

Recommended Core Outcome Measures for Improving routine dementia Care (COM-IC)

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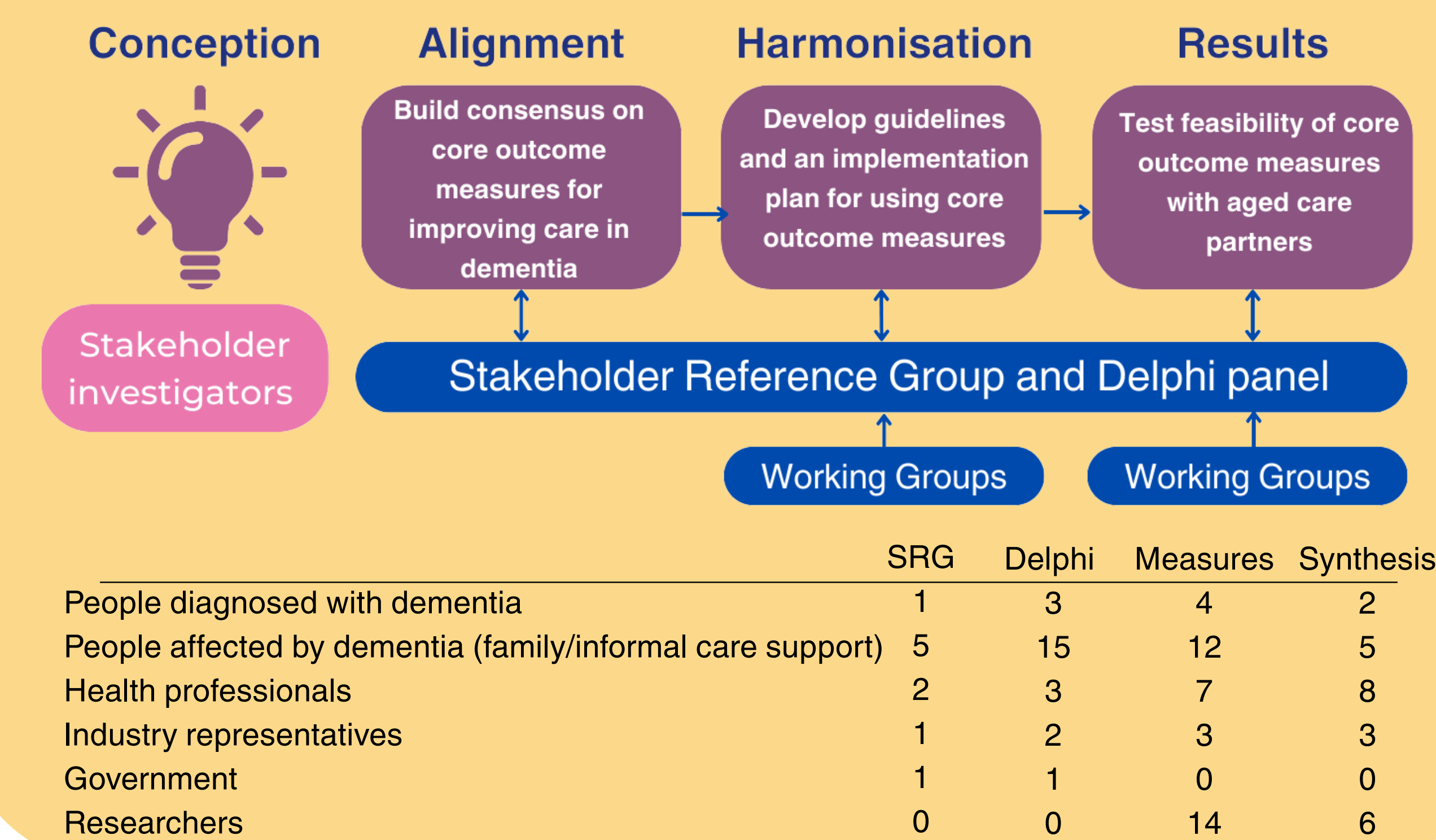
Purpose

The Core Outcome Measures for Improving Care (COM-IC) project used co-design methods to deliver practical recommendations for the selection and implementation of a suite of core outcome measures that can be collected during routine care and used to evaluate the effectiveness of interventions.

These recommendations were developed with and for people living with dementia, their families and carers, aged care providers, researchers and aged care staff.

Methods

SRG and panel members collaborated using synchronous (videoconferencing) and asynchronous (Loomio, email) methods to meet the varying time commitments and communication needs of members.



Co-design

The COM-IC project was a co-designed program of research, informed by the Stakeholder Reference Group (SRG) using Participatory Action Research (PAR) methodology. The COM-IC SRG was established in two parts, the representative SRG and associate SRG. The representative SRG was established through a recruitment process, including advertisement through dementia support networks, selection and screening of appropriate candidates and offer of appointment. This group worked with investigators for the duration of the research program. The associate SRG were recruited for specific research activities, combining efforts with investigators and representative SRG to expand the breadth of experience and knowledge considered in the generation of the core outcome set.

“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.”

Quote from SRG member

RECOMMENDATIONS

Recommendation 1: Core Outcome Measures

Core outcome measures that should be implemented by all service providers

Outcome	Setting	Measure
Dignity	Home and Residential	QCE-ACC
Hygiene	Home	Barthel Index
Pain	Residential	PainAD
Meaningful activities	Residential	EMAS

Recommendation 2: Core Outcomes without suitable measures

Further research is required to develop and validate appropriate measurement instruments for the outcomes highlighted by stakeholders as be core to quality care provision

Outcome	Setting	Measures*
Diagnosis of dementia	Home	MoCA
Feeling safe & secure	Home	NPSS
Quality of life	Home and Residential	QOL-AD
Dementia qualifications	Home and Residential	DKAS
Hygiene and comfort	Residential	COMFORT
Emotional wellbeing	Residential	WHO-5
Adverse events	Residential	No measure

* measure considered but not accepted by stakeholders

Recommendation 3: Extended measures

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.

Outcome	Setting	Measures
Behavioural symptoms of dementia	Home	NPI
Meaningful activities	Home	EMAS
Family/carer QoL	Home	ZBI
Neuropsychiatric symptoms of dementia	Residential	NPI
Staff/carer morale	Residential	MAGPI

Recommendation 4: Additional outcomes of care

Core outcome measures for improving care for people experiencing dementia in home care and residential aged care should be reviewed periodically for relevance & currency.

Outcome	Setting	Measures*
Advance care planning	Home and Residential	ACP Survey
Resource utilisation	Home and Residential	RUD-LITE
Safety incidents	Home and Residential	No measure
Opportunities for unpaid carers	Home	No measure
Importance of relationships	Home	CARE
Emotional wellbeing	Home	WHO-5
Dementia care navigation pathway	Home	No measure
Feeling safe and secure	Residential	NPSS
Medication appropriateness	Residential	STOPP-START

Recommendation 5: Maintain currency of measures

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.

Outcome selection

- A modified Delphi process designed by stakeholders was used to develop consensus over four rounds.
- Discussions between survey rounds were used to share perspectives, knowledge and resources between panel members and to collectively determine the focus of the next survey.
- These discussions and survey co-design ensured the outcomes selected were a reflection of what is meaningful and relevant to people impacted by dementia.
- The panel reviewed and discussed over 100 outcomes across 7 domains of care over eight months, resulting in the 32 outcomes included in the core outcome set recommendations.

	Round 1	Round 2	Round 3	Round 4
People diagnosed with dementia	1	3	2	2
People affected by dementia (family/informal care support)	5	15	11	8
Health professionals	2	3	3	3
Industry representatives	1	2	1	1
Government	1	1	1	0

Measure selection

- Working groups comprising investigators, the stakeholder reference group and Delphi panellists independently identified the best available measures for the selected outcomes.
- Working groups used the NHS criteria of clarity, timeliness, validity, reliability, ease of collection and value add to classify the suitability of measures.
- Working group findings were presented to the larger team, who then voted on whether the measure was suitable and feasible for use in routine settings where care is provided to people living with dementia.

Future Research

Policy	Immediate implementation of core outcomes for routine care
Practice	Incorporation and standardisation of best practice measurement instruments to evaluate quality of care provided to people living with dementia
Research	Determine and or develop appropriate measures for outcomes important to people impacted by dementia
Everyone	Commitment to evaluation and revision of best-practice outcome measurement relevant to people living with dementia

“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.”

Quote from SRG member