

Recommendations for researchers working with diverse patient and public involvement (PPI) contributors

These recommendations were co-developed by the NIHR Oxford Biomedical Research Centre (BRC) with public contributors and researchers, following a participatory evaluation of the **Diversity in Research Group** and its impact. It is designed to help BRC researchers get the most out of their PPI activities, for the benefit of research and all involved. It is not intended to be exhaustive and should be used in conjunction with national NIHR and other relevant guidance.

The recommendations are divided into three sections – **before, during** and **after** your PPI activity – although we advise reading and considering all sections at the outset.

Examples of a **PPI activity** include a steering group meeting, an advisory group meeting, a one-off focus group, a co-production workshop, a one-to-one meeting or an email conversation 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.

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

**Before
your
PPI
activity**

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**During
your
PPI
activity**

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**After
your
PPI
activity**

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We are very grateful to all those who contributed to developing these recommendations, including [list of names = total 169 characters including spaces, list of names = total 169 characters including spaces, list of names = total 169 characters including spacesXXX], all Diversity in Research Group members and researchers who took part in the study, and the Oxford BRC PPIE Advisory Group. Infographics designed by Naomi Waite.

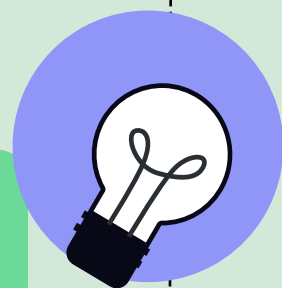
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Available from: <https://oxfordbrc.nihr.ac.uk/practical-tools-for-ppi/>

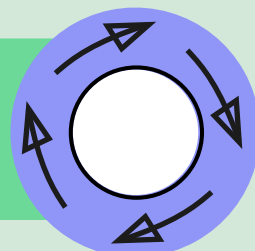
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Before your PPI activity

Seek PPI input **as early as possible** in the research cycle, ideally when research ideas and questions are beginning to form.



Consider whether and how to involve PPI contributors **throughout your project** or **at multiple stages**. Plan sufficient time and resources to do this properly – see further guidance on costing and funding PPI.



Be clear with PPI contributors about (i) **why** you are seeking their input; (ii) the particular **perspectives** you especially need (for example, groups or communities who are disproportionately affected by the health condition you are studying, or who are currently under-served by research in your field); (iii) whether you are seeking **one-off** input or offering opportunities for **further involvement** – if the latter, provide a role description including any particular experience you are looking for, the time commitment, expected project duration, and whether you are offering payment.



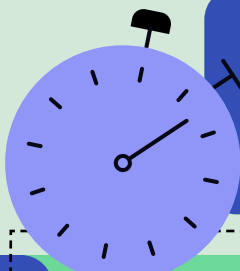
Plan to **continue the dialogue** with PPI contributor(s) as research plans and activities progress.

If this is your first contact with the PPI contributor(s) and you are planning a group activity, arrange a **1:1 meeting** with each contributor before the activity. This can help to build rapport, understanding and confidence, and manage expectations.

Plan your PPI activity **in person** (rather than online) if possible, particularly if this is the PPI contributors' first meeting. Consider who this might exclude and how they could be fully supported to attend. Provide a separate online option if needed.



Carefully consider the **timing and location** of meetings to meet the diverse needs of PPI contributors (e.g. accessibility, transport, religious obligations, work schedule, caring responsibilities, need for frequent breaks). Avoid Fridays for those practicing Islam or Judaism. See further guidance on involving diverse and under-represented groups.

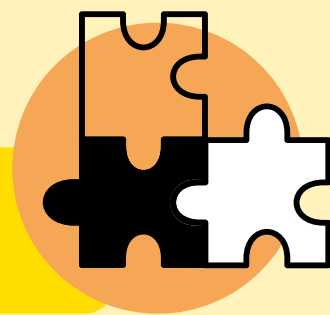


Plan opportunities for **informal conversation** with PPI contributors immediately after (and ideally also before) meetings with them. For example, schedule time for refreshments and networking even after short meetings.



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

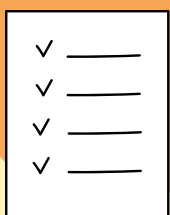
During your PPI activity



When requesting input from PPI contributors, be clear about the **scope** of input/advice sought (i.e. what can and cannot be changed).

Provide project information in a **clear, accessible** format.

- If you are planning to give a talk, see the [OxBRC guidance for PPI talks](#).
- Follow guidance on [writing in Plain English](#).



Ask **specific, open questions** to help PPI contributors give you the input you need.

If you need specific information about **PPI contributors' characteristics and/or experience**, don't be afraid to ask, but explain upfront and clearly **why** you need each piece of information and what you will do with it (including how you will store and use it).

- Offer "prefer not to say" options.
- Check you are not making assumptions about PPI contributors' characteristics or experience; this information should come directly from them.

Make sure you **record PPI contributors' suggestions** in some way. For example, the PPI Lead or another member of your team could be responsible for noting down suggestions on a flipchart or PowerPoint slide that is visible to everyone in the meeting; this could be reviewed/summarised at the end of the meeting and then shared with PPI contributors.

– Be careful that suggestions are not dismissed and therefore not recorded; it is important to note down everything at this stage. It may help if the notetaker is a PPI professional or someone else who is not a researcher.



Consider asking PPI contributors to complete a short questionnaire at the end of each activity to assess their **experience** of the activity and suggestions for **improvement**. Alternatively, you could schedule one-to-one debriefs – this is useful for building rapport if you are planning further activities with the same PPI contributors.

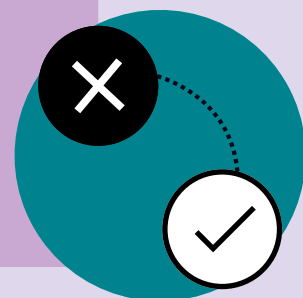
Acknowledge and offer thanks for all input.



After your PPI activity

Review the suggestions offered by PPI contributors. **Consider** how you will respond to each one, and why.

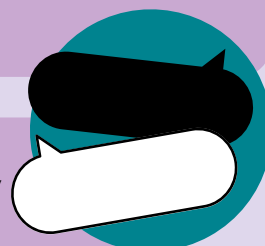
- If you have received advice or suggestions that seem irrelevant, before dismissing them ask yourself *why* they are irrelevant, and why you might not have got the input you want. Consider whether what you *need* to hear might not always be what you *want* to hear (and vice versa).
- If PPI contributors have offered suggestions you can't or won't act on within your current project, consider how to **respond sensitively** and whether you have **learned** anything that you might take forward into future research. Is there anything that could be highlighted in the project report/publication for future consideration? (e.g. "this was beyond the scope of the project but emerged as important for PPI contributors and should be considered in future research").



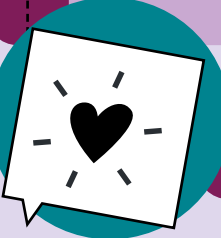
Review feedback from the post-activity questionnaire (if you have used one), and **reflect** on your own experiences of the PPI activity as researchers. What have you learned and what might you do differently in future?

- If your PPI activity will be repeated with the same PPI contributors (e.g. a recurring meeting), share the feedback from the previous activity's questionnaire at the beginning of the next activity and show how this has been considered and if improvements have been made.

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](#).



Continue communicating with PPI contributors throughout the research project, including sharing outcomes of grant applications, research findings and any outputs.



Acknowledge and offer thanks for all input and at the end of the project.



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](#).