

Getting started:

10 questions to ask about your public and patient involvement

1. Involve the right people - what patients, carers, service users or members of the public should be involved?

Try to involve people who reflect the diversity of backgrounds and experiences you expect your potential research participants to have. Do you need a mixture of urban/rural? Gender? Socio-economic backgrounds? People from different cultural/ backgrounds? What age categories? People for whom English is not a first language? Within your disease or condition, are there different subgroups, e.g. based on severity? Based on different diagnoses (e.g. Type I and Type II diabetes);

2. Involve the right number of people, but how many is that?

You want to involve people well: always involve more than one person, but meetings attended by 5-8 people are ideal to ensure everyone's voice is heard. Remember not everyone has to have the same role, but allow each PPI contributor to decide how much contribution they would like to make. Treat everybody equally and fairly in terms of giving them opportunities to get involved in different activities.

3. Do you need to involve other stakeholders? Consider who or what organisations should also have a voice in research?

Health care professionals? Health policy makers, managers in the health or social care system and other decision makers? Community or patient organisations (as distinct from individual contributors)? Consider what the

role and area of interest of each sector might be. Be particularly aware of the power imbalances that may exist if you bring a mix of people to the same table – bringing everyone to the same table from the start may not always be the correct approach.

4. How is the experience of PPI contributors relevant?

Why is this valuable for your study? At the start, you may not know “what you don’t know” – discussions with PPI contributors will help you to establish this.

5. In what way can PPI contributors influence the research design and research methods?

For example, shaping the research question, design of an intervention, defining the research protocol, outcome measures? Interpreting research data? Sharing research results?

6. Can PPI contributors help you to address the study’s ethical issues? Can their input help how you will manage potential risks and burdens?

For example, can people with lived experience of your research topic help to identify potential emotional obstacles for participants? Or practical obstacles?



7. Can PPI contributors make a difference to the consent and recruitment processes?

For example, will you co-develop the participant-facing information so that participants will be able to understand the study and be able to make an informed decision about whether or not to take part? Can the PPI contributors help you to decide how best to approach potential participants? where and when to have the initial conversation about participating?

8. How can their involvement make a difference to how the study results will be shared?

For example, is this helping you to plan how to make the study results available in a way that will be accessible to different audiences? Is there a role for your PPI contributors to bring the study results to their own communities? To use their own social networks to share key findings? To help influence policy and practice change? Think about “sharing results” rather than about “dissemination”.

9. What support will you need to provide to your PPI contributors?

This can include facilitating access to meetings, providing sufficient background information to allow PPI contributors to understand research sufficiently to be able to contribute and creating an appropriate environment in which every voice is heard, producing easy read materials focusing on key points.



10. What budget do you need for PPI activities? PPI contributors should be paid for their time and to cover their expenses. They may have to take time off work or have to pay carer or childcare costs to attend meetings. There is currently no agreed rate of payment. Consider also whether some budget should be set aside for patient organisations and charities who invest a significant amount of time as research partners.

There are also running costs associated with PPI activities. Check out the PPI cost calculator on the NUI Galway web site, for some suggestions on budgeting (www.nuigalway.ie/ppi).