



# 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  
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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 12 – Record keeping

It is important that you keep records as you go along as it is impossible to remember everything and in particular longer studies may change and become quite complex. Recording as you go along will save you time and frustration in the long run!

**12:1 PPI representative contribution to the work of the project** – recording according to the GRIPP2 formula

Further details to be put into this section when made available by national working group

Encourage your PPI representatives to comment on and suggest changes to these records, and make sure the final versions are agreed with them if possible. Keeping such records will help towards identifying and reporting PPI impacts at the end of your study, which is becoming increasingly important.

### 12:2 Financial record of PPI representatives work on the project

You should set up a PPI financial recording file for your project to help you keep track of expenditure and so that you can respond to queries from finance staff or PPI representatives.

You should include the financial record at the front of the file

See appendix for template [financial recording forms](#)

All receipts and forms to raise the BACS payments should be kept behind these records in the folder in date order.

They should be kept until the end of the Project and then advice sought from finance colleagues about what should be done with the records.

See Appendix for [record keeping format](#)

It is also good practice to encourage the PPI representatives to keep their own records of any payments that they receive so that they can be clear where they are up to and this dual recording can be used to clarify any discrepancies. If they do PPI work for more than one research project they might want to keep a separate record for each of these.

You should provide them with this as part of their induction. See appendix for [record keeping format](#)

### 12:3 Acknowledge the input of your PPI representatives

INVOLVE encourage you to acknowledge public contribution to your research in reports, publications, posters and presentations.

## 12.4 Writing a case study demonstrating the impact of your PPI involvement

This is something that you may be asked for and the following guidance is offered to assist you;

### Things to think about before you get started.

- ✓ Make a plan before you start, jotting down ideas based on the template guidelines
- ✓ Style of writing – feel free to write in a style that suits you. Using ‘I or we’ is usually more compelling for the reader than ‘It was felt that.’
- ✓ Aim to write between one and two sides of A4, not including illustrations (max 800 words). While short succinct case studies are great to read, they can be difficult to write well. So you may wish to ask your own communications/PR team for help with editing a longer draft to less than 800 words.
- ✓ Consider including section headers and sub-headers to help the reader
- ✓ Consider using bullets for lists
- ✓ Try to include some photos, graphs, diagrams or video footage
- ✓ You may have documents that you produced as part of your project that will interest readers, so please reference them as appendices in your work and attach them with your case study. Remember to name the attached file so it can be easily identified e.g. Appendix 1: Diagram illustrating process of work.
- ✓ Edit and proofread your draft and delete any repetition in different sections. Remember that your Communications team might be able to help with this.
- ✓ Finally, ensure you have received advice and permission on sharing information, names and documents publically.

See appendix for template of [case study](#)

## Section 13 Provide feedback to your PPI representatives

When you are working with PPI representatives you should give ongoing verbal feedback at the time. This should not be patronising. Do not tell them they have had a good idea if you do not believe that they have. Equally be encouraging where you can be. Your feedback will enable the PPI representative to improve their own input as they go along.

### 13.1 Two types of formal feedback

It is important to provide PPI representatives with **feedback on the work of the project**. What have been the research outcomes, what is being done with the evidence and analysis, what publications has it gone into etc. PPI representatives will want to understand what if any further research may be carried out on the back of, or as a result of the project.

It is equally important to provide PPI representatives with **feedback on the impact that their involvement had** in the work of the project (i.e. what has been helpful and why).

For this reason it will be important that you set up from the start mechanisms to record this impact (see section 11).

You should also consider how you are going to provide this feedback and at what intervals.

In both cases you will need to enable the PPI representatives to respond to the feedback and to consider any appropriate responses from your Department's point of view.

Regular feedback can improve PPI contributions in the future.

### 13.2 Generic feedback

In addition to the direct feedback that you will provide to your actual PPI representatives you may wish to consider some of the following ways to provide feedback to those who assisted;

It is important to provide feedback on the outcomes of your project to any of the following that you asked to help you in recruiting either PPI representatives or trial participants as this will encourage them to believe that their efforts were worthwhile and appreciated.

- GP practices or other clinicians
- Voluntary agencies
- Existing PPI groups
- Student groups
- Research Design Service
- University of Oxford research support service
- GP Patient & Participation groups (PPGs)
- Stakeholder groups

## How you could provide the feedback;

- You could send an item that could easily be inserted onto websites, with a link to your own organisation's web page
- You could provide a flyer that could be put on noticeboards giving a link to your results
- You could ask the PPI co-ordinator to include your outcomes in the PPI newsletter
- You could ask your Communications officer to include your outcomes in your department's newsletter, to place on your department's website, Facebook page and to tweet it.
- You could run a public event to showcase your results (or piggy back on some other event)

There is a developed model of providing feedback that is called FANFARE (Feedback Announcements to Facilitate Awareness of Research Endeavours) – for more information on this please contact Christine A'Court at the NDPHCS who can give details of pros and cons for each method.

- Email practices a selective update/ results summary for trials to which they have recruited patients. Suggest practices post it on their practice website, with a link to Departmental website. Participants could be told at recruitment/during the study that the link exists and how to find it
- Ensure each trial's patient information includes clear information about how to access results e.g. PI's email address, NDPCHS website address
- Send practice a paper version of results summary, requesting it be posted to patients involved – only really feasible if a small numbers of patients
- NDPCHS/CTU produce multi-study newsletters which can be left in practice waiting rooms, and/or posted to recruits
- In studies with high student population–display summarised results plus web site link on College/JCR/SCR noticeboards
- Tweet a snippet of results and/or availability of results on Departmental website/College noticeboards/practice noticeboards
- Text summary or availability of results – might only work if NDPCHS invest in mass texting software.
- Create a 'results' section on Departmental website. Use PPI groups to help compose content.
- Ask the practices' Patient Participation Groups (PPG) (virtual and face to face groups) for their input e.g. announcing results at any meetings they organise.

- As a PPI Group is now attached to every study as part of the grant application , include them in responsibility for dissemination e.g. via local radio, talks to relevant stakeholder groups such as parents' groups, Slimmers World, Diabetes UK etc.
- Ask PPI group or researchers to put on a 'results' meeting at the Department and invite all study participants
- Send all participants a copy of the journal article
- Send postcards to trial participants reporting on how trial is going. These could also highlight where/when results will be available. Send final easy-to-read ('lay') summary.
- Community meetings involving local population, hospital staff and local – this does not specifically target trial participants.

### 13.3 Certificate of Attendance

For some PPI representatives it may be appropriate and helpful to provide them with a certificate of attendance e.g. young people looking for means to boost their CV.

Please see the template [Certificate of Attendance](#) which you can adapt

## Section 14 – Review

### 14:1 PPI representative review process

You should arrange for either telephone or face to face opportunities to review the PPI representative's role at least 3 months into the project and again 6 months in. If the research goes on for more than one year you should also offer the review annually. The PPI representative should be encouraged to view this interview as an opportunity to explore any areas of training need they still feel they have and to raise any issues they have in fully contributing to the work. You should also view it as an opportunity to get their feedback on how you might support them better or run your research differently.

If the PPI representative is not contributing as fully or as well as the researchers had hoped this should be raised and reasons for it explored. The PPI representative should be offered every support available to enable them to improve their involvement.

Be open to the PPI representative's suggestions for how you might improve your own performance in this area. Ask open questions to encourage their feedback.

The 'interview' should be kept as informal as possible but key action points should be recorded and kept on their file.

## Section 15 Ongoing opportunities for your PPI representatives

Plan in advance what will happen to the people you have involved at the end of the project, as many of them will have enjoyed it and be keen to do more. Your colleagues will also be glad to know of people willing to get involved in their own work. They will have developed skills both in research and in involvement and it would be a shame for both them and us to waste this.

Talk to them about what else might be available and help them to get involved by making introductions.

**If they have given their permission, provide their details to the PPI Coordinator, who will help them to find another project.**

Alternatively you could direct them to these websites where they could find other PPI opportunities;

[Patients active in research \(Thames Valley\)](#)

or

[People in research \(national\)](#)