



Standards for Public Involvement in Research

1. What are the Public Involvement (PI) Standards, and who are they for?

The Standards are a set of statements that describe what good public involvement in research looks like. Together they provide a framework for improving the quality and consistency of public involvement in research. They complement existing Standards in Northern Ireland, and Scotland and those developed by specific groups;

<https://sites.google.com/nih.ac.uk/pi-standards/resources/examples-frameworks-and-user-guides>.

These Standards fulfil one of the recommendations of the NIHR strategy for public involvement in research: <https://sites.google.com/nih.ac.uk/pi-standards/the-project/background>.

Each standard has a set of 'indicators'. These are statements describing ways in which a standard can be met alongside 'illustrations' of what that might look like in practice. The Standards can be used by any individual, group or organisation as a self-assessment tool to review what they are doing now, and then identify and test out actions that aim to improve the quality of their public involvement.

The Standards reflect and are linked to previous work on Values and Principles in Public Involvement: <https://tinyurl.com/yawwof77>.

The Standards could be used in many ways, for example:

- Members of the public and community groups can use the Standards to assess the strengths and weaknesses of their involvement in a research project or organisation and identify how to improve that involvement.
- Researchers and research organisations can use the Standards to assess their plans for public involvement and identify how to improve those plans.
- Research funding agencies can note how PI is being implemented in projects and organisations that it supports.

2. What do we mean by Public Involvement (PI) in Research?

Public Involvement (PI) in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, undertaking interviews with research participants. When using the term 'public' we include patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services. Whilst all of us are actual, former or indeed potential users of health and social care services, there is an important distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services.

We are not referring to researchers raising awareness of research, sharing knowledge or engaging and creating a dialogue with the public. We are also not referring to the recruitment of patients or members of the public as participants in research. However, these different activities – involvement, engagement and participation – are often linked and, although they are distinct, can complement each other. For example, the public can and do play a valuable role in advising on recruitment of patients as participants and on ways of engaging with the public.

Definitions used in this document:

PI Standard: a statement of good practice that describes one of six core elements in PI in research.

PI Indicator: a statement of good practice that describes what you need to demonstrate in order to meet the standard.

Illustrations: different ways of demonstrating that you are meeting the standard, there are three examples per indicator, covering different contexts; organisational, project and individual.

Examples*: real life accounts of public involvement in research that model a standard or indicator (*not in the consultation version of the standard, but will be in the final version).

3. The Standards for Public Involvement (PI) in Research - Summary

1. Inclusive opportunities - We provide clear, meaningful and accessible opportunities for involvement, for a wide range of people across all research. We do this by embracing a broad spectrum of participation and involvement. This helps our research to be more fully informed, representative and relevant.

2. Working together – We create and sustain respectful relationships, policies, practices and environments for effective working in research. We do this because we deliver better research when we work well together, towards shared goals, and having complimentary but different roles and responsibilities. Working this way becomes the norm.

3. Support & learning - We ensure public involvement is undertaken with confidence and competence by everyone. We do this so that people have access to the appropriate support, learning and skills development that enables them to involve, and be involved effectively.

4. Communications - We provide clear and regular communications as part of all involvement plans and activities. We do this because full information exchange and effective communication helps build positive and strong relationships for meaningful involvement.

5. Impact - We assess report and act on the impact of involving the public in research. We want to capture the difference (positive or negative) public involvement makes to research, and ensure what we do is responsive.

6. Governance - We ensure the community of interest voices are heard, valued, and included in decision making. We implement, report and are accountable for our decisions. Visibility of power sharing at the highest levels gives credibility and shows a commitment to public involvement in research. Sharing our frameworks for PI structure, management and compliance within research also shows transparency.

4. The Standards for Public Involvement (PI) in Research - Detail

How each standard is laid out:

<p>Standard Statement that describes what good public involvement in research looks like</p> <p><i>In the document the 'We' refers to anyone using the Standards.</i></p>
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Indicator	Statements that describe ways in which the standard can be met
Illustrations	Different ways of demonstrating that you are meeting the standard, there are three examples per indicator, covering different contexts e.g. organisational, project and individual
Examples*	Links to real life accounts of public involvement in research that model a standard or indicator <i>*not in the consultation version of the standard, but will be in the final version</i>

Standard 1

Inclusive opportunities - we provide clear, meaningful and accessible opportunities for involvement, for a wide range of people across all research.



Indicator 1.1	We make information about opportunities for public involvement in research available, using different methods so that we reach relevant and interested people
	Illustrations of indicators below:
Organisational	<ul style="list-style-type: none"> An organisation has an up to date 'map' and regional database of potential communities of interest, with up to date contact details
Team/project	<ul style="list-style-type: none"> A clinical trial team recruited young people to join the research planning group by using Social Media
Individual	<ul style="list-style-type: none"> A member of the public wants to get involved in research and is able to find and read Plain Language Summaries of the ongoing and planned research opportunities
Indicator 1.2	We have a fair and transparent recruitment process for public involvement in research

Organisational	<ul style="list-style-type: none"> Organisations advertise their PI opportunities widely e.g. website, NHS, local papers
Team/project	<ul style="list-style-type: none"> A research project team finds new people for their PI opportunities, rather than approach the same people each time
Individual	<ul style="list-style-type: none"> A member of the public expresses interest in a PI opportunity, a short description of what they can expect is part of the information pack they receive
Indicator 1.3	We have choices and flexibility for people to take advantage of different opportunities for public involvement in research
Organisational	<ul style="list-style-type: none"> Organisations make available all the different ways that people can take part in different types of research
Team/project	<ul style="list-style-type: none"> Within research project teams information about everyone's different interests and aptitudes are shared and used to allocate tasks and activity
Individual	<ul style="list-style-type: none"> Involved members of the public take part in regular review meetings with research partners to discuss experiences and progress
Indicator 1.4	We identify barriers to taking up public involvement in research and address them
Organisational	<ul style="list-style-type: none"> Organisations have an efficient payment process for out of pocket expenses. This process is reviewed regularly
Team/project	<ul style="list-style-type: none"> Project teams plan and/or provide suitable transport to ensure that involved public can take part in face to face activity
Individual	<ul style="list-style-type: none"> Involved members of the public have the option to 'book ahead' transport so that they don't bear the cost up front
Indicator 1.5	We involve people affected by and interested in the research topic or issue at the earliest stage
Organisational	<ul style="list-style-type: none"> Organisations encourage research teams to involve the public in the exploration or new research and/or research prioritisation processes
Team/project	<ul style="list-style-type: none"> Research teams involve the public in reviewing and developing outcomes (measurements) for clinical trials
Individual	<ul style="list-style-type: none"> An involved member of the public can expect to take part in writing research plans and protocols

Standard 1 - Inclusive Opportunities

Standard 2

Working together – we create and sustain respectful relationships, policies, practices and environments for effective working in research.



Indicator 2.1	We ensure there is shared understanding of roles and responsibilities and expectations
	Illustrations of indicators below:
Organisational	<ul style="list-style-type: none"> An organisation runs an annual review with their involved public members to check on how they are finding the experience, and what can be improved
Team/project	<ul style="list-style-type: none"> A research team has role descriptions for everyone involved, including members of the public, that have been agreed and are reviewed
Individual	<ul style="list-style-type: none"> A public member of a research team feels able to communicate how they find their role and adjust it if needed (due to health state or other reasons)
Indicator 2.2	We provide and use a range of ways of being involved in research
Organisational	<ul style="list-style-type: none"> The research organisation has a policy of going to where people are, rather than inviting them to come to the research organisation for PI
Team/project	<ul style="list-style-type: none"> A research team is open to exploring and using innovative methods for engaging and involving people, such as café pop-ups, community outreach, social media conversations, intervention design days, use of Skype/video conferencing /teleconference and webinars
Individual	<ul style="list-style-type: none"> An involved member of the public can ask for time away, dipping in and out of the project as needed Involved public help to identify a range of ways people can be involved
Indicator 2.3	We develop public involvement plans (strategies) and activity together
Organisational	<ul style="list-style-type: none"> Involved public are part of the process of agreeing the organisations research strategy
Team/project	<ul style="list-style-type: none"> A clinical trial team discuss with their included public the ‘burden’ of the trial protocol for research participants, and adjust their planning as necessary

Individual	<ul style="list-style-type: none"> An involved member of the public can see how and where their contribution to research plans has been implemented
Indicator 2.4	We agree and uphold decision making that respects individual contributions
Organisational	<ul style="list-style-type: none"> Organisation ensures that chairs of meetings and panels have the necessary skills to genuinely involve public contributors in decision making
Team/project	<ul style="list-style-type: none"> Research project Steering Group minutes describe and reflect how decisions are made for the research, and where there is contribution from the public
Individual	<ul style="list-style-type: none"> Public contributors give feedback on their involvement such as whether they are able to contribute their ideas, (which are actively discussed) and involved in decision making

Standard 2 - Working together

Standard 3

Support & learning - we ensure public involvement is undertaken with confidence and competence by everyone.



Indicator 3.1	We offer a range of support to address identified needs (practical, emotional)
	Illustrations of indicators below:
Organisational	<ul style="list-style-type: none"> • A research organisation commits to providing access to interpreters and/or signers where needed in PI
Team/project	<ul style="list-style-type: none"> • A research project team assesses the need for communication aids as part of planning a consensus workshop, and provides them where needed
Individual	<ul style="list-style-type: none"> • An involved member of the public who is housebound has access to video/phone conferencing hardware/software so that they can participate
Indicator 3.2	We have a clearly identifiable point of contact for information and support
Organisational	<ul style="list-style-type: none"> • A research organisation has a PI section or page on its website with contact details for a named PI lead.
Team/project	<ul style="list-style-type: none"> • A research team has a named PI person and contact details (telephone and email) that is easy to find and accessible
Individual	<ul style="list-style-type: none"> • An involved member of the public can leave a message with the research organisation and expect to get a response within 2 working days
Indicator 3.3	We designate and monitor resources to ensure and support effective public involvement
Organisational	<ul style="list-style-type: none"> • The organisation has a PI budget and requires appropriate PI to be included and costed in all funding applications and plans.
Team/project	<ul style="list-style-type: none"> • Research teams allocate a budget to underpin the learning and support needs of their research project
Individual	<ul style="list-style-type: none"> • Public contributors ask for, and get support that is tailored to their individual needs (e.g. travel, carer/child care costs, accommodation, access requirements)

Indicator 3.4	We develop, deliver and monitor learning opportunities in partnership, for all involved in research
Organisational	<ul style="list-style-type: none"> • A research organisation compiles a record of, or annual learning report that describes the PI learning activity and uptake • The team develops an induction to introduce public members to the study, and discuss support needs and training • Public contributors are involved in designing and delivering PI support and learning activities
Team/project	
Individual	
Indicator 3.5	We actively learn from others, we build on what we have learned and share our learning
Organisational	<ul style="list-style-type: none"> • A research organisation facilitates a PI 'learning set' for all of its research project teams, so that learning is shared and built upon • A research project team reviews its' progress regularly, including how it is doing in PI • PI knowledge and skills developed over time by public contributors forms part of the induction of new public contributors – e.g. learning and support workshops • Involved members of the public are involved in any review
Team/project	
Individual	

Standard 3 - Support & learning

Standard 4

Communications - we provide clear and regular communications as part of all involvement plans and activities.



Indicator 4.1	We develop and maintain open dialogue with diverse groups of people/audiences
	Illustrations of indicators below:
Organisational	<ul style="list-style-type: none"> • An organisation has a policy that research project teams provide sufficient time periods for people to respond to consultations • Project teams provide 'jargon busters' of all the potential technical and research language • An involved member of the public can expect to be put into contact with other PI public contributors, for informal contact and support
Team/project	
Individual	
Indicator 4.2	We gather feedback, we provide feedback, we act on feedback
Organisational	<ul style="list-style-type: none"> • The research organisation does 'user experience' surveys, asking involved members of the public about their experiences of working with the organisation • Research project team adopts a 'You said - we did' model • Public contributors routinely hear from and about the research project or organisation that they are involved in • Public members take part in the development of 'user experience' surveys and are involved in the data analysis
Team/project	
Individual	
Indicator 4.3	We are flexible in our communication methods to meet the needs of different audiences
Organisational	<ul style="list-style-type: none"> • An organisation recognises, provides and promotes support for different communication methods (e.g. email, digital media, face to face, posters) • Project teams identify where there is a need to provide PI information in different languages or through different methods (e.g. email, phone call, social media, postal, face to face)
Team/project	

Individual	<ul style="list-style-type: none"> An involved member of the public can ask for, and easily access information in different formats
Indicator 4.4	We build a communications plan for our involvement activities
Organisational Team/project Individual	<ul style="list-style-type: none"> A research organisation develops and delivers a local communications plan to support a national campaign e.g. 'I Am Research' A research team includes a summary of its communication plan (target population and beneficiaries) in its funding application Public contributors are kept well informed by ensuring key messages are written in plain language, use methods and routes that will reach people and sent in good time

Standard 4 - Communications

Standard 5

Impact - we assess, report and act on the impact of involving the public in research.



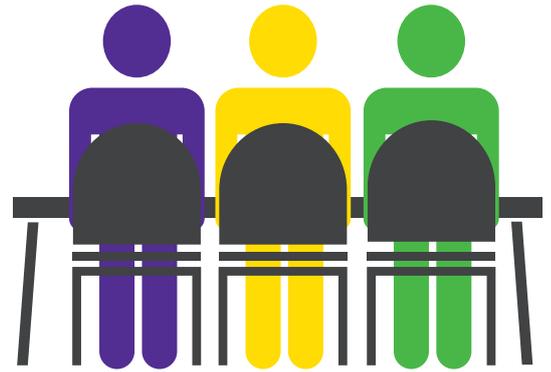
Indicator 5.1	We agree and describe our important and intended outcomes of PI activity before we start
	Illustrations of indicators below:
Organisational	<ul style="list-style-type: none"> • A research organisation clearly states in their plans what they want to achieve as a result of PI in their activities
Team/project	<ul style="list-style-type: none"> • A research team discusses and records expectations and outcomes of involvement with their involved public as early as possible, revisiting and reporting on these at appropriate times
Individual	<ul style="list-style-type: none"> • Public contributors are involved in agreeing the intended outcomes of PI in research and their importance
Indicator 5.2	We have processes for recording and monitoring important information as part of our PI activity
Organisational	<ul style="list-style-type: none"> • A research organisation collects information about successful and unsuccessful PI in grant applications and reviews this
Team/project	<ul style="list-style-type: none"> • A project team collates the number and nature of people involved in the research and includes this in their reporting
Individual	<ul style="list-style-type: none"> • Feedback from public contributor on their experience of PI in a research project or organisation is routinely recorded, monitored, reported and acted on
Indicator 5.3	We involve the public in assessing the impact and outcomes of PI in research activity
Organisational	<ul style="list-style-type: none"> • A research organisation sets up a group of public advisors to work with them to assess whether intended outcomes and impact have been achieved
Team/project	<ul style="list-style-type: none"> • The team works with public members to develop the evaluation process for PI e.g. a workshop to reflect on the impact of PI in the project

Individual	<ul style="list-style-type: none"> Public contributors are part of the team that writes an annual progress report on the delivery of PI plans Public members help analyse the PI evaluation data and contribute to future recommendations for PI
Indicator 5.4	We record and act on the results of our review of impact of PI activity
Organisational	<ul style="list-style-type: none"> An organisation publishes an annual report on the delivery of its PI plan including an assessment of impact and its future plans
Team/project	<ul style="list-style-type: none"> In publications, a research team writes about its PI activities and any impacts of PI and then uses their learning from the project to inform future projects
Individual	<ul style="list-style-type: none"> A public contributor can access case studies and reports that demonstrate the impact of PI

Standard 5 - Impact

Standard 6

Governance - we ensure the community of interest voices are heard, valued, and included in decision making. We implement, report and are accountable for our decisions.



Indicator 6.1	We have PI strategies and plans in place, with regular reporting
	Illustrations of indicators below:
Organisational	<ul style="list-style-type: none"> • A research organisation monitors and reports on a PI strategy that describes the objectives of PI for research and intended outcomes
Team/project	<ul style="list-style-type: none"> • PI is a standing item on senior management meetings • A research team plans the PI in their project and then monitors and reviews what they do to learn and improve the PI
Individual	<ul style="list-style-type: none"> • Public contributors are decision makers in developing, delivering, monitoring, reviewing and reporting plans for PI in research
Indicator 6.2	Responsibility for PI is visible and accountable through our management structure
Organisational	<ul style="list-style-type: none"> • An organisation has a publicly accessible PI strategy, and a named member of the senior management team (oversight) which sets out requirements for PI in individual studies • A named member of a research team is responsible for managing PI in a research project
Team/project	<ul style="list-style-type: none"> • The team regularly reviews progress against and updates the strategy for PI in the project
Individual	<ul style="list-style-type: none"> • Public contributors can identify who they should approach in a research team or organisation whether they want to raise a practical query or make a complaint • Public members are consulted about what resources might be needed to undertake PI effectively • Public members are involved in the review, development and implementation of the PI strategy for the organisation/project

Indicator 6.3	We allocate money and other resources for public involvement
<p>Organisational</p> <p>Team/project</p> <p>Individual</p>	<ul style="list-style-type: none"> • A research organisation has a designated PI budget that supports their PI plan and is reviewed regularly • A research team keeps records of resources to support PI so that this information can be used for project review, and design and proposals of future research • Public contributors are involved in decision making about the allocation of resources for PI • Public members have access to senior members of the team/organisation

Standard 6 - Governance

Public Involvement Standards and self assessment

This diagram shows the role of self assessment in the PI Standards. There are several models and examples of self assessment tools that organisations can use in the final full guidance.

