

RESEARCH ARTICLE

Co-design of medication management guidance tools for people living with dementia and carers at discharge

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Funding information

Medical Research Future Fund; Dementia Centre for Research Collaboration; Dementia Australia Research Fund

Abstract

INTRODUCTION: People with dementia and carers face challenges in understanding and managing medications at discharge. This study aimed to develop user-centered, co-designed medication management guidance tools to enhance medication management literacy post-hospitalization for these populations.

METHODS: A four-phase, multi-methods study integrating experience-based co-design: (1) literature review, qualitative study, and survey; (2) expert advisory panels involving people with dementia; (3) focus groups with people with dementia, carers, and healthcare professionals; and (4) quantitative readability and suitability analysis.

RESULTS: Two tools were developed: a simplified medication management guide for people with dementia and a carer-focused guide. Topics included shared decision-making, informed consent, and medications that can affect cognition. Participants valued the use of simple and active language, goal-of-care discussions, and the right to second opinion. Tools were acceptable for use from admission and during hospitalization.

DISCUSSION: This study addresses gaps in medication related health literacy tools for dementia care, offering a framework for developing similar resources.

KEYWORDS

care coordination, dementia care, health literacy, patient communication, shared decision making

Highlights

- Medication management guidance tools have not included people living with dementia or their carers in their development.
- This study is the first to describe the co-design of medication management guidance tools for people with dementia.
- Two tools were generated, one for people with dementia and one for carers to extend their agency.

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- This co-design study can serve as a framework to inform the development of future tools for people with dementia and carers.

1 | BACKGROUND

People with dementia and carers use various sources and tools to fill their gaps in health knowledge and have expressed a preference for tools that are tailored to their needs.¹ However, efforts to collaboratively design tools with people impacted by dementia (people with dementia and carers), to enhance their health literacy and care coordination have been lacking.² Co-designing tools yields user-centered outcomes, ensures priorities are addressed, and keeps content relevant, thereby increasing adoption in routine practice.³ Often, the involvement of people impacted by dementia in the design process is frequently overlooked or delayed until the later stages of development.^{4,5} There are various approaches to co-design that can be adopted for tool development, however methodological application of co-design adapted for people impacted by dementia is needed to ensure meaningful engagement with the original principles of co-design, specifically the distribution of power in research.³

A critical instance highlighting the necessity for co-design tools to enhance health literacy among people impacted by dementia is the provision of medication management guidance upon discharge. People with dementia often have multiple health conditions, leading to complex care in medication management, placing them at higher risk of hospitalization due to medication-related harm.^{6,7} Transitions of care, such as hospital discharge, are commonly associated with fractured communication and changes in medications, dosages, and administration schedules.⁸ The World Health Organization has highlighted the need to improve health literacy to ensure both successful navigation of care transitions and understanding of how to manage medications safely.⁹ However, previous studies have indicated that people with dementia and their carers typically receive limited guidance on medication management both during hospitalization and at discharge,^{10,11} leading to poor medication management which increases the burden and stress for people with dementia and their carers.¹² Practical guidance for co-designing tools to provide comprehensive medication management guidance to people impacted by dementia and improve care coordination is limited. The study aim was to describe the development of co-designed medication management tools for both people with dementia and carers during hospitalization and at discharge.

2 | METHODS

2.1 | Study design

This multi-methods study integrated four phases in a sequential explanatory process using the principles of experience-based co-design to develop and refine medication management guidance tools,

one for people with dementia and one for carers (Figure 1).^{13–16} The tools were modified in each phase based on feedback gathered and refined using graphic designers. Ethics approval was granted by the University of Sydney Human Research Ethics Committee, project number 2022/539.

2.2 | Research development group

A seven-member research development group was established at the beginning of the study comprising: academic experts on dementia, medication safety, and person-centered care; healthcare professionals (pharmacists, academic nurses); one person with dementia, and one carer. Co-design was employed with people impacted by dementia acting as partners throughout the full research process from initial content design to final tool analysis.^{5,15} The group were actively involved across all stages of the research process. The two tool prototypes were reviewed by the group at each stage.

2.3 | Phase 1: Identifying priorities for content

The priorities for what information should be contained within the tools were identified from the findings of work conducted by the research team: (1) a scoping review and environmental scan of available hardcopy and online tools for people with dementia and carers²; (2) a qualitative study of the experiences of carers across Australia regarding medication management advice they received at hospital discharge for people with dementia¹¹; and (3) a survey of carers characterizing their experiences of medication management guidance.¹⁷ The findings from these studies were content analyzed by members of the research team (M.J.S., A.J.C., D.G.) to derive the priority areas for medication management guidance during hospitalization and at discharge. The initial draft of the tool, containing the topics and further detailed textual information was developed by M.J.S. and A.J.C. (Data S1). The initial draft was sent to the entire research team for feedback for further refinement.

2.4 | Phase 2: Developing tool prototypes

The first draft of the tool from Phase 1 was presented, as a Word document, to two dementia expert advisory panels in Sydney, Australia: the Sydney Dementia Network's Lived Experience Expert Advisory Panel (LEEAP), and the Sydney Health Partners' Clinical Academic Group (CAG), with the identified topics arranged to align with the individual's hospital journey, along with detailed textual information (Data S1).

RESEARCH IN CONTEXT

- 1. Systematic review:** We conducted a qualitative study which explored the experiences of 31 carers of people with dementia across Australia about medication management advice they received at hospital discharge for people with dementia. The study identified that carers experienced: (1) insufficient medication management information at discharge; (2) limited involvement in decisions about medication management; and (3) challenges in obtaining medication supply at discharge. It was further reported that carers would like to access tailored medication information to support decision making. Secondly, we conducted a survey of 185 carers to characterize their experiences of medication management guidance at discharge, distributed between March and November 2022. The study found there was inadequate provision of information on potential drug interactions, possible side-effects of medications, and medications that may impact cognition. Finally, a systematic search of MEDLINE, Embase, CINAHL, and PsycINFO was performed in May 2022 to identify and evaluate tools for carers of people with dementia that provide guidance in medication management. Fifteen tools were identified, which largely focused on medication administration with limited discussion of shared decision-making. Current tools do not appear to have included people living with dementia or their carers in their development and did not address high-risk care settings.
- 2. Interpretation:** This study is the first to describe the co-design of novel medication management guidance tools specifically targeted for people with dementia and carers to improve health literacy during hospitalization and at discharge. Two tools were generated, one for people with dementia and one for carers that addresses their key priorities and provides support in care coordination and decision making. Based on previous studies and feedback from experts on dementia and people with lived experience of dementia, it was determined that the tools should include six topics to facilitate self-determination and confidence in medication management during hospitalization and at discharge. These were: (1) discharge checklist; (2) the role of the person with dementia and/or carer in medication management processes during hospitalization; (3) shared decision-making, (4) medications that impact cognition, (5) questions the person with dementia and/or carer may want to ask healthcare professionals during hospitalization, and (6) post-discharge support services.
- 3. Future directions:** This co-design study can serve as a framework to inform the development of future tools for people with dementia and carers that addresses their unique needs, so they are equipped with the knowledge to ensure safer and coordinated care.

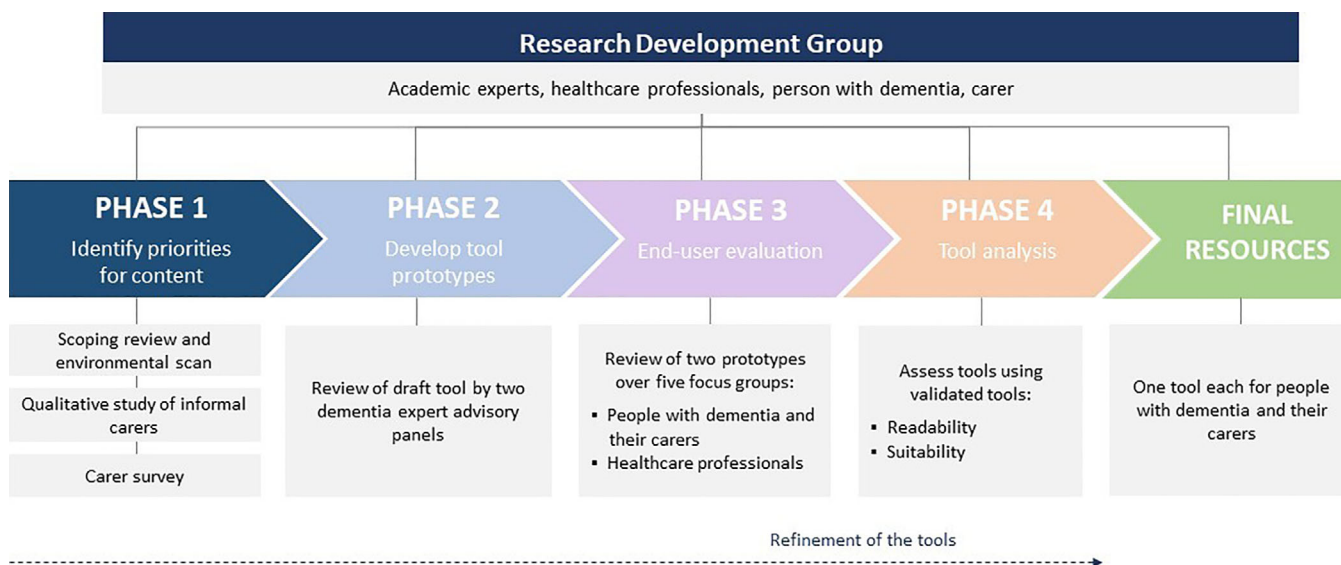


FIGURE 1 Project flowchart.

The LEEAP included people with dementia, carers, and former carers, whereas the CAG included healthcare professionals and academics who practice and research geriatric care and dementia. This method was chosen to facilitate iterative refinement of the content and wording based on expert feedback. The meetings were facilitated by MS and conducted via teleconferencing using Zoom and the feedback was recorded. Each session was approximately 45 min in duration.

The initial draft of the tool was circulated to the panel members via e-mail prior to the meeting, and it was subsequently presented during the meeting. During the meeting, specific questions were asked to generate discussion, including inquiries about potential content additions, suggestions for enhancing readability and understandability, and where and how the tool would be most useful. Detailed discussion notes were taken by A.J.C. and analytical memos were taken after

the panels by M.J.S. and A.J.C. The notes and analytical memos were checked and used to update the tool, which was then reviewed and approved by the research team. The findings were used to inform the development of two tool prototypes, one for people with dementia and one for carers.

2.5 | Phase 3: End-user evaluation through focus group design and participant selection

Two tool prototypes were created by A.J.C. using the online design tool, Canva (Canva Inc., Sydney, Australia). The topics were organized to align with the patient's journey through hospitalization and discharge, ensuring a logical flow of information. The design process was guided by standards for creating plain-language documents, as recommended by dementia advocacy groups, to enhance accessibility and readability for the target audience.¹⁸ Features that accommodate age-related changes in vision (e.g., increased font size) and memory and cognition (e.g., use of short messages) were incorporated into the design of the tools. The standards were also used to inform the tool color scheme. The tool prototypes were sent to the research team and research development group for feedback regarding formatting and design. The tools were created as a 12-page, A5-size booklet with font size at a 10-point minimum for ease of reading and visual appeal. Once the tool prototypes were agreed upon by the research team and research development group it was evaluated by end-users and providers via focus groups.

Focus group participants were recruited using: advertisements across Australia through consumer and personal networks (previous participation in research, carer networks); a research participation and engagement service (StepUp for Dementia Research¹⁹); the research team's professional networks (professional organizations and research contacts); and snowball sampling. Focus group recruitment continued until no new information was provided regarding feedback on the tool topics and how well the prototype tools could meet participants' needs. People with dementia, carers, and healthcare professionals were recruited.

Focus groups were conducted in line with recommendations from a previous scoping review on co-designing effectively with people with dementia, including using small groups and clearly outlining the purpose of the focus groups.⁴ Using focus groups allowed for participants to share their own experiences with a collection of people who may have a similar understanding and involvement in medication management, stimulating the sharing of ideas and providing a comfortable environment for feedback on the tools to be given.²⁰ Five focus groups of three to four participants were conducted via Zoom, with equal representation of people with dementia and carers, and including healthcare professionals.

The focus groups were facilitated by researchers (M.J.S. and A.J.C.). All participants were sent a copy of the tools and briefed about the structure of the focus groups prior to their conduction, with considerations made for those participants with dementia, such as the ability to

have their carer accompany them if they chose.²¹ Participants provided written and verbal consent prior to the beginning of the focus groups.

The focus groups encompassed two steps. First, participants provided feedback on the content for each of the tool's topics, how they could be improved to meet end-user needs, and their overall value. The second phase generated further ideas to improve the prototype by examining the understandability and overall design of the tools. Participants were asked to consider when the tools should be given during hospitalization to provide the most benefit, and in which format (i.e., print, online, or another means). During the focus groups, the prototype tools were displayed using Adobe Acrobat in PDF format. Participants were guided through the tool page-by-page to provide feedback.

After the initial focus groups with people with dementia, carers, and healthcare professionals, researchers (M.J.S., A.J.C.) collaborated with graphic designers to incorporate participant feedback and ideas for tool design and layout. The revised tool was then reviewed in subsequent focus groups with people with dementia and carers who had not participated in the initial focus groups. The updated versions were shared to the research team and research development group for further input, and iterative changes were made to ensure the tools aligned with participant needs. Through this collaborative process, the graphic designers created finalized polished versions that reflected the collaborative efforts and input from all stakeholders.

2.6 | Focus group analysis

Content analysis of the focus groups was conducted.²² Focus groups were audio recorded, transcribed verbatim, de-identified and reviewed for accuracy. Researchers (M.J.S. and A.J.C.) familiarized themselves with data and independently conducted line by line coding of the data using pre-established coding forms to enhance consistency in the analytic process. The forms included topics on tool content, layout, general impressions of the tool, and suggestions for alterations to the tools. Codes were grouped into broader categories to provide a description of participants views on the tool and compared with the research team to ensure reliability. Consensus and resolution were achieved through discussion among the research team for any discrepancies in independent interpretation. Demographic data including age, state, education, ethnicity, and year of most recent discharge was collected after the focus groups and descriptively analyzed. Reporting of the results are in line with the Guidance for Reporting Involvement of Patients and the Public 2 (GRIPP2) checklist.²³

2.7 | Phase 4: Tool analysis

The readability and suitability of the final tools were quantitatively analyzed by one researcher (A.J.C.) using validated tools^{24,25} (see [Data S2](#)). Suitability Assessment of Materials (SAM) assessed the suitability of health information materials.²⁴ Readability of the final tools was calculated using the Simple Measure of Gobbledygook (SMOG).²⁵

TABLE 1 Mapping priorities to tool topics.

Topic	Priority themes	Areas to address	Source
Discharge checklist	Prepare people with dementia and carers for medication management post-discharge	<ul style="list-style-type: none"> - Carers felt overwhelmed by hospital discharge processes and reported there was limited time to discuss important information about medications. - There was a need to feel more confident and knowledgeable about how to manage medications after discharge. 	Qualitative study
Role of people with dementia and carers in medication management processes conducted in-hospital	Highlight opportunities for people with dementia and carers to be included in medication management processes	<ul style="list-style-type: none"> - Carers reported limited carer involvement in medication management processes throughout hospitalization (e.g., medication reconciliation, medication review). 	Qualitative study
Shared decision-making	Support people with dementia and carers in shared decision-making	<ul style="list-style-type: none"> - Carers reported limited carer involvement in decisions about medications. - Available resources had limited discussion of shared decision-making. 	Qualitative study and scoping review
Medications that impact on cognition	Highlight medications the person and carer need to know	<ul style="list-style-type: none"> - Carers reported a lack of information on medications that may impact cognition. 	Qualitative study and survey
Questions the person or their carer may want to ask	Provide question prompts to empower the person with dementia and carers	<ul style="list-style-type: none"> - Carers reported the need for question prompts to enhance communication between carers and hospital staff and improve medication management at discharge 	Survey
Support services to help manage medications post-discharge	Provide information on further resources people can use to help with medication management	<ul style="list-style-type: none"> - Carers reported proactively seeking information post-discharge online and there is a need to ensure people are referred to reliable and trustworthy sources. 	Qualitative study

3 | RESULTS

3.1 | Phase 1: Identifying priorities for content

Six priority topics that need to be included to address the information needs of people with dementia and carers were derived from previous research.^{2,11,17} These were: (1) discharge checklist; (2) the role of the person with dementia and/or carer in medication management processes during hospitalization; (3) shared decision-making, (4) medications that impact cognition, (5) questions the person with dementia and/or carer may want to ask healthcare professionals during hospitalization, and (6) post-discharge support services (Table 1).

3.2 | Phase 2: Developing tool prototypes

The expert panels' recommendations included introducing a topic describing informed consent as it related to medication management (e.g., the right to refuse medications), informing the expansion of the section on shared decision-making to include information on informed consent and withdrawing consent. For the section on support services, the panels mentioned the role of healthcare professionals other than prescribers, such as pharmacists, should be highlighted and that advice on services should be categorized by their availability in aged-care or community settings.

3.3 | Phase 3: End-user evaluation

Five focus groups with 16 different participants took place between November 2022 and December 2023, two with carers ($n = 4$ and $n = 3$), two with people with dementia ($n = 3$ and $n = 3$), and one with healthcare professionals ($n = 3$) (Table 2). Most participants were female ($n = 12$, 75.0%), had a bachelor's degree or above ($n = 10$, 62.5%), and lived in New South Wales ($n = 9$, 56.3%).

Participants with dementia reported the language should be modified to the active voice to improve understandability (Data S3). As Participant 2 remarked: "It's got to be real if you're going to give me prompts as a woman living with dementia." Participants suggested changing the term "carer" to "support person" or "supporter" to target a wider audience and requested more detail on how to withdraw consent for a medication. Participants recommended placing the discharge checklist at the start so "then it zeroes in on what you're discussing" (Participant 3). People with dementia highlighted that the tool was text heavy, and the text was significantly reduced to address this.

They indicated the tool would be most useful "when you're going in for a routine admission" (Participant 2) as part of the hospital process and "given to whoever is discharging you to go through with when you get home" (Participant 2). They also suggested it would be useful for the hospital staff to confirm that the processes in the discharge checklist have occurred by reading through it with the person being discharged.

Overall, participants valued the tool as it is "covering what we don't have yet, all in one booklet" (Participant 3). Participants with dementia

TABLE 2 Participant characteristics.

Characteristic	Total, <i>n</i> = 16	Carers, <i>n</i> = 7	People with dementia, <i>n</i> = 6	Healthcare professionals, <i>n</i> = 3
Age, years (mean, range)	60.7, 26–81	61.0, 26–81	70.2, 68–72	41.0, 31–50
Gender, female (<i>n</i>)	12	5	4	3
Highest level of education (<i>n</i>)				
Below year 12	3	0	3	0
Certificate III/IV or advanced diploma	3	3	0	0
Bachelor's degree or above	10	4	3	3
Ethnicity				
Australian	9	4	4	1
Asian	4	2	0	2
European	1	1	0	0
Australian-Asian	1	0	1	0
Indigenous Australian	1	0	1	0
Carer relationship to person with dementia			Not applicable	Not applicable
Spouse	3	3		
Child	3	3		
Friend/neighbor	1	1		
State				
New South Wales	9	4	3	2
South Australia	3	2	1	0
Victoria	4	1	2	1
Residence of person with dementia				Not applicable
Own home	7	3	4	
Someone else's home	2	1	1	
Residential aged care facility	3	3	0	
Retirement village	1	0	1	
Year of most recent discharge				
2023	2	0	2	
2022	8	6	2	
2019	2	0	2	
Earlier (not specified)	1	1	0	

reported the tool would be beneficial as it prepares them for hospitalization and discharge, facilitating involvement and advocacy in their own healthcare. As Participant 1 articulated: *"Having it well in advance is going to be a big advantage because you, you go in there pre-armed with a degree expectation of what's going to happen."*

Carer participants reported the carer tool could be improved in specific areas (Data S4). Notably, participants suggested changing the terms 'carer' and 'shared decision-maker' to 'supporter' and 'substitute/supported decision-maker', respectively. For the section on shared decision-making, participants highlighted the importance of discussing goals of care and the right to a second opinion. As Carer 3 stated: *"When my mother was diagnosed with dementia, treatment options was not something we discussed with her."*

For the table on medications impacting cognition, participants indicated *"the list needs to be greater"* (Carer 4), should include information on opioids, and mention potential side-effects and how to discuss them with hospital staff. For the question prompts, participants advised emphasizing the option to approach general practitioners (GPs) with questions if they were not asked during hospitalization.

Healthcare professional participants (HCPs) recommended reducing the use of medical terminology throughout the tools (Data S4). For example, they suggested changing the term "quality use of medications" to a term more understandable for people impacted by dementia. For the page on shared decision-making, participants recommended mentioning healthcare professionals in the community setting alongside hospital staff.

Both carers and healthcare professionals determined the tool for carers to be acceptable and indicated its potential usefulness and benefit if provided “*at the start of hospitalization, ideally*” (Carer 5) as part of routine practice. They said that it contained “*invaluable information*,” and may reduce their burden when “*it can be overwhelming*” (Carer 3).

The final tools for people with dementia and carers are presented in Data S5 and S6.

3.4 | Phase 4: Tool analysis

The SMOG readability grade score of the final tools for both people with dementia and carers was 11.4, indicating that readers need to have completed 12 years of education to fully understand the text of the tools. The SAM score of both tools were 79.5%, indicating they are suitable.

4 | DISCUSSION

This is the first known study to describe the co-design of tools designed to improve medication management health literacy to people with dementia and carers during hospitalization and at discharge. The adoption of a multi-methods approach, and involvement of people impacted by dementia across all stages of the study ensured the tools meet the needs of people with dementia, carers, and healthcare professionals. The tools were found to be of an acceptable level of suitability and readability. Based on previous studies and expert advisory panel feedback, it was determined that the tools should include six topics to support people with dementia and carers in medication management in care co-ordination during hospitalization and at discharge.^{2,11,17} These were the inclusion of: a discharge checklist; the role of the person with dementia or carer in medication management; shared decision-making and informed consent information; a list of need-to-know medications; question prompts; and post-discharge support services.

Our co-designed tools are the first, that we could identify, which provide people with dementia and carers key information on what to expect during hospitalization regarding medication management processes. Involving the person with dementia and encouraging their involvement in decisions, has been recognized as important and beneficial by people with dementia, carers, and healthcare professionals.^{26–28} Interventions aimed at improving health literacy, specifically on medication management in people with dementia at hospital discharge, have not been widely documented and tend to focus on adherence or administration by carers, as opposed to shared decision-making and holistic partnership with healthcare professionals.^{29,30} In the context of medication management, this means there are very few, if any, interventions aimed at improving skills and communication around medications overall, areas which if improved can overcome barriers in medication use.^{30,31} These components are directly addressed within our tools with the question prompts and guidance on how to participate in shared decision-making and care coordination, as well as promoting autonomy and self-determination in people with dementia and carers.

Historically, people impacted by dementia have not been involved in all stages of research, meaning that the services and tools intended for them commonly do not meet their specific needs. In health literacy research, co-design is a growing practice, however application varies.³ Indeed, there are suggestions the term has been co-opted in a way that side-steps meaningful engagement with original principles of co-design, specifically the distribution of power in research.³ Our co-design process was underpinned by collaborating with people impacted by dementia from the start, from identifying the research question (the need for tool based on previous research¹¹), informing the research design and priorities, to collecting and analyzing the data, and creating the tools through an iterative process. The value of this process is demonstrated by improvements made to the tools to improve understandability terminology to enhance inclusivity (e.g., “carer” to “supporter”). We also worked with those impacted by dementia to optimize the use of questions prompts and discharge checklist and usage of direct and active language to support communication in a health-care structure, in which “power” is not usually shared between healthcare professionals, people with dementia, and carers.³²

This is a first-time multiple method study to co-design user-centered medication management tools for a vulnerable patient group. This innovative approach can serve as a framework to develop other tools for people with dementia and carers, such as guidance on common medications used by people with dementia (e.g., antipsychotics). People impacted by dementia were consulted in developing and modifying the initial content of the tool before any design had been considered, and full and transparent feedback was received at every design stage preceding content development. Furthermore, repeated focus groups with updated designs ensured that saturation of ideas to improve the tools was achieved. There are several limitations of this study. The study focus is on the Australian context, which may limit the generalizability of the findings to other health-care systems. The priorities for tool content were identified mainly from data that included carers of people with dementia. Future studies need to include people with dementia to determine what information should be contained within the tools. Additionally, while we collaborated with graphic designers to refine the layout and presentation of the tools based on participant feedback, we did not consult with an information designer, which may have limited the potential to optimize presentation of information. This aspect will be explored in more detail during future user-testing to ensure the tools are accessible and user-friendly. Finally, although the reading level of the tools is higher than ideal, this was primarily due to the repeated usage of polysyllable words such as “hospital,” “dementia,” and “medication” which we consider as widely understood. Nevertheless, the readability and overall understandability of the tools will be further investigated through user-testing.³³

5 | CONCLUSIONS

This study addresses a significant gap in healthcare tools by developing co-designed tools for people with dementia and carers to improve their

health literacy on medication management and promote care coordination during hospitalization and discharge, a critical time associated with significant medication burden. The co-design approach ensures that the tools are user-centered and align with the evolving needs of the target audience to support people with dementia and carers in the healthcare journey and improve health outcomes. This co-design study can serve as a framework to inform the development of future tools for people with dementia and carers that addresses their unique needs.

ACKNOWLEDGMENTS

The authors thank the Sydney Dementia Network's Lived Experience Expert Advisory Panel (LEEAP), and the Sydney Health Partners' Clinical Academic Group (CAG). M.S.'s time is supported by Dementia Centre for Research Collaboration Postdoctoral Fellowship. This work was supported by grant Dementia Centre for Research Collaboration Postdoctoral Fellowship and Medical Research Future Fund and Dementia Australia Research Fund.

Open access publishing facilitated by The University of Sydney, as part of the Wiley - The University of Sydney agreement via the Council of Australian University Librarians.

CONFLICT OF INTEREST STATEMENT

All authors have no conflicts of interest. Author disclosures are available in the [Supporting Information](#).

CONSENT STATEMENT

All human subjects provided informed consent.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Sawan MJ, Clough AJ, Jokanovic N, et al. Co-design of medication management guidance tools for people living with dementia and carers at discharge. *Alzheimer's Dement*. 2025;21:e70257. <https://doi.org/10.1002/alz.70257>