

STANDARDS CONSULTATION - ANALYSIS



5/9/2019

Analysis results

Summary of the quantitative and qualitative results from the online consultation survey for the National Standards for Public Involvement. Including trend data and key themes and learning.

Standards Consultation - Analysis

BACKGROUND

Once the draft Standards were agreed an online survey (using Survey Monkey Software) was developed and piloted to enable feedback and ideas for improvements. Rachel Matthews from NIHR Research Design Service helped in this process, from her perspective of facilitating the NIHR Public Involvement in Research 'Going the Extra Mile' consultation in 2015.

The consultation period was from 30 June 2017, with a closing date of 01 September 2017. A wide range of individuals, groups and organizations were invited to take part, and cascade information about the consultation through their own networks and communities. A resource pack was provided including slide set and guidance for running meetings to gather feedback. Midpoint in July the Partnership reflected on the response rate to the consultation and agreed a variety of actions to encourage and increase participation, particularly amongst communities who as yet, had not responded in the numbers expected

AS part of the ongoing feedback on social media about the consultation process it was pointed out that we didn't have an easy read version of the draft Public Involvement Standards. This was produced swiftly and so as not to disadvantage any group or individual who has had to wait to be able to respond via this route, the deadline was extended to Friday 6th October - for responses by this route only.

ANALYSIS RESULTS

Methodology

This work was undertaken by NIHR INVOLVE staff using the SurveyMonkey data analysis function and Microsoft Excel packages.

RESPONSE PROFILES

677 responses were submitted through the online survey. These came from a cross section of people, some responding as individuals and others on behalf of group consultation exercises. More detail of the breakdown of responders is in Figures 1-2 and Table 1 shows the regional differences of respondents.

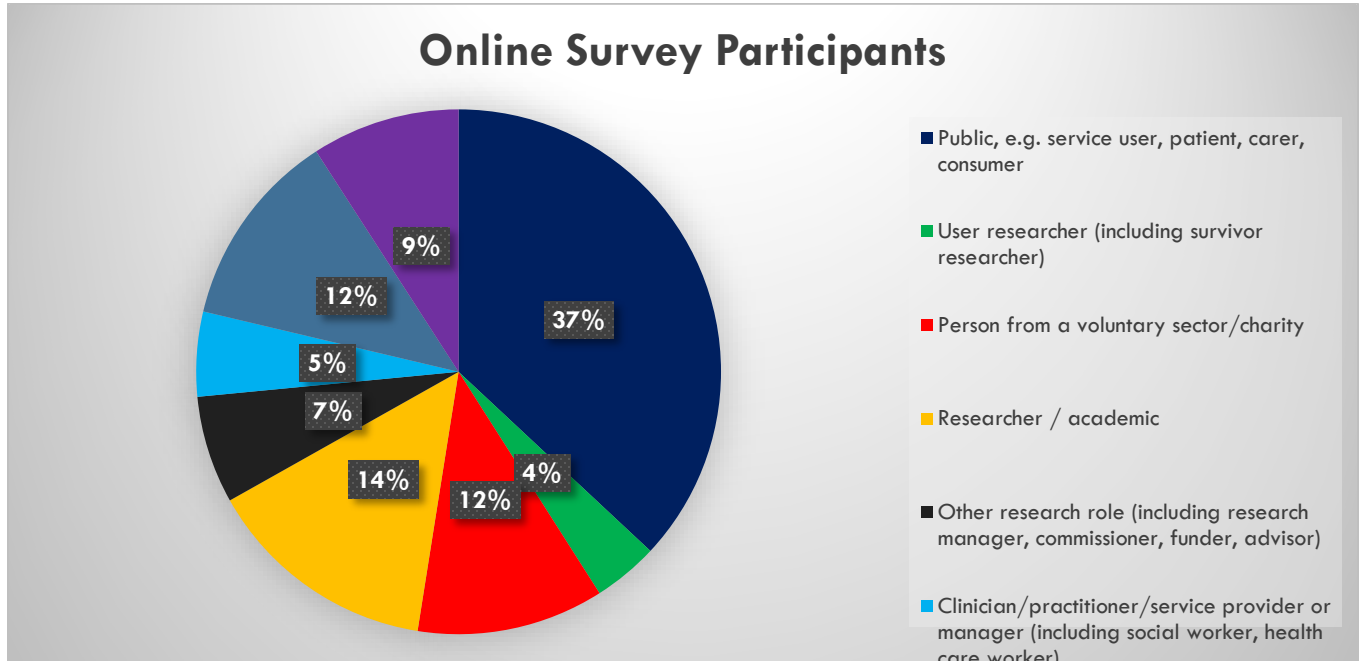


FIGURE 1: ONLINE SURVEY INDIVIDUAL PARTICIPANT CLASSIFICATION

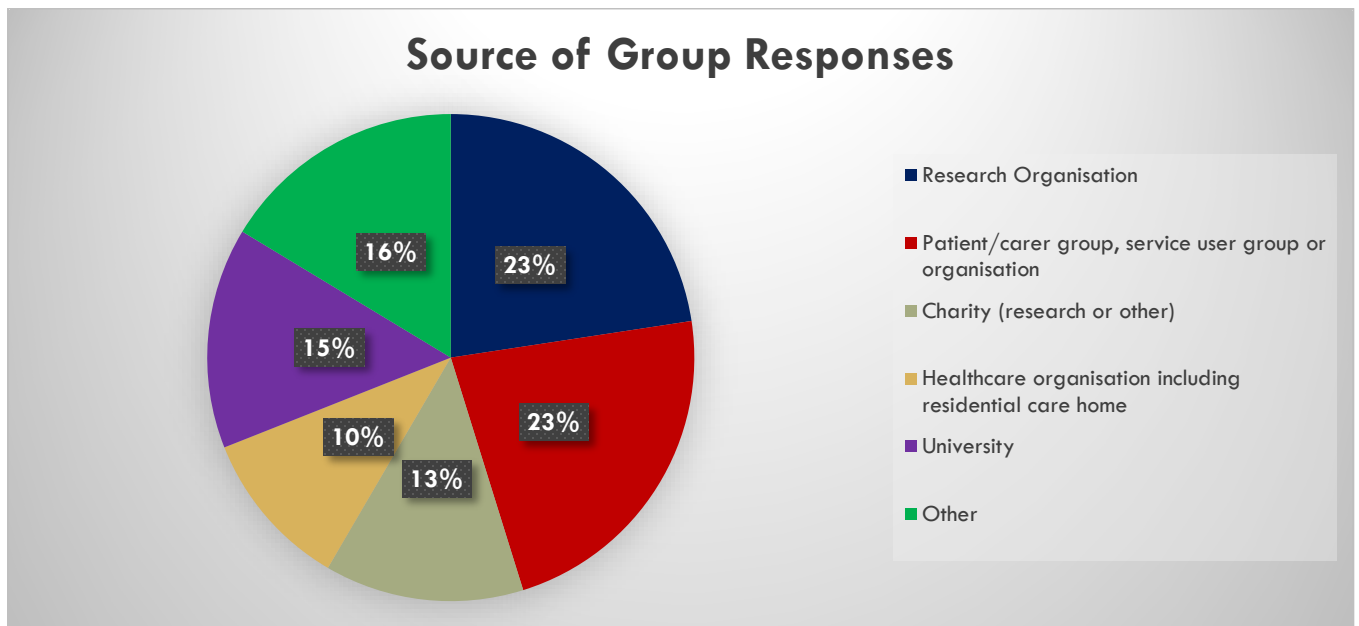


FIGURE 2: GROUP RESPONSE REPRESENTATION

Location of Responses	Number	Percentage
England	497	73.4%
Wales	65	9.6%
Northern Ireland	26	3.8%
Scotland	40	5.9%
International	15	2.2%
Did not say	34	5.0%

TABLE 1: OVERVIEW OF THE LOCATION OF RESPONDANTS TO THE ONLINE SURVEY

Question	Average Score out of 10	Question	Average Score out of 10	Question	Average Score out of 10
Agree with proposed standards	7.53	Indicator 2.3	7.81	Indicator 4.3	8.31
Standards will provide a framework	7.41	Indicator 2.4	7.47	Indicator 4.4	7.72
Indicator 1.1	7.47	Indicator 3.1	7.81	Indicator 5.1	8.11
Indicator 1.2	7.56	Indicator 3.2	8.65	Indicator 5.2	7.97
Indicator 1.3	7.37	Indicator 3.3	8.05	Indicator 5.3	8.48
Indicator 1.4	7.63	Indicator 3.4	7.77	Indicator 5.4	8.26
Indicator 1.5	8.10	Indicator 3.5	8.05	Indicator 6.1	7.76
Indicator 2.1	8.09	Indicator 4.1	7.70	Indicator 6.2	8.06
Indicator 2.2	7.77	Indicator 4.2	8.14	Indicator 6.3	8.03

TABLE 2: OVERALL AVERAGE SCORE FOR SURVEY QUESTIONS

QUESTION RESPONSES FOR STANDARDS AND INDICATORS

Respondents completed the sliding scales within the survey (0 = completely disagree with this standard) to (10 = fully agree with the standard) indicating their support for, or against the standards as a whole, and for each indicator. Table 2 shows the average scores for the standards and indicators. It was important to view the distribution curves to show that while there were a few data outliers over all the majority of survey respondents were supportive of both the example indicators and the standards.

Figure 3 shows distribution curves for responses to the first two questions in the survey;

Q. 1 What difference if any, will the standards make?

Q. 2 Who will be responsible for implementing the standards?

Figure 4 shows the distribution of the scores (from 0 – 10) for each indicator (different colours) within each standard. Table 3 shows the number of individuals who answered each question.

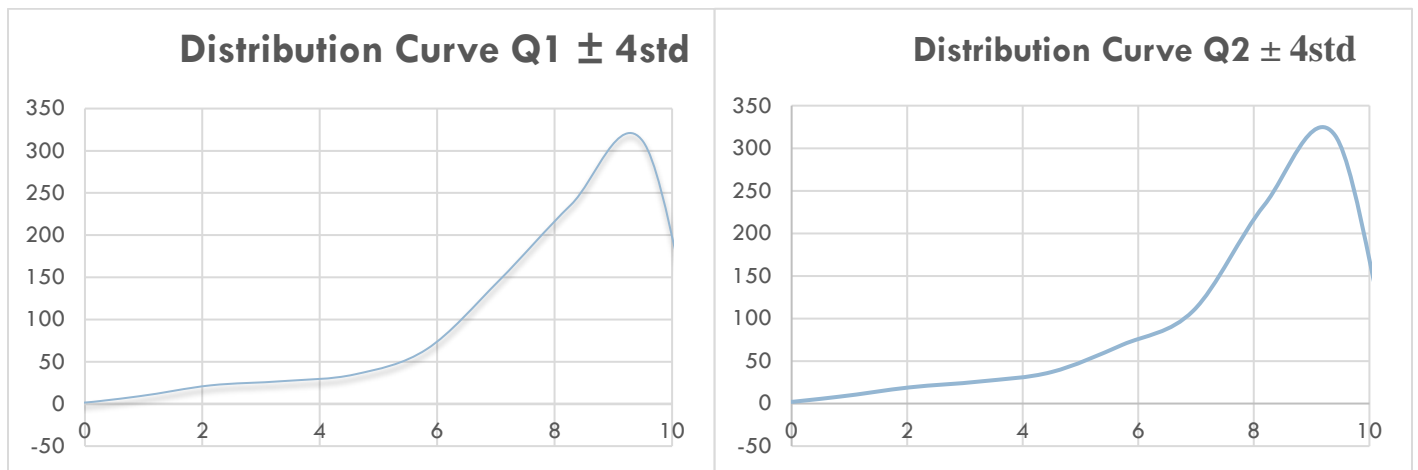


FIGURE 3: DISTRIBUTION CURVES FOR RESPONSES TO QUESTIONS 1 AND 2 SHOWING THE NUMBER OF INDIVIDUALS WHO SELECTED EACH SCORE FROM 0-10.



FIGURE 4: DISTRIBUTION CURVES FOR RESPONSES FOR EACH INDICATOR WITHIN A STANDARD SHOWING THE NUMBER OF INDIVIDUALS WHO SELECTED EACH SCORE FROM 0-10.

Question	Response Number	Question	Response Number
Q1	407	Indicator 3.4	331
Q2	401	Indicator 3.5	336
Indicator 1.1	363	Indicator 4.1	332
Indicator 1.2	360	Indicator 4.2	335
Indicator 1.3	349	Indicator 4.3	333
Indicator 1.4	354	Indicator 4.4	331
Indicator 1.5	357	Indicator 5.1	324
Indicator 2.1	349	Indicator 5.2	327
Indicator 2.2	349	Indicator 5.3	328
Indicator 2.3	347	Indicator 5.4	327
Indicator 2.4	345	Indicator 6.1	327
Indicator 3.1	335	Indicator 6.2	328
Indicator 3.2	334	Indicator 6.3	329
Indicator 3.3	333		

TABLE 4: DISTRIBUTION OF ALL SCORES FOR ALL QUESTIONS (Q 1 AND 2) AND EACH INDICATOR UNDER THE RELEVANT STANDARD.

A small proportion of responders only responded to the first 2 questions (and in the survey it was indicated that this was acceptable), but the majority responded through the whole standard set averages were calculated on the basis of those who responded to the individual question rather than the full 677 respondents.

QUALITATIVE DATA

Methodology

The Research Design Service North East (RDS NE) undertook the evaluation of the free text data from the survey. This is their summary.

The team (including public members) began the analysis process with a familiarization of the open-ended responses to questions 1 and 2, and the responses to each separate standard and their respective indicators.

Following the initial familiarisation, the researchers met with a specially convened group of members of the public (see below) to discuss their views on the responses, allowing the cross-referencing and confirming the coding frame at a later stage of analysis. A broad thematic analysis was conducted involving identification of 'patterned response or meaning' (Braun & Clarke, 2006, p.82) alongside key issues or concerns across the standards as well as issues specific to a particular standard. Following these initial stages of analysis, the responses were exported to Excel (Microsoft) software for ease of data management. Researchers sorted the responses into themes identified for each respondent group. This also facilitated identification of any additional, and/or consultation wide cross-sectional themes. The analysis was informed primarily by the constant comparative method (Glaser, 1965; Strauss and Corbin, 1990) with some reference to the framework approach (Pope et al., 2000; Ritchie and Spencer, 2002). Finally, the summary findings were presented to the National Institute Health Research (NIHR) RDS NE Public Involvement Consumer Panel as a way of 'member checking' themes that were generated from the data.

Consumer Panel input

A sub-group of the NIHR RDS NE consumer panel (a group of members of the public who met monthly to work on the analysis of the consultation on the National Standards) was convened. The panel consisted of four members of the public and met once, they were asked to do some preliminary reading. Members of the panel had previously submitted their feedback on the draft standards individually, so were familiar with the material under discussion. As a part of the analysis process of the responses to question 1 and 2, panel members were asked for their views on identified themes arising from the respondents' accounts. This was achieved by providing the consumer panel with a table of sample responses from the different respondent

groups, and encouraging them to record themes that they observed from reading the material. They discussed their thoughts with the research team.

Summary of key themes

Whether the standards would/could make a difference to public involvement in research was the first question and the panel felt there were a lot of positive comments within the responses. Primarily these focused on;

- Standardization across the Standards
- Accountability and consistency of PPI practices
- Potential for empowerment of public participants in research.

The panel also picked up on some limitations and skepticism in the responses to question 1, this skepticism focused on;

- the need to have more detail on implementation
- consider the resources to support implementation
- tensions in how standards would impact practice, and how they would be enforced.

The key issues that the consumer panel identified from the responses to question 2, highlighted the complexity of public involvement activity and diversity of organizations and individuals involved, and that everyone should have a responsibility for it. There was a need for clarity and questions around the details and practicalities of that responsibility, and monitoring/oversight and accountability.

The panel also commented on the contextual and environmental considerations, such as organizational culture and resources to support implementation of standards, when thinking about responsibility for implementation. The results from the consumer panel analysis, and that from the researchers were found to be similar.

More detailed analysis and themes

Question 1: What difference, if any, will it make to you to have a set of National Standards for public involvement in research?

Theme 1; Potential 'positive difference'

Within this theme four sub-themes were identified. Firstly, the standards were seen to potentially make a difference to the processes and practices of involving patients, public and service users in research, bringing standardization, clarity and operating as useful reference point and as guidance for best practice. Secondly, they were considered to help in establishing and/or legitimizing public involvement as a required component of research, providing a case for justifying it, and related funding. Thirdly, having standards was also perceived to be beneficial to members of the public involved for example; standardization of remuneration, what to expect, acknowledgement of their 'rights' and support for when things go wrong. Finally, there could be a positive impact in terms of outcomes for good public involvement and providing a reference point to measure involvement practice. This was thought to promote a more comprehensive inclusion of public involvement throughout the research process.

Potential negative/questionable difference

Many approached the difference the standards would make, with skepticism and concern. Whilst they saw the idea of the standards as positive, they were skeptical of the difference they would make in practice, especially where are issues with resource implications for their implementation. These resource implications were not thought to be sufficiently addressed within the standards and therefore this would weaken how much they would change public involvement in practice. There were questions about how they could work for the wide range of organizations and individuals with different scopes of practice and resources. Responses highlighted the need to have more clarity on how the standards would be implemented in practice, the roles and responsibilities of those involved as well as how they will connect/link with existing guidance. The respondents also called for more clarity on how the standards could be enforced, and by whom.

No difference

Finally, a few respondents saw the standards as making no difference at all, usually either due to the view that they were more directed at organizations than individuals. In addition, some thought that there was overlap with existing guidance, or similar practices were already being followed in their work.

Question 2: Whose responsibility is it to implement the Standards?

On the whole, the idea that ‘everyone’ or ‘everyone involved in all stages of the research process’ should be responsible for implementing the standards, came through as the shared, central thread running through the responses across different respondent groups.

Respondents’ comments reflected the wide range of organisations and/or professionals, that are potentially responsible for implementing the standards. Organisations included government and research institutions, research organisations, research funders, medical research charities and universities. People encompass, researchers, PPI practitioners and specialists, volunteers, patients, carers.

Some responses contained more detail about the different roles and responsibilities for implementation of the standards, for example overall responsibility for monitoring adherence to the standards.

Responses to specific standards

Standard 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.

Overall the comments were positive. Respondents felt that this standard in particular offered a systematic way to collect evidence of persistent and common barriers to public involvement which should be addressed strategically. More clarity was requested for words such as meaningful, inclusivity and representative, and explanation is required of who the “we” refers to. Suggestions for improvement included; signposting for more awareness of involvement opportunities that are available, how to work with people who don’t use the internet, and targeting those working. It was suggested that case studies or examples would help here. Several respondents referred to payment over and above ‘out of pocket expenses’ and other forms of recognition. Comments also referred to other forms of support people may need to participate fully such as information technology support, mentoring, and support for involved public with mental health problems.

Standard 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

For standard 2 there were suggestions of overlaps with other indicators and other illustrations. There were further requests for clarification of words such as ‘meaningful’, and concern about how this will be measured. Many respondents commented on the need for respectful, co-created, defined relationships which would in turn promote respectful involvement. One question raised by all groups was that experience in public involvement ought to be valued. It should not be necessary to have new ‘public’ for all work, the role of an experienced public member could change, but should not be disregarded. Some respondents went further to request that different roles for public involvement need to be defined. A concern raised by some was that a public member may not have made an identifiable contribution, but will still have played a valuable role. How would such a contribution of working together be measured?

Standard 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.

There were several suggested changes in wording and grammar, these are in the table in Appendix 3. Examples are the use of terms such as ‘confidence’ and ‘competence’ in the standard. There should be revised with consideration to the service user perspective. Generally, more precision, avoidance of jargon and clarity was requested for the wording of this standard and indicators ensuring that they are easier to read and understand. Respondents requested more information about how this standard has drawn from and fits with existing NIHR INVOLVE guidance, and other relevant standards.

More clarity was requested regarding remuneration and the potential tax/benefit implications for payment to involved public. Also, the standard needs to recognise the need for training and funding to support this specialist knowledge. The resource implications of the activities outlined in this standard should be considered to address practical considerations of implementing this standard. The issue of recruitment also requires more detail, including a specific indicator for ‘recruiting the right people’. Details of what is meant by ‘emotional support’ and clarity around boundaries of responsibility were underscored by respondents.

Standard 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

Respondent commentary on wording, grammar and editorial changes for standard 4 included a general request for clarity and making it easier to read and understand. Adding 'active listening' to the definition of communication and a more nuanced expression of the benefits of feedback would help. A definition of 'involvement' was also requested, as this was currently unclear to many. Respondents felt there was some overlap around the topic of 'diversity' across standards 1 and 4, which required unpicking. Full details of the comments about clarity can be found in the table in the Appendices. Specific feedback about the frequency, timeliness and types of content regarding communication updates and feedback should be built into the standard. It should also be acknowledged that communication is a two-way process. There is a need for more consistency in use of terminology referring to public contributors/public members/involved members of the public. Additional comments highlighted a need for a glossary, and guidance on producing reports that utilize accessible language to non-academics.

Sufficient details about review, monitoring and feedback, as well as budget implications of the activities described are absent from the standard. Clarity about what constitutes a 'communication plan' would help, perhaps with examples illustrating how the different components of this standard can be achieved. Several respondents commented on the importance of recognizing the time, work and resources required, including detail on how they apply to the different stakeholders involved in communication activity.

Standard 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.

There were several specific comments on wording, grammar and editorial changes that focussed on adding terms such as 'regular' into reporting, and using 'monitor' as the action verb within this standard. Some copy-editing comments were made by respondents, which are outlined in the table in the Appendices for Standard 5. In terms of the overall wording of the standard, it was felt that it should be written as 'something we do' rather than as something we 'hope to do'.

Consistency and clarification on the use of abbreviations, mainly PI was pointed out, and term PPI was preferred to avoid confusion with other meanings attached to the abbreviation PI (e.g. performance indicator.) Respondents requested clarification on what is meant by 'nature of people' and on the role of public contributors in developing dissemination outputs such as journal articles and conference presentations. This should be included in the indicators and/or illustrations.

Overall, respondents felt it was not clear what was meant by 'impact', 'important information' and 'assessment'. A definition and examples of what impact should look like would be essential part of this standard. There was some concern regarding measurement, and whether this would mean subjecting the public contributors to more scrutiny and evaluation. Additional comments from respondents focussed on the importance of practical detail regarding implementation, resources and measurement, and the wider reaching impact of PPI. This should also include details on how successful/unsuccessful impact is defined, including learning from bad experiences. Inclusion of information about outcomes, assessment of outputs and monitoring would improve this standard. Emphasis on openness, transparency, and clarity of roles and responsibilities in relation to impact was also underscored by the respondents. Finally, the role of feedback should be made more explicit within this standard.

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. 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

Overall the comments received about this standard were positive, and many thought it was critically important to emphasize that adequate and appropriate governance is a keystone to public involvement in research. Questions were raised about how would this standard should be implemented and monitored, and if there are implications of achieving or not achieving the standard?

One phrase which brought much confusion was that of "community of interest", many had not heard of the term before and were uncertain as to who this referred to. Some respondents referred to the 'easy read' version and felt that this provided clearer wording, without the jargon for this standard. Several respondents felt that governance is much wider than referred to in the standard, and should incorporate conflicts of interest. Possibly as a result of comments about how earlier standards will be implemented and how would they be monitored, concerns were raised about this standard and how confusing it could be.