THE UNIVERSITY OF QUEENSLAND
AUSTRALIA
CREATE CHANGE

Core Outcome Measures for Improving dementia Care

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Foreword

Codesigning a Core Outcome Set (COS) appropriate for broadscale use in the routine care provided to people experiencing dementia was always ambitious, but 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 share, learn, and grow together, despite the persistent and stigmatising beliefs surrounding dementia in broader society.

> *My early expectation was that the 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 leads 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 tissue 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 owe, both to ourselves and each other, to ensure that evolution is in a positive direction.

> *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, and we may be able to begin from some place new. The whole person. – Kaye Elle*

We offer these recommendations to dementia stakeholders to envision and codesign 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

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

We have a lot of institutions to acknowledge for their continued support and commitment to improving the quality of dementia care in Australia.

The University of Queensland

Science for All

Bolton Clarke

Hammond Care

Global Brain Health Institute

COMET Initiative

University of Liverpool

Dementia Australia

The University of Western Australia

Stakeholder Reference Group

Subin Acharaya

Debbie Brittain

Benedict Davies

Kaye Elle

Fleur O'Keefe

Sonia Markoff

Bronte Parkin

Ruth Semler

Jane Thompson

Delphi Consensus Panel

Anthony Arrigo

Virginia Aquilzan

Wernher Dela Cruz

Joy and Bruce How

Michelle Ferguson

Karen Gainey

Sandra Lewis

Margaret and Myles Hampton-Chubb

Lynda Henderson

Mithrani Mahadeva

Deborah Remfry

Julie Smith

Investigator team

Osvaldo Almeida

Safa Alrababah

Tracy Comans

Colm Cunningham

Hanh Dao-Tran

Susanna Dodd

Leon Flicker

Len Gray

Anna Kearney

Danelle Kenny

Sue Kurrle

Judy Lowthian

Asmita Mancha

Carly Meyer

Kim-Huong Nguyen

Tom Morris

Jack Nunn

Glenys Petrie

John Quinn

Zoe Selby

Dominic Trépel

Paula Williamson

Alyssa Welch

Abbreviations

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

Key Concepts

Concept used in Recommendations	Definition	Synonyms
Alzheimer's disease	Alzheimer's is a type of dementia characterised by buildup of abnormal protein deposits that damage the brain.	None.
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	Panel members, Delphi panel.

Concept used in Recommendations	Definition	Synonyms
	consideration in the COM-IC core outcome set.	
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.
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 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

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 (starting in July 2025), 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, not routine 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.

1.1 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.
- Consider how easy it is to collect this information in different care settings and the existing workload of home and aged care providers in Australia.

1.2 Scope

1.2.1 Purpose of These Recommendations

These recommendations have been created for the Australian 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 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.

1.2.2 Why These Recommendations Matter

This document helps simplify and standardise how aged care providers collect and report data on dementia care. Using the recommended measures ensures that:

- Care quality is evaluated in a clear and consistent way.
- Information can be compared across different aged care services.
- 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 needs of people with dementia, their carers, and aged care providers in Australia.

Who These Recommendations Are For

These recommendations have been developed for the current Australian context to effectively monitor and evaluate quality of routine care provided through the Australian aged care system to people experiencing dementia, including:

- The Australian Government to inform and shape future aged care policies.
- All aged care services that provide home or residential aged care services to people with symptoms of dementia.
- Researchers conducting trials or evaluating interventions for people with neurodegenerative disease in home or residential aged care settings.
- Regulatory bodies considering the introduction of mandatory reporting of information related to quality of care provided to people experiencing dementia.
- Recommendations are NOT inclusive of:
- Services provided to people experiencing dementia accessing care outside of the aged care sector.
- Care provision outside of routine aged care services, such as volunteer programs, Dementia Support Australia and Dementia Training Australia.
- People experiencing specific types of uncommon forms of dementia that may require more sensitive measures or specialised treatment.
- Care provided to people experiencing dementia symptoms in settings outside of home or residential aged care settings, such as hospital, respite, and palliative care settings.

1.2.3 Who developed these recommendations?

The recommendations were created through a collaborative process involving:

- People living with dementia,
- Their families,
- Carers,

- Advocates,
- Health professionals,
- Researchers,
- Aged care providers, and
- Government representatives.

A Stakeholder Reference Group (SRG) was formed, including members from these groups. They used a structured decision-making process to identify the most important outcomes for dementia care. Researchers also reviewed existing frameworks for measuring dementia care quality. This process ensures that the recommendations are practical, relevant, and reflect the needs of the people they are meant to support.

This document provides guidance and recommendations for the standardisation and simplification of data collected by providers of home or residential aged care services for people experiencing dementia. Implementation of recommended core outcome measures maximises the consistency, accuracy, and comparability of outcome measures used to evaluate the effectiveness and cost-effectiveness of any interventions for people experiencing dementia who receive home or residential aged care services, without adding to the data collection burden on service providers or people accessing care.

We acknowledge that adoption of published COS in routine care is increasing, which can only improve the comparability of interventions, but also recognise that these COS are not necessarily specific to routine dementia care, are not widely recognised by or known to care providers in Australia, and may not have been developed with people impacted by dementia (2). These recommendations evaluate and adapt existing dementia-related COS for implementation into the home or residential aged care settings in Australia in a manner that acknowledges the needs and priorities of people experiencing dementia and those who support them.

1.3 Target audience

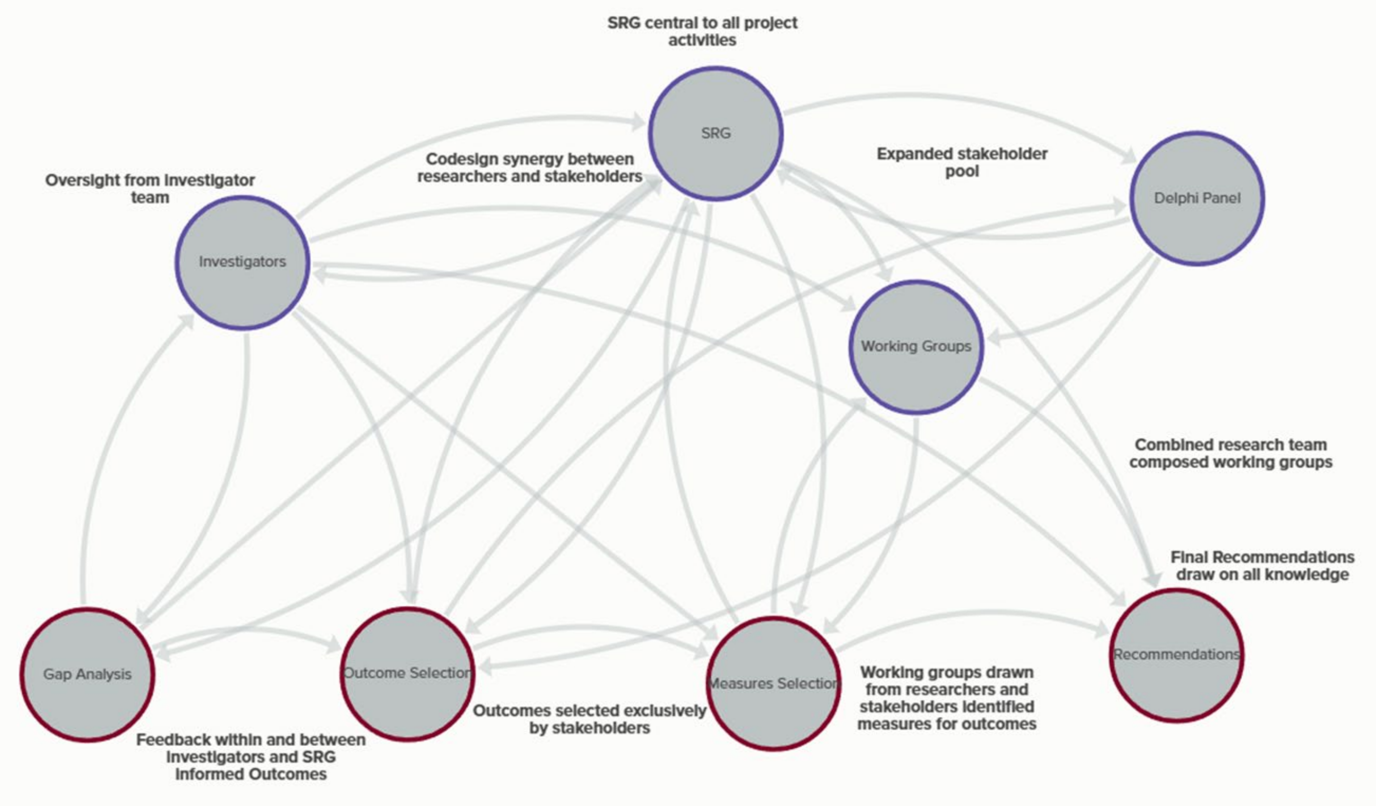
These recommendations were developed to aid future policy review and development in aged care quality improvement. They are also intended for use by Australian aged care providers (home or residential aged care) who may review and modify their current dementia care practices, incorporating evidence-based approaches to improve their standard of care. The intention is for integration of recommended outcome measurement instruments into existing data collection and reporting frameworks. While these recommendations have evaluated home or residential aged care, they may be of relevance in other settings where people experiencing dementia receive care, such as palliative care, hospitals and general practice.

Researchers, policy-makers, advocacy agencies, training agencies and other health services involved in the care of people experiencing dementia and related conditions may also find benefit from using these recommended outcome measures in their work.

1.4 How the recommendations were developed

The rigorous process used to develop these recommendations is illustrated in Figure 1. Recommendations were developed using the Alignment-Harmonisation-Results framework and applying co-design participatory action methodology that combined the efforts of the investigator team and community stakeholders (3). A Stakeholder Reference Group (SRG) was established that included members from government, research, industry, education, management, advocates, clinicians, carers/former carers, and people experiencing dementia. The SRG received education on core outcome measurement that included videos, written materials, and access to experts from the COMET (Core Outcome Measures in Effectiveness Trials) Initiative. Following this, they were invited to participate in a multi-part modified Delphi consensus process to identify outcomes relevant and important to routine dementia care. Industry representatives provided a list of outcomes currently measured. for people experiencing dementia. Researchers identified existing COS and Core Outcome Measures (COM) currently developed for research use through a scoping review (2).

Figure 1 Development of COM-IC Recommendations



The scoping review findings and industry contributions provided a framework and taxonomy for thinking about outcomes and outcome measurement that informed discussions and the consensus survey instruments (4). Outcome recommendations from the modified Delphi process, existing industry outcomes, and research-based core outcomes for use in dementia care were mapped to identify any gaps or overlap between sectors. The final set of outcomes was then matched to measurement instruments suitable for measuring outcomes without increasing data collection burden. Standardised data on initiatives (STARDIT) reports were used throughout to report stakeholder contributions, with further information about stakeholder engagement available in the associated STARDIT report at STARDIT.Wikimedia.org.au/wiki/0202208100258 (5).

1.5 Evidence-base for the recommendations

Four main sources of information formed the evidence base for COS related to home and residential aged care:

Research	Industry
A scoping review of published COS in aged care was interrogated and sets related to dementia were extracted, yielding 14 existing COS specific to dementia. Most of these COS (11/14) were developed for use only in research, 2 for research and practice and one specific to practice only. These COS measured 6 areas, 19 domains, and 87 outcomes. Psychiatric, physical and cognitive functioning, quality of life, and carer burden were common measurement domains across the COS.	Industry representatives provided a list of outcome measures currently routinely collected during care provision for people experiencing dementia. Domains were relatively consistent between providers, namely cognitive abilities, functional capacity and independence, behavioural and neuropsychiatric symptoms, patient quality of life, carer quality of life, health, social care, treatment related outcomes and medical. The outcomes and outcome measures within these domains differed widely.

Registries	Community
A review of dementia registries in Australia found outcome measurement for people experiencing dementia extended beyond dementia specific outcomes, including individuals' socio-demographic data, health-related characteristics, and resource use.	A modified Delphi consensus process was conducted with dementia care stakeholders extending beyond the SRG and collectively referred to as ‘panellists’. Panellists reviewed existing outcomes and outcome measures and provided input to develop consensus on what outcomes were most important and relevant to quality of dementia care provided in the Australian aged care sector. Their knowledge, thoughts, perspectives, and beliefs informed the recommended outcome list considered by working groups that subsequently identified the current best measures for the identified outcomes.

1.6 How the evidence was used

The Alignment, Harmonisation, Results framework was used to process and filter results at each stage. Information from the scoping review provided a taxonomy and scaffolding for stakeholders to understand outcome measurement. This was applied to existing outcome measurement in research, industry, and registry information to develop a discussion about which outcomes were relevant and meaningful to the primary stakeholders in care provision, namely people experiencing dementia carers and families accessing care, care providers, and the system that enables that care provision.

The results of this discussion, drawing on information from a wide range of international sources and stakeholder engagement, are the recommendations for a COS designed for monitoring and evaluating the quality of care provided to people experiencing dementia and accessing services through the Australian aged care system.

Measures were selected based on attributes of appropriate guidelines, namely outcome measures that are:

- Clear.
- Valid.
- Measurable.
- Timely.
- Consistent.
- Valuable.

1.7 Structure of the recommendations

This document describes outcomes and associated measures considered central to quality care by dementia stakeholders. They are designed to inform routine data collection by providers and regulators of home and residential aged care.

Section 2 – About dementia care data in Australia – provides justification for the development of a COS specifically for dementia related care. This information is useful for any health care service providing care for people experiencing dementia and may be of interest to any person impacted by dementia.

Section 3 – Understanding Core Outcome Sets – explains outcome measurement, its evolution and value in clinical practice and an illustration of how implementing core outcome measurement can benefit the health system in myriad ways.

Section 4 – COS for routine dementia care: short-term – describes the core outcome measures considered suitable for immediate use and defines a dementia-specific COS for 1) home care and 2) residential aged care, though sets may be transferable to other settings.

Section 5 – COS for routine dementia care: medium-term – contains information on other dementia-specific outcomes considered important by stakeholders, but for which no appropriate measure could not be identified. These areas require further research to develop and validate measures for these outcomes appropriate for use in routine care provided to people experiencing dementia.

Section 6 – COS for routine dementia care: expanded – details recommendations for extended measures. These are outcomes that were initially identified as core by the Delphi panel, but when they were jointly considered with appropriate measurement tools and their priority re-assessed by the working groups, they were judged to be supplementary to, or extensions of, a COS. The identified measures, however, are considered robust, valid, reliable, timely, consistent, and valuable. These extended outcome measures would be of benefit to service providers and policymakers interested in developing quality improvement in the care they provide for people experiencing dementia.

Section 7 – COS for routine dementia care: optional – describes outcomes that are not recommended. These are outcomes that were initially considered core but, when combined with the most appropriate available measure, no longer reached the consensus threshold to be considered core in the context of routine care provision to people experiencing dementia. Whilst these outcome measures are not currently recommended as part of a COS for improving quality in dementia care, the evidence is constantly evolving, and recommendations should be regularly re-evaluated and updated to reflect current best-evidence. These elements were identified in a consensus process as being important to stakeholders and so should be considered and re-evaluated as our understanding of dementia and routine care for people experiencing dementia evolves.

Section 8 – Implementation – discusses the significance of the findings and their transferability to routine care.

Section 9 – COS Summary – summarises the recommendations and expresses them in plain language.

Section 10 – Resources – contains references and links to additional resources that support and explain the development and application of recommendations in industry.

2. About dementia care in Australia

2.1 Dementia care in Australia

Dementia is a syndrome common to a variety of neurodegenerative diseases, characterised by declining cognitive function that may present as changes in level of alertness, mood, and behaviour (6). Changes can be sudden or gradual. There are many different underlying causes of dementia. The variability of types and presentation of symptoms makes dementia a particularly difficult health condition to treat and manage at a system level. While our understanding of dementia pathophysiology has improved, there is still limited understanding of disease manifestation, progression, and management.

Dementia is a global public health priority, increasing in prevalence, incidence, morbidity, and mortality (7). In 2023, an estimated 55 million people worldwide were diagnosed with dementia, with approximately 9.9 million new diagnoses annually (8). Australia accounts for 411,100 of global dementia diagnoses (9). Based on AIHW estimates, this is equivalent to 15 in every 1,000 Australians. With an ageing and growing population, it is predicted that the number of Australians with dementia will more than double by 2058 (10). Although dementia is not a condition of normal ageing, older people are significantly more likely to be diagnosed with dementia, where prevalence increases to 84/1000 over the age of 65. There is also an increasing number of people diagnosed with dementia under the age of 65 (referred to as younger onset dementia) who may be future users of aged care services provided in HC or RAC settings (11).

Dementia is the second leading cause of mortality in Australia, and soon to overtake cardio-vascular disease as the leading cause of death, currently attributed to approximately 10% of all deaths (10). In Australian women, it is the leading cause of death. The number of deaths, age-standardised, is also increasing, from 38/100,000 in 2012 to 41/100, 000 in 2021. Dementia is Australia's second largest contributor of disease burden, and the leading contributor for both women and Australians aged over 65. Approximately 2/1000 hospitalisations in Australia list dementia as the primary reason for admission.

Dementia is also the global leading cause of disability and dependency, impacting memory, cognition, behaviour, independence, and livelihood Dementia has far-reaching consequences, economically and socially, not only for the individual, but for their families, communities, countries, and the world. Dementia explains approximately 11.9% of global non-communicable disease related YLDs (years lived with disability). The cost of providing care is also high and increasing, with estimates in 2015 of US$818 billion and in 2019 of US$1.3 trillion (8). As dementia is a highly complex group of conditions, approaches to management and care need to be at a system level, demanding a whole-of-government, multi-stakeholder approach. The only way to achieve this is to view dementia as a public health priority.

Ethical Considerations

Dementia care presents unique ethical challenges at all levels, from the global public health implications to an individual's premature loss of decision-making capability, the stigma surrounding the condition, and the balance between welfare and autonomy(12). Communication difficulties present the greatest challenges to ethical considerations of care. Because there is substantial stigma associated with dementia, communicating the diagnosis to individuals and their families is complicated. It is also difficult to determine at what stage a person with a diagnosis of dementia retains cognitive capacity to legally make decisions. Symptoms of dementia are highly variable, so a diagnosis does not determine an individual's ability to act autonomously. Dementia impacts cognitive function, which includes many features people identify as a person's individuality. Behavioural and psychological symptoms in people experiencing dementia can sometimes lead to situations that complicate care. In some instances, these symptoms can present danger or risk to the person, others and the people providing care. As dementia progresses, individuals may lose the ability to function independently in the community, making a move to residential aged care (RAC) necessary to meet their care needs. This is a common source of anxiety for stakeholders, as most people express a desire to remain living at home, so the decision for anyone to move the person with dementia into residential care is often accompanied by intense, prolonged guilt, sadness and grief.

Care Delivery

There is currently no standardised diagnostic or treatment pathway for people experiencing dementia in Australia (9). Health services are provided through General Practitioners (GPs), medical specialists, and Allied Health Professionals (AHPs), and symptoms may be managed with medication, some distributed through the Pharmaceutical Benefits Scheme (PBS) (9). Dementia care is predominantly managed by GPs , with 49% of Medicare Benefits Scheme (MBS) services related to dementia designated as GP consultations. 12% is attributable to specialist services, with 15% of specialist services being gerontologist (as opposed to 1.1% of people without dementia).

Although there is currently no cure for dementia, there are 4 medications subsidised through the PBS to manage symptoms of dementia and potentially slow its progression (9). All are targeted at Alzheimer’s disease. In 2022–23, there were almost 688,000 prescriptions dispensed for dementia-specific medications to about 72,400 Australians with dementia aged 30 and over, under the PBS. People with dementia may experience changed behaviours, such as aggression, agitation and delusions, commonly known as behaviours and psychological symptoms of dementia. Non-pharmacological interventions are recommended to manage these symptoms, but antipsychotic medicines may be prescribed as a last resort. Inappropriate prescribing of antipsychotic medicines is a major concern for older people and was a key issue raised in the Royal Commission into Aged Care Quality and Safety (13). In 2022–23, antipsychotic medications were dispensed to about one-fifth (20%) of the 72,400 people who had scripts dispensed for dementia-specific medication.

A diagnosis of dementia does not mean an immediate or absolute loss of capacity, skills or independence, and many people are able to live with dementia with minimal reliance on carers, families and friends for assistance. In Australia, people aged 65 and over (50 and over for First Nations people) can access a range of health and care support services through various Australian Government aged care programs such as Commonwealth Home Supports Program (CHSP), Home Care Packages (HCP) program, and RAC.(14). Eligibility for aged care services is assessed by Aged Care Assessment Teams (ACAT) and services are provided through nationally registered service providers (15). In 2022, there were approximately 811 organisations providing RAC across 2671 services and 916 HC providers covering 2427 services. Younger people with a diagnosis of dementia under the age of 65 can access similar supports through the National Disability Insurance Scheme (NDIS) until they turn 65.

Costs

There are large direct and indirect costs associated with supporting people experiencing dementia in Australia. Direct costs to government for dementia care consumed approximately $3.0 billion in 2018/19 (10). The bulk of this funding was spent in RAC ($1.7billion), with community based aged care services ($595 million) being second and hospital services ($382 million) third. Additional hidden costs include the impact on carers. While caring can be rewarding, it is also associated with physical, mental, emotional, and financial stress. Nearly half of primary carers provide greater than 60hrs per week of care for a person experiencing dementia. 75% report physical and emotional impacts, 25% require increased support and 50% report financial impacts as a consequence of their caring role.

Workforce

A skilled and better remunerated workforce is essential for quality dementia care provision in both HC and RAC settings (9). The 2021 Royal Commission into Aged Care Quality and Safety identified gaps in resources and skills of the current dementia care workforce and has recommended mandatory dementia care training for all workers in the aged care space (13). The *Aged Care Act 2024* will be implemented 1 November 2025, strengthening aged care quality standards (16). In addition, the Government has supported development of a new national dementia education and training standards framework which is expected to shape future training courses for aged care workers (17). Meanwhile, the Government has allocated additional funding to permit wage increases for workers across the aged care sector (18). These initiatives, following on from the Royal Commission augur well for improvement in the quality of aged care and dementia care into the future.

The clinical care environment presents a complex interplay of competing and conflicting priorities. For care workers, there is an inherent desire to provide a high-quality level of care without compromising their own Quality of Life (19). Systemic and environmental factors such as stigma, workplace culture, and the perspectives, attitudes, and beliefs of other people in the community, including family and friends of the worker and the person experiencing dementia, add to the complexity (20). Many care-workers feel they are not able to connect with the person experiencing dementia, feeling conflicted as to how they can best protect the person with dementia, and having to balance care priorities.

Experience of Receiving Care

Each person’s experience of dementia is different. How a person manages their diagnosis, seeks and finds support through various stages, determines suitability and appropriateness of care providers, and navigates the aged care system is unique (21). The fragmented nature of the current system and the over-reliance on GPs creates confusion and inefficiencies. Lack of training and understanding from care workers can exacerbate negative feelings between care providers, carers, and the person experiencing dementia. Continually changing care workers can be overwhelming and disorienting for people with cognitive impairment.

For carers, the impact of providing care is associated with high levels of stress and reduced Quality of Life (22). Many are forced to trade-off their careers, social connections, and personal hobbies to provide adequate care. Family caregivers also do not necessarily have the skills and training to communicate with people who have cognitive impairment, and the changed behaviour of people for whom carers have previously been able to easily communicate can increase carer distress, leaving them feeling unsupported and overwhelmed. In some instances, they may develop resentment toward the person experiencing dementia because the carer feels they have an obligation to accept the impact of care and have no choice themselves.

2.2 Aged care data collection and reporting in Australia

Dementia care in Australia’s regulatory and policy environment

Worldwide, there is increasing pressure for governments to improve the overall quality of aged care, with particular attention to prevalent diseases in aged care, such as dementia (7). The Australian government first began legislative consideration of dementia care in 1992, with the *National Plan for Dementia Care 1992-1997*. There were further refinements made to subsequent plans with the *National Dementia Action Plan 2024–2034* being the most recent (23). Of relevance to our recommendations is the call to improve dementia data, to maximise the impact of dementia research and promote innovation in aged care. Dementia has remained a care priority on the national age care agenda since. In 2017, Australia adopted the World Health Organisation's global action plan on the public health response to dementia 2017-2025 (24). This plan calls for action in several areas, including strengthening information systems for dementia and research and innovation. In 2021, the Royal Commission into Aged Care Quality and Safety identified some key points specific to dementia care, including accessibility to post-diagnosis support, specialist dementia care units, improved dementia care standards, improvements to accommodations for dementia care, mandatory dementia care training, and improvements to data collection (13).

Policy and program implications of these recommendations

Development of a co-designed, stakeholder informed COS for improving routine dementia care meets targets set by the World Health Organisation (WHO) and the Royal Commission into Aged Care Quality and Safety to improve the lives of people experiencing dementia, their carers and families, and decrease the burden of dementia on both communities and countries (3). Implementation of these recommendations institutes a benchmark for efficient evaluation and monitoring of routine care provided to people experiencing dementia that is sensitive to changes in quality of care. COS provide for streamlining, reducing duplication of data collection and associated resource use, they provide for comparisons to identify factors or areas that may require assistance to improve quality of care, and also to evaluate the effectiveness of new interventions such as new clinical guidelines (25,26).

2.3 History of outcome measurement for dementia care

Current practices

The Australian Royal Commission into Aged Care Quality and Safety identified care and support for people experiencing dementia as one of four critical areas requiring immediate attention (13). There is presently no singular policy for providing care to people experiencing dementia separate to the *Aged Care Act 1997* (27). As a consequence, dementia is often not perceived as a key priority area for care or quality improvement in aged care, despite the high prevalence of cognitive impairment and dementia in people using aged care services, particularly RAC. Dementia is not identified or appropriately captured in the current Aged Care Quality Standards (ACQS) (28). The complexity and heterogeneity of the various neurodegenerative diseases causing dementia, and the individuality of people's experiences means pathways and access to information, support, and accurate diagnosis can often be variable and unreliable. This variability has led to an ad-hoc, piecemeal approach to monitoring and evaluating routine services for care of people experiencing dementia, with different organisations creating their own outcome measurement frameworks and recommendations.

Registries

A review conducted in 2016 found 31 dementia registries internationally (29). Registries were grouped into five classifications; 1. dementia research (n=9), 2. preclinical dementia research (n=4), 3. epidemiological dementia (n=8), 4. quality of dementia care (n=4), and 5. dementia research volunteer (n=6). The review found that outcomes commonly collected by dementia registries include individuals' socio-demographic data, health-related characteristics, and resource use.

The review also reported measurement scales routinely used by the dementia registries (29). These include the Charlson Comorbidity Index, Clinical Dementia Rating (CDR), Hachinski Ischemia Scale, Mini-Mental State Examination (MMSE), Boston Naming Test, Rey Auditory Verbal Learning Test, ADCS Activities of Daily Living Inventory (ADCS-ADL) (Basic ADL) and Instrumental ADL), Instrumental ADL-Functional Activities Questionnaire (IADL-FAQ), The Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE), Neuropsychiatric symptoms (NPS), The Neuropsychiatric Inventory Questionnaire (NPI-Q), Geriatric Depression Scale, Relative Stress Scale, and Lubben Social Network Scale.

Industry outcome measures

There is no standardised list of outcomes for measuring the quality of dementia care in Australia. Two service providers from the aged care industry have provided details for the outcomes currently measured in the delivery of routine care for dementia in HC or RAC settings, based on the outcomes of the scoping review of COS specific to dementia and following its taxonomy framework. Identified outcomes and measures can be seen in Table 1. Many of the measures listed in Table 1 are not specific to dementia and could be considered part of a comprehensive assessment routinely conducted for all aged care residents.

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

Domains	Core outcomes	Related variables/source
Cognitive abilities	Memory	Whether a resident has been diagnosed with dementia or not? † (Yes/No) Whether a resident has been diagnosed with Alzheimer's or not? † (Yes/No) Whether a resident has been diagnosed with cognitive impairment or not? * (Yes/No) Level of cognitive impairment*: (Normal/Mild/ Moderate/Severe) PAS score: Numeric
	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
	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	

Domains	Core outcomes	Related variables/source
	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)

Contextual factors relevant to stakeholder concerns.

These recommendations were developed with input from a diverse range of stakeholders who are responsible for and impacted by dementia care related decisions. The most prevalent request among stakeholders was the importance of collaboration, enhanced by transparency and sharing of information across all groups and project activities. There was acknowledgement that the roles of stakeholders are context-dependent and, subsequently, the amount of input from stakeholders is equally context-dependent. However, there should be capacity to include members of all groups in decisions that concern them.

The Australian Government is working diligently on a range of initiatives in response to the Royal Commission into Aged Care Quality and Safety, showing strong support and commitment to implementing the recommendations (30). For dementia care, this means a focus on improved assistance at the point of diagnosis, supporting people with a diagnosis of dementia to navigate the aged care system, improving training for workers in dementia care, improving facilities to be dementia friendly, improving the experience of aged care services, increasing capacity and quality of care, and supporting carers.

Aged care providers have emphasised that interventions or changes to care delivery should be evidence-based and improve resident experience while minimising provider burden. While COS have proven effective in trials as evidence-based practice, industry professionals are concerned about the applicability in routine care settings, particularly if outcome measures cannot be linked to improvements in quality of care outcomes. Furthermore, care providers seek genuine collaboration with people impacted by dementia to inform the focus of quality improvement. This ensures care and resources are focused on the person whilst remaining pragmatic and evidence-based, including reliability, feasibility, and fit for purpose use.

While the input of clinical experts is highly valued, carers have reported a potential over-reliance on input from this group, and that their own perspectives are lost. Carers provide 80% of total dementia care in HC, and therefore need to be equipped with adequate knowledge, skills, and training to support a person experiencing dementia without harming themselves. Establishing carer advisory groups can be an efficient and productive way of providing this important carer perspective to policymakers.

People experiencing dementia are asking to be considered for collaborative involvement in decision making about treatment options, including care provided to them after receiving their diagnosis (6). While people experiencing dementia face cognitive decline, there is a broad spectrum of dementia severity and progression, with many people retaining capacity to contribute to discussions and decisions about their care. Additionally, the way that dementia care is currently considered and prescribed often omits holistic components such as mental health (31). Psychological symptoms of dementia are currently defined within a narrow construct of behavioural compliance or behaviour management, neglecting contextual factors causing behaviour disruptions. Increased input from mental health professionals like neuropsychologists can improve understanding between stakeholders and develop capacity to cope for people experiencing dementia and their carers.

Researchers advocate for balanced collaboration between stakeholders for research, acknowledging the expectations, strengths, and weaknesses from different stakeholder groups (32,33). Using evidence-informed participatory methods to appropriately balance stakeholder input and the research task ensures a sound evidence-base for research outcomes that are efficient and relevant to the context, i.e., fit for purpose.

3. Understanding core outcome measures

3.1 Outcomes, measurement, and COS

Decisions in health care are made using evidence-based practice or gold-standard approaches (34). The evidence-base is generated by research. Effectiveness of a treatment or intervention is determined by looking at its impact, i.e. measuring outcomes. Presently, research outcomes are not standardised, and research in the same clinical area can evaluate effectiveness or impact against different measures, for example, one clinical trial investigating migraines may examine sick-days as an outcome, where another uses a pain-scale. This is not an issue for the individual study, but it complicates evidence-based practice that relies on examination of multiple evidence sources, because the study results are not comparable.

The rationale behind core outcomes is that studies in a particular area will have results for the same outcomes, which means they are directly comparable (34). Comparability of studies across settings, regions, and countries means the power of the research can be magnified, reducing duplication and distributing the cost of research across multiple research venues so that everyone can benefit. While the idea of ‘core outcomes’ has been predominantly focused on clinical trials and research work, there is overlap in their function between research and monitoring and evaluation processes. If there is consistency in outcome measurement, i.e., the same thing is measured in the same way by everybody, the system gains transparency. Potential areas of weakness, poor performance, or poor quality are easily identifiable as targets for quality improvement, and impacts of effective interventions can be quickly and easily identified as benchmarks or gold-standards.

There is still a drawback in that determining what to measure, and what should be considered ‘core’ is complex. There are many stakeholders in dementia care, including people experiencing dementia, , family and friends of people experiencing dementia, carers, care workers, AHPs, GPs, specialists, service provider organisations, government departments, advocacy groups, and researchers. There are also thousands of outcomes to measure in health care.

3.2 The COMET Initiative

The Core Outcome Measures in Effectiveness Trials (COMET) initiative brings together people interested in the development and application of agreed standardised sets of outcomes, known as ‘Core Outcome Sets’ (COS) (34). COS represent a minimum set of health outcomes that should be measured for a given health condition. COMET promotes methodological research to identify high quality methods for COS development. Standards for the development of COS for use in research (COS-STAD) state patient stakeholder groups (patients, carers or patient advocacy organisations) should be involved in deciding what outcomes are most important to be included in COS (35).

COS are regularly mapped and added to the COMET website to avoid duplication and to facilitate uptake (36–38). In July 2023 there were over 770 COS available across a range of health conditions (34). However, COS can specify a particular sub-population, setting or intervention within their scope so despite the number of COS available it may not always possible to identify one that exactly matches the planned area of implementation (39). To develop a high-quality COS from scratch can be resource and time intensive. Therefore, where potentially relevant COS exist, COMET works with developers to explore methods for adapting existing COS through a stakeholder review process.

3.3 Settings

3.3.1 Home Care

The Australian government is committed to supporting services that enable Australians to live independently at home for as long as possible (40). The HC package program is the primary mechanism of funding delivery for older Australians experiencing dementia in the community (41). There are additional supplements for people experiencing moderate or severe cognitive impairment, reflecting the increased costs associated with care for this cohort. In 2022, more than 17,200 Australians were receiving the HC dementia supplement, and 80% of supplement recipients were receiving a level 3 (intermediate needs) or level 4 (high needs) package.

Carers for people experiencing dementia can be heavily impacted in HC settings as onset of dementia symptoms is variable and unpredictable, and the caring role is resource intense, particularly the demands on time (41). The number of carers of people experiencing dementia in Australia is unknown, though estimates in 2023 are in excess of 140,900 (41). Half of these provide care for their spouse. 47% of carers provide more than 60 hours of care every week. Carers of people experiencing dementia are more likely to be unemployed than carers of older people without dementia, and they are also more likely to be dependent on government benefits as their main source of income.

3.3.2 Residential Aged Care

RAC services are available to Australians who have been assessed as no longer able to live independently in the community (41). Over half (54%) of people living in RAC have a diagnosis of dementia. A third of these have a diagnosis of younger onset dementia (under 65). Further to this, 98,700 people without a diagnosis of dementia were deemed to have some level of cognitive impairment, this equates to 41% of all RAC residents. Combined with 54% of people with a diagnosis of dementia, 95% of people in RAC have some degree of cognitive impairment.

Dementia is often associated with co-morbidities. In RAC, depression and arthritis are the most common co-morbid health conditions among residents experiencing dementia. Further, people experiencing dementia were more likely than those without dementia to experience urinary incontinence, hypertension, and falls with no known cause. There is also evidence of overuse of psychotropic medications contributing to falls, and an over-reliance on psychotropics to chemically restrain people demonstrating undesirable behaviours.

According to funding information, people experiencing dementia in RAC required support in the domains of cognition and behaviour (84%), Activities of Daily Living (ADLs) (76%), and complex health care (61%) (42). People requiring assistance with ADLs tended to be older, and women required assistance with ADLs at a younger age than men. People diagnosed with younger onset dementia were more likely to need assistance with cognition and behaviour, whereas older people of both sexes were more likely to need assistance in the complex health care domain.

Length of stay in RAC varies, though median duration is not meaningfully different for people experiencing dementia or not. People experiencing dementia tend to remain alive in RAC for longer than people without dementia, though the cause of this is not definitive. Research speculates this may be because people without dementia are able to remain living independently longer in the community and so enter RAC closer to death (43). People with dementia also tend to use hospital services less toward end of life, and dementia remains a common cause of death in RAC.

3.4 Identification of Core Outcome Measures via Consensus and Working Groups.

3.4.1 Modified Delphi Consensus

Outcomes considered core in routine dementia care were identified by a modified Delphi consensus over four rounds. Twenty-three core outcomes were identified (Table 2). Outcomes were presented to panellists in a hierarchical fashion following COMET taxonomy, beginning with domain areas identified as core in routine dementia care settings, expanding to include panel suggestions and outcome domains/categories. Subsequent rounds forced trade-offs within domain areas of specific outcomes. This process allowed the identification of outcomes across HC and residential care that were important, meaningful and relevant to dementia care stakeholders.

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

3.4.2 Measurement selection

A two-hour Zoom session was held where the identified outcomes and existing measurement instruments were presented to SRG members, Delphi panellists, and the COM-IC investigator team. At the conclusion of this meeting, attendees were divided into four working groups and tasked with identifying the best available measure for each of the core outcomes identified by the Delphi panel (Table 3). The details of methodology and composition can be found in the STARDIT report here: https://stardit.wikimedia.org.au/wiki/0202208100258

Groups conducted independent work over a six-week period, concluding with a presentation of their evidence on the best available measure for each outcome (

Table 4). The best available measure was determined by consideration and comparison of available measures against the criteria adapted from ‘Accounting for the Quality of NHS Output’:

- Clarity
- Timeliness
- Validity
- Reliability
- Ease of Collection
- Add Value

The GRADE handbook and NHMRC Guidelines for Guidelines were also available for decision-making, and online discussion boards were available to working groups for asynchronous collaboration. Copies of measurement instruments and associated research were stored on a shared drive that working group members could access and modify to suit their needs.

Following the working group presentations, working group members were invited to complete a Qualtrics survey presenting each outcome partnered with its identified measurement tool. Respondents were asked to classify each outcome measure as part of the COS, a component of a broader outcome set, or not suitable as an outcome measure in the setting at this time (Table 5). Results of this survey form the recommended COS and classify outcome measures into four categories:

1. Recommended Core Outcome Measures: These outcomes and measures were considered core by greater than 70% of survey respondents.
2. Suggested Outcome Measures: These outcomes were considered core by greater than 70% of respondents, however, there was no agreement on the suitability of the measurement instrument in dementia care settings.
3. Extended Outcome Measures: These outcomes were not considered core by at least 70% of respondents, but the measure was considered appropriate, so would give useful clinical information in situations where resources were available.
4. Not recommended: Neither the outcome nor the associated measure were considered core by at least 70% of respondents.

Table 3 Starting Measures for Identified Core Outcomes

HOME CARE	RESIDENTIAL AGED CARE
Dignity	**Dignity**
The Patient Dignity Inventory (Chochinov)	The Patient Dignity Inventory (Chochinov)
The Jacelon’s Attributed Dignity Scale (Jacelon)	The Jacelon’s Attributed Dignity Scale (Jacelon)
The Inpatient Dignity Scale (Ota)	The Inpatient Dignity Scale (Ota)
Advanced Care Planning	**Advanced Care Planning**
ACP Engagement Survey (Sudore)	ACP Engagement Survey (Sudore)
Behavioural Symptoms of Dementia	**Neuropsychiatric Symptoms of Dementia**
NRM	Neuropsychiatric Inventory – Nursing Home (Cummings)
Diagnosis of Dementia	Neuropsychiatric Inventory (Cummings)
RUDAS	Brief Clinical Form of NPI (Kaufer)
KICA (Russell)	Care Planning Assessment Tool (Fleming)
FAST (Sclan)	Clinical Dementia Rating Scale (BOOK)
Psychogeriatric Assessment Scales	**Pain**
MMSE (BOOK)	Visual Analog Scale (Bijur)

HOME CARE	RESIDENTIAL AGED CARE
Addenbrooke’s (Mioshi)	Numeric Rating Scale (Mankoski)
Trail Making (Reitan)	Verbal Rating Scale (Karcioglu)
MoCA (Nasreddine)	Abbey pain scale (Abbey)
ADAS – Cog Sub (Kueper)	**Meaningful Activities**
Rey AV Learning Test (Estevez)	Barthel (Barthel)
Hygiene (No Direct Measure)	**Hygiene and Comfort (No Direct Measure)**
Barthel (Barthel)	Barthel (Barthel)
Care Planning Assessment Tool	**Feeling Safe and Secure**
Meaningful Activities	NRM
Barthel (Barthel)	**Emotional Wellbeing**
Importance of Relationships	Hamilton Rating Scale (Hamilton; Keetzman)
NRM	Cornell Scale for Depression in Dementia (Korner)
Feeling Safe and Secure	Geriatric Depression Scale (Korner)
NRM	Dimensional Apathy Scale (Radakovic)
Emotional Wellbeing	**Quality of Life**
Hamilton Rating Scale (Hamilton; Keetzman)	Quality of Life in Alzheimer’s Disease (Barrios)
Cornell Scale for Depression in Dementia (Korner)	Dementia Quality of Life – DEMQOL
Geriatric Depression Scale (Korner)	Quality of Life in Late Stage Dementia (Falk)
Dimensional Apathy Scale (Radakovic)	EQ5D-5L
Quality of Life	EQ5D-3L
Quality of Life in Alzheimer’s Disease (Barrios)	World Health Organisation Quality of Life (WHO)
Dementia Quality of Life – DEMQOL	**Medication Appropriateness**
Quality of Life in Late Stage Dementia (Falk)	Bear check list for Medication Appropriateness
EQ5D-5L	**Staff/Carer Morale**
EQ5D-3L	Hospitalist Morale Index (Chandra)
World Health Organisation Quality of Life (WHO)	**Resource Utilisation**
Dementia Care Navigation	Resource Utilisation in Dementia (RUD)
Aged Care System Navigator Measure	**Safety Incidents**
Resource Utilisation	The global trigger tool (Hibbert)
Resource Utilisation in Dementia (RUD)	Beer check list for Medication Appropriateness (Am Ger Soc)
Family/Carer Quality of Life	**Adverse Effects**
Carer Quality of Life	Dementia Knowledge Assessment Scale (DKAS) (Annear)
Zarit Burden Interview (Hebert)	Outcome metrics to measure quality of clinical education (Nolte)
Caregiver Distress Scale	
Hamilton Rating Scale for Depression	
Safety Incidents	
The global trigger tool (Hibbert)	
Beer check list for Medication Appropriateness (Am Ger Soc)	
Dementia Specific Qualifications for Service Providers	
Dementia Knowledge Assessment Scale (DKAS) (Annear)	

HOME CARE	RESIDENTIAL AGED CARE
Outcome metrics to measure quality of clinical education (Nolte)	
Opportunities for Unpaid Carers	
Caregiver Activity Survey (Davis)	

Table 4 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	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		

Table 5 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)
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)

NOTES: HC-Home Care; RAC- Residential Aged Care; **Bold** – Reached consensus

4. Recommendation 1 – COS for routine dementia care: short-term

Identified core outcome measures to be implemented by service providers as a minimum standard of care quality audit

Recommendation 1 defines a recommended COS for use in Australian home and residential aged care services that provide care to people experiencing dementia (Table 6). These 5 measures – 2 in home care and 3 in residential care have been identified as central to quality of care for people experiencing dementia. They are considered to be valid, reliable, timely, and available measures that accurately reflect the central intention of the outcome.

These measures are already widely used and are appropriate for immediate implementation by service providers. Their routine collection by all providers will enable the benchmarking, monitoring, evaluation and improvement of care delivery for the home or residential aged care of people experiencing dementia. They are consistent with current mandatory reporting, including the QI Program for residential aged care and the strengthened Aged Care Quality Standards.

Table 6 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

4.1 Dignity for home care (QCE-ACC)

Outcome

The outcome of **dignity** was consistently rated by stakeholders as central to quality care of people experiencing dementia and its inclusion in the COS for routine dementia care was recommended by 75% of stakeholders.

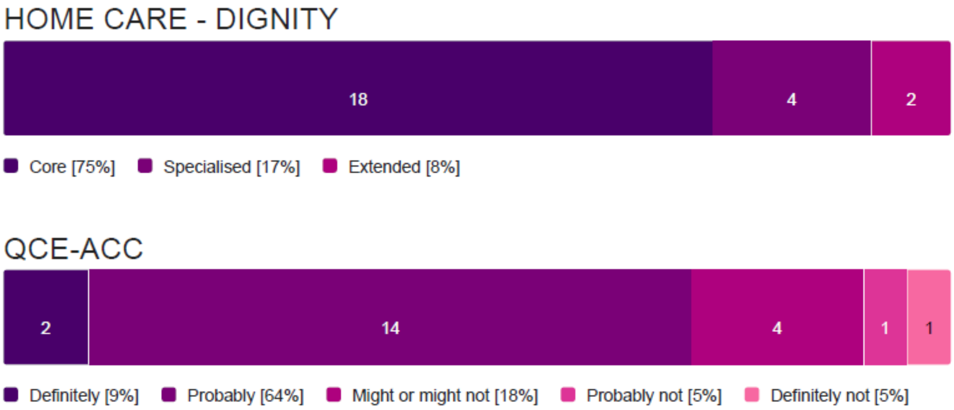
Dignity was defined as the experience of being treated with respect.

Measure

The Quality of Care Experience – Aged Care Consumers (QCE-ACC) survey was identified as the simplest, most comprehensive measurement of dignity for home care by 73% of stakeholders. The QCE-ACC survey is mandated for collection in residential aged care as part of the QI Program. The QCE-ACC incorporates the concepts of respect and dignity; independent decision-making; skills and training of staff; appropriate care; social relationships; and complaints processes. The QCE-ACC has been validated for home care, but its use is not currently mandated or widespread in this setting.

Considerations

Acknowledging the advantages, there remained concerns around universal definitions of concepts measured by the instrument, whether the QCE-ACC was person-centred, and whether the instrument was suitable for proxy or appropriate for people with impaired cognition. Overall, the QCE-ACC was considered a good starting point, acknowledging further work is needed to ensure the validity and reliability of the instrument in situations where the person experiencing dementia may not have capacity to respond.



4.2 Hygiene for home care (Barthel)

Outcome

The outcome of **hygiene** was consistently rated by stakeholders as central to quality care of people experiencing dementia and its inclusion in the COS for routine dementia care was recommended by 75% of stakeholders.

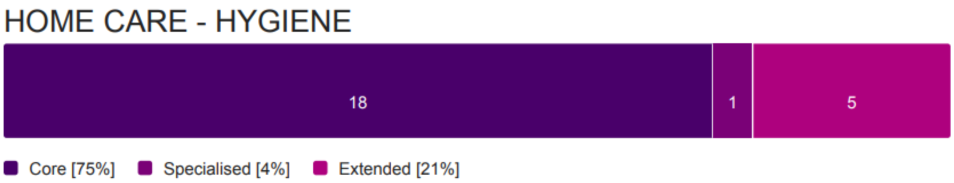
Hygiene was defined as the conditions and practices around cleanliness.

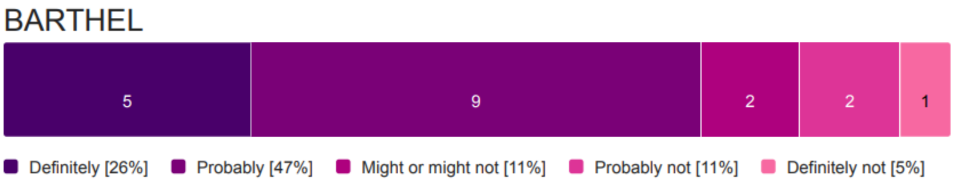
Measure

The Barthel instrument was selected for inclusion in the COS by 73% of stakeholders due to its clarity, simplicity and long history of use across multiple settings. The Barthel instrument is a 10 item scale measuring functional ability through consideration of activities of daily living, including continence, showering, and toileting behaviours.

Considerations

Some stakeholders were concerned that the instrument was not specific to dementia or hygiene and had a ceiling effect in home care. Alternatives to the Barthel instrument considered by stakeholders included: measuring living status as an indicator; adopting an overall rating scale as opposed to scales for each category; measuring with additional indicators reflective of hygiene practices (such as skin condition and regularity of toileting); or inclusion of environmental factors that may contribute to overall hygiene.





4.3 Dignity in residential aged care (QCE-ACC)

Outcome

The outcome of **dignity** was consistently rated by stakeholders as central to quality care of people experiencing dementia and its inclusion in the COS for routine dementia care was recommended by 79% of stakeholders.

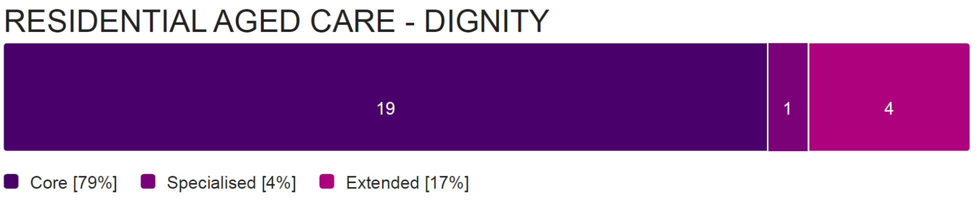
Dignity was defined as the nature of death and surrounding care, and being treated with respect

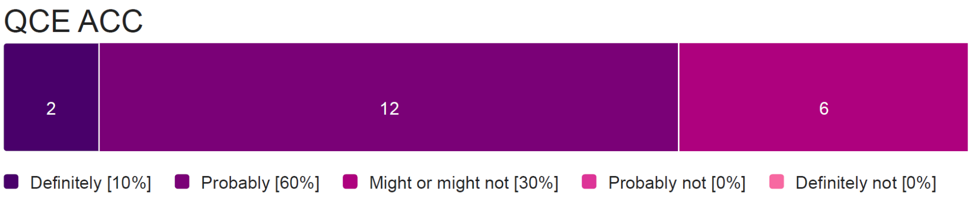
Measure

The Quality of Care Experience – Aged Care Consumers (QCE-ACC) survey was selected as the dignity measure by 70% of stakeholders due to its brevity and capacity to integrate easily into existing measures of care, such as resident experience surveys. The QCE-ACC survey is mandated for collection in residential aged care as part of the QI Program. The QCE-ACC incorporates the concepts of respect and dignity; independent decision-making; skills and training of staff; appropriate care; social relationships; and complaints processes.

Considerations

Some stakeholders raised concerns about the appropriateness of the QCE-ACC for people experiencing dementia, the robustness of proxy measurements in situations where a person experiencing dementia is not able to communicate, and whether the outcomes reported with QCE-ACC would significantly influence quality of care. There were no suggestions for alternative measures of dignity, though there was a preference for specific, measurable and auditable actions such as staff wearing name-tags in visually friendly formats.





4.4 Pain in residential aged care (PAINAD)

Outcome

The outcome of **pain** was consistently rated by stakeholders as central to quality care of people experiencing dementia and its inclusion in the COS for routine dementia care was recommended by 83% of stakeholders.

The concept of pain was included in the context that *pain should be attended to with respect and monitored/managed at all time points.*

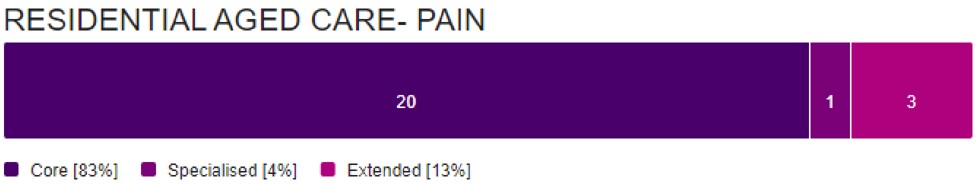
Measure

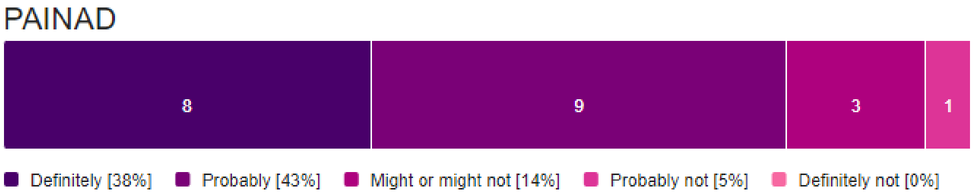
The Pain Assessment in Advanced Dementia (PAINAD) scale was selected as the pain measure by 81% of stakeholders due to its applicability to people experiencing dementia, having been specifically designed for this cohort. The PAINAD is simple and fast, with a proven efficacy in monitoring changes in pain in the presence of communication difficulties. It has proven superiority over other widely used pain measures such as the Abbey Pain Scale.

Considerations

The PAINAD has limited history of use outside of research trials, so caution was recommended for its use in routine care. Reports suggested that PAINAD was only useful when the person shows pain with agitation. Additional training may be required for its accurate use, and it may not be sufficient as an outcome measure in isolation. It was questionable whether separate pain measures are necessary for people experiencing dementia, or whether a universal pain measure was appropriate for all residents in residential aged care.

Alternatives to the PAINAD instrument considered by stakeholders included simple indicators (i.e. adding a question to experience surveys about whether pain is always measured and treated appropriately) through to complex technical measurements (i.e. self-reported pain scales or technologically advanced AI facial recognition). One suggestion was a potential tool-box of pain measures, though specific tools for inclusion were not suggested. Some respondents questioned whether this was an outcome or process measure.





4.5 Meaningful activities in residential aged care (EMAS)

Outcome

The outcome of **meaningful activities** was consistently rated by stakeholders as central to quality care of people experiencing dementia and its inclusion in the COS for routine dementia care was recommended by 79% of stakeholders.

The meaningful activities outcome included preserving 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.

Measure

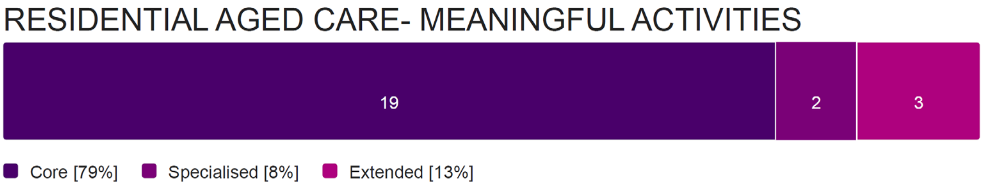
The Engagement in Meaningful Activities Survey (EMAS) was selected as the meaningful activities measure by 71% of stakeholders due to its simplicity, timeliness and relevance to the central meaning of the outcome. Respondents felt this measure would enhance provider focus on the need to realise quality care improvements through the type of activities offered to people experiencing dementia. There was a general feeling that the tool was useful for monitoring mental health generally, so may have broader application (outside of dementia) in residential aged care settings.

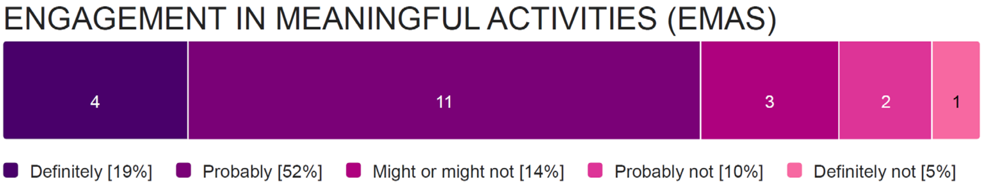
Considerations

The EMAS scale has not (yet) been validated in populations of people experiencing dementia, which may impact its performance with this population. This outcome urgently requires an appropriate definition and understanding of 'Meaningful Activities' to be developed and accepted across the sector. There also needs to be recognition of the capacity of residential aged care services to provide all activities that each individual finds meaningful, given the potential restrictions and limitations of the setting.

The interrelationship between meaningful activities and quality of life should be considered.

Alternatives to EMAS considered by stakeholders included alignment with the strengthened aged care quality standards, recording of behaviours and observable traits rather than specific questioning, or using instruments already used by the service providers, such as HammondCare's GAS-light, which measures goals and outcomes.





5. Recommendation 2 – COS for routine dementia care: medium-term

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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).

Recommendation 2 describes outcomes that reached the consensus threshold to be considered core outcomes in both the Delphi consensus and working group measures selection processes but did not reach agreement on the best way to measure the outcome (Table 7). There were 4 outcomes in the home care setting and five for residential aged care settings, with overlap in two outcomes (Quality of life and Dementia Qualifications), reinforcing different priorities of care in different settings.

These outcomes are considered essential to quality of care by stakeholders, however there is currently no identified reliable way to measure these outcomes where people receive dementia care. The measures presented to stakeholders as the best available measure for the identified outcome have been included in Table 7. These measures may serve as interim indicators in the absence of validated tools and are used in clinical trials, however, it is recommended that future research focus on developing more valid, reliable, and timely methods to accurately capture the core intent of these outcomes in routine care settings.

Table 7 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

5.1 Diagnosis of dementia for home care (MoCA)

Outcome

The outcome of **diagnosis of dementia** was consistently rated by stakeholders as important for quality care of people experiencing dementia and its inclusion in the COS for routine dementia care was recommended by 79% of stakeholders.

Diagnosis of dementia was defined as accurate diagnosis (and aetiology) of dementia.

Accurate diagnosis is essential to the provision of appropriate, individualised, person-directed care planning. Early intervention has been shown to improve outcomes, ensuring people experiencing dementia are supported to receive the care services they need at the time they are needed. Additionally, there is increased morbidity and mortality associated with incorrect diagnosis (e.g. assumed Alzheimer's Disease) leading to inappropriate prescription of medication and other interventions

Measure

No appropriate instrument was identified for measuring diagnosis of dementia.

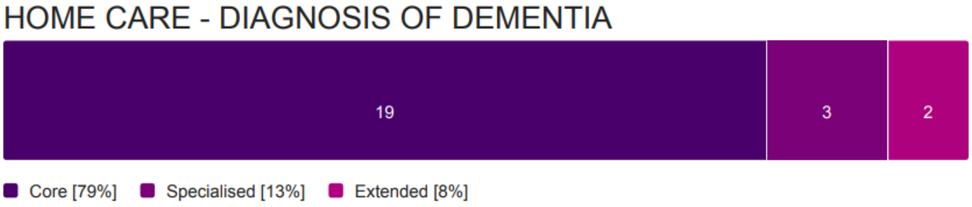
Considerations

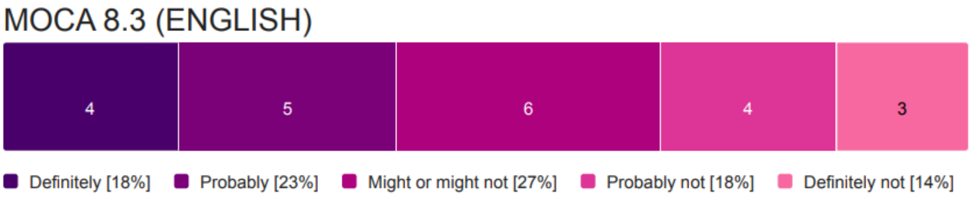
The diagnosis of dementia is a complex process that should be carried out by trained medical physicians. Screening tools for cognitive impairment are important in the identification of individuals at risk of developing or having a type of dementia; however, as measures of diagnostic accuracy, are not appropriate. The Montreal Cognitive Assessment (MoCA) was identified by 41% of stakeholders as an appropriate tool for measuring the diagnosis of dementia outcome, despite agreement that screening tools are not diagnostic.

Alternatives to MoCA considered by stakeholders included brain imaging, spinal fluid pathology, and referral to specialist memory assessment services.

The diagnosis of dementia is outside the scope of most routine home care providers, so its inclusion as an outcome measure was queried. However, the absence of an accurate diagnosis to guide treatment and management complicates appropriate care-planning.

This outcome was clearly important to stakeholders and further research is required to identify or develop an appropriate measure to ensure accuracy in care-planning.





5.2 Feeling safe and secure for home care (NPSS)

Outcome

The outcome of **feeling safe and secure**, including psychological safety, was consistently rated by stakeholders as fundamental for quality care of people experiencing dementia and its inclusion in the COS for routine dementia care was recommended by 79% of stakeholders.

Feeling safe and secure was defined as feeling psychologically safe, including not being punished or humiliated for sharing ideas, asking questions, voicing concerns, or making mistakes.

Measure

No appropriate instrument was identified for measuring feeling safe and secure.

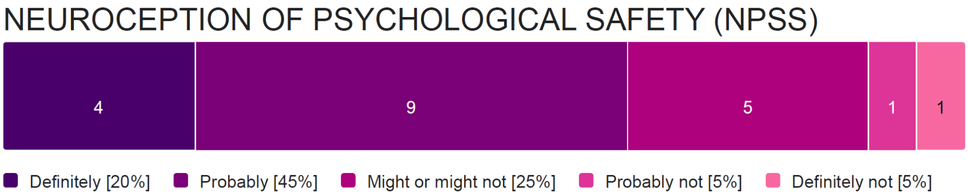
Considerations

The Neuroception of Psychological Safety Scale (NPSS) was identified by 65% of stakeholders as the best available measure for this outcome, but not suitable for inclusion in a core outcome set. The scale was considered to be comprehensive and covered multiple areas, including those relevant to basic human rights.

However, the suitability of the NPSS for people with cognitive impairment was queried, particularly the role of proxy responses, power imbalances, risk of responder bias, and lack of actionable outcomes if responses were undesirable. Concerns were raised about the nature of the questions, information gaps, and the general length of the instrument.

The risk of overlap with other instruments was of concern to stakeholders, as minimising data collection burden is a key consideration for this COS.

No alternative measures were considered for the outcome of feeling safe and secure in the home care setting.



5.3 Quality of life for home care (QOL-AD)

Outcome

The outcome of **quality of life** was consistently rated by stakeholders as fundamental for quality care of people experiencing dementia and its inclusion in the COS for routine dementia care was recommended by 92% of stakeholders.

Quality of life was defined as the experience of health and well-being.

Measure

No appropriate instrument was identified for measuring quality of life.

Considerations

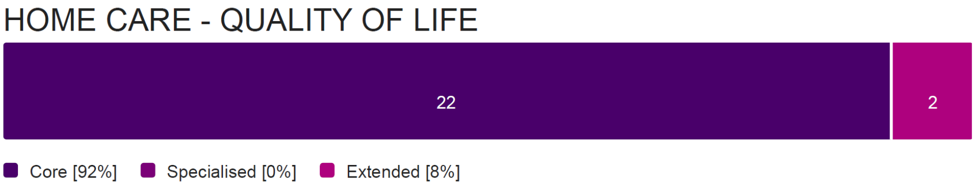
Myriad tools have been developed to measure quality of life, including several specifically for people experiencing dementia, and reaching consensus on a preferred measure was not possible. The Quality of Life in Alzheimer's Disease (QOL-AD) was the tool considered appropriate by the most stakeholders, although only 19% considered it should be included in the COS. QOL-AD was brief, specific to people experiencing dementia, is relevant to the setting and people experiencing dementia and was a good baseline.

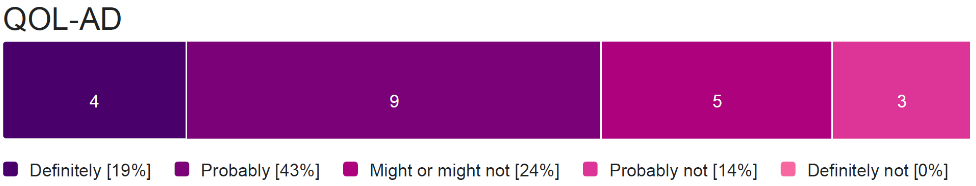
Concerns about the QOL-AD included licensing restrictions precluding widescale use, responsiveness to changes in quality of life (therefore appropriateness to routine care), and its brevity omitting several elements of quality of life that reflect quality of care.

Alternative measures considered for the outcome of quality of life in the home care setting included the World Health Organization Wellbeing Index (WHO-5), the Alzheimer's Disease Five Dimensions (AD-5D) which was derived from the QOL-AD, the DEM-QOL, QUALIDEM and CARE (with substitutions).

The Quality of Life – Aged Care Consumers (QOL-ACC) was also considered for use in home care due to its mandatory reporting through the QI Program for residential aged care.

A question for future research is whether the quality-of-life indicator is sufficient to reflect the importance of this outcome, or whether more in-depth measurement instruments are needed.


HOME CARE - QUALITY OF LIFE


QOL-AD

5.4 Dementia qualifications for home care (DKAS)

Outcome

The outcome of **dementia qualifications** was consistently rated by stakeholders as fundamental for quality care of people experiencing dementia and its inclusion in the COS for routine dementia care was recommended by 83% of stakeholders.

The outcome of 'dementia qualifications' was defined as 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.

Stakeholders acknowledged that specific qualifications did not guarantee currency of knowledge or ability of care staff to apply knowledge in service delivery, but there was agreement that a baseline level of current knowledge specific to dementia was required.

Measure

No appropriate instrument was identified for measuring dementia qualifications.

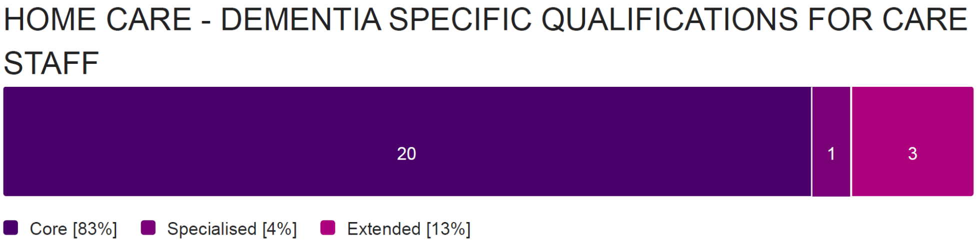
Considerations

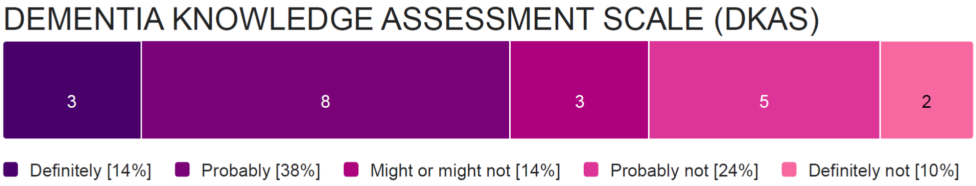
The Dementia Knowledge Assessment Scale (DKAS) was identified by 52% of stakeholders as capturing the core sentiment of this outcome, but not suitable for inclusion in a core outcome set. Concerns about the DKAS included its currency (a lot of the content was already outdated), its minimalism and approach (similar to a gameshow) and exclusion of important soft skills. The content was considered more appropriate as a pre-assessment of knowledge before training rather than for measuring their knowledge outcomes after training.

There was a general sentiment that this outcome does not have a universal measurement solution.

Alternative measures considered for the outcome of dementia qualifications included a simple affirmation that "care staff have the skills and knowledge and understanding of my disease and its impacts to support me to live as well as possible" through to evidence of holding a formal qualification. Stakeholders expressed a need for mandatory minimum standards of education (with DKAS included in refresher training), similar to CPR and first-aid certification in VET programs.

This outcome requires further considered research to develop an appropriate measure that captures the essence of the outcome.





5.5 Hygiene and comfort for residential aged care (COMFORT)

Outcome

The outcome of **hygiene and comfort** was consistently rated by stakeholders as fundamental for quality care of people experiencing dementia and its inclusion in the COS for routine dementia care was recommended by 75% of stakeholders.

Hygiene and comfort were considered as 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.*

Stakeholders noted that further clarification and definition of this outcome would be useful.

Measure

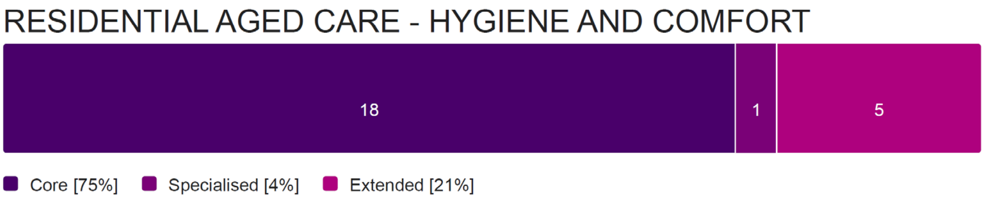
No appropriate instrument was identified for measuring hygiene and comfort.

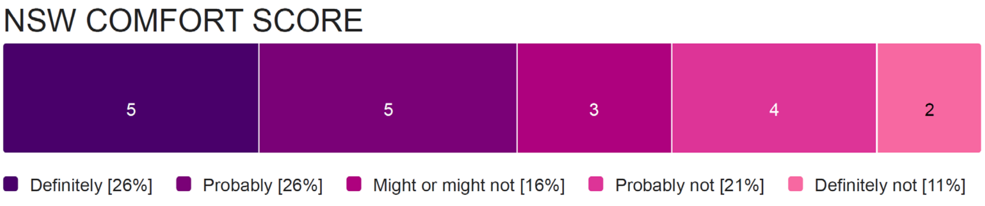
Considerations

The COMFORT scale was identified by 52% of stakeholders the most appropriate measure for this outcome, but not suitable for inclusion in a COS. Concerns about COMFORT's suitability included its practicality and applicability in people experiencing dementia (the instrument was designed for palliative care settings), its requirement for clinical observation skills, and its lack of actionable items.

Measuring a person's hygiene and comfort was important to stakeholders and few instruments have been developed to measure these aspects of care. Work is needed to develop an instrument that focuses on the experience of care, incorporating multiple outcomes like dignity, hygiene, comfort, and pain. Once this groundwork has been done, measures suitable for care provided to people experiencing dementia can be validated.

Overall, respondents felt hygiene and comfort would be better measured with other outcome measures like pain and dignity.





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

Outcome

The outcome of **emotional wellbeing** was consistently rated by stakeholders as fundamental for quality care of people experiencing dementia and its inclusion in the COS for routine dementia care was recommended by 75% of stakeholders.

Emotional wellbeing was defined as supporting people experiencing dementia to realise their potential, cope with normal stress, work productively, and contribute to their community.

Measure

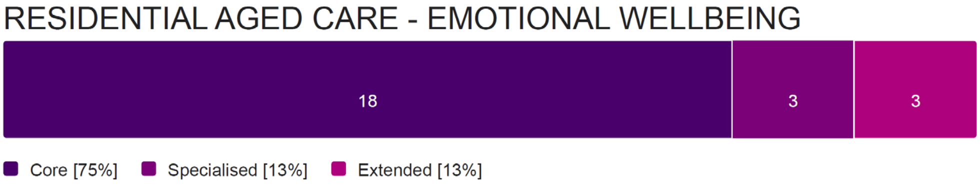
No appropriate instrument was identified for measuring emotional wellbeing.

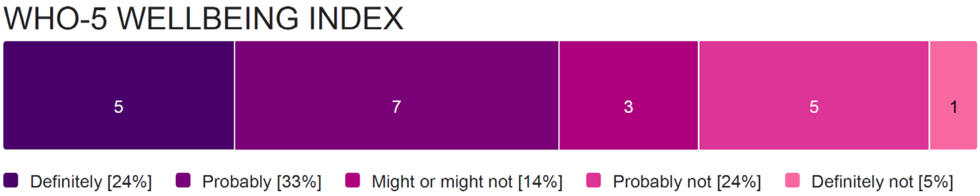
Considerations

The World Health Organization Wellbeing Index (WHO-5) was identified by 52% of stakeholders the most appropriate measure for this outcome due to its simplicity and ease of interpretation without loss of comprehensiveness, but not suitable for inclusion in a COS.

The inclusion of emotional wellbeing as a core outcome in residential aged care was questioned by some stakeholders. Some considered the WHO-5 was too general to adequately capture emotional wellbeing, questioned whether its brevity undermined its validity and reliability, and wondered if it was sensitive enough to respond to changes. The WHO-5 has not been tested in populations of people experiencing dementia, and there is no evidence about its suitability for proxy completion.

No alternative measures were considered for the outcome of emotional wellbeing, just a sentiment that ‘we can do better.’





5.7 Quality of life for residential aged care (QOL-AD)

Outcome

The outcome of **quality of life** was consistently rated by stakeholders as fundamental for quality care of people experiencing dementia and its inclusion in the COS for routine dementia care was recommended by 92% of stakeholders.

Quality of life was defined as the experience of health and well-being.

Measure

No appropriate instrument was identified for measuring quality of life.

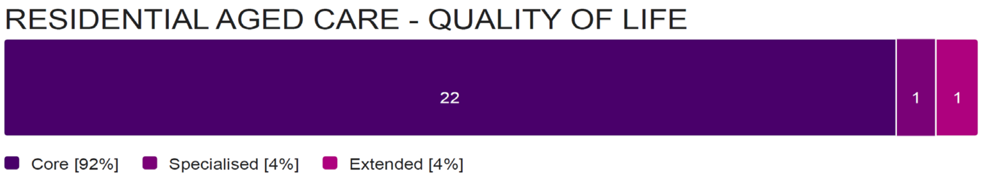
Considerations

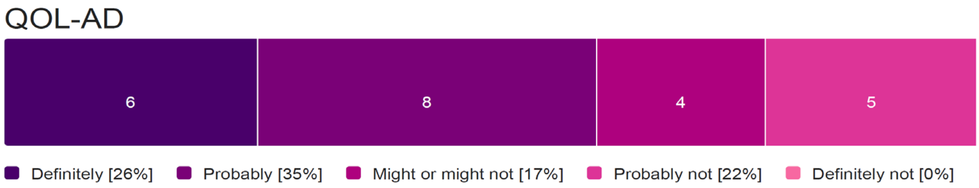
The Quality of Life in Alzheimer's Disease (QOL-AD) was the tool considered the best available by 61% of stakeholders, but not suitable for inclusion in the COS. QOL-AD was considered a well-utilised and explained tool already validated for use in this cohort.

Concerns about the QOL-AD included the use of antiquated language (marriage rather than relationship), potential duplication, inclusion of items not relevant to residential aged care, and the potential omission of key elements of quality of life.

Alternative measures preferred by some stakeholders included instruments they are familiar with, such as the Alzheimer’s Disease Five Dimensions (AD-5D), DEMQOL and GAS-light process. The diversity of validated and frequently used instruments for quality-of-life outcomes complicates selection of a universally applicable measure for inclusion in a COS, despite the obvious importance to the majority of stakeholders.

The Quality of Life – Aged Care Consumers (QOL-ACC) was also considered for inclusion in the COS due to its mandatory reporting through the QI Program for residential aged care.





5.8 Adverse events for residential aged care (no measure)

Outcome

The outcome of **adverse events** was consistently rated by stakeholders as important for quality care of people experiencing dementia and its inclusion in the COS for routine dementia care was recommended by 71% of stakeholders.

The adverse events outcome was defined as prevention, monitoring and tracking of harmful or negative outcomes occurring during provision of medical care.

Measure

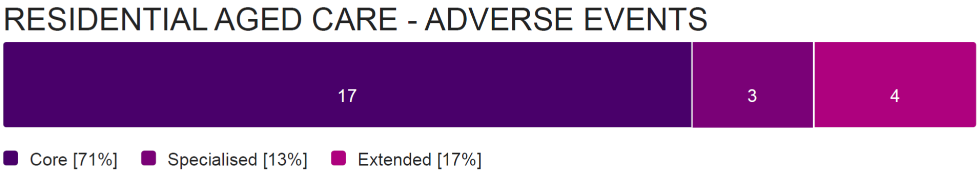
No appropriate instrument was identified for measuring adverse events.

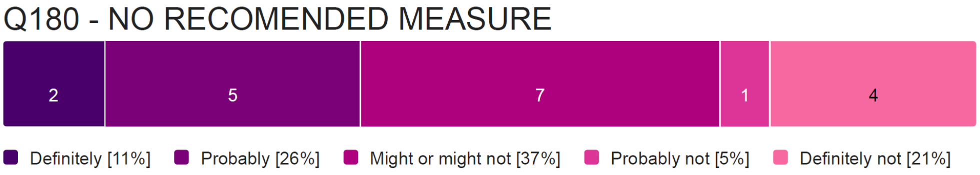
Many stakeholders considered a measure for the adverse events outcome was unnecessary as significant events are adequately captured in the QI Program.

Considerations

Stakeholders identified clear links between adverse events and quality of care that is reflected in the recommendations of the Royal Commission into Aged Care Quality and Safety and the Aged Care Quality Standards.

The primary difficulty with identifying a measure for this outcome was a lack of clarity around definition and scope. It was unclear how adverse events differ from safety incidents or singular clinical incidents. There was no guidance around whether the adverse events outcome was intended to capture preventable events, non-preventable events, or both, or if there was any distinction between these two types. The definition of an event was also unclear, including whether an event was purely physical or should consider other types of harm such as mental, emotional, or social harm.





5.9 Dementia qualifications for residential aged care (DKAS)

Outcome

The outcome of **dementia qualifications** was consistently rated by stakeholders as important for quality care of people experiencing dementia and its inclusion in the COS for routine dementia care was recommended by 79% of stakeholders.

The outcome of 'dementia qualifications' was defined as 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.

Measure

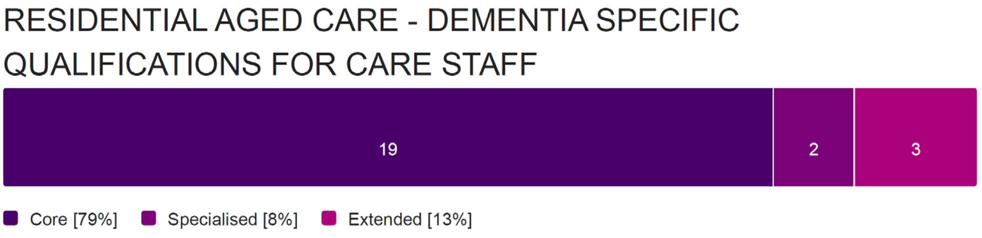
No appropriate instrument was identified for measuring dementia qualifications.

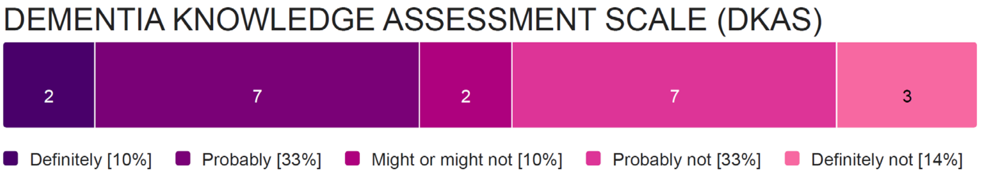
Considerations

The Dementia Knowledge Assessment Scale (DKAS) was an appropriate measure for gauging critical and practical knowledge and understanding about dementia and dementia care derived from formal training by 43% of stakeholders, but was not considered suitable for inclusion in a COS.

Measurement of formal qualifications was largely undeveloped in the literature. For the measure to be appropriate, it needs to consider support from formal qualifications (VET, university) and requires adaptation to specific settings. Any measure needs to maintain relevance and currency, reflecting best-practice care. While some respondents felt the DKAS was excellent, others had difficulty understanding it and indicated attention to level of qualification required consideration.

Alternative measures considered by stakeholders include mandating minimum education standards for care providers and incorporating modules into existing accredited aged care certificate courses. Knowledge assessment could be a component of ongoing professional development for care workers in this space, similar to refresher requirements of first-aid resuscitation or manual handling that are already common practice in care facilities.





6. Recommendation 3 – COS for routine dementia care: extended

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.

Recommendation 3 is concerned with outcomes defined as core outcomes by the Delphi consensus panel but did not meet the consensus threshold to be considered a COM by the working groups (Table 8). Despite this, the measures identified for these outcomes was considered appropriate and best-practice by the majority of working group members. As such, these COM represent opportunities for service providers to take innovative action to improve the quality of routine dementia care provided by their organisation as these measures are already robust, validated for use, and reliable measures of important outcomes. We discuss three outcomes in the home care setting and two in the residential aged care setting. These outcomes are important to stakeholders and are considered by many to improve care quality, even though they are not the 'most' important at this time. There are three outcomes in home care and two in residential aged care, with some conceptual overlap between settings but no identical outcomes between settings.

Table 8 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

6.1 Behavioural symptoms of dementia for home care (**NPI**)

Outcome

The outcome of **behavioural symptoms of dementia** was rated by stakeholders as important for quality care of people experiencing dementia, but it did not reach the consensus threshold for inclusion in the COS.

The behavioural symptoms of dementia outcome was defined as behavioural and psychological symptoms need to be charted, with changes documented.

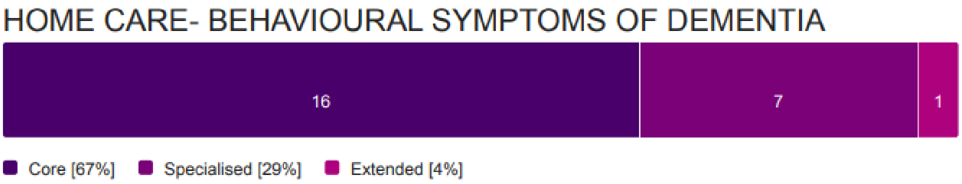
Measure

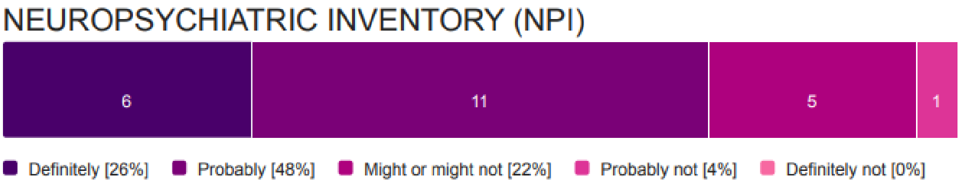
In situations where behavioural issues have been identified, the Neuropsychiatric Inventory (NPI) was considered an appropriate measure by 74% of stakeholders. Concerns were raised about the specificity of the items to dementia and whether the NPI reflected the intention of the outcome. The NPI was deemed a comprehensive instrument, but risks duplication of effort in data collection as many items were collected by other instruments.

Considerations

Behavioural symptom measurement was generally considered appropriate only when behavioural issues have been identified. Premature inclusion of this as a core outcome may perpetuate disabling and disempowering care environments. Improvements in care technology and understanding combined with a shift in focus away from behaviour management may eventually make this domain redundant.

Alternatives considered by stakeholders included focusing on environmental design and identifying triggers of abnormal behaviours. Comprehensive care planning within an integrated, person-centred care model should mean this outcome is not required.





6.2 Meaningful activities for home care (**EMAS**)

Outcome

The outcome of **meaningful activities** was rated by stakeholders as important for quality care of people experiencing dementia, but it did not reach the consensus threshold for inclusion in the COS.

The meaningful activities outcome included preserving 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.

Measure

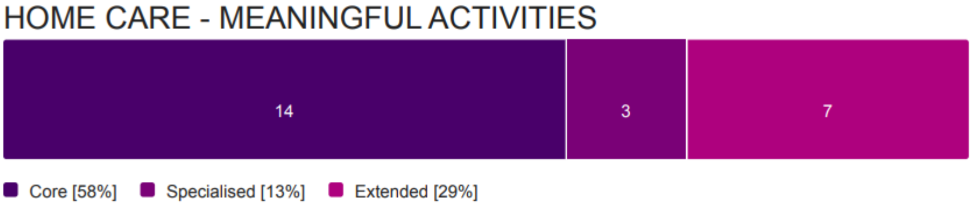
The Engagement in Meaningful Activities Survey (EMAS) was considered the best available measure for meaningful activities outcomes by 88% of stakeholders, despite reservations about its validity in a population of people experiencing dementia.

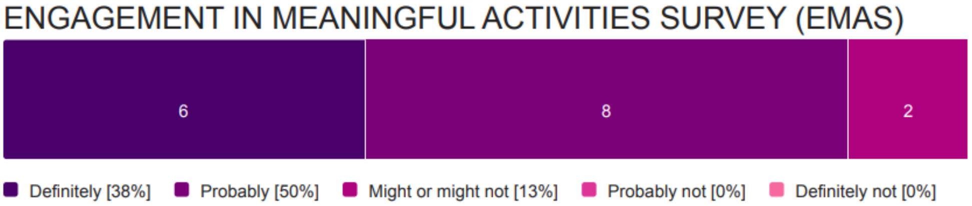
Considerations

Stakeholders generally acknowledged the need for meaningful engagement to be measured across the trajectory of care. Engagement is measurable and trackable, and its importance to quality care outcomes is well supported in dementia care literature. However, some stakeholders queried the need for an additional measure, arguing that this outcome could be adequately described with screening questions, such as those included in QOL-ACC.

Stakeholders struggled to clearly define the concept of meaningful activities but agreed on its importance. New research defines meaningful activities as those that provide for social, physical and psychological stimulation that are personally enriching for the care recipient. Interpretation of what activities fit this definition was subjective, and care providers may not always agree with or comprehend activities that are enriching to people experiencing dementia.

If service providers had additional resources available to focus on improving quality in their dementia care services, inclusion of EMAS was a highly regarded and robust instrument to measure engagement in meaningful activities for people experiencing dementia in the home care setting.





6.3 Family and carer quality of life for home care (**ZBI**)

Outcome

The outcome of **family and carer quality of life** was rated by stakeholders as important for quality care of people experiencing dementia, but it did not reach the consensus threshold for inclusion in the COS.

The outcome of family and carer quality of life was defined as supporting main caregivers to maintain their own health and wellbeing to sustain appropriate care-giving arrangements in the home.

Measure

The Zarit Burden Index (ZBI) was considered an appropriate measure of quality of life for carers and families in the home care setting by 71% of stakeholders. The ZBI was the most widely used instrument for this outcome. Concerns were raised about its focus on negative aspects (e.g. the connotations of the word 'burden'), its data collection burden (for more comprehensive versions), and its generalisability to vulnerable groups.

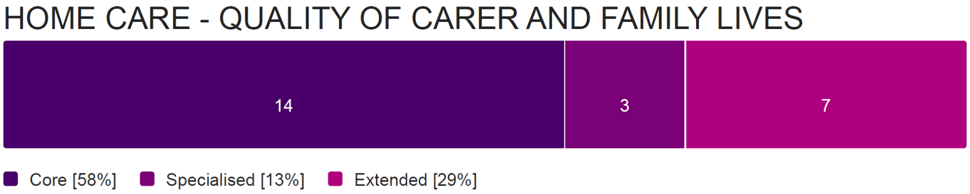
Considerations

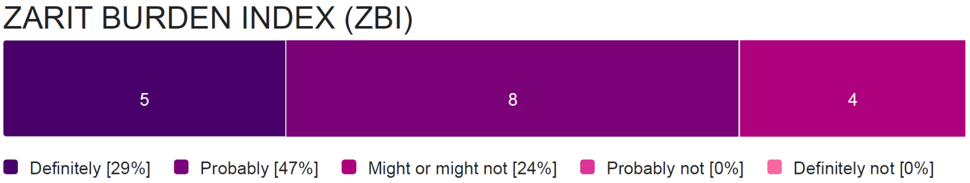
Although family and carer quality of life was not included in the COS, service providers wishing to support carers and improve the sustainability of informal carer relationships can reliably measure family/carer quality-of-life with the ZBI.

Stakeholders considered family and carer quality of life was an essential and often overlooked aspect of home care, especially in situations where the person experiencing dementia was highly dependent on informal carer supports. The sustainability of informal caregiving arrangements in home care is a key factor in the long-term success of home care programs, particularly in situations of high dependency such as caring for people experiencing advanced symptoms of dementia. Sustainability of the carer relationship is also one of the largest predictors of transfer to residential aged care.

A potential barrier to the inclusion of family and carer quality of life was the need to differentiate dementia-specific measures and outcomes from those central to all care.

Alternative measures considered by stakeholders included already validated quality-of-life surveys such as DEM-QOL proxy, which has been adapted to suit carers specifically. Internationally-validated indicators and scales such as interRAI's caregiver stress scale may also provide sufficient information to measure, monitor, and evaluate carer quality of life from the perspective of sustainability of the care relationship.





6.4 Neuropsychiatric symptoms of dementia for residential aged care (**NPI**)

Outcome

The outcome of **neuropsychiatric symptoms of dementia** was rated by stakeholders as important for quality care of people experiencing dementia, but it did not reach the consensus threshold for inclusion in the COS.

The outcome of neuropsychiatric symptoms of dementia was defined as neurological and psychological symptoms of dementia need to be charted, managed, and documented as part of routine care.

Measure

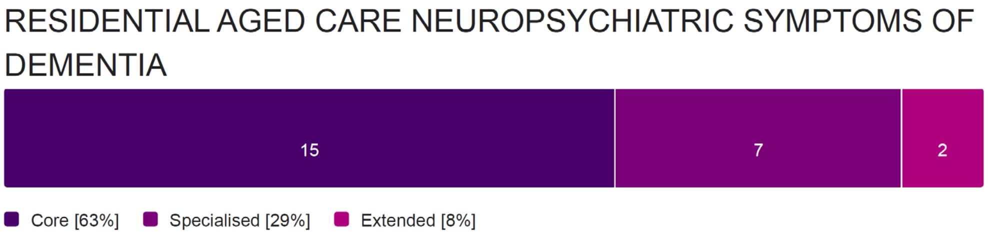
The Neuropsychiatric Inventory (NPI) was considered an appropriate measure of neuropsychiatric symptoms of dementia by 77% of stakeholders due to its specificity and relevance to residential aged care and its widespread use. Repeated measures with NPI would be useful and informative for care and care planning, providing much needed visibility on the impact of interventions over time. The instrument was considered comprehensive, though links to quality were not clear to all stakeholders.

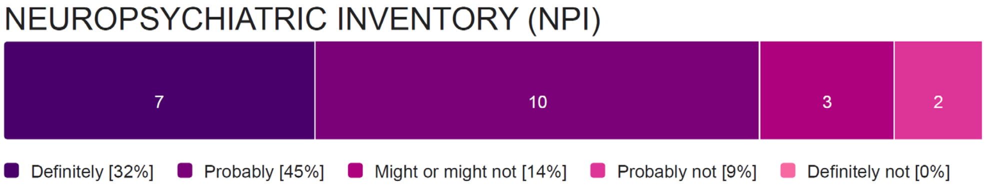
Concerns were raised about the NPI’s high data collection burden, noting its full application could be overkill. The instrument was also considered complex to interpret and required trained staff for accurate collection. There was also recognition that not all behavioural problems are related to dementia and not all people experiencing dementia have behaviour problems, so there was a mismatch between measure and outcome.

Service providers wishing to focus on behaviour symptom management can use the NPI for robust and reliable measurement of neuropsychiatric symptoms of dementia in residential aged care settings.

Considerations

Alternative measure considered by stakeholders included improvements in care-planning (i.e. tracking trends over time) to identify people with behaviour concerns and providing appropriate interventions for the causes of that behaviour. AI may provide improved capacity to detect and predict problematic behaviours. A shorter version of the NPI was also available and may be more appropriate for broader use.





6.5 Staff carer morale for residential aged care (**MAGPI**)

Outcome

The outcome of **staff carer morale** was rated by stakeholders as important for quality care of people experiencing dementia, but it did not reach the consensus threshold for inclusion in the COS.

The outcome of staff carer morale was defined as acknowledgement that high quality care can only be attained with an engaged, valued, and supported workforce.

Stakeholders noted that further clarification and definition of this outcome would be useful.

Measure

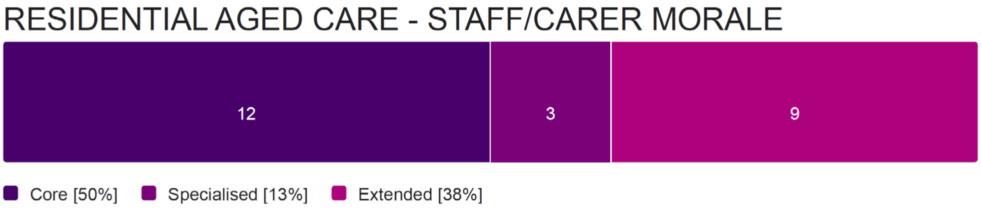
The Morale Assessment in General Practice Index (MAGPI) was considered an appropriate measure of staff and carer morale by 73% of stakeholders. Concerns about MAGPI included its relevance to residential aged care, validity and veracity of staff responses in self-reported measures, and omission of other aspects of care delivery.

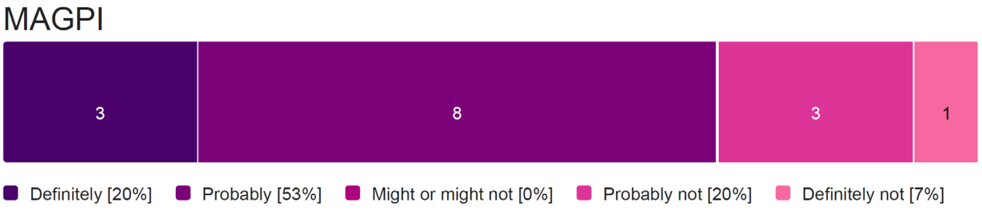
Service providers who considered the link between care worker wellbeing and service outcomes for people experiencing dementia may consider using MAGPI to monitor changes in care worker capacity before it begins to impact care delivery.

Considerations

Stakeholders acknowledged that high quality care necessitates wellbeing in the person providing care. Research supports that workers who feel isolated, unsupported, overworked, and underpaid become disenfranchised and disengaged, subsequently limiting their capacity to provide high quality care.

Approaches to measuring staff carer morale should use random sampling of staff rather than a whole workforce approach to reduce data collection burden. It may be possible to deduce staff well-being through objective measures, such as sick days, missed shifts, or staff turnover.





7. Recommendation 4 – COS for routine dementia care: optional

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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.

Recommendation 4 is concerned with outcomes defined as core by the modified Delphi panel, but failed to meet consensus to be included as core outcomes in the final core outcome measurement AND the best-practice measure identified by the working groups did not meet consensus as the most appropriate way to measure the outcome (Table 9).

These outcomes are considered important by stakeholders, but the current evidence does not support their inclusion in a COS for routine dementia care. There were three outcomes consistent across home care and residential aged care, and the same instrument was considered the most appropriate measure for the outcome in both settings. There were a further four outcomes in home care and two in residential aged care.

These domains and associated measures are **not** currently recommended but may become important in future iterations. Stakeholders with additional resources to monitor and evaluate quality of care for people experiencing dementia should consider including these measures in their data collection. Additionally, measurement techniques and practices may improve so that the benefit of the information associated with these outcomes outweighs the challenges of its collection.

Table 9 Summary of outcome measures Recommendation 4: Extended outcomes with no reliable measure (not recommended)

Outcome	Definition	Measure
Combined Home Care and Residential Aged Care		
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

7.1 Advance care planning for home care and residential aged care (ACP Engagement Survey)

Outcome

Stakeholders agreed that advance care planning is an important conversation and should be offered early in the care experience but should not be compulsory. Its inclusion in the COS was supported by 58% of stakeholders for home care and 67% for residential aged care.

Advance care planning was defined as the opportunity to discuss and make an advance care plan.

Measure

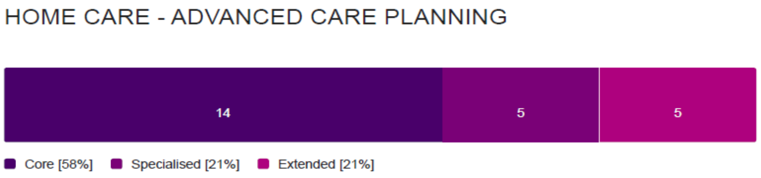
No appropriate instrument was identified for measuring advance care planning.

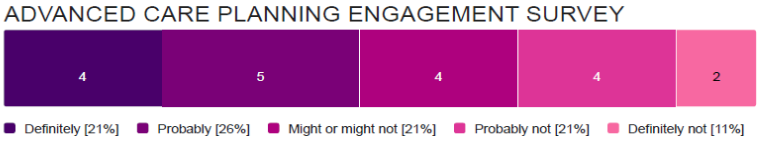
Considerations

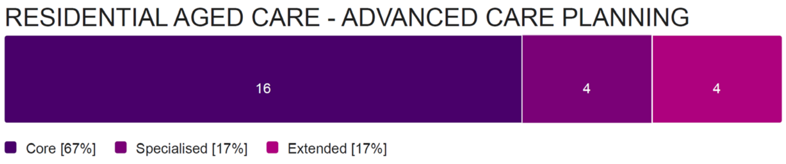
The Advance Care Plan (ACP) Engagement Survey was considered an appropriate measure for home care by 47% of stakeholders and for residential aged care by 45% of stakeholders. Concerns were raised about whether it was too long, exhausting, complicated, irrelevant in home care, and the need for administration by a specialist with medico-legal experience.

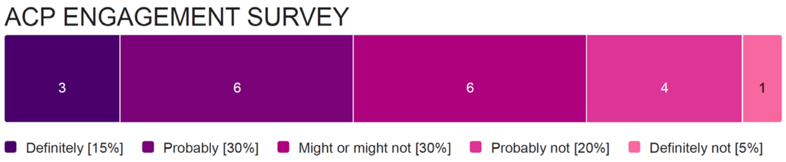
The increased significance of advance care planning with deteriorating health conditions was acknowledged. However, the ability of the presence or absence of an advanced care plan to change routine care, and whether it should be a component of quality of care, was questioned.

More work is required on the best way to measure advance care planning and facilitate conversations. Most stakeholders preferred a simpler screening approach, such as whether a care plan was in place, had been offered or was able to be discussed. Clear guidelines for scope and onus of responsibility are required to appropriately include advance care planning as a measure of quality care for people experiencing dementia home care or residential aged care.









7.2 Resource utilisation for home care and residential aged care (RUD-LITE)

Outcome

Stakeholders agreed that **resource utilisation** is important, but should not be included in a COS. Its inclusion in the COS was supported by 43% of stakeholders for home care and 54% for residential aged care.

Resource utilisation was defined as facilitate high level decision-making and efficient allocation of resources to be able to appropriately cost and budget for quality improvement activities.

Measure

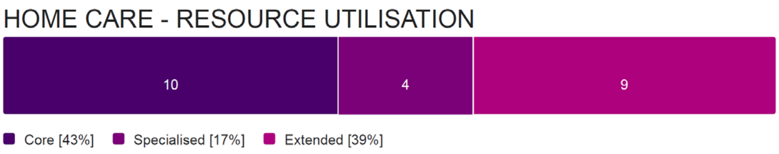
No appropriate instrument was identified for measuring resource utilisation.

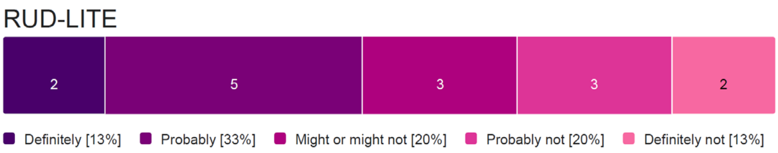
Considerations

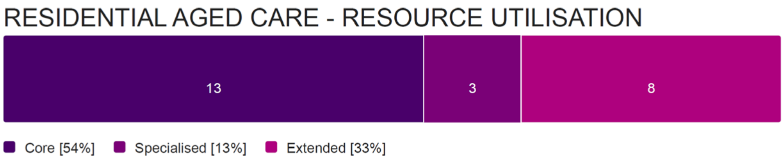
The Resource Utilisation in Dementia Lite (RUD-LITE) was considered an appropriate measure by 46% of stakeholders for home care and 50% of stakeholders for residential aged care. For some in residential aged care, RUD-LITE was provided insight into resource expenditure and assisted efficient resource allocation in acknowledgement that the cheapest care is not necessarily correlated with best practice care and vice-versa. Concerns were raised about its applicability for home care, the consistency and transparency of self-reported data (particularly when linked to funding), and the instrument being time-consuming and onerous to complete, potentially requiring financial expertise.

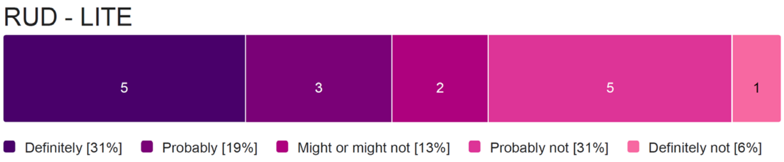
No viable alternatives were suggested by respondents.

It was noted that the Australian National Aged Care Classification (AN-ACC) currently determines funding for residential aged care, so addition of RUD-LITE would duplicate existing processes.









7.3 Safety incidents for home care and residential aged care (no measure)

Outcome

Stakeholders agreed that **safety incidents** are important, but should not be included in a COS. Its inclusion in the COS was supported by 67% of stakeholders for home care and for residential aged care.

Safety incidents were defined as unplanned or unintended event or circumstance which could have resulted or did result in harm to a care recipient.

Measure

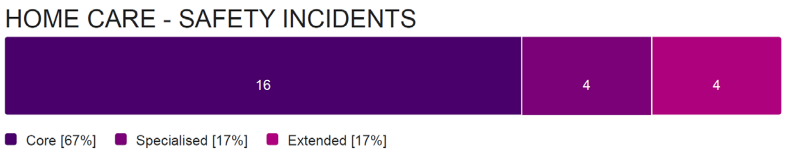
No appropriate instrument was identified for measuring resource utilisation.

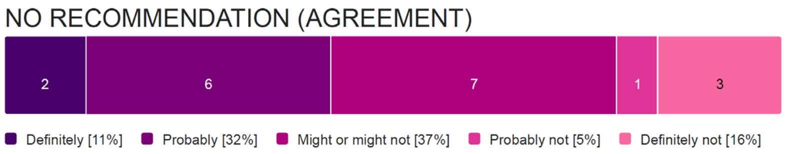
Considerations

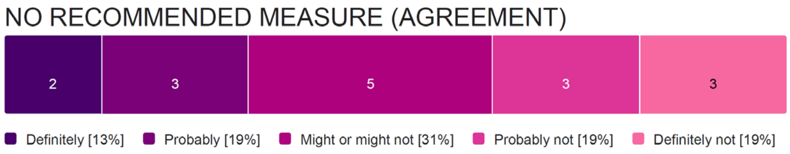
Stakeholders were surprised to identify no available measure for safety incidents in home care, though they acknowledged the known problems with attributing incidents to providers and the ability to assign responsibility for safety incidents occurring in a care recipient's home.

In residential aged care, the QI Program includes quality indicators for some specific safety incidents such as falls, and most service providers have robust incident reporting systems. What happens with this data varies across service providers, as do the systems used to report and manage incidents.

Generally, there was an acknowledgement that safety incidents were not exclusive to dementia care and should be a consideration in baseline data collection for all care recipients, not exclusively for people experiencing dementia.







7.4 Opportunities for unpaid carers in home care (no measure)

Outcome

Stakeholders agreed that **opportunities for unpaid carers** are important, but are not an outcome of care and should not be included in a COS. Its inclusion in the COS was supported by 38% of stakeholders.

Opportunities for unpaid care were defined as carers are supported with resources and clinical education they need to learn about aspects of dementia care they can assist with.

Measure

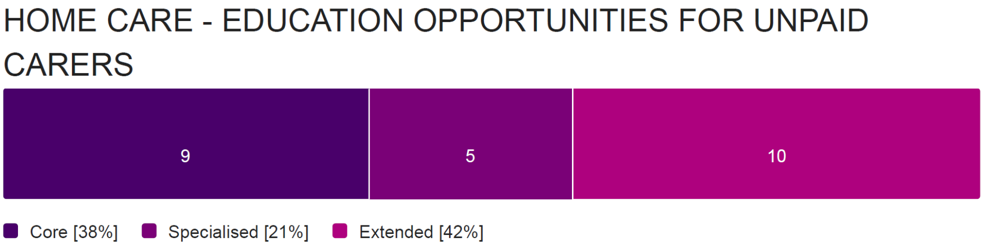
No appropriate instrument was identified for measuring opportunities for unpaid carers.

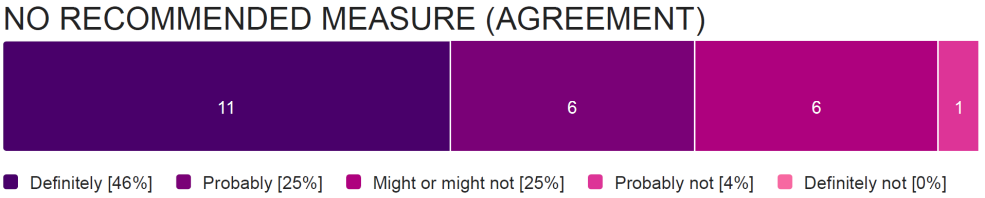
Considerations

Stakeholders acknowledged the value of unpaid carers and the need for parity. They also acknowledged that supporting carers was integral to supporting the person experiencing dementia. However, others felt it was too challenging to measure appropriately in an evolving care landscape.

There were opportunities for unpaid carers to upskill and build knowledge, and some of these were freely available. Development of care navigation pathways for dementia would also be beneficial as an intervention, though was not associated with a specific outcome.

Stakeholders considered this outcome could potentially be assessed with an indicator question such as *I have been provided with sufficient information, education, and support to fulfil my role*.





7.5 Importance of relationships for home care (CARE)

Outcome

Stakeholders agreed that the **importance of relationships** outcome was important, but should not be included in a COS. Its inclusion in the COS was supported by 63% of stakeholders.

Importance of relationships was defined as 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.

Measure

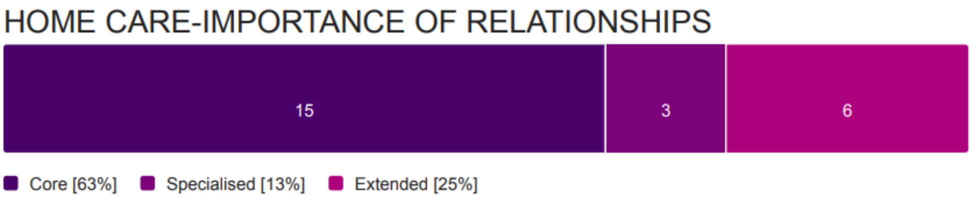
No appropriate instrument was identified for measuring opportunities for importance of relationships.

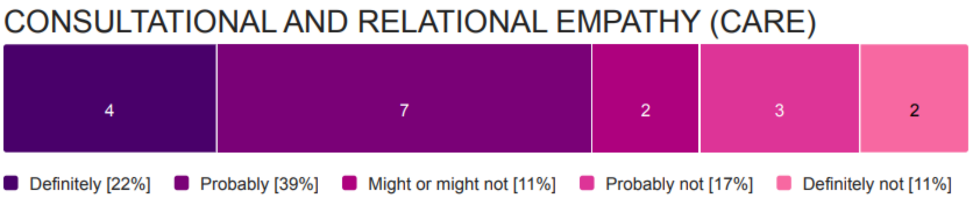
Considerations

High quality care is dependent on communication and how well the person experiencing dementia is supported to live their best life. Accepting this, it was not clear how the importance of relationships was an indicator of quality of care. Further clarification on the central meaning of the outcome is required to decide on appropriateness of the outcome in a core set and how to appropriately measure it.

If the importance of relationships was measured, the CARE survey was identified as an appropriate measure of the importance of relationships in home care by 61% of stakeholders due to its perceived adaptability to the home care setting. Concerns were raised about suitability of the scale for people experiencing dementia in home care, as the questions are specific to doctor-patient relationships rather than personal relationships for the person experiencing dementia.

Many stakeholders considered tools such as the QOL-ACC for in the QI Program for residential aged care would better capture the sentiment of this outcome.





7.6 Emotional wellbeing for home care (WHO-5)

Outcome

Stakeholders agreed that **emotional wellbeing** was important and relevant to all people receiving care, not just dementia care, so should not be included in a COS. Its inclusion in the COS was supported by 63% of stakeholders.

Emotional wellbeing was defined as supporting people experiencing dementia to realise their potential, cope with normal stress, work productively, and contribute to their community.

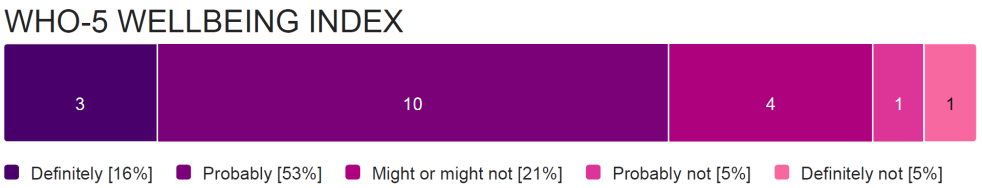
Measure

No appropriate instrument was identified for measuring opportunities for emotional wellbeing.

Considerations

If emotional wellbeing was measured for home care, the WHO-5 wellbeing index was considered to be an appropriate measure of emotional wellbeing by 63% of stakeholders. The WHO-5 was considered short, easy to implement, and focused on the presence/absence of wellbeing rather than a focus on disease. Concerns were raised about its focus on quality of life rather than wellbeing, and there were reservations about usability for people requiring a proxy, sensitivity of the instrument to changes in wellbeing, and narrow scope (i.e. a lot of aspects of wellbeing were not covered).

Alternatives considered by stakeholders included co-production of selected key instruments that were culturally sensitive, and the potential of technological solutions to elucidate how people experiencing dementia might flourish in the present.



7.7 Dementia care navigation for home care (Pathway)

Outcome

Stakeholders agreed that **dementia care navigation** was important, but should not be included in a COS. Its inclusion in the COS was supported by 58% of stakeholders.

Dementia care navigation was defined as developing partnerships between stakeholders to navigate complex health care systems and treatment landscapes.

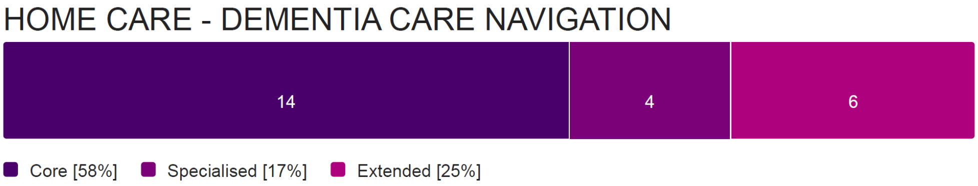
Measure

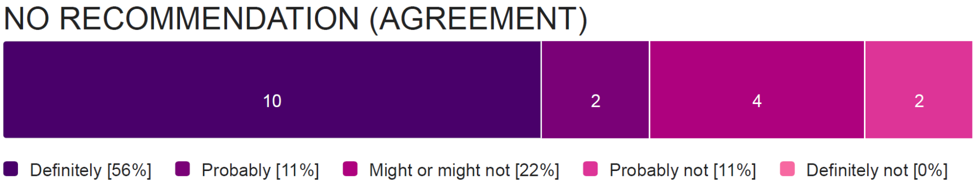
No appropriate instrument was identified for measuring dementia care navigation.

Considerations

Stakeholders noted that care-planning was critical, and navigation promised significant benefits for people experiencing dementia, their supports, and the wider community. It is long overdue.

There was no available measure for Dementia Care Navigation, or an approved dementia care navigation pathway for home care. Existing pathways have been developed for hospital settings, although they are highly complex, and have limited suitability for non-specialists.





7.8 Feeling safe and secure for residential aged care (NPSS)

Outcome

Stakeholders agreed that **feeling safe and secure** was important, but are not an outcome of care and should not be included in a COS. Its inclusion in the COS was supported by 67% of stakeholders.

Feeling safe and secure was defined as feeling psychologically safe, including not being punished or humiliated for sharing ideas, asking questions, voicing concerns, or making mistakes.

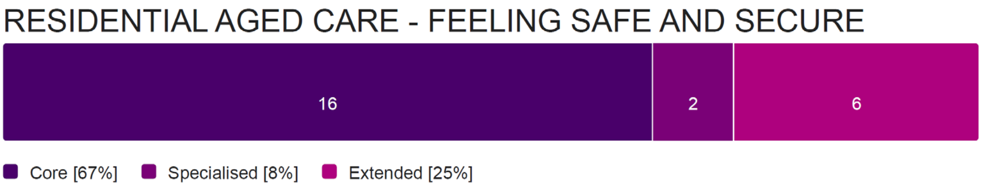
Measure

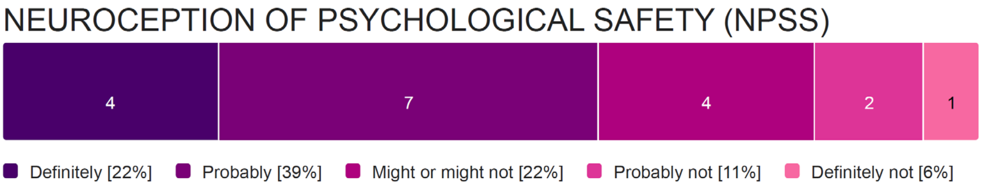
No appropriate instrument was identified for measuring opportunities for feeling safe and secure.

Considerations

he Neuroception of Psychological Safety Scale (NPSS) was identified by 61% of stakeholders as the best available measure for this outcome, but not suitable for inclusion in a COS. It was considered a good attempt at filling gaps in measuring aspects of care outside physical aspects, was clear, simple, and considerate of a vital outcome that is traditionally challenging to measure. Concerns were raised that the NPSS was not specific to dementia, was too long, and lacked relevance in residential aged care settings. While lengthy, NPSS did not appear to miss a lot of aspects of care in physical, sexual, spiritual, cultural, gendered, financial, coercive, and psychological abuse domains. Not all stakeholders agreed that psychological safety was the essence of the *feeling safe and secure* outcome. Additionally, this scale was not validated in populations of people experiencing dementia.

Alternatives considered by stakeholders included whistleblowing protection, the ready to listen MAP, a shorter version of NPSS, resident experience surveys, quality of life measures, and trauma measures. It is likely these instruments have the same deficits in reliability, validity, feasibility, and purpose as NPSS.





7.9 Medication appropriateness for residential aged care (STOPP-START)

Outcome

Stakeholders agreed that **medication appropriateness** was important, but should not be included in a COS. Its inclusion in the COS was supported by 58% of stakeholders.

Medication appropriateness was defined as increased awareness and appropriate use of medication prevents adverse events associated with polypharmacy, reduces costs, and improves clinical care outcomes.

Measure

No appropriate instrument was identified for measuring opportunities for unpaid carers.

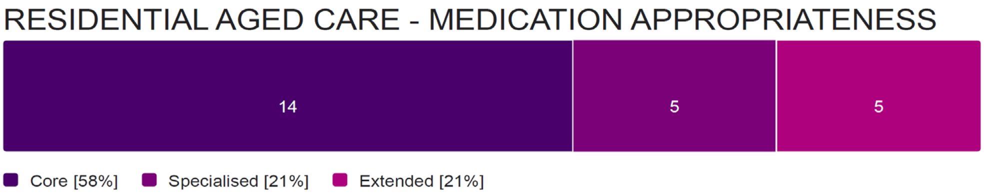
Considerations

Medication appropriateness in dementia care is dependent on accurate diagnosis, and prescription as an outcome of quality care in aged care settings is controversial.

STOPP START v2 was considered an appropriate measure of medication appropriateness in residential aged care by 52% of stakeholders. However, it was considered a complicated instrument that requires trained assessors. Some stakeholders did not feel qualified to consider its inclusion as an outcome measure.

Alternatives considered by stakeholders included acquiring the appropriately skilled staff to conduct medication reviews, such as the employment of clinical pharmacists in residential aged care, as is being introduced by the Australian Government through the Aged Care On-site Pharmacist (ACOP) measure.

There was an acknowledgement that medication appropriateness was not exclusive to dementia care and should be a consideration in baseline data collection for all care recipients, not exclusively for people experiencing dementia.



8. Implementation and significance

Following extensive community consultation, international research, consensus discussions, working groups, and broad stakeholder engagement, a preliminary COS for improving care of people experiencing dementia was created, and potential outcome measures for individual outcomes were assessed for their suitability and relevance.

None of the outcomes or measures considered by the project team achieved universal consensus for inclusion in a COS for improving the quality of routine care services provided to people experiencing dementia in either home care or residential aged care settings. This reflects the complexity and diversity of thought across all sectors of the Australian dementia care sector.

A variety of outcomes and measures were considered, resulting in a preliminary set of outcome measures identified and classified into four categories.

Table 10.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 outcome measures survey, undertaken by the working group members, some outcomes no longer satisfied the consensus condition for consideration as a core outcome measure. There were a number of reasons for this. Principally, the working group membership was different to the modified Delphi consensus panel. While all participants were stakeholders in routine dementia care, there were vastly different experiences and perspectives. Secondly, perceptions and understanding of outcomes evolved with new learning, so the significance of the outcome changed for some people between outcome selection and outcome measurement. Thirdly, measures in research, with defined time horizons and specific research questions, differ dramatically from routine care measurement, where measures are repeated, often over lengthy time periods, and interventions are varied across multiple domains of care.

Finally, consideration should be given to the arbitrary consensus threshold of 70%. Several outcomes in the Extended and Not Recommended category had greater than 65% agreement, which may have been a single vote between inclusion as a core outcome or not recommended. In some situations, respondents felt the outcome was core to quality care in general (not specific to dementia) and so may have voted to include the outcome in an extended set rather than considered it exclusively in a COS for dementia care. Measures also posed difficulties with consensus in that there was an agreed consensus that no measure was available, but ‘no measure’ was not considered best practice or an acceptable way to measure the outcome of interest.

Comprehensive outcome measures were generally criticised for being overly complex, lengthy, and requiring specialist training to adequately apply. Longer measures were also more likely to contain data items collected by other processes or alternative measures, leading to duplication of effort and an unnecessary increase in data collection burden. Brief and simple outcome measures were criticised for having gaps, lacking specificity and applicability, and being insensitive to changes in outcomes.

For many of the instruments presented, links to quality of care and potential for impact depends on what happens to the information collected. Outcomes can illuminate the impact of interventions, however, if the results are not fed back to generate inputs as part of a monitoring and evaluation cycle focused on quality improvement, the benefits will not be realised. This was true for any outcome measurement used over time.

The majority of outcome measurement instruments available for the outcomes considered important to quality care have not previously been considered for use in routine care settings generally, and certainly not for specific vulnerable groups such as people experiencing dementia. A substantial research effort is required to adapt and validate appropriate measurement instruments for outcomes that are considered important to stakeholders in dementia care, including engagement and involvement of people experiencing dementia, their carers, families and friends, service providers, care workers, medical and allied health professionals, advocates, policy makers, researchers, and educators.

In several ways the COM-IC project has been ground-breaking in dementia care research – at least in the Australian context - and is an example of implementation research which aligns with the stated objectives of its funder, the Medical Research Future Fund (MRFF).

Firstly, from the perspective of the research methodology used, i.e., research that was co-designed with a diverse range of stakeholders including people diagnosed with dementia and carers directly impacted by dementia. Several of these stakeholders are also actively engaged as advocates or advisors in recent dementia research and policy making, across other universities and for Government. These stakeholders were able to contribute useful, personal, and sometimes emotional insights into dementia and dementia care that academic researchers and others might not otherwise have obtained or understood. They represented the unspoken voices of the many thousands of Australians experiencing dementia, their carers and families, whose lives intersect at some point with the aged care sector and who wish for better outcomes in dementia care.

Secondly, the core outcomes identified in this project which specifically focus on dementia care, and their relevant measurement instruments, can and should supplement existing indicators of the QI Program. While clinical care outcomes dominate the current indicators, this project has demonstrated there are other core outcomes of equal importance that providers should consider as part of improving the quality of routine dementia care. Recognition of these additional outcomes would support a more humanistic approach to dementia care in Australia which, arguably, underpins what policy makers, regulators and providers mean when they speak of “person-centred” care.

Finally, these results obtained through a rigorous research methodology should now be carefully considered by the Government’s aged care policymakers and regulators and by innovative aged care providers, to complement and strengthen the recent reforms across the sector. The findings are also directly relevant to the implementation of the National Dementia Action Plan, which aims to improve the lives of people living with dementia. That this project was funded by the Medical Research Future Fund (MRFF) underscores the significance of its recommendations and the level of attention they warrant in efforts to enhance the quality of dementia care in Australia.

9. Summary of Recommendations

The COM-IC project makes the following recommendations (Table 11):

Table 11 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.

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

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THE UNIVERSITY OF QUEENSLAND
AUSTRALIA

CREATE CHANGE

Contact details

Professor Tracy Comans
T +61 7 3176 5530
E health.econ@uq.edu.au
W uq.edu.au

CRICOS Provider 00025B • TEQSA PRV12080