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## Recent findings: Dementia Outcomes Measurement Suite

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## Recent findings: Dementia Outcomes Measurement Suite

### Abstract

#### Project Aims

- Develop a set of recommended measures for routine use in the assessment, diagnosis, screening and outcomes monitoring of dementia conditions and the evaluation of treatments that are applicable for the Australian health care context.
- Standardise the assessment and evaluation procedures used in this field to enhance comparability of findings across research and practice settings.
- Make recommendations concerning the clarification and standardization of the clinical terminology applicable in this field.

### Keywords

recent, suite, findings, dementia, outcomes, measurement

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An Australian Government Initiative

## Recent Findings: Dementia Outcomes Measurement Suite

Jan Sansoni, Nick Marosszeky,  
Emily Sansoni



### Project Aims

- Develop a set of recommended measures for routine use in the assessment, diagnosis, screening and outcomes monitoring of **dementia conditions** and the evaluation of treatments that are applicable for the Australian health care context.
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- Make recommendations concerning the clarification and standardization of the clinical terminology applicable in this field.

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## Project Team: Principal Investigators

- Ms Jan Sansoni (Project Manager)
- Assoc Prof Marc Budge (Senior Clinical Advisor)
- Prof Lynn Chenoweth (clinical, dementia, BPSD and cognitive)
- A/Prof Graeme Hawthorne (utility, social isolation, patient & carer satisfaction)
- Dr Madeleine King (HRQOL, cognitive, BPSD)
- Dr Yun-Hee Jeon (clinical, dementia, BPSD and cognitive)
- Mr Nick Marosszeky (all – function, CALD, Proxy)
- Associate investigators (e.g. Kate Senior: Indigenous)

Advised by National Expert Group for Dementia

Advised by Expert Measurement Group

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## Review Processes

- Initial overall literature search (MEDLINE, PsycINFO) on 20 terms (e.g. dementia, cognition, memory, function, Qol etc)
- Examined major texts in the field (e.g. psychometric review texts, Burns, Kane & Kane, Lezak, McKeith etc)
- Identified list of instrument categories and names and then searched on these names
- Developed database with comparative data for instruments in each category
- Developed CD containing papers and abstracts for each category of instruments

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## Review Processes

- Developed an impact sheet for the EMG and the review team – Medline, text and web impacts, presence in instrument databases, use in clinical practice (based on field surveys, NEP and clinical feedback)
- Identified a shortlist of about 12 leading contender instruments for each category
- Categories: global dementia, cognitive, associated symptoms (e.g. BPSD; delirium; individual symptoms e.g. apathy), function, HRQOL, MAU, social isolation, patient and carer satisfaction)

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## Review Processes (Cont.)

- Applied additional criteria to reduce to 5-6 instruments per category
- Produced decision summary sheet justifying selection or non selection of contenders for the short list
- Undertook more extensive searches for short-listed instruments e.g. other databases –CINAHL, Cochrane etc and commenced review

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### **Additional Selection Criteria**

- Whether there is a copy of the instrument and the original article available for review
- The number of citations found (save new instruments)
- The amount and range of the published psychometric evidence
- Whether the instrument used in clinical practice (searches; surveys) & applicability to Australian context
- Availability of normative and clinical reference data

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### **Additional Selection Criteria**

- Administration time (< 30 minutes and shorter preferred)
- Applicability for patients / clients with varying levels of severity of dementia.
- Proprietary considerations (e.g. prohibitive cost)
- Applicability for use in routine care – does not require specialist skills for administration (e.g. as for many neuropsychological/medical assessments)

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## AHOC Review Sheet

- Author, publication information, availability
- Cost
- Training requirements
- Purpose & who developed for
- Administration time
- Structure
- Scoring
- Applications, normative and clinical reference data
- Psychometric criteria – reliability, validity, responsiveness
- Cultural applicability and cultural adaptations
- Gender and age appropriateness

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## Review of Instruments

With all instruments we considered

- Type and stages of dementia
- Purpose of instrument (assessment, screening, outcomes monitoring and evaluation of interventions)
- Self-reporting and proxy reporting
- Respondent and staff burden
- Appropriateness for CALD and indigenous groups
- Appropriateness for setting (e.g. acute, primary and community care, residential care, specialist, and research)

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## Instrument Scores and Weights

- Availability of comparison data (3)
- Length/feasibility (2)
- Complexity of administration /cognitive burden (3)
- Ease of obtaining score (2)
- Cultural Appropriateness (1)
- Sensitivity to dementia (3)
- Reliability evidence (3)
- Validity evidence (3)
- Cost of instrument (2)
- Cost of instrument administration (2)

Scores: generally 1=poor, 2= moderate 3=good – refer to detail in the paper

Multiply the score by the weight and then sum to get a total instrument score

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## Example: Cognitive Contenders

- 93 instruments identified
- Abbreviated Mental Test, Addenbrookes, ADAS, Blessed IMC Test, Cambridge Cog, Cambridge Mental Disorders, Cog. Capacity Screen, Cog. Abilities Screen, Clock Drawing, Geriatric Mental State, GP Cog, Informant Q on Cog, KICA-Cog, Mattis DRS, Mini Cog MMSE, Memory Impairment Screen, Mental Status Q, RUDAS, and Short Portable Mental amongst contenders
- Proprietary issues some instruments – e.g. some forms of MMSE
- Excluded neuropsychological specialist instruments (focus on routine care)

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## Recommendations: Cognitive

- The instrument with the highest scores were the **MMSE-3MS** and the **ADAS-Cog**
- 3MS was selected from the MMSE family for routine settings; better psychometrics and less proprietary issues
- ADAS-Cog may be preferred if more in depth assessment required (e.g. clinical research)
- **GP-Cog** most appropriate for primary care
- **MDS-Cog** can also be considered for residential care settings
- **RUDAS** (Interim) for CALD and the **Kimberley Indigenous Cognitive Assessment** (Interim) for indigenous groups

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<b>Cognitive Assessment</b>	<b>W</b>	<b>MMSE 3MS</b>	<b>ADAS COG</b>	<b>GPCOG</b>	<b>RUDAS</b>	<b>MDS COG</b>	<b>KICA COG</b>
Avail. comparison data	<b>3</b>	3	2	1	1	1	1
Length	<b>2</b>	2	1	3	3	3	2
Complex. admin	<b>2</b>	2	2	3	2	3	2
Cultural app.	<b>1</b>	2	3	1	3	1	3
Ease: scoring	<b>2</b>	3	3	3	3	3	3
Sensitivity Dementia	<b>3</b>	3	3	2	2	2	2
Reliability	<b>3</b>	3	3	3	3	2	2
Validity	<b>3</b>	3	3	3	3	3	1.5
Cost	<b>2</b>	3	3	3	1	2	3
Cost of admin	<b>2</b>	2	1	1	2	2	2
<b>Weighted Total</b>		<b>62</b>	<b>56</b>	<b>54</b>	<b>52</b>	<b>51</b>	<b>46.5</b>

## Example: Dementia-HRQOL

- Seven leading dementia – HRQOL contenders identified
- QOL-AD, QAULID, DEMQOL were chosen for in depth review. Proxy versions were also available. (DQOL a runner up)
- Preferred instruments were the QOL-AD and the DEMQOL for mild to moderate dementia and the QUALID for late stage dementia
- Australian reference data required for all instruments

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HRQOL Dementia	W	QOL -AD	DEM QOL	QUALID	DQOL	CBS	ADR QOL
Avail. comparison data	3	2	2	2	2	1	2
Length	2	3	2	3	2	2	1
Complex. admin	2	3	3	3	3	3	3
Cultural app.	1	2	1	2	1	1	2
Ease: scoring	2	2	2	2	2	2	1
Sensitivity Dementia	3	3	3	2	2	2	2
Reliability	3	3	3	3	3	3	3
Validity	3	3	3	3	3	3	3
Cost	2	3	2	2	2	3	1
Cost of admin.	2	2	2	2	2	1	2
<b>Weighted Total</b>		<b>61</b>	<b>56</b>	<b>56</b>	<b>53</b>	<b>50</b>	<b>48</b>

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## Some Other Recommendations

- **Dementia Assessment** - Global Deterioration Scale (GDS) / Clinical Dementia Rating Scale (CDR)
- **BPSD Global** – Neuropsychiatric Inventory (NPI)
- **Delirium** – Confusion Assessment Method (CAM)
- **Individual Symptoms**
  - Rating Scale for Aggression in the Elderly (RAGE)
  - Cohen Mansfield Agitation Inventory (CMAI) and Pittsburgh Agitation Inventory (PAI)
  - Rating Anxiety in Dementia (RAID)
  - Apathy Evaluation Scale (AES)
  - Cornell Scale for Depression in Dementia (CSDD) and Geriatric Depression Scale (GDS) – the latter for community settings

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## Some Other Recommendations (Cont.)

- **Function Generic:** FIM, Barthel, OARS-IADL, **Function Dementia:** Alzheimer's Disease Cooperative Study-ADL, Disability Assessment for Dementia (proxies), Cleveland Scale-ADL (observation)
- **Social Isolation** – De Jong Gieveland Loneliness Scale (requires adaptation)
- **MAU** – EQ-5D, AQoL (require adaptation)
- **Patient & Carer Satisfaction** – Short Assessment of Patient Satisfaction (SAPS), Satisfaction with Care at the End of Life in Dementia Scale

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## Some Identified Research Gaps

- Some measures need pilot testing in Australia to obtain reference data (e.g. HRQOL)
- Some of the newer measures (GPCOG, RUDAS, KICA-COG, SAPS) need further psychometric data
- Need further research to assess the point at which people can no longer self-rate (e.g. MMSE score) under different modes of administration (e.g. self report, interview, interview assisted) for each instrument
- Need for further research to streamline measures of function

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## Some Identified Research Gaps

- Social function / social support areas may need follow up research if we wish to focus on more than social isolation
- Further research required to address identified problems with Multi-attribute Utility measures: AQoL (shorten) and/or EQ-5D (scoring and distribution issues)
- Carer satisfaction is addressed in this project but not other informal care measures – this will require a follow up project
- CALD and ATSI applicability of instruments needs further research

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## Implementation Issues

- Recommending or mandating
- Guide to the use of recommended instruments with regard to stages of assessment and settings for assessment
- Training Issues – audit curricula, develop certified modules
- A Dissemination Strategy (e.g. toolkit, brochures, workshops, videos, papers, web-site etc) and
- Identified a range of research gaps

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## Report Details

- Citation:  
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- *Report available shortly*  
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