

Patient and Public Involvement (PPI) Guidance

PPI Researcher Guidance 2: Recruitment of PPI contributors from clinic

This guidance has been developed by PPI leads from the Oxford PPI Staff Group¹. It is being piloted with researchers².

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](#).

Consultations in clinic provide an obvious place to invite people to become PPI contributors to your research. It is the clinic consultation where you have individual contact and a conversation, which gives you the opportunity to talk about what PPI is and how that person might become involved. It is also a successful means of recruitment, as people are much more likely to be interested if it is something that is extended as an individual invitation, rather than just seeing something online or picking up a leaflet.

Risks:

There are potential risks associated with this approach that need to be considered.

- **The risk of misunderstanding.** People might not understand what PPI is. It is easy to confuse an invitation to be a PPI contributor with an invitation to be a study participant. If you add issues with hearing, capacity and fluency in English to the mix, there is a lot of potential for misunderstanding and people committing to something unexpected.
- **The risk of coercion.** People tend to feel obliged to say yes to their doctors. A patient sitting in clinic is not in a position of power. They might feel anxious to please, or obliged to you for the treatment and care you provide. There is a real risk that people end up agreeing to attend a meeting, or sign up for an activity, not because it is what they want to do but because they would feel guilty if they said no. That's not the best basis for contributing to research; it also creates a risk that such people are less likely to be critical.
- **The risk of biased selection.** You are likely to ask the people you think will be good at PPI. These are probably the people who are well educated, articulate, and 'on the same page' as you. This is not necessarily a problem – much can come of the contributions of people like this. They have experience and often the confidence to participate in discussions with researchers. But this tends to

¹ 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.

² This document is being piloted (December 2023-April 2024) with researchers. Any suggestions for improvements should be sent to Rachel.taylor@ouh.nhs.uk.

exclude people who you pre-judge to be 'inappropriate' contributors. Other strategies are needed to ensure more inclusivity.

- **The risk of conflict of interest.** Some researchers report that it is difficult to be someone's doctor and also their colleague in the research environment. It can be hard to have a comfortable working relationship with someone who you also care for in a clinical setting – and they may be less likely to be critical about the research, making PPI less effective.
- **The risk of 'gate-crashing'.** Clinic is an important moment in someone's life. It is an often rare and fleeting opportunity to speak to a doctor. People will have much on their mind at that point in time and it is important not to compromise the quality of the clinical encounter – the important discussion around that person's illness and care – with a discussion about your research ideas.

Recruitment of PPI contributors from clinic needs to be conducted with these risks in mind. Other methods of recruitment, such as ensuring that the clinic environment promotes research and PPI in multiple ways, will help ensure that people get involved for their own reasons and interests, independent of what happens in the consultation room.

Contacting potential PPI contributors via post or email

You might wonder if it is OK to write to patients who are already known to you. These might be people you see in clinic, or people who have been participants in a trial. In practice this happens a lot; a Chief Investigator 'finding' a PPI person who has just been in one of their trials is very common. However, this approach raises some of the same issues as recruiting in clinic. There are also important information governance constraints regarding unsolicited contact with patients.

Generally speaking, GDPR requires that patients' information is not used in a way that will come as a surprise to that patient. So, someone you are seeing in clinic will expect to have communications from you about an appointment or about their condition. They won't expect to have an invitation to become a PPI contributor. If you are already writing to them for reasons relating to their care, you might want to consider including something like a generic flyer about PPI opportunities; so, you can piggy-back onto existing communications but initiating communications with people who are not expecting to hear from you - or communications for unexpected purposes - is problematic.

In addition to Information Governance issues, there are welfare concerns to bear in mind. Letters or emails from a doctor or hospital can cause great alarm and distress, especially for people who have had serious or life-threatening conditions. The sight of the envelope on its own can cause people to panic. Written communications with patients should not be unexpected for this reason, too. And, as with recruitment face-to-face in clinic, some people might also feel unable to say no to a direct request from a doctor.

Mitigation

- Don't be discouraged about asking your patients to help with your research. It is a way of turning a bad experience into something of value, and people value the opportunity to contribute.
- Cultivate visibility of PPI – in clinic, online, on related social media channels. This way, people have an opportunity to learn about PPI in tandem with conversations you might have with them in person.
- Have engaging generic resources that can be shared with patients on the occasions that you see them in clinic or write to them in person.

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