**Research**

Partnering with people with dementia and their care partners, aged care service experts, policymakers and academics: A co-design process

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**Objective:** To describe the co-design process in a project that “evaluated how the key worker role can best support people living with dementia in the community setting.”

**Methods:** People with dementia, care-partners, aged-care service experts, policymakers and academics utilised a co-design process to undertake a systematic literature review and a qualitative evaluation study.

**Results:** The development of a successful co-design process that includes people living with dementia and their care-partners (“consumers”) at all stages of the research process and addresses their individual needs.

**Conclusions:** The co-design approach utilised in this project provided support, for consumers living in the community to be fully involved in the research design, conduct and plans for dissemination and implementation of the findings. Consequently, the research outcomes are based on solid evidence and consumer need. Additionally, a successful model for supporting consumers to facilitate their involvement in all aspects of the research process, was developed.

**Keywords**
co-design, consumers, dementia, qualitative research, support worker

1 | INTRODUCTION

In line with the National Health and Medical Research Council (NHMRC) Statement on Consumer and Community Involvement in Health and Medical Research (NHMRC\(^1\)) and to meet its aim of improving the lives of people with dementia, the Cognitive Decline Partnership Centre (CDPC) brought together consumer representatives, industry partners, researchers and clinicians to develop a program of research. The focus for all involved was to actively involve consumers and community representatives to ensure that the research questions, design and findings were applicable, relevant and beneficial to people living with dementia and their care-partners.\(^1\)

In 2012, it was estimated that approximately 425 416 Australians were living with dementia\(^2\) and an estimated 1.2 million people were caring for a person with dementia.\(^3\) By 2016, dementia was the second leading cause of...
death amongst Australians and the main cause of death for women in Australia. Dementia is usually gradual, irreversible and progressive in nature, and the associated functional decline inevitably leads to decreasing independence in areas of daily living. In order for a person experiencing dementia and their care-partners to access appropriate health and social care services, a formal dementia diagnosis is required. A delay in diagnosis not only prevents access to support services but also increases risk of inappropriate management, poor psychological adjustment and reduced coping capacity and ability to make future plans. To mitigate these risks, a variety of support worker roles have been implemented worldwide.

The purpose of the “support worker” is assisting people with dementia and their care-partners adjusting to living with dementia, navigating the health and aged-care system and accessing services, information and support. Due to the lack of evidence of the efficacy for the support worker roles, the “The Key worker Role for People with Dementia and Their Carers” was identified as a priority research activity under the CDPC theme “Pathways and Service Navigation”. A 2-year project consisting of a systematic review of international literature focusing on support worker roles followed by a qualitative evaluation of dementia support workers roles operating across Australia was developed, and completed, with the aims to:

- Assess how the support worker role can best assist community-dwelling people with dementia and their care-partners.
- Develop recommendations to inform policy and practice.
- Provide a framework for implementing support worker models within primary health networks (PHNs), community groups, and advocacy and other organisations including residential aged-care providers.

Results from the systematic review of literature revealed that the essential components of support worker models that demonstrated positive impact and improved quality of life for people with dementia and their care-partners included the following: (a) long-term intervention; face-to-face contact; (b) individualised education and support; (c) multidisciplinary teams; (d) collaborative input; (e) a health or clinical background of support workers; (f) ongoing follow-up; and (g) inter-professional and inter-sectoral collaborations. These results together with the findings from the evaluation of Australian support worker models informed the development of an “Overarching philosophy and framework” for an optimal “key worker” support model and a set of recommendations to inform future policy and practice. These recommendations included the following:

- Exploring the options for increasing access to dementia support workers within consumer-directed care.
- Trialling and aligning the dementia support worker within PHNs, particularly in rural and remote areas.
- Addressing issues of accessibility for diverse groups.
- Raising awareness of the “support worker” model and what it offers.
- Ensuring continuous service improvement for existing services and any new services, including consumer feedback.
- Utilising the “key worker framework” as a human resources recruitment, service review and development tool.

While the importance of consumer involvement in the development of research and health-care policy has been acknowledged, there has been little research that delineates the best way of involving consumers. To address this deficit, this paper outlines the co-design process that we developed and utilised to include people living with dementia and care-partners of people with dementia at all stages of the research evaluation project.
2 | METHODS

Prior to commencement of the study, the chief investigator met with future project partners from the aged-care services industry and a dementia advocacy group for the purpose of the development of an inclusive co-design approach to the evaluation and governance of the study. This inclusive approach was established through the setting up of an expert working group and reference group.

The expert working and reference groups consisted of the following: (a) consumer volunteers; (b) residential aged-care service provider (“RACP”) representatives; (c) policymakers; and (d) academics. Their backgrounds included the following: people with dementia and care-partners of people with dementia; well-being and dementia support co-ordinators/consultants/dementia key worker; senior members of aged-care services’ research and development/research design teams; national dementia policy advisors/officers, government policy officers; National Cross Cultural Dementia Network and Ethnic Communities Council representatives, a general practitioner with expertise in dementia-related research, a Medicare Local Aged-Care representative and academic researchers with expertise in dementia research including one who also had a background in health services development.

As a partner in the CDPC, Alzheimer’s Australia (Now known as Dementia Australia) provided access to the Alzheimer’s Australia Consumer Dementia Research Network (now the Dementia Australia Consumer Network) members as consumer representatives. As the research was national, attempts were made to avoid bias through ensuring RACP and consumer representation from multiple states.

2.1 | Working group

Consumers participated in the working group in order to share their expertise and lived experience of dementia, guide the development of an overarching evaluation philosophy, assist in refining the protocol for undertaking the systematic review, devise interview questions for a range of groups (People with dementia and/or care-partners/family members, support workers, organisations that provide support workers) and analyse the literature review outcomes and interview data (Table 1).

2.2 | Reference group

The primary purpose of the reference group was to support the working group. While the reference group was not a decision-making body responsible for management of the project, members of the reference group provided advice in regard to feasibility, applicability, policy, funding implications and appropriate language utilisation for reporting outcomes and recommendations (Table 1).

2.3 | Teleconferences and face-to-face meetings

Each group met for regular monthly or quarterly teleconferences (Working group met on a monthly basis; reference group on a quarterly basis), and both groups came together for two interactive face-to-face annual workshops during the course of the 2-year project. The cost of airfares and accommodation for consumers and partners, and for other participants, to attend the workshops was funded through the project if the costs were ineligible to be funded by an organisation. These meetings were structured with a set agenda and considered monitoring by the meetings’ Chair to guarantee that everyone, including consumers, had an opportunity to participate equally.

3 | RESULTS

The co-design approach to undertaking the research study included working alongside people with dementia and/or their care-partners as consumer representatives for the purpose of generating ideas throughout the entirety of the project timelines. The research team worked with people with dementia and/or their care-partners to ensure that consumer representatives were embedded at research governance levels, that all members were listened to, received information that was accessible and suited to their individual needs and that involvement was not unreasonably costly (see Figure 1).

At the inaugural working group meeting, members, including consumer representatives, determined the following: (a) the project milestones; (b) evidence for achievements; (c) reference group membership and terms of reference; and (d) agendas for face-to-face meetings of the working and reference groups. The terms of reference defined the following: (a) the purpose of the group; (b) what was expected from members; (c) the objectives and areas that the research would explore; (d) a project timeline including an estimate of the milestones; and (e) proposed meeting dates and agendas. The members of the working and reference groups stated that their involvement in the process outlined above provided them with a better understanding of the value of consumers in the research project.

3.1 | Teleconferences

Working and reference group teleconferences focused on the progress and aims of the study with the aim of guaranteeing everyone, including consumer representatives, an opportunity to participate equally which was identified as critical for consumer involvement. One industry partner, with a senior role, commented she:
really enjoyed the meetings, sometimes things were explained so well that it highlighted a lack of knowledge on my part … dementia friendliness is useful to all of us.

3.2 | Face-to-face meetings

To assist workshop participants in developing a framework and to evaluate current Australian support worker roles, a summary document of results from the systematic literature review was provided to attendees two weeks prior to the first face-to-face meeting (see Table 2).

A list summarising current support worker models identified as operating across Australia was also distributed to provide participants with time for personal and representative reflections and insights into the models to highlight other models not already identified.

To ensure feedback from the participants was balanced, the format for the second face-to-face workshop involved the setting up of groups’ representative of all member cohorts. Each group was provided with a selection of summaries of interviews that were undertaken with consumers, support workers and organisations providing support worker models. Participants then mapped the various models against both the overarching philosophical support worker framework and the framework for evaluating the “key worker” role (support for people with dementia and their care-partner living in the community) that they had developed during the first face-to-face workshop (see Table 2).

The overall results from the group work were then later collated by the research team, written up as a draft report and circulated to all members of the working and reference groups for their feedback. All responses were incorporated into a final report describing the study findings and recommendations for policy change.

The presence of people with dementia and/or their care-partners of people living with dementia as consumer representatives at the two annual face-to-face workshops was identified as having been an important step to ensure the lived experience of consumers adequately influenced the direction of the research and whether a proposed optimal model of support would in fact meet the various needs of both those living with dementia and their care-partners. One workshop participant living with dementia described the value of consumer representation at the monthly teleconferences and especially the face-to-face workshops as:

![Model for successful inclusion of consumers and community representatives (consumer representatives) in research](image_url)
Being involved in this project was an example of truly meaningful and tangible engagement. Not once did I feel like a tick box, but rather that all consumers were fully valued, and our input was useful and included. Importantly, it was imperative the design of the support worker role included consumers, who are clearly the end users.

4 | DISCUSSION

There is a growing awareness of the importance of including people with dementia and care-partners in research; however, the lack of information on how to include them poses a challenge to researchers.\textsuperscript{18–20} The co-design research process focussing on consumer involvement in the practice and governance of the research utilised throughout the duration of our study provides an innovative model on how to successfully address this challenge.

The social participation during the face-to-face meetings afforded an opportunity for the research team to understand the needs of people with dementia and their care-partners, to gain deeper insight into the lived experience of dementia.

Emphasis on consumer and community involvement not only challenged the way health professionals and researchers undertook this research, it resulted in their professional growth which included the following: an increased respect for people living with dementia and the care-partners of people living with dementia, gained from their broader knowledge of the day to day reality of living with dementia; acknowledgement of the importance of language use when talking about someone with dementia; and a focus on how “ability” and meaningful engagement can lead to improvement in the quality of life of a person living with dementia.

4.1 | Weaknesses and strengths

Due to inexperience with how consumer representative engagement would work in practice, at the commencement of the project the funding structure for consumer reimbursement was under budgeted and although project funds covered the cost of travel and accommodation to attend the annual face-to-face workshops, the project was at times reliant on the generosity of the consumers to participate in a volunteer capacity and for incidental out of pocket expenses.

The CDPC research activity’s successful process of including consumers in the study working and reference groups, and recognising the value of consumers’ input from the initial stages, is now endorsed by the CDPC as a useful model for future projects in dementia care research.

5 | CONCLUSIONS

The co-design aspect of the “evaluation of the key worker role” project has not only led to a model for the successful inclusion of consumers in research but it has also ensured that the proposed optimal model of “key worker” support for people with dementia and their care-partners has a solid evidence base and reflects the support needs of people with dementia, their family and care-partner living in the community. A further outcome from the co-designed research study has been the development of a cluster randomised controlled trial protocol to evaluate the efficacy of the new “optimal support worker” model that resulted from this evaluation study, including whether the model is effective in improving the emotional and psychological well-being of people living with dementia and their care-partners and whether it leads to a delay in placement into residential aged-care.\textsuperscript{16} The team is currently seeking funding to undertake this evaluation.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.
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