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

UNIVERSITY OF OXFORD
NUFFIELD DEPARTMENT OF
PRIMARY CARE
HEALTH SCIENCES

NHS
National Institute for
Health Research

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 Contributors is welcome to use this resource to guide them.

Thank you to all the researchers and PPI Contributors
who gave their time to help develop this resource in 2015
and those who helped with a review in October 2016.

Contents

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

http://www.healthtalk.org/peoples-experiences/medical-research/researchers-experiences-patient-public-involvement/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 of the PPI Contributors interviewed 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 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

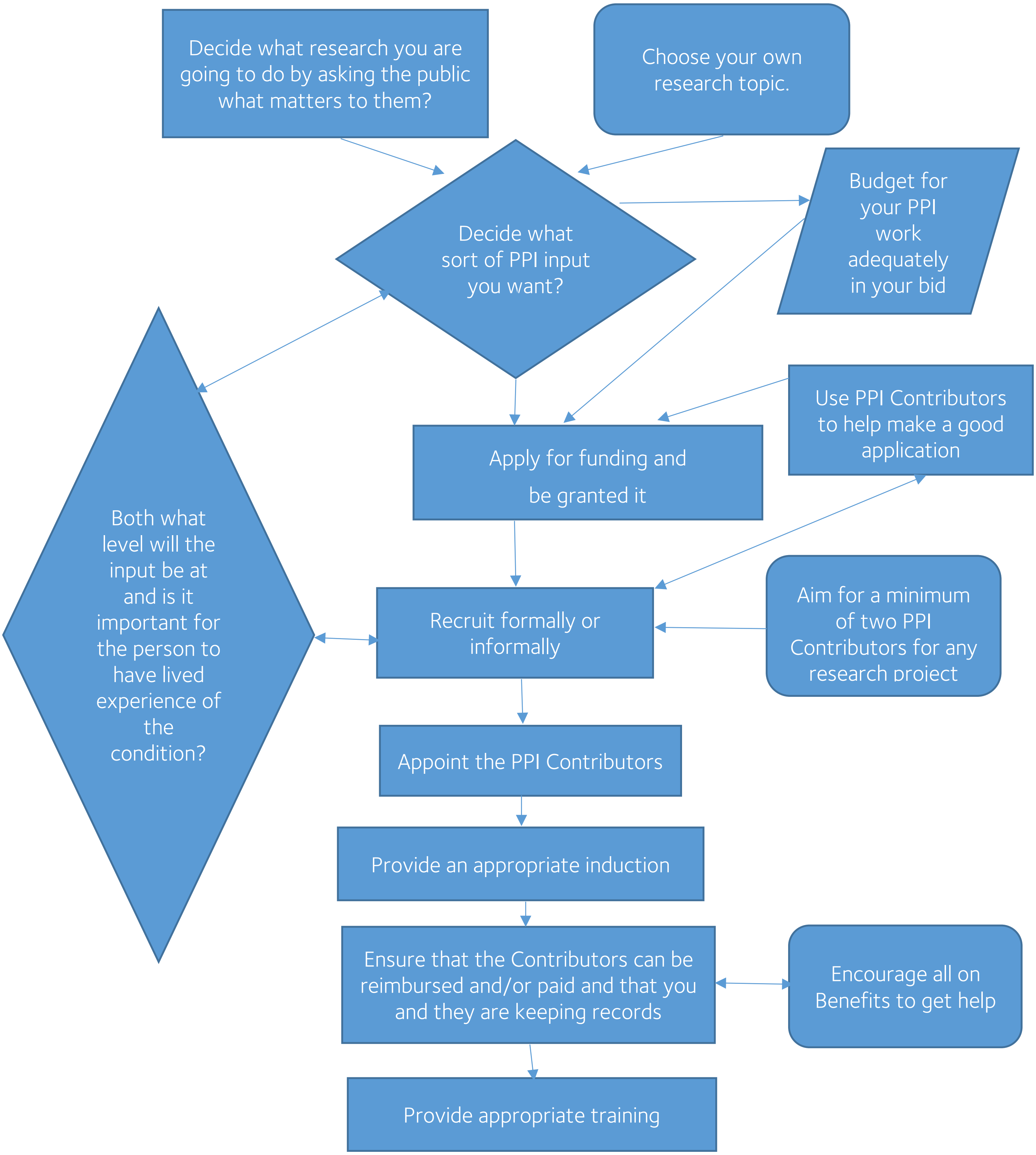
For this document the terminology chosen is PPI Contributor. However, this is one choice amongst many and there is no one term that is correct or even preferable. It is important for researchers to be aware that some PPI Contributors feel strongly about the terminology used, although most are agreed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

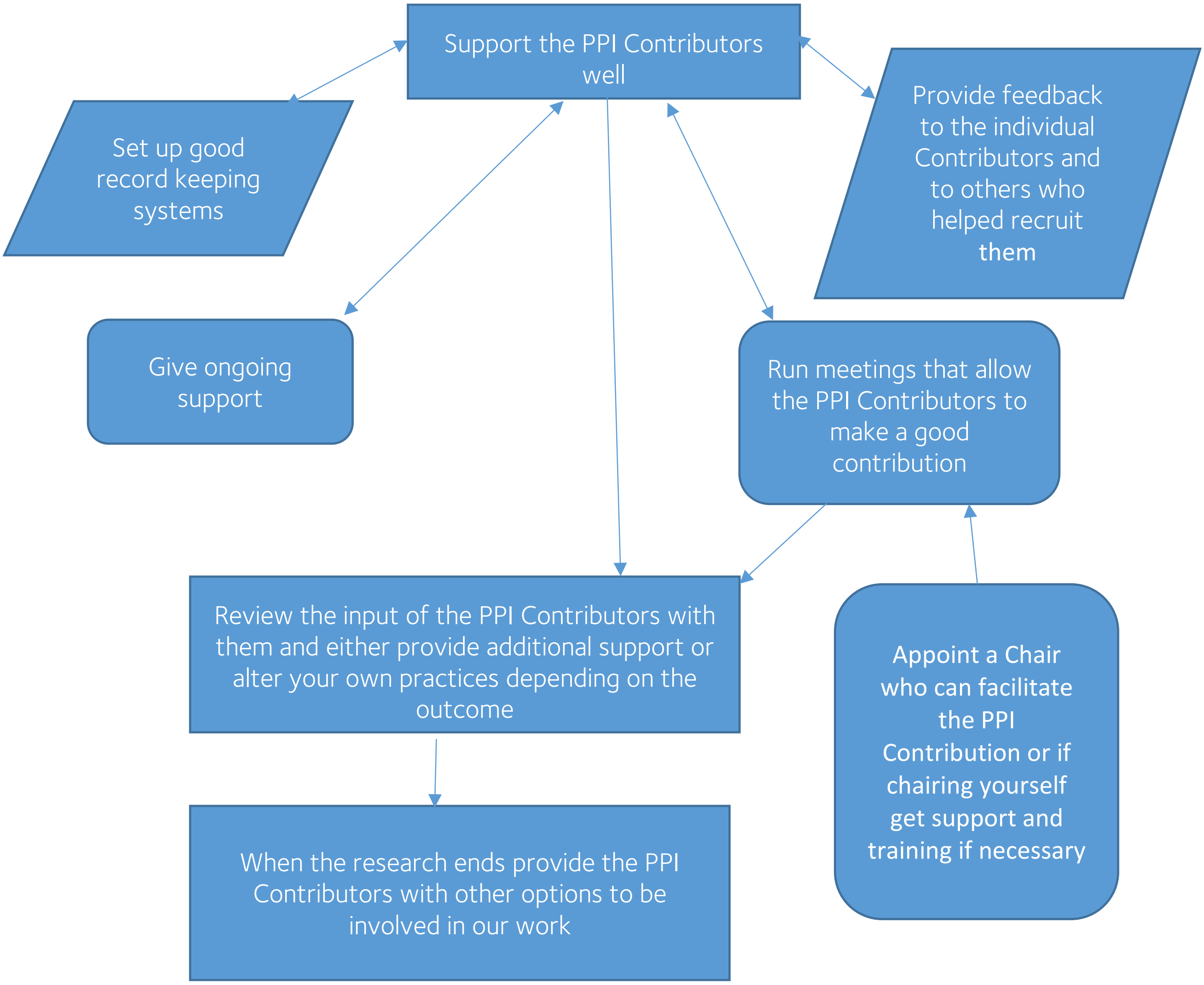
One solution is to ask people how they would like to be called at the start of a new project. However, Healthtalk points out that how people refer to themselves may change as they recover from illness and become more involved, so researchers need to think about this too.

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

☐ PPI Contributor
☐ 'PPI' representative/member
☐ Lay representative/member
☐ Public representative
☐ Lay researcher
☐ User/service user
☐ Survivor
☐ Research partner
☐ Expert by experience
☐ Patient (or carer) representative/member
☐ Member of the public
☐ Lay/patient advocate
☐ Citizen representative or researcher
☐ Consumer or client
☐ Patient/public/citizen partner
☐ User or patient research consultant

1.4 Flowchart describing the PPI process




Support the PPI Contributors well
Set up good record keeping systems
Provide feedback to the individual Contributors and to others who helped recruit them
Give ongoing support
Run meetings that allow the PPI Contributors to make a good contribution
Review the input of the PPI Contributors with them and either provide additional support or alter your own practices depending on the outcome
Appoint a Chair who can facilitate the PPI Contribution or if chairing yourself get support and training if necessary
When the research ends provide the PPI Contributors with other options to be involved in our work

Section 2 – Before you begin

2.1 Using Public Engagement 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. Once the researcher has a broad topic of potential interest, they then work with PPI Contributors to refine the research question and specify potential endpoints.
It is however, also possible 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.

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 can look at the James Lind Alliance (JLA) to see if they have already done any work identifying uncertainties in your research area of interest; http://www.lindalliance.org/. The JLA uses Priority Setting Partnerships (PSPs) which enable clinicians, patients and carers to work together to identify and prioritise uncertainties about the effects of treatments that could be answered by research. The principles behind a PSP are that it brings patient, carer and clinician groups together on an equal footing, it identifies treatment uncertainties which are important to all groups and the whole group agree on a final list. You could apply these methods to your research even if you do not do a full JLA PSP.
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. See section 3.6.

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.

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 the 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 , the University's own Public Engagement web pages and the East Midlands AHSN 10 top tips in planning an engagement event

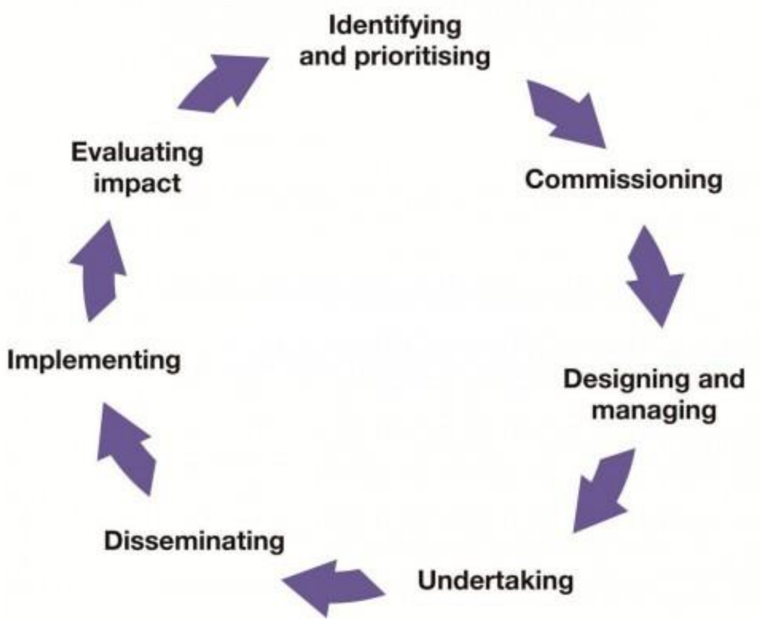
If you do decide to consider a public engagement exercise, use this checklist to plan the event;

- 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.
- Remember to aim your language appropriately to your audience. The average reading age in the UK is 12, and the advice in writing a press release for example is to aim at that level.

2.2 Where in your research to involve the public?



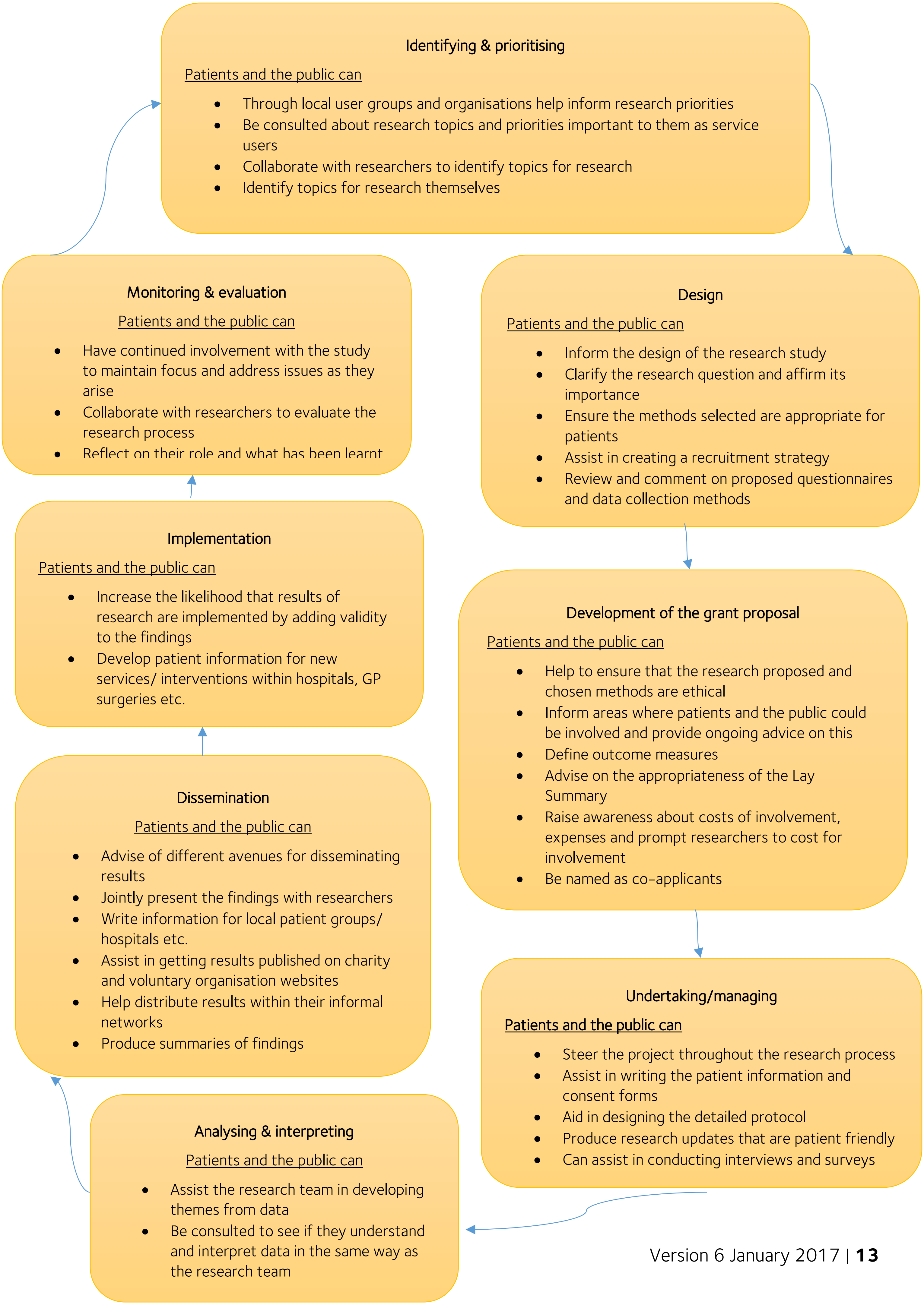
Good Practice in PPI work states that PPI Contributors can be involved in your work at every stage of the research cycle. Involve people at an early stage so that they feel part of the research and also have a sense of ownership of the research. Consider involving people in the identification and prioritisation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



Identifying & prioritising

Patients and the public can

- Through local user groups and organisations help inform research priorities
- Be consulted about research topics and priorities important to them as service users
- Collaborate with researchers to identify topics for research
- Identify topics for research themselves

Design

Patients and the public can

- Inform the design of the research study
- Clarify the research question and affirm its importance
- Ensure the methods selected are appropriate for patients
- Assist in creating a recruitment strategy
- Review and comment on proposed questionnaires and data collection methods

Development of the grant proposal

Patients and the public can

- Help to ensure that the research proposed and chosen methods are ethical
- Inform areas where patients and the public could be involved and provide ongoing advice on this
- Define outcome measures
- Advise on the appropriateness of the Lay Summary
- Raise awareness about costs of involvement, expenses and prompt researchers to cost for involvement
- Be named as co-applicants

Undertaking/managing

Patients and the public can

- Steer the project throughout the research process
- Assist in writing the patient information and consent forms
- Aid in designing the detailed protocol
- Produce research updates that are patient friendly
- Can assist in conducting interviews and surveys

Analysing & interpreting

Patients and the public can

- Assist the research team in developing themes from data
- Be consulted to see if they understand and interpret data in the same way as the research team

Dissemination

Patients and the public can

- Advise of different avenues for disseminating results
- Jointly present the findings with researchers
- Write information for local patient groups/ hospitals etc.
- Assist in getting results published on charity and voluntary organisation websites
- Help distribute results within their informal networks
- Produce summaries of findings

Implementation

Patients and the public can

- Increase the likelihood that results of research are implemented by adding validity to the findings
- Develop patient information for new services/ interventions within hospitals, GP surgeries etc.

Monitoring & evaluation

Patients and the public can

- Have continued involvement with the study to maintain focus and address issues as they arise
- Collaborate with researchers to evaluate the research process
- Reflect on their role and what has been learnt

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.

Can participants also be PPI Contributors?

For most studies it is not appropriate for people involved in the research as PPI Contributors 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 Contributors 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 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 (RDS) 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 Contributors, facilitating initial meetings, offering advice on long term PPI strategy, and supporting PPI costs.

The RDS has a budget to ensure that PPI Contributors 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 2 dedicated PPI officers whose details are below;

Paul Hewitson	Oxford based
01865 289445	paul.hewitson@dph.ox.ac.uk
Megan Barlow-Pay	Southampton based
Tel : 023 8120 4772	m.s.barlow-pay@soton.ac.uk

RDS PPI handbook

2.6 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 Contributors 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

2.7 Budgeting for your PPI work

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 involvement takes both time and money and it is important to have an adequate budget for both. Be realistic. Also be specific.

The NDPCHS and NIHR CLAHRC Oxford payment policy is available here.

You should include not just expenses and any payment for time, but the cost of providing lunch or other refreshments at meetings 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.

You should remember that payment for time is recommended by INVOLVE even if the work is done remotely and not in a meeting.

You should build in additional budget if you are going to recruit PPI Contributors from further afield, as travel costs will then be higher.

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

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

Details on rates of payment are also given in section 7 on finances.

Section 3 – Advertising

Before you can begin the process of advertising you need to decide what you want your PPI Contributor 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 also work with the family carer of someone with that condition or 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 Advertising to the internal pool of volunteers

The PPI Coordinator holds a list of PPI Contributors who have expressed an interest in our research. They can be selected according to;

- locality (national or Thames Valley),
- age range
- gender
- interests
- lived experience of a particular condition.
- whether they are new recruits or experienced PPI Contributors.

There is also the possibility of asking these volunteers to review Lay or Plain English summaries.
To advertise to these PPI Contributors simply contact the PPI Coordinator.

The Department also coordinates the Weight Management Panel. These PPI Contributors (many of whom are not local) can be contacted about any diet related issue through the Professors' PA.

3:2 Potential methods of advertising:

- ✓ Adverts/flyers in surgery/clinic waiting rooms/ pharmacies/dentists (see 3.4) This would include PowerPoint slides for a TV monitor.
- ✓ Adverts/flyers placed with Voluntary Sector infrastructure organisations. These directories of voluntary sector organisations that support people with specific conditions could be a starting point.
- ✓ 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 nationally from NIHR's People in Research
- ✓ Face to face discussion with relevant patients during clinical encounters
- ✓ Letters to potentially-interested patients/service users
- ✓ Adverts on local community message boards or parish magazines
- ✓ Use of personal contacts and word-of-mouth
- ✓ Local radio and T.V.

If you need to recruit PPI Contributors 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. (This topic is covered in more detail in section 10)

3.3 Recruitment websites

You can use any of the following websites to try to recruit Patient & Public Involvement Contributors. However, some of them either include or are many focused on participants in studies so you will need to be very clear in your advert the sort of help you want.

People in research	National and run by NIHR.	This service is free to use.	http://www.peopleinresearch.org/
Patients Active in Research	Local (Thames Valley) and run by Oxford's Biomedical Research Centre.	This service is free to use.	http://patientsactiveinresearch.org.uk/
Call for Participants	Set up by researchers who were struggling to recruit participants themselves.	This is free to academic researchers.	https://www.callforparticipants.com/

Prolific Academic	Company spun out by Isis Innovation. On Prolific you can find reliable on-demand participants from around the globe. You can check your newly collected data before you approve participant rewards.	You have to pay for this service.	https://www.prolific.ac/
Amazon Mechanical Turk	Amazon Mechanical Turk is a marketplace for work that requires human intelligence. The Mechanical Turk service gives businesses access to a diverse, on-demand, scalable workforce who complete tasks whenever it's convenient.	You have to pay for this service.	https://www.mturk.com/mturk/welcome
BioResource	National and run by NIHR and is specifically for participants. Researchers are able to select volunteers for studies based on their genetic make-up or on other characteristics, such as markers in their blood cells.	This service is free to use.	https://bioresource.nihr.ac.uk/

3:4 Information for potential applicants

Potential applicants should be told;

- Basic details about the project, what you hope to achieve and why it may be of interest to them
- What the format of involvement will be (trial steering committee or one off focus group etc.)? Include if known how their input will be used e.g. to r/define the research questions, to help write the lay summary etc.
- How often they will be asked to attend meetings, how long meetings will last and if they will take place in central Oxford?
- How long will the project go on for and are they expected to commit to the whole time period?
- Do they need to have ‘lived experience’ of the condition you are researching?
- Whether they will be reimbursed their expenses?
- Whether they will be paid an honorarium and if so how much?
- If more people apply than are needed how they will be selected?

- What is the deadline for their application?
- [If this is before you have grant funding will you want to include them if you are successfully funded in the future?]

3:5 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.)

3.6 Directories of Voluntary sector health organisations

These directories hold a large range of voluntary sector groups who support people with particular health conditions, illnesses and diseases.

Contact a Family – for families with disabled children	www.cafamily.org.uk/medical-information/conditions
Patient - trusted medical information and support – NHS Choices	www.patient.co.uk/directory
Self-Help UK – the guide to patient support and self help	www.self-help.org.uk/directory
Shaping our Lives - National network of service users and disabled people	http://www.shapingourlives.org.uk/list-of-members

Rare Disease UK – the national alliance for people with rare diseases and all who support them	http://www.raredisease.org.uk/members.htm#patient
McPin Foundation – transforming mental health research	http://mcpin.org/resources/service-user-and-carer-groups/
Coach – County of Oxfordshire advice on care & health set up by GP Federation	http://directory.my-coach.org.uk/#/search/list

3.7 Advertising on social media

Social media is the new normal - up to 70% of emails are opened using a mobile phone and around two million blog posts are written every day globally. The web can be used to simply inform, for example through a corporate website, or to consult and gather views. This might be through online surveys, by setting up a discussion forum or by encouraging discussion through social media sites such as Facebook or Twitter.

The main advantages of social media are the ability to reach large numbers of people who might not formally volunteer to attend meetings and the ability to seek the views of people who might not want to come forward due to the nature of their experience (so for example if you want to conduct research with pregnant women that drink alcohol).

The possible disadvantages are that negative comments may stay 'live' and there is an increased potential for others to hijack the agenda.

Don't dive in and start using multiple social media platforms at the same time. Unless you are able to resource this for a sustained period of time your efforts are likely to go unrewarded. Start small: plan – do – review. Increase as you become more confident and established. Recommended daily posts are twitter x 3, Facebook x 2.

If you blog, you're likely to attract more visitors to your website, and regular posting can generate more interest. Don't be half-hearted as blogging takes planning, commitment and dedication – don't start something that you cannot sustain

When posting on social media platforms such as Facebook or Twitter, have a point and put it upfront in your post. Your audience will instantly know if their thinking is aligned with yours and you'll attract many more meaningful engagements.

If another organisation, or someone you follow/like has published something that you think would be of interest to your chosen audience(s) share it – but remember to quote your source. As a general rule of thumb no more than a 3rd of your posts should be from other sources.

Resources to help you

Take advantage of free tools and monitor your performance with tools like Hootsuite or Tweetdeck to schedule all your messages and track the responses and engagement you are getting. You can also use Google Analytics to monitor your website. These are all free tools. Set metrics; likes and follows are nice, but shares, mentions and 2-, or even 3-way conversations are much more powerful engagement metrics.

Ask for help from our Communications Officers (see section 16 for their contact details).

Access this advice from the University Research Services;

http://www.admin.ox.ac.uk/media/global/wwwadminoxacuk/localsites/curec/documents/BPG_06_Internet-Based_Research.pdf

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 Contributor 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 Contributor. 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 e.g. a PPI Contributor on a theme steering group for the CLAHRC. For other roles (involvement as above), you may adopt a more informal approach e.g. being on a focus group for a research project.

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 and know how you will make your selection (see 3.3).

See Appendix for template role description and person specifications

You can also find templates of role descriptions at INVOLVE

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, such as wearing hearing aids, using a wheelchair, having English as a second language etc.

In all cases you need to be clear in your own mind what your selection criteria is so that you can select candidates if you have more applicants than you need.

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 Contributor 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 offer the candidates expenses, but payment for their time should not be applied until they are appointed.

Section 5 – Appointing

When you appoint someone make sure 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 an email. 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) if known
- 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 Contributor 'personnel' file

If you are appointing a PPI Contributor who will be on your trial steering committee for the full length of your project you will probably find it helpful to keep all information about them in one place. 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 details needed for Payment Request Form
- all review records
- copies of any letters provided for them to the Job Centre or outlining different ways of paying them

This level of detail will not be necessary for PPI Contributors who are just helping with a one-off focus group. However, you should keep contact details of them so that you can let them have updates on the project and thank them for their input. It may also be helpful if the project changes and you decide to hold a follow up meeting with the same group. In articles you should acknowledge their input and your records should show that you have their permission to name them.

In addition you should provide their contact information to the PPI Coordinator (with their permission) so that they can receive information and support from the Department or CLAHRC, more generic than just for your project. Ask the PPI Coordinator for a flyer which can be shared with your PPI Contributor to help them see the benefits of being part of the ‘virtual pool’.

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 Contributor to contribute as fully as possible. They should all be given the basic induction and introductory reading material. Remember that the PPI Contributor 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 Contributor induction

The following should be offered as a minimum:

- Opportunity to meet the other PPI Contributors 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
- Information about the full research team members
- 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 Contributor 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 Contributor to fully understand the project
- Glossary of terms and acronyms so that the PPI Contributor 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

Section 7 – Finances

Please refer to Section 2 for information about budgeting for PPI work in your funding application.

These points are all general to any financial transactions with PPI Contributors;

- Be sensitive in handing out claim forms and talking to people about Benefits. Some people may be embarrassed if they are making a claim when others do not – nobody should be made to feel awkward about this. Assume that everyone may be on Benefits and do not make assumptions about this based on how they dress or speak!
- You should always be clear with people that they do not have to accept either expenses or payment but that we think it is fair to reward people for the time they spend helping us.
- Some people might ask you to donate their expenses or payment to a charity of their choice but because the University of Oxford is a charity we are unable to make a direct transfer payment. It would of course be entirely up to the recipient what they choose to do with any monies they receive from us.
- In principle payment relates to children & young people as much as it does to adults. However, it is good practice to get permission from parents or guardians before giving payment to a minor. Where a young person or child is involved and it is their parents who have incurred expenses to enable their involvement, then it is the parents who should make the claim for their expenses to be reimbursed.

The payment policy is available here.

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.

7:1 Reimbursement of PPI Contributor expenses

Reimbursement for expenses are not taxable. Reimbursed expenses will not be seen as earnings and will not affect a person's benefits if they are a PPI Contributor with us.

The University of Oxford expense form can be found here; expenses form

Where you are paying expenses you should be clear with the PPI Contributor right from the start that they must get your permission before claiming expenses not listed in their agreement with you. You should pay expenses as follows;

- Mileage for private vehicles at 45p per mile for the first 10,000 business miles in the tax year and then 25p for each business mile over 10,000 in the tax year.
- Cost of public transport
- Taxi in cases which can be justified e.g. multiple people travelling to same place, personal safety, disability or efficiency.
- Cost of a paid carer providing the PPI Contributor's caring role in their absence. This to include travel/accommodation/subsistence requirements and hourly costs.
- Cost of a paid carer supporting the PPI Contributor to attend the meeting due to their own support needs. This to include travel/accommodation/subsistence requirements and hourly costs.

Make sure that you have plenty of expense claim forms available at meetings. You could also prefill them in with some details including 'n/a' in the employee number box.

You should encourage your PPI Contributor to make their expenses claims as soon as possible and arrange the payment to be made as soon as possible after they do so. Anything that is more than 12 months old will not be paid. Evidence of expenses in the form of a receipt or ticket must be provided and the form must have a 'wet signature' so scanned/emailed forms are not acceptable. Where receipts are difficult to obtain (for example the use of Oyster cards or calls made on mobile phones) copies of bills or computer printouts with the relevant section highlighted can be accepted.
Whether your project is part of the work of the Nuffield Department of Primary Health Care Sciences or the Oxford NIHR CLAHRC Oxford you should send your claim forms to the budget holder or delegated authority for authorisation and they will then send it on to your Department's finance team.

It is good practice to pay people on Benefits (at least) their expenses on the day and for this reason you may prefer to arrange for petty cash, although restrictions on amounts may make this difficult. (You would do this across the board so as not to embarrass any individuals)
To do this at the **Nuffield Department of Primary Health Care Sciences**:

a) Ask the Finance Officer for a float from petty cash up to a limit of £50 for a meeting and each claim can only be a maximum of £20
b) If you will need more than £50 per event then give the Finance Officer a week's notice of needing a bigger float. The maximum for any one claim will remain at £20
c) You could reimburse the PPI Contributor out of your own pocket and then use their receipts to make your own expense claim to the department.

The use of petty cash only applies to expenses, not payment for time.

At **NDORMS** it is not possible to pay petty cash and all expenses should be paid via the University expense form.
At the **Dept of Population Health** petty cash payments are only available for very minor amounts such as local bus fares – speak to your finance team about accessing this.

At the **Dept of Psychiatry** it is possible to pay petty cash when small amounts are involved or the recipient does not have a bank account. However, generally speaking expense claim forms are preferred.

Please note that if a PPI Contributor asks for payment by cheque they should be warned that this may delay payment – BACS transfer is the University's preferred method.

If a PPI Contributor does not have a bank account speak to the PPI Coordinator about alternative options.

7:2 Payment of PPI Contributor

This refers to payment for time which is over and above the reimbursement of expenses
Payment for time is taxable and should be declared for tax purposes.

You can either use the expense form to cover this element too or the Payment Request Form. (**NDPCHS prefer the Payment Request Form. Check with your finance team to see which they would prefer).** The relevant forms can be found; expenses form or AP Payment Order form. **In either case it is important to show expenses and reimbursement amounts separately because of their tax status and the potential impact on Benefits.**

In order to complete a Payment Request Form you will need your PPI Contributor's contact details, bank details & NI Number. If they are coming to multiple meetings get these details at the start of their involvement and keep a record of this on their file to assist with any payment or reimbursement issues that might arise. Ensure that you password protect this document.

It is strongly recommended that you encourage any PPI Contributor in receipt of State Benefits to contact the helplines at 7.3 to ensure that there are no adverse effects of their involvement work with you, prior to their involvement.

You will have made clear to the PPI Contributor from the advertisement onwards what, if any, payment is available. This will be based on what you budgeted for when you made your funding application.

You may use the INVOLVE recommended rates which are;

Full day meetings	£150	to include all prep and follow-up
Half day meetings	£75	to include all prep and follow-up
Short pieces of work	£20	require little prep or follow-up, such as a telephone meeting or reviewing short documents; 1-2 hours:
2 hour meeting	£50	No prep or follow up
Reviewing document of 50 – 200 pages	£150	

Payments made for time to PPI Contributors are deemed by HMRC as income. This applies even if payment is made via vouchers. PPI Contributors receiving any payments or incentives should be made aware that this may impact on their entitlement to Benefits. Breach of benefit conditions can result in an individual's Benefits being stopped. It is the person's responsibility to keep to the conditions of those Benefits on what they can do and amount they can be paid. (Direct them to the helplines at 7.3)

PPI Contributors are also responsible for their own related pension contributions, National Insurance (NI) and income tax.

In some cases you may decide that you would rather pay the person with **vouchers.**

Nuffield Department of Primary Health Care Sciences	Uses the Gifts for All company for this. You will need to raise a purchase order and wait for them to be paid before they will send you the vouchers so you would need to allow at least a month for this process. Alternatively you can request Blackwell's vouchers from the Finance Officer and they will be available within 3 working days.
NDORMS	Staff are not able to pay with vouchers
Dept of Population Health	Staff should speak to their finance team about the possible purchase of High St vouchers (usually M & S).
Dept of Psychiatry	Staff may pay vouchers (usually Amazon) – they should speak to their finance team who will raise a purchase order or for smaller amounts will purchase by credit card (N.B. this means that smaller amounts will take less time to arrange)

In either reimbursing or paying, the PPI Contributor may ask you to make a direct payment for the item such as direct payment to their carer. In such circumstances speak to the PPI Coordinator who will help.

Please note that if a PPI Contributor asks for payment by cheque they should be warned that this may delay payment – BACS transfer is the University's preferred method.

If a PPI Contributor does not have a bank account speak to the PPI Coordinator about alternative options.

For advice on paying children and young people see http://www.invo.org.uk/find-out-more/how-to-involve-people/involving-children-and-young-people/resources-for-involving-children-and-young-people/

7.3 Benefits Advice Service for involvement

There are **two** confidential free services providing advice and support, depending on the funder. For this reason it will be important that you tell each PPI Contributor where the funding for your project comes from.

It is strongly recommended that you encourage any PPI Contributor in receipt of State Benefits to contact the appropriate helpline to ensure that there are no adverse effects of their involvement work with you, prior to their involvement.

1. **INVOLVE** which will offer personal advice and support on how payment of fees and expenses for public involvement might affect people in receipt of state Benefits.

   It is available to:

   - members of the public involved with NIHR organisations
   - members of the public involved in studies funded by the NIHR
   - staff within NIHR organisations who are supporting members of the public to get involved

   The process is:

   - contact INVOLVE on benefits@invo.org.uk or 023 8059 5628, stating which part of the NIHR you work in (for example, BRU, NIHR CLAHRC Oxford, LCRN)
   - members of the public can contact INVOLVE using the contact details above (INVOLVE staff do not need to know anything about their Benefits situation)
   - the person enquiring will then be given an email address (or telephone number) to contact the Benefits advice service directly, together with a unique code that will need to be quoted.
   - E-mail is preferred for the first contact. The service will then arrange a time to call.

   It is important to allow members of the public with enquiries to contact the Benefits advice service directly, rather than raising any enquiries on their behalf. This will avoid misinterpretation or confusion in any advice offered.

   If you are not sure whether your project qualifies to use this service, please contact INVOLVE on Benefits@invo.org.uk or 023 8059 5628.

   N.B The service is not able to give advice on tax or National Insurance enquiries, or on Benefit queries relating to payment for participating in research (for example, for taking part as a subject of a clinical trial or research study).

2. **NHS England** has also arranged for a helpline to be available to patients and staff who have queries about being involved with NHS England's work. Bedford Citizens Advice Bureau provides a telephone helpline service to help resolve any benefit concerns that arise from payment of fees and expenses for public involvement. The service should be contacted via email involve@bedfordcab.org.uk with a brief summary of the query, or by calling 01234 330604.

Relevant to both helplines

One of the biggest difficulties for people on benefits because of ill health or disability is that Jobcentre Plus offices can interpret involvement as readiness for work whether or not payment is being offered. Suggest that the CAB is asked for help with this where appropriate.

Section 8 – Training

Training can be provided to;

1) PPI Contributors
2) Research staff
3) PPI Contributors and Research staff together

In all cases the aim will be to encourage delegates to feel better able to work together, with a greater understanding of how to do so and why it matters.

INVOLVE hold a database of available training.

8:1 PPI Contributor training

The principle behind offering training is to enable the PPI Contributor to contribute as fully as possible. They should all be given the basic induction and introductory reading material (see section 6). In addition, it may be necessary to arrange specific training for a given project as need arises. This cannot be prescriptive because of the nature of the research (some will be more technical than others) and because the starting knowledge and experience of PPI Contributors will vary. The main aim will be to encourage PPI Contributors to feel able to ask questions and to challenge appropriately. They should also be encouraged to contribute their working/life experience where it would help the research project (i.e. not just health issues)

A series of training sessions ran Jan – May 2016 to provide PPI Contributors with a grounding in the basics of research terminology and practices.

2016	Topic	Trainer
January	What is evidence? What is a randomised controlled trial? What is meant by the research cycle?	Dr Katherine Tucker
February	What is the difference between quantitative & qualitative research?	Dr Veronika Williams
March	Understanding ethics and what is meant by informed consent.	Dr Andrew Papanikitas
April	What is a systematic review?	Dr Nicola Lindson-Hawley & Dr Rachna Begh
May	How can we work together to improve PPI?	Dr Anne-Marie Boylan

When more are arranged they will be advertised on the websites and through internal communication channels.

8.2 Training in best practice in PPI for researchers

Training for researchers is provided in a variety of ways.

a) This document is always available on NDPCHS and CLAHRC websites
b) The PPI Coordinator is available for consultation
c) The PPI Coordinator holds monthly drop in sessions for staff working at venues outside NDPCHS

	Dept of Psychiatry **Café at Warneford Hospital**	**Dept of Population Health** **Tulip Tree Cafe** **Richard Doll Building** **Old Road Campus**	**NDORMS** **Retreat restaurant** **In the atrium area of NOC, Windmill Road**
Thr 16th June 16	1 – 2 p.m.	2.15 – 3.15 p.m.	3.30 – 4.30 p.m.
Tue 19th July 16	11.30 – 12.30 a.m.	9 - 10 a.m.	10.15 – 11.15 a.m.
Wed 21st Sept 16	3.30 – 4.30 p.m.	2.15 – 3.15 p.m.	1 – 2 p.m.
Thr 20th Oct 16	9 - 10 a.m.	10.15 – 11.15 a.m.	11.30 – 12.30 a.m.
Wed 16th Nov 16	1 – 2 p.m.	2.15 – 3.15 p.m.	3.30 – 4.30 p.m.
Tue 6th Dec 16	1 – 2 p.m.	2.15 – 3.15 p.m.	3.30 – 4.30 p.m.

d) Training offered by other organisations (such as RDS) are advertised in internal communication channels
e) Occasional seminars are offered in-house
Two examples are;
How to involve PPI Contributors before you have funding
Thursday, 10 November 2016, 10.30am to 11.30am

Running meetings that include PPI Contributors
Thursday, 24 November 2016, 10.30am to 11.30am

f) New staff and PPI Contributors are invited to attend an induction session led by the PPI Coordinator – contact her to get dates.
g) Introductory sessions on PPI are embedded in NDPCHS' MSc in Evidence Based Health Care.

8.3 Training for staff and PPI Contributors together

The **Leading Together** programme enables lay people and health professionals to develop genuine partnerships that make a difference to local health organisations and communities and lead to improvements in healthcare and research.
Between February and October 2016 a total of 60 health professionals and 60 lay people took part in the programme at six different venues across southern England.
http://www.oxfordahsn.org/our-work/patient-and-public-engagement-involvement-and-experience/leading-together/

Other training for PPI Contributors and staff together will be developed in 2017. If you would like to be part of the planning for this please speak to the PPI Coordinator.

Section 9 - Running meetings that involve PPI Contributors

Remember that it is vitally important to acknowledge your PPI Contributors input and encourage their involvement. Say thank you to them at the end of the meeting. Send a follow up email that thanks them for their input. Make sure that PPI Contributors input is minuted. Contact the person before and after their first meeting to help put them at ease and see if they have any questions about the agenda. Ideally contact them like this before all meetings.

It is considered good practice to always have at least two PPI Contributors in any meeting. This enables them to gain confidence from each other and for the meeting to get more than one view. It also means that if one of them is unable to make a meeting you have not lost your entire PPI Contribution.

There are many different types of meetings that may include PPI Contributors and how they are run will vary accordingly.

Style	Definition
Trial steering committee	Group that has overall strategic and overall responsibilities for the research throughout its funding period. Will include clinicians, researchers, statisticians, health economists etc. and at least 2 PPI Contributors
Advisory or focus group	When you get a group of PPI Contributors together to ask them specific questions and it is just them with 1 or more facilitators.
Stakeholder group	An advisory/focus group that contains PPI Contributors but also clinicians and researchers or others relevant to the study.
Visit to an existing group	Commonly a voluntary or charitable support group or peer support group of people with a particular condition or need in their own setting at an existing meeting
Virtual panel	Where you consult with PPI Contributors by email or telephone or Skype etc. If this is set up as a meeting it can conform to any of the models above.

9.1 Terms of Reference

Whether you are managing your PPI input through focus groups or including Contributors on trial steering committees or other groups you will have to consider how the group functions. It will be good practice for the group to discuss and agree its own Terms of Reference at the beginning of their work and to review these occasionally.

See Appendix for template Terms of Reference

You can also find sample Terms of Reference at INVOLVE

9.2 Good practice in running a meeting

Things to consider when setting up a meeting that includes PPI Contributors

- ✓ Make sure that the room you are using is accessible that there are disabled toilets that can be accessed by someone in a wheelchair and that there is a hearing loop.
- ✓ Make sure that there is disabled parking and that other parking is as easy as possible. In a place like Oxford if parking is not possible then ensure that you consider holding the meeting out of town where people can park or ensure that you choose a venue on easy bus routes.
- ✓ Provide not just the address of the venue but a map and any other details necessary to make it easy to find for someone coming for the first time. Provide the phone number for the reception in case of last minute difficulties.
- ✓ Think about how people are going to enter the building – will they need to be met, given a parking permit or directed to the actual room?
- ✓ Ask people if they have any special dietary needs (e.g. vegetarian, gluten free etc.) and be sensitive to the patient population you could be meeting with e.g. people with diabetes.
- ✓ Provide up-to-date travel expenses and payment forms and ensure they are filled out correctly – be aware that some people may be embarrassed to claim if others are not and alter your system appropriately (providing in a sealed envelope etc.)
- ✓ Don't make the meetings too long and plan breaks (particularly relevant if your PPI Contributors have a disability or condition that means they need the toilet more often or they cannot sit in a chair for too long…) Breaks will generally be welcomed by all!
- ✓ Consider evening or weekend meetings if you need to attract working age and young adult participants.
- ✓ Consider your venue if you want to attract a particular cohort. For example holding a group in a Sure Start Centre with facilities for play may attract young parents.
- ✓ Have an agenda for your meeting that you share at least a week before the meeting.
- ✓ Create an atmosphere where people feel able to share ideas by always welcoming input from all, encouraging people to speak up and thanking those who make suggestions.
- ✓ Give plenty of notice of meetings – do not assume that because your PPI Contributor is retired for example that they do not have many other commitments.

Before the meeting, facilitators should

- ➢ Try to ensure that they are working in pairs as meetings can often be busy and it is hard to welcome people, deal with the room and refreshments as well as taking a leading role or taking minutes.`
- ➢ Try to provide basic refreshments such as tea and coffee on arrival, and allow time for this in the agenda. If the meeting is longer consider whether it is appropriate to provide a light meal or another drinks break and make arrangements for this. If you

are doing this you will need to find out about any special dietary requirements of attendees beforehand. When thinking about your venue remember to book an accessible room: Are there disabled toilets on the same floor? Lifts? Is there a hearing loop?

- Think about how you are going to fully involve those with a disability or condition but how you are going to do this respectfully without drawing unnecessary attention to them.
- Think about what you want to get out of the meeting but also what the attendees could get out of it.
- Make sure that you think about how you are going to gather feedback about the meeting.
- Offer PPI Contributors the opportunity for a chat to answer any questions they have individually and check that they are happy

On the day facilitators should

- Ensure the room is comfortable, warm and not too noisy and that the seating allows attendees to see and interact with each other
- Bring with you enough copies of any paperwork sent to the attendees; do not assume that they have been able to print them out at home. (You should establish with new PPI Contributors if they have a printer at home and if using it is acceptable to them)
- Greet each attendee and start the session with introductions. It's a good idea to get each person to introduce themselves and say a little bit about why they came; this helps break the ice and makes people more confident about contributing later on. Name badges may help for those with poorer memories or who did not hear a name. You may find that name plaques stood in front of the person if the meeting is round a table are helpful if distances make name badges hard to read.
- Remember basic housekeeping; make people aware of fire alarms and exits, toilet location etc.
- Remind people of the purpose of the meeting, run through the agenda and mention the beginning and ending times, and whether there will be any breaks.
- Discuss and agree ground rules of the session. Is it ok for people to ask questions at any time? Remind people not to talk over one another. Ask people to respect each other's contributions. Make a clear statement about the confidentiality of the information provided by participants. Explain how the information from the meeting will be used. Ask people to respect each other's confidentiality too. (see 9.1 for Terms of Reference)
- Ask if there are any questions before you start.
- Make sure that everyone has the chance to speak – you might need to actively encourage quieter members to do so and discourage some from dominating proceedings.
- Try to avoid becoming defensive if there is criticism or problems are raised as this will stifle further conversations about these issues.
- Avoid letting the meeting run overtime; people may need to get back for caring responsibilities etc.

- Ensure people are clear about what will happen next; will there be another meeting? Will there be further correspondence? What are the next steps for the project?
- Ensure people have filled out their expense forms and know what to expect from the reimbursement procedure, such as how long it can take.
- Thank the group for their time.
- Provide an opportunity for feedback – verbal, written etc. Consider how you are going to make this open – does it need to be anonymous for example? How real can that be in a small group? Do not assume that everyone can read or write.
- If a meeting is being recorded for accuracy give people the opportunity to confirm that they are happy with this.

After the meeting

Write to people and thank them for participating. Summarise what happened and let them know what will happen next. Invite people to give you feedback.

9.3 Helping people to contribute effectively during meetings

There are many reasons for non-participation during meetings including lack of preparation, shyness, being overawed by rank or someone's specialist knowledge or being put off by another's aggressiveness or dominant behaviour.

To draw out the silent type and protect them from intimidation it might be helpful to ask questions that tap their expertise, praise their good ideas, openly note their contributions, and call on those that are shy or junior first.

Of course you may also have to limit the long winded. This can be done by setting the ground rules at the start including how long any one person can speak for at a time. You should also request that remarks be confined to the topic of discussion. If someone still insists on an opera length speech you may have to tactfully but firmly insist that you move on.

It is equally important to remain focused on the agenda and what needs to be achieved. To do this you will want to summarise progress and remind everyone of the meeting's objectives. You will also have to interrupt if the discussion gets out of hand, off topic, too heated or rowdy. Act quickly if a serious disagreement arises.

Sometimes a participant may have something worthy to contribute but may not be the best public speaker. At such times it is the chair's job to rescue that person by helpfully summating what they think he/she was trying to say.

You should work to encourage diverse points of view, especially if it is a problem solving or brainstorming session. Well run meetings enable a group of people to achieve more than the sum of their individual efforts, through the creation of synergy and the combination of their collective expertise.

You should encourage all opinions and perspectives to be explored but be prepared to highlight bias and oversights. Some participants will need to broaden their viewpoints while others must be encouraged to be more realistic.

To generate ideas you may want to try brainstorming, asking open questions (ones that cannot be simply answered by yes or no), encourage partial ideas, reserve your own ideas until the end, clarify and paraphrase for others (make sure you ask them to confirm that you have it right), and the use of verbal and non-verbal reinforcement

You may wish to offer a de/briefing meeting for PPI Contributors before and/or after the meeting.

9.4 Facilitator tips for running a focus group

Focus groups

Focus groups are a good way to explore issues in depth.

Plan what you want to achieve

Clarify your objectives – how will the output be used, what do you already know and what new information do you need?

Arrange participants – about 6 people

Arrange a venue – make it a comfortable setting and provide nice refreshments

Plan the discussion guide – with a list of 6 – 8 primary questions you would like answers to and secondary questions to probe people's responses to primary questions.

Example of a typical approach

Ground rules 10 mins	Introduce yourself, objectives and ground rules
Introductions 15 mins	Each person introduces and says a bit about themselves and their interest in this topic
Headlines 30 mins	Ask people to jot down headlines of two or three issues that are most important to them. Go round the room, each person raising one topic and discuss for 5 mins. Ask 'why is this important?' and 'who else had something like this'? When everyone has spoken agree 3 key issues to discuss in details.
Focus 30 – 60 mins	Raise your questions if they were not included in participants' lists. Discuss views about each issue in turn. (see notes for facilitators below)

Thank you 5 mins	Tell them what the next steps will be and how they will be told of any outcomes.

Notes for facilitators

What is a facilitator?

A facilitator is the person who moderates a workshop or focus group. Anyone can facilitate PPI provided they have an open mind, are a good listener and are happy to hear others' views without judging or imposing their own.

The role of the facilitator

The facilitator's role is to help people express their views:

- ✓ To guide the discussions following the agreed agenda and to meet the agreed objectives
- ✓ To encourage everyone to have a say, without judging
- ✓ To take care no one person dominates the conversation (thank them for their energy/enthusiasm and ask their permission to give others the chance to air their views)
- ✓ To listen to others views', not to take over the debate and impose your own opinions on people
- ✓ To ask open questions rather than state opinions or facts
- ✓ To ensure each sections runs to time, so that people have a chance to talk about all the topics on the agenda
- ✓ To regularly sum up discussions and to prioritise key points for feeding back

Introductions and ground rules

Briefly introduce yourself, your role (for example to help everyone in the group express their views and opinions on the topic) and your objectives for the session

Ask attendees to set the ground rules which could include;

- Confidentiality and anonymity
- Listen to and respect each other's individual views
- Participation from everyone who wants to
- Challenging points of view not individual people
- Honesty and an open attitude
- Agree to cover all topics and to move on if necessary
- Mobiles and pagers off or on silent

During the workshop

The following prompts and questions may be helpful for people to express their views and the move discussions along:

Open: What is your experience? What happened to you?

Probe: Can you tell me a little more about that?

Probe: Do you have an example of that?

Motivation: What is it that makes you say/think that?

Be careful with asking 'why?' – this can sometimes lead people to second-guess reason unless you are very specific.

At the end ask people to note on a flipchart what went well and what could have been better about the session.

Afterwards

Summarise key points of the workshop illustrated with quotes from participants written as people said them.

Hints and tips

- You could ask an independent person to run your focus group and offer to run one for them
- Tape or ask a colleague to note the conversation, so that you can concentrate on listening and questioning, but do make sure you get their permission to do so
- Or ask people to write their own ideas onto post-it-notes, then play 'snap' to group them into themes

Section 10 – Working with the seldom heard

10.1 Working with children & young people

Most of the principles of working with PPI Contributors apply to working with children and young people too but there are some variations and rather than attempting to lay it all out here please refer instead to this range of good practice and expert publications in this area.

If you have any specific queries or would like further help please speak to your PPI team.

1 INVOLVE can direct you to young people's advisory groups, guidance on involving young people in research, advice on reward & recognition and a video by a young PPI Contributor.

www.invo.org.uk/find-out-more/how-to-involve-people/involving-children-and-young-people/resources-for-involving-children-and-young-people

and

http://www.invo.org.uk/find-out-more/involving-children-and-young-people/

3. NIHR provide information about young people's advisory groups they support

http://www.nihr.ac.uk/get-involved/young-people-and-research.htm

4. The National Children's Bureau have young Research Advisers and are also able to provide guidance on how they work

http://www.ncb.org.uk/what-we-do/how-we-work/research/involving-children-young-people-research

5. Participation Works Partnership has developed guidelines in working with young PPI Contributors in research in line with the National Children's Bureau

http://www.participationworks.org.uk/resources/guidelines-for-research-with-children-and-young-people

6. Nuffield Council on bioethics report looks at how children and young people can ethically be involved in research, and makes recommendations about the roles and responsibilities of children, their parents or guardians, researchers and others.

http://nuffieldbioethics.org/project/children-research/

7. This report discusses how to shape Health Services through young people's participation, so may be helpful if your research crosses into service provision settings.

http://www.myapt.org.uk/wp-content/uploads/2015/06/Taking-on-The-Challenge-Young-Peoples-Participation-in-Health-Services-Ebook.pdf

8. Royal College of Paediatric and Child Health 'Infants', Children's and Young People's Child Health Research Charter

http://www.rcpch.ac.uk/cyp-research-charter

10.2 Reaching adult seldom heard groups

Seldom heard' is a term used to describe groups who may experience barriers to accessing services or are under-represented in healthcare decision making.
Traditionally, some of the groups identified include;

- rural communities,
- black & minority ethnic (BME) groups,
- gypsies and travellers,
- lesbian, gay, bisexual & transgender,
- asylum seekers and refugees
- prisoners
- homeless
- young carers.

However, in reality, teenagers, employees, people with mental health issues or a learning disability or substance misuse issues and many others may be considered as seldom heard, due to the fact engagement may not be straightforward.
The only way to actually engage with different groups is to understand them individually and tailor involvement to them accordingly.

- **Understand their needs and priorities** – this will help to define the way you engage
- **Find out how they like to get involved** – align your approach with this
- **Determine the way they prefer to be communicated with and what tools they use** – tailor your method, for example, to social media, video, or even workers in the community
- **Find out who they trust and have good relationships with** – develop a relationship with those stakeholders and ask them to help you reach people
- **Don't expect everyone to feedback in the same way** – from online snap surveys to face-to-face discussions, adjusting the approach to get the right results is important

Professor Louise Locock of Oxford University has done some specific work in this area; http://www.invo.org.uk/posttypeconference/patient-involvement-as-a-route-to-seldom-heard-groups/

Oxfordshire County Council has been proactive in both training their staff in this area and recruiting PPI Contributors from traditionally seldom heard groups. Contact with them can be made via your PPI Coordinator.

Some specific advice is available from the Social Care Institute for Excellence;

and the East Midlands Academic Health Science Network

If you have any specific queries or would like further help please speak to your PPI Coordinator.

Section 11 – Ongoing support

11:1 PPI Contributor ongoing support

Many people choose to become involved with research for the opportunity to learn new skills, make a contribution, and meet new people. Aim to create an atmosphere that allows this.

Remember that even if you are paying people for their time it is important to thank them for their contribution regularly. A formal letter of appreciation from the head of the research project will also be much appreciated.

You should arrange to provide the following support as a minimum;

- Meeting papers to be sent 1 – 2 weeks in advance
- Phone contact in the weeks before and after meetings to answer any project related queries
- Access to additional information provided on PPI by INVOLVE as needed
- Clear instructions on how to claim expenses and payment
- The template logbook form for them to record their expenses received etc.
- Informal in-house training to explain the project
- Additional formal training as it becomes available
- Regular feedback about what progress being made on the project, including feedback on how they have made a difference to the work.
- Providing their contact details to the PPI Coordinator so that they may be included in any relevant support such as PPI Pulse, the PPI newsletter.

Consideration should be given to other forms of support and recognition to enhance the experience for individuals who get involved. This might include, for example, training and learning, attending conferences, confidence building, help with ongoing learning, CV development and future employment. If you do not feel able to provide this please talk to the PPI Coordinator to discuss possibilities.

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! This relates to your PPI work as much as it does to your research.

12:1 PPI Contributor contribution to the work of the project

There are various tools to assist you in recording the impact of your PPI Contribution.

Public Involvement Impact Assessment Framework has been produced to help researchers assess the impacts of involving members of the public in their research in diverse fields from health care to local history.

Guidance for Reporting Involvement of Patients and Public. The GRIPP checklist represents the first international attempt to enhance the quality of PPI reporting

Further details of GRIPP Phase 2 to be put into this section when made available by national working group.

Encourage your PPI Contributors 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 Contributors 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 Contributors.

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 Contributors to keep their own records of any payments that they receive so that they can keep track of claims they make and when these are paid. 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 the record keeping chart in template section as part of their induction. **See appendix for** record keeping format

12:3 Acknowledge the input of your PPI Contributors

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

Acknowledgment in journals

Anyone wishing to submit an article to *The BMJ* is now required to answer the following questions and this should be considered at the start of a project, when considering what you will record of your PPI work?

- How was the development of the research question and outcome measures informed by patients' priorities, experience, and preferences?
- How did you involve patients in the design of this study?
- Were patients involved in the recruitment to and conduct of the study?
- How will the results be disseminated to study participants?
- For randomised controlled trials, was the burden of the intervention assessed by patients themselves?

Patient advisers should also be thanked in the contributorship statement or acknowledgements.

If patients were not involved please state this.

If this information is not in the submitted manuscript *The BMJ* will ask you to provide it during the peer review process.

Please also note also note that *The BMJ* now sends randomised controlled trials and other relevant studies for peer review by patients.

http://www.bmj.com/about-bmj/resources-authors/article-types/research

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

This is something that you may be asked to do by your funders and the following guidance is provided to assist you;

- ✓ Make a plan before you start, jotting down ideas based on the template guidelines (see appendix of templates)
- ✓ 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 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 Contributors

When you are working with PPI Contributors 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 Contributor to improve their own input as they go along.

13.1 Two types of formal feedback

It is important to provide PPI Contributors 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 Contributors 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 Contributors 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 12).

You should also consider how you are going to provide this feedback and at what intervals. If your PPI Contributor is on a trial steering committee (TSC) that only meets annually, make a point of giving them at least quarterly updates that invite their comment. This will enable them to contribute more effectively at the TSC.

In both cases you will need to enable the PPI Contributors 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.

With your PPI Contributor's consent you could name them and acknowledge their contribution in articles etc.

13.2 Feedback to those who helped you to recruit

In addition to the direct feedback that you will provide to your actual PPI Contributors 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 <u>you asked</u> to help you in recruiting either PPI Contributors or trial participants and to thank them, as this will encourage them to believe that their efforts were worthwhile and appreciated. Blind copy your PPI Contributors so that they have an understanding of what communications are taking place, outcomes and needs going forward.

- 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 Coordinator 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)
- You could ask relevant voluntary sector groups to include your outcomes in their newsletters

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, 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
- Dept/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 Dept 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 Contributors 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 Contributor review process

You should arrange for either telephone or face to face opportunities to review the PPI Contributor'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 Contributor should be encouraged to view this conversation 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 Contributor is not contributing as fully or as well as the researchers had hoped this should be raised and reasons for it explored. The PPI Contributor should be offered every support available to enable them to improve their involvement.

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

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

In addition to reviewing the process of PPI Contribution you should encourage your PPI Contributors to feel that they can contact you between meetings or in an adhoc way with any queries that they have. Most contact can be done my email and can be very informal.

If your PPI Contributor is on a trial steering committee (TSC) that only meets annually, make a point of giving them at least quarterly updates that invite their comment. This will enable them to contribute more effectively at the TSC and help them to feel engaged in your work.

Section 15 Ongoing opportunities for your PPI Contributors

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 may also be glad to know of people willing to get involved in their own work. The PPI Contributor will have developed skills both in research and in involvement and it would be a shame (for both them and us) not to put this to good use.

If your project has come to an end talk to your PPI Contributors about whether they might be interested in continuing their PPI work, what other opportunities might be available and help them to get involved by making introductions. Or you could simply ask the PPI Coordinator to do this, if you have their permission to pass on contact details.

Wherever possible try to get PPI Contributors' permission to provide their details to the PPI Coordinator, who will help them to find another project.

In addition you could direct them to these websites where they could find other PPI opportunities for other organisations;

Patients active in research (Thames Valley)

and

People in research (national)

Section 16 – Contacts of your PPI team

Lynne Maddocks
PPI Coordinator
lynne.maddocks@phc.ox.ac.uk
01865 617198

Support with Communications

Dan Richards-Doran
Communications Manager
dan.richards-doran@phc.ox.ac.uk
01865 617870

Gavin Hubbard
NIHR CLAHRC Oxford Communications Officer
gavin.hubbard@phc.ox.ac.uk
01865 617881

www.phc.ox.ac.uk www.clahrc-oxford.nihr.ac.uk/

Nuffield Department of Primary Care Health Sciences, University of Oxford, Radcliffe Primary Care Building, Radcliffe Observatory Quarter, Woodstock Road, Oxford, OX2 6GG.

Section 17 PPI resources and web links

Organisation	PPI Resource	Link
INVOLVE - part of, and funded by, the National Institute for Health Research, to support active public involvement in NHS, public health and social care research.	Briefing notes for researchers Evidence library Cost calculator Plain English summaries	Resource for researchers Evidence library Cost calculator Plain English summaries
Health Research Authority - Protects and promotes the interests of patients and the public in health research and streamlines the regulation of research	The HRA has set out its commitment to improving the level and quality of public involvement in research in the HRA Public Involvement Strategy.	Health Research Authority
Association of Medical Research Charities (AMRC) - National membership organisation of leading medical and health research charities	Provided to assist with searches for alternative funding sources.	AMRC
Healthtalk - provides free, reliable information about health issues, by sharing people's real-life experiences.	Range of interviews of patients and researchers on all aspects of PPI	PPI Contributor's views Researcher's views
James Lind Alliance - non-profit making initiative that brings patients, carers and clinicians together in Priority Setting Partnerships (PSPs) to identify and prioritise the Top 10 uncertainties, or	Learn about what researchers and the public working together decide are the top research questions in your field	James Lind Alliance Oxford BRC is a co-ordinating hub for JLA PSPs

unanswered questions, about the effects of treatments.		
PAIR – Patients Active in Research	Find recruits for PPI in the Thames Valley	Patients Active in Research
People in Research	Find recruits for PPI nationally	People in Research
Research Design Service - NIHR funded to support all applications to them	Range of advice including on PPI	RDS Information for researchers
University Administrative Services	Research support at Oxford University	Research support
School for Primary Care Research	Partnership between the Universities of Bristol, Cambridge, Keele, Manchester, Newcastle, Nottingham, Oxford, Southampton and University College London.	SPCR
Scottish Health Council	PPI toolkit	Participation toolkit
Public Involvement Impact Assessment Framework	A toolkit for researchers to assess the impact of the PPI work they do	PiiAF

Section 18 Appendix of Template documents

3 Advertisement for PPI Contributor with a specific perspective

Are you interested in improving services provided by your GP and their team?
Have you or are you experiencing [insert illness or condition]? Could you help us to improve the research that we are doing into this [insert illness or condition]? Do you care for someone with this [insert illness or condition]? Do you work in the voluntary sector with people who experience [insert illness or condition]?

Become a Patient and Public Involvement Contributor

We are looking for people to join our [insert the nature of the group/work you are recruiting to]. This work will involve you in [insert number of meetings per year] mostly lasting [insert timing of meetings] at [insert venue]. The project is expected to last [insert months].

You do not need to have any specific skills to join our research project – we are keen to work with people who have living experience of [insert illness or condition] and who are able to explain what that is like and contribute to our group discussions to help make our research better.

We will reimburse all expenses that you have to help us with this work.

If appropriate also state
We are able to pay Patient & Public Involvement (PPI) Contributors an honorarium. The rates are currently [insert amount that most readily relates to the work that you have for them and the budget you have e.g. £75 for a 3 hour meeting including preparation and follow up].

If you are interested in this role then please contact [insert main link name, phone number and email] to discuss the details and ask for an application form.

3 Advertisement for PPI Contributor who will bring general management skills

Are you interested in improving services provided by your GP and their team?

We are looking to recruit people from all walks of life and with a range of skills. We need people who can provide [insert what is relevant from strategic overview, project management, skills in defining research parameters, improving dissemination of research findings to the wider community, skills as joint grant holders or co-applicants on a research project, assistance with the development of patient information leaflets or other research materials, undertaking interviews with research participants]

We are looking for people to join our [insert the nature of the group you are recruiting to]. This work will involve you in [insert number of meetings per year] mostly lasting [insert time of meetings] at [insert venue]. The project is expected to last [insert months].

We will reimburse all expenses that you have to help us with this work.

If appropriate also state
We are able to pay Patient & Public Involvement (PPI) Contributors an honorarium. The rates are currently [insert amount that most readily relates to the work that you have for them and the budget you have e.g. £75 for a 3 hour meeting including preparation and follow up].

If you are interested in this role then please contact [insert main link name, phone number and email] to discuss the details and ask for an application form.

3.3 Template letter to send to a GP Practice Senior Partner/ Organisational Lead

Date

Dear Dr / other title …………………

I am a researcher on [insert the nature of the group/work you are recruiting to]. As you will be aware the NHS has made a firm commitment in its Constitution to involve patients and the public in all aspects of its service delivery and this is echoed in research by NIHR. I am therefore looking to recruit patients to get involved in the planning, delivery and management of my project. I would be most grateful if you would allow [insert name of GP] to approach directly those of their patients that they feel would be able to help. It will of course be entirely the patient's choice and would have no impact on the care that they receive from your practice or the NHS more generally.

I am looking for patients who have a if appropriate [insert lived experience of ………….] or [insert general management / scrutiny skills]. If you or any of your other colleagues would be willing to ask specific patients of your own that would be much appreciated too.

This work will involve the patient in [insert number of meetings per year] mostly lasting [insert timing of meetings] at [insert venue]. The project is expected to last [insert months].

I have enclosed a patient information leaflet which could be given to any potential recruits and can provide more if needed.

We will reimburse all their expenses.
If appropriate also state
We are able to pay Patient & Public Involvement (PPI) Contributors an honorarium. The rates are currently [insert amount that most readily relates to the work that you have for them and the budget you have e.g. £75 for a 3 hour meeting including preparation and follow up].

I do hope that you will feel able to support me in this. Please do not hesitate to ask if you require more information about the research.

I look forward to your kind response

Yours sincerely.

3.3 Template letter to be given to patients

Dear ....

We are looking for people who might, from time to time, be able to meet with, or communicate with medical researchers seeking the input of patients to decide how and what they should study.

The sorts of issues you might be able to comment on are how best to promote recruitment to studies, production of helpful patient information sheets, and feedback of results to trial participants.

People who choose to get involved in this voluntary work generally find it stimulating and rewarding. You can read more about this at http://www.phc.ox.ac.uk/about/patient-and-public-involvement-ppi

If you would like to be included in a register of potentially interested people please email lynne.maddocks@phc.ox.ac.uk or phone 01865 617198. Or if you prefer send a letter with your contact details and interests to;

Patient and Public Involvement Co-ordinator,

Nuffield Department of Primary Care Health Sciences

Radcliffe Observatory Quarter

Woodstock Rd

Oxford

OX26GG

We will reimburse all your expenses for attending any meetings and may also be able to make a payment for your time.

Thank you very much giving this your consideration.

Yours ....,

4.1 PPI Contributor role description

The main purpose of this role is to provide a public and patient perspective into the research project [insert name].

- You will be expected to attend and contribute to meetings which will plan, monitor and review the work of this research project.
- Include from the list below as appropriate, and tailor to your own project.
- You will be asked to provide specific insights based on your own experience (or that of people you support) in relation to a specific illness or condition, or your experiences of health services. While we ask that you speak directly from your own experiences, PPI work is not an opportunity for discussions about the specifics of your medical treatment. Your input should be aimed at helping the researchers to understand their work from the point of view of someone who experiences the topic of the research.
- You will be asked to review documents – assessing their suitability for a general public audience.
- You may be asked to contribute ideas on the suitability of research for potential participants.
- You may be asked to contribute ideas and input into recruiting or advertising to potential research participants.
- You may be asked to devise new documents
- Researchers are required to produce plain English summaries of their work, you may be asked to review them for their readability.
- You may be asked to contribute to the design of questionnaires or other aspects of the research which will be received by patients and members of the public
- You may be asked to help interpret the results that researchers are gathering
- You may be asked for ideas on how to disseminate the results of research to the people who would most benefit from them
- You may be asked to take part in telephone conference calls or to work remotely via email, not meeting in person with the researcher or other PPI Contributors.
- You may be asked to provide feedback on the impact of your PPI role

4.1 PPI Contributor person specification

Include from the list below as appropriate, and tailor to your own project.

Essential requirements

- Ability to confidently express your views at meetings attended by a range of professionals
- Ability to keep asking questions until you get enough information or an explanation to fully understand what people are talking about
- A willingness to listen to, and consider, different perspectives and opinions
- An ability to challenge current thinking in ways that are both creative and supportive
- The ability to manage and plan your own time
- The commitment to attend meetings as agreed (medical condition allowing)
- The commitment to prepare for meetings by reading information sent to you in advance
- To give and maintain a firm commitment to keep our research confidential and declare any conflicts of interest if they arise
- Willingness to review your involvement with the support of your lead contact

Desirable requirements

- Some knowledge of the NHS; how it is structured, funded and managed
- Some knowledge of how the government supports health research
- Some understanding of how research is conducted in a health setting

Requirements relating to a PPI Contributor with a specific perspective [use as relevant]

- Experience of [insert illness or condition] within the last 5 years
- Experience of caring for someone with [insert illness or condition] within the last 5 years
- Experience of [insert treatment or procedure] as part of your healthcare treatment
- Current work in a voluntary sector role where you support people with [insert illness or condition]

Requirements relating to a PPI Contributor required to provide strategic management perspective [use as relevant]

- demonstrate commitment to continuously improving outcomes, tackling health inequalities and delivering the best value for money for the taxpayer
- embrace effective governance, accountability and stewardship of public money and demonstrate an understanding of the principles of good scrutiny
- bring a sound understanding of, and a commitment to upholding, the NHS principles and values as set out in the NHS Constitution
- be committed to ensuring that the organisation values diversity and promotes equality and inclusivity in all aspects of its business;
- be able to demonstrate a special interest in the Thames Valley by, for example, living or working in the area or by being closely involved in projects that affect the area

- have the skills, knowledge, qualifications and experience to assess and confirm that appropriate systems of internal control and assurance are in place for all aspects of governance, including financial and risk management
- have an understanding of the resource allocations devolved to NHS bodies
- have the ability to chair meetings effectively

4.2 PPI Contributor application form – suitable for more leadership roles

Name:	
Address:	
Telephone Number:	
Email Address (wherever possible):	
Do you have a long term health condition (for more than 6 months which is expected to continue for some time)? If yes please state what?	We ask this question to help us understand if you approach the project with a specific perspective relating to the research topic. You do not have to answer if you prefer not to and people with no health condition are also welcomed.
Are you applying because you work for the voluntary sector supporting people with a condition related to our research?	If yes please state the name of the voluntary organisation and your role within it
Are you a carer? (If you have been a carer in the past how long ago did you stop being a carer?)	Please state their relationship to you and what their condition is;
Have you recently used NHS services in Thames Valley? If yes please state what.	
Please tell us why you would like to be involved in our research and in what project?	
Please state what skills you believe that you would bring to this role.	

Please state if you have any specific needs that you would like us to accommodate in order for you to contribute?	For example if you use a wheelchair, a hearing aid, speak English with difficulty etc.
Any other comments or queries.	
We may ask you more questions once you have submitted this form.	

4.2 Patient and Public Involvement Expression of interest form – suitable for guiding a conversation with potential recruits to clinical projects where the approach is more informal

Name:	
Address:	
Telephone Number:	
Email Address (wherever possible):	
It will help us to know if you have any ongoing health conditions and if you want to specifically get involved in research into that condition. If this applies to you please give us a few details here.	We ask this question to help us understand if you approach the project with a specific perspective relating to the research topic. You do not have to answer if you prefer not to and people with no health condition are also welcomed
Are you applying because you work for the voluntary sector supporting people with a condition related to our research?	If yes please state the name of the voluntary organisation and your role within it
If you are a carer (or have been) and you want to specifically get involved in research into the condition of the person you care for.	Please state who you care/d for and what their health condition is;
Please say why you would like to be involved in our research and in what project?	
We want you to be able to get as involved as possible. So it will help us to know if you have	For example if you use a wheelchair, a hearing aid, speak English with difficulty etc.

any specific needs that you would like us to accommodate in order for you to contribute?	
Do let us know if you have more questions at this stage.	

5 PPI Contributor working agreement

Suitable in more formal, leadership role appointments.

Introduction

- Thank you very much for agreeing to be part of [insert title of project]. This project is part of the work of [insert Department or NIHR CLAHRC Oxford Theme] and is funded by [insert funder]. The project aims to [insert main aim of the project] and you will be given further information on this as part of your induction.

- Your main link person throughout the work of the project will be [insert name, email and phone number – put in bold]. Please feel that you can contact this person with any concerns or queries you may have at all times, not just at fixed meetings. Their working hours are [insert working hours].

Involvement and Time Commitment

- As discussed the project is expected to last [insert months or years]. If this changes at any point you will be informed and given the option to extend your involvement if appropriate.

- You will be expected to give the following time commitment;

[insert all meetings that the PPI Contributor will be expected to attend - frequency and length]
[insert how much time they will need to spend preparing for the meetings listed above]
[insert how much time they may be expected to spend reviewing documents or working on other items such as lay summaries]
[insert any time that they may be asked to be in virtual meetings or telephone conference calls]
[insert any other time commitment that relates to your work such as helping with the research itself by interviewing participants]
This will not be significantly altered without your agreement.

- The meetings that you are asked to attend will generally be held at [insert venue giving directions and travel / parking / public transport arrangements]. If you are unable to attend please give your apologies to your link contact, but if there is an emergency on the day you can contact the venue by phoning [insert venue phone number]. We will give you plenty of notice if the venue changes.

Specific Requirements

- We want you to feel fully able to contribute to our project in all of the ways that we ask you to do. You should have let us know in your application form if you have any specific support requirements and this is how we will ensure that these are accommodated [insert specific arrangements you are making where appropriate]. However, if there are any other needs that arise at any time please do not hesitate to let us know.

Expenses and tax implications

- As agreed with you verbally we will [insert whether you will just reimburse their expenses or if you will pay the PPI Contributor and reimburse their expenses]. The expenses that will be reimbursed include [insert travel, carer costs, child care, stationary/printing/phone costs and any others that you are offering]. Expenses must be agreed with your link contact in advance. For your work on this project there is also payment for your time. The payment rates are [insert agreed payment based on the funding and budget that you have for your project, specifying nature of the work, time duration and amounts]. Use if appropriate.

- The process for having your expenses reimbursed is that you complete a University of Oxford expense claim form (your link contact will provide you with these or you can find them on the University website at http://www.admin.ox.ac.uk/finance/processes/forms/expensesandrelocation/) You must provide original receipts and a 'wet' signature. Put n/a in the employee number box. In the claimant address details put the details of your link contact. When completed you give it to your contact link person for authorisation and processing.

- (Only include this paragraph to those you are paying for their time) The process for claiming for payment of your time is that your link person will complete a Payment Request Form for you. All you will need to do is provide them with your personal contact details, bank contact details and NI Number at the start of your involvement. We will review these payments with you if the circumstances of the project change significantly. Payments can be declined or smaller payments requested. It is also possible to arrange a different payment method for those on state Benefits concerned about breaching their earnings limit. Please speak to your contact link researcher about this.

- If you are in receipt of State Benefits it is **very important** that you check if there may be any implications for your Benefits from being paid for your time. You should contact INVOLVE on benefits@invo.org.uk or 023 8059 5628, stating which project you have been asked to get involved with. You will then be given an email address (or telephone number) to contact the Benefits advice service directly, together with a unique code that will need to be quoted. E-mail is preferred for the first contact. The service (a Citizens Advice Bureau) will then arrange a time to call.

- (Only include this paragraph to those who refuse payment for their time) You have refused the payment for your time that is offered to our PPI Contributors. You may use this agreement as proof with the Job Centre Plus if appropriate. If at any point in the future you wish to change your mind about accepting payment please speak to your main link contact who will make the necessary arrangements, but please note no payments will be made retrospectively.

- These payments are regarded by HMRC and the Jobcentre as income. You will be responsible for declaration to HMRC or the Benefits agency of any payments received and for any liability to HMRC/Benefits agency arising from them.
- We would strongly encourage you to keep a personal record of all the reimbursement and payments that you receive from us so that you can keep track and ensure that you are not out of pocket. We will provide you with a template form which you can use or you may prefer to have your own system.

Contractual standing

- PPI Contributors are not employees, officers or agents of Oxford University. You are expected to adhere to this agreement but are not subject to Oxford University's employment policies and procedures.
- You are a volunteer and so can withdraw from the project at any time. We very much hope however that you will give notice whenever you can and that you will also let us know why you are withdrawing.
- Your link contact will review your input into the project with you at various points during the course of the work. This will be an opportunity for you to ask additional questions and give feedback on how you are finding the role. You should not leave any pressing issues to this review, but it may be a chance to explore any additional training or support needs that you feel you may have.
- If at any point you are having any difficulties with the work that you do not feel able to discuss with your link contact then please speak to the PPI Coordinator (currently Lynne Maddocks on 01865 617198 or email at ppi@phc.ox.ac.uk.)

- We very much hope that you will enjoy the work of being a PPI Contributor on our project and very much appreciate your commitment to it.

With all best wishes

[insert project lead or theme lead signature, name and job title]

This agreement was received by [insert PPI Contributor name] on [insert date]

Signed --

Date ---

Finally, we would like to be able to send you our department's newsletter and other occasional items of interest. For this purpose we would need your permission to share your contact details with colleagues in the department. Please sign here to confirm that you are happy to be contacted by other staff in the department.

Signed --

Date --

5 PPI Contributor appointment letter

Suitable for less formal appointments

Dear ....
I am delighted you will be joining us on the .... project. Your participation is greatly appreciated.
As discussed at our recent meeting (phone call) the details of your involvement will be set out in the attachment to this letter. Payment for agreed expenses will be reimbursed as set out in attachment 2 .... (and the process for claiming payment for your time is set out in Attachment 3............)
I shall be your main link throughout the project so if you have any questions or concerns please let me know.
I look forward to seeing you again at the next meeting and working with you over the coming months.

Yours sincerely
....

9.1 Template Terms of Reference for groups that have PPI Contributors within them

The role of the Group

The role of the Group is to advise on the development and co-ordination of [insert project details] and to act as a 'critical friend'.

Responsibilities

- Provide views on the plans for design, implementation & evaluation of applied interventions
- Providing advice and guidance as appropriate to progress the work of the [insert details of the project]
- Developing appropriate documents and policies to support the development of [insert details of the project]
- Providing information and advice based on your experience and that of others you know.
- Guide and advise on the dissemination of individual research projects within the project
- To help guide the development of recommendations for further work.
- The group may request members to speak at meetings as seems appropriate and reasonable and may request feedback with regard to the recommendations it makes.
- It is each member's responsibility to make it clear where a matter shall remain confidential and not for discussion outside the Group

Ways of working

- The Group will be chaired by [insert job role] and co-chaired by [insert PPI Contributor]
- The Group will meet a minimum of [insert times a year]. Not all of these meetings will be face to face.
- Members of the Group will receive papers one week before each meeting. PPI Contributors should be consulted about whether this is adequate and the timing revised accordingly.
- Secretariat for the meeting will be provided by [insert job role]
- Members may be contacted between meetings for advice should the need arise.
- From time to time sub-groups may be formed to work on specific issues as appropriate.
- From time to time individuals may be co-opted to provide specific advice and expertise as required.
- When sharing documents, members should make it clear if there is a restriction as to:
    - Circulation of the documents beyond the Group
    - Copyright / use of the contents

Membership

The Group will have [insert details specifying staff roles and PPI ratios. It is best practice to always have a minimum of 2 PPI Contributors so that they are able to gain confidence

from each other and can reflect different views. Specify clearly if PPI Contributors are recruited to reflect their lived experience]
Group membership would normally last for a period of [specify*] years but there would be the opportunity to (alter as appropriate) continue for another year. After [*] years the opportunity to participate would be opened up to new people. Rotation of the membership will be staged to ensure that continuity is maintained.
Non members may be invited to join Group meetings on a one-off basis to aid discussion of a particular topic, for example, as speakers, observers or invited guests.
All members should be asked for any conflicts they feel may arise from any other studies or organisations they are working with.

Review

On an annual basis, the group will review the relevance and value of its work, as well as membership.

12.2 Financial record keeping templates

Reimbursement records for researchers to keep

Name of the Project		Reimbursement records				
PPI Contributor name		Type of expense (travel, carer etc.)	Amount & type of claim	Date sent claim to Finance team	Payment made date & how	Receipt attached?
e.g Sarah Jones	*4/2/15*	*Travel to Steering group meeting*	*£3.60 bus fare*	*n/a*	*Paid cash on 4/2/15*	*Yes*

Payment records for researchers to keep

Name of Project			Payment records		
	Date of work done	Type of work (meeting etc.)	Hours completed	Date sent claim to Finance team	Payment made date (specify if payment declined)
e.g Tom Smith	*4/2/15*	*Steering group meeting*	*2 hours*	*4/2/15*	*Paid by BACS on 8/2/15*

Financial records for PPI Contributor to keep

Name						
PPI Contributor work	Date of work done	Date of claim	Hours worked	Amount of claim stating rate of pay	Payment received	Any comments
e.g steering group meeting *reviewed patient information document*	*4/2/15* *7/2/15*	*9/2/15* *9/2/15*	*2 hours* *1 hour*	*£75 for mtg and prep work* *Bus fare of £3.60* *£20 agreed rate*	*Paid by BACS on 15/2/15* *Paid by BACS on 15/2/15* *Paid by BACS on 15/2/15*	

13.3 Certificate of Attendance

Once you have selected this template why not put a border round it and insert a watermark of Oxford Spires?

Certificate of Attendance

Title of Event

Date of event

Insert other relevant logos

Insert Department

Thank you to ……………………………………………………………………………………………

Who attended this workshop to give the ……………………………………………… Team information and support for their research from a patient and public perspective.

Signature of lead researcher ……………………………………………………………

Alter the following as appropriate

Nuffield Department of Primary Health Care Sciences

……………………………………, Radcliffe Observatory Quarter, Woodstock Road, Oxford, OX2 6GG

www.phc.ox.ac.uk | @OxPrimaryCare www.healthtalkonline.org 01865 …………………

13.4 Template for Case Study

Summary

Concisely explain the project, who was involved and who benefited (in a nutshell).
It's often easier to write this once you've completed your first draft.

The purpose

Describe the original aims or objectives of your project. What was the problem, challenge or opportunity that got you started?

Who

Describe all the groups, organisations or roles that were involved, and how you involved them. This might include: who commissioned the work or project; who carried it out; who was meant to benefit. Include names – they will usually want to see their efforts credited!

Breadth

Explain how wide the work was spread, so that people can understand the scale.

What you did (and what worked!)

Explain the process you went through, and mention what elements stood out as key to your project's success. You might have rejected some methods too, or tried things and changed your mind. Just tell the story as it was.

Timescales

How long did the project take? How long might its Benefits last?

The difference your project made

Describe the outcomes and Benefits of your programme/project, for all or any of these:

- patients (directly)
- staff
- processes
- organisations

This could include saving money, speedier recovery for patients, improved well-being, meeting targets or objectives, contented patients who feel like they are being listened to, culture changes, and improvements for partnership. It could also include personal/professional change. Imagine a local citizen reading it and wondering what the time and effort was for.

What you learnt

Reflect on the learning for the people, and the organisation

What people said

Quotes from colleagues or patients will bring your case study to life.

With hindsight...

Say what you would do differently if you were to do it again

Conclusions and what next?

Where have you got to at this stage? Looking forward, are there future plans or spin-offs?

Contact details

If you're willing to further share your experiences with others, please make this clear and give your preferred contact details. **When you have completed your case study please share it with the Department or NIHR CLAHRC Oxford's Communications Officer.**