

## **SYNOPSIS: Dementia Outcomes Measurement Suite (DOMS) Report**

*(The DOMS Report was provided to the Department of Health & Ageing in October 2007)*

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### ***Project Aim and Description***

The purpose of this project is to develop a set of recommended instruments/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. By developing a set of recommended measures it is hoped to standardise the assessment and evaluation procedures used in this field to enhance comparability of findings across research and practice settings.

A related aim is to make recommendations concerning the clarification and standardization of the clinical terminology applicable in this field. To enhance comparisons between studies it is important that standardized approaches to diagnosis and patient classification be undertaken. The recommendations of Section 3 of the Final Report can be found in **Attachment A** (Recommendations Concerning Classification and Clinical Terminology).

The Executive Summary of the DOMS Report further outlines the particular focus of the report and outlines the limitations to the project scope.

The project was managed by Jan Sansoni of the University of Wollongong, the leading clinical advisor was Associate Professor Marc Budge and the project team included a range of experts from across Australia (refer citation above). This project has been advised by two expert groups – the National Expert Panel (DOMS-NEP) and the Expert Measurement Group (DOMS-EMG). The National Expert Panel contains representatives from key dementia groups across Australia. The Expert Measurement Group consists of members of the project team with acknowledged expertise in the area of psychological measurement. The terms of reference and the membership of these groups can be found in Appendices 1 and 2 of the Final Report.

### ***Methodology***

Details of the methodology used to determine the recommended instruments are outlined in **Attachment B** (Methods of Instrument Review).

### ***The Recommended Measures***

**Attachment C** contains a matrix showing the appropriate application of each of the 36 recommended measures for different service settings and for different stages of dementia. Sections 4 – 11 of the DOMS Report provide summaries and recommendations for the instrument categories reviewed to date. The following are details of the recommended measures which are summarised in **Attachment C**.

### ***Dementia Specific Assessment Measures***

Five instruments were selected for comprehensive review in this class. The highest rated instrument was the Global Deterioration Scale (GDS) followed by the Clinical Dementia Rating (CDR). Both these instruments provide a rating of the severity of dementia although the GDS is somewhat easier to use than the CDR scale and is coupled with a much shorter administration time. The GDS can also be administered by care staff as well as clinicians. The GDS is also related to the Functional Assessment Staging (FAST) instrument.

- It is recommended that the GDS would be more appropriate for use as an initial assessment instrument and the CDR might be more appropriate where a more comprehensive assessment is required. However, both instruments have good psychometric properties and are appropriate for use in both clinical and research settings for both assessment and outcomes evaluation.
- The Dementia Severity Rating Scale (DSRS) also performed quite well but this is a rating scale for use by the caregiver rather than a clinical rating scale per se. It is, however, often used by care staff. This scale would be recommended for use in community/residential settings and where information needs to be obtained from the caregiver.

Burns et al (2004) indicates these instruments are widely used as staging measures in descriptive and intervention studies. It is noted that specialist clinicians are less likely to use these global staging instruments than other clinical or research personnel. Such instruments may not be particularly useful for fine differentiation at an early stage of dementia. However, global functional scales like the GDS and the CDR have their place in broadly describing people with dementia; particularly for research purposes and in residential care and community care settings.

## **Health Related Quality of Life and Health Status Measures**

Health related quality of life and health status instruments may be generic or disease-specific. A generic instrument can be used for comparisons across diseases and health conditions. In contrast, disease or condition specific health related quality of life instruments focus on those aspects of health (e.g. symptoms) and health related quality of life that are relevant to a particular health condition such as cancer or heart disease. Dementia-specific examples include the Quality of Life in Alzheimer's disease scale (QOL-AD) or the DEMQOL.

With regard to the assessment of health related quality of life of those experiencing dementia there are significant limitations concerning the use of generic health related quality of life scales with people with dementia. Section 5 of the DOMS report provides a more detailed discussion of the generic health related quality of life measures and no generic health related quality of life instrument is recommended for use with people with dementia. At the present time the dementia specific quality of life instruments, would seem more appropriate measures to use with people with dementia.

## **Dementia Specific Health Related Quality of Life Instruments**

Six leading dementia-specific HRQOL instruments were identified. After considering the key attributes of the instruments, and the evidence about their psychometric properties, the following recommendations were made:

- Three instruments are recommended for the assessment of HRQOL in dementia; the QOL-AD and the DEMQOL for mild to moderate dementia and the Quality of Life in Late Stage Dementia Scale (QUALID) for late stage dementia only.
- It is recommended that such data be collected in an Australian field test of these instruments

## **Instruments for the Assessment of Cognitive Status**

After consideration of a large number of contender instruments, five instruments were selected for comprehensive review. These instruments were selected because they covered a range of settings including primary care and residential care settings.

- The Modified Mini Mental State Exam (3MS) is recommended as a widely used instrument that assesses global cognitive status in older people. It is applicable in both community and institutional settings. It has superior psychometric properties and has been extensively used in large scale epidemiological studies internationally (mostly North American studies). There is also extensive normative and clinical data available.
- The Alzheimer's Disease Assessment Scale - Cognition (ADAS-Cog) is recommended for second stage or more detailed assessments and/or for particular research evaluations rather than for applications in routine care settings. However, ADAS-Cog administration requires staff with specialist qualifications, its use requires additional training and it takes 30-45 minutes to complete the assessment.
- The General Practitioner Cognition Scale (GPCOG) is recommended because of its usefulness in the primary care setting. Although it is a relatively new instrument, and has not been widely used in research studies, it has scored well on the psychometric criteria.
- The Minimum Data Set - Cognition (MDS-COG) is recommended, despite having the lowest ranking total. It was felt it was important to include a cognitive rating scale that would be useful in the residential care setting. The strength of this instrument is that it enables evidence about the cognitive status of patients to be obtained without any extra effort on the part of staff. The information is routinely entered as the patient enters long term care.
- The Rowland Universal Dementia Assessment Scale (RUDAS) is a new instrument that was designed to enable the easy translation of the items into other languages and to be culture fair. There are relatively few papers published as yet concerning its psychometric properties but in the interim it is recommended for use with those from culturally and linguistically diverse backgrounds. The RUDAS, however, contains an item on judgement that may be inappropriate for remote Indigenous people (refer below).

An interim recommendation is to use the Kimberley Indigenous Cognitive Assessment (KICA-Cog) tool for the cognitive assessment of rural and remote Indigenous people. The KICA-Cog is a new instrument and although there is little published evidence concerning this tool available as yet, and further research is required, this instrument has been designed for use with Indigenous people.

### **Multi-attribute Utility Measures**

Multi-attribute utility measures are health related quality of life instruments that are designed for economic evaluations of health care interventions particularly when using cost utility analysis. As indicated in Section 7 there are major difficulties in using self reported multi-attribute utility instruments with patients experiencing moderate to severe dementia. However, on the other hand it is generally preferred to use patient assessments rather than those of proxies, as evidence indicates these assessments can differ widely.

The three instruments that score most highly on these criteria are the European Quality of Life Measure (EQ-5D), the Assessment of Quality of Life (AQoL) and the Health Utilities Index-3 (HUI-3). However both the HUI-3 and the AQoL are lengthier instruments which may place considerable cognitive burden on people with dementia.

- It is recommended that the EQ-5D, the AQoL and the HUI-3 are to be the preferred instruments when undertaking economic evaluation of dementia interventions.

The EQ-5D might be preferred because of the simplicity of its' descriptive system. There are, however, very good technical reasons which provide caveats to its widespread use, including competing scoring algorithms, ceiling effects, inconsistent utility scores and poor score distribution.

- It is recommended that an Australian study be undertaken into these aspects of the EQ-5D with a view to validate and/or revise existing EQ-5D scoring algorithms.

Based on the evaluation criteria, the next best-performing MAU-instrument was the AQoL. Although the AQoL's descriptive system is simple, the wording of items is stilted. The AQoL is a longer instrument (12-items) which may explain higher rates of missing data when compared with the EQ-5D, and inconsistent scores for those with severe cognitive impairment. It is recommended that a study be undertaken to examine the effect of simplifying the AQoL items and removing four items to make it more appropriate for use in dementia research.

### **Measures of Social Isolation and Participation**

Fifteen instruments were initially identified (refer Section 8). Following further consideration of their psychometric properties and applicability to dementia, seven instruments were selected for a more detailed examination.

Given the discussion in Section 8, none of the reviewed instruments can be given an unqualified recommendation for use in Australian studies with older adults who have cognitive impairment or dementia. Subject to this finding, the standout instrument was the De Jong Gierveld Loneliness Scale. The reasons were that it was carefully conceived over a very substantial period of time, that it was developed in population samples (including older adults), and that there is a very substantial body of evidence supporting its reliability and validity. The reason the scale, especially the short 6-item version, cannot be recommended outright is that the response categories may be inappropriate for use in Australian samples of people with cognitive impairment. However, a study can easily be completed to undertake a linguistic validation of the De Jong Gierveld Loneliness Scale instrument for Australian use.

### **Measures of the Associated Symptoms of Dementia**

Associated symptoms of dementia relate to characteristics of dementia that are not historically considered as such major features as cognitive impairment and related functional consequences, yet have a significant impact on the well-being of the persons with dementia and their family and caregivers. Measuring outcomes of care, service, treatment and interventions related to the associated symptoms of dementia is an important aspect. For the purpose of the DOMS project, the assessment of associated symptoms of dementia comprises:

1. Measures of global behavioural and psychological symptoms of dementia (BPSD Global, henceforward);
2. Measures of delirium, which is one of the two most frequently mistaken features requiring differential diagnosis from dementia (the other commonly mistaken feature is depression); and
3. Measures of particular symptoms of BPSD including aggression, agitation, anxiety, apathy, and depression.

### 1. Recommendations Concerning BPSD Global Instruments

A number of global measures of behavioural and psychological disturbance (Global BPSD) have been reviewed. The examination of key attributes and psychometric properties of the five final instruments measured against the weighting criteria indicates the Neuropsychiatric Inventory (NPI) and the Behavioural Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD) as the best measures for assessment of BPSD, followed by the Consortium to Establish a Registry for Alzheimer's Disease – Behaviour Rating Scale for Dementia (CERAD-BRSD), the Dementia Behaviour Disturbance Scale (DBDS) and the Neurological Rating Scale (NRS). Based on these reviews it is recommended that:

- The NPI and the BEHAVE-AD be used in both clinical and research settings for assessment of Global BPSD. These instruments both have well established psychometric properties.
- The CERAD-BRSD is recommended for research rather than routine practice given its cost and the time required for its administration. A 17 item abbreviated version may be considered better for clinical utility, but limited evidence on this version is currently available.

### 2. Recommendations Concerning Measures of Delirium

- It is recommended that the Confusion Assessment Method is used to assess the presence of delirium across most service settings.
- It is recommended that the Delirium Rating Scale (DRS-R-98) is used where a more comprehensive assessment of both the presence and severity of delirium are required. It is noted this instrument is not appropriate for use in community settings.

### 3. Recommendations Concerning Measures of Particular Symptoms of BPSD

In many cases the use of Global BPSD measures such as the NPI may suffice for the assessment of the associated symptoms of dementia. A full discussion of these measures and their assessment can be found in Section 9 and Appendix 10 of this report. It is recommended that the following instruments are used if a more detailed assessment of a particular symptom is required:

Aggression:	Rating Scale for Aggressive Behaviour in the Elderly (RAGE)
Agitation:	Cohen Mansfield Agitation Inventory (CMAI); Pittsburgh Agitation Scale (PAS)
Anxiety:	Rating Anxiety in Dementia (RAID)
Apathy:	Apathy Evaluation Scale (AES)
Depression:	Cornell Scale for Depression in Dementia (CSDD) Geriatric Depression Scale (GDS Yesavage) – for less severe cases and in community settings

### Measures of Function

The Functional Independence Measure (FIM), the Barthel Index and the Lawton and Brody IADL and the Older Americans Resources and Services (OARS-IADL) instruments were chosen as generic measures of ADL and IADL respectively. These instruments have good psychometric properties and have been used in geriatric settings.

- The Functional Independence Measure (FIM) and the Barthel Index are recommended as the generic measures of ADL.
- The Lawton and Brody IADL and the Older Americans Resources and Services (OARS-IADL) are recommended as generic instruments for the assessment of instrumental activities of daily living (IADL). The OARS-ADL is preferred as it is an advance on the Lawton and Brody IADL scale with improved psychometric properties and less reliance on gender role stereotypes; and it has been adapted for use in primary and community care settings in Australia (see Green, et al. 2006).

The recommended dementia specific instruments for the assessment of function (ADL and IADL) for people with dementia include both proxy measures and clinical rating scales. While it is acknowledged that proxy reports have their limitations (refer Section 12.3), they will generally be used where assessment by interview or self rating is no longer possible due to the degree of cognitive impairment of the person with dementia. Proxy measures are also useful in primary and community care settings in order to monitor the maintenance of functional status or its decline, in conjunction with drug therapy or in terms of care management as the disease progresses. The direct observation rating scale may be more appropriate for acute care and residential care settings.

- The Alzheimer's Disease Co-operative Study – ADL (ADCS-ADL) and Disability Assessment for Dementia Scale (DAD) are the two proxy report instruments that are recommended.
- For the direct observation of functioning the Cleveland Scale for Activities of Daily Living (CSADL) is recommended.

The discussion of measures of functional status in Section 10 highlights a number of measurement problems with regard to the assessment of function with people with dementia. It is clear there is an urgent need for a program of research and development in this area. It is recommended that in the absence of a research consensus for the measurement of function in dementia, and given a high degree of overlap in items, there is a clear need for a streamlining of the various functional instruments and items across each of the practice settings (Spector, 1997).

## **Measures of Patient and Carer Satisfaction**

### **Patient Satisfaction**

The two standout instruments were the Short Assessment of Patient Satisfaction (SAPS) and the Consultation Satisfaction Questionnaire (Consult SQ). None of the other patient satisfaction instruments reviewed could be considered truly satisfactory. Given the above considerations the following recommendations are made:

- It is recommended that a study be undertaken to test and validate the SAPS, the Consult SQ and the two single patient satisfaction items identified with samples of people with dementia and their carers. It is noted that all these items would also require minor rewording to make them suitable for use with an informant/carer.
- That a single item patient satisfaction measure should be adopted for use in Australian settings by clinicians wishing to assess the satisfaction of their patients 'on the spot'. Strategies should be put in place to encourage clinicians to adopt this measure as a common metric across Australia.
- Until the recommended research is implemented and the results published, it is recommended that the SAPS be used.

### **Carer Satisfaction with Services**

Carer satisfaction is addressed by the literature in a number of ways. There are studies that examine: a) carer experience with the caring role (including carer burden); b) carer satisfaction with services and c) carer health and well-being. This project focuses on the examination of carer satisfaction with services and specifically excludes an examination of instruments used to assess carer burden.

Given the findings of the review in Section 11.2 none of the reviewed instruments can be given an unqualified recommendation for use in Australian studies with carers of older adults who have cognitive impairment or dementia. The following recommendations are made:

- The most promising instrument appears to be the SWC-EOLD (Volicer, et al. 2001), and it is recommended that this instrument is used in an Australian study specifically designed to test its measurement properties.
- The alternative would be to mount a specific carer satisfaction study, where all items from all reviewed instruments were pooled and tested. The explicit purpose would be identifying well performing items and/or the best performing instrument.
- It is recommended that a more detailed follow up project be undertaken to examine issues relating to the assessment of instruments used to assess carer burden, carer appraisal and carer wellbeing.

## **Measurement Issues**

Some key measurement issues relevant to the use of these measures with people with dementia and their carers are outlined (see page 27 of the DOMS Report). The first of these is the issue of the use of proxies (formal and informal carers) for the assessment of the person with dementia. People with severe dementia may not be able to be assessed directly and may be unable to provide a self report where this may be required. This is followed by a discussion of the level of cognitive impairment at which people with dementia may lose the capacity to self rate. Importantly, many carers of those with dementia may suffer mild cognitive impairment themselves. These issues are most important to consider when assessing subjective phenomena from both care recipients and carers, such as health related quality of life, social isolation or satisfaction with services.

The applicability of these measures for particular population groups is also discussed. The issue of the applicability of the measures for those from culturally and linguistically diverse (CALD) populations is considered, as is the applicability of these measures for use with Aboriginal and Torres Strait Islander people. A number of key recommendations pertaining to these issues are outlined in the DOMS Report.

### **Implementation Issues**

Although issues pertaining to implementation have been discussed throughout the DOMS Report, and particularly in Section 12.6, a number of key areas to address are identified. These are:

- The issue of mandating the recommended measures
- The application of the instruments in different settings and for different stages of dementia
- Stages of assessment
- Training issues
- A dissemination strategy
- Identified research gaps

With regard to a discussion of the issue of mandating the recommended measures the reader is referred to Section 12.6.2 of this report. Advice received from the Department of Health and Ageing in August 2006 indicated there was no desire to mandate the recommended instruments at this stage.

Section 12.6.3 provides a discussion of the appropriate application of each of the recommended measures for different service settings and for different stages of dementia. Readers are also referred to Attachment 1. This is supplemented by a discussion of a staged approach to assessment in Section 12.6.4, and the potential for tiered assessment is also outlined.

A dissemination strategy, to facilitate the adoption of the recommended instruments has been outlined in Section 12.6.6. This could include the development of an instrument toolkit, presentations at conferences, training workshops (managers, service providers, clinical and care staff) the development of web materials, brochures, training videos, and journal articles.

- It is recommended that a dissemination strategy project be undertaken to facilitate the dissemination and uptake of findings from this report.
- It is recommended that a project be sponsored to a) ascertain coverage of assessment and the use of recommended instruments in current curricula and b) to develop appropriate education modules for insertion in the training curricula of relevant professional and paraprofessional groups.

Throughout the course of this project a large number of research gaps have been identified. These are outlined in Section 12.6.7 of the DOMS Report and included at **Attachment D** to this Synopsis.

These research gaps include issues such as the need for Australian reference data for some of the instruments, the need to streamline instruments in order to remove redundancy (especially in the area of functioning), the modification of some of the recommended instruments for CALD and Aboriginal and Torres Strait Islander Groups, and the need for research concerning proxy assessment and the level of cognitive capacity required to self rate/report.

### **Conclusion**

While further research may need to be undertaken to clarify some assessment issues the DOMS Report provides a useful review of the best measures/instruments to assess the status and symptoms of people with dementia.

The project has identified a set of recommended measures/instruments 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.

By developing this set of recommended measures it is hoped to standardise the assessment and evaluation procedures used in this field to enhance comparability of findings across research and practice settings.



## ATTACHMENT A

### ***Recommendations Concerning Clinical Terminology and Diagnostic Classification***

Section 3 of the DOMS Report provides a detailed discussion of these issues. The recommendations below have been based on the review of literature, clinical feedback and these recommendations have also been reviewed by the National Expert Panel.

It is recommended that:

- The ICD-10-AM is used to inform the diagnostic classifications for dementia and its subtype given this system is already in place in collecting national data in Australia.
- The ICD-10-AM and ICD-10 are used for diagnostic criteria for dementia and Alzheimer's disease (AD). Following consultation it seemed appropriate to recommend the ICD-10 instead of DSM-IV. Clinicians do not necessarily follow either of the classifications as they often rely on their clinical judgement. Given that majority of the health related information is collected based on the ICD-10 and the ICD-10-AM it is more efficient for clinicians to use one system rather than two (i.e. DSM-IV diagnostic criteria and ICD-10 for coding exercise).
- For research, the DSM-IV is preferred as it is more inclusive of mild to moderate dementia and most epidemiological studies use the DSM-IV because of ease of comparison with prior studies. However this is not mandatory, providing the study states the type of the classification used, as there is no evidence available to say the DSM-IV is superior to the ICD-10.
- In terms of differential diagnosis (DD) and diagnoses of frontotemporal dementia (FTD) and dementia with Lewy bodies (LBD), additional criteria are used: the National Institute of Neurologic Disorders and Stroke and the Association Internationale pour la Recherche et l'Enseignement en Neurosciences (NINDS-AIREN) (Roman, et al. 1993) for DD of Vascular dementia from Alzheimer's type; the Lund-Manchester criteria for FTD (1994) and the consensus criteria for LBD (McKeith, et al. 2005).
- Mild cognitive impairment (MCI) is not to be included in this project as a diagnostic entity, however screening measures for those who are suspected of cognitive impairment need to be considered.
- For assessing the severity of dementia, the CDR scale has been used for two main reasons: the AIHW recommends this and, in addition to three stages of dementia, the CDR allows room to record abnormal cognitive function without necessarily labelling it as MCI. It is well validated and widely recognised. Similarly the GDS has also been widely used to assess the severity of dementia. A detailed review of these instruments is provided in Section 4 and in Appendix 5.
- The ICF may be used as a conceptual framework for classification of measurement scales. However, given its early developmental status as a classification system in Australia, hence its unfamiliarity among clinicians and researchers, and lack of evidence relating to validity and reliability of the classification, it is deemed beyond the scope of the DOMS project to provide a definite recommendation on this subject.
- Behavioural and psychological symptoms of dementia (BPSD) are an integral part of dementia outcome measures. The guidelines provided by the International Psychogeriatric Association (IPA) are to be used for the definitions. Whilst the AIHW recommends Caldwell and Bird's guideline for the severity of BPSD, it has been suggested that a more widely recognised measure is selected for this project. Readers are referred to the discussion in Section 9 of this report.

## ATTACHMENT B

### **Methodology [Methods of Instrument Review]**

An initial overall literature search was undertaken (MEDLINE, PsycINFO) on twenty key terms (e.g. dementia, cognition, memory, function, Quality of Life etc). The major texts in the field were examined which included psychometric texts containing instrument reviews (e.g. McDowell, 2006; Bowling, 2001, 2005) as well as those containing instrument reviews applicable for dementia and assessment of the elderly (e.g. Burns, 2004; Kane and Kane, 2000; Lezak, 2004; McKeith, 1999). This process identified a list of instrument names and then searches were undertaken on all measures identified. A database was then developed which provided comparative data for instruments for each domain / category. This database included 844 named instruments.

An impact sheet was then developed for consideration by the review teams and the DOMS-EMG. This considered MEDLINE, text and web impacts, presence in instrument databases (e.g. PROQOLID) and its use in clinical practice. This process usually identified the leading twelve or so instruments for consideration in each category.

Additional selection criteria were then applied to reduce this to the leading 5-6 instruments in each domain / category. These criteria were:

- Whether there is a copy of the instrument and the original article concerning its development available.
- The number of citations found. In the case of new instruments some care was taken to assess this criterion as it was considered that recently developed instruments may not have a high citation rate. However, for instruments developed more than 5 years previously a low citation rate might indicate limited adoption by the field.
- The amount and range of the published psychometric evidence.
- Whether the instrument is used in clinical practice (evidence from the literature and data from NEP and other surveys).
- The availability of normative and clinical reference data.
- Administration time (generally 30 minutes or less) where a shorter administration time would be preferred. It was noted that as a number of instruments assessing different aspects (e.g. symptoms, cognition, HRQOL) will need to be utilized, lengthy instruments that may be more appropriate for detailed follow-up assessment may not be appropriate for use in routine assessment and across the range of practice settings.
- Whether the instrument is applicable for people with varying levels of dementia severity.
- Proprietary considerations (e.g. prohibitive cost).
- Applicability for use in routine care. Instruments would be preferred if they did not require specialist skills for administration or if extensive training in their use was not required (e.g. as for many neuropsychological/medical assessments).

Using the criteria above, the shortlist of contender instruments was reduced to 5-6 measures for each category of measures and a decision summary sheet was developed to justify the selection or non-selection of contender instruments. Further searches were then undertaken for the selected instruments using other databases (e.g. CINAHL, Cochrane Library etc) and the comprehensive reviews of these instruments commenced.

All instrument reviews make use of the AHOC instrument review sheet (refer Final Report, Appendix 3) and provide information concerning the instrument's availability, applicability, requirements for administration, psychometric properties (reliability, validity, responsiveness, sensitivity, specificity) and the availability of normative and clinical reference data.

With all instruments consideration was also given to the following aspects:

- Type and stages of dementia
- Purpose of the instrument (assessment, screening, outcomes monitoring and the evaluation of interventions)
- Self-reporting and proxy reporting

- Respondent and staff burden
- Appropriateness for CALD and Aboriginal and Torres Strait Islander groups
- Appropriateness for a range of settings (e.g. community and residential care)

Once the comprehensive review for each instrument was completed an Instrument Scoring and Weighting Sheet was also completed for each instrument as indicated in Table 1 below.

**Table 1** *Table of Criteria and Weights for Instrument Ranking*

**Criteria and weights used to assess instruments (DOMS)\***

**Instrument Name ..... Total Score = .....**

Evaluation Criteria	Scoring system	Score	Weight	Weighted Score
Availability of comparison data	1 = minimal or no comparison data available 2 = some international comparison data available 3 = Australian and international dementia comparison data available including normative data and clinical reference data		3	
Length/feasibility of instrument for inclusion in battery	1 = long instrument, 30+ items 2 = medium length instrument, 15-30 items 3 = short instrument, less than 15 items		2	
Complexity of administration (for clinician use); and cognitive burden (for self report or proxy instruments)	1 = demanding to understand or administer 2 = some difficulties to understand or administer 3 = easy to understand and administer		2	
Cultural Appropriateness (ease of use with an interpreter, client literacy, CALD criteria including Indigenous Australians)	1 = not appropriate for use by CALD or illiterate clients, or with an interpreter 2 = limited appropriateness for use by CALD or illiterate clients and interpreters 3 = appropriate for use by CALD or illiterate clients and interpreters		1	
Ease of obtaining score by the evaluator	1 = scoring complex and requires computer 2 = can be scored without computer but time consuming 3 = scoring easy and does not require computer		2	
Sensitivity to dementia	1 = not known to be sensitive to dementia status 2 = sensitive to dementia status 3 = good sensitivity to dementia status		3	
Reliability evidence available	1 = little published evidence identified 2 = evidence suggests moderate reliability 3 = evidence suggests good reliability		3	
Validity evidence available	1 = little published validity evidence identified 2 = evidence suggests moderate validity 3 = evidence suggests good validity		3	
Cost of the instrument	1 = costs charged for using instrument 2 = costs for commercial use/training costs 3 = instrument available free of charge		2	
Cost of instrument administration	1 = professional 2 = paraprofessional/ staff member 3 = self complete		2	

The instrument is given a score against each criterion and this is multiplied by the weight for this criterion. The resulting weighted score for each criterion is then added to form a total score for each instrument. For each category of instruments a comparative table of scores for the instruments is then produced and it is on this basis the recommendations for each category of instruments is formed.

## ATTACHMENT C

## A Matrix Model for the Recommended Instruments

Recommended Instruments	Settings							Severity of Dementia		
	Acute	P&CC	Resi.Care	More Detailed Assessment	Research	Indig.	CALD	Mild	Mod	Severe
<b>Dementia Assessment</b>										
Global Deterioration Scale	✓	✓	✓		✓	?	?	✓	✓	✓
Clinical Dementia Rating	✓	✓	✓		✓	?	?	✓	✓	✓
Dementia Severity Rating Scale		✓	?		✓	?	?	✓	✓	✓
<b>Cognitive Assessment*</b>										
MMSE-3MS	✓	✓	✓		✓	?	?	✓	✓	✓
ADAS-Cog		✓		✓	✓	?	?	✓	✓	
MDS-Cog	?	✓	✓		✓	?	?		✓	✓
GP-Cog	?	✓	✓		✓	?	?	✓	✓	
RUDAS	?	✓	✓		✓	?	✓	✓	✓	
KICA-Cog	?	✓	✓		✓	✓	?	✓	✓	
<b>Global BPSD</b>										
NPI	✓	✓	✓	✓	✓	?	?	✓	✓	✓
BEHAVE-AD	✓	✓	✓	✓	✓	?	?	✓	✓	✓
CERAD	✓	✓	✓	✓	✓	?	?	✓	✓	✓
<b>Diff. Diagnosis Delirium</b>										
CAM	✓		✓		✓	?	?	✓	✓	✓
DRS-R-98	✓			✓	✓	?	?	✓	✓	✓
<b>Individual Symptoms</b>										
RAGE - aggression		✓	✓	✓	✓	?	?	✓	✓	✓
CMAI - agitation	✓		✓	✓	✓	?	?	✓	✓	✓
PAI - agitation		✓	✓	✓	✓	?	?	✓	✓	✓
RAID - anxiety		✓	✓	✓	✓	?	?	✓	✓	✓
AES - apathy		✓	✓	✓	✓	?	?	✓	✓	✓
Cornell - Depression	?	✓	✓	✓	✓	?	?	✓	✓	✓
Geriatric Depression Scale	✓	✓	✓		✓	?	?	✓	✓	
<b>Function - Generic</b>										
FIM (ADL)	✓	✓	✓		✓	?	?	✓	✓	✓
Barthel Index (ADL)	✓	✓	✓		✓	?	?	✓	✓	✓
Lawton & Brody (IADL)		✓	✓		✓	?	?	✓	✓	✓
OARS - IADL		✓	✓		✓	?	?	✓	✓	✓
<b>Function - Dementia Spec.</b>										
ADCS-ADL		✓	✓		✓	?	?	✓	✓	✓
DAD		✓	✓		✓	?	?	✓	✓	✓
CSADL		✓	✓		✓	?	?	✓	✓	✓
<b>HRQOL- Dementia Spec.</b>										
DEMQOL		✓	✓		✓	?	?	✓	✓	
QOL-AD		✓	✓		✓	?	?	✓	✓	
QUALID			✓		✓	?	?			✓
<b>Multi-attribute Utility</b>										
AQoL					✓	?	?	✓	?	
EQ-5D					✓	?	?	✓	✓	
<b>Social Isolation</b>										
De Jong Gieveland Loneliness		✓	✓		✓	?	?	✓	✓	
<b>Patient Satisfaction</b>										
SAPS		✓	✓		✓	?	?	✓	✓	
<b>Carer Satisfaction</b>										
SWC-EOLD		✓	✓		✓	?	?	✓	✓	✓

- ✓ = Yes, some evidence for the instruments potential application in Australia  
 ? = Unsure, minimal evidence requiring further research in the Australian context

\* These are cognitive tests for people with dementia, if an informant / proxy measure is required use the IQCODE

## ATTACHMENT D

### **Identified Research Gaps**

During the course of the DOMS project a number of research gaps were identified:

1. Some measures need pilot testing in Australia to obtain reference data (e.g. Dementia Specific HRQOL measures, associated symptom measures).
2. Further research work is required to assess the point at which people can no longer self-rate (e.g. the relevant MMSE-3MS score) that applies under different modes of administration (e.g. self report, interview, interview assisted). This will be required for all recommended self-report instruments.
3. Future research might also address how training, the framing of questions, the terminology used and the administration of instruments influences the results of proxy assessment and more research is needed to compare proxy reports with performance-based measures as well as information from medical records and health utilization data.
4. Many of the recent papers on proxy assessment use single or dual item informant measures (e.g. Tierney, et al. 2003; Watson, et al. 2004; Li, et al. 2006). Further research is required to ascertain whether these items have the requisite accuracy compared to longer proxy measures.
5. Further research is required to address identified problems with Multi-attribute Utility Measures: AQoL (shorten) and/or EQ-5D (scoring and distribution issues).
6. A linguistic validation study needs to be undertaken for the De Jong Gierveld Loneliness Scale to develop response categories more appropriate to the Australian context.
7. It is recommended that the three social isolation instruments which performed relatively well (the De Jong Gierveld Loneliness Scale, the Friendship Scale and the Medical Outcomes Study Social Support Survey) be trialled in at least one large dementia study for the explicit purpose of identifying the instrument to be recommended for future use. This trial should also assess proposed modifications to these instruments. From this study a statistically-derived single item measure could also be identified for use in everyday clinical consultations.
8. Social function / social support areas may need follow up research if there is a wish to focus on social participation as well as social isolation but this could be combined with research outlined in research gap no.7 (above). It might also include an examination of social support items from relevant ABS Surveys.
9. In the absence of a research consensus for the measurement of function in dementia, and given a high degree of overlap in items, there is a clear need for a streamlining the various functional instruments and items across each of the practice settings (Spector, 1997). A study including a large group of dementia patients could examine and calibrate functional items from the short-listed functional status instruments (both generic and dementia specific) to create a comprehensive item bank. This dementia item bank could then be used to examine item redundancy and coverage across the range of severity levels and could be used to develop new tools or provide cross-calibration between the existing instruments. This project would also need to examine the relationship of these items with the recommended cognitive and functional assessment staging instruments.
10. It is recommended that a study be undertaken to test the Short Assessment of Patient Satisfaction scale and the two global patient satisfaction items identified with samples of dementia samples and their carers. It is noted that all these items would require minor rewording to make them suitable for use with an informant/carer.
11. Carer satisfaction with services has been addressed in this project but an examination of the instruments used to assess carer burden, carer appraisal and carer wellbeing was outside the scope of this project. It is recommended that a more detailed follow up project be undertaken to examine issues relating to the assessment of instruments used to assess carer burden, carer appraisal and carer wellbeing.
12. A further project is necessary to ensure the development of a more comprehensive database of dementia outcome measures solely for use with CALD communities - where translated versions of the DOMS selected measures are further reviewed and made available if possible.
13. Further studies analysing the measurement equivalence of the core recommended measures be undertaken for major language groups within Australia.

14. Research should be undertaken to examine further instruments developed in Australia such as the RUDAS, the GPCOG, the KICA-Cog to ensure their validity and reliability in different groups of CALD populations.
15. There needs to be further detailed research on the meaning of dementia in Indigenous communities, and how to ask questions which capture the experience of living with dementia in an Indigenous community.
16. Further research be undertaken to adapt the recommended tools, as necessary, for Aboriginal and Torres Strait Islander Groups – particularly for rural and remote populations.
17. Further research should be undertaken to assess the psychometric properties of the KICA-Cog and its appropriateness for the assessment of cognitive impairment with both urban and remote Indigenous people.
18. Individual assessment methods such as Goal Attainment Scaling, advocated by Rockwood (2007), to individualise outcome measurement for people with dementia, have not been examined in this project. It is recommended that a systematic review be undertaken to assess these methods.
19. A decision was made by the DOMS-EMG that the project should focus on the instruments/tools that are available for use in routine care and this would exclude many of the more detailed neuropsychological instruments or instruments that require specialist training for their administration and interpretation. It is recommended that a further study could examine neuropsychological and specialist tests for people with dementia, in association with the relevant professional groups.
20. Further investigation in the field should be undertaken to fine tune the recommendations for the use of these instruments with people with Late Stage Dementia. This could also include an examination of instruments used in palliative care settings.
21. There is a need for training on the principles of undertaking systematic assessment as well as the specific characteristics of a recommended instrument. A project to develop modules addressing these issues, which can be incorporated in the curricula for relevant professional and para-professional groups, should be undertaken.
22. Issues concerning safety / risk assessment are outside the scope of this project. It is recommended that a further project be undertaken to examine risk assessment issues (e.g. elder abuse, aggression, self harm etc) for people with dementia.