

Patient and public involvement

What is PPI?

It's a good question and one that can cause confusion. **INVOLVE**, which is the part of NIHR which focuses on supporting PPI in research, has produced definitions to try to clarify the difference between involvement, engagement and participation – two other terms that no doubt you will have heard.

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| Involvement | Research that is carried out with or by patients and the public, rather than to, about or for them. |
| Engagement | This tends to come later on and is more about researchers telling the public about their work and raising awareness of it, so for example, at a science fair or public talk. |
| Participation | Taking part in a study or trial, something that a patient will have been asked to give informed consent for, and for which you will need to have obtained ethics approval. |

These are distinct activities although there can be overlap between them. One thing in particular that characterises involvement is that you don't need ethics approval because the people you are working with are helping to shape the research, they aren't research subjects.

Benefits of PPI

Some researchers view patient and public involvement (PPI) as making research more complicated and long-winded, sometimes feeling like it's yet another box to be ticked. But that shouldn't be the case –

rather, when it's planned well in advance and done in ways that suits the research, PPI brings benefits not only for participants but also researchers:

- It's important that patients have a say in driving the research agenda. As people with first-hand experience of disease, therapies and healthcare services, they have valuable insight that can help to make research more meaningful and efficient.
- Patient involvement can help to improve recruitment and retention rates for studies.
- Involving patients and the public can make your results more accessible meaning you will reach more people, thus raising the level of public understanding of research – this creates greater transparency in how money from taxes or donations to medical charities is spent.
- PPI is a way of showing respect for the people who give up their time to participate in studies and trials.

It's also worth keeping in mind that many funders (especially NIHR) now expect you to demonstrate that you've taken patients' and the public's views into account and have worked with them on your studies.

When and how to do PPI

Ideally, you need to start thinking about PPI early on in your project before you get too far into it. This includes budgeting for PPI, although in the pre-funding stage you may be surprised how little you need to spend and how willing people are to help for free.

Depending on your project, you can integrate PPI at various different stages and there is a wealth of tasks that your contributors can carry out. These include:

- suggesting ideas for research
- helping with ethics applications
- co-designing the study
- carrying out interviews
- helping to disseminate the research results

Don't feel you have to involve patients and the public at every stage if it's not sensible or feasible to do so, but don't underestimate how much they can bring to your research and how valuable their contributions can be.

Plenty of PPI contributors have specific, professional skills, but a lot of the time, their experience as a patient or carer is what is most significant.

More information

This leaflet gives only a very brief introduction to PPI so if you'd like any advice or guidance on how to incorporate PPI into your research, don't hesitate to get in touch – there are no stupid questions. We can help you get started with PPI, including recruiting patients, and offer advice on incorporating it at different stages. Please contact the Oxford BRC PPI Manager: polly.kerr@phc.ox.ac.uk

