Appendix 1: Delphi Survey ROUND 1 and ROUND 2 Questions related to PI Impact

ROUND 1 Questions related to PI Impact

ROUND 1.1. We are interested in exploring differing and conflicting reasons for, and purposes of, PI in research. Thinking about your own beliefs and experience of working in research, please rate your level of agreement with the following statements [Response scale: Agree strongly; Agree somewhat; Neither agree nor disagree; disagree somewhat; disagree strongly]:
 	
  ➤ Research led by the public is primarily concerned with making changes to services, rather than generating new knowledge
  ➤ Public involvement can make a major difference to the way research findings are used to bring about change in service provision
  ➤ The public should be actively involved in any publicly funded research which may impact on their health status
  ➤ The public should be actively involved in any publicly funded research which may impact on the functioning of the NHS
  ➤ People who are affected by research have a right to have a say in what and how research is undertaken
  ➤ There is a tension between what the public and researchers see as the purpose of research and what constitutes a good study

ROUND 1.2. Please comment on whether you agree/disagree with the following statement and why [Free text box]: If the scientific evidence were to demonstrate that PI in research has harmful effects, then the ethical dimension to the policy would be seriously undermined

ROUND 1.3. We are interested in exploring the potential factors influencing effective PI in research. Listed below are a number of factors which may act as either barriers or facilitators to public involvement. Please rate each of them on a scale of 1 to 5 [Response scale: Where 1 represents a 'significant barrier' and 5 represents a 'significant driver']:
 	
a) The first set of factors relate to the nature of the research process:
  ➤ The importance of the research question
  ➤ The study design and methods
  ➤ Having an explicit definition of public involvement
  ➤ The scientific language used in research
  ➤ Training for members of the public about research methods
  ➤ Consistent application and monitoring of an agreed framework for public involvement
  ➤ Designated funding for public involvement
  ➤ Training for academic researchers/clinicians about public involvement
  ➤ Financial reward for time spent by service users on research activity
  ➤ The clarity of research team roles
  ➤ The lack of support from funders for public involvement in research
  ➤ The perceived importance of public involvement generally in research

b) The second set of factors relate to the interpersonal aspects of research:

- Clear communication between research team members
- The perception that members of the public have biased views
- The attitudes of academic researchers/clinicians to relinquishing control and power over the research
- The attitudes of academic researchers/clinicians to involving the public in research
- The ability to be flexible and open to difference
- The perception that academic researchers/clinicians have biased views
- The lack of research experience of members of the public
- Recognising members of the public are individuals with something of value to contribute
- Time to build up partnerships and trust between the public and academic researchers

ROUND 1.4. In your opinion what is the single greatest barrier to effective PI in research? [Free text response]

ROUND 1.5. If you wish, please outline what problems or barriers you have faced in becoming a PI 'expert'? [Free text response]

ROUND 1.6. In your opinion what is the single greatest driver to effective PI in research? [Free text response]

ROUND 1.7. If you wish, tell us what has helped or made it easier for you to become a PI 'expert'? [Free text response]

ROUND 1.8. Is there anything else you would like to add about factors influencing effective PI in research? [Free text response]

ROUND 1.9. We are interested in exploring the potential impacts of PI in the research process. Thinking about your own beliefs and experience of working in research, please rate your level of agreement with the following statements [Response scale: Agree strongly; Agree somewhat; Neither agree nor disagree; disagree somewhat; disagree strongly]:

- Public involvement does not necessarily lead to health research of greater quality and clinical relevance
- Public involvement in research has the potential to lead to greater uptake of the findings
- Public involvement in research is vital if research is to deliver outcomes that are meaningful to those who use health and social care services.
- Public involvement in the development of research instruments ensures they are worded in such a way as to be accessible to the target population
- Members of the public may well identify priorities that professionals neglect.
- Public involvement has the potential to improve the status of disadvantaged groups in society
- Research is no more likely to be used, just because the public are involved
- The inclusion of the perspectives of the public during discussions about research findings is likely to enhance the robustness of the conclusions reached
- Assessing how the involvement of the public influences a research project is highly problematic
- Public involvement in research promotes the development of new skills and knowledge for both professionals and

members of the public ➢ Public involvement in the development of research materials leads to potentially sensitive issues being handled better ➢ Public involvement in research provides an opportunity for those who use services to validate personal experience by making it more explicit. ➢ Public involvement in research provides an opportunity for those who use services to contribute to care, rather than just be recipients of care
ROUND 1.10. In your opinion what would be appropriate ways of assessing how effectively PI is implemented within the research process? [Free text response]
ROUND 1.11. In your opinion what would be appropriate ways of assessing the impact of PI on research outcomes? [Free text response]
ROUND 1.12. Is there anything else you would like to add about the impacts and outcomes of PI in research? [Free text response]
ROUND 2 Questions related to PI Impact
ROUND 2.1. In your opinion does it matter if different groups hold views others consider biased? [Free text response]
ROUND 2.2. In your opinion can tensions be resolved? [Free text response]
ROUND 2.3. In your opinion, are there any circumstances where PI is inappropriate? [Free text response]
ROUND 2.4. In your opinion what is the key thing needed to make PI more than tokenistic? [Free text response]
ROUND 2.5. In your opinion how important is it to assess PI in research? [Free text response]
ROUND 2.6. In your opinion does lack of agreement about PI in research undermine value? [Free text response]