



Better public involvement for better health and social care research

Supported by the UK Public Involvement Standards
Development Partnership

UK Standards *for* Public Involvement in Research



Introduction

The National Institute for Health Research (NIHR), Chief Scientist Office (CSO) Scotland, Health and Care Research Wales, and the Public Health Agency Northern Ireland invites people to use the UK Standards for Public Involvement in all types of research activity. People, teams and organisations in health research often ask ‘What does good public involvement in research look like?’. High quality public involvement can make a real difference to research and healthcare, however it needs to evolve and improve over time.

The UK Standards for Public Involvement provide clear, concise statements of effective public involvement against which improvement can be assessed. The Partnership also want these standards to encourage approaches and behaviours that are the hallmark of good public involvement such as flexibility, sharing and learning and respect for each other. It is possible that some organisations will achieve many of the standards, others may achieve a few. Success is not about meeting ***all the standards all the time***, but about ***improvement over time*** as experienced by all the people involved.

Values and Principles of Public Involvement

The standards are based on initial work in values and principles of public involvement undertaken by NIHR INVOLVE and Health and Care Research Wales. Examples of public involvement standards used in different settings were collected and reviewed as part of developing these standards. All of these examples are available on the standards website.

The standards are:

- a framework for what good public involvement in research looks like and are adaptable to different situations;
- designed to encourage reflection and learning, including where lessons have been learned when public involvement has failed to lead to expected outcomes;
- a tool to help people and organisations identify what they are doing well, and what needs improving;
- intended to be used with any method or approach to public involvement in research.

Standard users could start by reflecting on where they are in their public involvement, to help manage expectations, for example;

First Steps – for those new to public involvement in research;

Everyday practice – established public involvement groups or infrastructure;

Aiming high – established and experienced groups and people, trying out new approaches.

Using the standards

The standards can be used in different ways. Members of the public and community groups can use the standards to assess the strengths and weaknesses of their involvement in research, and identify improvements. Researchers can use the standards to review their plans for public involvement. Research funders and charities can use them to assess how public involvement is being implemented in projects and organisations they support.

Between May 2018 and May 2019 forty different 'pilot' organisations and people used the standards and reported back to the partnership. The feedback has been very helpful in understanding how the standards can be used and what needed to change to make them more useful.

Pilot organisations approached using the standards in different ways. Some tackled them one or two at a time, organisations that were newer to public involvement in research focused on one standard only. Others started with a mapping exercise or audit, prioritising work on the standards with the greatest need for improvement.

Pilot organisations described how using the standards encouraged them to reflect on their current public involvement in research plans and activity, by providing a framework and guide for conversations. Many set themselves targets to meet the standards and agreed systems for monitoring progress. The diagram below shows which approaches to using the standards were most used during the testing phase.



How you use the standards will be influenced by many issues, such as the purpose of public involvement in research, and the amount of resources (money, people, skills) available. These resources, and continuity of support for public involvement are important factors in creating a research culture that welcomes the public into research, and helps researchers and organisations work with the public.



INCLUSIVE OPPORTUNITIES

Offer public involvement opportunities that are accessible and that reach people and groups according to 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 may help you reflect on and decide if you meet the standard:

- **Are people affected by and interested in the research involved from the earliest stages?**
- **Have barriers to involvement, such as payment for time or accessible locations for meetings been identified and addressed?**
- **How is information about opportunities shared, and does it appeal to different communities?**
- **Are there fair and transparent processes for involving the public in research, and do they reflect equality and diversity duties?**
- **Is there choice and flexibility in opportunities offered to the public?**

A standard user said...

“This standard made us think more broadly. Previously we had variable involvement, no clear role descriptions or expenses policies. We began to make small changes – accepting what was realistic given our limited resources.”



WORKING TOGETHER

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

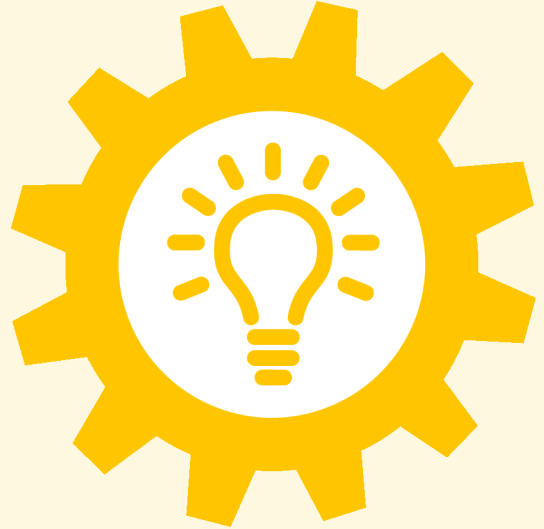
Public involvement in research is better when people work together towards a common purpose, and different perspectives are respected.

The questions below may help you reflect on and decide if you meet the standard:

- **Has the purpose of public involvement been jointly defined and recorded?**
- **Have the practical requirements and arrangements for working together been addressed?**
- **Have all the potential different ways of working together been explored, and have these plans and activities been developed together?**
- **Is there is a shared understanding of roles, responsibilities and expectations of public involvement?**
- **Have individuals' influence, ideas and contributions' been recognised and addressed?**

A standard user said...

“Standards gave us a framework to stand back, think clearly and work with researchers, members of the public and others to develop an action plan to support joint working.”



SUPPORT AND LEARNING

Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.

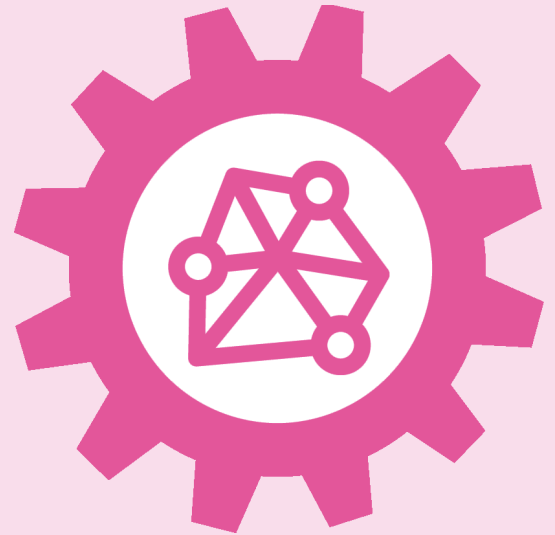
Remove practical and social barriers that stop members of the public and research professionals from making the most of public involvement in research.

The questions below may help you reflect on and decide if you meet the standard:

- **Is there a range of support to address identified needs?**
- **Have specific resources been designated to support learning and development opportunities for both the public, researchers, and staff?**
- **Do the public know where to go for information and support about public involvement?**
- **Is there a culture of learning by doing, building on and sharing that learning for researchers, staff and the public?**

A standard user said...

“Our team developed a simple spreadsheet to capture our current involvement activities and ideas for areas we could improve. We’ve created a ‘real time board’ as a visual summary of all our activities and areas for future focus.”



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 may help you reflect on and decide if you meet the standard:

- **Has a communications plan been developed for involvement activities?**
- **Are the needs of different people being met through inclusive and flexible communication methods?**
- **Are processes in place to offer, gather, act on and share feedback with the public?**
- **Are you sharing your public involvement learning and achievements, good and bad?**

A standard user said...

“We focused on making all our communications accessible. This one standard crossed over to other standards. It completely changed our thinking.”



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 may help you reflect on and decide if you meet the standard:

- **Are the public involved in deciding what the assessment of impact should focus on, and the approach to take?**
- **Is it clear what information to collect to help assess impact, including who has been involved and how?**
- **Are there processes in place to help reflect on public involvement?**
- **Are the changes, benefits and learning resulting from public involvement acted on?**

A standard user said...

“We approached this by carrying out an assessment from the patients’ perspective of their experience of being involved in implementing the standards focusing on what was good / not so good / what should happen next.”



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 may help you reflect on and decide if you meet the standard:

- **Are public voices heard, valued and respected in decision making?**
- **Are public involvement plans in place that are regularly monitored, reviewed and reported on?**
- **Is there visible and accountable responsibility for public involvement throughout the organisation?**
- **Are realistic resources (including money, staff, time) allocated for public involvement?**
- **Is the privacy of personal information protected by collecting and using it in a suitable way?**

A standard user said...

“A skills audit of public contributors and other members of governance groups can be useful, both to play to people’s strengths and assets and to make skills and value more transparent to the group.”

Definitions used in the standards

- **Public:** In these standards the 'public' includes; patients, service users, survivors, carers and family members.
- **Public involvement in research:** Research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. (NIHR INVOLVE 2017).
- **Public involvement standard:** A statement of good practice that describes one of six core elements of public involvement in research.

Acknowledgements

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For more information about the UK Standards *for* Public Involvement

<https://sites.google.com/nih.ac.uk/pi-standards/home>

If you would like an Easy Read booklet about the standards, please contact us:

NIHR Central Commissioning Facility

Email: ccfppi@nih.ac.uk

Telephone: 020 8843 8041

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