

Dementia Awareness Survey

Web report | Last updated: 24 Apr 2024 | Topic: [Dementia](#) | [Media release](#)

About

The Dementia Awareness Survey is the largest nationally representative community survey of its kind in Australia. It collects information on how much people know about dementia and their attitudes towards dementia and people living with dementia. The survey results will help inform priorities and areas for dementia awareness initiatives and prevention activities that can reduce the risk or delay the development of dementia.

Cat. no: DEM 10

Findings from this report:

- [Australians with lower incomes or education, or no personal experience with dementia know less about dementia](#)
 - [Australians generally do not know that certain behaviours they adopt may reduce their risk of dementia](#)
 - [Most Australians are engaged in one or more behaviours that can reduce their risk of developing dementia](#)
 - [Australians who know more about dementia tend to hold fewer dementia-related stigmatic beliefs, feelings, and behaviours](#)
-

Summary

Dementia is a significant and growing health and aged care concern in Australia. More than 400,000 Australians are living with dementia, and this number is projected to double by 2058 (AIHW 2023). Dementia is a term used to describe a group of conditions characterised by cognitive decline interfering with daily function (AIHW 2023). It can affect people's memory, speech, cognition (thought), behaviour, mobility, and personality, and their health and functional ability decline as the disease progresses. Dementia can have a profound impact on the person living with dementia, as well as their family, friends, and carers.

While dementia is more common with age, it is not a normal part of ageing and there are health behaviours that can increase or decrease the risk of developing dementia (known as 'modifiable risk factors'). Despite the significant impacts of dementia, previous research (Keage et al. 2021; Nagel et al. 2021) has shown that the community generally has a poor understanding of dementia and what can be done to reduce the risk of developing it.

The Dementia Awareness Survey (the survey) collected information on Australians' knowledge of dementia and modifiable risk factors for dementia, and Australians' attitudes towards dementia and people living with dementia. Survey findings will inform priorities and specific focus areas for dementia awareness initiatives and possible prevention activities stemming from the [National Dementia Action Plan](#).

More than 5,400 people aged 18 and over across Australia were surveyed between July and August 2023. The 2023 survey is the first Dementia Awareness Survey of this kind conducted. Subsequent surveys will provide information on whether knowledge of dementia and behaviours and attitudes have changed over time. All the differences between groups reported in this report are statistically significant ($p < 0.05$).

Generally, Australians know little about dementia

Survey respondents were asked whether statements about dementia were 'true', 'probably true', 'probably false', 'false', or 'don't know'. Statements cover broad topics, including general characteristics, causes and symptoms, behaviour and communication with people with dementia, and risks and health promotion. Knowledge was higher among:

- women
- those with higher levels of education and income
- those with a family member or friend with dementia
- those who have worked with people with dementia
- those who were born in Australia or in culturally similar countries (the United Kingdom (UK), United States of America (USA), Canada and New Zealand (NZ))
- non-heterosexual people
- people who lived in *Inner regional* areas of Australia, when compared with those who lived in *Major cities*.

While more than half of Australians knew that Alzheimer's disease is the most common form of dementia (63% responded with 'true' or 'probably true'), only around 1 in 6 (17% responded 'false' and 'probably false') knew that common forms of dementia do not have a sudden onset of cognitive problems.

Australians need to know various dementia risk factors

A large proportion of Australians were able to recognise some ways to reduce their risk of dementia such as being physically (77%), cognitively (continually learning new things; 77%), and socially active (70%) - along with cutting down alcohol consumption if they drink excessively (72%) and preventing head injuries (70%). However, fewer than 1 in 3 Australians were sure about their knowledge.

Australians did not know about less known dementia risk or protective factors such as avoiding polluted air (35%) and eating a Mediterranean diet (50%).

Almost all Australians do one or more things that can reduce their risk of developing dementia

Although most Australians (99.6%) engaged in one or more behaviours that can reduce their risk of developing dementia, they generally did so for other reasons. For example, a person may maintain healthy blood pressure or be socially active, not realising that this also reduces their risk of dementia.

People who knew more about dementia tended to take more action than those who knew less.

2 in 3 Australians believe people with dementia need constant supervision

There are several commonly held stereotypes about people with dementia. About 2 in 3 (67%) people believed that people with dementia needed constant supervision and that they are unpredictable (62%). However, more than 4 in 5 Australians believed that people with dementia can enjoy life (83%), 3 in 4 (77%) did not fear people with dementia, and fewer than 1 in 10 people would exclude a person with dementia (8.3%) or ignore them (4.8%).

Australians with symptoms of dementia would seek help from their general practitioner (GP)

Nine in 10 (89%) Australians would seek help from a GP if they had signs of dementia. Half (51%) would seek help from a specialist and 4 in 10 (39%) would seek help from family or friends.

Australians would share a dementia diagnosis with family members

Almost all (94%) Australians would share a diagnosis of dementia with family members. Two in 3 Australians would share a diagnosis with friends, and 1 in 3 people with their employer and colleagues. Very few people (4%) would tell nobody.

References

AIHW (Australian Institute of Health and Welfare) (2023) *Dementia in Australia: summary*, AIHW, Australian Government, accessed 10 January 2024.

Keage HAD, Villani G and Hutchinson AD (2021) 'What do young Australian adults know about modifiable risk factors for dementia?', *BMC Public Health*, 21(1):2166, doi:10.1186/s12889-021-12220-7.

Nagel AK, Loetscher T, Smith AE and Keage HA (2021) 'What do the public really know about dementia and its risk factors?', *Dementia*, 20(7):2424-2440, doi:10.1177/1471301221997301.

© Australian Institute of Health and Welfare 2024



About the Dementia Awareness Survey

In 2023, more than 5,400 people aged 18 and over (refer to [Table S1](#)) completed the Dementia Awareness Survey (the survey) to understand general knowledge of dementia and dementia risk factors and community attitudes towards dementia and people living with dementia in Australia.

The survey builds on previous Australian surveys of dementia knowledge and attitudes (Low & Anstey 2009; Talbot et al. 2021; Farrow 2008; Hosking et al. 2015; Nagel et al. 2021) and is the largest Australian survey undertaken on dementia knowledge and attitudes from a nationally representative sample of adults. Findings from the survey will inform:

- national policy priorities for the next 10 years under the [National Dementia Action Plan](#)
- the design and implementation of dementia awareness-raising initiatives and other relevant interventions aimed at
 - improving the community's attitudes and knowledge of dementia
 - reducing dementia-related stigma and discrimination
 - reducing dementia risk
 - delaying dementia onset
 - slowing down its progression
- baseline measures to monitor the National Dementia Action Plan (in development)
- dementia data improvements in Australia.

How was the survey done and reported?

The Australian Government Department of Health and Aged Care commissioned the AIHW to manage the Dementia Awareness Survey, and the AIHW commissioned the [Social Research Centre](#) to conduct the survey fieldwork. A Dementia Awareness Survey Reference Group comprising experts in dementia research and survey design supported the AIHW in the development of the survey.

The questionnaire was generally completed online (98%) with a small proportion (2.5%) completing a telephone interview. The survey was available in 6 languages: English, traditional Chinese, simplified Chinese, Arabic, Vietnamese, and Punjabi.

For more information on the survey design and implementation, refer to the [Technical notes](#).

The report presents estimates derived from survey responses weighted to the appropriate Australian population. Proportions are shown as percentages rounded to one decimal place. All differences reported in estimates across groups are statistically significant at the 95% level of confidence unless specified otherwise.

References

- Farrow M (2008) *Dementia risk reduction: what do Australians know?* [PDF 237KB], Alzheimer's Australia, accessed 24 November 2023.
- Hosking DE, Sargent-Cox K and Anstey KJ (2015) '[An Australian survey of cognitive health beliefs, behaviours, and intentions through the adult life course](#)', *Preventive Medicine Reports*, 2:498-504, doi:10.1016/j.pmedr.2015.06.008.
- Low L-F and Anstey KJ (2009) '[Dementia literacy: recognition and beliefs on dementia of the Australian public](#)', *Alzheimer's & Dementia*, 5(1):43-49, doi:10.1016/j.jalz.2008.03.011.
- Nagel AK, Loetscher T, Smith AE and Keage HA (2021) '[What do the public really know about dementia and its risk factors?](#)', *Dementia* 20(7):2424-2440, doi:10.1177/1471301221997301.
- Talbot, LA, Thomas M, Bauman A, Manera KE, and Smith BJ (2021) '[Impacts of the national your brain matters dementia risk reduction campaign in Australia over 2 years](#)', *Journal of Alzheimer's Disease*, 82(3):1219-1228, doi:10.3233/JAD-210317.
-



Knowledge of dementia

In general, Australians were unsure about what they know about dementia and what can be done to reduce the risk of developing dementia. Australians need to improve their knowledge of dementia

Over 3 in 4 Australians knew some ways to reduce their risk of developing dementia including doing regular physical activity (77%) and continually learning new things (77%)

One in 5 Australians (20%) believed the misconception that aluminium cookware increases their risk of developing dementia

Knowledge of dementia was higher in women, people who have personal experience with people living with dementia, those with higher levels of education and household income, those born in Australia, the UK, the USA, Canada, and NZ, and non-heterosexual people. Groups of people with less dementia knowledge could be targeted for dementia awareness and education initiatives

Knowledge of dementia

How is knowledge of dementia measured?

General dementia knowledge was measured with the Dementia Knowledge Assessment Scale (DKAS; Annear et al. 2017), which comprises statements about the most common forms of dementia that are factually correct or incorrect. The total DKAS score was calculated by summing all 25 items into a score between 0-50, with a higher score representing better dementia knowledge. Refer to the [Technical notes](#) for more information on the scale.

What does previous research tell us about Australians' knowledge of dementia?

Despite the widespread impact of dementia, Australians generally have a poor understanding of dementia, and dementia is commonly misunderstood as a normal part of ageing (Kim et al. 2022; Smith et al. 2014). Previous research has shown that knowledge of dementia is lower in people who have no personal experience with a person living with dementia (Eccleston et al. 2021).

Prior research also found that although most Australians could recognise symptoms of dementia, they did not know that it affects cognitive function as well as the ability to perform everyday tasks (Nagel et al. 2021). Around half (Farrow 2008) knew that dementia risk could be reduced, but most did not realise that cardiovascular risk factors were also risk factors for dementia (Low & Anstey 2009; Talbot et al. 2021; Farrow 2008; Hosking et al. 2015).

How much do Australians know about dementia?

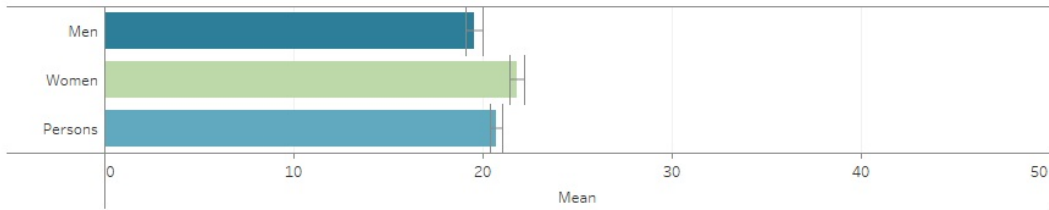
According to the 2023 Dementia Awareness Survey (the survey), Australians had an average general dementia knowledge score of 21 with a median score of 20 out of a maximum possible score of 50 (Figure 1.1a). This is lower than Australian surveys of people interested in dementia training (median score of 35; Eccleston et al. 2019) or where the majority (59%) had either completed dementia training or had experience with persons with dementia (median score of 28; Eccleston et al. 2021). The difference could be due to differences between the people surveyed - the general public versus those in a dementia-related workforce.

Women had higher dementia knowledge than men (mean score of 22 compared to 20) (Figure 1.1a). This gender difference was significant in the 35-74 age groups (Figure 1.1b).

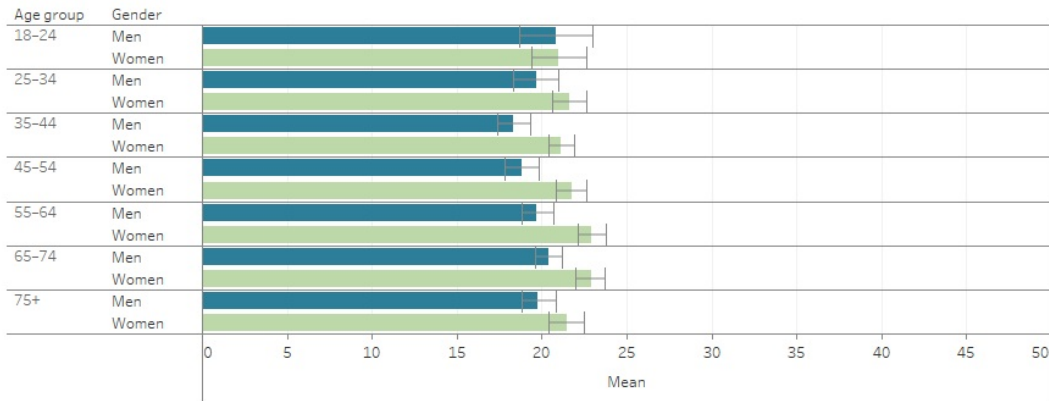
Figure 1.1: General dementia knowledge score by gender and age group, 2023

The bar charts show that overall, women had a higher general dementia knowledge score than men, but that the difference was not significant in those aged less than 35 or over 75 years.

a) General dementia knowledge by gender



b) General dementia knowledge by age and gender



Source: Dementia Awareness Survey 2023
<http://www.aihw.gov.au>

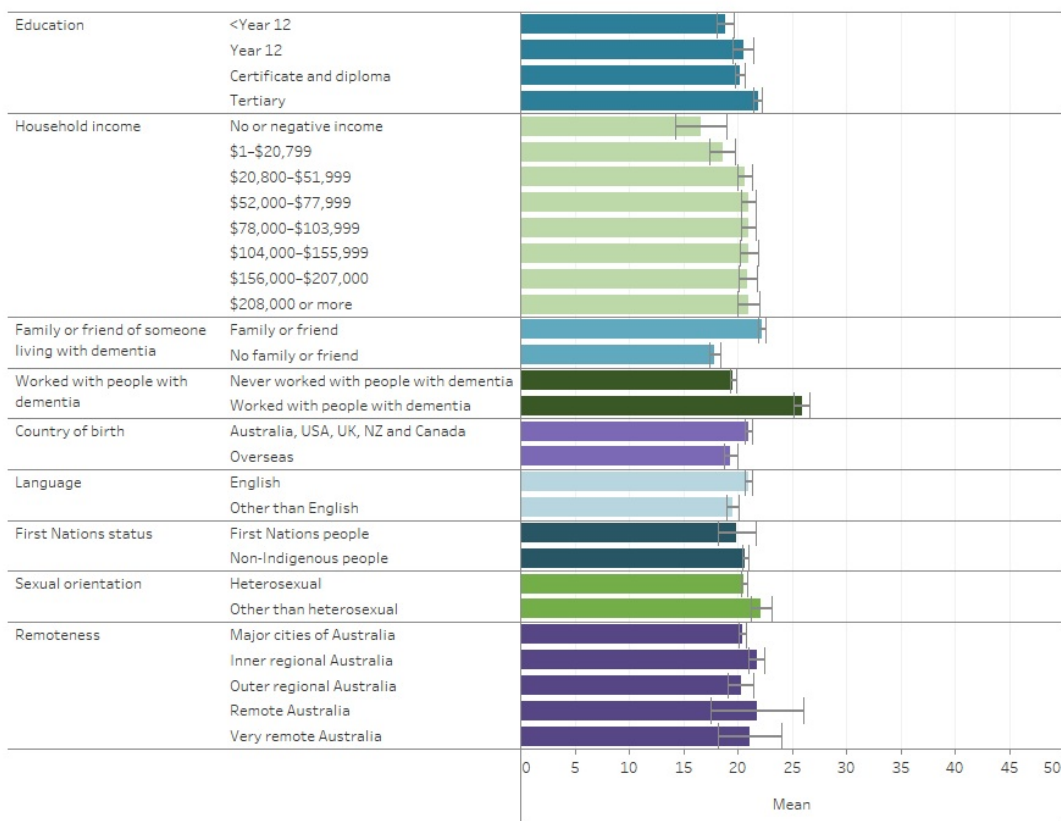
Who knows the most about dementia?

The average general dementia knowledge score was compared for each sociodemographic group (Figure 1.2). However, the group difference could be due to other factors, therefore these sociodemographic groups were compared together to identify which groups predict better dementia knowledge (refer to [Table S2.1](#)). Significantly higher levels of general dementia knowledge were found in:

- women
- people with higher levels of education, in particular tertiary qualifications
- people with a household income of \$20,800 or more per year
- people with a family member or friend living with dementia
- people who had work experience with people living with dementia
- people born in Australia, the UK, the USA, Canada, and NZ
- non-heterosexual people
- people who lived in *Inner regional* areas of Australia, when compared with those living in *Major cities*.

Figure 1.2: Average general dementia knowledge score by demographics and experience with people with dementia, 2023

The bar chart shows that respondents who have worked with people with dementia have the highest general dementia knowledge score (26).



Note: This data is not adjusted for other demographic variables, and differences between groups are not present when adjustment for other demographic variables have occurred. Please refer to Table S2.1 for adjusted results.
 Source: Dementia Awareness Survey 2023
<http://www.aihw.gov.au>

What dementia knowledge do people have or lack the most?

Survey respondents were asked whether statements about dementia were ‘true’, ‘probably true’, ‘probably false’, ‘false’, or ‘don’t know’, and most and least correctly answered statements are shown in Figure 1.3.

The onset of dementia is usually very gradual but over half of Australians (58%) answered ‘true’ or ‘probably true’ to the statement that the sudden onset of cognitive problems is characteristic of common forms of dementia.

Dementia is often mistakenly believed to be a natural part of ageing. Around 1 in 5 (22%) Australians agreed with the statement that ‘dementia is a normal part of the ageing process’, by indicating it as ‘true’ or ‘probably true’. This is lower than a review of public surveys on dementia knowledge and attitudes performed internationally from 2012 to 2017 (Cations et al. 2018), which found that nearly half of all respondents agreed that dementia is a normal part of ageing. This could indicate that understanding of dementia has improved over time or is better in Australia.

Early or timely diagnosis can improve the quality of life for people with dementia as it may provide options for treatment and planning. Three in 5 (61%) Australians believe that early diagnosis improves the quality of life for people with dementia (Figure 1.3).

There is no cure for neurodegenerative dementias yet and just under 3 in 4 Australians (74% answered ‘false’ or ‘probably false’) do not believe that people can recover from dementia (Figure 1.3).

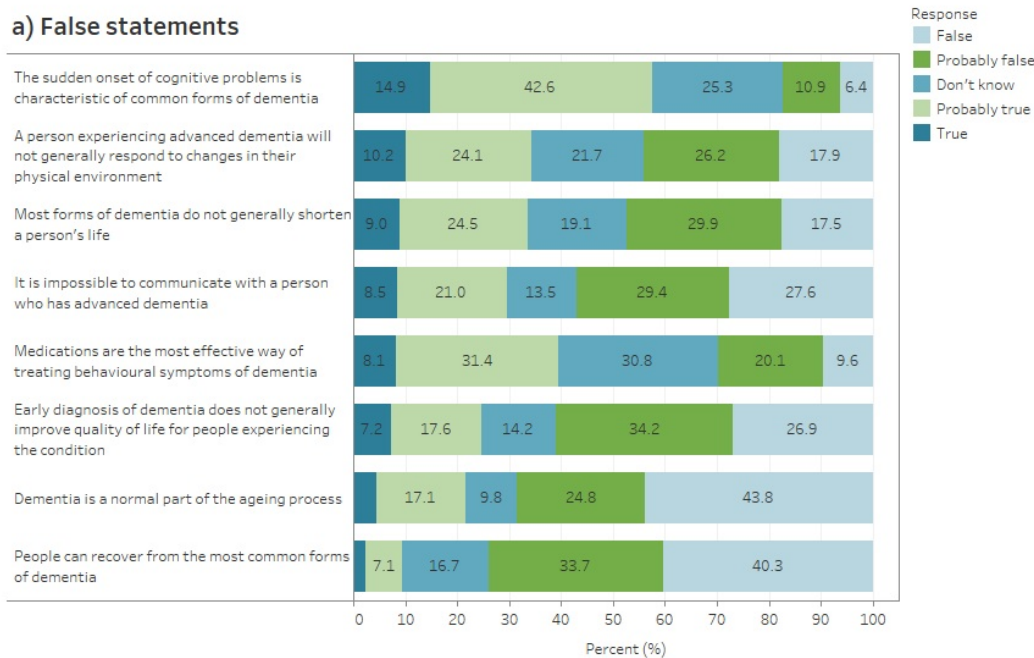
Three in 5 (63% answered ‘true’ or ‘probably true’) Australians knew that Alzheimer’s disease is the most common form of dementia. Around 4 in 5 Australians (82%) agreed that daily care for a person with advanced dementia is effective when it focuses on providing comfort and people with advanced dementia may have difficulty speaking (78%).

The proportion of Australians who agreed with these statements with certainty (‘true’ for true statements and ‘false’ for false statements) however was low, suggesting Australians are not certain whether what they know about dementia is correct.

Figure 1.3: Percentage of people who responded to true and false statements about dementia, 2023

The stacked bar charts show that many Australians incorrectly responded that false statements about dementia were ‘true’ or ‘probably true’, while the majority of respondents correctly identified true statements as ‘true’ or ‘probably true’.

a) False statements



Source: Dementia Awareness Survey 2023
<http://www.aihw.gov.au>

References

- Annear MJ, Toye C, Elliott K-EJ, McInerney F, Eccleston C and Robinson A (2017) 'Dementia knowledge assessment scale (DKAS): confirmatory factor analysis and comparative subscale scores among an international cohort', *BMC Geriatrics*, 17:168, doi:10.1186/s12877-017-0552-y.
- Cations M, Radisic G, Crotty M and Laver KE (2018) 'What does the general public understand about prevention and treatment of dementia? A systematic review of population-based surveys', *PLoS ONE*, 13(4):e0196085, doi:10.1371/journal.pone.0196085.
- Eccleston C, Doherty K, Bindoff A, Robinson A, Vickers J and McInerney F (2019) 'Building dementia knowledge globally through the understanding dementia massive open online course (MOOC)', *NPJ Science of Learning*, 4:3, doi:10.1038/s41539-019-0042-4.
- Eccleston CE, Courtney-Pratt H, McInerney F, Johnstone A and Doherty K (2021) 'Predictors of dementia knowledge in a rural general public sample', *Aust J Rural Health*, 29(4):530-537, doi:10.1111/ajr.12777.
- Farrow M (2008) *Dementia risk reduction: what do Australians know?* [PDF 237KB], Alzheimer's Australia, accessed 24 November 2023.
- Hosking DE, Sargent-Cox KA and Anstey KJ (2015) 'An Australian survey of cognitive health beliefs, behaviours, and intentions through the adult life course', *Preventive Medicine Reports*, 2:498-504, doi:10.1016/j.pmedr.2015.06.008.
- Kim S, Anstey KJ and Mortby ME (2022) 'Who displays dementia-related stigma and what does the general public know about dementia? Findings from a nationally representative survey', *Aging & Mental Health*, 27:1111-1119, doi:10.1080/13607863.2022.2040428.
- Low L-F and Anstey KJ (2009) 'Dementia literacy: recognition and beliefs on dementia of the Australian public', *Alzheimer's & Dementia*, 5:43-49, doi:10.1016/j.jalz.2008.03.011.
- Nagel AK, Loetscher T, Smith AE and Keage HA (2021) 'What do the public really know about dementia and its risk factors?', *Dementia*, 20(7):2424-2440, doi:10.1177/1471301221997301.
- Smith BJ, Ali S and Quach H (2014) 'Public knowledge and beliefs about dementia risk reduction: a national survey of Australians', *BMC Public Health*, 14:661, doi:10.1186/1471-2458-14-661.
- Talbot LA, Thomas M, Bauman A, Manera KE, and Smith BJ (2021) 'Impacts of the national your brain matters dementia risk reduction campaign in Australia over 2 years', *Journal of Alzheimer's Disease*, 82(3):1219-1228, doi:10.3233/JAD-210317.



Knowledge of dementia

Several factors may increase or decrease a person’s risk of developing dementia which are called risk and protective factors, respectively. Some risk factors, such as ageing and genetics, cannot be changed, but others can be modified by changing behaviours or lifestyles. See [What puts someone at risk of developing dementia?](#) for more information.

How is knowledge of dementia risk factors and misconceptions measured?

Knowledge of dementia risk factors was measured with the Knowledge of Dementia Risk Reduction (KoDeRR) scale (Bartlett et al. 2022), measuring knowledge of dementia risk factors as well as common misconceptions. The KoDeRR risk score (KoDeRR_R) was calculated by summing 14 known risk factors of dementia¹, ranging from 0-28, and a higher score represents a better ability to recognise dementia risk factors. Similarly, the KoDeRR misconception score (KoDeRR_M) was calculated by summing 6 common misconceptions of dementia, ranging from 0-12, and a higher score represents a better ability to recognise misconceptions. Refer to the [Technical notes](#) for more information on the scale.

1. The KoDeRR items were developed primarily based on the review papers (Livingston et al. 2017, 2020) and WHO recommendations (2019). At the time it appeared that there was strong evidence to support the use of hearing aids for dementia risk reduction. However, the evidence is currently under reconsideration (Lin et al. 2023).

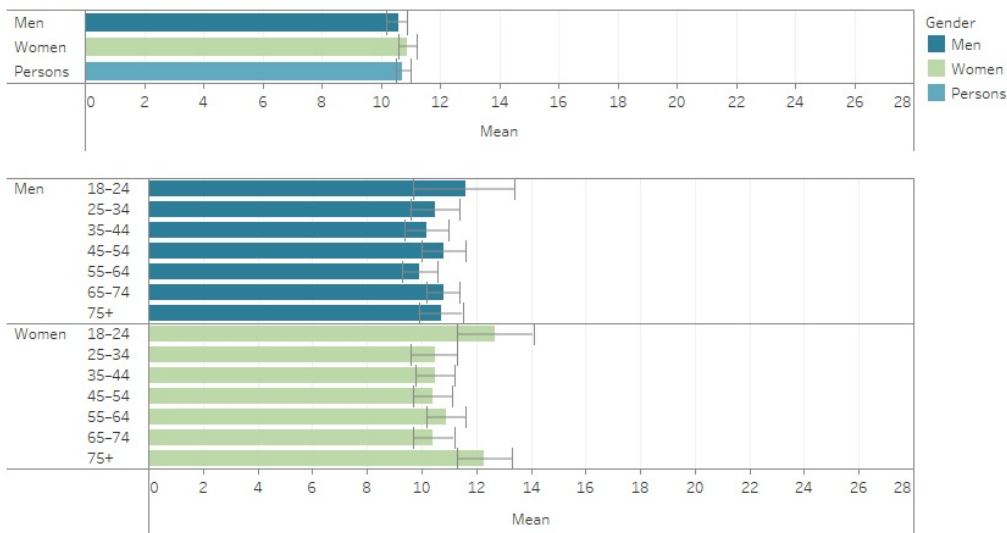
How much do Australians know about dementia risk reduction?

Australians had an average risk score (KoDeRR_R) of 10.7 (out of 28) and a misconception score (KoDeRR_M) of 2.0 (out of 12), suggesting Australians’ knowledge of evidence-based ways to reduce modifiable risk factors and ability to identify misconceptions about ways to reduce dementia risk was low. The levels of dementia risk knowledge and misconception knowledge were similar for men and women and for different age groups (Figure 2.1).

Figure 2.1: Dementia risk knowledge and misconception scores by gender and age group, 2023

The horizontal bar charts show similar scores for all genders and age groups, with women and the youngest and oldest age groups having slightly higher scores than men and other age groups.

Dementia risk knowledge



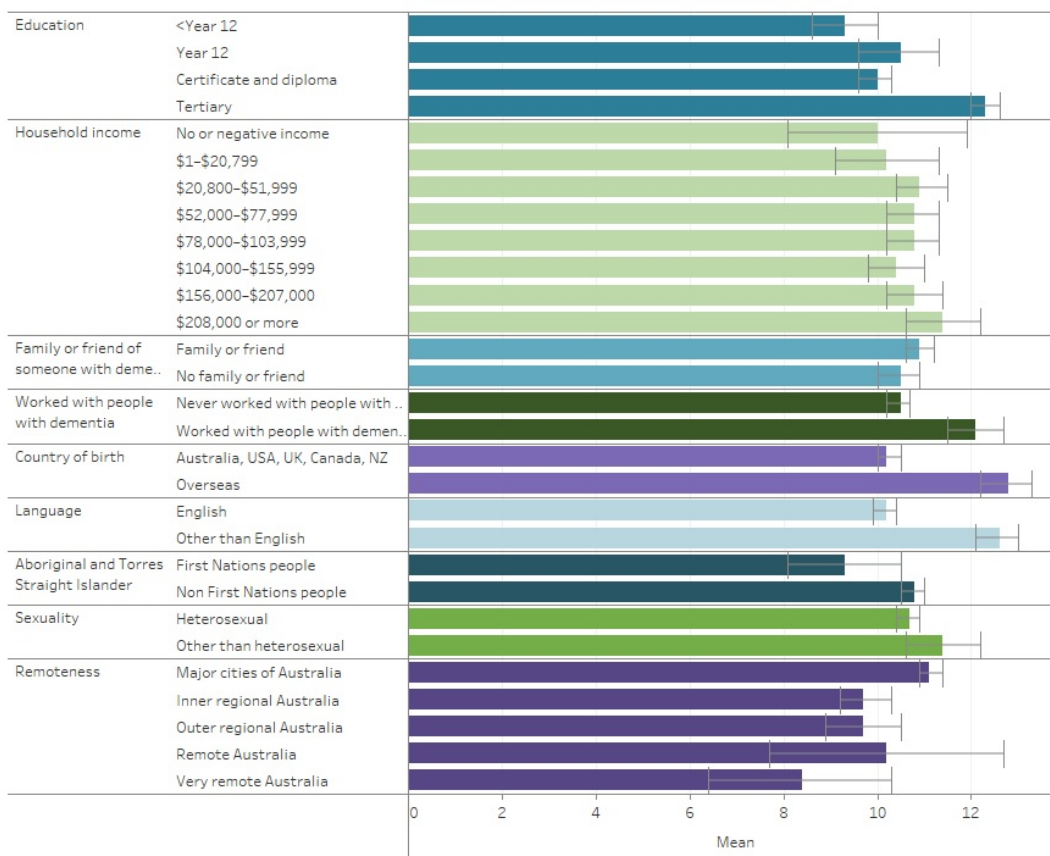
Source: Dementia Awareness Survey 2023
<http://www.aihw.gov.au>

How does dementia risk knowledge vary among population groups?

People’s knowledge of dementia risk and protective factors was compared among different socioeconomic groups as well as exposure groups (those without any relationship with people living with dementia; those living with dementia; those who know someone with dementia; and those who care (formally and informally) for someone living with dementia) (Figure 2.2).

Figure 2.2: Dementia risk reduction knowledge and demographics, 2023

The bar chart shows that those who were born overseas had the highest dementia risk knowledge (13), while respondents in very remote Australia had the lowest (8.4).



Note: These are unadjusted results. Please refer to Table S2.2 for adjusted results.
 Source: Dementia Awareness Survey 2023
<http://www.aihw.gov.au>

Dementia risk knowledge was compared within sociodemographic groups (refer to Table S2.2). After adjusting for other demographic factors, knowledge of dementia risk factors was significantly higher among:

- those aged between 18 and 24
- women (Figure 2.1)
- those with a Bachelor’s degree or above
- those who worked with people with dementia
- those who had a family member or friend with dementia
- non-heterosexual people
- those who spoke languages other than English at home.

Being born overseas, being First Nations people, and level of household income did not significantly contribute to the level of dementia risk knowledge.

Do Australians recognise dementia risk factors?

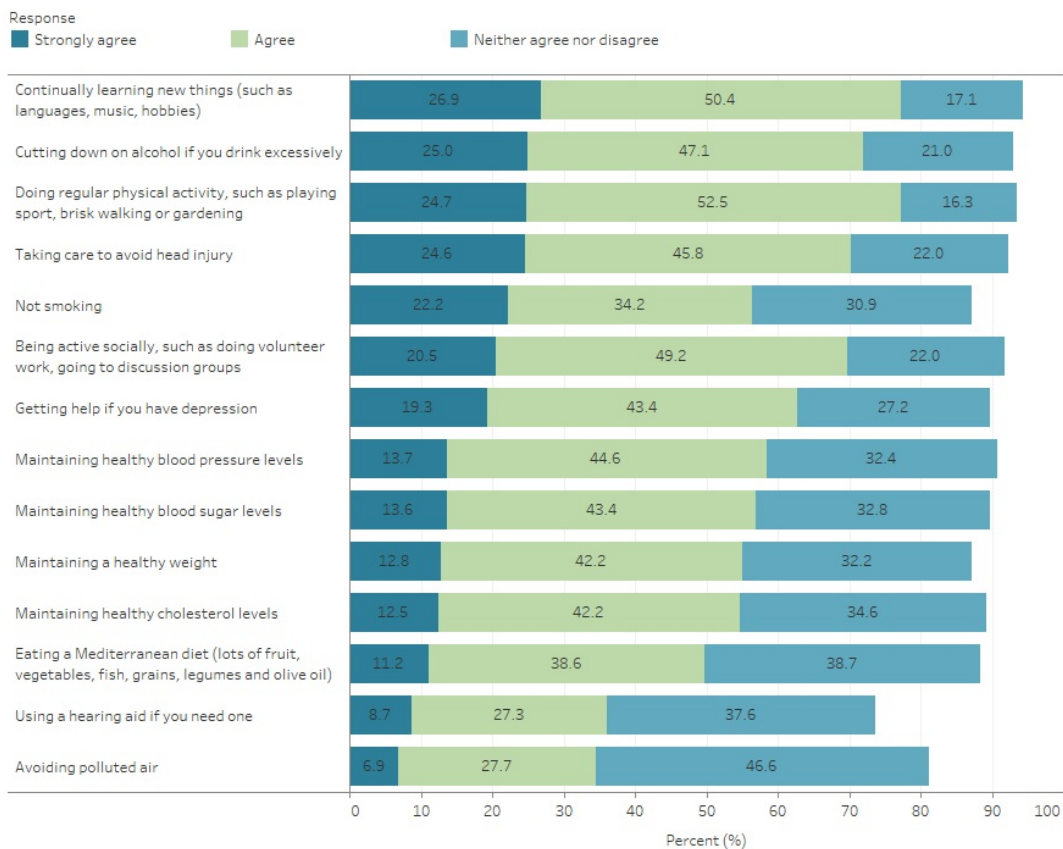
The survey outlined key modifiable risk and protective factors of dementia to seek levels of dementia risk knowledge. The number and percentage of people who correctly recognised dementia risk and protective factors are shown in Figure 2.3 below. The most identified ways to reduce the risk of developing dementia included being physically (77%), cognitively (continually learning new things; 77%), and socially active (70%) along with cutting down alcohol consumption if they drink excessively (72%) and preventing head injuries (70%). A large proportion of Australians were able to recognise key dementia risk factors, but most of these people answered with ‘agree’ rather than ‘strongly agree’, suggesting Australians may not be confident about what they know about dementia risk factors.

Only about 1 in 3 Australians (35%) knew that avoiding polluted air could reduce their risk of dementia.

Respondents in this survey recognised more modifiable dementia risks than a 2005 Australia study (Low and Anstey 2009) where respondents suggested dementia risk factors such as mental exercise (39%), physical exercise (30%), socialising (14%), and not smoking (5.7%). This may suggest that dementia risk knowledge has improved over time, or that recognition of risk factors is higher when respondents are provided prompts (such as risk factor statements) than when identifying risk factors without any prompts.

Figure 2.3: Number and percentage of people who recognised evidence-based modifiable dementia risk and protective factors, 2023

The stacked bar chart shows that most respondents selected ‘agree’ (28% to 50%) for the majority of the risk and protective factors.



Source: Dementia Awareness Survey 2023
<http://www.aihw.gov.au>

How much do Australians know about dementia misconceptions?

There are common misconceptions about the things that affect a person’s risk of dementia such as that cooking in aluminium pots and pans can lead to dementia.

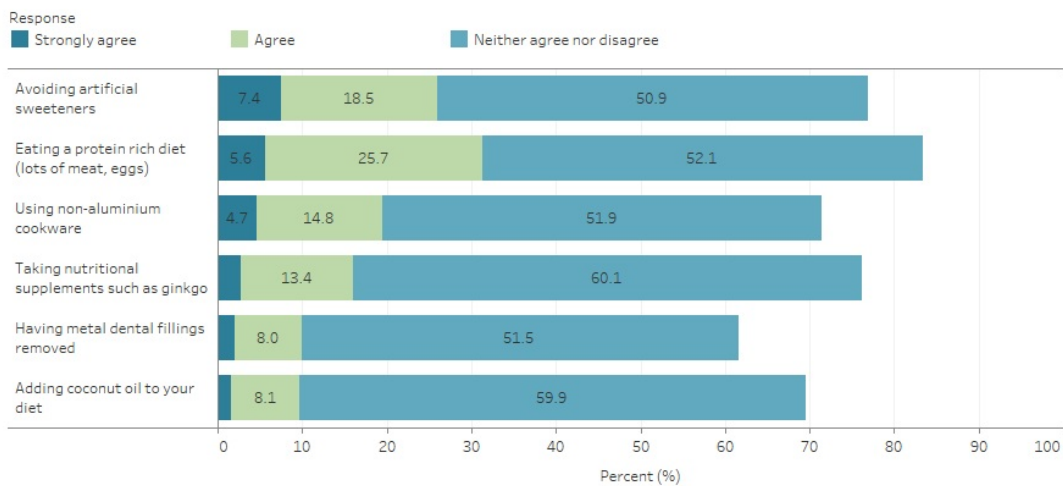
Many people did not correctly answer questions about misconceptions about ways to reduce dementia risk. The number and percentage of people who did not correctly identify common misconceptions of dementia are shown in Figure 2.4. The most common misconceptions believed by Australians was that eating a protein-rich diet could lower the risk of dementia (31%), followed by avoiding the use of artificial sweeteners (26%) and aluminium cookware (20%).

Belief in the misconception that aluminium cookware is a risk factor for dementia was lower in this survey (20%) than in a 2005 Australian survey (55%; Low and Anstey 2009). This indicates that while recognition of some dementia risk misconceptions has improved over time, misconceptions among Australians persist.

More than half of people (51% to 60%) were also unsure whether these misconceptions were true or false (answered ‘neither agree nor disagree’) suggesting that greater awareness of the evidence-based risk factors for dementia is needed.

Figure 2.4: Percentage of people who hold common misconceptions of dementia, 2023

The stacked bar chart shows how 62% to 83% of respondents either strongly agreed, agreed or neither agreed nor disagreed with the common misconceptions.



Source: Dementia Awareness Survey 2023
<http://www.aihw.gov.au>

References

Bartlett L, Doherty K, Farrow M, Kim S, Hill E, King A, Alty J, Eccleston C, Kitsos A, Bindoff A and Vickers JC (2022) 'Island study linking aging and neurodegenerative disease (ISLAND) targeting dementia risk reduction: protocol for a prospective web-based cohort study', *JMIR Research Protocols*, 11(3):e34688, doi:10.2196/34688.

Lin FR, Pike JR, Albert MS, Arnold M, Burgard S, Chisolm T, Couper D, Deal JA, Goman AM, Glynn NW, Gmelin T, Gravens-Mueller L, Hayden KM, Huang AR, Knopman D, Mitchell CM, Mosley T, Pankow JS, Reed NS, Sanchez V, Schrack JA, Windham BG and Coresh J (2023) 'Hearing intervention versus health education control to reduce cognitive decline in older adults with hearing loss in the USA (ACHIEVE): a multicentre, randomised controlled trial', *The Lancet*, 402(10404):786-797, doi:10.1016/S0140-6736(23)01406-X.

Livingston G, Sommerlad A, Orgeta V, Costafreda SG, Huntley J, Ames D, Ballard C, Banerjee S, Burns A, Cohen-Mansfield J, Cooper C, Fox N, Gitlin LN, Howard R, Kales HC, Larson EB, Ritchie K, Rockwood K, Sampson EL, Samus Q, Schneider LS, Selbæk G, Teri L and Mukadam N (2017) 'Dementia prevention, intervention, and care', *The Lancet*, 390(10113):2673-2734, doi:10.1016/S0140-6736(17)31363-6.

Livingston G, Huntley J, Sommerlad A, Ames D, Ballard C, Banerjee S, Brayne C, Burns A, Cohen-Mansfield J, Cooper C, Costafreda SG, Dias A, Fox N, Gitlin LN, Howard R, Kales HC, Kivimäki M, Larson EB, Ogunniyi A, Orgeta V, Ritchie K, Rockwood K, Sampson EL, Samus Q, Schneider LS, Selbæk G, Teri L and Mukadam N (2020) 'Dementia prevention, intervention, and care: 2020 report of the *Lancet* Commission', *The Lancet*, 396(10248):413-446, doi:10.1016/S0140-6736(20)30367-6.

Low L-F and Anstey KJ (2009) 'Dementia literacy: recognition and beliefs on dementia of the Australian public', *Alzheimer's & Dementia* 5:43-49, doi:10.1016/j.jalz.2008.03.011.

WHO (World Health Organization) (2019) *Risk reduction of cognitive decline and dementia: WHO guidelines*, WHO, accessed 10 January 2024.

Reducing the risk of dementia

Almost all Australians (99.6%) are engaged in one or more actions or behaviours that can reduce their risk of developing dementia

Australians were 5 times more likely to take actions for 'other reasons' than for 'dementia risk reduction'

People who know more about dementia tend to take more actions to reduce risk

What are the risk factors for dementia?

Several factors may increase or decrease a person's risk of developing dementia - these are called risk factors and protective factors, respectively. Some risk factors, such as ageing and genetics, cannot be changed, but others can be modified by changing behaviours or lifestyles. Current evidence indicates that about 40% of the risk can be reduced by avoiding or changing certain behaviours or lifestyles, such as maintaining healthy blood pressure levels, not smoking, and social engagement (Livingston et al. 2017; AIHW 2023). For more information, see [What puts someone at risk of developing dementia?](#)

Taking steps to minimise exposure to dementia risk factors (such as reducing alcohol consumption and managing existing health conditions) and increasing protective factors (such as engaging in physical and social activities) is the best way to reduce the prevalence of dementia until there is a cure or significant advancements in treatments (Livingston et al. 2017; WHO 2019). However, people often do not know what they can do to reduce their risk of developing dementia or delay the onset of dementia (Mansfield et al. 2023).

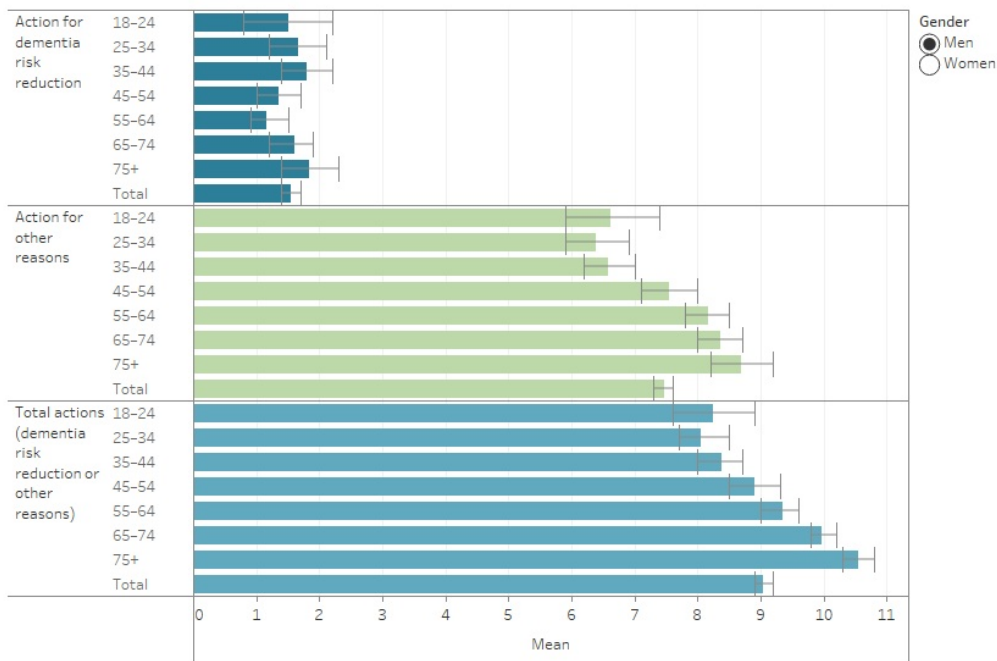
Are Australians taking action to reduce their risk of developing dementia?

Australians were asked if they were engaged in 14 actions or behaviours that can reduce their risk of developing dementia and if they were doing these for dementia risk reduction or other reasons.

Many Australians are engaging in these behaviours even though they may not be doing so specifically for dementia prevention. Almost all Australians (99.6%) undertook one or more actions/behaviours that can reduce the risk of developing dementia but less than 2 in 5 Australians were undertaking one or more actions/behaviours specifically to reduce their risk of developing dementia. This may be because people do not know these actions can reduce their risk of developing dementia. Older Australians tended to take more actions/behaviours that can potentially reduce their risk of developing dementia compared to younger Australians, and older women (65 and over) were generally more likely to undertake these actions to reduce dementia risk than younger women (Figure 3.1).

Figure 3.1: Average number of actions taken for dementia risk reduction and for other reasons, by gender and age group, 2023

The bar chart shows respondents, on average, performed 1.5 out of 14 actions to reduce dementia risk compared to 7.5 actions for other reasons.



Source: Dementia Awareness Survey 2023
<http://www.aihw.gov.au>

What actions do people take?

Keeping cognitively active was the main action that people took specifically to reduce the risk of dementia (25%). This was followed by avoiding sports that can cause head injury (17%) and being socially (13%) and physically active (12%). On the other hand, fewer than 10% of Australians followed the Mediterranean diet, maintained a healthy weight, or checked their blood sugar and cholesterol levels and maintained it within a normal range.

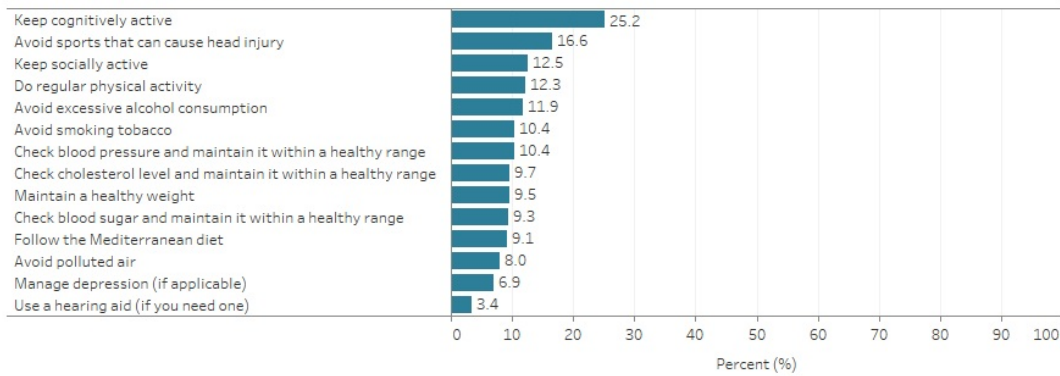
The main preventative health actions/behaviours Australians take (for any reason) include keeping cognitively active (87%) and avoiding smoking tobacco (86%), sports that can cause head injury (84%), and excessive alcohol consumption (81%). Undertaking these actions should continue to be encouraged even though people are not undertaking them for dementia risk reduction as they can reduce the risk of developing dementia.

Hearing loss (not corrected with hearing aid use) and depression (not managing depression) are estimated to be responsible for 8% and 4%, respectively, of the risk of developing dementia (Livingston et al. 2020), yet actions to prevent these risks to reduce dementia were low (3.4% and 6.9%, respectively; Figure 3.2). This indicates that despite robust evidence around dementia risk reduction, this is not translating to actions for dementia risk reduction.

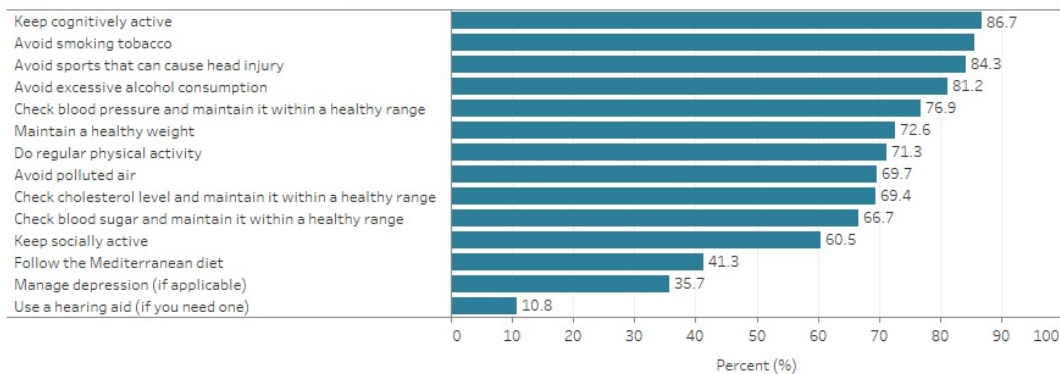
Figure 3.2: Number and percentage of preventative health actions taken for (a) dementia risk reduction and for (b) any reason, 2023

The bar chart compares the percentage of people taking actions for dementia (3.4% to 25%) with the percentages of people taking actions for various other reasons (11% to 87%).

(a) Actions taken for dementia risk reduction



(b) Total actions taken for any reason



Source: Dementia Awareness Survey 2023
<http://www.aihw.gov.au>

Does better knowledge of dementia lead to action?

Australians who knew more about dementia tended to take more actions that can reduce their dementia risk. This was demonstrated by a small (Pearson correlation coefficients less than 0.3) to medium (Pearson correlation coefficients between 0.3 and 0.49) association between the number of actions and both general dementia knowledge ($p < 0.0001$) and knowledge of dementia risks ($p < 0.0001$; refer to [Table S3](#)).

Just over half of Australians (53%) felt that information about reducing their dementia risk was easily available (refer to [Table S4](#)).

Four in 5 Australians (83%) agreed that they would be more likely to adopt lifestyle changes if they knew it may help them reduce their risk of dementia (refer to [Table S4](#)).

References

AIHW (Australian Institute of Health and Welfare) (2023) *Dementia in Australia: summary*, AIHW, Australian Government, accessed 10 January 2024.

Livingston G, Sommerlad A, Orgeta V, Costafreda SG, Huntley J, Ames D, Ballard C, Banerjee S, Burns A, Cohen-Mansfield J, Cooper C, Fox N, Gitlin LN, Howard R, Kales HC, Larson EB, Ritchie K, Rockwood K, Sampson EL, Samus Q, Schneider LS, Selbæk G, Teri L and Mukadam N (2017) 'Dementia prevention, intervention, and care', *The Lancet*, 390(10113):2673-2734, doi:10.1016/S0140-6736(17)31363-6.

Livingston G, Huntley J, Sommerlad A, Ames D, Ballard C, Banerjee S, Brayne C, Burns A, Cohen-Mansfield J, Cooper C, Costafreda SG, Dias A, Fox N, Gitlin LN, Howard R, Kales HC, Kivimäki M, Larson EB, Ogunniyi A, Orgeta V, Ritchie K, Rockwood K, Sampson EL, Samus Q, Schneider LS, Selbæk G, Teri L and Mukadam N (2020) 'Dementia prevention, intervention, and care: 2020 report of the *Lancet Commission*', *The Lancet*, 396(10248):413-446, doi:10.1016/S0140-6736(20)30367-6.

Mansfield E, Watson R, Carey M and Sanson-Fisher R (2023) 'Perceptions of community members in Australia about the risk factors, symptoms and impacts of dementia: a cross-sectional questionnaire study', *Australasian Journal on Ageing*, 42(1):140-148, doi:10.1111/ajag.13109.

WHO (World Health Organization) (2019) *Risk reduction of cognitive decline and dementia: WHO guidelines*, WHO, accessed 10 January 2024.

Attitudes towards dementia and people living with dementia

Australians hold varying levels and types of stigma towards dementia and/or people living with dementia

Australians who know more about dementia tend to have less stigma towards dementia and people living with dementia

Sociodemographic groups that were less likely to hold stigma towards dementia and/or people living with dementia included women, people who were born in Australia, the UK, the USA, Canada, and NZ, people who speak English at home, people who had personal experience with people with dementia, either through family or friends with dementia or working with people with dementia, and non-heterosexual people

How are attitudes towards people living with dementia measured?

The Dementia Public Stigma Scale (DePSS, Kim et al. 2022) was used to measure cognitive (dementia-related stereotypes), emotional (negative prejudices and emotional reactions), and behavioural (discriminatory behaviours) aspects of stigma. The total DePSS score was calculated by summing all 16 items, ranging from 16-112, with a higher score indicating a higher public stigma of dementia. Sub-scores were calculated by summing relevant items for three aspects of stigma (ranging from 10-70, 4-28, and 2-14 for cognitive, emotional, and behavioural aspects of stigma respectively). Refer to the [Technical notes](#) for more information on the scale.

What do we mean by dementia-related stigma?

The negative and often unfair beliefs, prejudices, and discriminatory behaviours that people have about dementia and people living with dementia are called dementia-related stigma.

Stigma about dementia is common (ADI 2019), particularly when people have little understanding or knowledge of the condition. Stigma can lead to delays in people seeking help, a timely diagnosis and treatment. People living with dementia often report experiencing discrimination, judgement, and preconceived ideas about their abilities (Kim et al. 2019). Stigma can also influence how individuals accept their dementia diagnosis and whether they share their diagnosis with others.

Do Australians hold stigma towards people living with dementia?

The Dementia Awareness Survey collected information on Australians' attitudes towards dementia and people living with dementia. It did this by looking at the concept of dementia-related stigma.

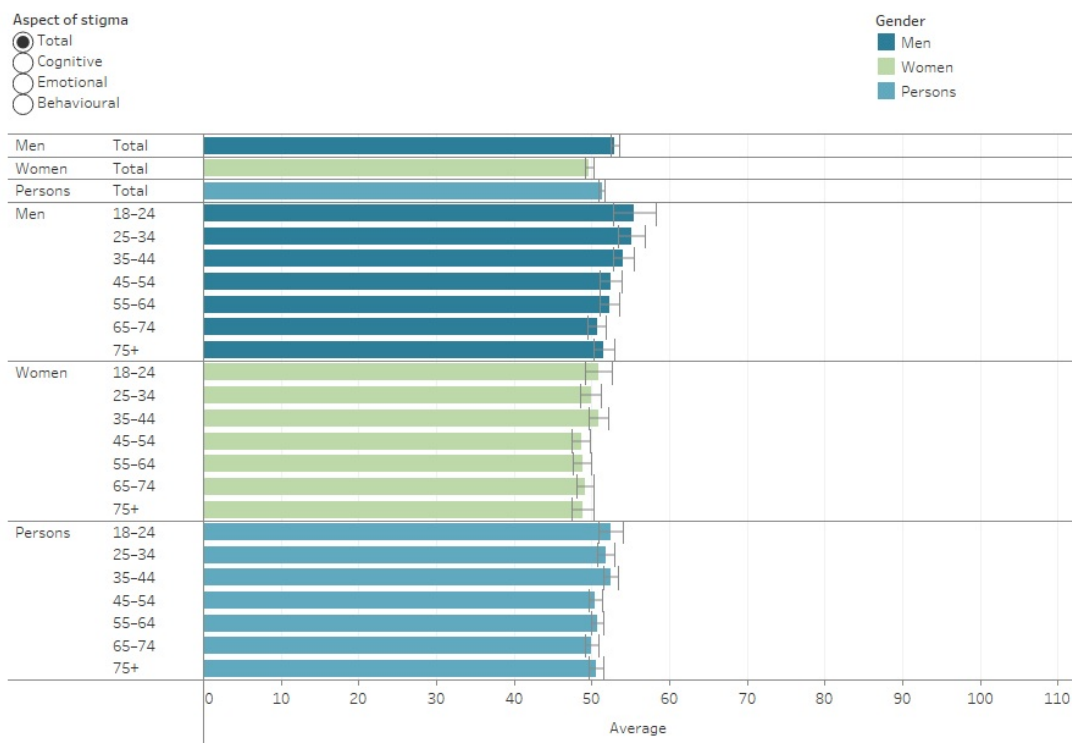
The survey found that Australians hold stigma towards dementia and/or people living with dementia (average overall stigma score of 51 out of 112, where a lower score means a lower level of stigma; Figure 4.1). Women tended to have lower levels of dementia stigma than men, as found in a previous study (Werner and Kim 2021). Results for the individual aspects of stigma also indicated varying levels and types of stigma towards dementia and/or people living with dementia:

- Cognitive: this aspect measures what kind of dementia-related stereotypes Australians hold, e.g., believing a person living with dementia is an old person with a memory problem and behaves unpredictably. People scored an average of 35 out of 70 on the cognitive aspect of stigma.
- Emotional: this aspect measures negative emotional reactions such as feeling comfortable or confident around people with dementia. People scored an average of 12 out of 28 on the emotional aspect of stigma.
- Behavioural: this aspect measures what kind of discriminatory behaviours Australians take towards people living with dementia, e.g., avoiding people living with dementia. People scored an average of 4.6 out of 14 on the behavioural aspect of the stigma.

It is possible that respondents understated their level of stigma due to social desirability bias, where respondents provide a response that they think is more socially acceptable rather than how actually they think or behave.

Figure 4.1: Average stigma score, by aspect of stigma, gender and age group, 2023

The bar chart shows in total, older Australians had lower levels of overall stigma, largely driven by emotional and behavioural stigma scores.



Source: Dementia Awareness Survey 2023
<http://www.aihw.gov.au>

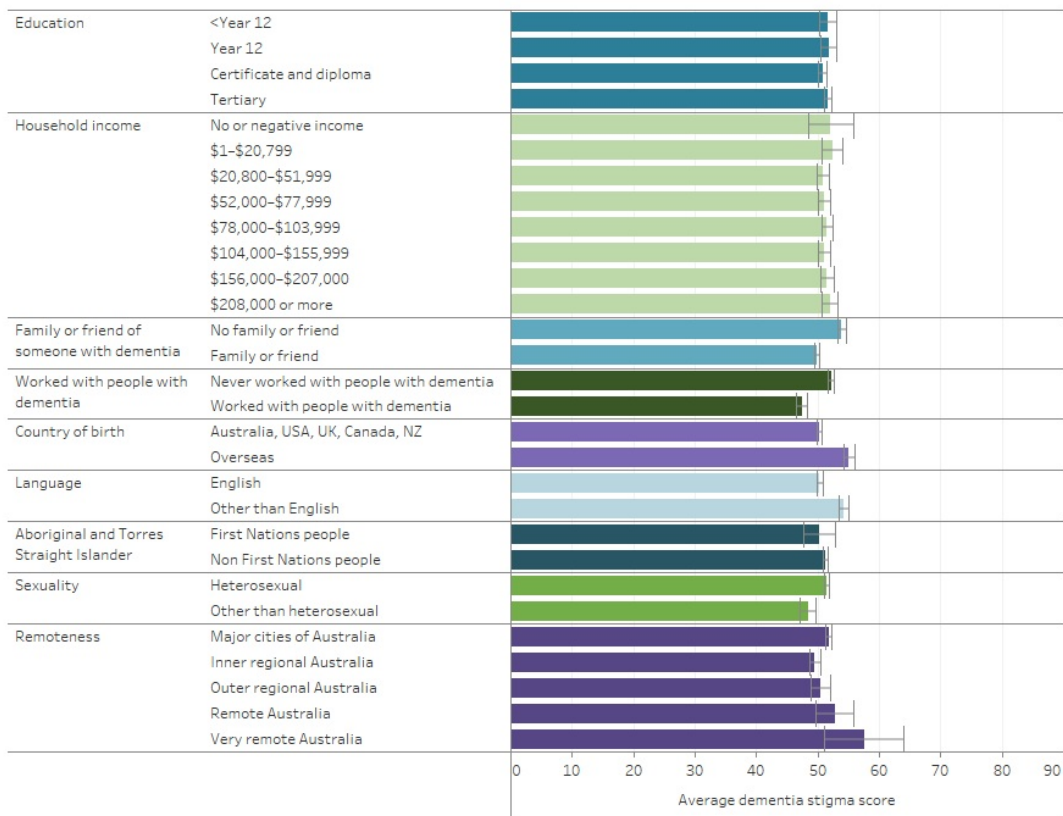
How did the results vary for different population groups?

The average total dementia stigma score was compared among the different sociodemographic groups (Figure 4.2) and these groups were compared all together to identify which groups had higher or lower levels of stigma (refer to [Table S2.3](#)). Significantly lower levels of dementia-related stigma were found in:

- women (Figure 4.1)
- those born in Australia, the UK, the USA, Canada, and NZ and those who spoke English at home
- non-heterosexual people
- those with a family member or friend with dementia
- those who had worked with people with dementia.

Figure 4.2: Dementia-related stigma and demographics, 2023

The bar chart shows respondents from very remote Australia had the highest dementia stigma score (58), while respondents who worked with people with dementia had the lowest (47).



Note: Please refer to Table S2.3 for adjusted findings.
 Source: Dementia Awareness Survey 2023
<http://www.aihw.gov.au>

What do Australians think of dementia and people living with dementia?

There are several commonly held stereotypes about people with dementia, ranging from the capabilities of people with dementia to dementia’s impact on society. More than half of Australians agreed that people with dementia should always be supervised (67%) and that people with dementia are unpredictable (62%; Figure 4.3). Only around half of Australians indicated that they feel confident with (54%) or relaxed around (47%) people with dementia.

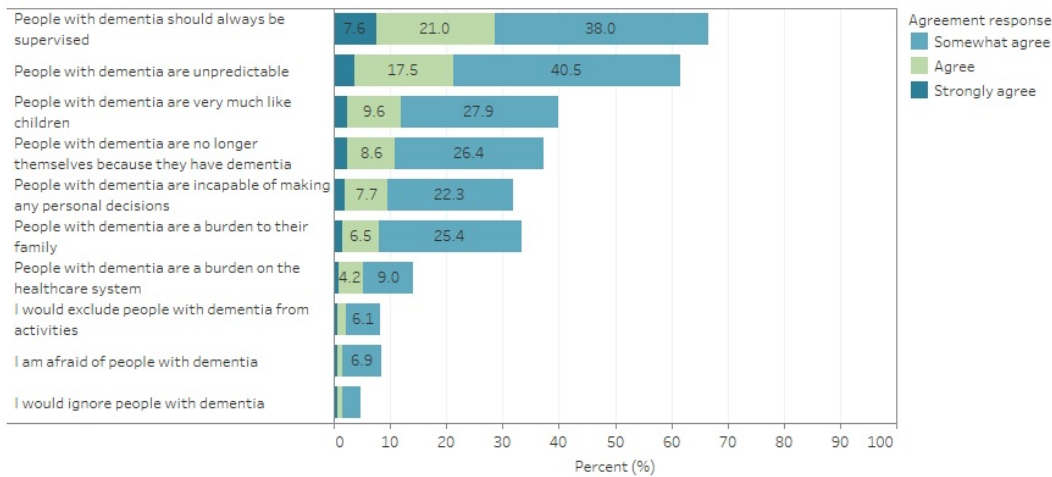
Positively, more than 8 in 10 Australians agreed that people with dementia can enjoy life (83%) and that it is possible to enjoy interacting with people with dementia (83%), suggesting that Australians believe that people with dementia can have quality of life. More than 3 in 4 people (77%) were not afraid of people with dementia and 2 in 3 (66%) were comfortable touching people with dementia.

Only a small number of Australians indicated they would exclude people with dementia from activities (8.3%) or ignore them (4.8%).

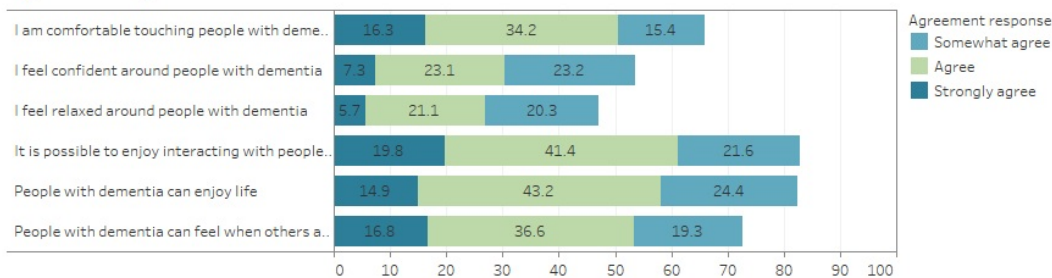
Figure 4.3: Percentage of people who hold positive or negative attitudes towards people living with dementia, 2023

The stacked bar charts show that respondent’s agreement with negatively framed statements was varied (4.8% to 67%), while their agreement with positively framed statements was reasonably high (47% to 83%).

a) Negatively framed attitudes



b) Positively framed attitudes



Source: Dementia Awareness Survey 2023
<http://www.aihw.gov.au>

Does better dementia knowledge lead to lower levels of stigma?

Australians who knew more about dementia tended to have lower levels of dementia stigma, suggested by a small correlation (Pearson correlation coefficients less than 0.3) between stigma and both the level of general dementia knowledge and dementia risk reduction knowledge ($p = <0.0001$; refer to [Table S3](#)).

Reference

ADI (Alzheimer's Disease International) (2019) *World Alzheimer report 2019: attitudes to dementia*, Alzheimer's Disease International, accessed 10 January 2024.

Kim S, Werner P, Richardson A and Anstey KJ (2019) 'Dementia stigma reduction (DESeRvE): study protocol for a randomized controlled trial of an online intervention program to reduce dementia-related public stigma', *Contemporary Clinical Trials Communication*, 14:100351, doi:10.1016/j.conctc.2019.100351.

Kim S, Eccleston C, Klekociuk S, Cook PS and Doherty K (2022) 'Development and psychometric evaluation of the Dementia Public Stigma Scale', *International Journal of Geriatric Psychiatry*, 37(2), doi:10.1002/gps.5672.

Werner P and Kim S (2021) 'A cross-national study of dementia stigma among the general public in Israel and Australia', *Journal of Alzheimer's Disease*, 83(1):103-110, doi:10.3233/JAD-210277.



How would Australians manage a potential diagnosis of dementia?

Almost half (49%) of Australians would seek help immediately if they had symptoms of dementia

Nine in 10 (89%) Australians would seek help from a GP

Almost all (94%) Australians would share a diagnosis of dementia with family members

Where would people go for help?

The survey examined Australians' help-seeking behaviours that are important for receiving a timely diagnosis, accessing support programs, and reducing stigma related to receiving or sharing a diagnosis.

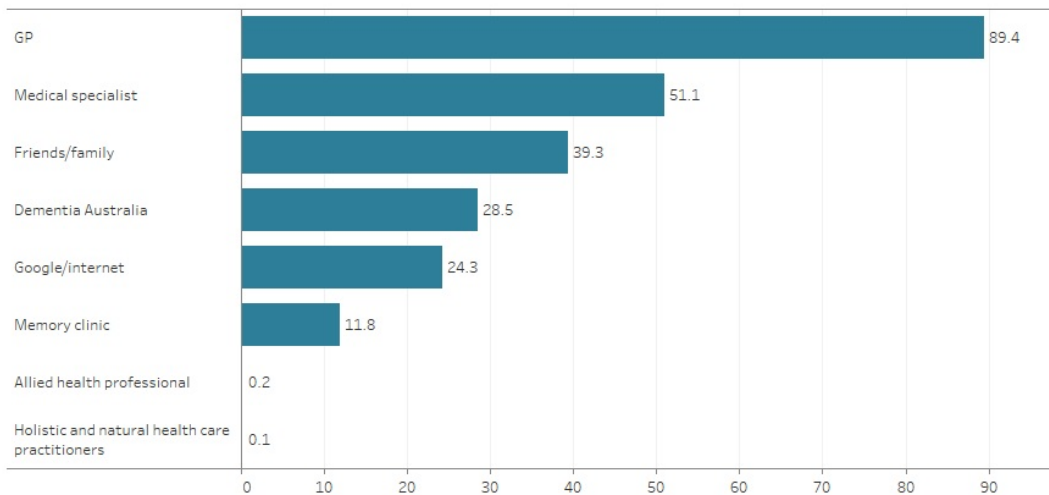
Almost all (94%) Australians reported that they would seek help if they had symptoms of dementia. Half (49%) said they would seek help immediately, around 2 in 5 (37%) would wait a while and the rest (14%) would seek help only when the symptoms became obvious to others. General practitioners (89%), medical specialists (51%), and family and friends (39%) were the preferred sources of help (Figure 5.1).

The 49% of people who would seek help immediately contrasts with the larger proportion of people (61%) who responded that early diagnosis generally improved quality of life (Figure 1.3). It is possible that these responses are affected by self-stigma towards their own dementia symptoms that would delay them in obtaining immediate help.

Almost all (94%) Australians reported that they would share their diagnosis with family members if they were diagnosed with dementia. Two in 3 (66%) Australians would share their diagnosis with friends. One in 3 (27%) people said they would share their diagnosis with their employer and colleagues and less than 4% said they would tell nobody.

Figure 5.1: Where people would seek help from if they had symptoms of dementia, 2023

The bar chart shows that GPs were the preferred source of help (89%), while holistic and natural health practitioners and allied health professionals were the least preferred sources (0.1% and 0.2%, respectively).



Note: Multiple responses were allowed.
Source: Dementia Awareness Survey 2023
<http://www.aihw.gov.au>

Technical notes

All estimates contained in the Dementia Awareness Survey report are based on information obtained from people aged 18 and over from all states and territories.

Methodology

The Social Research Centre (SRC) was commissioned by the AIHW to conduct the survey fieldwork. The survey was conducted from 24 July to 15 August 2023. This included a soft launch period from 24 to 25 July 2023, where a small number of people completed the questionnaire to ensure the questionnaire was performing as intended.

Questionnaire design

The AIHW drafted the questionnaire in consultation with the Dementia Awareness Survey Reference Group, based on existing validated scales developed in Australia as well as questions developed specifically for the survey based on literature review and expert review ([Appendix](#)). Three sets of validated scales were used in the survey to measure 1) general dementia knowledge, 2) knowledge of dementia risk factors and misconceptions, and 3) dementia-related stigma.

The Dementia Knowledge Assessment Scale (DKAS; Annear et al. 2017) was used to measure what people know about the most common forms of dementia. It has been widely used in Australia and internationally, which enables comparison with other studies. It comprises statements about the most common forms of dementia that are factually correct or incorrect (Annear et al. 2017). An item score of 0 indicates an incorrect response to a factually true or false statement or an acknowledgment that the respondent does not know the truth of the statement. A score of 1 indicates an individual's assessment that an item is probably true or probably false with some remaining uncertainty. A score of 2 indicates an individual's unequivocal alignment with the correct response. The total DKAS score was calculated by summing all 25 items and ranges from 0-50, with a higher score representing better dementia knowledge.

Knowledge of Dementia Risk Reduction (KoDeRR; Bartlett et al. 2022) measures the knowledge of evidence-based risk factors of dementia as well as common misconceptions (or myths). Knowledge of modifiable factors was calculated where 'strongly agree' was scored 2 for each risk reduction strategy, 'agree' scored 1 and other answers scored 0. The total correct contribution score ranges from 0-28. Scores were also calculated for the six common misconception items by the reverse process where 'strongly disagree' was scored 2, 'disagree' scored 1 and other answers scored 0, ranging from 0-12, where a score of 12 represents correctly disagreeing with all 6 misconceptions. The overall KoDeRR score was calculated by adding these two sub-scores.

The Dementia Public Stigma Scale (DePSS) is a scale designed to measure dementia-related public stigma amongst community-dwelling adults (Kim et al. 2022). DePSS was validated with over 3,000 Massive Open Online Course (MOOC) enrollees (those who had not previously enrolled in the dementia MOOCs). As most MOOC enrollees are from Australia, the acceptability of this scale has been tested with the Australian public. Five factors of the scale broadly reflect all three (cognitive, emotional, and behaviours) aspects of stigma. It has sixteen items measuring cognitive (dementia-related stereotypes), emotional (negative prejudices and emotional reactions), and behavioural (discriminatory behaviours) aspects of stigma, each item with a seven-point Likert-type scale (1 = 'strongly disagree' to 7 = 'strongly agree'). The total DePSS score was calculated by summing all 16 items (including 6 reversed items), with total possible scores ranging from 16-112. A higher score indicated higher public stigma of dementia. Sub-scores were calculated by summing relevant items for three aspects of stigma (possible scores range from 10-70, 4-28, and 2-14 for cognitive, emotional, and behavioural aspects of stigma respectively).

Cognitive testing

In total, twenty interviews were completed with participants from various locations across Australia to identify potentially problematic areas of the questionnaire. Recruitment was completed using the SRC's dedicated qualitative participant database. Participants were sent a primary approach email and asked to fill out a brief screening questionnaire and could then be invited to participate by phone. The purpose of the research was explained, and a convenient time and date scheduled for each participant to join an online video interview. All participants were provided with an information sheet outlining the purpose of the research in greater detail. Participants were reimbursed with an \$80 e-voucher for their participation. All participants gave consent verbally prior to taking part in the interview.

Cognitive response processes examined through cognitive testing included:

- comprehension of survey items
- retrieval from memory of relevant information
- judgement or decision processes used when answering survey items
- response processes.

After addressing issues arising from cognitive testing in consultation with project stakeholders, an updated AIHW endorsed version of the survey tool was finalised. This included details of all introductory scripts, sequencing instructions, validity checks, conditional displays (e.g., variations between the Life in Australia™, language other than English (LOTE), and Remote versions), display preferences (e.g., display of multiple questions on the same page) and functionality specifications.

Prior to fieldwork starting, standard operational testing procedures were applied to ensure that the script reflected the agreed final electronic version of the questionnaire. These included:

- programming the skips and sequencing instructions as per the final questionnaire
- rigorous checking of the questionnaire in ‘practice mode’ by the SRC including checks of the on-screen presentation of questions and response frames on a range of devices
- randomly allocating dummy data to each field in the questionnaire and examining the resultant frequency counts to check the structural integrity of the script
- rigorous checking of programming of the skips and sequence instructions as per the final questionnaire.

Rigorous checking of the questionnaire in ‘test mode’ by the SRC, including checks of the on-screen presentation of questions and response frames for all three panels (Life in Australia™, LOTE, and Remote). Representatives from AIHW also contributed to testing the online survey (Life in Australia™, LOTE, and Remote versions) prior to data collection, including testing translated versions of the questionnaire.

Soft launch (formal pilot) testing was undertaken on Life in Australia™ to confirm the integrity of the questionnaire. This involved initiating a small number of offline records on the first planned day of fieldwork, 24 July 2023. The interviewing team was debriefed, and SRC checked ‘Day 1’ data (i.e., one day after the survey soft launch) to ensure that data collection was operating properly in the live survey instrument and as per the final questionnaire (see [Appendix](#)).

Translations

To improve the representation of people from a non-English speaking background, the online survey and supporting participant information sheets, the SRC project team and AIHW chose five languages for translation: Traditional Chinese, Simplified Chinese, Arabic, Vietnamese, and Punjabi. The translations and in-context checking were carried out by Multicultural Management and Marketing (MMM).

For each language, the steps involved in translation included:

- briefing translators regarding the overall tone and messaging, the level of language to use, and general formatting requirements
- preparing text for translation (e.g., exporting the programmed questionnaire into Excel and Word documents for letter and email text)
- back-translations of all materials in one workflow
- independent checking by separate translators for each language
- in-language data collection program (online survey) set up
- typesetting (layout and formatting) of web content and printed materials
- final in-context checks of translated materials.

Sample design

Both probability and non-probability panels were used to recruit participants for the survey.

Probability panel

Most of the sample (5,108 persons) was recruited through the SRC probability panel, Life in Australia™. Life in Australia™ includes Australian residents aged 18 and over, who are contactable via either a landline or a mobile phone, not including Australian external territories. Members of the panel are recruited via random digit dialling or address-based sampling.

A stratified random sample was drawn from Life in Australia™ panellists on strata defined by age (18-34, 35-44, 45-54, 55-64, 65+), gender, education (less than a bachelor’s degree, bachelor’s degree or above) and speaking a language other than English at home, with the sample being selected in proportion to the number of active panellists in each stratum.

Non-probability panels

Non-probability panels were used to oversample the hardest-to-reach populations to maximise inclusion from groups such as Aboriginal and Torres Strait Islanders, residents of the Northern Territory, those from remote or very remote Australia, and those who use languages other than English at home.

Multicultural Management and Marketing (MMM) provided translation services for the questionnaire and supporting information into five most common languages spoken other than English (ABS 2021a; traditional Chinese, simplified Chinese, Arabic, Vietnamese, and Punjabi). MMM recruited total 249 participants in the five languages using their own research panel, community networks and in-language social media.

People who reside in very remote Australia were sourced from the online panel provider i-Link Research, that has over 160,000 panellists. The survey was administered in English with a final sample size of 88.

Sample profile

The final sample profile is shown below in Table 1.

Table 1: Sample profile (unweighted)

Subgroup	Life in Australia™ (%)	MMM (%)	i-Link (%)	Total (%)
----------	---------------------------	------------	---------------	--------------

Gender				
Male	41.8	57.4	38.6	42.4
Female	57.4	42.6	61.6	56.8
Non-binary/ Other gender	0.8	0.4	-	0.7
Age				
18-24 years	4.6	5.2	9.1	4.7
25-34 years	12.5	33.3	14.8	13.5
35-44 years	16.3	38.6	21.6	17.4
45-54 years	16.5	14.1	13.6	16.4
55-64 years	18.4	3.2	11.4	17.6
65-74 years	20.3	4.8	26.1	19.7
75 years or more	11.3	0.8	3.4	10.7
Unable to establish	0.1	-	-	0.1
Education				
Have not completed a qualification	15.0	3.2	15.9	14.5
Certificate I and/or II Level	2.8	4.8	11.4	3.0
Certificate III and/or IV Level	15.4	11.2	27.3	15.4
Advanced Diploma and/or Diploma Level	11.4	22.1	17.0	11.9
Bachelor Degree Level	24.8	25.3	17.0	24.7
Graduate Diploma and/or Graduate Certificate Level	10.1	16.9	8.0	10.4
Postgraduate Degree Level (incl. master degree, doctoral degree, other postgraduate degree)	18.2	16.5	2.3	17.9
Location				
New South Wales	30.6	34.1	6.8	30.4
Victoria	25.6	30.9	-	25.4
Queensland	19.6	14.5	4.5	19.1
South Australia	8.4	5.2	8.0	8.3
Western Australia	9.8	10.8	15.9	10
Tasmania	2.6	1.6	1.1	2.5
Northern Territory	0.6	0.8	63.6	1.6
Australian Capital Territory	2.8	2.0	-	2.7
Remoteness				
<i>Major cities of Australia</i>	73.6	94.8	-	73.4
<i>Inner Regional Australia</i>	19.1	2.4	-	18
<i>Outer Regional Australia</i>	6.5	2.4	45.5	6.9
<i>Remote Australia</i>	0.5	0.4	14.8	0.8
<i>Very Remote Australia</i>	0.2	-	39.8	0.9
Total number	5,108	249	88	5,445

Subgroups with small numbers (e.g. non-binary and other gender) were grouped together in the table.

Completion rate

The completion rate represents completed surveys as a proportion of all members invited to participate in this survey. The overall completion rate for the Life in Australia™ survey was 73.3% (online population = 73.5%; offline population = 61.2%) (see Table 2). Completion rate data is not available for the MMM or i-Link Research sample.

Table 2: Life in Australia™ completion rate

Outcome categories	Total (n)	Total (%)	Online members (n)	Online members (%)	Offline members (n)	Offline members (%)
Invited to participate	6,970	100.0	6,841	100.0	129	100.0
Completed interview	5,108	73.3	5,029	73.5	79	61.2
Refusal and mid-survey terminations	168	2.4	164	2.4	4	3.1
Non-contacts	1497	21.5	1455	21.3	42	32.6
Other	197	2.8	193	2.8	4	3.1
Completion Rate (%)	-	73.3	-	73.5	-	61.2

Survey mode

The survey was conducted primarily as an online survey. Telephone interviewer-administered questionnaires were offered to those who could not or did not want to complete questionnaires online (approximately 2.5% of panellists).

Computer-Assisted Telephone Interviewing (CATI) fieldwork

Interviewer briefing

All interviewers and supervisors selected to work on the survey attended a two-hour briefing session, which focused on all aspects of survey administration, including:

- survey context and background, including a detailed explanation of Life in Australia™
- survey procedures and sample management protocols
- the importance of respondent liaison procedures
- strategies to maintain co-operation
- detailed examination of the survey questionnaire, with a focus on the use of pre-coded response lists and item-specific data quality issues.

After the initial briefing session, interviewers engaged in comprehensive practice interviewing. A total of 9 interviewers were briefed on the survey.

Fieldwork quality control procedures

The in-field quality monitoring techniques applied to this project included:

- monitoring (by remote listening) of each interviewer within their first three shifts, whereby the supervisor listened in to at least 75% of the interview and provided comprehensive feedback on data quality issues and respondent liaison techniques
- validation of 16% of the telephone surveys conducted via remote monitoring (covering the interviewers' approach and commitment-gaining skills, as well as the conduct of the interviews)
- field team debriefing after the first shift and, thereafter, whenever there was important information to impart to the field team about data quality, consistency of interview administration, techniques to avoid refusals, appointment-making conventions, or project performance
- examination of 'Other (specify)' responses
- monitoring of timestamps for segments of the survey and overall time taken to complete the survey
- monitoring of the interview-to-refusal ratio by interviewer.

Contact methodology

Life in Australia™ members were contacted with an initial survey invitation via email and SMS (where available), followed by multiple email reminders and a reminder SMS. Up to five reminders in different modes (including email, SMS, and telephone) were administered during the July to August 2023 fieldwork period. Telephone non-response of online panel members who had not yet completed the survey commenced in the second week of fieldwork, with reminder calls encouraging completion of the online survey. Offline members with a valid mobile telephone number were sent a short SMS invitation that contained a link to the survey as well as a reminder SMS halfway through fieldwork. Life in Australia™ call procedures included:

- a six-call regime for the landline sample, with an upper limit of eight call attempts
- a four-call regime for the mobile sample, capped at four call attempts to avoid appearing overzealous in attempts to achieve interviews

- contact attempts were spread over weekday evenings (6:30 pm to 8:30 pm), weekday late afternoon/early evenings (4:30 pm to 6:30 pm), Saturdays (11 am to 5 pm), and Sundays (11 am to 5 pm)
- appointments available any time that the call centre is operational (weekdays between 9 am to 8:30 pm; weekends 11 am to 5 pm)
- an 1800 number to address sample member queries and support the response maximisation effort and the establishment of a respondent page on our website (with responses to frequently asked questions).

MMM contacted their panel of culturally and linguistically diverse members and distributed information about the survey around the community through word-of-mouth to complete the online survey in one of the five languages (Traditional Chinese, Simplified Chinese, Arabic, Vietnamese, Punjabi).

i-Link Research contacted their panel members residing in Northern Territory and very remote parts of Australia to complete the online survey in English.

Incentives

All Life in Australia™ members were offered a \$10 incentive to complete the survey. Members could also opt out of receiving an incentive. The incentive options were a:

- Coles / Myer gift card
- payment into a PayPal account
- charitable donation to a designated charity (Children's Ground, Food For Change, Spinal Cord Injuries Australia).

All respondents recruited via i-Link Research received standard points based on their reward system for a survey of this length. Respondents recruited through MMM received no incentive for participating in the survey.

Limitations in the survey scope

While the survey was available in five main languages used in Australia (Simplified Chinese, Arabic, Vietnamese, Traditional Chinese and Punjabi) as well as English, those who do not use these languages may have been excluded from taking part in the survey. Additionally, those from these cultural backgrounds without internet access would have been excluded from taking part in the survey.

Coding

Open-ended questions and back-coding of questions with an 'Other (specify)' option were undertaken by experienced, fully briefed coders. Outputs were validated in accordance with ISO 20252 procedures, using an independent validation approach.

Data quality checks

Data quality checks for surveys completed online across all three panels (Life in Australia™, LOTE, remote) consisted of checks for:

- logic
- proportion of 'don't know' and 'refused' responses
- speeding
- straight lining
- verbatim responses to open-ended questions.

All these indicators were used to determine respondent removal for poor data quality. Data quality indicators other than verbatim responses were used to identify potentially problematic cases. Generally, verbatim responses were decisive, with those indicating thoughtful engagement with the survey being kept and others being removed (e.g., nonsense responses like 'asdfgh,' *non sequiturs*, swearing).

Data quality is tracked for panel members over time and those with repeated issues are retired from the Life in Australia™ panel.

After these checks, four survey responses were removed due to poor data quality and are not counted toward the Life in Australia™ completion rate. Additionally, five survey responses were flagged with i-Link Research following quality checks and replacements organised.

Weighting

The sample was designed to provide a random sample of the Australian population aged 18 and over.

The Dementia Awareness Survey consisted of three components that were combined for weighting purposes:

1. A random (probability) sample of adults from Life in Australia™.
2. A convenience (non-probability) sample of LOTE respondents who speak simplified or traditional Chinese, Arabic, Vietnamese, or Punjabi.
3. A convenience (non-probability) sample of adults from very remote Australia or the Northern Territory.

The usual approach to weighting random (probability) samples is a two-step process that aims to reduce biases caused by non-coverage and non-response and to align weighted sample estimates with external data about the target population (Kalton and Flores-Cervantes 2003). First, base weights are calculated to account for each respondent's initial chance of selection and for the survey's response rate. Next, the

base weights are adjusted to align respondents with the population on key sociodemographic characteristics (Särndal et al. 1992; Valliant et al. 2018).

The convenience (non-probability) samples used non-random mechanisms to recruit participants to the survey, which means that the usual probability (two-step) approach does not apply (Elliott and Valliant 2017). There are several methods for weighting convenience samples and making estimates from them (Valliant 2020) including the 'quasi-randomisation' method used here. Cases from the convenience sample are matched to cases from the reference sample. Each case from the convenience samples is assigned the base weights of the matching reference sample case. For this survey, the reference sample was the probability cases from Life in Australia™.

The combined sample then had base weights for two groups - a probability-based one for Life in Australia™ cases and an estimated one the convenience cases. To derive the adjusted weights, consideration was given to the characteristics on which to align the base weights with the population. The choice of characteristics was guided by those most:

- different between the probability and convenience samples
- associated with the survey's key questionnaire items
- different between the combined sample and the population.

The set of characteristics used to adjust the weights were state or territory of residence, language spoken at home, age group by highest education, gender and remoteness area. Australian adult population counts and percentages for those aged 18 years and over were obtained from Census 2021 TableBuilder (ABS 2021b) for this set of characteristics (Table 3). For the unweighted demographic data for the Dementia Awareness Survey respondents, refer to the [supplementary data tables](#).

Base weights were adjusted using regression calibration (Deville et al. 1993), implemented in R (R Core Team 2022) using the survey package (Lumley 2021). For more information on the weighting of sample surveys, refer to Valliant et al. (2018).

Table 3: Characteristics used for adjusting adult base weights based on the 2021 Census

Category	Benchmark Target (#)	Benchmark Target (%)
State or territory of residence		
New South Wales	6,403,715	31.54
Victoria	5,201,515	25.62
Queensland	4,086,793	20.13
South Australia	1,449,803	7.14
Western Australia	2,150,234	10.59
Tasmania	459,012	2.26
Northern Territory	189,570	0.93
Australian Capital Territory	359,967	1.77
Language spoken at home		
Speaks a language other than English	4,901,335	24.14
Does not speak a language other than English	15,399,274	75.86
Age group by highest education		
18-24 years	2,234,139	11.01
25-34 years x Less than Bachelor degree	2,087,909	10.28
25-34 years x Bachelor degree or higher	1,682,319	8.29
35-44 years x Less than Bachelor degree	1,977,498	9.74
35-44 years x Bachelor degree or higher	1,590,276	7.83
45-54 years x Less than Bachelor degree	2,186,785	10.77
45-54 years x Bachelor degree or higher	1,117,226	5.5
55-64 years x Less than Bachelor degree	2,270,012	11.18
55-64 years x Bachelor degree or higher	784,591	3.86
65+ years x Less than Bachelor degree	3,556,689	17.52

65+ years x Bachelor degree or higher	813,163	4.01
Gender		
Man or male	9,971,164	49.12
Woman or female	10,329,445	50.88
Remoteness Area		
<i>Major Cities of Australia</i>	14,654,020	72.19
<i>Inner Regional Australia</i>	3,642,222	17.94
<i>Outer Regional Australia</i>	1,642,975	8.09
<i>Remote Australia</i>	224,531	1.11
<i>Very Remote Australia</i>	136,860	0.67

Sources: Census 2021 (ABS 2021b)

Benchmark comparisons

The average absolute bias, defined as the absolute percentage point difference between the estimates and the benchmark proportions, was computed as an average across all available categories within each item. The closer this measure is to 0, the more similar the distribution is to the population.

The average absolute difference between the population and weighted estimates of the study are shown in Table 4. There are large biases in the non-probability boosts, which is caused by the specific groups targeted. They are either LOTE respondents who speak simplified or traditional Chinese, Arabic, Vietnamese, or Punjabi or they are adults from very remote Australia or Northern Territory.

The non-probability samples greatly over represent non-English speakers, but this is balanced out by Life in Australia™ which underrepresents this group. Both cohorts have an education bias, Life in Australia™ over represent people with Technical and Further Education (TAFE) qualifications while underrepresenting people who did not finish high school. The non-probability sample over-represents people with post-graduate qualifications, while under-representing those with a who did not have a TAFE or university qualification, regardless of whether they completed high school or not. When combined, the postgraduate and year 12 representation reduced, but some bias still exists around people with TAFE qualifications, which are still overrepresented. For remoteness, there are very few cases from Inner Regional Australia, but when combined with Life in Australia™, this bias is reduced to approximately 0. For LOTE, combining Life in Australia with the non-probability sample, results in minimal bias for LOTE.

Table 4: Comparison of the average absolute difference between the population and weighted estimates

Variable	Life in Australia™	Non-Probability Boosts	Combined
Age	0.9%	7.7%	0.6%
Birthplace	5.0%	33.2%	3.1%
Education	6.3%	10.8%	6.4%
Gender	0.6%	4.1%	0.6%
LOTE	2.6%	50.2%	0.0%
Remoteness	0.4%	6.5%	0.0%
SEIFA	1.7%	3.3%	1.7%
State	0.2%	3.3%	0.0%

Note: LOTE = Language other than English, SEIFA = Socio-Economic Indexes for Areas

Presentation of estimates

The report presents estimates derived from survey responses weighted to the appropriate Australian population. Proportions are shown as percentages rounded to one decimal place. All differences reported in estimates across groups are statistically significant at the 95% level of confidence unless specified otherwise.

Means and medians

In some cases, estimates are presented as medians as well as means. This has been done when there was a concern that the means may be skewed by outliers. As the mean is a summary of all data points, it will be distorted by very large outliers. In contrast, the median is simply a description of the mid-point of data - close to half of the responses will be below the median, and half will be above. As a result, the median is not affected greatly by a small number of outliers.

Throughout the report, medians are only used in cases where the mean was noticeably affected by outliers or a skewed distribution, or when this enabled comparison to other published data. All means and medians in the report have been indicated.

Degree of correlation

When reporting correlations, it is a perfect correlation when the correlation coefficient is ± 1 ; strong correlation if the coefficient value lies between ± 0.50 and ± 1 ; medium correlation if the coefficient value lies between ± 0.30 and ± 0.49 ; small correlation if the coefficient value lies below ± 0.29 ; no correlation when the value is zero.

Significance testing

When comparing two different estimates, it is important to determine whether the difference is likely to reflect a true difference in the underlying population or whether it may be due to sampling error. This process is called 'significance testing'. There are several variables that are used to calculate whether two estimates are significantly different - the size of the difference, the variability in the sample collected (which indicates the level of sampling error present), and the size of the sample. In this report, a difference is deemed to be statistically significant if the chance of seeing the observed difference under the null hypothesis was less than 5% ($p < 0.05$).

All group differences in the survey are statistically significant at the 95% level of confidence (unless otherwise specified). If a difference is statistically significant, it has been marked with a '#' symbol in the supplementary tables.

Sometimes, even large apparent differences may not be statistically significant. This is particularly the case where there are small sample sizes. Conversely, with a sufficiently large sample, small changes are more likely to be statistically significant.

References

ABS (Australian Bureau of Statistics) (2021a), *Cultural diversity: Census*, ABS Website, accessed 25 January 2024.

ABS (2021b), Counting Persons, Place of Usual Residence [Census TableBuilder], accessed 10 May 2023.

Annear MJ, Toye C, Elliott K-EJ, McInerney F, Eccleston C and Robinson A (2017) 'Dementia knowledge assessment scale (DKAS): confirmatory factor analysis and comparative subscale scores among an international cohort', *BMC Geriatrics*, 17:168, doi:10.1186/s12877-017-0552-y.

Bartlett L, Doherty K, Farrow M, Kim S, Hill E, King A, Alty J, Eccleston C, Kitsos A, Bindoff A and Vickers JC (2022) 'Island study linking aging and neurodegenerative disease (ISLAND) targeting dementia risk reduction: protocol for a prospective web-based cohort study', *JMIR Research Protocol*, 1:11(3):e34688, doi: 10.2196/34688.

Deville J, Särndal C and Sautory O (1993) 'Generalized raking procedures in survey sampling', *Journal of the American Statistical Association*, 88(423):1013-1020, doi:10.1080/01621459.1993.10476369.

Elliott M and Valliant R (2017) 'Inference for nonprobability samples', *Statistical Science*, 32: 249-264, doi:10.1214/16-STS598.

Kalton G and Flores-Cervantes I (2003) 'Weighting methods', *Journal of Official Statistics*, 19(2):81-97.

Kim S, Eccleston C, Klekociuk S, Cook PS and Doherty K (2022) 'Development and psychometric evaluation of the Dementia Public Stigma Scale', *International Journal of Geriatric Psychiatry*, 37(2), doi:10.1002/gps.5672.

Lumley T (2021) *Survey: Analysis of complex survey samples*, <http://r-survey.r-forge.r-project.org/survey/>.

R Core Team (2022). R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria. <https://www.R-project.org/>.

Särndal C.-E, Swensson B and Wretman J (1992) *Model assisted survey sampling*, Springer Verlag Publishing, doi:10.1007/978-1-4612-4378-6.

Valliant R, Dever J and Kreuter F (2018) *Practical tools for designing and weighting survey samples*, 2nd edn, Springer-Verlag Publishing, doi:10.1007/978-3-319-93632-1.

Valliant, R (2020) 'Comparing alternatives to estimation from nonprobability samples', *Journal of Survey Statistics and Methodology*, 8(2), 231-263, doi:10.1093/jssam/smz003.





Appendix





Data





Related material

Related topics

- [Aged care](#)
-

