

Personal and Public Involvement in Health & Social Care Research

Insights for Research Proposals from PIER/PPI Panel members

Eileen Wright and Ignatius Maguire are members of [PIER* \(NI\)](#) and also experienced members of various HSC R&D Division Research Award Panels. Here they offer some insights about involving the public in research as well as a personal perspective on PPI in research. These insights are intended to help applicants with the development of their research idea from a PPI point of view and provide guidance for writing research funding proposals.

* PIER stands for “Public Involvement Enhancing Research”.

Firstly some general points for Research Proposals from Ignatius:

- Personal contact i.e. talking to someone always looks like a positive start on the road to engagement.
- Seeking out an appropriate focus group and ‘picking their brains’ is a clear way forward but be prepared to offer something to the group in return.
- It may not be difficult to form a focus group if no existing group appears appropriate.
- If people are willing to assist be considerate about their time and the extent to which they can participate. Show consideration and gratitude in tangible ways e.g. offer expenses, child care facilities and time / locate meetings to suit willing participants.
- Advice is always readily available from the R&D office. It should probably be the first place to target for appropriate advice.
- Do not present extracts and lifts from the Involve website as an explanation of your attempts to address the PPI requirements!
- Have a plan which looks like a plan and not a collection of disjointed notions and names dropped here and there to (hopefully) tick the box.
- If the researcher, at the outset, has a focus on the benefit of the proposed research to the Public and consciously maintains that focus throughout the life of the project, the involvement of the Public in the identification, preparation, participation and dissemination will be automatically achievable and apparent to all.

Ignatius also offers a personal perspective on his consideration of completing the question of PPI in a submission for research funding...

I can easily verify that not all researchers appear to understand the requirements of completing the section in their proposal about involving patients and the public in research. It is also clear that those who take the time to understand what they need to do will succeed and it will be obvious from their applications that they are compliant with the level of engagement required.

So what do I look for in PPI terms and expect to see in a funding application?

The first aspect is self-explanatory but I will always allow for the capacity or potential within each application i.e. to involve service users and the public. Clearly if the proposed research is laboratory based there is less capacity but there is always room to engage if there is a willingness to so do. If the research is about children the obvious people to target are parents and carers (and children if deemed appropriate and permissions obtained); if an elderly population then families and carers should be the target (as well as the willing elderly) and if focuses on a disease or condition then I think those who have survived or are coping with the condition (and their carers) are a predictable starting point for engagement.

In terms of choosing an appropriate group with whom to engage, there are innumerable groups of varying size and composition but the key word is appropriate. It should be clear that the chosen group has relevant experience and people capable of making a worthwhile contribution to the project.

The level to aim for is one that will engage the interest of the target audience and retain that interest through an appropriate level of involvement. People need to feel involved and to feel their views are being received appreciated. Not enough engagement will result in people losing interest and too much information will leave people overwhelmed and lead to rapid disengagement! Representation may also need to be appropriate in terms of a geographical area and clearly it would be beneficial if people are genuinely representative of a bigger group.

The benefits of PPI need to be firstly appreciated and accepted by the researcher and if that appreciation is in place at the outset the choice of service users and groups and their subsequent engagement should flow through the application and should be 'jumping off the page' when I read it!

Finally, the dissemination of information is vital. This is not a time for 'an arm round the homework' and there has never been such a selection of ways and methods of telling others about whatever we have been doing! It's merely a question of choosing the most appropriate vehicles for dissemination so it would not be best to rely on websites solely, if the target audience does not have access to technology or is not computer literate. I think that regardless of what stage (in the project) information is being disseminated the researcher needs to ensure that the message is received by the target audience in an appropriate way.

Applicants should be able to describe how service users and the public have been involved in the project to date *and* how they will be involved as the research progresses.

The past tense refers to the extent of involvement in identifying the research topic and/or prioritising the research question(s) and / or any involvement in the preparation of the application. The present or future tense refers to the ongoing involvement as partners/ advisers in the proposed research and the benefits of this should be highlighted. Researchers are asked to justify the level of involvement.

Some pointers from Eileen, which might be helpful in fulfilling the PPI element of a research proposal. It is useful to consider these in three broad areas under the headings of "how" "when" "where" and "why".

	<i>planning stage</i>	<i>implementation stage</i>	<i>reporting stage</i>
How	Consider support groups, organisations and fora which are relevant to your area of research and from these collect the advice as to the need for the research and the perceived benefits which will accrue.	Engage with your steering committee as to how you will recruit your patients and listen to the views of your advisers to ensure that the patient view is integral in the process.	Involve your PPI reps to critique the reports, leaflets, etc to validate the impact on the public.
When	At the very outset, collect these views to support the need.	At this point it would also be beneficial to have another independent PPI view to provide balance to the process.	Before publication
Where	Consider giving short presentations to these groups and recruit two or more interested people to sit on any steering committee you may form for the duration of the research.	Interim reports at each stage could be provided to the interested fora within the area of research for continued engagement.	Involve your PPI reps at presentations, ideally to tell their story and enhance the benefit of the research to the wider public and raise the profile of the need for research for the benefit of all.
Why	Articulate how this engagement helped define the direction of travel of the research and amended or changed your own view.	To recruit PPI representation at all stages of the research underwrites the value the researcher places on them and fulfils the criterion that asks if the researcher understands the benefit of PPI involvement.	Real engagement as above, meets all the criteria and displays a real understanding of the need for and benefit of PPI.

And some pitfalls:

Some areas are very specialised and the recruitment exercise becomes very much restricted to that area, however if possible some "independent" PPI can bring an alternative viewpoint which can enhance the process.

Some of the research can attract individuals whose input is considered key to the particular area of research and their view, while very valuable, is the only one sought. Consider then the impact this may have on one person, the time factor in line with the above and the possibility that they may not be available at some crucial time in the process. Always aim to have at least two or more reps to air differing views and create useful discussion.