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# Trends in prevalence of dementia for people accessing aged care services in Australia

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### Abstract

**Background:** Studies in some high-income countries have reported a potential decline in the prevalence of dementia. Improvements in cardiovascular health may be contributing to this decline. The objective was to examine trends in prevalence of dementia and survival with dementia for people accessing aged care in Australia.

**Methods:** A retrospective study of older people who accessed long-term care 2008-2014 (n=348,311) and home care 2005-2014 (n=188,846) in Australia. The age- and sex-standardized prevalence for dementia by year of access to aged care were determined using direct standardization. Generalised linear models were used to determine change in the prevalence of dementia over time and change in one-year mortality for people who accessed long-term care.

**Results:** The age- and sex-standardized prevalence (95% confidence interval) of dementia declined from 50.0% (49.6, 50.5) in 2008 to 46.6% (46.0, 47.2) in 2014 for people accessing long-term care (Absolute change 2008-2014: -3.8 (-4.6, -3.1)) and for people accessing home care from 25.9% (25.0, 26.5) in 2005 to 20.9% (20.2, 21.7) in 2014 (Absolute change 2005-2014: -5.2 (-6.2, -4.1)). This decline in dementia occurred in concurrence with a decline in cerebrovascular disease in long-term care but despite the prevalence of hypertension, diabetes, high cholesterol, malnutrition, obesity, depression and head injury increasing. For people accessing long-term care, one-year mortality remained stable over time.

**Conclusions:** The decline in prevalence of dementia for people accessing aged care services in Australia is critical to future projection estimates and for planning of services. Further research to determine contributing factors to the decline is needed.

Key words: Alzheimer's disease, nursing homes, cardiovascular risk factors.

### Introduction

The number of people with dementia is projected to increase markedly from almost 50 million in 2017 to 131.5 million in 2050 worldwide (1). Despite these projections there is uncertainty about the future prevalence and incidence of dementia. Most studies have reported a potential decline or stability in dementia prevalence and incidence estimates over time in countries including the UK, Sweden, Spain, the Netherlands, France, Nigeria and the US (2). Whereas a study in Japan reported an increase in the prevalence of dementia (3). The underlying reasons for a decline in age-specific dementia prevalence and incidence in some studies are uncertain. Changes to underlying factors which contribute to dementia risk such as improvements in levels of education and public health interventions to improve cardiovascular health may be contributing. Conversely an increase in physical inactivity and western diet may be contributing to an increase in the prevalence of dementia in countries such as Japan. Trends in the prevalence of dementia over time in Australia have not been explored recently and hence projection estimates for the future scale of dementia are primarily based on projected continued ageing of the population and the assumption that the age-specific prevalence of dementia will remain constant (4).

The World Health Organisation (WHO) reported that estimates of prevalence and service utilisation for people with dementia are largely outdated and as prevalence estimates can change over time up-to-date figures are required (5). Furthermore, changes in the prevalence of dementia in people accessing aged care services would impact policy recommendations and planning of services. Determining the factors affecting the prevalence of dementia would also impact public health recommendations for the wider population. It has previously been suggested that potentially modifiable risk factors such as midlife hypertension, depression, midlife obesity, physical inactivity, smoking, low education levels and diabetes mellitus account for over 48% of dementia cases in Australia (6). In the general population in recent

years some conditions that contribute to dementia have increased in Australia (e.g. obesity in Australian adults increased recently from 19% to 28% in a 10-year period), but other factors relating to dementia risk such as educational attainment have improved (7).

There is also limited and inconsistent evidence about trends in survival in people with dementia (8). It has been suggested that public health efforts to reduce the risk of dementia may delay the age of onset of dementia and therefore the time living with dementia may reduce. This 'compression of comorbidity' hypothesis may therefore result in a longer time spent in relatively good health with a better quality of life and a reduction in the time spent in aged care (8, 9).

In March 2018 almost 85,000 older people were receiving home care services in Australia and this number increased by over 20% from the previous year. Home care services for older people are provided to help people live at home for as long as possible. There are different levels of home care depending on whether the person is assessed to have basic care needs to high-level care need. Many types of services fall under home care packages such as assistance with personal activities (e.g. bathing), meal preparation, mobility, transport, nursing and allied health services. The number of people living in long-term care has also increased from 167,000 in 2007 to 201,000 in 2017 (10). Long-term care includes accommodation and 24-hour care for people who are unable to continue to live independently in their own homes. Recent estimates show that people access home care on average for 2 years 5 months, whereas people access long-term care on average for 2 years and 11 months (10). The prevalence of dementia in people accessing aged care services is high worldwide, for instance nearly two-thirds of older people using long-term care (nursing homes) in the US (11) and 52% of people using long-term care in Australia are living with dementia (12).

The aim of this study was to examine changes in prevalence of dementia for older people accessing aged care services in Australia as determined during aged care assessments. Furthermore, changes in mortality over time for people accessing long-term care with dementia were evaluated.

# Methods

#### *Study sample*

As part of the Registry of Older South Australians (ROSA) a National Historical cohort of all people who accessed government-subsidised aged care services between 1997 and June 2014 was developed. In Australia, since 2003, when someone applies to access aged care services a trained Aged Care Assessment Team (ACAT) assess their needs for services in an interview (13). Similarly, since 2008 when someone enters a long-term aged care home, an assessment using the Aged Care Funding Instrument (ACFI) is undertaken to determine core care needs as a basis for allocating funding to aged care homes (14). In the ROSA National Historical cohort, de-identified data collected during aged care assessments were linked to information on mortality and information on the aged care services the person received.

Two cohorts are examined in this study: 1) people who accessed long-term aged care (i.e. 24hour care accommodation, nursing homes) between 2008 (the year the ACFI was introduced) and 2014 and 2) people who accessed home care services between 2005 (the first year the ACATs were introduced nationally) and 2014.

### Determination of prevalence of health conditions

Dementia and other health conditions were determined from identification in the person's ACAT or ACFI assessment. The ACAT assessments list up to ten health conditions for an individual. ACFI assessments can list up to three mental and behavioural conditions and three other health conditions. These conditions are mapped to equivalent health condition codes in the International Statistical Classification of Disease & Related Health Problems-Tenth Revision-Australian Modification (ICD-10-AM) (Supplementary Table 1).

The diagnoses were recorded by the assessor accessing the medical history of the individual, conducting a clinical assessment or referring to a specialist (e.g. geriatrician, psychogeriatrician or general practitioner) if dementia was suspected. The professions of the

ACATs are variable and may include nurses, geriatricians, psychogeriatricians, general medical practitioners, other health professionals and social workers or any combination of these which may influence the clinical judgement of whether to conduct a clinical assessment for dementia or ability to refer to a specialist, so the professions of the assessors were examined in this study.

# **Covariates**

Covariates were included to examine their contribution to associations between year and dementia prevalence. After reviewing large population-based studies and systematic reviews of risk factors and risk models for dementia (6, 15-21), the following covariates were included in the models based on their associations with dementia in previous studies and based on the data available in the dataset: age, sex, location (state) and reported health conditions (cerebrovascular disease including stroke, diabetes, hypertension, ischaemic heart disease, high cholesterol, obesity, malnutrition, depression, alcohol abuse/dependence and head injury).

### Statistical analysis

The age- and sex-standardized prevalence for dementia by year of access to aged care services was determined using direct standardization. Generalised linear models were used with dementia as the dependent variable and year of accessing care as the independent variable to examine the annual change in prevalence of dementia. Age and sex were also included in the models. Location and health conditions were then added to the models to determine their effect on the change in prevalence of dementia. A second set of models to compare 2014 estimates with 2008 as the reference group for the long-term care cohort (or 2005 for the home care cohort) were also used to show the absolute change in dementia prevalence. Generalised linear models were also used to determine the annual and absolute change in one year-mortality after starting long-term care. Poisson regression models were

also used to estimate rate ratios for mortality after entering long-term care for people with dementia compared to those without dementia. Statistical analyses were performed using Stata v.15.0 (Stata Corp LP, College Station, TX, USA).

### Results

#### Participant characteristics

In Australia, 348,311 people accessed government-subsidised long-term care between 2008 and June 2014. The largest proportion of people entering long-term care were female (61.8%) and aged 85-89 years (31.5%) (Table 1). Of the people who entered long-term care 22.9% (n=79,652) were also included in the home care cohort as they had previously accessed home care services.

For the 188,846 people accessing home care for the first time between 2005 and 2014 the majority were also female (65.1%). Similar proportions of people were aged 70-79 years (27.2%) and 80-84 years (27.7%).

# Trends in prevalence of dementia

The age- and sex-standardized prevalence (95% confidence interval (CI)) of dementia for people accessing long-term care decreased from 50.0% (49.6, 50.5) to 46.6% (46.0, 47.2) between 2008 and 2014 (age- and sex-adjusted absolute change 2008 to 2014: -3.8 (-4.6, -3.1), p<0.001 and age- and sex-adjusted annual change: -0.7 (-0.8, -0.6), p<0.001) (Figure 1, Table 2). The results were stratified by sex and this decline was statistically significant for men and women. The decline in dementia prevalence was also statistically significant across all age groups.

For those accessing home care, the age- and sex-standardized prevalence (95% CI) of dementia also decreased from 25.9% (25.0, 26.5) to 20.9% (20.2, 21.7) between 2005 and 2014 (age- and sex-adjusted absolute change 2005 to 2014: -5.2 (-6.2, -4.1), p<0.001 and age- and sex-adjusted annual change: -0.5 (-0.6, -0.4), p<0.001) (Figure 1, Table 2). The decline was also statistically significant for men and women and across all age groups apart from those aged 65-69 years. The findings for changes in dementia prevalence over time were not apparent across all states and territories for both the long-term care and home care cohorts (Supplementary Tables 4 and 5). Dementia prevalence declined over time in New

South Wales, Victoria and Queensland. For those starting long-term care dementia prevalence also declined in Tasmania. In contrast, for those starting home care, dementia prevalence increased in Western Australia.

### Prevalence of dementia adjusted for other health conditions

For those entering long-term care, over time the prevalence of cerebrovascular disease declined from 25.2% (24.8, 25.6) to 22.9% (22.4, 23.4) between 2008 and 2014 (age- and sex-adjusted absolute change -2.3 (-2.9, -1.7), p<0.001) (Figure 2, Supplementary Table 2). Whereas for those starting home care there was no statistically significant change in the prevalence of cerebrovascular disease (0.4 (-0.6, 1.3), p=0.427) (Figure 3, Supplementary Table 3). The prevalence of hypertension, depression, high cholesterol, diabetes, obesity, malnutrition and head injury increased in both cohorts. The prevalence of alcohol dependency/abuse decreased in those starting long-term care. Ischaemic heart disease remained stable in those entering long-term care but increased in people starting home care. For people accessing long-term care the absolute change (95% CI) in dementia prevalence (-3.8 (-4.6, -3.1)) was not explained by adjusting for these health conditions (absolute change adjusted for health conditions -4.0 (-4.7, -3.2), p<0.001). For people accessing home care controlling for these health conditions explain 0.3 percentage points in the absolute change (Table 2).

### Numbers of people accessing aged care with dementia

The number of people accessing long-term aged care increased by 9.6% from 50,580 in 2008 to 55,411 in 2013, but the number of people accessing long-term care with dementia only increased by 2.1% from 25,358 in 2008 to 25,892 in 2013 (Supplementary Table 6). The number of people accessing home care increased by 80.6% from 12,570 in 2005 to 22,699 in 2013 whereas the number of people with dementia increased by 50.8% from 3,250 in 2005 to 4,900 in 2013.

#### Professions of the aged care assessment teams

The ACATs which included a geriatrician, psychogeriatrician or general medical practitioner were more likely to record dementia (51.6% vs. 45.1%, p<0.001 for the long-term care cohort and 27.4% vs. 21.8%, p<0.001 for the home care cohort). Additional adjustment for whether the ACAT included a geriatrician, psychogeriatrician or general medical practitioner did not significantly affect any of the results for change in dementia prevalence (data not shown). The proportion of ACATs which included a geriatrician, psychogeriatrician or general medical or general medical practitioner increased over the study period for the long-term care cohort (from 43.1% in 2008 to 52.4% in 2014) and for the home care cohort (from 27.6% in 2005 to 49.6% in 2014).

### Dementia and mortality after accessing long-term care

People with dementia starting long-term care had a lower risk of 30-day, 90-day and one-year mortality compared to people without dementia (adjusted RR (95% CI) for one-year mortality 0.88 (0.87, 0.89)) which remained statistically significant for both males and females (Supplementary Table 6). One-year mortality remained stable over time. For people without dementia there was a small but statistically significant decrease in one-year mortality (age-and sex-adjusted absolute change: -1.1 (-2.0, -0.1), p=0.029) but the annual change was not statistically significant. For people with dementia there was a small increase in the annual change for one-year mortality, but the absolute change was not statistically significant. Stratification by sex showed for females with dementia there was a small but statistically significant increase in annual and absolute changes in one-year mortality (Supplementary Table 7).

### Discussion

This is the largest study of people aged 65 years or older who accessed aged care services in Australia and provides the most comprehensive examination of trends in prevalence of dementia in Australia to date. The prevalence of dementia declined for those accessing longterm care and home care. Controlling for health conditions related to dementia including cerebrovascular disease, diabetes, hypertension, ischaemic heart disease, high cholesterol, obesity, malnutrition, depression and head injury did not explain the decline in prevalence of dementia.

Overall current evidence concludes that worldwide the age-specific prevalence of dementia is staying constant (8), but the WHO has stated that projections may not be accurate, especially for older age groups (5). A need was identified by the WHO for more studies to examine trends in dementia prevalence as changes in risk factors for dementia may affect prevalence and incidence estimates. A decline in the prevalence or incidence of dementia has been reported in studies in the US and the UK and in Sweden and Spain for men only (9, 22-26). A reduction in the incidence of dementia has also been reported in the Netherlands but this did not reach statistical significance (27). Furthermore, evidence from Denmark and the US suggests older people are living longer with better cognitive functioning (28, 29). Previous studies have suggested increases in educational attainment and advances in treatment for cardiovascular health may be underlying factors contributing to a decline in dementia prevalence, but a full understanding is needed (9, 23).

In this study we identified that one-year mortality remained stable over time for people accessing long-term care. We did find that one-year mortality rates were increasing for females with dementia, but the change was very small. Females with dementia may be

starting long-term care with a later stage of dementia and therefore surviving for a shorter time in long-term care, but this could not be explored further in this study.

In this study we also showed that dementia was associated with a lower risk of mortality for people starting long-term care. In population-based studies dementia is associated with a higher mortality risk (30). Many people entering long-term care are at the end-stage of life requiring palliative care, but people with dementia may be more likely to move to long-term care for other reasons such as the need for more skilled care for changed behaviours (31).

The prevalence of dementia declined in this study even though the prevalence of hypertension, high cholesterol, obesity, malnutrition, depression and head injury increased over time, but cerebrovascular disease declined for people starting long-term care. Some of the decline in dementia prevalence in this population may be explained by advances in treatment options following cerebrovascular disease in Australia and other countries worldwide, but the efficacy of treatment options to inhibit or mitigate the development of post-stroke dementia are unclear (32). Most people in this study were aged over 80 years old and studies have shown that associations between cardiovascular conditions and an increased risk of cognitive decline at mid-life are not always apparent or reversed in late-life populations. This may be due to a survivor effect as people who live to this age may represent a minority who are protected against a risk factor for dementia deemed "successful cognitive ageing" (33).

In Australia, the population age structure is changing, and the proportion of people aged 65 and over increased from 8.3% in 1971 to 14% in 2011 (and from 0.5% to 1.8% for those aged 85 years and over) (34). With the changing population structure there will be an increased demand for aged care services. The number of people accessing long-term aged care in Australia increased by 6% between 2007-08 to 2016-17 and by 72% for people accessing

home care (34). It is important to understand the prevalence of dementia for people accessing aged care services to develop future projections and inform evidence-based policy changes for future care planning. People with dementia may require different services and specialist training programs which should be effectively planned for. In Australia, recent policy changes in the aged care sector have promoted 'ageing in place' which includes improving home care to help older people stay at home for longer, but these were only formalised in 2013. In this study we found Western Australia had an increase in dementia prevalence for people accessing home care, but not in long-term care. There has been a rise in consumer directed care in Australia and the general preference of consumers is to be better supported to stay at home for as long as possible which may influence the prevalence of dementia in home care compared to long-term care. We also found other differences between states which may be explained by differences in the rate of admissions to aged care services in different geographic regions such as admissions to long-term care are higher in urban areas of Australia and admissions of younger people to aged care are higher in rural and regional areas (35) which may explain some of the findings but were not explored further in this study.

#### Strengths and limitations

This is the largest study of dementia prevalence and associated mortality in Australia. Presence of dementia was based on reporting in the individual's most recent aged care assessment on accessing long-term or home care. The overall estimate of the prevalence of dementia may be underestimated as dementia is often undiagnosed (36) and previous research using Australian linked health data suggested the aged care assessments used in this study may only capture 79% of those with dementia (37). Furthermore, the accuracy of dementia diagnosed in medical records also depends on the skills of the healthcare professional who made the diagnosis (38).

The professions of the assessment teams may influence the likelihood to conduct further clinical assessments and subsequently report dementia but adjusting for whether the ACAT assessment teams included a geriatrician, psychogeriatrician or general medical practitioner did not significantly change the results. Furthermore, the inclusion of these professions in the assessment teams increased over time which indicates the reported decline in prevalence of dementia may be a conservative estimate. The ACFI manual states assessors must indicate the source of the evidence to support their ratings (e.g. Aged care client record, GP comprehensive medical assessment, GP notes or letters, Psychogeriatrician notes or letters, Psychiatrist notes or letters, Other medical specialist notes or letters) (14). We did not have information on the professions of the ACFI assessors or the sources they reported in relation to reporting if a person had dementia, so this could not be explored in this study. Extensive cognitive testing in combination with medical records would provide better estimates of dementia but conducting extensive cognitive testing within a vulnerable population accessing aged care services on this scale is unlikely to be feasible.

With the data collected we were able to adjust for many health conditions related to dementia, but we were unable to adjust for other suggested factors associated with dementia including years of formal education. The cognitive reserve hypothesis suggests increased educational attainment allows people to tolerate dementia pathology for longer but may also result in accelerated cognitive decline once symptoms develop (39). In Australia education attainment levels have increased over time; however, much of this change has occurred over recent decades (e.g. a substantial increase in the numbers of people accessing higher education in Australia has occurred since the mid-1960s) (40), therefore, changes to education levels may not be as relevant to this predominately older cohort. Further factors which have been associated with dementia but were not available in this dataset include body-mass index (or waist circumference), smoking status, sleep disturbances, physical activity levels, diet, high-

density lipoprotein levels, alcohol consumption and social engagement (15). Furthermore, there are restrictions on the number of conditions which can be recorded during aged care assessments. According to the ACAT data dictionary assessors will report on conditions that have "an impact on the person's need for assistance with activities of daily living and social participation". Therefore, less severe conditions which do not impact a person's need for care are less likely to be recorded and some estimates (e.g. obesity) are likely to be underestimated in this study.

In Australia there were 3.8 million people aged 65 and over in 2017 and in 2017-2018 over 358,000 people received home care packages or long-term aged care (approximately 9.4% of the population aged 65 and over) (35). Therefore, a substantial portion of Australians over 65 are captured in the studied cohorts. The prevalence estimates of dementia in the long-term care cohort are likely to be higher than the general population and the prevalence estimates for the home care cohort are more likely to be closer to that of the general population. We do not have reason to believe that the prevalence of dementia in the home care study cohort would be different than in the community-dwelling general population. However, we cannot comment on this with the current data we have and as the mean ages in the studied cohorts are 82-84 years, younger age groups may be under-represented.

The prevalence of dementia is dependent on the incidence of dementia and the duration people live with dementia. The decline in prevalence of dementia may be due to a decline in incidence of dementia or an increase in people dying with dementia before they access aged care services. The stable mortality rates for people with dementia accessing long-term care in this study indicate that the decline in prevalence of dementia may be due to a decline in incidence rates but this is not clear from this study.

### Conclusions

Using the largest study of people accessing aged care services in Australia we found a significant decline in dementia prevalence for older people accessing long-term care (2008-2014) and older people accessing home care (2005-2014). This occurred despite an increase in many cardiovascular conditions in these cohorts in the same time. Future studies should aim to further examine trends in dementia prevalence in different countries and the underlying factors. This will have important implications for future projection estimates of dementia in the ageing population and will help to inform policy recommendations to optimise aged care services for people living with dementia.

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# **Ethical Approval**

This study received ethical approval from the University of South Australia (Protocol ID: 200489; Evaluating Healthy Ageing in Australia, 1997-2017).

# **Conflicts of interest**

The authors do not report any conflicts of interest.

# References

Alzheimer's Disease International. Dementia statistics; 2017; 06/07/2018
 <a href="https://www.alz.co.uk/research/statistics">https://www.alz.co.uk/research/statistics</a>.

 Wu YT, Beiser AS, Breteler MMB, *et al.* The changing prevalence and incidence of dementia over time - current evidence. Nature reviews Neurology. 2017;**13**:327-339. doi: 10.1038/nrneurol.2017.63

3. Ohara T, Hata J, Yoshida D, *et al.* Trends in dementia prevalence, incidence, and survival rate in a Japanese community. Neurology. 2017;**88**:1925-1932. doi:

10.1212/WNL.00000000003932

4. Brown L, Hansnata E, La H. Economic Cost of Dementia in Australia; 2017; https://static.treasury.gov.au/uploads/sites/1/2017/06/C2016-052\_NATSEM-for-Alzheimers-Australia.pdf.

5. World Health Organization. Dementia: a public health priority. 2012.

 Ashby-Mitchell K, Burns R, Shaw J, Anstey KJ. Proportion of dementia in Australia explained by common modifiable risk factors. Alzheimer's research & therapy. 2017;9:11. doi: 10.1186/s13195-017-0238-x

7. Australian Institute of Health and Welfare. Australia's health 2018; 2018;

https://www.aihw.gov.au/reports/australias-health/australias-health-2018/contents/table-ofcontents.

8. Prince M, Ali GC, Guerchet M, Prina AM, Albanese E, Wu YT. Recent global trends in the prevalence and incidence of dementia, and survival with dementia. Alzheimer's research & therapy. 2016;**8**:23. doi: 10.1186/s13195-016-0188-8

9. Dufouil C, Beiser A, Chêne G and Seshadri S. Are Trends in Dementia Incidence Associated With Compression in Morbidity? Evidence From The Framingham Heart Study. Journals of Gerontology Series B:Psychological Sciences and Social Sciences.

2018;16;73:S65-S72. doi: 10.1093/geronb/gby001.

10. Australian Government Australian Institute of Health and Welfare. Older Australia at a glance; 2018; <u>https://www.aihw.gov.au/reports/older-people/older-australia-at-a-</u>

glance/contents/health-and-aged-care-service-use/aged-care.

11. Gaugler JE, Yu F, Davila HW, Shippee T. Alzheimer's disease and nursing homes.

Health affairs. 2014;33:650-657. doi: 10.1377/hltaff.2013.1268

12. Australian Institute of Health and Welfare. Australia's welfare: in brief. ; 2017; <a href="https://www.aihw.gov.au/reports/australias-welfare/australias-welfare-2017-in-">https://www.aihw.gov.au/reports/australias-welfare/australias-welfare-2017-in-</a>

brief/contents/ageing-and-aged-care.

 Australian Government Department of Social Services. Aged Care Assessment Programme Guidelines; 2015; 13/07/2018

https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/05\_2015/acap\_guidelines\_accessible\_version\_-\_may\_2015\_0.pdf.

14. Australian Government Department of Health. Aged Care Funding Instrument (ACFI) User Guide; 2018; <u>https://agedcare.health.gov.au/funding/aged-care-subsidies-and-</u> <u>supplements/residential-care-subsidy/basic-subsidy-amount-aged-care-funding-</u>

instrument/aged-care-funding-instrument-acfi-user-guide.

15. Baumgart M, Snyder HM, Carrillo MC, Fazio S, Kim H, Johns H. Summary of the evidence on modifiable risk factors for cognitive decline and dementia: A population-based perspective. Alzheimer's & dementia. 2015;**11**:718-726. doi: 10.1016/j.jalz.2015.05.016

16. Livingston G, Sommerlad A, Orgeta V, *et al.* Dementia prevention, intervention, and care. Lancet. 2017 ;390;**10113**:2673-2734. doi: 10.1016/S0140-6736(17)31363-6.

Tang EY, Harrison SL, Errington L, *et al.* Current Developments in Dementia Risk
Prediction Modelling: An Updated Systematic Review. PloS one. 2015;10:e0136181. doi:
10.1371/journal.pone.0136181

 Anstey KJ, Cherbuin N, Herath PM. Development of a new method for assessing global risk of Alzheimer's disease for use in population health approaches to prevention.
 Prevention science. 2013;14:411-421. doi: 10.1007/s11121-012-0313-2

Kivipelto M, Ngandu T, Laatikainen T, Winblad B, Soininen H, Tuomilehto J. Risk score for the prediction of dementia risk in 20 years among middle aged people: a longitudinal, population-based study. The Lancet Neurology. 2006;5:735-741. doi: 10.1016/S1474-4422(06)70537-3

20. Deckers K, van Boxtel MP, Schiepers OJ, *et al.* Target risk factors for dementia prevention: a systematic review and Delphi consensus study on the evidence from observational studies. International journal of geriatric psychiatry. 2015;**30**:234-246. doi: 10.1002/gps.424

Li J, Ogrodnik M, Devine S, Auerbach S, Wolf PA, Au R. Practical risk score for 5-,
10-, and 20-year prediction of dementia in elderly persons: Framingham Heart Study.
Alzheimer's & dementia. 2018;14:35-42. doi: 10.1016/j.jalz.2017.04.013.

22. Satizabal C, Beiser AS, Chouraki V, Chêne G, Dufouil C and Seshadri S. Incidence of Dementia over Three Decades in the Framingham Heart Study. The New England journal of medicine. 2016;**375**:93-94. doi: 10.1056/NEJMoa1504327

23. Matthews FE, Arthur A, Barnes LE, *et al.* A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II. Lancet. 2013;**382**:1405-1412. doi: 10.1016/S0140-6736(13)61570-6

24. Lobo A, Saz P, Marcos G, *et al.* Prevalence of dementia in a southern European population in two different time periods: the ZARADEMP Project. Acta psychiatrica Scandinavica. 2007;**116**:299-307. doi: 10.1111/j.1600-0447.2007.01006.x

 Qiu C, von Strauss E, Backman L, Winblad B, Fratiglioni L. Twenty-year changes in dementia occurrence suggest decreasing incidence in central Stockholm, Sweden. Neurology. 2013;80:1888-1894. doi: 10.1212/WNL.0b013e318292a2f9.

26. Wimo A, Sjolund BM, Skoldunger A, *et al.* Cohort Effects in the Prevalence and Survival of People with Dementia in a Rural Area in Northern Sweden. Journal of Alzheimer's disease. 2016;**50**:387-396. doi: 10.3233/JAD-150708.

27. Schrijvers EM, Verhaaren BF, Koudstaal PJ, Hofman A, Ikram MA, Breteler MM. Is dementia incidence declining?: Trends in dementia incidence since 1990 in the Rotterdam Study. Neurology. 2012;**78**:1456-1463. doi: 10.1212/WNL.0b013e3182553be6.

Christensen K, Thinggaard M, Oksuzyan A, *et al.* Physical and cognitive functioning of people older than 90 years: a comparison of two Danish cohorts born 10 years apart.
 Lancet. 2013;382:1507-1513. doi: 10.1016/S0140-6736(13)60777-1.

29. Dodge HH, Zhu J, Lee CW, Chang CC, Ganguli M. Cohort effects in age-associated cognitive trajectories. The journals of gerontology Series A, Biological sciences and medical sciences. 2014;**69**:687-694. doi: 10.1093/gerona/glt181.

Guehne U, Riedel-Heller S, Angermeyer MC. Mortality in dementia.
 Neuroepidemiology. 2005;25:153-162. doi: 10.1159/000086680

Buhr GT, Kuchibhatla M, Clipp EC. Caregivers' reasons for nursing home placement:
 clues for improving discussions with families prior to the transition. The Gerontologist.
 2006;46:52-61. doi: 10.1093/geront/46.1.52

32. Mijajlovic MD, Pavlovic A, Brainin M, *et al.* Post-stroke dementia - a comprehensive review. BMC medicine. 2017;**15**:11. doi: 10.1186/s12916-017-0779-7

33. Silverman JM, Schmeidler J. Outcome age-based prediction of successful cognitive aging by total cholesterol. Alzheimer's & dementia. 2018;14:952-960. doi:

10.1016/j.jalz.2018.01.009.

34. Australian Bureau of Statistics. Australia's changing population; 2012; http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/2071.0main+features752012-2013.

35. Australian Government Department of Health. 2017–18 Report on the Operation of the Aged Care Act 1997; <u>https://www.gen-</u>

agedcaredata.gov.au/www\_aihwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf

36. Lang L, Clifford A, Wei L, *et al.* Prevalence and determinants of undetected dementia in the community: a systematic literature review and a meta-analysis. BMJ Open.

2017;7:e011146. doi: 10.1136/bmjopen-2016-011146.

37. Waller M, Mishra GD, Dobson AJ. Estimating the prevalence of dementia using multiple linked administrative health records and capture-recapture methodology. Emerging themes in epidemiology. 2017;**14**:3. doi: 10.1186/s12982-017-0057-3

 Flicker L, Visvanathan R, Ratcliffe J. Timely Diagnosis for Dementia: The Need for Specialists. Journal of the American Medical Directors Association. 2016;17:462-463. doi: 10.1016/j.jamda.2016.02.031

39. Stern Y. Cognitive reserve and Alzheimer disease. Alzheimer disease and associated disorders. 2006;**20**:112-117. doi: 10.1097/01.wad.0000213815.20177.19

40. Abbott M, Doucoculiagos C. The changing structure of higher education in Australia, 1949-2003. 2003.

# **Figure Legends**

# Figure 1.

**Figure Title:** Change in the age- and sex-standardized prevalence of dementia for older people (≥65 years) starting home care or long-term aged care in Australia.

# Figure 2.

**Figure Title:** Change in prevalence of conditions related to dementia for older people ( $\geq 65$  years) starting long-term aged care in Australia.

**Notes:** NOTE: Conditions with very low prevalence (<3%) not shown: obesity, malnutrition, alcohol abuse/dependence and head injury.

# Figure 3.

**Figure Title:** Change in prevalence of conditions related to dementia for older people ( $\geq 65$  years) starting home care in Australia.

**Notes:** NOTE: Conditions with very low prevalence (<3%) not shown: obesity, malnutrition, alcohol abuse/dependence and head injury.

Characteristic	Long-term aged care	Home care
	(n=348,311)	(n=188,486)
Year <sup>a</sup>		
2005		12,570 (6.7)
2006		17,540 (9.3)
2007		18,259 (9.7)
2008	50,580 (14.5)	19,249 (10.2)
2009	51,602 (14.8)	19,445 (10.3)
2010	52,974 (15.1)	19,971 (10.5)
2011	53,819 (15.5)	23,343 (12.4)
2012	55,627 (16.0)	23,539 (12.5)
2013	55,411 (15.9)	22,699 (12.0)
2014 <sup>b</sup>	28,578 (8.2)	12,051 (6.4)
Female	215,095 (61.8)	122,619 (65.1)
Age (years)		
Mean (SD)	84.2 (7.0)	82.1 (7.0)
65-69	15,769 (4.8)	10,154 (5.4)
70-79	45,302 (13.8)	51,331 (27.2)
80-84	84,909 (25.8)	52,199 (27.7)
85-89	103,497 (31.5)	48,105 (25.5)
90-94	61,378 (18.7)	21,898 (11.6)
95+	17,883 (5.44)	4,799 (2.6)
State		
New South Wales	120,354 (34.6)	63,518 (33.7)
Victoria	89,818 (25.8)	46,189 (22.9)

Table 1. Characteristics of older people (≥65 years) who accessed home care or long-

term aged care in Australia

Queensland	61,881 (17.8)	35,152 (18.7)
South Australia	32,982 (9.5)	15,622 (8.3)
Western Australia	28,224 (8.1)	21,859 (11.6)
Tasmania	10,062 (2.9)	4,598 (2.4)
Australian Capital Territory	3,855 (1.1)	3,452 (1.8)
Northern Territory	562 (0.2)	1,096 (0.6)
ACAT professions <sup>c</sup>		
Geriatrician	98,644 (28.6)	30,761 (16.3)
Psychogeriatrician	4,603 (1.3)	1,170 (0.6)
Generalist Medical Practitioner	83,389 (24.2)	48,006 (25.5)
Other Medical Practitioner	69,058 (20.0)	13,970 (7.4)
Nurse	288,086 (83.6)	138,088 (73.3)
Health conditions		
Dementia	167,697 (48.2)	44,997 (23.9)
Cerebrovascular disease	84,190 (24.2)	33,824 (18.0)
Diabetes	71,843 (20.6)	38,423 (20.4)
Hypertension	173,222 (49.8)	88,429 (46.9)
Ischaemic heart disease	48,006 (13.8)	17,619 (9.4)
High cholesterol	43,032 (12.4)	23,073 (12.2)
Obesity	2,906 (0.8)	1,807 (1.0)
Malnutrition	3,220 (0.9)	582 (0.3)
Depression	115,009 (33.0)	26,981 (14.3)
Alcohol abuse/dependence	8,869 (2.6)	1,625 (0.9)
Head injury	2,787 (0.8)	1,039 (0.6)

NOTE. Characteristics are presented as n (%) unless otherwise indicated. <sup>a</sup>Year started home care or long-term aged care <sup>b</sup>Data only available to end of June 2014. <sup>c</sup>Other professions not listed included occupational therapist, physiotherapist, speech pathologist/therapist, podiatrist, pharmacist, aboriginal

health worker, other health professional, social worker, welfare & community worker, counsellor, psychologist, other social professional, other profession and rehabilitation specialist. ACAT: Aged Care Assessment Team, multiple people form an Aged Care Assessment team therefore multiple professions are recorded. Year Long-term aged care Home care (n=348,311) (n=188,846) 2005 25.9 (25.0, 26.5) \_ 2006 24.8 (24.1, 25.4) 2007 25.1 (24.5, 25.8) 2008 50.0 (49.6, 50.5) 25.5 (24.9, 26.1) 2009 49.3 (48.9, 49.7) 24.5 (23.9, 25.1) 2010 48.3 (47.8, 48.7) 24.0 (23.4, 24.6) 2011 48.3 (47.9, 48.7) 23.9 (23.4, 24.5) 2012 47.2 (46.8, 47.6) 22.6 (22.1, 23.2) 2013 47.0 (46.5, 47.4) 21.6 (21.1, 22.2) 2014\* 46.6 (46.0, 47.2) 20.9 (20.2, 21.7) Annual change (95% CI), -0.7 (-0.8, -0.6) -0.5 (-0.6, -0.5) p<0.001 p<0.001 adjusted for age and sex Annual change (95% CI), -0.7 (-0.8, -0.6) -0.5 (-0.6, -0.4) p<0.001 p<0.001 adjusted for age, sex, location and health conditions# -5.2 (-6.2, -4.1) Absolute change (95% CI), -3.8 (-4.6, -3.1) p<0.001 p<0.001 adjusted for age and sex± Absolute change (95% CI), -4.0 (-4.7, -3.2) -4.9 (-6.0, -3.9) p<0.001 p<0.001 adjusted for age, sex,

 Table 2. Age- and sex-standardized prevalence estimates for dementia for people

 starting long-term aged care or home care in Australia.

location and health

conditions#±

\*Data only available to June 2014. #cerebrovascular disease, diabetes, hypertension, ischaemic heart disease, high cholesterol, obesity, malnutrition, depression, alcohol abuse/dependence and head injury.

 $\pm 2014$  vs. 2008 for the long-term care cohort and 2014 vs. 2005 for the home care cohort.