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Thank you very much to the Editor and Reviewers for your helpful suggestions.

| **Location** | **Comment** | **Response** |
|---|---|---|
| | **Reviewer 1** | |
| Page 2 | 'Currently 900,000 people in the UK have a diagnosis of dementia, and this figure is predicted to rise to 1.6 million people by 2040 (Wittenbery et al. 2019)'. Given that the reference is 4 years ago it possible that the statistics quoted here is no longer current. Are there no publications in the last 2 years at least that can be used to render this statement representative on the current state of the art? | Thank you for your comments, however this is the statistic that the Alzheimer's Society are still using. Recent statistics are either global predictions or linked to the Covid-19 pandemic. |
| Page 2 and throughout | Para 3 (Low and Purwaningrum 2020reference). Please proof read the entire piece to identify minor errors such as this one. | Addressed thank you |
| Page 4, 5, 6 | Tables to be formatted with appropriate font size. I am sure the guidelines specify how they should be presented | Thank you for your suggestion, tables are clearly labelled and numbered as per guidelines. Unfortunately there is no extra information on format or font size in the author guidelines that I could find. Please see exert below:<br>*Boxes, tables and figures must be numbered, captioned and cited in the article in their order of appearance. They should be easy to read and uncluttered. All symbols and abbreviations should be explained. Sources should be indicated and included in the references. Tables and figures are usually redrawn by RCNi* |
| Page 8 | Conclusion: This could be enhanced further by capturing what the reflection on the process delivers in terms of value given earlier sentiments (see below) | Addressed thank you |
| | | |

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

## Abstract

### Background

There is increasing recognition of the need to include people living with dementia to inform the research process. While the literature about patient and public involvement (PPI) in research is extensive, particularly in the UK, fewer papers report on PPI in doctoral research.

### Aim

The article will reflect on establishing an advisory group for a doctoral study, exploring the opportunities and challenges associated with including people living with dementia.

### Discussion

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

### Conclusion

Ultimately, establishing an advisory group for a doctoral study can facilitate mutual learning and enhance the quality of the study.

## Introduction

This article will reflect on establishing an advisory group for a doctoral study, exploring the opportunities and challenges associated with including people living with dementia. It will reflect on the process and contribution of patient and public involvement (PPI) in doctoral research and provide guidance for others who are embarking on this journey. Over the last decade, there has been an increased emphasis on developing and evaluating PPI in research. 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, p.1). The importance of PPI is embedded in key health research frameworks (NIHR 2019a, Health Research Authority [HRA] 2022) with research funders expecting transparent PPI in the development of the research design, conduct and dissemination of research. In the United Kingdom (UK), the NIHR (2019b) fund a national PPI advisory group, similarly, America has the Patient-Centred Outcomes Research Institute [PCORI] that promotes PPI in research (PCORI 2022). Both organisations aim to support and empower researchers to include PPI, and help fund and guide research, ensuring people who have lived experience have a valued place in research.

This article will explore the establishment and work of a PPI advisory group involving people living with dementia in a doctoral study. There is much literature around the importance and impact of PPI in research, yet little is written about PPI in doctoral research.  There is thus a need to examine and discuss PPI in doctoral research.

## Background

### PPI in dementia research

Involving people with lived experience of a health condition, including patients and their families/carers, is the foundation for any research study (Snowball et al. 2022). The importance of PPI in research is underpinned by three key arguments, firstly the philosophical and ethical argument asserting that people have the right to be involved in research that may affect their lives

(Boivin et al. 2018). Secondly, the funding or political argument, that research is subsidised, therefore the public have the right to be involved in the research process (Jackson et al. 2020). Lastly, a quality argument - involving people who have lived experience of the phenomena of study can improve research quality and relevance (HRA 2022). People living with dementia typically have cognitive impairment such as memory or perception deterioration that can impact on their ability to engage with research. However, there is increasing recognition of the need to include people living with dementia as advisors in the research process (Alzheimer Europe 2018; Department of Health 2016). This is crucial due to the increase in the prevalence of dementia. Currently 900,000 people in the UK have a diagnosis of dementia, and this figure is predicted to rise to 1.6 million people by 2040 (Wittenbery et al. 2019). Building capacity and capability to conduct research alongside people living with dementia is therefore essential as evidence is generated with individuals with relevant lived experience (Morbey et al. 2019).

The involvement of people living with dementia and their contribution to research is varied and may occur at different stages of the research process. Miah et al.'s (2019) scoping review reported various methods of including PPI members, such as meetings, conferences, drop-in sessions and workshops. PPI members' activities included involvement in proposal development for funding applications, design, data analysis and interpretation of the results, but this was varied with some PPI members being involved in just one, or all, of the identified stages of the research (Miah et al. 2019). Alongside this, pressures within research associated with funding, time, costing and tendering, and potential individual researcher unconscious bias, can contribute to inconsistent participation (Biddle et al. 2020). However, involving people with dementia in research has been evaluated as meaningful (Waite et al. 2016), with individuals recognising the value and quality of their contribution to research and society (Miah et al. 2019).

Unfortunately, the barriers associated with involving people living with dementia in PPI groups may be associated to the prevalent cultural depictions of dementia and the language used to describe the disease and its trajectory (Low and Purwaningrum 2020). A person with dementia is stereotypically portrayed as someone who is older, with an unpredictable nature who typically, do not have a 'voice' (Low and Purwaningrum 2020). Carers and family members of a person living with dementia may also experience stigma associated with dementia (Low and Purwaningrum 2020). Engaging people living with dementia and their carers or family members can help challenge this stigma, by encouraging not only researchers but the public to understand how people with dementia live, and how they can knowledgeably contribute to research by sharing their experience of the disease.

The implementation of PPI across European healthcare research is unequal and not firmly embedded into the research process, possibly due to the lack of support and guidance in certain countries (Biddle et al. 2020). Challenges around the dementia trajectory and symptoms such as deterioration, the need for additional measures in supporting facilitation, and the lack of research training are still experienced by PPI members and researchers (Burton et al. 2019). Therefore, to establish meaningful, effective PPI in research, a more structured approach is required, 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, where postgraduate researchers develop their research knowledge and skills. Becoming a researcher involves interaction with many individuals, developing social networks that help the individual learn and navigate the world of research (Wang and DeLaquil 2020). While the literature about PPI in research is extensive, particularly in the UK (Biddle et al. 2020; Dawson et al. 2020; Brett et al. 2014), fewer papers report on PPI in doctoral research (Coupe and Mathieson 2020), including how to operationalise effective PPI. The limited existing literature reports the overall positive impact of PPI on doctoral research (Dawson et al. 2020), including the personal development of the doctoral researcher (Tomlinson et al. 2019). Despite these possible benefits from engaging with PPI, many doctoral researchers may be apprehensive (Coupe and Mathieson 2020). Doctoral healthcare researchers may have limited prior exposure to the research process and may also be bound to time and financial constraints which can add to the lack of confidence in incorporating PPI in their research. Furthermore, early career researchers may avoid including 'hard to reach' participants due to the potential challenges of the process and the pressures associated with the research (Miah et al. 2019). These perceived challenges may include difficulty in reaching PPI members, needing additional measures to facilitate participation and worsening symptoms during long term projects (Troya et al. 2019; Burton et al. 2019).

Developing knowledge and skills to facilitate PPI as part of a researcher's apprenticeship is a key aspect of the doctoral journey. Doctoral students will benefit from developing these knowledge and skills, the impact that a PPI advisory group can have on the study design and dissemination can also be invaluable to doctoral students (Coupe and Mathieson 2019).

## Establishing a PPI advisory group for a dementia doctoral study

This section will reflect on facilitating a PPI advisory group and the involvement of this group in developing a research protocol for a doctoral study. The doctoral study aims to explore the clinical decision-making process of healthcare professionals caring for patients with dementia at the end of life within primary care, using an ethnographic methodology (for further details see published protocol – Anonymised 2023).

### Overall approach to PPI

The PhD studentship was developed for a national funder (blinded for peer review) and the importance of PPI was evident throughout the application process, including the interview where a lay person was part of the panel. While the challenges of involving people with dementia in PPI are acknowledged (Miah et al. 2019; Litherland et al. 2018), doing so facilitates the recognition of their perspectives that can influence the design and delivery of the research process. This is something that we wanted to accomplish in the research. The realisation that the key values involved in the co-production of research are the sharing of power, respect, inclusion and making joint decisions (NIHR 2015), is the turning point in making the commitment to PPI, and the commitment should begin at the start of the research journey.

Therefore, we planned to develop an advisory group to gather insights from people who were either living with dementia, worked within the field of dementia care or had cared for a relative with dementia, with the intention of making the research more relevant to the needs of patients, carers and staff working in healthcare. This process was daunting for a doctoral researcher and prompted many questions about building relationships and trust, the nature and scope of the advisory group, and maintaining communication. In the context of individual doctoral research, PPI involvement can refer to many different activities at different stages of the research process, with different types of expertise, sometimes making it hard to standardise the involvement of the PPI members (Staley 2015). The overarching approach to PPI for this study followed the UK Standards for Public Involvement (NIHRb 2019). This framework encourages reflection on the process of PPI to promote a rigorous and transparent approach. Table one outlines how the six standards were utilised within this study, which are explored in more detail throughout the paper.

| UK Standards for Public Involvement in Research | Meaning | Reflection |
|---|---|---|

| | | |
|---|---|---|
| **Communications** | Use relevant communication | Communication was adapted individually to suit the needs of all 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, the understanding of shared roles and responsibilities were discussed and outlined. |
| **Inclusive opportunities** | Opportunity for people to be involved from diverse backgrounds | Public involvement opportunities 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 to offer learning opportunities to members. |
| **Impact** | Understand the benefits of PPI in research | Disseminated the difference that PPI can make to research, such as conferences. |

Table 1 UK Standards for Public Involvement in Research (NIHR 2019b).

**Recruitment**

Upon deciding the approach to PPI within this study, the first stage was to recruit interested people with relevant experience. The only criteria we had for recruitment was a diagnosis of dementia or the involvement in care of someone with dementia (either as a relative or healthcare professional). We met with one person who was interested in dementia research as a relative and a healthcare professional, and they suggested other people who may be interested in joining the PPI group. We held initial online discussions with each interested person, where we outlined the research topic and their potential involvement. All interested individuals had already engaged in PPI work throughout their adult lives to varying extents, with some individuals who had worked extensively in the field of dementia. This was a benefit to the advisory group as the participants had knowledge of the research process and PPI. We succeeded in recruiting three people who were living with dementia, one healthcare professional who worked with people with dementia and one relative who cared for a family member with dementia. This made a group of people with different experiences and exposure to dementia, and where we could draw on their professional and personal experiences and viewpoints.

The long-term commitment between researcher and PPI members is important to establish at the start of the research process, particularly as dementia can have varying trajectories for individuals. This was particularly pertinent with this part-time doctoral study that would likely take five years to complete. Researchers have reported that this long-term commitment can be a barrier to the involvement of people living with dementia in PPI advisory groups, as difficulties and challenges are associated with the disease symptoms and progression (Morbey et al. 2019; Clarke et al. 2018). Yet some studies have shown that by identifying this as a barrier and working with PPI members to overcome these enables better engagement in research activities for these individuals (Greenhalgh et al. 2019; Bethell et al. 2018). Upon establishing the PPI advisory group and recruiting members, we were clear in the management and expectations of members about the timeline of their involvement.

**Scope of involvement**

When engaging an advisory group, it is important to acknowledge how the members would like to be involved (Concannon et al. 2016), and how much engagement they are able to provide. Within this doctoral study, the involvement of group members was discussed, and Terms of Reference (ToR) were drafted in line with guidance from Health and Care Research Wales (2022) – these are outlined in table two. This discussion was undertaken on a virtual platform during the COVID-19 pandemic when face-to-face meetings were not possible.

| | **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** | Advice and support will be provided by the researcher around the role of involvement throughout the time of the research project.<br>Methods of contact will include email, telephone and face to face if required and safe to do so.<br>Travel expenses can be discussed if a face-to-face meeting is required.<br>Feedback of the PhD work will be provided.<br>Review of involvement and the role can be addressed yearly or when needed.<br>All data and information will be kept confidential in line with legal frameworks.<br>Recordings of team meetings will be stored securely on a password protection file and computer only accessible to the researcher, and only used for the researcher to refer to discussions that took place during the advisory panel meetings. | Commitment to the learning and understanding of the role and activities.<br>Commitment to respond to follow up on work.<br>Commitment to engagement with the review of the role.<br>Maintain confidentiality and ensure documents are kept secured in line with legal frameworks. |
| **Communications** | Methods of communication will be via email, video calls and telephone calls.<br>Extra ways of contribution will be through research articles, and documentation linked to the research topic. | Respond to any communications |

| | | |
|---|---|---|
| **Practice** | The researcher will be respectful and courteous of others.<br>The researcher will be punctual at meetings, ensure meetings run to time and follow an agreed agenda.<br>Acknowledge all input. | Respect and be courteous to others.<br>Attend meetings in a punctual manner. |
| **Training and induction** | Links to information and support around involvement can be given if required | To ask for links/information if required around the role. |

Table 2: Terms of reference (Health and Care Research Wales 2022).

Following group agreement of the ToR, the group's first role was to advise on the research protocol prior to it being submitted for ethical and governance approvals. PPI is undertaken in a variety of ways in healthcare research, including the reviewing of documents such as protocols, interview guides and survey questions, and revising and discussing research related materials (Concannon et al. 2016). It is important to note that the aim of these engagement activities may not focus on trying to find an agreement about the research. Preferably engagement should be around collaboration and acknowledging the ways in which each member works, and how they can make that research more equitable (Locock and Boaz 2019).

By discussing the doctoral study protocol with the advisory group, all aspects of the research could be deliberated, including the aim and objectives, methodology, recruitment and potential dissemination of findings. Discussions around the aim and objectives included conversations on the current issues and problems affecting end of life care for those living with dementia, and how decisions affect healthcare professionals and carers of people with dementia. These discussions also helped clarify the aim and objectives, affirming the importance and relevance of the wording. This provided the research protocol with a robust and thorough foundation, where we were able to understand the research aim and objectives more clearly and how they link to the current demands on end-of-life care for this patient group. All members were encouraged to share their varying perspectives on the study's aim and objectives, making them more adaptable to current issues surrounding the topic area. Some of these suggestions needed to be discussed further to ensure that the aim of the funded research was not lost.

Careful navigation of the meetings was also needed to ensure all members could contribute equally to the discussion. A clear agenda was set for each meeting and careful encouragement was also practiced, e.g. if someone had not spoken for a while a question would be posed to them from the research team asking if they would like to contribute or add anything to the discussion. This was similar to a study carried out by Burton et al. (2019), where it was identified that different strategies should be used for effective PPI meetings, this included clear agendas, a ToR, the allowance of extra time and encouragement. Similarly, Oksnebjerg et al. (2018) found that PPI members appreciated interventions during meetings that assisted with social engagement and inclusion. Researchers must be attuned to listening and acting even if it challenges their own beliefs and ideas that they may have not deliberated before (Mitchell et al. 2019). Alongside this, researchers must be aware of the ethical implications that may arise amongst the PPI group.

### Ethical considerations

There is no requirement to get ethical approval in the UK when recruiting PPI members to a research advisory group (INVOLVE 2016), but it is important to ensure that PPI activity is carried out using an ethically informed approach (Staniszewska et al. 2011). In this study, three key ethical considerations were apparent when establishing the advisory group: ongoing consent, communication strategies and wellbeing of the advisory group members.

Respecting everyone's roles and ensuring inclusive opportunities throughout the process included ongoing consent. All PPI members were asked if they consented to be involved in the advisory group. Initially, written consent was drafted in line with the Health and Care Research Wales (2022) template and signed by all members, consent was then reconfirmed verbally with each member at the start of each meeting. This was important to continue as consent may fluctuate, especially with the symptoms of dementia and any associated health problems. We found that members sometimes had "bad days" leading up to, or during, the meetings and they needed to be supported, or the meeting needed to be adjusted accordingly. This was achieved mostly through listening, as sometimes members just needed to discuss issues or symptoms they were experiencing.

Communication forms one of the NIHR (2019a) PPI standards and remains one of the key parts of PPI activity in our study. From the first meeting there was a consensus that virtual online meetings would be beneficial, including once the COVID-19 pandemic eased. Members of the group explained that using public transport to meeting venues could be a stressful task, which is similar to the findings in Waite et al.'s (2019) qualitative study. Their study found that incorporating a dementia-friendly meeting and taking a flexible approach resulted in overturning some of the potential barriers associated with including people living with dementia in PPI. It is therefore important to be person-centred during this process, recognising individuality and removing any potential barriers to PPI involvement (Gove et al. 2017). Communication strategies also included methods for sharing information between the group. Initially we agreed that email would be the main form of communication. However, one group member started having difficulties with this due to her symptoms of dementia, and we therefore agreed an alternative way to disseminate information. This showed the importance of offering a range of communication strategies tailored to individual needs, recognising that this may not be stagnant throughout the research journey.

Lastly ensuring the wellbeing of the advisory group members was important, ensuring we were practising in line with the Nursing and Midwifery Council (2018) requirements. Members were very candid in meetings and we had not anticipated the extent of the support they needed during PPI sessions. During early meetings, the group members spoke at length about their current situation that included their feelings, wellbeing, thoughts and problems. Research has found that people living with dementia are potentially vulnerable and therefore researchers have an ethical duty to promote wellbeing (Gove et al. 2017). We therefore supported group members emotionally, taking appropriate steps that included the awareness of where to signpost individuals if they required additional support and care following meetings, this may be family members, the GP, or voluntary services. Therefore, 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.

### Outcomes

It has been reported that PPI in doctoral research has helped improve and contribute to study recruitment, participation, quality of research and its relevance (Coupe et al. 2020; Tomlinson et al. 2019). In this study, PPI has positively influenced the study protocol, consent form, participant information sheet and the research interview guide. The advisory group will continue to impact the study at different stages of the research process and will act as a catalyst to tackle challenges. Working as researchers alongside a variety of PPI advisory members allows for diverse and varied viewpoints when making decisions during the research process (Dawson et al. 2020).

## Conclusion

The article has highlighted important aspects of being a doctoral researcher new to research and 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 key to ensuring meaningful PPI. The growing practice of PPI, not only in dementia research but in health and social care research more broadly, will undoubtably contribute to healthcare and society, helping to improve quality relevant research. This article has highlighted that PPI can help to support doctoral students, adding value and insight to their research despite the feelings of apprehension or limited exposure prior to the research process. In turn and in the context of your own individual doctoral research, the commitment to using PPI can add to the overall quality of your research throughout the different stages of the research process. Despite the process being daunting, it has also shown that establishing relationships with PPI members and committing to long term involvement can lead to a mutually beneficial PPI experience, enabling a relationship built on trust and commitment.

## References

Alzheimer Europe (2018) The ethics of dementia research. Available at: https://www.alzheimer-europe.org/resources/publications#fragment1 (Last accessed 28th November 2022).

Anonymised (2023) Anonymised for peer review.

Bethell J (2018) Patient engagement in research related to dementia: a scoping review. Dementia. 17, 8, 944-961.

Biddle M, Gibson A, Evans D (2020) Attitudes and approaches to patient and public involvement across Europe: A systematic review. Health and Social Care in the Community. 29, 1, 18-27.

Boivin A, Richards T, Forsythe L (2018) Evaluating patient and public involvement in research. British Medical Journal. 6, 363.

Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, Suleman R (2014) Mapping the impact of patient and public involvement on health and social care research: a systematic review. Health Expect. 17, 637-650.

Burton A, Ogden M, Cooper C (2019) Planning and enabling meaningful patient and public involvement in dementia research. 6, 557-562.

Clarke C, et al. (2018) Relational care and co-operative endeavour- reshaping dementia care through participatory secondary data analysis. Dementia. 19, 4, 1151-1172.

Concannon T, Kotzias V, Khodyakov D et al. (2016) What takes stakeholders want to become involved in research? The RAND Blog. Available at: https://www.rand.org/blog/2016/05/what-makes-stakeholders-want-to-become-involved-in.html. (Last accessed 03rd April 2023)

Coupe N, Mathieson A (2020) Patient and public involvement in doctoral research: impact, resources and recommendations. Health Expectation. 23, 1, 25-26.

Dawson S, et al. (2020) Patient and public involvement in doctoral research: reflections and experiences of the PPI contributors and researcher. Research Involvement and Engagement. 6, 23,

Department of Health (2016) Prime Ministers Challenge on Dementia 2020. Implementation Plan. Available at: www.gov.uk/dh (Last accessed 28th November 2022)

Gove D, et al. (2017) Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). Aging and Mental Health. 22, 6, 723-729,

Greenhalgh T, et al. (2019) Framework for supporting patient and public involvement in research: systematic review and co-design pilot. Health Expectation. 22, 4, 785-801.

Health and Care Research Wales (2022) Terms of reference template. https://padlet.com/healthandcareresearch/public-involvement-toolkit-a-guide-to-involving-members-of-t-cifc7jknonpjqmr5/wish/2225688455

Health Research Authority (2022) Public involvement. Available at: https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/ (last accessed 19th October 2022)

INVOLVE (2016) Public Involvement in Research and Research Ethics Committee Review. Available at: http://invo.org.uk/wp-content/uploads/2016/05/HRA-INVOLVE-updated-statement-2016.pdf (Last accessed: 29 September 2020.)

Jackson T, Pinnock H, Liew S, et al. (2020) Patients and public involvement in research: from tokenistic box ticking to valued team members. BMC Medical. 18, 79.

Litherland R, Burton J, Cheeseman M, et al. (2018) Reflections on PPI from the 'Action on Living Well: Asking You' advisory network of people with dementia and carers as part of the IDEAL study. Dementia. 17, 8, 1035-1044

Locock L, Boaz A (2019) Drawing straight lines along blurred boundaries: qualitative research, patient and public involvement in medical research, co-production and co- design. Evidence and Policy. 15, 3, 409-421.

Low L, Purwaningrum F (2020) Negative stereotypes, fear and social distance: a systematic review of depictions of dementia in popular culture in the context of stigma. BMC Geriatric. 20, 477.

Miah J, Dawes P, Edwards S, et al. (2019) Patient and public involvement in dementia research in the European Union: a scoping review. BMC Medical. 220, 220.

Mitchell S, Slowther A, Coad J, et al. (2019) Ethics and patient and public involvement with children and young people. Archives of Disease in Childhood – Education and practice. 104, 195-200.

Morbey H, et al. (2019) Involving people living with dementia in research: an accessible modified Delphi survey for core outcome set development. British Medical Journal. 20, 12.

National Institute for Health and Care Research (2019a) Values and Principles framework. NIHR. Available at: https://www.nihr.ac.uk/documents/nihr-adding-value-in-research-framework/20147 (Last accessed 28th November 2022).

National Institute for Health and Care Research (2019b) UK Standards for Public Involvement. Better Public Involvement for better health and social care research, NIHR.

National Institute for Health and Care Research (2022) Briefing notes for researcher – public involvement in NHS, health and social care research. Available at:

https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371 (last accessed: 19th October 2022)

Nursing and Midwifery Council (2018) The Code. NMC.

Oksnebjerg, L, Diaz-Ponce, A, Gove, D, et al. (2018) Towards capturing meaningful outcomes for people with dementia in psychosocial intervention research: A pan-European consultation. *Health Expect*. 2018; 21: 1056–1065. https://doi.org/10.1111/hex.12799

Patient-Centered Outcomes Research Institute (2022) Available at: https://www.pcori.org/ (last accessed: 16th August 2023)

Snowball E, et al. (2022) Engagement of people with lived experience of dementia advisory group and cross-cutting program: reflections on the first year. Research Involvement and Engagement. 8, 28,

Staley K (2015) 'Is it worth doing?' Measuring the impact of patient and public involvement in research. Research Involvement and Engagement 1, 6

Staniszewska S, Brett J, Mockford C (2011) The GRIPP checklist: strengthening the quality of patient and public involvement reporting in research. International Journal Technology Assessment Health Care. 27, 4, 391-399.

Tomlinson J, et al. (2019) Patient and public involvement in designing and conducting doctoral research: the whys and the how's. Research Involvement Engagement. 5, 23.

Troya M, Chew-Graham C, Babatunde O, et al. (2019) Patient and Public Involvement and engagement in a doctoral research project exploring self-harm in older adults. Geriatric Psychiatry. 4, 617-631.

Waite J, Poland F, Charlesworth G (2019) Facilitator and barriers to co-research by people with dementia and academic researchers: Findings from a qualitive study. Health Expectations. 22, 4, 761-771.

Wang L, DeLaquil T (2020) The isolation of doctoral education in the times of COVID-19: recommendations for building relationships within person-environment theory. Higher Education Research and Development. 39, 7.

Wittenbery R, Barraza-Araiza L, Rehill A (2019) Projections of older people with dementia and cost of dementia care in the United Kingdom, 2019-2040. Available at: https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf (Last accessed: 15th September 2023).