
Values, principles and standards for public involvement in research

October 2013

Contents

- 1. Introduction**
- 2. Search strategy**
- 3. Background and context**
- 4. Remit of the review**
- 5. INVOLVE definitions**
- 6. Principles of public involvement**
- 7. Standards and quality assessment**
- 8. Current work on standards**
- 9. Conclusions**
- 10. Next steps**

About this paper

This paper was written by Marisha Palm, INVOLVE Coordinating Centre, with input and guidance from Sarah Buckland, Maryrose Tarpey, and Helen Hayes from the INVOLVE Coordinating Centre.

1. Introduction

This report was undertaken by INVOLVE to review what work had already been done on principles and standards for public involvement in NHS, public health and social care research. The review is not exhaustive but provides an overview of how others have discussed and defined principles and standards for public involvement.

The review draws out commonly identified public involvement principles and describes the values that underpin them. It explores the potential benefits and challenges to identifying a set of core standards for public involvement, and also looks at the connection between standards and quality indicators or assessment frameworks.

The purpose of this piece of work is not to propose a set of core public involvement standards, but rather to describe the context within which standards might be developed. The feasibility and appropriateness of shared core standards are explored, and next steps proposed.

2. Search strategy

Information on principles and standards for public involvement in research was found:

1. by reviewing the INVOLVE 'Resource centre', which has an Evidence library, Putting it into practice database, and various publications and resources for researchers
2. by performing internet searches with key words 'standards for public involvement' and 'principles for public involvement' and reviewing the first five pages
3. through consultation with colleagues and review of recommended papers and involvement documents.

3. Background and context

The public involvement field has an active community that share learning and good practice in a range of ways, for example via recommendations, guidance, briefing notes, examples of public involvement, how-to-guides, resource packs, toolkits, models, and research on public involvement.

However, increasingly, discussions within INVOLVE and across the National Institute for Health Research (NIHR) have raised questions as to whether it is appropriate and feasible to develop a shared set of principles and standards for public involvement in research.

To help to explore this further, and as a first step, we reviewed a selection of resources, publications and reports that identify principles and standards for public involvement. We also reviewed INVOLVE publications and guidance for researchers on public involvement in NIHR funding schemes.

The reasoning behind this was that:

1. it would help the involvement community to think critically and consider issues around why and how the public is involved in health and social care research, and what is considered good practice
2. having a shared set of core standards could be practically useful in reporting on involvement and assessing the quality of involvement in:
 - proposals for research
 - the conduct of research
 - research structures and organisations.

4. Remit of the review

Guidance and good practice examples are often specific rather than general in order to aid a certain approach to involving the public in research or support involvement of a particular population. This review will not focus on more specific guidance or recommendations; instead it will concentrate on articles, reports and other documents that discuss the underlying principles or standards that may be common across different types of involvement and in different contexts.

Included in the review are some examples of the documents below that specifically mention values, principles, or standards of public involvement in research:

- peer-reviewed articles
- published reports
- briefing or guidance documents
- funder evaluations.

Also included are INVOLVE publications, and articles that relate to quality assessment of public involvement or instruments created to document involvement activity.

5. INVOLVE definitions

The terms values, principles and standards have been used in different ways, and in some cases they have been used interchangeably. In this report we define the three terms as follows:

- values – overarching ideals that are of importance to the public involvement community
- principles – statements that describe those ideals in more detail, providing further information and potentially some context
- standards – the operationalisation of principles, giving a clear idea of the agreed way to involve the public and allowing assessment to take place.

6. Principles of public involvement

Telford et al. (2004) made one of the first attempts to gain consensus around principles of involvement in order to guide good practice, provide recommendations and increase understanding about involvement. Eight principles of involvement were put forward based on an expert workshop that used a structured process of brainstorming which encouraged participation from everyone. This was followed by a two-round postal Delphi process that obtained consensus (see Appendix B).

The Telford study concluded by stating that researchers need to look at how transferable the eight principles are to different research methodologies and models of involvement. This highlights the challenge of identifying one set of standards that are flexible and appropriate to the variety of activity that falls under the term ‘public involvement’.

Boote et al. (2006) took the Telford study’s principles and looked at whether consumers, researchers and consumer-researchers rated the principles and indicators differently. Researchers found that all three groups showed similar ratings, and noted that principles developed by study participants cover moral, ethical and practical issues, and address process rather than outcome measures.

Telford et al. went on to use the principles of involvement that were agreed in the 2004 Delphi study in a national postal survey of completed health research projects selected from the National Research Register and the INVOLVE database (Barber et al., 2007). Of 88 projects that involved consumers, 80 met one or more of the eight indicators, with most meeting between one and four.

In the same year that Telford et al. published their Delphi study, Faulkner (2004), writing about the ethical conduct of research carried out by mental health service users and survivors, concluded that there was considerable consensus around the principles underlying this research. These were outlined (see Appendix C) and researchers and the public were encouraged to talk about and consider these principles prior to starting a research project.

Outside of peer-reviewed publications, organisations such as the Service User Research Group England (2005) and INVOLVE (2009) have included a description of underlying principles as part of good practice guidance around involvement (see Appendices D and E). A report by the Toronto Group (Hanley, 2005) and INVOLVE’s

'Briefing notes for researchers' (2012) also provide advice on what good practice in public involvement might look like (see Appendices F and G).

While the focus of this review is principles and standards related to public involvement in research, it is worth noting that there are a number of publications on public involvement in health and social care service delivery that mention principles. There are large overlaps between the principles presented in the documents related to involvement in research and those represented in the service delivery publications. To give an illustration, Appendix H shows the principles listed in the Joint Health and Social Care Regulators' Patient and Public Involvement Group publication.

The Nolan Principles, defined by the Committee for Standards in Public Life, are also relevant to this review (see Appendix I). The Committee spent six months inquiring into standards of public life and the resulting principles have been established and are now included in the Ministerial Code. They overlap with the summary principles of public involvement in research around issues of accountability and openness.

The public involvement guidance provided by the NIHR to researchers who are planning to submit grant applications is also relevant to this review, as the guidance gives an indication of the way in which plans for public involvement are assessed. Guidance from three of the NIHR programmes – Research for Patient Benefit; NIHR Programme Grants; and Health Technology Assessment – was reviewed. This guidance did not discuss principles or standards and did not map onto these things in a useful way, therefore these are not included as appendices. However, it may be useful to review them again in future.

A review of the existing literature found that, although the principles of public involvement have been described in different ways, they are underpinned by a set of values that are broadly similar across a number of peer-reviewed publications and published documents. These values are outlined below in Table 1, along with principles that are an amalgamation of the descriptions from the 9 publications and reports included in Appendices B to M.

Appendix A includes a more detailed overview of the six values along with the summary principles, which reflect descriptions identified in the review of publications and reports.

Table 1. Public involvement values and summary principles

Values	Summary principles
Respect	Researchers and the public should show mutual respect for each other's roles and perspectives
Support	Researchers and the public should have access to the support necessary to enable them to involve and be involved
Transparency	Researchers should provide accessible information, and show clarity and openness around the aims and scope for involvement in the research
Responsiveness	Researchers should show a commitment to act on involvement and make changes to decisions and policies
Diversity	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
Accountability	There should be accountability to communities and groups that are affected, and involvement should be assessed with feedback provided to those involved

Although the principles put forward in peer-reviewed articles and other published documents have significant overlaps and show similar values, a number of challenges to this exercise have also been identified, with the three main difficulties being:

1. developing principles that are relevant across the many different contexts within which public involvement takes place
2. agreeing principles that are transferable to the variety of activity included within public involvement
3. operationalising principles in a useful way to create standards for public involvement.

7. Standards and quality assessment

Part of the impetus for the development of public involvement standards comes from the desire to enable assessment of the quality of involvement activity. Some have argued that there is a need to move beyond guidance on public involvement in research to the development of instruments that assess the quality of that involvement (Boote et al., 2006; Staniszewska et al., 2011a; Wright et al., 2010). This is driven in part by the requirement to demonstrate value for money and in this way justify the time and resource spent on public involvement. Some researchers,

research-related staff and members of the public have called for standards as a synthesis of information that will enable this assessment.

Until recently there was a dearth of published research on assessment of the quality of public involvement. However, more recently information has begun to be collected, and suggestions made about how to improve the assessment and reporting of involvement. Some of this focus has been on the impact of involvement (for example Minogue et al., 2005; Staley, 2009; Barber et al., 2011a,b; Brett et al., 2012; Staniszewska et al., 2011; Nilsen et al., 2013), However, this is a separate issue that will not be covered in this review apart from where it intersects with quality assessment.

Those who call for assessment acknowledge that public involvement is a complex activity with interacting components that can differ according to context, and that this means evaluation can be difficult (Staley, 2009; Staley et al., 2012; Staniszewska et al., 2011a). However, they reason that this type of exercise is nevertheless useful in order to look at quality in a consistent way.

Although there are some who argue that it would be useful to be able to assess the quality of involvement, there are others who question the appropriateness of this exercise (for example Purtell and Wyatt, 2011). A number of challenges with attempting to assess the quality of involvement have been identified, including:

- there is no universal definition of involvement
- there is wide variation in how involvement is conducted within projects and programmes
- when attempting to look at quality the context and process are important.

Researchers have tackled the perceived need for assessment of public involvement in different ways, developing quality measures and assessment frameworks. Telford et al. (2004), mentioned earlier as having gained consensus on eight principles of successful consumer involvement, developed indicators that matched these principles (see Appendix B). The indicators provide more detail about how the principles can be assessed, and whether each has been met by a research project or programme that involves the public.

When indicators of the eight principles were assessed, authors were able to look at their clarity and validity but not feasibility, as the Delphi participants found this difficult to rate. They felt that this was difficult to judge outside of the context of a particular research project; therefore feasibility was removed from the analyses and flagged for future research (Boote et al., 2006).

More recently, Morrow et al. (2010) developed a model of quality involvement based on theoretical perspectives of power and empowerment from social theory literature (see Appendix J). Researchers note that their model fits within the principles identified by Telford et al. (2004); however, they emphasise that due to the range of

involvement activities and the broad notion of what constitutes health research, they are not proposing a one-size-fits-all solution. Instead they feel it is useful for researchers and service users to have a framework for critical reflection and reporting.

Wright et al. (2010) employed the Critical Appraisal Skills Programme (CASP), which is typically used as a framework for measuring research quality, as the basis for the creation of a tool to allow for the assessment of the quality and impact of public involvement (see Appendix K). The criteria have been developed to be applied flexibly as the relevance and applicability of each is dependent on the context, research method and level of involvement.

Morrow et al.'s (2010) framework looks at the involved member's ability to access information, achieve goals and make decisions; their potential to gain status, expertise and credibility; and their sense of being valued, enabled and empowered. This is all framed within the context of the research relationships, ways of doing research and research structures. Wright et al. (2010) approach assessment by breaking research activity into different stages and applying appraisal criteria against each of these stages.

In this review Telford et al. (2004) have been alone in pairing principles with assessment. However, further research has shown that the indicators that were defined are often only minimally or partially met by involvement activity, with most projects meeting between one and four of the eight indicators (Barber et al., 2007). It is not clear whether this is due to the accuracy of the indicators, the quality of the involvement, or simply the wide variation in activity and context making this type of assessment difficult.

8. Current work on standards

It is a sign of the interest in this area that in addition to attempts to provide more widely applicable quality assessment frameworks, new models are currently being developed in more specific contexts. The NIHR Evaluations, Trials and Studies Coordinating Centre (NETSCC) is developing a standards framework; the Clinical Research Networks are developing standards that will work across the National Institute for Health Research; the National Survivor User Network is developing and testing standards for involvement in mental health services (see Appendix L); and the Health Research Authority is also developing standards (see Appendix M).

In September 2013, a study funded by the Medical Research Council's Methodology Research programme finished its work assessing the impact of public involvement in health and social care research. Researchers looked at whether evidence about the impacts of public involvement and factors causally linked to these impacts can be used to develop good practice standards for public involvement in research more

generally. As part of its final report, this study, led by Professor Jennie Popay at Lancaster University, launched a web based resource on assessing impact of involvement in research projects, the Public Involvement Impact Assessment Framework (PiiAF; see www.piiaf.org.uk).

At this stage it is still unclear how feasible it is to develop standards, quality assessment tools or frameworks that are applicable across the range and diversity of involvement activity that takes place in health and social care research. Recent attempts have emphasised the necessity for flexibility in application or use as a critical reflection tool rather than a measurement tool. They have also acknowledged the importance of context and process and the difficulty of developing a framework in the absence of this information.

9. Conclusions

We reviewed the work that had been done on principles and standards for public involvement in NHS, public health and social care research and found that, although groups had defined some of these principles in different ways, many times they were underpinned by a common set of values.

Part of the impetus for development of core standards comes from the desire to operationalise the principles of public involvement in order to assess its quality. We therefore went on to review the literature on quality assessment, and highlighted some of the challenges that have been identified.

There is currently ongoing work around principles and standards being carried out by a number of organisations working in health and social care research. However, all of these appear within the specific context of the organisation within which they will be implemented.

Recent work in this area appears to be moving away from a one-size-fits-all model to the creation of tools for reflection and reporting or flexible application of guidance. It remains unclear what is most important to report, and there is still disagreement about what is essential for good practice in public involvement.

A consistent theme throughout the review was the importance of context and the huge variety of activity – with different purposes, aims and objectives – that falls within ‘public involvement’. This has made it more difficult to identify common standards that could be applied across different projects and types of involvement.

10. Next steps

This review is not comprehensive and therefore further sources of information about values, principles and standards would be welcomed. Feedback on the values and principles identified and whether there are any gaps would also be useful.

Following initial discussions at the INVOLVE symposium for Group members in September 2013, it was agreed that the next step will be to explore the feasibility of adapting the summary principles into a framework that can be used to identify good practice in public involvement in research.

We have established an advisory group of INVOLVE Group members and a representative from the Health Research Authority to discuss what this framework should look like and how it will be populated. This group will begin its work in early 2014.

We will also have a wider reference group who will be consulted at crucial stages, and we will seek feedback from others on the wording and content of the principles outlined and whether they accurately reflect the literature.

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List of appendices

Appendix A	Table of values and summary principles
Appendix B	The principles and indicators of successful consumer involvement in NHS research (Telford et al., 2004)
Appendix C	The ethics of survivor research: Underlying principles (Faulkner, 2004)
Appendix D	Guidance for good practice (Service User Research Group England, 2005)
Appendix E	Good practice in active public involvement in research (INVOLVE, 2009)
Appendix F	Research as empowerment (Hanley, 2005)
Appendix G	Briefing note for researchers, Briefing note five (INVOLVE, 2012)
Appendix H	Joint Health and Social Care Regulators' Patient and Public Involvement Group (October, 2010)
Appendix I	The Nolan Principles
Appendix J	Quality involvement framework (Morrow et al., 2010)
Appendix K	Critical appraisal criteria for assessing the quality and impact of user involvement on health research (Wright et al., 2010)
Appendix L	National Involvement Partnership: Baseline standards (National Survivor User Network, 2011)
Appendix M	Health Research Authority: Our principles and standards for public involvement (August 2013 for consultation)

Appendix A – Table of values and summary principles

The table lists the public involvement principles put forward by published documents (see Appendices B-J and groups them according to overarching values. The right column is the number of documents within which the principles are mentioned.

Values and summary principles	9
Respect	7
Respect for patient/publics' skills, knowledge and experience	3
Ensuring patients/public have a voice as key stakeholders	2
Everyone respects each other and each other's right to express their views	2
Involvement from the outset, full/equal membership for public	4
The public will be recognised and acknowledged for their contributions (reward and recognition)	1
Support	8
Support in terms of training, learning and development	7
Financial support for involvement (payment of fees and expenses)	7
Flexibility to support involvement (timescales, resources, expectations)	3
Enabling workforce to support involvement (part of job description, administrative, supervisory, emotional support)	2
Transparency	9
Accessibility of materials and information	7
Clarity around the role, time, expectations, scope to change, organisational responsibility, terminology	8
Honesty and openness about the research, scope for involvement, why involving, the aims of the project, roles	4
Responsiveness	6
Empowerment / shared decision making	3
The ability of involvement to impact the research and/or research to impact practice	3
Commitment to involvement on behalf of the organisation/funder	3
Diversity	8
Equitable access / inclusion of diverse communities and/or individuals	8
Provide different activities/ways of being involved to attract a wider range of people	1
Accountability	7
Feedback to those who have been involved	3
Plan to review / monitor / evaluate and report public involvement	5
Accountable to society and service user movement/communities/groups	2
Duty of care; policies for handling sensitive, difficult issues when they arise	2

Appendix B

The principles and indicators of successful consumer involvement in NHS research (Telford et al., 2004)

Principle	Indicator(s)
1 – The roles of the consumers are agreed between the researchers and consumers involved in the research	The roles of consumers in the research were documented
2 – Researchers budget appropriately for the costs of consumer involvement in research	Researchers applied for funding to involve consumers in research; consumers were reimbursed for travel costs; consumers were reimbursed for their indirect costs
3 – Researchers respect the differing skills, knowledge and experience of consumers	The contribution of consumers' skills, knowledge and experience were included in research reports and papers
4 – Consumers are offered training and personal support, to enable them to be involved in research	Consumers' training needs related to their involvement in the research were agreed between consumers and researchers; consumers had access to training to facilitate their involvement in the research; mentors were available to provide personal and technical support to consumers
5 – Researchers ensure that they have the necessary skills to involve consumers in the research process	Researchers ensured that their own training needs were met in relation to involving consumers in the research
6 – Consumers are involved in decisions about how participants are both recruited and kept informed about the progress of the research	Consumers gave advice to researchers on how to recruit participants to the research; consumers gave advice to researchers on how to keep participants informed about the progress of the research
7 - Consumer involvement is described in research projects	The involvement of consumers in the research reports and publications was acknowledged; details were given in research reports and publications of how consumers were involved in the research process
8 – Research findings are available to consumers, in formats and in language they can easily understand	Research findings were disseminated to consumers involved in the research in appropriate formats; the distribution of the research findings to relevant consumer groups was in appropriate formats and easily understandable language; consumers involved in the research gave their advice on the choice of methods used to distribute the research findings

Appendix C

The ethics of survivor research: Underlying principles (Faulkner, 2004)

Underlying principles*

Clarity and transparency	A clear and open approach towards all of the people involved in a project
Empowerment	Adopting an agenda for change; ensuring that service users' voices are heard through the research; challenging attitudes about people with a mental illness diagnosis
Identity	Power relationships that exist between the researcher and the researched are challenged through process and participation; a definition of service user is debated and agreed
Commitment to change	Research leading to change and not knowledge for its own sake; if not immediate change, contribution to a change in views or attitudes
Respect	Respecting people and their right to express their views
Equal opportunities	All views need to be represented; it is important to hear from people on the margins of service use
Theoretical approach	Transparency about the theoretical underpinnings of the research
Accountability	Consideration of the extent to which research is accountable to society and/or mental health service users locally and nationally

***Protection from harm is included as a note following these underlying principles, as it is of ethical importance but there was also concern that it could be patronising and inappropriate**

Appendix D

Guidance for good practice (Service User Research Group England, 2005)

Underlying principles	It is important for all researchers and service users participating in a research project to take time to consider the principles underlying their work
Clarity and transparency	Researchers need to be clear about why they are seeking user involvement, and service users about why they are taking part. Clarity is needed from the start about the nature and aims of a project and the roles and responsibilities of all parties.
Respect	It is important that everyone taking part in a research project respect each other and respect each other's right to express their own views
Diversity	Researchers need to ensure that they take account of diversity of the population they serve when seeking to build capacity amongst local service users. It is important that the diversity of service users to be involved in a research project should reflect the nature of the research project itself.
Flexibility	Flexibility needs to be built into research projects from the start: flexibility in relation to timescales and resources as well as working practices and expectations of service users whose mental health may affect their attendance and ability to work from time to time.
Accessibility	Researchers need to use plain language and avoid jargon where possible (or explain it clearly). Accessible formats for the presentation of all materials may be necessary: it is good practice to establish any access needs at the start of the project.

Appendix E

Good practice in active public involvement in research (INVOLVE, 2009)

Basic principles of good practice

From the beginning, plan to:

- involve people with personal experience relevant to your research topic
- involve people as early on in your project as possible
- take into account diversity and equality issues
- involve more than one person in your project
- utilise communities and groups
- allow time to build relationships
- be prepared to negotiate the levels and types of involvement with the groups you want to involve
- offer individuals a choice about how they want to be involved in your project
- plan for sufficient time, and build in resources to support involvement.

Aim to build respect by:

- reflecting on the value of everyone's time, knowledge and experience in all project activities
- negotiating 'ground rules' for meetings
- considering diversity and the cultural relevance of your involvement plans to those who should be involved.

Ensure equitable access in your project by:

- giving clear, adequate and usable information in good time
- providing plain language summaries of long or complex documents
- using plain language in all communications
- where possible, giving plenty of notice for meetings
- ensuring meetings are inclusive
- ensuring venues are comfortable and accessible for all involved
- adjusting meeting times according to need and allowing times for breaks
- making adjustments for the particular needs of the individuals involved
- ensuring expenses are paid promptly.

Support people in your project by:

- offering informal chats and an induction process at the beginning
- offering training/mentoring/guidance for both members of the public and researchers
- establishing networks, and good communication links for those involved
- offering support when involvement ends, for example closure event, or helping individuals identify their next steps.

Offer reward and recognition by:

- acknowledging contributions and thanking people in person and in print
- considering the value of people's time and offering payment as well as expenses (in cash if possible)
- consider offering other benefits such as training, support with gaining qualifications, attending conferences, co-authorship.

Appendix F

Research as empowerment (Hanley, 2005)

Good practice might include the following components

Service users are involved from the beginning of the project and there is a commitment to acting on the results of the research

The project funders are committed to the involvement of service users and ensure that the project is adequately resourced

Appropriate training and support are available for service users and researchers

There is a shared commitment to making research available and accessible to a variety of people, including those whose voices are not often heard

The researchers are committed to sharing power and control with service users

Appendix G

Briefing notes for researchers, Briefing note five (INVOLVE, 2012)

Consider the following points to help plan public involvement

Involve people as early as possible

- Involve people at an early stage so that they feel part of the research and also have a sense of ownership of the research.

Be clear with the people you want to involve

- It is important that both you, as a researcher, and the people you involve have a shared and clear understanding of what they are being invited to do.

Be accessible

- Consider your plans for who are you going to involve and if they reflect the diversity of people or cultures in the research.

Resource public involvement in research

- Think about how you resource public involvement both in terms of budget and the additional time required to involve the public in your research.

Offer training and support

- We suggest you plan for training and support for both members of the public and the researchers in your team.

Clarify organisational responsibilities

- It is important that you liaise well in advance with the relevant departments within your organisation such as finance and human resources.

Document and record public involvement in your research

- Think how you are going to track the public involvement throughout your research so you can report and reflect on it as your project develops.

Appendix H

Joint Health and Social Care Regulators' Patient and Public Involvement Group
(October 2010)

On what principles should patient and public involvement be based?*

- a. The public and patients should have access to relevant information.
 - b. There must be honesty about the scope of the public and patients' involvement since the public cannot make some decisions.
 - c. There must be transparency and openness in the procedures for involving the public and patients.
 - d. The public and patients should have access to training and funding to allow them to participate fully.
 - e. A wide range of individuals and groups should represent the public, not particular 'patient groups'.
 - f. The mechanisms for involvement should be evaluated for their effectiveness.
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*The principles above see involvement being based upon the values of partnership – regulation is a partnership between professionals and the public where there is a need to negotiate to achieve the best outcomes

Appendix I

The Nolan Principles

Seven principles of public life

Selflessness

Holders of public office should act solely in terms of the public interest. They should not do so in order to gain financial or other benefits for themselves, their family or their friends.

Integrity

Holders of public office should not place themselves under any financial or other obligation to outside individuals or organisations that might seek to influence them in the performance of their official duties.

Objectivity

In carrying out public business, including making public appointments, awarding contracts, or recommending individuals for rewards and benefits, holders of public office should make choices on merit.

Accountability

Holders of public office are accountable for their decisions and actions to the public and must submit themselves to whatever scrutiny is appropriate to their office.

Openness

Holders of public office should be as open as possible about all the decisions and actions that they take. They should give reasons for their decisions and restrict information only when the wider public interest clearly demands it.

Honesty

Holders of public office have a duty to declare any private interests relating to their public duties and to take steps to resolve any conflicts arising in a way that protects the public interest.

Leadership

Holders of public office should promote and support these principles by leadership and example.

Appendix J

Quality involvement framework (Morrow et al., 2010)

‘Ability to’	Research relationships
<ul style="list-style-type: none"> • Access research resources 	Requirements and incentives
<ul style="list-style-type: none"> • Achieve goals, make contributions 	Funding opportunities
<ul style="list-style-type: none"> • Make decisions about how to do research 	Information about involvement
<ul style="list-style-type: none"> • Express views and deliberate issues 	Expectations and prevailing conditions
<ul style="list-style-type: none"> • Adapt to change 	Communication structures
	Privileged outcomes
‘Potential to’	Ways of doing research
<ul style="list-style-type: none"> • Take up or resist particular roles 	Roles available to be taken up
<ul style="list-style-type: none"> • Loyalty to ideas or ways of working 	Criteria and responsibilities
<ul style="list-style-type: none"> • Gain status, expertise, credibility 	Rules of practice and know-how
<ul style="list-style-type: none"> • Identify and organise interests 	
‘Sense of being’	Research structures
<ul style="list-style-type: none"> • Valued as partner not controlled 	Research organisations and programmes
<ul style="list-style-type: none"> • Enabled rather than constrained 	Research ethics and governance
<ul style="list-style-type: none"> • Empowered rather than exploited 	Methods and techniques of research
<ul style="list-style-type: none"> • Consenting not coerced 	Research technologies, monitoring and reporting
<ul style="list-style-type: none"> • Conscious of power 	

Appendix K

Critical appraisal criteria for assessing the quality and impact of user involvement on health research (Wright et al., 2010)

Research activity	Appraisal criteria
Planning and project design	1 – Is the rationale for involving users clearly demonstrated? 2 – Is the level of user involvement appropriate?
Recruitment and training	3 – Is the recruitment strategy appropriate? 4 – Is the nature of training appropriate?
Data collection and analysis	5 – Has sufficient attention been given to the ethical considerations of user involvement and how these were managed? 6 – Has sufficient attention been given to the methodological considerations of user involvement and how these were managed?
Dissemination	7 – Have there been any attempts to involve users in the dissemination of findings?
Evaluation and impact assessment	8 - Has the 'added-value' of user involvement been clearly demonstrated? 9 - Have there been any attempts to evaluate the user involvement component of the research?

Appendix L

National Involvement Partnership: Baseline standards (National Survivor User Network, 2011)

Four headings used to describe and monitor involvement

Purpose	Having a clear purpose for involvement enables everyone to understand their roles and avoids the risk of tokenism and involvement for its own sake
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Presence	The number of service users and carers involved; their characteristics in relation to the project / programme e.g. age, gender, ethnicity, specific (service/diagnosis/ treatment) experience, etc.
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Process	<p>At what level in the project / programme are service users and carers involved?</p> <p>What role(s) are they occupying?</p> <p>How is the process of involvement experienced by all?</p> <p>Is the programme / workstream engaging good practice guidelines to involve people?</p> <p>This includes: clear communications, support for involvement, training to enable equitable involvement, payment of fees and expenses, feedback to all who have been involved about the results of that involvement, provision of a range of different activities or ways of being involve in order to attract a wide range of service users and carers and flexibility to enable people to take advantage of different opportunities and to move in / out of involvement when they wish / need</p>
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Impact	<p>What impact – if any – are service users having on the programme or workstream?</p> <p>Impact might be explored in terms of ethos, policy and planning, delivery and outcomes and outputs</p>
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Appendix M

Health Research Authority: Our principles and standards for public involvement
(August 2013 for consultation)

Good practice principles for involving patients and the public

1 – We will adopt key principles for the involvement of patients and the public in our work that we have identified from a range of organisations that fund and manage health research and that fit with our organisational values. These include:

- being clear about what we mean by public involvement
- openness and honesty about why we are involving people, how much involvement is possible and the influence that it will have
- transparency and openness about the way we will involve people
- providing support for people to be involved including information, training, expenses and funding
- involving a diverse range of individuals and groups
- reviewing the effectiveness of the way we involve people and the difference it makes to us, our work and the people whom we involve
- embracing and building on the unexpected consequences of public involvement such as sensitive or difficult issues that people may raise from their lived experience
- sharing examples of effective public involvement and good practice.

2 – When we involve patients and the public in our work we will ensure there is:

- support for public involvement at senior management level linked to our strategy and objectives
- adequate resourcing to ensure we can support those we involve to contribute fully
- defined roles, responsibilities and objectives for those who we involve to ensure they know what is expected of them
- good partnership working that leads to co-production, which means those we involve contribute as equals with our staff to the work they are doing
- effective evaluation of our involvement and the difference it makes, sharing the lessons learnt
- feedback to the people we engage with and involve in our work. This will include the extent to which we have been able to use their input, following a “you said, we did” approach. Where it has not been possible to use their input in full we will explain the reasons for that.

3 – We will use a range of methods of involvement appropriate to the individual tasks and contributions we seek. This is because involvement cannot be effective through a “one size fits all” approach. Each and every time we want to involve patients and the public we will consider:

- whether involving patients and the public will make a difference to the task or area of work and add value
- if so then whether there are clear tasks or roles patients and the public can fulfil and how

- whether those we involve will have the necessary skills for the roles or tasks or could acquire them quickly.

4 – Further, we will seek to be creative in the ways we involve the public in keeping with our values, principles and standards for involvement. We will also seek input from patients and the public on the way that they would like to be involved.

5 – We believe that effective public involvement:

- happens early and continues throughout a process
- is inclusive
- is informed
- is fit for purpose
- is transparent
- is influential, it makes a difference
- is two-way and includes feedback and continuous improvement
- is proportionate to the issue.

INVOLVE

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