Recommendations for researchers planning patient and public involvement (PPI) activities

About this guidance

These recommendations are designed to help researchers get the most out of their PPI activities, for the benefit of research and all involved. They were co-developed by the NIHR Oxford Biomedical Research Centre (OxBRC) with PPI contributors and researchers, following a participatory study of the impact of the Diversity in Research Group on research.

The recommendations are not intended to be exhaustive and should be used alongside other relevant guidance such as the UK Standards for Public Involvement, NIHR briefing notes for researchers, University of Oxford guidance and OxBRC practical tools.

Key terms

PPI contributors are patients and/or members of the public involved in an activity to support researchers in designing, conducting, disseminating and/or implementing research.

PPI activities include steering group meetings, advisory group meetings, workshops, one-off focus groups, 1:1 meetings, email conversations or other activities with PPI contributors to inform research. We do not advise that PPI activities are undertaken solely by email, rather that emails can be used as part of the mix when undertaking PPI long term.

How to use this guidance

The recommendations are divided into three pages: **before**, **during** and **after** your PPI activity. We advise reading and considering all three pages when you are planning a PPI activity or applying for PPI funding. You can then revisit each page at the relevant stage of your activity.

You may find that you are already following these recommendations or you can implement some of them immediately. Other recommendations may only be feasible with additional time or funding.

Credits

Before your PPI activity

1 **Seek PPI as early as possible,** ideally when research ideas and questions are beginning to form. See guidance for recruiting patients and the public and examples from our review about involving under-served communities.

2 **Plan PPI across multiple stages:** Consider when and how to involve PPI contributors throughout the research cycle. Plan sufficient time and resources to support this - see further guidance on costing and funding PPI and paying PPI contributors.
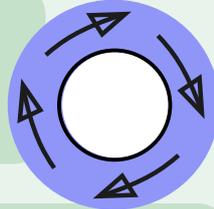
3 **Clarify purpose and expectations:** Explain clearly to PPI contributors (i) why you are seeking their views; (ii) which perspectives you especially need; (iii) whether their involvement is one-off or there are opportunities for further involvement - if the latter, provide a role description.

4 **Share timelines and potential challenges:** Tell PPI contributors about challenges that may delay or prevent research from happening (unsuccessful grant applications, fixed term contracts, regulatory approvals, etc.)

5 **Arrange introductory meetings:** If this is your first contact with the PPI contributors and you are planning a group activity, consider arranging a 1:1 meeting with each contributor beforehand. This helps to build rapport, manage expectations and develop successful working relationships.

6 **Consider in-person meetings** (rather than online) to support relationship building with and between PPI contributors, particularly if this is their first of several meetings. Consider who this might exclude and how they could be fully supported to attend. Provide a separate online option if needed.

7 **Choose meeting times and places to suit diverse needs** (e.g. accessibility, familiarity or neutrality, safety, transport, religious obligations, work schedules, caring responsibilities, need for frequent breaks). Avoid Fridays for those observing Islam or Judaism. See further guidance on involving people from under-represented groups and diverse communities.
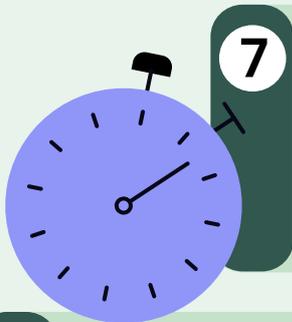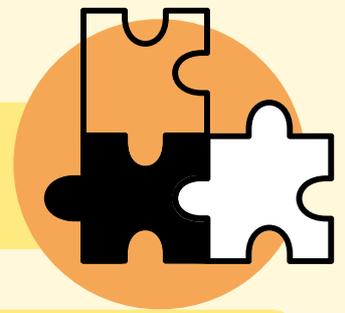
8 **Plan opportunities for informal conversation** with and between PPI contributors immediately before and/or after meetings with them. For example, schedule time for refreshments and networking even after short meetings.

See further guidance on planning online and in-person meetings.

During your PPI activity

1   **Clarify scope of input requested:** Be clear with PPI contributors about which aspects of your research can and cannot be changed.

2   **Provide clear, accessible information** about your research.
- If you are planning to give a talk, use the OxBRC guidance for PPI talks.
- Follow guidance on writing in Plain English.

3   **Ask specific, open questions** to help PPI contributors give useful advice. You could consider using creative methods if appropriate.

4   **Request personal information transparently:** If you need specific information about PPI contributors' characteristics or experience, don't be afraid to ask, but explain clearly *why* you need each piece of information and what you will do with it (including how you will store and use it).
- Offer "other" and "prefer not to say" options.
- Avoid making assumptions about PPI contributors' characteristics or experience; this information should come directly from them.

5   **Record contributions visibly and inclusively:** For example, a member of your team could be responsible for noting down all PPI contributors' suggestions on a flipchart or shared screen; this could then be collectively reviewed at the end of the meeting and a final version distributed to contributors.
- Be careful that suggestions are not immediately dismissed and therefore not recorded. It may help if the notetaker is a PPI professional or someone else who is not a researcher.
- Invite PPI contributors to correct any misinterpretations.

6   **Gather feedback after activities:** Consider asking PPI contributors to complete a short questionnaire about their experience of the activity and suggestions for improvement. Or schedule 1:1 debriefs – this is useful for building rapport if you are planning further activities with the same PPI contributors.

**7**   **Acknowledge and offer thanks** for all contributions.

After your PPI activity

1 **Review and respond to suggestions:** Consider each suggestion offered by PPI contributors and why you will or won't act on it.

If a suggestion seems irrelevant, before dismissing it ask yourself *why* it is irrelevant, and why you might not have got the advice you wanted. Consider whether what you *need* to hear might not always be what you *want* to hear (and vice versa).

If a suggestion can't or won't be implemented within your current project, consider how to respond sensitively and whether you have learned anything you might take forward into future research. Is there anything that could be highlighted in the project report/publication for consideration in future research?
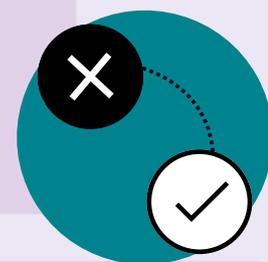
2 **Reflect on feedback and learning:** What have you learned from the post-activity questionnaire (if you used one) and your own experiences of the PPI activity as researchers? What might you do differently in future?

If your PPI activity will be repeated with the same contributors (e.g. a recurring meeting), share feedback from the previous activity at the beginning of the next activity and show how this has been considered or led to improvements.

3 **Provide feedback to PPI contributors** regarding the difference they have made to you, your project and/or your future research, ideally in conversation (rather than just email). This could be in a "you said, we did" format. Include your own learning as well as any impacts on your research. See [guidance on feeding back to PPI contributors](#).
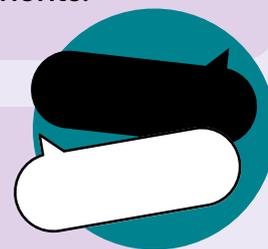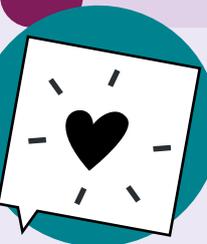
4 **Continue communicating** with PPI contributors throughout the research, including sharing updates on grant applications, research findings and outputs.

5 **Acknowledge and offer thanks** for all contributions and at the project end.

For queries or information about this guidance please contact **Dr Joanna Crocker at joanna.crocker@phc.ox.ac.uk**.

For more PPI guidance, including recruiting PPI contributors, setting up a PPI group, raising difficult issues, training and resources, see the [OxBRC practical tools for researchers](#), the University of Oxford's [Medical Sciences Division guidance](#) and the [NIHR's briefing notes for researchers](#).