

Policy Innovation and Evaluation Research Unit (PIRU) – Patient and Public Involvement and Engagement Strategy

November 2024 (v2)

Who we are

The National Institute for Health Research (NIHR) Policy Research Unit in Policy Innovation and Evaluation (PIRU) is one of 20 Policy Research Units funded by the NIHR. Our research looks at new policies and what they may mean for people who use health and social care services, the wider public, professionals, and others. Our work is agreed with the Department of Health and Social Care. PIRU began its work in January 2011, and our funding has been renewed to run from January 2024 to December 2029.

What we do

We aim to produce high quality, relevant research to support national policy makers, providing them with evidence and information they need to make decisions about health care, social care, and public health. In particular, we evaluate initiatives, for example pilots, and explore what they have achieved and how they can be improved.

Our work is led by the principles of co-production and we work with patients and members of the public at all stages of the research. Working this way will help make our research relevant, insightful, impactful, and easy to understand. Public advisers are core members of our project teams and we will ensure that our work together is ethical, appropriate and inclusive. We aim to specifically work with people who have historically been underrepresented in research to ensure that our work benefits everyone.

Much of our work responds to requests from government and potentially could be on any topic around health care, social care or public health. We therefore work with people with a wide range of experiences of, or who will be affected by policies, that we are evaluating. Our approach is supported by the PIRU Public Involvement Panel.

Patient and Public Involvement and Engagement Strategy

PIRU's Patient and Public Involvement and Engagement Strategy is led by the principles that are most important to our public advisers, which are:

- Inclusivity
- Accessibility
- Diversity of voices
- Creating impact

This approach reflects the shared values of the wider community at the [London School of Hygiene and Tropical Medicine \(LSHTM\)](#). To develop our Strategy, we followed the [UK National Standards for Public Involvement in Research](#) and focused on four key areas—reach, relevance, refinement, and relationships—as highlighted in the [Going the Extra Mile](#) report.



Diagram produced by the UK Standards Partnership

PIRU's PPIE Strategy has five key commitments:

1. We will support inclusive and accessible opportunities for involvement in PIRU

We will:

- a) Openly and widely advertise opportunities for involvement in PIRU projects and activities. This includes targeted recruitment and the offer of a choice of activities to take part in.
- b) Be guided by public advisers how to best support their participation and provide them with adequate assistance.
- c) Work with partners, such as nongovernmental organisations, to reach and involve a diverse range of people in our work.

- d) Make timely payment and reimbursement for involvement activities, recognising individual circumstances (we follow [NIHR guidelines on reimbursement](#))
- e) Offer a range of ways for people to be involved that work best for them in order to optimise their contribution.
- f) Provide a variety of accessible communication formats.
- g) Build confidence and skills for public involvement in research through offering training in different aspects of research including research methods and dissemination of results, resources and advice to PIRU researchers.

2. We will work together to champion diversity

We will:

- a) Support participation of people with different perspectives and experiences that are relevant to our research.
- b) Continue to include people who are new to research and PPIE.
- c) Draw on the different skills and perspectives that people bring to enrich PIRU's work.
- d) Be mindful of long-standing social inequalities and pay attention to emerging forms of marginalization.

3. We will communicate clearly about our research and PPIE activities

We will:

- a) Have a named researcher for public advisers to contact for each research project in addition to the PIRU PPIE Lead.
- b) Provide clear information about the involvement activity, the role and expectations so researchers and public advisers have a shared understanding of the work.
- c) Ask public advisers about the impact they would like to see as a result of the work and set those intentions at the beginning.
- d) Ensure research materials (for example information sheets) are appropriate for participants in our research projects.
- e) Communicate our research findings in ways that reach audiences that are likely to be interested, but might not otherwise access our work.
- f) Contribute to the development of PPIE practice in research through sharing our practices and learning with the research community.
- g) Develop processes for PIRU researchers and public advisers to provide feedback on their experience of involvement, to help us to improve our approach to PPIE.

- h) Provide a system for PIRU researchers to access PPIE for their research.
- i) Ensure public advisers are kept informed about the progress of the research and subsequent outcomes.

4. We will capture and share the impact of our PPIE activities

We will:

- a) Collect information that will help us assess the impact of public involvement in our research.
- b) Review and share learning about the impact of PPIE in our work.
- c) Discuss what impact public advisers envision as a result of research projects they support and work towards achieving it.

5. We will include public advisers in the management of PIRU

We will:

- a) Include public advisers in PIRU Management Team meetings and research project teams.

How we developed our Strategy

This Strategy has been developed collaboratively by the PIRU Management Team and the PIRU Public Involvement Panel: Peter Atkins, Clara Martins de Barros, Sandra Paget and Reshma Punjabi.

Putting the Strategy into practice

All members of PIRU are responsible for putting the Strategy into practice, supported by:

Ellen Nolte – PIRU Director

Mustafa Al-Haboubi – PIRU Deputy Director

Agata Pacho – PPIE Lead

CJ Iliopoulos – PIRU Manger

Resources will be allocated to expenses and payments for public advisers, staffing, administration, and direct costs of PPIE activities.

How we will review our Strategy

The PIRU Management Team and the PIRU Public Involvement Panel will review this Strategy annually.

Glossary

Co-production in research: A collaborative approach where researchers and the public work together to share power and responsibility throughout the course of a research project. Its goal is to enhance the quality of the research by ensuring it addresses the questions most relevant to those impacted by its findings. Co-production can occur at various stages of a project, including identifying research questions, designing and prioritising studies, management, co-delivering research activities, communicating key findings, and engaging in knowledge exchange.

Marginalised people: Groups or individuals excluded or discriminated against due to unequal power relationships. Marginalisation can arise from various factors, including ethnicity, gender, sexual orientation, disability status, socioeconomic background, and age. It prevents individuals or groups from fully participating in social, economic, and political life.

Underrepresented people in research: An underrepresented population refers to subgroups whose participation in research is disproportionately low relative to their prevalence in the broader population. These subgroups may be defined by race, ethnicity, age, sex, gender, socioeconomic status, and more. Examples of underrepresented populations include people with disabilities, individuals from disadvantaged backgrounds, and underrepresented racial and ethnic groups.

Patient and Public Involvement and Engagement (PPIE):

- **Patient and Public Involvement** refers to conducting research and activities *with* or *by* members of the public or patients, rather than doing research *to*, *about*, or *for* them. This approach actively involves patients and members of the public in the development, execution, and management of research projects or initiatives.
- **Patient and Public Engagement** focuses on disseminating information and outcomes from research or activities to patients and the public. This ensures they are informed about ongoing work and creates opportunities for gaining insights and feedback from these groups.

Policy research: The process of analysing public policies to provide insights that can inform policy decisions. The primary goal of policy research is to enhance the effectiveness of government services and improve people's lives.