





A review of recommended outcomes and measurement tools within Core Outcome Sets (COS) developed for dementia

Anna Kearney^{1*}, Hanh Dao², Paula R Williamson¹, Susanna Dodd¹ ¹ Dept. of Health Data Science, University of Liverpool. ² University of Queensland. *Author ^Presenting Author

Background

A core outcome set (COS) is a minimum set of health outcomes to be measured for a given condition. COS can be developed for specific populations, interventions, or settings, so several COS may exist for a condition e.g., dementia.

COS are regularly identified and collated in the COMET initiative database which is a free, online, searchable resource aimed at helping people looking to develop or implement core outcome sets.

As of June 2023 there are 769 published COS on the COMET database. However, this doesn't guarantee that a set will be available for use with a particular population or intervention.

The development of well-designed COS takes time and resources. Where multiple COS exist, a review of previously recommended outcomes and measurement tools could be used as a method for creating a new COS.

AIM: To review existing core outcome sets for dementia and to assess the overlap in outcomes and measurement instruments recommended within them

Methods

Design: Review of published COS for use in dementia

Identification of studies: COS developed for people living with any type of dementia were identified through the COMET database by searching for COS categorised within 'Neurological conditions'. Searches were undertaken on the 14th Nov 2022. Hand searches of references within eligible papers were also undertaken.

Inclusion / exclusion criteria: All COS developed for use in dementia, Alzheimer's disease and Mild Cognitive Impairment were included with no limitations on interventions or setting. Quality Indicators were excluded.

Data extraction: COS scope (population, intervention), stakeholders and COS development methods, and the outcomes and tools recommended within each COS.

Quality Assessment: Quality of the COS development was assessed using COS-STAD guidance² although it is noted that many of the COS were developed before the guidance was published. Therefore informal quality measures such as the inclusion of patient stakeholders (patients, carers or patient organisations) were given particular emphasis.

Analysis: Recommended outcomes were classified against COMET's outcome taxonomy³. Where needed classification considered any recommended tools to understand the focus of the outcome itself. Any classification queries were resolved through discussion with clinical teams working in dementia care. Measurement tools were then grouped by outcome across COS.





for Improving Care

COM-IC is developing a set of outcome measures for dementia services in Australia.

Want to join a working group for the next stages of COM-IC?

Contact us for more information

com-ic.study@uq.edu.au https://chsr.centre.uq.edu.au/com-ic

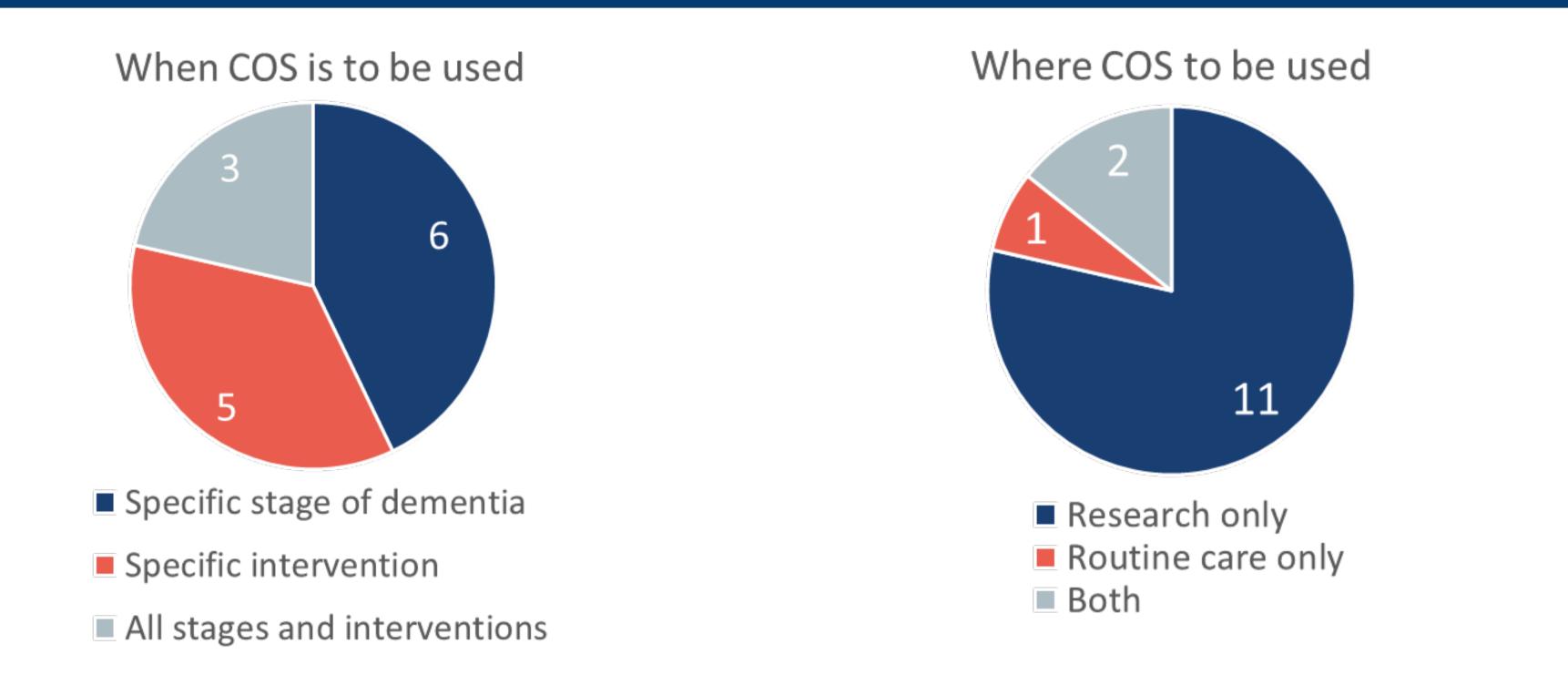
¹https://www.comet-initiative.org/

²Kirkham JJ et al. (2017) Core Outcome Set-STAndards for Development: The COS-STAD recommendations. PLoS Med 14(11): e1002447. Dodd S et al. A taxonomy has been developed for outcomes in medical research to help improve knowledge discovery. J Clin Epidemiol. 2018;96:84-92.

Results

14 COS for dementia were identified from 10 papers

SCOPE: Most COS were for use in research. Several specified a stage of dementia or intervention.





Outcome Area	Outcome Domain	Katona 2007	Moniz-Cook 2008	Vellas 2008a	Vellas 2008c	Vellas 2008c	Vellas 2008d	Vellas 2008e	JPND 2015	Webster 2017	Reynish 2017	Nelson 2018	McGrattan 2019	Reilly 2020	Goncalves 2020	
Death	Mortality/survival										1					1
Physiological/ clinical*	Eye													1		1
	Injury and poisoning										1		1			2
	Nervous system									1						1
	Psychiatric		1					1	1		1	1	1			6
Life Impact (Functioning)	Physical functioning	1	1	1	1	1	1	1	1		1	1		3	4	17
	Social functioning										1			2		3
	Role functioning															
	Emotional functioning		1						1					4	3	9
	Cognitive functioning	1	1	1	1	2	2	2		1	2	1		3		17
Other life Impact	Global quality of life		1						2		1	1	1			6
	Perceived health status															
	Delivery of care							1					2			3
	Personal circumstances															
Resource use	Economic	1							1							2
	Hospital							1			1					2
	Need for further intervention															
	Societal/carer burden		4					2	5		2	1				14
Adverse event	Adverse events/effects	1											2			3
TOTAL OUTCOMES		4	9	2	2	3 ^b	3	8	11	2	11	5	7	13	7	87

*Only physiological outcome domains recommended within COS have been included here due to space. The full list of domains is listed in the taxonomy³

QUALITY: Half the COS included people with dementia in the development process COS-STAD score 7 atona 2001 Cook 2008 18 2008 18 2008 18 2008 18 2008 18 2008 18 18 2008 18 18 2015 18 18 2011 18 2011 18 2012 18 18 2019 18 COS for dementia (First author and year) Only included professional / clini-Included representatives from chari-Included PwD as well as people from charities and carers ties as well as carers but not PwD

TOOLS: 8/14 (57%) of COS included measurement tools for the recommended outcomes. There was little overlap of tools across COS

Cognitive functioning	Physical functioning	Societal/ Carer burden	Emotional functioning	Global QOL
ADAS-COG	ADCS-ADL	EQ-5D	CSDD	DQOL
CDR	ADCS-ADL-SEV	GHQ- 12 or 28	GDS-15	EQ-5D
CDR-SOB	ADFACS	HADS		QOL-AD
CIBIC_PLUS	AMPS	MBI		QUALIDEM
GBS	BADLS	NPI (carer distress)		QWVB-SA
MMSE	LAWTON-PSMS-IADL	NPI-NH		
MoCA		RMPBC (carer reac-	Psychiatric	Other
SIB		tion)	CMAI	Serial structural MRI
		SCQ27/ SSCQ7	NPI	
		WHQOL_BREF	NPI-NH	
		ZBI	RMPBC	
			SIB	

Conclusions

Assessing the commonality of outcomes recommended across multiple COS provides further evidence of which outcomes are likely to be most important to stakeholders. Physical and cognitive functioning outcomes were common to most COS. Other frequently recommended outcome domains included societal / care burden, global quality of life and psychiatric (including behavioural) outcomes. This data will be used by a COM-IC stakeholder panel along with data on outcomes used in registries and industry in order to create a new COS for use with dementia care services in Australia. Given there was little commonality across measurement instruments updated assessments of existing and new tools is warranted when selecting instruments for the COM-IC COS outcomes.



Email: a.kearney@liverpool.ac.uk

Funding: COM-IC is funded by MRFF. This work also forms part of a PhD studentship for Anna Kearney which is funded by the National Institute for Health and Care Research Applied Research Collaboration. tion North West Coast (ARC NWC). The views expressed in this publication are those of the author(s) and not necessarily those of the National Institute for Health and Care Research or the Department of Health and Social Care.