



**Guide to Patient and Public involvement for researchers**

This “guide” is designed to give you a quick outline of what you need to know about patient and public involvement and how you can effectively include it in your research. This document will give you a general overview of some of the important information.

What is Patient and public involvement (PPI)?

[INVOLVE](http://www.invo.org.uk/) describes public involvement as “research being carried out with or **by** members of the public rather than **to**, **about** or **for** them” [1]. It means involving people in decisions about all aspects of the research, from which research should be done, to how it is done and how results are disseminated. Involvement is distinct from participating in research and does not generate any data. The involved public and patients actively contribute to the research process as experts and as co-researchers. Patients and the public can provide unique insight and first-hand experience of the topic being researched. In the UK most major funders now require PPI in research, making it an important and essential part of any grant proposal or research project. Some of the benefits of PP to research may be:

* Identification of research topics and clarification of research questions, ensuring that the questions meet the needs of the group the research is about
* Improvement to research design
* Including research outcomes that are more translatable to patient benefit
* Better recruitment due to the design of more appropriate trials
* Dissemination of findings to a much wider public and patient audience.
* Increased public awareness and confidence in health research

PenPIG

PenPIG (Peninsula Public Involvement Group) is PenCLAHRC’s user-led advisory group made up of the public, service users and careers. PenPIG and its members volunteer their time to help ensure that PenCLAHRC’s research involves meaningful PPI. Members of this group can be on hand to help you with lay reviews be part of project steering groups.

When can PPI be included in research?

PPI can be implemented in all stages of the research cycle (See “how to incorporate patient and public involvement in the research process” on the resources for researchers page). It is however good practice to establish links with and involve patients and the public in the early stages of project development. This means thinking about PPI should begin as you are applying for funding or conceptualising a research idea. Patients and members of the public can be involved in:

* Identifying and prioritising research questions
* Development and design of study protocol e.g. identify outcomes, making the protocol or information sheets more “user friendly”
* Trial management. Patients and members of the public can also form part of the trial steering committee.
* Analysis and interpretation of results.
* Dissemination of results.

**PPI basics**

Before you start involving patients and public in your research it is important that you are clear about:

**Why?:** Why doyou want to involve patients or members of the public in your research?

**What?:** Whatcan you see being influenced by the patient and public involvement in your research?

**Who?:** What relevant experience would best suit the needs of your research?

**How?:** How would you like to involve patients and the public? One off meeting/ workshop or someone as part of a project steering group?

Is ethical approval needed?

Involvement of patients or members of the public does not normally require ethical approval. This is because they are not acting in the same way as research “participants” and no data is being collected. If you wish to involve the public in your research as “advisors” then you do not need to apply for ethical approval. That said the PPI plan should be included in the ethics application for the proposed research.

Ethical concerns may arise if you plan to involve patients and members of the public in areas where they are in direct contact with study participants (e.g. involvement in recruitment of collecting data) or in analysing data. In this instance it is important to include details about this in your ethics applications, ensuring that the well-being and safety of the public “involved”, the research participants and the researchers.

Communication

It is essential to carefully think about how to communicate with “lay advisors”. It is important that they can understand you’re research ideas so that you can benefit from their input. The communication can also influence the level of engagement from those involved [2].

* Consider what those involved would want to know about your research and what it is important for them to know to be able to actively contribute.
* Be clear what information you provide is fact, and what areas are open for discussion. This will avoid people spending time trying to input into areas of the project that you are not willing to change.
* Include all relevant information and not just information that may get the response that you want.
* Enough information needs to be provided without overloading those involved, whilst still providing the relevant detail. Keep communication clear and concise.
* It is important to communicate that you have understood the points raised and the actions you will take
* Be sure to update those involved on how they have helped to influence the research.

Avoid:

* Overly scientific and technical language ( including acronyms)
* Conducting PPI as a box ticking exercise, be open minded to how it can improve the work.

Recruitment

Finding the right patients/ public can be challenging. Researchers need to consider:

* What expertise/ experience would suit the project?
* What skills are needed?
* What time commitment will be asked of them?

Advisors can be found from existing participation groups, or if needed from adverts to the public asking for experience with specific conditions or aspects of health care. It is a good idea to create a roll description of what is required so that people know what they are committing to.

Planning a meeting

To plan a meeting effectively you need to consider what you what to get out of a meeting. Take time before the meeting to plan an approach that fits the outcomes you would like from the meeting. It is also important to consider:

* Accessibility of room, accessible toilets on the same floor, with lift access.
* Is your meeting location easily accessible by public transport?
* Organisation barriers ( timing and place of meeting, are you excluding people by when and where the meeting is, consider multiple meeting times?)

Account for possible illness and how it might affect participants in meetings as well as caring responsibilities that people might have.

Budgeting for PPI

INVOLVE have a handy cost calculator [here](http://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/).

* £25 for a half day ( up to 3.5 hours) meeting- If lots of preparation is needed then this may be £50
* £50 for a full day meeting ( 4 hours or more)
* Reviewing of lay summary £10
* Cost of participant transport (45p/ mile for first 100 miles, 25p thereafter)
* Cost of catering if meeting falls before or after lunch (this is not essential but another nice thank you to your public advisors) (~ £5-6/person for lunch and ~£2/ person for tea/coffee/biscuits)

Next steps

* Read through some of the more extensive documents:
  + INVOLVE: [Briefing notes for researchers: public involvement in NHS, public health and social care research](http://www.invo.org.uk/resource-centre/resource-for-researchers/)
  + NIHR: Patient and public involvement in health and social care research: [A handbook for researchers](http://www.rds.nihr.ac.uk/wp-content/uploads/RDS-PPI-Handbook-2014-v8-FINAL.pdf)
* If you need more specific questions answered or would like more help with planning your PPI you can book into one of our PPI clinics from our [Eventbrite page](http://www.eventbrite.co.uk/o/penclahrc-patient-and-public-involvement-team-8431494188) or give the PPI team an email ([piexeter@ex.ac.uk](mailto:piexeter@ex.ac.uk))

Useful links

|  |  |  |
| --- | --- | --- |
|  | **Description** | **Link** |
| **INVOLVE** | Funded by the National Institute of Health Research, INVOLVE supports the active public involvement in NHS, public health and social care. Website includes lots of useful resources. | [INVOLVE](http://ac.els-cdn.com/S0168851001002147/1-s2.0-S0168851001002147-main.pdf?_tid=e5ad7bc8-bc65-11e6-b591-00000aacb360&acdnat=1481105831_125d912ca9a26396cc731c341220fd45http://www.invo.org.uk/resource-centre/) |
| **Health talk** | Interviews with researchers and patients discussing aspects of PPI | [Health talk](http://www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/topics) |
| **Public involvement impact assessment framework (PiiAF)** | Information and resources to help researchers assess the impacts of involving members of the public in their research | [PiiAF](http://piiaf.org.uk/) |
| **Health research authority (HRA)** | Protects and promotes the interests of patient and the public in health and social care research. Useful information about how the HRA involve patients and public in their work. | [HRA](http://www.hra.nhs.uk/) |
| **Research Design Service (RDS)** | The RDS is funded by the National Institute of Health Research (NIHR) to provide design and methodological support, including PPI, to health and social care researchers. Section of website dedicated to public involvement. | [NIHR-RDS](http://www.rds.nihr.ac.uk/public-involvement/) |

References

1. *INVOLVE and NRES. Patient and public involvement in research and research ethics committee review. [ONLINE] [document on the Internet]. Available from URL:* [*http://www.invo.org.uk/wp-content/uploads/2011/12/INVOLVENRESfinalStatement310309.pdf*](http://www.invo.org.uk/wp-content/uploads/2011/12/INVOLVENRESfinalStatement310309.pdf)*. 2009. Accessed date 18 Feb 2016*.

2. Hardavella, G., et al., *How to optimise patient and public involvement in your research: Doing science.* Breathe, 2015. **11**(3): p. 223-227.