APPENDIX 7: Methodology

Approach

The approach to updating and reviewing the original *Best Practice Guidelines for Behaviour Management* (2006) was three pronged:

- extensive consultation with experienced DBMAS clinicians, researchers, industry representatives and relevant stakeholders throughout Australia
- a comprehensive review of academic and grey literature
- an expert Working Group met on four occasions during the course of the project to provide advice and feedback on the review process and the draft documents

Sections of the existing *Best Practice Guidelines for Behaviour Management; Best Practice Guidelines for People with Dementia from a CALD Background who have Changing Behaviours; Aboriginal and Torres Strait Islander Cultural Considerations for Best Practice Guidelines for Behaviour Management* and previous literature reviews were retained where the information remains relevant and current.

Consultation

DBMAS clinicians were consulted at face–to-face meetings in each State and Territory. Telephone interviews with regional and outer urban DBMAS clinicians were conducted where a face-to-face meeting was impractical. A representative of each DBMAS service was also included in the expert Working Group (see acknowledgments for Working Group members). Resources developed by the individual DBMAS services were collected and tabled.

Consultations regarding dementia and BPSD in Aboriginal and Torres Strait Islander and CALD communities involved face-to-face meetings with individuals and groups engaged in Aboriginal and Torres Strait Islander and CALD mental health and dementia across NSW. Teleconference consultations were conducted with experts in Queensland, the Northern Territory, South Australia and Western Australia. Feedback and comments on relevant sections of the draft documents were provided by the Expert Working Group as well as Aboriginal and Torres Strait Islander and CALD advisors (see Introduction: acknowledgements).

Literature Review

A systematic literature review was performed to examine the evidence for psychosocial, environmental and biological interventions for the management of BPSD. Databases searched from 2006 (the date of the previous Guide) to 2011 were SCOPUS, MEDLINE, PsycINFO, EMBASE and the Cochrane Library Database. MeSH terms were checked. This yielded a total of 2,280 potentially relevant papers. Abstracts were reviewed and articles were critically examined for inclusion if they were available in English and full text. Studies met criteria if they included participants with a diagnosis related to dementia. All care settings and both qualitative and quantitative studies were eligible. Over-the-counter products such as vitamins and herbal products were not excluded. A total of 1,080 papers were retained after screening. Reference lists of relevant articles were later hand searched. Where two or more articles based on similar studies by the same authors were available, the better or best study was selected for inclusion. This decision was made according to the

most recent, most relevant and/or most complete study or those with a greater number of participants. Grey literature and websites were also searched for relevant resources.

A systematic literature review for apathy had been completed, previously. This review included studies from the year 2000 onwards. Some BPSD were very limited in the amount of literature available e.g., wandering and vocally disruptive behaviours. Where this occurred, intervention studies were again not limited to 2006 onwards. In contrast, the search for depression in dementia yielded more literature than could be included in one module. The decision was made to include studies from review articles and a cross section of the different types of interventions reported. An additional scoping review of academic and grey literature related to dementia and BPSD in Aboriginal and Torres Strait Islanders and CALD communities was subsequently undertaken.

Search terms

The following search terms were used in the literature search:
"BPSD" *or* "behav* *and* “psychological symptoms of dementia" *or* "challenging behav*" *or* "disturbing behav*" *or* "difficult behav*" *or* "disruptive behav*" *or* “behav* of concern” *or* agitat* *or* restles* *or* pacing *or* resist* *or* "social disinhibition" *or* "sexual disinhibition" *or* "catastrophic reaction" *or* "verbal outbursts" *or* screaming *or* delusion *or* hallucination *or* anxiety *or* depression *or* “sleep disruption” *or* “nocturnal disruption” *or* aggress* *were combined with each of the following:* "psychosocial management" *or* "psychosocial intervention" *or* "psychosocial treatment" *or* "pharmacological management" *or* "pharmacological intervention" *or* "pharmacological treatment" *or* "nonpharmacological management" *or* "nonpharmacological intervention" *or* "nonpharmacological treatment" *as well as* dementia *or* alzheim* *or* "lewy body disease".

Quality Criteria

In order to better guide clinical practice, all intervention studies reported in the modules and outlined in the intervention tables (Appendix 3: *psychosocial/environmental* and *Appendix 4: biological)* have been assessed to determine the strength of the evidence for the findings reported. The criteria for assessing the quality of the studies is defined below.

Based on the criteria outlined below and the total quality rating score for each intervention study, the strength of the evidence presented was grouped into the following categories:

- **Strong:** total quality score ≥ 11
- **Moderate:** score of 6 - 10
- **Modest:** score of 1- 5

While individual case study/series were included and they may lend support to the interventions, evidence based on these is not strong and research quality was not rated.

Criteria for rating quality of intervention studies

Quality Criteria

Design

- Randomised
- Randomised according to Delphi specifications *(must be unpredictable e.g., coin toss, table of random numbers OK, but DOB, admission date or MRN does not qualify, no credit for coin toss of clusters)*
- Control or comparison group *(credit for repeated measures)*
- Blind ratings *(partial blinding OK if primary outcome is blinded)*

Subjects

- Groups similar at baseline regarding most important prognostic indicators *(≤20% difference OK. Must include: age, gender & baseline "behaviour" score or an indication that there is no significant difference in these. Where groups are not matched but baseline "behaviour" scores are used as a covariate in analysis – OK. Behaviour change score only does not qualify)*
- Eligibility criteria specified *(could the study be replicated based on only the information reported?)*
- Use of standardised diagnostic criteria *(yes/no/not stated "written in notes by dr" does not qualify, GDS, MMSE, DSM IV, etc OK)*
- All subjects accounted for or withdrawals noted

Outcomes

- Well-validated, reliable measures - caregiver and/or patient *(known or reported as validated, published generally OK)*
- Objective outcome *(based on observations, not self-rated)*
- Follow-up assessment 6 months or beyond *(f/u period must be from cessation of intervention to qualify)*

Statistics

- Point estimates and measures of variability presented for primary outcome measures *(means & SDs to be provided, effect sizes OK)*
- Statistical significance considered
- Adjustment for multiple comparisons *(e.g., adjusted p-value, Bonferroni, Scheffe, Tukey's, post hoc)*
- Evidence of sufficient power *(stated or not/large sample size)*
- Intention-to-treat analysis included

Total quality score = 1 point for each criterion met