

INVOLVE



*National Institute for
Health Research*

Public involvement in research: values and principles framework

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INVOLVE (2015) **Public involvement in research: values and principles framework**, INVOLVE: Eastleigh.

This document is a revised version of a previous draft. It replaces: **Values, principles and standards for public involvement in research, Draft framework**, Version 4, February 2015.

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Introduction: values and principles of public involvement in research

Background

In 2013 INVOLVE reviewed literature, publications and reports¹ that looked at values, principles and standards for public involvement in research². An INVOLVE Advisory Group was brought together in 2014 to consider adapting the findings from the review into a draft framework³ to identify and reflect on good practice, which was then put out for wider comment and discussion.

This revised version of the framework reflects the extensive feedback received from this exercise, including two key conceptual changes to previous drafts⁴. These are:

- The examples for each of the six values have been redefined to illustrate principles in practice for each value rather than setting out standards and examples of standards in action. The reasons for this are that, given that the framework is still in development, it was considered pre-emptive to be establishing standards at this stage of the process.
- In earlier versions of the framework, the heading for Value 5 was 'Diversity'. This heading has now been changed to 'Fairness of opportunity' to better reflect the purpose of this specific value and to emphasise that the term 'diversity', alongside the terms 'equality' and 'inclusion', as defined in the [Equality Act 2010](#), are overarching ideals within which all six values of this framework must be situated.⁵

Purpose

The purpose of this work is to develop a framework of good practice for public involvement in research. It is intended that this framework is a living document that will continually evolve over time and be useful for reporting public involvement in research as well as for assessing the quality of involvement.

¹ INVOLVE (2013) [Values, principles and standards for public involvement in research](#) INVOLVE: Eastleigh.

² INVOLVE's definition of public involvement in health and social care research: www.involve/nih.ac.uk/find-out-more/what-is-public-involvement-in-research-2/

³ INVOLVE (2015) [Values, principles and standards consultation report](#) INVOLVE:Eastleigh.

⁴ This includes: INVOLVE (2015) Values, principles and standards for public involvement in research, Draft framework, Version 4, INVOLVE: Eastleigh www.involve/nih.ac.uk/wp-content/uploads/2015/03/Draft-framework-Values-principles-and-standards-Version-4-February-2015.pdf

⁵ INVOLVE (2015) Equality, diversity and inclusion: INVOLVE's action plan – forthcoming December 2015

Values, principles and principles in practice - Definitions

Values – overarching ideals that are important to the public involvement community

Principles – statements that describe those ideals in more detail, providing further information and context

Principles in practice – putting principles into practice, giving examples of good practice

Summary table - Values and principles for public involvement in research

Values	Summary principles
Respect	Researchers, research organisations and the public respect one another's roles and perspectives
Support	Researchers, research organisations and the public have access to practical and organisational support to involve and be involved
Transparency	Researchers, research organisations and the public are clear and open about the aims and scope of involvement in the research
Responsiveness	Researchers and research organisations actively respond to the input of public members involved in research
Fairness of opportunity	Researchers and research organisations ensure that public involvement in research is open to individuals and communities without discrimination
Accountability	Researchers, research organisations and the public are accountable for their involvement in research and to people affected by the research

How were the values and principles developed?

The 2013 INVOLVE review of the literature⁶ identified six values as underlying good practice in public involvement in research: respect, support, transparency,

⁶ INVOLVE (2013) [Values, principles and standards for public involvement in research](#) INVOLVE: Eastleigh.

responsiveness, fairness of opportunity⁷ and accountability. The principles associated with each of these values provide more detail about what the values mean in terms of public involvement in research.

How should the framework be used?

The framework needs to reflect the fact that public involvement in research happens in different contexts and with different groups. There are complexities and tensions in setting out, delivering and evolving good practice, and the framework is likely to be used differently by each organisation or research project.

To illustrate this Appendix A provides helpful examples of three National Institute for Health Research (NIHR) research organisations – the Central Commissioning Facility, the National Horizon Scanning Research & Intelligence Centre and the Trainees Coordinating Centre, who used the previous draft framework⁸ to provide summary self-assessments for each of the values, based on their internal practices of involving public members in their organisations' research processes and procedures.

The framework recognises that:

- research organisations have a responsibility to support public involvement activity;
- good quality public involvement depends upon a culture of support as well as individual good practice; and
- the responsibility for upholding the values and principles in the framework should be shared by researchers, research organisations and public members involved in research.

Appendix A reflects the intention for this framework to evolve over time, and to be used to build, support and share learning of good practice.

Who is the framework for?

The framework is for researchers, organisations and others involved in supporting and managing public involvement in research, as well as for members of the public involved in research.

⁷ 'Fairness of opportunity' - Value 5. As explained in the background section of the introduction, 'Diversity' was the original summary heading for Value 5 but was changed to 'Fairness of opportunity' to more accurately reflect the overarching ideals within which all six values are situated.

⁸ INVOLVE (2015) Values, principles and standards for public involvement in research, Draft framework, Version 4, INVOLVE: Eastleigh www.involve.nihr.ac.uk/wp-content/uploads/2015/03/Draft-framework-Values-principles-and-standards-Version-4-February-2015.pdf

Value 1: Respect

Principle: Researchers, research organisations and the public respect one another's roles and perspectives

Principles in practice

- 1a. Public members' skills, knowledge and experience are respected
- 1b. The knowledge and experience of researchers and others involved in administering or managing research skills are respected
- 1c. Public members are included as key partners of research
- 1d. Public members are involved from the outset
- 1e. Public members' contributions to the research are recognised

Examples

Below are some examples of what each of the principles linked to respect might look like in practice. The examples are not exhaustive but give an idea of the types of activities that could fall under each of the principles.

- 1a. Researchers and organisations involved in research recognise the importance of public members' knowledge and the impact of including people with different perspectives throughout the research process.
- 1b. Public members respect the knowledge and expertise of researchers and others involved in research.
- 1c. Public members are included in decisions about research in a number of different ways, for example as grant co-applicants, members of research funding boards or project steering groups.
- 1d. Public members are involved in the ideas phase of the research, working with researchers and others to discuss priorities and research questions; public members help to make decisions about the research protocol and ethics application; public members review and provide feedback on grant applications.
- 1e. Public members' contributions are acknowledged, for example as co-applicants in research applications, as authors or co-authors of publications, or as presenters or co-presenters of research findings.

Value 2: Support

Principle: Researchers, research organisations and the public have access to practical and organisational support to involve and be involved

Principles in practice

- 2a. Public members have access to learning and development to support their involvement in research
- 2b. Researchers and others have access to learning and development to support public involvement in research
- 2c. There is flexibility to support public involvement
- 2d. Public members' expenses are covered, and they are informed in advance if payment will be offered for their time
- 2e. Infrastructure within research organisations enables and supports public involvement in research

Examples

Below are some examples of what each of the principles linked to support might look like in practice. The examples are not exhaustive but give an idea of the types of activities that could fall under each of the principles.

- 2a. Public members are supported to develop their skills and understanding of involvement in research; public members have a key contact or mentor who can provide advice and guidance about involvement in research.
- 2b. Researchers and others have access to learning and support on public involvement helped by their university or another organisation; researchers and others have the opportunity to shadow those who are involving the public in their research and/or have a mentor who provides advice and guidance.
- 2c. Researchers and others ensure that the study timelines are realistic and negotiated to allow a reasonable amount of time for public members to input into the research; alternative ways to input into meetings (e.g. via Skype, teleconferencing, social media channels) are explored.
- 2d. Public members are given clear information in advance of what expenses and other costs related to involvement are available and how they will be reimbursed

(including for travel, carer costs, preparing for and attending meetings).

2e. Organisations have policies that work for public members, where arrangements are explained clearly and delays are minimised; organisations recognise public involvement as important and support researchers and others to take time to involve public members; organisations allocate resources and time to support public involvement, learning and mentoring opportunities.

Value 3: Transparency

Principle: Researchers, research organisations and the public are clear and open about the aims for and scope of the involvement in research

Principles in practice

- 3a. Researchers and others involved in the research openly discuss with public members the purpose, scope and expectations in advance of their involvement in the research
- 3b. Researchers provide clear information to public members about their role and their input
- 3c. Public members are open about their ability to contribute

Examples

Below are some examples of what each of the principles linked to transparency might look like in practice. The examples are not exhaustive but give an idea of the types of activities that could fall under each of the principles.

- 3a. Researchers and others discuss and agree with public members why and how they will be involved.
 - 3b. Clear information is given about public members' role and what has been agreed; information is given about the period of time over which involvement will be required and the type of contribution (e.g. partnership, advisory role, reviewer).
 - 3c. Public members are open about their availability and the time commitment that they would be able to make to the research; public members are clear about the experience and the perspective that they are bringing to the research.
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Value 4: Responsiveness

Principle: Researchers and research organisations actively respond to the input of public members involved in research

Principles in practice

- 4a. Public members, researchers and others contribute to collaborative decision-making
- 4b. Researchers and research organisations are committed to public involvement and are willing to act on the input of the public
- 4c. Public members commit to their involvement in research and are willing to contribute to the research

Examples

Below are some examples of what each of the principles linked to responsiveness might look like in practice. The examples are not exhaustive but give an idea of the types of activities that fall under each of the principles.

- 4a. All those involved in the research are able to input into research decisions and voice their opinions; for example meetings are structured so that public members are able to contribute to, lead or chair discussions.
 - 4b. Public members are listened to and changes are made to the research as a result of the insights, advice and guidance received; where changes are not made there is feedback about the reasons for this.
 - 4c. Public members agree a framework for their contribution, for example as co-applicants, advisors, reviewers; public members agree timelines for providing feedback and the provision of support needed to facilitate their contributions.
-

Value 5: Fairness of opportunity

Principle: Researchers and research organisations ensure that public involvement in research is open to individuals and communities without discrimination

Principles in practice

5a. Public members, researchers and others understand and sign up to the principles of equality, diversity and inclusion as defined in the Equalities Act 2010

5b Researchers and research organisations ensure that public involvement opportunities are accessible to all

5c. Information is presented in accessible and alternative formats and written in plain English

Examples

Below are some examples of what each of the principles linked to fairness of opportunity might look like in practice. The examples are not exhaustive but should give an idea of the types of activities that fall under each of the principles.

5a. The diversity required for the research is considered and an effort is made to involve those who reflect that diversity.

5b. Researchers and others act to ensure fairness of opportunities and reach out to groups and individuals who may not have been involved in research before; relationships are developed with communities to enable people to understand the research and how they can be involved.

5c. Information about involvement in research is provided in a range of ways, such as through social media, printed information, speaking at meetings; people are asked what they need to be involved; all information is written in plain English, free of acronyms; glossaries or jargon busters are provided for terms used in the research process.

Value 6: Accountability

Principle: Researchers, research organisations and the public are accountable for their involvement in research and to people affected by the research

Principles in practice

- 6a. Researchers and research organisations have policies in place for the governance of public involvement in research and public accountability
- 6b. Researchers and research organisations are accountable to public members involved in the research
- 6c. Public members are accountable to researchers, research organisations and others for their involvement
- 6d. Researchers, research organisations and public members assess the impact of public involvement in the research

Examples

Below are some examples of what each of the principles linked to accountability might look like in practice. The examples are not exhaustive but give an idea of the types of activities that fall under each of the principles.

- 6a. Researchers and research organisations include the governance of public involvement in their policies related to research accountability; there are clear policies in place for how researchers or public members can ask questions or voice concerns about the arrangements or conduct of involvement activities linked to research; the people who will be affected by the research are recognised and informed and an effort is made to reach out to them in the development and dissemination of the research.
 - 6b. Researchers and research organisations openly communicate with public members and tell them what has been changed as a result of their input; public members are contacted to tell them how their contributions have had an impact.
 - 6c. Public members agree clear aims and objectives for their involvement with the opportunity for review and discussion.
 - 6d. At the end of a research study all those who have worked together actively reflect on the public involvement in the project and assess the learning and how it has gone; everyone is given an opportunity to feed back about their experience of involvement.
-

Appendix A

Examples of principles in action reflecting current practices

Self-assessments by three National Institute for Health Research (NIHR) research organisations (2015)

- 1. NIHR Central Commissioning Facility**
 - 2. NIHR Horizon Scanning Research and Intelligence
Centre**
 - 3. NIHR Trainees Coordinating Centre**
-

1. NIHR Central Commissioning Facility (CCF)

Value 1: Respect

Principle: Researchers, research organisations and the public respect one another's roles and perspectives

Principle in practice at CCF:

- CCF's Patient and Public Involvement and Engagement ([PPIE](#)) Plan describes our purpose in involving patients, carers and the public in our research management activities and outlines the roles and perspectives that they bring to research.
 - CCF regularly involves members of the public in two different ways: as reviewers of funding applications and as members of funding panels and committees. The latter happens through an open recruitment process.
-

Value 2: Support

Principle: Researchers, research organisations and the public have access to practical and organisational support to involve and be involved

Principle in practice at CCF:

Support for public contributors

- Online [resources for patients, members of the public](#) and [researchers](#) about patient and public involvement.
- Clearly defined roles, welcome pack, '[Top tips](#)' and a list of learning and support offered to public members.
- Learning and support meetings for public members who contribute to the work of a panel/committee.
- Written [guide](#) as well as one-to-one support for public reviewers who provide an assessment of an application.
- Central patient and public involvement ([PPI](#)) team to contact.

Support for CCF staff

- 'PPI Masterclass' sessions for all CCF staff (inviting speakers from other organisations to talk about their approach to and practice in PPI).
 - Internal PPI Working Group for team leads.
 - One-to-one induction for new-starters.
 - Developing organisational policy for learning and support.
 - Developing support for research programme managers to actively monitor the delivery of PPI in funded research projects.
 - Central [PPI team](#) to contact.
-

Value 3: Transparency

Principle: Researchers, research organisations and the public are clear and open about the aims for and scope of the involvement in research

Principle in practice at CCF:

- We work with public contributors to develop information, resources and our Patient and Public Involvement and Engagement ([PPIE plan](#)). When we work with patients and members of the public, we always provide them with information about what the task involves, their expected contribution, the support we can provide them with and the remuneration we can offer for the time and effort for getting involved. We also offer paper copies of electronic documents.
-

Value 4: Responsiveness

Principle: Researchers and research organisations actively respond to the input of public members involved in research

Principle in practice at CCF:

- We involve patients and members of the public in developing key documents and policies such as the [PPIE plan](#), [Reviewers' guide](#) and [Fees and expenses guide](#).
 - Reviews submitted by public contributors inform panel/committee meetings. Public members are an equal part of the panel/committee and their voice and vote count as much as anyone else's on the panel/committee.
 - Researchers receive feedback about their planned project through reviews and comments provided by the panel/committee.
-

Value 5: Fairness of opportunity

Principle: Researchers and research organisations ensure that public involvement in research is open to individuals and communities without discrimination

Principle in practice at CCF:

- Working with relevant groups: We are developing an online form that will record information about public contributors' personal experience of health conditions as patients or carers. Once we have rolled this form out, we will analyse the range of health topics covered by our current public contributors. We will also begin to target recruitment on identified gaps in health topic coverage.
- Equal opportunity: We are developing and testing a monitoring system that will provide information about the diversity of CCF's public contributors. Once

we have established gaps in diversity of current public contributors, we will begin to target recruitment.

Value 6: Accountability

Principle: Researchers, research organisations and the public are accountable for their involvement in research and to people affected by the research

Principle in practice at CCF:

- We regularly submit updates on our activities to INVOLVE and the Department of Health, as well as report on past, current and planned activities publicly. We have just launched our new [PPIE plan](#) for the coming year and a report on the delivery of our plan will be publicly available in 2016.
 - We notify public reviewers of the outcome of applications they have assessed.
 - We send informal email updates to public contributors on our database.
 - We are using Plan-Do-Study-Act (PDSA) cycles to improve our work and processes.
-

Patient and Public Involvement Team, CCF March 2015

2. NIHR Horizon Scanning Research and Intelligence Centre

As reported in: Horizon Scanning Research & Intelligence Centre (2015) Patient and Public Involvement & Engagement Strategy 2015 – 2016, p5

* PPI VALUES WITHIN THE HSRIC

Summary principles

Respect

Researchers and the public should show mutual respect for each other's roles and perspectives
e.g. at the HSRIC hear and consider all comments made by patients/public with respect and patience

Support

Researchers and the public should have access to the support necessary to enable them to involve and be involved
e.g. at the HSRIC offering reimbursement for expenses incurred if group is convened within Public Health e.g. website review

Transparency

Researchers should provide accessible information, and show clarity and openness around the aims and scope for involvement in the research

e.g. at the HSRIC being honest and open about why we are involving them and what is our organisational responsibility

Responsiveness

Researchers should show a commitment to act on involvement and make changes to decisions and policies

e.g. at the HSRIC to include, where appropriate, comments made by patients/public in outputs

Fairness of opportunity

Involvement should be offered to relevant groups with equal opportunity, and effort should be made to ensure involvement is inclusive and seldom heard voices are represented

e.g. at the HSRIC involve patients/public regardless of the burden of their disease

Accountability

There should be accountability to communities and groups that are affected, and involvement should be assessed with feedback provided to those involved

e.g. at the HSRIC letting patients/public know how their comments on a briefing/review were incorporated

* Drawn from INVOLVE 'Values, principles and standards for public involvement in research', Version 3 Oct 2013, INVOLVE: Eastleigh. **Examples have been added in blue font to show how it may apply to the HSRIC.**

NIHR Horizon Scanning Research & Intelligence Centre, April 2015

3. NIHR Trainees Coordinating Centre (TCC)

Framework principles in action:

Values 1 Respect

The scope of the role of public members is made clear in the role description at the point of recruitment as well as in the guidance for PPI members.

Staff are instructed to ensure that public members are treated and supported as other panel members.

Due to the nature of the awards application process at TCC and the volume of applications to assess, TCC only requires public members to assess and score the PPI aspects of the applications.

Public members are expected to attend all three days of interviews, and are encouraged to attend all evening dinners for the panel.

Value 2: Support

In order to ensure that public members have the knowledge, skills and support to carry out their role, TCC provides public members with an induction pack into NIHR and NIHR TCC, named staff to contact, guidance notes on the assessment process and what happens at interviews.

An Induction Day into NIHR and TCC is now introduced with input from a TCC Director, existing PPI panel member and panel Chairs to welcome and support new public members.

Through relationship-building TCC also aims to ensure that public members feel comfortable sharing any concerns and issues that they may have. Anonymised evaluation of PPI is also planned this year, in addition to staff requesting feedback.

Value 3 Transparency

Our strategy documents and roles are publicly available and shared with panel members

Value 4: Responsiveness

Public members are encouraged to take active roles as panel members and to question interview candidates on any aspect of their PPI that can be improved or is unclear prior to funding being approved.

Value 5: Fairness of opportunity

TCC is committed to operating in a non-discriminatory way with equal access and opportunity for all panel members within the scope of their roles.

- a) When recruiting, TCC now uses a standard recruitment process for public members. It advertises nationally using roles descriptions and person specifications, application forms are anonymised at shortlisting and assessed by a mixed panel of staff and Chairs/Deputy Chairs/panel members. Public members are interviewed against the criteria in the person specification. Any reasonable adjustments required at interview are noted and acted upon.

TCC staff observed the interviews and ensured, amongst other things, that the interview panel considered that public members who may not necessarily understand the whole academic trajectory, may have used different vocabulary to respond to questions, which must still be considered legitimate answers. This was to ensure that the assessment process was fair to all applicants, including those from a non-research or non-academic background who met the criteria, and to encourage different points of view when discussing public member candidates' performance at interview.

- b) In order that all panel members can contribute to the review panel interviews and can carry out their roles in the best possible way, TCC makes reasonable adjustments.

For the face-to-face Fellowships interviews, which take place over three days, there is significant liaison with the hotel and the PPI members on any reasonable adjustments for those with additional needs. For instance, TCC ensures that a Personal Emergency Evacuation Plan (PEEP) is in place at the hotel for all disabled members, and that arrangements are made for carers (including arranging specific carer rooms). In terms of considering rooms for the panel interviews, the size, location and layout are all chosen to ensure that any additional needs are met, where reasonably possible.

Whilst TCC uses an online assessment system for applications, it has printed and couriered applications to PPI members, and arranged for the annotated forms to be couriered back in time for the interviews.

Value 6: Accountability

Governance and responsibility: The Panel Chair's brief includes a specific section on the role of public members, and all panel members, including public members, are expected to act within the TCC terms of reference for review panels and sign the code of practice.

On an organisational level, TCC is subject to audits by the Department of Health on patient and public involvement. It also includes quarterly metrics on involvement.

The TCC strategy and opportunities are in the public domain.

NIHR Trainees Coordinating Centre: October 2015

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