



ENGAGING THE PUBLIC: PAST, PRESENT AND FUTURE

Making your PhD research stronger: A researcher's reflections on undertaking patient and public involvement (PPI)

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Abstract: Patient and public involvement is considered an integral part of research by funding bodies in the United Kingdom. However, there has been little emphasis on patient and public involvement within the context of doctoral studies. This paper outlines the author's key learnings on undertaking such involvement work as part of their PhD. Specifically, they provide a brief overview about mixed methods research, followed by a step-by-step description of the PPI process and opportunities for reflection applicable to other student's research. The paper also highlights some key considerations for doing PPI, before finishing with resources which provide useful, more detailed information about patient and public involvement. By outlining this process, this paper is intended as an initial, useful guide for PhD students considering using PPI for their doctoral research.

Keywords: patient and public involvement, health sciences, medical research, public engagement



1 Introduction

Patient and public involvement (PPI) is defined as conducting research *with or by* members of the public (National Institute for Health Research, 2021). Members of the public are often people who are affected by a specific health condition and/or use the services within a research field (for example, domestic violence support organisations), carers or family members within health or social sciences. Involving these members means they are actively involved in research activities such as co-writing grant applications, being part of a research management group, interviewing research participants and presenting results.

In the United Kingdom (UK), grant applications to funding bodies such as the National Institute for Health Research (NIHR) require evidence of PPI, or explicit reasons for not embedding such activities. There are various benefits to PPI. Commonly cited reasons include accountability to the public, improving the quality of research and making it more relevant (NIHR, 2021). However, there has been little emphasis on PPI within the context of doctoral studies.

The aim of this paper is to reflect on and share my key learnings about embedding PPI into my research. By doing so, I hope to provide some initial ideas how you can initiate a PPI journey as part of your own PhD. Before starting, I would like to acknowledge the context in which my research and PPI work was undertaken. This paper focuses on my perspectives as a *PhD researcher* working within *applied health sciences*. This paper does not provide the ‘right way’ but *an example* of doing PPI. Further, the term *patient partner* refers to members of the public which is specific to the Epidemiology Group at the University of Aberdeen. There are a range of terms which other members of the public and research teams may prefer. However, this paper may be useful for others who are active in research in other disciplines and in various roles.

2 My mixed methods PhD

I undertook my PhD as part of a larger programme of work, ‘Patient-centred Care for Fibromyalgia: New pathway Design’ (PACFiND). Fibromyalgia is a common long-term pain condition and poses numerous healthcare delivery challenges, for example, delays



in diagnosis. Involving patient partners throughout the research cycle and in various formats (study management group and PPI group), the programme aims to design a new model of care for people with fibromyalgia. My overall research aim was to provide evidence to help inform this new care model, and that from the perspective of those affected by the condition. For this purpose, all research participants had symptoms suggestive of fibromyalgia or reported such diagnosis. I conducted a cross-sectional survey with 328 people residing across three Scottish National Health Service (NHS) boards which were followed by semi-structured interviews with 31 people living across the UK. I worked with patient partners who have a fibromyalgia diagnosis throughout my PhD.

3 Working with patient partners – step-by-step

These are my key learnings step-by-step, including reflection points to encourage you to think about your own research.

3.1 Why do you want to do PPI?

There were numerous reasons why I undertook PPI as part of my PhD. The main reason referred to the fact that, as any researcher, I bring my own assumptions and values into a research inquiry. My thinking is shaped by my past experiences of working within interdisciplinary, community-based healthcare services with a holistic understanding of health and a pragmatist worldview. I believe that people's individual experiences need to be seen within a historical, cultural and societal context; there are different ways of knowing; and there should be a focus on solving real-life problems (Morgan, 2014). Further, I am aware of instances where well-intended solutions were considered as unsuitable by those who accessed services and were supposed to benefit. Hence, working with patient partners who could support improving healthcare delivery which directly affects them and others living with fibromyalgia, was an essential and natural fit for me.

Reflection point: it is likely that you will be asked at some point why you want to or did undertake PPI. So, ask yourself what motivates you to do PPI. Think about your assumptions and values, or the valuable knowledge and skills you could learn as a



researcher for the future. Finding genuine interest and enthusiasm will enable you to start engaging with patient partners in a positive way, which is critical for successful PPI work.

3.2 Recruiting patient partners

My supervisor had an established relationship with a local peer support group so she organised our attendance at their regular meeting session. I introduced myself and my PhD as part of PACFiND. We informed attendees about the opportunity to become a patient partner. In comparison, the other patient partners were either already involved in PACFiND before I started my PhD or were recruited via a patient advocacy organisation and the funding body.

Reflection point: it is important to include patient partners with different lived experiences. Be aware of potential concerns within some communities due to being taken advantage of in the past. Think about how you can reach different communities and enable people from different walks of life to become a patient partner. Flexibility will be key. Approaching a healthcare professional/researcher with an established relationship with a specific community or a member of a special interest group within your professional association can be a helpful first step.

3.3 First meeting

My first meeting with two patient partners aimed at getting to know each other and building relationships. We also clarified the aim of the research, our roles and other important matters such as responsibilities to each other. I also used the first meeting to do a 'mapping exercise' which allowed both patient partners to share their own journeys through the healthcare system (and those of others they know of). Hearing these experiences and challenges first hand, as opposed to reading about it in my previous narrative reviews, was invaluable to me. As a result, we discussed important issues to consider for developing the survey questionnaire and interview topic guide. The decision to combine the first meeting with the exercise was made due to the extended travel involved for one patient partner and enabled us to make the best use of our time together.



Reflection point: the first meeting will set the scene for your upcoming PPI work. Think about the purpose of your first meeting and plan accordingly. In any case, establishing common ground and clarity about your joint PPI activities and attached expectations will be critical.

3.4 Developing the cross-sectional survey questionnaire and interview topic guide

After our first meeting, I had two ‘questionnaire’ meetings in person and virtually. I had sent the questionnaire draft, which built on the mapping exercise from the first meeting, with guidance on providing feedback to the patient partners in advance. Similarly, I sent an interview topic guide draft with guidance, to an advisory panel meeting which included patient partners. In the meetings, we discussed the drafts and other matters such as a sampling strategy for interview participants. I received constructive feedback for improving the documents. Further, patient partners piloted the documents and provided feedback on additional research documents including the participant information sheet and the survey reminder letter.

Reflection point: patient partners often have health conditions and/or other commitments which can impact their ability to focus on a task or availability to read documents. Ensure that you send files well in advance and include clear instructions.

3.5 Keeping patient partners updated

I kept my patient partners updated via email or in regular PACFiND study management group meetings. For example, after finalising the questionnaire, I kept patient partners updated about key milestones such as approval by the research ethics committee and the start/finish of the survey. These updates varied according to patient partners’ involvement in different research activities and their preferences. One patient partner could not continue after developing the survey but was still interested in being kept informed throughout my PhD.

Reflection point: as any other member of the research team, patient partners commonly appreciate being kept updated. Clarify the details in the first meeting, keep to agreed timelines and be flexible around specific needs.



3.6 Discussion of (preliminary) results

We discussed the survey results within a PACFiND study management group meeting which included patient partners. Further, I presented and discussed the preliminary findings from the interviews with a PACFiND PPI group. The meeting with seven members of the PPI group enabled a conversation about how my findings resonated with their own experiences and the experiences of others they know of (in addition to an opportunity to provide critique and ask questions). Their constructive feedback was invaluable for interpreting and writing up my final results.

Reflection point: patient partners bring different experiences and perspectives into discussions. Pro-actively seek out these wide-ranging perspectives. Plan enough time for getting and incorporating patient partner feedback into your final analysis/write up.

3.7 Manuscripts and plain language summaries

I am a co-author of a peer-reviewed, published paper on the cross-sectional survey results. Patient partners provided feedback on the manuscript and plain language summary drafts. For example, their feedback that the summary was short, easy to read and understandable was reassuring.

Reflection point: patient partners are interested in ensuring that research is disseminated in an accessible way with a wide range of audiences. Ask patient partners who they think are important stakeholders to share the research results with. Also clarify with patient partners how they specifically want to be involved in disseminating the results.

3.8 Assessing PPI impact

I did not 'formally evaluate' my PPI work due to practical reasons such as a dedicated PACFiND PPI coordinator and time constraints. Instead, I recorded my PPI work in a word document to keep track of our specific activities and how patient partners shaped the research. I started the document right at the beginning of the project, as I wanted to treat my PPI work as an integral part of my research and prevent myself from



forgetting important information over the course of my PhD. This documentation has also proved useful for presentations and outlining the PPI work in my thesis.

Reflection point: whilst a ‘formal evaluation’ of PPI activities is critical for advancing both our knowledge and its quality long-term (NIHR, 2021), such an evaluation can often be work intensive and time consuming. Nevertheless, documenting the research impact of patient partners is important and can provide valuable insights. So, think about how you can take a balanced approach and start recording right from the beginning.

4 Key considerations

4.1 Rapport and relationships

PPI requires trusting relationships. Hence, time needs to be invested into building rapport from the start. In the end, you are not ‘only’ a PhD student. You represent your research group or university. Making the involvement a positive experience will help to attract others to become patient partners in the future. You will also feel more excited about your research.

4.2 People’s interests and needs

Whilst patient partners may have some commonalities (such as a health condition), their lived experiences often vary widely. They come with different interests and needs, which you should accommodate to make PPI work enjoyable and successful for everyone involved. For example, it is important to clarify what kind of research activity a patient partner feels comfortable to do or is interested in gaining experience in, as well as to check for any specific requirements such as accessible rooms/toilets/or an option to virtually join in-person meetings. Further, be prepared that people may be unable to work with you throughout your entire PhD due to various reasons (such as a worsening health condition or competing commitments).



4.3 Your own commitment and time

Undertaking PPI requires your ongoing commitment and time. Some research phases can be more intensive (such as developing a survey) than others (such as keeping patient partners updated). Understanding PPI work as an integral research skill to learn, as part of your PhD, helps to give this area the importance that it requires. Having an understanding and/or supportive supervisor is an advantage. You could clarify potential PPI opportunities before signing up for your PhD.

5 Conclusion

PPI is considered an integral part of research by funding bodies in the UK. PPI can ensure that our research addresses issues that matter to people (especially those who are most affected) and is accessible to everyone. Hence, PPI skills are becoming increasingly critical in the research job market. A PhD offers a unique opportunity to gain PPI knowledge and skills as part of your research training. By outlining my own experiences, my hope is to provide an initial starting point and encourage other PhD students to consider undertaking PPI work.

6 Resources

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