Core Outcome Measures for Improving Dementia Care

Evaluating the Care of People with Dementia
to Improve their Quality of Life

THE UNIVERSITY
OF QUEENSLAND
AUSTRALIA

A PLAIN LANGUAGE SUMMARY

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Core Outcome Measures for Improving Dementia Care

COM-IC

Evaluating the Care of People with Dementia to Improve Their Quality of Life.

A **core outcome measure** (COM) is a standardised way to track and evaluate how well care is working and if it’s improving the quality of life for people with dementia. These measures help ensure everyone is focused on the same important outcomes and that the care being provided is effective.

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This emblem identifies this paper has been translated from an academic paper to plain language for greater inclusivity and distribution of research findings into dementia care. The transcribers have a deep insight into the daily life of living with dementia through personal experience, academic knowledge and a commitment to promote better care.

Inclusive
Research
Project
Plain Language

Acknowledgements

These recommendations are the key output of a mammoth multi-institutional, multinational, multi-stakeholder effort to develop standardised measures that are relevant and meaningful to people experiencing dementia.

* Multi-institutional Collaborations	Stakeholder Reference Group	Delphi Consensus Panel	Investigator team
The University of Queensland	Debbie Brittain	Virginia Aquilzan	Safa Alrababah
Science for All	Benedict Davies	Wernher Dela Cruz	Tracy Comans
Bolton Clarke	Kaye Elle	Joy and Bruce How	Colm Cunningham
Hammond Care	Fleur O'Keefe	Michelle Ferguson	Hanh Dao-Tran
Global Brain Health Institute	Sonia Markoff	Karen Gainey	Susanna Dodd
COMET Initiative	Bronte Parkin	Sandra Lewis	Leon Flicker
University of Liverpool Dementia Australia	Ruth Semler	Margaret Hampton-Chubb	Len Gray
The University of Western Australia	Jane Thompson	Myles Hampton-Chubb	Alyssa Welch
		Julie Smith	Paula Williamson
		Lynda Henderson	Anna Kearney
		Mithrani Mahadeva	Danelle Kenny
		Deborah Remfry	Sue Kurrle
			Judy Lowthian
			Asmita Manchi
			Carly Meyer
			Kim-Huong Nguyen
			Tom Morris
			Jack Nunn
			Glenys Petrie
			John Quinn
			Zoe Selby
			Dominic Trépel

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Abbreviations

Descriptor	Acronym
Aged care assessment team	ACAT
Aged Care On-site Pharmacist	ACOP
Aged Care Quality Standards	ACQS
Allied Health Professional	AHP
Activities of Daily Living	ADL
Alignment Harmonisation Results	AHR
Commonwealth Home Support Program	CHSP
Core Outcome Measures for Improving Care	COM-IC
Core Outcome Set	COS
Core Outcome Measure	COM
Core Outcome Measures in Effective Trials	COMET
General Practitioner	GP
Home Care Program	HCP
Medicare Benefit Scheme	MBS
Mild Cognitive Impairment	MCI
National Disability Insurance Scheme	NDIS
National Aged Care Mandatory Quality indicator Program	QI Program
Pharmaceutical Benefits Scheme	PBS
Stakeholder Reference Group	SRG
World Health Organisation	WHO
Years Lived with Disability	YLD

Descriptor	Definition	Synonyms
Carer	People providing unpaid care and support to a person experiencing dementia.	Unpaid carer, loved one, support person, proxy, caregiver.
Care worker	Professionals employed to provide care and support services to a person experiencing dementia.	Paid carer, formal carer worker, dementia support worker, staff.
Dementia	A term for several diseases that affect memory, thinking, and the ability to perform daily activities.	Cognitive impairment, neurodegenerative disease, cognitive decline.
Domains	Categorical groupings of outcomes by function or area of health care.	Categories, groupings, functional areas.
Evaluation	Systematic analysis of effects or impact of an entity, e.g. care provision.	Benchmarking, comparators, indicators.
Experience of dementia	A person diagnosed with dementia.	Lived experience, living experience, life expert.
First Nations	A person who identifies with Aboriginal or Torres Strait Islander decent	Indigenous Australians, Aboriginal and Torres Strait Islanders.
Impact	Effect of dementia as measured by cost, mortality, morbidity, quality, or disability.	Burden.
Home care	Care and support services to help older people to remain living in their own home.	Home services, domiciliary care, social care, community care, home care, community-based care.
Impacted by dementia	A person directly affected by dementia in any capacity (see stakeholder)	Stakeholder.
Measures	Instruments that provide for evaluation and monitoring of outcomes, including their changes over time.	Tools, instruments, assessments, questionnaires, forms.
Monitoring	Observance of and continual tracking of progress over time in a system.	Tracking.
Outcomes	Change in status (of an individual or group) attributable to planned intervention(s).	Results, effects, changes.
Panellists	Composite group of stakeholders contributing to the modified Delphi consensus to select core outcomes for consideration in the COM-IC core outcome set.	Panel members, Delphi panel.
Residential aged care	Accommodation and personal round-the-clock care provided to older people who can no longer live in their own home (1).	Aged care home, nursing home, nursing facility, long-term care, institutional care.
Routine care	Sequence of care activities a person can reasonably expect on an ongoing basis to ensure appropriate care and monitoring for their health	Standard care, expected care, regular care.

Descriptor	Definition	Synonyms
Stakeholder	A person with connection to and interest in systems of routine dementia care, including but not limited to: person with a diagnosis of dementia, person with cognitive impairment, formal and informal carers of people living with dementia, family and friends supporting people living with a diagnosis of dementia, service providers who provide routine care for people living with dementia, health care professionals providing care to people living with dementia, dementia advocates, divisions of government responsible for development and implementation of health care policy related to dementia, and researchers with a focus on dementia.	Consumer, life expert, care community, health system, service user, service drawer.
Younger onset dementia	A person receiving a diagnosis of dementia who was under 65 years of age.	

NOTES: Definitions here have been developed over the project through lengthy discussions, and reflect the language preferred by stakeholders in this group, specific to the Australian context. Synonyms are terms used frequently by different stakeholder groups to reference the same concept, though these terms are not necessarily preferred by the COM-IC project team.

Outcome Measures

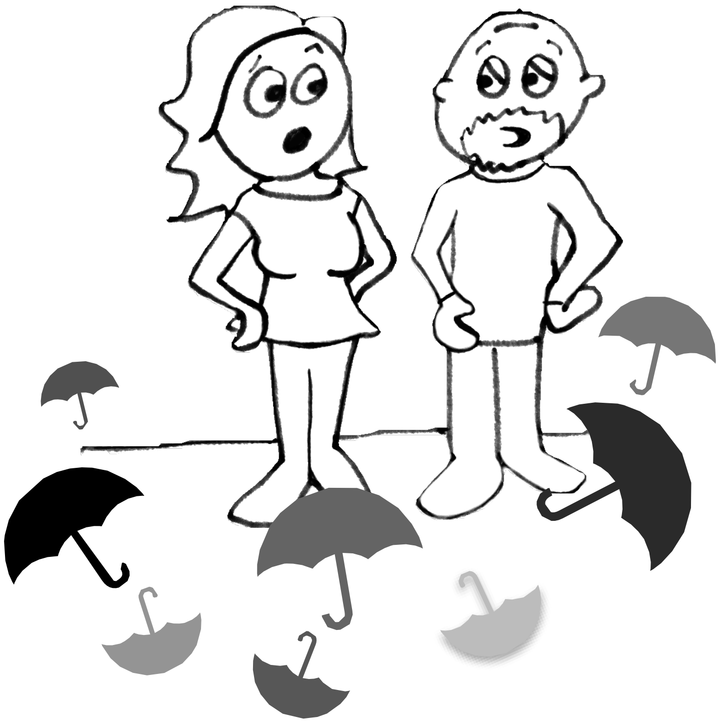
Short Form	Measure	Reference
ACP Survey	Advanced Care Planning Engagement Survey	https://pmc.ncbi.nlm.nih.gov/articles/PMC5730058/
Barthel	The Barthel Index	https://pubmed.ncbi.nlm.nih.gov/14258950/
CARE	Consultation and Relational Empathy Measure	https://pubmed.ncbi.nlm.nih.gov/15528286/
COSA	NSW Health Comfort Observation and Symptom Assessment Chart	https://www.cec.health.nsw.gov.au/__data/assets/pdf_file/0003/359346/NH700138-COSA-Chart-Adult.pdf
Dementia Care Navigation	Dementia Pathways Tool	https://www.dementiapathways.com.au/
DKAS	Dementia Knowledge Assessment Scale	https://pubmed.ncbi.nlm.nih.gov/28760154/
EMAS	Engagement in Meaningful Activities Survey	https://pmc.ncbi.nlm.nih.gov/articles/PMC3298038/
MAGPI	Morale Assessment in General Practice	https://www.researchgate.net/publication/233637769_The_MAGPI_Morale_Assessment_in_General_Practice_Index_A_new_way_for_doctors_to_self-assess_their_morale
MoCA	Montreal Cognitive Assessment	https://mocacognition.com/
NPI	Neuropsychiatric Inventory	https://dementiaresearch.org.au/wp-content/uploads/2016/01/NPI.pdf
NPSS	Neuroception of Psychological Safety Scale	https://www.traumascience.org/neuroception-of-safety-scale
NRM	No Recommended Measure	NA
PAINAD	Pain Assessment in Advanced Dementia	https://www.apsoc.org.au/PDF/Publications/Pain_in_RACF2-Appendices/6_APS_Pain-in-RACF-2_Appendix-6_PAINAD.pdf
QCE-ACC	Quality of Care Experience	https://www.qol-acc.org/quality-of-care-instrument
QOL-AD	Quality of Life -Alzheimer's Disease	https://www.cogsclub.org.uk/professionals/files/QOL-AD.pdf
RUD-LITE	Resource Utilisation in Dementia - Lite	https://pubmed.ncbi.nlm.nih.gov/23142433/
STOPP-START	Screening Tool of Older Persons' Prescriptions and Screening Tool to Alert to Right Treatment	https://pubmed.ncbi.nlm.nih.gov/37256475/
WHO-5	World Health Organisation - 5 Wellbeing Index	https://www.who.int/publications/m/item/WHO-UCN-MSD-MHE-2024.01

Foreword

This Core Outcome Set (COS) for use in the routine care of people experiencing dementia was an ambitious project, but necessary to capture the true quality of dementia care. Co-designing a Core Outcome Set (COS) appropriate for broad scale use is crucial to truly capture the quintessential essence of quality care. Without understanding unique stakeholders' experiences of care, we lack capacity to see and feel what is valid, meaningful, and important. This co-design research project has continuously evolved and adapted its design over 18 months to support differing capacities for engagement, and to provide a safe space to consider information, learn from others' experiences, and foster exchanges, despite persistent and stigmatising beliefs surrounding dementia in broader society.

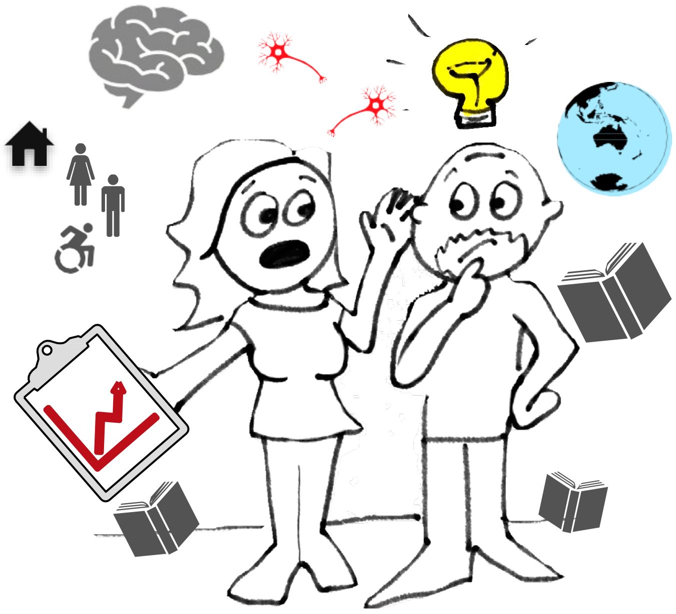
"My early expectation was that researchers were experts in their own right about dementia. I figured their baseline knowledge would be considerable and any contribution I may add would simply support what they already knew. However, I was surprised to learn the research team knew very little about the complexity of living with neurodegenerative brain diseases. It is important to note the umbrella term 'dementia' is generically used to refer to 100 different types of terminal neurodegenerative diseases, therefore, understanding dementia as a complex neurodegenerative disease with many starting points symptomatically is vital." - Kaye Elle

We have formed a set of recommendations based on findings from rigorous processes, but beyond that, we have formed vital connections across stakeholder groups that, over time, have built shared understanding and appreciation for the varied viewpoints and experiences that link us together. We all have a vested interest in seeing improved care outcomes for people experiencing dementia, acknowledging its complexity and the challenges it presents to current systems of care. Above all, we wish for a person to be seen as a person, with extraordinary capacity to feel connected to others and their environment in meaningful ways, despite the disruption and fluctuation in brain function that dementia brings. We believe healthcare should be about a person and not about systematic treatment of a collection of symptoms and challenges that can be solved with a checklist.



"*With greater understanding of another's experience, many can then empathise and understand not only what is lost, but what remains. This acknowledgement can then generate an opportunity to explore what may assist another to experience life more fully. People are natural problem solvers when given an opportunity to be with another. This symbiotic relationship of care establishes a unit. Carers attending to checklists alone are quickly exhausted, however, when there is a reciprocal encounter, both parties are rewarded by the shared experience and a meaningful life can flourish despite the challenges. The educated carer helps people experiencing dementia to interpret the world meaningfully." – Kaye Elle*

One common and overlooked thread which gained clarity and traction over the project is the role of education. Whilst acknowledging that formal qualifications do not necessarily translate to improved care, the lack of dementia-specific training in aged care and resulting knowledge gaps lead to breakdowns in communication and erodes the foundation of positive care relationships between those receiving and giving care. It was the development of shared understanding about the links between knowledge and quality care that defined our process to select core outcome measures and make these recommendations.

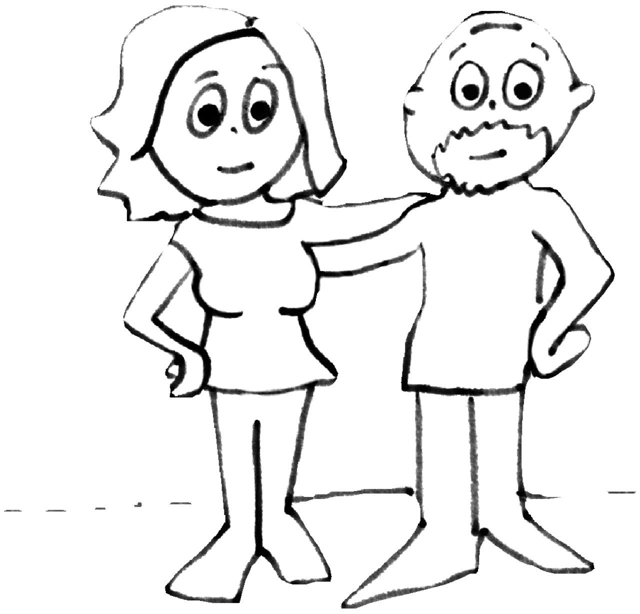


"Although this research study examined many areas of the lived experience- the connective tissues linking all domains was missing. Knowledge. Education, knowledge and insights into self and others is essential if we are to build a comprehensive understanding beyond automated prescriptive care." - Kaye Elle

Whilst we agree and endorse these recommendations from the perspective of a whole project team, we recognise there is more work to be done. We have agreed upon a selection of core outcomes and measures that are ready to use, but there are many more important outcomes that are not able to be uniformly measured currently, some measures that reveal important aspects of quality care that are not feasible for routine care assessments, and yet others that are important to stakeholders but not the most important at this time.

Healthcare is complex, dementia is complex, and people are complex. The landscape we exist within is constantly evolving and we have an obligation to ensure that evolution of dementia care remains relevant and continuously improves.

"Perhaps a new way of seeing the whole person needs to be established first rather than trying to borrow assessments designed and validated clinically for other reasons. A map of personhood could be developed, if we begin by designing an assessment tool of what a whole person needs to flourish before dissecting areas for assessment, we may begin from some place new.
The whole person." - Kaye Elle



We offer these recommendations to dementia stakeholders to envision and co-design better systems of care that are reflexive and responsive to what is truly important in a high-quality health care system. They have been carefully considered from multiple perspectives and offer a wealth of insight into what quality care means to people impacted by and experiencing dementia.

The Stakeholder Reference Group.

How This Document is Structured

This document explains the key measures for dementia care and how they can be used in everyday practice.

I'm interested to learn more about this study and see how it might assist us in the future

Section 1 – Introduction
Outlines the COM-IC Project.

Section 2 – Dementia Care in Australia
Explains why a special Core Outcome Set (COS) is needed for dementia care and how it can benefit people living with dementia, carers, and aged care providers.

Section 3 – Understanding Core Outcome Measures (COM)
Breaks down what outcome measurement is, why it matters, and how tracking key measures can improve dementia care.

Section 4 – Core Outcome Measures (COM) for Routine Dementia Care: Short-Term (Essential)
Lists the core measures that can be used immediately in home and residential aged care. These measures may also be useful in other care settings.

Section 5 – Core Outcomes for Routine Dementia Care: Medium-Term (Suggested)
Identifies important care outcomes that currently **lack reliable measurement tools**. More research is needed to create ways to track these outcomes properly.

Section 6 – Core Outcomes for Routine Dementia Care: Expanded (Best-practice)
Describes additional measures that were initially considered essential but are now seen as **useful extensions** rather than core requirements. These measures can still help improve care quality.

Section 7 – Core Outcomes for Routine Dementia Care (Optional)
Lists measures that were considered but not included in the core recommendations. Although not currently required, they may become relevant as dementia research and care practices evolve.

Section 8 – Implementation
Explains how the recommended measures can be applied in real-world dementia care.

Section 9 – Outcome Measures Summary
Provides a plain language summary of the key recommendations.

Section 10 – Resources
Includes links to further information for aged care providers, policymakers, and researchers.

Section 11 – Reference list

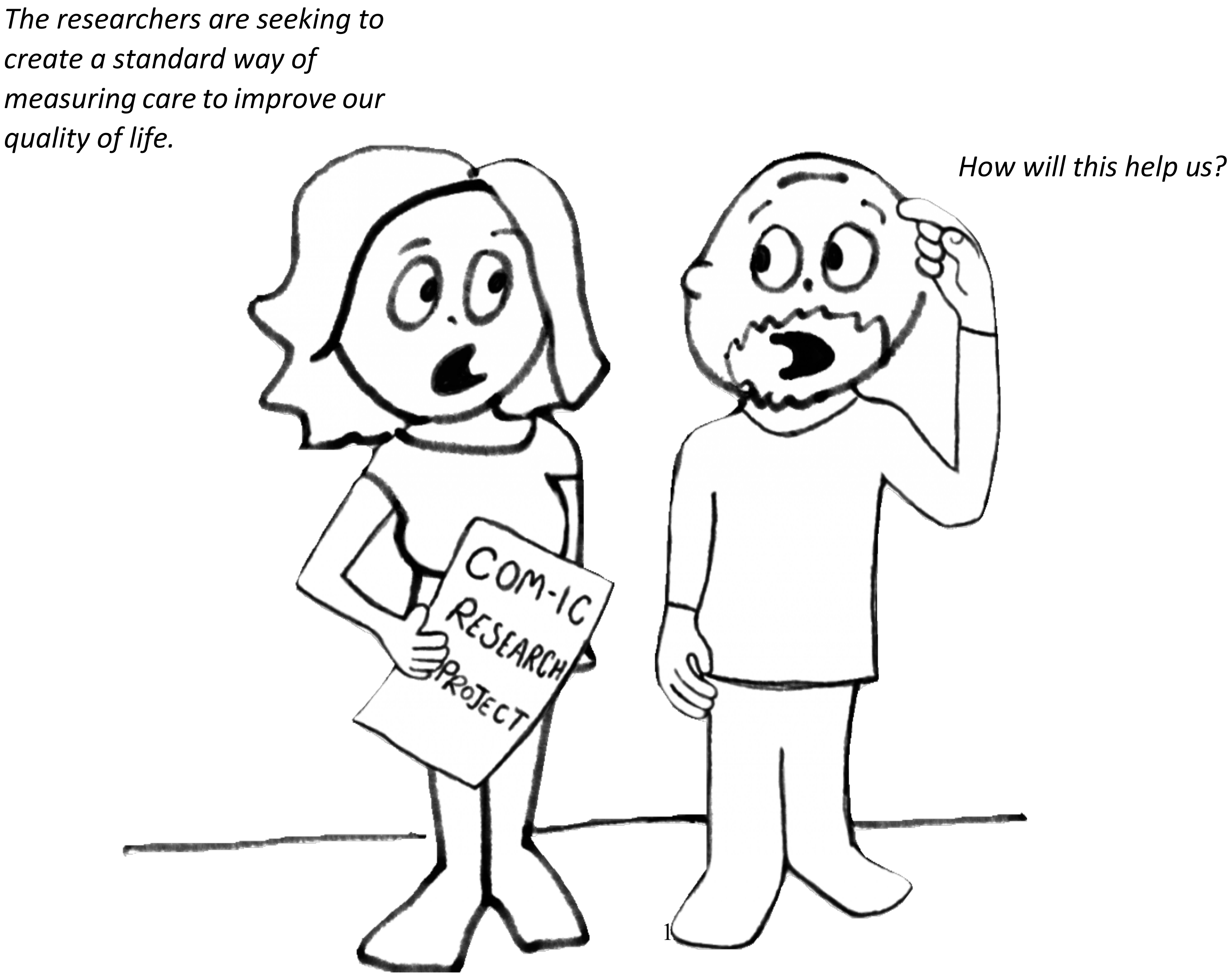
Section 1
Introduction

Dementia is a condition that affects memory, thinking and behaviour. It can make daily activities difficult and impact a person's independence. Dementia is a major health issue worldwide causing challenges for individuals, families and healthcare systems. In Australia, more than 420,000 people are estimated to have dementia. About two-thirds live at home with support services, while the rest live in residential aged care. More than half of aged care residents are thought to have dementia, whether diagnosed or not.

There has been a strong focus on improving dementia care. Different treatments, care approaches, and guidelines have been introduced to ensure people receive the best possible support. The Australian government has also developed new policies, such as the National Dementia Action Plan and the updated Aged Care Act to improve care quality. Care providers must report on various quality indicators, like medication use and patient well-being, but the information collected can vary between providers.

To improve care, we need consistent, high-quality data on the support people with dementia receive. One way to achieve this is through Core Outcome Sets (COS), which are standardised measures used in research to compare different treatments. However, COS are mostly designed for clinical trials and are not specific enough for routine or everyday dementia care.

The COM-IC project aims to develop a Core Outcome Set specifically for routine dementia care. This will help ensure that the care provided meets the needs of people living with dementia. The project is funded by the Australian Government's Medical Research Future Fund (MRFF), which supports important health research to improve care and treatment.



Aim

These recommendations aim to identify a set of key measures to improve the quality of everyday dementia care.

These measures:

- Should be regularly recorded as part of caring for people with dementia.
- Have been developed together with people with dementia, their families and carers, health professionals, policy makers, researchers, and service providers to ensure they reflect what matters most in quality care.
- Take into account how easy it is to collect this information in different care settings at regular intervals and the existing workload of home and aged care providers in Australia.

Scope

Purpose of These Recommendations

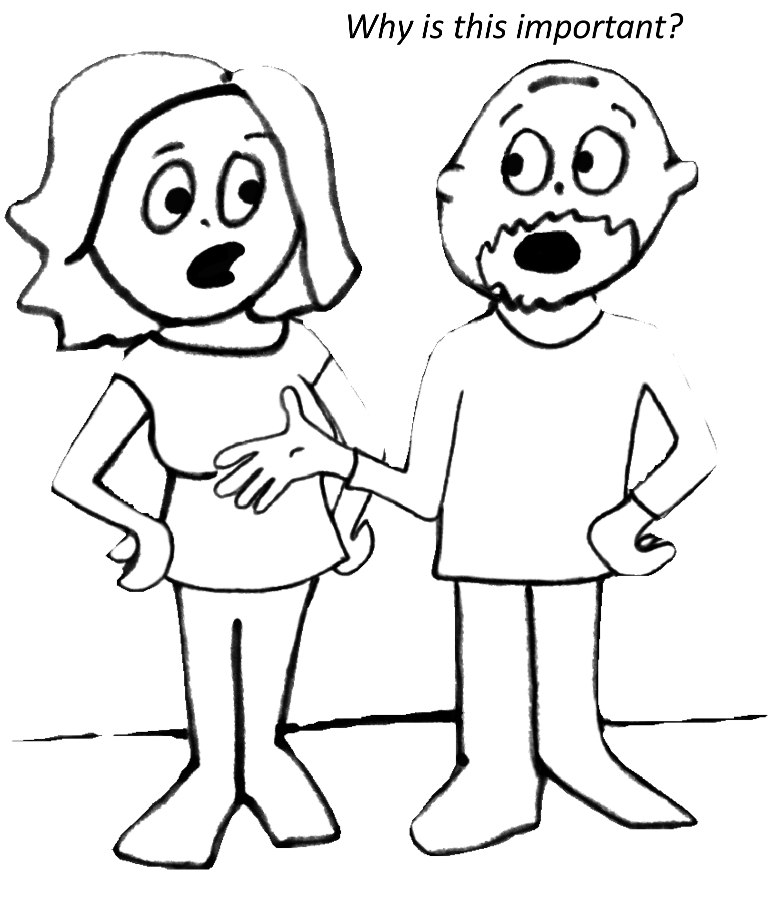
These recommendations have been created for theAustralian aged care system to help track and improve the quality of everyday dementia care.

They apply to:

- All aged care services that provide home or residential aged care for people with dementia.
- Researchers studying treatments or care approaches for people with dementia in home or residential aged care.
- Government and regulatory bodies that may introduce rules about reporting on dementia care quality.

These recommendations do not cover:

- Dementia care provided outside of the aged care system.
- Services outside of regular aged care, such as volunteer programs, Dementia Support Australia, or Dementia Training Australia.
- People with rare types of dementia that need highly specialised care.
- Dementia care provided in hospitals, respite care, or palliative care settings.



Why These Recommendations Matter

This document helps simplify and standardise how dementia care services provided at home or in residential aged care settings are reported and evaluated.

Using the recommended measures ensures that:

- Care quality is assessed in a clear and consistent way.
- Information can be compared across different aged care services and locations.
- Data collection does not become an extra burden for care providers or families. Currently, some

international frameworks exist for measuring care outcomes, but they may not be widely known or relevant in the Australian aged care system.

These recommendations adapt existing research-based measures so they align with the everyday needs and opinions of people living with dementia, their carers, and aged care providers in Australia.

Who these Recommendations are for

These recommendations are mainly for the Australian Government to help shape future aged care policies. They are also useful for:

* Aged care providers (home or residential) who want to improve dementia care using research-based methods.
* Researchers, policy-makers, advocacy groups, training organisations, and healthcare services involved in dementia care.
*. Other care settings such as hospitals, palliative care, and general practice, where they may also be relevant.

How these recommendations were developed

The recommendations were created through a collaborative process involving:

- People with dementia, their families, carers and advocates
- Health professionals
- Researchers
- Aged care providers
- Government representatives

A Stakeholder Reference Group (SRG) representing people from different sectors was formed. These experts followed a structured decision-making process to identify the most important outcomes for dementia care. Researchers also reviewed existing frameworks for measuring dementia care quality.

It is essential the recommendations are practical, relevant and reflect the needs of those they are meant to support

I agree, this research is an opportunity to illuminate areas of the lived experience needing more attention to assist us to live as freely and fulfilled as possible

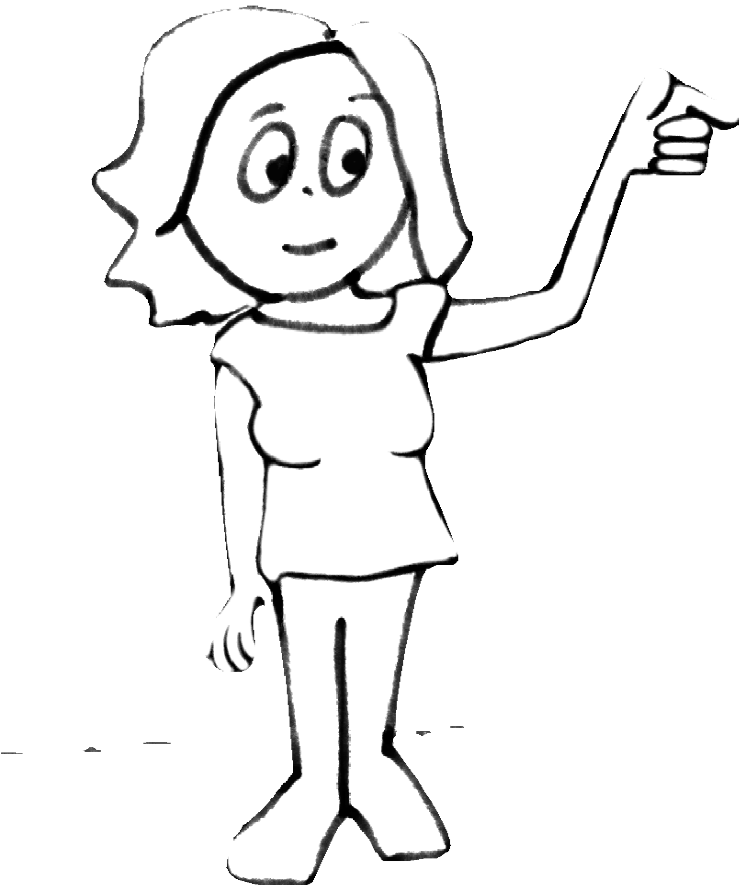
How the evidence was used

A structured approach called the Alignment, Harmonisation, Results framework was used to carefully review and select the most important measures for dementia care.

- A broad research review helped organise and explain different ways to measure care quality.
- This information was applied to real-world data from aged care services, research studies, and industry reports.
- Discussions with key groups—including people with dementia, families, carers, aged care providers, and policymakers—helped determine which measures were most meaningful and useful.

The final recommendations, based on international research and community feedback, outline a Core Outcome Set (COS) to monitor and improve the quality of dementia care in Australia.

To be included in the COS, a measure had to be:



Clear
Timely
Measurable
Valid
Consistent
Valuable

Section 2
Dementia Care in Australia

What is Dementia?

Dementia is a condition that affects memory, thinking, and behaviour. It happens when diseases damage the brain over time. Symptoms can appear suddenly or develop slowly, and everyone experiences dementia differently. While scientists have learned a lot, there is still much we don't know about how dementia starts, progresses, and the best ways to manage it.

Dementia is a growing health issue worldwide. In 2023, about 55 million people had dementia, with nearly 10 million new cases each year. In Australia, around 411,100 people live with dementia, and this number is expected to more than double by 2058. Although dementia is not a normal part of ageing, older people are more likely to develop it. Younger people (under 65) can also get dementia, called younger onset dementia.

Dementia is the second leading cause of death in Australia and the number one cause of death for Australian women. It also places a huge burden on the health system and economy, requiring significant resources for care and support.

Ethical Issues in Dementia Care

Caring for people with dementia can be challenging. Some important issues include:

- **Decision-making**: People with dementia may struggle to make decisions, so families and doctors must discuss legal and medical choices.
- **Stigma**: Many people don't understand dementia making it harder for those experiencing this disease to talk about their diagnosis, get the support they wish for, and be understood as an individual with desires about their life.
- **Balancing care and independence**: Families and caregivers must keep the person safe while respecting their independence.
- **Moving into aged care**: Many people want to stay at home, but as their needs grow, they may need to move into residential care, which can be difficult for families.

How Dementia Care Works in Australia

There is no single treatment for dementia, but care is provided through different services:

- **General Practitioners (GPs)**: GPs handle nearly half of all dementia-related medical visits.
- **Specialists**: Doctors like geriatricians provide about 12% of dementia-related healthcare.
- **Medications**: There is no cure, but some medicines can help manage symptoms. In 2022-23, about 72,400 Australians received dementia medication.
- **Other treatments**: Lifestyle changes, therapy, and community support can help manage symptoms.

Aged Care Services for People with Dementia

The Australian government funds different care options:

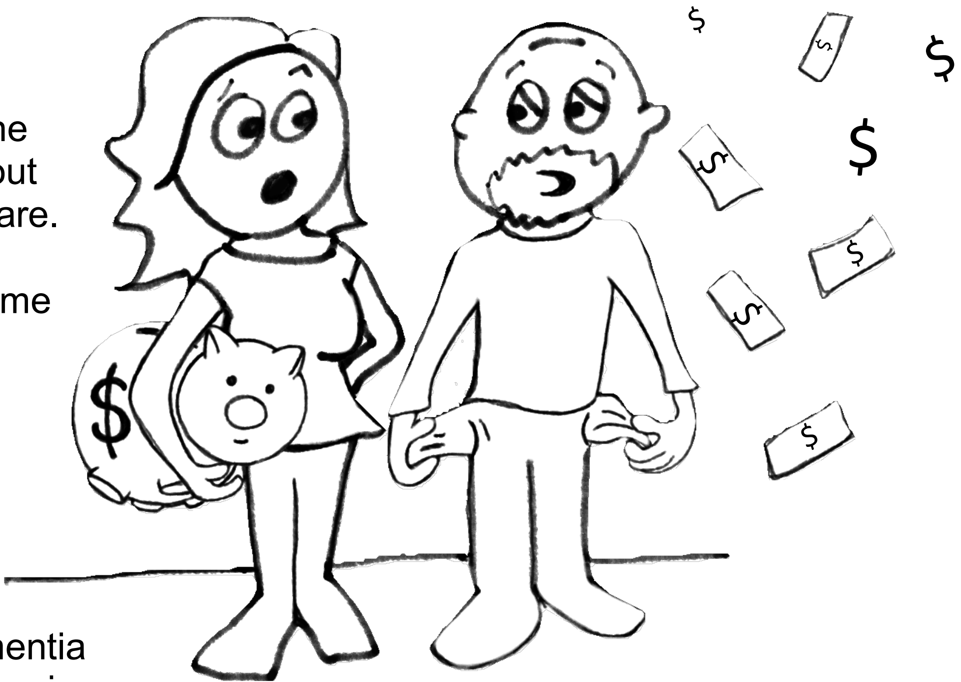
- **Home care**: Programs like the Commonwealth Home Support Program (CHSP) and Home Care Packages (HCP) help people stay in their homes longer.
- **Residential aged care (RAC)**: For those who need full-time care.
- **National Disability Insurance Scheme (NDIS)**: Supports people under 65 with younger onset dementia.

These services are provided by approved aged care organisations. As of 2022, there were 811 residential aged care providers and 916 home care providers across Australia.

Costs of Dementia Care

Dementia care is expensive for both families and the government. In 2018-19, the government spent about $3 billion on dementia care, mostly on residential care.

Families also face hidden costs. Many people become unpaid caregivers, which affects their finances, health, and well-being. Nearly half of primary caregivers provide over 60 hours of care per week, leading to stress and financial strain.



The Dementia Care Workforce

A well-trained workforce is essential for quality dementia care. However, Australia's aged care laws do not require specific dementia training. The 2021 Royal Commission into Aged Care found major gaps in training and recommended mandatory dementia training for all aged care workers. In response, the government has introduced new training standards and increased funding to improve wages and working conditions.

Experiences of People with Dementia

Each person's experience of dementia is unique. Many find the aged care system difficult to navigate, especially since GPs handle most diagnoses and care management.

Key challenges include:

- Changing care workers: Having different caregivers can be confusing and stressful for people with dementia.
- Carer stress: Many family carers experience high stress and struggle to balance their responsibilities.
- Communication issues: People with dementia may have trouble expressing themselves, leading to frustration.

Other Health Issues (Co-morbidities)

People with dementia often have other health conditions, like diabetes or heart disease, which can make care more complicated. Sometimes, other health problems are mistaken for dementia, leading to delays in treatment.

Dementia Care Policies in Australia

Australia has been working on dementia care policies for decades. The first National Plan for Dementia Care was introduced in 1992, and dementia remains a national health priority.

Key actions include:

- Following the World Health Organisation's *Global Dementia Action Plan - 2017-2025*
- The 2021 Royal Commission into Aged Care, which highlighted the need for better care, training, and support.
- Release of the new Australian *National Dementia Action Plan 2024-2034*

Measuring and Improving Dementia Care

There is no single way to measure and improve dementia care in Australia. Different organisations use different methods, making it hard to track progress. Some countries have dementia registries to collect data, but Australia does not yet have a national dementia registry.

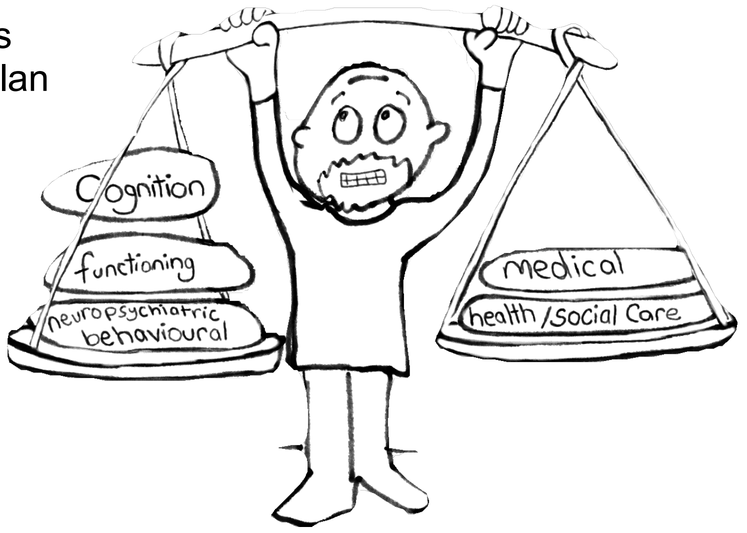
The Future of Dementia Care

Dementia care in Australia needs continued improvement. A clear, standardised approach to measuring and monitoring dementia care will help improve outcomes for people with dementia, their families, and caregivers. By prioritising dementia as a public health issue, increasing training for care workers, and improving support systems, Australia can better meet the needs of people living with dementia now and in the future.

Dementia Care in Australia's Policies and Regulations

Governments around the world are working to improve aged care, with a strong focus on dementia care. In Australia, the government first created a plan for dementia care in 1992. Since then, new plans have been introduced, with the most recent being the *National Framework for Action on Dementia 2015-2019*. Dementia remains a key issue in aged care policies.

In 2017, Australia adopted the World Health Organisation's (WHO) *Global Action Plan on Dementia 2017-2025*. This plan encourages countries to improve dementia research, data collection, and support systems. In 2021, the *Royal Commission into Aged Care Quality and Safety (ACQS)* recommended several key improvements, including better post-diagnosis support, dementia care training for staff, and improved data collection.
A *National Action Plan for Dementia 2023-2033* has been drafted, but it has not yet been finalised.



What These Policies Mean for Dementia Care

A well-designed, stakeholder-informed system for tracking dementia care can help meet WHO and Royal Commission goals. Such a system would improve the lives of people with dementia and their families while reducing the burden on the healthcare system.

Standardised data collection can:

- Reduce duplication of information and unnecessary work
- Identify areas where care quality needs improvement
- Measure the success of new dementia care programs and guidelines

Tracking Dementia Care Outcomes

Current Practices

The *Royal Commission into Aged Care Quality and Safety* identified dementia care as a critical issue. However, Australia does not have a specific policy for dementia care—it is only covered under the broader *Aged Care Act 1997*. This means dementia is not always seen as a priority in aged care, even though many aged care residents have cognitive impairments.

Dementia is not clearly recognised in the *Aged Care Quality Standards (ACQS)*, making it harder to track care quality. Additionally, because dementia affects people in different ways, access to diagnosis, information, and support is inconsistent. This has led to different organisations creating their own ways of measuring dementia care quality, rather than using a unified system.

Dementia Registries

A 2016 review found 31 dementia registries worldwide. These registries track information in five categories:

1. Dementia research
2. Preclinical (early-stage) dementia research
3. Dementia population studies
4. Quality of dementia care
5. Volunteer dementia research programs

Most registries collect data on people's health, demographics, and care services. They also use common assessment tools, such as memory tests and scales measuring daily living skills, depression, and caregiver stress.

Measuring Dementia Care Quality in Australia

Australia does not have a standard set of measures to assess dementia care quality. Two aged care providers have shared the measures they currently use based on existing dementia care research.

Table 1 Measures routinely collected from people living with dementia in Australian aged care

Domains	Core Outcomes	Related Variables / Source
Cognitive abilities	Memory	
	Communication, verbal fluency	Whether English is first language (Yes/No) Whether a resident is using hearing aids or not? (Yes/No) Whether a resident is using vision aids? (Yes/No) Hearing status: (Impaired/ Not Impaired) Vision status: (Impaired/ Not Impaired)
Functional capacity and independence	ADL	ADL Bowel (categorical) ADL Bladder (categorical) ADL Grooming (categorical) ADL Toilet Use (categorical) ADL Feeding (categorical) ADL Transfer (categorical) ADL Mobility (categorical) ADL Dressing (categorical) ADL Stairs (categorical) ADL Bathing (categorical) ADL score (Numeric, Range: 0-20)
	Hygiene and comfort	See above
	Social (community affairs and relationships)	Possible variables based on available data: Whether a resident took any social leaves in a certain time: (Yes/No) Number of social leaves over a certain period: (Numeric) More information on individual leaves can include: date of social leave date of return from a social leave

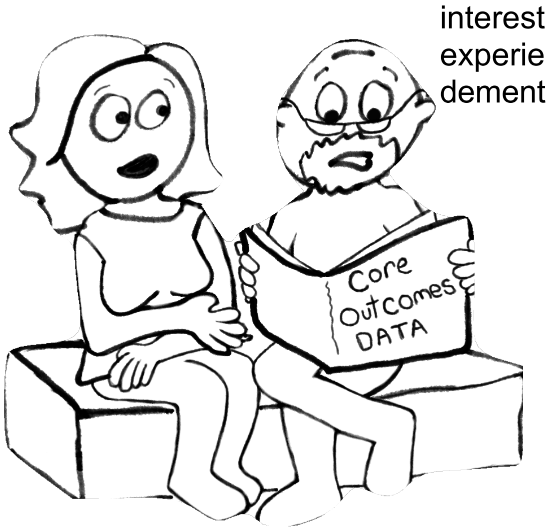
Domains	Core Outcomes	Related Variables / Source
Functional capacity and independence	Staying healthy and fit, walking better, being able to stand up and climb stairs.	Ambulation (Physically assist x1 +aid/Only with Physiotherapy staff/Non-ambulant/Supervise with aid) Transfer: (Physically assist x1/Sara Steady Hoist/ Physically assist x1/ Full hoist/ Supervise/ Stand up hoist) Managing stairs:(Unable/Needs help (verbal, physical, using aid)) Rolling back to side: (Physically assist x2 +slide sheet/ Supervise) Lying to sitting: (Physically assist x2 / Supervise) Sit up on side of bed (Physically assist x2 +slide sheet/ Supervise) Sitting to standing (Physically assist x2 +slide sheet/ Supervise) Standing to sitting (Physically assist x2 +slide sheet/ Supervise)
Behavioural and neuropsychiatric symptoms	Behavioural disorders	Possible variables would be a binary on whether a resident have any of the listed disorders: (Yes/No)
	Depression	
	Apathy/ indifference	
	Anxiety	
	Mood	
Health, social care, and treatment-related outcomes	Falls	Risk of fall assessed at patient level (High, Medium, Low)? Aggregate number of falls over a certain period per resident/home?
Medical	Vital Status	To check availability/ability to retrieve possible variables: Vital status: (Alive/Deceased) Number of deaths/care home over a specific period
	Vision and hearing	Hearing status (impaired/not impaired) Vision status (impaired/not impaired)
	Hospital admissions	Example of variables related to hospital transfer that can be extracted: Dates of hospital transfer and hospital returns: (Dates, D/M/Y) LOS: (Numeric) Reason for hospital transfer: (Text)

Factors That Matter to Stakeholders

These recommendations were created with input from a wide range of people involved in dementia care including those who provide care and those who are affected by it. The most common request from stakeholders was for better collaboration, with more transparency and information sharing between all groups. Stakeholders also recognised that their level of involvement may depend on the specific situation, but all relevant groups should have a say in decisions that affect them.

The government is actively working on several initiatives in response to the *Royal Commission into Aged Care Quality and Safety* and is committed to improving dementia care. This includes:

- Better support for people at the time of diagnosis
- Helping people with dementia navigate the aged care system
- Improved training for dementia care workers
- Making facilities more dementia friendly
- Enhancing the experience of aged care services
- Expanding the capacity and quality of dementia care
- Supporting carers



Researchers are interested in our experience of dementia

The aged care industry wants any changes to care to be based on strong research evidence. By using a standardised system to track dementia care in home care and residential aged care, care quality can improve. Industry experts also want to work closely with people living with dementia and their carers to ensure any recommendations are practical, effective, and based on real-life experiences. Person-centered care—where individuals receive the time, resources, and expert support they need—is a priority.

Carers play a vital role, providing 80% of dementia care in home care settings. However, they often feel that their voices are not heard, with too much emphasis placed on input from medical experts. Carers need proper training and support to provide care without risking their own well-being. One solution is to create advisory groups where carers can share their insights with policymakers.

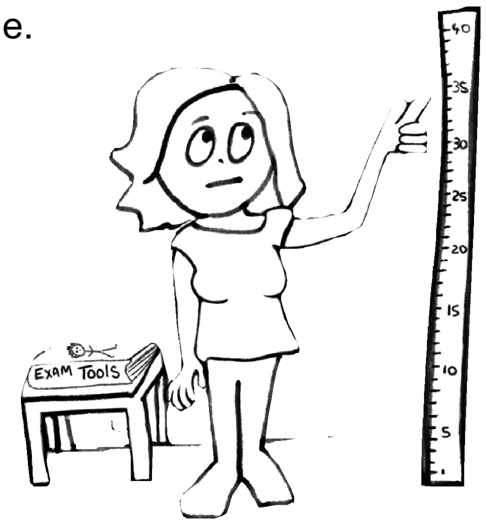
People living with dementia also want to be included in decisions about their own care. While dementia affects thinking and memory, many people can still contribute to discussions about their treatment, especially in the early stages. However, dementia care often focuses only on managing behaviours, rather than considering mental health and emotional well-being. Greater involvement from mental health professionals, such as neuropsychologists, could help improve care and support for both people with dementia and their carers.

Researchers emphasise the need for balanced collaboration between all stakeholder groups, ensuring research is based on real-world needs. By using evidence-based methods, research outcomes can be more effective and relevant to those they impact.

Section 3
Core Outcome Measures

Why Measuring Outcomes Matters

Decisions in healthcare are based on research. To understand whether a treatment or care approach is effective, researchers measure its impact. However, different studies often use different ways to measure success. For example, one study on migraines might track how many sick days a patient takes, while another might use a pain scale. This makes it difficult to compare studies and apply the findings in real-world care.



The Importance of Core Outcomes

A C***ore Outcome Set*** (COS) ensures that studies in a specific area measure the same outcomes, making results directly comparable. This helps:

- Strengthen research by allowing results to be combined across different studies
- Reduce unnecessary duplication in research
- Improve transparency in healthcare by identifying where care needs improvement
- Make it easier to measure the impact of new treatments and care guidelines

However, deciding which outcomes should be included in a COS is complex. Dementia care involves many different groups, including people living with dementia, their families, carers, healthcare workers, researchers, and policymakers. There are also thousands of possible outcomes to measure in healthcare.

The COMET Initiative

The *Core Outcome Measures in Effectiveness Trials (COMET)* initiative was created to standardise outcome measurement in research. It promotes the development of COS—agreed-upon sets of outcomes that should be measured for a specific health condition.

COS must include input from people affected by the condition, including patients, carers, and advocacy groups. The COMET website tracks available COS to prevent duplication and encourage adoption. As of July 2023, over 770 COS have been developed for various health conditions. If a COS already exists for a certain area, COMET works with stakeholders to adapt it rather than creating a new one from scratch, saving time and resources.

Dementia Care Settings

Home Care (HC)

The Australian government supports services that help older people live at home for as long as possible. The *Home Care (HC) package program* is the main way that funding is provided for people with dementia living in the community. Additional financial support is available for those with moderate or severe cognitive impairment.
As of 2022:

- More than 17,200 Australians received the HC dementia supplement
- 80% of these recipients were receiving intermediate or high-level care packages

Caring for someone with dementia at home is demanding, as symptoms can change unpredictably. In 2023, an estimated **140,900 carers** were supporting people with dementia in Australia.

- About half of these carers are spouses
- 47% provide more than 60 hours of care per week
- Many carers are unemployed or rely on government benefits due to the demands of caregiving

Residential Aged Care (RAC)

Residential Aged Care (RAC) is available for people who can no longer live independently at home. Dementia is highly common in RAC:

- **54%** of residents have a dementia diagnosis
- **41%** of residents without a dementia diagnosis still show signs of cognitive impairment
- **95%** of all RAC residents have some level of cognitive decline

Dementia is often linked with other health conditions. In RAC, the most common co-existing conditions for people with dementia are:

- Depression
- Arthritis
- Urinary incontinence
- Hypertension (high blood pressure)
- Falls (which can be worsened by overuse of medications)

There are concerns about the overuse of psychotropic medications in RAC, which may adversely impact the person's mental activity, behaviour and perception. These medications can lead to falls and be used as a form of chemical restraint for managing behaviours.

Funding data shows that people with dementia in RAC require the most support in:

- **Cognition and behaviour (84%)**
- **Activities of daily living (76%)** (e.g., dressing, eating)
- **Complex health care (61%)**

Younger people with dementia are more likely to need support for cognition and behaviour, while older residents typically require more help with medical care.

The length of time people stay in RAC varies, but people with dementia often live in RAC longer than those without dementia. This may be because people without dementia can remain at home longer and enter RAC only in the final stages of life. Additionally, people with dementia tend to use hospital services less at the end of life, and dementia itself is a leading cause of death in RAC.

How Core Outcome Measures Were Identified

Step 1
Consensus Process Using the Modified Delphi Method

To determine the most important outcomes for routine dementia care, experts used a structured process called the *Modified Delphi Consensus*. This method involved four rounds of discussion and voting, where participants reviewed and refined a list of potential core outcomes.
A total of 23 core outcomes were identified (see Table 2). The process followed the *COMET system of categorising outcomes*, starting with broad outcome areas that were already recognised as essential in dementia care. Panel members then suggested additional outcomes, which were categorised and prioritised.

In later rounds, participants had to make trade-offs, selecting the most important outcomes within each category. This approach helped ensure that the final list included outcomes that were **important, meaningful, and relevant** to all dementia care stakeholders, covering both home care (HC) and residential aged care (RAC).


There is a lot to discuss in our working groups

Table 2 Identified Core Outcomes from Delphi Consensus

Outcome
Activities of Daily Living (ADLs)
Advanced Care Planning
Behavioural Symptoms of Dementia
Dementia Care Navigation
Dementia Specific Qualifications for Service Provider
Diagnosis of Dementia
Dignity
Education Opportunities for Unpaid Carers and Family
Emotional Wellbeing
Falls Prevention
Family/Carer Burden
Family/Carer Quality of Life
Feeling Safe and Secure
Feeling Useful and Having a Purpose
Hygiene
Hygiene and Comfort
Importance of Relationships
Medication Appropriateness
Quality of Life
Resource Utilisation
Safety and Security
Safety Incidents
Wellbeing

Step 2

Measurement Selection

A two-hour Zoom meeting was held with experts, including members of the stakeholders reference group, Delphi panel, and the COM-IC investigator team.
During this session, participants reviewed the identified core outcomes and existing measurement tools.

At the end of the meeting, attendees were divided into four working groups. Their task was to find the best measurement tool for each core outcome identified in the Delphi process (see Table 3).

More details on the methodology and group composition can be found in the STARDIT report here: https://stardit.wikimedia.org.au/wiki/0202208100258

How the Best Measurement Tools Were Chosen

- The working groups had six weeks to research and compare different measurement tools.
- Each group presented their findings on the best available tool for each outcome (Table 4).
- Tools were assessed using key criteria based on the *Accounting for the Quality of NHS Output* framework:
    - **Clarity** – Is it easy to understand?
    - **Timeliness** – Can it provide up-to-date data?
    - **Validity** – Does it measure what it’s supposed to?
    - **Reliability** – Will it give consistent results?
    - **Ease of Collection** – Can it be easily gathered?
    - **Added Value** – Does it improve dementia care?

To guide decision-making, groups also had access to GRADE Handbook guidelines and NHMRC Guidelines for Guidelines.

They collaborated via online discussion boards and shared relevant documents on a shared drive.

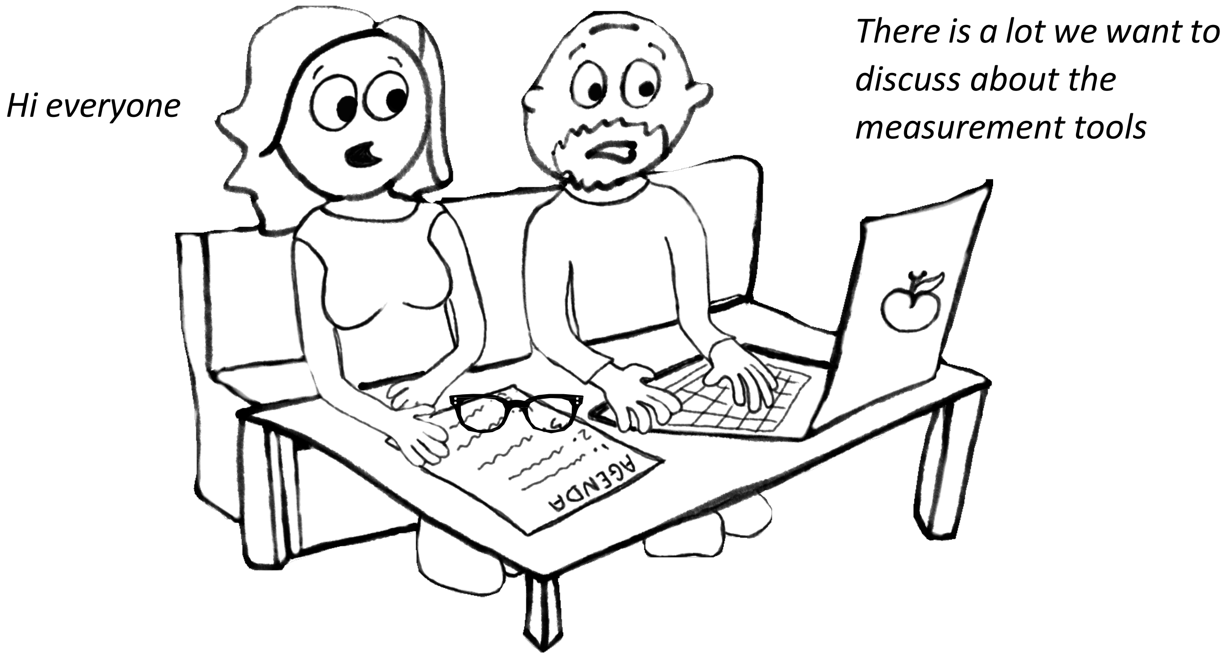


Table 3 Identified 'Best' Outcome Measures

Area	Home Care Outcome	Measure	Residential Aged Care Outcome	Measure
Death	Dignity	QCE-ACC	Dignity	QCE-ACC
	Advanced Care Planning	ACP-ES	Advanced Care Planning	ACP-ES
Physiological	Behavioural Symptoms of Dementia	NPI	Neuropsychiatric Symptoms of Dementia	NPI
	Diagnosis of Dementia	NRM (proxy - MoCA)	Pain	PAINAD
	Hygiene	Barthel		
Functional	Meaningful Activities	EMAS	Meaningful Activities	EMAS
	Importance of Relationships	CARE	Hygiene and Comfort	NSW COMFORT SCORE
	Feeling Safe and Secure	NPSS	Feeling Safe and Secure	NPSS
	Emotional Wellbeing	WHO-5	Emotional Wellbeing	WHO-5
Other Life Impact	Quality of Life	QOL-AD	Quality of Life	QOL-AD
	Quality of Carer and Family Lives	ZBI	Medication Appropriateness	STOPP START V2
Resource Use	Resource Utilisation	RUD-LITE	Staff Carer Morale	MAGPI
	Dementia Care Navigation	NRM	Resource Utilisation	RUD-LITE
Adverse Events	Safety Incidents	NRM	Safety Incidents	NRM
			Adverse Effects	NRM
Education	Dementia Specific Qualifications	DKAS	Dementia Specific Qualifications	DKAS
	Opportunities for Unpaid Carers	NRM		

Final Selection Process

After the presentations, working group members completed a Qualtrics survey where they reviewed each outcome and its proposed measurement tool.
They classified the tools into four categories (Table 4):

1. **Recommended Core Outcome Measures** – More than 70% of respondents agreed that both the outcome and its measurement tool should be part of the core outcome set (COS).

2. **Suggested Outcome Measures** – More than 70% agreed on the outcome, but there was no consensus on the best measurement tool.

3. **Extended Outcome Measures** – Not considered essential, but the measurement tool was still useful for certain situations.

4. Not Recommended - Less than 70% agreed on both the outcome and measurement tool.

These survey results determined the final recommended COS for dementia care.

Table 4 Identified Outcome Measures and Categories Described by Working Groups

Result	Outcome Measure
Recommended (COS)	HC Dignity (QCE-ACC) HC Hygiene (Barthel) RAC Dignity (QCE-ACC) RAC Pain (PAINAD) RAC Meaningful Activities (EMAS)
Suggested (no measure)	HC Diagnosis of Dementia (MoCA) HC Feeling Safe and Secure (NPSS) HC Quality of Life (QOL-AD) HC Dementia Qualifications (DKAS) RAC Hygiene and Comfort (COMFORT) RAC Emotional Wellbeing (WHO-5) RAC Quality of Life (QOL-AD) RAC Adverse Effects (No Measure) RAC Dementia Qualifications (DKAS)

Result	Outcome Measure
Extended (Non-Core Outcome)	HC Behavioural Symptoms of Dementia (NPI) HC Meaningful Activities (EMAS) HC Family/Carer QoL (ZBI) RAC Neuropsychiatric Symptoms of Dementia (NPI) RAC Staff Carer Morale (MAGPI)
Not Recommended	HC Opportunities for Unpaid Carers (NRM) HC Advanced Care Planning (ACP Engagement Survey) HC Importance of Relationships (CARE) HC Emotional Wellbeing (WHO-5) HC Resource Utilisation (RUD-LITE) HC Dementia Care Navigation (Pathway) HC Safety Incidents (NRM) RAC Advanced Care Planning (ACP Engagement Survey) RAC Feeling Safe and Secure (NPSS) RAC Medication Appropriateness (STOPP-START) RAC Resource Utilisation (RUD-LITE) RAC Safety Incidents (NRM)

Section 4

Recommendation 1: Core Outcome Set for Routine dementia Care- Immediate Use (Essential)

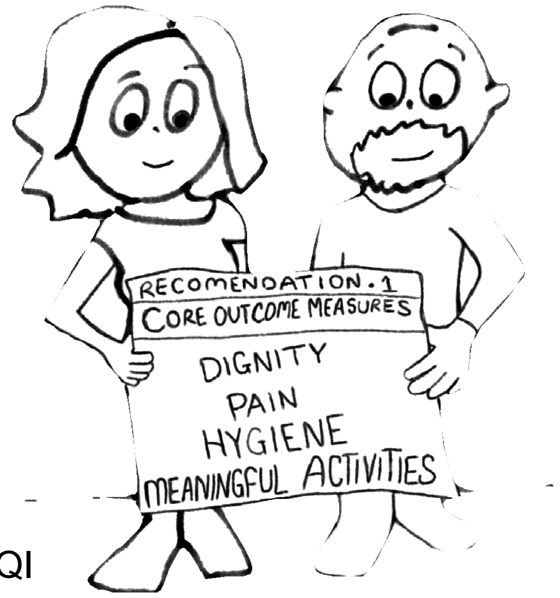
Recommendation 1 outlines five key measures (2 in home care, three in residential aged care) that should be used in Australian aged care settings for people living with dementia (see Table 6).

These measures are:

- Essential for assessing care quality
- Accurate, reliable, and up to date
- Already widely used and ready for immediate implementation

By collecting these measures regularly, service providers can:

- Monitor and improve care quality
- Compare performance across different providers (benchmarking)
- Ensure consistency with existing reporting requirements, including the QI Program for residential aged care and the Aged Care Quality Standards.



These measures set a minimum standard for auditing care quality and are a practical first step toward better dementia care.

Table 5 Summary of outcome measures Recommendation 1: COS

Outcome	Definition	Measure
Home Care		
Dignity	Experience of being treated with respect	QCE-ACC
Hygiene	Conditions and practices around cleanliness	Barthel
Residential Aged Care		
Dignity	Experience of being treated with respect	QCE-ACC
Pain	Pain should be attended to with respect and monitored/managed at all time points	PAINAD
Meaningful activities	Preserve the right for people experiencing dementia to engage in activities that develop connections and develop a sense of meaning or purpose that align with the care recipient's values, sense of accomplishment, and overall positive affect.	EMAS

Key Outcomes and Recommended Measures for Dementia Care

Dignity in Home Care

Why it matters:

- 75% of stakeholders agreed that dignity is a key measure of quality dementia care.
- **Definition**: Being treated with respect.
- **Recommended Measure**: The **Quality of Care Experience – Aged Care Consumers (QCE-ACC) survey** was chosen by 73% of stakeholders as the most comprehensive and simple way to measure dignity in home care.
- **Considerations**:
    - The QCE-ACC survey is already used in residential aged care but not widely in home care.
    - Some concerns exist about its suitability for people with cognitive impairment and proxy reporting.
    - Further refinement is needed to ensure accuracy for all people with dementia.

Hygiene in Home Care

Why it matters:

- 75% of stakeholders agreed that hygiene is essential for quality care.

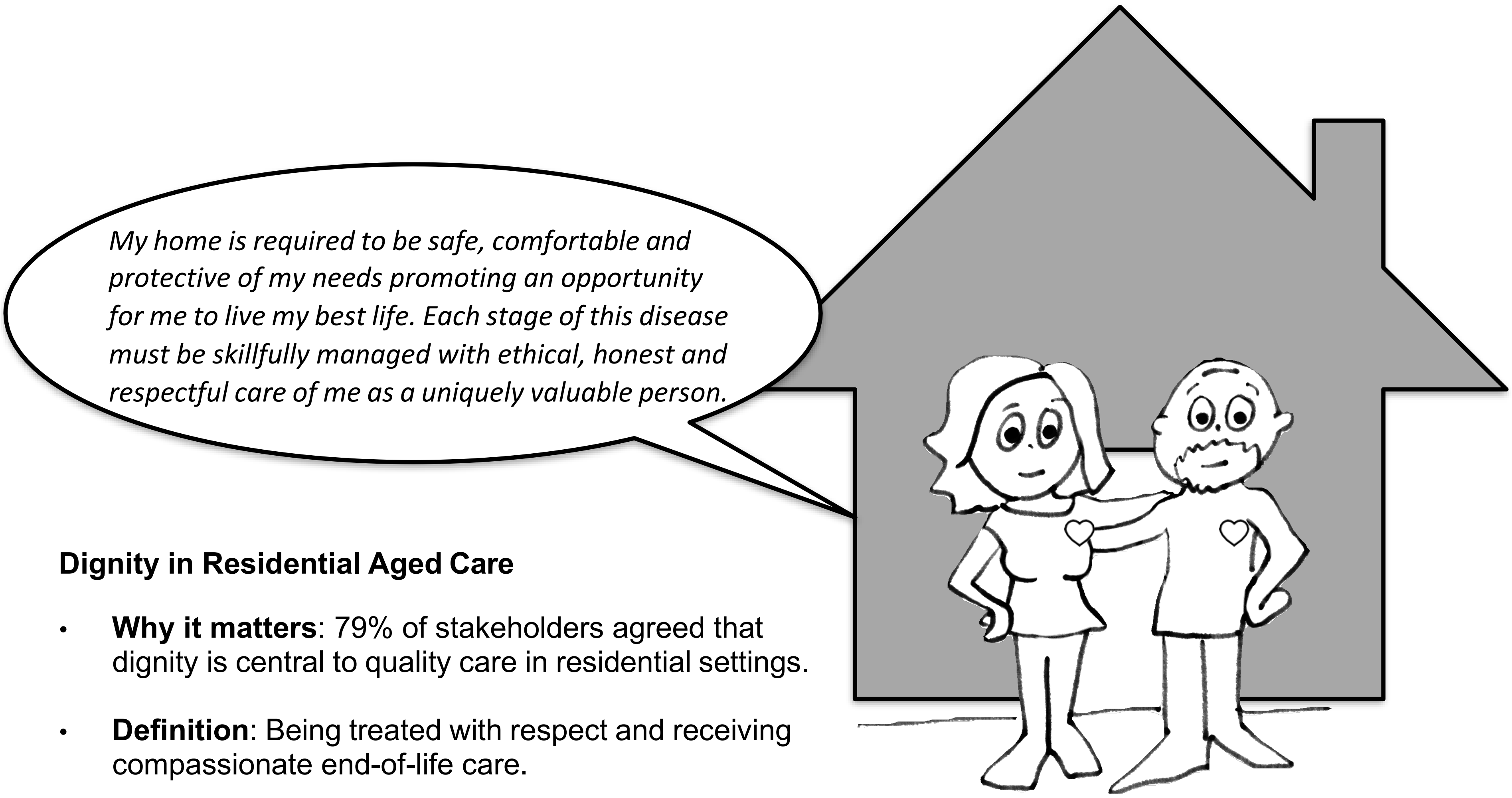
Definition: Cleanliness-related conditions and practices.

Recommended Measure:

- The Barthel Instrument was chosen by 73% of stakeholders due to its clarity, simplicity, and long history of use.

Considerations:

    - Some concerns that it is not specific to dementia or hygiene.
    - May not be the best fit for home care settings.
    - Alternative ideas included assessing living conditions, additional hygiene indicators (e.g., skin condition, toileting regularity), or environmental factors.



Dignity in Residential Aged Care

- **Why it matters**: 79% of stakeholders agreed that dignity is central to quality care in residential settings.
- **Definition**: Being treated with respect and receiving compassionate end-of-life care.
- **Recommended Measure**: The QCE-ACC survey, selected by 70% of stakeholders, as it integrates well into existing care assessments.
- **Considerations**:
  - Concerns about its effectiveness for people with dementia who cannot communicate.
  - Proxy reporting may not always be accurate.
  - No alternative measures were suggested, but some preferred specific actions (e.g., staff name-tags in accessible formats) to improve dignity in care.

Pain Management in Residential Aged Care

- **Why it matters**: 83% of stakeholders agreed that pain management is essential for dementia care.
- **Definition**: Pain should be **consistently monitored and managed** with respect.
- **Recommended Measure**: The **Pain Assessment in Advanced Dementia (PAINAD) scale**, selected by 81% of stakeholders for its effectiveness in identifying pain in people who have difficulty communicating.
- **Considerations**:
  - PAINAD is mainly used in research and may need further validation in routine care.
  - It works best when pain is linked to agitation but may not capture all cases.
  - Some suggested a toolbox of pain measures instead of a single scale.
  - Alternative ideas included self-reported pain scales, AI-based facial recognition, and simple experience survey questions on whether pain is measured and treated properly.

These measures provide a starting point for monitoring and improving dementia care in both home and residential settings, with further work needed to ensure their effectiveness in all care situations.

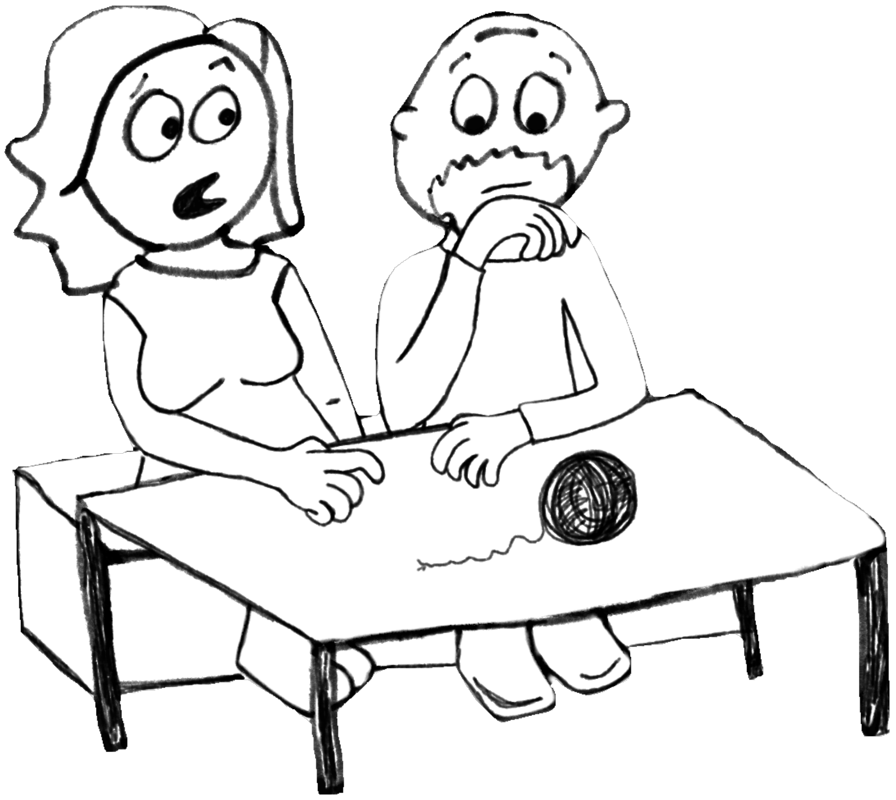
Meaningful Activities in Residential Aged Care

Why It Matters

- 79% of stakeholders agreed that meaningful activities are essential for quality dementia care.
- Meaningful activities help people with dementia stay connected, feel a sense of purpose, and experience positive emotions in line with their personal values.

Recommended Measure

- The Engagement in Meaningful Activities Survey (EMAS) was chosen by 71% of stakeholders because it is simple, relevant, and helps improve care quality.
- EMAS could also be useful for monitoring mental health in aged care beyond dementia care.



Let’s explore some new activities together

Considerations

- EMAS has not been tested specifically with people who have dementia, so it may not work as well for this group.
- The sector needs a clear definition of "Meaningful Activities" that applies across different care settings.
- Aged care facilities may not always be able to offer activities that are meaningful to every individual due to resource limitations.
- Meaningful activities are closely linked to overall quality of life.
- Alternative Approaches.
- Aligning meaningful activities with the strengthened aged care quality standards.
- Observing behaviours and engagement levels instead of relying on direct questioning.
- Using existing tools like **H**ammondCare’s GAS-light, which measures personal goals and outcomes.

Section 5

Recommendation 2: Core Outcome Set for Routine Dementia Care - Medium-Term Goals (Suggested)

Why This Matters

Some important aspects of dementia care were identified as core to quality care, but there was no clear agreement on how to measure them.

What Needs to Happen

- More research is needed to create and test better ways to measure these outcomes.
- Without reliable measurement tools, it is difficult to track progress and improve care in these areas.
- These outcomes are important, but we currently lack a standard way to assess them in dementia care settings.

Recommendation 2 calls for robust, high-quality research to develop better measurement tools that accurately reflect key aspects of dementia care.

Table 6 Summary of outcome measures recommendation 2: Core outcomes with no acceptable measure

Outcome	Definition	Measure
Home Care		
Diagnosis of dementia	Accurate diagnosis (and aetiology) of dementia.	NRM (proxy MoCA*)
Feeling safe and secure	Feeling psychologically safe, including not being punished or humiliated for sharing ideas, asking questions, voicing concerns, or making mistakes.	NPSS
Quality of life	Experience of health and well-being.	QOL-AD
Dementia qualifications	All professional care staff providing care to people living with dementia should understand the condition, its manifestation, and appropriate responses to provide care with respect and dignity.	DKAS
Residential Aged Care		
Hygiene and comfort	Two separate concepts: Hygiene – conditions or practices conducive to maintaining health and preventing disease, especially through cleanliness. Comfort – transient, multi-dimensional state that is free from pain, including psychological distress.	COMFORT
Emotional wellbeing	Supporting people experiencing dementia to realise their potential, cope with normal stress, work productively, and contribute to their community.	WHO-5
Quality of life	The standard of health, comfort, and happiness experienced by an individual or group.	QOL-AD
Adverse events	Prevention, monitoring and tracking of harmful or negative outcomes occurring during provision of medical care.	NRM
Dementia qualifications	All professional care staff providing care to people living with dementia should understand the condition, its manifestation, and appropriate responses to provide care with respect and dignity.	DKAS

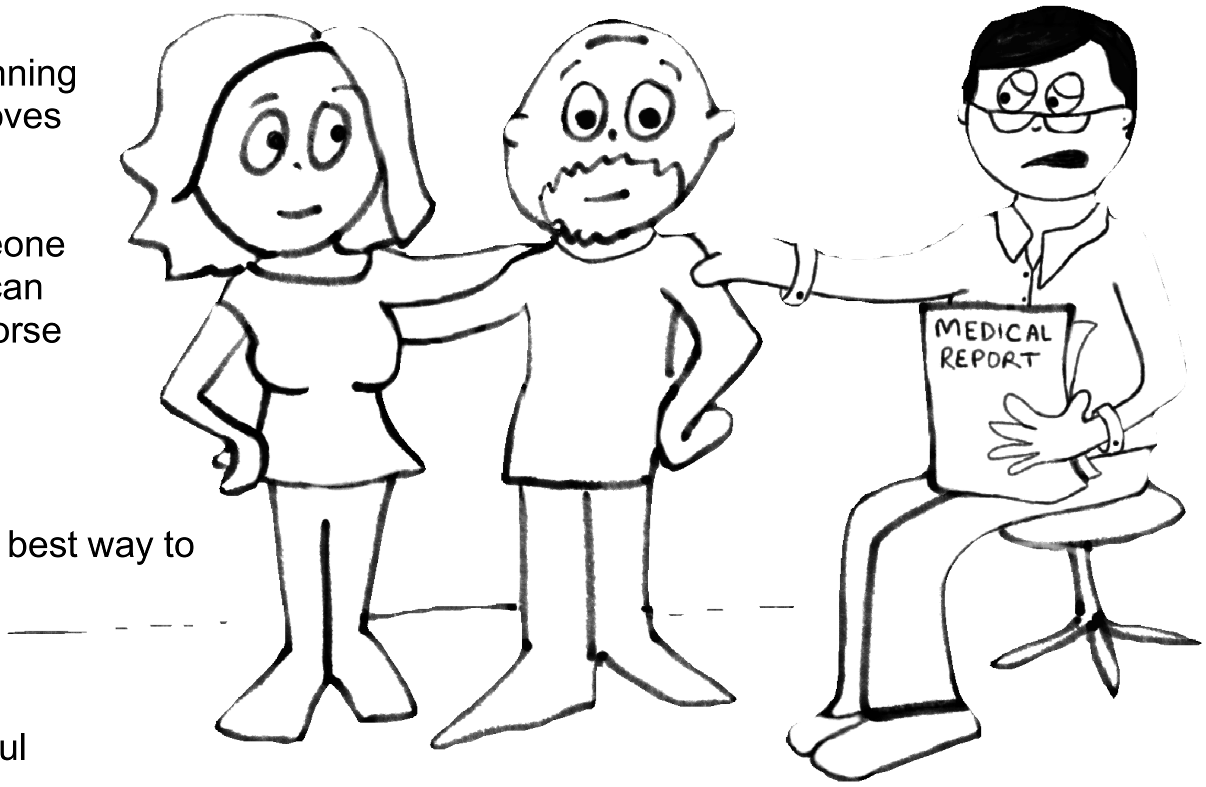
* We know that MoCA is a screening tool and not a diagnostic tool, however, we agree that screening for dementia can improve a person's chance of receiving appropriate care in a timely manner. There is no appropriate measure for dementia diagnosis, but accurate diagnosis is essential for the right treatment plan.

Diagnosis of Dementia for Home Care

Why It Matters

- 79% of stakeholders agreed that diagnosing dementia is essential for quality care.
- A correct diagnosis helps ensure personalised, appropriate care planning and early intervention, which improves outcomes.
- Misdiagnosis (e.g., assuming someone has Alzheimer's when they don't) can lead to incorrect treatments and worse health outcomes.

It is important to learn all you can about your diagnosis so you can continue to find ways to live your best life as the disease progresses



Measurement

- No single tool was identified as the best way to measure dementia diagnosis.
- The Montreal Cognitive

Assessment (MoCA) was seen as a useful

screening tool but is

not a full diagnostic tool.

- Dementia diagnosis should be done by trained medical professionals, not general home

care providers.

- MoCA can help identify people at risk, but it shouldn't be used as a standalone diagnostic tool.
- Other potential methods include brain imaging, spinal fluid tests, or specialist memory clinics.
- While home care providers may not be responsible for diagnosis, accurate diagnosis is essential for guiding care decisions.
- More research is needed to find or develop a reliable tool for tracking dementia diagnosis in home care.

Feeling Safe and Secure in Home Care

Why It Matters

- 79% of stakeholders agreed that feeling safe—both physically and emotionally—is essential for dementia care.
- Psychological safety means not feeling punished, judged, or humiliated for speaking up, asking questions, or making mistakes.

Measurement

- No single tool was identified as the best way to measure feeling safe and secure.
- The Neuroception of Psychological Safety Scale (NPSS) was considered the best option by 65% of stakeholders but wasn't seen as suitable for routine use.

Considerations

- NPSS covers many important areas, but it may not be suitable for people with cognitive impairments.
- Challenges include power imbalances, bias in responses, and unclear actions to improve safety based on the results.
- The scale is also quite long, which could add to data collection burden for care providers.
- No alternative measures were suggested, meaning further research is needed.

Quality of Life in Home Care

Why It Matters

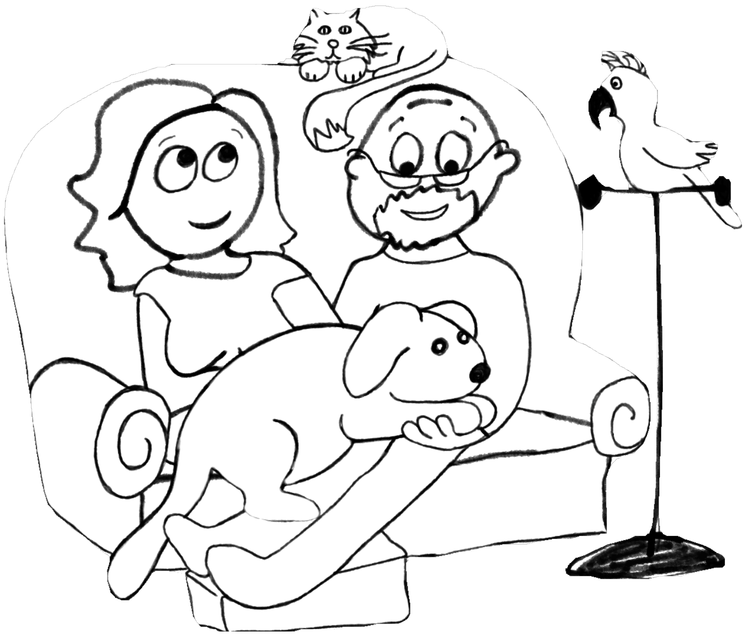
- 92% of stakeholders agreed that quality of life is central to dementia care.
- Quality of life includes overall health and wellbeing

Measurement

- No single tool was identified as the best way to measure quality of life.
- The Quality of Life in Alzheimer's Disease (QOL-AD) scale was the most preferred option but was only supported by 19% of stakeholders.

Considerations

- QOL-AD is brief and specific to dementia, but concerns include:
  - Licensing restrictions that limit widespread use.
  - Limited ability to track changes in quality of life over time.
  - Omission of key aspects of care quality.
- Other potential tools include:
  - World Health Organisation Wellbeing Index (WHO-5)
  - Alzheimer's Disease Five Dimensions (AD-5D)
  - DEM-QOL, QUALIDEM, and CARE
  - Quality of Life – Aged Care Consumers (QOL-ACC), which is already used in residential care.
- Future research should explore whether a simple quality of life measure is enough, or if more detailed tools are needed.



Dementia Training for Home Care Staff

Why It Matters

- 83% of stakeholders agreed that all professional care staff should have a basic understanding of dementia to provide respectful and appropriate care.
- While qualifications don't guarantee skill, a minimum knowledge level is needed for good care.

Measurement

- No single tool was identified as the best way to measure dementia knowledge.
- The Dementia Knowledge Assessment Scale (DKAS) was preferred by 52% of stakeholders but wasn't considered suitable for routine use.

Considerations

- DKAS was seen as outdated and too simplistic, focusing on trivia rather than practical skills.
- The scale is more useful for assessing knowledge before training than for measuring the effectiveness of training.
- Stakeholders suggested alternatives, such as:
    - A simple statement of competency, like "My care staff understand dementia and how to support me."
    - Evidence of formal qualifications.
    - Mandatory training standards, similar to CPR and first aid certifications.
- Further research is needed to develop a practical way to assess dementia knowledge among care staff.

Hygiene and Comfort in Residential Aged Care

Why It Matters

- 75% of stakeholders agreed that hygiene and comfort are fundamental to dementia care.
- These were considered as two separate but related areas:
    - Hygiene: Cleanliness and infection prevention.
    - Comfort: A state free from pain or distress.

Measurement

- No single tool was identified as the best way to measure hygiene and comfort.
- The COMFORT scale was the most preferred option (52% support), but it wasn't considered

suitable for routine use.

Considerations

- The COMFORT scale was originally designed for palliative care, making it less practical for dementia care.
- Measuring hygiene and comfort effectively requires:
  - Clinical observation skills.
  - Actionable data that can improve care.
- Few existing tools measure hygiene and comfort in dementia care, meaning new tools need to be developed.
- Many stakeholders felt hygiene and comfort could be measured through related outcomes like pain and dignity.

Emotional well-being for residential aged care

Why It Matters

- 75% of stakeholders said emotional wellbeing is essential for quality dementia care.
- Emotional wellbeing means helping people with dementia live to their full potential, manage stress, stay engaged, and feel a sense of belonging.

Measurement

Emotional wellbeing for residential aged care (WHO-5) Measurement

- No specific tool was found to measure emotional wellbeing for those experiencing dementia.

These outcomes are critical for dementia care, but there is no universally accepted way to measure them. More research is needed to:

- Develop better assessment tools that are reliable and practical.
- Ensure these measures can be used effectively in routine home and residential care.
- Reduce the burden on care providers while still tracking important aspects of quality care.

Considerations

- The World Health Organisation Wellbeing Index (WHO-5) was seen as a good option by 52% of stakeholders because it is simple and easy to understand. However, it was not considered suitable for routine use in dementia care.
- Some stakeholders felt the WHO-5 was too general and not sensitive enough to capture emotional wellbeing.
- The tool has never been tested for people with dementia, and it’s unclear if it works when completed by a caregiver on their behalf.
- No other measurement tools were suggested, but there was agreement that a better option is needed.

Quality of Life in Residential Aged Care

Why it matters

- 92% of stakeholders said quality of life is crucial for dementia care.
- Quality of life means a person's overall health and well-being.

Measurement

- No single tool was identified as the best way to measure quality of life.

Considerations

- The Quality of Life in Alzheimer's Disease (QOL-AD) tool was preferred by 61% of stakeholders because it is well-known and validated for people with dementia. However, it was not considered suitable for routine use in dementia care.
- Concerns about QOL-AD included outdated language, possible duplication, missing key aspects of quality of life, and not being specific to residential care settings.
- Other tools suggested included AD-5D, DEMQOL, and GAS-light, but the variety of available tools made it difficult to select one universal measure.
- The QOL-ACC tool, already used in aged care reporting, was also considered.

Adverse Events in Residential Aged Care

Why it matters

- 71% of stakeholders said tracking adverse events is important for quality dementia care.
- Adverse events include any harmful or negative incidents that happen during care.

Measurement

- No specific tool was found to measure adverse events.
- Many stakeholders felt it wasn't needed because serious events are already tracked through the Quality Indicator (QI) Program.

Considerations

- There was agreement that adverse events impact care quality and are included in major aged care guidelines.
- The main challenge was defining what should be measured—should it include only preventable incidents, or all types of harm (physical, emotional, or social)?
- More clarity is needed before a suitable measurement tool can be developed.

Dementia Training and Qualifications for Residential Aged Care

Why it matters

- 79% of stakeholders said all professional care staff should have a basic understanding of dementia to provide respectful and appropriate care.

Measurement

- No specific tool was found to measure dementia qualifications.

Considerations

- The Dementia Knowledge Assessment Scale (DKAS) was supported by 43% of stakeholders for measuring dementia knowledge from formal training, but it was not suitable for routine use.
- There is little research on how to measure formal dementia qualifications.
- A suitable measure would need to reflect best-practice care and consider various levels of education (e.g., vocational training, university degrees).
- Some stakeholders supported setting minimum education requirements for care providers and adding dementia modules to existing aged care courses.

- Ongoing training could be required, similar to first-aid or manual handling refresher courses.

Recommendation 3: Core Outcome Set For Routine Dementia Care: Extended Goals (Best Practice)

Service providers who want to improve the quality of dementia care should have access to validated measures for outcomes that are not considered core, but still important.

Recommendation 3 focuses on outcomes that were identified as core by the Delphi panel, but did not meet the criteria to be considered a core outcome measure (COM) by the working groups (see Table 8). Even though these outcomes did not meet the threshold, the measures for them were seen as appropriate and best-practice by most working group members. These outcomes provide opportunities for service providers to take innovative steps to improve routine dementia care, as the measures are reliable, proven, and important.
While these outcomes may not be the "most" important right now, they are still valuable to stakeholders and many believe they can help improve the quality of care.

Table 7 Summary of outcome measures Recommendation 3: extended outcomes with reliable measure

Outcome	Definition	Measure
Home Care		
Behavioural symptoms of dementia	Behavioural and psychological symptoms need to be charted, with changes documented	NPI
Meaningful activities	Preserve the right for people experiencing dementia to engage in activities that develop connections and develop a sense of meaning or purpose that align with the care recipient’s values, sense of accomplishment, and overall positive affect.	EMAS
Family/carer quality of life	Supporting main caregivers to maintain their own health and wellbeing to sustain appropriate care-giving arrangements in the home.	ZBI
Residential Aged Care		
Neuropsychiatric symptoms of dementia	Neurological and psychological symptoms of dementia need to be charted, managed, and documented as part of routine care.	NPI
Staff carer morale	Acknowledgement that high quality care can only be attained with an engaged, valued, and supported workforce.	MAGPI

Behavioural Symptoms of Dementia for Home Care

Outcome

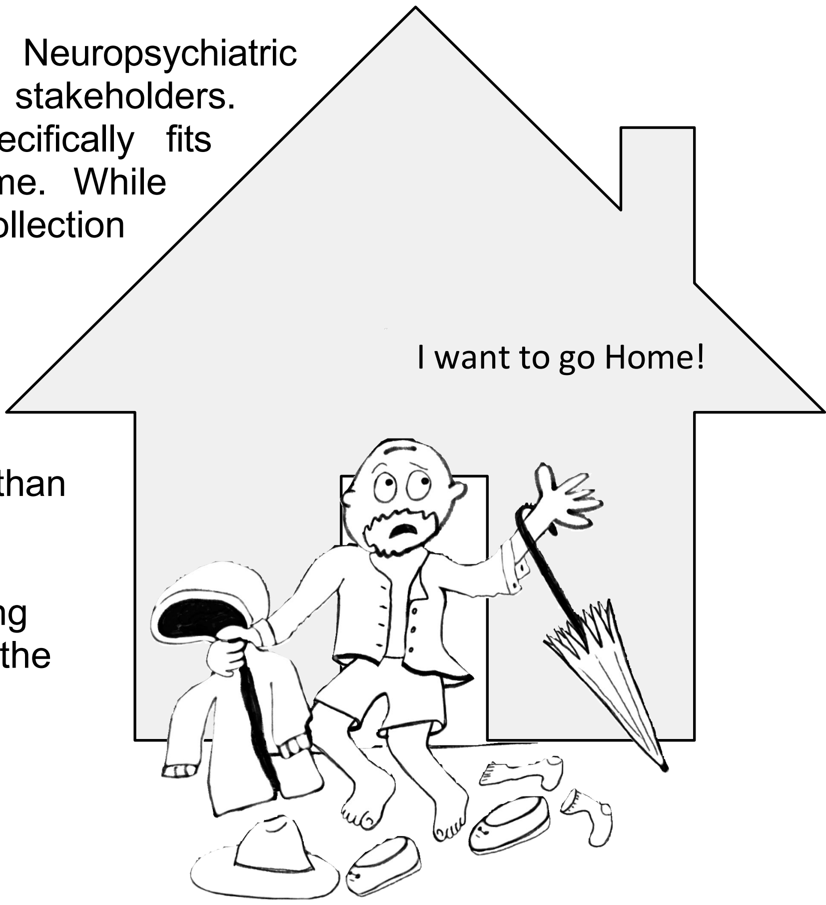
Stakeholders considered the outcome of behavioural symptoms of dementia important for quality care, but it didn't meet the threshold to be included in the Core Outcome Set (COS). This outcome involves tracking and documenting any changes in a person's behavioural and psychological symptoms.

Measure

For situations where behavioural issues are identified, the Neuropsychiatric Inventory (NPI) was seen as an appropriate tool by 74% of stakeholders. However, there were concerns about whether the NPI specifically fits dementia, and whether it truly reflects the intended outcome. While comprehensive, some felt that the NPI overlaps with other data collection tools, making it somewhat redundant.

Considerations

Behavioural symptoms should only be measured when they are present. Including this as a core outcome too early could reinforce care that is too focused on managing behaviours rather than improving quality of life. Over time, as care technologies and approaches evolve, this focus might become less relevant. Stakeholders suggested alternative approaches, such as designing environments supporting person-centred care plan may eliminate the need for this outcome.



Meaningful Activities for Home Care

Outcome

Stakeholders agreed that meaningful activities were important for quality care, but it didn't meet the threshold to be included in the COS. This outcome includes ensuring people with dementia have the opportunity to engage in activities that provide connection, meaning, or purpose, based on their own values and sense of accomplishment.

Measure

88% of stakeholders agreed that the Engagement in Meaningful Activities Survey (EMAS) is the best measure for tracking meaningful activities, although some had concerns about its validity for people with dementia.

Considerations

There's broad support for measuring engagement in meaningful activities throughout care. This is seen as crucial for quality care, but some felt that simpler screening questions (like those in QOL-ACC) might be enough. There was some difficulty defining "meaningful activities," but generally, they are understood as those providing social, physical, and psychological enrichment. Care providers may not always agree on what activities are truly meaningful to people with dementia. If more resources were available, EMAS could be a strong tool to track engagement in meaningful activities.

Family and Carer Quality of Life for Home Care

Outcome
Stakeholders agreed that supporting carers to maintain their own health and wellbeing is important for quality care, but it didn’t meet the threshold for inclusion in the COS. This outcome focuses on helping caregivers sustain their caregiving role by ensuring they stay healthy and supported.

Measure
71% of stakeholders felt that the Zarit Burden Index (ZBI) is a suitable measure of family and carer quality of life. However, concerns were raised about its focus on negative aspects (like the word "burden"), its data collection demands, and whether it applies to all carer situations.

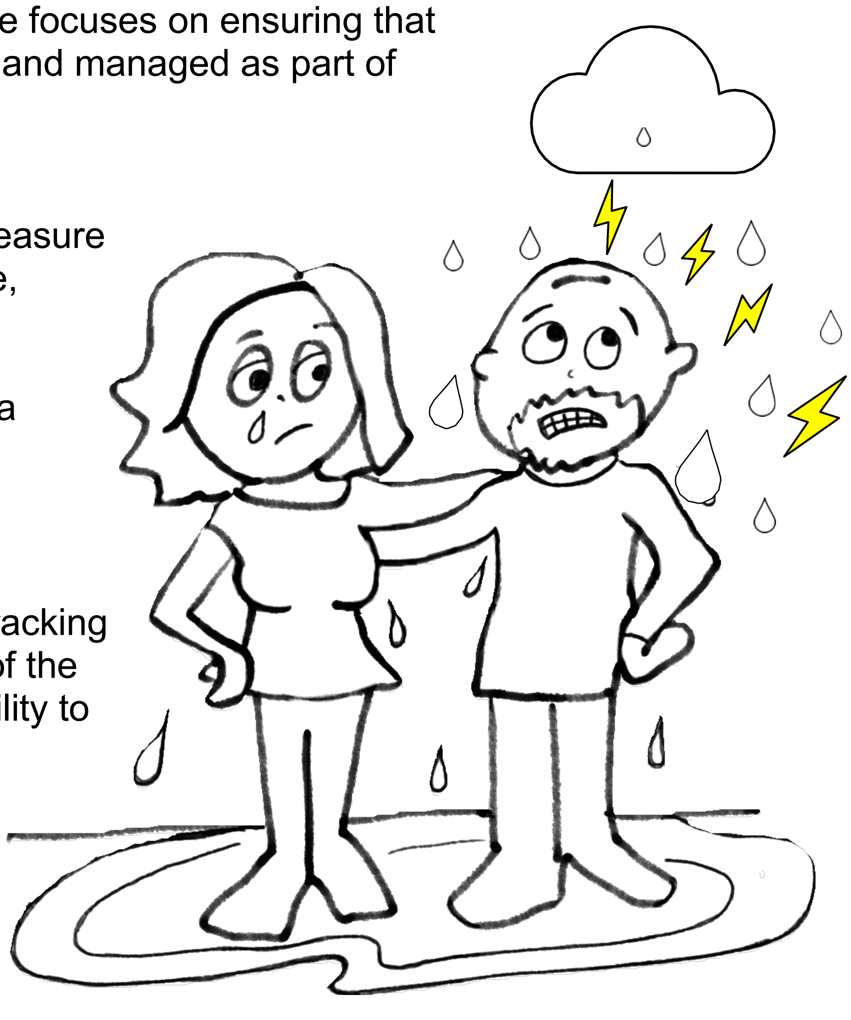
Considerations
While not included in the COS, the ZBI remains a reliable measure for those who wish to support carers and improve the sustainability of caregiving. Quality of life for carers is critical, especially when the person with dementia is highly dependent on informal care.
Sustainability of caregiving is a major factor in whether a person stays in home care or moves to a residential care setting. Stakeholders also considered other tools, like DEM-QOL proxy or interRAI’s caregiver stress scale, as potential alternatives.

Neuropsychiatric Symptoms of Dementia for Residential Aged Care

Outcome
Stakeholders considered neuropsychiatric symptoms of dementia important for quality care but did not meet the COS threshold. This outcome focuses on ensuring that neurological and psychological symptoms are tracked and managed as part of routine care.

Measure
77% of stakeholders saw the NPI as an appropriate measure for neuropsychiatric symptoms in residential aged care, valuing its relevance and widespread use. However, concerns were raised about its complexity, the burden of data collection, and its relevance, as not all dementia patients show behavioural issues.

Considerations
Service providers focused on managing behavioural symptoms may find the NPI useful. Some suggested tracking trends over time using care plans or shorter versions of the NPI to reduce the burden. AI may also improve the ability to predict problematic behaviours.



Staff Carer Morale for Residential Aged Care

Outcome

Stakeholders felt that staff carer morale is crucial for quality care, but it did not meet the COS threshold. This outcome stresses the importance of having an engaged, valued, and supported workforce providing high-quality care.

Measure

73% of stakeholders agreed that the Morale Assessment in General Practice Index (MAGPI) is an appropriate measure for staff and carer morale, although concerns were raised about its relevance and potential bias in staff responses.

Considerations

High morale among staff is critical for quality care, and stakeholders recognised that staff who feel unsupported or overworked may provide lower-quality care. Approaches to measuring morale should aim to reduce data collection burden by sampling a smaller group of staff. Objective measures like staff turnover or sick days might also provide insights into staff wellbeing.

Section 7

Recommendation 4: Core Outcome Set for Routine Dementia Care: (Optional)

Outcomes that are important but not considered core should be discussed as possible areas for improving care quality in both home care and residential aged care settings. These outcomes could become core in the future.

Recommendation 4 focuses on outcomes that were considered core by the modified Delphi panel but did not reach a consensus to be included as core outcomes in the final list. Additionally, the best-practice measures identified by the working groups were not agreed upon as the best way to measure these outcomes (see Table 9).

These outcomes are seen as important by stakeholders, but the current evidence doesn't support their inclusion in the Core Outcome Set (COS) for routine dementia care.

While these outcomes and measures are not currently recommended, they might become more relevant in future updates. Service providers with extra resources to track and assess the quality of dementia care should consider including these measures in their data collection. Furthermore, as measurement methods improve, the benefits of collecting this data may outweigh the challenges involved.

(See Table 8 for a summary of outcome measures for Recommendation 4: Extended outcomes with no reliable measure and not recommended.)

Table 8 Summary of outcome measures Recommendation 4: Extended outcomes with no reliable measure (not recommended)

Outcome	Definition	Measure
Both		
Advanced care planning	The opportunity to discuss and make an Advanced Care Plan	ACP Survey
Resource utilisation	Facilitate high level decision-making and efficient allocation of resources to be able to appropriately cost and budget for quality improvement activities	RUD-LITE
Safety incidents	Unplanned or unintended event or circumstance which could have resulted or did result in harm to a care recipient.	NRM
Home Care		
Opportunities for unpaid carers	Carers are supported with resources and clinical education they need to learn about aspects of dementia care they can assist with.	NRM
Importance of relationships	Providing people experiencing dementia the freedom to express emotions and adapt to change, to flourish, feel connected, have a sense of purpose and agency, and a positive sense of self.	CARE
Emotional wellbeing	Supporting people experiencing dementia to realise their potential, cope with normal stress, work productively, and contribute to their community.	WHO-5
Dementia care navigation	Developing partnerships between stakeholders to navigate complex health care systems and treatment landscapes.	Pathway
Residential Aged Care		
Feeling safe and secure	Feeling psychologically safe, including not being punished or humiliated for sharing ideas, asking questions, voicing concerns, or making mistakes.	NPSS
Medication appropriateness	Increased awareness and appropriate use of medication prevents adverse events associated with polypharmacy, reduces costs, and improves clinical care outcomes.	STOPP-START

Advance Care Planning for Home Care and Residential Aged Care

Outcome

Stakeholders agreed that advance care planning is an important conversation to have early in the care process, but it shouldn't be mandatory. 58% of stakeholders supported its inclusion for home care, and 67% supported it for residential aged care.

Advance care planning means giving people the opportunity to discuss and make a plan for their future care.

Measure

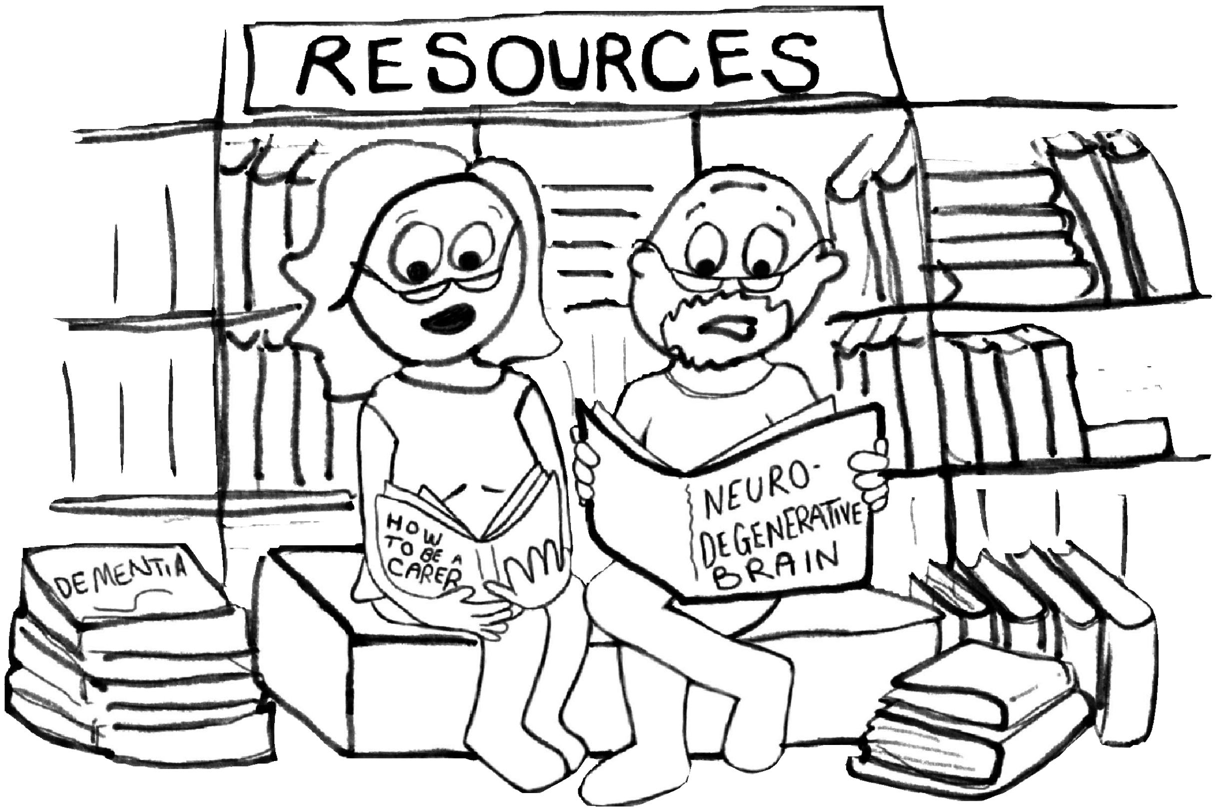
No suitable tool was found for measuring advance care planning.

Considerations

The ACP Engagement Survey was considered an appropriate tool by 47% of stakeholders for home care and 45% for residential aged care. However, some concerns were raised about the survey being too long, complex, and potentially irrelevant in home care. It may also require a specialist with legal knowledge to manage it.

While stakeholders acknowledged the importance of advance care planning as health declines, there were questions about whether simply having an advanced care plan changes the care provided or if it should be considered part of the quality of care. More work is needed to find the best way to measure and support advance care planning conversations. Most stakeholders preferred a simpler approach, such as asking if a care plan is in place, offered, or discussed. Clear guidelines are needed to decide how to include advance care planning as a measure of quality care.

Resource Utilisation for Home Care and Residential Aged Care



Outcome

Stakeholders agreed that resource utilisation is important but should not be included in a COS. 43% of stakeholders supported its inclusion for home care, and 54% supported it for residential aged care.
Resource utilisation means making decisions about how to efficiently allocate resources and budget for quality improvement activities.

Measure

No suitable tool was found for measuring resource utilisation.

Considerations

The RUD-LITE tool was considered useful by 46% of stakeholders for home care and 50% for residential aged care. In residential aged care, it helped to understand resource use and ensure resources were allocated effectively. However, concerns were raised about its applicability in home care, the accuracy of self-reported data (especially related to funding), and the time it took to complete.
No alternative tools were suggested. It was noted that the Australian National Aged Care Classification (AN-ACC) already determines funding for residential aged care, so adding RUD-LITE would duplicate existing processes.

Safety Incidents for Home Care and Residential Aged Care

Outcome

Stakeholders agreed that safety incidents are important but should not be included in a COS. 67% of stakeholders supported its inclusion for both home care and residential aged care.
Safety incidents refer to unplanned events that could result in harm to the person receiving care.

Measure

No suitable tool was found for measuring safety incidents.

Considerations

Stakeholders were surprised that no measure for safety incidents in home care was available, although they acknowledged the challenges of assigning responsibility for incidents in a care recipient's home.

In residential aged care, some quality indicators already track specific safety incidents, such as falls, and most service providers have incident reporting systems in place. However, how this data is used varies between providers.

There was general agreement that safety incidents are not unique to dementia care and should be considered when collecting baseline data for all care recipients, not just those with dementia.

Opportunities for Unpaid Carers in Home Care

Outcome

Stakeholders agreed that opportunities for unpaid carers are important but not an outcome of care, so it should not be included in a COS. 38% of stakeholders supported its inclusion.

Opportunities for unpaid carers means offering support and education to help them learn about aspects of dementia care they can assist with.

Measure

No suitable tool was found for measuring opportunities for unpaid carers.

Considerations

Stakeholders acknowledged the value of unpaid carers and their role in supporting people with dementia, but some felt it was too difficult to measure this in an evolving care environment.

There are opportunities for carers to up skill, with some resources available at no cost. Developing care navigation pathways for dementia would also be helpful but was not linked to a specific outcome.

A potential way to measure this could be with a simple question, like: "Have I been provided with enough information, education, and support to do my role?"

Importance of Relationships for Home Care

Outcome

Stakeholders agreed that the importance of relationships is important but should not be included in a COS. 63% of stakeholders supported its inclusion.

The importance of relationships means supporting people with dementia to express emotions, adapt to change, and feel connected, with a sense of purpose and self-worth.

Measure

No suitable tool was found for measuring the importance of relationships.

Considerations

Quality care relies on communication and supporting people with dementia to live their best life, but it's unclear how measuring the importance of relationships would indicate care quality.

If measured, the CARE survey was considered a good option for home care by 61% of stakeholders. However, there were concerns that the questions focus more on doctor-patient relationships, not personal relationships for people with dementia.

Some stakeholders felt tools like the QOL-ACC would better capture this outcome in residential aged care.

Emotional Wellbeing for Home Care.

Outcome
Stakeholders agreed that emotional wellbeing is important for all people receiving care, not just those with dementia, so it should not be included in a COS. 63% of stakeholders supported its inclusion.
Emotional wellbeing means helping people with dementia realise their potential, cope with stress, work productively, and contribute to their community.

Measure
The WHO-5 wellbeing index was considered a suitable measure by 63% of stakeholders for home care. It is short, easy to use, and focuses on wellbeing rather than illness. However, there were concerns that it doesn't cover all aspects of wellbeing, may not be sensitive to changes in wellbeing, and could be problematic for people who need a proxy to respond.

Considerations
Alternatives suggested by stakeholders included developing culturally sensitive tools and using technology to better understand how people with dementia are flourishing.

Dementia Care Navigation for Home Care

Outcome
Stakeholders agreed that dementia care navigation is important but should not be included in a COS. 58% of stakeholders supported its inclusion.
Dementia care navigation means developing partnerships to help people with dementia navigate complex health care systems and treatment options.

Measure
No suitable tool was found for measuring dementia care navigation.

Considerations
Stakeholders noted that care planning is critical, and care navigation could offer significant benefits for people with dementia. However, there is no available measure for dementia care navigation in home care, and existing pathways are designed for hospital settings, making them complex and not suitable for non-specialists.

Feeling Safe and Secure for Residential Aged Care

Outcome
Stakeholders agreed that feeling safe and secure is important but not an outcome of care, so it should not be included in a COS. 67% of stakeholders supported its inclusion.
Feeling safe and secure means feeling psychologically safe, including being able to share ideas, ask questions, and voice concerns without fear of punishment or humiliation.

Measure
The Neuroception of Psychological Safety Scale (NPSS) was considered by 61% of stakeholders as the best available measure, but not suitable for a COS. The NPSS was seen as a good attempt to measure aspects of care beyond the physical, but concerns were raised about its length, relevance to dementia care, and its validation for people with dementia.

Considerations

Other alternatives suggested included whistleblowing protection, shorter versions of the NPSS, resident experience surveys, quality of life measures, and trauma measures. However, all of these instruments have similar concerns about reliability, validity, and feasibility.

Medication Appropriateness for Residential Aged Care

Outcome

Stakeholders agreed that medication appropriateness is important but should not be included in a COS. 58% of stakeholders supported its inclusion.

Medication appropriateness means using medications correctly to prevent problems from taking too many medications, reduce costs, and improve health outcomes.

Measure

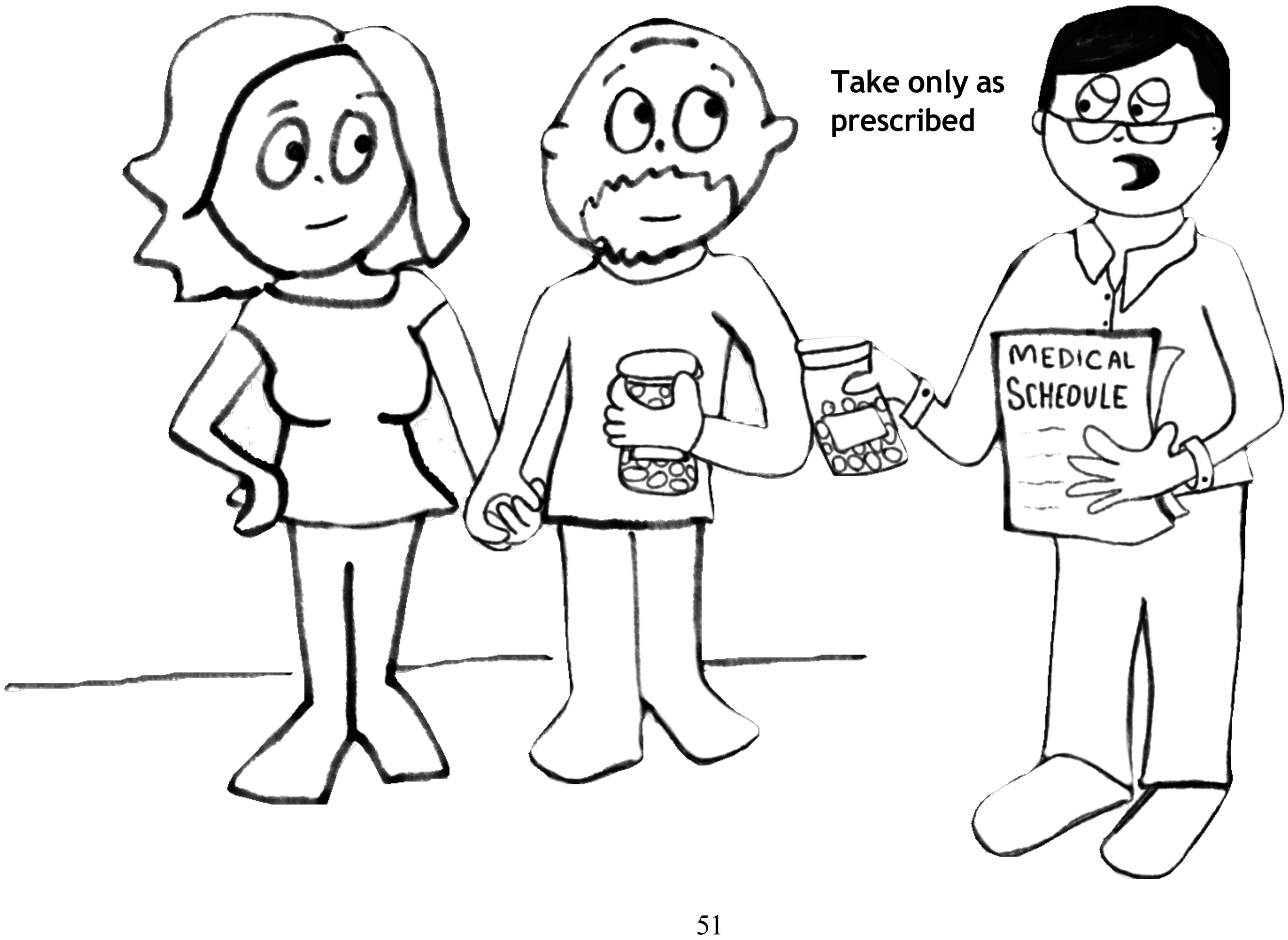
No suitable tool was found for measuring medication appropriateness.

Considerations

Medication appropriateness in dementia care depends on accurate diagnosis, and using it as an outcome to measure quality care in aged care settings is debated.

The STOPP START v2 tool was considered appropriate by 52% of stakeholders or measuring medication appropriateness in residential aged care. However, it was seen as a complicated tool that requires trained assessors, and some stakeholders felt they were not qualified to use it.

Alternatives suggested included having qualified staff, like clinical pharmacists, to conduct medication reviews. The Australian Government's Aged Care On-site Pharmacist (ACOP) program is introducing this approach. It was noted that medication appropriateness is important for all care recipients, not just those with dementia, and should be considered when collecting baseline data for all care recipients.



Section 8
Implementation and Significance

After extensive consultation with the community, international research, and stakeholder discussions , a preliminary Core Outcome Set (COS) for improving the care of people with dementia was created. Potential outcome measures for individual outcomes were assessed for their relevance and suitability.

However, none of the outcomes or measures proposed received unanimous agreement for inclusion in a COS for improving the quality of routine care for people with dementia in home or residential aged care settings. This reflects the diverse views and complexity across the Australian dementia care sector.

A range of outcomes and measures were considered, resulting in a preliminary set of outcome measures grouped into four categories.

Table 9 Summary of Outcome Measures to Improve dementia Care

Core (short-term)	Suggested (medium-term)
• Dignity for home care and residential aged care (QCE-ACC) • Hygiene for home care (**Barthel**) • Pain for residential aged care (PAINAD) • Meaningful activities for residential aged care (EMAS)	• Diagnosis of dementia for home care (MoCA) • Feeling safe and secure for home care (NPSS) • Quality of life for home care (QOL-AD) • Dementia qualifications for home care (DKAS) • Hygiene and comfort for residential aged care (COMFORT) • Emotional wellbeing for residential aged care (WHO-5) • Quality of life for residential aged care (QOL-AD) • Adverse effects for residential aged care • Dementia qualifications for residential aged care (DKAS)
Extended	Optional
• Behavioural symptoms of dementia for home care (NPI) • Meaningful activities for home care (EMAS) • Family and carer quality of life for home care (ZBI) • Neuropsychiatric symptoms of dementia for residential aged care (NPI) • Staff carer morale for residential aged care (MAGPI)	• Advance care planning for home care and residential aged care (ACP Engagement Survey) • Resource utilisation for home care and residential aged care (RUD-LITE) • Safety incidents for home care and residential aged care • Opportunities for unpaid carers for home care (NRM) • Importance of relationships for home care (CARE) • Emotional wellbeing for home care (WHO-5) • Dementia care navigation for home care (Pathway) • Feeling safe and secure for residential aged care (NPSS) • Medication appropriateness for residential aged care (STOPP-START)

In the final survey of outcome measures, some outcomes were no longer considered core outcomes for dementia care. This change happened for several reasons. First, the working group had a different set of members compared to the modified Delphi consensus panel, and the group included people with various experiences and perspectives. Second, people's understanding of the outcomes changed over time as they learned more, so some outcomes became more or less important to individuals. Third, the way outcomes are measured in research is different from how they are measured in routine care. Research measures are usually for specific studies and time periods, while routine care measures are repeated over long periods and can cover a wide range of care areas.

Additionally, the threshold for consensus was set at 70%. Some outcomes in the "Extended and Not Recommended" category had over 65% agreement, which means there was only a small difference in votes between including it or not. In some cases, participants felt the outcome was important for overall care quality (not just dementia care) and voted to include it in a broader set rather than just focusing on dementia care. There were also difficulties in reaching consensus on measurement tools because while it was agreed that no suitable measure was available, using "no measure" was not seen as best practice for measuring outcomes.

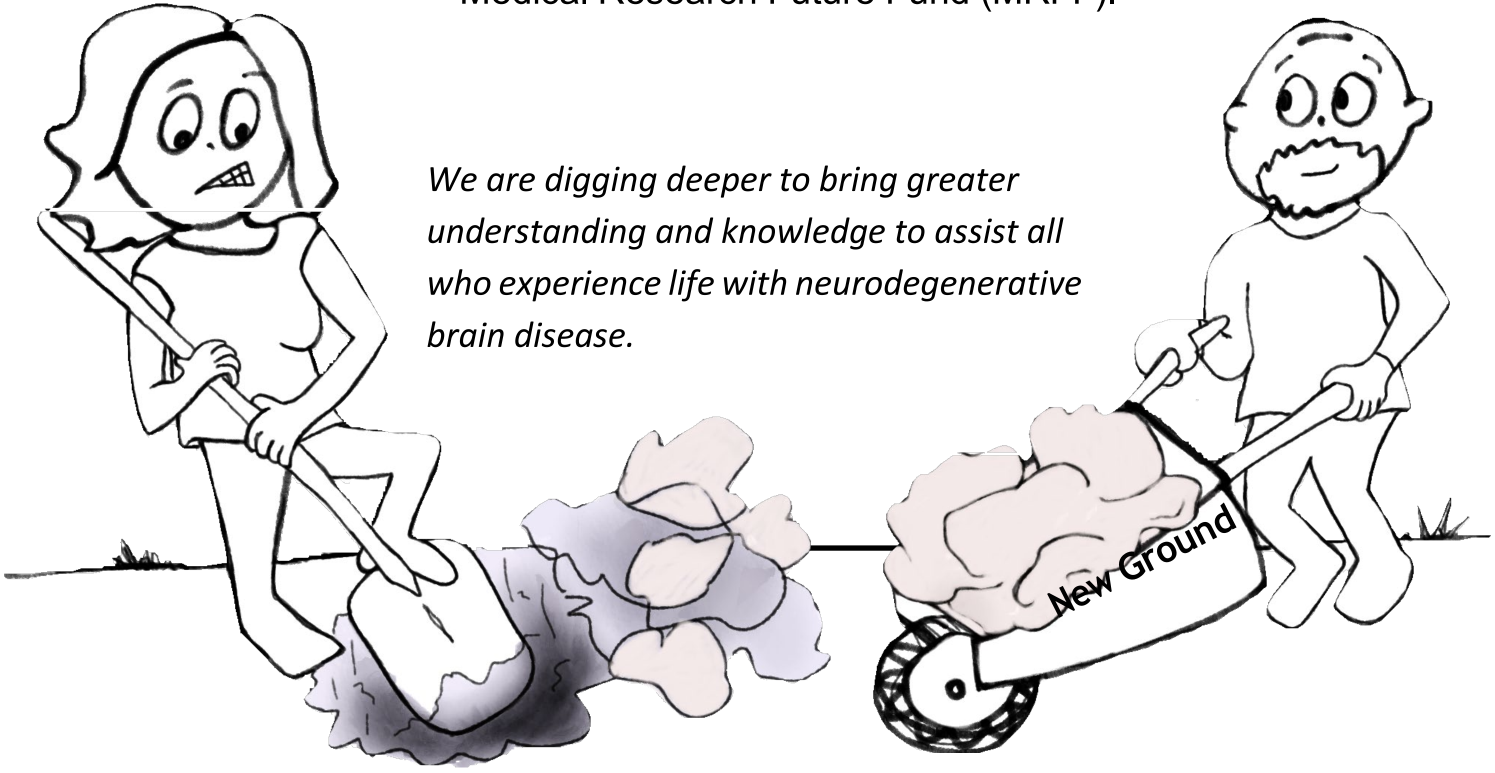
People generally criticised comprehensive outcome measures for being too complex, long, and requiring special training to use. Longer measures often overlapped with data collected by other processes, leading to unnecessary extra work. On the other hand, shorter measures were criticised for missing important details and being unable to capture changes in outcomes.

The effectiveness of outcome measures depends on how the data is used. If the information is not shared and used to improve care, the benefits of measurement won't be realised. This is true for any outcome measurement used over time.

Most of the measurement tools for outcomes important to dementia care have not been used in routine care settings before, especially for vulnerable groups like people with dementia. A lot of research is needed to adapt and validate the right tools for measuring these outcomes. This involves engaging people with dementia, their families, care workers, health professionals, policymakers, and researchers.

The COM-IC project has been groundbreaking in dementia care research, especially in Australia.

It is an example of implementation research that aligns with the objectives of its funder, the Medical Research Future Fund (MRFF).



First, the research used a methodology that was co-designed with a diverse group of stakeholders, including people with dementia and their carers. Some of these stakeholders also play active roles as advocates or advisors in dementia research and policy-making. They were able to offer personal, sometimes emotional insights into dementia care that academic researchers might not have fully understood. These stakeholders represent the voices of many Australians with dementia and their families who want better outcomes in dementia care.

Second, the core outcomes identified in this project focus specifically on dementia care and should be added to the existing Quality Improvement (QI) Program indicators. While clinical care outcomes are important, this project has shown that other outcomes are just as important for improving routine dementia care. Recognising these additional outcomes would support a more compassionate approach to dementia care in Australia, which is a key part of what policymakers and care providers mean when they talk about "person-centred" care.

Finally, the findings from this project should be considered by the Australian Government's aged care policymakers and regulators, as well as innovative care providers. These results could complement the recent reforms in the aged care sector. They might also be helpful when the Government finalises the National Dementia Action Plan, which aims to improve dementia care as a national priority. This MRFF-funded project shows that its recommendations should be taken seriously for improving the quality of dementia care.

At the end of the project, some outcomes that were first thought to be important for dementia care were no longer included. There were a few reasons for this. The group making the final decisions had different members than before, with new experiences and ideas. Also, as people learned more about dementia care, their views about what was most important changed. Plus, outcomes are measured differently in research compared to everyday care — research looks at short-term results, but everyday care needs long-term tracking across many areas.

The group needed 70% agreement to decide an outcome was essential. Some outcomes came close but didn't quite reach that level. Sometimes, outcomes were seen as important for general care, not just dementia care, so people thought they should be included in broader measures.

Choosing the right tools to measure outcomes was also tricky. Everyone agreed that no perfect tools existed yet, but simply not measuring anything wasn't seen as a good option either.

People found that longer tools were too complicated, took too much time, and often repeated information already collected. Shorter tools were quicker but sometimes missed important details.

In the end, measuring outcomes only makes a difference if the information is actually used to improve care. If it isn't shared and acted on, the effort doesn't help anyone.

Right now, most of the tools we have for dementia care haven't been tested much in real-world care settings, especially for people with dementia. We need more research to find the right tools, and it's important to involve people with dementia, their families, care staff, health workers, decision-makers, and researchers.

The COM-IC project has been a big step forward for dementia care research in Australia. It's a great example of research that aims to make real-world changes, matching the goals of its funder, the Medical Research Future Fund (MRFF).

Some key points about the project:

- It was designed together with people living with dementia, carers, and other important voices. These people shared personal and emotional insights that researchers might not have known on their own. They helped speak up for many Australians who want better care.
- It found new outcomes that should be added to Australia's Quality Improvement Program, showing that care is about more than just medical results — it's also about quality of life and emotional wellbeing.
- Finally, the results of this project should be taken seriously by the Government, aged care regulators, and care providers. They could help with the current changes in aged care and the new National Dementia Action Plan, which aims to make dementia care better across the country.

This project shows that real improvements in dementia care are possible — and that listening to the people who live with dementia is the key.

Improving Dementia Care: What We Learned

The COM-IC project worked with people living with dementia, carers, and experts to find out what really matters in dementia care.
They discovered that:

- Some outcomes once seen as important changed over time.
- Good care isn't just about medical tests — it's about wellbeing and quality of life too.
- Measuring care properly is important, but it must lead to real improvements.
- We need better tools for tracking care in everyday settings, not just in research.

The project's results could help shape better aged care policies and support more compassionate, person-centred care across Australia.

Real voices. Real change. A better future for dementia care.

Section 9

Summary of Recommendations

Recommendations	Plain Language Description	Target Audience
Identified core outcome measures be implemented by service providers as a minimum standard of care quality audit.	There are five ways of measuring components of quality dementia care that are important to people experiencing dementia in home and residential care settings. These measures can be used immediately by service providers to improve quality of dementia care in these settings.	This recommendation is directed at the Australian Government agencies responsible for aged care policy and regulation.
Further research is required to develop and validate appropriate measurement instruments directed at the outcomes highlighted by stakeholders as being core to quality care provision (i.e., suggested outcomes).	Further research is needed to find better ways of measuring some additional components of quality care that are important to people experiencing dementia.	This recommendation is directed at the MRFF, university researchers and others in a position to contribute.
Validated measures for outcomes not considered core should be made available for service providers with an interest in improving quality of dementia care in those areas.	Other components of quality care were considered less critical to people experiencing dementia in home and residential care settings, however, suitable measures for these components are available and can be used by service providers with an interest in improving the quality of dementia care.	This recommendation is directed at aged care service providers willing and able to take additional innovative steps against which other providers might benchmark best practice over time.
Outcomes identified as important but not core should be discussed as potential areas for care quality improvement in home care and residential aged care settings. These items may be considered core items in future.	Components of care considered less important at the time research was conducted should be reconsidered as a potential focus in future reviews of quality improvement initiatives.	This recommendation is directed at government policy and regulatory agencies, university researchers, peak authorities for aged care and dementia care, dementia advocacy groups, conference organisers and interested others.
Core outcome measures for improving care for people experiencing dementia in home care and residential aged care should be reviewed periodically for relevance and currency.	Improving the care of people experiencing dementia in home care and residential aged care settings requires ongoing periodical reviews incorporating perspectives of stakeholder groups in the pursuit of meeting evolving societal expectations of quality health care.	This recommendation acknowledges our understanding of dementia and associated sequelae are constantly evolving and it stands to reason that our ability to measure and subsequently improve quality of care needs to evolve concurrently.

Section 10
Resources

AIHW Dementia in Australia	https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary
Protocol Paper	https://pubmed.ncbi.nlm.nih.gov/38072498/
Identification of core outcomes for quality in routine care provided to people living with dementia in Australia: a multilevel modified Delphi consensus study	https://bmjopen.bmj.com/content/15/6/e096059
Rapid Review of outcome measures	Under review
Dementia Australia recommended language guidelines	https://www.dementia.org.au/sites/default/files/2023-10/Dementia-language-guidelines.pdf
Final Report – Australian Royal Commission into Aged Care 2021	https://www.royalcommission.gov.au/aged-care/final-report
GRADE handbook	https://gdt.gradepro.org/app/handbook/handbook.html
NHMRC Guidelines for Guidelines	https://www.nhmrc.gov.au/guidelinesforguidelines
STARDIT Report	https://stardit.wikimedia.org.au/wiki/0202208100258
Systematic Review of Core Outcome Sets	https://pubmed.ncbi.nlm.nih.gov/36948407/
UQ CHSR COM-IC	https://chsr.centre.uq.edu.au/com-ic

Section 11

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