

Values, principles and standards for public involvement in research:

Draft framework, version 3, 27 October 2014

Introduction

Background

In 2013 INVOLVE reviewed resources, publications and reports that looked at values, principles and standards for public involvement in research¹. While there was broad agreement about the underlying values, there had been challenges to developing shared principles and standards. An INVOLVE Advisory Group was brought together in 2014 to consider adapting the findings from the review into a framework to identify and reflect on good practice. This framework comprises values, summary principles, standards and examples of standards in action.

How were the values, principles and standards developed?

The 2013 review identified six values as underlying good practice in public involvement in research: respect, support, transparency, responsiveness, diversity and accountability. The principles provide more detail about these values, explain what each value means in terms of public involvement, and summarise the review findings. The principles are broken down into standards, then standards in action that outline examples of what each standard might look like in practice.

How should the framework be used?

The framework has been developed to be flexible and to allow people who want to involve the public in their research to learn, reflect and share. Wherever you are in your experience of public involvement, there is room for growth and continuous development. This framework reflects the fact that public involvement happens in different contexts and with different populations, and that not all good practice looks the same. There are complexities and tensions in meeting standards, and the framework might be implemented differently by each organisation or research project.

Who is the framework's intended audience?

The framework focuses on researchers and members of the public. However, it is important to note that organisations – for example, hospital trusts, universities, funding bodies, governance bodies, research commissioners and research units – also have a responsibility to support public involvement activity. Good quality public involvement depends upon a culture of support as well as individual good practice. The responsibility for upholding the values, principles and standards in the framework should be collective: organisational and personal².

Footnotes

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

² Please note that while the text in the framework refers to researchers and members of the public, many of the principles and standards could be adapted to have relevance for organisations (including parts of the organisations that support researchers, such as finance offices and human resources)

Value 1: Respect

Principle: Researchers and the public show mutual respect for each other's roles and perspectives

Standards

- 1a. Public members' skills, knowledge and experience are respected
- 1b. Researchers' skills, knowledge and experience are respected
- 1c. Public members have a voice as key stakeholders of research
- 1d. Public members are involved from the outset, alongside researchers
- 1e. Public members are recognised and rewarded for their contribution

Standards in action

Below are some examples of what each of the respect standards might look like in practice. The examples are not exhaustive but should provide an idea of the types of activities that could fall under each of the standards.

- 1a. Researchers are aware of the importance of public members' knowledge of their condition and the usefulness of including someone with a different perspective in the design and delivery of research; public members' voices are heard in the research process and their comments and suggestions are recognised and acknowledged / taken on board
 - 1b. Public members are aware of the importance of researchers' knowledge about the science of health conditions and their experience with research processes and procedures
 - 1c. Public members are included in the project steering group; public members are grant co-applicants; public members' input makes an impact on the design, management and dissemination of the research
 - 1d. Public members are included in the ideas phase of the research, where they meet with researchers and discuss priorities and research questions; public members are partners in the research process, helping to make decisions about the research protocol and ethics application
 - 1e. Public members' contributions are acknowledged, for example in meetings and in publications; public members attend conferences and present alongside researchers
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Value 2: Support

Principle: Researchers and the public have access to the practical and organisational support necessary to enable them to involve and be involved

Standards

2a. Public members have access to training, learning and development to enable their involvement in research

2b. Researchers have access to training, learning and development in public involvement in research

2c. Public members are offered payment for their time and expenses are covered

2d. There is flexibility within the project (e.g. appropriate timelines, adequate resources, realistic expectations) to support public involvement

2e. Infrastructure within research organisations enables and supports public involvement

Standards in action

Below are some examples of what each of the support standards might look like in practice. The examples are not exhaustive but should provide an idea of the types of activities that could fall under each of the standards.

2a. Public members have access to training that may develop their skills or confidence to get involved in research; public members have a key contact or mentor who may provide advice and guidance about involvement in research

2b. Researchers have access to public involvement training hosted by their university or another organisation; researchers have the opportunity to shadow others who are involving the public in their research; researchers have a mentor who provides advice and guidance

2c. Public members are offered an agreed fee for time spent preparing for, travelling to, and attending meetings; public members are offered a fee for reviewing a research protocol or study documents; the costs related to involvement (transport, etc.) are covered

2d. The study timelines allow a reasonable amount of time for members of the public to provide input; the resources allow for researchers to involve public members and reimburse them, provide accessible meeting rooms, refreshments and

other requirements

2e. Organisations have policies that enable a payment process that works for public members, where arrangements are explained clearly and delays are minimised; organisations recognise public involvement as important and support researchers to take the time required to involve public members; organisations allow access to and time for public involvement training and learning opportunities

Value 3: Transparency

Principle: Researchers provide accessible information, and show clarity and openness about the aims and scope for involvement in the research

Standards

3a. Information is written in plain English and presented in accessible formats

3b. Public members are provided with clarity about their role, the timelines of their involvement, and expectations of their contributions

3c. Researchers are honest and open with public members about the purpose and scope of involvement in research

3d. Public members are honest and open with researchers about their ability to contribute

Standards in action

Below are some examples of what each of the transparency standards might look like in practice. The examples are not exhaustive but should provide an idea of the types of activities that could fall under each of the standards.

3a. Information about the study, potential plans for its design and ideas about the methods that may be used are in plain English and free of acronyms; information is provided in large print if needed, or in audio or Braille

3b. Researchers give clear information about the role that public members will have - where they will be able to provide input and have an impact on the research; researchers give information about the period of time input will be required; researchers give advice about what type of contribution is required or possible (partnership, advisory role, reviewer, etc.)

3c. Researchers have considered why and how they wish to involve public members before inviting people to get involved, and they communicate this to public members

3d. Public members are open about their availability and the time commitment that they would be able to make to the research; public members are open about their experience and their perspective

Value 4: Responsiveness

Principle: Researchers show a commitment to act on involvement and an openness to making changes to decisions and policies

Standards

4a. Researchers and public members contribute to collaborative decision-making

4b. Researchers are committed to public involvement and show a willingness to act on the advice of the public

4c. Public members show a commitment to their involvement in research and a willingness to contribute to research

Standards in action

Below are some examples of what each of the responsiveness standards might look like in practice. The examples are not exhaustive but should provide an idea of the types of activities that could fall under each of the standards.

4a. Researchers and public members have their voices heard in meetings and are able to input into research decisions; researchers structure meetings so that public members are able to contribute to the conversation and have a say in decisions

4b. Researchers listen to the public members that they have involved and make changes to the research as a result of the advice and guidance that they receive

4c. Public members (where supported to do so) contribute to meetings, respond to emails and provide feedback within reasonable timelines

Value 5: Diversity

Principle: Public involvement is offered to relevant groups with equal opportunity, and action is taken to ensure involvement is inclusive and that seldom heard voices are represented

Standards

- 5a. Researchers enable equitable access to involvement opportunities
- 5b. Researchers strive for inclusion of diverse communities³
- 5c. Researchers provide different activities and/or ways for people to get involved

Standards in action

Below are some examples of what each of the diversity standards might look like in practice. The examples are not exhaustive but should provide an idea of the types of activities that could fall under each of the standards.

- 5a. Researchers consider the diversity of people who may be affected by their research and reach out to people who reflect that diversity; researchers reach out to groups and organisations where people affected by their research might be and ensure that their involvement will be supported with adaptations they require
- 5b. Researchers take action to involve members of the public whose voices are heard less often; researchers look outside the usual areas and reach out to groups and individuals who may not have been involved in research before
- 5c. Researchers establish a public advisory group but also give public members the option to review and comment via email; researchers ask public members to help to determine research priorities and include a subset of them on a project steering group; researchers provide information in different media in order to enable people with communication differences or learning difficulties to contribute

Footnote

³Differences might include race and ethnicity, culture and belief, gender and sexuality, pregnancy and maternity, age and social status, ability and use of health and social care services

Value 6: Accountability

Principle: There is accountability to communities and groups that are affected, and involvement is assessed with feedback provided to those involved

Standards

- 6a. Feedback is given to those who have been involved
- 6b. Plans are put in place to review or evaluate the process and impact of public involvement
- 6c. Researchers are accountable to the public and service user groups who will be affected by the research
- 6d. Public members take responsibility for their contribution
- 6e. Researchers have policies for handling issues around public involvement in research
- 6f. Researchers demonstrate a duty of care to public members

Standards in action

Below are some examples of what each of the accountability standards might look like in practice. The examples are not exhaustive but should provide an idea of the types of activities that could fall under each of the standards.

6a. Researchers keep open communication lines with public members and let them know how the research has been changed as a result of their input; researchers get in touch with public members after the research is complete to tell them how their contributions have had an impact on the research; researchers feed the findings of the study back to the public members who have been involved

6b. Researchers establish clear aims and objectives for involving public members and review this at the end of the research; researchers and public members actively reflect on the public involvement in the project and how it has gone; public members are given an opportunity to feed back to researchers about their experience of involvement; researchers and public members agree an evaluative framework and assess the impact of public involvement against this framework

6c. Researchers recognise the public groups who will be affected by the research and involve them in it; researchers are aware of the service user groups to whom their research is relevant and reach out to them in the development and/or

dissemination of their work

6d. Public members are responsible for contributing to joint-decision making; public members make clear the reasons for their comments and suggestions

6e. Researchers put a complaints process in place; researchers agree a process for dealing with ill health during involvement; there is a named support person for public members to go to ask questions or voice concerns

6f. Researchers put processes in place that ensure public members have the support they need if involvement leads to any upset or distress
