

Nurse Researcher

Why you should read this article

- (Q please provide three short sentences to be added here as bullet points)
- **To understand the importance of using PPI in doctoral and dementia research**
- **To become aware of the opportunities and challenges associated with including patients with dementia in PPI advisory groups**
- **To gain insight into the practicalities of establishing PPI**

The importance of patient and public involvement in doctoral research involving people living with dementia

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Abstract

Background There is increasing recognition of the need to include patients and the public in the research process. There is extensive literature about patient and public involvement (PPI) in research, but fewer articles report on PPI in doctoral research.

Aim To reflect on establishing an advisory group for a doctoral study, exploring the opportunities and challenges associated with including patients with dementia in the research process.

Discussion The authors discuss the practicalities of establishing an advisory group, the challenges of being a novice researcher, long-term commitment to PPI, the overall approach to PPI and ethical considerations.

Conclusion Establishing an advisory group for a doctoral study can facilitate mutual learning and enhance the study's quality.

Implications for practice (Q: PLEASE PROVIDE) **Achieving high quality patient and public involvement in health and social care research can ultimately improve its quality and relevance. Developing knowledge and skills to facilitate patient and public involvement as part of a researchers' apprenticeship is a key aspect of the doctoral journey.**

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Keywords

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Introduction

Patient and public involvement (PPI) is defined as ‘research being carried out “with” or “by” members of the public rather than “to”, “about” or “for” them’ (National Institute for Health and Care Research (NIHR) 2022). There is much literature about the importance and impact of PPI in research, particularly in the UK (Brett et al 2014, Biddle et al 2020, Dawson et al 2020). It has various benefits, including allowing for diverse and varied viewpoints when making decisions during research (Dawson et al 2020).

There has therefore been greater emphasis over the past decade on developing and evaluating PPI in research. It is also embedded in major health research frameworks, such as NIHR (2019a) and Health Research Authority (HRA) (2022). Research funders in the UK and the US expect transparent PPI in the development of studies’ designs, as well as their conduct and dissemination. The NIHR in the UK and the Patient-Centered Outcomes Research Institute (PCORI) in the US aim to ensure people with lived experiences have a valued place in research. They fund and guide research (NIHR 2019b, PCORI 2022) to support and empower researchers to include PPI.

PPI has been found to improve and contribute to recruitment and participation in doctoral research, as well as its quality and relevance (Tomlinson et al 2019, Coupe and Mathieson 2020). However, few papers report on PPI in doctoral research (Coupe and Mathieson 2020), including how to operationalise PPI effectively. There is therefore a need to examine and discuss PPI in doctoral research further.

This article will reflect on the establishment and work of an advisory group for a doctoral study. It will explore the opportunities and challenges of including patients with dementia in the research process. It will also reflect on the process of PPI in doctoral research and its contribution, as well as provide guidance to researchers who are embarking on this journey.

Background

PPI in dementia research

The foundation of any study concerning a health condition is to involve people with experience of that condition, including patients, their families and carers (Snowball et al 2022). There are three main arguments for this:

1. People have the right to be involved in research that could affect their lives (Boivin et al 2018).
2. The government subsidises research, so the public has a right to be involved (Jackson et al 2020).
3. Involving people who have experienced the phenomenon being studied can improve the quality and relevance of the research (HRA 2022).

There were 900,000 people in the UK with a diagnosis of dementia in 2019; this was predicted to rise to 1.6 million people by 2040 (Wittenberg et al 2019). Involving people with dementia in research is meaningful (Waite et al 2019), with participants recognising their contributions’ quality and value to research and society (Miah et al 2019). There is increasing recognition that researchers investigating dementia should include people with dementia as advisers in their studies (Department of Health 2016, Alzheimer Europe 2018). Building capacity and the capability to conduct research with people with dementia is therefore essential (Morbey et al 2019).

PPI members’ contributions can be varied and occur at different stages of a study. Miah et al’s (2019) scoping review reported various methods studies had used to include PPI members, including meetings, conferences, drop-in sessions and workshops. Their activities included developing proposals for funding applications, assisting in designing studies, analysing data and interpreting results (Miah et al 2019). PPI members were involved in just one stage or **all of the stages of the study** (Miah et al 2019). However, the pressures of funding, time, costing and tendering, as well as researchers’ possible unconscious biases, can contribute to inconsistent participation (Biddle et al 2020).

Unfortunately, there are barriers to involving people with dementia in PPI groups related to prevalent cultural depictions of dementia as well as the language used to describe the disease and its trajectory (Low and Purwaningrum 2020). Stereotypically, a person with dementia is older, unpredictable and without a ‘voice’ (Low and Purwaningrum 2020). The carers and families of people with dementia may also experience stigma associated with the disease (Low and Purwaningrum 2020). Engaging people with dementia and their carers and families in research can challenge this stigma, as

it encourages researchers and the public to understand how people with dementia live and can knowledgeably contribute to research by sharing their experiences of the disease.

People with dementia typically have cognitive impairments such as memory or perception deterioration. This can affect their ability to engage in research (Litherland et al 2018, Miah et al 2019). Challenges experienced by PPI members and researchers include deterioration from the disease, the need for additional measures in supporting facilitation and members' lack of research training (Burton et al 2019). Therefore, a more structured approach is required to establish meaningful, effective PPI in research involving people with dementia, alongside a system to support PPI members and researchers alike (Jackson et al 2020).

PPI in doctoral research

The doctoral programme is a research apprenticeship in which postgraduate researchers develop their research knowledge and skills. Becoming a researcher involves interacting with many people to develop social networks that help them learn and navigate the world of research (Wang and DeLaquil 2020).

The limited literature about PPI in doctoral research reports an overall positive impact (Dawson et al 2020), including personal development of the researcher (Tomlinson et al 2019). However, many doctoral researchers are still apprehensive about PPI (Coupe and Mathieson 2020). Doctoral healthcare researchers may have had limited exposure to the research process and be bound by temporal and financial constraints, which can contribute to this lack of confidence in incorporating PPI.

Furthermore, early-career researchers may avoid including 'hard to reach' participants as they perceive there to be challenges and pressures involved (Miah et al 2019). These include needing additional measures to facilitate participation and the worsening of participants' symptoms during long-term projects (Burton et al 2019, Troya et al 2019).

A major aspect of the doctoral journey is the development of the knowledge and skills needed to facilitate PPI. Doctoral students will benefit from this, while the impact a PPI advisory group can have on their studies' designs and dissemination can also be invaluable (Coupe and Mathieson 2020).

Overall approach to PPI

The doctoral ethnographic study described in this article aims to explore the clinical decision-making processes of healthcare professionals in primary care working with patients with dementia at end of life (Anonymised 2023). The PhD studentship was developed for a national funder (Anonymised 2023) and the importance of PPI was evident throughout the application process.

The turning point in making the commitment to PPI is realising the key values involved in the co-production of research are the sharing of power, respect, inclusion and making joint decisions (NIHR 2015). This commitment should begin at the start of the research journey.

We wanted to recognise the perspectives of people with dementia in the design and delivery of the study. Our intention was to make the research more relevant to the needs of patients, carers and staff working in healthcare. We therefore planned to develop an advisory group to gather insights from people with dementia, people working in dementia care and people who had cared for relatives with dementia.

This process was daunting for the doctoral researcher (CS). It prompted many questions about building relationships and trust, the nature and scope of the advisory group, and maintaining communication.

PPI involvement in the context of individual doctoral research can refer to many different activities at different stages with different types of expertise. This sometimes making it hard to standardise the involvement of the PPI members (Staley 2015). The UK Standards for Public Involvement (NIHRb 2019) is a framework that encourages reflection on the process of PPI to promote a rigorous and transparent approach. Our overarching approach to PPI follows this framework (see Table 1).

Table 1. Reflection on our use of NIHRb (2019) in the study

Standard	Meaning	Reflection
Communications	Use relevant communication	Communication was adapted to suit the needs of individual members

Governance	Involve the public in research management and decision-making	Aligned to university policy on PPI
Working together	Work together to value all contributors	Terms of reference were established; shared roles and responsibilities were discussed and outlined
Inclusive opportunities	Opportunity for people from diverse backgrounds to be involved	Opportunities to be involved were offered to people with a diagnosis of dementia from different areas in south Wales. We removed barriers such as travelling to meetings
Support and learning	Offer and promote support and learning	Support available and learning opportunities aligned with university PPI policy provided for members
Impact	Understand the benefits of PPI in research	Disseminated the difference PPI can make to research

Recruitment

The only criteria for inclusion in the PPI group were either:

- A diagnosis of dementia.
- Being involved in caring for someone with dementia as a relative or healthcare professional.

We met with someone who was interested in dementia research as a relative and a healthcare professional; they then suggested other people who might want to join the group. We held initial online discussions with those who were interested, to outline the research topic and their potential involvement. All had engaged to varying extents in PPI work throughout their adult lives, with some having worked extensively in the field of dementia. This was a benefit to the advisory group as they knew about the research process and PPI.

We recruited three people **living** with dementia, one healthcare professional working with people with dementia and one person caring for a relative with dementia. The resulting group therefore had different experiences of and exposure to dementia, and we could draw on their professional and personal experiences and viewpoints.

Scope of involvement

We were clear in our management and expectations of members about the timeline of their involvement, when we established the PPI advisory group. It is important to establish a commitment from PPI members at the start of any long-term research, but this was particularly the case in this part-time doctoral study, as it was likely to take five years to complete and dementia can have different trajectories with different people.

The difficulties and challenges associated with the disease's symptoms and progression mean this long-term commitment can be a barrier to people with dementia being involved in PPI advisory groups (Morbey et al 2019, Clarke et al 2020). However, working with PPI members to overcome these issues facilitates their engagement in research (Bethell et al 2018, Greenhalgh et al 2019).

It is important when working with an advisory group to acknowledge how its members would like to be involved (Concannon et al 2016) and how much engagement they can provide. Face-to-face meetings were prohibited during the COVID-19 pandemic so we used a virtual platform to discuss our group's involvement and draft terms of reference that followed Health and Care Research Wales (2022)'s guidance (see Table 2).

Table 2. Terms of reference

	What a member of the public involved in our research can expect	What will be expected from you as a member of the public involved in our research
Practicalities	<ul style="list-style-type: none"> • Advice and support will be provided by the researcher around the role of involvement throughout the time of the research project • Methods of contact will include email, telephone and face to face if required and safe to do so • Travel expenses can be discussed if a face-to-face meeting is required • Feedback on the PhD work will be provided • Review of involvement and the role can be addressed yearly or when needed • All data and information will be kept confidential in line with legal frameworks • Recordings of team meetings will be stored securely in a password protected file on a computer only accessible to the researcher and only used for the researcher to refer to discussions that took place during the advisory panel meetings 	<ul style="list-style-type: none"> • Commitment to the learning and understanding of the role and activities • Commitment to respond to follow up on work • Commitment to engagement with the review of the role • Maintain confidentiality and ensure documents are kept secured in line with legal frameworks
Communications	<ul style="list-style-type: none"> • Methods of communication will be via email, video calls and telephone calls • Extra ways of contribution will be through research articles and documentation linked to the research topic 	<ul style="list-style-type: none"> • Respond to any communications
Practice	<ul style="list-style-type: none"> • The researcher will be respectful and courteous of others • The researcher will be punctual at meetings, ensure meetings run to time and follow an agreed agenda • Acknowledge all input 	<ul style="list-style-type: none"> • Respect and be courteous to others • Attend meetings in a punctual manner
Training and induction	<ul style="list-style-type: none"> • Links to information and support around involvement can be given if required 	<ul style="list-style-type: none"> • To ask for links/information if required around the role

The group agreed to these terms of reference, after which their first task was to advise on our research protocol before we submitted it for ethical and governance approvals. Different types of PPI can take place in healthcare research, including reviewing protocols, interview guides and survey questions, and discussing and revising research-related materials (Concannon et al 2016). It is important to note these activities may not focus on agreeing about the research. Rather, engagement should preferably concern collaboration and acknowledging the ways in which each member works, as well how to make the research more equitable (Locock and Boaz 2019). Researchers must be attuned to listening and acting even if it challenges their own beliefs and involves ideas they may have not previously have deliberated (Mitchell et al 2019).

We held several meetings with the group. It was important to ensure all members could contribute equally to the discussions during these meetings. We therefore set clear agendas for each meeting and practised careful encouragement. For example, if someone had not spoken for a while, we would ask them if they would like to contribute or add anything to the discussion. Burton et al (2019) found that effective PPI meetings require several strategies to be used, such as setting clear agendas and terms of reference and providing extra time and encouragement. Øksnebjerg et al (2018) also found PPI members appreciated interventions to assist with social engagement and inclusion.

Discussing the research protocol with the members of the advisory group meant they could deliberate all aspects of our study, including its methodology, recruitment and potential dissemination of findings. Conversations included discussions of the issues and problems affecting end of life care for those with dementia, and how decisions (Q: Whose decisions?) affect healthcare professionals and carers of people with dementia – **the key aim of the doctoral study (CS)**.

We encouraged everyone to share their perspectives of the study’s aim and objectives, to make them more adaptable to current issues surrounding the topic area. The discussions helped to clarify the study’s aim and objectives as well, affirming

the importance and relevance of the wording (Q: of what?) **of the key documents such as consent forms, participant information sheet and interview guide.** It also provided a robust and thorough foundation for our research protocol, enabling us to understand more clearly how the study's aims and objectives link to the demands on end of life care for people with dementia. Some of the suggestions needed to be discussed further, to ensure the aim of the funded research was not lost.

Ethical considerations

There is no requirement in the UK to obtain ethical approval to recruit members to a PPI research advisory group (INVOLVE 2016). However, it is important to use an ethically informed approach to carry out PPI activity (Staniszewska et al 2011).

Three important ethical considerations were apparent when we established the advisory group: obtaining ongoing consent; what communication strategies we would use; and ensuring the well-being of the advisory group's members.

Obtaining ongoing consent

We drafted an initial written consent form for PPI members in line with Health and Care Research Wales (2022)'s template. All the group signed this form. We verbally reconfirmed consent with each member at the start of each meeting because the symptoms of dementia and any associated health problems can cause consent to fluctuate. **(Q I really do not like the way this section is written can it be reworded back to its original please?)**

Communication strategies

Communication is an NIHR (2019a) PPI standard and is an important part of PPI activity in our study. We initially agreed email would be the main medium of communication. However, one group member began to have difficulties using email because of her dementia symptoms. We therefore agreed an alternative way to disseminate information **which was carried out through telephone conversations.** (Q: What was this? Was it just for her or everyone?).

There was consensus from the first meeting that virtual online meetings would be beneficial, even once the restrictions from the COVID-19 pandemic eased, as PPI members said using public transport to get to in-person meetings could be stressful. Waite et al (2019) found taking a flexible approach and incorporating a dementia-friendly meeting (Q: Could you briefly explain what a dementia-friendly meeting involves?) overturned some of the barriers involved in including people with dementia in research, **this included accessibility, communication, building trust and familiarity.**

This shows the importance of offering a range of communication strategies tailored to individual needs, which may change during the research (Gove et al 2017).

Advisory group well-being

It is important to anticipate and respond to the needs of individuals who participate in research advisory groups, to ensure they are supported to contribute. People with dementia are potentially vulnerable and therefore researchers have an ethical duty to promote well-being (Gove et al 2017). It was therefore important to ensure the well-being of the advisory group's members, practising in line with **the** Nursing and Midwifery Council (2018).

However, we had not anticipated the extent of the support some members would need during meetings. They were candid, speaking at length in early meetings about their situations, including their feelings, well-being, thoughts and problems. We therefore supported group members emotionally. If they required additional support and care following meetings, we took appropriate steps, including signposting people to family members, their GPs or voluntary services.

Members sometimes also had 'bad days' leading up to or during meetings. This meant they either needed support or we had to adjust the meetings accordingly. We did this mostly by listening, as members sometimes just needed to discuss issues or symptoms they were experiencing.

Conclusion

This article has highlighted important aspects of being a novice doctoral researcher establishing a PPI advisory group. It has explored how an advisory group can be established, the impact it can have and the ethical considerations that are vital in ensuring meaningful PPI.

The growing practice of PPI – not only in dementia research but in health and social care research more broadly – will undoubtedly contribute to healthcare and society, helping to improve relevant research. It has improved our doctoral study, including its protocol, consent form, participant information sheet and research interview guide. Our PPI advisory group will continue to inform our research and catalyse us to tackle challenges.

Doctoral students may feel apprehensive about or have limited exposure to the research process. However, PPI can help to support them, adding value, quality and insight. The process can be daunting, but establishing relationships with PPI members built on trust and commitment to long-term involvement can lead to a mutually beneficial PPI experience.

Key points

- *(Q please provide three or four key points from your article to be added here as bullet points)*
- **Involving people with health conditions such as dementia in research is vital to help with its quality and relevance.**
- **Even though establishing a PPI advisory group as a doctoral student is challenging, if done well can overall positively influence research.**
- **Being open minded with the process ensures PPI members are supported to contribute to research**

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