



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*

Version 1, July 2015 | 1

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 1 Introduction

1.1 What is Patient & Public Involvement?

Involvement = where people are actively involved in research projects and in research organisations, planning what should be researched and how it should be done.

Participation = where people take part in a research study or clinical trial.

Engagement = where information and knowledge about research is shared with the public, with some interaction and listening to the public.

<http://www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/topics>

Healthtalk has drawn together a range of views on what people think public involvement in research is for which included;

- the best way to find cures;
- to improve care and treatment;
- to improve patients' quality and length of life;
- to prevent illness.

However, many felt research does not always address the things patients think most important. They suggested patient and public involvement is about making sure the right research is done and challenging research that may be driven by the interests of pharmaceutical companies or individual researchers. This might mean;

- suggesting different research questions or priorities;
- helping medical researchers understand what outcomes matter most to patients;
- raising the profile of particular diseases or symptoms;
- challenging wasteful or unnecessary research.

At another level, people said patient and public involvement is not just about doing the right research, but making sure research is done right.

Patient and public input can help by;

- making sure researchers explain clearly what their study is about;
- communicate more sensitively with people;
- design studies so they are easier to take part in and more efficient;
- tell people the results.
- In some cases patients may get involved in doing the research, helping to collect data or analyse the findings from a patient perspective.
- They can also help to raise awareness amongst the public of what research is going on and how to get involved.

It can also be argued that involving people is a democratic right (because as tax-payers or givers to medical research charities we all fund research), or that researchers have a moral duty to involve patients, even if it makes no real difference to the research that gets done.

1.2 How to use this document.

This document can be used by any research staff involving patients, carers, members of the public and members of voluntary organisations that provide services in their research work.

It is intended as a **reference document** to prompt thinking and not as a 'bible'. Researchers can **dip into sections** that they need and they may **download templates** that they think could be useful to them. This 'Guide' is just that, and is offered as a way to encourage thinking around good practice in PPI work; **it does not claim to have all the answers or to be fully comprehensive**. It will be a living document as the work of involving the public becomes more established within research and constantly updated, **so please provide feedback if when using this guide you were unable to get the help you wanted or found errors**.

1.3 Terminology

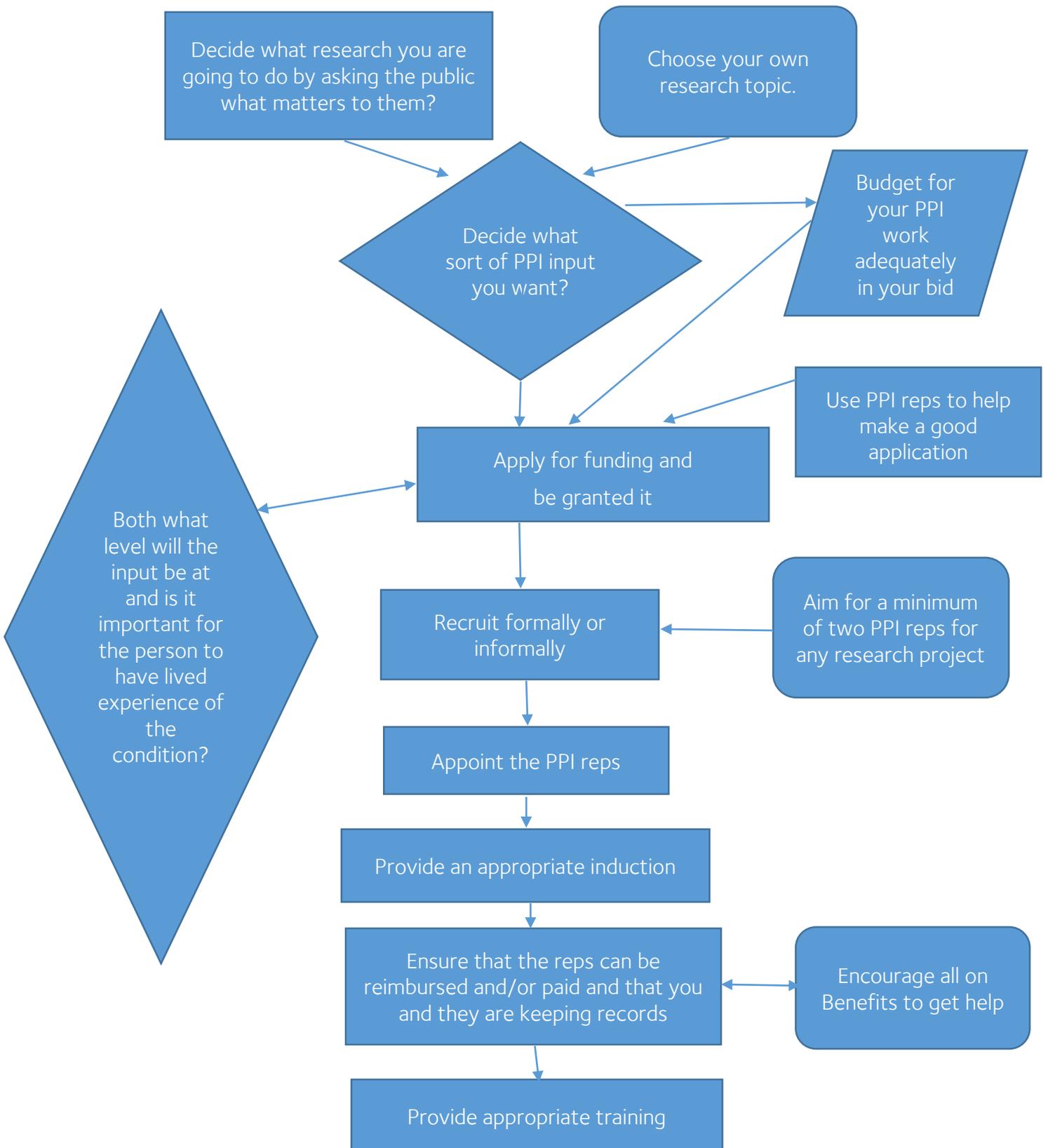
For this document the terminology chosen is PPI representative. However, this is one choice amongst many and there is no one term that is correct or even preferable. It is important for researchers to be aware that some PPI representatives feel strongly about the terminology used, although most are agreed that there is no easy answer to this issue, as there are many different preferences amongst those currently recruited.

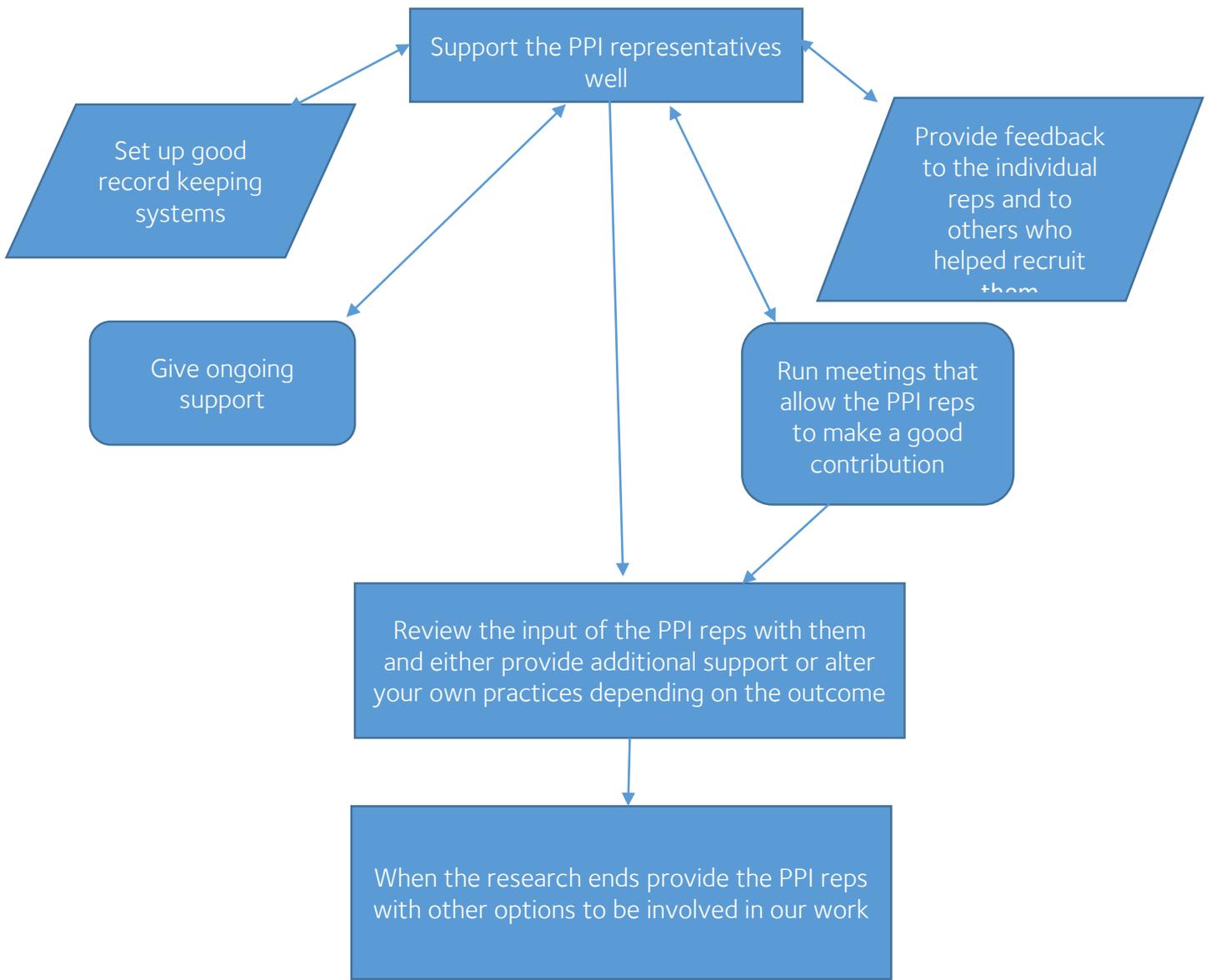
One solution is to ask people how they would like to be called at the start of a new project. However, Healthtalk points out that how people refer to themselves may change as they recover from illness and become more involved, so researchers need to think about this too.

Some of the options to offer the people that you are working with;

- | | |
|--|---|
| <input type="checkbox"/> 'PPI' representative/member | <input type="checkbox"/> Patient (or carer) representative/member |
| <input type="checkbox"/> Lay representative/member | <input type="checkbox"/> Member of the public |
| <input type="checkbox"/> Public representative | <input type="checkbox"/> Lay/patient advocate |
| <input type="checkbox"/> Lay researcher | <input type="checkbox"/> Citizen representative or researcher |
| <input type="checkbox"/> User/service user | <input type="checkbox"/> Consumer or client |
| <input type="checkbox"/> Survivor | <input type="checkbox"/> Patient/public/citizen partner |
| <input type="checkbox"/> Research partner | <input type="checkbox"/> User or patient research consultant |
| <input type="checkbox"/> Expert by experience | |

Flowchart demonstrating how PPI can be used throughout the research cycle;





Section 2 – Before you begin

2.1 Using PPI to define the research topic

Generally speaking researchers decide what research they want to do based on their own working experiences and contact with patients in clinic. It is however, also possible (and desirable!) to hold **public engagement** meetings where you can ask open questions about the sorts of topics people would like research to be carried out in. You might choose this option in collaboration with colleagues, so that a broad range of expertise could potentially be utilised. [You may also wish to look at the James Lind Alliance to see if they have already done any work identifying uncertainties in your research area; <http://www.lindalliance.org/>]

If you do decide to consider a public engagement exercise use this checklist to plan the event;

- Think about the goal of your event and the key answers that you are looking for.
- Involve stakeholders in planning the event. Understanding what would get this group interested in your activity will not only help you attract an audience but will also help you develop a more interesting activity.
- Decide who your target audience is – the more tightly this is defined, the easier it will be to develop activities that are relevant & enjoyable and to use appropriate communication styles. Consider your motives and why you feel this group should be targeted? Why should they be interested in your activity?
- Consider why a particular group would be interested in your findings – this will help you tailor your event to their interests and needs. Successful events rely on finding a spark or point of relevance that engages the audience.
- When you begin planning your event, think about any practical issues that may affect audience participation – try to identify potential barriers and remove them. These might include: timing – for example, think about what day of the week or time of day suits your audience best, choosing a venue that is accessible, or take your activity to a place the audience already uses (such as a community centre), develop an activity your participants can engage with (for example an activity that takes account of disability issues) and consider the costs of your event.
- Consider how you can market your event and whether you can tap into existing groups or networks. Allow plenty of time to carry out promotional activities, including planning and developing material.
Use group newsletters to promote your event, but bear in mind that many organisations only have quarterly newsletters.
Use media coverage, such as local newspapers and social media to generate awareness.
Use direct mail, email and existing electronic news groups to reach audiences.
Ask whether the venue can help promote your event – for example they may have a mailing list you could use.

- Consider working with a voluntary organisation to run a joint event, so that they could assist with much of the set up work and marketing. Be clear about what their role will be and what input you expect to have into decisions. Ensure you get a full quote from the agency that clearly outlines the different costs involved in the project.

There are many ways to engage the public with research and research issues. The method you choose will depend on your reasons for engaging the public and your own preferences and expertise. Examples include;

- 1 Patient / peer support groups – These might be run by a charitable group or be entirely self run. Examples might be a ‘Breathe Easy’ group, a carer’s group or a group for people with mental health problems. You might approach such a group at one of their regular meetings, and ask for some of the time of the meeting to consult with them.
- 2 Focus groups - A focus group is a form of qualitative research in which a group of people are asked about their perceptions, opinions, beliefs, and attitudes towards a product, service, concept, advertisement, idea, or packaging. Questions are asked in an interactive group setting where participants are free to talk with other group members.
- 3 Charities – some charitable groups would be willing to consult their members for you. They might do this at established meetings or remotely. Depending on the numbers they will contact and the method, you will need to build in adequate time to allow this to happen and ensure that you are prepared to reimburse their expenses (if for example posting is involved).
- 4 You may also wish to look at the James Lind Alliance to see if they have already done any work in your research area; <http://www.lindalliance.org/>
- 5 Online. You may use social media, for example contacting an established network for feedback (such as MumsNet) or you might create your own platform. Advice on this will be available from your Communications officers.
- 6 Citizens' jury - A Citizens' Jury is a mechanism of participatory action research that draws on the symbolism, and some of the practices, of a legal trial by jury. It generally includes three main elements:
 - a) The "jury" is made up of people who are usually selected "at random" from a local or national population, with the selection process open to outside scrutiny.
 - b) The jurors cross-question expert "witnesses" — specialists they have called to provide different perspectives on the topic — and collectively produce a summary of their conclusions, typically in a short report.
 - c) The whole process is supervised by an advisory panel composed of a range of people with relevant knowledge and a possible interest in the outcome. They take no direct part in facilitating the citizens' jury. Members of this group subsequently decide whether to respond to, or act on, elements of this report.

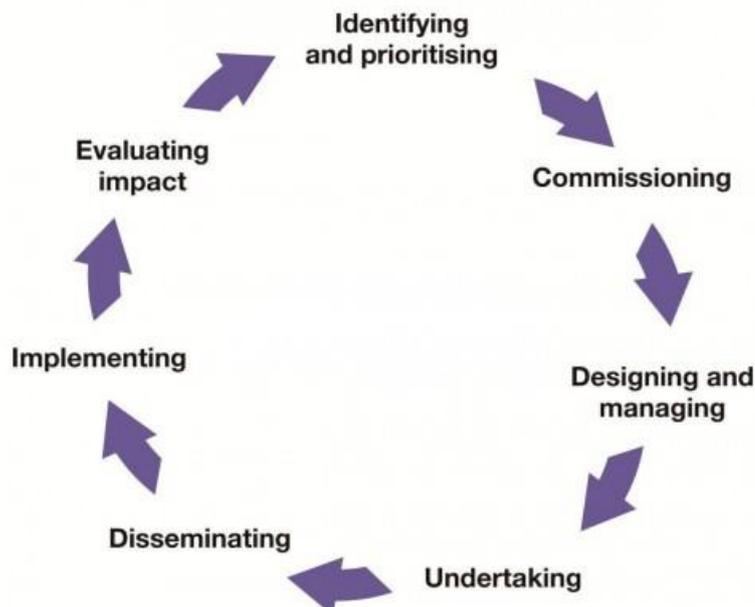
- 7 Consensus conference – Participants are selected from the lay public that have no specific knowledge of the issue at hand and are demographically representative.

Members of the consensus conference participate in preparatory events and are given material to gain a basic understanding of the issue at hand. They then participate in a conference. Over the duration of the conference, the delegates participate in a Q&A session with experts, where they get opposing views. Citizens then prepare a final document containing their views, opinions, stances, and recommendations for the issue. On the final day of the conference, the conference delegates then discuss their final document with policy & decision makers.

- 8 Debates – Debating is commonly carried out in many assemblies of various types to discuss matters and to make resolutions about action to be taken, often by a vote.
- 9 Festivals and public events – For example, you could encourage the public to come up with a treatment uncertainty by engaging with them at a public event.
- 10 Public lectures – You could use a lecture on a related subject to then consult with the audience.

For further information on these and other types of engagement activities use this helpful checklist; [Participation tools](#)

2.2 Where in your research to involve the public?



Good Practice in PPI work states that PPI representatives can be involved in your work at every stage of the research cycle. Involve people at an early stage so that they feel part of the research and also have a sense of ownership of the research. Consider involving people

in the identification and prioritisation of the research topic and the development of the research question. See 2.1.

Even if you decide to **define your own research topic** you will still need to consider how you are going to incorporate your PPI element.

Several funding bodies, as well as research ethics committees ask grant applicants about their plans for public involvement with an expectation that if they are not involving members of the public in the research then they need to have thought through why they have made this decision and explain the reasons.

For example, the National Institute for Health Research (NIHR) ask applicants to describe how they have involved the public in the design and planning of their study as well as their plans for further involvement throughout the research, and if not, to explain why.

Responses to these questions will be considered by the reviewers, research panels and boards (which increasingly include members of the public) and will influence funding decisions.

The National Research Ethics Service (NRES) will ask about the plans for public involvement in your research if you apply for ethical approval, and it will be part of their assessment process.

2.3 When is ethical approval required for involvement?

The involvement of patients or members of the public does not generally raise any ethical concerns for the people who are actively involved, even when those people are recruited for this role via the NHS. This is because they are not acting in the same way as research participants.

Therefore ethical approval is not usually needed for the involvement element of the research, (even when people are recruited via the NHS).

However, if you plan to consult patients and members of the public using formal research methods (e.g. surveys, focus groups or interviews), and plan to analyse the data and publish the findings as research, then the people you are consulting are also research participants, and the usual governance approvals (including research ethics) are required.

Or, where people's involvement results in direct contact with study participants the ethics committee will need to give specific consideration to the involvement as an element of the ethical review process. A Research Ethics Committee will need to check that the person carrying out the research has adequate training, support and supervision appropriate to the circumstances in the usual way.

For most studies it is not appropriate for people involved in the research as PPI representatives to also be participants in the research, as that can compromise both the

researcher and the person involved. However, many clinical trial or pilot participants go on to become actively involved as PPI representatives when their participation is over.

2.4 Help in defining the impact your PPI work will have on your research outcomes

If you consider what you want public involvement to achieve in your research from the start, you will be able to plan your research work such that it makes the most of positive PPI input. There is useful guidance on how to do this at [PiiAF guidance document](#)

2.5 Refer to the Dept/NIHR CLAHRC Oxford payment policy

This will be available on the website once the payment policy is agreed. For further advice please speak to the PPI team (contacts at section 16).

2.6 Funding PPI to inform your application

If researchers seek funding from any NIHR grant, programme or themed call then they can access the support of the Research Design Service South Central. (They may also be able to provide a less fulsome level of support for applications to other funding sources – please ask them)

There are various ways in which the RDS may be able to help with PPI; such as providing assistance in identifying suitable PPI representatives, facilitating initial meetings, offering advice on long term PPI strategy, and supporting PPI costs.

The RDS has a budget to ensure that PPI representatives are reimbursed for their time and expenses throughout the application process.

If you would like PPI, or any other advice from the RDS, please visit their website <http://www.rds-sc.nihr.ac.uk/> and choose the 'Request Support' option. RDS South Central has a dedicated PPI officer whose details are below;

Megan Barlow-Pay

Patient and Public Involvement Officer

Tel : 023 8120 4772

Megan.Barlow-Pay@nihr.ac.uk

[RDS PPI handbook](#)

2.7 Maximising the impact of PPI work in your funding application

When applying for a grant, one of the aspects to be considered will be the quality of PPI involvement in the research to date (prior to submission) and the quality intended for the proposed research itself.

Most panels, including those of the NIHR, include lay members that are patient representatives who provide guidance to the panel on the quality of the PPI input.

Some of the key aspects that are considered are the following:

a. PPI members' involvement in the research to date, including:

- Have they been involved from the beginning?
- Have they had an input into the design of the research?
- Is there any evidence that PPI involvement to date has made a difference to the proposal?

b. The quality of the PPI arrangements in the project, including:

- Strengths of the PPI proposed and any concerns that undermine it (e.g. is there sufficient funding to undertake the PPI activities proposed).
- Is the PPI element truly embedded in the proposal or is it tokenism?
- Have relevant PPI members with knowledge of the disease area or topic been sourced (e.g. from patient support groups)?
- Will PPI members continue to be involved (e.g. as members of a Steering Group, undertaking research themselves, designing Patient Information Sheets if relevant, designing questionnaires if relevant)?
- Will PPI members be involved in the dissemination of the research results?
- Will the patients, carers and members of the public who participated in the research be advised of the findings?

c. The quality of the Plain English summary, including:

- Does the summary give a clear explanation of the research?
- Is it complete enough to describe the research if it is used on a stand-alone basis?
- Does the language used make sense to a lay person with no medical training (i.e. remove all medical terms and "jargon")?
- Are any acronyms used (hopefully limited) clearly explained?

d. Other aspects of the proposal from a PPI member perspective, including:

- Is the study sufficiently attractive to lay members to become involved (recruitment) and to stay involved (retention)?
- Is the research of real benefit to patients and carers and would they rank it high in importance in meeting their needs?

For further information please see; http://www.nihr.ac.uk/CCF/PPI/Public_reviewer_guidance.pdf

2.8 Using the INVOLVE cost calculator

Some research funders, such as the NIHR, will actively encourage and expect public involvement to be adequately costed in research proposals. It is very difficult to obtain funding for public involvement later if it has not been built into your research grant application.

Effective public engagement takes both time and money and it is important to have an adequate budget for both. Be realistic.

You should include not just expenses and any payment for time, but the cost of providing lunch at meetings or other refreshments and any times when you may have to pay for an external venue. If you are going to deliberately recruit people with disabilities or think it highly likely that they will want to be involved be ready to also pay for additional costs such as taxis if they cannot use the bus or paying a carer to escort them.

Use the INVOLVE Cost Calculator to work out what your PPI will cost;

<http://www.invo.org.uk/resource-centre/payment/>