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Using Patient and Public Involvement to Develop a Survey for Economic Evaluation in Dementia Research

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Abstract

Background: This methodological paper reflects on how people with lived experience of dementia contributed to the development and refinement of a survey intended to identify priorities for future economic evaluation in dementia research. Although Patient and Public Involvement (PPI) is increasingly recognised as essential for producing relevant and ethical health research, people living with dementia are rarely included in PPI activities related to health economics, where outcomes are often predetermined by decision-making bodies.

Method: To support the development and refinement of the survey, a small bespoke PPI group comprising four individuals with lived experience in England reviewed draft survey materials through online meetings and helped ensure the survey was accessible and meaningful through feedback on survey clarity, accessibility, and response options.

Results: PPI contributions led to important refinements, including simplifying terminology, removing ambiguous or burdensome items, and enhancing overall usability.

Discussion: The findings demonstrated the significant value of involving PPI contributors early and collaboratively, showing that co-design approaches enrich the relevance and sensitivity of research tools. The experience also highlighted the need for tailored support and an accessible introduction to health economic concepts for PPI contributors, alongside broader participation across study stages and engagement in dissemination activities.

Key words

Dementia, health economics, non-pharmacological therapies, Patient and Public Involvement, PPI

Key Points for Decision Makers

- Involving people living with dementia at an early stage can strengthen decisions about which interventions are worth evaluating economically.
- PPI can improve inclusivity and accessibility in research design, supporting independent participation by people with cognitive or sensory challenges.
- Small, well-supported PPI groups can meaningfully influence research design with modest time and resource requirements.

1 Introduction and Aim

Patient and Public Involvement (PPI) embodies the principle of “Nothing about us without us,” a phrase long championed by disability advocacy groups that emphasises inclusion in decision-making processes (1). Adopted by the Alzheimer’s Society in 2018, this principle was applied to dementia research to end exclusion and promote active involvement of people affected by dementia in shaping research agendas (2). PPI refers to the active involvement of people with lived experience in all stages of the research as co-production partners who influence design, conduct, and dissemination, rather than as study participants (3). Increasingly, funders mandate PPI to enhance research integrity and reduce waste caused by irrelevant questions or poorly designed studies (4). Involvement of people with lived experience in related research is recognised nationally and internationally as essential for improving quality, relevance, impact, and transparency (5).

PPI is a collaborative process built on partnership, where contributors and researchers work together to shape research (6). Public contributors may engage in a range of collaborative roles within research, including shaping research priorities and design, informing study materials and methods, conducting interviews, analysing data, contributing to interpretation and dissemination, and supporting shared decision-making across different stages of the research process. Throughout this paper, the term ‘public contributor’ refers to people with lived experience actively involved in shaping and informing the research.

A gold-standard model of PPI begins with involvement as early as possible in the research process, contributing to idea generation and priority setting (7). Early discussions with PPI groups about roles, expectations, and available support are

essential, particularly when involving people living with dementia (PLwD) (8). Best practice also includes covering expenses and offering payment for involvement. National Institute for Health Research (NIHR) guidance recommends fair and transparent acknowledgment of contributions and at the time of this study, advised £20 for involvement requiring minimal preparation and approximately one hour of participation (9). NIHR guidance was subsequently updated in 2025, with revised public involvement payment rates (10), including a commonly cited rate of £27.50 for around one hour of involvement.

Recent work has increasingly highlighted the importance of involving patients and the public within health technology assessment (HTA) and economic evaluation processes, particularly in shaping outcome selection, evidencing lived experience, and informing value assessment frameworks (11). Emerging literature also emphasises the contribution of patient and public involvement to improving the relevance, transparency, and legitimacy of economic evaluation and decision-making processes (11).

PPI is becoming more visible within health economics, with emerging evidence demonstrating its value in priority setting, defining research questions, and informing outcome selection (12). Evidence demonstrates that PPI improves healthcare decision-making and fosters a people-centred system (13). In recent years, PPI has been considered increasingly important in health policy decision-making, including areas such as service planning, resource allocation and priority setting (14). As PPI becomes increasingly central to health research, there is growing emphasis on incorporating wider outcomes and societal perspectives into economic models (15). This reflects a shift toward holistic, person-centred approaches that balance efficiency with equity, ethics, and real-world impact.

However, PLwD are rarely involved in the design or conduct of economic evaluations, despite growing recognition that lived experience is essential for selecting meaningful outcomes and informing model assumptions. Their involvement is further constrained by the fact that key outcomes in economic evaluation, most notably quality-adjusted life years (QALYs), are strongly preferred by national decision-making bodies such as the National Institute for Health and Care Excellence (NICE), which recommends QALYs as the reference outcome for cost-utility analyses (16). As a result, the scope for PLwD to influence outcome selection is limited, and their perspectives are often absent from the foundational assumptions that shape economic models. Most studies rely on carer or public contributors rather than PLwD themselves, reflecting perceived challenges around communication, fluctuating capacity, and facilitating meaningful involvement, despite evidence that these barriers can be addressed through appropriate support and adaptation (8,12). Gove et al. (8), in collaboration with Alzheimer Europe and the European Working Group of People with Dementia, emphasised the importance of meaningful involvement of PLwD, offering recommendations such as adapting communication methods, using accessible formats, providing training, and engaging PLwD from the earliest stages of research.

The Alzheimer Europe approach to PPI has a strong emphasis on ethical inclusion, empowerment, and co-production with people who have lived experience of dementia. Alzheimer Europe advocates for meaningful engagement that goes beyond tokenistic involvement, promoting active participation in priority setting, research design, data interpretation, and dissemination (17).

PPI activities are often poorly reported in research publications, limiting transparency and opportunities for learning (5). Inadequate reporting can contribute to research waste through inefficient resource use, poor study design, and duplication of effort (4).

Strengthening understanding of PPI in health economics requires transparent reporting and critical reflection on collaborative processes to support shared learning and inform future practice (18). Several frameworks and guidance documents support reflective practice and transparent reporting of PPI, including the Public Involvement Impact Assessment Framework (19), Guidance for Reporting Involvement of Patients and the Public (GRIPP2) (5), and the Public Involvement in Research Impact Toolkit (20).

Given these challenges and the need for clearer reporting of PPI processes, particularly in studies involving people living with dementia, this paper provides a detailed account of how PPI was embedded within an economic research study.

This methodological paper describes and critically evaluates the process and impact of involving people with lived experience of dementia in the development and refinement of a survey intended to identify research priorities for future economic evaluation of non-pharmacological therapies (NPTs) in dementia research. The paper focuses on the PPI processes used to shape the survey, rather than reporting findings from survey administration.

2 Methods

A bespoke PPI group was formed to inform and refine the design of a survey intended to identify research priorities and guide the selection of NPTs for economic evaluation within a wider study. The group contributed to survey development, participated in decision-making processes, and remained involved throughout different stages of the study. The PPI approach adopted was guided by published recommendations for meaningful engagement in dementia research (8).

This methodological work focused on the development and refinement of that survey, rather than reporting findings from survey administration. The work was conducted as part of the first author's doctoral thesis (21), in which economic evaluations of two NPTs for PLwD were undertaken. Ethical approval for the wider PhD study was granted by the University of Greenwich Research Ethics Committee (REF: UREC). As the PPI activities focused on collaborative contribution to the development and refinement of the survey, rather than participation as research subjects, these activities were considered outside the scope of formal research and therefore did not require separate ethical approval.

The initial draft survey was developed as part of the wider doctoral study exploring economic evaluation of NPTs for PLwD. Survey content was informed by existing literature on dementia care interventions, economic evaluation, and non-pharmacological therapies, alongside discussions within the wider research study team.

2.1 Recruitment

An advertisement was placed on the Dementia Engagement and Empowerment Project (DEEP) website to recruit a small group of volunteers for the PPI group. DEEP is a UK-based support network of people with lived experience of dementia or MCI, many of whom engage in research and advocacy activities (22). The advertisement, approved by the DEEP team, invited individuals to self-select by responding for more information.

2.2 Roles and responsibilities

The study was supported by NIHR ARC, which promotes public involvement and co-production in research. A local PPI coordinator from ARC provided expert guidance on recruitment of PLwD, appropriate payment rates, and suitable tasks for involvement, drawing on experience from NHS research settings. Initial tasks for the group included reviewing survey materials to ensure accessibility and relevance for participants. To ensure meaningful and impactful involvement rather than tokenistic participation, the study adopted the NIHR Standards for Public Involvement (23). The group was intended to take a leading role in meeting planning and format as part of the planned PPI methods. Opportunities for learning and support were built into the design, with plans for subsequent involvement in dissemination activities, such as developing lay summaries and contributing to conference presentations.

Following an expression of interest from the advertisement, interested participants received a plain-language summary of the survey and anticipated areas of involvement (Supplementary file 1). An initial online meeting provided an opportunity for contributors and the researcher to discuss the study and shape expectations around involvement. Contributors were informed that involvement would require approximately four to six hours in total, with flexibility to accommodate individual preferences and availability. The group contributed to the development and refinement of the draft survey by reviewing survey materials, sharing perspectives on the clarity and accessibility of language, suggesting modifications to question structure and layout, identifying potentially burdensome or confusing items, and recommending options to support participation for people with cognitive or technical challenges. Contributors were also invited to help shape how the survey findings could inform the

selection of non-pharmacological therapies for subsequent economic evaluation. All involvement activities were collaborative in nature, and participants were offered gift vouchers in recognition of their time, expertise, and lived experience.

2.3 Reimbursement

Guidance from the NIHR ARC team informed payment at £20 per hour; however, as PPI funding was not included in the original budget, support was secured from the Institute for Lifecourse Development at the University of Greenwich to provide shopping vouchers as a token of appreciation.

2.4 Group characteristics

The characteristics of the PPI group are shown below (Table 1). These characteristics aligned with UK national standards for PPI, which emphasise diversity and inclusion of individuals new to research (23). Cognitive function varied across members, reflecting different stages of dementia, and these differences were evident during group interactions. Research experience also varied: two members were highly research-active, having contributed to advisory groups and spoken at academic events, while the other two had no prior involvement in research. The group brought a range of life experiences, skills, and perspectives, contributing lived experience insights that informed the development and refinement of the study. Members drew on different diagnoses, cognitive challenges, and personal circumstances and previous experience of research involvement, enabling discussion of the survey from multiple viewpoints.

Table 1 Characteristics of the PPI Group

Characteristic	Details
Group size	4 members
Role	3 people living with dementia (PLwD); 1 spousal care partner
Gender	2 males; 2 females
Age range	67–80 years
Ethnicity	All White British
Location	Southeast England
Dementia diagnoses	Alzheimer's disease, young onset (n=1); Dementia (unspecified) (n=1); Mixed dementia (n=1); Care partner (n=1, no diagnosis)

2.5 PPI input into survey refinement

Group members contributed to the review and refinement of the draft survey. The original study design did not initially include a survey or PPI involvement; therefore, the group became involved after the initial draft survey development stages. As the study evolved, PPI was integrated, and members provided perspectives that informed and strengthened the development of the survey.

Feedback on the draft survey was gathered through online group discussions, email correspondence, and annotated review of survey materials. Notes from meetings and written contributor feedback were reviewed by the researcher and used to identify key areas for refinement relating to survey wording, structure, accessibility, and response options. Suggested changes were discussed and implemented iteratively across

successive versions of the survey. Revised drafts were subsequently circulated to contributors for further comment and refinement, enabling ongoing collaborative input throughout the survey development process.

The UK Standards for Public Involvement in Research (23) guided the design and reflection of PPI activities. These six standards: Inclusive Opportunities, Working Together, Support and Learning, Governance, Communication, and Impact, offer a framework for effective involvement and a tool for reflection on strengths and areas for improvement.

2.6 Meeting format

The lead author led the PPI group and acted as the main point of contact for members. Potential barriers to involvement, such as meeting accessibility, payment, and information sharing, were identified and mitigated through flexibility and choice. Although group members and the researcher were geographically close, contributors preferred online meetings, likely influenced by residual concerns following the COVID-19 pandemic. Consequently, all meetings were held via Zoom between August and September 2022. Meetings lasted one hour and included a short break to support engagement.

Accessibility was prioritised to support inclusive involvement. Group members set the pace of meetings, and documents were shared in advance to allow adequate time for reflection. Meeting formats were adapted in response to contributors' needs and preferences; screen-sharing was avoided because members found it difficult to follow; email communication was preferred for reviewing materials. Individual needs were

considered throughout, and members were consulted on how interactions could be made more accessible and effective (6).

The first meeting focused on introductions, roles, responsibilities, and expectations. While sharing personal details was optional, members voluntarily shared their experiences of dementia, which is recognised as a key motivator for PPI participation (24). Members already knew each other through DEEP, which facilitated rapport. They consented verbally to share demographic information and discussed prior research experience and use of dementia therapies. All attendees agreed to become public contributors and were reminded they could withdraw at any time (8).

Following this, members were emailed a link to the draft online survey for testing and review. This step ensured accessibility and gathered feedback from people with lived experience. Members held an independent meeting to discuss their reviews before a second meeting with the researcher to provide collective feedback. They tested the survey via a separate link, and responses were deleted after review, consistent with common PPI practice (8,25). Meeting notes documented discussions and decisions throughout.

3 Results

3.1 Impact

Contributor feedback informed iterative revisions to survey wording, structure, accessibility, and response options, resulting in several substantive refinements to the survey design. Feedback from the PPI group informed significant improvements to the survey format and design (Supplementary file 2). Contributors highlighted that the

initial draft was considered lengthy, with excessive text that could overwhelm PLwD. In response, a modified version tailored for PLwD and family care partners was developed, incorporating changes to layout and appearance to enhance readability and comprehension. The amended survey was approved by UREB and tested by the group, who confirmed that the revised version was much improved and ready for distribution. Their test responses were deleted and excluded from data analysis.

Based on contributor input, an option to complete the survey via telephone or online meeting was introduced in the participant information sheet (Supplementary file 3). This provided additional support for participants who might experience cognitive or technical challenges, enabling participation without relying solely on care partners. One contributor emphasised that this option was important in supporting people to complete the survey independently, without relying on assistance from friends or family members.

Feedback on the impact of PPI contributions was shared verbally and via email, with specific acknowledgment of contributors' suggestions and how these informed subsequent revisions. Group members described valuing the opportunity to participate, reflecting findings from previous research that motivations for involvement can include contributing to research, making a difference and staying socially and intellectually engaged (26).

3.2 Engagement and reimbursement

Once the survey results had been analysed a newsletter was developed and emailed to PPI group members to share study progress and findings. The newsletter included a link to the published systematic review, summarised survey results, and outlined plans for the next study phase. Each PPI contributor spent approximately three hours

on the study and received £60 in shopping vouchers as a token of appreciation for their involvement. Vouchers were sent after completion of survey reviews and were gratefully accepted. Contributors were asked whether they had incurred any expenses during participation; none requested reimbursement, as all meetings were conducted online.

3.3 Reporting and transparency

For this study, the GRIPP2 short form was used to evaluate and report PPI activities (Table 2), following recommendations for studies where PPI is not the primary focus (27). All elements of the tool have been addressed and discussed in this paper to ensure transparency and contribute to the growing evidence base on effective PPI practice.

Table 2 GRIPP2 – Short Form "PPI group involvement to develop a survey to determine research priorities in health economics"

Section and topic	Item
Aim	• A dedicated PPI group was established to inform the development and refinement of a survey designed to identify dementia research priorities. • Their input was intended to guide the selection of non-pharmacological therapies (NPTs) for subsequent economic evaluation.
Methods	• Feedback was gathered through online discussions, email correspondence, and annotated review of survey

	drafts. • Contributors informed iterative revisions to survey structure, content, accessibility, and response options across successive versions of the survey. • Revised drafts were circulated to contributors for further comment and refinement throughout the development process.
Study Results	• Contributor feedback identified concerns regarding survey length, density, clarity, and accessibility, informing substantive revisions to wording, layout, and structure. • Iterative revisions resulted in a streamlined version tailored for PLwD and care partners, with simplified language, revised formatting, and clearer instructions to improve readability and comprehension. • Following ethical approval of amendments, contributors reviewed the revised survey and confirmed that the amended version was more accessible and suitable for distribution. • Contributor feedback also informed the introduction of telephone/online completion options to improve inclusivity for individuals with cognitive or technical challenges.
Discussion and conclusions	• Contributor perspectives informed multiple stages of survey refinement, shaping decisions relating to accessibility, wording, structure, and participation options.

	• Maintaining engagement across the multi-year timeline required flexibility, and ongoing adaptation to contributors' changing circumstances and availability.
Reflections/ critical perspective	• Contributors described the experience as rewarding and meaningful, consistent with wider evidence that PLwD value opportunities to contribute to and shape research. • Earlier involvement may have enabled greater collaboration and co-design; future studies should consider providing accessible introduction to health economic concepts and clearer pathways for involvement across later stages of research, including analysis and dissemination.

4 Discussion

4.1 Principal findings

The survey was significantly improved through the involvement of the PPI group, consistent with evidence that PPI enhances trial design and participant-facing materials (28). Although the group was not engaged from the outset, its contributions were highly valuable. Walter et al. (6) emphasise that it is never too late to initiate PPI, and this study supports that recommendation. PPI contributors played a vital role in shaping the survey by offering insights grounded in lived experience, strengthening the research despite acknowledged limitations.

Early involvement of public contributors would have supported a more co-productive approach; however, this was not possible due to the fixed design and timelines of the overarching doctoral study. As a result, PPI was introduced once the study was underway, which limited opportunities for shaping the initial research questions.

4.2 Strengths and limitations

The study highlighted several strengths of collaborative PPI involvement alongside practical and methodological limitations relevant to long-term dementia research.

Sustaining engagement over the three-year duration proved challenging. The intention was to support broader and more sustained collaboration with the PPI group as the study progressed, enabling greater co-production across different stages of the research. Reduced involvement following the survey review may have reflected declining cognition, worsening symptoms, or changing personal circumstances among some members. More sustained involvement in technical aspects of the study may have benefited from accessible introductory support in health economic concepts and terminology for PPI contributors, which was not provided but should be considered in future studies to support meaningful participation and shared decision-making. This may also require training and reflective practice for health economists and researchers to support accessible, inclusive, and collaborative PPI approaches.

On reflection, issuing shopping vouchers immediately after survey review may have signalled the end of involvement to contributors, making re-engagement difficult. This highlights the importance of planning for sustained engagement in long-term studies. Previous research emphasises that ongoing involvement and engagement are critical for successful PPI in economic evaluations (12). Initially, the spousal care partner was

expected to play a supportive role; however, they became actively involved and provided valuable feedback based on their lived experience. Their contributions were acknowledged, and they received shopping vouchers alongside PLwD members.

The PPI group lacked ethnic diversity, with all members identifying as White British. Although steps were taken to promote inclusivity, such as recruitment via Join Dementia Research, offering translations, and providing accessible materials, representation from ethnic minority groups among both PPI members and survey respondents remained limited. Additionally, sexuality data were not collected, constraining the inclusiveness of the sample. Future research should prioritise more diverse recruitment strategies, alongside broader demographic data collection, to strengthen representation and relevance.

4.3 Implications for future research and practice

The invaluable contributions of the PPI group have been acknowledged verbally, in a recent poster presentation, and at conferences, with the agreement of group members. While PPI contributors have not yet presented at conferences, this remains a potential avenue for future dissemination activities to further enhance co-production and visibility of their involvement.

This methodological paper demonstrates that involving people with lived experience of dementia can meaningfully inform the development and refinement of research tools within dementia health economics research. Although involvement began after the initial stages of the study, contributor perspectives informed important improvements to accessibility, structure, and participation options. Future work should continue to

strengthen collaborative and sustained approaches to PPI within economic evaluation research.

5 Conclusion

This study demonstrates the value of involving people with lived experience of dementia in economic research, even when involvement begins later in the research process. Contributor perspectives informed important improvements to the accessibility, clarity, and usability of the survey, ensuring it was better tailored to the needs of PLwD and care partners. Although challenges were encountered in sustaining engagement over a long study timeline and achieving broader representation within the group, the experience highlights that meaningful involvement is possible and impactful, even in complex research areas such as economic evaluation. Future work should prioritise earlier and sustained involvement, accessible support for participation in technical aspects of research, and approaches that strengthen long-term engagement and representation. Transparent reporting and critical reflection on PPI processes, including the use of frameworks such as GRIPP2, may support shared learning and inform future practice.

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Their lived experience perspectives informed important refinements to the accessibility, structure, and relevance of the survey and wider study.

5.2 Declaration of interest statement

The authors report there are no competing interests to declare.

5.3 Availability of data and material

No datasets were generated or analysed for this study. The patient and public involvement (PPI) activities focused on collaborative contribution to the development and refinement of the survey and did not involve the collection of research data. Materials developed during the study (e.g. survey drafts) are available from the corresponding author on reasonable request.

5.4 Ethics approval

Ethical approval for the wider doctoral study was granted by the University of Greenwich Research Ethics Board (UREB; reference number: UREC). The PPI activities reported in this paper focused on collaborative contribution to the development and refinement of the survey and did not involve the collection of research data from participants; therefore, they were considered public involvement rather than research and did not require separate ethical approval, in accordance with UK guidance. All procedures were conducted in line with the ethical standards of the institutional research committee and with the principles of the Declaration of Helsinki and its later amendments or comparable ethical standards.

5.5 Consent to participate

Not applicable

5.6 Consent for publication

Not applicable

5.7 Code availability

Not applicable

5.8 Author contributions

GE led the development of the survey, designed and delivered the patient and public involvement (PPI) activities, conducted the analysis, and drafted the manuscript.

PM, RP, and CS contributed to the design of the study and the development of the survey, provided methodological guidance, and critically reviewed the manuscript for important intellectual content.

All authors meet the International Committee for Medical Journal Editors (ICMJE) authorship criteria, contributed to the work described, and read and approved the final manuscript.

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