Editorial: Driving innovation: harnessing the power of patient input in research

Public and patient involvement (PPI) refers to a research design approach that purposefully involves non-research/non-clinical stakeholders (i.e. patients and public) with lived experience of a particular condition/phenomenon (e.g. a chronic illness) as partners throughout a research program. Thus, PPI facilitates both a more comprehensive approach to designing research for specific cohorts and increases lay accessibility to research (Crocker *et al.*, 2018; Joyce *et al.*, 2021). Ideally, PPI is embedded within the research throughout the duration of the program's life cycle, though level of involvement can vary substantially (e.g. see Figure 1 from Pyne *et al.*, 2024). In light of developing PPI approaches, it is important that health research is informed by those who most rely on health services in Ireland, particularly people with disabilities and chronic health conditions. The value of PPI in research is mounting and has been shown to improve quality, accessibility and relevance of health research (McCarron *et al.*, 2021; Price *et al.*, 2018). Despite this, many remain sceptical. Indeed, much research on PPI focuses on its benefits, while unfortunately, failing to address such sceptical concerns. Here we (coming from the perspectives of researcher, clinician and PPI member) address such common PPI-associated concerns, often associated with the uninitiated.

Why would I take research/clinical advice from someone without research/clinical experience?

Though PPI members may not have conducted research or provided clinical care, they are *impacted by research* and have *received clinical care*. These experiences can be invaluable. Indeed, CORU Criteria for Education and Training Programmes (2017) require service-user involvement and teaching as a necessary part of health-care professional training – recognising the need for and the value in the lived experiences of those with whom we work.

With respect to research, you might only take the advice when it's feasible to integrate (e.g. consistent with good methodological design/practice). When it is not feasible, communicate this. Perhaps a compromise is possible. With respect to clinical advice, PPI may provide useful insight into the outcomes of whatever activities you propose (e.g. possible consequences potentially ignored/forgotten or unknown by researchers/clinicians).

Won't PPI make my process longer?

No, not if it is done in a meaningful way. It should not be seen as an "extra step" but integrated into the research process, as with all other elements of the research process. If you value the feedback obtained and work closely with your PPI partners, such feedback will save you time and effort in the long run.

In much the same way as you might get feedback on the patient experience of your clinical service to improve, PPI ultimately aims to enhance participant outcomes by directly inputting into the research process. Those working in health promotion guideline development have been successfully using this method of co-production-giving people a voice at the start and throughout the phases of development (Lis *et al.*, 2008) – for years and the approach has been adapted for use in different settings because it is efficient and ethically sound.

Won't PPI be more resource-intensive?

If it is believed that PPI is an extra step, then it could be a cost in time and funding, but if the PPI voice is integrated in the research, then it is not so easy to separate out the extra "cost". If the PPI representatives have additional needs to accommodate their participation, this is no different to the accommodations which would be made for the non-PPI researchers, if they had a disability (for instance).

Funders are increasingly looking for the involvement of those who will ultimately benefit from the research and have accepted the extra financial cost associated with using PPI. There are also some funders who allocate a fixed percentage for PPI-associated cost. In this way, it is not as though funding is being directed to PPI and away from other core research activities. It is a standalone and separately budgeted item.

Because of their "closeness" to the topic, would not PPI members make recommendations consistent with motivated reasoning (e.g. what is best for them) as opposed to what is methodologically sound?

Yes, we are all biased in this respect; but the question becomes why would you do something that is empirically/methodologically sound but is *not* what is best for patients? As a researcher/clinician, it is *you* that needs to find what is both "sound" and "best" for patients.

It is vital to the success of PPI, and in turn to the effectiveness and positive impact of health research in Ireland, that we are able to account for diverse yet relevant viewpoints in our research. In our experience, PPI members of the research team are able to differentiate between their specific needs and the needs of the community they represent. Having a member of the research team who is a

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part of the community you are conducting research for has multiple benefits, for example:

- *More relevant research*: Having a person living with the illness can help focus research on topics which are needed by the targeted group.
- *Easier to translate into the clinical environment*: The research would be adapted to the express needs of the patient group, and those funding the treatment will be more confident of the utility of the intervention.
- *Trust*: the patient community will have more trust in the outcomes, as a member of the patient community is a member of the research team.

Next steps

We hope we have addressed some of the hesitations that may have been present for those thinking about dipping their toes or launching head-first into PPI. We have written this using both clinical evidence and our personal experience.

Researchers should use their existing contacts in the patient community to understand the gaps in research which the users of their service need filled. Positive early engagement will ensure relevant studies, and by incorporating PPI throughout the research process, the project will be relevant, accessible and of higher quality and easier to implement in the clinical setting.

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Further reading

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