

## Appropriateness of using a symbol to identify dementia and/or delirium: a systematic review

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### Executive summary

**Background** Alzheimer's Australia contracted the Dementia Collaborative Research Centre – Consumers, Carers and Social Research to conduct a systematic review to explore the appropriateness of a symbol for dementia.

The concept of a symbol for people with dementia was an outcome of the Alzheimer's Australia National Consumer Summit on Dementia held in Canberra in October 2005. People living with dementia and their carers identified that a national symbol would be helpful in order to encourage appropriate treatment of people with dementia.

Funding was provided as part of the Australian Government's Dementia Initiative to Alzheimer's Australia to work in collaboration with the Queensland University of Technology and Catholic Health Australia to explore, through research, the viability and potential impact of such a symbol in a range of care settings.

**Objectives** The main objective of this systematic review was to evaluate any published and unpublished evidence regarding the appropriateness of developing a symbol for dementia and/or delirium, which could be used in a variety of settings to indicate that a person has dementia and/or delirium.

**Search strategy** A literature search was performed using the following databases: Ageline, APAIS Health, CINAHL, Dissertations and Theses Abstracts, Embase, MEDLINE, PsycEXTRAS, PsycINFO, PsycArticles, Current Contents, LegalTrac, Health and Society, Sociological Abstracts, Family and Society, CINCH, and Hein Online databases. The reference lists of articles retrieved were hand searched, as well as a range of literature from health, legal, ethical and emergency services. Grey literature was searched for using a number of Internet sites, and personal email communication with authors of relevant studies and known researchers in the field was initiated.

**Selection criteria** Papers were retrieved if they provided information about attitudes or perceptions towards the appropriateness of symbols, identifiers or alerts used to inform others that someone has dementia, delirium and/or another medical condition

or functional impairment. Any references to symbols, identifiers or alerts being used to indicate a particular type of service were also considered.

**Data collection and analysis** Retrieved papers were critically appraised by two reviewers, using tools developed by the Joanna Briggs Institute. Due to the type and clinical heterogeneity of papers retrieved, meta-analysis was not possible, and a narrative summary was developed instead.

**Findings** The systematic review revealed that several different symbols and identifiers are in current use, in various parts of the world, to represent a range of medical and functional conditions, including dementia, delirium, falls risk, diabetes, and vision impairment. According to the papers reviewed, the most commonly used colour of symbols representing dementia was blue. There was general consensus amongst the literature that a symbol for dementia is appropriate in the acute care setting. It was also clear from the research that an abstract symbol, as opposed to one which explicitly attempts to depict dementia, was most acceptable to staff, people with dementia and their carers. There appeared to be some support for the use of a body worn symbol (on a bracelet) for people with dementia who may go missing from their home, aged care facility or day centre. Future research should concentrate on the appropriateness of a dementia symbol for commonly used services such as public transport and banking, and the acceptability of large scale marketing campaigns if a dementia symbol were to be introduced at a state or national level. In addition, further research is recommended into the acceptability of such a symbol across a wide range of different cultural and linguistic groups.

**Keywords:** nursing, dementia, wandering, carers, patient safety

## Background

Dementia encompasses a devastating set of disorders that, in their later stages, may result in an inability to communicate one's own needs, extreme memory loss and a tendency to wander from places of safety. Dementia is an umbrella term for a large group of conditions that cause progressive decline in a person's functioning, particularly cognitive functioning. For the purposes of this systematic review, dementia includes Alzheimer's disease, vascular dementia, fronto-temporal dementia, dementia with Lewy bodies, Wernicke Encephalopathy and Creutzfeldt-Jakob Syndrome<sup>[1]</sup>.

A suggestion made at the *National Consumer Summit on Dementia* held in Canberra, Australia, October 2005, was that people with dementia and their carers need a national dementia symbol<sup>[2]</sup>. The Australian Government, through the National Dementia Initiative, funded Alzheimer's Australia, in partnership with QUT and Catholic Health, to produce a report examining the viability of a national dementia symbol for use in a range of care settings and the general community. There are a range of reasons why the idea of a dementia symbol has been put forward, and these are explored in this systematic review, along with the potential risks and benefits of introducing a national symbol for dementia. It has been suggested that the existence of such a symbol may result in people living with dementia experiencing "...better standards of care, lower levels of mistakes and misunderstandings, increased levels of knowledge and ultimately give [people with dementia] a more dignified quality of life..."<sup>[2]</sup>.

This systematic review is part of a study investigating the appropriateness and viability of developing and implementing such a symbol. The word 'symbol' is used interchangeably with

'identifier', 'client flag', 'emblem' and 'alert' throughout this review. Where a study is reported, the term used in this review is the same as that used by the study's author(s). The appropriateness of a dementia symbol to all settings (acute, residential, community, transitional and emergency) is investigated in this systematic review. Examples of locations where a symbol could be placed include "...on the hospital bed head, on the hospital file, on the GP's file, on identification tags, on the Centrelink file, in remote health services, in day care centres, in respite facilities, and being used by allied health providers"<sup>[2]</sup>.

Fear of further stigmatisation as a result of displaying a symbol that denotes cognitive impairment may also be a concern for people with dementia and their carers. In one recent study, 12 participants with early stage dementia clearly expressed concerns about how other people perceived dementia and reacted towards them<sup>[3]</sup>. Another question is whether displaying a symbol may expose already vulnerable older people to further personal risk. For example, it is documented that some older evacuees from Hurricane Katrina with decreased cognitive function and physical strength had their medication, money and belongings stolen<sup>[4]</sup>. The possibility that wearing a symbol which clearly identifies cognitive impairment would make such people even more susceptible to crime and exploitation should be considered.

Issues concerning dignity, civil liberties and personhood have been particularly prominent in recent discussions regarding tagging and tracking people with dementia<sup>[5-7]</sup>. Tracking refers to the use of satellite technology to help locate someone who has wandered. Tagging refers to devices which activate an alarm should the wearer step outside a pre-defined area<sup>[8]</sup>. Such surveillance devices or interventions are beyond the scope of this review, and have been explored in a systematic review by Robinson et al.<sup>[9, 10]</sup>.

The focus of this systematic review is the appropriateness of a symbol, identifier or alert to denote that someone has dementia and/or delirium, whether it be displayed on clothing, non-tracking body-worn items (such as bracelets, watches, tags or cards), at patient bedsides, in patient notes or on signs.

## Objectives

To examine evidence regarding the appropriateness of developing a symbol for dementia and/or delirium that could be used in a variety of settings. The settings include:

- Acute
- Community
- Residential
- Transitional
- Emergency services

### The specific points of interest for this review were:

- What are the attitudes towards using a symbol to denote a person has dementia and/or delirium?
- What symbols currently exist to denote a person has a medical condition and/or functional impairment?
- What symbols currently exist to denote a person has dementia and/or delirium?

- What are the issues pertinent to using a symbol to denote a person has dementia and/or delirium?

### **The research questions for this review were:**

1. What is the current practice in the use of symbols to alert people that someone has a medical condition/functional impairment?
2. How appropriate is using a symbol to identify dementia and/or delirium perceived to be, and does this perception differ across care and service settings?
3. What are the issues pertinent to the use of a symbol to alert people to the fact someone has a dementia and/or delirium?

## **Criteria for considering studies for this review**

### **Phenomena of interest**

The phenomena of interest were attitudes and perceptions towards the appropriateness of symbols, identifiers or alerts used to denote someone has dementia and/or delirium, and/or a medical condition and/or a functional impairment.

### **Outcomes of interest**

Outcomes of interest included:

- Attitudes and opinions regarding the appropriateness of a symbol to identify someone with dementia and/or delirium
- Evidence that informs the need for the development of a symbol to identify someone with dementia and/or delirium

### **Types of studies**

The review considered any quantitative/descriptive studies, qualitative studies (including ethnographies, phenomenologies, grounded theory studies) and discussion papers. In the absence of these, opinion papers, letters or reports that met the inclusion criteria were considered. No date limiters were set, in order to retrieve the widest range of studies.

### **Language**

Only studies reported in English were considered for inclusion. We acknowledge the potential bias this introduces to the review.

## **Search strategy**

The search strategy aimed to identify both published and unpublished studies, reported in English. A three-step strategy was followed, the initial phase being searches of the CINAHL, Medline and PsycINFO databases using search strategies adapted from the Cochrane Dementia and Cognitive Improvement Group. Secondly, a more extensive search was performed using the appropriate Subject Headings and/or keywords/phrase/strategy for each of the databases listed below. Reference lists of identified reports and articles were hand searched for additional studies, and the contents pages of core journals or journals not indexed in databases, were hand searched. Authors who were known to be knowledgeable

about the phenomena of interest were emailed to identify further published, unpublished or ongoing studies.

## Databases

Searches were conducted from the year of commencement of each of the following databases:

CINAHL (*EBSCO Host* – 1982 to September 2007) (includes Pre-Cinahl)

Medline (*EBSCO Host* – 1966 – October 2007)

PsycINFO (*CSA Illumina Earliest* –2007)

Embase - (*Elsevier*, 2003 – 2007)

PsycARTICLES (*EBSCO Host*, earliest – 2007)

Ageline (*via CSA Illumina*, 1960-2007)

APAIS-Health (*Informit*, earliest – 2007)

Current Contents (*Web of Science* 1998 - 2007)

Dissertation and Thesis Abstracts (*Proquest Earliest* – 2007)

Social Science Citation Index (*Web of Science* – 1992 - 2007)

Sociological Abstracts/Social Services Abstracts (*CSA Illumina* 1960-2007)

AGIS (*Informit*, 2004 – 2007)

CINCH (*Informit*, 2004 – 2007)

Health & Society (*Informit*, 2004 – 2007)

HeinOnline (earliest - 2007)

Family & Society Plus (*Informit*, 2004 – 2007)

National Rehabilitation and Information Centre (NARIC's Disability Information Center) – REHABDATA, (1956 – 2007) – search terms: dementia + tag/identifier/symbol/alert

LegalTrac (*Thomson Gale*, earliest -2007)

## Hand searching

Hand searching was conducted through the following specialised relevant journals:

*Alzheimer's and Dementia* (July 2005 1(1) – July 2007 3(3 supp))

*Alzheimer's Disease and Associated Disorders* (Jan/March 2000 – Sept 2007)

*Dementia: International Journal of Social Research and Practice* (Feb 2002 – May 2007)

*Australian Journal of Emergency Management* (Winter 1996 – November 2002)

*Emergency Medicine Alert* (Nov 2001 – Oct 2007)

*Geriatric Emergency Medicine Reports* (2001 – 2002)

*Information Design Journal* (1-15 1979/80-2007)

*International Journal of Disaster Medicine* (2003 – 2006)

*SIGNPOST - Journal of Dementia and Mental Health for Older People* (1997 - 2006)

*The Internet Journal of Emergency Medicine* (1(1)1 Jan 2003-Vol 3(2) 2007)

Searching reference lists of included articles.

## Grey literature

The grey literature search consisted of:

- contacting authors who may be knowledgeable about the phenomena of interest to identify further published, unpublished or ongoing studies
- searching the following:
- Google Scholar (Advanced Scholar Search – “dementia AND appropriateness AND identification” ; “dementia and acceptability”
- NHMRC guidelines – (aged care, carers and volunteers, clinical practice guidelines, ethics in research)
- PsycEXTRA (*EBSCO Host* – earliest - 2007)
- National Institute of Clinical Studies (NICS)
- Australian Centre for Evidence Based Clinical Practice (<http://www.acebcp.org.au>)
- GrayLit Network <http://www.osti.gov/graylit/>

A search of the Alzheimer's Disease Education and Referral Centre Clinical Trials Database (<http://www.alzheimers.org/trials/index.html>) identified forty-seven trials, however none were relevant. Similarly a search of the National Institutes of Health (NIH) Clinical Trials Database (<http://clinicaltrials.gov/ct>) identified no relevant trials.

## Search terms

Words such as *symbol*, *label*, *identification* and *alert* have multiple meanings, which compounded the search. The search strategies used in the databases were composed from the following four sets of concepts covering the main concepts of the review questions (subject/MeSH headings are capitalised):

Cognitive function: DEMENTIA, DELIRIUM, DELIRIUM, DEMENTIA, AMNESTIC, COGNITIVE DISORDERS, ALZHEIMER'S DISEASE / ALZHEIMERS DISEASE

WERNICKE'S ENCEPHALOPATHY, AIDS DEMENTIA, dement\* / deliri\* / alzhem\* / cognitive impairment / organic brain\*, Front\* temporal

Identification: EMBLEMS AND INSIGNIAS, Medic alert\* / tag\* / bracelet\*, logo\* / symbol\* / emblem\* / insignia\*, patient identification / identifier (not trial\* registration)

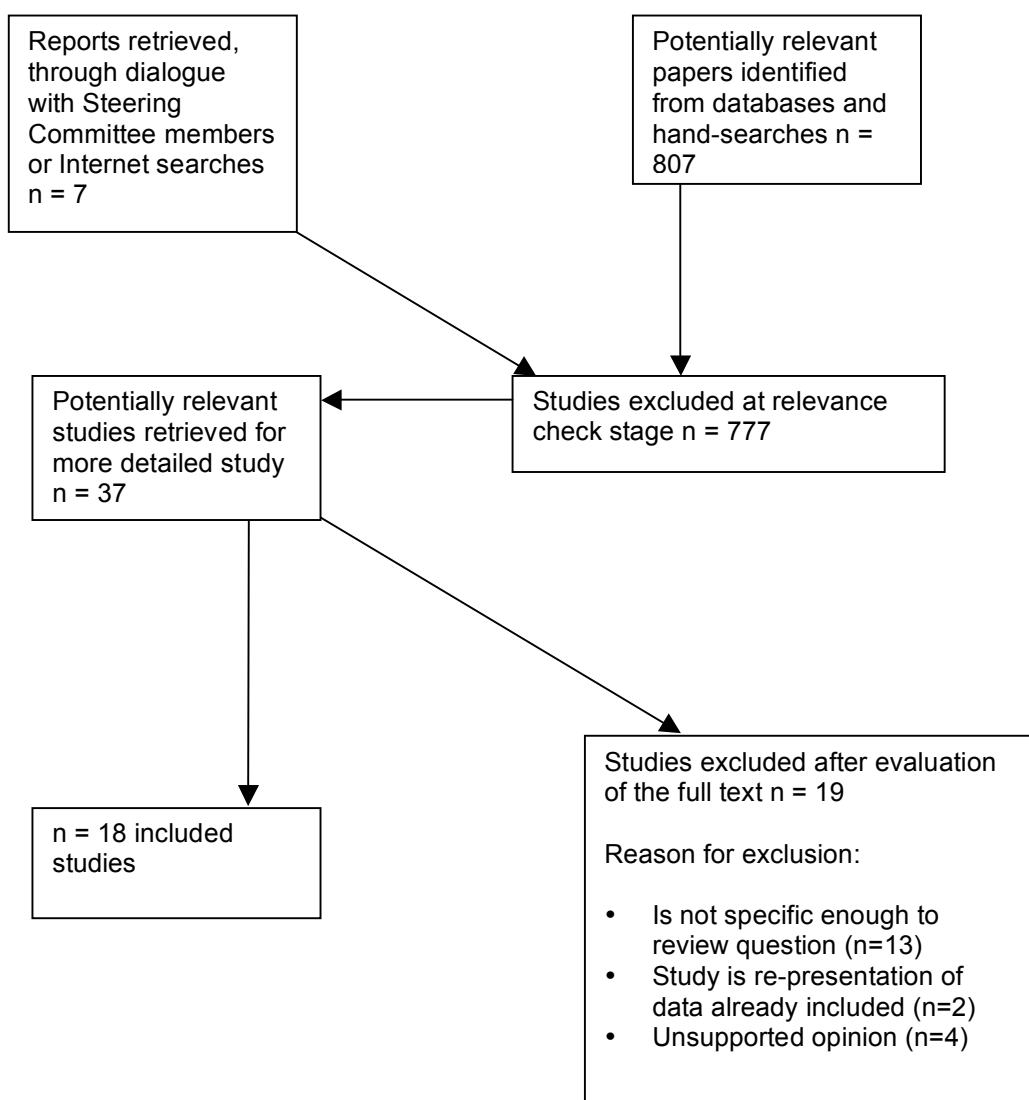
EMERGENCY MEDICAL SERVICE COMMUNICATION SYSTEMS

Belief / perspective: stigma\* / ethic\* / privacy / dignity, approp\* / accept\* / attitud\*

EMERGENCY MEDICAL TECHNICIAN ATTITUDES (CINAHL Heading)

Setting: Patient management / service delivery / patient safety, wander\* / sundown\*,

NATURAL DISASTERS



**Figure 1: Searching figure**

## Methods of the review

### Data retrieval

All studies identified by the database searches were assessed for relevance to the review based on the title and abstract. For studies that appeared to meet the inclusion criteria, the full paper was retrieved and assessed for relevance to the review criteria. Literature which was not accessible in the public domain was requested via email or letter correspondence.

### Criteria on which quality of studies were assessed

The appraisal and extraction tool used for each paper was the one perceived by the reviewers to best capture the data/information relevant to the review question. Qualitative studies were assessed using the Qualitative Assessment and Review Instrument (JBI-QARI) critical appraisal tool developed by JBI (Appendix 1). Conclusions/recommendations from opinion papers, discussion papers and letters were extracted using the Narrative, Opinion and Text

Assessment and Review Instrument (JBI-NOTARI) critical appraisal tool developed by JBI (Appendix 2). The quality of quantitative studies was assessed using the Meta Analysis of Statistics Assessment and Review Instrument (JBI-MAStARI) critical appraisal tools developed by JBI for descriptive and experimental studies (Appendices 3&4). Any disagreements that arose between the reviewers regarding inclusion of a paper were resolved by a third reviewer (SS).

### **Data extraction**

Data from qualitative studies were extracted using JBI-QARI (Appendix 5) and conclusions/recommendations from non-research papers (such as opinion papers, discussion papers and letters) were extracted using JBI-NOTARI (Appendix 6). Data from randomised controlled trials and quantitative/descriptive studies were extracted using data extraction tools developed by JBI (Appendix 7 and Appendix 8 respectively). Many of the papers included both qualitative and quantitative components.

### **Data synthesis**

Meta-analysis of included studies was not performed due to significant clinical heterogeneity and so findings were summarised in narrative form.

## **Results**

Using the outlined search strategies in Appendix (9), 37 papers were identified for retrieval. Following the process outlined in Figure 1, 18 papers were included in the review (Appendix 10). Nineteen papers were excluded: 13 that did not meet the inclusion criteria, 2 did not add unique information to the systematic review because they were re-presentations of identical data from studies already included, and 4 unsupported opinion papers (Appendix 11).

Study quality across the quantitative studies was generally low, with only one unblinded RCT able to be included. Similarly, the quality of the textual/opinion works was also low overall. The qualitative studies were of higher quality, providing credible evidence for practice in this area.

### **Current practice in relation to symbols for medical or functional conditions**

One of the specific objectives of this review was to explore current practice in relation to the use of symbols to alert people to the fact that an individual has a medical condition or functional impairment. Sixteen studies were found which reported on the use of symbols, identifiers and alerts to signal the existence of a particular condition or risk. Several (n=6) of the included studies do not specifically refer to a symbol for dementia, but were included because they provide secondary evidence for the acceptability or appropriateness of symbols to identify other illnesses or functional impairments and the information from these studies may also be applicable to symbols to identify dementia.

#### **Quantitative Studies**

Eight quantitative works provided data for this research question: one unblinded RCT<sup>[11]</sup>, five quality improvement projects<sup>[12-16]</sup>, and 3 surveys<sup>[17-19]</sup>.

## Acute Care

Haines et al.<sup>[11]</sup> conducted a randomised controlled trial to investigate an intervention intended to prevent falls in a Melbourne sub-acute care facility. A random number table was used to allocate consecutively admitted patients (between March – December 2002) to either the intervention or control group (with the control group receiving usual care). The intervention comprised of a falls alert risk card with an information brochure targeted at family members and carers, as well as an exercise programme, education programme and hip protectors. Patients with cognitive impairment were not excluded, and family members were asked to provide consent where necessary (specified as where patients had obtained abbreviated mini mental score of <7). It was noted that “many” had dementia, although the exact number was not quantified.

The falls risk alert card was described as an A4 size card and was positioned at the patient's bed head. Over the period of the project, 151 patients had a falls risk alert card displayed above their bed. Of relevance to this review were concerns regarding the possibility that alert card imposed on patient privacy. However, the following statement suggests that these fears were not realised:

*“...though the falls risk alert card may violate participant privacy and cause distress to participants and their families, we used a falls alert symbol identifiable by hospital staff rather than a sign with words to minimise this risk. During the study no official complaints or request to remove falls risk alert cards were received” (p 5).*

It was reported that no participants withdrew from the trial and no adverse events were recorded. During this study period, falls reportedly were reduced by 30%; however no separate data is presented for the effectiveness of the falls alert identifier.

A Clinical Practice Improvement project conducted between November 2005 and February 2006 by North Coast Area Health Service (NCAHS) (Australia), aimed to improve the assessment, diagnosis, documentation and management of delirium for older hospitalized people<sup>[12]</sup>. For patients deemed to be at risk of delirium, a ‘patient identifier’ was displayed at the patient's bedside (see Appendix 13). The identifier was simple in design, featuring the words “delirium alert” above a purple coloured pointed shape.

The project report did not evaluate the effectiveness of the alert separately from other components of the program, nor did it include an exploration of any dignity or privacy issues associated with the use of the alert, nor patient or family reactions to the use of the alert. However from the results of the report, it is clear that the identifier, as part of a larger intervention, was a valuable tool in raising staff awareness of this cognitive impairment. As a result of this program, 67% of all persons older than 70 years admitted to this Health Service were screened for delirium risk factors and of those, 33% were found to be positive for delirium and had an identifier placed at the bedside.

The Ballarat Health Service (BHS), in Victoria, Australia, conducted a comprehensive project to introduce a Cognitive Impairment Identifier (CII) (see Appendix 12)<sup>[13]</sup>. Prior to the implementation of the BHS CII, the project team conducted a quantitative audit of identifiers already displayed in wards. They reported that 21% of audited patients had a sensory identifier (vision or hearing impairment) displayed at their bedside<sup>[14]</sup>, which would indicate widespread usage in current practice. This study also highlighted the importance of sustaining the increased visibility of cognitive impairment through the use of the identifier, which was an important part of embedding the change in normal hospital practice. Thirty-eight percent of direct care staff reported coming into contact with the identifier on a daily basis and 79%

reported that seeing the CII changed the way they communicated and interacted with patients.

A falls risk alert symbol was used in a study conducted through the Western Australia Country Health Service – South West (WACHS South West) (Australia). The report did not include a discussion about dignity or privacy issues<sup>[15]</sup>. However, personal communication with the author of the report indicated that, initially, some clinicians were concerned about these aspects. Nevertheless it did not appear to surface as an issue when the program was evaluated (and thus was not included in the report)<sup>[20]</sup>. The symbol was placed in various key places at 12 acute care facilities: above patient's beds; outside their rooms (on the door); on the whiteboard of patient details in the staff office; and as a sticker in patient notes. Staff participants who completed evaluation forms listed the symbol as an effective communication method. Feedback from 10 of the 13 participants indicated that the:

*“Falls risk identification stickers and signs are a good visual aid for all personnel” (p14).*

There was some concern that staff may become desensitised to the symbol, because of its competition with other signage, so use of the symbol was limited to only those cases where the reason for admission was because of a fall, or where a patient had fallen whilst an inpatient or when a patient had been classed as high risk for falling. This concern has not been mentioned in any of the other papers retrieved. The report states that approximately half the participating hospitals in this program recorded a reduction in the number of falls in the study period.

The North Coast Area Health Service (NCAHS), in New South Wales, Australia, developed a Bedside Patient Identifier for patients with vision impairment, with the wording *“I am a Vision Impaired Person, please introduce yourself and ask if I need assistance”*. The vision impairment identifier was a component of a program to raise staff awareness regarding how to make a hospital stay more comfortable for people with visual impairment<sup>[16]</sup>. The program, conducted in 2005, was initiated following feedback from consumers with vision impairment that their needs were not well understood by staff. Evaluation of the effectiveness of the identifier was conducted by asking 10 patients if they found the signage helpful. Of interest to this review is one particular thematic response from this questionnaire:

*feelings of safety experienced by patients, because their special needs were being addressed<sup>[16]</sup>*

While the needs of persons with dementia are very different to those of persons with a visual impairment, each group has special needs which may not be apparent on first meeting and therefore each group may benefit from a type of visual indicator or alert to draw attention to these needs and provide them and their relatives with feelings of added security and safety.

## **Emergency**

In emergency situations, it is common for healthcare staff to search for any alerts that indicate an individual has a health condition. Morton et al.<sup>[17]</sup> explored the awareness of, and credibility of emergency identification schemes, by sending questionnaires to Accident and Emergency (A & E) department senior staff (n=380) and operational directors of ambulance headquarters (n=39). The hospitals were all based in the United Kingdom and were divided by region to evaluate any differences. Details of the questionnaire were not clearly reported in the paper. Respondents were asked for their opinion regarding the potential benefits of emergency identification schemes, although it is not apparent whether these were recorded using a Likert scale (or similar) or as free text.

Responses indicated that 97% of ambulance personnel and 71% of A & E personnel who responded to the survey stated that they routinely search for body worn medical alerts. Most respondents (99%) were aware of emergency identification schemes. More A & E department staff (88%) than ambulance operational directors (59%) reported having seen patients wearing medical identification in the past year.

The findings of this study were not reported in sufficient detail to allow full assessment of their significance regarding current practice among emergency personnel. The authors stated that “most personnel” perceived it to be important that people with hidden conditions wear or carry identification regarding those conditions. However the number who responded this way is not specified in the paper. Although it was reported that there were no statistically significant differences between occupations or across regional divisions, specific statistical results and significance levels were not reported.

### Community

Studies by Devor et al.<sup>[18]</sup> and Farrell<sup>[19]</sup>, suggested that wearing an alert or identifier for a medical condition is not something people generally tend to prefer. Devor et al.<sup>[18]</sup> reported on a study of 124 community dwelling frail older people (n=101 with dementia), who were participants in a comprehensive outpatient assessment program. Participants were provided with a number of suggestions, including (a) altering a living situation, (b) implementing an advanced directive for health care, (c) attending day care, (d) wearing a medical alert bracelet, (e) instituting home safety techniques and (f) using external support services. Compliance with wearing a medical alert bracelet was evaluated by a brief (5 – 10 minute) telephone survey, administered by a physician and a geriatric nurse specialist, using a specifically designed interview protocol. Responses were rated by the two interviewers conducting a conference call and simultaneously recording responses. Interrater reliability on responses was reported to be 89.7%. Reasons for non-compliance with recommendations were recorded as free text, and later coded.

Over half (57.5%) who were given recommendation (d) complied with wearing a medical alert bracelet. Higher cognitive impairment and lower function were associated with higher compliance with wearing a medical alert, although not significantly. The authors suggested this may be due to “*greater willingness of caregivers to accept recommendations when emotionally stressed by caring for the cognitively disabled*” (p. M171) or that “*patients and caregivers may only appreciate the need to comply as the disability caused by the dementing illness’ progress*” (p. M171). The most common reason for non-compliance (stated by 61.2% of respondents) was there was seen to be no need to wear the medical alert.

This was one of the few studies that investigated medical identification (medical alert bracelet) by itself, even though it was instituted as part of an outpatient comprehensive geriatric assessment program with other interventions. It was noted that there was a non-significant association between compliance with wearing the bracelet and higher cognitive and functional impairment. This implied that if people felt they had a choice, they might not choose to wear a medical alert bracelet.

To investigate the prevalence of wearing medical identification for diabetes, Farrell<sup>[19]</sup> surveyed six men and 12 women with insulin-dependent diabetes. Less than half (n=8) reported that they wore medical identification. Many of the concerns about wearing medical identification that were reported by participants related to feelings of being stigmatised or finding the jewellery unattractive. Some of the concerns were encapsulated in the following responses:

*“Medical ID is not attractive, and it’s psychologically labelling”*

*"I use a wallet ID card. I can update it and fill it out myself, it costs nothing and I don't feel branded by diabetes"*

## **Appropriateness of a symbol for dementia**

Both staff and health consumers seem to have largely positive perceptions and attitudes towards the use of a symbol for dementia. A small, subtle, abstract design appears to be the most acceptable. Stigma was identified as an issue by some groups<sup>[13]</sup> however this was not seen as outweighing the benefits, though fear of stigmatisation was seen as a factor in deciding the appropriateness of marketing and promotion of a symbol.

## **Perceptions and attitudes**

### **Quantitative Studies**

One pre- and post-test quantitative study<sup>[21]</sup>, one retrospective audit<sup>[22]</sup> and one case-control study<sup>[23]</sup> provided data for this research question.

### **Acute care**

The implementation of the CII program at BHS was evaluated by the Lincoln Centre for Ageing and Community Care Research in a report published in April 2005<sup>[21]</sup>. A pre and post survey design, completed by clinical and non-clinical staff, and carers, was used for this evaluation. The survey was completed pre-implementation by 170 (85%) of the 200 staff who were sent surveys. The majority of staff who completed the surveys were direct care workers such as nurses, allied health and medical staff (62%), with the remaining respondents being cleaners and other environmental service, engineering and security staff. Questions were asked under a number of domains, and included rating their confidence, level of comfort and degree of job satisfaction in dealing with patients with cognitive impairment (specifically dementia, delirium and memory or thinking difficulties). Ratings of confidence and comfort and satisfaction levels were made using a 5 point scale; 1 = very low; 2 = low; 3 = satisfactory; 4 = high; 5 = very high.

Following attendance at education sessions, the identical survey was distributed to 200 staff in April and June 2004 to evaluate any shifts in perceptions. Completed surveys were returned by 82 (41%) of staff. Increased ratings of confidence, level of comfort and level of job satisfaction when dealing with people with dementia, delirium and memory or thinking difficulties were reported by both direct and non-direct care staff.

In April 2004, all staff who participated in the education program were also given the opportunity to complete a survey regarding their perceptions of the CII. Most direct care staff (83%) and non-direct care staff (62%) reported having had some contact with the CII. Furthermore, frequency of contact was high, with 38% of direct care staff and 27% of non-direct care staff reporting they came into contact with the CII on a daily basis. Both direct care (79%) and non-direct care staff (61%) reported that the CII impacted upon the manner in which they interacted with the patient. Changes in interaction included paying greater attention to their communication, displaying more tolerance and understanding, and lowering their expectations of the patient's capabilities.

The CII was reported to have far less impact on the way staff interacted with carers however; 43% of direct care staff and 29% of non-direct care staff responded positively to the question "Did seeing the Cognitive Impairment Identifier change the way you interact with others?". Of the 122 respondents, 28 (23%) reported that they were more likely to involve carers, and were more likely to use carers in communicating with patients and provide them with

information regarding the patient's progress. Increased understanding of the carer's role was also reported.

### **Residential and/or community care settings**

Few studies were identified that discussed the utility of a symbol in the general community. However some support for a symbol comes from analyses of the Safe Return (SR) program facilitated by the United States Alzheimer's Association. Registrants in the SR program are provided with identification bracelets that state they have a memory problem, and are inscribed with a 24-hour toll free emergency hotline number. Rowe and Glover[22] analysed 675 files collected by the SR program between January 1997 and January 1998 that documented the registration, discovery and number of people who went missing. The mean age of discovered people was 77.8 years ( $\pm$  8.3), with ages ranging from 48 years to 102 years. Just over half (51.3%,  $n$  = 331) were male. A large proportion (35.8%) of the discoveries of people with dementia was made by Good Samaritan.

A study which compared whether people with dementia have more way-finding problems than controls, provided some very weak evidence for use of a dementia symbol on signs in the community<sup>[23]</sup>. The researchers reported that the people with dementia in their sample all had early stage dementia. The controls used in the study were already control participants in a prospective study (Oxford Project to Investigate Memory and Aging – OPTIMA), all of which had been previously screened as not having dementia. All participants were aged 60 or older and capable of taking outside walks. Each participant was accompanied by two others on a walk of the participant's choosing. One researcher walked with the participant and asked questions concerning the route taken and what way-finding techniques the participant was using. The second researcher walked behind and noted obstacles, signs and behavioural cues, as well as the participant's responses to stimuli. It was reported that people with dementia were just as likely as the controls to use signs in way-finding. One participant made the following comment about a sign that appeared in his community, which he used in his way-finding:

*'I know the colour and the little symbol' (p279)*

The development of a symbol to represent dementia may be seen as more appropriate if persons with dementia are able to understand what it represents. This study would tend to indicate that, at least in the early stages of the disease, persons with dementia are able to recognise signs and symbols and understand their meaning.

### **Qualitative Studies**

Four qualitative works (or mixed-method works with a qualitative component) provided data to answer this question. These were three focus groups<sup>[9, 13, 24]</sup>, and one survey utilising qualitative questions<sup>[25]</sup>.

### **Acute Care**

Ballarat Health Services (BHS) in Victoria has been working on the concept of a Cognitive Impairment Identifier (CII) since 2003<sup>[14]</sup>. The CII, which is copyright to BHS, has been adopted for bedside use by seven other Victorian acute care providers; Austin Health, Barwon Health, Broadmeadows Health Service, Latrobe Regional Hospital, Melbourne Health, Northeast Health Wangaratta and St Vincent's Health.

Separate focus groups conducted with carers from Greek and Italian backgrounds through St Vincent's Health (Melbourne) provided insight into how people from culturally and linguistically diverse backgrounds perceived a symbol for dementia<sup>[13]</sup>. Although participants were carers whose relatives with dementia were either in residential care or receiving a Community Aged

Care Package, this study is reported as providing evidence for the appropriateness of a symbol for dementia in acute care, as the questions asked related to the acute care setting. Five carers of Greek ethnicity participated in a focus group on 15 February 2007. All participants reported having previously seen bedside signs denoting 'nil by mouth' or falls risk. No negative effects were identified when they were specifically asked what problems might exist about using the signs. None in the group expressed any concerns about the CII being seen as a label, and many supported the use of the CII being worn on the individual with dementia, as a badge or a pin.

Interestingly, these sentiments were not universally shared by members of a focus group held with four carers of people with dementia who were of Italian background. Participants in this group all stated that they did not wish for people other than staff to know what the CII symbolised and there was concern that other people might 'make fun' of a patient with a bedside CII. They did acknowledge, however, that over time, visitors would probably become aware of what the CII stood for, and agreed that any benefits from displaying the CII would outweigh any negative effect. Overall, there was general consensus amongst members of this group, regarding the utility of a CII amongst members of this group. However, a public campaign to market the CII was not seen as an appropriate activity by the Italian focus group members.

A second project at an Australian acute care setting to also use an abstract symbol for dementia was conducted at Ballina Regional Hospital. Photographs or stamps of pelicans were used by Taylor et al.<sup>[25]</sup> in their study, which aimed to develop a better practice model for the management of people with dementia. It was noted that identifiers other than pelicans could be used if preferred, although whether or not other identifiers were actually used was not reported. A baseline survey was completed by 12 members of staff in June 1997 where staff were asked (Q1) what they believed was done well for patients with dementia; (Q2) how difficult they found caring for patients with dementia and (Q3) what ideas and suggestions they had for helping with these difficulties. A long list of ideas was generated in response to these questions, none of which specifically referred to the introduction of a symbol for dementia. Data collection proceeded over an 18 month period and included evaluating (and where appropriate, redesigning) ward protocols, policies, procedures and forms.

The study resulted in the development of Flagging Procedures, meaning that patients admitted through Accident and Emergency had a pelican stamp (or other agreed identifier) placed on their outpatient record. The patient was also physically flagged as having dementia by being given a blue armband (or agreed identifier) to wear, and a pelican photo (or agreed identifier) being displayed above their bed. Taylor et al.<sup>[25]</sup> noted that these procedures were not used only to flag people with dementia, but also people with acute confusion or delirium.

A second, post-implementation survey was completed by 12 staff respondents, who were asked the same questions as listed previously. When asked what they felt the Hospital was doing well for inpatients with dementia, six responded positively to the patient identification labels, wrists bands and pelican photos. An interview with two staff members provided the following feedback:

*"New staff are getting involved as well...People know...you've always got people asking about pelicans and what that means. So they're more aware of the dementia client as such, and the aged. They're keen to be involved and to take part in anything that's happening...So I think overall, care has definitely improved". (p171)*

*"And...the pelicans...on the bed, for the nursing staff to know that these patients are feeling some sort of...confusion...or some type of dementia...The blue band that they wore on their arm...that was good..." (p172)*

A pilot study funded by the Western Australian Country Health Service (WACHS) was aimed at improving the care of people with dementia and their carers included the use of a forget-me-not flower (Appendix 14) to symbolise dementia<sup>[24]</sup>. An action research approach was taken to develop, pilot and evaluate a care pathway for people with dementia who were admitted to acute care. Initially, an audit was conducted of documentation associated with inpatients with dementia was conducted. In addition, focus groups were conducted with both carers of people with dementia (to identify issues), and staff (to identify gaps in dementia knowledge as well as their experiences of caring for someone with dementia). In the second, third and fourth phases, the care pathway was drafted and piloted, and evaluated. As part of this process, it was concluded that an alert symbol for dementia, chosen to be a forget-me-not flower, should be placed in the front of patients' files, on nursing care plans, and as a magnet above the bed or on the patient allocation board at the nurses' station.

For people to have the symbol (which is still in use in the Great Southern region) displayed, they must have had a diagnosis of dementia, made by a general practitioner on admission or else during a prior admission. Family members were not involved in the decision to display the symbol, although they were made aware of what the symbol represented. At the time of personal communication with one of the researchers in October 2007, no complaints or requests to remove the symbol had been received<sup>[26]</sup>.

Another aspect of symbols/alerts/identifiers that was identified in this study was the question of whether prompts should be placed on the reverse side of signs. Focus group participants of Italian background suggested that prompts at the back of the symbol could include checking whether the person with dementia has a hearing aide or not. The specific wording suggested was "Ensure hearing aides are used and working as required". Carers in the focus group of Greek background suggested it might be beneficial to add "Use an interpreter if indicated" on the back of the sign<sup>[13]</sup>.

### **Residential and Community Care**

People in the community seem to be in favour of some kind of identifier, though the specifics of what type is most acceptable is not clear. Participants in a qualitative study by Robinson et al.<sup>[9]</sup> were not in favour of tagging and tracking devices. However, they did indicate an acceptance of identity cards. Robinson et al. conducted two discussion groups with formal carers (n=10), and one each with lay carers (n=3) and people with mild dementia (n=6). The three lay carers had all had experienced wandering in the person with dementia whom they cared for. Participants were presented with the findings of a systematic review conducted by Robinson and colleagues<sup>[9]</sup>, which investigated the effectiveness and ethical/acceptability issues of non-pharmacological interventions to prevent people with dementia from wandering. Of relevance to this systematic review, were comments made by people with dementia with regard to tagging and tracking devices. Participants felt such devices could be embarrassing if they emitted electronic noises, and strongly preferred a familiar 'intervention', such as identity cards, which were carried by many in the World War II.

The Ballarat Health Services CII<sup>[14]</sup> was developed as part of an all-of-hospital education program intended to improve the awareness of and communication with people with dementia. Semi-structured interviews were held with participants recruited from the local Alzheimer's Australia support group (Grampians region) to evaluate the acceptability of a cognitive impairment identifier. Of the 39 participants, 37 found the concept of such an identifier to be acceptable. Placement of an identifier at the patient's bedside, as opposed to placement on clothing, was strongly preferred by 32 of the 37 participants who responded positively to the use of an identifier.

### **Textual Data**

Three textual works refer at least in part to this research question. Two textual analyses<sup>[22, 27]</sup>, and one article from a national organisation<sup>[28]</sup> provide some low-level evidence.

### **Residential and Community Care**

An analysis<sup>[27]</sup> of newspaper reports regarding approximately 50 incidents between 1998 – 2002 concerning people with dementia who became lost and were discovered dead was conducted. Among other findings, it was noted that Good Samaritans (i.e. one who voluntarily helps someone else who is in distress) were most likely to have discovered the body (18 cases, out of 40 cases which included information regarding the finder). Rowe and Glover<sup>[22]</sup> recommended that “*public awareness media campaigns about the problem of unattended wandering, including information on looking for and recognising the safe return bracelet or ID card*” (p. 352) should be conducted. This study also found that the settings from which people most commonly disappeared (17.9% of 146 cases) were day care, nursing homes or other care-giving facilities. The authors made the point that:

*“...even with sophisticated monitoring systems available in professional settings, CI individuals living in these remain at risk of unattended wandering. It is apparent that CI persons in all situations are at risk” [22].*

This seems to provide some conceptual support for the notion that people with dementia in residential aged care facilities may benefit from wearing an identifier.

In 2005, the Alzheimer’s Foundation of America and MedicAlert® developed an identification bracelet specifically for people with dementia. The bracelets, which feature the internationally recognised caduceus, have now been coloured teal (in contrast to the traditional red), to make them specific to Alzheimer’s disease, which is said to be the internationally recognised colour of Alzheimer’s disease. It is said to be the first time that a Medic Alert bracelet has been coloured differently to symbolise a specific condition<sup>[28]</sup>. This appears to highlight the perceived importance of being able to identify dementia. However, the current review did not identify any studies which investigated the opinions towards or effect of colouring of the caduceus. This magazine article is included however, because of its direct relevance to the review question.

### **Issues pertinent to the use of a symbol to alert people to the fact someone has a dementia and/or delirium**

There are several issues involved with the use of a symbol for dementia and/or delirium. The design of the symbol itself needs to be meaningful, unique and respectful of dignity and privacy. Identifying a person as suffering from any particular medical condition may put them at risk of stigmatisation or depersonalisation and the more well-known the symbol is, the higher that risk may be. Conversely, a symbol which is not known by the people it is intended to alert cannot be effective either. If a symbol for dementia is developed and introduced, it seems clear that it should be an option for people with dementia and their caregivers/ decision-making proxies, and not a requirement.

### **Colours, shapes and symbolism**

#### **Qualitative Studies**

Three qualitative studies<sup>[13, 24, 25]</sup> reported data in relation to this aspect of the review.

Four themes were identified in relation to style, colour, shape and size regarding the acceptability of a symbol for cognitive impairment in this study. With respect to style, focus

group participants strongly preferred an abstract design. When provided with prototypes which included a symbol of a brain, and maze-like shapes, participants made comments such as:

*“...it is too focused on deficiencies”*

*“We don’t want it to look like someone is losing their mind”*

*“...it generates negative feelings”*

Subtlety was preferred, when colour of an identifier was being discussed and there was consensus that the identifier should not be too prominent. Participants made comments such as:

*“...the colours need to be subtle and friendly”*

*“...there are enough red and yellow signs already, this one needs to be different”*

The colours that were eventually selected for the CII were two shades of blue – navy and teal. Nearly all (36 out of 39 participants) chose a blue prototype. Twenty-two chose Model 1, which is identical to the currently used CII, although the ball was originally red, not navy. The prototype was re-coloured to shades of blue, based on this being the preference of 19 of the 22 participants who favoured Model 1. Blue is also the colour of the forget-me-not symbol<sup>[24]</sup> while the colour of the caduceus on Medic Alert ® items that are specifically used in the United States for people with dementia is teal. In addition, the armbands used in Taylor et al.’s<sup>[25]</sup> study were blue. A suggestion made by one focus group participant of Greek ethnicity was that the symbol could appear in a different colour, to indicate if the person with dementia did not speak English<sup>[13]</sup>.

In terms of the preferred shape of the CII, the majority of focus group participants (n = 16) could not decide, although there were 15 who requested that the CII be round. Participants made comments such as:

*“...it is more comforting that shape”*

*“...it isn’t as sharp and looks more soft and gentle”*

*“...it’s too much like a box if it’s square”*

Two of the other cognitive impairment symbols identified in this study, the forget-me-not flower and the pelican, also had soft edges.

With respect to sizing of the CII, small and low prominence was strongly preferred by 21 of the participants. Participants made comments such as:

*“I don’t want everyone to know...they aren’t the ones with dementia”*

*“...needs to be kept the same size as the others”*

In the second phase of the Ballarat Health Services study, the research involved eliciting verbal descriptors of an identifier, to assist the graphic designer in creating identifier prototypes<sup>[14]</sup>. Nearly all of the original participants (37 out of 39) were able to participate in a second focus group, where they were presented with prototypes developed by the graphic designer. The agreed upon CII features a solid navy blue coloured ball in the top left hand corner, with teal coloured lines going radiating from it, creating an overall circular shape (Appendix 12). When asked what the CII seemed to represent, focus group members responded that it seemed to symbolise shared contributions to a common goal; and a similarity to a lighthouse; or a shining beacon. Comments made by the group regarding the

acceptability of the symbol design were divided into four themes which are discussed later in this review.

## Stigma

### Textual Data

*One opinion-based work<sup>[29]</sup> reported data directly relating to stigma as associated with the wearing of hospital identification.*

In the design and use of any symbol for dementia, care must be taken that the dignity of people with dementia and their carers is not compromised. Stigma associated with physical identification was a key concern of some mental health professionals in a case study reported by Aspinall<sup>[29]</sup>. The patient reported upon was a 65 year old man, with possible dementia, who absconded from a specialised psychiatric unit in a London hospital. He was located six days later and shortly after that, he suffered a fatal cardiac arrest. It was later found, that during the time of his abscondment, he had presented at the casualty department of another hospital. Aspinall described the man as appearing physically well and suggested that “*with hindsight, if he had been wearing something identifiable such as an identification bracelet, staff there [in the casualty department] could have alerted the unit*” (pg 116). He also noted the absence of a policy regarding patient identification and labelling, on the ward from which the patient absconded. Aspinall goes on to suggest that:

*The idea that psychiatric patients should be asked to wear identification bracelets may cause conflict in nurses who could see this as stigmatising the patient or as an infringement of civil liberties. However, bracelets are unobtrusive and can carry sufficient information for a member of the public or fellow health worker to identify and facilitate the patient's return to safety. (p 117)*

### Qualitative Studies

One qualitative study utilising focus group methodology<sup>[13]</sup> reported data on stigma associated with the wearing or use of a symbol for dementia.

Focus group participants from the Ballarat Health Services study identified stigma as a concern for them regarding the use of an identifying symbol for dementia<sup>[13]</sup>. Common themes from this discussion group were the need for privacy – not publicising the symbol's meaning to minimise the risk of persons with dementia being ‘made fun of’ or having hospital visitors know what was wrong with the person. But other viewpoints were also expressed such as this one:

*“I would like the symbol to be on a pin so that my father could wear it for everyone to know that he has a problem with his memory. He is fascinated by people's hair and sometimes his behaviour can be embarrassing. It would be good for people to know without me having to explain all the time”*

It may be inferred from the participants' responses that while the risk of stigmatisation is a concern for them, the benefit of the person's condition being conveyed without constant explanation or misunderstanding may outweigh it.

### Promotion and awareness

We found little available data regarding this objective. Six works made some reference to this aspect and we were able to include data from the quantitative components of three studies<sup>[14, 24, 25]</sup>, the qualitative component of one study<sup>[13]</sup> and two textual works<sup>[22, 29]</sup>.

## Public awareness and marketing

### Qualitative Studies

Carers from an Italian cultural background (n=4) who participated in the focus groups conducted by Behm<sup>[13]</sup> were not in favour of public awareness marketing campaigns about the symbol. They did acknowledge however that over time, people would learn what the symbol represented, although they strongly preferred that only staff be directly educated about its meaning.

*“Only staff and family should know.” (p.7)*

### Quantitative Studies

A factor which was found to facilitate effective use of the CII in the Ballarat CII project was the marketing of the symbol throughout the hospital<sup>[14]</sup>. This project found that promotion of the symbol increased public awareness and acceptance.

### Textual Data

Rowe and Glover<sup>[22]</sup> recommended that “*public awareness media campaigns about the problem of unattended wandering, including information on looking for and recognising the safe return bracelet or ID card*” (p. 352) should be conducted.

## Staff education

Education for staff regarding the use of any symbol for dementia would be a vital part of the introductory period. Most of the educational activities discussed in the included studies referred to educating staff about dementia, rather than the use of a symbol or identifier; however we were able to include the quantitative component of three studies<sup>[14, 24, 25]</sup> and the qualitative component of one<sup>[25]</sup>.

### Quantitative Studies

An objective of the Ballarat CII<sup>[14]</sup> project was to develop and implement an educational program to accompany the introduction of the identifier. Seventy-nine percent of staff respondents reported the education program and use of the identifier changed the way they interacted with patients and 43% reported that it changed the way they interacted with carers.

Studies used a variety of educational strategies to inform staff about use of the identifiers; workshops, notice-boards, videos, and inservice education sessions were utilised in the various settings.

### Qualitative Studies

Semi-structured interview questions were used by one study<sup>[25]</sup> to examine staff perceptions and attitudes regarding the education that accompanied the identifier’s introduction. Staff found both helpful and stated:

*“And...the pelicans...on the bed, for the other nursing staff to know that these patients are feeling some sort of...confusion or some type of dementia...”*

## Decision making considerations

Consent would appear to be an important issue when the use of a symbol or identifier is considered. Two works addressed this issue, one opinion piece<sup>[29]</sup> and one qualitative study<sup>[13]</sup>.

### **Textual Data**

Consideration should be given to including family members in the decision to display a symbol for dementia. Aspinall<sup>[29]</sup> advocated for the inclusion of family members in the decision to use identification:

*“There is no reason why relatives should not be involved in the decision of whether their vulnerable relative wears a bracelet” (p 117) <sup>[29]</sup>*

### **Qualitative Studies**

The five carers from a Greek cultural background who participated in one focus group <sup>[13]</sup> unanimously supported the CII as a bedside identifier. They felt that it was implicit that permission would always be sought from the person with dementia or carer before the symbol was displayed. Similarly, the four carers of Italian descent in the focus group unanimously reported that they would want permission asked of them first.

## **Findings**

The projects discussed in this review were similar in that they used a symbol not overtly associated with dementia or cognitive impairment. The forget-me-not flower<sup>[24]</sup> was the most closely associated with dementia or memory problems, and even then, not everyone would immediately make the association or even recognise the type of flower. Placement of the symbol varied, including at bedside<sup>[14, 24, 25]</sup>, on armbands<sup>[22, 25, 30]</sup>, whiteboard at nurse's station<sup>[24]</sup>, patient files/care plans<sup>[24, 25]</sup>, or on an identification card<sup>[9]</sup>. Permission to display the symbol was either sought or seen as necessary in the majority of studies<sup>[13, 14, 25]</sup>. All of the studies which developed and implemented a dementia symbol in acute care<sup>[14, 24, 25]</sup> included a staff educational component. None reported any negative outcomes from using their respective symbol.

A symbol for dementia has specific issues regarding stigmatisation, potential to increase the vulnerability of the wearer to crime, or expose them to ridicule or discrimination, so that it is difficult to make a definitive recommendation regarding its appropriateness. The possibility that wearing a symbol which clearly identifies cognitive impairment would make people even more susceptible to crime and exploitation should be considered. However no study that met the inclusion criteria was identified that investigated this area. Given the above findings, it is recommended that before the introduction of a dementia or delirium symbol, the following issues should be addressed:

- Ensuring that the benefits outweigh the risks
- Appropriate community education is conducted
- Any introduction of a symbol should be done as part of facility-wide education programs
- Further research into the cultural appropriateness of a symbol for dementia is suggested

According to the documents explored in this review, there are several factors which are likely to lead to greater acceptability of a symbol/alert/identifier for cognitive impairment. These include:

- The use of an abstract symbol or symbol not immediately associated with dementia<sup>[13, 14, 24, 31]</sup>

- Keeping the size of the symbol small <sup>[14]</sup>
- Making the symbol a non-angular shape <sup>[14]</sup>
- Blue appears to be an acceptable colour <sup>[14, 24, 25]</sup>
- Using examples may help people decide acceptability of an idea <sup>[14, 32]</sup>
- Inclusion of family members/significant others etc in discussions <sup>[13, 29]</sup>
- Introduction of the symbol in conjunction with staff education <sup>[14, 24, 25]</sup>
- Familiarity <sup>[9]</sup>
- A symbol for dementia seems acceptable for use in Australian acute care settings <sup>[14, 24]</sup>

## Discussion

This systematic review has attempted to explore the literature regarding symbols/alerts/identifiers for dementia across all settings, as well as for delirium in the acute care setting. Whilst alerts or identifiers such as the Medic Alert ® have been in existence since the 1950s, few publications were identified that specifically discussed their appropriateness. There seemed to be broad consensus among the studies that using a symbol for dementia and/or delirium in the acute setting is appropriate and would be accepted by staff, carers and people with cognitive impairment in a range of situations. By far, the most comprehensively researched and reported upon symbol was the Cognitive Impairment Identifier (CII) that was developed by Ballarat Health Service. This project included the development of symbol prototypes and has been embedded into at least eight acute care facilities in Victoria to date. However, views expressed by people of culturally and linguistically diverse backgrounds suggest that further research would be needed to ascertain the cultural appropriateness of such a symbol.

The use of symbols is not a new concept. Cowgill and Bolek <sup>[33]</sup> discussed different types of symbol categories. One category they identified is “*image related/form/pictorial/ concrete, which includes resemblance or use of analogous images*” (p 1.7). These symbols are *deliberately* intended to pictorially depict that which they are symbolising. An example is the aeroplane symbol used on road signs, to denote airports. A second category is “*concept related/arbitrary abstract when the image “has no relationship to the referent. “Referent” in this case means the subject represented by the graphical symbol*” (<sup>[34]</sup> cited in <sup>[33]</sup>, p 1.7). An example provided by the authors includes the biohazard symbol; “*unless you are told what it means, it is just a combination of some pointed shapes*” (<sup>[33]</sup> p 1.7).

Cowgill and Bolek <sup>[33]</sup> also reported on a project which evaluated the use of symbols in medical settings. They sent requests for information to approximately 275 graphic designers and medical practitioners internationally, and received around 40 responses. They reported finding that symbols appear to be an effective way to communicate across cultures. However, the focus of research supporting this has been mainly conducted on symbols for transportation, recreation and sports <sup>[33]</sup>. In their report, Cowgill and Bolek <sup>[33]</sup> discussed how differences between cultures can impact on the comprehension of a symbol. Differences may relate to meanings associated with colour, language, gender and even numbers (e.g. the number 13 is seen as unlucky in Western cultures, while the number eight is seen as lucky in Chinese cultures). Even the traditional Western “ladies” restroom symbol is not straightforward when one considers that traditional Scottish male clothing includes a kilt, and men of many other countries wear flowing clothes <sup>[33]</sup>. For these reasons, this systematic

review also includes any studies that investigated the cultural appropriateness of a dementia symbol.

Identifiers for cognitive impairment that are already used in some Australian acute care settings have tended to take the abstract approach. Ballarat Health Services began working on the concept of a Cognitive Impairment Identifier (CII) in 2003 to identify the presence of conditions such as dementia and delirium. An extensive literature search conducted as part of the Ballarat project did not identify any previous use of an alert for cognitive impairment in the acute care setting<sup>[14]</sup>. Other more abstract symbols to identify cognitive impairment that were identified in the current systematic review include a pelican<sup>[25]</sup> and a forget-me-not flower<sup>[24]</sup>.

In 2005, the Alzheimer's Foundation of America and MedicAlert® developed an identification bracelet specifically for people with dementia. The bracelets, which feature the internationally recognised caduceus, have now been coloured teal (in contrast to the traditional red), to make them specific to Alzheimer's disease. Teal is said to be the internationally recognised colour of Alzheimer's disease<sup>[35]</sup>. However, this review did not identify any studies which investigated opinions regarding colouring the caduceus.

Countries such as Australia and the United States run programs in which registrants are provided with a medical alert bracelet that is inscribed with wording saying that they have dementia, as well as a toll-free number for someone to call if the wearer appears to require assistance. The program used in the United States is called Safe Return. Rowe et al.<sup>[36]</sup> looked at the combined findings of one study which analysed Safe Return data<sup>[22]</sup> and two that analysed newspaper reports about people with dementia who became lost and were found dead<sup>[36, 37]</sup>. The age of people with dementia who became lost ranged from 42 to 102 years. The period between time when registered with the Safe Return program, and time when the person with dementia went missing ranged from one month to more than five years. Rowe et al.<sup>[36]</sup> interpreted these findings as providing evidence that all people with dementia are at risk of becoming lost, irrespective of age and severity of dementia.

An important consideration is the potential application of a dementia symbol in emergency and disaster situations. In the immediate aftermath of Hurricane Katrina in Louisiana in 2005, workers experienced difficulty in the timely identification of the special needs of some older people. This resulted when older people with dementia appeared to be in good health or, were simply unable to communicate effectively because of cognitive or sensory impairment<sup>[38]</sup>. In emergency situations, it is common for healthcare staff to search for any alerts that indicate individuals have health conditions. One study reported that 97% of ambulance personnel and 71% of accident and emergency personnel routinely search for body worn medical alerts<sup>[17]</sup>.

It may be that even non-healthcare workers could be assisted by a symbol for people with dementia. Following the hurricanes experienced in the United States, a coalition of long-term care and consumer organisations convened to develop dementia care guidelines for disaster situations<sup>[39]</sup>. The guidelines are intended for lay people, unlicensed staff and volunteers, and are in recognition that people with dementia have special needs, which cannot be ignored in time of crisis or emergency, regardless of whether properly trained medical staff are available<sup>[40]</sup>. The means to identify people with dementia, even by people who are not healthcare professionals, may improve the efficiency and effectiveness of a rescue effort. A dementia symbol would not necessarily have to be limited to healthcare settings. Other service settings, such as banks and public transport, could display a dementia symbol to indicate that they have specialised ability to assist someone with dementia. This could be similar to a Victorian Government Initiative; the development and implementation of an Interpreter Symbol<sup>[41]</sup>. This symbol is available for display in settings such as client contact

areas (e.g. reception desks), public areas (e.g. corridors, main entrances), client files or on staff name cards or badges (e.g. to indicate a bilingual staff member).

Although most of the documents explored in this review were published papers and reports, many of the papers were unpublished reports, which were identified through internet searches or word of mouth. There remain many gaps in the current research in this field and this has necessarily limited the results of this review. Finally, it is acknowledged that there may be other studies internationally and perhaps in languages other than English, that have addressed the issue of a symbol for dementia and that we have not been able to include in this review.

## Implications for practice

The introduction of a symbol for dementia would have the following implications for practice:

- Education for nurses and other hospital staff should accompany any implementation of a symbol to identify cognitive impairment
- A consent process should be developed for the use of the symbol with individual patients
- The consent process should necessarily involve not only the patient, but their family or next-of-kin, especially when the patient's ability to give informed consent is impaired
- Processes should be in place to preserve the person with dementia's dignity, privacy and personhood

## Implications for research

Further research into the appropriateness of a symbol for dementia should focus on the following:

- Investigation of cultural appropriateness, as only one study was identified which investigated whether people of culturally and linguistically diverse backgrounds find a symbol for dementia appropriate
- Investigation of appropriateness of a symbol for people of Aboriginal and Torres Strait Islander background
- Investigation of how appropriate and helpful people who provide commonly used services such as public transport and banking would find a symbol for dementia
- Investigation of whether a large scale marketing campaign should be conducted, if a dementia symbol was to be introduced by government
- Investigation of whether displaying a body worn symbol for dementia makes the wearer more vulnerable to crime and exploitation
- Investigation of appropriateness of using a dementia symbol in residential aged care facilities.
- Investigation of how appropriate and helpful people with dementia and their carers would find displaying such a symbol in their own home (for the benefit of, for example, home help workers, emergency workers etc)

## Conclusion

Although there are a range of reasons why a dementia symbol may be useful and helpful, care must be taken in the design and use of any symbol for cognitive impairment to ensure that the dignity of people with dementia or their carers is not compromised. As Jennings<sup>[6]</sup> acknowledges in his essay, "requiring all persons diagnosed with Alzheimer's disease to carry a special kind of identification card..."(p 597) is not uncontroversial. According to Astell<sup>[42]</sup> the "fundamental issue in dementia care"(p 18) is whether an intervention is empowering or dehumanising to a person with dementia.

## Potential conflict(s) of interest

This systematic review is supported by a research grant from Alzheimer's Australia and funded by the Department of Health and Ageing.

## Acknowledgements

The feedback and provision of information by the Steering Committee Members is acknowledged. Thanks are extended to all who made material regarding their projects available – Anne Moehead (North Coast Area Health Service), Ms Jenny Rodwell (Coffs Harbour Base Hospital), Ms Jaklina Michael (Royal District Nursing Service, Melbourne), Ms Christine Behm (St Vincent's Hospital, Melbourne), Dr Mark Yates (Ballarat Health Service), Ms Wendy McIntosh (Western Australia Country Health Service – South West), Professor Bev Taylor (Southern Cross University) and Associate Professor Barbara Horner (Centre for Research On Ageing, Curtin University of Technology). The advice of Mrs Lynn Evans, Liaison Librarian, Queensland University of Technology regarding the development of the database searches is acknowledged.

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## Appendix 1

### JBI-QARI Critical Appraisal Form

**Author:** \_\_\_\_\_ **Record No:** \_\_\_\_\_

**Journal:** \_\_\_\_\_ **Year:** \_\_\_\_\_

**Reviewer:** \_\_\_\_\_

Criteria	Yes	No	Unclear
1) There is congruity between the stated philosophical perspective and the research methodology			
2) There is congruity between the research methodology and the research question or objectives			
3) There is congruity between the research methodology and the methods used to collect data			
4) There is congruity between the research methodology and the representation and analysis of data			
5) There is congruity between the research methodology and the interpretation of results			
6) There is a statement locating the researcher culturally or theoretically			
7) The influence of the researcher on the research, and vice-versa, is addressed			
8) Participants, and their voices, are adequately addressed			
9) The research is ethical according to current criteria or, for recent studies, there is evidence of ethical approval by an appropriate body			
10) Conclusions drawn in the research report do appear to flow from the analysis, or interpretation, of the data			

### TOTAL

Reviewers Comments:

## Appendix 2

### JBI-NOTARI critical appraisal form

Author: \_\_\_\_\_ Record No: \_\_\_\_\_

Journal: \_\_\_\_\_ Year: \_\_\_\_\_

Reviewer: \_\_\_\_\_

Criteria	Yes	No	Unclear
1) Is the source of the opinion clearly defined?			
2) Does the source of the opinion have standing in the field of expertise?			
3) Are the interests of the patients/clients the central focus of opinion?			
4) Is the opinion's basis in logic/experience clearly argued?			
5) Is the argument developed analytical?			
6) Is there reference to the extant literature/evidence and any incongruence with it logically defended?			
7) Is the opinion supported by peers?			

Include: Yes / No

Reason:

## Appendix 3

### JBI-MAStARI critical appraisal form (descriptive studies)

Author: \_\_\_\_\_ Record No: \_\_\_\_\_

Journal: \_\_\_\_\_ Year: \_\_\_\_\_

Reviewer: \_\_\_\_\_

Criteria	Yes	No	Unclear
1 Was the study based on a random or pseudo-random sample?			
2 Were the criteria for inclusion in the sample clearly defined?			
3 Were confounding factors identified and strategies to deal with them stated?			
4 Were outcomes assessed using the objective criteria?			
5 If comparisons are being made, was there sufficient description of the groups?			
6 Was follow up carried out over a sufficient time period?			
7 Were the outcomes of people who withdrew described and included in the analysis?			
8 Were outcomes measured in a reliable way?			
9 Was appropriate statistical analysis used?			

Include: Yes / No

Reason:

## Appendix 4

### JBI MASTARI

#### Critical Appraisal of Evidence of Effectiveness

Reviewer \_\_\_\_\_ Date \_\_\_\_\_ Record No \_\_\_\_\_

Author \_\_\_\_\_ Year \_\_\_\_\_

1. Was the assignment to treatment groups random?  
Yes  No  Not clear  NA
2. Were the participants blinded to treatment allocation?  
Yes  No  Not clear  NA
3. Was allocation to treatment groups concealed from the allocator?  
Yes  No  Not clear  NA
4. Were the outcomes of people who withdrew described and included in the analysis?  
Yes  No  Not clear  NA
5. Were those assessing the outcomes blind to the treatment allocation?  
Yes  No  Not clear  NA
6. Were control and treatment groups comparable at entry?  
Yes  No  Not clear  NA
7. Were groups treated identically other than for the named interventions?  
Yes  No  Not clear  NA
8. Were outcomes measured in the same way for all groups?  
Yes  No  Not clear  NA
9. Were outcomes measured in a reliable way?



## Appendix 5

### JBI-QARI Data Extraction Form

#### Qualitative Data Extraction Tool

Author: \_\_\_\_\_ Record Number: \_\_\_\_\_

Journal: \_\_\_\_\_ Year: \_\_\_\_\_

Reviewer: \_\_\_\_\_

#### Methodology

##### Method

##### Data Analysis

##### Setting & Context

##### Geographical Context

##### Cultural Context

##### Participants:

*Number:*

*Description:*

##### Phenomena of Interest

**Findings****Narrative Description****Qual  
Evid.  
Rating  
1,2,3****Authors conclusion****Comments**

## Appendix 6

### JBI-NOTARI Data Extraction Tool

Author: \_\_\_\_\_ Record No: \_\_\_\_\_

Journal: \_\_\_\_\_ Year: \_\_\_\_\_

Reviewer: \_\_\_\_\_

Type of text:

Those represented:

Stated allegiance/position:

Setting:

Geographical:

Cultural:

Logic of argument:

Data analysis:

Author's conclusion:

Reviewers Comments:

## Appendix 7

### JBI-MAStARI Data Extraction Tool (descriptive studies)

Author: \_\_\_\_\_ Record No: \_\_\_\_\_

Journal: \_\_\_\_\_ Year: \_\_\_\_\_

Reviewer: \_\_\_\_\_

Method

Setting

Participants

# Participants

Interventions

Authors

conclusions

Reviewers

comments

## Appendix 8

### JBI Data Extraction Form for Experimental/Observational Studies

Reviewer \_\_\_\_\_

Date \_\_\_\_\_

Author \_\_\_\_\_  
No \_\_\_\_\_

Year \_\_\_\_\_

Record

**Study Method**RCT Quasi RCT Longitudinal Retrospective Observational Other **Participants**Setting \_\_\_\_\_  
\_\_\_\_\_Population \_\_\_\_\_  
\_\_\_\_\_**Sample size**Intervention 1 \_\_\_\_\_  
3 \_\_\_\_\_

Intervention 2 \_\_\_\_\_

Intervention

**Interventions**

Intervention 1 \_\_\_\_\_

Intervention 2 \_\_\_\_\_

Intervention 3 \_\_\_\_\_

**Clinical Outcome Measures****Outcome Description****Scale/measure****Study results****Dichotomous data****Outcome****Intervention ( )****Intervention ( )****Number/total number****Number/total number**

**Continuous data**

<b>Outcome</b>	<b>Intervention ( )</b>	<b>Intervention ( )</b>
	<b>Mean and SD (number)</b>	<b>Mean and SD (number)</b>

**Author conclusions**

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**Reviewer conclusions /comments**

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Include 
 Exclude 
 Seek further info

## Appendix 9

### Search strategies

#### **Set1: cognitive function**

DEMENTIA  
 DELIRIUM  
 DELIRIUM, DEMENTIA, AMNESTIC, COGNITIVE DISORDERS  
 ALZHEIMER'S DISEASE / ALZHEIMERS DISEASE  
 WERNICKE'S ENCEPHALOPATHY  
 AIDS DEMENTIA  
 dement\* / deliri\* / alheim\* / cognitive impairment / organic brain\*  
 Front\* temporal

#### **Set 2: identification**

EMBLEMS AND INSIGNIAS  
 Medic alert\* / tag\* / bracelet\*  
 logo\* / symbol\* / emblem\* / insignia\*  
 patient identification / identifier (not trial\* registration)  
 EMERGENCY MEDICAL SERVICE COMMUNICATION SYSTEMS

#### **Set 3: belief / perspective**

stigma\* / ethic\* / privacy / dignity  
 approp\* / accept\* / attitud\*  
 EMERGENCY MEDICAL TECHNICIAN ATTITUDES (CINAHL Heading)

#### **Set 4: setting**

Patient management / service delivery / patient safety  
 wander\* / sundown\*  
 NATURAL DISASTERS

### CINAHL

1. DEMENTIA
2. DELIRIUM
3. DELIRIUM, DEMENTIA, AMNESTIC, COGNITIVE DISORDERS
4. ALZHEIMER'S DISEASE
5. WERNICKE'S ENCEPHALOPATHY
6. AIDS DEMENTIA
7. dement\* or deliri\* or cognitive impairment or organic brain disease or alzheimer\*
8. 7 or 6 or 5 or 4 or 3 or 2 or 1

9. medic alert\* or tag\* or bracelet\*
10. EMERGENCY MEDICAL SERVICE COMMUNICATION SYSTEMS
11. logo\* or symbol\* or emblem\* or insignia\*
12. patient identification or identifier NOT trial\* registration
13. EMBLEMS AND INSIGNIAS
14. 13 or 12 or 11 or 10 or 9
15. appropri\* or accept\* or attitude\*
16. stigma\* or ethic\* or privacy or dignity\*
17. EMERGENCY MEDICAL TECHNICIAN ATTITUDES
18. 17 or 16 or 15
19. patient management or service delivery or patient safety
20. sundown\* or wander
21. NATURAL DISASTERS
22. 21 or 20 or 19
23. 22 or 18 or 14 or 8

## MEDLINE

1. DEMENTIA
2. DELIRIUM
3. DELIRIUM, DEMENTIA, AMNESTIC, COGNITIVE DISORDERS
4. ALZHEIMER DISEASE
5. AIDS DEMENTIA COMPLEX or DEMENTIA, MULTIE-INFARCT or DEMENTIA, VASCULAR
6. dement\* or deliri\* or cog\* imp\* or organic brain\* or alzhem\*
7. 6 or 5 or 4 or 3 or 2 or 1
8. EMBLEMS AND INSIGNIAS
9. logo\* or symbol\* or emblem\* or insignia\*
10. EMERGENCY MEDICAL SERVICE COMMUNICATION SYSTEMS or EMERGENCY MEDICAL TAGS
11. patient identification or identifier\* NOT trial\* registration
12. medic\* alert or tag\* or bracelet\*
13. 12 or 11 or 10 or 9 or 8
14. appropri\* or accept\* or attitud\*
15. stigma\* or ethic\* or privacy or dignity\*
16. 15 or 14
17. patient manage\* or service delivery or patient safety

18. sundown\* or wander\*
19. 16 AND 13 AND 7
20. 18 AND 13 AND 7
21. 17 AND 13 AND 7

## PSYCINFO

1. dementia
2. delirium
3. dementia or delirium or amnestic or cognitive disorders
4. alzheimers disease
5. wernickes encephalopathy
6. aids dementia complex
7. demen\*
8. demen\* or deliri\* or cognitive impairment or organic brain disease or alzheimer
9. logo\* or symbol or emblem or insignia
10. medic alert or tag or bracelet
11. emergency medical service communication system
12. aids dementia complex and wernickes encephalopathy and alzheimers disease and dementia or delirium or amnestic or cognitive disorders and delirium) and dementia
13. aids dementia complex and wernickes encephalopathy and alzheimers disease and dementia or delirium or amnestic or cognitive disorders and delirium and dementia
14. medic alert or tag or bracelet and dementia
15. patient identification or identifier and not trial\* registration
16. emblems and insignia
17. appropria\* or accept\* or attitud\*
18. patient management or service delivery or patient safety
19. emergency medical technician attitudes
20. stigma or ethic or privacy or dignity
21. sundown or wander
22. natural disasters
23. natural disasters and dementia
24. logo\* or symbol or emblem or insignia and dementia or delirium or amnestic or cognitive disorders and delirium and dementia
25. sundown or wander and demen\* or deliri\* or cognitive impairment or organic brain disease or alzheimer\*
26. demen\* or deliri\* or cognitive impairment or organic brain disease or alzheimer\* or aids dementia complex or wernickes encephalopathy or alzheimers disease or dementia or delirium or amnestic or cognitive disorders or delirium or dementia

27. emergency medical technician attitudes or emblems and insignia or patient identification or identifier and not trial\* registration or medic alert or tag or bracelet and dementia or logo\* or symbol or emblem or insignia
28. stigma or ethic or privacy or dignity or emergency medical technician attitudes or appropria\* or accept\* or attitud\*
29. stigma or ethic or privacy or dignity or emergency medical technician attitudes or appropria\* or accept\* or attitud\* and emergency medical technician attitudes or emblems and insignia or patient identification or identifier and not trial\* registration or medic alert or tag or bracelet and dementia or logo\* or symbol or emblem or insignia and demen\* or deliri\* or cognitive impairment or organic brain disease or alzheimer\* or aids dementia complex or wernickes encephalopathy or alzheimers disease or dementia or delirium or amnestic or cognitive disorders or delirium or dementia
30. stigma or ethic or privacy or dignity or emergency medical technician attitudes or appropria\* or accept\* or attitud\* and emergency medical technician attitudes or emblems and insignia or patient identification or identifier and not trial\* registration or medic alert or tag or bracelet and dementia or logo\* or symbol or emblem or insignia and demen\* or deliri\* or cognitive impairment or organic brain disease or alzheimer\* or aids dementia complex or wernickes encephalopathy or alzheimers disease or dementia or delirium or amnestic or cognitive disorders or delirium or dementia
31. demen\* or deliri\* or cognitive impairment or organic brain disease or alzheimer\* or aids dementia complex or wernickes encephalopathy or alzheimers disease or dementia or delirium or amnestic or cognitive disorders) or delirium or dementia and logo\* or symbol or emblem or insignia and dementia or delirium or amnestic or cognitive disorders and delirium and dementia
32. sundown or wander and demen\* or deliri\* or cognitive impairment or organic brain disease or alzheimer\* and logo\* or symbol or emblem or insignia and dementia or delirium or amnestic or cognitive disorders and delirium and dementia
33. sundown or wander and stigma or ethic or privacy or dignity

## EMBASE

1. DEMENTIA exp
2. demen\* OR deliri\* OR cognitive impairment OR organic brain
3. DELIRIUM exp
4. 'aids'/exp/mj AND 'dementia'/exp/mj AND complex
5. wernickes AND 'encephalopathy'
6. alzheimers
7. logo\* OR symbol\* OR emblem\* OR insignia\*
8. 'emergency'/exp/mj AND medical AND service AND communications AND systems
9. 'medic alert' OR bracelet\*
10. 'patient identification'/exp/mj OR identifier NOT trial\* AND 'registration'/exp/mj
11. 'delirium'/exp/mj OR 'dementia'/exp/mj OR 'aids'/exp/mj AND 'dementia'/exp/mj AND complex OR wernickes AND 'encephalopathy'/exp/mj OR alzheimers OR logo\* OR symbol\* OR emblem\* OR insignia\* OR 'emergency'/exp/mj AND medical AND

- service AND communications AND systems OR 'medic alert' OR tag\* OR bracelet\* OR 'medic alert' OR bracelet\*
12. logo\* OR symbol\* OR emblem\* OR insignia\* OR 'emergency'/exp/mj AND medical AND service AND communications AND systems OR 'medic alert' OR bracelet\* OR 'patient identification'/exp/mj OR identifier NOT trial\* AND 'registration'/exp/mj OR emblems AND insignia
  13. appropria\* OR accept\* OR attitud\*
  14. 'stigma'/exp/mj OR ethic\* OR 'privacy'/exp/mj OR 'dignity'/exp/mj
  15. appropria\* OR accept\* OR attitud\* OR 'stigma'/exp/mj OR ethic\* OR 'privacy'/exp/mj OR 'dignity'/exp/mj OR 'emergency medical technician attitudes'
  16. sundown\* OR wander
  17. 'natural disasters'/exp/mj
  18. 'patient management'/exp/mj OR 'service delivery'/exp/mj OR 'patient safety'/exp/mj
  19. logo\* OR symbol\* OR emblem\* OR insignia\*
  20. #2 AND #17 AND #20
  21. #2 AND #19 AND #20
  22. #2 AND #9
  23. #3 AND #7
  24. #12 AND #14
  25. #11 AND #12 AND #17
  26. #11 AND #12
  27. #2 AND #12 AND #13
  28. #2 AND #9 AND #11
  29. #2 AND #9 AND #16
  30. #3 AND #16 AND #19 AND #20
  31. #2 AND #12 AND #17
  32. #2 AND #3 AND #4 AND #5 AND #6 AND #7 AND #12
  33. #1 AND #8 AND #9 AND #12

## CURRENT CONTENTS

1. DEMENTIA
2. DELIRIUM
3. ALZHEIMER
4. dement\*
5. deliri\*
6. cognitive impairment
7. organic brain disease

8. alzheimer\*
9. 9 or 8 or 7 or 6 or 5 or 4 or 3 or 2 or 1
10. MEDIC ALERT
11. medic alert\*
12. tag\*
13. bracelet\*
14. logo\*
15. symbol\*
16. emblem\*
17. insignia\*
18. patient identification
19. patient identifier
20. 19 or 18 or 17 or 16 or 15 or 14 or 13 or 12 or 11 or 190
21. approp\*
22. attitud\*
23. accept\*
24. 23 or 22 or 21
25. stigma\*
26. ethic\*
27. privacy
28. dignity
29. 28 or 27 or 26 or 25
30. patient management
31. patient safety
32. service delivery
33. SUNDOWN
34. sundown\*
35. wander\*
36. 35 or 34 or 33 or 31 or 30
37. natural disaster
38. 29 AND 24 AND 20 AND 9
39. 36 AND 20 AND 9
40. 38 AND 20 AND 9

**PSYCARICLES**

1. DEMENTIA or AIDS DEMENTIA COMPLEX or DEMENTIA WITH LEWY BODIES of PRESENILE DEMENTIA of SENILE DEMENTIA or VASCULAR DEMENTIA
2. ALZHEIMERS DISEASE
3. DELIRIUM
4. dement\* or deliri\* or cog\* impair\* or organic brain\* or alzhem\*
5. 4 or 3 or 2 or 1
6. medic alert\* or tag\* or bracelet\*
7. logo\* or symbol\* or emblem\* or insignia\*
8. patient identification or identifier
9. 8 or 7 or 6
10. appropr\* or accept\* or attitud\*
11. stigma\* or ethic\* or privacy or dignity
12. 11 or 10
13. patient manag\* or service delivery or patient safety
14. sundown\* or wander\*
15. 12 AND 9 AND 5
16. 15 AND 13
17. 15 AND 14

**AGELINE**

- 1 dement\* or delir\*
- 2 alzhem\*
- 3 cog\* imp\* or organic brain
- 4 cog\* imp\* or organic brain or alzhem\* or dement\* or delir\*
- 5 medic alert\* or tag\* or bracelet\*
- 6 logo\* or symbol\* or emblem\* or insignia\*
- 7 patient identification or identifier
- 8 patient identification or identifier or logo\* or symbol\* or emblem\* or insignia\* or medic alert\* or tag\* or bracelet\*
- 9 appropr\* or accept\* or attitud\*
- 10 stigma\* or ethic\* or privacy or dignity\*
- 11 stigma\* or ethic\* or privacy or dignity\* or appropr\* or accept\* or attitud\*
- 12 patient manag\* or service delivery or patient safety
- 13 sundown\* or wander\*

- 14 stigma\* or ethic\* or privacy or dignity\* or appropri\* or accept\* or identification or identifier or logo\* or symbol\* or emblem\* or alert\* or tag\* or bracelet\* AND cog\* imp\* or organic brain or alzhem\* or dement\* or delir\*
- 15 stigma\* or ethic\* or privacy or dignity\* or appropri\* or accept\* or identification or identifier or logo\* or symbol\* or emblem\* or alert\* or tag\* or bracelet\* AND cog\* imp\* or organic brain or alzhem\* or dement\* or delir\*AND sundown\* or wander\*
- 16 stigma\* or ethic\* or privacy or dignity\* or appropri\* or accept\* or identification or identifier or logo\* or symbol\* or emblem\* or alert\* or tag\* or bracelet\* AND cog\* imp\* or organic brain or alzhem\* or dement\* or delir\*AND patient manag\* or service delivery or patient safety

## LEGALTRAC

- R1 dementia
- R2 delirium
- R3 dement\* or alzhem\*
- R4 medic alert\* or tag
- R5 emblem\* or insignia
- R6 patient identificat\*
- R7 R1 or R2 or R3
- R8 R4 or R5 or R^
- R9 stigma\* or privacy\*
- R10 appropri\* or attitude\*
- R11 R9 or R10
- R12 R7 AND R8 AND R11

## PSYCEXTRA

- 1 DEMENTIA
- 2 DEMENTIA OF THE ALZHEIMERS TYPE or DEMENTIA OF TYPE or DEMENTIA PATIENTS ALZHEIMER'S
- 3 DELIRIUM of DELIRIUM & DEMENTIA & ORGANIC MEDICAL DISORDERS
- 4 AIDS DEMENTIA
- 5 FRONTOTEMPORAL DEMENTIA or FRONTOTEMPORAL DEMENTIAS or FRONTOTEMPORAL DEMENTIAS CONFERENCE
- 6 dement\* or deliri\* or cog\* impair\* or organic brain\* or alzhem\*
- 7 6 or 5 or 4 or 3 or 2 or 1
- 8 logo\* or symbol\* or emblem\* or insignia\*
- 9 patient identification or identifier NOT trial\* registration
- 10 9 or 8

- 11 appropri\* or accept\* or attitude\*
- 12 stigma\* or ethic\* or privacy or dignity
- 13 patient delivery or service delivery or patient care
- 14 sundown\* or wander\*
- 15 12 or 11
- 16 15 AND 10 AND 7
- 17 10 AND 7
- 18 15 AND 7
- 19 14 AND 10 AND 7
- 20 13 AND 10 AND 7

### APAIS Heath

- 1 dement\*
- 2 deliri\*
- 3 alzhem\* or cog\* imp\* or organic brain\*
- 4 alzhem\* or cog\* imp\* or organic brain\* or dement\* or deliri\*
- 5 medic alert\* or tag\* or bracelet\*
- 6 logo\* or symbol\* or emblem\* or insignia\*
- 7 identification or identifier\*
- 8 identification or identifier\* or logo\* or symbol\* or emblem\* or insignia\* or medic alert
- 9 identification or identifier\* or logo\* or symbol\* or emblem\* or insignia\* or medic alert\* or tag\* or bracelet\* AND alzhem\* or cog\* imp\* or organic brain\* or dement\* or deliri\*

### HEALTH AND SOCIETY

- 1 DEMENTIA
- 2 dement\* or deliri\* or alzhem\* or cognitive impairment or organic brain\*
- 3 dement\* or deliri\* or alzhem\* or cognitive impairment or organic brain\* OR DEMENTIA
- 4 medic alert\* or tag\* or bracelet\*
- 5 logo\* or symbol\* or emblem\* or insignia\*
- 6 identification or identifier
- 7 identification or identifier OR logo\* or symbol\* or emblem\* or insignia\* OR medic alert\* or tag\* or bracelet\*
- 8 appropri\* or accept\* or attitud\*
- 9 stigma\* or ethic\* or privacy or dignity
- 10 stigma\* or ethic\* or privacy or dignity OR appropri\* or accept\* or attitud\*

- 11 stigma\* or ethic\* or privacy or dignity OR approp\* or accept\* or attitud\* AND  
 identification or identifier OR logo\* or symbol\* or emblem\* or insignia\* OR medic alert\* or  
 tag\* or bracelet\* AND dement\* or deliri\* or alzhem\* or cognitive impairment or organic  
 brain\* OR DEMENTIA

## **SOCIOLOGICAL ABSTRACTS**

- 1 dement\* or deliri\*
- 2 alzhem\*
- 3 cog\* imp\* or organic brain\*
- 4 cog imp\* or organic brain\* or alzhem\* or dement\* or deliri\*
- 5 medic alert\* or tag\* or bracelet\*
- 6 emblem\* or insignia\*
- 7 logo\* or symbol\*
- 8 patient identification or identifier
- 9 patient identification or identifier or logo\* or symbol\* or emblem\* or insignia\* or medic  
 alert\* or tag\* or bracelet\*
- 10 stigma\* or privacy or ethic\* or dignity\*
- 11 approp\* or accept\* or attitude\*
- 12 approp\* or accept\* or attitude\* or stigma\* or privacy or ethic\* or dignity\*
- 13 approp\* or accept\* or attitude\* or stigma\* or privacy or ethic\* or dignity\* AND patient  
 identification or identifier or logo\* or symbol\* or emblem\* or insignia\* or medic alert\* or  
 tag\* or bracelet\* AND cog imp\* or organic brain\* or alzhem\* or dement\* or deliri\*
- 14 sundown\* or wander\*
- 15 sundown\* or wander\* or approp\* or accept\* or attitude\* or stigma\* or privacy or ethic\* or  
 dignity\* AND patient identification or identifier or logo\* or symbol\* or emblem\* or  
 insignia\* or medic alert\* or tag\* or bracelet\* AND cog imp\* or organic brain\* or alzhem\*  
 or dement\* or deliri\*
- 16 patient manag\* or service delivery or patient safety
- 17 patient manag\* or service delivery or patient safety AND approp\* or accept\* or attitude\*  
 or stigma\* or privacy or ethic\* or dignity\* AND patient identification or  
 identifier or logo\* or symbol\* or emblem\* or insignia\* or medic alert\* or tag\* or bracelet\*  
 AND cog imp\* or organic brain\* or alzhem\* or dement\* or deliri\*

## **FAMILY AND SOCIETY**

- 1 DEMENTIA
- 2 dement\* or deliri\* or alzhem\* or cognitive impairment or organic brain\*
- 3 dement\* or deliri\* or alzhem\* or cognitive impairment or organic brain\* OR  
 DEMENTIA
- 4 medic alert\* or tag\* or bracelet\*
- 5 logo\* or symbol\* or emblem\* or insignia\*

- 6 identification or identifier
- 7 identification or identifier OR logo\* or symbol\* or emblem\* or insignia\* OR medic alert\* or tag\* or bracelet\*
- 8 appropri\* or accept\* or attitud\*
- 9 stigma\* or ethic\* or privacy or dignity
- 10 stigma\* or ethic\* or privacy or dignity OR appropri\* or accept\* or attitud\*
- 11 stigma\* or ethic\* or privacy or dignity OR appropri\* or accept\* or attitud\* AND identification or identifier OR logo\* or symbol\* or emblem\* or insignia\* OR medic alert\* or tag\* or bracelet\* AND dement\* or deliri\* or alzhaim\* or cognitive impairment or organic brain\* OR DEMENTIA

## DISSERTATIONS AND THESES ABSTRACTS

1. (dement\* or deliri\* or organic brain disease or alzheimer disease)
2. (medic alert or bracelet or identifier) AND NOT (trial registration)
3. (medic alert or bracelet or identifier) AND ((dement\* or deliri\* or organic brain disease or alzheimer disease)) AND NOT (trial registration)
4. (logo or symbol or emblem or insignia)
5. (logo or symbol or emblem or insignia) AND ((dement\* or deliri\* or organic brain disease or alzheimer disease))
6. (logo or symbol or emblem or insignia) AND ((dement\* or deliri\* or organic brain disease or alzheimer disease)) AND (appropriat\* or accept or attitud\*)
7. (patient management or service delivery or patient safety)
8. (wander\* or sundown\*) AND ((dement\* or deliri\* or organic brain disease or alzheimer disease))
9. (patient management or service delivery or patient safety)
10. (patient management or service delivery or patient safety) AND ((dement\* or deliri\* or organic brain disease or alzheimer disease))
11. (patient management or service delivery or patient safety) AND ((dement\* or deliri\* or organic brain disease or alzheimer disease)) AND ((wander\* or sundown\*))

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## CINCH

- 1 dement\* or deliri\* or alzhaim\* or cognitive impairment or organic brain\*
- 2 medic alert\* or tag\* or bracelet\*
- 3 logo\* or symbol\* or emblem\* or insignia\*
- 4 identification or identifier
- 5 identification or identifier OR logo\* or symbol\* or emblem\* or insignia\* OR medic alert\* or tag\* or bracelet\*

- 6 identification or identifier OR logo\* or symbol\* or emblem\* or insignia\* OR medic alert\* or tag\* or bracelet\* AND dement\* or deliri\* or alzhaim\* or cognitive impairment or organic brain\*

### **Hein Online**

dementia AND identifier

delirium AND identifier

dementia AND symbol AND ethic

## Appendix 10

### Included Articles

No	Reference	Design	Sample / Setting	Objectives	Conclusion	Study Quality
1	Devor M, Wang A, Renvall M, Feigal D & Ramsdell J (1994). Compliance with social and safety recommendations in an outpatient comprehensive geriatric assessment program <i>Journal of Gerontology: MEDICAL SCIENCES</i> 49(4), M168-M173	Telephone survey -	124 geriatric patients.  Community geriatric program in USA	Assess compliance with recommendations from geriatric program, including wearing medic-alert style bracelet.	Compliance with safety recommendations increased with severity of dementia. 57.5% of sample patients complied with wearing alert bracelet.	L-IV
2	Aspinall P (1994). When a vulnerable patient absconds. <i>Journal of Clinical Nursing</i> , 3, 115-118	Case study, opinion	Single patient Psychiatric hospital. UK	Recommendations for safety of vulnerable wandering-prone patients.	Recommends patients wear ID bracelet.	Credible
3	Behm C (January 2007) Cognitive impairment identifier project (St Vincent's) – final report  Includes: CALD focus groups – Greek & Italian	Focus groups (x2)	9 carers. Victorian acute hospital	Assess acceptability of cognitive impairment identifier.	In favour of identifiers, but cognisant of stigmatisation, privacy and safety issues.	Credible
4	L Morton, S Murad, Omar RZ & K Taylor (2002). Importance of emergency identification schemes <i>Emergency Medicine Journal</i> , 19(6), 584 – 7	Questionnaire	Snr A+E staff and op dir of ambulance headquarters	Assess awareness and practices concerning emergency medical identifiers.	71% of A&E staff routinely search for body worn alerts. 97% of ambulance staff search for alerts.	L-IV
5	Theobald M et al. 2004. An all of hospital education program to improve the awareness of and communication	Action research	Hospital staff, carers and patients. Number not stated.	Improve awareness of dementia and cognitive impairment in acute hospital. Implementation of	Carers find CII acceptable. Effective method of improving awareness of CI and improving care.	Credible

No	Reference	Design	Sample / Setting	Objectives	Conclusion	Study Quality
	with people with cognitive impairment, linked to a visual cognitive impairment identifier (CII). Ballarat Health Services. July.			CI identifier.		
6	Rowe M (2003). People with dementia who become lost. <i>AJN</i> , 103(7), 32-9.	Analysis of newspaper reports	Dementia patients, carers, hospital staff	Discussion of wandering in PWD.	Registration with Safe Return-type programs maximises chances of return of wandering PWD. Recommends wearing of identifier at all times.	Credible
7	Moehead A. (2006). North Coast Area Health Service delirium clinical practice improvement project report. 5 July.	CPI project report	51 patients >70 years with orthopaedic trauma.	Introduction of screening program for delirium	68% of patients screened had positive risk factors for delirium. Project increased staff awareness of, and diagnoses of, delirium.	L-IV
8	Rowe M & Glover J (2001). Antecedents, descriptions and consequences of wandering in cognitively impaired adults and the Safe Return (SR) Program. <i>American Journal of Alzheimer's Disease and Other Dementias</i> , 16, 344-52	Analysis of Safe Return data	675 patients who had wandered and become lost. USA	Analysis of wandering behaviour and circumstances of return. Recommends strategies for safety of PWD.	Unattended wandering unpredictable. 16.8% of wanderers from care facilities. Community awareness needed.	L-IV
9	Foreman P & Gardner I (2005). Evaluation of education and training of staff in dementia care and management in acute settings. Evaluation Report for Aged Care Branch, Dept Human Services	Pre and post survey evaluation of Ballarat Health Service CII project	Australian hospitals (Victoria). Sample size not stated.	Evaluate education programs, introduction of carepaths, satisfaction surveys, implementation of cognitive impairment identifier	Programs increased staff satisfaction with care of CI patients. Improved carer satisfaction. Decreased agitated behaviour.	L-IV

No	Reference	Design	Sample / Setting	Objectives	Conclusion	Study Quality
10	(Vic). April McIntosh W (2006). Review and closure report. SW inpatient falls risk management collaborative. 20 January.	Project report	Australian hospital (WA).	Evaluate effectiveness of multi-focal falls reduction strategy.	Staff found use of falls alert identifier to be one of the most useful strategies in project.	L-IV
11	Taylor B (1999) Developing a better practice model for the hospital care of people with dementia. Southern Cross University. December	Report -	9 hospital staff. 5 carers of PWD	Evaluate experiences of changes to dementia unit environment and procedures including CI identifier (pelican symbol)	Pelican symbol and ID bands for identification of CI welcomed by staff.	L-IV
12	Sheehan B, Burton E & Mitchell L (2006) Outdoor wayfinding in dementia. <i>Dementia</i> , 5, p271	Observational study	13 PWD in community (10 control subjects). UK	Investigate outdoor wayfinding in PWD compared to comparable persons without dementia.	PWD worse at wayfinding, but still used signs.	LIII-2
13	Robinson et al. (2006) A systematic literature review of the effectiveness of non-pharmacological interventions to prevent wandering in dementia and evaluation of the ethical implications and acceptability of their use. <i>Health Technology Assessments</i> . 10(26)1-125	Focus grps, which were presented with findings of systematic review	19 total. Carers and PWD	Assess stakeholders' perceptions on non-pharmacological interventions for wandering.	Identity cards one of the most acceptable interventions.	Credible
14	Van Clarke D, Horner B, Rose S, Todorovich N, Grogan M, Stewart J & Jones J (2006). Improving the care of people with dementia within the acute	Action research	Hospital inpatients	Project to improve care of PWD	Recommends use of symbol to identify PWD.	Credible

No	Reference	Design	Sample / Setting	Objectives	Conclusion	Study Quality
	care setting. Funded by The Western Australian Country Health Service (WACHS) September.					
15	Haines TP, Bennell KL, Osborne RH & Hill KD (2004) Effectiveness of targeted falls prevention programme in subacute hospital setting: randomised controlled trial. British Medical Journal, 328, p1- 6.	RCT	Intervention 1: n=310. Intervention 2: n=316. Metropolitan hospital, Australia.	Evaluate effectiveness of falls prevention program.	Program reduced injury severity of falls. No mention of objections to use of identifier. Falls identifier appears to have been acceptable to staff, patients and families.	L-II
16	Patient Care; New ID bracelet available for Alzheimer disease in Obesity, Fitness and Wellness Week, Jun 11, 2005. P1202	Announcement		New Alzheimer- specific ID bracelet available through MediAlert.	Teal caduceus to indicate Alzheimer's and other dementias.	Credible
17	Farrell T (1998) Identity crisis – most don't wear medical ID even though it saves lives Diabetes Health, 1 January.	Survey – non scientific – with people with diabetes, emergency workers, doctors, educators	18 people with insulin dependent diabetes. Poorly specified number of emergency personnel.	Assess numbers who wear medic alerts	Many people with serious illnesses don't wear medic alerts. Majority of emergency personnel routinely search for medical alerts.	Credible
18	Rose, V (2006) Improving the care of patients with a vision impairment at Coffs Harbour Health Campus. North Coast Area Health Service.	Action research	10 vision impaired patients	Improve practice/care of visually impaired patients, assess effectiveness of new programs	Identifier improved care of visually impaired persons. Resulted in improved awareness of needs, better communication, greater patient satisfaction.	Credible

## Appendix 11

### Excluded Articles

No	Reference	Design	Sample / Setting	Objectives	Conclusion	Reason for exclusion
1	George, JE & Quattrone, S (1985) Search for patient identification: an invasion of privacy? <i>Journal of Emergency Nursing</i> , 11(6), pp335-6	Opinion	Emergency depts	Provide legal opinion on nurses searching for ID on impaired patients.	Searching for ID on impaired patients probably legal.	Does not answer review question. Legal opinion not translatable across jurisdictions.
2	Rowe M, Feinglass NG & Wiss ME (2004). Persons with dementia who become lost in the community; a case study, current research and recommendations. <i>Mayo Clinic Proceedings</i> , 79(11), 1417-22	Case study and retrospective case review	619 wandering dementia patients. USA	Encourage awareness of wandering.	Patients who are found more quickly less likely to be found dead. Lost wandering PWD do not ask for help.	Re-presentation of data from authors' previous study. No new data.
3	Fisher, M (1985). Medic alert bracelets. <i>Medical Journal of Australia</i> . 142(January). P167-8.	Letter to the editor		Discussion of medic-alert bracelets	Bracelets not worn because unattractive	Unsupported opinion.
4	Mearns CA (2002). A talisman to ward off bad anaesthetics. <i>Anaesthesia</i> , 57, 943	Letter to the editor	Pre-operative patient	Discussion of worth of medic alerts	Doctors should pay attention to alerts	Does not answer review question
5	Gilbert-Fogland, W (1985). Medic alert bracelets. <i>The Medical Journal of Australia</i> , 142, May 27	Letter to the editor	Wife	Discussion of worth of medic alerts	Hospital staff don't pay attention to alerts	Does not answer review question
6	O Callaghan, DJP. Hughes, K. (2005). The hidden dangers of taped jewellery. <i>Anaesthesia</i> . 60. p828-9	Letter to the editor	Hospital patient	Discussion of medic alerts	Highlight dangers of hiding alerts by taping jewellery pre-operatively.	Does not answer review question

7	Richards S (2005). With dementia the label becomes so powerful that staff lose sight of the individual and their rights Mental Health Today, May, 18	Opinion	Hospital and community. No sample.	Discussion of labelling and personhood.	Labelling of PWD can lead hospital staff to ignore patients' wishes.	Does not answer review question
8	Sabat SR (1998). Voices of Alzheimer's disease sufferers: a call for treatment based on personhood. The Journal of Clinical Ethics, 9(1), 35 – 48	Ethical discussion	Persons with Alzheimer's Disease	Theoretical discussion of ethics of dealing with persons with Alzheimer's Disease	PWD still have intact sense of personal identity.	Does not answer review question.
9	Thomas P & Evans C (2004). An identity crisis? Aspects of patient misidentification. Clinical Risk, 10(1), 18 – 22	Risk analysis	233 incidents	Analysis of clinical incidents	Incorrect identification of patients leads to clinical incidents.	Does not deal specifically with dementia. Does not answer review question.
10	Robinson et al. (2007). Effectiveness and acceptability of non-pharmacological interventions to reduce wandering in dementia: a systematic review. International Journal of Geriatric Psychiatry, 22(1), 9-22.	Systematic review	11 included studies	To determine clinical and cost-effectiveness and acceptability of non-pharmacologic interventions to reduce wandering in dementia.	More research need to assess acceptability of interventions to PWD	Outside scope of review – focus is on electronic tagging and tracking.
11	Lai CK (2005). What's in a label? An exploration of the psychosocial impact on an individual diagnosed with mild cognitive impairment. Abstracts: Impact on Policy, Ethics and Care, 1(suppl 1), p S55	Literature search	People with mild cognitive impairment (MCI)	Literature search of medical databases, to explore publication of articles about psychosocial aspects of people diagnosed with MCI	More studies re experiences of people with MCI are needed. Assessment needed of cost/benefit risks of early diagnosis of MCI	Does not answer review question.

12	Blaines CJ (1994). Medic alert bracelets. Canadian Medical Association, 150(8), 1201.	Letter to the editor				Essentially an advertisement for Canadian Medic Alert Foundation.
13	Dalsania, P (2006) Dementia dashboard. A proactive risk reduction management guideline. Topics in Geriatric Rehabilitation, 22(3) p228-42	Care guidelines	No sample stated. USA.	Recommendations for caring for PWD.	Among other recommendations, author suggests use of ID bracelet for PWD.	Does not provide new information. Doesn't cite supporting references.
14	Jennings B (2001). Freedom fading: on dementia, best interests and public safety. Georgia Law Review. 35(2). P593-619	Discussion	Patients with dementia, caregivers, legislators	Discussion of ethical theories connected with identification of people with dementia.	Requiring people with dementia to give up some of their freedoms to ensure their safety may be ethical, provided efforts are made to preserve personhood in other ways.	Not specific to review question.
15	Rowe M, Bennett V (2003). A look at deaths occurring in persons with dementia lost in the community. American Journal of Alzheimer's Disease and Other Dementias. 18. P343-8	Discussion	PWD lost in community	Retrospective examination of reports regarding lost PWD	Suggests search strategies for finding lost PWD.	No unique evidence.
16	Mayo N, Gloutney L, Levy A (1994). A Randomized Trial of Identification Bracelets to Prevent Falls Among Patients in a Rehabilitation Hospital. Arch Phys Med Rehabil. 75 P1302-8	RCT	Acute hospital. 65/69 intervention/control	Trial of ID bracelets to prevent falls in acute hospital patients	Bracelet had no effect on rate of falls	Does not provide information regarding appropriateness of intervention. Does not answer review question.

17	Cleopas A et al. (2004). Acceptability of identification bracelets for hospital inpatients. <i>Quality and Safety in Health Care</i> . 13(5) 344-8.	Patient survey	1411 patients in Swiss acute hospital	Assess if wearing of patient identification bracelet acceptable to patients.	Wearing of ID acceptable to majority of patients.	Identifier was for all patients, not to indicate a functional impairment or illness, outside review criteria.
18	Desmaizieres M et al.(2001). Difficulties with identification of living patients after fires in hospitals. <i>Prehospital and Disaster Medicine</i> , 16(1) pS22.	Case presentation	134 patients of French health facilities where fires occurred.	Discuss difficulty of identifying survivors of disasters when pts unable to speak/cognitively impaired.	Recommends patient IDs and accessible data system.	Identifier was for all patients, not to indicate a functional impairment or illness, outside review criteria.
19	Arveson A (1992)Medical ID Worthwhile. <i>Nursing92</i> . P4&6.	Letter to the editor	Personal experience	Discuss worth of medical alerts.	Medical alerts help preserve patient dignity by correctly identifying patient's illness.	Unsupported non-expert opinion.

## Appendix 12

### Cognitive Impairment Identifier



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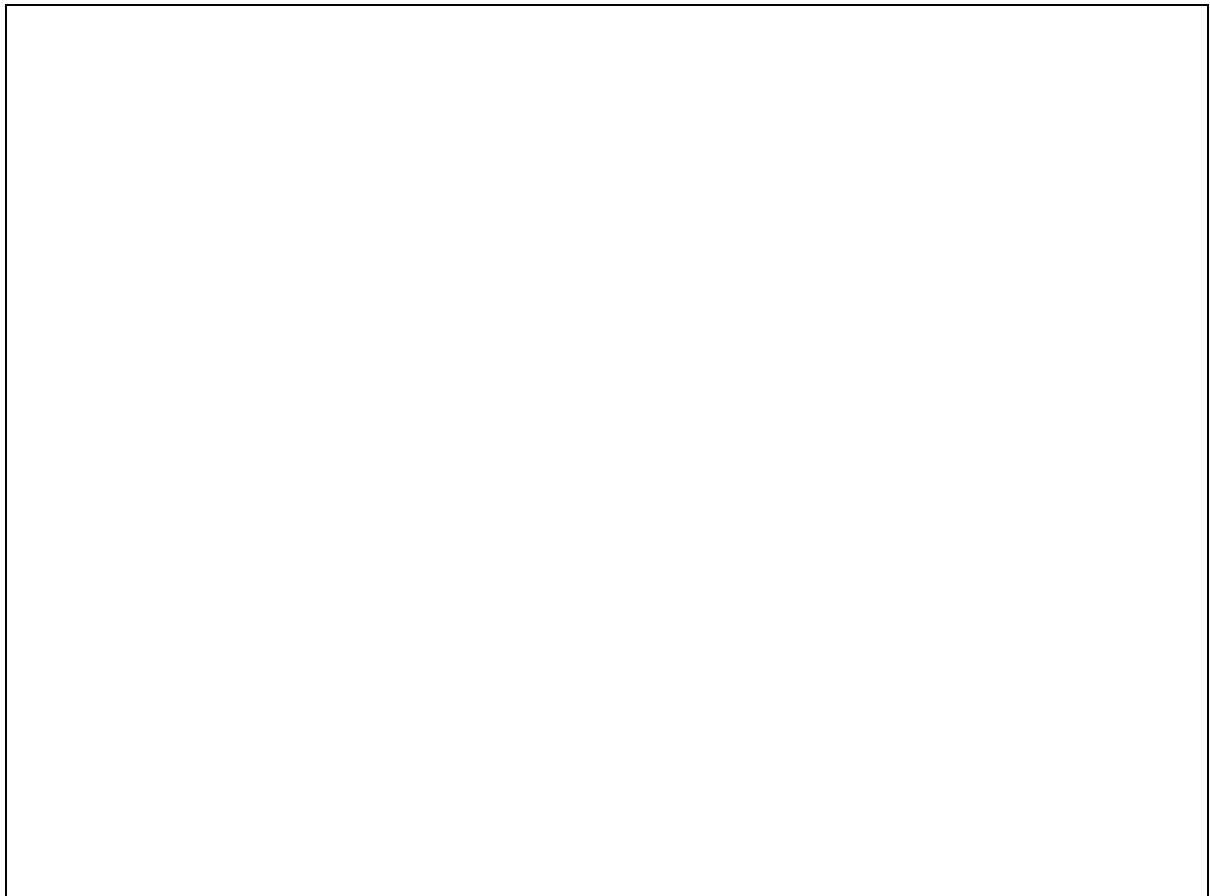
**Appendix 13**

# DELIRIUM ALERT

**THINK:**

- **HYDRATION & NUTRITION**
- **PAIN RELIEF**
- **FALLS RISK**
- **BOWEL & BLADDER MANAGEMENT**
- **ORIENTATION to environment**

**SEE OVER  
for  
DETAILS of STRATEGIES  
to  
PREVENT DELIRIUM**



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## Appendix 14

**Forget-me-not symbol – used by Western Australia Country Health Service (WACHS) – Great Southern**



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