How to guide

How to review the extent of public involvement in a research study

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Introduction

This brief document simply catalogues each step of the process by which research is planned, delivered and implemented. You can use it to:

- clarify what you are being asked to do and where your expertise lies

- audit the extent to which research is being co-produced in your organisation

- collect examples of good practice

- develop a strategy for increasing the level of involvement by working on these issues one by one (but not necessarily in the order they are listed here!)

This paper was written by Peter Bates for the East Midlands Academic Health Science Network. As readers provide feedback, further insights will be used to update the paper. Please contact shahnaz.aziz@nottingham.ac.uk to suggest improvements or tell us how you have made use of this paper.

Advice and Decision making

1. **Management Group.** Join a group that meets regularly to make decisions or give advice that will affect the way in which the research for a study is carried out. This may involve become a public co-applicant.

2. **Recruiting researchers.** Join a panel to interview and appoint new research staff to the study team. For some studies, it may be advantageous to recruit researchers who themselves have lived experience of the issue being investigated.

3. **Focus Group.** Attend a single meeting where members of the public are brought together to comment on specific issues, perhaps at the pilot stage of the work, or later on to hear about and feedback on early findings or discuss the final results and help to decide on next steps where several options exist.

4. **Minuting meetings**. Attend meetings and take minutes, type them up and distribute them to interested people, or simply read them and check them for accuracy.

Research Process

5. **Hypothesis.** Think up and discuss ideas for what should be investigated through research. What are the important topics and key questions that matter?

6. **Review proposals.** Read the proposals that have been made by researchers and give your view about the quality of the proposal, either in a meeting or in writing. You might do this before the funding application is submitted and suggest improvements, or you may act as a 'lay reviewer' on behalf of the funding body to help them to decide whether to approve the request for funding.

7. **Study Design.** Help to design the research study and highlight key steps that will be needed to realise it.

8. **Prepare the funding application.** Work with academics and clinicians to define how best to marry up the funding requirements with the research questions.

9. **Prepare the ethics application.** Ensure that the final documentation outlining the research has been thoroughly checked and reviewed and perhaps accompany the research team to the Ethics Review Committee to help answer questions. Sit on the Research Ethics Committee to assess submissions from other research teams.

10. **Review processes and protocols.** Following funding and ethical approval of key processes and protocols, Standard Operating Procedures need to be created to ensure the same standards are kept by all members of the research team in carrying out the research which has gained approval.

11. **Select data.** In addition to investigating objective factors, such as body height, focus the research on patient and public perceptions, opinions and preferences.

12. **Review written materials.** See written materials <u>before</u> they are sent to patients or the public to ensure they contain the right messages, in the right tone and use everyday words. This might include participant information sheets about the research study, questionnaires or standard interview questions. Also, help to develop the researcher's documentation such as topic guides for semi-structured interviews and standard rubrics to make sure the correct information is sent out/collected at the right times to/from study participants.

13. **Find participants.** Encourage people to take part in the research study as a 'research subject' or become a research participant yourself (but not normally both at the same time in a single study, as this might create conflicts of interest).

14. **Collect data.** Join the team of researchers and get involved in interviewing people and posting out questionnaires to collect information for the research.

15. **Database creation.** The collected data needs somewhere to be stored electronically, so use your IT skills to help to create the databases and test them with sample data before the information needs to be input. Then help to input the masses of data which are collected from the research.

16. **Analysis**. Use your research or computer skills to bring the data together and analyse it or to think about and discuss the meaning of the findings.

17. **Co-produce progress reports.** Help to create regular progress reports about the research for interested parties and relevant stakeholders. Attend the meetings and provide added value by presenting personal experiences of the research treatment or intervention.

18. **Write Up.** Help to write up or edit the research report, perhaps for a publication. This may mean that your name appears as a joint author or you explain or write an account of your experiences that is used as a case study. Perhaps target newsletters or journals that are written specifically for community audiences.

19. **Presentations.** Give a speech at a conference or at a meeting to help people understand the importance of the research study. Alternatively, make a film that can be shown at an event like this.

Implementation

20. **Manage your own health.** Take up the findings of the research by adopting the recommendations in your own personal life.

21. **Set standards.** Help quality assurance staff to convert the research findings into measurable things that should be seen to be done in the NHS.

22. **Co-produce/review dissemination materials.** Besides formal conferences, there are plenty of opportunities to tell people about the research findings and what it means for them. Help to create these materials while the research is ongoing and once it has finished and been written up. Help to develop and present these materials by incorporating both your own lived experiences with your knowledge and experience of the research. Help to publicise new tools and the research findings amongst new, interested people long after the formal research study has concluded.

23. **Provide feedback on dissemination events.** Attend events, suggest improvements to content, layout, format, language etc., suggest new locations, venues or interested groups.

24. **Training.** Give training sessions for NHS staff or others to help them adopt the findings from the research.

25. **Mystery shopping.** Visit health or social care settings anonymously to check out whether the research findings have been implemented. This can be part of an organised review of services or an informal and even spontaneous action.