



# Guide for researchers working with Patient and Public Involvement (PPI) representatives



**Get involved - make a difference**

Like the writing through a stick of rock,  
we place public involvement at the centre of our research.



NUFFIELD DEPARTMENT OF  
**PRIMARY CARE**  
HEALTH SCIENCES

**NHS**  
*National Institute for  
Health Research*

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This document has been put together primarily to support researchers in the University of Oxford's Nuffield Department of Primary Care Health Sciences and those funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Oxford at Oxford Health NHS Foundation Trust.

However, any researcher at the University of Oxford working with PPI representatives is welcome to use this resource to guide them.

Thank you to all the researchers and PPI representatives who gave their time to help develop this resource.

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## Section 3 – Advertising

Before you can begin the process of advertising you need to decide what you want your PPI representative to provide;

- a) a specific perspective based on their understanding of the issue you are researching? This is generally referred to as **lived experience**. If this is what you want you should also consider if it will be acceptable to you to work with someone from a voluntary organisation that represents the illness or condition involved?
- b) a general public contribution in terms of the management of your work?

Be clear in your advertising and when you speak to candidates which of these you require.

Before launching into an advertising campaign it is important first to clearly define who your audience is, and plan *how* and *where* you will reach them; then you can match the advertising activities to suit. Think about whether you will reach them directly through word-of-mouth activities such as emails or letters, or indirectly through adverts, flyers etc.

To get a better understanding of your target audience ask yourself where they go, what websites do they visit, who do they interact with?

For example, to reach people for weight or diet-related research target local weight loss groups. Or for a study on child or women's health target Mumsnet.

Don't just put an advert up on your department website if members of the public don't visit it, or Tweet something from a Twitter account with few followers or the wrong type of followers; keep your advertising activities well targeted and you will have a higher success rate.

See appendix for sample [adverts](#)

### 3:1 Potential methods of advertising:

- ✓ Adverts/flyers in surgery/clinic waiting rooms/ pharmacies/dentists (see 3.3)
- ✓ Adverts/flyers placed with Voluntary Sector infrastructure organisations. Ask PPI Coordinator for advice on this.
- ✓ Adverts in local/national newspapers
- ✓ The web pages of your department or NIHR CLAHRC Oxford
- ✓ Adverts on the Patients Active in Research website for the Thames Valley [PAIR](#) or national [People in Research](#)
- ✓ Face to face discussion with relevant patients during clinical encounters
- ✓ Letters to potentially-interested patients/service users
- ✓ Adverts/emails/letters sent to relevant local or national voluntary groups/charities for distribution around their membership. Ask Coordinator for advice on this.
- ✓ Adverts on local community message boards or parish magazines
- ✓ Use of personal contacts and word-of-mouth

If you need to recruit PPI representatives from ‘seldom heard’ communities discuss this with the PPI Coordinator so that you can focus on some targeted recruitment methods. Please note that this will almost certainly take longer to achieve and you should build this into your planning.

### 3:2 Information for potential applicants

If people express an interest they can be sent the “Information leaflet for patients and members of the public interested in getting involved in our research”. This document is currently in draft form but as soon as it is ready will be put on the website. Please ask the PPI Coordinator for this document.

### 3:3 Method for approaching clinicians to recruit patients

A good method of recruiting people to be involved in your project will always be from personal recommendation. It may be that you are a GP yourself or you have a colleague who is, or you have contacts in allied health professions who feels able to approach some of the patients at their surgery/clinic. This is acceptable but should only be done with the full agreement of the Practice’s senior partner or clinic’s organisational lead. You could contact them informally if you know them, you could ask your colleague to approach them or you could write formally. Whichever method you use it would be advisable to get their approval in writing, to save any misunderstandings at a later stage.

See Appendix for template letter to send to a [GP Practice Senior Partner/ Organisational lead](#)

#### Produce a flyer

It may be the case that a GP practice or clinical setting feels that a direct approach puts too much pressure onto the patient. In such cases consider creating a flyer (A5 or smaller) that primary or secondary care colleagues could hand to patients to take away with them, giving them the opportunity to contact you if they are interested, without feeling obliged to say yes to the health professional that asks them.

Before sending it make it into a pdf (as many people may not be able to open Publisher documents etc.)

## Section 4 – Recruiting

The key message in any contact that you have with people who show any kind of interest in getting involved in research should be gratitude. Make it clear that you are delighted at their input and welcome their inclusion in your work.

There are various sorts of roles in PPI representative work. For our purposes they will be allocated in the following diagram into either involvement or leadership. You will need to decide which is the more relevant for your role and tailor your recruitment approach accordingly.



Developed by the Thames Valley Patient Experience Strategy Group

### 4.1 Develop a role description and person specification

It will be an important part of recruiting for you to consider what you are looking for in your PPI representative. For some roles (leadership as above) it will be appropriate to develop a written role description and person specification and to use a job application form and formal process.

For other roles (involvement as above), you may adopt a more informal approach. However, even if you do not develop a written role description and person specification you will need to think about the kind of person you are looking for so that you can be clear with candidates in your conversations with them.

See Appendix for template [role description](#) and [person specifications](#)

### 4.2 The application process

As there are different types of roles at different levels there will be different approaches to how you contact applicants. For the leadership roles you may need to be more formal in

your approach, and ask people to complete an application form (or do so for them over the phone). For other roles you might decide that you can be less formal and might want to simply discuss with the person what they are interested in, and gather their details as you do so.

See Appendix for template [application form](#) and [expression of interest forms](#)

In dealing with any potential involvement level recruits you should be conscious that for some, paperwork and forms may be off putting. You should also ensure that you check if your potential recruit has any special needs which you will need to accommodate to help them to fully contribute.

### 4:3 Interview

It is always better to have an open and transparent recruitment process but particularly so if you are paying someone for their time.

An interview does not need to be a very formal affair or have to be face to face. However, it is good practice on receipt of the application/expression of interest form to contact the applicant and discuss further with them the skills that they think they will bring to the role, why they are applying and what they hope to get out of involvement as well as to explore further any issues that may arise.

If you are in a position to have formal interviews for PPI representative roles then these should be carried out similarly to the interviews for staff; with 3 people on the panel, with standardised questions that relate to the role etc.

Interviews conducted face to face should as standard offer the candidates expenses, but payment for their time should not be applied until they are appointed.

## Section 5 – Appointing

As there are different roles that you are appointing to you will need to decide how formally you wish to approach the appointing process. What is important however is that you thank the person for their willingness to get involved and that you provide them with some basic information. How you choose to present this information is up to you. You might decide that you want to provide people with a written working agreement or you might just want to send them a letter. Much of the details will have been part of the process of discussing with those who show an interest. You might opt to put some details in separate documents that they can refer to. Whichever route you choose this is the checklist of information to consider providing;

- Title of project and Department research group or NIHR CLAHRC Oxford theme
- Who is the work funded by
- Main aim of the project
- Link person and their contact details and working hours
- Alternative contact person in case of absence (or difficulties with main link person)
- What level of time commitment is expected, and how long the project will last
- Where most meetings will be held (and its reception phone number for late cancellations)
- Details of how to claim for reimbursement of expenses
- Details (where appropriate) of how to claim for payment for time
- Details of the Benefits advise line
- Clarity that they are a volunteer and can withdraw at any time

See Appendix for template [working agreement](#) (formal) and [appointment letter](#) (informal)

### *5:1 PPI representative 'personnel' file*

Once the PPI representative is appointed set up a file for them. This can include;

- a copy of their application / expression of interest form
- a copy of their working agreement / appointment letter
- any notes taken at the interview
- record of all training that they have undertaken however informal
- record of their bank details
- all review records
- copies of any letters provided for them to the Job Centre or outlining different ways of paying them

Finally provide their contact information to the PPI Coordinator so that they will receive information and support from the Department or CLAHRC, more generic than just for your project.

If the person is on Benefits and asks for a letter for the Jobcentre Plus to state that their involvement does not suggest capacity to work, speak to the PPI Coordinator who can help.

If the person is on Benefits and asks about having their payments made differently (such as averaging one meeting over several weeks) so that they do not breach their earnings limit, speak to the PPI Coordinator who can help.

## Section 6 – Induction

The principle behind offering an induction is to enable the PPI representative to contribute as fully as possible. They should all be given the basic induction and introductory reading material. Remember that the PPI representative has volunteered their time and they need to be encouraged and supported throughout their time with us, but particularly in the early stages.

An example of how to make someone feel valued and welcome is to ensure that they receive specific and clear instructions on finding the meeting venue, with details on how to get there and contact details of reception for last minute queries (in case the contact person has gone to the meeting and is no longer available on their phone).

### 6:1 PPI representative induction

The following should be offered as a minimum:

- Opportunity to meet the other PPI representatives on the project
- Opportunity to see the venue of the research (where this may have a significant effect on the person's ability to understand the work) and/or the meetings
- Opportunity to witness the research and/or meet some of the researchers
- Basic information about how the project fits into the Department or the NIHR CLAHRC Oxford
- Details of how to claim expenses (and payment if appropriate)
- Opportunity to ask questions about the written agreement and to sign it for their file
- Welcome pack for new PPI recruits [available on website](#) or at [CLAHRC website](#)

### 6:2 PPI representative introductory reading material

- Written information clear to a lay audience about the research project
- Sufficient information about the research methods being used for the PPI representative to fully understand the project
- Glossary of terms and acronyms so that the PPI representative has all the knowledge needed for your project (a basic version is available from the Coordinator on request which could be tailored to your project.)
- PPI strategy for the NDPHCS and NIHR CLAHRC Oxford ([when approved will be available on the website](#))
- Payment policy for the NDPHCS and NIHR CLAHRC Oxford ([when approved will be available on the website](#))