

# Australian Community of practice in Research in Dementia

## ACcORD Legacy Project



## Executive Summary

The ACcORD Legacy Project aimed to translate over 40 research papers from the Australian Community of practice in Research in Dementia (ACcORD) into accessible, user-friendly resources. This initiative was designed to support people living with dementia (PLWD), their carers, and healthcare professionals through informed, compassionate, and evidence-based insights. By engaging ACcORD researchers, conference attendees, and dementia advocates, the team ensured that the materials reflected both rigorous research and real-world perspectives.

Key feedback emphasised the importance of respectful and clear language, relevant visuals, and inclusive design. Reviewers highlighted areas where language could be more empowering, such as replacing the term "wandering" with "walking with purpose," and recommended greater visual contrast in charts for clarity. Suggestions also included simplifying technical terminology, streamlining layouts, and increasing accessibility for readers with cognitive or visual impairments. Advocates particularly valued practical guidance for dementia care.

While limitations existed due to the scope of ACcORD's research and the terminology used in the surveys, the final resources were revised in response to this broad feedback as far as practicable. We would recommend greater engagement of advocates and consumers in co-design of the research instruments as well as in lay summaries and interpretation of the research outcomes.

The Legacy co-design process demonstrated the power of collaboration in shaping materials that not only convey research insights but also resonate with the lived experiences of the people the materials are intended for.



The Australian Community Of practice in Research in Dementia (ACcORD) conducted research aimed at improving the well-being and health outcomes for people living with dementia and the people who care and support them. The ACcORD project produced over 40 research papers covering a broad domain of dementia related research topics. From these papers, the ACcORD Legacy Project aimed to draw out the key learnings and insights, translating them into succinct accessible information for a broader audience.

The process began with a thematic analysis of the research papers where we brainstormed key themes and stakeholders (see Figure 1)

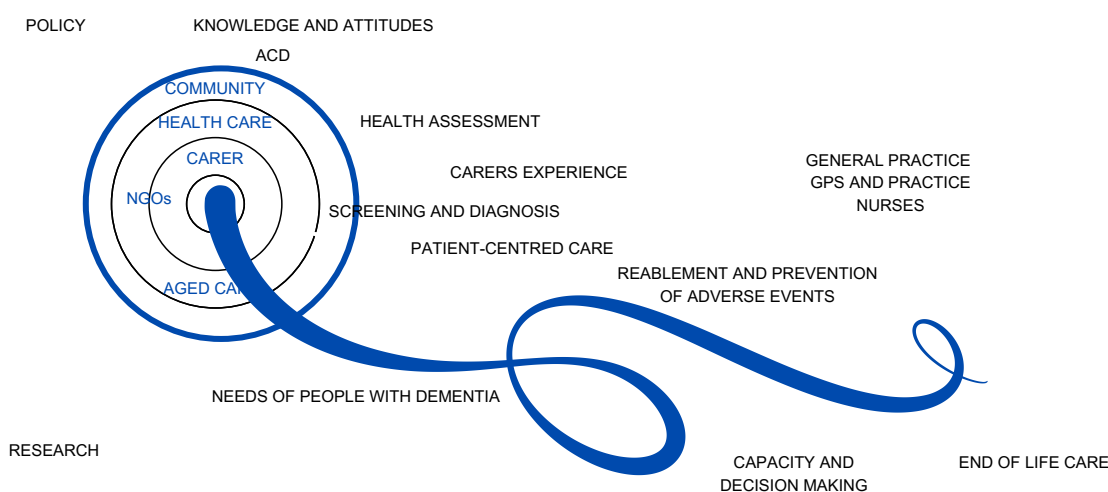


Figure 1.  
Visualisation of ACcORD research themes across the course of dementia, for people living with dementia and other stakeholders.  
Designed by Emeritus Professor Julie Byles.

From this, we identified the following topics for the Legacy materials:

- Community knowledge and attitudes
- Screening and diagnosis
- Health Assessments
- Needs of people living with dementia
- Carers' experiences
- Advance care directives
- Research capacity and decision-making
- End-of-life care

We then extracted key insights from the research papers related to these themes and drafted initial prototypes, each ranging from four to six pages.



These early prototypes were circulated among ACcORD researchers and authors for comment. In November 2024, we brought printed revised versions of the materials to the Australian Association of Gerontology Conference in Tasmania, and displayed them at a conference booth. This gave us a great opportunity to gather feedback from researchers, professionals, and others in the field of ageing and aged care. Based on this input, we further revised and refined the materials.

Following this, we engaged four dementia advocates through Dementia Australia. They were emailed the updated prototypes along with feedback forms. Their responses were then discussed more deeply during interviews over Zoom, giving us space to explore their feedback and reflect it in the next round of edits.

The advocate feedback was incredibly helpful. While some suggestions—such as including newer research findings—couldn't be incorporated due to the scope of the original ACcORD studies, many others helped shape and strengthen the final versions.. Others highlighted the absence of risk factors such as hearing loss (identified by The Lancet Commission on Dementia). These risk factors are important, but were not present in the original ACcORD publications. We were able to reflect these in the materials by reference to the Lancet Commission.

Through this process, we refined and consolidated the final themes into the following:

- Community knowledge and attitudes
- Screening and diagnosis
- Health assessments
- Needs of people living with dementia
- Carers' experience
- Advance care directives
- Advance care directives during end of life
- People living with dementia: future research



Despite some limitations, the overall feedback on the prototypes was very positive. Advocates and professionals alike acknowledged the value and usefulness of the resources, and the process helped surface critical issues around language, context, and inclusiveness in dementia-related materials.

The final step for the project was to circulate the refined materials once more to ACcORD researchers for any final feedback. After this, the documents were uploaded to the ACcORD webpage, where they are now publicly accessible. The aim being to ensure that the insights and knowledge from this important body of research continue to reach a wider audience and support informed, compassionate, and evidence-based dementia care.

The ACcORD Legacy Project was led by Professor Julie Byles, with assistance from Jemma Holford and Phillip Ross.