

The Importance of Patient & Public Involvement

Paul Hewitson

Planning for Patient and Public Involvement in NIHR Grant Applications: A Brief Overview

Effective Patient and Public Involvement (PPI) in developing research applications requires planning. How you approach the planning stage of your PPI component will have a dramatic effect on the quality of the PPI information you will include in your application. Start early. The following provides a brief overview of the steps you will need to undertake in planning and delivering your PPI pre-grant activities (and beyond).

Guidance

Familiarise yourself with the specific guidance for that particular grant. It is important that you understand what you are being asked to include about PPI in your application, and how you should be presenting this information in the application. This includes what you will be required to write in the PPI section of the application, and also, the content and format for the plain English summary.

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Draft PPI Plan

Have you written a draft PPI plan, detailing what you will be asking PPI contributors to do over the course of the research?

- The draft PPI plan should include the 'what', the 'when', and the 'why' for PPI contributors during the research (if you were funded...)
- This means 'what' are you asking them to do, 'when' are you asking them to do it, and 'why' is it important for the research
- This should include PPI representation for any steering/advisory group associated with the research
- The draft PPI plan should reflect the 'milestones', or most important points of your research where involving PPI will contribute to the research
- This can include:
 - Reviewing submissions ethics committees
 - Writing/commenting on participation information materials
 - Assisting with developing questionnaires or semi-structured interview schedules
 - Providing comments on the relevance of findings from a patient/public perspective
 - Writing or presenting research findings as part of the dissemination strategy
 - Opportunities for support and learning for PPI contributors (e.g. bespoke training in research methods or formal courses)

Note: Your draft PPI plan does not have to be extensive, nor should it be the 'final' version. It is a good idea to give it to potential PPI contributors (before/during your pre-grant PPI activity) so you can discuss any potential changes that may be required. Discussion with the PPI contributors should result in a shared understanding of the roles, responsibilities and expectations of involvement in research.

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Role/Responsibilities

Do you have a draft 'roles and responsibilities' document you can give potential PPI contributors?

- Drafting a brief 'roles and responsibilities' document outlining what the PPI contributors' roles will be in the research, and what they will be responsible for during the research
- You should also include what the roles and responsibilities are for the research team (and specifically, the PPI Lead, if required)
- This is not a formal contract, and should be in draft, as any final decision on PPI roles and responsibilities should be negotiated and agreed with the PPI contributors

Flexibility

Have you considered whether there is some choice or flexibility in opportunities for PPI contributors?

- Not all potential PPI contributors will be interested or available for all aspects of the research. Giving people options for how they can be involved in your 'roles and responsibilities' document can facilitate pre-grant discussions and improve your chances of recruiting PPI contributors to your study

People

Do the people you are approaching have a 'lived experience' of the condition you are researching?

- Ideally, you are looking to involve people who have personal, direct knowledge and experience of living with the condition you intend to investigate
- 'Lived experience' can include people with the condition, but also includes those who care for people with the condition (e.g. dementia), parents of children with a condition, or people who have experienced treatment, but no longer have the condition (e.g. cancer survivors)
- **Note:** *Health professionals who treat, manage or care for people with a condition are not considered PPI contributors. They may have a wealth of experience in delivering services to people with the condition, but this is not viewed as 'lived experience' of the condition*

Are the people you intend to approach representatives of all those who suffer from the condition?

- Diversity, inclusion and equality are at the centre of identifying and approaching potential PPI contributors. The people you are approaching should be representative of all the people with the condition, not a more accessible subset of people

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Recruiting

What strategies do you have for recruiting PPI contributors for your pre-grant activity and your research?

- Direct Contact: If you are in direct contact with patients/public either through clinical practice or in another professional capacity, you can approach
- Advertisements: NIHR host a website (www.peopleinresearch.org) where you can advertise for potential PPI contributors
- Charity/patient advocacy groups: Contact national/regional charity or patient/public advocacy group(s) to ask for their help in identifying or being directly involvement as PPI contributors to your research

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Costings

Have you budgeted for all costs associated with including PPI contributors in your research?

- Payment for PPI contributors' time is currently (*Feb 2022*) set at £25 per/hour. This includes both direct contact with PPI contributors (e.g. meetings), but also payment for time performing other agreed duties (e.g. reading/commenting on documents). For example, if you have a two-hour steering group meeting, with two hours' expected reading time prior to the meeting, then the cost for the PPI contribution would be £100 (2x2hr meeting + 2x2hr reading time)
- Payment for travel for the PPI contributor (and potentially payment for subsistence) also is required
- Payment may also be required to cover costs associated with childcare or carer support costs
- Note: see www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392 for further guidance on the NIHR requirements for PPI costings
- It is important to include your PPI costings in your draft PPI plan

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Resources

- UK Standards for Public Involvement - sites.google.com/nihr.ac.uk/pi-standards/standards
- NIHR Briefing Notes for Researchers - www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371
- RDS Brief Guide to Pubic Involvement in Funding Applications: How can the RDS Help? - [www.rdsblog.org.uk/Resources/A5_PPI_Pocket_Guide_V3%20\(1\).pdf](http://www.rdsblog.org.uk/Resources/A5_PPI_Pocket_Guide_V3%20(1).pdf)

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