Reflections on involving people living with dementia in research in the Australian context

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Funding information
National Health & Medical Research Council; Dementia Australia; HammondCare; Helping Hand Aged Care; Brightwater Group

Contemporary developments in dementia research have emphasised including the experiences and perspectives of people living with dementia, and care-partners, in all stages of research [1]. This signals a shift from previous practice, in which ‘consumers’ (as they are currently identified in the Australian context) were typically included as passive subjects in research that was conducted ‘on’ or ‘about’ them, rather than ‘by’ or ‘with’ them [2]. The recent Alzheimer Europe position statement on involving people with dementia in research asserts the rights of community members, including people living with dementia, to have an active role in determining how public research funds are directed [2,3], with research organisations having a responsibility to address the cultural, social and economic barriers, which (along with illness-related impacts) can limit the full involvement of people with dementia as active participants, advisors and co-researchers [2].

This article outlines the process of consumer involvement during a three-year research project investigating supported decision-making among people living with dementia [4]. We reflect on our experiences with this process, from the perspective of a person living with dementia and a researcher. Based on these practical experiences of what worked, and areas for improvement, we make a number of suggestions for developing practice in the area of consumer involvement in dementia research in the Australian context.

1 | THE SUPPORTED DECISION-MAKING IN DEMENTIA PROJECT

The supported decision-making in dementia project was stimulated by Australia’s international human rights obligations under the United Nations Convention on the Rights of Persons with Disabilities, and aimed to document the current legislative and policy situation as well as the perspectives of people living with dementia, care-partners and practitioners on this issue. We wanted to effectively bring these voices ‘to the table’, acknowledging the expertise that comes from lived experience, on an equal footing to that derived from training and academia [4]. Additional objectives included developing practical resources to assist practitioners and the community in understanding and implementing supported decision-making.

The consumer involvement process took a range of forms throughout the project. These included mandatory and researcher-initiated processes, with varying degrees of structure. For example, a mandatory process of consumer consultation was embedded within the Cognitive Decline Partnership Centre’s governance structure during the project development stage. This included a requirement for the project application to be formally endorsed by the assigned consumer representative prior to qualifying for funding approval. Other processes were researcher-initiated and less structured, such as consultation with a group of people living with dementia.
with dementia and care-partners to inform the implementation of the ‘process consent’ approach to obtaining consent for research participation [5]. Open-ended consultation sensitised the researchers to key issues and informed the study design and application for human research ethics approval. The study was approved by the University of Western Australia Human Research Ethics Committee (RA/4/1/8307).

The most substantial element of consumer involvement in the project was a structured and researcher-initiated process of advisory group meetings, run in each of the three states in which the project was active, and supported by aged care service provider organisations who partnered on the project. These advisory groups were termed ‘supported decision-making interest groups’, and aimed to bring together consumer, industry and advocacy perspectives, to advise the research team on the design and conduct of the research and the practical implementation of study findings. The groups ranged in size from six to fifteen members, and each included a person living with dementia and a current or former care-partner of a person living with dementia. Each group discussed and agreed upon their own terms of reference. The quarterly meetings ran for two to three hours and were facilitated, recorded and minuted, with aggregated feedback provided to the broader research team. Interest groups were explicitly established in an advisory capacity. Their input was documented and respected, but the research team took responsibility for decisions to implement this input. Interest group members were formally acknowledged in project presentations and publications; however, it was clarified that members would not have access to raw research data and were not eligible to be research participants and that membership did not imply endorsement of the study findings or responsibility for the published materials. The advisory input from interest group members was overseen by a human research ethics committee; however, meeting participation did not require a formal consent process.

Given our aim of bringing diverse perspectives and voices ‘to the table’, the research team made the decision to include consumer members as part of each of the interest groups, rather than separating consumers into different groups. A range of supports and processes were implemented to enable the active involvement of consumer interest group members. These included the following:

- a nominal fee to cover time associated with attending the meeting;
- encouragement to attend meetings with a support person;
- accessible meeting materials provided in advance, which defined key discussion topics and questions, used larger font, included graphics and space for participant comments, and were provided to consumer members in hard copy by post;
- strategic use of full-group and small-group discussion formats for seeking feedback;
- regular breaks in meeting agenda;
- a consensus-based approach to running the meetings, which encouraged a range of perspectives; and
- agreements about the confidential nature of the meeting discussions and materials.

At the time of writing, the three interest groups are still active, and currently providing feedback to the research team on disseminating research outputs and implementing the study findings.

The following two sections provide reflections on the process from the perspective of a person living with dementia and a researcher respectively.

2 | PERSPECTIVE OF A PERSON LIVING WITH DEMENTIA

I was invited to become a member of one of the supported decision-making ‘interest groups’ in early 2017. While I had previously been approached to participate in other research projects as a ‘research subject’, this was my first chance to be involved at a higher level. From a personal perspective, I jumped at the chance to be useful again. Having to withdraw from the workforce following my diagnosis with dementia was a severe blow. This opportunity to get out, meet people and contribute restored my self-esteem and gave me a sense of purpose. I am particularly passionate about this project because I have personal experience in my family of caring for my mother-in-law, who also had a cognitive impairment (probable dementia) in her later life. As a family, we grappled with how best to help her participate in decisions, both big and small. We desperately wanted to help her to be involved, but we had no understanding about how to put supported decision-making into practice. This project has given me a deeper understanding of how supported decision-making works, and a sense of self-esteem that comes from being able to see my suggestions being taken on board.

In the case of this project, I have felt supported and respected in my involvement. Working alongside a group of dedicated and enthusiastic practitioners and researchers has been rewarding. I was encouraged to attend with support people and family members when I felt this was necessary. During the early part of my involvement in the project, my feedback led to changes in the recruitment methods, as well as adjustments to the wording of some questions. When it came time to make decisions about the practical resources to be developed from the project, I was able to advocate that the project consider the needs of people with younger onset dementia, and ensure that the emphasis was not too heavily focused on the aged care sector. There has been learning on both sides, and this has benefited the project.
In reflecting on what could have been better, resourcing is always an issue. Additional assistance with transportation would assist me, given that I have a long commute into the city to attend the meetings. While I was supported in my contribution to the group, as the only person with dementia in the group, I initially found the meetings somewhat intimidating. In some of the small-group discussion situations, I found the compassion of other group members distracting, and relied on my own professional experience to stay ‘on task’ and model the behaviour that I wanted to see. While not everyone would react in this way, it is something that researchers need to be aware of when setting up such groups.

3 | A RESEARCHER PERSPECTIVE

From a researcher's point of view, my first experience of an ongoing process of consumer involvement in this project has been invaluable, and taught me a lot. I have seen the need to develop and maintain strong, collaborative relationships with consumers involved in the project. Not only has this assisted in navigating the differences of opinion that inevitably emerge in complex projects such as this, these relationships have also connected me to the real-world outcomes, fuelled my motivation for the work and provided a sense of reward from our collaborative achievements. I have observed how the authentic involvement of consumers from the earliest stages of the project has yielded benefits, including persuading funding bodies and ethics committees about the importance of the project and the appropriateness of the proposed methods. I have also developed an appreciation for how researchers need to advocate for adequate resourcing for consumer involvement, and make the case for streamlined processes that reduce administrative burden for consumers. As researchers, we need to develop our own practice in the ‘craft’ of consumer involvement, in the same way that we would develop skills in data analysis or academic writing.

4 | RECOMMENDATIONS

While the process of consumer involvement in this project has been sufficiently structured, and mostly successful, this is by no means always the case. Further, it did not occur across all stages, but instead was focused on processes of advice, interpretation and governance. We recommend that guidelines for researchers could be developed (or adapted from existing material), with input from people living with dementia, and care-partners, who have experience with involvement in research. These guidelines should advise researchers on the full range of consumer involvement activities, and provide best practice examples as identified by consumers. The benefits of such guidelines will be that both consumers and researchers can work together safely and productively, and help the Australian dementia research community to quickly move towards current international best practice standards in consumer involvement [3].

ACKNOWLEDGEMENTS

The authors acknowledge the contribution of funding bodies (National Health & Medical Research Council) and funding partners (Dementia Australia, HammondCare, Helping Hand Aged Care, Brightwater Group). The contents of the above materials are solely the responsibility of the individual authors identified and do not reflect the views of the funding bodies or the funding partners. The authors declare no conflicts of interest.

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How to cite this article: Flavin T, Sinclair C. Reflections on involving people living with dementia in research in the Australian context. Australas J Ageing. 2019;38(Suppl. 2):6–8. https://doi.org/10.1111/ajag.12596