

Using the UK Standards for Public Involvement to Guide Personal and Public Involvement (PPI) Initiatives



Overview of the UK Standards for Public Involvement

The [UK Standards for Public Involvement](#) provide a framework to support high quality Personal and Public Involvement (PPI) in Health and Social Care research. Developed collaboratively by public contributors, researchers, charities and research organisations across the UK, the standards aim to support meaningful and inclusive involvement in health and social care research. The six standards include:

- Inclusive Opportunities
- Working Together
- Support and Learning
- Communications
- Impact
- Governance

Together, the standards are designed to help researchers, organisations and public contributors reflect on their practice and identify ways to strengthen involvement in research. They are not intended to be a checklist, but rather a framework to guide discussion, learning and continuous improvement.

Purpose of this document

We advise applicants to various HSC R&D Division funding schemes to consider the UK Standards for Public Involvement when detailing their PPI plans, when reporting on project progress, and when working with members of [Public Involvement Enhancing Research \(PIER\)](#). This document provides an overview of each of the six standards, and a series of questions which will you plan and reflect on your PPI activity. A list of helpful resources is also presented under each standard.



Inclusive Opportunities

Public involvement partnerships are accessible and include a range of people and groups, as informed by community and research needs.

Research to be informed by a diversity of public experience and insight, so that it leads to treatments and services which reflect these needs.

The questions below will help you plan your PPI activity and align with the 'Inclusive Opportunities' standard:

- Will your PPI initiative enable people affected by and interested in the research topic/area to be involved from the earliest stages and if so, how?
 - Have you considered any potential barriers to involvement in your PPI initiative (e.g. payment for time, accessible meeting locations, ability to use/access technology) and how these barriers could be overcome?
 - If you are sharing information about this PPI initiative or opportunity, have you considered how to share this in a way that appeals to and will reach different communities?
 - Will you establish a fair and transparent process for involving public contributors in this PPI initiative (ensuring equity, inclusion and diversity)?
 - Have you built in choice and flexibility into the PPI initiative? (e.g. meeting style and timings, opportunity to offer written feedback)
-

Inclusive Opportunities: Useful Resources

- NIHR: [Supporting Equity and Tackling inequality. How can NIHR promote inclusion in public partnerships?](#)
- Healthtalk.org: [Raising awareness of opportunities for involvement and finding new volunteers](#)
- National Disability Authority: [Conducting Collaborative Research with people with disabilities](#)

- NIHR: [Being Inclusive in Public Involvement in Health and Care Research](#)
 - Alzheimer Europe: [Guidelines on Inclusive Travel and Meetings for People with Dementia](#)
 - Oxford Public Health, The Listening Series: [Including everyone in public engagement in research. Guidance for Researchers.](#)
 - PHA Engage: [Health Literacy resources](#)
 - Public Involvement Front Door: [Involving Public Members](#)
 - Healthtalk.org: [Difficulties and Barriers to Involvement](#)
-



Working Together

Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

Public involvement in research is better when people work together towards a common purpose, and different perspectives are respected.

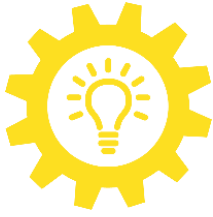
The questions below will help you plan your PPI activity and align with the ‘Working Together’ standard:

- How will the purpose of your PPI initiative be jointly defined and recorded with the public contributors who are involved?
 - How will the practical requirements and arrangements for working with public contributors be identified and addressed?
 - How will different ways of working be explored, and how will plans and activities be developed collaboratively with your public contributors to ensure they can contribute fully?
 - How will you establish a shared understanding of roles, responsibilities, and expectations for the PPI initiative (e.g. role descriptions, what do your PPI contributors need to know)?
 - How will PPI contributor’s influence, ideas, and contributions be recognised and acted upon within your PPI initiative?
-

Working Together: Useful Resources

- NIHR Guidance for [Co-Producing a Research Project](#)
- NIHR Applied Research Collaboration West: [A map of resources for co-producing research in health and social care](#)
- NIHR Applied Research Collaboration North East and North Cumbria: [Ethical Practice Guidelines for Public Involvement and Community Engagement](#)

- NIHR Applied Research Collaboration West: [A Guide to Working Effectively with Public Contributors](#)
 - Imperial College London: [Patient and Public Involvement trauma informed guidance for organisations and healthcare professionals](#).
 - Shaping our Lives: [A guide for people who want to share their lived experience](#).
 - [Service Users and Carers Checklist](#): What do I need to consider? What do I need to do?
 - Healthtalk.org: [Factors which make it easier to get involved](#)
 - Public Health Agency, Engage: [Example Feedback Template](#)
-



Support and Learning

We offer and promote support and learning that builds confidence and skills for public involvement in research.

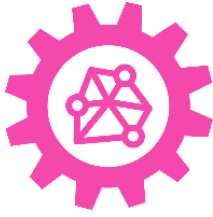
We seek to remove practical and social barriers that stop members of the public and research professionals from making the most of public involvement in research.

The questions below will help you plan your PPI activity and align with the ‘Support and Learning’ standard:

- Have you asked public contributors involved in your PPI initiative if they have any physical or emotional support needs and planned for how you will address such needs to reduce any risks (e.g. technical support, accessible venues, named person for support)?
- Have you considered what training and/or ongoing support the public contributors involved in your PPI initiative might need and who will lead on this?
- How will public contributors be informed about where to go for information and support on research and /or public involvement and who their point of contact will be?
- How will a culture of learning by doing be encouraged, with learning built on and shared among researchers, staff, and the public who are involved in your PPI initiative?

Support and Learning: Useful Resources

- HSC R&D Division's [PPI Resource Library for the public](#)
- HSC R&D Division's [list of training resources to support your PPI contributors.](#)
- HSC R&D Division's ['Building Research Partnerships' training](#) which introduces PPI in Health and Social Care research.



Communications

Use plain language for well-timed and relevant communications, as part of involvement plans and activities.

Communicate with a wider audience about public involvement and research, using a broad range of approaches that are accessible and appealing.

The questions below will help you plan your PPI activity and align with the 'Communications' standard:

- Do you need to develop a communications plan for your PPI initiative and if so, how will you do this?
 - How will the needs of different people be met through inclusive and flexible communication methods?
 - How will processes be put in place to offer, gather, act on, and share feedback with the public contributors involved in the PPI initiative on a regular basis?
 - How will learning and achievements from your PPI initiative (both positive and negative) be shared?
-

Communications: Useful Resources

- Free guides from the [Plain English Campaign](#)
- [Do's and don'ts for approaching accessibility from a design perspective](#), Home Office Digital (2016)
- [Feedback from researchers to Patient and Public Involvement contributors](#), NIHR Applied Research Collaboration, East of England (2018)
- [Co-creating communications with patient and public groups](#), NIHR Applied Research Collaboration West.
- [Involving Public Members](#), Public Involvement Front Door
- [Example recruitment flyer](#), Public Involvement Front Door
- Public Health Agency, Engage: [How to recruit service users and carers to Get involved in your Involvement Opportunity](#).



Impact

Seek improvement by identifying and sharing the difference that public involvement makes to research.

Understand the changes, benefits and learning gained from the insights and experiences of patients, carers and the public.

The questions below will help you plan the public involvement activity and decide if you align with the 'Impact' standard:

- How will the public be involved in deciding what the assessment of impact on the PPI initiative should focus on, and which approach to take?
 - How will it be made clear what information needs to be collected to assess impact, including who has been involved and how?
 - How will processes be established to support reflection on public involvement?
 - How will changes, benefits, and learning resulting from public involvement be acted on?
-

Impact: Useful Resources

- [Public Involvement in Research Impact Toolkit \(PIRIT\)](#): The PIRIT Tracking Tool is a simple spreadsheet to record when and how the public contributed, what they hoped to influence, what changed (if anything), why it matters, and the related standards.
- [AllHPC Public and Patient Involvement \(PPI\) Impact Evaluation Framework](#): AllHPC co-produced the framework with PPI contributors from AllHPC's Voices4Care and researchers from AllHPC's Palliative Care Research Network and Early Career Research Forum, in collaboration with the PPI Ignite Network at University College Cork.
- [PPI Impact Log](#): this log from People in Health West of England aims to capture the impacts of Patient and Public Involvement (PPI)
- Public Health Agency, Engage: [Example Feedback Template](#)

- NIHRtv: [Reflections on impact & evaluation of public involvement: Who, Why & What?](#)
-



Governance

Involve the public in research management, regulation, leadership and decision making.

Public involvement in research governance can help research be more transparent and gain public trust.

The questions below will help you plan the public involvement activity and align with the ‘Governance’ standard:

- How will public voices be heard, valued, and respected in decision-making within your PPI initiative?
 - How will public involvement plans be developed, regularly monitored, reviewed, and reported on?
 - How will visible and accountable responsibility for public involvement be embedded throughout the organisation (if applicable)?
 - How will realistic resources (including money, staff, and time) be allocated for public involvement?
 - How will the privacy of personal information be protected by ensuring it is collected and used appropriately?
 - How will individual preferences around the use of personal information during involvement activities be identified (e.g. use of quotes, images, social media use)?
-

Governance: Useful Resources

- [Recommendations to more equitably share power on research teams that include patient/public partners](#)
- [NIHR PPIE Planner](#): The PPIE Planner is designed to help researchers plan their PPIE activities.
- [Stroke Association: Toolkit](#) - Involving people affected by stroke in your work and research

- [NIHR Payment Guidance for Researchers and Professionals](#)
 - Health Research Authority: '[Payment for public involvement in health and care research: a guide for organisations on employment status and tax](#)'.
 - Health and Social Care Northern Ireland: [Service Users and Carers – Guidance on Reimbursement of Out of Pocket Expenses](#)
 - [Budgeting for Involvement: cost calculator](#) (an excel spreadsheet to help create a budget for PPI)
 - Public Health Agency, Engage: [Understanding Data protection](#)
-

Further Information

For further information on Personal and Public Involvement in Health and Social Care Research please visit [HSC R&D Division's website](#).

You can also access our [PPI Resource Library for Researchers](#) and our [PPI Resource Library for the Public](#).

