

PiiAF

Exploring areas of consensus and conflict underpinning values and impacts of public involvement in health and social care research: A modified Delphi technique

PiiAF Study Group

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Lay Summary

The purpose of this modified Delphi study was to examine areas of agreement and disagreement about the values underlying public involvement (PI) and the possible impacts of PI in health and social care research.

The study involved initial workshops with PI experts, to identify topics for exploration in the Delphi Study. Experts were representative of the various stakeholder groups subsequently recruited to a larger scale survey. These were members of the public involved in research; clinical and non-clinical researchers; research managers and research funders. Following the workshops, a pilot survey was conducted to develop and refine the survey questionnaires. Two survey rounds were then conducted, involving 318 respondents in round 1 and 231 in round 2. Both quantitative and qualitative responses were collected.

Overall, we identified high levels of agreement across the stakeholder groups for many of the issues explored. These areas of agreement reflect the extent to which PI is already embedded in health and social care research.

However, we also found some areas of conflict between stakeholder groups.

Key findings in relation to the values underlying PI were -

- High levels of agreement that members of the public can and should influence how research is used
- Different and sometimes conflicting views across stakeholder groups about the possible biases and lack of representativeness in PI
- Different and sometimes conflicting views across stakeholder groups as to whether the purpose of PI in research is to bring about change or generate new knowledge
- Agreement that there are tensions between what members of the public and researchers see as the purpose of research, and also what constitutes good research

- Stakeholder differences in the percentages endorsing the ethical justification for PI

Key findings in relation to practical or process values were:

- Research support infrastructures [e.g. training, financial processes and support] were reported as lacking
- The need for 'best practice' standards to assist research teams to understand, implement and evaluate PI was highlighted
- Embedding PI practice and evaluation in research study designs was seen as essential to strengthening the evidence base around PI

Key findings in relation to PI impact and evaluation were -

- There were high levels of agreement about the most important barriers and facilitators to positive PI impact
- PI was seen as having intrinsic value, but it was felt this did not and should not reduce the importance of evaluating its impact
- There was a strong belief that demonstrating the value of PI was more difficult because of the persistence of tokenistic practice
- Addressing tokenistic practice robustly remains a priority
- The value of good team work and the need for appropriate resources from the inception of a project was considered essential
- Stakeholders agreed that doing PI well can be challenging but can be made easier by clear guidance on what PI means, together with models of good practice and measurable standards

In conclusion, our findings highlight a need for PI best practice standards to assist researchers when involving members of the public in their research projects. This is particularly important when trying to think about and measure possible impacts of PI in health and social care research. These findings have been used in the development of Public Involvement Impact Assessment Framework (PiiAF), which will assist both researchers and members of the public involved in the PI process.

Acknowledgements

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List of Contents

Lay summary	2
Acknowledgements	4
List of contents	5
List of figures	6
List of tables.....	7
List of appendices	8
1. Introduction.....	9
2. Methods.....	12
2.1. Delphi technique.....	12
2.2. Delphi process.....	13
2.2.1. Stage 1: Expert workshops.....	14
2.2.2. Stage 2: Pilot testing.....	14
2.2.3. Stage 3: Survey rounds 1 and 2.....	15
3. Results	19
3.1. Delphi survey sample.....	19
3.2. Kinds of knowledge.....	21
3.3. Purposes of PI	23
3.4. Levels of PI	25
3.5. What factors influence effective PI?	27
3.6. What are the impacts and outcomes of PI?	30
4. Discussion	34
4.1. Key Themes	34
4.2. Delphi study limitations.....	37
4.3. Conclusions.....	38
References.....	40

List of Figures

Figure 1: Public involvement in health and social care research: Overview of inter-related study phases.....	10
Figure 2: What kinds of knowledge should inform health and social care research?	21
Figure 3: What are the purposes of PI in health and social care research?.....	23
Figure 4: What levels of involvement should the public have in health and social care research?	25
Figure 5: What are the impacts and outcomes of PI in health and social care research?.....	30
Figure 6: PI tokenism as self-fulfilling prophecy.....	33

List of Tables

Table 1: The Modified Delphi Process.....	13
Table 2: Response percentage per stakeholder group at Survey Round 1 and Round 2.....	20
Table 3: Does it matter if stakeholder groups hold views considered biased by others?	22
Table 4: Can tensions be resolved in health and social care research?.....	24
Table 5: How important is it to assess PI in health and social care research?.....	31
Table 6: Does lack of agreement about the contribution of PI to research undermine its value?	32

List of Appendices

Appendix 1: Recruitment Strategy.....	44
Appendix 2: Round 1 Delphi survey Questionnaire	46
Appendix 3: Round 2 Delphi survey Questionnaire	47
Appendix 4: Qualitative Analytic Framework	48

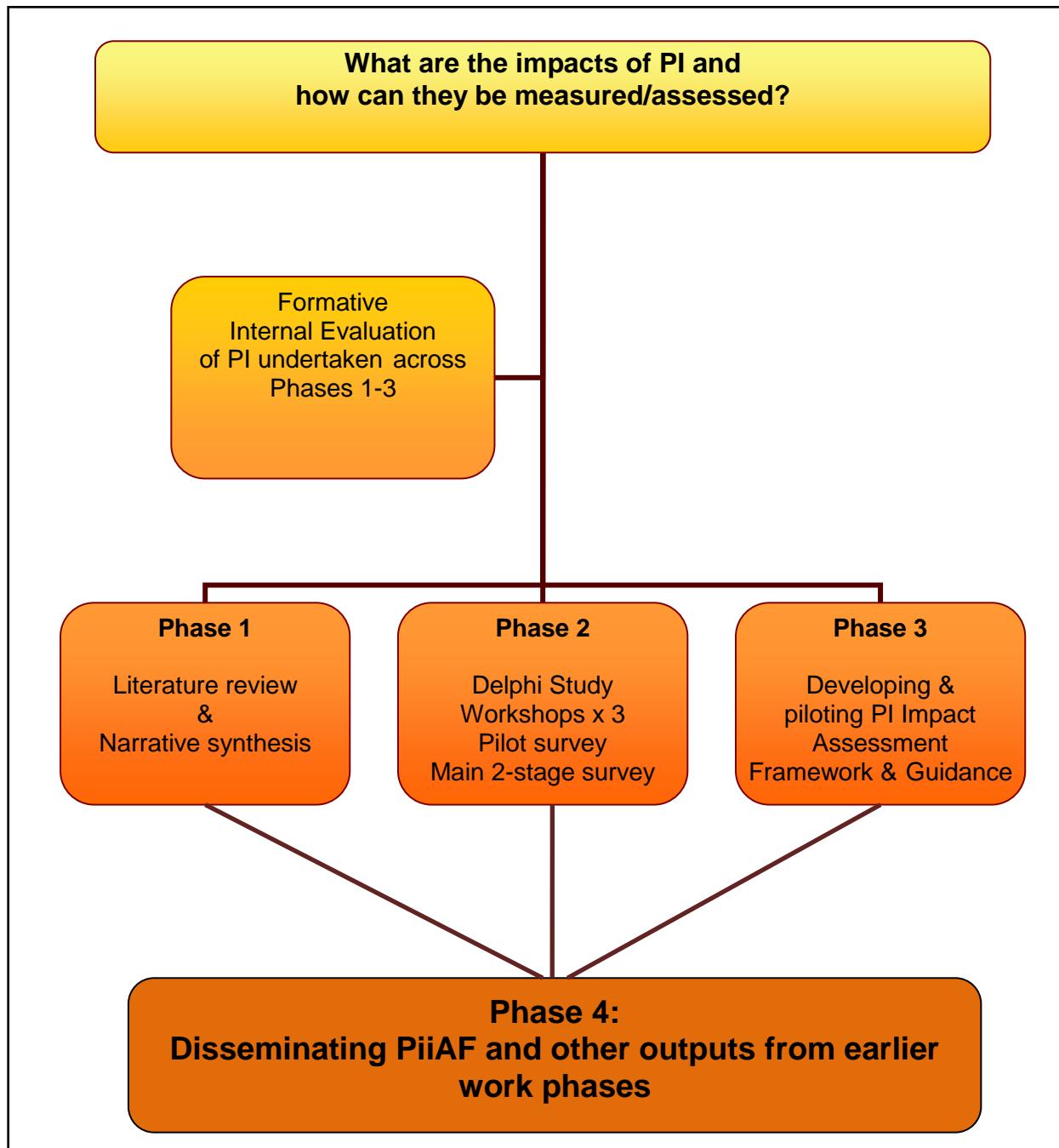
1. Introduction

The involvement of members of the public in research is firmly established in United Kingdom (UK) health and social care policy (DoH, 2005; Myrhaug, 2006; Nilsen et al, 2009) and many funders including, for example, the National Institute for Health Research (NIHR, 2012) identify Public Involvement (PI) as a pre-requisite for funding. There is a growing literature illuminating the experiences of members of the public and health researchers, and the process of PI and its potential impacts (Beresford, 2002; 2003; Popay et al, 2007; Wyatt et al, 2008). However, while some studies report PI as impacting on priority-setting (Caron-Flinterman et al, 2005; Wright et al, 2007), the conduct of clinical trials (Marsden & Bradburn, 2004) and the identification of treatment outcomes (Hewlett et al, 2006), there has been relatively little systematic examination of the real impacts of PI on the research process and how those impacts might be measured effectively (Minogue et al, 2005; Boote et al, 2002; Staley, 2009; Barber et al, 2011; Staniszewska, 2011). Possible arguments for the limited number of impact studies are that evaluating the impact of PI is often perceived as too difficult and that PI is of intrinsic value and, as such, needs no further justification (Entwistle et al, 1998; Oliver et al, 2001; 2008; Staley, 2009). However, other authors have articulated counter-arguments for evaluating impact, which broadly relate to the issues of effectiveness, ethics, economics and the need for evidence (Staniszewska et al, 2008, 2011; Boote, 2013). We would argue that evidence of the impact of PI is important to ensure integrity, identify the ways in which PI can have an impact and learn how to maximise this to improve research, avoid adverse effects for those involved and justify the use of resources. In light of this, the modified Delphi study reported here is one part of a larger MRC multi-phase User Involvement Study (Figure: 1), the overall aim of which seeks to advance knowledge of the implementation and impacts of PI and to contribute to a more robust assessment of these impacts and hence to improved standards of practice in PI in health and social care research.

Overall, the multi-phase study consists of four inter-related phases: i) an evidence review and narrative synthesis (Gradinger et al, in press); ii) a three-stage modified Delphi study; iii) the development and piloting of a PI Impact Assessment Framework (PiiAF) and accompanying

guidance and iv) dissemination of study outputs. Running in parallel with these four study phases is an internal formative evaluation of PI, led by the user-researcher team members.

Figure 1: Public involvement in health and social care research: overview of inter-related study phases



The purpose of this report is to provide a detailed, descriptive account of the research process and study findings from the second phase - a modified Delphi study. This study sought to explore areas of consensus and conflict underpinning three over-arching value systems and their potential impacts, identified from the literature review and narrative

synthesis (Gradinger et al, in press). These values relate to (i) normative arguments about PI, which consider involvement as an end in itself, for example, rights and empowerment; (ii) substantive arguments which consider the consequences of PI, for example quality and relevance, and (iii) process-related values associated with good involvement, for example, partnership and equality.

2. Methods

2.1. Delphi technique

The main premise of the Delphi technique is based on the assumption that group opinion is more valid than individual opinion. The technique offers a reliable data collection method in circumstances where there is uncertainty or paucity of knowledge surrounding the topic area under investigation (Dalkey & Helmer, 1963; Gallagher et al, 1993; McKenna, 1994; Crisp et al, 1997; Hassen, 2000). Originally developed by the RAND (Research and Development) Corporation for technological forecasting, the Delphi technique has been used extensively within health and social science research (Jones & Hunter, 1995; Walker & Selfe, 1996; Keeney et al, 2001; Campbell et al, 2002; Daykin et al, 2002; Sheild et al, 2003; Boote, 2006; Efstathiou et al, 2008). Since its inception, subsequent users of the Delphi technique have modified its process and no universal Delphi design is apparent. Format variations include, for example, the ‘modified Delphi’ (McKenna, 1994), the ‘real time’ Delphi (Beretta, 1996) and the ‘policy Delphi’ (Crisp et al, 1997). Similarly, there are also variations in panel size with reported sample sizes ranging from four to 3000 (Campbell et al, 2002) as well as numerous variations in the criterion for judging consensus agreement between participants, with ‘agreement’ represented as ranging from a low as 51% (Loughlin & Moore, 1979) to as high as 100% (Williams and Webb, 1994). The Delphi technique has been criticised, as it is perceived to force consensus and as weakened by not allowing panellists to elaborate on their views (Walker & Selfe, 1996). For this reason the current Delphi study used a modified technique wherein consensus was not sought; rather panellists were provided with opportunities to elaborate on why they held the views they expressed or endorsed (Keeney et al, 2001) and to try to tease out areas of conflict as well as areas of consensus. Despite variations in approach, however, there are a number of key concepts and assumptions which distinguish the basic Delphi technique from other research methods. These are anonymity, multi-stage iteration and controlled feedback, exploration of consensus via statistical group response and the use of experts (Lynn et al., 1998; Hasson et al, 2000). Each of these distinguishing characteristics has been given due consideration, in order to enhance the validity and reliability of the research design and the quality of responses (Linstone and Turoff, 1975; Sackman, 1975; McKenna, 1994; McDonnell et al, 1996; Hardy et al, 2004).

2.2. Delphi process

The modified Delphi process, outlined in brief in Table 1, consisted of three stages and was conducted between November 2011 and September 2012. For the purposes of the Delphi process we defined PI as an active partnership between members of the public and researchers in the research process, rather than the use of people as the 'subjects' of research. The term, 'public' was used as developed by the UK National Advisory Group, INVOLVE (2012a); and includes patients and potential patients, carers and people who use health and social care services.

Table 1: The Modified Delphi Process

Criteria	Expert Workshops	Pilot Testing	Round 1 Survey	Round 2 Survey
Panel Size	<i>Northwest</i> Invited n=25 Attended n=15 <i>Southwest</i> Invited n=25 Attended n=19 <i>Public Advisory Group</i> Invited n=11 Attended n=8	Invited n=11 Responded n=10	Invited n=740 Opted-out n=23 Responded at R1 n=318	Eligible n= 318 Opted-out of R2 n=3 Invited to participate in R2 n=315 Responded at R2 n=231
Reminders	N/A	Yes x 1	Yes x 2	Yes x 2
Response Rate	N/A	91%	43%	73% (of 43%)
Area of Expertise	Members of the Public User / Academic / Clinical Researchers Research Managers Research Commissioners	Members of the Public User / Academic / Clinical Researchers Research Managers Research Commissioners	Members of the Public User/Academic/Clinical Researchers Research Managers Research Commissioners	Members of the Public User/Academic/Clinical Researchers Research Managers Research Commissioners
Problem Exploration	Round-table discussions / group activities to explore normative debates around the value / potential impacts of PI	Questionnaire - Questions derived from literature review and Expert Workshop outcomes with 5 and 7-point Likert scales for close-ended questions. Open question options	Questionnaire - As for pilot testing with revisions to unclear questions and formatting Additional open questions added to provide further opportunities for comment	Questionnaire - Questions derived from analysis of Round 1 responses with 5-point Likert scale for close-ended questions
Consensus	N/A	N/A	70% endorsement with at least 55% in the extreme category = critical consensus 60 % endorsement = clear consensus 60 % endorsement = clear consensus	70% endorsement with at least 55% in the extreme category = critical consensus 60 % endorsement = clear consensus 60 % endorsement = clear consensus
Feedback	Expert Workshop outcomes fed back to participants and members of the Public Advisory Group	Consultation process	Expert panel members fed back responses with response %age of their own sub-group and those of other sub-groups. Summaries of comments made by respondents also fed back	Wide-spread project dissemination of findings: Study report(s) Workshops Conference Presentation(s); Peer-reviewed journal publication(s)
Access route(s) to data collection	E-mail Group discussions Video-conference	E-mail Face-to-face Tele-conference	E-mail On-line questionnaire	E-mail On-line questionnaire

PI within the Delphi process was achieved through collaboration with academic researchers with experience of working in the field of PI, user investigators and members of the Advisory Network and the Patient Advisory Group. The Delphi process was granted exemption from NHS Research Ethics approval¹ and received a favourable ethical opinion from the University of Liverpool Committee for Research Ethics. Each of the stages; three expert workshops, Delphi survey pilot testing, and the subsequent two-round modified Delphi survey are detailed as follows:

2.2.1. Stage 1: Expert Workshops

The first stage - generating ideas - involved conducting two face-to-face 'Expert' workshops, one in the Northwest (n=15) and one in the Southwest (n=19) of England. Expert status for the purpose of this study was defined as having some clear previous experience of PI in research, for example membership of a group or a committee with a focus on PI in health and social care research or having experience of conducting and / or participating in PI-focused research. Each workshop consisted of a mixed group of participants which included members of the public, academic and user-researchers, researcher / clinicians, research funders and research managers. A third workshop was conducted via videoconference link with members of the MRC PI study Patient Advisory Group (n=8). The purpose of the three workshops was to generate qualitative data. Participants were asked to comment on the values and debates identified in the previously conducted literature review (Gradinger et al, in press), with a view to gaining a better understanding of these areas to develop questions for rounds 1 and 2 of the modified Delphi survey.

2.2.2. Stage 2: Pilot Testing

The purpose of the pilot stage of the modified Delphi process was to test the Round 1 survey questionnaire. As a strategy to reduce attrition (Duffield, 1988; Hatton and Nunnelee, 1995), careful attention was paid to the content and layout of the invitation e-mail and the survey layout and clarity of questions. Piloting was conducted with academic (n=6) and user-researchers (n=3) and Patient Advisory Group member reviewers (n=2). Responses were

¹ Head of Operations England, National Research ethics Service, National Patient Safety Agency as at 15/06/11

received from nine of the ten individuals approached. Language, question type and questionnaire formatting were edited based on their questionnaire responses and feedback.

2.2.3. Stage 3: Survey Rounds 1 and 2

Two survey rounds were conducted to explore areas of consensus and dissent around understanding ethical and scientific value sets and beliefs underpinning PI and its impacts in health and social care research.

- *Sampling and the use of ‘experts’*

In order to reduce bias, our sampling strategy for panel composition was both reflective of the population subgroups under investigation and geographically representative (Jones & Hunter, 1995; Keeney et al, 2001). To increase the reliability of the results a large heterogeneous panel of ‘experts’ consisting of unique stakeholder groups was recruited (Duffield, 1993). We defined ‘expert’ as a group of *informed individuals* (McKenna, 1994) or someone who has knowledge or experience of a specific subject (Lemmer, 1998; Green et al, 1999). The sampling was purposive, drawn from three sub-samples: members of the public; user, academic and clinical researchers; and research managers, directors, commissioners and funders. These groupings were thought meaningful in capturing the various PI perspectives and interests. Potential panellists were identified in one of three ways (see Appendix 1): directly, through research team members’ contacts and networks; through conducting on-line searches of open-access research information and funding sites; and, via a review of literature in the field of PI in health and social care research.

- *Anonymity*

Complete anonymity could not be met as the names of survey participants and their responses were known to members of the research team. However, anonymity amongst participants was guaranteed. Reactions to participant sub-group opinions, arguments and levels of consensus for each sub-group were fed back to participants at Round 2 of the modified Delphi survey (see for example Appendix 3); each opinion carried the same weight and was afforded the same degree of importance in the analysis. In this way,

subject bias was eliminated (Keeney et al, 2001). This approach also enabled panellists to be open and honest about their views on various issues as well as providing them with an opportunity to express an opinion without feeling pressured psychologically to conform to the views of others (Keeney et al, 2001).

- *Quantitative data analysis survey Round 1 and Round 2*

As Crisp and colleagues (1997) indicate, determining how consensus cut-off points are reached and understanding how they were derived is often problematic as the reporting of such criteria is limited within many published studies. In order to address this aspect of the Delphi method in the present study, statistical advice was sought and specific criteria for determining consensus thresholds were applied. These criteria are articulated below.

We took, as representing **clear** consensus (in either a positive or negative direction) around a statement, endorsement of the corresponding response categories/scores (strongly agree/agree; strongly disagree/disagree) by at least 60% of respondents. We took, as representing **critical** consensus (in either a positive or negative direction) around a statement, endorsement of the corresponding response categories/scores by at least 70% of respondents, with at least 55% endorsing the extreme categories in the scales (i.e. strongly agree/disagree; major barrier/facilitator). Where an item reached the level specified above as 'clear consensus', attention was paid to the distribution of responses of the remaining 40%. Where these were evenly distributed across the remaining response options, the definition of consensus was accepted. Where responses clustered in one response option only, consensus was not assumed and this item was further explored in Round 2 of the survey. For each statement, we examined levels of consensus for all participants as a group and by 'role' subgroup (defined from responses to Question 1.4 as: clinical academic, non-clinical academic, member of the public, research manager or funding/commissioning body employee, and occupying multiple roles). We identified those items within each section where consensus, as defined above was reached within and across subgroups. We also identified those items within each section where no consensus was reached within and across subgroups.

- *Survey Round 1 content* (see Appendix 2)

The Round 1 survey questionnaire was divided into 7 Sections, with variable numbers of questions and response formats, as follows:

- Section 1: 4 fixed-choice socio-demographic questions
- Section 2: 6 items relating to what kinds of knowledge should underpin research; response format = 5-point scale, strongly agree to strongly disagree
- Section 3: 6 items relating to the purpose of involvement of the public and patients in research; response format = 5-point scale, strongly agree to strongly disagree
- Section 4: 8 items relating to views about the different levels of PI in research; response format = 5-point scale, strongly agree to strongly disagree
- Section 5: 21 items focusing on factors affecting how effective PI is; response format = 7-point scale, significant barrier to significant facilitator
- Section 6: 13 items about potential impacts and outcomes of PI in research; response format = 5-point scale, strongly agree to strongly disagree
- Section 7: 6 fixed choice questions about research experience

In line with Keeney and colleagues (2001), panel experts were also provided with the opportunity to make further comments as they saw fit, through open questions.

- *Survey Round 2 content* (See appendix 3)

In Delphi surveys there is no consistent method for feeding back findings (Schmidt, 1997). A number of approaches can be employed including graphical presentation (Malhotra et al, 1994), and textual presentation of statistical results (Woff et al, 1996; Chocholik et al, 1999).

At Round 2 the results from the Round 1 survey were fed back to panel experts in the form of bar charts, textual summaries of statistical data and summarised descriptions of qualitative findings. Feedback at Round 2 also included comparison of participants' own responses with responses of their own sub-group and those of the other sub-groups for each item. Particular attention was drawn to items demonstrating within-subgroup dissent, and within-subgroup consensus but across-subgroup dissent. Items at Round 1 where responses for all participants as a group reached the level defined for consensus (i.e. 60%), but the between-subgroup % differences for consensus were large (i.e. more than 10% difference in percentages endorsing agreement/disagreement between subgroups), were also explored in Round 2. Round 2 also explored any 'unexpected' (as defined by the study team)

endorsements of items by the subgroups. As in Round 1 panel experts were also provided with the opportunity to make further comments through open questions.

- *Qualitative data analysis survey Round 1 and Round 2*

Qualitative analysis of participant responses to the open-ended questions in both Round 1 and Round 2 of the modified Delphi survey was undertaken to enable depth exploration of quantitative findings.

Qualitative data was managed within a Microsoft Excel spread sheet. Thematic codes were identified using Framework Analysis (Ritchie & Spencer, 1994), a matrix-based method for ordering and synthesising data. The analysis was conducted by DS. Quality checking of the coding process and reduction of coding bias was ensured by AJ who reviewed 10% of the qualitative data. In the first instance, data were reviewed inductively to identify recurring themes and concepts raised by participants. These were coded and formed the initial major and sub themes. Additional codes were then incorporated through an iterative process involving DS and AJ. The thematic framework was further refined (see Appendix 4) before being applied systematically to the whole data set. This process facilitated the identification of any inconsistencies in coding which were subsequently discussed and reconciled prior to charting.

3. Results

Here we explore the value sets that various stakeholder groups hold about PI in health and social care research as we believe that these will shape peoples' opinions about the effectiveness and the value of PI assessment and impact. In particular, those values that underpin stakeholder views about: what kinds of knowledge should inform research; stakeholder bias and tensions; the purpose of PI; and, the level of PI were explored. Due to the iterative nature of the Delphi technique, with the survey content for Round 2 being informed by the results of Round 1, the results for both rounds will be discussed together in sequence.

3.1. Delphi survey sample

- *Round 1*

Using our recruitment strategy (see Appendix 1) seven hundred and forty (n=740) potential 'expert' Delphi panellists were invited, via e-mail, to participate in the on-line survey. Non-responding panellists were e-mailed up to two reminder letters as appropriate, yielding a total response of three hundred and eighteen (n=318) (RR 43%). Responding panellists self-selected themselves into one of five 'stakeholder' groups (clinical academic [CA]; non-clinical academic [NCA]; member of the public [MP]; research manager or funding/commissioning body employee [RM], or occupying multiple roles [MR]) as outlined in Table2.

- *Round 2*

All panellists (n=318; RR 43%) who submitted the Round 1 questionnaire were eligible to participate in Round 2. Of the 318 responders, three electronically 'opted out' of receiving further communications at the end of Round 1. The Round 2 questionnaire was therefore sent out to three hundred and fifteen (n=315) [Table 2]. Up to two reminders were sent to panellists as required. A total of two hundred and thirty one (n=231) Round 2 survey responses were received, yielding a response rate of 73% (of 43%).

Table 2: Response percentage per stakeholder group at Survey Round 1 and Round 2

Stakeholder Group	Round 1 n=318* Response percentage per stakeholder group	Round 2 n=231 Response percentage per stakeholder group
Clinical academic [CA]	63 (20%)	40 (17%)
Non-clinical academic [NCA]	88 (28%)	67 (29%)
Member of the public [MP]	55 (17%)	41 (18%)
Research manager or funding/commissioning body employee [RM]	76 (24%)	56 (24%)
Occupying multiple roles [MR]	34 (11%)	27 (12%)

*Information about stakeholder group was missing for 2 panellists;

Analysis of the characteristics of those who took part confirmed the high level of expertise among panellists. Most had at least five years experience in research, with three-quarters having some responsibility for PI. At Round 1, panellists reported being involved in a wide range of research roles including, for example:

- Drafting research proposals and protocols (n = 239; 86%),
- Developing plain English summaries (n = 238; 86%),
- Sitting on project advisory and steering groups (n = 228; 82%),
- Presenting research findings (n = 226; 82%), and
- Being involved in data collection (n = 223; 81%).

However, despite this high level of expertise, it is interesting to note that fewer than half (n = 134; 48%) of the panellists had training relevant to PI in health and social care research; rather they 'learned by doing'. Panellists cited a number of practical learning opportunities which underpinned their PI skills acquisition; including, for example:

"Good networking and communication skills". [NCA, Round 1]

"...hard work building rapport and understanding of the patients' perspective, putting myself in their shoes". [NCA, Round 1]

"Support from others, learning alongside others, and time". [CA, Round 1]

"It is a work in progress, so learning from mistakes and trying to listen to what both the patients and the researchers need to make it a meaningful experience". [MP, Round 1]

"Various policy documents for engaging the public in research on which we can rest our local framework and priorities". [RF, Round 1]

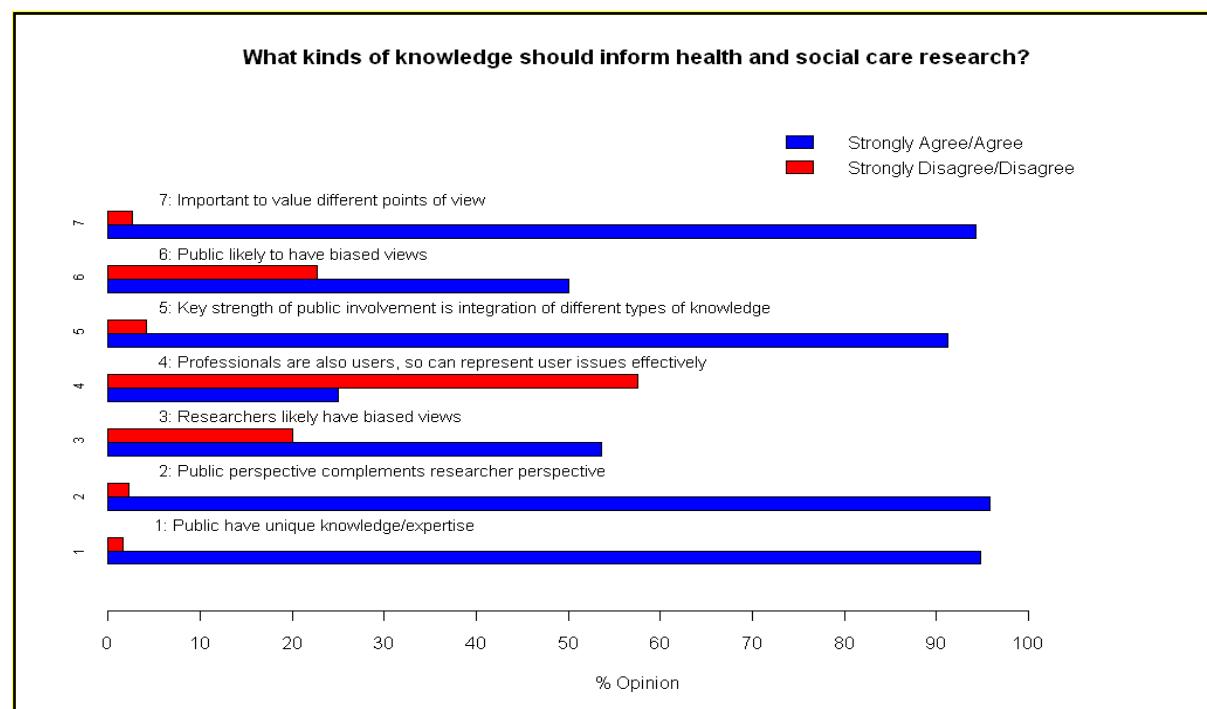
3.2. Kinds of knowledge

Round 1 responses revealed ‘critical’ consensus across the different stakeholder groups for the substantive argument that members of the public have unique knowledge and expertise that is *complementary* to that of professionals/clinicians and researchers, and should be valued equally (Fig.2, plot items 1 & 7). A comment from one clinical academic panellist illustrates this:

“It is important not to conflate the complementary perspectives of clinical / health, social care professional researchers versus methodologists. Both have important knowledge and expertise to bring to the table in informing health and social care research, as do patients, their informal carers and advocates and members of the public...it is important that all of these perspectives are regarded as equally important, rather than privileging any one view over the others”. [CA; Round 1]

Though it did not quite reach our definition of ‘clear’ consensus, there was broad support across the stakeholder groups (58%) for the idea that while professionals/clinicians and researchers may also be service users, they cannot represent user issues effectively. Again, though it did not quite reach our definition of clear consensus , there was support across stakeholder groups (just over 50%) for the idea that *both* members of the research community and members of the public are likely to have biased views about research.

Figure 2: What kinds of knowledge should inform health and social care research?



At Round 2 and in response to views about knowledge type, we asked panellists to comment on whether they felt it mattered if different stakeholder groups held views which others considered biased. Fifty six percent felt that it did not matter if different stakeholder groups held ‘biased’ views; of the 43% who felt it did matter, the percentages ranged from 29-59% between the five stakeholder groups. Individual stakeholder group responses are outlined in Table 3.

Table 3: Does it matter if stakeholder groups hold views considered biased by others?

Stakeholder Group	n	Bias Matters	Bias Doesn't Matter
Clinical Academic Researcher	39	23 (59%)	16 (41%)
Non-Clinical Academic Researcher	66	32 (48%)	34 (52%)
Member of the Public	41	17 (41%)	24 (59%)
Research Manager/Funder	56	16 (29%)	40 (71%)
Dual Role	27	10 (37%)	17 (63%)

A common theme across panellists' written comments and one articulated by a panellist holding multiple roles was that all researchers are biased to some degree, holding different views based on individual knowledge and / or experience:

“All views will have a bias of some kind, but I think it is more important that the view is ‘informed’. Bringing together the different perspectives in an open, collaborative way is one of the strengths of patient involvement, not a weakness”. [MR, Round 2].

Many panellists articulated that differences in perspective should not necessarily be viewed as a negative occurrence; rather they should be acknowledged as a “given”. Interestingly, at Round 2 the issue of power (who holds power to enforce their viewpoint) was highlighted as more important than the question of bias.

Process values that involve, *“building relationships of trust between the different stakeholder groups”* [NCA, R2], were viewed as key for managing difference and essential for effective stakeholder partnerships and shared decision making.

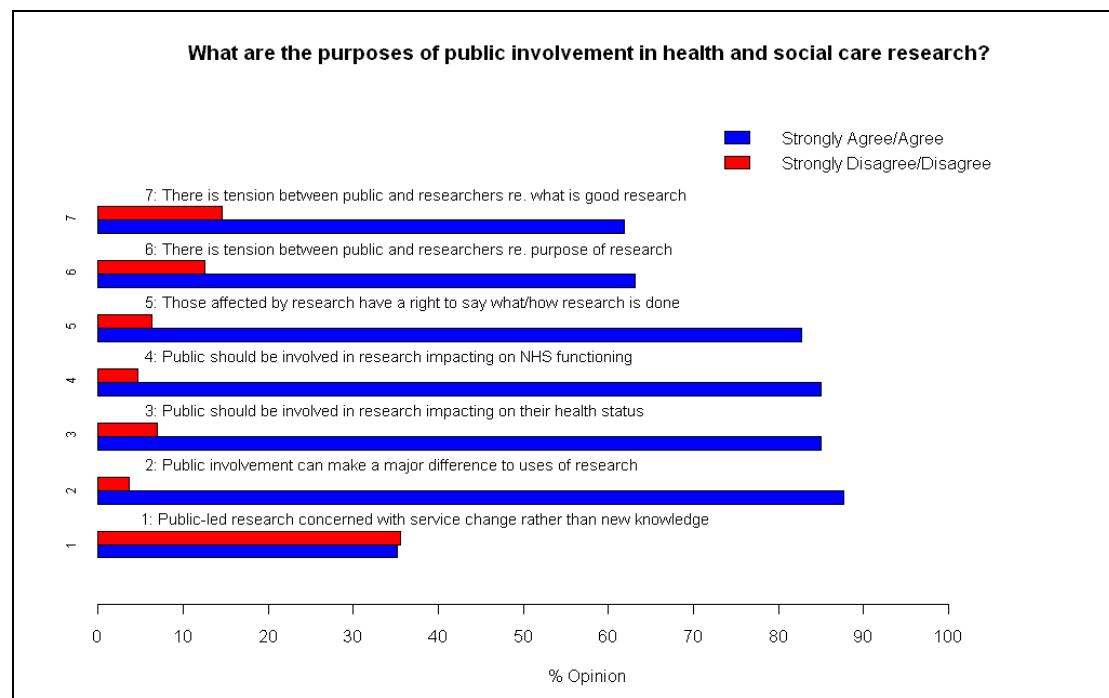
3.3. Purposes of PI

Figure 3 provides an overview of panellist responses at Round 1 related to the purpose(s) of PI in health and social care research. There was critical consensus (Fig. 3, plot items 3-5) across stakeholder groups (over 80% strongly agreed/agreed) that members of the public should be involved in publicly funded research, and are entitled to say what and how research is undertaken.

There was also critical consensus that members of the public should be involved in research impacting on their own health or NHS functioning (Fig. 3, plot items 3 & 4) and clear consensus that they can influence how such research is used (Fig. 3, plot item 2). However, there was also clear consensus (over 60% strongly agree/agree, (Fig.3, plot items 6 & 7) that there are tensions between what members of the public and researchers see as:

- The purpose of research, and
- What constitutes good research

Figure 3: What are the purposes of PI in health and social care research?



At Round 2 we asked panellists to comment on whether they believed tensions within the arena of health and social research could be resolved. Seventy five percent (75%) said yes tension resolution was possible, with a percentage range of 67%-89% across stakeholder groups. Individual stakeholder group responses are outlined in Table 4.

Table 4: Can tensions be resolved in health and social care research?

Stakeholder Group	n	Tension Resolution YES	Tension Resolution NO
Clinical Academic Researcher	38	34 (89%)	4 (11%)
Non-Clinical Academic Researcher	66	44 (67%)	22 (33%)
Member of the Public	41	35 (85%)	6 (15%)
Research Manager/Funder	54	37 (69%)	17 (31%)
Dual Role	26	18 (69%)	8 (31%)

Tension, it was argued, was an inevitable consequence of potential differences in perspective and / or expectations of various research team members. However, tension was not entirely perceived as a negative concept, rather it was seen by many as a tool to stimulate critical debate:

"There should be tensions because that indicates passion; but the differences need to be managed in an open and transparent manner". [MP, Round 2]

"...if researchers, clinicians and members of the public work together at the start of a trial, it will significantly reduce these tensions. However I also think that you can never entirely remove the tensions, and to some extent this is a good thing as the element of struggle helps to refine the research question." [MP, Round 2]

Once again, the need to promote values of effective partnership - including, for example, mutuality, communication, reflexivity and learning from each other - was seen as key to effecting tension resolution over time. The recognition that tensions are inevitable and can be used productively through questioning and discussion has also been highlighted by Abma and Widdershoven (2005).

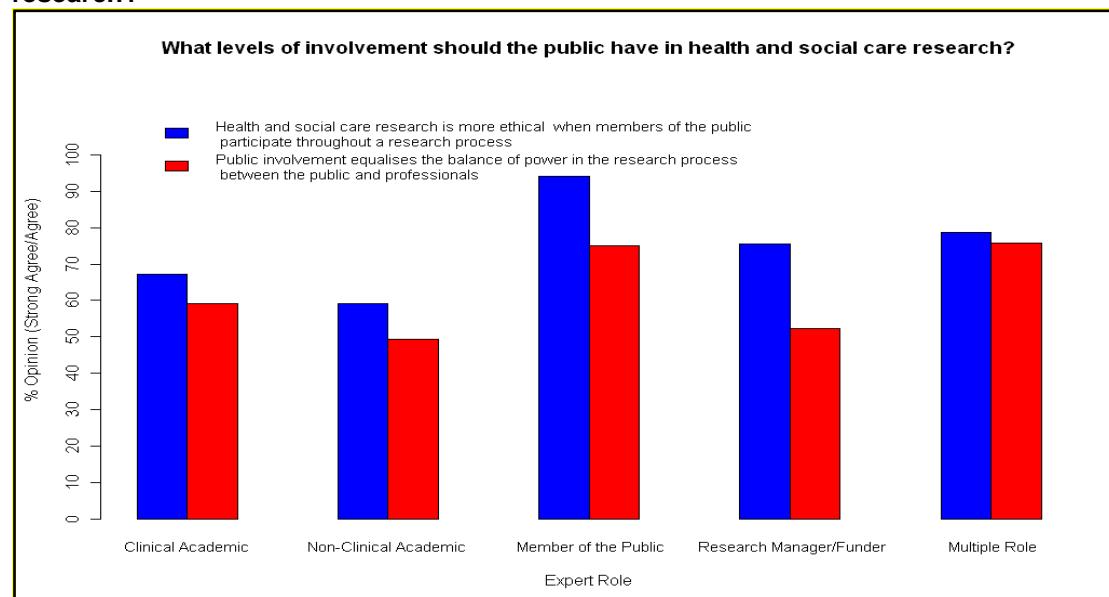
There was support in panellists' written responses at Round 1 for the idea that PI training for members of the public needed to not only include an overview of research design and methods but should also involve education about political and policy context(s) which would

lead to greater understanding of research drivers and processes. It was articulated by some panellists that training could also increase the empowerment of members of the public, promoting and facilitating partnership working within the research team. However, it did not go unrecognised by panel members that a lack of training should not stop academic researchers from recognising and valuing the experiential knowledge of members of the public themselves.

3.4. Levels of PI

There was clear consensus across all panellists as a single group that research is more ethical when members of the public are involved at all stages of the process. However, as indicated in Figure 4, this statement was most strongly endorsed by members of the public (94% strongly agreed/agreed); and least endorsed by members of the research community (63% strongly agreed/agreed). There was critical consensus across all stakeholder groups (81% strongly agreed/agreed) that involvement is empowering for members of the public. However, members of the public and those with multiple roles were much more likely to agree (75% strongly agreed/agreed) than were other groups (54%) that PI equalises the power between them and professionals. Clear consensus was also reached (over 65% agreed strongly/agreed) in relation to the belief that PI was often a ‘tick the box’ exercise, with members of the public disappointed by the lack of opportunity to influence the process.

Figure 4: What levels of involvement should the public have in health and social care research?



Our Round 2 data indicated, perhaps somewhat disappointingly, that despite the positive aspects of PI identified by all stakeholder groups, there was a strong perception that PI in research could still be tokenistic:

"There is the perception that it is an inconvenient tick box exercise giving no added value and actually slowing research process down" [CA, R2].

"Until researchers recognise the importance and value of public involvement, and how it can improve the quality of their research, they are likely to give it low priority" [CA, R2].

"While PI is no longer an optional it can still feel like a hassle for the academic community with gains that can seem remote. That needs to change otherwise people will continue being tokenistic" [NCA, R2]

A number of concerns were voiced by panellists about involving members of the public in the research process. Such concerns included the lack of funding to involve the public in research question and grant development. Time pressures related to grant applications and project-specific time-lines were also highlighted as problematic, including lack of time to take account of public members' health problems and / or work commitments, the lack of provision for realistic timeframes for reviews and, not least, the lack of time needed to develop and nurture research team relationships.

At Round 1, a number of panellists expressed the view that a "*fit-for-purpose*" model of PI, which reflected study and social contexts, was a more appropriate way of assuring effective PI than the '*levels of PI*' frameworks proposed in the PI literature (see for example, Hanley et al 2004). Such frameworks were not popular among panellists, who argued that the hierarchy implicit in the notion of PI levels was misleading and not necessarily an indication of PI quality. The levels approach to PI was further criticised for not addressing all the facets of involvement and as such having limited application and potential "*drivers for tokenism*". This finding is consistent with the latest guidance from Involve (2012b) which places emphasis on 'approaches' to PI rather than on levels of PI and also recognises that different approaches to PI might be used within the same project

Following these responses we asked panellists at survey Round 2 whether in their opinion they felt there were any circumstances where PI was inappropriate. There was virtually total agreement across written responses that members of the public could be involved in all / any type of research, with the caveat that PI may be more challenging within the field of basic science research. The following observation made by one panellist, a research manager / funder, serves to illustrate the potential for variation in the way members of the public can be involved:

“...hard to imagine a rationale for no involvement, but it will vary from project to project. One argument is often made that there shouldn't be public involvement in pure basic biomedical research and certainly the level of involvement will be very different to that, say, of a clinical trial. But there is still potential for involvement for example in wider public debate/involvement about evaluating this type of research and making policy decisions about how much money to invest in this type of research than more applied research. Some scientific projects may require human samples and there is a role for the public in the governance issues around this type of research - or motivating others to donate tissue etc. I have come across some aspects of clinical trials where, for example. two different scales for measuring depression were compared - a very technical and limited bit of work - with no room for influence from public involvement - but this was one part of a much larger trial where there was plenty of scope for involvement. So it may not always be appropriate for public involvement to influence the design and delivery of a project if it is very technical - but there is likely to be value of involvement in other aspects of the project around governance and funding decisions and perhaps dissemination in informing people that the research is going on - and explaining the implications of the research to a lay audience”[RM, Round 2].

3.5. What factors influence effective PI?

Panellists were asked at Round 1 to consider a number of factors which may act as either barriers or facilitators to PI. The 21 factors were identified from data collected at our previously conducted workshops or from the extant PI literature; and related to both the nature (12 items) and the interpersonal aspects (9 items) of the research process. Panellists were asked to rate, on a 7-point scale from ‘major barrier’ through to ‘major facilitator’, each factor as either a barrier or a facilitator to PI.

- *Factors agreed as barriers*

There was consensus at Round 1 across all panellists that the following four factors act as major or moderate barriers to effective PI:

- Attitudes of researchers to relinquishing power and control (71% agreement)
- Scientific language used in research (70% agreement)
- Lack of support for PI from research funders (70% agreement) and
- The perception that members of the public have biased views (63% agreement)

There was also consensus at Round 1 that the following five factors act as major or moderate facilitators to effective PI:

- Recognising members of the public have valuable contribution to make (69% agreement);
- Clear communication between research team members (67% agreement);
- Designated funding for PI (66% agreement);
- Time to build partnerships and trust (65% agreement); and,
- Training for researchers about PI (63% agreement)

At Round 2, the twelve factors for which there was no consensus at Round 1 were presented back to panellists, who were asked to rank in order of importance which they regarded as the three greatest barriers and, similarly, the three greatest facilitators. Three factors emerged as being seen as the most important barriers:

- Attitudes of researchers
- Perceived importance of PI
- Lack of research experience of members of the public

The first two barriers in the list were cited consistently and endorsed across all stakeholder groups.

The three top-ranked facilitators were:

- Ability to be open and flexible to difference
- Attitude of researchers
- Perceived importance of PI in health and social care research

The first of these facilitators were cited consistently and endorsed across all stakeholder groups.

There was weaker agreement for the remaining nine factors, listed below:

- Clarity of research team roles
- Consistent application/monitoring of an agreed PI framework
- Financial reward for service users
- Importance of research question
- Study design and methods
- An explicit definition of PI
- Research methods training for members of the public
- The ability to be flexible and open to difference
- The perception that researchers have biased views

Overall, at Round 2 panellists recognised that PI facilitators are the well managed opposite of PI barriers. Written responses highlight that time to develop team cohesion as well as PI training experience for both members of the public and researchers were seen as pivotal factors in affecting meaningful PI.

Panellists at both rounds repeatedly acknowledged that stakeholder motivation and the positive attitude of all involved were essential pre-requisites for “*doing good PI*”. As one clinical academic explained:

“I was involved in a collaborative group that met consistently since 2007. It has been a journey of experience. Over time that understanding has evolved and grown about good public involvement. This experiential learning took theoretical ideas and made them a reality. It gave the opportunity to challenge the internal subtle prejudice that most clinicians have to public involvement to create a real working relationship that can produce research”. [CA, Round 1]

At survey Round 2 panellists were invited to suggest what, in their opinion, needed to change in order to make PI more than just ‘tokenistic’. A number of key factors emerged from the analysis:

- Provision of clear guidance on what PI means, together with models of good practice
- Definition of measurable standards for PI
- Redressing of the power imbalances that favour clinical and non-clinical academic researchers – for example, by involving users at the earliest stages in the research process and defining timelines that take account of constraints operating upon users
- Provision of appropriate PI education / training / support / mentoring for both members of the public and clinical and non-clinical academic researchers – for example, via the national research networks, NIHR Research Design Service and INVOLVE
- Addressing of accountability issues through monitoring of PI processes and outcomes
- Provision of funding early on (pre-protocol) to enable PI to take place during the design stage of the research study
- Demonstration of added value / benefits of PI through examples / body of evidence
- Designation of individuals to drive forward PI agenda within institutions i.e. networks and mentors
- Integration of PI into research design
- Funding made dependant on PI
- Clarity with regard to PI strategy and individual roles, to be defined at project outset
- Enduring involvement, so relationships develop
- Adequate provision of resources required
- Definition of roles of research ethics committees; journals and funders in promoting PI reporting
- Definition of roles of hosting institutions with regard to facilitating and embedding PI
- Transparency / openness / flexibility / commitment / honesty

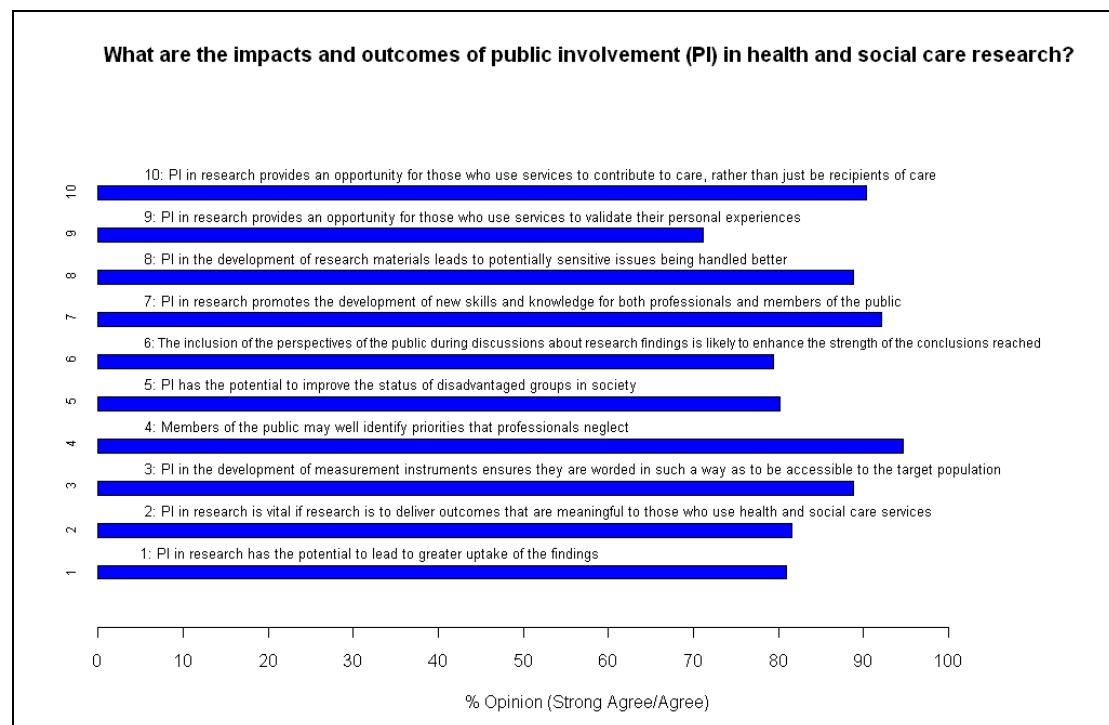
INVOLVE (2012a) promotes active ‘partnerships’ with members of the public in the research process, emphasising the need for engagement, support and training. Our panellists also commented that effective PI was embedded in partnership and process values; “*doing good PI*” involves the development of relationships. Interestingly, many panellists expressed the

view that when involvement was done well it was often difficult to deconstruct the process in order to evaluate discrete elements of PI contribution and / or impact.

3.6. What are the impacts and outcomes of PI?

As outlined in Figure 5 there was consensus for 10 of the 13 impact and outcome statements, with critical consensus among panellists for 3 (2;4;7) and clear consensus for 7 (1;3;5;6;8;9;10) of the items.

Figure 5: What are the impacts and outcomes of PI in health and social care research?



However, it was also agreed that assessing how PI influences a research project is methodologically problematic. Non-clinical academics were the group that most strongly endorsed this position. Seventy-one percent strongly agreed/agreed, compared to 56% of members of the other stakeholder groups. A surprising finding was that despite high endorsement of the positive impacts and outcomes of PI in research, there was no consensus that it improves quality and relevance. Members of the public were most likely to think (55%) that PI leads to research of greater quality and relevance; while academic researchers were least likely to think this (32%).

Likewise, there was no consensus across the stakeholder groups for the statement that PI makes it more likely that research will be used. However, as one clinical academic pointed out:

“...absence of evidence isn't evidence of absence and just 'cos we can't yet demonstrate the impact of PI on research quality and relevance it doesn't mean we never will. As the body of evidence grows the likelihood of showing how and whether PI impacts on research quality and relevance grows and views on this may change”
[CA, R2]

Given the level of consensus about methodological difficulties in assessing PI, we asked panellists at Round 2 to consider how important they felt it was to assess PI? Overall, panellists expressed the view that assessment of PI was either very (58%) or fairly (31%) important, with the minority believing PI assessment only slightly important (7%) or not important at all (4%). As shown in Table 5, the range of %s across stakeholder groups endorsing ‘very important’ was 40-75%.

Table 5: How important is it to assess PI in health and social care research?

Stakeholder Group	n	Very important	Fairly important	Only slightly important	Not important at all
Clinical Academic Researcher	36	20 (56%)	12 (33%)	3 (8%)	1 (3%)
Non-Clinical Academic Researcher	62	36 (58%)	19 (31%)	6 (10%)	1 (2%)
Member of the Public	40	30 (75%)	7 (18%)	2 (5%)	1 (3%)
Research Manager/Funder	53	29 (55%)	17 (32%)	4 (8%)	3 (6%)
Dual Role	25	10 (40%)	12 (48%)	1 (4%)	2 (8%)

A number of panellists made the observation that to evaluate PI in isolation was discriminatory; rather, it was argued, all research aspects of the research process (including ethically driven PI) required evaluation. A number of justifications for undertaking PI evaluation were cited, including:

- As good practice
- To build an evidence base
- To improve the quality of PI
- As a means to continually examining policy and practice (including evaluation as an advocate for change)
- To promote critical debate about the value of PI / to convince sceptics
- To justify time and resources
- To evaluate benefit / harm / limitations to PI

- For ethical reasons – PI unethical if no benefit / value
- To satisfy funding criteria
- To promote PI as ‘normalised’ research practice / as a mechanism for securing its long term security and sustainability

Again, at Round 2, and in response to Round 1 findings in relation to PI impact, we also asked: “Does lack of agreement about the contribution of PI to improving quality, relevance and use of research, undermine its value?” (Table 6). Over half the panellists (58%) said *no*, they did not believe that lack of agreement undermined the value of PI (endorsement ranged across stakeholder groups from 42% to 67%). Rather, panellists suggested a number of issues that likely contribute to lack of agreement about the contribution of PI to improving quality, relevance and use of research. Not least of these was the perceived lack of common understanding as to the what, when and how of PI. Panellists articulated that questions of value were answerable only by good evidence; however, lack of sophistication in conceptualising PI, together with the lack of clarity around PI implementation and practice, made identifying appropriate mechanisms for evaluation (and thus contributing to the evidence base) problematic.

Table 6: Does lack of agreement about the contribution of PI to research undermine its value?

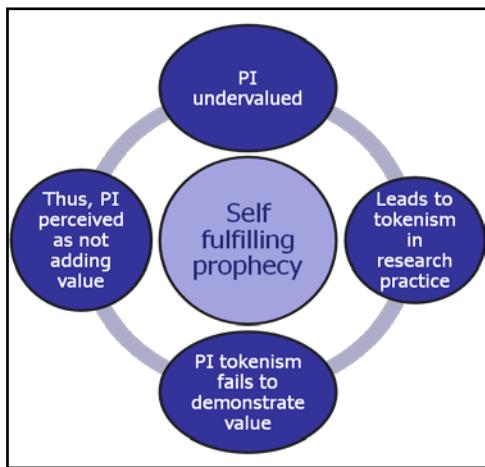
Stakeholder Group	n	Yes	No
Clinical Academic Researcher	36	12 (33%)	24 (67%)
Non-Clinical Academic Researcher	62	22 (35%)	40 (65%)
Member of the Public	40	23 (58%)	17 (42%)
Research Manager/Funder	53	24 (44%)	29 (55%)
Dual Role	25	13 (52%)	12 (48%)

However, the fact that at R1 only 33% and 35% of clinical and non-clinical academic researchers respectively said PI *added value* to research was felt by some R2 panellists to be “*damaging to the public involvement cause*” and was perceived as a “*lever for providing academics with the excuse not to participate in future public involvement*”. Conversely, others argued that the *no value* perception put forward by the academic community should not be interpreted as *PI not having value*, but rather as a reflection of the way in which academics themselves practiced PI tokenistically:

"If it is not seen to have value it is less likely to be embedded and will thus remain tokenistic without reaching its full potential value". [NCA, R2]

It could be argued therefore that PI tokenism presents itself as a self-fulfilling prophecy (Fig. 6): PI when undervalued leads to tokenism in research practise, tokenistic practice fails to demonstrate the value of PI, PI is therefore perceived as not adding value to health and social care research.

Figure 6: PI tokenism as self-fulfilling prophecy



4. Discussion

This report describes findings from an on-line, modified Delphi study involving a range of stakeholder groups to explore values and issues underpinning PI in health and social care research. This approach to gathering experts' opinions and suggestions without the need to bring them together physically, proved both versatile and resource-efficient. Key to this process is the representative panel composition and a high level of panellist motivation. In this study, responses across the various stakeholder groups was fairly evenly balanced; and the response rate was, in our view, acceptable given the 'cold call' approach (Sitzia & Wood, 1998; Arber, 2001; Edwards et al, 2008). Allowing panellists an opportunity to comment on their interpretation of the items and to express their views via open-question feedback increased the reliability of the study and improved the validity of the results (McDonnell et al, 1996).

Our purpose in the following discussion is three fold. Firstly, to consider key themes emerging from the data in relation to PI in health and social care research; secondly, to highlight the potential limitations of our research approach; and thirdly, to present our conclusions.

4.1 Key themes

Overall, we identified high levels of consensus across our stakeholder groups for many of the normative, substantive and process-related issues explored. These included: that members of the public have an entitlement to be involved in the research process, including in consideration of what research is undertaken and how it is used; and that different types of knowledge are important and members of the public have unique knowledge to offer. There were also high levels of consensus about the most important barriers and facilitators to PI, (though there were a number of other factors for which consensus was less clear). These areas of consensus highlight the extent to which PI is already embedded in health and social care research. However there were also areas of conflict between stakeholder groups. In particular, there was a lack of consensus about the substantive issues of bias and

representativeness; and the normative issues around whether the purpose of PI in research is to bring about change or generate new knowledge. There were large differences by subgroup in the percentages endorsing the ethical justification for PI; and the argument that PI equalises power imbalances. Overall, across-group consensus was less clear for substantive issues than for normative or process ones. In particular, there was no consensus that PI improves the quality and relevance of research; or that it increases the utility/uptake of research findings. Further, although there were high levels of consensus about the need to assess impacts and outcomes of PI, non-clinical academics emerged as the group most likely to support the position that assessing these impacts is methodologically problematic. Finally, there was wide variation in the percentages by subgroup endorsing that the value of PI is undermined by lack of agreement about its contributions to the research process.

Our findings suggest that timely and appropriate training is important to support members of the public in research involvement; similarly, that other actors in the research process would also benefit from training in how to engage and support members of the public in their research roles. Support strategies suggested by our panellists included, for example, advice and mentoring schemes and financial reimbursement. This is in line with current NIHR Research Design Service strategy and provision (NIHR, 2013) and echoes the conclusions of Boote and colleagues (2010).

Overall, our Round 1 survey identified high consensus across stakeholder groups for many of the issues explored, for example, that members of the public have: unique knowledge; an entitlement to be involved in publicly funded research, and an entitlement to say what and how research is undertaken and used. However, there were large differences by stakeholder group in the percentages endorsing the position that research is more ethical where there is PI throughout. Although ethical concerns are paramount in the context of health and social care research, it is interesting to note that the two stakeholder groups least likely to endorse the importance of PI to ensure research probity were clinical and non-clinical academics. There was also disagreement by stakeholder group in the extent to which PI was seen as

equalising power between public and professionals; and in the importance of potential stakeholder group bias.

Most health and social care research areas, including pre-clinical, were deemed appropriate for PI; with many panellists articulating their beliefs about how and when it might be feasible to introduce and evaluate involvement. This reflects recent changes in the commitment by UK funding bodies to incorporating PI across all research designs and at all stages of the research process (NIHR, 2012). Assessments about the appropriateness of PI need to be viewed within the overall opportunities for members of the public to influence project-specific agendas. In a recent review of PI case studies conducted by Boote and colleagues (2010) the issue was highlighted of potential tensions between different stakeholder groups in the PI enterprise. However, in our study the potential for tension was articulated as an inevitable consequence of collaborative working; individuals' agendas can be different when designing research studies. The acknowledgement and management of this standpoint was deemed essential in reconciling potential stakeholder difference. By promoting values of effective partnership including, for example, communication, reflexivity and learning from each other, research relationships can develop overtime, and tension can lessen as individuals work towards a common goal.

It is interesting to note that although panellists recognised significant progress in involving members of the public in health and social care research, they also reported shortcomings in PI uptake and practice, not least in the need for quality standards where involvement was embedded methodologically in research study designs. At an operational level, research support and development infrastructures were described as flawed – for example, panellists felt there was a lack of monitoring of whether or not proposed PI activity had actually taken place in the manner in which it was described; and highlighted difficulties in negotiating research governance processes that ran counter to user participation. In addition, research funding limitations, problems with user payments and existing time pressures were identified by many as barriers to meaningful PI. Such practical difficulties around implementation have

been highlighted previously (Staniszewska et al, 2011; INVOLVE, 2012c;) and may help explain disparities between current PI rhetoric and its practice.

It is interesting to note that the most frequently endorsed facilitators of PI were, in essence, the well-managed converse of the most frequently endorsed barriers. In this respect, they can all be seen as factors which will likely influence, for better or worse, the impacts and outcomes of PI. They therefore offer a useful checklist for research teams wishing to optimise the PI process.

Although PI was viewed by many as having intrinsic value, the majority of panellists believed its intrinsic value did not and should not diminish the importance of evaluating its impact alongside other research processes and outcomes. However, there was also a strong belief that demonstration of the value of PI was made more difficult by tokenistic practice, since assessing the impact of PI is clearly highly dependent on the quality of its conduct and on the openness and clarity with which it is reported.

4.2. Delphi study limitations

In this investigation, we opted to use a modified Delphi approach for data collection. This involved the use of both fixed choice and open questions in order to try to maximise our understanding of the issues under consideration. As with all survey approaches, there are inevitably limitations to the depth of the data obtained; and it could be important to follow up key issues using more in-depth approaches, which would allow for more detailed exploration of less well understood and articulated issues.

Although Delphi techniques vary, face-to-face contact with participants at Round 1 has been found useful in increasing the response rate (McKenna, 1994). However, due to the size of our sample, many of the panellists were targeted ‘cold’ without any prior notices. This approach may have had an impact on our response rate at Round 1. The use of reminders is generally endorsed in texts on survey methods (McColl et al, 2001) and in line with Peterson and colleagues (1989), two reminder cover letters were e-mailed to non-responding

participants at both Round 1 and Round 2 of the survey to stimulate additional responses. That our response rate to Round 1 was low was unsurprising given our approach; however, it was encouraging that a large percentage of responders to Round 1 subsequently completed Round 2. The Delphi technique requires continued commitment from participants throughout the data collection process. Consideration must be given to the fact that individual time constraints and lack of familiarity with the Delphi technique may have prevented some participants from being able to make such a commitment. Nonetheless, the quality of the responses provided made clear that those who did take part were firmly committed to offering us detailed and extremely thoughtful answers to our questions.

Another potential limitation relates to the representativeness of our panellists. Under half of those we approached participated in Round 1 of the study, and this proportion was further reduced at Round 2. Since those who opted in to the survey self-selected the stakeholder group with which they aligned themselves, we have no information about the groupings of those who opted out. We also have no information about other characteristics of interest for which we collected information from participants, for example, years of involvement in PI or extent of training in PI. We are therefore unable to comment meaningfully on the representativeness or otherwise of the study population. A further limitation arising from this is that those opting to take part in the Delphi study may have been individuals with a particularly strong commitment to PI in research, who were therefore keen to endorse its validity; and our findings may therefore offer an overly optimistic picture. This needs to be borne in mind when interpreting the findings.

4.3. Conclusions

This study has identified a number of key issues around PI implementation, particularly in relation to potential value conflict, tensions and associated impacts. To our knowledge, this is the first study offering empirical evidence about what different stakeholders in the ‘PI world’ think. Based on the experiences of our own team members, we would suggest that our Delphi Study panellists are likely to be representative of an emergent group of individuals with a substantial involvement in the delivery of PI. The survey therefore provides a snapshot of

current areas of consensus and conflict and suggests a relatively healthy and lively level of debate, for example around the issue of evaluating impact; but also agreement that doing this well is difficult. Similarly, there is recognition of the value of different perspectives and forms of knowledge, but also appreciation of how these link to issues of power which may be difficult to address.

Our findings also link to the conclusion of Boote and colleagues (2012) that there is a need for PI best practice standards which research teams can follow when seeking to actively involve members of the public in the research process. The overall aim of the wider User Involvement project (Figure 1), within which the Delphi study sits, is to develop and pilot a PI Framework and Guidance document, from which we will propose Best Practice Standards. Findings from our modified Delphi study about commonly held PI values and about assessment of PI impacts are contributing to this wider work by identifying areas where conflict is likely to arise and suggesting ways such conflict can be negotiated so the PI agenda can move forward meaningfully. It is hoped that use of the framework and standards by research teams will not only support the implementation of PI but enable its impact to be measured; thus making a robust contribution to the PI evidence base.

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Appendices

Appendix 1

Public and Patient Involvement in Health and Social Care Research: A two-round, modified Delphi survey

Recruitment Strategy

To be eligible to complete the Delphi survey questionnaire(s) participants must meet the following criteria of 'expert':

Participants must have some clear previous experience of user involvement in research, for example membership of a group or a committee with a focus on public and patient involvement in health and social care research or have experience of conducting and / or participating in service user-focused research

The two-round Delphi survey involved a purposive sampling strategy to recruitment potential participants from three sub-samples:

1. Members of the *public* (The term public is used as developed by the UK National Advisory Group, INVOLVE);
2. Academic researchers/research clinicians reflecting different topic areas/methodological approaches; and,
3. Research managers/directors/policy makers/funders

Potential participants were identified in one of four ways:

- I. Directly, through research team members' contacts and networks
- II. By conducting on-line searches of open-access research information and funding sites
- III. By reviewing key literature in the field of PI in health and social care research

Source, population type and mode of recruitment:

Recruitment Source	Targeted Population	Recruitment Mode
ESRC + LINKS		
ESRC Grant Holders	1; 2	II;
Beacons Project (Connecting research with society)	1; 2; 3	II; III
SOLAR (Action research)	1; 2; 3	II
EPILEPSY RESEARCH NETWORK (UK)		
Study Portfolio PI's	2	II
Clinical Study Group Leads	2	II
EPILEPSY RESEARCH GROUP (NW)		
Group Members	1; 2; 3	I
GENETIC ALLIANCE UK		
Project Officers and Co-ordinators	1; 2; 3	II
INVOLVE		
Research Study Database 2008-2012 inclusive PI's	1; 2	II
Core team and Members and Observers	1; 2; 3	II
INVOLVE Conference 2010 Delegate List	1; 2; 3	I; II
JAMES LIND ALLIANCE		
Strategy and Development Group Members	1; 2; 3	II
Corresponding authors - relevant reports	2	II
MEDICAL RESEARCH COUNCIL (MRC)		
MRC Public Panel / Consumer Liaison Group	1	II
NIHR CRN		
NIHR Research Networks - National		
Cancer	1; 2; 3	II
Dementias, Parkinson's, Huntington's and Motor Neurone Disease	1; 2; 3	II

Medicines for Children	1; 2; 3	II
Mental Health	1; 2; 3	II
Primary Care	1; 2; 3	II
Stroke	1; 2; 3	II
NIHR Research Networks – (North West)		
Cheshire, Merseyside & North Wales Medicines for Children (MCRN)	1; 2; 3	I; II
Greater Manchester & Cheshire Cancer Research Network (NCRN)	1; 2; 3	I; II
North West Dementias & Neurodegenerative Disease RN (DenDRoN)	1; 2; 3	I; II
North West Diabetes Research Network	1; 2; 3	I; II
North West Mental Health Research Network	1; 2; 3	I; II
North West People in Research Forum (NWPiRF)	1; 2; 3	I; II
North West Primary Care Research Network (PCRN)	1; 2; 3	I; II
North West Stroke Research Network (SRN)	1; 2; 3	I; II
Clinical Leads		
National	2	II
Local (North West)	2	I; II
Research Portfolio Database		
PI's	1; 2;	II
NRR ARCHIVE		
Grant Holders for PI-focused Studies	1;2; 3	II
RESEARCH DESIGN SERVICE (RDS) NIHR		
RDS Yorkshire and The Humber	1; 2; 3	II
RDS North East	1; 2; 3	II
RDS North West	1; 2; 3	I; II
RDS East Midlands	1; 2; 3	II
RDS West Midlands	1; 2; 3	II
RDS London	1; 2; 3	II
RDS South Central	1; 2; 3	II
RDS South East	1; 2; 3	II
RDS South West	1; 2; 3	II
RESEARCH for PATIENT BENEFIT (RfPB) NIHR		
RfPB Grant Holders - purposive sample by region/clinical speciality/methodology	1; 2	II
OTHER		
Service Users Experts	1	I
Academic Researchers/Research Clinicians	2	I; II
UK PUBMED CENTRAL		
Academic Researchers/Research Clinicians/PI's	2	II

Appendix 2

Public and Patient Involvement in Health and Social Care Research: Round 1 Questionnaire

This is a separate PDF document available on request.

Appendix 3

Public and Patient Involvement in Health and Social Care Research: Round 2 Questionnaire

This is a separate PDF document available on request.

Appendix 4

Qualitative Data Analytic Framework

1. IMPACT – Beneficial

- 1.1 Quality (Overall)
- 1.2 Appropriateness (i.e. via Steering/Advisory groups)
 - 1.2.1 Research Q/topic development/research design
 - 1.2.2 Research process (including recruitment; instrument development)
 - 1.2.3 Research Outcomes
- 1.3 User-focused / reflects user concerns
 - 1.3.1 Commissioning briefs / setting research priorities (i.e. panel member on funding committee)
 - 1.3.2 Data interpretation
 - 1.3.3 Data Presentation
 - 1.3.4 Dissemination/Language (i.e. grounded in experience/advocate of findings)
 - 1.3.5 Implementation
 - 1.3.6 Sensitivity to research context/cultural issues

2. IMPACT – Challenges

- 2.1 Divergence from scientific methods
- 2.2 Colliding world perspectives (i.e. tension between academic criteria for good / important study v public perspective of what constitutes good / important research, including also about the nature of knowledge)
- 2.3 Lay perception of 'lone voice' disempowerment / -ve experience
- 2.4 Discrepancy between PI Policy and / or rhetoric and actual practice
 - 2.4.1. PI 'Levels' / fixed models inappropriate
- 2.5 Consideration and assessment of PI impact on individuals involved (i.e. researchers and MoP's)
- 2.6 Lack of agreement about intrinsic value

3. PI MODELS / METHODS (how and when involved)

- 3.1 Consultation
- 3.2 Collaboration
- 3.3 User-led
- 3.4 Fit- for- purpose/context
- 3.5 Action/participatory
- 3.6 Standardised approach/framework
- 3.7 NICE Citizen Council / Public Opinion Poll
- 3.8 Consortium
- 3.9 FGD's
- 3.10 PI recruitment policies that ensure regeneration of PI personnel resource (i.e. generating 'new blood' to ensure up to date / relevant experiences)
- 3.11 Engagement
- 3.12 Diverse PI Stakeholder Group

4. PI ROLES

- 4.1 Network/Advisory/Steering group member or similar
- 4.2 User-researcher (to include interviewer) / co-applicant
- 4.3 Document/instrument development/review

5. PI FACILITATORS

- 5.1 [Provision of] User training/mentorship (Appropriate/timely)
- 5.2 Deconstructing and managing differences in perspective and expectation
- 5.3 Promoting PI in research (PR) generally through schools / public education / Hospital Trusts / social media networks.
- 5.4 +ve PI Ethos
- 5.5 Researcher training experience
- 5.6 User training experience
- 5.7 User motivation/willingness
- 5.8 Educational/information resources

- 5.9 Researcher and / or clinician motivation / willingness / positive attitude
- 5.10 Commitment from Commissioners / RM's / Principal Investigators / Senior Academics
- 5.11 Recruiting more than one user representative onto project team
- 5.12 Awareness of the inevitability of stakeholder bias
- 5.13 Facilitators are opposite to barriers when appropriately managed and supported
- 5.14 Methods training for users
- 5.15 Paradigm shift – general (including incentives to undertake PI)

6. PI BARRIERS

- 6.1 Researcher and / or clinician tokenism / tick box / convenience
- 6.2 Researcher and / or clinician reluctance to relinquish power
- 6.3 PI recruitment difficulties (i.e. hard to reach groups/low attendance rates)
- 6.4 Journal word counts (including the difficulty of including PI in publication and dissemination; lack of structured framework for PI reporting / lack of lay authorship)
- 6.5 Cost of PI v funding limitations /finding inflexibility
- 6.6 Grant application and / or project time-lines (including taking account of users own workload/illness; providing realistic timeframes for reviews etc., and time needed to develop relationships)
- 6.7 PI spasmodic involvement (no identified role)
- 6.8 Lack of training opportunities for users
- 6.9 User payments
- 6.10 Lack of researcher and / or clinician training/experience in PI
- 6.11 Unrealistic user and / or researcher expectations / antagonistic research culture
- 6.12 -ve PI Ethos
- 6.13 Researcher ignorance / apathy / unwillingness / -ve attitude towards PI
- 6.14 The perception that user knowledge / experience has limited generalisability
- 6.15 User bias
- 6.16 Researcher / clinician bias
- 6.17 Disenfranchised / minority PI groups afforded [even] less power
- 6.18 Lack of interest and / or willingness of MoP to participate in PI
- 6.19 Lack of knowledge / education about science / medicine / H&SC research in general population
- 6.20 Public / researcher / clinician perception that as a MoP individuals lack knowledge to contribute to research in a meaningful way
- 6.21 Public perception that research does not have relevance / impact outside the research community
- 6.22 Time intensive activity for MoP's
- 6.23 Lack of opportunities for MoP's to become involved
- 6.24 PI activity afforded limited career recognition within academia
- 6.25 PI not perceived as 'specialism' and therefore not requiring expertise
- 6.26 PI used by MoP's as mechanism for access to people / services / emotional support
- 6.27 Researcher / clinician lack of time to undertake PI training
- 6.28 Definitional issues / lack of clarity around PI (i.e.: impact v outcome; involvement v engagement; patient v public; what is/decides what 'quality' / 'meaningful' is)
- 6.29 Time lag: Benefit / impact of PI not always immediately obvious or measurable (e.g. partnership development; research uptake)
- 6.30 PI afforded little recognition within academia (not included in REF)
- 6.31 Perception by researcher / clinician that PI too difficult and / or time consuming
- 6.32 Issues related to Organisations' 'PI Infrastructure support'

7. STRATEGIES TO PROMOTE PI

- 7.1 Developing project-specific PI Strategy
- 7.2 Involvement throughout study for users
- 7.3 Partnership involvement
- 7.4 Ensuring understanding of the unique contributions made by all perspectives
- 7.5 Role identification for all
- 7.6 Promoting PI reporting (i.e. organisational, funders, REC reports, national database of studies with PI reports; wider dissemination incl. academic / lay / open access journals / media networks)
- 7.7 Innovative approaches/multifaceted approaches to PI
- 7.8 User Ownership
- 7.9 PI Policy Implementation (i.e. National; Organisational; funding bodies REC's ;)
- 7.10 Communication (including reduction in the use of jargon / elitist language) / IT facilities / training
- 7.11 Designated PI facilitator / 'Champion' of PI / PI Liaison
- 7.12 Developing an evidence base around PI (incl. Systematic reviews)
- 7.13 Developing PI infrastructures (e.g. across initiatives/agencies/organisations as a mechanism for information and training, networking; access to users, PI evaluation and dissemination)

- 7.14 PI as an integral component of research methodology (justified and approved by Funders, REC's and RG bodies; to include 'if not, why not' justification(s))
 - 7.15 Funding to enable early PI project development activities
 - 7.16 Provision of formal training in PI with recognised qualification
 - 7.17 Develop a 'bank' of service user mentors to assist those involved in PI (could be a role that links in with 7.13)
 - 7.18 PI activities written into job descriptions
- 8. NORMATIVE ARGUMENTS (PI as end in itself i.e. rights)**
- 8.1 Rights (Political, social, economic, civil, legal)
 - 8.1.1 PI as rule not exception
 - 8.2 Fairness
 - 8.3 Justice
 - 8.4 Democracy
 - 8.5 Empowerment (including transfer of power)
 - 8.6 Accountability and transferability (clarification of the relationship between the research and wider society)
 - 8.7 Change/action
 - 8.8 Ethical/Moral (includes professional codes)
 - 8.9 As a function of responsible citizenship
 - 8.10 Human-centred
 - 8.11 Counter arguments to PI (related to Normative debates; Scientific and / or Process values)
 - 8.11.1. PI as 'Red herring'
 - 8.11.2. PI Counterproductive / irrelevant / inappropriate
 - 8.11.3. 'Professionalisation' of user
 - 8.11.4. PI as potentially harmful / partisan
- 9. SUBSTANTIVE / SCIENTIFIC ARGUMENTS (related to substance or consequence of PI)**
- 9.1 Effectiveness/impact
 - 9.2 Quality/relevance and/or utility/importance of research
 - 9.3 Validity/Reliability (includes nature of knowledge claims)
 - 9.4 Representativeness/Objectivity/generalisability
 - 9.5 Strengthens the evidence base around H&SC
 - 9.6 Practicality / feasibility / acceptability
- 10. PROCESS VALUES (associated with the 'doing' of good PI – those values based on principles of mutuality and reciprocity/reflexivity and learning from each other)**
- 10.1 Partnership/Equality
 - 10.2 Respect/Trust
 - 10.3 Openness/flexibility/commitment/honesty
 - 10.4 Independence (related to independent research and independent voice)
 - 10.5 Clarity (of strategy and roles in terms of doing PI)
 - 10.6 Shared decision making
 - 10.7 Stakeholder disclosure
- 11. PI Trajectory (including, time-lines of experience and practice; reflective practice change; 'trial and error' endeavours)**
- 12. EVALUATION OF PI**
- 12.1 Justification for evaluation of PI [including any references re: 'Robust' methodology]
- 12.1.1 Arguments for evaluation
 - 12.1.1.1 To build an evidence base
 - 12.1.1.2 All research/aspects require evaluation (including ethically driven PI)
 - 12.1.1.3 PI unethical if no difference/value
 - 12.1.1.4 To justify time and resources
 - 12.1.1.5 To evaluate benefit / harm/ limitations of PI
 - 12.1.1.6 As a means to continually examining policy and practice (including evaluation as an advocate for change)
 - 12.1.1.7 To promote future PI involvement / PI involvement as 'normalised' practice / as a mechanism for securing its long term security / sustainability
 - 12.1.1.8 To promote critical debate about value of PI
 - 12.1.1.9 'PI Difficult to assess' argument over exaggerated
 - 12.1.2 Arguments against evaluation
 - 12.1.2.1 Difficult to assess / difficulty of assessing individual items including PI
 - 12.1.2.2 Ethical necessity so no need to evaluate
 - 12.1.2.3 PI as 'red herring'

- 12.1.2.4 Time intensive activity
- 12.1.2.5 Cost intensive activity
- 12.1.2.6 Evaluation of PI in isolation perceived as discriminatory

12.2 Evaluation Methods

- 12.2.1 Case Study
- 12.2.2 Public opinion/perspective on research outcome
- 12.2.3 Internal project evaluation
- 12.2.4 Target-driven indicators (i.e. improved recruitment)
- 12.2.5 Research uptake/translational success
- 12.2.6 Critical Reflection and / or debate (incl. FGD / interviews)
- 12.2.7 Project/context specific evaluation (incl. involvement pathway / action plans / change)
- 12.2.8 Evaluation as process, not outcome related
- 12.2.9 Public / Researcher / Clinician Stories / narratives
- 12.2.10 Validated PI outcome tool
- 12.2.11 Longitudinal Surveys
- 12.2.12 Examination of cost effectiveness of PI
- 12.2.13 Validated evaluation framework / toolkit
- 12.2.14 Study comparison methodology pre and post PI (to incl. RCT's)
- 12.2.15 Post-study follow-up
- 12.2.16 Specific research to assess PI (study methods to include survey; observational/ethnographic)
- 12.2.17 Outcome measures designed, monitored and regulated by the public (PI Governance)
- 12.2.18 PI Audit / PI Governance
- 12.2.19 PI Practice Standards
- 12.2.20 Multi-level / multi-approach / multi-disciplinary