

Exploring pathways for younger people living in residential aged care



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Summary

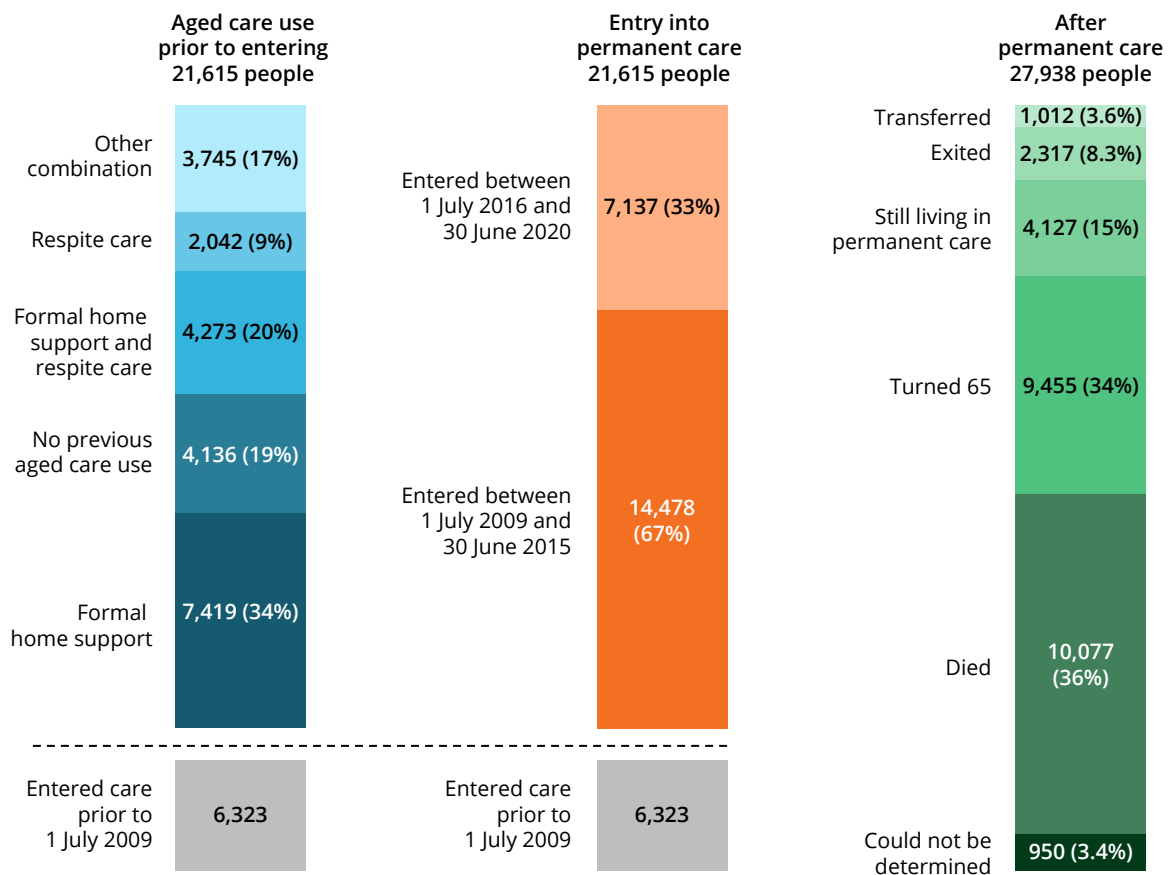
Aged care services in Australia are provided based on need and, due to a range of circumstances, younger people (aged less than 65 years) are living in permanent residential aged care (permanent care).

This publication explores the characteristics of younger people entering permanent care and their pathways through the aged care system using linked data that enables an expanded view of the impact of various initiatives over time.

Focusing on a cohort of more than 27,900 younger people who lived in permanent care at some stage over an 11-year period, between 2009–10 to 2019–20, analysis of key characteristics of the cohort and their patterns of care use over time show:

- The number of younger people living in permanent care has been decreasing since 2016–17. The number of younger people living in permanent care during a financial year peaked at 8,400 in 2013–14, reaching the lowest number of 6,700 in 2019–20.
- The number of younger Indigenous Australians living in permanent care increased from 490 in 2009–10 to 600 in 2019–20, but this increase was seen only in the 50–64 age groups.
- Of the 21,600 younger people to have their first entry to permanent care from 2009–10 and onwards, nearly 1 in 5 (19%) had no prior contact with an aged care service.
- Dementia was the most reported health condition; recorded for more than 1 in 6 (18%) of the younger people who entered permanent care for the first time in the study period between 2016–17 to 2019–20.
- Receiving a formal home support service prior to entering permanent care was the most common pathway for younger people first entering permanent care; a third (34%, 7,400) followed this pathway.
- Dying (42%) and turning 65 (40%) were the main reasons people in the study cohort were no longer considered younger people living in permanent care.

Younger people living in permanent care between 1 July 2009 and 30 June 2020 (27,938)



Opportunities for future work in this area include further examination of how health and disability services interact with the aged care system to support younger people who are living in, or at risk of entering, permanent care. This future work will provide a more comprehensive picture of younger people in permanent care, exploring how younger people in permanent care are supported outside of the aged care system, and providing insights into the circumstances of younger people who are at risk of entering permanent care.

The [GEN aged care](#) data website publishes quarterly snapshot data on younger people in residential aged care.

1 Introduction

Aged care services in Australia are provided based on need rather than age. This means people from a range of ages, including young adults, can access aged care services, including living in permanent residential aged care (permanent care). In the context of aged care services, 'younger' people are those aged under 65. Despite this, it is widely considered that the aged care system is primarily designed to support the needs of older people and that younger people's needs are better supported by other more age-appropriate services (Commonwealth of Australia (Department of Social Services (DSS)) 2020).

Over many years, a range of initiatives have been implemented with the aim to support younger people out of residential aged care. These initiatives included, from 2006 to 2011, the first Younger People in Residential Aged Care (YPIRAC) Initiative, and in 2019, the *Younger People in Residential Aged Care – Action Plan*. The rollout of the National Disability Insurance Scheme (NDIS) from 1 July 2013 has also played a role in supporting younger people with disability living in residential aged care.

In their *Interim report* released in 2019, the Royal Commission into Aged Care Quality and Safety highlighted the need for immediate action to address the number of younger people living in residential aged care. In response, the Australian Government announced YPIRAC targets, apart from in exceptional circumstances, to work towards there being:

- 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; and
- no people under the age of 65 living in residential aged care by 2025.

The overall progress being made towards the YPIRAC targets is being tracked on the GEN aged care data website *Younger people in residential aged care*.

Administrative data can only provide so much information on the experiences of younger people living in permanent care. The consideration of lived experience can provide a human perspective to the data. [The Summer Foundation website](#) has a suite of videos that capture the lived experience of younger people living in permanent care.

Exploring pathways for younger people living in permanent residential aged care

The analysis presented in this publication uses administrative aged care and National Death Index (NDI) data linked through the Pathways in Aged Care (PIAC) link map. This provides a person-based, rather than episode-based, description of younger people who have lived in permanent care anytime between 2009–10 to 2019–20, including their pathways through aged care services. For more information on the PIAC link map, see *Appendix A: Methods and data sources*.

The study cohort of younger people living in permanent care does not include other aged care that may be provided in a residential setting, such as respite residential aged care or flexible aged care programs such as the National Aboriginal and Torres Strait Islander Flexible Aged Care (NATSIFAC) Program. It should be noted that whilst it is not explicitly stated that the YPIRAC targets only include younger people in permanent care, the current publication focuses on permanent care.

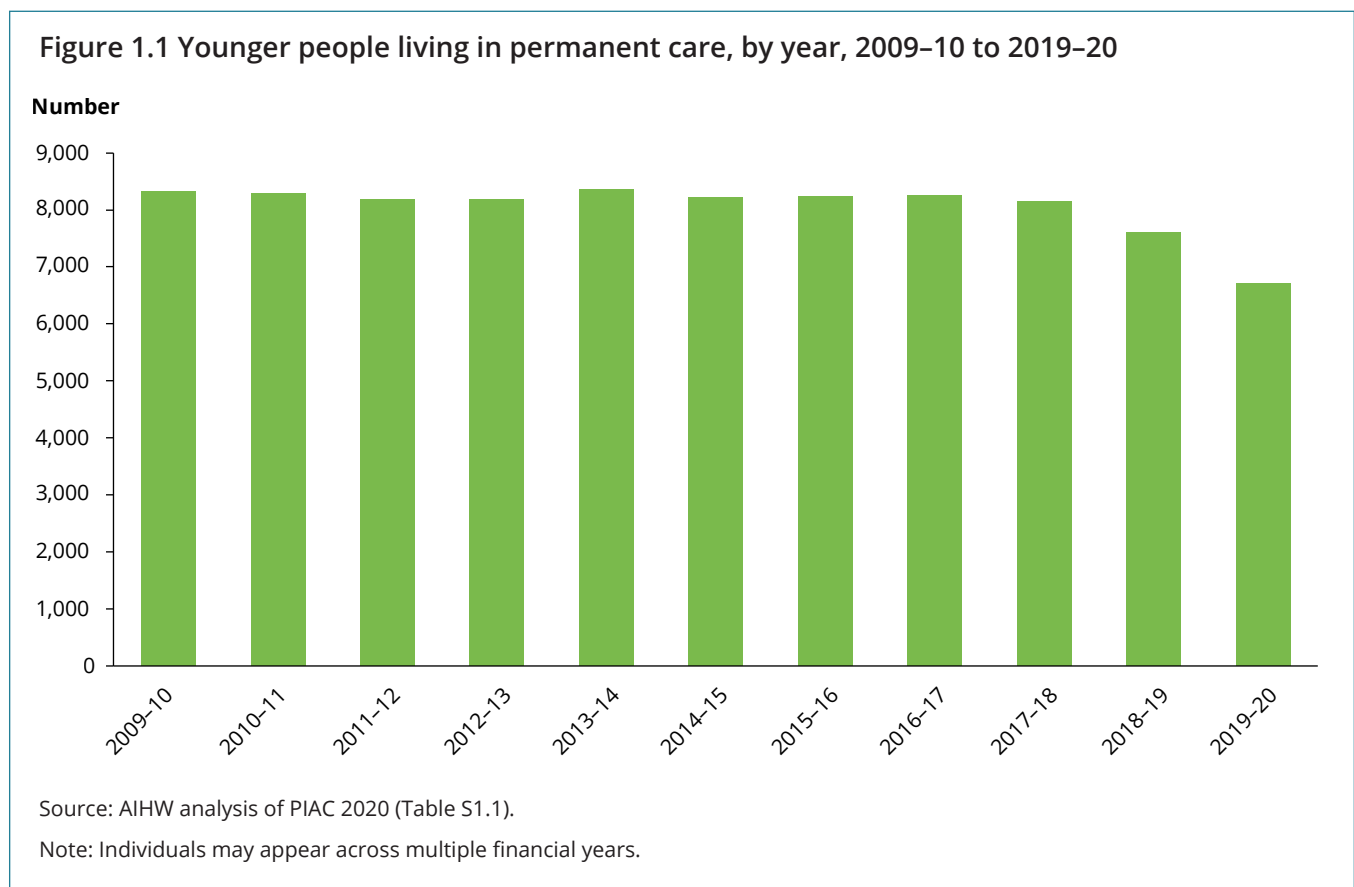
A number of younger people also use respite residential aged care. Respite care is available on either a planned or emergency basis to people who intend to return to their own home but require temporary residential aged care. It supports people in transition stages of health, as well as providing carers with a break from their caring duties (AIHW 2019b). Younger people receiving an equivalent of permanent care via the NATSIFAC program or other flexible programs are of interest, but data are not currently available to the Australian Institute of Health and Welfare (AIHW) in order to quantify trends in entries or number of younger people using the program (or the crossover between these programs and permanent care).

It should be noted that access to aged care services in Australia is determined by need, rather than age. The Aged Care Act 1997 designates some groups of people as 'people with special needs'; Indigenous Australians are one such group. (AIHW 2019a). Planning for aged care services takes into account the specific needs of the Indigenous population aged 50 and over (and the non-Indigenous population aged 65 and over) (Commonwealth of Australia (Department of Health and Aged Care) 2022).

Younger people living in permanent residential aged care study cohort

Between 2009–10 and 2019–20, 27,900 younger people lived in permanent care at some stage. Most younger people entered permanent care once during this period, however nearly 1,400 younger people had multiple episodes of permanent care, with almost 30,800 episodes of permanent care for younger people. An episode is a period of care in permanent care based on an entry date, and if applicable, an exit date. Episodes without an exit date are ongoing with the person still living in permanent care.

The number of younger people living in permanent care during a financial year remained relatively stable between 2009–10 and 2016–17, peaking at 8,400 younger people during 2013–14. The number of younger people has decreased since 2016–17, reaching the lowest number of 6,700 during 2019–20 (Figure 1.1).



Younger people receiving aged care services not included in the study cohort

Whilst the study cohort of younger people (aged less than 65 years) who lived in permanent care is the focus of the more detailed analysis presented in the following chapters, there are many other younger people who interacted with aged care services between 2009–10 and 2019–20. During this time, 558,000 younger people, in addition to those in the study cohort, used aged care services other than permanent care. Note that these younger people may have used permanent care before or after the study period.

2 Younger people living in permanent residential aged care

This section focuses on all permanent residential aged care (permanent care) episodes for the study cohort. Between 2009–10 and 2019–20, 27,900 younger people lived in permanent care at some stage, with 30,000 episodes of permanent care. More than 1,600 younger people lived in permanent care for the 11 years of the study period, with most of these younger people ‘ageing out’ of the younger people cohort (turning 65) during this period (1,200) (Table S2.1).

Interpretation notes

The following notes apply to the analysis presented in this section:

Ageing out: Ageing out refers to when a younger person turns 65 and is no longer considered a younger person in permanent care. This publication identifies where a younger person turned 65 within the study period, and whether they were living in permanent care at the time of turning 65.

Unless otherwise specified, ageing out of the YPIRAC cohort is not considered an end to a permanent care episode during the year. However, once a younger person has turned 65, they are not counted in subsequent financial years

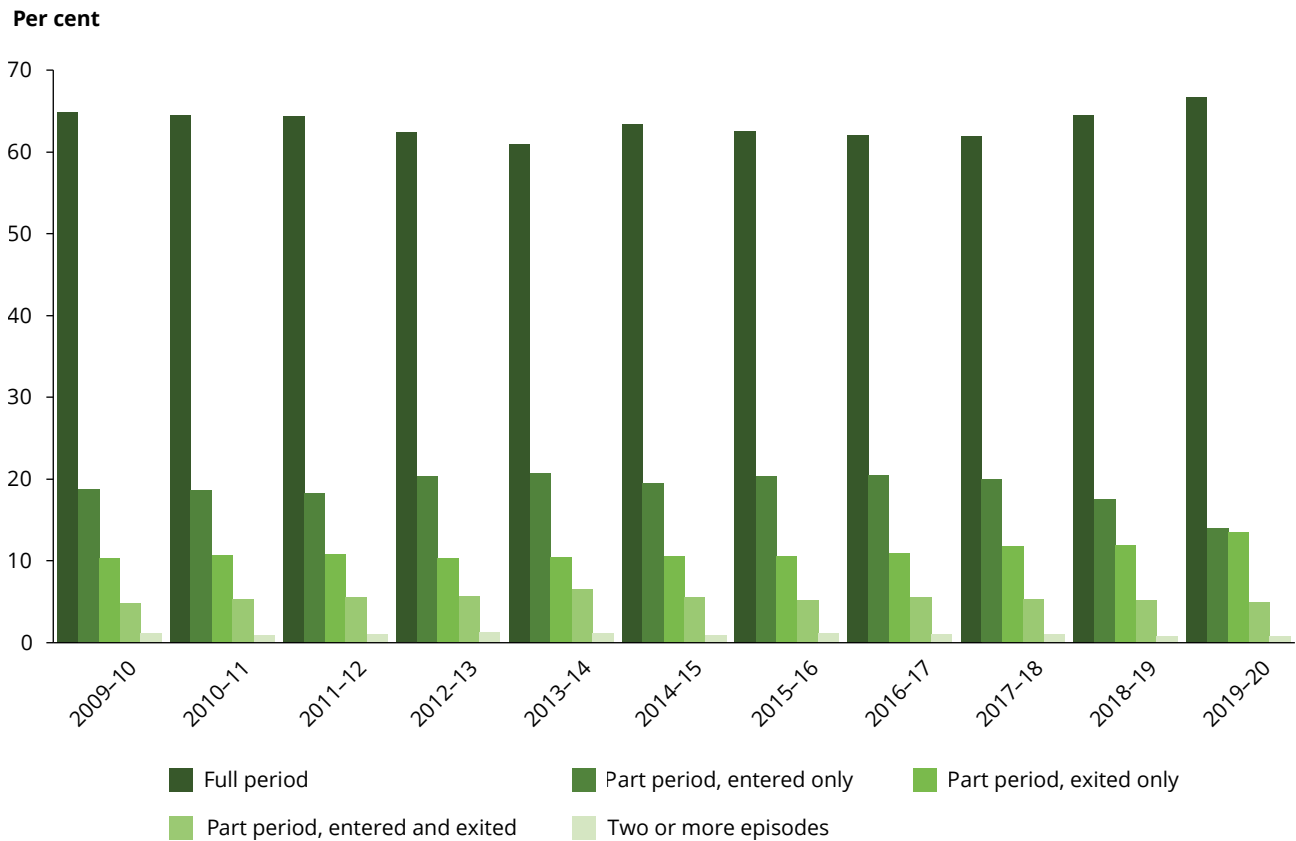
Episode end: An episode of permanent care may have ended due to the younger person exiting permanent care or passing away whilst living in permanent care.

Length of stay: Length of stay is the total length of time spent in permanent care as a younger person during the study period. If a younger person has had multiple episodes of permanent care, the length of stay combines the length of all episodes within the study period. For this analysis, a permanent care episode may end due to the younger person exiting permanent care, passing away or ageing out of the younger people cohort (turning 65). If a permanent care episode had not ended, the length of stay is calculated to 30 June 2020.

During each year of the study period, most younger people lived in permanent care for the whole year. The number of younger people entering permanent care each year has decreased from a peak of 1,700 during 2013–14, to 940 during 2019–20. Between 330 and 550 younger people each year started and ended an episode of permanent care during each year of the study period, and a further 60 to 110 had multiple permanent care episodes (Table S2.1).

Across the study period, 2019–20 saw the highest proportion of younger people living in permanent care for the whole year (67%) and ending an episode of permanent care (14%), and the lowest proportion of younger people starting an episode of permanent care (14%) (Figure 2.1).

Figure 2.1 Younger people living in permanent care by permanent care movements and year, 2009–10 to 2019–20



Source: AIHW analysis of PIAC 2020 (Table S2.1).

Notes:

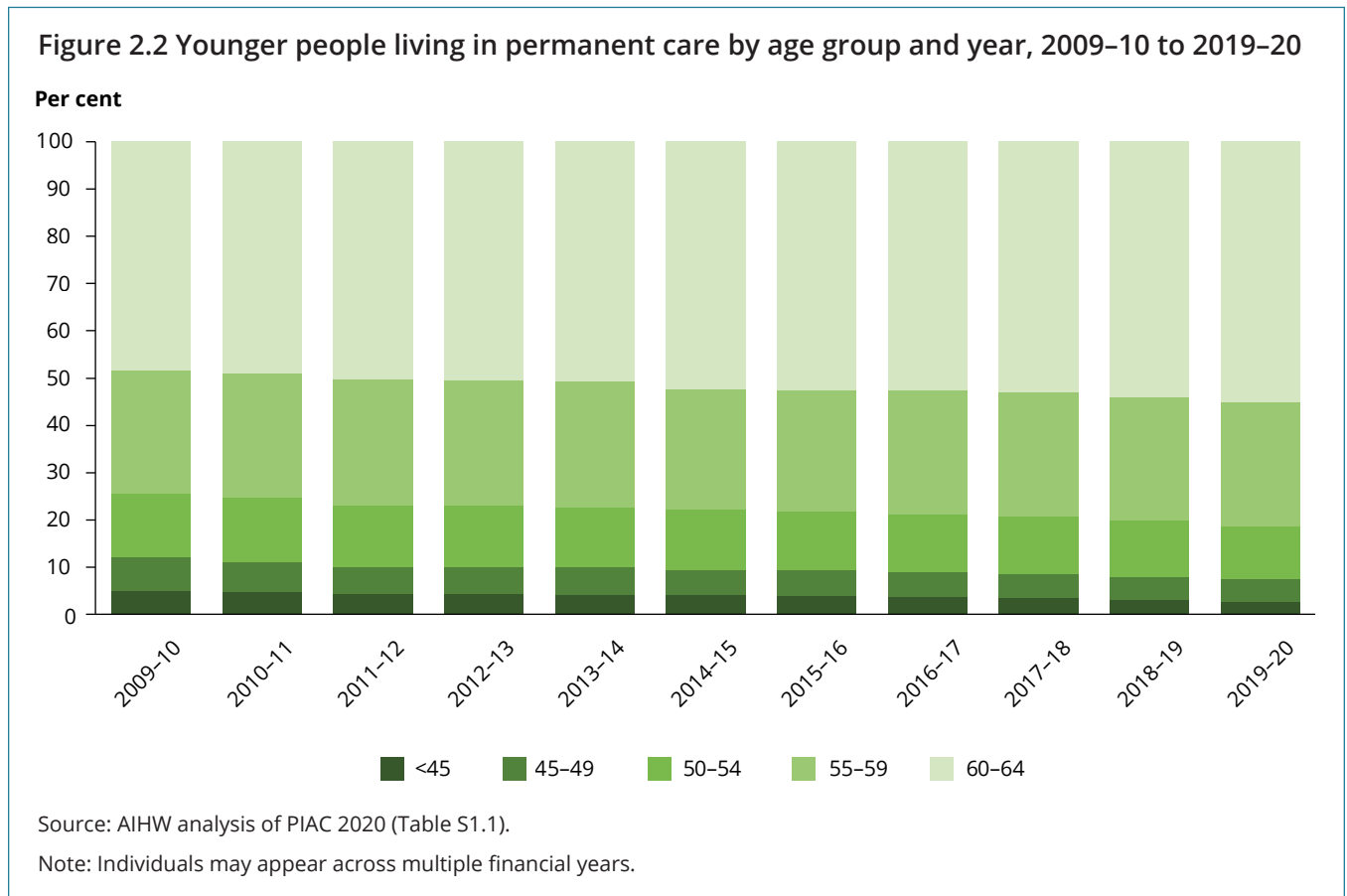
Individuals may appear across multiple financial years.

Turning 65 ('ageing out' of the younger people cohort) in permanent care is not considered an end to a permanent care episode during the year. However, once a younger person has turned 65, they are not counted in subsequent financial years.

The number of younger people living in permanent care in each jurisdiction reduced between 2009–10 and 2019–20 (Table S2.2).

Characteristics

Around half of younger people living in permanent care each financial year were aged between 60–64 at the start of the financial year; ranging from 48% to 55%. Each year, this proportion increased slightly as we see ageing of the cohort (Figure 2.2).

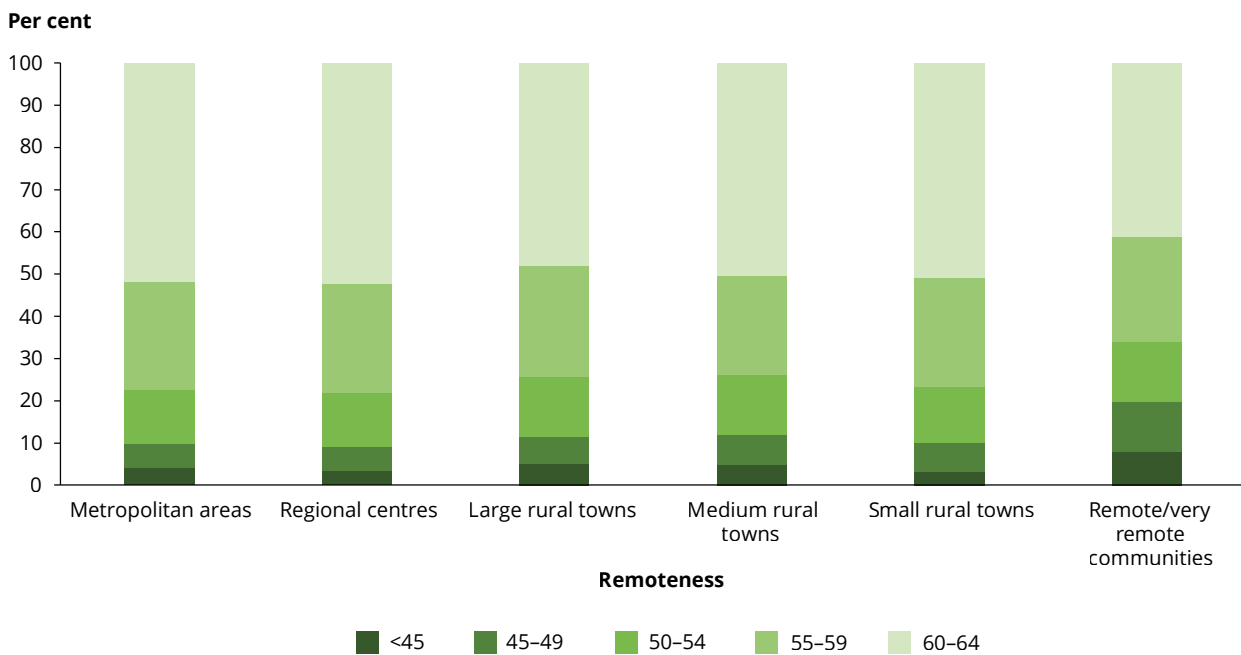


Overall, just over half (55% 15,400) of the study cohort were male and over 2,000 (7.2%) younger people identified as Indigenous Australians (Table S1.1).

Across both Indigenous Australians and Other Australians, there were more younger males than younger females living in permanent care in each year of the study period. Whilst there were more younger Indigenous Australians living in permanent care in 2019–20 (600) than in 2009–10 (490), this increase was seen only in the 50–64 age groups (540 in 2019–20 and 380 in 2009–10) (Table S1.1).

The age distribution of younger people living in permanent care differed by remoteness, with the proportion of younger people in younger age groups increasing as remoteness increased. Almost 1 in 5 younger people living in permanent care in a remote or very remote area were aged less than 50 years (20%), compared with 1 in 10 in metropolitan areas (9.9%) (Figure 2.3). Part of this is due to the geographic distribution of younger Indigenous Australians living in permanent care; three-quarters (76%, 410) of younger people living in permanent care in remote and very remote areas were Indigenous Australians (Table S2.3).

Figure 2.3 Younger people living in permanent care by age group and remoteness area (Modified Monash Model), 2009–10 to 2019–20



Source: AIHW analysis of PIAC 2020 (Table S2.3).

Note: Individuals may appear across multiple financial years.

Length of stay

The median time spent in permanent care as a younger person during the study period was one and a half years, with around 1 in 4 of the study cohort (26%, 7,300) living in permanent care for less than 6 months (Table 2.1). Almost 400 younger people lived in permanent care for 11 years; the length of the study period.

Table 2.1. Proportion of younger people living in permanent care any time between 2009–10 and 2019–20, by length of stay and sex

Length of stay	Males	Females	Persons
< 6 months	27.3	24.7	26.1
6 months to less than 12 months	13.3	13.5	13.4
1 year to less than 2 years	18.3	18.8	18.5
2 years to less than 3 years	12.4	12.5	12.4
3 years to less than 4 years	8.6	8.9	8.8
4 years to less than 5 years	6.1	6.1	6.1
5 years to less than 8 years	9.4	10.9	10.1
8 years to less than 11 years	3.2	3.0	3.1
11 years	1.3	1.4	1.4
Total	100.0	100.0	100.0

Source: AIHW analysis of PIAC 2020.

3 Younger people's pathways into permanent residential aged care

It is important to understand the triggers and pathways for younger people entering permanent residential aged care (permanent care). Whilst the study cohort consists of 27,900 younger people who lived in permanent care at some stage between 2009–10 to 2019–20, their first entry into permanent care may have occurred prior to 2009–10. For 1 in 4 younger people (23%, 6,300), their first entry occurred prior to 2009–10, while for the remainder (77%, 21,600) their first entry during the study period was from 2009–10 onwards.

This section focuses on the 21,600 younger people who had their first entry (in the study period) to permanent care from 2009–10 onwards (Table S3.1). It is possible that some of these younger people lived in permanent care prior to the period of analysis, meaning that the first permanent care episode in the study period may not be the first time they entered permanent care.

Circumstances at assessment for younger people approved for permanent residential aged care

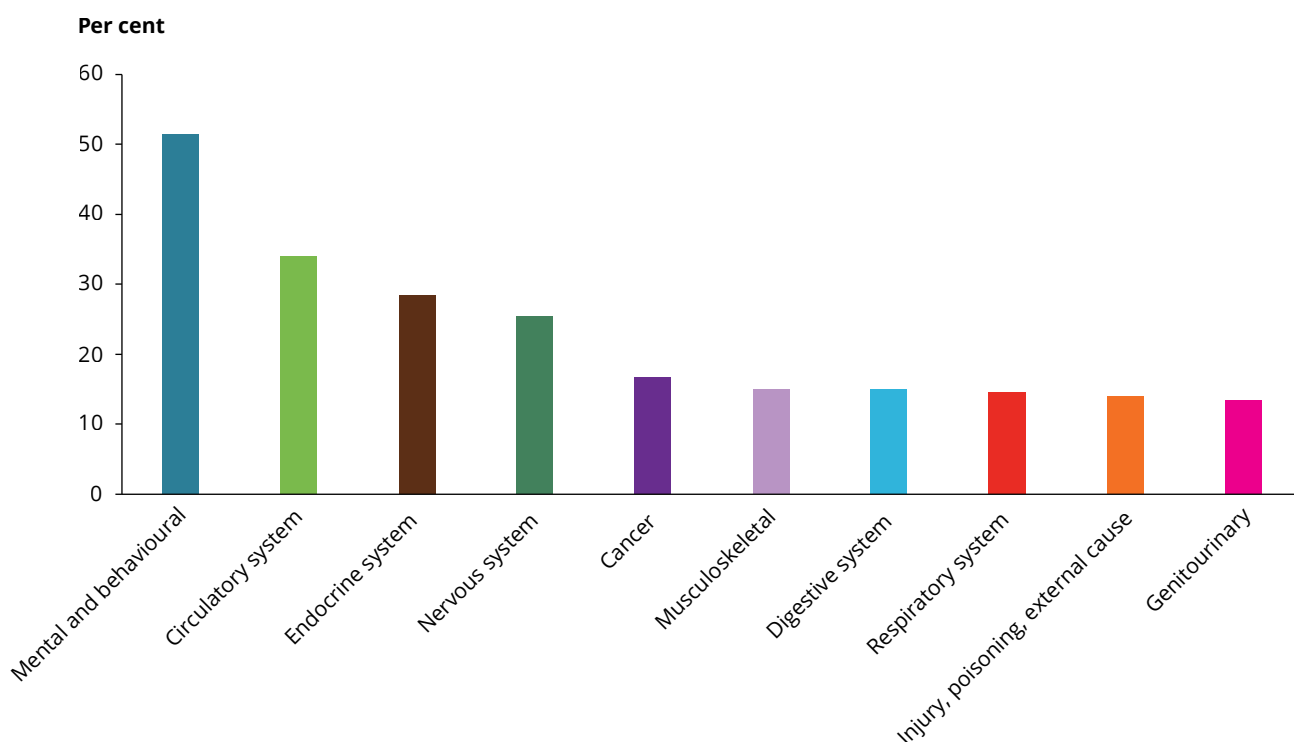
Before entering permanent care, people undergo a comprehensive assessment using the National Screening and Assessment Form (NSAF); assessments were previously conducted under the Aged Care Assessment Program by Aged Care Assessment Teams commonly known as ACATs. The NSAF captures details of a person's current care and health needs, activity limitations and support requirements, makes recommendations for their future care needs, and provides approval for formal aged care services. This section looks at younger people's circumstances at the time of the assessment when they were approved for permanent care.

Due to a change in assessment methods, with the NSAF coming into effect during 2015–16, assessment data captured through previous processes cannot be directly compared to NSAF data. For more information on changes in assessment process see *Box A1.1: Aged care programs included in PIAC*. For this reason, analysis of the circumstances of younger people approved for aged care is based on NSAF data from 2016–17 onwards, that is, the 7,100 younger people whose first entry to permanent care was between 2016–17 and 2019–20.

The NSAF captures information on an individual's health through reporting of health conditions that can include physical or mental health conditions, disability or signs/symptoms. Health conditions may or may not be formally diagnosed, and not every health condition reported for an individual may impact their ability to carry out day-to-day personal, household or social activities, or be a contributing factor in an individual's need for aged care services. The analysis presented below looks at how frequently health conditions or groups were recorded for the study cohort; it does not consider combinations of health conditions or co-morbidity for individuals.

More than 9 in 10 (91%) younger people had at least one health condition recorded at their comprehensive assessment, with 2 in 3 (65%) having multiple health conditions recorded. Half (51%) of these 7,100 younger people had a mental or behavioural condition, e.g. dementia, at the time of assessment. The next most common health condition groups were circulatory system conditions, e.g. stroke (34%), endocrine conditions, e.g. type 2 diabetes (28%), nervous system conditions, e.g. epilepsy (25%) and cancer (17%) (Figure 3.1).

Figure 3.1 Younger people who first entered permanent care by top 10 health condition groups, 2016–17 to 2019–20



Source: AIHW analysis of PIAC 2020 (Table S3.1).

Notes:

Includes only younger people whose first entry to permanent care was between 2016–17 and 2019–20.

Health conditions data are available from 2016–17 only.

A person could have more than one health condition group recorded.

Mental and behavioural conditions were the most commonly recorded health conditions across all age groups. The next most common recorded health condition groups differed by age group (Figure 3.2) including:

- Nervous system conditions were more commonly reported for younger people aged less than 45 than any other age groups.
- Injury, poisoning and other external causes were also more commonly recorded for younger people aged less than 50 years.
- Circulatory systems conditions were more common for younger people aged 50 and over.

Figure 3.2 Younger people who first entered permanent care by top 5 health condition groups and age group, 2016–17 to 2019–20

		Age group (years)					
		<45	45–49	50–54	55–59	60–64	Total
1st		Mental and behavioural (45%)	Mental and behavioural (47%)	Mental and behavioural (49%)	Mental and behavioural (54%)	Mental and behavioural (51%)	Mental and behavioural (51%)
2nd		Nervous System (42%)	Nervous System (33%)	Circulatory system (33%)	Circulatory system (30%)	Circulatory system (37%)	Circulatory system (34%)
3rd		Injury, poisoning (25%)	Circulatory system (28%)	Nervous System (28%)	Endocrine system (29%)	Endocrine system (30%)	Endocrine system (28%)
4th		Circulatory system (21%)	Endocrine system (22%)	Endocrine system (27%)	Nervous System (25%)	Nervous System (23%)	Nervous System (25%)
5th		Endocrine system (17%)	Digestive system (16%) Injury, poisoning (16%)	Cancer (16%)	Cancer (17%)	Musculoskeletal system (17%)	Cancer (17%)

Source: AIHW analysis of PIAC 2020 (Table S3.1).

Notes:

Includes only younger people whose first entry to permanent care was between 2016–17 and 2019–20.

Health conditions data are available from 2016–17 only.

A person could have more than one health condition group recorded.

The top 4 health condition groups recorded were similar for males and females (mental and behavioural, circulatory system, endocrine system and nervous system). The biggest difference was seen in circulatory system health conditions, with 37% of males having a circulatory system health condition recorded, compared with 30% of females.

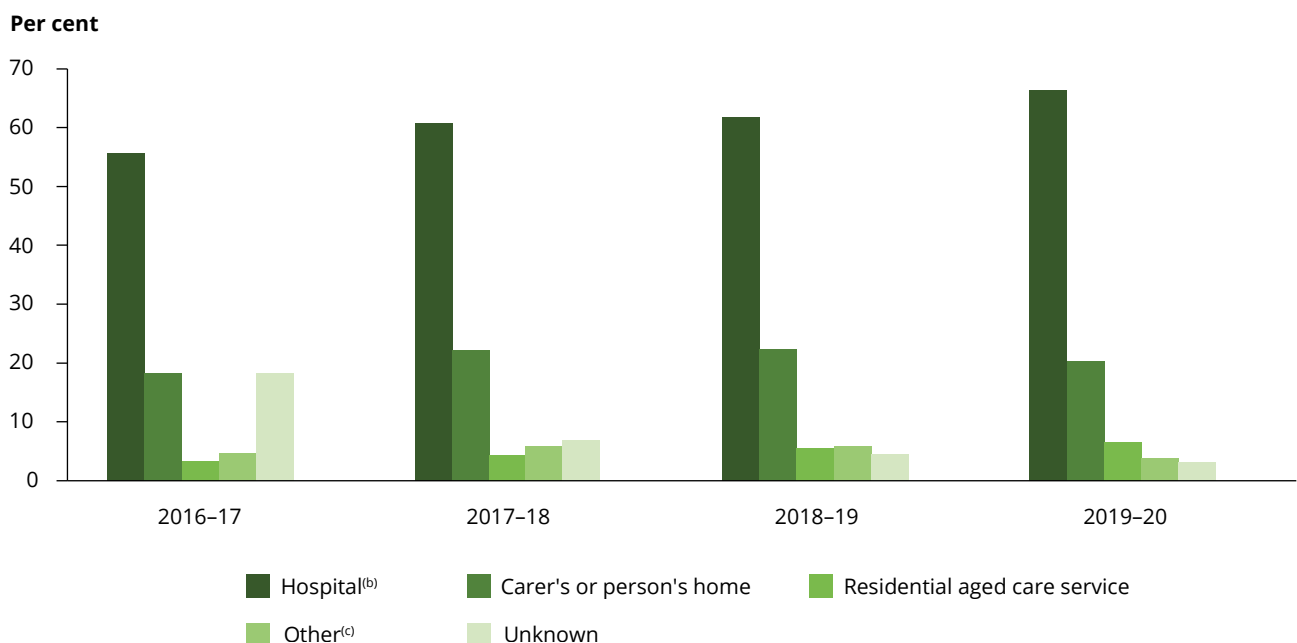
More than 1 in 4 (26%) younger people with no previous aged care use prior to entering permanent care had cancer recorded; considerably higher than younger people with previous aged care use (14%).

Dementia was the most commonly reported health condition; recorded for more than 1 in 6 (18%) younger people. High blood pressure (17%), Type 2 diabetes (16%), depression/mood affective disorders (15%) and chronic lower respiratory diseases (12%) were the next most common health conditions. Health conditions differed by age, sex and Indigenous status; key points include:

- Injuries to the head were the most common health condition recorded for younger people aged less than 45 years (17%).
- Schizophrenia was the fourth highest health condition for younger people in the 0–44, 45–49, and 50–54 age groups. In contrast, Schizophrenia did not appear within the top 5 health conditions for the 55–59 and 60–64 age groups.
- Depression/mood affective disorders were the only health condition to appear in the top 5 for each age group.
- Stroke was considerably higher for males (12%) compared with females (6.5%).
- Almost 1 in 5 Other Australians (19%) had dementia recorded, compared with 11% of Indigenous Australians.
- Type 2 diabetes was the most common health condition recorded for Indigenous Australians (29%), compared with 15% for Other Australians.

Across the 4 years, the setting in which permanent care approved assessments occurred has largely remained unchanged, with hospitals the most common setting for younger people entering permanent care for the first time (56% in 2016–17, increasing to 66% in 2019–20). The second most common assessment setting was at the carer’s or person’s home (18% of those first entering in 2016–17 and 20% of those first entering in 2019–20) (Figure 3.3).

Figure 3.3 Younger people who first entered permanent care, by assessment setting^(a) and year of admission, 2016–17 to 2019–20



Source: AIHW analysis of PIAC 2020 (Table S3.2).

Notes:

Includes only younger people whose first entry to permanent care was between 2016–17 and 2019–20.

a) Assessment setting data are available from 2016–17 only.

b) Hospital includes private, public, acute and inpatient settings.

c) Includes clinics and other community settings.

Time between assessment and entry

Of the 7,100 younger people entering permanent care for the first time since 2016–17, one in three (35%) entered within a month from assessment. This was followed by 29% of younger people entering within one to under three months, 11% entering within three to under six months, and 16% entering within six months or more. It should be noted that an individual may access other aged care services in the time between assessment and entry into permanent care. Comparing age groups, younger people under 50 were more likely to enter permanent care within a month from assessment (37%), compared with those aged 60–64 (33%). For times between assessment and entering of one month and greater, proportions were similar across the age groups (Table 3.1). Only slight differences in the length of time between assessment and entry into permanent care were seen between males and females (Table S3.3).

Table 3.1. Number and proportion of younger people living in permanent care by time between assessment and entry to permanent care and age group, 2016–17 to 2019–20

Time between assessment and entry in permanent care	<50	50–54	55–59	60–64	Total
	Number				
Under 1 month	210	328	663	1,305	2,506
1 month to under 3 months	167	264	510	1,150	2,091
3 months to under 6 months	62	88	187	421	758
6 months and over	86	112	280	661	1,139
No assessment identified ^(b)	46	71	151	375	643
Total	571	863	1,791	3,912	7,137
	Per cent (%)				
Under 1 month	36.8	38.0	37.0	33.4	35.1
1 month to under 3 months	29.2	30.6	28.5	29.4	29.3
3 months to under 6 months	10.9	10.2	10.4	10.8	10.6
6 months and over	15.1	13.0	15.6	16.9	16.0
No assessment identified ^(a)	8.1	8.2	8.4	9.6	9.0
Total	100.0	100.0	100.0	100.0	100.0

Source: AIHW analysis of PIAC 2020 (Table S3.3).

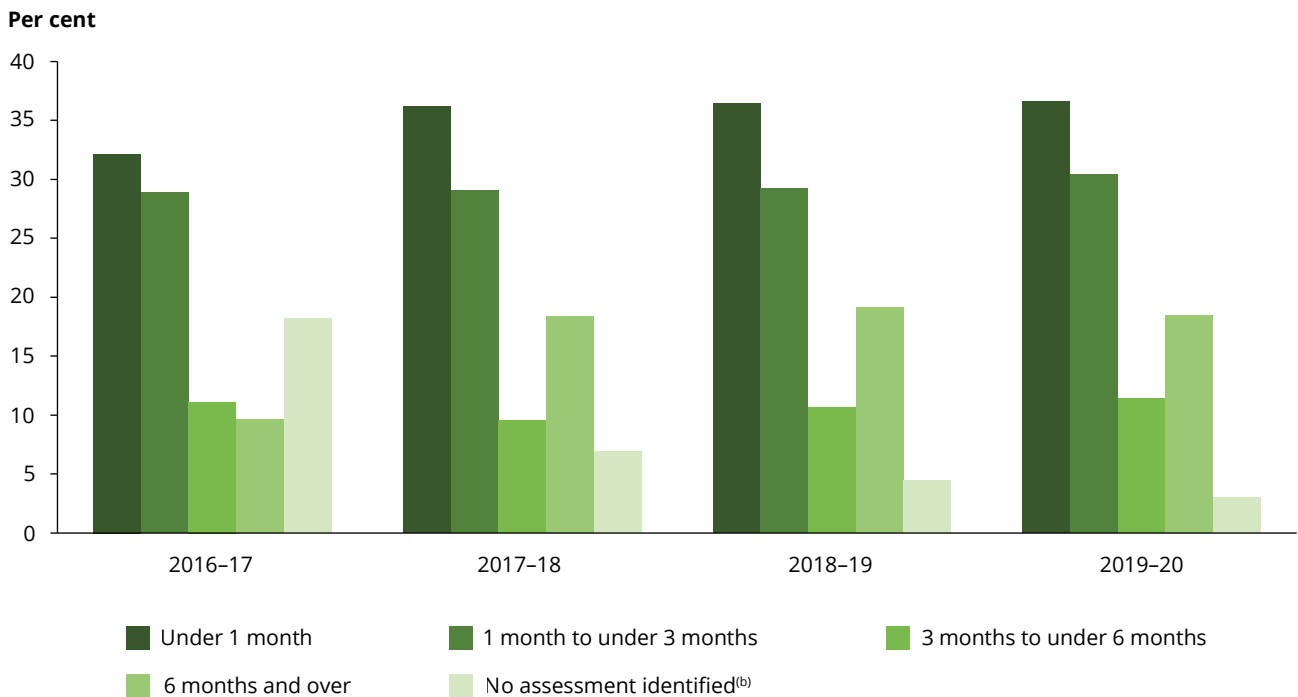
Notes:

Includes only younger people whose first entry to permanent care was between 2016–17 and 2019–20.

a) Includes people with no assessment information and people who had more than one permanent care approved assessment and therefore a time value could not be calculated.

The length of time between assessment and entry to permanent care has changed over time. Younger people entering within a month has increased from 32% of the cohort entering in 2016–17 to 37% of the cohort entering in 2019–20. In addition, younger people entering after six months or more has increased from 10% of the cohort entering in 2016–17 to 18% of the cohort entering in 2019–20. While these changes have been observed across the years, it is important to note the proportion of people with no assessment information has decreased over the same period, likely indicating improvements to the data quality (Figure 3.4).

Figure 3.4 Younger people’s time between assessment and entry (a) by year of entry to permanent care, 2016–17 to 2019–20



Source: AIHW analysis of PIAC 2020 (Table S3.4).

Notes:

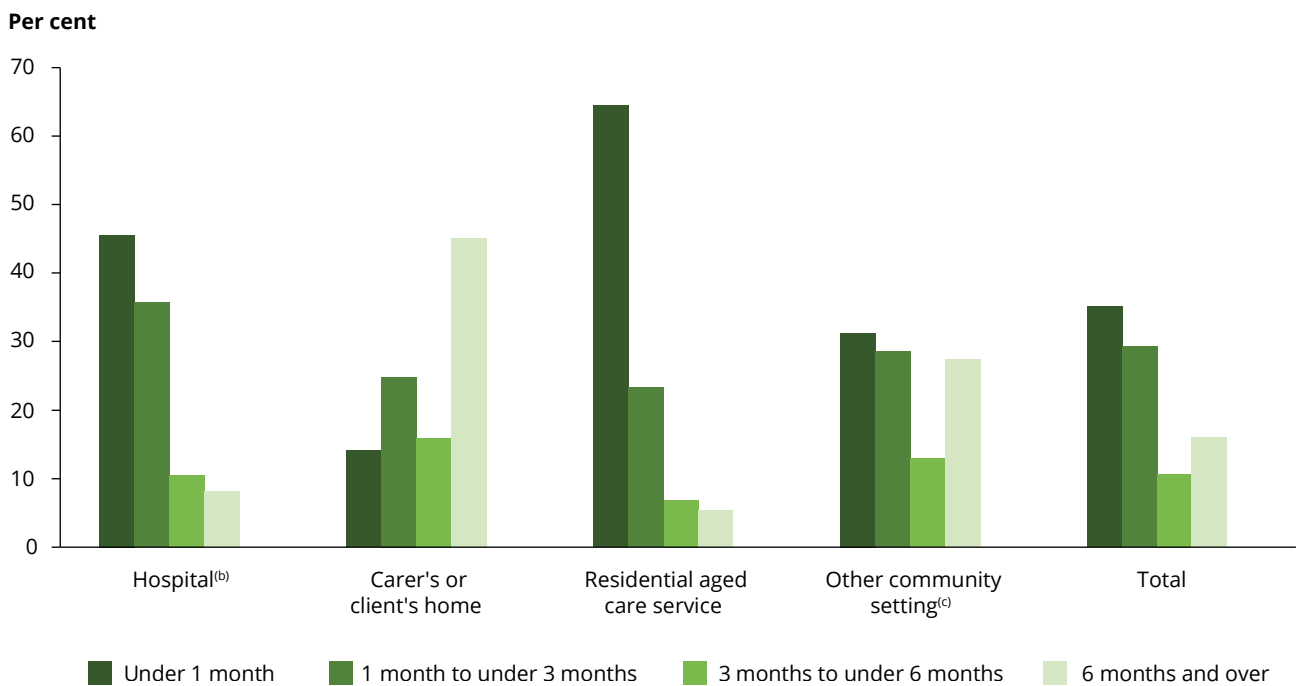
Includes only younger people whose first entry to permanent care was between 2016–17 and 2019–20.

a) Assessment data are available from 2016–17 and onwards.

b) Includes people with no assessment information and people who had more than one permanent care approved assessment and therefore a time value could not be calculated.

The amount of time between assessment and entry to permanent care was found to differ according to the assessment setting. Of the 4,300 younger people who had their assessment at a hospital, 46% entered within a month and a further 36% entered within 1 to under 3 months. Younger people who had their assessments at the carer's or person's home experienced the longest time between assessment and entering, with 45% of people entering six months or more after assessment. Of the 340 younger people who had their assessment at a residential aged care service, two-thirds (64%) entered within a month (Figure 3.5). Assessments that occur within a residential aged care service may result in emergency entries into permanent care or entries where a respite care approval was already in place.

Figure 3.5 Younger people's time between assessment and entry^(a) by assessment setting, 2016–17 to 2019–20



Source: AIHW analysis of PIAC 2020 (Table S3.5).

Notes:

Includes only younger people whose first entry to permanent care was between 2016–17 and 2019–20.

a) Assessments data are available from 2016–17 and onwards.

b) Hospital includes private, public, acute and inpatient settings.

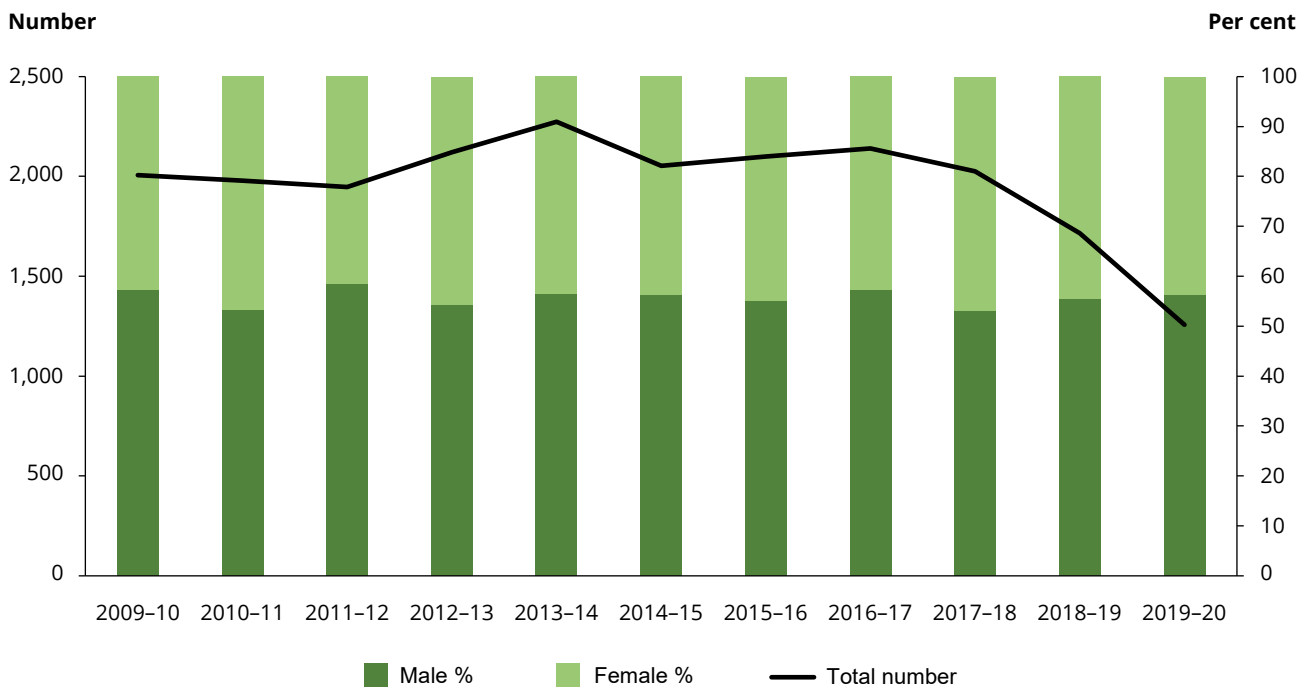
c) Includes clinics and other community settings.

Whether a person lives alone or has support from those they live with can be a contributing factor to the length of time it took to enter permanent care. Around 3 in 4 younger people living alone (74%) or living with friends or others (74%) entered permanent care within 3 months of assessment (compared with 66% of younger people living with family or a partner). More than 1 in 5 younger people living with family or a partner (21%) entered permanent care 6 months or more after assessment (compared with 14% of younger people living alone and 17% of younger people living with friends or others).

Characteristics of younger people at first entry

Over the last decade, the number of first-time entries of younger people to permanent care has decreased to 1,300 in 2019–20, after peaking at 2,300 in 2013–14. Although the number of first-time entries of younger people to permanent care has decreased to its lowest level in 2019–20, the proportions by sex have remained relatively stable over the study period. Slightly more males (56%) than females (44%) entered permanent care in 2019–20, with similar proportions observed in other years (Figure 3.6).

Figure 3.6 Younger people entering permanent care for the first time by sex and year, 2009–10 to 2019–20

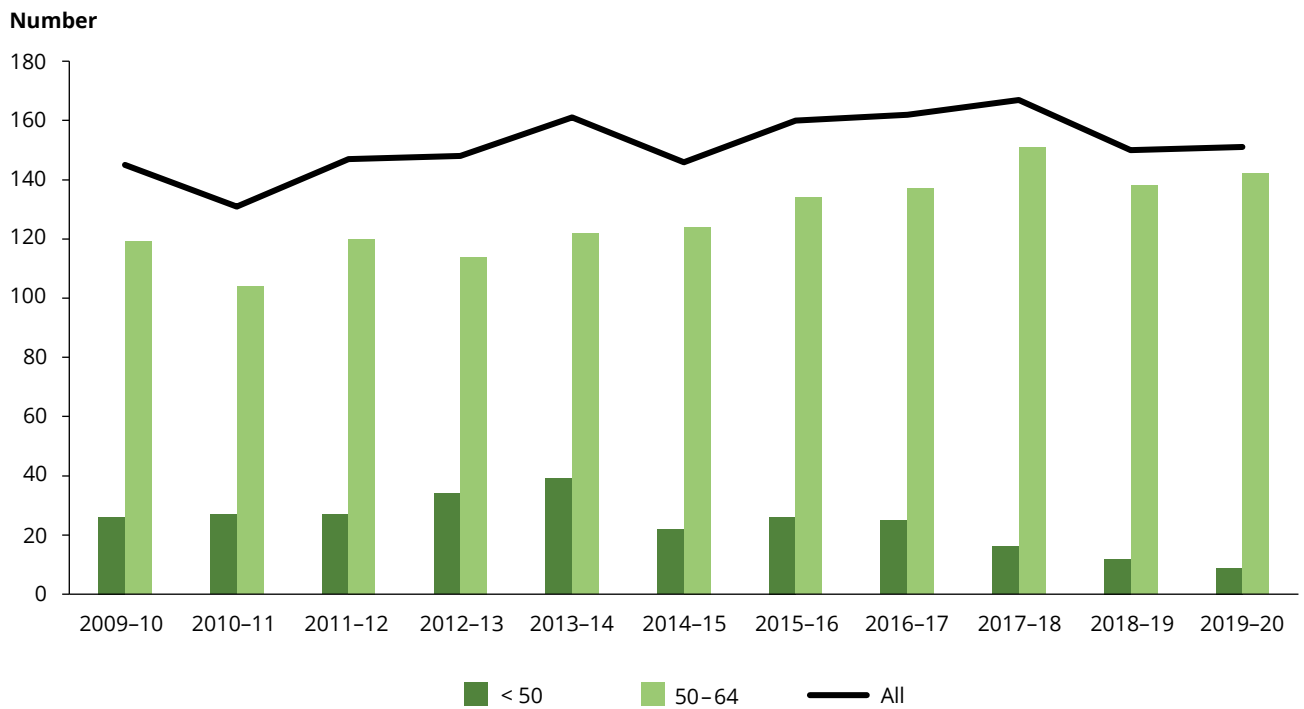


Source: AIHW analysis of PIAC 2020 (Table S3.6).

Note: Includes only younger people whose first entry to permanent care was between 2009–10 and 2019–20.

Across the years, the number of first-time entries of younger Indigenous Australians to permanent care has varied from 130 to 170 people, with approximately 150 Indigenous Australians entering in 2019–20. First-time entries to permanent care decreased for Indigenous Australians under 50, going from a peak of 40 entries in 2013–14 down to approximately 10 entries in 2019–20. For Indigenous Australians aged 50 to 64, first-time entries have increased over the years, from 120 entries in 2009–10 to 140 entries in 2019–20 (Figure 3.7).

Figure 3.7 Younger Indigenous Australians entering permanent care for the first time by age group and year, 2009–10 to 2019–20



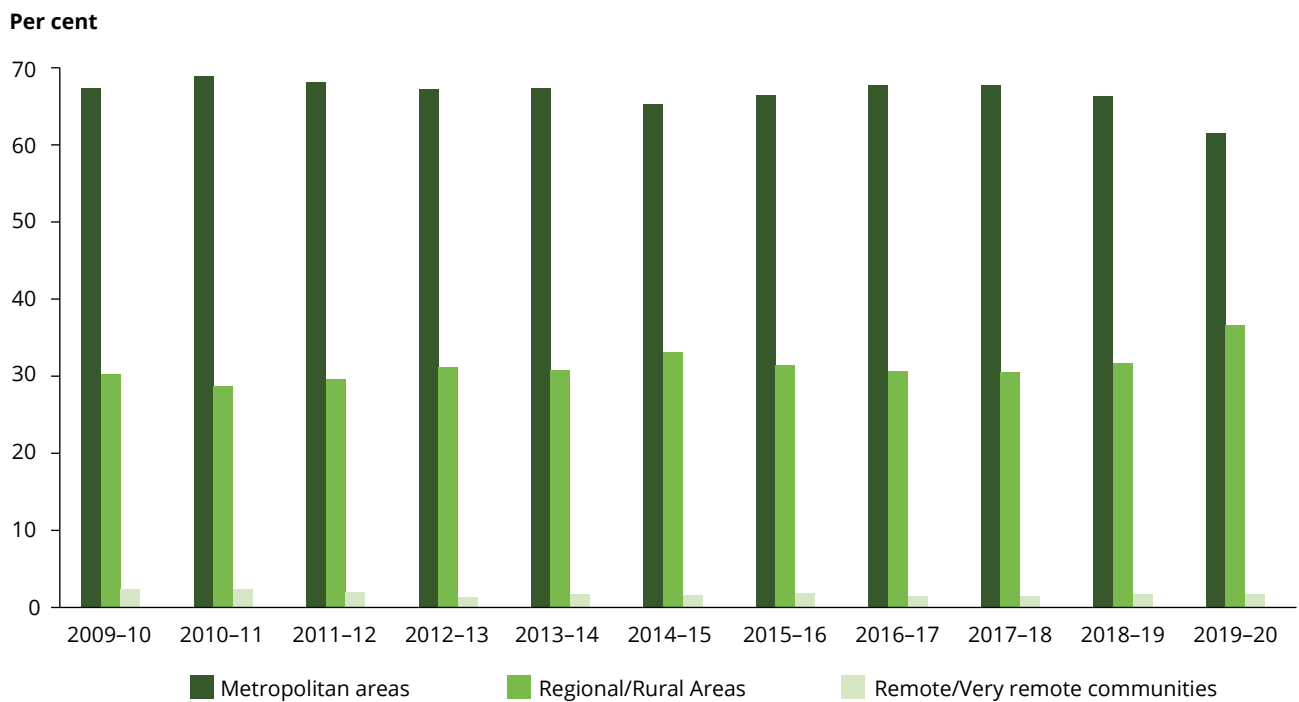
Source: AIHW analysis of PIAC 2020 (Table S3.7).

Note: Includes only younger people whose first entry to permanent care was between 2009–10 and 2019–20.

The number of first-time entries of younger Other Australians to permanent care has declined from a high of 2,100 in 2013–14 to 1,100 in 2019–20. For Other Australians, declines in first-time entries to permanent care were observed in both the under 50 and the 50–64 age group. For the under 50 age group, first time entries peaked at 220 entries in 2012–13 before declining to 70 entries in 2019–20. Similarly, the 50–64 age group peaked at 1,900 in 2013–14 before decreasing to 1,000 entries in 2019–20 (Table S3.6).

Throughout the study period, most first-time entries of younger people to permanent care occurred in metropolitan areas, peaking at 69% in 2010–11 before decreasing to its most recent level of 62% in 2019–20. The proportion of first-time entries in regional and rural areas fluctuated before increasing each year from 2017–18, to a peak of 37% of first-time entries in 2019–20 (Figure 3.8).

Figure 3.8 Younger people entering permanent care for the first time by remoteness area (Modified Monash Model) and year, 2009–10 to 2019–20



Source: AIHW analysis of PIAC 2020 (Table S3.8).

Note: Includes only younger people whose first entry to permanent care was between 2009–10 and 2019–20.

Pathways into permanent care

Of the 21,600 younger people to have their first entry to permanent care from 2009–10 and onwards, nearly 1 in 5 (19%) had no prior contact with an aged care service. This differed by age, with people aged 45 and under more likely to have no previous history of aged care use (26%), compared with people aged 60–64 (18%). Across all age groups, formal home support was the most used aged care service prior to permanent care entry; ranging between 65% to 69% across the age groups. The second highest service used was respite care, with increasing use by age; 28% for people under 45 years of age, increasing to 39% for people aged 60–64 (Table 3.2).

Table 3.2: Number and proportion of younger people living in permanent care by previous aged care use and age group, 2009–10 to 2019–20^(a)

Previous aged care use	<45	45–49	50–59	60–64	Total
	Number				
Formal home support ^(b)	552	824	5,572	7,730	14,678
Home care packages ^(c)	23	43	680	1,432	2,178
Transition care ^(d)	33	53	587	1,134	1,807
Respite care	238	401	2,951	4,356	7,946
<i>Any aged care service</i>	629	953	6,594	9,303	17,479
No previous aged care service	222	286	1,646	1,982	4,136
Total^(e)	851	1,239	8,240	11,285	21,615
	Per cent (%)				
Formal home support ^(b)	64.9	66.5	67.6	68.5	67.9
Home care packages ^(c)	2.7	3.5	8.3	12.7	10.1
Transition care ^(d)	3.9	4.3	7.1	10.0	8.3
Respite care	28.0	32.4	35.8	38.6	36.8
<i>Any aged care service</i>	73.9	76.9	80.0	82.4	80.9
No previous aged care service	26.1	23.1	20.0	17.6	19.1
Total^(e)	100.0	100.0	100.0	100.0	100.0

Source: AIHW analysis of PIAC 2020.

Notes

- a) Excludes people who had their first entry before 2009–10.
- b) Home and Community Care (HACC) or Commonwealth Home Support Programme (CHSP).
- c) Home care or pre-2013 programs (Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH), Extended Aged Care at Home—Dementia (EACHD)).
- d) Transition care includes short-term restorative care.
- e) Sum of items will not equal total as a person could have accessed more than one aged care service.

Receiving a formal home support service prior to entering permanent care was the most common pathway for younger people first entering permanent residential aged care; a third (34%, 7,400) followed this pathway. The next most common pathways were formal home support and respite care (20%), and no previous aged care service use (19%). Pathways differed by age with younger people aged less than 50 years more likely to enter permanent care having used only formal home support (41%) or no other aged care services (24%), than those aged 50 and over (Table 3.3).

Table 3.3: Number and proportion of younger people living in permanent care by pathway into permanent care and age group, 2009–10 to 2019–20

Aged care service(s) used prior to permanent care	<50	50–54	55–59	60–64	All
	Number				
Formal home support	852	1,033	1,921	3,613	7,419
Formal home support and respite care ^(a)	423	549	1,103	2,198	4,273
No aged care use	508	607	1,039	1,982	4,136
Respite care	161	254	527	1,100	2,042
Other	146	331	876	2,392	3,745
Total	2,090	2,774	5,466	11,285	21,615
	Per cent (%)				
Formal home support	40.8	37.2	35.1	32.0	34.3
Formal home support and respite care ^(a)	20.2	19.8	20.2	19.5	19.8
No aged care use	24.3	21.9	19.0	17.6	19.1
Respite care	7.7	9.2	9.6	9.7	9.4
Other	7.0	11.9	16.0	21.2	17.3
Total	100.0	100.0	100.0	100.0	100.0

Source: AIHW analysis of PIAC 2020.

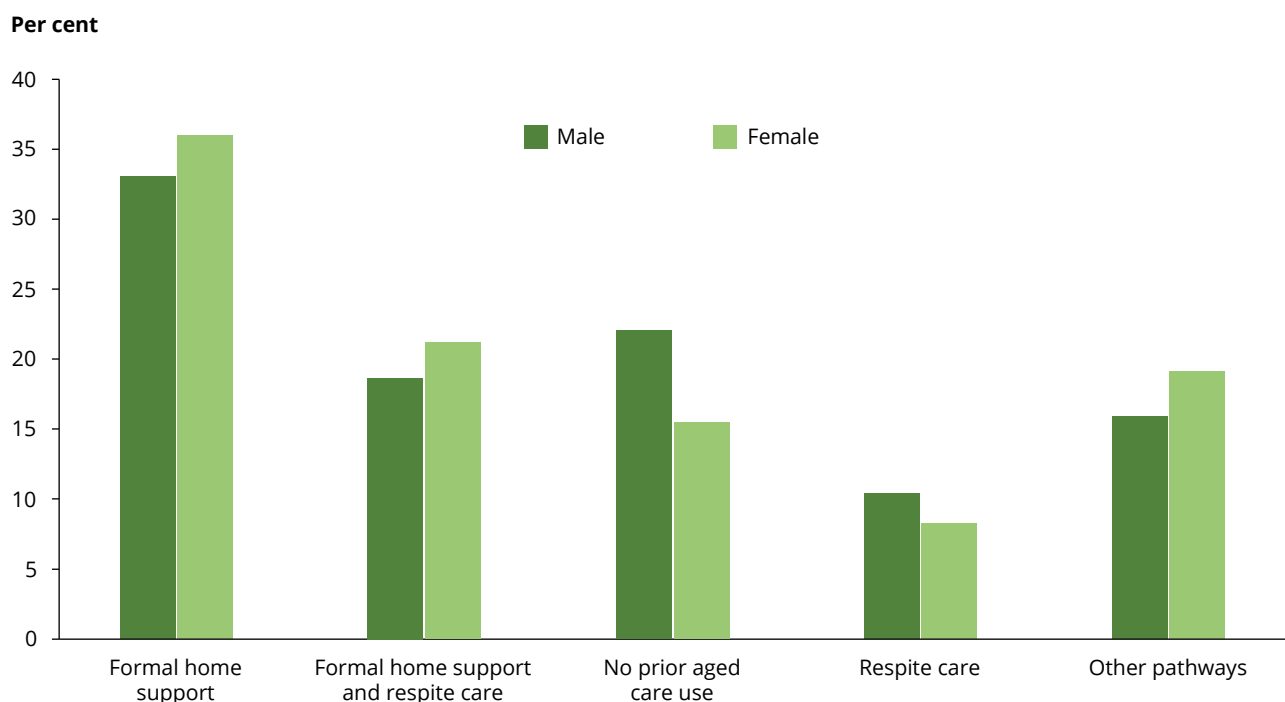
Notes:

Excludes people who had their first entry before 2009–10.

Formal home support and respite care includes all combinations of formal home support and respite care prior to entering permanent care.

Differences in the pathways taken were evident for males and females. Males were more likely than females to enter permanent care with no recorded prior use of aged care services (22% for males compared with 15% for females). While for females, they were more likely to have used formal home support or formal home support and respite care (36% and 21%) compared to males (33% and 19%) (Figure 3.9).

Figure 3.9 Younger people's pathways into permanent care by previous aged care service(s) used and sex, 2009–10 to 2019–20



Source: AIHW analysis of PIAC 2020 (Table S3.9).

Note: Includes only younger people whose first entry to permanent care was between 2009–10 and 2019–20

Formal home support and respite care includes all combinations of formal home support and respite care prior to entering permanent care.

Circumstances of younger people approved for permanent residential aged care but did not enter

Whilst many younger people who are approved for permanent care go on to enter, others do not. This section looks at the 3,900 people who had a permanent care approved assessment in 2016–17 and focuses on the 1,800 younger people who never entered permanent care despite having an approved assessment.

Assessments in 2016–17 were chosen as this allows analysis of the NSAF data and a subsequent two-year period to follow younger people's aged care journey.

Of the 3,900 younger people who had a permanent care approved assessment in 2016–17:

- almost half (48%, 1,900) entered permanent care within a year of the assessment
- around 1 in 14 (7.2%, 280) entered after a year
- the remaining 45% (1,800) never entered permanent care.

A number of differences in the circumstances of younger people who are approved for permanent care and whether they go on to enter or not were found, including:

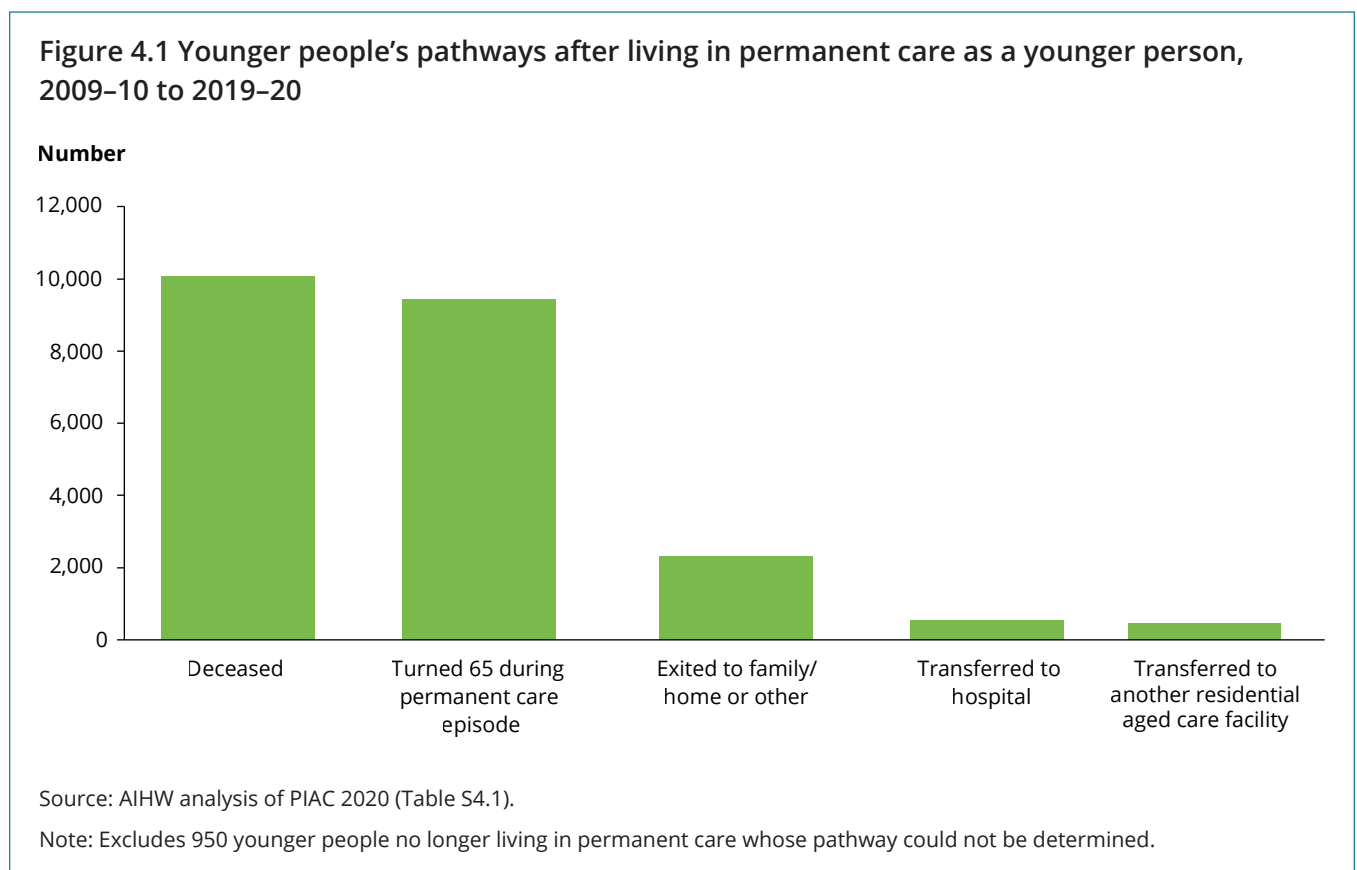
- Nearly 2 in 5 (37%, 650) younger people who had not entered permanent care had died within a year of the assessment.
- Younger Indigenous Australians were less likely to enter permanent care (69% (340) of Indigenous Australians had not entered permanent care; compared with 41% (1,400) of Other Australians). As noted in the introduction, there are Indigenous-specific aged care programs that can provide residential-like services. The current data does not capture how many younger Indigenous Australians entered permanent care in one of these programs.
- Younger people living in remote and very remote communities were less likely to enter (63% (55) did not enter compared with a range of 41% (910) in metropolitan areas to 52% (120) in medium rural towns).
- Younger people assessed at the carer's or person's house were less likely to enter (58% (860) did not enter compared with 35% (730) of people assessed at a hospital).
- A younger person living with family or others was less likely to enter (48% (1,100) did not enter compared with 41% (580) of people living alone).
- Around 3 in 5 (62%, 480) people with cancer had not entered permanent care; this was the highest percentage of any health condition.

4 Younger people's pathways after permanent residential aged care

This section focuses on younger people's pathways after permanent residential aged care (permanent care). By 30 June 2020, most of the study cohort (85%, 23,800) were no longer considered to be younger people living in permanent care (the remaining 15% (4,100) of the study cohort were still living in permanent care as a younger person). This section focuses on these 23,800 people and their pathway after living in permanent care as a younger person.

The main reason younger people were no longer living in permanent care was due to death, with 42% (10,100) dying during a permanent care episode and before the age of 65. A further 40% (9,500) of younger people turned 65 during a permanent care episode, that is, they 'aged out' of the younger people cohort whilst living in permanent care. After ageing out of the younger people cohort, half of these people had died by the end of the study period (51%, 4,400) and 45% (4,300) were still living in permanent care aged 65 or older.

One in 10 younger people were no longer living in permanent care due to exiting to different accommodation, such as returning to family or home (10%, 2,300) (Figure 4.1).



Only limited analysis is possible with the data available after a person leaves permanent care. While exploration is possible if a person re-enters permanent care at a later stage or if they use any other aged care services in scope, nothing further is known about supports provided outside of the aged care sector. Future projects that address this limitation by exploring how the health and disability sectors support younger people who have lived, are living in, or are at risk of living in, permanent care are discussed in *Chapter 6 Where to from here?*

5 Younger people at risk of entering permanent residential aged care

The reasons behind why younger people live in permanent residential aged care (permanent care) are wide-ranging and diverse. This makes identifying younger people at risk of entering permanent care, complex. Some younger people may live in permanent care as the result of an isolated event such as an acquired brain injury. Other younger people may live in permanent care due to an ongoing, chronic health condition or disability. For some younger people, there can be a combination of both ongoing circumstances and a sudden event that can lead to entry into permanent care.

Analysis presented in *Chapter 3 Younger people's pathways into permanent residential aged care*, identified the most common circumstances at assessment for younger people who went on to live in permanent care. These results can inform what cohorts of younger people may be at particular risk of entering permanent care. Based on this analysis, younger people who may be at risk of entering permanent care, may be younger people:

- with dementia, schizophrenia or another type of mental or behavioural health condition
- who live alone and do not have support from someone at home.

Whilst the current data are limited in the ability to explore this last point in more detail, similar circumstances that may put younger people at risk of entering permanent care include where a younger person's support needs exceed the capacity of their support network or their home, for example where full-time care or home modifications are required.

Given the complexities involved in identifying younger people who may be at risk of entering permanent care, further exploration and analysis in this area would be of value. The cohorts listed above are limited examples based on the current analysis. These cohorts, along with additional cohorts of interest, are discussed further in *Chapter 6 Where to from here?*

6 Where to from here?

The analysis presented in this report has demonstrated the value of integrating information in providing a longitudinal person-based view of aged care use across programs, from early assessments, to pathways through care to end of life. In addition, it has shown where data from different sources and other sectors could inform a more comprehensive picture of how health and disability services interact with the aged care system to support younger people who are living in, or at risk of entering, permanent care.

Work is currently underway on two projects that will explore these interactions:

1. *Aged care, health and hospital services*: health service and hospital data is being used to further explore the temporal circumstances leading to entry to permanent care, including the transition from hospital to permanent care, and health service use patterns during and after younger people live in permanent care, including primary health care and prescriptions dispensed (using Medicare Benefits Schedule and Pharmaceutical Benefits Scheme data).
2. *Aged care, disability and NDIS services*: disability services and NDIS data is being used to better understand the characteristics of younger people with disability living in permanent care, and service pathways before admission and after exiting permanent care.

There are several additional special populations among younger people in permanent care including, people who are homeless, people with younger onset dementia, veterans and younger Indigenous Australians. Some of these groups are identified as special needs groups in aged care legislation and can access entry from a younger age, and other groups may have unique care needs. Further analysis of these groups would provide insights into the circumstances of younger people who are at risk of entering permanent care.

Since the end of the study period (30 June 2020), progress has been made against YPIRAC targets agreed by Government, and the number of younger people living in permanent care has declined steadily since 2019 – at 30 June 2022, there were 2,934 younger people living in permanent care (AIHW 2022). Ideally, any future analysis will include an expanded time period that allows for further exploration over this period of decline.

Over the longer term, the development of a National Aged Care Data Asset, currently being scoped by the AIHW as part of a suite of aged care data improvement activities in response to the final recommendations from the Royal Commission into Aged Care Quality and Safety, will facilitate further analysis. The data asset will be a multi-source enduring linked data set that integrates people-centred data related to aged care. The data asset will create connections between aged care, health and welfare-related data to augment the information that is collected by these data sources individually.

Appendix A: Methods and data sources

The Pathways in Aged Care (PIAC) link map

The Pathways in Aged Care (PIAC) link map connects millions of records allowing people's pathways through the aged care system to be studied. While national unit record level data are available for most of the aged care programs, the data collections for the different programs do not use a common client identifier, and so are not fully integrated. The PIAC link map brings the data together at a person level using statistical data linkage processes. The PIAC link map is a person level concordance file that contains the relationship between all aged care identifiers, including deaths and a unique person identifier. A short description of the creation of the PIAC link map is provided below.

The PIAC link map was used to create analysis datasets that allow exploration of an individual's aged care service use, potentially all the way from assessment through to the end of their lives. This publication focused on younger people (a person aged less than 65 years) who lived in permanent residential aged care (permanent care) anytime between 2009–10 and 2019–20. PIAC analysis datasets were used to explore this YPIRAC cohort in detail including their pathways into permanent care and their pathways after permanent care.

PIAC link map methodology

The PIAC link map uses the Medicare Consumer Directory (MCD) as the spine for data linkage given the MCD consists of high-quality identifying linkage information over a long period of time at the person level. The MCD contains Medicare data for all persons enrolled in Medicare since its inception in 1984, and each person on the MCD has a unique personal identification number. The MCD contains very accurate information about person name, date of birth, sex and address, including the history of official name changes. To identify person level aged care use, all the aged care datasets included in the National Aged Care Data Clearinghouse (NACDC), and National Death Index (NDI) data were linked individually to the MCD based on available information on the person's name, date of birth, sex, address, and last date of program use and/or date of death. Both name- and key-based linkage were used, depending on the data available on the individual dataset.

More information on the linkage techniques used to create the PIAC link map can be found in the PIAC technical guide.

Aged care programs included in the PIAC linkage map are:

- permanent residential aged care
- respite residential aged care
- transition care and short-term restorative care
- home care (Home Care Packages Program and previous counterparts)
- home support (Commonwealth Home Support Program and its prior counterpart Home and Community Care).

Additionally, comprehensive assessment data from the Aged Care Assessment Program (ACAP) and National Screening Assessment Form (NSAF) is included for people who do, and do not, go on to engage in residential aged care.

Box A1.1: Aged care programs included in PIAC

The 3 mainstream types of aged care available are residential aged care, home support, and home care, as well as several flexible care programs. Not all aged care services and programs are captured in the NACDC. The following types of care are included in the NACDC and PIAC analysis datasets.

Residential aged care

Residential aged care provides accommodation and care at a facility on a permanent or respite (temporary) basis. Permanent residential aged care (permanent care) is intended for those who can no longer live at home due to increased care needs, while respite residential aged care (RRAC) provides a break from normal living arrangements. After entry to permanent care, people's care needs and health conditions are assessed using the Aged Care Funding Instrument (ACFI).

Home support

The Commonwealth Home Support Programme (CHSP) provides entry-level support at home for people as well as their carers. Services available through home support include domestic assistance, personal care, social support, allied health, and respite services. CHSP commenced on 1 July 2015, replacing Home and Community Care (HACC).

Like CHSP, HACC provided a large range of services to support people at home and to prevent premature or inappropriate admission to residential care. An Aged Care Assessment Team (ACAT) approval was not needed to access HACC services, and the program generally provided lower-level support: people with higher needs were more likely to require a Home Care Package (HCP) (or before July 2013, 1 of its predecessors). Prior to mid-2012, HACC was funded jointly by state and territory governments and the Australian Government, with states and territories responsible for managing the program. From 1 July 2012, the Australian Government assumed responsibility for HACC services provided to older people (all people aged 65 and over, and Indigenous Australians aged 50–64), which became known as 'Commonwealth HACC' (states and territories continued to fund and administer HACC services for people under this age). These arrangements did not extend to Victoria and Western Australia, where HACC services for people of all ages continued to be delivered as a jointly funded program (and this remained the case when Commonwealth HACC was incorporated into CHSP). Where this publication refers to 'HACC', this includes both Commonwealth HACC and its Victorian and Western Australian equivalents.

Home care

Home Care Packages (HCP) provide different levels of aged care services for people in their own homes. It is targeted towards people with needs that go beyond what home support can provide. Ongoing services are available to keep people well and independent (such as nursing care), stay in their home (through help with cleaning, cooking, and home maintenance) and remain connected to their community through transport and social support. HCP provides support at 4 levels of care for people living at home and are designed for those with more complex or intensive support needs than what CHSP can provide. In August 2013, HCP replaced 3 different community-based aged care packages programs: CACP, which corresponds to HCP level 2; EACH, which corresponds to HCP level 4; and EACHD, which also corresponds to HCP level 4. Many of the people who received community-based aged care packages before entry into permanent care during 2013–14 would have received services under 1 or more of the pre-July 2013 programs.

continued

Box A1.1 (continued): Aged care programs included in PIAC

There are also several types of flexible care available that extend from home support to residential aged care, including:

Transition care program

TCP provides short-term care to older people leaving hospital, and it aims to improve recipients' independence and functioning to delay their entry into permanent care. Access requires an ACAT approval, which must assess the person as medically stable, able to benefit from the program, and eligible for residential care if they applied for it. The person must be concluding an in-patient hospital episode (and still be in hospital). Care can be provided in the community or in home-like residential facilities.

Short-term restorative care (STRC)

STRC commenced in 2018 and provides early intervention services to reduce difficulty with everyday tasks and maintain or restore independence.

Aged Care Assessments

There are 2 aged care assessment programs; Regional Assessment Services (RAS) and Aged Care Assessment Program (ACAP). Assessors across both programs use the National Screening and Assessment Form (NSAF) to screen and assess older people for aged care services.

RAS assessors carry out assessments for home support for people who may need entry-level support. ACATs carry out comprehensive assessments under the ACAP for people with more complex needs. To access residential aged care (permanent care and RRAC), HCP (and before July 2013, CACP, EACH and EACHD—see below), TCP or STRC, people must have relevant ACAT approval. Approval can be given for more than 1 program at a time and people may be re-assessed as their situation changes.

During the study period, the assessment process changed with the NSAF coming in from 2016–17. Prior to this, there was not a universal assessment form for aged care services.

Abbreviations

ACAP	Aged Care Assessment Program
ACAT	Aged Care Assessment Team (conducting assessments under ACAP)
ACFI	Aged Care Funding Instrument
AIHW	Australian Institute of Health and Welfare
CACP	Community Aged Care Packages
CHSP	Commonwealth Home Support Programme
EACH	Extended Aged Care at Home
EACHD	Extended Aged Care at Home—Dementia
HACC	Home and Community Care
HCP	Home Care Packages [Program]
NACDC	National Aged Care Data Clearinghouse
NATSIFAC	National Aboriginal and Torres Strait Islander Flexible Aged Care
NDI	National Death Index
NDIS	National Disability Insurance Scheme
NSAF	National Screening Assessment Form
PIAC	Pathways in Aged Care
RRAC	Respite residential aged care
STRC	Short-term Restorative Care
TCP	Transition Care Program
YPIRAC	Younger people in residential aged care

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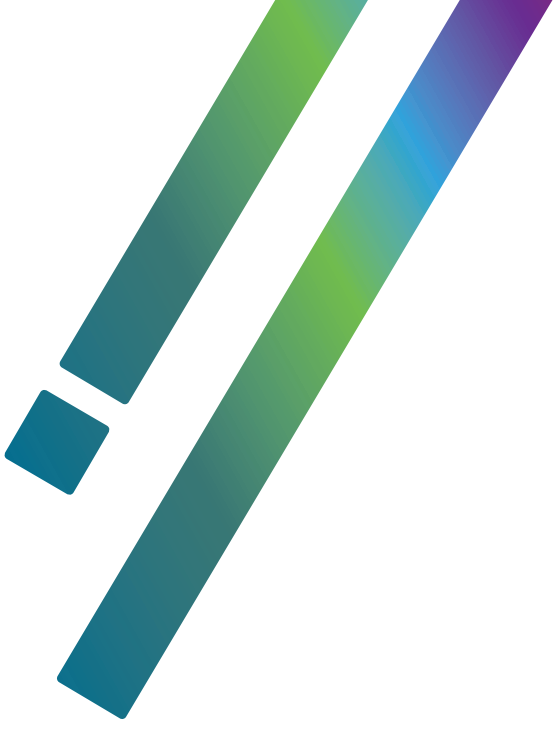
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Related publications

AIHW's dedicated aged care data website—GEN aged care data.

Australian Institute of Health and Welfare 2019. Pathways of younger people entering permanent residential aged care. Cat. no. AGE 89. Canberra: AIHW.



Aged care services in Australia are provided based on need and, due to a range of circumstances, younger people (aged less than 65 years) are living in permanent residential aged care. Using linked data, this report explores a cohort of more than 27,900 younger people who lived in permanent residential aged care at some stage over an 11-year period, between 2009–10 to 2019–20. Key characteristics and patterns of care use are presented.

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