “emergent design” or “nominal group” techniques. However, these would still be considered to be research rather than PPI, and the methodology would be described in a protocol and subject to ethical review. Data which are collected may subsequently be used in publications. PPI is still required to complement these forms of qualitative research to inform the preparation for, and conduct of, these events - how and where an event should take place, who should be involved and so on.

Table 3: Key characteristics of a qualitative focus group and a PPI workshop

	Qualitative focus group	PPI workshop
Intent	To address research questions through the collection and analysis of non-numerical data	To inform the research: question, design or process
Aim or purpose of the activity	<p>To address a previously established (by the research team and PPI) initial research question</p> <p>The purpose or aim may be theory generation or theory building; inductive (data driven) or deductive (theory driven), confirmatory or exploratory</p>	<p>To enable research to be informed by a public perspective</p> <p>Researcher aims to get a better fit of research to the needs of end-users through collaborative solutions to the design and conduct of research</p>
Ethics	Ethical approval is required (e.g., via Health Research Authority or University Ethics Committee)	Ethical review is not required as participants are informing the research not providing research data. Good practice should be followed as indicated by the UK Standards for Public Involvement
Recruitment/ participants	Participants recruited according to research protocol (e.g., maximum variation, pragmatic)	<p>Often opportunistic. Public contributors are volunteers with relevant lived experience (patients, carers, supporters etc.) recruited via flyers, advertisements or personal approach. Patient support groups or condition-specific charities may be approached</p> <p>Researchers should consider inclusivity and diversity in their recruitment</p>
Payment	Research participants are reimbursed for travel and other costs incurred and may be offered a small “thank you” payment, depending on ethical and other considerations	Public contributors are paid for their time at appropriate rates. Depending on the host institution this may be an hourly rate or lump sum “thank you” payment) plus out of pocket expenses e.g., travel, carer cover or childcare
Who are participants/ contributors representing?	Participants speak about their own experiences but may also speak about the experiences of others or on behalf of a group they feel they represent	
Who sets the agenda/ content of the meeting	Agenda (topic guide for the focus group) addresses research question and usually set by research team including PPI input. There should be opportunity to follow up and explore issues raised by participants which may not have been previously anticipated by the researchers	Agenda should be decided on by both researcher and public contributors or, if not, then flexible enough to allow for public-led items or a change of direction
Conduct	<p>Engaging with either research participants or public contributors must adhere to standardised guidelines including General Data Protection Regulation (GDPR), Chatham House Rule1</p> <p>Public contributors often agree informal terms of reference at the outset of a workshop/series of meetings</p>	

	Qualitative focus group	PPI workshop
How data/workshop outcomes are collected	Conversations are audio recorded and transcribed, anonymised and securely stored and managed according to university, ethical and legal requirements.	Public contributors' lived/life experiences contribute to the co-design of solutions to research issues and questions. PPI often contributes to decision making in "real time". Researcher, clinician and public perspectives are concurrently and equally considered through discussion and sharing of ideas. No research data are collected Outputs are captured via informal means, often flipcharts, sticky notes, meeting notes etc. Workshop may be audio recorded with prior consent of all participants but only as a memory aid not for analysis
Outputs	Data are analysed formally by the research team using a predefined qualitative approach Subsequent outputs (e.g., peer reviewed journals) will be developed and agreed by research team including PPI, and usually include supporting verbatim quotes	Output may be agreement on a way of working, suggestions for improvement to research idea, changes to documents and processes and sense-checking/ interpretation of results etc. Summaries of what is said during workshops may be used to illustrate what conclusions were arrived at, or new information disclosed in order to blend PPI into a grant application
Potential bias resulting from the influence of the researcher	Researchers reflect and report on the possible influence of their own views, perceptions and/or backgrounds may have on biasing the research findings. Reflection is part of the analysis process	Consideration of bias is not part of a formal process but researchers should be aware of creating an environment that enables a reciprocal exchange of ideas
Generalisability	Findings should be trustworthy and may be generalizable	Outcomes of PPI workshops are not expected to be generalizable
Creating a safe environment	Participants and contributors may talk about painful experiences and appropriate provision should be put in place for supporting people after the end of the meeting. It is also necessary to ensure provisions are made for the support of researchers' wellbeing. For example, practical field working procedures should be in place alongside supervision, debriefing opportunities, and team meetings	

Writing about PPI and qualitative research in your grant application

Using appropriate language when writing about PPI and qualitative research will help convince the funding committee that you are aware of the differences between the two and that you are committed to collaborating with patients as partners with valuable experiential knowledge. It is also worth noting that public engagement, participation and involvement do have distinct meanings when describing how patients and the public interface with science and research.

- **Engagement:** Whilst there may be some opportunities for discussion, public engagement refers to activities where researchers and scientists disseminate the results of their research. Engagement also covers activities where researchers and members of the public come together to find out more about research, perhaps with the purpose of supporting and encouraging future participation or involvement
- **Participation:** Patients and members of the public provide informed consent to trial a new treatment or therapy
- **Involvement:** Public contributors are active partners in designing and doing research

Writing about PPI in the development of your proposal

Applications to NIHR funding streams are often made via the Standard Application Form. Guidance on completing this form has been extensively updated to include much more detail around the expectations for PPI in research proposals at both stage 1 and stage 2. RDS SW has produced a downloadable checklist for researchers based upon this guidance around PPI ([link to our website](#)).

The funding committee will be looking for:

- Active and meaningful PPI in the development of your proposal
- Clear, detailed and realistic plans of who, where and how you will involve public contributors throughout your research

"We invited public contributors to comment on our research plans"

"We consulted with patients to find out their views on our research proposal"

"In the development of our application we engaged with a group of patients with lived experience..."

Regardless of whether the activities that resulted in the above comments were "active and meaningful" PPI, the way they are referred to sounds more consultative (possibly tokenistic) than collaborative. They might be taken by reviewers to suggest that researchers were "checking out" their intentions with public contributors rather than allowing them to be part of a conversation in which their suggestions and comments helped shape or inform the research. It would be better to write:

"We involved public contributors in a workshop to help us think through our patient pathway..."

"Our collaborations with patients in the design of this study changed our thinking..."

"Conversations with a range of public contributors enabled us to refine..."

It is also important to **reflect on how your involvement of public contributors has impacted on the design of your research already**, for example "During our involvement activities, our outcome measures were updated to include the EQ5D, as patients felt the intervention would have an impact on quality of life that was important to measure"

Using similar language will help convince the funding committee that you intend to involve public contributors in an appropriate way throughout your research (see table 1). You may wish to refer to running "workshops" (not focus groups) with members of a "public advisory group", or having regular "public contributor members of project management/steering group meetings".

The NIHR Standard Application Form (SAF) guidance provides further details on committee expectations around PPI in submitted applications ([see for example](#)).

Writing about qualitative research in your grant application

The term 'Qualitative research' refers to a very diverse and complex range of methodologies, philosophies and analytical approaches. A discussion of theoretical approaches and qualitative paradigms (consisting of the ontological, epistemological and methodological underpinnings) or "basic set of beliefs that guides action" (Guba, 1990, P 17) is beyond the scope of this guide. When developing a funding application, the chosen methodology and procedures will be most appropriate to address the research question with the available resources. Using reporting standards to guide initial thinking and grant application may be helpful. For example the Consolidated Criteria for Reporting Qualitative Research (COREQ) is designed to ensure the reporting of research submitted for publication meets particular criteria (Tong et al., 2007). However, considering each of the items in the planning stage can be helpful to ensure proposed research is adequately detailed and may indicate at the outset any potential ethical or procedural issues which could later cause problems in conducting the research.

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Further information

For further information about the Research Design Service or to book a consultation with a PPI or qualitative research adviser contact your [regional RDS](#).

For further information about how to involve public contributors in your research see our [brief guide to public involvement](#) in funding applications.

