



Australian Government

NHMRC National Institute for Dementia Research

2021 Census Review Submission

Dementia

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Recommendation

That a single-item, self-report or proxy/informant report question regarding the presence of chronic diseases, including dementia and /or diagnosis of dementia, is introduced to the upcoming National Census. It is further recommended that the question is modelled on Canadian and US questions currently used in large, government-mandated population-based surveys, examples of which are provided in this submission.

1. National Importance

Dementia is a leading cause of burden of disease and mortality in Australia estimated to be responsible for 99,957 years of life lost, and 13, 496 deaths in 2015 (Australian Institute of Health and Welfare, 2018). In 2017 the annual cost of dementia in Australia exceeded \$14 billion dollars (Brown, Hansnata, & Anh La, 2017), with this cost expected to grow to unsustainable levels without a comprehensive National Dementia Strategy (Alzheimer's Australia, 2017).

A significant component of such a strategy includes accurate data on dementia prevalence. Currently, the best estimates of Australian figures are based on international data. In 2012 the Australian Government identified dementia as a leading health priority area. The resulting National Framework for Action on Dementia 2015-2019 provided key areas of action for primary and secondary risk reduction. Without Australian population-based prevalence data, measurable outcomes against the Framework are unattainable, affecting Australia's ability to successfully plan for the economic and social impact of the disease.

2. Need for data from a Census for the whole population

There is currently no Australian population based study that collects data on rates of dementia in Australia, and the accuracy of the potential sources of data is inadequate. Death certificates indicating international criteria for causes of death have been shown to seriously under-estimate dementia prevalence. Reliability of hospital admission data has not been demonstrated, whilst MBS, PBS and Aged Care Assessment data does not effectively capture all sufferers. To date, there is no single epidemiological study that has comprehensive data on dementia prevalence, and the results of such data if it existed would not be representative of the entire Australian population due to limitations in sampling from regional, rural and remote areas.



Accurate population based data are essential for valid and reliable estimates to the prevalence of dementia, to understand the efficacy of primary and secondary risk reduction strategies and interventions, to effectively plan for future needs and services for those living with dementia and people who care for them, and to obtain reliable data to generate new understandings about dementia prevalence.

3. Data can be accurately collected in a form which the household completes themselves

Dementia is defined as a general term describing a range of symptoms associated with decline in mental functioning affecting a person's ability to perform everyday activities (World Health Organisation, 2012). This definition has been shown to be widely recognisable in the Australian population through vignette studies (Low & Anstey, 2009), as well as dementia literacy and identification of risk factors research (Kim, Sargent-Cox, & Anstey, 2015).

Studies have shown that a single-item, self-report or proxy/informant report measure regarding the presence of chronic diseases, including dementia and /or diagnosis of dementia, to show good psychometric properties. For example Kappa agreement statistics between medical records and self-report of disease and diagnosis in a number of chronic diseases, particularly non-cardiac conditions, have been shown to be high (>70%) (Okura, Urban, Mahoney, Jacobsen, & Rodeheffer, 2004; Simpson et al., 2004). Of particular interest to dementia data, survey reports of Alzheimer's disease has been shown to yield higher and more accurate reporting of cases than diagnosis data or medication / PBS data (Lin et al., 2010).

Large, population-based surveys from Canada (Canada's Community Health Survey, CCHS) and the United States (US Healthy People 2020) both use self-report and proxy/informant single-item questions to obtain National dementia estimates, underlining the acceptance and reliability of capturing dementia rate data in this method. The CCHS asks "*Do you have Alzheimer's disease or any other dementia*" (Yes/No), and the US Healthy People 2020 question asks "*Has a doctor ever told you that you had Alzheimer's disease / any type of dementia*" (Yes / No). The CCHS is a Government mandated annual general survey, targeted to represent up to 96% of the population, that includes focused health topics (Statistics Canada, 2016). The survey is used to collect reliable, population level estimates on health and health status. US Healthy People 2020 is a combination of a wide range of data systems (including censuses of events and nationally representative sample surveys) that provides collective information to monitor and improve the health of Americans (Healthy People, 2018).

4. Topic is acceptable to Census respondents

Whilst there is evidence of stigma attached to dementia for both people who have been diagnosed with dementia and their carers, there is no evidence that this results in under-reporting either by self-report or through proxy / informant reports. Nationally representative surveys including questions related to dementia are widespread, including comparable countries such as Canada (e.g. CCHS), and the United States (e.g. US Health People 2020), indicating a general acceptance of dementia questions in population-based health surveys. The CCHS is used to estimate national prevalence data, whilst the US Healthy People 2020 data is used to measure focused objectives, for example, increasing the awareness of older adults' dementia diagnoses (Healthy People, 2018; Statistics Canada, 2016).



5. Data can be collected efficiently

Dementia as a significant health condition for which a diagnosis is possible is well recognized in the Australian population with research showing that identification of the symptoms, and knowledge of dementia are high (e.g. Loi & Lautenschlager, 2014; Low & Anstey, 2009). Studies have shown high sensitivity and specificity of both self- and proxy / informant reported measures of dementia, (e.g. Hendry, Quinn, Evans, & Stott, 2015; Rabin et al., 2015). Evidence also shows simple, self-report, single-item questions in a tick-box type format that ask about presence and diagnosis of chronic disease, including dementia, show high agreement with physician / medical records of diagnosis (Corser et al., 2008; Okura et al., 2004; Simpson et al., 2004).

6. Continuing need for data on topic in the following Census

The high burden of dementia, in both social and economic terms, highlights the need to understand the trends of dementia prevalence over time. Evidence of change, or indeed evidence of prevalence stability, provides much needed information on the efficacy of current strategies and interventions as well as informing future directions.

Epidemiological studies in the United States, United Kingdom and some areas of Europe provide some evidence of a reduction in dementia rates (e.g. The Cognitive Functioning and Ageing Study, UK, Framingham Heart Study, US, Einstein Aging Study, US). Currently, without accurate time-series, population-based dementia prevalence data, understanding the trends of Australia's dementia rates, and efficacy of National strategies, is not possible.

7. No other suitable data sources or solutions that meets the topic need

While, use of single sources of data to estimate dementia prevalence has been shown to significantly underestimate prevalence (Lin et al., 2010), there is work underway to develop a national Dementia Database that aims to collate and link multiple sources of cohort and repeated cross-sectional data to estimate dementia prevalence. Nevertheless, there are limitations to these data sources as they are not based on National studies and therefore not generalizable to the whole of the Australian population. In particular, current studies are limited in accurately reflecting people living in remote, rural and regional areas. A National Dementia Register, also currently being developed in Australia, is limited in that a formal diagnosis by type of dementia is necessary for a person to be included on the Register, with current estimates indicating that this could exclude up to 50% of prevalence, with formal diagnosis taking on average three years to achieve in Australia, from onset of symptoms

Therefore **Census data would complement data** from a Dementia Register and Database by capturing broader and more representative demographic characteristics. Further, Census data would provide the opportunity to triangulate agreement across data sources to increase confidence in findings.



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