

## Patient and Public Involvement (PPI) Guidance

### PPI Guidance 3: Recruiting PPI contributors (general)

This guidance has been developed by PPI leads from the Oxford PPI Staff Group<sup>1</sup>. It is piloted with researchers<sup>2</sup>.

Any changes to the original document are those of the users and not necessarily those of the Oxford PPI leads group. Original versions of Researcher PPI guidance and templates are available on the Oxford BRC website or from one of the [PPI staff leads](#).

There are various ways of recruiting PPI contributors to help with your research – some of these will be more straightforward than others but it's important to consider which will be most appropriate for your PPI, so that the input you get is as helpful as possible.

#### Who do you want to involve?

Think about who the target 'audience' is for your research – who will be affected by it? This could be a particular group of patients, or maybe it is the general public more broadly. It might even be healthcare professionals. Whoever it is, these are the people you want to involve in your PPI activities.

It's also important to think about under-represented communities – for example people who are less likely to take part in research or those who may be at risk of health inequalities – and how you can reach them.

Then think about where you would find these people, and that will give you an idea of where to advertise and recruit.

#### What do you want to achieve?

If you know what you want to learn as a result of PPI, what outputs you would like to create, or what issues you need help with, this will help you to recruit strategically.

Sometimes you will need a different kind of contribution for different challenges. So, for example, you might not need people with specific lived experience to review a lay summary, but you might need to understand patient experience of a specific condition when considering the research question or understanding obstacles to taking part in your study.

#### Places to advertise and recruit

Where you advertise for your PPI contributors will depend on who they are. It is usually advisable to advertise in more than one place – this will mean you are more likely to recruit the number of people you need, and from a range of backgrounds. Below are some suggestions of places to try to recruit people.

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<sup>1</sup> The group meets quarterly and includes leads from the [local NIHR organisations](#) and departments of the Oxford University Medical Sciences Division. One or more PPI contributors from these [PPI groups](#) have also reviewed.

<sup>2</sup> This document is being piloted (December 2023-April 2024) with researchers. Any suggestions for improvements should be sent to [Rachel.taylor@ouh.nhs.uk](mailto:Rachel.taylor@ouh.nhs.uk).

There is separate guidance if you are thinking of recruiting patients who are attending clinics - Researcher Guidance link.

### **Charities and support groups**

Some charities, especially the bigger ones, will already have relationships with motivated patients. They may be able to put you in touch with people who are interested in PPI. These patients may be quite familiar with research and the research process.

Smaller, more informal support groups may be a good way to reach patients who are comfortable speaking about their lived experience.

### **Community groups**

Working with a community group can be a good way to reach a wide diversity of people, and you can easily find out about different groups on the internet (examples of local groups are: [Oxfordshire Asian Women's Voice](#), [Age UK Oxfordshire](#), [Cherwell Collective](#)).

It is important to consider what you can offer the community group in exchange for them helping you. Ask the community group what would be useful (e.g. time, money, practical support). Examples might include a clinician coming to speak about a health-related question and be clear about whether this is a one-off request or if there is the possibility to explore building a lasting relationship with the group.

### **Community venues**

Community venues can be a good place to advertise eg libraries, GP practices, religious/faith venues, community centres, supermarkets etc. How you target these kinds of adverts might be linked to the specific communities you want to reach.

### **Existing PPI groups/ mailing lists**

There are a number of long-standing PPI groups, mostly for specific condition areas, in MSD and OUH. Keep in mind that they may get a lot of requests for PPI help and may not meet very often. We have compiled a list of [PPI groups](#) in Oxford and who to contact.

### **Previous trial participants**

People who have taken part in a trial or study, or have a relative who has, can be great PPI advocates because they have seen the potential benefits of research, and understand something about it. Make sure you have permission to contact previous participants and ensure they understand that what you are asking them to do is different to taking part in research.

### **Public engagement events**

Events such as science fairs or public talks can be a way of reaching potential PPI contributors. Public engagement events can be a good way of involving younger people and those of working age.

### **Social media**

Using different social media platforms can be an effective method of recruiting PPI contributors. Different platforms will have different demographics of users, for example Facebook is typically used by individuals > 30 years old, while Twitter and TikTok is used by younger individuals and also by companies or organisations. Facebook is also often used as informal support groups for patients,

particularly for conditions which are rare and where there is no support from charities. Some clinics, charity, and related organisations may be able to share your ad on their own social media. Depending on who you want to reach out to, these could be effective methods of sharing your PPI ad.

### Websites/ mailing lists

Some easy ways of reaching people are through existing groups or mailing lists – your department may have [resources](#) that you can access. There is also the national [NIHR People in Research](#) website which has a register of people who have signed up expressing their interest in PPI, and you can post your opportunity on it. Keep in mind that these methods can be a helpful starting point, but they are unlikely to help you reach under-represented groups.

### Personal networks

There is nothing to stop you from asking friends and family from helping with your PPI, if they have the relevant experience. You could also try other networks such as work colleagues, parents at your child's school or any other groups you are part of. However, it is worth remembering that if people know you in a personal capacity, they may feel anxious about being too critical, or not want to upset you with their comments.

### How to advertise

How you advertise your opportunity will vary depending on where you are advertising. For example, if you are using a website, it is likely to be quite straightforward and structured, but if you are approaching a community group, it will probably take longer and may require you to go and speak to members of the group.

Wherever you are advertising for your PPI opportunity, make sure it is clear who you are looking for and why you would like them to be involved. Is it because they have specific lived experience or because they have skills that would be helpful (e.g. communications experience)? It may be that you are looking for members of the general public without any specific experience, in which case it is helpful to make this clear.

Make sure you include a deadline by which you would like people to respond and are clear about when you will get back to them.

### How will you decide who to work with?

Depending on your area of research, you may only get a small number of people who respond. This can make it easier to decide who to work with, but it still important to ensure that everyone understands what is expected.

However, you may find yourself in a situation where you have more people interested in getting involved than you are able to accommodate. It is a good idea to think about how you will handle this ahead of time. For example, making it clear in your advert how many people you are hoping to recruit and offering alternatives if people are not selected for this work (e.g. signposting to mailing lists they can join).

You may wish to think about a light-touch recruitment process, such as asking people to complete a short application form, or writing a paragraph about why they are interested and what experience

they have. However, keep in mind that this will exclude many people for different reasons. See PPI Guidance 1: Key guidance for researchers when recruiting and working with PPI contributors<sup>3</sup>

### Expectation management

It is important that both you and the people you involve have a shared and clear understanding of what they are being invited to do.

If you are recruiting people to work with over the length of a study, it is important that there is an induction. This can clarify everything that should have been covered during advertising and recruitment. So for example:

- The aims of the research (to understand the bigger picture and where they fit in).
- The time commitment – both the length of the study and how often they will be asked to do things, and how much time this is expected to take.
- Information about payment and expenses.
- What can they expect from you – e.g. regular feedback, training.

For more ad hoc and one-off PPI activities, it is still important to be clear about all the above.

If you are setting up a PPI group, it is a good idea to work with everyone to draw up a code of conduct that you all commit to.

There is further guidance in the [PPI guidance for researchers](#) and in the 'PPI Guidance 1: Key guidance for researchers when recruiting and working with PPI contributors' document. For support with recruiting PPI contributors, please contact [the PPI lead in your department or organisation](#).

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