Engaged Health Research Group Code of Practice

February 2025

Introduction

Patient and public involvement is defined as doing research with patients and the public rather than ‘to’, ‘about’ or ‘for’ them. We, the Engaged Health Research Group, take a values-led approach to all patient and public involvement and engagement (PPIE) work that we do. We want to demonstrate to colleagues what this looks like in practice, to set clear expectations of what working together with our team would look like. Therefore, this document contains the principles of practice that we uphold at all times.

The Engage Health Research Group Code of Practice has three themes – ***Respectful Partnership***, ***Inclusive Working*** and ***Purposeful Involvement***. Each of these themes contain a series of statements that together encapsulate values-led PPIE from the perspective of the Engaged Health Research Group.

This document concludes with a ***Working Agreement*** that the Principal Investigator and a member of the Engaged Health Research Group signs at the outset of working together. It signifies their mutual agreement to adopt a values-led approach to all the PPIE work within the research being undertaken together.

Terminology

The phrase ‘public collaborator’ will be used throughout this document to mean patients, carers or members of the public. We use this phrase because the core group of public collaborators that the Engaged Health Research Group works with, called the Peninsula Public Engagement Group (PenPEG), have chosen this as the preferred term.

The term ‘we’ will be used throughout this document to mean the Engaged Health Research Group; however, engaged research is a whole research team responsibility. Therefore, the research team in which members of the Engaged Health Research Group work have a responsibility to uphold the values-led approach outlined in this document.

Respectful Partnership

We work in partnership with public collaborators and researchers. We support public collaborators to be collaboratively involved in research and we support researchers to work in equal partnership with public collaborators.

1. Demonstrate to public collaborators that they are valued

To achieve this, we must:

1.1 Treat public collaborators as our equals, showing them kindness, respect and empathy.

1.2 Recognise and respect the complementary expertise that public collaborators bring to research alongside researchers' technical knowledge.

1.3 Create space within the project for continuous feedback loops about what is working well and what small changes could be made to working arrangements so that public collaborators are supported to engage in shared decision making with researchers.

1.4 Provide ongoing updates for public collaborators on how research projects are progressing, including outcomes of applications for funding.

1.5 Communicate with public collaborators in a timely manner, give notice for meetings dates, ensure they can get there and try and work around their life commitments (e.g., school pick up times)

2. Support public collaborators in a way that suits their needs

To achieve this, we must:

2.1 Allocate budget to reimburse public collaborators for their travel expenses and time in line with PenARC payment rates or project appropriate guidance (e.g., NIHR payment rates).

2.2 Meet with public collaborators prior to meetings to assess their needs (e.g., vision aids and disability access) and communicate the purpose of the meeting and what the meeting will be like.

2.3 Collaborate with the meeting chair in advance of the meeting to organise the meeting in a way that pragmatically meets public collaborators needs

2.4 Make time available to meet with public collaborators after meetings to attend to any needs (e.g., signposting to appropriate mental health support) and to get feedback on how it was for them

2.5 Establish and be flexible to public collaborators preferred mode of communication. For example, they may not use emails as their main form of communication.

2.6 Be supportive of public collaborators health problems and adapt our working approach to meet their changing needs. Reassure public collaborators that it is ok to change how much they are involved in a project throughout its duration depending upon their changing needs.

3. Support researchers to work alongside public collaborators

To achieve this, we and the research team must:

3.1 Support the process to enable the conditions for the integration of the complementary expertise that public collaborators bring to research alongside researchers' technical knowledge, whilst acknowledging that this is the entire research team's responsibility.

3.2 Be allocated sufficient resources within the project budget to reimburse public collaborators for their valuable time, for travel and expenses.

3.3 Be allocated sufficient resources within the project budget for training that supports researchers to improve their skills relating to working with public collaborators.

3.4 Be allocated a minimum of 10% FTE for a PPIE lead, within a project budget, so that public collaborators and research teams can be properly supported to create effective environments for working together.

Inclusive Working

We are committed to engaging with diverse communities and working together with a broad range of people, especially those who are not typically involved in research. We support researchers to integrate this approach into their practice.

1. Build meaningful relationships with a broad range of local communities

To achieve this, we must:

1.1 Recognise the importance of relationships and trust in the engagement process; therefore, be allocated sufficient time to be a continued and trusted presence in diverse local communities related to the research being done.

1.2 Support researchers to be a continued and trusted presence in the diverse local communities related to their area of research.

1.3 Actively listen to the needs of diverse groups of people in the local community.

1.4 Respectfully establish the basis of a reciprocal relationship with diverse groups of people in the local community and that this is relational not transactional.

2. Uphold the mutually agreed terms of a reciprocal relationship with a broad range of local communities

2.1 Identify the opportune moment to introduce the concept of research and the benefits of research to diverse groups of people in the local community.

2.2 Adapt our communication approach so that it is clear and accessible to the audience that we are communicating with (i.e., find a common language).

2.3 Provide a broad range of ways in which diverse groups of people in the local community can be involved in research.

2.4 Provide timely reimbursement to people in the local community based upon the agreed terms of the relationship.

3. Continually seek to improve competency to work with diverse communities

To achieve this, we must:

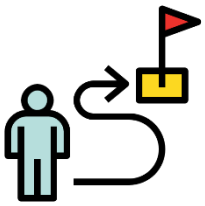
3.1 Actively identify appropriate training around cultural competency and inclusive research.

3.2 Share our skills, knowledge and experience related to cultural competency and inclusive research with colleagues within and outside the team.

3.3 Support public collaborators to undertake learning around cultural competency and inclusive research.

Purposeful Involvement

We work with public collaborators and researchers to ensure that public collaborators are involved in the research throughout its entire life cycle.



1. Have clarity on why public collaborators are involved in the research

To achieve this, we must:

1.1 Establish an agreement amongst the research team at the outset of project development about why public collaborators are being involved in the research and support this rationale to underpin all work on the project.

1.2 Establish mutually agreed upon roles and responsibilities for public collaborators that work on the project, but be adaptable to change as relationships and emergent directions arise within the project (see 2.3 below)

1.3 Only agree to researchers requests to organise a PPI meeting/workshop if you are contacted a minimum of 8 weeks ahead. This can only be reduced in exceptional circumstances.

2. Share a variety of opportunities for involvement within the research

To ensure this, we must:

2.1 Ensure that opportunities for involvement are shared via different avenues to increase the likelihood of reaching a broader range of public collaborators.

2.2. Integrate different modes of involvement within the project to meet the different needs of public collaborators involved.

2.3 Be open to adapting involvement opportunities to meet the needs of different public collaborators involved.

3. Have transparent involvement of public collaborators in the research

To achieve this, we must:

3.1 Ensure public involvement plans are regularly monitored, evaluated and reported.

3.2 Ensure there are built in opportunities for continuous feedback through open and honest communication between researchers and public collaborators.

3.3 Support opportunities for shared learning and understanding by ensuring there is clarity amongst the research team and public collaborators on why actions are done being taken (e.g., explaining the reasons why on this occasion the decision made by public collaborators on the project cannot be actioned).

3.4 Ensure involvement is tailored to the needs of the research and public advisers, and pragmatic decisions are made to balance contradicting demands and limited resources.

3.5 Ensure that public collaborators involved in the development of a project are kept informed of the outcome of an application in a timely manner.

4. Capture and report the impact of involvement in research

To achieve this, we must:

4.1 Create an agreement between the research team and public collaborators about what the focus for impact assessment will be. Approach to impact assessment can be light touch (e.g., noting input from public collaborators and project decisions made as a result) or more in depth (e.g., using a formal impact assessment tool).

4.2 Establish and adhere to the approach to impact assessment that will be taken on the project and what information needs to be collected to facilitate this.

4.3 Agree who will be involved in capturing the information required to assess impact and support the people involved in this role by enabling timely access to the required information throughout the project.

4.4 Establish and adhere to a procedure for regularly reporting the impact of involvement to the research team and public collaborators involved. This should include space to reflect upon the learning gained from involvement.

Working agreement

The PenARC PPIE team are keen to collaborate with researchers that are seeking to address the immediate issues facing the health and social care system. An integral component of addressing these issues in a relevant way, is working with public collaborators to develop and do the research. This document details the principles that the PenARC PPIE team uphold in our practice when working with researchers and public collaborators on research. By signing this working agreement, you are confirming that:

	Tick to confirm
You have read this document and have had sufficient opportunities to ask questions about its contents to ensure that you understand the principles outlined within it.	
You will support the PenARC PPIE team member you are working with to work in line with the principles in this document whilst working together.	
You will be committed to the principles within this document when working with public collaborators to develop and do research.	

Project name:

Researcher's name:

Researcher's signature:

Date:

PPIE team member's name:

PPIE team member's signature:

Date