Australian Government
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Younger onset dementia: new insights using linked data

AIHW

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Australian Institute of Health and Welfare
Canberra

Cat. no. DEM 05

A complete list of the Institute's publications is available from the Institute's website www.aihw.gov.au.

ISBN 978-1-76054-991-6 (Online)
ISBN 978-1-76054-992-3 (Print)
DOI: 10.25816/cc5a-tm25

Suggested citation

Australian Institute of Health and Welfare (2022) *Younger onset dementia: new insights using linked data*, catalogue number DEM 05, AIHW, Australian Government.

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Published by the Australian Institute of Health and Welfare.

**Please note that there is the potential for minor revisions of data in this report.
Please check the online version at www.aihw.gov.au for any amendments.**

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Summary

Younger onset dementia in Australia

Dementia is a major health issue in Australia. It is not a single disease – there are many types of dementia with symptoms in common, and these are caused by a range of conditions affecting brain function. Dementia is most common among older people; 'younger onset dementia' refers to dementia that begins before the age of 65. While exact numbers are not known, the Australian Institute of Health and Welfare (AIHW) estimated that around 27,800 Australians had younger onset dementia in 2021, and this number is projected to increase to 39,000 by 2050 (AIHW 2021b).

The needs and care requirements of people with younger onset dementia, their families and informal carers are often different from those of older people. A diagnosis may occur at an age when the demands of family and work are at a peak, placing a severe strain on family and carer dynamics and finances. People with younger onset dementia often retain good physical health, which can affect the appropriateness of dementia services that are targeted at older people. In the absence of age-appropriate options, people with younger onset dementia may need to enter residential aged care (AIHW 2021b). Recent policy changes seek to provide better alternatives for supported accommodation (Department of Health 2020; DSS 2020).

Better evidence using linked data

Most dementia research focuses on older people. There is a need for better evidence to inform policy and service responses to support younger people with dementia, including work responding to the Royal Commission into Aged Care Quality and Safety (the Royal Commission).

Linked data provide a new opportunity to present a more comprehensive picture of people with younger onset dementia. This report presents findings from 2 new multi-source enduring linked data sets, each of which focuses on different information:

- The Multi-Agency Data Integration Project (MADIP) includes information on Pharmaceutical Benefits Scheme (PBS) medicines, sociodemographic characteristics in the 2016 Census, and income support payments received through Centrelink.
- The National Integrated Health Services Information Analysis Asset (NIHSI AA) contains information on PBS medicines, health services, residential aged care (RAC) and mortality.

PBS claims data were used to create a younger onset dementia study cohort in both linked data sets, allowing parallel analysis of the same group of people over a 5- to 6-year period between 2011–2012 and 2017. The information in the 2 linked data sets was used to describe the social and financial circumstances of people with younger onset dementia, their general practitioner (GP) and specialist attendances, medicines dispensed, emergency department (ED) visits and hospital stays, use of respite and permanent RAC services, and causes of death.

Box 1: The study cohort of people with younger onset dementia

Rather than looking at all people with younger onset dementia, this study focused on people at a relatively early stage of dementia – as identified by the dispensing of dementia-specific medications. This allowed analysis of characteristics and service use over time from a similar starting point.

More specifically, in this report, ‘people with younger onset dementia’ refers to a cohort of about 5,400 Australians aged 30–69. This is a subset of the total population with younger onset dementia, including only those who were relatively early in their disease progression and who were dispensed dementia-specific medications through the PBS in 2011–2012.

- The inclusion of people aged 65–69 made an allowance for delays between the onset of disease, diagnosis and treatment, and for people who started taking the medication before the start of the study period while aged under 65.
- There were slightly more women in the cohort (52%) than men (48%).
- There were some small differences in the number of people in the MADIP and NIHSI AA cohorts, but on average there were about 2,500 people aged 30–64 and about 2,900 people aged 65–69.

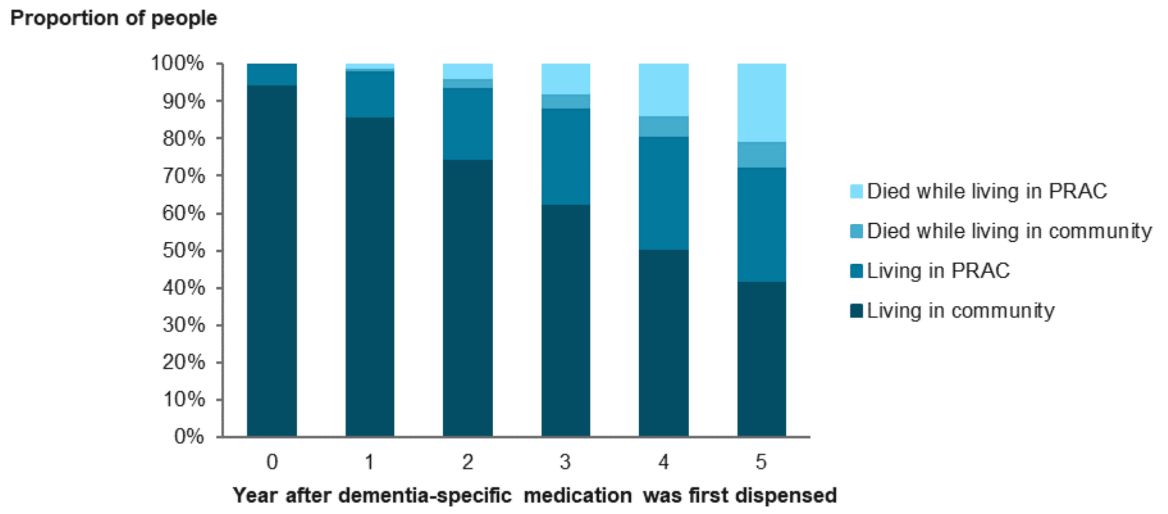
Not all types of dementia are represented in the study cohort

Dementia-specific medications (anticholinesterases) are targeted at people with mild to moderate Alzheimer’s disease. Other types of dementia that are common in younger people (such as dementia with Lewy bodies, frontotemporal dementia and secondary dementias) are not usually treated with these medicines and are therefore under-represented in the cohort, and the specific needs of these groups (such as greater problems with language or mobility) are not fully identified. In addition, not all people with Alzheimer’s disease are dispensed dementia-specific medication. As a result, generalisation of these results to all people with younger onset dementia should be done with caution.

Overview of outcomes for people with younger onset dementia

Most people (95%) in the younger onset dementia cohort were living in the community when dementia-specific medication was first dispensed in 2011–2012, with 5% living in permanent residential aged care (PRAC) (Figure 1). By the fifth year after medication was first dispensed, 42% of people were still living in the community and 31% were living in PRAC. About one-quarter (27%) of the cohort had died within 5 years, predominantly those who had lived in PRAC.

Figure 1: Outcomes for people with younger onset dementia (ages 30–69), by year since dementia-specific medication was first dispensed in 2011–2012



Source: AIHW analysis of NIHSI AA v0.5, Table S5.2.

Most people with younger onset dementia live in major cities

In 2016 (4 to 5 years after the start of the study period), 72% of the study cohort lived in *Major cities* (ABS 2022), but unlike the pattern for all Australians, this proportion did not decrease in older ages. The relationship between place of residence and dementia is complex, and further work is required to tease out issues relating to the prevalence of dementia and adequate access to services.

Cultural and linguistic diversity among people with younger onset dementia

Australians from culturally and linguistically diverse (CALD) backgrounds may face numerous barriers in accessing dementia services, including language barriers. According to the 2016 Census, 21% of people with younger onset dementia were born in a non-English speaking country, most commonly Southern and Eastern European countries. This reflected the pattern for all Australians of a similar age. One-quarter of the study cohort (26%) spoke a language other than English at home, most commonly Italian, Greek or Chinese languages.

A relatively high proportion of the study cohort spoke English not well or not at all (9.0%), compared with 4.4% of all Australians of a similar age. This may be partly related to the progression of dementia, but also highlights the need for culturally appropriate services in the community, in supported accommodation, and for family and carers.

A high proportion of people with younger onset dementia received income support through Centrelink

People who develop dementia while still working may face a sudden or early retirement, resulting in significant social, emotional and financial impacts on the person and their family. In the 2016 Census (4 to 5 years after the first dispensed dementia-specific medication), 21% of the study cohort who were still aged under 65 reported that they were employed, and 72% were unemployed or not in the labour force. When only people aged 60–64 were analysed, people with younger onset dementia were less likely to be employed (7.4%) than all Australians of the same age (46%).

People aged 60–64 with younger onset dementia were also more likely (53%) to report lower income categories (personal annual income between $1 and $25,999) than all Australians of the same age (30%). This may partly reflect the high proportion of the study cohort receiving income support through Centrelink. Four years after their first dispensed dementia-specific medication, 71% of those in the 30–64 age group who were still alive received a Centrelink payment: 36% received the Disability Support Pension and 29% received the Age Pension.

Many people with younger onset dementia needed help with day-to-day activities while living at home

In the 2016 Census, 3 in 5 people (61%) of the study cohort who were living at home needed help with at least one of the 3 core activity areas of self-care, mobility and/or communication, compared with 7.4% of all Australians of a similar age. Nearly half of those living at home who were not married or in a de-facto relationship were living by themselves. The available data did not reveal whether people were receiving the help that they needed. Children whose parents have younger onset dementia face particular challenges, including reversal of the parent-child caring role: 18% of people with younger onset dementia aged under 65 in 2016 had dependent children.

Comparing the health service use of people who entered PRAC with those who did not

One of the aims of this study was to explore any potential differences in health service use between people with younger onset dementia who went on to enter PRAC, and those who remained in the community for the duration of the study period.

People who went on to enter PRAC had fewer GP and specialist attendances on average than people who remained in the community

While living in the community, in the first year after dementia-specific medication was dispensed, people in the 30–64 age group who went on to enter PRAC had 8.7 GP and 2.9 specialist attendances, compared with 12 GP and 3.8 specialist attendances by those who remained in the community. This may point to differences in access to services that enable people to stay at home, however, without more detailed data on the reasons for GP and specialist attendances (dementia-related or otherwise), it is difficult to tease out potential areas of inequity. The most common types of specialists seen by both groups were consultant physicians in psychiatry, neurology and geriatric medicine.

People who went on to enter PRAC were more likely to continue being dispensed dementia-specific medication for at least 6 years (76% of those in the 30–64 age group) than those who remained in the community (63%), and were also more likely to start being dispensed memantine, a drug used for later stages of dementia.

People who went on to enter PRAC were 4 times as likely to have an overnight hospital stay for dementia as people who remained in the community

Each year while living in the community, about one-quarter of people with younger onset dementia had an ED presentation, and one-quarter had a hospital stay. *Neurological system illness* was the most common reason for ED presentations, and about half of ED presentations ended with the person being admitted to hospital. For those who went on to enter PRAC, about 1 in 5 overnight hospital stays (21%) ended with the patient moving to a residential aged care facility that was not their usual place of residence.

Respite RAC was used by a third (34%) of people who went on to enter PRAC

In contrast, only 15% of people who remained in the community had a respite RAC stay. One-quarter (26%) of people were aged under 65 when they first used respite RAC and men were more likely to use respite RAC than women.

One-quarter of people with younger onset dementia were aged under 65 when they first entered PRAC

More than half (58%) of the cohort had a PRAC stay by the end of the 5- to 6-year study period. About 1 in 10 people (11%) had their first PRAC stay within one year of the first dispensed dementia-specific medication, and nearly half (49%, cumulative) within 3 years. Younger people (aged under 65) whose PRAC stay ended in death had a median length of stay of 2 years, compared with 3.4 years for PRAC stays that were ongoing at the end of the study period.

Health conditions and care needs of people in PRAC

The Aged Care Funding Instrument (ACFI) is used to allocate government funding to aged care providers based on the day-to-day needs of the people in their care. At their first ACFI assessment, 83% of people with younger onset dementia were assessed as needing high levels of care in at least one of 3 domains, most commonly in the *Cognition and behaviour* domain. In addition to dementia, depression and incontinence were commonly recorded health conditions.

Health service use changed after entry to PRAC

Entry to PRAC is often accompanied by a change in health service use: in the 12 months after entry to PRAC, GP attendances for people with younger onset dementia more than doubled, while specialist attendances halved. These patterns were similar to those seen for people with dementia of all ages (AIHW 2021b) and for the residential aged care population overall (AIHW 2020a).

Injuries were the most common reason for hospitalisation after entry to PRAC, accounting for 21% of ED presentations, 23% of same-day and 16% of overnight hospital stays.

The dispensing of antipsychotic medicines increased from 44% to 63% of people in the 6 months after entry to PRAC

Changes in medication often reflect the events that have led to a move to PRAC, such as changed behaviours. Non-pharmacological interventions are recommended as the first approach, but medical professionals may also prescribe antipsychotic medicines to help manage these symptoms. Inappropriate prescribing of antipsychotic medicines, sometimes as a form of chemical restraint to control behaviour, and the prescription of medicines that have negative interactions with each other, were key issues raised in the Royal Commission (2021).

In the 6 months before and after entry to PRAC, the proportion of people with younger onset dementia with polypharmacy (where 5 or more distinct medicines are dispensed) increased from 40% to 61%.

During this time, there was also an increase in the proportion of people dispensed drugs that act on the central nervous system (other than dementia-specific medications). For example, the dispensing of antipsychotic medicines increased from 44% to 63% of people. Over a quarter (28%) of people were new users of antipsychotics, with a median of 29 days between entry to PRAC and new dispensing.

About 2 in 5 people (42%) in the cohort had died by the end of the study period

Dementia is a degenerative condition that leads to reduced life expectancy. Most (78%) of those in the younger onset dementia cohort who died had lived in PRAC. About three-quarters of people (78%) had dementia recorded as an underlying cause of death or associated cause of death, but 22% did not have dementia recorded on their death certificate. Parkinson’s disease was the most common underlying cause of death recorded for these people. The inconsistent recording of dementia on death records remains a significant issue in dementia data in Australia and internationally.

1 Introduction

Overview of younger onset dementia in Australia

Dementia is not a single disease – there are many types of dementia with symptoms in common, and these are caused by a range of conditions affecting brain function. Dementia is commonly associated with memory loss but can affect speech, cognition, emotional control, behaviour and mobility (WHO 2019). As the condition progresses, a person with dementia will require increasing care, eventually in all aspects of daily living. Dementia is a major health issue in Australia: it was the third-leading cause of burden of disease and injury in 2018, and the second-leading cause of death in 2019 (AIHW 2021b).

Dementia is most common among older people. ‘Younger onset dementia’ refers to dementia that begins before the age of 65. The AIHW report *Dementia in Australia* (2021) estimated that around 27,800 Australians had younger onset dementia in 2021 – about 7% of all people with dementia in Australia. Based on population projections, this number is expected to increase to 39,000 by 2050 (AIHW 2021b).

Younger onset dementia has a more diverse range of causes than later-onset dementia: Alzheimer’s disease and vascular dementia are still relatively common, but frontotemporal dementia and dementia with Lewy bodies are more frequent, as well as 'secondary dementias' due to causes such as alcohol, traumatic brain injury, Parkinson’s disease, Huntington’s disease and Down Syndrome (RANZCP 2013; Sansoni et al. 2016).

The study of dementia is dominated by themes related to older age. This can be problematic as the concerns, needs and care requirements faced by people with younger onset dementia and their families are often different from those of older people (Brown et al. 2012). A diagnosis of younger onset dementia may occur at an age when the demands of family and work are at a peak, or when people are planning for retirement. Dementia at younger ages can place severe strain on family dynamics, relationships and finances. Services designed for older people with dementia are often not suitable for younger people due to differences in strength or mobility, or age-related eligibility criteria for support services. These factors can also affect how people with younger onset dementia are supported through changes in the way they respond or engage with others (Cations et al. 2017; Withall et al. 2013).

Younger people in residential aged care

There often comes a point when people with younger onset dementia need supported accommodation services, and in the absence of age-appropriate options, these people may need to enter residential aged care. In 2019–20 about 1,100 men and 930 women with dementia aged under 65 were living in a residential aged care facility (AIHW 2021b). For some younger people with dementia, residential aged care may be their setting of choice. However, younger people are generally considered to be better served by more age-appropriate accommodation with the supports they need (Cations et al. 2021).

The Royal Commission into Aged Care Quality and Safety

The interim report of the Royal Commission into Aged Care Quality and Safety (2019) recommended urgent action ‘to stop the flow of younger people with disability going into aged care, and expediting the process of getting those younger people who are already in aged care out’. This was reinforced in the final report under recommendation 74. The report highlighted people with dementia as one of 4 core groups of younger people in aged care facilities.

The Australian Government has committed to minimising the need for younger people to live in aged care facilities, through the Younger People in Residential Aged Care Strategy 2020–25 (DSS 2020; Department of Health 2020). Under this strategy the Australian Government's targets, apart from in exceptional circumstances, seek to ensure there are:

- no people under the age of 65 entering residential aged care by 2022
- no people under the age of 45 living in residential aged care by 2022
- no people under the age of 65 living in residential aged care by 2025.

Achieving these changes will require new policies and pathways to provide short-term and long-term accommodation and support options for people with younger onset dementia. Progress towards these targets is being tracked through the Younger people in residential aged care dashboard (AIHW 2022).

The final report of the Royal Commission (2021) had a number of recommendations with relevance to people with younger onset dementia, including:

- embedding high quality aged care (Recommendation 13)
- support for informal carers (Recommendation 42)
- better access to health care (Recommendations 56–58)
- restricted prescription of antipsychotics in residential aged care (Recommendation 65) and regulation of restraints (Recommendation 17)
- no younger people in residential aged care (Recommendation 74).

The importance of better information about people with younger onset dementia

Given the majority of services for dementia are targeted at older people, there is a need for better evidence to inform policy and service responses to support younger people with dementia.

Linked data provide an opportunity to present a more comprehensive picture of people with younger onset dementia by exploring their patterns of use of health and residential aged care services, as well as some of their social characteristics and patterns of income support.

The aims of this study were to:

- select a group of younger people who were relatively early in their dementia journey, and use linked data sources to describe the social and financial characteristics of the group, and to follow their service use and outcomes over a number of years
- explore any potential differences in health service use between people with younger onset dementia who entered permanent residential aged care (PRAC) and those who did not
- provide evidence to inform policy and service responses to support younger people with dementia, including reforms relevant to the recommendations of the Royal Commission into Aged Care Quality and Safety.

2 Methods

Data sources

Sources of information about people's social and financial characteristics, and health and residential aged care service use, are not all contained in a single linked data set. For this study, 2 new multi-source enduring linked data sets were analysed in parallel, each focusing on different types of information, as summarised below. More detailed information can be found in the Technical Document and supplementary data tables (denoted as 'Table Sx') can be found under Data.

Multi-Agency Data Integration Project

The MADIP is a partnership between Australian Government agencies that combines information on health care, education, government payments, personal income tax, and population demographics. The MADIP is managed under the custodianship of the Australian Bureau of Statistics (ABS 2021).

The MADIP data sets used for this study were:

- Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS, available for eligible veterans, war widows/widowers and their dependants) (2011 and 2012) – for construction of the younger onset dementia cohort, based on dispensing of dementia-specific medications
- Census of Population and Housing (2016) – for sociodemographic characteristics, income and employment
- Department of Social Services Data Over Multiple Individual Occurrences (DOMINO) (2009 to 2016) – for patterns of income support and other payments received through Centrelink
- Death Registrations – for the date of deaths registered up to 31 December 2017.

National Integrated Health Services Information Analysis Asset

The NIHSI AA is a multi-source, enduring linked data asset that contains de-identified health-care, residential aged care and mortality data. This study used the NIHSI AA version 0.5, containing data from 2010–11 to 2016–17. The NIHSI AA is managed under the custodianship of the AIHW (AIHW 2018c).

The NIHSI AA data sets used for this project were:

- PBS and RPBS – for construction of the younger onset dementia cohort and patterns of prescriptions dispensed
- Medicare Benefits Schedule (MBS) – for patterns of GP and specialist attendances
- Admitted Patient Care – for public hospital separations in 4 participating states (New South Wales, Victoria, South Australia and Tasmania)
- National Non-Admitted Patient Emergency Department Care Database – for emergency department presentations in the 4 participating states
- Residential Aged Care activity data – for permanent and respite residential aged care use

- Aged Care Funding Instrument data – for assessed health conditions and care needs in permanent residential aged care
- National Death Index (NDI) data – for the date and cause of deaths registered up to 31 December 2017.

Study population

Using dementia-specific medications to identify people in the early stages of dementia

Rather than looking at all people with younger onset dementia, this study focused on younger people who were at a relatively early stage of dementia. This allowed analysis of characteristics and service use over time from a similar starting point.

The lack of data on dementia incidence is a known data gap (AIHW 2020c) and there are no incidence data available in the NIHSI AA or MADIP. One way of identifying people who are in the early stages of dementia is through the dispensing of dementia-specific medications through the PBS/RPBS. In this report, ‘dementia-specific medication’ refers to 3 anticholinesterase drugs (donepezil, rivastigmine and galantamine), also known as cholinesterase inhibitors. These medicines are used to treat mild to moderately severe Alzheimer’s disease (see Box 2.1): medication is usually prescribed early in the progression of dementia (DUSC 2016). Dementia cases identified in the PBS/RPBS are picked up earlier in the disease course compared with other administrative data sources such as hospitals, aged care or deaths (Welberry et al. 2020).

Unless otherwise stated, in this report ‘dementia-specific medication’ does not include the drug memantine, which is used to treat later stages of dementia (DUSC 2016).

Scope of ‘younger onset’ dementia

Younger onset dementia typically refers to dementia with an onset of symptoms before the age of 65. This study selected people who were aged 30–64 when their first dispensed dementia-specific medication was recorded in the NIHSI AA. In addition, people aged 65–69 were included in the study, to allow for delays between the onset of disease and diagnosis and subsequent dispensing of dementia-specific medication (Thompson 2011; Brown et al. 2012; Withall et al. 2014; Loi et al. 2022). The 65–69 age group also includes people who might have started taking dementia-specific medication before the start of the analysis period, when they were aged under 65. These age groups have been analysed separately where possible.

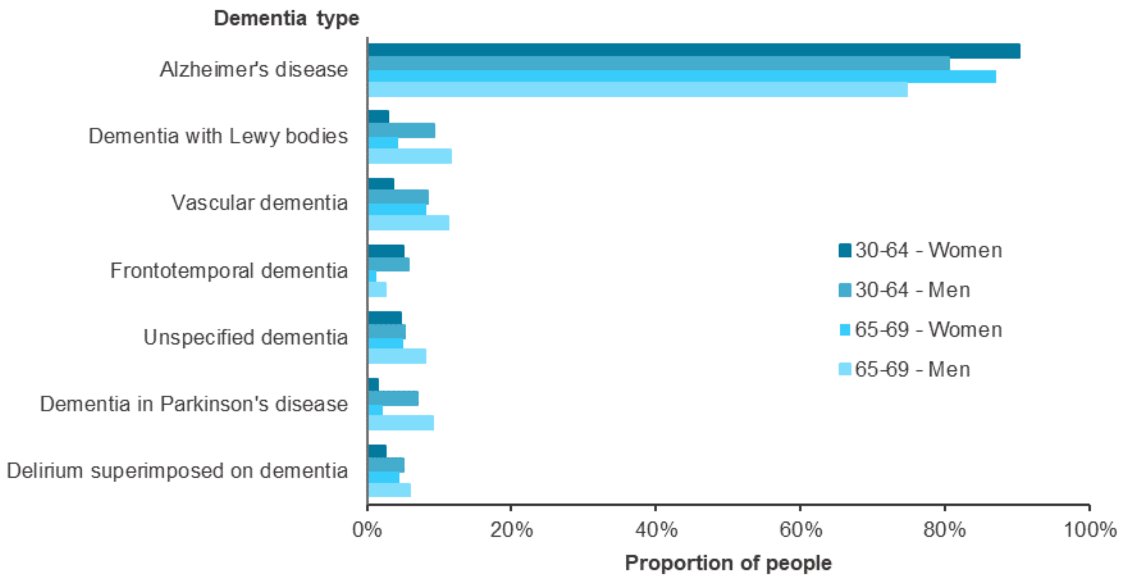
Box 2.1: Not all types of dementia are represented in the study cohort

For ease of reading, people in the study cohort are referred to as ‘people with younger onset dementia’. The advantage of using the PBS/RPBS to define the study cohort is that people are at a similar, relatively early, stage of their condition. However, this method does result in a bias towards people with presumed Alzheimer’s disease, or those with symptoms similar to Alzheimer’s disease, due to the conditions placed on prescribing of anticholinesterases under the PBS/RPBS (DUSC 2016). In the current data sets, people with other types of dementia (such as dementia with Lewy bodies, frontotemporal dementia and secondary dementias) cannot be specifically identified in the early stages of their condition, and hospital or aged care records are likely to occur at a later stage of their condition when people may be older than 65. As a result of this ascertainment bias, these other types of dementia are under-represented in this study cohort, and the specific needs of these groups (such as greater problems with language or mobility) are not fully identified.

It should also be noted that not all people with Alzheimer's disease are prescribed dementia-specific medications and there is variation in the rate of anticholinesterase dispensing across Australia that may be related to access issues (ACSQHC 2015; Welberry et al. 2020). As a result, generalisation of these results to all people with younger onset dementia should be done with caution.

Some information on dementia type is available in the NIHSI AA: 70% of people in the study cohort had a dementia type recorded in a hospital record, ACFI assessment of care needs at PRAC entry or death record, and, not surprisingly, the majority of these (83%) were Alzheimer's disease (Figure 2.1). Men were more likely to have dementia types other than Alzheimer's disease recorded, particularly dementia with Lewy bodies and dementia in Parkinson's disease. People in the 30–64 age group were more likely to have frontotemporal dementia recorded than people in the 65–69 age group.

Figure 2.1: Proportion of people in the cohort with a dementia type recorded in the NIHSI AA, 2010–2017, by age group and sex



Source: AIHW analysis of NIHSI AA v0.5 Table S2.1

Notes

1. Dementia type was extracted from Aged Care Funding Instrument, Admitted Patient Care and National Death Index data.

2. The proportion of people with each dementia type sums to more than 100% because some people had more than one dementia type recorded. It was not possible to determine whether this was due to administrative coding variations or a person having mixed dementia.

When was dementia-specific medication 'first' dispensed?

The years 2011 and 2012 were selected as the earliest complete calendar years available in both linked data sets, allowing parallel analysis of approximately the same people in the MADIP and the NIHSI AA over several years (Box 2.2; Figure 2.1). However, as mentioned above, some people were dispensed dementia-specific medication before the start of the analysis period: about half of the cohort (48%) had a NIHSI AA record of dementia-specific medication dispensed in the latter half of 2010 (Table S2.2). For the purposes of this report:

- in the MADIP analysis in chapters 3 and 4, the ‘first’ dispensed dementia-specific medication was the first record between January 2011 and December 2012
- the NIHSI AA includes PBS/RPBS data from July 2010, so in chapters 5–10, the ‘first’ dispensed dementia-specific medication was the first record between July 2010 and December 2012
- people were assigned to an age group based on their first record, resulting in small differences between the MADIP and NIHSI AA cohort age groups.

Overview of analysis

A overview of the analysis method is shown in Box 2.2 and Figure 2.2. More details on the variables used from each data source and the decisions that were made to conduct the analysis are provided in the Technical Document.

Box 2.2: Overview of analysis

Step 1. Select study cohort of younger people dispensed dementia-specific medications.

- **1a.** A person was included in the MADIP or NIHSI AA study cohort if, during 2011–2012, they were aged 30–69 and dispensed a dementia-specific medication claimed through the PBS/RPBS.
- **1b.** In the NIHSI AA, if a person in the cohort had dementia-specific medication dispensed in 2010, the earliest script was flagged as the ‘first’ script.
- **1c.** The age and sex profiles of the study cohort in the MADIP and NIHSI AA were compared.

Step 2. In the MADIP, examine sociodemographic characteristics using the 2016 Census, and patterns of income support payments between 2009 and 2016 using DOMINO.

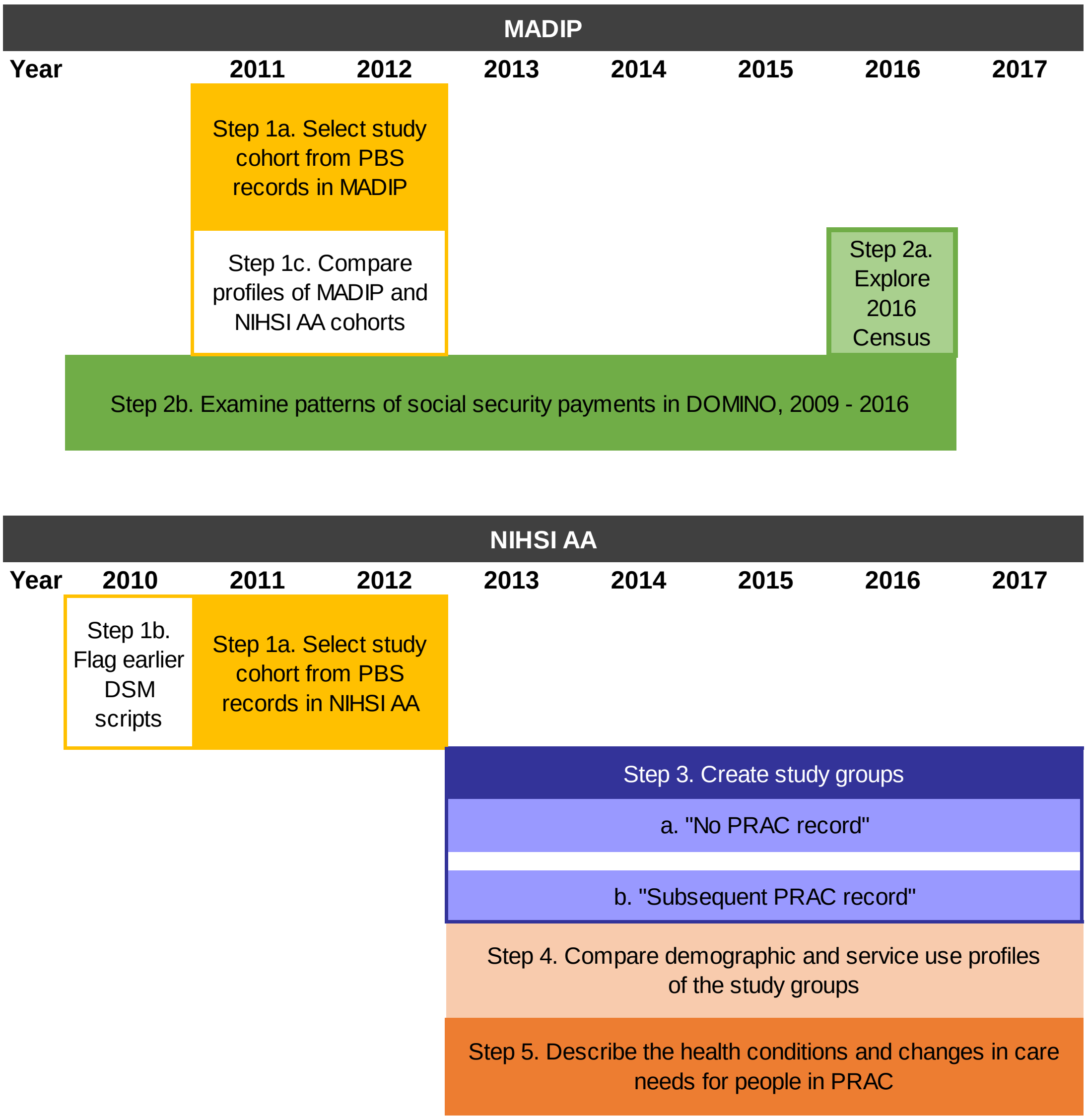
Step 3. In the NIHSI AA, create study groups based on whether people entered permanent residential aged care:

- ‘No PRAC record’: People who did not live in PRAC from the time that dementia-specific medication was first dispensed, to the end of the data period, or death.
- ‘Subsequent PRAC record’: People who lived in PRAC at or after the time that dementia-specific medication was first dispensed.

Step 4. Compare demographic profiles and service use by people in the 2 study groups using MBS, PBS, hospital and RAC data.

Step 5. Explore the health conditions and assessed care needs recorded in ACFI data for people living in PRAC.

Figure 2.2 Overview of analysis of the younger onset dementia cohort using the MADIP and NIHSI AA linked data sets, 2009 to 2017



Notes

1. DSM = dementia-specific medication; PBS = Pharmaceutical Benefits Scheme; PRAC = permanent residential aged care.

2. A condition of use of the MADIP is that only one Census data set can be linked in a project. Use of the 2016 Census allowed analysis of the cohort at a later stage of their dementia diagnosis, when there were more likely to be observable changes in dwelling type, employment and income.

Comparison between the MADIP and NIHSI AA cohorts

In 2011 and 2012, 5,519 people aged 30–69 were identified in the MADIP study cohort (see Table 3.1) and 5,192 people were identified in the NIHSI AA study cohort (see Table 5.1). That is, 327 more people were identified in the MADIP cohort than in the NIHSI AA cohort.

Although the additional people were identified across all age groups in the MADIP, the difference mainly affected the proportions of people in the youngest age group (30–49 years) (see Table C1 in the Technical Document). To minimise the impact of these differences on the interpretation of results, subsequent analyses used the combined age group 30–64 for people aged under 65. See the Technical Document for more details on the 2 cohorts, and a discussion of possible reasons for different cohort numbers.

People with evidence of younger onset dementia in the NIHSI AA

The 5,192 people in the NIHSI AA study cohort comprised approximately 45% of the 11,500 people who had any evidence of younger onset dementia in PBS/RPBS, hospital or ACFI records in 2011 and 2012. See Appendix A for more details on all people with evidence of younger onset dementia in the NIHSI AA. The people who were not included in the study cohort had not been dispensed dementia-specific medications, but had dementia recorded in a hospital admission and/or an ACFI assessment, and were more likely to be at a later stage of dementia.

Report structure

Chapter 3 presents the sociodemographic characteristics of people with younger onset dementia, including age, sex, patterns of cultural and linguistic diversity, place of residence, education levels, family and household structures.

Chapter 4 presents information on the financial impacts of younger onset dementia, including income and employment, and patterns of income support payments in the 2 years before and 4 years after the first record of dispensed dementia-specific medication.

Chapter 5 describes the younger onset dementia cohort and study groups used in the NIHSI AA analysis.

Chapter 6 summarises the use of GP and specialist services in the 6 years after dementia-specific medication was first dispensed, and 12 months before and after entry to PRAC.

Chapter 7 presents information on prescriptions dispensed in the 6 years after the first record of dispensed dementia-specific medication, and in the 6 months before and after entry to PRAC.

Chapter 8 summarises emergency department presentations and hospitalisations in the 4 states for which data were available.

Chapter 9 explores patterns of respite and permanent RAC use, and presents ACFI data on the health conditions and care needs of people in PRAC.

Chapter 10 summarises the leading causes of death for people with younger onset dementia.

Chapter 11 is a concluding discussion of results and how they contribute to the evidence base and help inform work relating to the Royal Commission. Limitations of the current study are discussed, along with future directions.

3 Characteristics of people with younger onset dementia

Age and sex profile of the MADIP study cohort

In 2011 and 2012, nearly 2,600 Australians aged 30–64 and more than 2,900 Australians aged 65–69 were dispensed dementia-specific medications through the PBS/RPBS, as identified in the MADIP linked data set.

> It is important to note that these numbers do not represent an estimate of all people with younger onset dementia. The MADIP study cohort is a subset: those who were aged 30–69 in 2011 and 2012, relatively early in their disease progression, and dispensed dementia-specific medications through the PBS/RPBS.

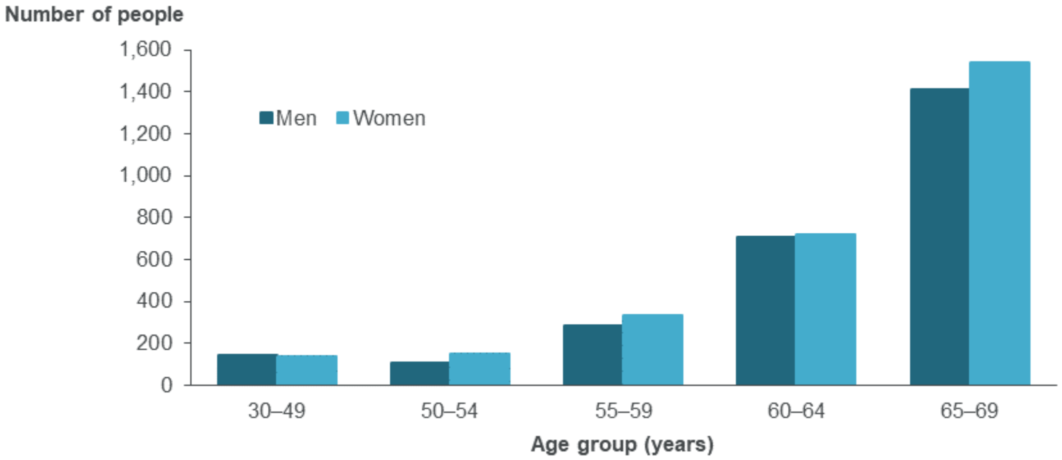
About 10% of the cohort were aged 30–54, 37% were aged 55–64 and 53% were aged 65–69 (Table 3.1; Figure 3.1). Overall, there were slightly more women in the cohort (52%) than men (48%), with the highest proportion of women in the 50–54 age group (58%).

Table 3.1: Number and proportion of people dispensed dementia-specific medications, by sex and age group, 2011–2012, MADIP

	Number of people			Proportion of cohort	Proportion of women in age group
Age group (years)	**Men**	**Women**	**People**		
30–49	140	136	276	5.0%	49%
50–54	105	146	251	4.5%	58%
55–59	283	333	616	11%	54%
60–64	709	717	1,426	26%	50%
Total 30–64	*1,237*	*1,332*	*2,569*	*47%*	*52%*
65–69	1,411	1,539	2,950	53%	52%
Total 30–69	**2,648**	**2,871**	**5,519**	**100%**	**52%**

Source: AIHW analysis of the MADIP, Table S3.1.

Figure 3.1: Number of people dispensed dementia-specific medications in the MADIP linked data set, by sex and age group, 2011–2012



Source: AIHW analysis of the MADIP. Table S3.1.

Census data

Census data can provide important insights into characteristics that have an impact on how people experience younger onset dementia, and the types of services and support that may be required. The characteristics examined in this report include country of birth, languages spoken, English proficiency, where people live and who they live with, and their need for assistance while living in the community.

Of the 5,519 people identified in the MADIP younger onset dementia cohort in 2011–2012, 1,573 people (29%) had died and 3,946 (71%) were alive at the time of the 2016 Census (4 to 5 years later). Of those who were alive, 85% (n=3,353) had a linked 2016 Census record which was used for analysis, representing 61% of the total younger onset dementia cohort. The age profile of those with a linked Census record (Table S3.2) was similar to the age profile of the total cohort (Table S3.1).

Box 3.1 summarises some of the issues to note with the Census data.

Box 3.1: Analysing the study cohort using 2016 Census data

- The 2016 Census occurred 4 to 5 years after the beginning of the study period (2011–2012). Age groups have been adjusted to reflect the age of the cohort at the time of the Census.
- The data do not capture 1,573 people who died prior to the 2016 Census, a group that was likely to include people with more advanced or faster-progressing disease and/or those living in residential aged care (see Chapter 10).
- There are challenges in collecting information from and about people with cognitive impairments. For ease of reading, ‘reported’ refers to the Census responses filled in by the person with dementia or by others on their behalf (their family, carers, or staff at a facility). As a result, the Census questions may be only partially completed, which can in turn affect the ability to link Census data to other data sets. Linkage rates may also be different for people born overseas (AIHW, forthcoming).

Comparisons with all Australians in the 2016 Census

Direct comparisons with all Australians are difficult due to the age structure of the younger onset dementia study cohort. Where feasible, indirect age standardisation was used to compare the cohort to the Australian population aged 34–74. Otherwise, people aged 60–74 accounted for 90% of the study cohort at the time of the 2016 Census (a person aged 69 in 2011 could be 74 in 2016), so comparisons are presented for all Australians aged 60–74.

Dwelling type at the 2016 Census

At the time of the 2016 Census, many people in the study cohort lived in the community: 66% of people aged 30–64 when dementia-specific medication was first dispensed, and 54% of those aged 65–69 (Table 3.2). This included people living in private dwellings or shared accommodation such as boarding houses.

About one-third (34%) of people aged 30–64 when dementia-specific medication was first dispensed, and nearly half (46%) of people aged 65–69, were living in cared accommodation at the time of the 2016 Census (Table 3.2). This included people residing in nursing homes, accommodation for the retired or aged (not self-contained), hospitals and hostels for the disabled (Table S3.3).

By comparison, 99% of all Australians aged 60–74 were living in the community at the time of the 2016 Census, and 1% in cared accommodation (Table S3.3).

Table 3.2: Place of residence at 2016 Census, by age group at first dispensed dementia-specific medication in 2011–2012, people with younger onset dementia

Age group in 2011–2012	Residence at time of 2016 Census	Number	Denominator	Proportion
30–64	In community	1,076	1,632	66%
	Cared accommodation	556	1,632	34%
65–69	In community	922	1,721	54%
	Cared accommodation	799	1,721	46%
Total 30–69	In community	1,998	3,353	60%
	Cared accommodation	1,355	3,353	40%

Source: AIHW analysis of the MADIP; Table S3.3.

Note: Cared accommodation includes these non-private dwelling types: nursing homes, accommodation for the retired or aged (not self-contained), hospitals and health institutions.

Cultural and linguistic diversity

Australia has an increasingly diverse community: in 2016, almost half of the general population (49% or 10.6 million people) were either born overseas or had one or both parents who were born overseas, and 1 in 5 Australians (21%) spoke a language other than English at home (ABS 2017). These groups of people are generally referred to as culturally and linguistically diverse (CALD) populations. Australians from CALD backgrounds may face numerous barriers when it comes to accessing services to diagnose and support a person with younger onset dementia, including language barriers, stigma and a lack of knowledge about dementia, particularly at younger ages (Brown et al. 2012). It is not only the diversity of the people with dementia that needs to be considered, but also their support systems (family and friends) (AIHW 2021b).

It is not always easy to identify CALD people in data, nor to provide more nuance in statistics beyond country of birth, because the relevant information is often not systematically recorded within individual data sets (AIHW 2020c). However, by linking PBS data with the 2016 Census, the MADIP provides a new opportunity to explore measures of cultural and linguistic diversity among people with younger onset dementia.

Country of birth

According to the 2016 Census, 41% of people with younger onset dementia were born overseas and 21% were born in a non-English speaking country, most commonly Southern and Eastern European countries (Table 3.3). Indirect age standardisation was used to examine whether particular CALD populations were more likely to be in the younger onset dementia cohort (that is, dispensed dementia-specific medications) for reasons other than age. The standardised incidence ratio (SIR) allows pair-wise comparison between the Australian population and the study cohort for each country or region of birth. For example, for people born in the United Kingdom, the number of people in the study cohort was not significantly different from what would be expected if the cohort had the same age profile as the Australian population (SIR 0.98, 95% confidence interval (CI): 0.88, 1.09). For people born in Italy, the number of people in the study cohort was 41% higher than would be expected if they had the same age profile as the Australian population (SIR 1.41, 95% CI: 1.13, 1.70). There were significant differences for people born in Canada and the United States of America (USA), North Africa and the Middle East and India. These statistics should be interpreted with caution, as numbers are small and the cohort is a subset of all people with younger onset dementia. Further research is required into the factors affecting the diagnosis and treatment of dementia for people from different CALD backgrounds.

Further information on CALD among Australians with dementia, including changes in migration patterns over time, is available in the *Dementia in Australia* report (AIHW 2021b).

Table 3.3: Country or region of birth of people in the younger onset dementia cohort, and all Australians, 2016 Census

Country or region of birth	Number in YOD cohort	YOD cohort (crude proportion)	All Australians (proportion)	SIR (95% CI)
Main English speaking countries / regions	*2,415*	*72%*	*72%*	*1.00 (0.96, 1.04)*
Australia	1,976	59%	61%	1.00 (0.95, 1.04)
United Kingdom (UK)	310	9.2%	6.6%	0.98 (0.88, 1.09)
New Zealand	62	1.8%	2.8%	0.87 (0.65, 1.09)
Canada and USA	30	0.9%	0.6%	1.69 (1.09, 2.29)(a)
South Africa	25	0.7%	0.9%	1.17 (0.71, 1.63)
Ireland	12	0.4%	0.4%	0.92 (0.40, 1.44)
Non-English speaking countries / regions	*702*	*21%*	*21%*	*1.07 (0.99, 1.15)*
Southern and Eastern Europe (excl. Italy and Greece)	121	3.6%	2.3%	1.05 (0.86, 1.24)
South-East Asia	99	3.0%	4.7%	0.99 (0.79, 1.18)
Italy	94	2.8%	0.8%	1.41 (1.13, 1.70)(a)
North Africa and the Middle East	78	2.3%	1.9%	1.43 (1.11, 1.75)(a)
North-west Europe (excl. UK, Ireland and Germany)	65	1.9%	0.9%	1.15 (0.87, 1.43)
Greece	55	1.6%	0.5%	1.32 (0.97, 1.67)
Germany	38	1.1%	2.0%	1.09 (0.79, 1.40)
China (excl. SARs and Taiwan)	50	1.5%	0.6%	0.91 (0.62, 1.20)
Americas (excl. Canada and USA)	29	0.9%	0.7%	1.34 (0.85, 1.83)
Southern and Central Asia (excl. India)	27	0.8%	1.3%	1.17 (0.73, 1.61)
India	18	0.5%	1.8%	0.57 (0.30, 0.83)(b)
North-East Asia (excl. China)	14	0.4%	0.4%	1.08 (0.51, 1.64)
Sub-Saharan Africa (excl. South Africa)	n.p.	n.p.	0.8%	n.p.
Oceania and Antarctica (excl. Australia and New Zealand)	n.p.	n.p.	0.9%	n.p.
Not stated / Inadequately described / At sea	236	7.0%	7.4%	0.85 (0.74, 0.96)(b)

Source: AIHW analysis of the MADIP, Table S3.4.

Notes

1. The younger onset dementia (YOD) cohort country of birth profile using Census data did not differ substantially from a similar profile generated using the MADIP demography file (Table S3.5).

2. SIR = Standardised incidence ratio, 95% CI = 95% confidence intervals. The 2016 Census Australian population was used as the standard population. The SIR cannot be compared between countries/regions of birth; the SIR value is compared to 1:

(a) if SIR > 1 then the incidence is (SIR-1)x100% higher than would be expected if the study population had the same age profile as the standard population;

(b) if SIR < 1 then the incidence is (1-SIR)x100% lower than would be expected if the study population had the same age profile as the standard population;

(c) if SIR = 1 (or more specifically, the SIR 95% CI contains 1) then the incidence is not significantly different from what would be expected if the study population had the same age profile as the standard population.

3. SARs = Special Administrative Regions.

Language spoken at home

Understanding the language background of people with dementia is particularly important, as people will often revert to their first language or mix languages as their dementia progresses (AIHW 2021b).

Three-quarters of people with younger onset dementia (74%) spoke only English at home (Table S3.6). Almost all (99%) of those born in an English-speaking country spoke only English at home.

Of those born in a non-English speaking country, 19% spoke only English at home (compared with 28% of all Australians aged 60–74 born in a non-English speaking country) (Table 3.4). A further 74% also spoke a language other than English at home, most commonly Southern European languages including Italian and Greek (total of 29%, compared with 19% of all Australians aged 60–74) and Chinese languages (12% and 14%, respectively).

Table 3.4: Common languages spoken at home by people born in a non-English speaking country: younger onset dementia cohort (ages 34–74), and all Australians (ages 60–74), 2016 Census

	Proportion of people born in a non-English speaking country	
Language group	**Younger onset dementia (ages 34–74)**	**All Australians (ages 60–74)**
English	19%	28%
Italian	12%	7.2%
Chinese languages	12%	14%
Southwest and Central Asian languages	10%	7.1%
Greek	8.9%	5.7%
Southern European languages (excl. Italian and Greek)	8.2%	6.4%
Eastern European languages	7.7%	10%
Northern European languages (excl. English)	5.7%	3.3%
Vietnamese	5.1%	3.8%
Southeast Asian languages (excl. Vietnamese)	2.8%	5.4%
Indo-Aryan languages	2.3%	4.0%
Not stated / Not applicable	5.0%	0.6%

Source: AIHW analysis of the MADIP, Table S3.7.

Note*:* The 2016 Census occurred 4 to 5 years after the beginning of the study period (2011–2012). Age groups have been adjusted to reflect the age of the cohort at the time of the Census. People aged 60–74 accounted for 90% of the study cohort at the time of the 2016 Census (a person aged 69 in 2011 could be 74 in 2016), so comparisons are presented for all Australians aged 60–74.

English language proficiency

Nearly 1 in 10 (9.0%) people with younger onset dementia (or 50% of those who spoke a language other than English) reported speaking English not well or not at all in the 2016 Census, compared with 4.4% of all Australians aged 60–74 (or 28% of those who spoke a language other than English) (Table S3.6). For people with younger onset dementia who did not speak English well or at all, the most common languages spoken at home were Chinese languages (18%), a smaller proportion than for all Australians (34%) (Table 3.5).

Table 3.5: Most common language spoken at home by people who spoke English not well or not at all: younger onset dementia cohort (ages 34–74), and all Australians (ages 60–74), 2016 Census

	Proportion of people who spoke English not well or not at all	
Language group	**Younger onset dementia (ages 34–74)**	**All Australians (ages 60–74)**
Chinese languages	18%	34%
Southwest and Central Asian languages	15%	11%
Greek	14%	7.5%
Italian	11%	4.0%
Vietnamese	10%	11%

Source: AIHW analysis of the MADIP; Table S3.8a.

Note*:* The 2016 Census occurred 4 to 5 years after the beginning of the study period (2011–2012). Age groups have been adjusted to reflect the age of the cohort at the time of the Census. People aged 60–74 accounted for 90% of the study cohort at the time of the 2016 Census (a person aged 69 in 2011 could be 74 in 2016), so comparisons are presented for all Australians aged 60–74.

The majority (70%) of people with younger onset dementia who did not speak English well or at all lived in the community at the time of the 2016 Census, and 30% lived in cared accommodation (Table S3.8b). People living in the community had a higher rate of speaking English not well or not at all (11%) than people living in cared accommodation (6.8%) (Table S3.8c). However, the proportion of 'not stated' responses was higher for people living in cared accommodation (18%, compared with 1.8% of people living in the community), which means these results should be interpreted with caution.

Ancestry

Ancestry reporting provides additional detail about a person's cultural affiliations. Respondents were able to report up to 2 ancestries in the 2016 Census, although 14% of people with younger onset dementia did not state any ancestry (Table S3.9). Where ancestry information was reported, the most common were:

- British (37%)
- Australian (27%)
- Southern and Eastern European (including Italian and Greek) (11%)
- Irish (7.6%)
- German (3.5%).

These proportions were similar to those of all Australians aged 60–74 (Table S3.9).

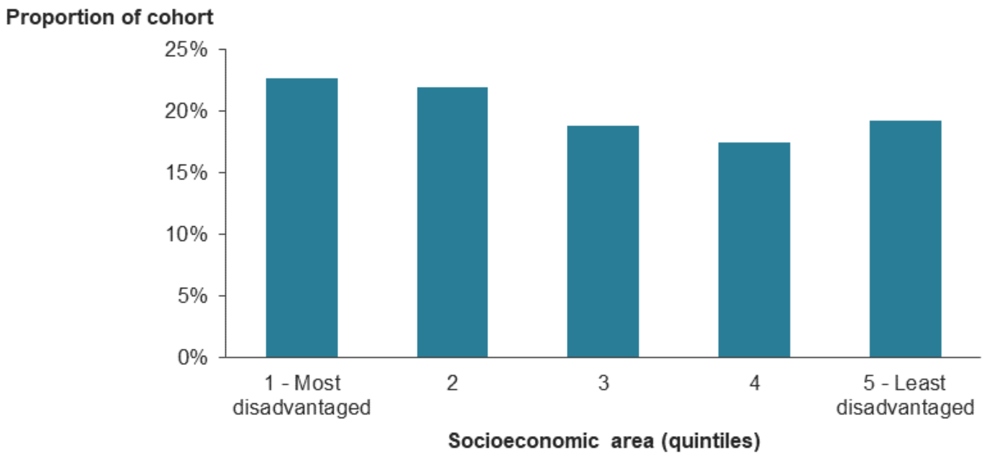
Religious affiliation

Christianity was the most commonly reported religious affiliation for people with younger onset dementia: 65% of Australian-born and 61% of overseas-born people. Less than 1% of Australian-born people reported a non-Christian religion, whereas people born overseas more commonly reported other religions, including Buddhism (5.4%), Islam (3.3%) and Judaism (1.2%). Similar proportions (20% of Australian-born and 19% of overseas-born people) reported secular and other spiritual beliefs and no religious affiliation, and the remainder did not state a religious affiliation (Table S3.10).

Socioeconomic status

A number of risk factors for dementia, such as childhood education, smoking, obesity, excessive alcohol consumption and traumatic brain injury, are associated with socioeconomic disadvantage (Livingston et al. 2020). At the 2016 Census, a slightly higher proportion of people with younger onset dementia resided in the most disadvantaged areas (23%), compared with the least disadvantaged (19%) (Figure 3.2). The number of people in the cohort living in the most disadvantaged areas (quintile 1) was 16% higher than would be expected if they had the same age profile as the Australian population (SIR 1.16, 95% CI: 1.08, 1.24). However, area-level socioeconomic measures can mask variations in disadvantage within areas, particularly for people living in cared accommodation. These patterns may also be influenced by variation in the dispensing of dementia-specific medications (ACSQHC 2015).

Figure 3.2: People with younger onset dementia, by socioeconomic area of residence, 2016 Census



Source: AIHW analysis of the MADIP, Table S3.11.

Notes

1. Socioeconomic area is based on the Socioeconomic Indicators for Areas (SEIFA) Index of Relative Socioeconomic Disadvantage (IRSD) score of the SA2 of usual residence.
2. Output excludes those with ‘not stated’ usual residence or IRSD score.

Remoteness areas

Remoteness Areas divide Australia into 5 classes of remoteness on the basis of a measure of relative access to services (ABS 2022). About 3 in 4 people (72%) with younger onset dementia resided in *Major cities* in 2016, while 27% lived in *Inner regional* or *Outer regional* areas, and 0.7% lived in *Remote* or *Very remote* areas (Table S3.12). These proportions did not differ substantially by accommodation type: 71% of people in cared accommodation and 73% of people residing in the community lived in *Major cities*.

There was also little difference between age groups for people with younger onset dementia: 74% of people aged 34–49 and 73% of people aged 70–74 lived in *Major cities* (Table 3.6). In contrast, the proportion of all Australians living in *Major cities* decreased with increasing age: from 73% of people aged 34–49 to 64% of people aged 70–74.

Table 3.6: Proportion of people living in *Major cities*, people with younger onset dementia and all Australians, by 5-year age group, Census 2016

Age at Census	Younger onset dementia	All Australians
34–49	74%	73%
50–54	75%	69%
55–59	70%	67%
60–64	72%	65%
65–69	71%	64%
70–74	73%	64%

Source: AIHW analysis of the MADIP, Table S3.12.

Note*:* The 2016 Census occurred 4 to 5 years after the beginning of the study period (2011–2012). Age groups have been adjusted to reflect the age of the cohort at the time of the Census.

Need for assistance with day-to-day activities

As the symptoms of dementia progress, people have increased needs for assistance. The 2016 Census included a question about whether a person needed assistance in their day-to-day lives with any or all of the following core activities: self-care, mobility, and communication, because of a disability, long-term health condition (lasting 6 months or more) or old age.

By the time of the 2016 Census, people in the younger onset dementia cohort had had their dementia diagnosis for at least 4 to 5 years. The proportion of people who reported a need for assistance with core activities increased with age, from 66% of people aged 34–69 (who were aged 30–64 at the time of first dispensed dementia-specific medication) to 75% of people aged 70–74 (who were aged 65–69 at the time of first dispensed dementia-specific medication) (Table S3.13).

- 61% of people living in the community reported a need for assistance with core activities, while 37% reported that they did not need assistance (2.3% ‘not stated’).
- Most people (85%) living in cared accommodation reported a need for assistance with core activities, and only 2.7% reported that they did not need assistance (12% ‘not stated’).

By comparison, 7.1% of all Australians aged 60–69 and 10% of those aged 70–74 reported a need for assistance. Of all Australians aged 60–74, 7.4% of those living in the community and 53% of those living in cared accommodation reported a need for assistance (Table S3.13).

Families and household composition

Marital status and household composition can be important factors in the social engagement of people with dementia and can have a significant influence on their ability to stay living in the community (AIHW 2021b). However, dementia at younger ages can also place a severe strain on family dynamics and carer relationships (Brown et al. 2012). At the 2016 Census (Table S3.14):

- 70% of people with younger onset dementia were in a married or de-facto relationship; 23% were divorced, separated or widowed; and 7.4% had never been married. These proportions were similar to those for all Australians aged 60–74 (69%, 25% and 6.0%, respectively)

- of the 435 people who were living in the community and were not in a married or de-facto relationship, nearly half (46%) were living in a lone person household. The proportion was higher for people who were divorced, separated or widowed (50%) than for people who had never married (37%)
- the proportion of people who were divorced, separated or widowed was higher for people living in cared accommodation (32%) than for those living in the community (16%).

Of the 734 people with younger onset dementia who were aged between 30 and 64 at the 2016 Census, more than 1 in 6 (18%) reported having dependent children. For those aged 65 or over, this proportion was lower (1.9%) (Table S3.15). Children whose parents have younger onset dementia face particular challenges, including reversal of the parent-child caring role (Dementia Australia 2021). Caring for a parent with dementia can affect a young person's physical and mental health, schooling, early career and socioeconomic status (Hutchinson et al. 2014).

4 Financial impact of younger onset dementia

People who develop dementia while still working often experience a gradual process of increasing problems at work and changing workplace relationships, followed by a sudden or early retirement. This can compound difficulties that accompany younger onset dementia and affect a person's wellbeing, self-esteem, financial position and social status (Evans 2019).

Employment status and income

The 2016 Census provides a snapshot of employment status and income for the younger onset dementia cohort, 4 to 5 years after they first had dementia-specific medication dispensed. For both variables, it is important to note the proportion of 'not stated' responses, as this was usually higher for the younger onset dementia cohort than for all Australians.

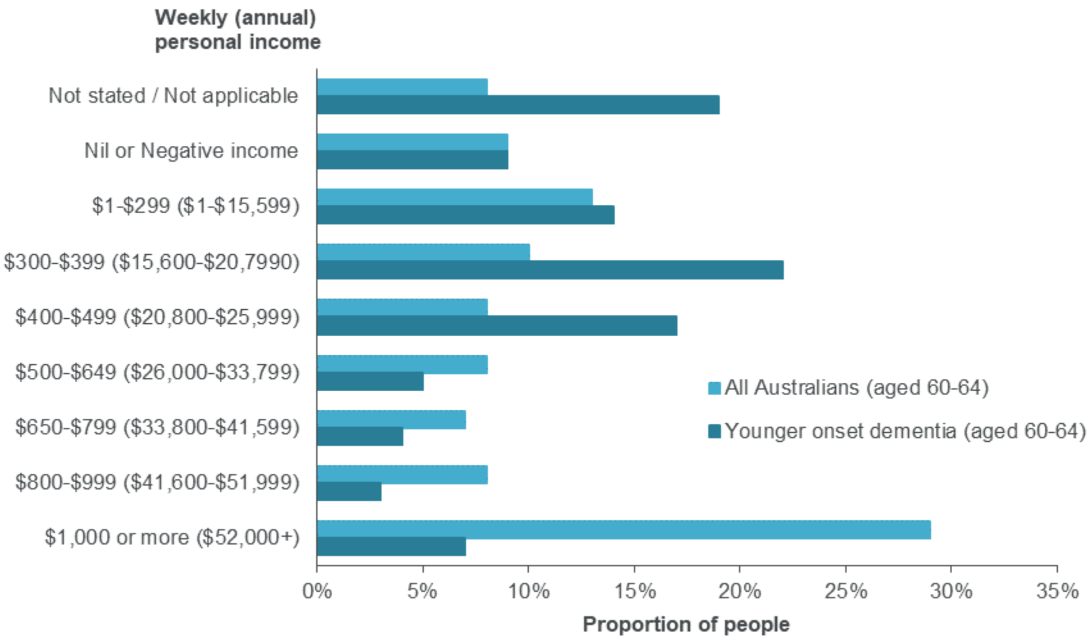
In 2016, 21% of the cohort aged 30–64 were employed; 72% were not in the labour force or were unemployed; and the remainder (6.4%) did not state their employment status (Table S4.1).

For those aged 65 or over, employment rates were lower, with 1.5% employed and 87% not in the labour force (12% did not state their employment status).

Employment status and personal income bands were compared with all Australians aged 60–64, as this age group represented the majority of people of working age with younger onset dementia.

- A lower proportion of people aged 60–64 with younger onset dementia (7.4%) were employed compared with all Australians of the same age (46%) (Table S4.1).
- People aged 60–64 with younger onset dementia were more likely (53%) to be in lower income categories (personal annual income between $1 and $25,999) than all Australians of the same age (30%) (Figure 4.1). This may reflect the high proportion of people with younger onset dementia receiving the Age Pension or Disability Support Pension (which had a single rate of about $22,700 per annum in 2016 (DSS 2016)), as discussed in the following section.

Figure 4.1: Weekly (and annual) personal income for people with younger onset dementia and all Australians, ages 60–64, Census 2016



Source*:* AIHW analysis of the MADIP, Table S4.2.

Note*:* Income categories were combined where necessary due to small counts in the younger onset dementia study cohort.

Income support recipients

Box 4.1: How were patterns in receipt of income support payments measured?

The MADIP DOMINO data set contains information on income support and other payments received through Centrelink for all Australians from January 2009 to December 2016.

Income support payments are those that generally serve as a recipient's primary source of income; they are regular payments that assist with the day-to-day cost of living, and a person can receive only one at a time. For this study, the income support payments of interest were the Disability Support Pension, Age Pension and Carer Payment. These payments offer insights into people's changing circumstances over time: their capacity to work, levels of disability and caring responsibilities. Where numbers permitted, 'other income support payments' were reported as a group (including Austudy, Newstart Allowance, parenting payments, Sickness Allowance, Special Benefit and Wife Pension). 'Other Centrelink payments' are a group of supplementary payments that do not serve as a primary source of income. Other government payments, such as the Veteran Payment, are not in the DOMINO data set. See the Technical Document for more details.

Disability Support Pension (DSP)

The Disability Support Pension (DSP) provides financial assistance for people who have reduced capacity to work because of their disability, including those with a physical, intellectual or psychiatric condition. This pension is available to people aged 16 and over (but under Age Pension age at claim), with eligibility based on the person's condition and level of impairment, and their assessable income and assets (Services Australia 2022).

It should be noted that the National Disability Insurance Scheme (NDIS), which was implemented in 2016, funds disability-related support and generally does not affect the DSP (NDIA 2021).

Age Pension

The Age Pension is the main income support payment for people who have reached Age Pension age. The age of eligibility was 65 for this study period.

Carer Payment and Carer Allowance

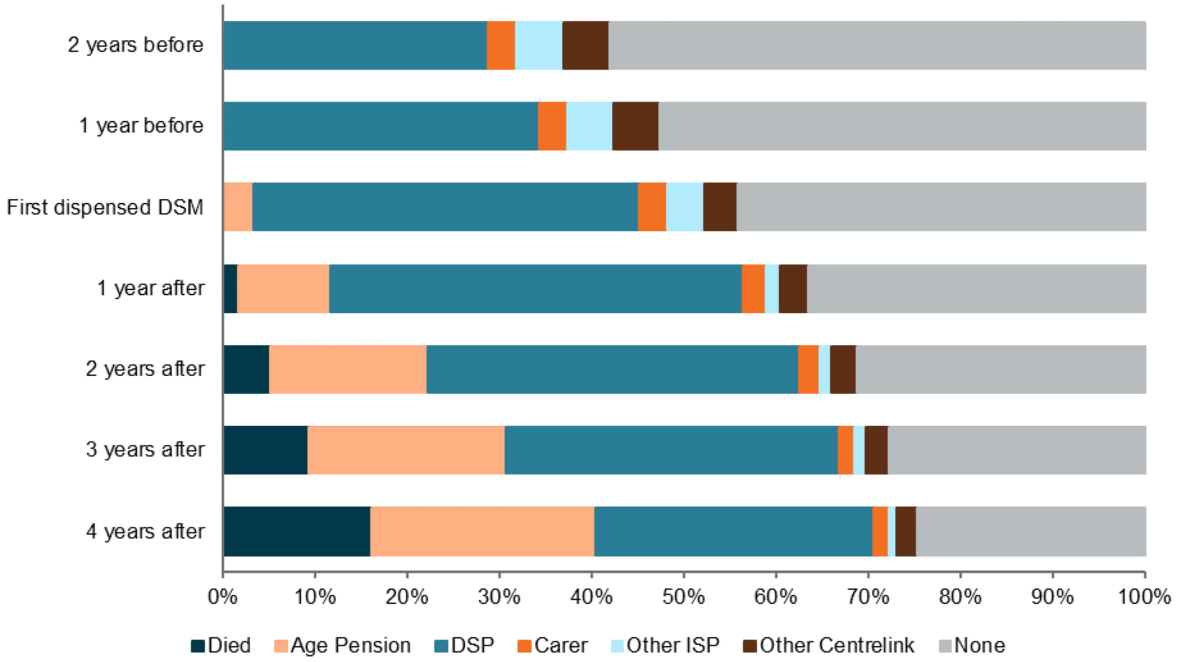
The Carer Payment is an income support payment for people who provide constant care for a person with a disability, severe medical condition or who is frail aged. Due to small numbers, Carer Payment recipients were grouped together with Carer Allowance recipients (an income-tested supplementary payment for people providing care).

Payment patterns in the younger onset dementia cohort (n=5,519) were analysed for the 2 years before, and 4 years following, the first dispensed dementia-specific medication in 2011–2012 (Figure 4.2; Table S4.3). Figure 4.2 represents people aged 30–64 at the time of their first dispensed dementia-specific medication, as this group was less likely to already be on the Age Pension. Data for people aged 65–69, and for the total cohort by sex, are in supplementary tables S4.3 and S4.5.

- **Two years before** the first record of dispensed dementia-specific medication in the MADIP, 42% of people in the 30–64 age group received income support or other payments through Centrelink. Nearly one-third (29%) of people received the DSP, 5.2% received other income support payments, 5.0% received other Centrelink payments and 3.0% received carer payments. Analysis of NIHSI AA data revealed that about half of the cohort had dementia-specific medication dispensed prior to 2011 (see Chapter 5), and these people might have already started receiving the DSP, along with people with pre-existing conditions often associated with younger onset dementia, such as Down Syndrome (see Table 4.1 ‘Primary medical conditions’).

- **At the time of the first record of dementia-specific medication dispensed in 2011–2012**, 56% of people in the 30–64 age group received a Centrelink payment. The proportion receiving the DSP increased to 42%; these people had been on DSP for a median of 4 years. By comparison, about 7.3% of all Australians of a similar age (35–64) received the DSP in 2013 (ABS 2013; DSS 2013; Table S4.4). A smaller proportion of people received other payments: 4.1% other income support payments, 3.5% other Centrelink payments, 3.0% carer payments. A small proportion (3.4%) started to receive the Age Pension.
- **Four years after** the first record of dispensed dementia-specific medication, 71% of those still alive received a Centrelink payment. There was a shift from the DSP and other payments to the Age Pension. After accounting for people who had died, the proportion receiving the DSP had decreased to 36%; 5.8% received the other payments; and the proportion receiving the Age Pension increased to 29%.

Figure 4.2: Receipt of Centrelink payments by people with younger onset dementia (30–64 age group), before and after their first dispensed dementia-specific medication



Source: AIHW analysis of the MADIP, Table S4.3.

Notes:

1. ‘First dispensed DSM’ refers to the time of the first record of dementia-specific medication dispensed in 2011–2012.

2. Centrelink payments shown are: DSP = Disability Support Pension; Carer = Carer Allowance and Carer Payment; Other ISP (income support payments) = Austudy, Newstart Allowance, parenting payments, Sickness Allowance, Special Benefit and Wife Pension, Other Centrelink = other supplementary payments, see Technical Document for full list.

Primary medical conditions for Disability Support Pension recipients

Primary medical condition information is available for several income support payments, including the DSP. There are 21 primary medical condition classification groups that each cover a number of individual medical conditions. The medical condition with the highest impairment rating determines which primary medical condition is recorded for a recipient, and offers insights into the most common conditions that result in functional impairment and reduced capacity to work. This analysis focuses on primary medical conditions for the DSP, as it is the most common form of income support received through Centrelink for this cohort.

The most common primary medical conditions for DSP recipients differed based on when the person began receiving payments. *Nervous system conditions* (including dementia) were the most common conditions before and after the first dispensed dementia-specific medication (Table 4.1). People who started on the DSP after dementia-specific medication was first dispensed were almost twice as likely to have *Nervous system conditions* as their primary medical condition (86%) than those who were already on the DSP (47%). A broader range of conditions was recorded for people who were already on the DSP, including *Musculo/skeletal and connective tissue conditions* (18%), *Psychological/psychiatric conditions* (13%) and *Intellectual learning conditions* (5.7%). This suggests that while younger onset dementia is prevalent in populations with other conditions that are eligible for the DSP, people also start on the DSP because of their dementia.

Table 4.1: Most common medical conditions recorded for people with younger onset dementia on the Disability Support Pension, before and after the first dispensed script for dementia-specific medication

Primary Medical Condition	Proportion of DSP recipients	
	DSP started before first script	DSP started after first script
Nervous system	47%	86%
Musculo/skeletal & connective tissue	18%	n.p.
Psychological/psychiatric	13%	4.4%
Intellectual/ learning	5.7%	n.p.
Circulatory system	3.5%	n.p.
Other conditions (grouped)	13%	9.2%

Source: AIHW analysis of the MADIP, Table S4.6.

Note: n.p. = not publishable due to small counts (<11).

5 The younger onset dementia cohort in the NIHSI AA

Age and sex profile of the NIHSI AA study cohort

Analysis of the NIHSI AA study cohort differed from the MADIP cohort in that PBS/RPBS data were available from July 2010. Where relevant, the 2010 data were used to flag a person's first record of dispensed dementia-specific medication and their age at that time. As a result, about half the cohort (48%) were allocated to an age group based on their age in 2010, rather than their age in 2011–2012 (Table S2.2). This allowed for more accurate reporting on the number of people aged 30–64 at the first record of dispensed dementia-specific medication.

Nearly 2,400 Australians aged 30–64 and about 2,800 Australians aged 65–69 were dispensed dementia-specific medications through the PBS/RPBS, as identified in the NIHSI AA linked data set.

It is important to note that these numbers do not represent an estimate of all people with younger onset dementia. The NIHSI AA study cohort is a subset: those who were aged 30–69 in 2011 and 2012, relatively early in their disease progression and dispensed dementia-specific medications through the PBS/RPBS.

About 7% of the cohort were aged 30–54, 39% were aged 55–64 and 54% were aged 65–69 (Table 5.1). Overall, there were slightly more women in the cohort (52%) than men (48%), with the highest proportion of women in the 50–54 age group (58%).

Table 5.1: Number and proportion of people dispensed dementia-specific medications, by sex and age group, NIHSI AA

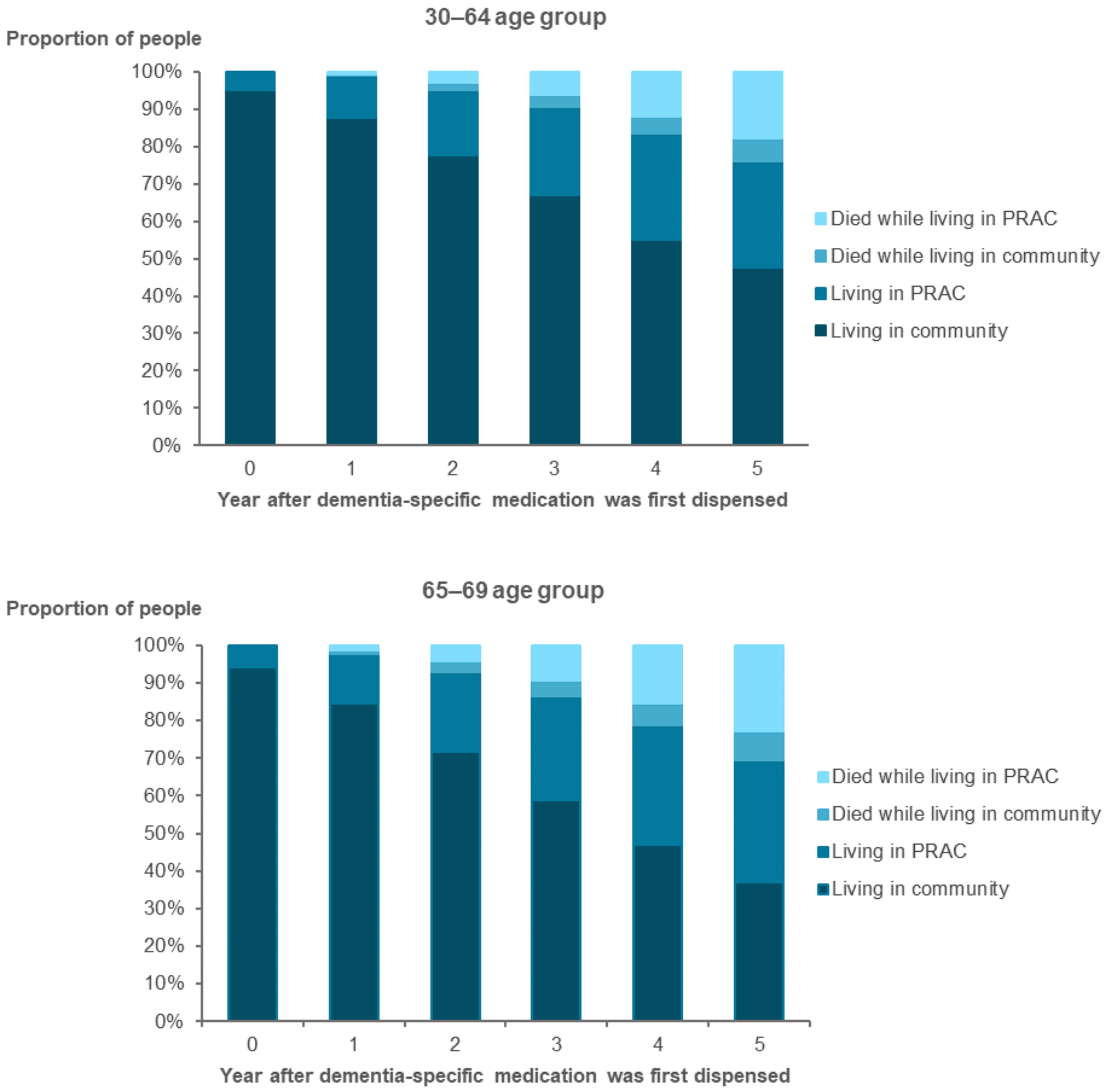
	Number of people			Proportion of cohort	
Age group (years)	**Men**	**Women**	**People**	**Age group**	**Women in age group**
30–49	58	65	123	2.4%	53%
50–54	96	133	229	4.4%	58%
55–59	277	323	600	12%	54%
60–64	714	722	1,436	28%	50%
Total 30–64	*1,145*	*1,243*	*2,388*	*46%*	*52%*
65–69	1,333	1,471	2,804	54%	52%
Total 30–69	**2,478**	**2,714**	**5,192**	**100%**	**52%**

Source: AIHW analysis of the NIHSI AA, Table S5.1.

Overview of outcomes for people with younger onset dementia

Most people (95%) in the younger onset dementia cohort were living in the community when dementia-specific medication was first dispensed; 5% were living in permanent residential aged care (PRAC) (Table S5.2). Over the next 5 years, the number of people living in PRAC increased steadily. By the fifth year, 47% of people in the 30–64 age group were still living in the community and 29% were living in PRAC, while 37% of people in the 65–69 age group were living in the community and 32% were living in PRAC (Figure 5.2). One in 4 people in the 30–64 age group (24%) and 30% in the 65–69 age group had died within 5 years, predominantly those who had lived in PRAC. More information about deaths of people with younger onset dementia is in Chapter 10.

Figure 5.2: Outcomes for people with younger onset dementia, by age group and year since dementia-specific medication was first dispensed



Source: AIHW analysis of NIHSI AA v0.5, Table S5.2.

Creating study groups based on subsequent permanent residential aged care use

The aims of this part of the study were:

- to follow the service use and outcomes of the younger onset dementia cohort in the 5 to 6 years after their first record of dispensed dementia-specific medication

- to explore any potential differences in health service use between people who subsequently entered permanent residential aged care, and those who did not (in the time for which data were available).

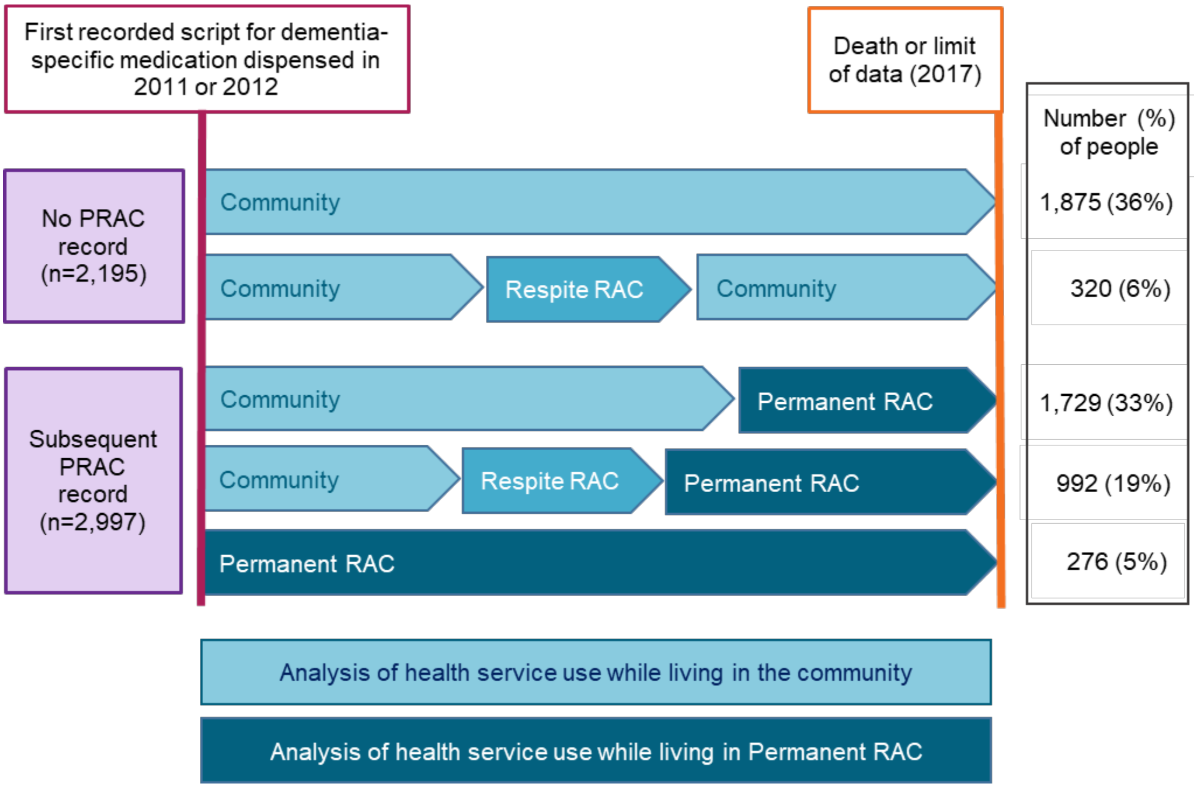
Box 5.1: Study group definitions

No PRAC record: People who did not live in permanent residential aged care (PRAC) from their first record of dispensed dementia-specific medication to the end of the data period, or death. People in this group might have used respite residential aged care (RAC) (see Chapter 9). A small number of people in this group had lived in PRAC before being dispensed dementia-specific medication but had subsequently returned to living in the community.

Subsequent PRAC record: People who lived in PRAC at or after the time of their first record of dispensed dementia-specific medication. People in this group might have used respite RAC prior to entry to PRAC (see Chapter 9). The time between the first dispensed script and entry to PRAC is referred to as 'living in the community'.

Figure 5.3 summarises the use of residential aged care for each group.

Figure 5.3: Creating younger onset dementia study groups based on permanent residential aged care (PRAC) use at or after the time that dementia-specific medication was first dispensed



Source: AIHW analysis of NIHSI AA v0.5, Table S5.3

Note: the NISHI AA does not include data on home and community based aged care services or disability support services.

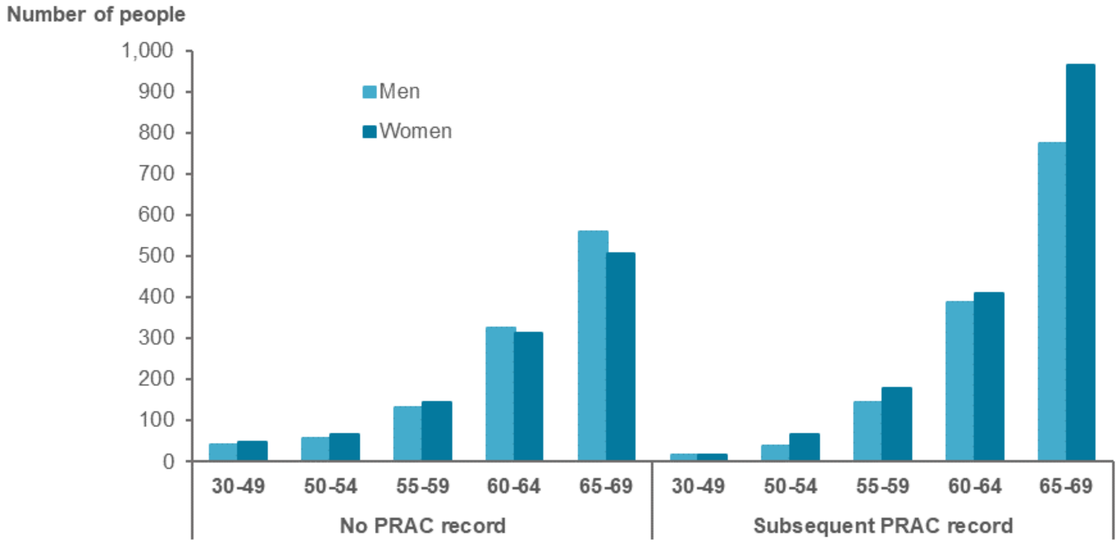
Nearly 2,200 people with younger onset dementia (42%) had no PRAC record during the study period: 47% of the 30–64 age group (1,130 people) and 38% of the 65–69 age group (1,070 people) (Figure 5.4).

About 3,000 people with younger onset dementia (58%) lived in PRAC at some time during the study period: 53% of the 30–64 age group (1,260 people) and 62% of the 65–69 age group (1,740 people) (Figure 5.4).

Living in PRAC was more common for women than for men:

- 54% of women and 51% of men in the 30–64 age group entered PRAC
- 66% of women and 58% of men in the 65–69 age group entered PRAC.

Figure 5.4: Number of people in the younger onset dementia cohort, by study group, sex and age at first dispensed dementia-specific medication



Source*:* AIHW analysis of NIHSI AA v0.5, Table S5.1.

6 General practitioner and specialist attendances

Patterns of attendance while living in the community

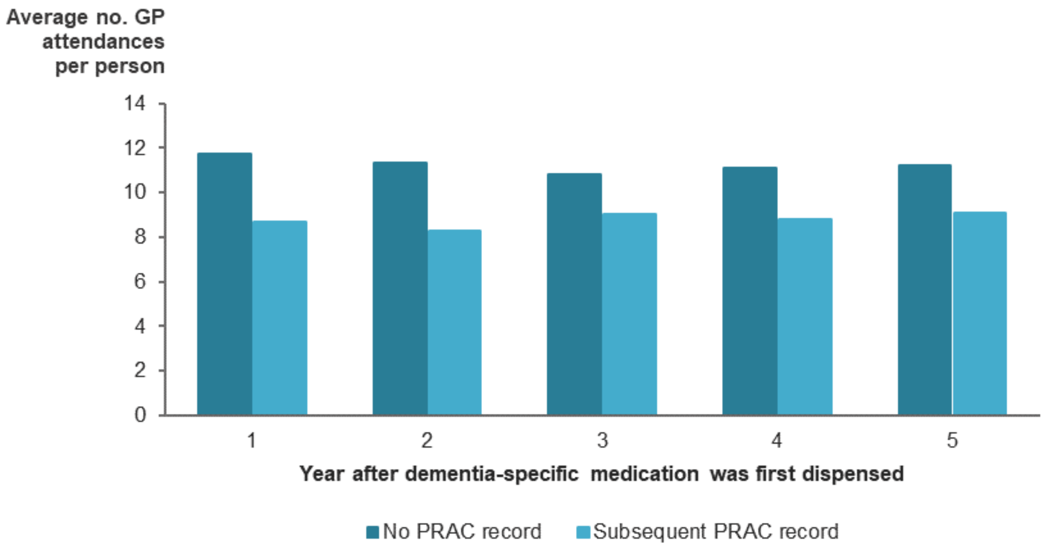
The Medicare Benefits Schedule (MBS) data collection contains claims data for Medicare services subsidised by the Australian Government. This includes services provided by community-based health professionals, including general practitioners (GPs), medical specialists (such as geriatricians and psychiatrists) and allied health professionals (such as physiotherapists and speech pathologists), who play a crucial role in the diagnosis and treatment of dementia (AIHW 2021b). This section presents data on GP and specialist services provided under the MBS. Dementia diagnostic information is not available in the MBS, so it is not possible to distinguish between dementia-specific services and services for the management of other health issues. However, by linking MBS data with other data sets that have dementia diagnostic information (such as the PBS), some exploration of the use of these community-based health services by people with dementia is possible.

It should be noted that people may receive primary care services in ways that are not captured in MBS data, including services delivered under Department of Veterans' Affairs arrangements; services provided through hospitals; services provided under a state-funded service; dementia-specific services such as the Dementia Behaviour Management Advisory Service or Severe Behaviour Response Teams; and services provided by a salaried GP or any other salaried medical officer arrangement (AIHW 2020e).

GP attendances

While living in the community, people with no PRAC record tended to have more GP attendances than people with a subsequent PRAC record. People aged 30–64 at the first dispensed script with no PRAC record had an average of 11 to 12 GP attendances per year in the 5 years after the first dispensed dementia-specific medication (Figure 6.1). People in the 30–64 age group with a subsequent PRAC record had a consistently lower average number of GP attendances, at 8 to 9 per year (Figure 6.1). Both rates were higher than those for all Australians of a similar age, who had an average of 6.5 GP attendances per person in 2016–17 (ages 45–64) (AIHW 2018b). There was little difference between men and women in each group, but younger people (aged 30–64 at the first dispensed script) in both study groups had a lower average number of GP attendances per year than older people aged 65–69 (Table S6.1). This may be due to older people often having more comorbidities.

Figure 6.1: Average number of GP attendances by people with younger onset dementia (30–64 age group) while living in the community, by study group and year after dementia-specific medication was first dispensed

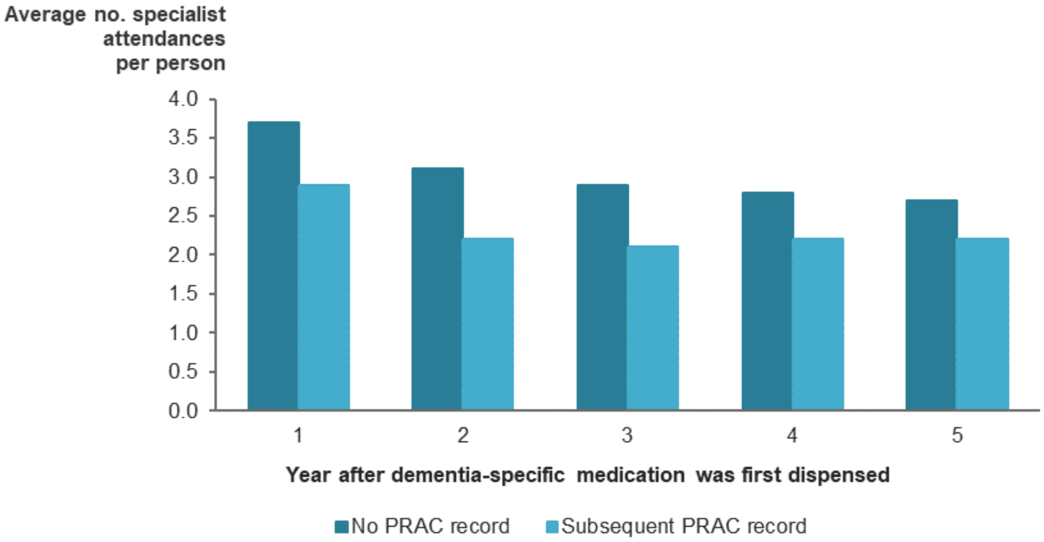


Source: AIHW analysis of NIHSI AA v0.5, Table S6.1.

Specialist attendances

The pattern of specialist attendances was similar to that for GP services. People with a subsequent PRAC record had a lower average number of specialists attendances while they were living in the community (2.9 per person for the 30–64 age group in the first year after dementia-specific medication was first dispensed) than people with no PRAC record (3.7 per person) (Figure 6.2). From the second year, specialist attendances per year for people with a subsequent PRAC record decreased to a steady average of 2.2. The rate for people with no PRAC record remained higher, but decreased over time. These rates were higher than those for all Australians of a similar age, who had an average of 1.1 specialist attendances per person in 2016–17 (ages 45–64) (AIHW 2018b). Overall, men had more specialist attendances than women, and older people (aged 65–69 at their first dispensed dementia-specific medication) had more specialist attendances than younger people aged 30–64 (Table S6.2).

Figure 6.2. Average number of specialist attendances by people with younger onset dementia (30–64 age group) while living in the community, by study group and year after dementia-specific medication was first dispensed

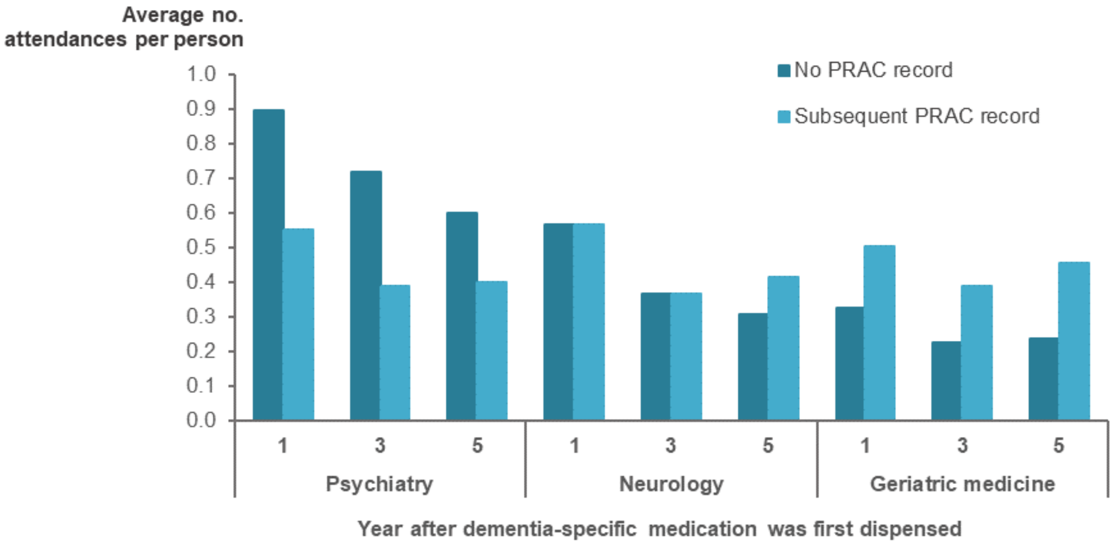


Source: AIHW analysis of NIHSI AA v0.5, Table S6.2.

Most common specialist types

Psychiatry was the most common specialist type used by people with younger onset dementia in the first year after dementia-specific medication was first dispensed (Figure 6.3, showing people in the 30–64 age group). People with a subsequent PRAC record had a lower average number of attendances (while living in the community) than people with no PRAC record, for most specialist types. The main exception was for geriatric medicine: people with a subsequent PRAC record, including those aged 30–64, had a higher average number of attendances than those with no PRAC record.

Figure 6.3. Most common specialist type attendances by people with younger onset dementia (30–64 age group) while living in the community, by study group and year after dementia-specific medication was first dispensed



Source: AIHW analysis of NIHSI AA v0.5, Table S6.3.

Other specialist services used by the study cohort are listed in Table S6.3, and the most common types of specialist services used by all people with dementia in 2016–17 are described in the *Dementia in Australia* report (AIHW 2021b, Figure 7.8).

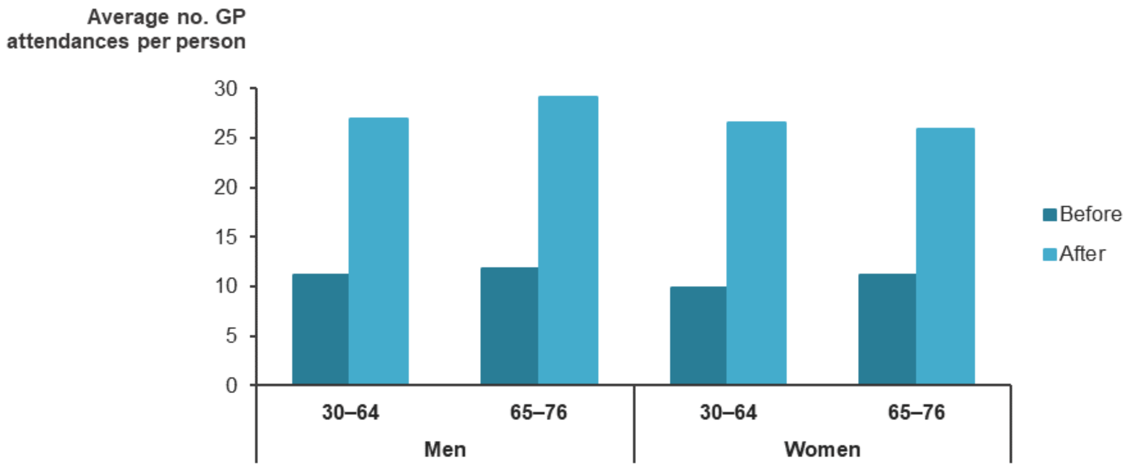
Other services claimed under the MBS, such as pathology tests, diagnostic imaging and allied health professionals, had a similar pattern of higher number of services for people with no PRAC record than for people with a subsequent PRAC record (Table S6.4). More information on all services claimed under the MBS by people with dementia can be found in the *Dementia in Australia* report (AIHW 2021b).

GP and specialist attendances before and after entry to permanent residential aged care

This section explores GP and specialist attendances for people with younger onset dementia who had a PRAC record, in the 12 months before and after entering PRAC.

The average number of GP attendances more than doubled from 11 per person in the 12 months before to 27 per person in the 12 months after entry to PRAC. Rates of GP attendance after entry to PRAC were slightly higher for men than for women (29 and 26 per person, respectively) but did not differ substantially by age at entry (Figure 6.4).

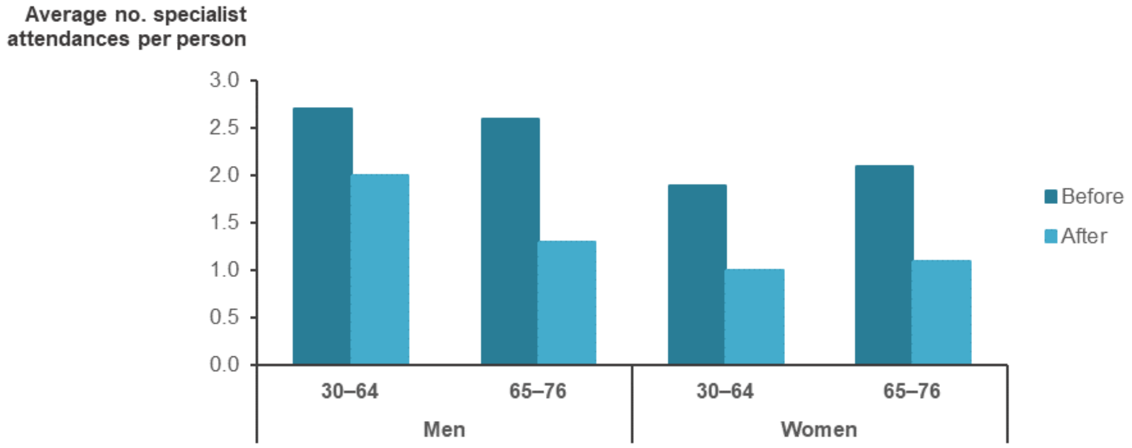
Figure 6.4: Average number of GP attendances per person in the 12 months before and after entry to PRAC, by sex and age at entry to PRAC



Source: AIHW analysis of NIHSI AA v0.5, Table S6.5.

Conversely, the average number of specialist attendances was lower in the 12 months after entry to PRAC than in the previous 12 months. In the 12 months after entry to PRAC, rates halved for men aged 65 and over (from 2.6 to 1.3 per person) and for women (from 2.1 to 1.1 per person). Of note, younger men (aged under 65 at entry to PRAC) had a higher average number of specialist attendances before entry to PRAC (2.7 per person), which decreased by a third to 2.0 per person after entry to PRAC (Figure 6.5).

Figure 6.5. Average number of specialist attendances per person in the 12 months before and after entry to PRAC, by sex and age at entry to PRAC



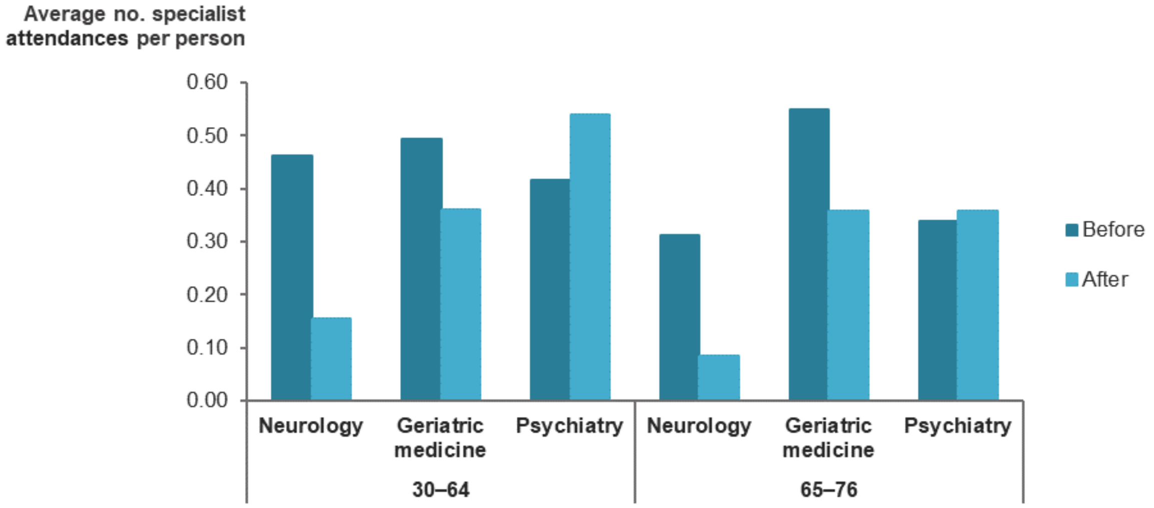
Source: AIHW analysis of NIHSI AA v0.5, Table S6.6.

These patterns of increasing GP attendances and decreasing specialist attendances after entry to PRAC were similar to those seen for people with dementia of all ages (AIHW 2021b) and for the residential aged care population overall (AIHW 2020a).

For people with younger onset dementia aged under 65 at entry to PRAC, the most common types of specialists seen in the 12 months before entry were consultant physicians in geriatric medicine, neurology and psychiatry (accounting for 21%, 20% and 18% of specialist attendances, respectively) (Table S6.7). Younger people (aged under 65 at entry) had a higher rate of specialist attendances for neurology and psychiatry, and a lower rate of attendances for geriatric medicine than people aged 65 and over before entry to PRAC (Figure 6.6).

In the 12 months after entry to PRAC, the average number of specialist attendances for neurology and geriatric medicine decreased for both age groups, and attendances for psychiatry increased, particularly for younger people aged under 65 at entry (psychiatry accounted for 37% of specialist attendances for people aged under 65 at entry and 29% of attendances for people aged 65 and over). These changes were likely to be related to a person's stage of disease, from assessment, diagnosis and care in the community to ongoing support and treatment within the PRAC setting.

Figure 6.6. Most common specialist types used by people with younger onset dementia in the 12 months before and after entry to PRAC, by age at entry to PRAC



Source: AIHW analysis of NIHSI AA v0.5, Table S6.7.

7 Prescriptions dispensed to people with younger onset dementia

This section provides information on prescription dispensing patterns over time for people living in the community with younger onset dementia, and in the 6 months before and after entering PRAC.

This analysis is restricted to prescriptions for medicines that were dispensed under the PBS/RPBS. Medicines are organised into Anatomical Therapeutic Chemical (ATC) classification groups according to the body system or organ on which they act. The PBS/RPBS does not include private prescriptions, medicines supplied to public hospital inpatients or over the counter medicines. The data provide information on drug types dispensed, but do not provide information about whether a person took the medicine as prescribed.

Patterns of dispensing over time while living in the community

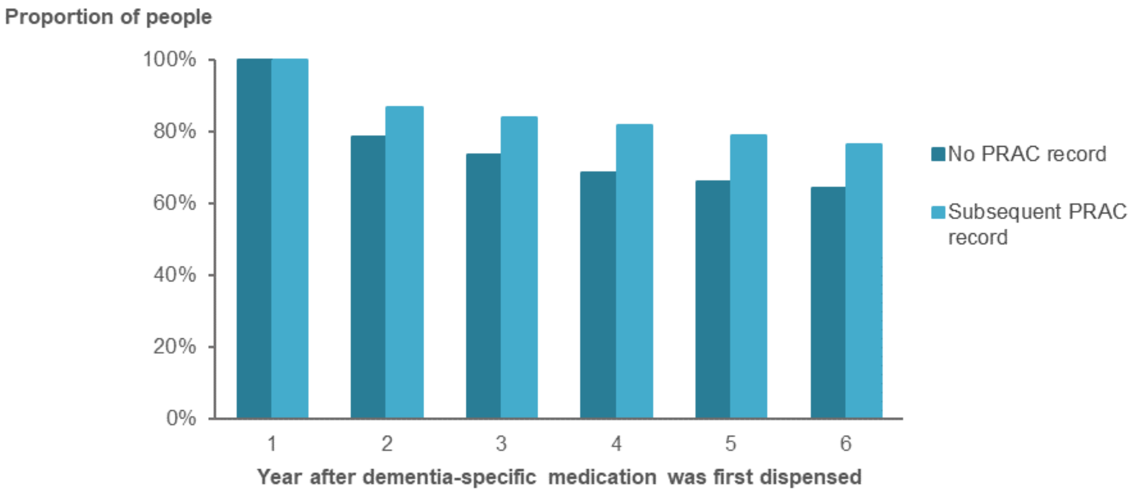
Prescribers of dementia-specific medications

Dementia-specific medications can be prescribed by GPs, other medical specialists and/or allied health professionals such as nurse practitioners (AIHW 2019a, 2021b). In this study cohort, people aged 30–64 and 65–69 whose first record of dispensed dementia-specific medication was in 2011 or 2012 were more likely to have had it prescribed by a specialist (78%) than by a GP (22%), while those whose first record was in 2010 had a different ratio (52% specialist and 48% GP) (Table S7.1). Overall, about 1 in 5 (21%) of first recorded scripts were prescribed by a specialist in geriatric medicine, 17% by neurology specialists and 14% by psychiatry specialists (Table S7.1).

Prescriptions dispensed for dementia-specific medications while living in the community

The proportion of people dispensed dementia-specific medications (excluding memantine) decreased over time, from 100% of the cohort at year 1 (due to the cohort definition), to 65% at year 6 (Table S7.2). This reduction was greater for people with no PRAC record (64% at year 6) than for people with a subsequent PRAC record (77% at year 6) (Figure 7.1). Data are not available on reasons for discontinuing treatment with dementia-specific medications, but it is usually due to a lack of clinical benefit or intolerance of side effects.

Figure 7.1: Proportion of people dispensed dementia-specific medication while living in the community, by study group and year after dementia-specific medication was first dispensed



Source: AIHW analysis of NIHSI AA v0.5, Table S7.2.

Note: Does not include memantine. Proportions were similar for 30–64 and 65–69 age groups.

The proportion of people dispensed memantine, which is approved for the treatment of moderately severe Alzheimer's disease (PBS 2022), increased for both groups, but more so for people with a subsequent PRAC record (from 2.8% at year 1 to 13% at year 6) than for people with no PRAC record (from 1.1% at year 1 to 5.2% at year 6) (Table S7.3).

Other common drug groups dispensed while living in the community

While living in the community, people in the study cohort were dispensed a median of 3–4 distinct medicines (identified at ATC level 4) per person each year (Table S7.4). Other than the dementia-specific medications, many of the most common drug groups dispensed to people with younger onset dementia (for example, lipid modifying agents and drugs for peptic ulcer and gastro-oesophageal reflux disease (GORD), Table 7.1) were similar to those used by all Australians of a similar age (Morgan et al. 2012).

However, for people with younger onset dementia (aged 30–69) living in the community, antidepressants were the most commonly dispensed drug group (identified by ATC level 3): 48% of people with no PRAC record and 47% of people with a subsequent PRAC record in the first year after dementia-specific medication, increasing to 50% and 63%, respectively, by the sixth year. These rates were substantially higher than those reported in a 2009–2010 national census of medicine use: 9.4% of people aged 50–64 and 7.8% of people aged 65–74 (Morgan et al. 2012). In addition:

- antipsychotics were dispensed to 16% of people with no PRAC record and 15% of people with a subsequent PRAC record in the first year, increasing to 22% and 37%, respectively, by the sixth year.
- opioids were more commonly dispensed to people with no PRAC record (20% in the first and sixth year) than to people with a subsequent PRAC record (12% in the first and 16% in the sixth year).

Table 7.1: Other common drug groups (ATC level 3) dispensed to people with younger onset dementia living in the community (aged 30–69), by study group and year since first dispensed dementia-specific medication

ATC code	Drug group	Proportion of people dispensed the drug			
		No PRAC record		Subsequent PRAC record	
		Year 1	Year 6	Year 1	Year 6
N06A	Antidepressants	48%	50%	47%	63%
C10A	Lipid modifying agents, plain	46%	48%	42%	39%
A02B	Drugs for peptic ulcer and GORD	34%	39%	25%	29%
J01C	Beta-lactam antibacterials, penicillins	29%	28%	20%	22%
N02B	Other analgesics & antipyretics	24%	23%	18%	20%
B01A	Antithrombotic agents	22%	22%	17%	19%
J01D	Other beta-lactam antibacterials	21%	21%	16%	21%
C09A	Angiotensin-Converting Enzyme inhibitors, plain	16%	15%	15%	18%
N05A	Antipsychotics	16%	22%	15%	37%
N02A	Opioids	20%	20%	12%	16%

Source: AIHW analysis of NIHSI AA v0.5, Table S7.5.

Note*:* Data for the 30–64 and 65–69 age groups are in Table S7.5.

Prescriptions dispensed before and after entry to permanent residential aged care

This section explores medicines dispensed to people with younger onset dementia who had a PRAC record, in the 6 months before and after entering PRAC. Entry to PRAC is often accompanied by an increase in medicine dispensing, particularly for medicines that act on the central nervous system (AIHW 2019b) – see Box 7.1 for more details.

Box 7.1: Selected medicines dispensed in residential aged care

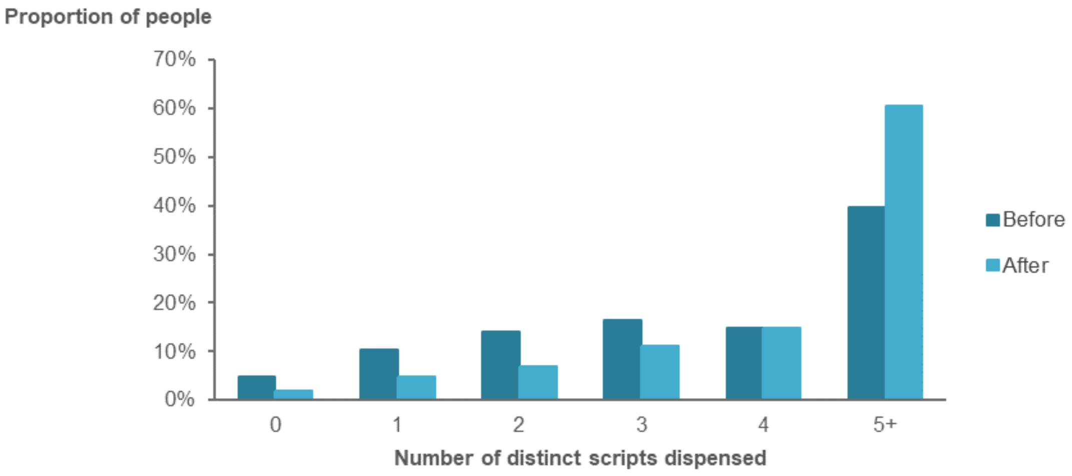
Medicines that act on the central nervous system are the most common type of prescription medicine used in PRAC (AIHW 2019b, 2020a), and they are used for various reasons. Selected medicines discussed in this section include:

- antidepressant medicines – used to treat symptoms of depression and anxiety, and some used to manage other mental health conditions
- antiepileptic medicines – used to control epileptic seizures, and some used for other purposes, such as mood stabilisers and tranquilisers
- antipsychotic medicines – used to manage the symptoms of certain mental health conditions, such as schizophrenia, and some used to manage the behavioural symptoms of dementia
- benzodiazepine medicines – used to manage the symptoms of certain mental health conditions, such as anxiety disorders, and to treat insomnia, seizures or muscles spasms
- opioid medicines – used to relieve pain and relax muscles; some may be used in palliative care.

While these medicines can be beneficial, they may also present a risk of harm through potential side effects and drug interactions (AIHW 2020b).

The median number of distinct medicines (identified at ATC level 4) dispensed to people with younger onset dementia increased slightly from 4 to 5 per person after entry to PRAC (Table S7.6). Polypharmacy is when people are using 5 or more medicines at the same time. Although polypharmacy may be appropriate, it can increase the risk of harm due to drug interactions or mistakes in taking the medicines (ACSQHC 2021). After entry to PRAC, the proportion of people with younger onset dementia dispensed 5 or more distinct medicines increased from 40% to 61% (Figure 7.2).

Figure 7.2: Frequency of distinct medicines (ATC level 4) dispensed to people with younger onset dementia in the 6 months before and after entry to PRAC



Source: AIHW analysis of NIHSI AA v0.5, Table S7.7.

Note*:* To be counted, a medicine must have had 2 or more prescriptions dispensed for it in the 6-month period. Medicines were counted as distinct if the ATC codes differed at the fourth level.

Most common drug groups dispensed before and after entry to permanent residential aged care

This section shows data for people aged under 65 at the time of entry to PRAC; people aged 65 and over had similar dispensing patterns and their data are in Supplementary Table S7.8.

The proportion of people aged 30–64 who were dispensed anti-dementia medication (including memantine) decreased in the 6 months after entering PRAC, from 76% to 60%. In the 6 months after entry to PRAC, there was an increase in the proportion of people dispensed other drugs acting on the central nervous system (Table 7.2), for example:

- dispensing of antipsychotic medicines increased from 44% to 63%
- dispensing of benzodiazepine medicines increased from 24% to 47%
- dispensing of antiepileptic medicines increased from 18% to 31%.

Table 7.2: Selected drug groups (ATC level 3) dispensed to people with younger onset dementia aged 30–64 at entry to PRAC, in the 6 months before and after entry to PRAC

		Proportion of people dispensed the drug	
ATC code	**Drug group**	**Before entry to PRAC**	**After entry to PRAC**
	Drugs acting on the central nervous system		
N05A	Antipsychotics	44%	63%
N06A	Antidepressants	56%	62%
N06D	Anti-dementia (includes memantine)	76%	60%
N02B	Other analgesics and antipyretics	18%	57%
N05BA, N05CD, N05CF	Benzodiazepines	24%	47%
N05B	Anxiolytics	17%	33%
N03A	Antiepileptics	18%	31%
N02A	Opioids	7.7%	22%
	Other common drug groups		
C10A	Lipid modifying agents, plain	28%	24%
J01C, J01D	Beta-lactam antibacterials	27%	43%
A06A	Drugs for constipation	12%	39%

Source: AIHW analysis of NIHSI AA v0.5, Table S7.8.

New dispensing of selected medicines after entry to permanent residential aged care

To further examine prescribing practices in the period after entry to PRAC, new users of selected medicines were identified (see Technical Document for details). To be counted as a ‘new user’ of a selected medicine, a person must not have had any scripts dispensed in the 24 months before entry to PRAC, and had at least 2 scripts dispensed in the 6 months after entry. This focused the analysis on people who were more likely to have used the medication rather than those who had a script dispensed in case they needed it. The median length of time between entry to PRAC and dispensing of these medicines was calculated, as this may indicate whether there was sufficient time to trial non-pharmacological approaches to care.

In the 6 months after entry to PRAC (Table 7.3):

- 28% of people dispensed a script for antipsychotic medicines were new users, with a median of 29 days between entry to PRAC and new dispensing (interquartile range (IQR) of 7 to 65 days)
- 34% of people dispensed a script for benzodiazepine medicines were new users, with a median of 20 days between entry to RAC and new dispensing (IQR of 6 to 50 days)
- 46% of people dispensed a script for opioid medicines were new users, with a median of 62 days between entry to RAC and new dispensing (IQR of 21 to 118 days).

Most new users were ‘repeat new users’ – that is, they were dispensed 2 or more scripts of the selected medicine – including 83% of people dispensed antipsychotic medicines and 70% of people dispensed benzodiazepine medicines (Table S7.9).

Table 7.3: Proportion of people with younger onset dementia dispensed selected medicines in the 6 months after entry to PRAC who were new users with repeat scripts, and median number of days from PRAC entry to newly dispensed script

Drug group	Total users (no.)	Repeat new users (no.)	Proportion of total users who were repeat new users (%)	Days from PRAC entry to first script (repeat users)	
				Median	Interquartile range
Antidepressants	1,100	148	13%	54	17 to 100
Anti-Parkinsons	202	17	8.4%	30	9 to 98
Antipsychotics	1,113	307	28%	29	7 to 65
Benzodiazepines	775	260	34%	20	6 to 50
Opioids	464	212	46%	62	21 to 118

Source: AIHW analysis of NIHSI AA v0.5, Table S7.9.

Note: ‘Repeat new users’ had at least 2 scripts dispensed in the 6 months after entry and zero scripts dispensed in the 24 months before entry to PRAC.

8 Hospital services

This chapter provides information on emergency department presentations and hospital stays of people with younger onset dementia who:

- lived in any of the 4 states (New South Wales, Victoria, South Australia and Tasmania) when their dementia-specific medication was first dispensed
- attended a public hospital in any of these 4 states.

See the Technical Document for more information about the analysis methods.

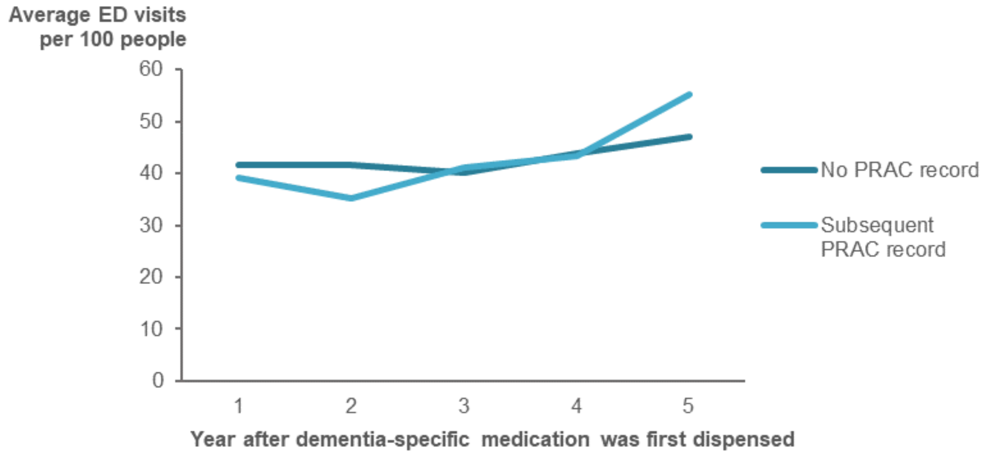
Use of hospital services while living in the community

About 3,600 (69%) of the people with younger onset dementia in the study cohort lived in New South Wales, Victoria, South Australia or Tasmania when their dementia-specific medication was first dispensed. A similar proportion of both study groups lived in these states: 70% of people with no PRAC record and 68% of people with a subsequent PRAC record.

Emergency department presentations

An ED presentation is when a patient arrives at the emergency department and is registered clerically, or triaged. While living in the community, about one-quarter of people in both study groups had at least one ED presentation in each year after their first dispensed dementia-specific medication (Table S8.1). The rate of ED presentations per year increased slightly over time for both study groups: from 42 to 47 per 100 people with no PRAC record, and from 39 to 55 per 100 people with a subsequent PRAC record (Figure 8.1). People in the 65–69 age group had a similar pattern but slightly higher number of ED presentations than people in the 30–64 age group (Table S8.2).

Figure 8.1: Average rate of ED visits by people with younger onset dementia while living in the community, by study group and year after dementia-specific medication was first dispensed

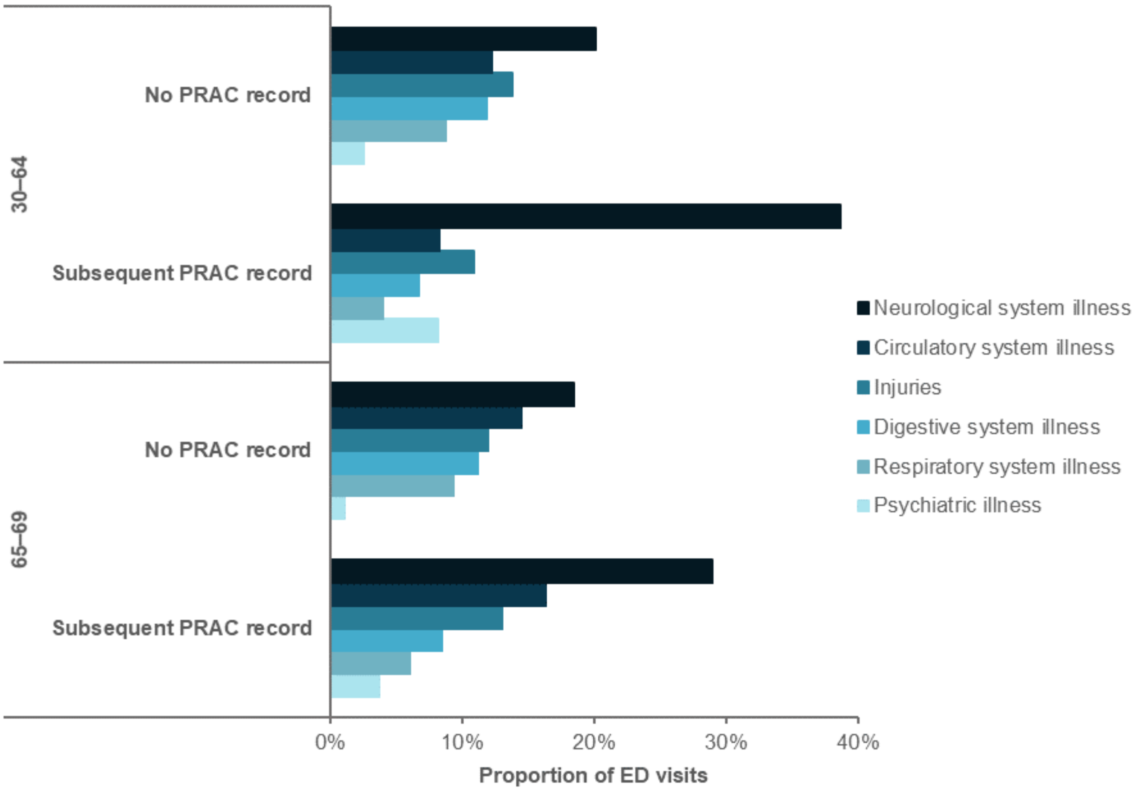


Source: AIHW analysis of NIHSI AA v0.5, Table S8.2.

There are known gaps in the completeness of ED data relating to dementia (AIHW 2020c), and specific codes for presenting problems or principal diagnoses were not available for this analysis. The major diagnostic block category (AIHW 2018a) was the most complete field available for exploring the reasons for ED presentation, and data were combined for the years 2013–14 to 2016–17.

The most common reason for ED presentation for both study groups was *Neurological system illness*, accounting for 1 in 3 visits (33%) for people with a subsequent PRAC record and 1 in 5 visits (19%) for people with no PRAC record (Table S8.3). Younger people (aged 30–64) with a subsequent PRAC record were the most likely to have an ED visit for *Neurological system illness* (39% of visits) or *Psychiatric illness* (8.1%) (Figure 8.2).

Figure 8.2: Most common reasons for ED presentation by people with younger onset dementia while living in the community, by age at first dispensed dementia-specific medication and study group, 2013–14 to 2016–17

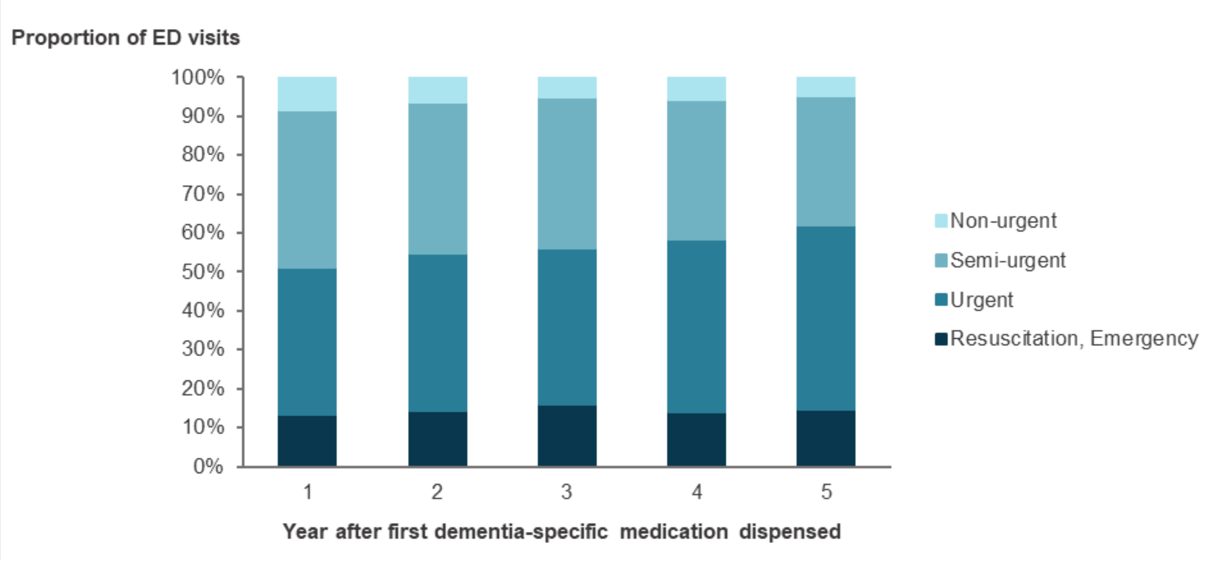


Source: AIHW analysis of NIHSI AA v0.5, Table S8.3.

When a patient presents to the ED, they are allocated a triage category to indicate the urgency of the patient’s need for medical and nursing care. In the first year after dementia-specific medications were dispensed, half (51%) of ED presentations by people with younger onset dementia were assigned to the more urgent triage categories (13% *Resuscitation* or *Emergency* and 38% *Urgent*), and half to the less urgent categories (41% *Semi-urgent* and 8% *Non-urgent)* (Figure 8.3). Over time, the proportion of visits assigned to the more urgent triage categories increased – by the fifth year, 62% were assigned *Resuscitation, Emergency* or *Urgent*, and 38% of visits were *Semi-urgent* or *Non-urgent*.

This pattern was more pronounced for people with no PRAC record than for people with a subsequent PRAC record; data broken down by study group, sex and age group are available in Supplementary Table S8.4.

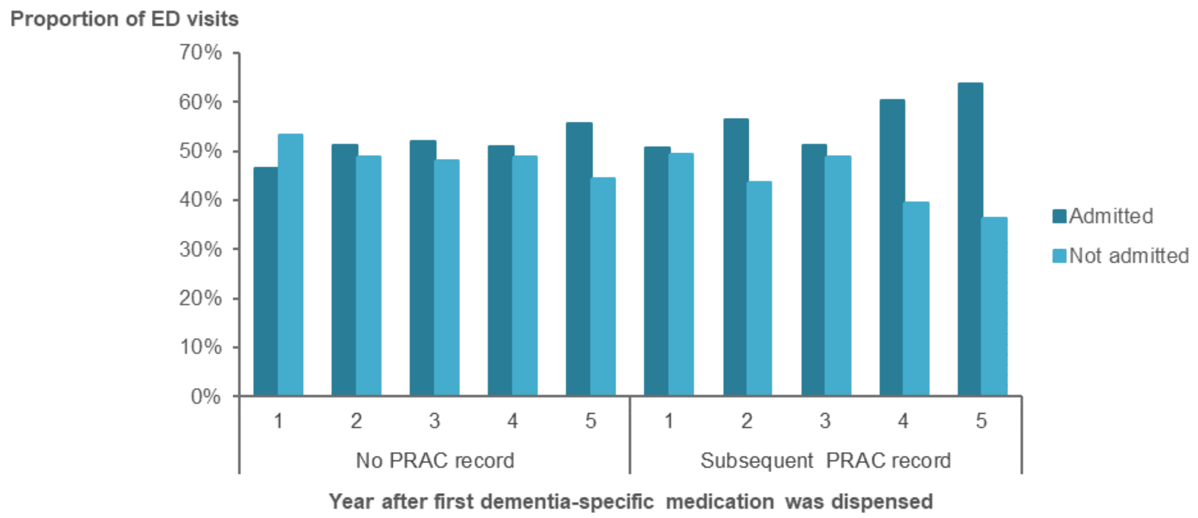
Figure 8.3: Triage category of ED presentations by people with younger onset dementia while living in the community, by year after dementia-specific medication was first dispensed



Source: AIHW analysis of NIHSI AA v0.5, Table S8.4.

About one-third of ED presentations to public hospitals in Australia end with admission to hospital for further care (AIHW 2020d). The rate of admission to hospital after an ED presentation was higher for people with younger onset dementia: in the first year after dementia-specific medications were dispensed, nearly half of ED presentations ended with the person being admitted to hospital (47% for people with no PRAC record and 51% for people with a subsequent PRAC record) (Figure 8.4). By the fifth year, the proportion of ED visits ending in admission increased to 56% for people with no PRAC record and 64% for people with a subsequent PRAC record. Data broken down by sex and age group are available in Supplementary Table S8.5.

Figure 8.4: Admission status of ED presentations by people with younger onset dementia while living in the community, by study group and year after dementia-specific medication was first dispensed



Source: AIHW analysis of NIHSI AA v0.5, Table S8.5.

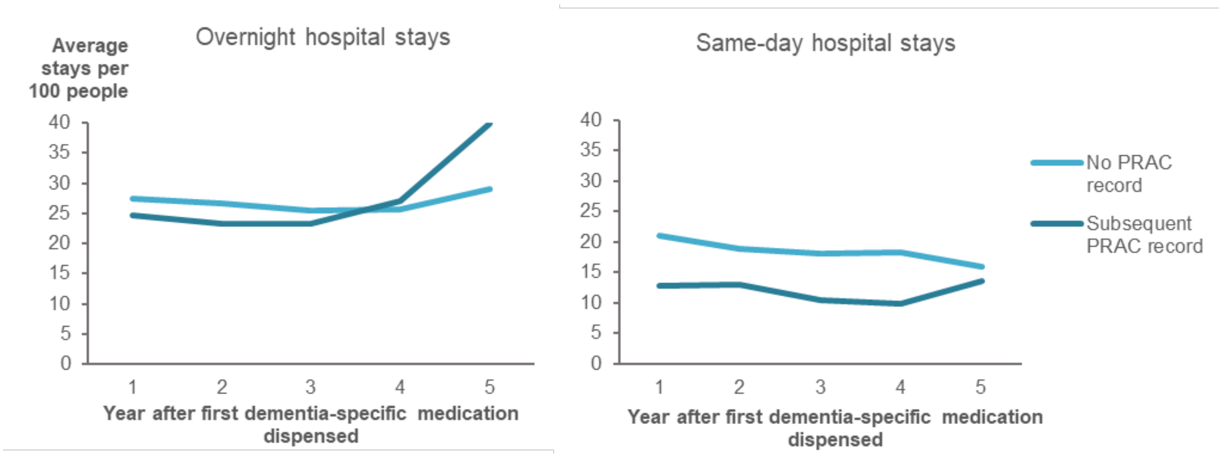
Hospital stays

Hospital episodes can be same-day (meaning that the person entered and left hospital on the same day) or overnight (meaning that the person spent at least one night in hospital), and a same-day hospital episode can be followed by a related overnight episode (AIHW 2020f). Hospital episodes that were determined to relate to the same broader period of hospital use were combined into a 'hospital stay' (AIHW 2020f) – see the Technical Document for more information.

While living in the community, about a quarter of people in both study groups had at least one hospital stay each year after their first dispensed dementia-specific medication (Table S8.1).

For the first 4 years after dispensing, the rate of overnight hospital stays was similar for both groups (about 23–27 per 100 people each year), increasing to 40 per 100 people in year 5 for people with a subsequent PRAC record (Figure 8.5). The difference in the rate of same-day hospital stays was slightly larger, with 16–21 per 100 people per year for people with no PRAC record, and 10–13 per 100 people per year for people with a subsequent PRAC record (Figure 8.5). Data broken down by sex and age group are available in Supplementary Table S8.6.

Figure 8.5: Average number of overnight and same-day hospital stays per 100 people with younger onset dementia living in the community, by study group and year after dementia-specific medication was first dispensed



Source: AIHW analysis of NIHSI AA v0.5, Table S8.6.

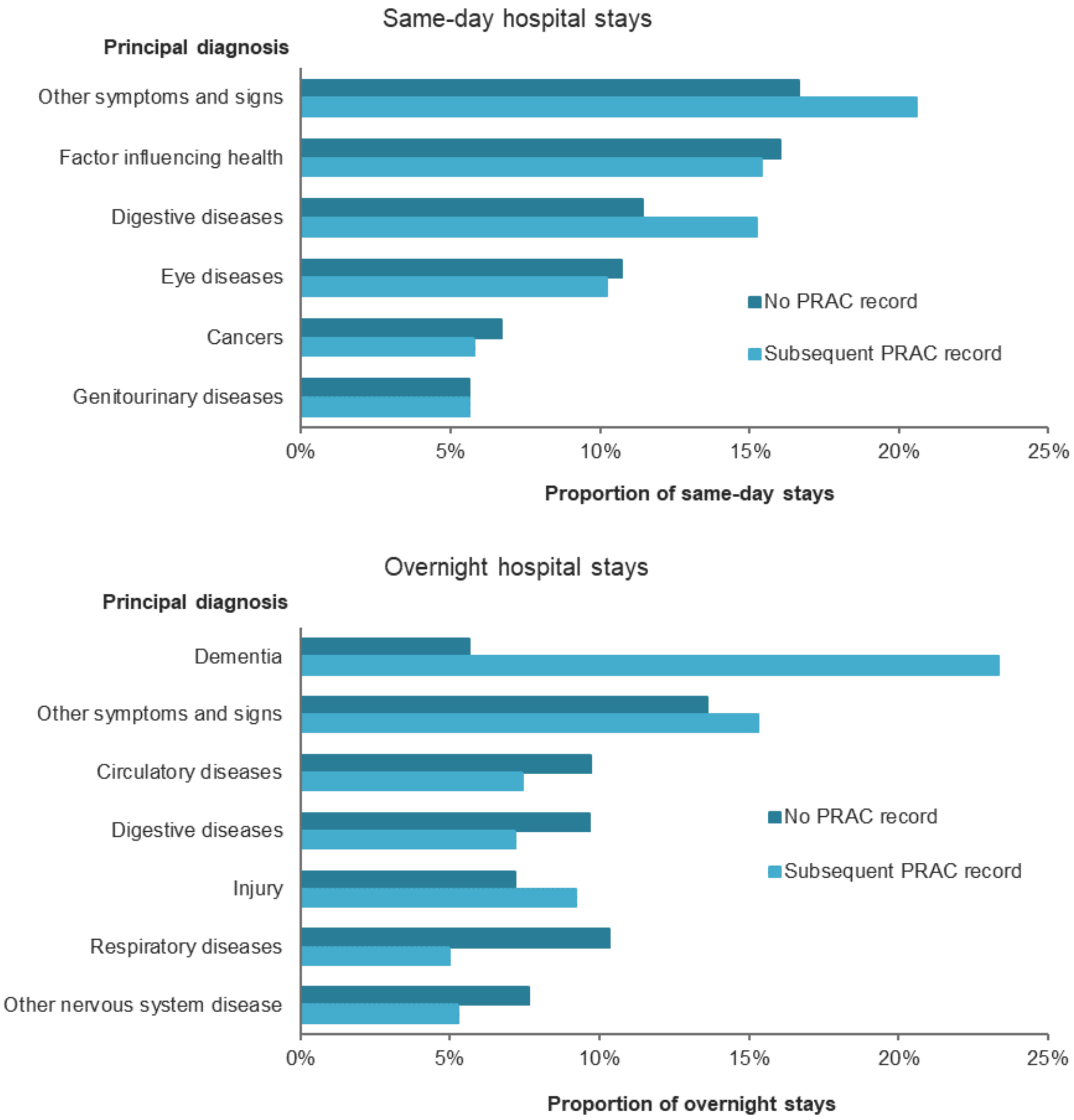
Note*:* Excludes admissions for dialysis (ICD-10-AM ‘Z49’).

The principal diagnosis is defined as the diagnosis established after study to be chiefly responsible for occasioning an episode of admitted patient care (AIHW 2019b). These can be grouped with other similar diagnoses. The reasons for hospitalisation for people with younger onset dementia tend to be different from those for older people with dementia, due to the lower likelihood of age-related comorbidities.

No specific diagnosis accounted for the higher rate of same-day hospital stays for people with no PRAC record. The most common specific principal diagnosis for same-day hospital stays (excluding dialysis) for both groups was cataracts (Table S8.7). The most common principal diagnosis groups were *Other symptoms and signs* (such as fainting and collapse or chest pain) and *Factors influencing health status* (such as waiting for admission to RAC, rehabilitation care, investigations and procedures) (Figure 8.6).

Other symptoms and signs was also the most common reason for overnight hospital stays, followed by dementia diagnoses, which accounted for 23% of stays for people with a subsequent PRAC record (31% for people aged 30–64 at first dispensed dementia-specific medication, 19% for those aged 65–69) and 5.7% of stays for people with no PRAC record (Figure 8.6). Parkinson’s disease was a common specific principal diagnosis for people with a subsequent PRAC record, and pneumonia for people with no PRAC record (Table S8.8). Data broken down by age group are available in supplementary tables S8.7 and S8.8.

Figure 8.6: Most common reasons for same-day and overnight hospital stays of people with younger onset dementia living in the community, by principal diagnosis group and study group

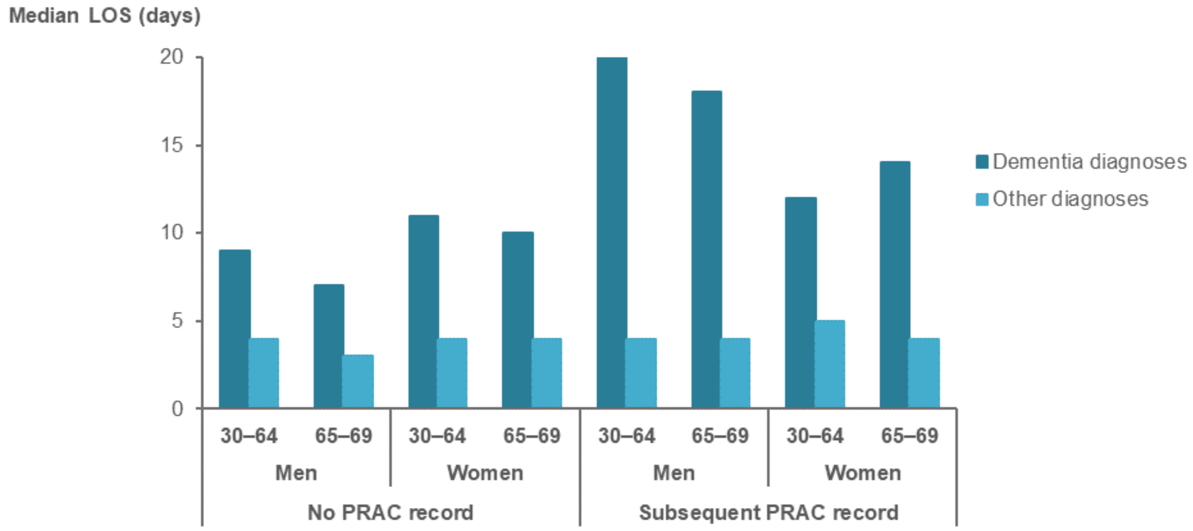


Source: AIHW analysis of NIHSI AA v0.5, Tables S8.7, S8.8.

Note: Excludes admissions for dialysis (ICD-10-AM ‘Z49’). ‘Other nervous system disease’ is labelled ‘Nervous system disease, excluding dementia’ in Table S8.8.

The median length of a hospital stay was 3 to 5 days for people with a principal diagnosis other than dementia (Table S8.9). The median length of stay for people with a principal diagnosis of dementia was longer, between 7 and 20 days, depending on age group and sex (Figure 8.7).

Figure 8.7: Median length of overnight hospital stay (days) for people with younger onset dementia living in the community, by diagnosis group, study group, sex and age at first dispensed dementia-specific medication



Source: AIHW analysis of NIHSI AA v0.5, Table S8.9.

Note: LOS = length of stay

Hospital stays ending with discharge to residential aged care

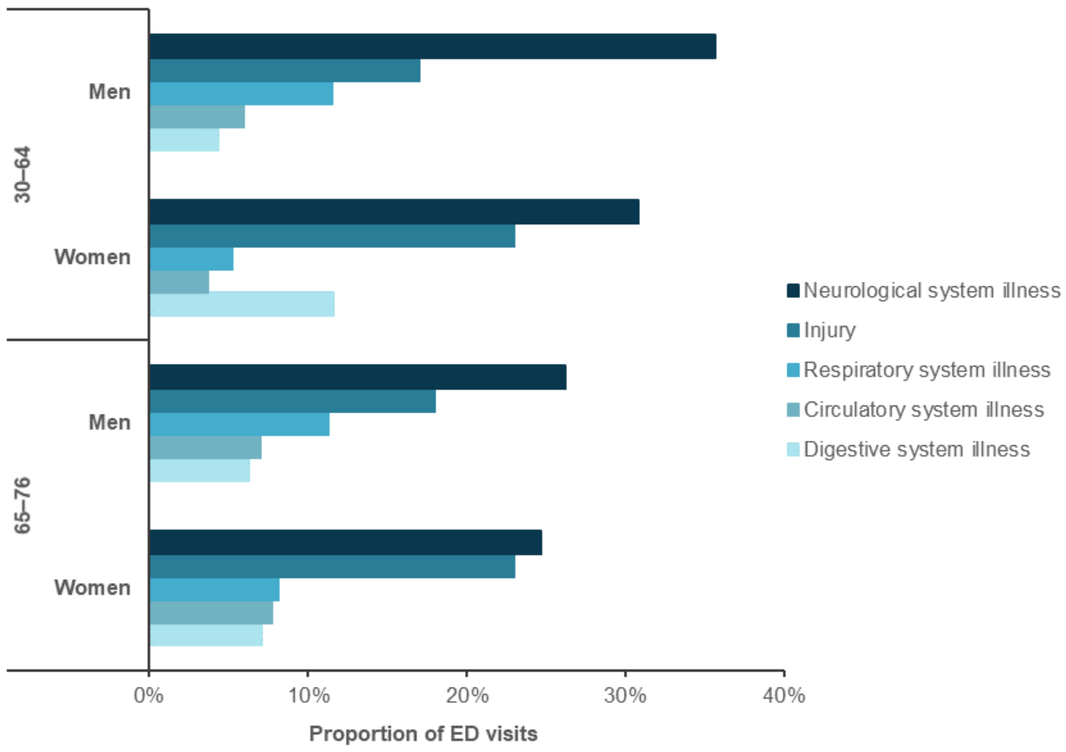
About 1 in 5 overnight hospital stays (21%) for people with a subsequent PRAC record ended with the patient being discharged or transferred to a RAC service that was not the usual place of residence (Table S8.10). Over half of these stays were for men (55%), and 22% of people were aged under 65 at the time of their entry to RAC. Dementia was the most common principal diagnosis of the initial hospital stay prior to discharge to RAC, accounting for 52% of stays for people aged 30–64, and 46% of those aged 65 and over (Table S8.11). The next most common principal diagnoses for all ages were *Injury* (9.3%) and *Other symptoms and signs* (8.7%).

Hospital service use after entry to permanent residential aged care

This section explores ED presentations and hospital stays of people with younger onset dementia while they were living in PRAC.

While people with younger onset dementia were living in PRAC, the most common reason for having an ED presentation was *Neurological system illness* (Figure 8.8), with higher rates in people who were aged under 65 at entry to PRAC (33% of visits), compared with 25% of visits by people aged 65 and over (Table S8.12). ED presentations for *Injury* accounted for 20–21% of visits across both age groups and were more common while living in PRAC than while living in the community (12–13% of visits, Table S8.3).

Figure 8.8: Most common reasons for ED presentation by people with younger onset dementia while living in PRAC, by sex and age at entry to PRAC

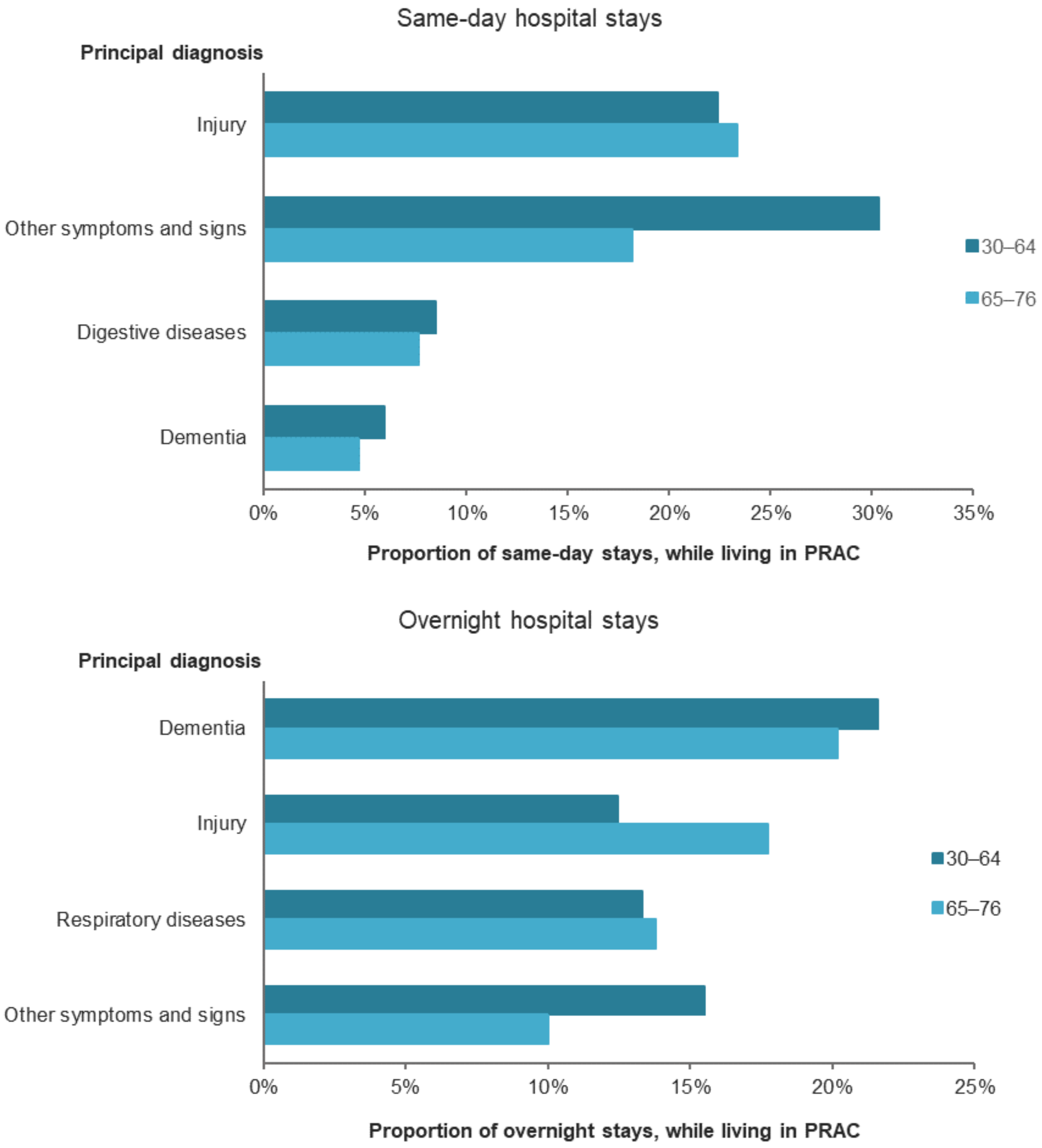


Source: AIHW analysis of NIHSI AA v0.5, Table S8.12.

Injuries were the most common reason for same-day hospital stays for people with younger onset dementia while living in PRAC (23%) followed by other symptoms and signs (22%, mostly convulsions or fainting and collapse) (Figure 8.9; Table S8.13).

The most common reason for overnight hospital stays while living in PRAC was dementia (21%), followed by injuries (16%) (Figure 8.9; Table S8.14). Women were more likely to have hospital stays for injuries (20% of overnight stays) than men (13%).

Figure 8.9: Most common reasons for same-day and overnight hospital stays by people with younger onset dementia while living in PRAC, by age at entry to PRAC



Source: AIHW analysis of NIHSI AA v0.5, tables S8.13, S8.14.

9 Residential aged care services

Declining cognitive function and increasing physical care requirements are common triggers for a person with younger onset dementia to need supported accommodation services. In the absence of age-appropriate options, people may need to enter residential aged care. This is a time of significant change in a person’s life, associated with higher care needs, a new environment and different carers, and a change in the use of health services (AIHW 2020a).

This chapter explores patterns of respite RAC and permanent RAC use by people in the younger onset dementia cohort, and presents ACFI data on health conditions and care needs of people in permanent RAC.

A small number of people (325) had a respite or permanent RAC episode before their first record of dispensed dementia-specific medication (see Table S9.1 for more details). These people were excluded from analyses looking at the time from first dispensed dementia-specific medication to RAC entry.

Respite residential aged care

The Australian Government subsidises community-based and residential respite care with the aim of providing a person and their carer with a break from their usual care arrangements, or during emergencies. Respite care is especially important for people caring for someone with dementia, where the demands of the caring role may involve providing substantial amounts of physical, psychological, cognitive and social support, while behaviour changes may add to the complexity of caring.

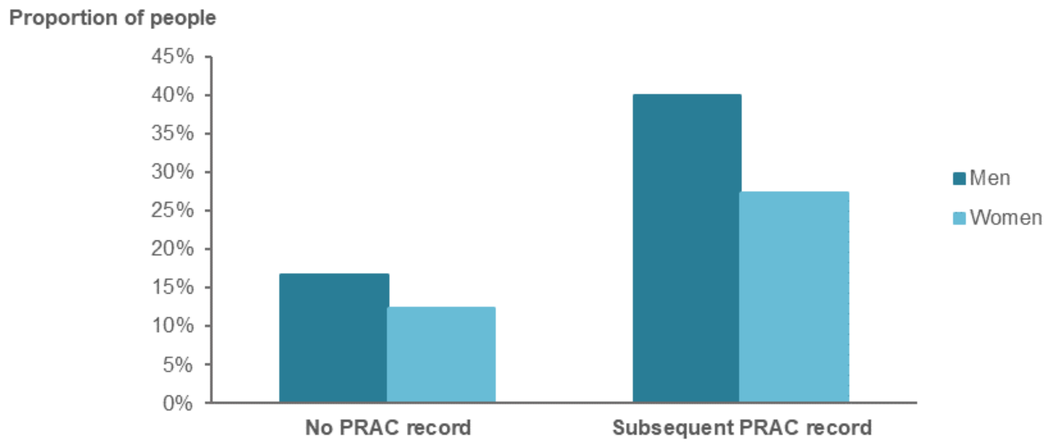
People often use respite RAC before entering PRAC. Respite care can be short, regular and planned episodes, but may also be unplanned (suggesting a person’s health, or their carer’s, has suddenly deteriorated) or used by people trying out or waiting for a permanent placement (AIHW 2020a). For instance, 35% of PRAC stays in this study cohort started as a respite RAC stay (Table S9.2).

People who use respite RAC are not appraised using the ACFI, so their dementia status cannot be determined using the currently available data. The use of linked data allows new analysis of the use of respite RAC services by people with younger onset dementia.

Men are more likely than women to access respite residential aged care

A total of 1,312 people with younger onset dementia (25%) used respite RAC between 2011 and 2017: 24% of the 30–64 age group (574 people) and 26% of the 65–69 age group (738 people) (Table S9.3). Men (29%) were more likely than women (21%) to access respite RAC. This was particularly so among those with a subsequent PRAC record (40% of men compared with 27% of women) (Figure 9.1).

Figure 9.1: Proportion of people with younger onset dementia accessing respite RAC, by study group and sex



Source: AIHW analysis of NIHSI AA v0.5, Table S9.3.

About one-quarter of men (26%) and 28% of women with a subsequent PRAC record were aged under 65 when they first used respite RAC (Table S9.4). Of those with no PRAC record, 21% of men and 32% of women were aged under 65 when they first used respite RAC.

Characteristics of respite stays

A relatively small proportion of people with no PRAC record accessed respite RAC (15%). Of these, half (51%) had only one respite RAC stay, while 18% had 4 or more respite RAC stays during the study period (Table S9.5). One in 10 people (11%) had their first respite RAC stay within a year of their first dispensed dementia-specific medication, and 38% within 3 years (Table S9.6).

About one-third (33%) of people with a subsequent PRAC record had a separate respite RAC stay prior to entry to PRAC. Half (52%) had only one respite RAC stay, and 15% had 4 or more respite RAC stays during the study period (Table S9.5). One in 5 people (20%) had their first respite RAC stay within a year of their first dispensed dementia-specific medication, and 65% within 3 years (Table S9.6).

For people with a subsequent PRAC record, the majority of men and women (92%) who used respite RAC had entered PRAC within 2 years of their first respite RAC episode (Table S9.7).

Permanent residential aged care

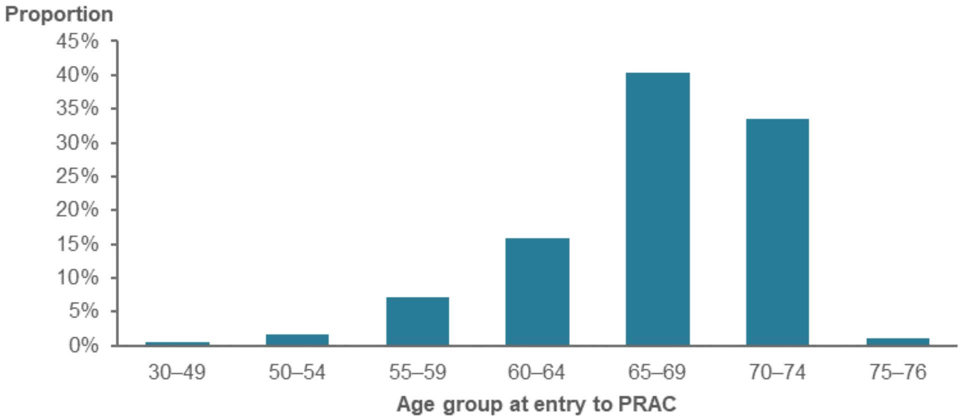
The following section relates to the 2,997 people in the 'subsequent PRAC record' study group and their use of PRAC services. As such, for ease of reading, the word 'subsequent' is not used in this section.

Due to the length of the study period (2011 to 2017), a person who was first dispensed dementia-specific medication in 2011 at the age of 69 could be 76 years old in 2017, so in this section, the upper age for analysis is 76.

Age at first entry

Of those in the study cohort with a PRAC record, one-quarter (25%, about 750 people) were aged 30–64 at the time of first entry. The majority of people (75%, 2,245 people) were aged 65–76 at the first time of entry (Figure 9.2).

Figure 9.2: Age at first entry to PRAC for people with younger onset dementia



Source: AIHW analysis of NIHSI AA v0.5, Table S9.8.

Note: The age of people entering PRAC is influenced by the length of the study period (2011 to 2017). For example, a person who was first dispensed dementia-specific medication in 2011 at the age of 64 could be 70 years old upon entering PRAC in 2017.

About 1 in 10 people (11%) had their first PRAC stay within one year of the first dispensed dementia-specific medication, and nearly half (49%, cumulative) were within 3 years (Table 9.2). There was little difference between sex and age groups (Table S9.9).

Table 9.2: Time from first dispensed dementia-specific medication to first PRAC episode

Years after first dispensed dementia-specific medication	No. people with first PRAC stay	Cumulative %
1	308	11%
2	461	29%
3	538	49%
4	549	69%
5	422	85%
6	278	95%
7	129	100%

Source: AIHW analysis of NIHSI AA v0.5, Table S9.9.

Note: The analysis did not include people who had a RAC stay before the first dispensed dementia-specific medication.

Length of stay

Various factors affect how long a person spends in PRAC, and a person may have more than one episode of care. 'Separations' from care are usually due to death, prolonged hospital admission or a transfer to a different facility. In this study, episodes have been merged where possible to present a more accurate picture of length of stay (see the Technical Document for more details).

One in 3 stays (33%; 41% of women and 24% of men) did not have a discharge code, which means that the person was still living in PRAC at the end of the study period (December 2017) (Table S9.10a).

Of the stays with a discharge code, the most common reason for discharge was death (83% of stays), followed by going to hospital (5.5%) and moving to another RAC facility (5.5%) (Table S9.10b).

For those stays with a discharge code of death, the median length of stay was 6 months longer for women (2.0 years) than for men (1.5 years) (Table 9.3). Younger men (aged 30–64 at entry to PRAC) had a longer median length of stay until death (2.0 years) than older men (1.4 years). There was less difference between age groups for women.

For stays that had not ended by December 2017, the median length of stay was longer for younger people (3.4 years) than for older people (2.3 years) (Table 9.3).

Table 9.3: Median length of stay (years) in PRAC, by discharge status, sex and age at entry to PRAC

	Age at entry to PRAC		
	30–64	**65–76**	**Total 30–76**
Stays with a discharge code of death			
Women	1.9	2.1	2.0
Men	2.0	1.4	1.5
Persons	2.0	1.8	1.8
Stays without a discharge code at end 2017			
Women	3.5	2.4	2.6
Men	3.0	2.2	2.3
Persons	3.4	2.3	2.5

Source: AIHW analysis of NIHSI AA v0.5, Table S9.11.

Notes

1. The analysis did not include people who had a RAC stay before the first dispensed dementia-specific medication.
2. The age of people entering PRAC is influenced by the length of the study period (2011 to 2017). For example, a person who was first dispensed dementia-specific medication in 2011 at the age of 64 could be 70 years old upon entering PRAC in 2017.

Health conditions and changes in care needs

The ACFI is used to allocate government funding to aged care providers based on the day-to-day needs of the people in their care. The ACFI data capture up to 3 behavioural or mental conditions, and up to 3 medical conditions affecting care, which are also considered when determining the level of funding required.

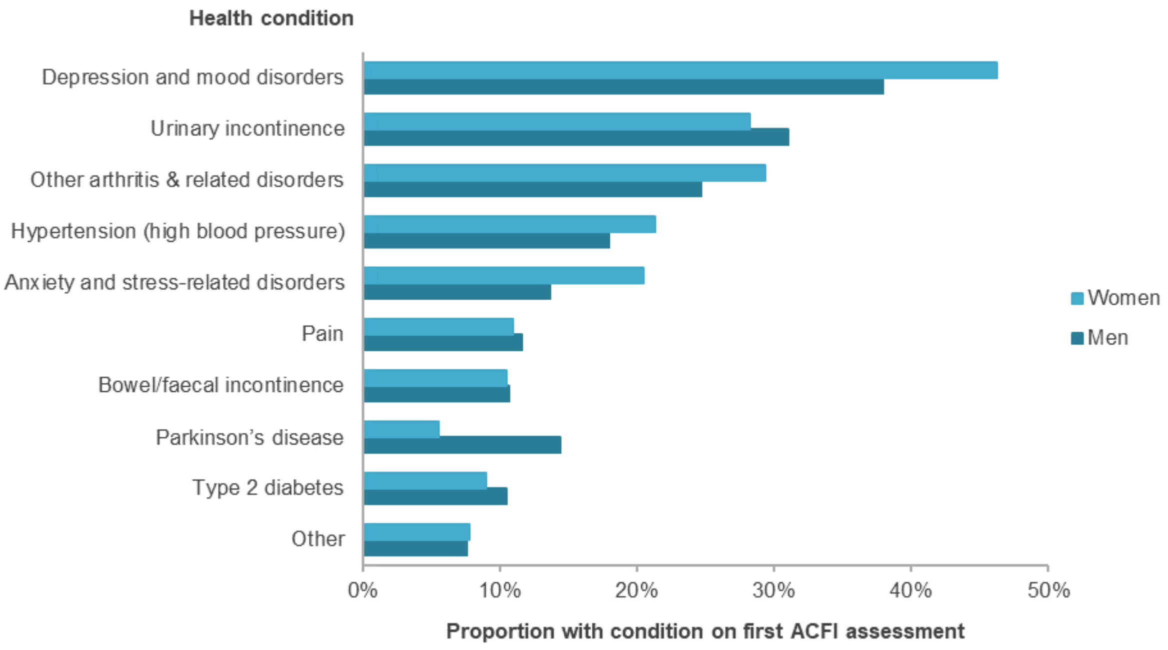
Although the ACFI is a funding instrument and not a diagnosis or comprehensive service tool, it does collect information on the assessed care needs of people in PRAC at the time of their appraisal. It is important to bear in mind that in some instances, not all services received will be captured in the ACFI assessment. An ACFI reappraisal can be conducted for various reasons, such as when a person has a significant change in care needs or after 12 months from when their classification has taken effect.

Almost everyone (99%) with a PRAC record had an ACFI assessment record for their first PRAC episode. The majority of these had dementia recorded (96% of 2,980 people), with little variation by sex or age group at entry to PRAC (Table S9.12).

Common health conditions

After dementia, depression and mood disorders were the most common conditions recorded on the ACFI for people with younger onset dementia (42% of people entering PRAC) (Table S9.13). Women were more likely to have depression and mood disorders recorded than men (46% compared with 38%), as well as anxiety and stress-related disorders (21% of women, 14% of men). Men were more likely to have Parkinson's disease recorded (14%) than women (5.5%) (Figure 9.3). Incontinence was a common condition recorded for all groups. Chronic conditions such as arthritic disorders and hypertension were more commonly recorded in people aged 65 and over than they were for people aged under 65 at the time of entry to PRAC (Table S9.13).

Figure 9.3: Common health conditions (other than dementia) recorded in an ACFI assessment of care needs for people with younger onset dementia living in PRAC, by sex



Source: AIHW analysis of NIHSI AA v0.5, Table S9.13.

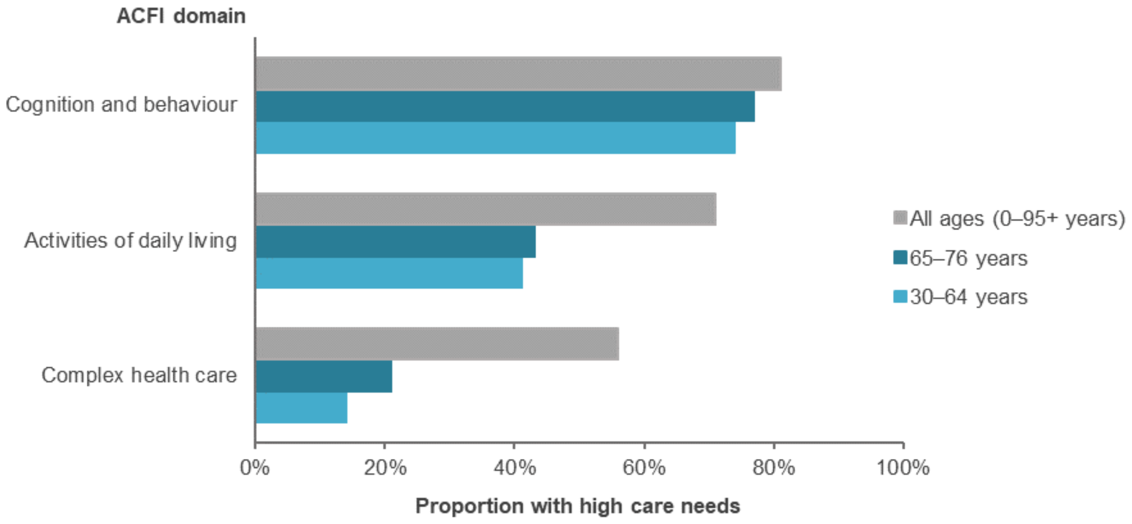
Level of assistance needs

As the ACFI is used to allocate funding, it captures the day-to-day care needs that contribute most to the cost of providing individual care. Care needs are categorised as ‘nil’, ‘low’, ‘medium’, or ‘high’ based on responses to 12 questions across 3 domains: *Activities of daily living*, *Cognition and behaviour* and *Complex health care*. People with high care ratings in a domain have more severe needs and require extensive assistance and care in that domain, whereas those with a low care rating have less severe needs (AIHW 2021b).

At their first ACFI assessment, 83% of people with younger onset dementia living in PRAC were assessed as needing high levels of care in at least one of the 3 ACFI domains, most commonly in the *Cognition and behaviour* domain (Figure 9.4):

- 76% required high levels of care in the *Cognition and behaviour* domain (including cognitive skills, wandering, verbal behaviour, physical behaviour and depression); this was similar to people with dementia of all ages (81%, AIHW 2021b)
- 43% required high levels of care in the *Activities of daily living* domain, compared with 71% of people with dementia of all ages (AIHW 2021b)
- 19% required high levels of care in the *Complex health care* domain, compared with 56% of people with dementia of all ages (AIHW 2021b). A smaller proportion of people aged under 65 (14%) required high levels of care in this domain than people aged 65–76 (21%).
- Men were more likely to require high levels of care than women in each domain, particularly for *Complex health care* (23% of men, 17% of women) (Table S9.14).

Figure 9.4: Proportion of people with younger onset dementia assessed with high care needs, by ACFI domain and age group at entry to PRAC



Sources: AIHW analysis of NIHSI AA v0.5, Table S9.14. All ages data (0–95+ years) are taken from *Dementia in Australia* (AIHW 2021b).

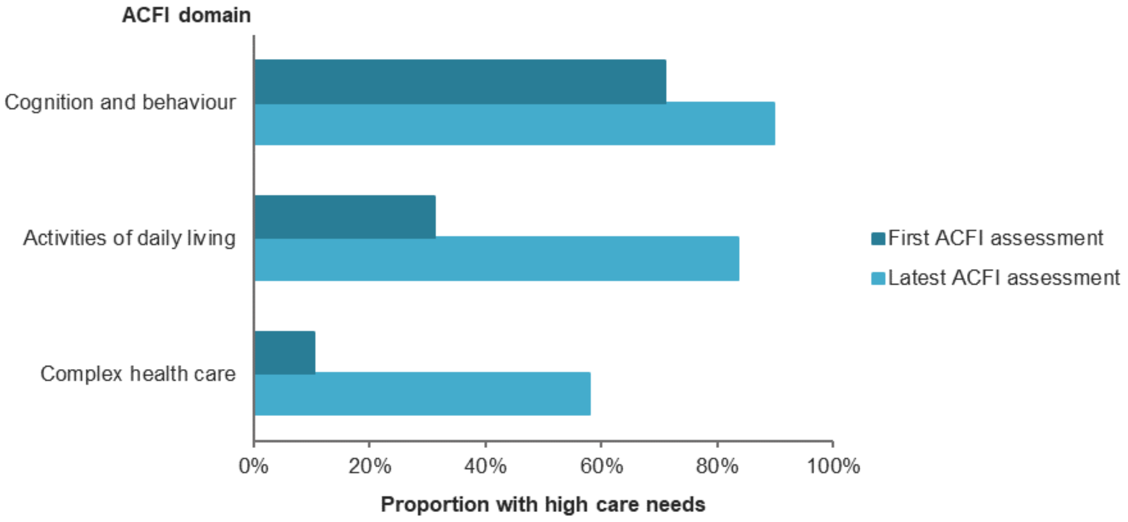
As part of the *Complex health care* domain, the ACFI records information on ongoing pain management services provided. About 1 in 3 people (30%) with younger onset dementia required complex pain management at least weekly (Table S9.15).

Changes in care needs over time

The care needs of people with younger onset dementia living in PRAC increased over time. The following data compare the proportion of people with high care needs at the time of their first and latest ACFI assessment (for people with more than one assessment). The median number of years between the first and latest assessment was 2 years, and 92% of people had their first and latest assessments within 4 years of each other (Table S9.16).

For people with more than one assessment, the proportion of people with high care needs increased from the first to the latest ACFI assessment in all 3 domains: *Cognition and behaviour* remained high (71% to 90%), with larger increases for *Activities of daily living* (31% to 84%) and *Complex health care* (11% to 58%) (Figure 9.5).

Figure 9.5: Change in the proportion of people with younger onset dementia with high care needs, by first and latest ACFI assessment and ACFI domain



Source: AIHW analysis of NIHSI AA v0.5, Table S9.17.

10 Causes of death

Dementia is a degenerative condition that leads to reduced life expectancy. However, time from diagnosis to death is highly variable. Survival time is affected by age, sex, dementia type and severity at diagnosis, among other factors (Brodaty et al. 2012; Sansoni et al. 2016). In addition, dementia is not always the direct cause of death as the condition often impairs a person's physical health and their ability to cope with other diseases.

About 2 in 5 people (42%) in the younger onset dementia cohort had died within the 5–6 year study period (Supplementary tables S10.1, S10.2):

- 38% of women and 47% of men died
- 38% of people in the 30–64 age group (at first dispensed dementia-specific medication) and 45% of people in the 65–69 age group died
- of those who died, 19% were aged under 65 at the time of death
- 78% of people who died had a PRAC record, 22% had no PRAC record
  - people who used respite RAC were more than twice as likely to have died as those who had not used respite RAC (43% and 18% for people with no PRAC record; 88% and 38% for people with a PRAC record) (Table S5.3).

Dementia as an underlying or associated cause of death

In addition to the underlying cause of death (UCOD), the National Mortality Database contains information on up to 19 associated causes of death (ACOD) – that is, other causes that were instrumental or significantly contributed to the death. This means that it is possible to examine people who die *due to* dementia (UCOD of dementia) and people who die *with* dementia (UCOD or ACOD of dementia) (Table 10.1).

Of those in the cohort who had died, 78% of people had dementia recorded as a UCOD or ACOD, while 22% did not have dementia recorded on their death certificate (Table S10.2). The complete and consistent recording of dementia on death records remains a significant gap in dementia data in Australia and internationally (AIHW 2021; Gao et al. 2018).

People with a subsequent PRAC record were more likely to be recorded as dying *due to* dementia (56% had a dementia UCOD) than people with no PRAC record (34%).

Table 10.1: Proportion of deaths by whether people died due to dementia (UCOD) or died with dementia (ACOD), by study group

	No PRAC record		Subsequent PRAC record	
Dementia record on death certificate	**Number**	**Proportion**	**Number**	**Proportion**
Dementia UCOD only	153	32%	885	52%
Dementia UCOD and ACOD	11	2.3%	75	4.4%
Dementia ACOD only	128	27%	454	27%
Total deaths with dementia UCOD and/or ACOD	**292**	**61%**	**1,414**	**83%**
Dementia not recorded	183	39%	288	17%
Total deaths	**475**	**100%**	**1,702**	**100%**

Source: AIHW analysis of NIHSI AA v0.5, Table S10.3. Data for people in the 30–64 and 65–69 age groups are also in Table S10.3.

The proportion of people with dementia as an ACOD only was the same in both groups (27%), and a small proportion had both a dementia UCOD and ACOD. Of all deaths among people with a subsequent PRAC record, 83% were recorded as *with* dementia (UCOD and/or ACOD), compared with 61% of people with no PRAC record.

Leading underlying causes of death

Of the 668 people who died with at least one type of dementia recorded as an ACOD, 13% also had dementia recorded as the UCOD (Table S10.4). The other most common UCODs recorded for people who had dementia recorded as an ACOD were Parkinson's disease (16%), cerebrovascular disease (14%) and coronary heart disease (11%). Chromosomal abnormalities such as Down syndrome were the UCOD for 10% of deaths in the 30–64 age group (Table S10.4).

Of the 440 people who did not have dementia recorded on their death certificate (excluding 31 people with no cause of death recorded), the most common UCODs were Parkinson's disease (15%), coronary heart disease (9.5%) and cerebrovascular disease (8.0%) (Table S10.5).

11 Discussion

Linked data sets as a source of information on people with dementia

Dementia support spans many sectors, including health, aged care and disability, and it is difficult to capture the complexity of services provided using standalone administrative data. By identifying people with younger onset dementia in 2 linked data sets, it has been possible to report more comprehensively on their social characteristics, income support, health service and residential aged care service use. Importantly, linked data have enabled the analysis of these services at key points in time, such as before and after entry into residential aged care, and over time from first dispensed dementia-specific medication.

The MADIP

This study is the first to use the MADIP to describe a population with younger onset dementia. By linking PBS/RPBS medications data to the 2016 Census and to DOMINO data, the MADIP offered a new opportunity to analyse cultural and linguistic diversity, sociodemographic information, and income and social security payments for people living with younger onset dementia. There were some overall limitations; for instance, the cohort was too small for analysis of all sub-groups of interest, and the age structure of the cohort made comparisons with the Australian population difficult. However, the results presented here offer some preliminary snapshots of the types of data available and their potential use to inform policy and service responses to support younger people with dementia.

- At the time of the 2016 Census, 61% of people with younger onset dementia who were living in the community needed assistance with core activities. Nearly half (46%) of those living in the community who were not married or in a de-facto relationship were living in lone person households. The available data did not reveal whether people were receiving the assistance that they needed.
- One-quarter of the study cohort (26%) spoke a language other than English at home, and a relatively high proportion of people spoke English not well or not at all (9.0%). The latter may be partly related to the progression of dementia, but also highlights the need for culturally appropriate services in the community, in supported accommodation, and for family and carers. The patterns of CALD in people with younger onset dementia are likely to be different from those in the older population with dementia, and will continue to change as they reflect shifting migration patterns in Australia (Wilson et al. 2020). Regular high-quality data on CALD among people with dementia are required for future service planning and development (NNIDR and NARI 2020).
- The relationship between place of residence and dementia is complex. Unlike the pattern for all Australians, the proportion of people in the study cohort living in *Major cities* did not decrease with increasing age. More research is needed to analyse these issues to help identify risk factors and to ensure that people can access diagnostic, health, aged care and social support services close to home.
- Investigation of household income was beyond the scope of this study, but this analysis suggests that by the time of the 2016 Census, many people with younger onset dementia had ceased employment before the age of 65, were more likely to report a lower personal income than all Australians of the same age, and/or received an income

support payment through Centrelink. These circumstances, occurring at a relatively early time of life, are likely to have significant social, emotional and financial impacts on the person and their family, and may create barriers to accessing appropriate care. Future research could investigate linked DOMINO, Census and Personal Income Tax data to give an indication of those experiencing high levels of financial disadvantage.

The NIHSI AA

The NIHSI AA contains a wealth of information on Australians' use of health and aged care services. This NIHSI AA analysis had some limitations: the study cohort was derived using the PBS/RPBS, to identify people in the early stages of dementia and to follow their service use over time. However, this method did not capture everyone with younger onset dementia (see Chapter 2 'Methods'). Data on home-based and community-based aged care was not available, and this study had access to hospital data from only 4 states (New South Wales, Victoria, South Australia, Tasmania). As more data are added to the NIHSI AA, future work could incorporate hospital data from additional states and territories, and other forms of aged care service data. As with the MADIP, the results presented here offer snapshots of the types of data available and their potential use to inform policy and service responses to support younger people with dementia.

One of the aims of this study was to explore any potential differences in health service use between people with younger onset dementia who entered PRAC during the study period, and those who did not (people with no PRAC record). The finding that, while living in the community, people with a subsequent PRAC record had fewer GP and specialist attendances on average than people with no PRAC record may point to differences in access to services that enable people with younger onset dementia to stay living in the community. However, without more detailed data on the reasons for GP and specialist attendances (dementia-related or otherwise), it is difficult to deduce potential areas of inequity. The differences may also be influenced by a person and their carer's health literacy, their financial status, and their access to other services such as home and community-based support (AIHW 2019c, 2020a). Primary care services not captured in the MBS (such as services received as part of hospital inpatient or outpatient admissions) may partly account for the differences, particularly if people with a subsequent PRAC record were at a later stage of disease and more likely to access these services (with, for example, a higher rate of overnight hospitalisations for dementia, Figure 8.6).

Royal Commission into Aged Care Quality and Safety

The Royal Commission into Aged Care Quality and Safety report (the Royal Commission) identified numerous issues and made several recommendations relevant to younger people in aged care. Some of the Royal Commission recommendations are specific for dementia:

- Recommendation 15: Establishment of a dementia support pathway
- Recommendation 16: Specialist dementia care services
- Recommendation 80: Dementia and palliative care training for workers.

A number of other recommendations will be important to consider for people with younger onset dementia who are accessing aged care services, for example:

- Recommendation 30: Designing for diversity, difference, complexity and individuality

- Recommendation 45: Improving the design of aged care accommodation
- Recommendation 67: Improving data on the interaction between the health and aged care systems
- Recommendation 94: Greater weight to be attached to the experience of people receiving aged care.

The following section discusses how this report contributes evidence on some of these issues for people with younger onset dementia. It should be noted that the period of this study (2011 to 2017) covers a time of changing policies in this area, particularly the introduction of the National Disability Insurance Scheme (Box 11.1).

Box 11.1: National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) began with trial sites in 2013 and the full scheme began to be implemented nationally in 2016 (NDIA 2021). The NDIS provides support for people aged under 65 who have a significant, ongoing disability. Through this scheme young people are provided with funding to access a range of support services and programs, including supports that assist people with daily personal activities, making home modifications to suit their needs, programs that enable and encourage participation in work or social activities, and funding towards therapeutic services. Data are not currently available on the number of people with younger onset dementia accessing the NDIS (AIHW 2021b).

No younger people in residential aged care (Recommendation 74)

In response to the interim report of the Royal Commission (2019), the Australian Government committed to minimising the need for younger people to live in aged care facilities, including funding for system coordinators to assist younger people to access appropriate services and supports across the disability, health, housing and aged care sectors (DSS 2020). This study examined several aspects of RAC use by people with younger onset dementia.

- Of those who entered PRAC, one-quarter (25%, about 750 people) were aged 30–64 at the time of first entry.
- From the sample of hospital data available, 21% of people were discharged from hospital to a RAC facility. The longer length of hospital stay for people with a principal diagnosis of dementia points to the challenges of timely access to appropriate accommodation for people with younger onset dementia (AIHW 2019c). Future studies will investigate the interface between hospitals and aged care for people with dementia.
- People with younger onset dementia may need to live in supported accommodation for relatively long periods of time. In this study, people who were still living in PRAC at the end of the study period had been there for a median of 3.4 years for those aged under 65 at entry, and 2.3 years for people aged 65 or over at entry. This is longer than the median length of PRAC stay for people of all ages with dementia (2.1 years) and people without dementia (1.9 years) (AIHW 2021b).

Support for informal carers (Recommendation 42)

Informal carers have an important role in the life of a person with younger onset dementia, particularly as this group often fall through the gaps between the disability and aged care sectors. Outcomes have improved with the introduction of the NDIS, but gaps in services remain, particularly in the provision of services for families and carers (Alzheimer's Australia 2017).

In 2018, 38% of primary carers of people with dementia of all ages reported they needed assistance or needed further assistance with the caring role, and of these, 23% reported they needed more respite care (AIHW 2021b). A previous study of the pathways of younger people entering PRAC between 2009–10 and 2013–14 found that 25% of younger people with dementia used Home and Community Care prior to entry to PRAC (AIHW 2019c). The use of linked data in the NIHSI AA has enabled more detailed analysis of the use of respite RAC services by people with younger onset dementia.

- In this study, 33% of people who entered PRAC had accessed respite RAC beforehand, and of these, half had only one respite stay.
- This study suggests that people do not access respite RAC until relatively late in the progression of disease, as only 15% of people with no PRAC record accessed respite RAC, nearly everyone with a subsequent PRAC record who used respite RAC had entered permanent care within 2 years of their first respite RAC episode, and people who used respite RAC were more than twice as likely to have died by the end of the study period as those who had not used respite RAC.
- The difference in use of respite RAC by men and women in the study cohort (29% and 21%, respectively) was similar to what is seen in the broader population of younger people using respite RAC (AIHW 2021a), and may reflect a range of differences in how men and women experience dementia, including time to diagnosis, dementia type and progression of disease, the availability of carer support and the use of other types of care prior to PRAC entry (AIHW 2019c).

These findings support previous research showing that many people with younger onset dementia do not access formal support services before entering PRAC (Cations et al. 2017).

Better access to health care (Recommendations 56–58)

Primary health care professionals can provide oversight of care during the transition to residential aged care and once a person is settled. This study found that for people with younger onset dementia, GP attendances were more frequent in the 12 months after entry to PRAC than in the previous 12 months living in the community. This pattern has previously been reported for the broader population aged 50 and over (AIHW 2020b). However, GP continuity can often be difficult to maintain upon entry to care (Royal Commission 2021), and a recent study found that changing GP upon entry to RAC was associated with increased polypharmacy and dispensing of psychotropic drugs for people with dementia of all ages (Welberry et al. 2021). Other analysis has shown that medication management reviews occurred more frequently in the RAC setting than in the community in 2016–17, but still for only about 1 in 3 people with younger onset dementia (AIHW 2021b).

This study also confirmed previous analysis showing that people living in PRAC have less access to specialist health care than people in the community (AIHW 2020b), despite having higher levels of care needs. Some reductions in specialist attendances may be expected once a diagnosis of dementia has been reached, and with increasing difficulties in the provision of some specialist services as dementia progresses. However, the Royal Commission noted a number of problems associated with reduced access to specialist health care for people living in RAC (Royal Commission 2021), some of which relate to the prescribing of antipsychotics, as discussed below.

Restricted prescription of antipsychotics in residential aged care (Recommendation 65) and regulation of restraints (Recommendation 17)

Changes in medication often reflect the events that have led to a move to residential aged care, such as changed behaviours (also known as behavioural and psychological symptoms of dementia or BPSD) (Welberry et al. 2021). People with younger onset dementia living in RAC may also experience higher rates of psychological symptoms such as anxiety, depression or agitation, due a lack of age-appropriate services, including exercise, purposeful activities and personal autonomy (Rimkeit and McIntosh 2017). Non-pharmacological interventions are recommended as the first approach, but medical professionals may also prescribe antipsychotic medicines to help manage these symptoms. Inappropriate prescribing of antipsychotic medicines, sometimes as a form of chemical restraint to control behaviour, and the prescription of medicines that have negative interactions with each other, were key issues raised in the Royal Commission (2021).

- In this study, the likelihood of polypharmacy and psychotropic drug dispensing increased upon entry to PRAC: in the 6 months before and after entry to PRAC, dispensing of 5 or more distinct medicines increased from 41% to 61% of people, and dispensing of antipsychotic medications increased from 44% to 63% of people. Although not directly comparable, a review of studies between 2000 and 2017 found the proportion of Australian RAC residents prescribed an antipsychotic ranged from 13% to 42% (Westaway et al. 2020). In 2019–20, the proportion of people with dementia prescribed antipsychotic medications (21% overall) increased slightly with decreasing age (AIHW 2021b).
- The median number of days after entry to PRAC for new dispensing of some medications (for example, 20 days for benzodiazepines (IQR 6–50 days) and 29 days for antipsychotics (IQR 7–65 days)) suggests that adequate time may not always have been taken to attempt non-pharmacological methods of managing changed behaviours.

It is important to note that the data reflect scripts dispensed, but do not indicate if a medication was taken. Some medications may be prescribed ‘as required’ in aged care settings, and dispensed but not ultimately administered (Bony et al. 2020). It should also be noted that these data are from 2011–2017 and may not reflect current practices; however, they provide a snapshot of the possible extent of problematic prescribing for people with younger onset dementia and are consistent with other studies of older people with dementia (AIHW 2021b; Harrison et al. 2020; Welberry et al. 2021).

Embedding high quality aged care (Recommendation 13)

The Royal Commission defined high quality care as ‘a standard of care designed to meet the particular needs and aspirations of the people receiving aged care’, and includes, among many factors, regular clinical review of a person’s health and wellbeing to ensure care is meeting individual needs, such as their risk of falls, mental health and cognitive impairment.

This study found that injuries were a significant issue for people with younger onset dementia living in PRAC, accounting for 20% of ED presentations, 23% of same-day hospital stays and 16% of overnight hospital stays. This was consistent with previous findings that injuries were the most common reason for ED visits and overnight hospital stays for people of all ages living in PRAC in 2016–17 (AIHW 2019b).

This study also confirmed that mental health conditions, particularly depression, were common among people with younger onset dementia. Anti-depressants were the most common drug dispensed to people while living in the community (other than dementia-specific medications); dispensing of anti-depressants and anxiolytics increased after entry to PRAC; depression and mood disorders, and anxiety and stress-related disorders, were the most common health conditions recorded on ACFI assessments (after dementia). There is significant overlap between the symptoms of mental health conditions and dementia, and more research on the interplay between these conditions is required.

Future directions

Using the linked data described in this study, and other sources as they become available, future AIHW reports are planned. These will examine:

- the health and aged care interface for people with dementia, including reasons for hospitalisation and changes in care needs following contact with the hospital system
- geographic differences in dementia-related outcomes and service use that might indicate potential unmet need or inequity in the distribution of support for people with dementia
- fall-related injuries and risk factors for falls among people with dementia
- the impact of COVID-19 on people with dementia
- the 2021 Census, which included new questions about dementia and other long term health conditions, allowing for more in-depth analysis of a broader group of people with dementia, not just those prescribed dementia-specific medications through the PBS/RPBS.

Many gaps remain in the availability of data relating to dementia. The AIHW National Centre for Monitoring Dementia was established in 2021 and will undertake routine monitoring of dementia, address existing data gaps and inform specific policy needs for Australians living with dementia, including people with younger onset dementia. As more data become available, analysis of primary care data, home and community aged care data, and NDIS data could be used to fill important gaps in knowledge about support services accessed by people with younger onset dementia, and their carers.

Appendix A: People with evidence of younger onset dementia in the NIHSI AA

The National Integrated Health Services Information Analysis Asset (NIHSI AA) is a new multi-source enduring linked data set. This section provides an overview of the available data concerning people with younger onset dementia in the NIHSI AA.

A person will have a dementia-related record only if they have been supplied with dementia-specific medication through the Pharmaceutical Benefits Scheme (PBS) or Repatriation Pharmaceutical Benefits Scheme (RPBS), or if dementia was listed as a condition on a hospital admission, Aged Care Funding Instrument (ACFI) assessment of care needs at permanent residential aged care entry, or on their death certificate. About 31,800 people aged 30–69 had some evidence of dementia in the NIHSI AA v0.5, based on PBS/RPBS, ACFI and Admitted patient care records (in 4 states: New South Wales, Victoria, South Australia and Tasmania) between 2010 and 2017 (Table SA.1a).

A further 5,200 people aged 30–74 died with dementia recorded on their death certificate (Table A.1).

Of the total 37,000 people with evidence of younger onset dementia, nearly 25,500 (69%) had a dementia record in only one data set; about 8,000 (21%) had records in 2 data sets; 3,000 (8.0%) had records in 3 data sets, and 700 people (1.9%) had a record in all 4 data sets (Table SA.1b; Figure A.1).

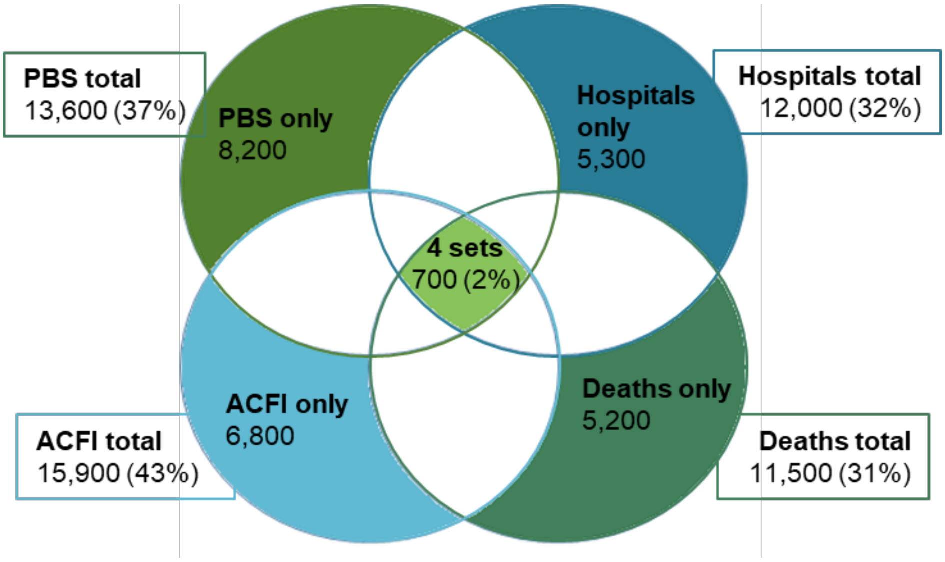
Table A.1: NIHSI AA records with evidence of younger onset dementia, 2010–2017

Data source	Definition of younger onset dementia	No. people with YOD	Proportion of total	No. in single data set
PBS/RPBS	People aged 30–69 supplied with any of 4 dementia-specific medications, including memantine	13,596	37%	8,173
ACFI	People aged 30–69 with dementia recorded on an ACFI assessment	15,911	43%	6,834
Admitted patient care	People aged 30–69 with a dementia-related hospital admission (New South Wales, Victoria, South Australia, Tasmania)	11,926	32%	5,254
Deaths	People aged 30-74 with dementia recorded on a death certificate	11,520	31%	5,223
Total	**People with a dementia record in any of the 4 data sources**	**37,041**	**100%**	**25,484**

Source: AIHW analysis of NIHSI AA v0.5, Table SA1a.

Note: Some people had a dementia record in more than one data source, so the sum of data sources does not equal the Total.

Figure A.1: Number of NIHSI AA records with evidence of younger onset dementia, and proportion of total dementia records, by data set, 2010–2017



Source: AIHW analysis of NIHSI AA v0.5, Table SA1a.

In each year between the calendar years 2011 and 2016, about 4,300 people had their first NIHSI AA record suggestive of younger onset dementia (Table SA.2). PBS/RPBS records accounted for about 37% of younger onset dementia records (Table SA.1a), most of which (96%) were for donepezil, rivastigmine and galantamine, which are used to treat mild and moderate dementia, and 4.4% for memantine, which is used for more advanced dementia (Table SA.3).

Of the 31,800 people with evidence of younger onset dementia in PBS/RPBS, ACFI and hospital data, nearly 12,600 (40%) had died by the end of 2017, of which only 52% had dementia recorded as an underlying or associated cause of death on their death certificate (Table SA.4). The proportion of records without dementia (48%) was higher than that for the study cohort (22%, Table S10.3), which may be related to the study cohort being mostly people with Alzheimer’s disease: an English study found that dementia was more likely to be recorded on a death certificate for people with Alzheimer's disease than other types of dementia (Perera et al. 2016).

These numbers should not be considered incidence or prevalence estimates for younger onset dementia in Australia; rather they are an indication of the coverage of people with younger onset dementia in the NIHSI AA. The data set does not include people hospitalised in Queensland, Western Australia, the Australian Capital Territory or the Northern Territory, nor people receiving home-based aged care services.

Acknowledgments

This report was prepared by Ingrid Evans, Megan Fraser and Ann-Kristin Raymer of the Dementia Unit of the Australian Institute of Health and Welfare (AIHW), with valued input from Fleur de Crespigny, Richard Juckes, Mardi Ellis, Michelle Gourley, Melinda Leake, Sushma Mathur, Jen Mayhew-Larsen and Michael McTigue. The authors also wish to acknowledge the analysis advice provided by the AIHW's Aged Care Data Improvement Unit, Ageing and Aged Care Unit, Analysis Support Unit, Burden of Disease and Mortality Unit, Centrelink Strategies Unit, Dementia Unit, Population Monitoring and COVID-19 Data Unit, and Specialist Capabilities Unit, as well as the support of the NIHSI AA through the NIHSI Advisory Committee, and of the MADIP through the Australian Bureau of Statistics Microdata Resources team.

Review and valuable input on the final draft was provided by the AIHW Dementia Expert Advisory Group whose members include Kaarin Anstey, Henry Brodaty, Colm Cunningham, Annette Dobson, Linda Fardell, Anthony Hobbs, Verity Russell, Velandai Srikanth, Kaele Stokes, Prue Torrance, Stephanie Ward and the Australian Government Department of Health.

The Australian Government Department of Health funded this report.

Abbreviations

ABS	Australian Bureau of Statistics
ACFI	Aged Care Funding Instrument
ACOD	Associated cause of death
AIHW	Australian Institute of Health and Welfare
ATC	Anatomical Therapeutic Chemical
BPSD	Behavioural and psychological symptoms of dementia
CALD	Culturally and linguistically diverse
CI	Confidence intervals
DSM	Dementia-specific medication
DSP	Disability Support Pension
DOMINO	Data Over Multiple Individual Occurrences
ED	Emergency Department
GP	General practitioner
GORD	Gastro-oesophageal reflux disease
HACC	Home and Community Care
IQR	Interquartile range

IRSD	Index of Relative Socioeconomic Disadvantage
ISP	Income support payment
LOS	Length of stay
MADIP	Multi-Agency Data Integration Project
MBS	Medicare Benefits Schedule
NDI	National Death Index
NDIS	National Disability Insurance Scheme
NIHSI AA	National Integrated Health Services Information Analysis Asset
PBS	Pharmaceutical Benefits Scheme
PRAC	Permanent residential aged care
RAC	Residential aged care
RPBS	Repatriation Pharmaceutical Benefits Scheme
SARs	Special Administrative Regions
SEIFA	Socioeconomic Indicators for Areas
SIR	Standardised incidence ratio
UCOD	Underlying cause of death
UK	United Kingdom
USA	United States of America
WHO	World Health Organization
YOD	Younger onset dementia

Symbols

. .	not applicable
n.p.	not publishable because of small numbers, confidentiality or other concerns about the quality of the data
%	percentage

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This report presents a comprehensive picture of people with younger onset dementia, using 2 linked data sets: the NIHSI AA and the MADIP. People with younger onset dementia were identified using pharmaceutical claims for dementia-specific medication. The linked data were then used to describe social characteristics from the 2016 Census, patterns of Centrelink payments, and patterns of health service use, residential aged care service use and causes of death.

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