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Interfaces between the aged care and health systems in Australia—where do older Australians die?

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Most Australians would prefer to die at home, rather than in hospital or residential aged care (Swerissen & Duckett 2014). However, many older people use both hospital and aged care services in their final years of life and often die in one of these settings. In particular, aged care plays a considerable role in caring for people at the end of their lives, either in the community or through residential aged care—and the older people are, the more likely they are to be living in residential aged care.

People's preferences may change over their lives as their health and circumstances change. In addition to where people die, it may also be important to consider whether people received the care they needed before death, and whether they were able to die well (PC 2018). Knowing where people die is an important first step towards planning and delivering palliative care, aged care and hospital services that support people's needs and preferences towards the end of life. In this way, where people die can be considered as one marker for their end-of-life care needs.

However, in isolation, no data source currently captures full information on where people die. By bringing multiple data sources together in a linked data set, it is possible to determine whether people had used hospital, residential aged care or other aged care near death and thus determine an indicative setting at death. The findings presented here complement other preliminary explorations seeking to fill this data gap using information captured on death certificates (ABS 2021). This report presents an alternative method for identifying where people die to inform future discussions on this important topic. For more information on the data sources and methods, see 'What's included in this report?'

Few older Australians (people aged 65 and over) die at home:

Hospital is the most common place of death (50% of deaths), followed by residential aged care (36%).



This changes as age increases:

Residential aged care is the most common place of death for people aged 85 and over (50%), followed by hospital (40%).



Of older people who had been living in residential aged care in the week before death, **4 in 5 (79%)** died in residential aged care. Of other older people, **7 in 10 (71%)** died in hospital.

What's included in this report?

This report forms part of a broader project to better understand how people in aged care use health services. The AIHW created a linked data set which covered people aged 50 and over for the period 2012–13 to 2016–17 and included data on:

- claims made under the Medicare Benefits Schedule (MBS)
- prescriptions dispensed under the Pharmaceutical Benefits Scheme (PBS) and the Repatriation Pharmaceutical Benefits Scheme (RPBS)
- deaths from the National Death Index (NDI)
- Emergency department presentations and hospital separations recorded via the National Non-Admitted Patient Emergency Department Care and the National Hospital Morbidity Database, respectively (including both public and private hospital data)
- aged care program use from the National Aged Care Data Clearinghouse (NACDC).

The data for emergency department presentations and hospital separations data included only Victoria and Queensland. The results presented here are for deaths in these 2 jurisdictions in 2016–17 for people aged 65 and over; the supplementary tables also include some data for people aged 50–64.

The process of bringing these data sources together and creating an analysis data set is outlined in *Interfaces between the aged care and health systems in Australia—movements between aged care and hospital 2016–17: technical document*. Hospital separations that were determined to relate to the same broader period of hospital use were combined into hospital stays and this concept is also used in this report (meaning, for example, that if a person moved between wards in hospital, this was counted as one hospital stay rather than as 2 separations). The technical document also highlights the linkage process and potential data gaps.

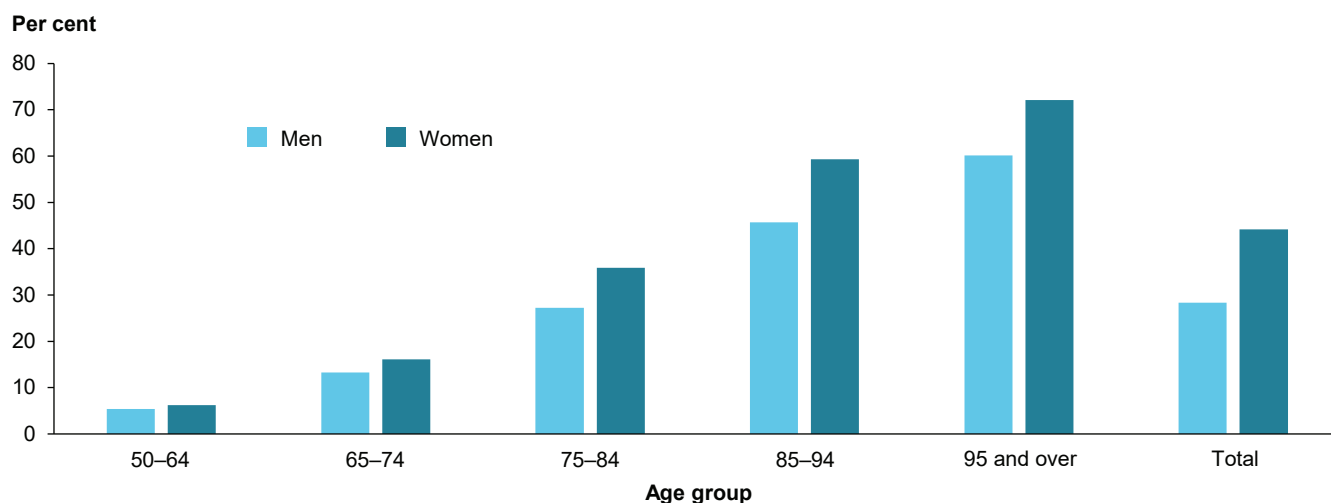
A set of hierarchical rules were developed to allocate 'setting at death' based on hospital stays, dates of aged care use and dates of death, with priority given to hospital and emergency department, followed by residential aged care, transition care, home care and finally home support. These rules are explained in Note 1 in the supplementary tables.

What care do older people receive at the end of their lives?

The majority of deaths in Australia happen in older age: in 2016–17, almost 149,000 people aged 50 and over died in Australia—131,000 (88%) were aged 65 and over, and almost 65,000 (44%) were aged 85 and over. In the years before death, many older people use aged care, with use ranging from days to years. In the last 2 years of life, over two-thirds (67%) of people aged 50 and over had used at least one aged care program. As could be expected, the use of aged care varied by age: three-quarters (75%) of people who died aged 65 and over had used aged care in the last 2 years (and 86% of those who died aged 85 and over), compared with only 10% of those aged 50–64.

In particular, many older people live in permanent residential aged care—this form of aged care provides both accommodation and daily care. People most commonly move into residential aged care in their 80s, and women outnumber men. Among those who died aged 65 and over, 52,700 people (36%) had used permanent residential aged care in the last 2 years (44% of women and 28% of men). This proportion increased as age increased (Figure 1).

Figure 1: Proportion of people who died aged 50 and over in Australia and had used permanent residential aged care in the previous 2 years, by sex and age group



Note: Data for this figure are available in supplementary table S1.

Source: Linked NDI, aged care and hospital data.

As with aged care, hospitalisation toward the end of life is common, and these hospitalisations may end with death in hospital. People who die in hospital may have been transferred there from residential aged care or the community, and they may have received palliative care services either in hospital or via another setting—some information on this is captured in hospital data, but it is not currently possible to identify these interactions reliably without linking different data sources across care settings. For example, linked data has been used to show that most people with dementia, who often have complex health care needs, were admitted to hospital at least once in their last month of life (AIHW 2020c). Many of these people may have been living in residential aged care, and this group of people are generally older, frail and have multiple health conditions.

Using linked data, it has also been shown that certain health conditions can affect people living in residential aged care in particular: for example, in 2016–17 respiratory diseases were a relatively more common cause of hospitalisation for people living in permanent residential aged care than for their counterparts in the community (AIHW 2019), and people who entered hospital from permanent residential aged care on account of respiratory diseases commonly died in hospital (AIHW 2020b).

The COVID-19 pandemic

The data in this report cover a period before the COVID-19 pandemic, which has had many global and local impacts. In 2020, residential aged care experienced some of Australia’s worst COVID-19 outbreaks and ongoing restrictions were in place for longer than in many other settings. This report presents baseline data which can be mapped against any future changes, for example to better understand how COVID-19 affected people living in residential aged care.

Currently, death registration data does not reliably capture a person’s place of death, but a pilot study undertaken by the Australian Bureau of Statistics showed that over 1 in 3 (35%) of in-scope deaths due to COVID-19 recorded residential aged care as the place of death (ABS 2021). A separate AIHW study showed that, of reported COVID-19 deaths in Australia to October 2020, almost 1 in 3 (30%) were for people who had dementia and the majority were for people aged 85 and over (AIHW 2021).

There were 57,700 Australians aged 65 and over who died in Victoria and Queensland in 2016–17. About half (49%) of the deaths were people aged 85 and over, and a similar proportion (51%) were women—in fact, women aged 85 and over accounted for 3 in 10 (29%) deaths of older Australians (Table S2).

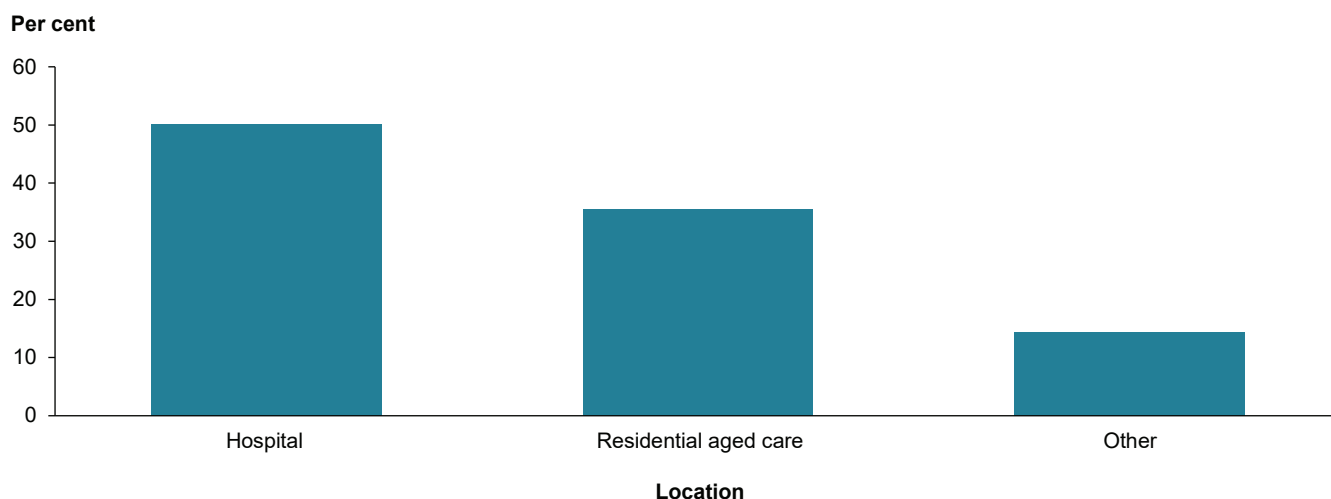
Overall, deaths among older people mostly take place in hospital

For half (50%) of deaths among older people in Victoria and Queensland in 2016–17, the setting at death was hospital (including emergency departments). Residential aged care was the second most common setting, accounting for over one-third (36%) of deaths (this included both permanent and respite residential aged care).

Note that for the purposes of this report, ‘setting at death’ is based on dates of service use; for example, people may leave residential aged care to die in another setting (other than hospital) and this would not necessarily be evident in the data. Further, some of the deaths that take place in hospital may relate to people who had been recently living in residential aged care but not immediately prior to death (for more on this, see ‘People who live in residential aged care towards the end of life commonly die in that setting’).

Few older Australians (14%) died somewhere other than hospital or residential aged care (Figure 2). In 7% of deaths, people had used other aged care beforehand (the aged care programs in scope were transition care, home care and home support), and in another 7% of deaths, older people were neither in hospital, residential aged care nor using other aged care near their death, meaning that the setting at death could not be determined using the data sources available here. Some deaths may take place in other health care settings, such as during an ambulance call-out, in non-admitted patient care or in hospices or other palliative care not captured by the hospital data; data for which were not in scope here.

Figure 2: People who died aged 65 and over in Victoria and Queensland, by setting



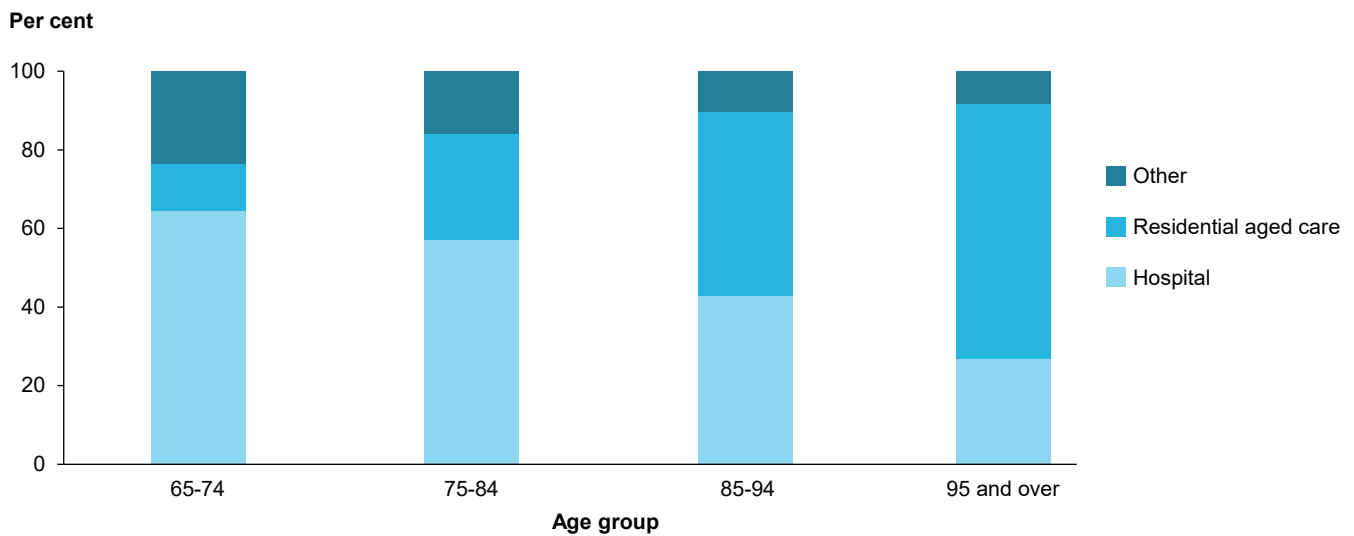
Note: Data for this figure are available in supplementary table S2.

Source: Linked NDI, aged care and hospital data.

‘Older’ older people are more likely to die in a residential aged care setting

People’s setting at death varied considerably by age: older people were more likely to die in residential aged care than in hospital, particularly those aged 85 and over. Almost half (47%) of people who died aged 85–94, and about two-thirds (65%) of those who died aged 95 and over, were in residential aged care at the time (Figure 3). This reflects the fact that most people enter residential aged care at older ages. On the other hand, people who died at younger ages were more likely to be in hospital at death (Figure 3).

Figure 3: People who died aged 65 and over in Victoria and Queensland, by setting and age group



Note: Data for this figure are available in supplementary table S2.

Source: Linked NDI, aged care and hospital data.

Men were more likely to have died in hospital (55%) or to not have been using aged care near death (9.6%) compared with women (45% and 5.2%, respectively). In contrast, women were more likely to be in residential aged care at death than men (43% compared with 28%). These patterns were similar across all age groups (Table S2).

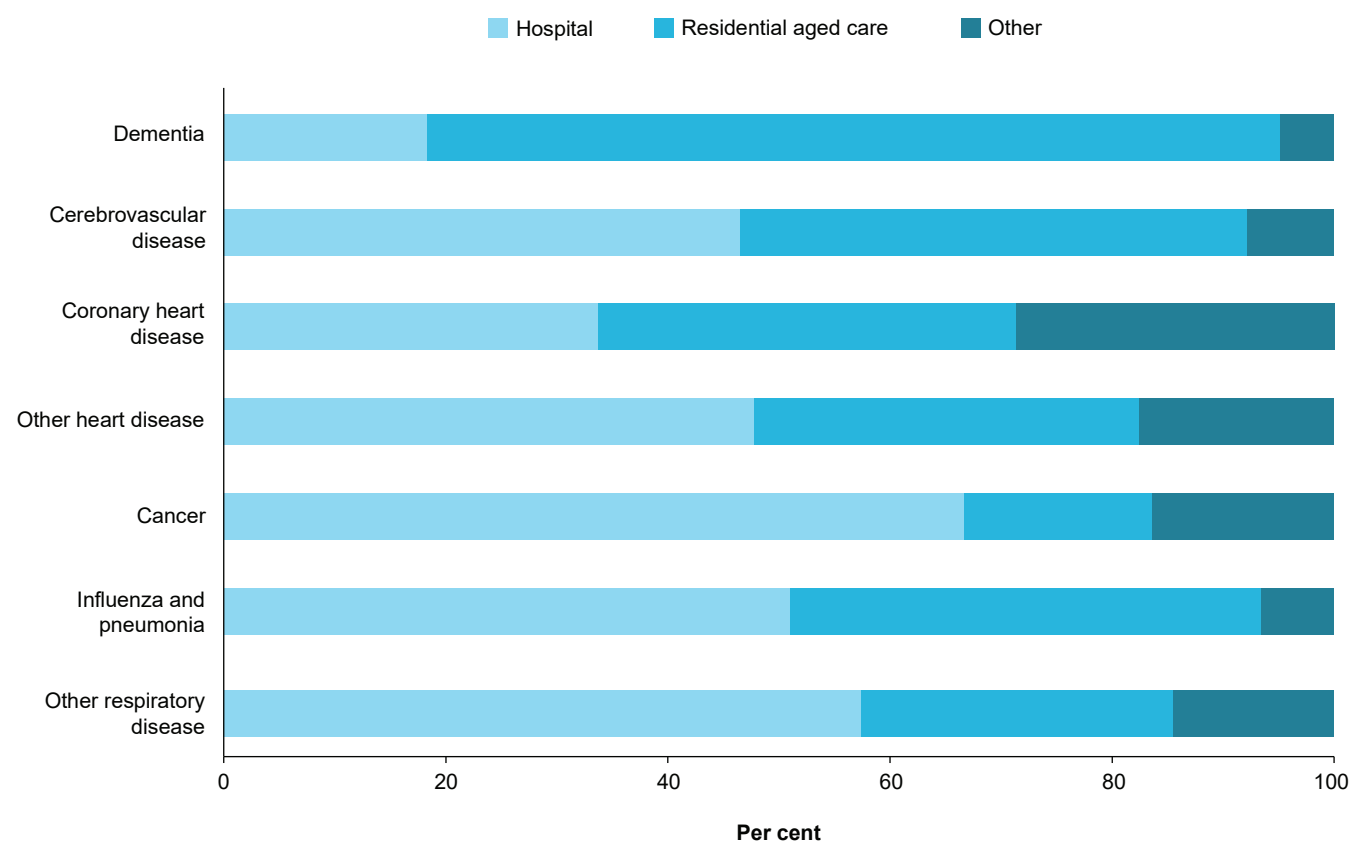
Causes of death vary between settings

Overall, the leading underlying cause of death for people aged 65 and over in Victoria and Queensland was coronary heart disease (13%), followed by dementia and Alzheimer disease (10%), cerebrovascular disease (7.2%), lung cancer (5.0%) and chronic obstructive pulmonary disease (4.9%), collectively accounting for 40% of the deaths (Table S3). However, these varied slightly by age, sex and setting at death:

- Dementia and Alzheimer disease accounted for 1 in 6 (17%) deaths of women who died aged 85 and over, compared with about 1 in 10 (11%) men who died aged 85 and over.
- Lung cancer and coronary heart disease were more common causes of death for men (6.2% of men's deaths were due to lung cancer and 14% due to coronary heart disease, compared with 3.9% and 12% for women, respectively).
- Of deaths that occurred in a hospital, lung cancer was the most common cause (accounting for 7.2% of deaths in hospital) while deaths due to dementia and Alzheimer disease occurred most commonly in residential aged care (accounting for 22% of deaths in residential aged care).

When selected underlying causes were grouped, this showed that 67% of cancer deaths for people aged 65 and over in Victoria and Queensland took place in hospital, while 77% of dementia deaths, 46% of cerebrovascular disease deaths, and 42% of influenza and pneumonia deaths took place in residential aged care (Figure 4).

Figure 4: People who died aged 65 and over in Victoria and Queensland, selected causes of death, by setting



Note: Data for this figure are available in supplementary table S4.

Source: Linked NDI, aged care and hospital data.

Season of the year has an impact across all settings

Across all deaths for older people in Victoria and Queensland in 2016–17, deaths were only slightly more likely to occur in the winter quarter (27%), compared with spring, summer and autumn (25%, 23% and 25%, respectively). This did not vary between settings of death: for example, for both hospital and residential aged care deaths, 27% of deaths among older people occurred in winter. By age group, the most common season of death were the winter months.

However, certain causes of death are more common at particular times of year—for example, diseases of the circulatory system, as well as pneumonia and influenza, are a highly seasonal cause of death, occurring most in winter (ABS 2020b). These patterns can be further altered—in 2017, there was an increased number of influenza deaths in Australia due to a worse-than-average flu season, while relatively few influenza deaths were observed 2020 (ABS 2020a). Here, too, it could be observed that deaths due to influenza and pneumonia were more common during the winter and spring quarters (31% and 32%, respectively, with just 18% in summer and 19% in autumn), but there was little variation by season when setting at death was also taken into account.

More than one condition can contribute to death

In mortality data, while only one condition is recorded as the underlying cause of death, others can be recorded as associated causes (together, these are 'multiple causes of death'). For example, respiratory diseases are commonly coded as an associated cause of death, with another (often chronic) condition taking precedence and coded as an underlying cause (AIHW 2020a).

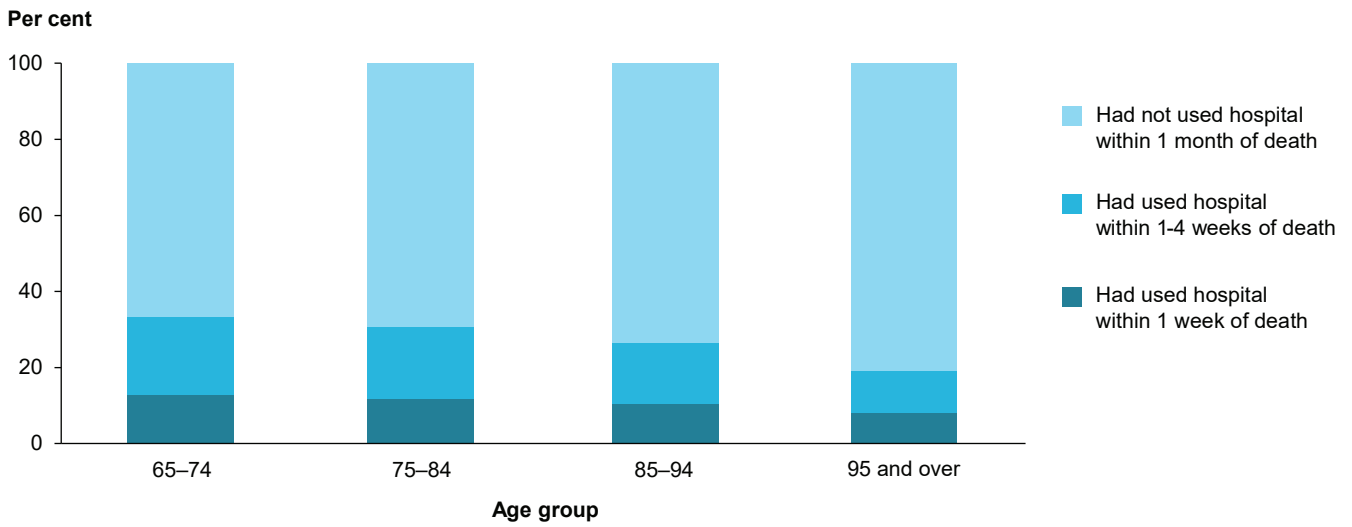
Looking at multiple causes of death using this linked dataset, the number of influenza and pneumonia deaths for older Australians in Victoria and Queensland in 2016–17 rose from just under 1,400 (when only underlying cause of death was included) to 7,900 when underlying and associated causes of death were both considered. Put another way, pneumonia and influenza were captured as the underlying cause of death in just 1 in 6 (17%) of all deaths involving these conditions. They were most commonly present in dementia-related deaths.

This contrasts with findings relating to deaths recorded in Australia during the COVID-19 pandemic. The majority of Australian COVID-19 deaths reported to August 2020 had both pre-existing chronic conditions (most commonly dementia) and a causal sequence noted, with pneumonia and respiratory failure the most common consequences that lead to death (ABS 2020b). In another study, it was shown that of the COVID-19 deaths reported in Australia to October 2020, where people also had dementia recorded, they were less likely to have other respiratory conditions noted than those without dementia (AIHW 2021). The differences may suggest that the incidence of other respiratory illnesses and/or that the coding practices regarding other respiratory illnesses changed during that time. The World Health Organization have directed that COVID-19 should be recorded on the death certificate where it caused, is assumed to have caused, or contributed to death (AIHW 2021; WHO 2020). It is also possible that the patterns of where people died changed during that time from that reported here.

People commonly use both hospital and aged care towards the end of life

Examining each type of service use separately can overlook the fact that people often use a mix of hospital and aged care services, particularly towards the end of their life. One in 4 (27%) older people who died in residential aged care had used hospital within a month of death. The proportion decreased as age increased: 33% of those aged 65–74 who died in residential aged care had used hospital within the month, decreasing to 19% for those aged 95 and over who died (Figure 5).

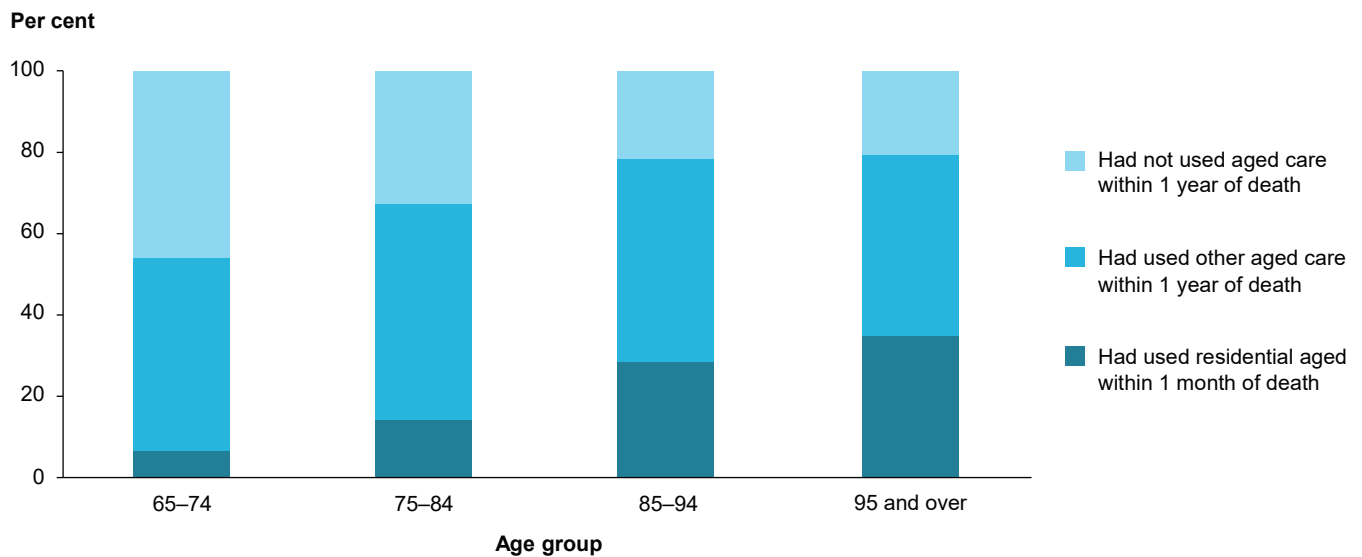
Figure 5: People who died aged 65 and over in residential aged care in Victoria and Queensland, by age group and prior hospital use



Note: Data for this figure are available in supplementary table S5.
 Source: Linked NDI, aged care and hospital data.

On the other hand, almost 1 in 5 (18%) older people who died in hospital had used residential aged care within 1 month of death, and another 50% had used other aged care within the year. These proportions both increased with age—for example, 29% of those who died in hospital aged 85-94, and 35% of those aged 95 and over, had used residential aged care in the month before (Figure 6).

Figure 6: People who died aged 65 and over in hospital in Victoria and Queensland, by age group and prior aged care use



Note: Data for this figure are available in supplementary table S6.
 Source: Linked NDI, aged care and hospital data.

Some people may have no contact with hospitals or aged care immediately before death

Fewer than 1 in 13 (7.3%) older people in these 2 jurisdictions died in neither hospital nor while using any form of aged care. They were commonly younger and male: 27% were men aged 65–74, compared with 15% of those who died in hospital and 3.4% of those who died in residential aged care. The leading underlying cause of death was coronary heart disease, followed by chronic obstructive pulmonary disease, diabetes, lung cancer, cerebrovascular disease and suicide, collectively accounting for half (50%) of these deaths among those aged 65 and over.

Almost half (47%) of this group of people had no record of using either hospital or aged care in the year before their death, and a further 32% had only used hospital (the remaining 21% had used some mix of aged care and/or hospital in the year). However, people may also access privately-funded services or use another service, such as disability support services, certain flexible aged care programs or support funded by the Department of Veterans' Affairs. No data on these services were available to be included in this linkage project.

People who live in residential aged care towards the end of life commonly die in that setting

People's service use can vary greatly in the months or years before death. Of those older people in Victoria and Queensland who had been living in residential aged care in the week before their death, 79% died in residential aged care, 19% died in hospital and 1.7% died in emergency department. For the remaining 0.2%, death may have taken place in the community (such as at home with or without other supports in place) (Table S7). This compares with 71% in hospital and 2.7% in emergency department for the 31,700 older people who had not been using residential aged care in the week before their death. For 26% of them, death most likely took place in the community, although precise information is not available.

People can spend many of their final years in residential aged care: of those people who had been living in residential aged care in the week before their death, the median total length of stay in residential aged care was 1.9 years (and half of people stayed in residential aged care for between 0.6 and 4.1 years). The median length of stay for women was higher in each age group, and increased as age increased.

People may use palliative care services before their death

Access to palliative and end-of-life care are important factors to a good death: they focus on managing symptoms and improving comfort for people with a life-limiting illness. People may receive palliative care for years and care can be provided by informal carers, communities and formal health and aged care services.

There is no comprehensive source of data on what care is provided to people who accessed palliative care services—whether in hospital, at home, or in residential aged care—but using linked data, it is possible to gain insights into how commonly people who died may have been receiving some form of palliative care (for the details on how this was done, see Note 2 in the supplementary tables).

Of the older people who died in 2016–17 in these 2 jurisdictions, 28% had been prescribed palliative care medications, had seen a palliative care specialist or had been admitted to hospital for palliative care during the preceding year. This varied depending on the setting at death: while nearly 2 in 5 (39%) of those who died in hospital had received some form of these palliative care services, only 1 in 6 (18%) of those who died in residential aged care did so. One in 4 (25%) of people who had used other aged care near death may have received some form of palliative care, decreasing to 1 in 9 (12%) people who had no record of hospital or aged care use near death (Table S8).

What are the opportunities for future work?

This report is part of a broader body of work at the AIHW examining the relationships between the aged care and health systems. Previous publications have looked at how people in aged care use other health services, such as general practitioners, specialists, medicines and hospital. As part of this work a comprehensive methodology for processing, defining and analysing the linked data has also been developed.

Future work will include developing national estimates of setting at death, once national linked data are available and/or place of death information are consistently captured in death registrations data. Improvements to aged care, hospital, emergency department, ambulance and palliative care data would also better capture the transitions between different settings. This will enhance understanding of where people die and what services they used towards the end of life. This is an important input for assessing whether those services and supports met their needs.

More information

Earlier reports can be downloaded for free from the AIHW website <https://www.aihw.gov.au/reports-data/health-welfare-services/aged-care/reports>. The website also includes information on ordering printed copies.

This report is accompanied by online supplementary data tables. A detailed account of how the linked data set was created and prepared for analysis is available in *Interfaces between the aged care and health systems in Australia—movements between aged care and hospital 2016–17: technical document*.

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