Fact of death analysis

Hospital use in the last year of life 2012-2019

December 2023



The information in this document should not replace a clinician's professional judgement.

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Fact of death analysis

At a glance

This report provides a summary of the evidence available on hospital use in the last year of life for NSW residents who died between 2012 and 2019.*



*Please see the data and methods for how the numbers on this page were derived.

Summary

This report analyses and presents hospital use between 2012 and 2019, examining the last year of life. It includes information on:

- cause and place of death
- life-limiting illnesses
- frequency and type of hospital presentations and admissions
- inpatient palliative care use.

The data definitions in the methods section of this report provides clarity about what is captured in these data points.

Seven key findings about hospital use in the last year of life

Increased demand on the health system

The population of NSW is growing and ageing but the life-limiting diagnosis profile at death has remained nearly the same. As people age, so does the incidence of life-limiting illnesses. In the last month of life, emergency department (ED) presentations and acute hospital overnight admissions more than double. This suggests there is a predictable population-based disease profile that can be used to inform planning activities and health promotion strategies.

Increased emergency department presentations and hospital admissions

The number of patients who died with more than four ED presentations is almost double those with three ED presentations. Further work is needed to develop strategies (including advanced care planning conversations) at the time of the third presentation. This requires coordination at discharge between the hospital, patient, families, carers and the general practitioner to reduce ED presentations and hospital admissions in the last year of life.

Frequent hospital admissions may indicate that the team managing the patient does not recognise the patient is dying. This suggests that earlier screening and planning for end-of-life transitions is needed. Or it may indicate poor management and a need for community services. It raises the question whether earlier action with recurring admissions will impact patient care, including later admissions.

Palliative care use increasing while start time stays the same

The overall trend of the use of palliative care across all life-limiting illnesses is increasing. However, it continues to be higher for people who died with a cancer diagnosis. The median times of the start of palliative care until death remains unchanged. But where a cancer diagnosis is present, palliative care begins earlier.

Data on the date of starting palliative care indicates that more work is needed to identify the endof-life episode of care earlier. More work may also be required to promote the role of specialist palliative care and/or a generalist palliative care approach to other speciality groups. Not all end-oflife care requires a referral to specialist palliative care services.

Place of death rates remain steady

Around half of all deaths in Australia occur in hospitals, with rates almost unchanged over the decade to 2020.¹ The NSW Health Clinical Principles for End-of-life and Palliative Care Guidelines supports people to:

- receive needs-based end-of-life care
- die in their preferred place, where possible.²

This report shows no changes in the place of death trend. This may reflect the need for end-of-life care to be increasingly delivered in institutions, such as hospitals and residential aged care facilities.³

The leading cause of death for people who died in a hospital was neoplasms. Diseases of the circulatory system were the leading cause of death for people who died outside of a hospital setting. Where a preferred place of death is identified as out of hospital, local transitions of care pathways can be explored to support this, where possible.

Small changes in cause of death profile

Over the last decade, the leading causes of death stayed mostly the same but dementia, including Alzheimer's disease, has increased and remains a main cause of mortality.

Earlier end-of-life care conversations

Intensive care unit (ICU) admissions are greater in the younger population and where organ failure is identified as a life-limiting illness. Further work is required to determine if more can be done to reduce ICU admissions where organ failure is identified. It might suggest that some level of care can be provided without the need for ICU admissions.

Surgical admissions are equally distributed across all age groups. Surgical admissions are most common where cancer is identified as a life-limiting illness. However, it accounts for a higher length of stay. Further work is required to determine if alternative treatment pathways would be more appropriate for those approaching end-of-life without the need for surgery.

As an example, this study points out that end-of-life discussions are associated with lower healthcare use in the last 30 days of life.⁴ This includes ED use, acute hospital admissions, ICU admissions and shorter length of hospital stay. Earlier end-of-life care discussions (30 or more days before death) are more strongly associated with less aggressive care outcomes than conversations occurring near death.

Data limitations in analysing palliative care use

Capturing palliative care activity remains a challenge in the administrative data set. Information is fragmented about:

- where Australians die
- their preferred place of death
- the end-of-life support they received.

No standardised data set or master record are maintained.³

Administrative data inadequately captures the involvement of specialist palliative care services in patient care.⁵ Work is required to identify patients with no selected morbidity and whose access to palliative care is minimal (5.7%). This will assist in identifying those patients who require:

- a palliative approach to their care
- supportive and end-of-life care
- a referral to palliative care services, when necessary.

The absence of datasets that work across primary care and residential aged care facilities and public and private hospitals, limit our ability to comment on concordance of care and preferred location of death.

Improvements to data identifying end-of-life care interventions may provide greater insights. This includes whether timely goals of care discussions and advanced care planning leads to:

- less non-beneficial care at end-of-life
- identifying unmet end-of-life care needs.

Introduction

Background

End-of-life care and palliative care is provided in various healthcare settings, including:

- inpatient units in public and private hospitals
- general practices
- residential and community aged care services.

Specialist palliative care is an example of one of these services. Most health services deliver care in a number of settings using different modalities to suit local needs. Where available, all models include Aboriginal and multicultural health workers and volunteer coordinators as key members of the multidisciplinary team.⁶

Communication between clinical teams is critical to ensuring quality end-of-life transitions of care between care settings and models. The NSW population is growing and ageing. This will require end-of-life care processes, systems and infrastructure in acute hospital settings to be managed flexibly to respond to these emerging needs.

Purpose

This report analyses and presents hospital use in the last year of life between 2012-2019. This includes information on:

- cause and place of death
- life-limiting illnesses
- frequency and type of hospital presentations and admissions
- inpatient palliative care use.

Data and methods

Literature and national data have been included in this report to illustrate why the NSW data is important and place it in context with other published information.

NSW data was extracted from the de-identified record-linked NSW Admitted Patient Data Collection (APDC), Emergency Department Data Collection (EDDC), Registry of Births Deaths and Marriages (RBDM), and Cause of Death Data (COD), accessed via the Hospital Performance Dataset (HoPeD), NSW Ministry of Health Secure Analytics for Population Health Research and Intelligence.⁷

The cohort included in this report is all NSW residents who died between 2012 and 2019 in NSW (death registered in NSW). Although more recent data is available, it overlaps with the COVID-19 pandemic which could not be indicative of usual practice. Below are some data definitions applied to this report.

- Underlying **cause of death** has been grouped to higher level diagnoses categories (chapters of International Classification of Diseases (ICD) codes) and reported.
- **Place of death** data is reported as those people who died in a public or private hospital or elsewhere.
- Life-limiting illnesses (which are amenable to palliative care) were identified using diagnoses recorded in NSW public and private hospital admission data within the last two years of life.
- Hospital use includes:
 - Inpatient palliative care use identified based on the care type and/or diagnosis code recorded as palliative care in the person's NSW public and private hospital admission data in the last year of life
 - Emergency department presentations to a NSW public hospital in the last year of life. Also reported is the triage category, frequency of admissions and principal diagnosis for presenting, grouped to higher level of diagnoses categories (chapters of ICD codes)
 - Hospital admissions including acute overnight hospital admissions (excludes same day or sub-acute admissions) to a NSW public or private hospital in the last year of life. Also reported the frequency of admissions and principal diagnosis for admission, grouped to higher level of diagnoses categories (chapters of ICD codes)
 - Intensive care unit admissions to a NSW public or private hospital in the last year of life
 - Surgical admissions reporting is limited to surgeries performed in NSW public hospitals only in the last year of life and identified using diagnosis related group (DRG) information.

More details on data analysis methods are provided in Appendix 1.

Supplementary data tables

The data and visualisations presented in this report have been sourced from a series of data tables and provided in a compendium digital file, Fact of death analysis: Hospital use in the last year of life 2012-2019, supplementary data tables. These supplementary data tables also feature local health district (LHD) of residence data for the main results within this report. Analysis by LHD of residence has not been captured within this report.

Results

Demographics

As Australia's population grows and ages, the need for appropriate end-of-life care and palliative care becomes more important. People will die due to chronic progressive diseases, increasing the need for an end-of-life care system that meets the needs and expectations of individuals and their families.³

Most deaths in Australia, occur among older people. In 2012, 66% of deaths registered in Australia were among people aged 75 or over. Less than 1% of all deaths occurred among children aged under four years. Table 1 shows the number of deaths registered and received by the Australian Bureau of Statistics in 2012 and 2019.⁸⁻¹⁰ This demonstrates the increasing deaths nationally but a stable median age at death across the reporting period. Approximately 2% of deaths were for people who identified as being of Aboriginal and Torres Strait Islander origin. They had a lower median age at death, although the 2019 data does illustrate an increase.

		2012		2019		
Australia's population		22,906,400		25,522,169		
Group		Deaths (% of total)	Median age at death	Deaths (% of total)	Median age at death	
	Male	74,794 (50.8%)	78.6	88,346 (52.2%)	78.8	
All deaths	Female	72,304 (49.2%)	84.6	80,955 (47.8%)	84.8	
	Total	147,098	81.5	169,301	81.7	
Aboriginal and	Male	1,426 (54.4%)	55.0	1,885 (54.9%)	Not available	
Torres Strait	Female	1,194 (45.6%)	61.3	1,550 (45.1%)	Not available	
	Total	2,620 (1.8% of all deaths)	56.9*	3,435 (2% of all deaths)	60.9 years	

Table 1. Deaths and median age at death in Australia

*Median age at death is based on 2011 data

The total number of NSW people who died between 2012 and 2019 was 412,856 of which 48.9% were female. The median age at death for males was 79 years and 85 years for females. The NSW data in Figure 1 closely reflects the national data above with less than 1% of deaths occurring in children aged 0-4 years; more than 67% of all deaths were residents aged 75 years and over; and only 6% of people who died were less than 50 years old.



Figure 1. Distribution of age and sex for people who died, NSW residents 2012-2019

The total number of NSW deaths for people who identified as Aboriginal or Torres Strait Islander origin who died between 2012 and 2019 was 9,907 (representing 2.4% of all deaths in the reporting period). The proportion has increased one percent from 1.9% in 2012 to 2.9% in 2019.

Cause and place of death

In 2012, the leading underlying cause of death for all Australians was ischaemic heart disease (13.6% of all deaths), which includes angina, blocked arteries of the heart and heart attacks. This was followed by cerebrovascular diseases (11.9%) as the second leading underlying cause of death. Cerebrovascular diseases include haemorrhages, strokes, infarctions and blocked arteries of the brain. The third leading cause of death was dementia and Alzheimer's disease. The top 10 leading causes of death accounted for 51.3% of all registered deaths in 2012.⁸

In 2019, ischaemic heart disease remained as the leading cause of death, accounting for 10.8% of all deaths. Dementia, including Alzheimer's disease, was the second leading cause of death followed by cerebrovascular diseases. Trends reported by the Australian Bureau of Statistics on cause of death highlight that ischaemic heart diseases and cerebrovascular diseases has decreased by 16.0% and 11.7% respectively, while dementia, including Alzheimer's disease, has increased by 66.8%. The top 10 leading causes accounted for 49.3% of all registered deaths in 2019.⁹



Figure 2. Number and percent of people who died by cause of death and year, NSW residents 2012-2019

The NSW cause of death data in Figure 2 illustrates consistent trends to the national data with diseases of the circulatory system trending down from 30.7% in 2012 to 26% in 2019 and all other causes of death remaining steady during the reporting period.



Figure 3. Percent of people who died by cause of death and age, NSW residents 2012-2019

Figure 4. Number and percent of people who died by cause of death and sex, NSW residents 2012-2019



Figure 3 and Figure 4 demonstrate the leading cause of death in all chapters increases with age with the exception of external causes of morbidity and mortality and diseases of the nervous system. The leading cause of death was diseases of the circulatory system for females (30.4%) and neoplasms for males (32.1%).

The proportion of people who died with neoplasm as cause of death is greatest in the 55-75 age group. This is reflected in the cause of death data (Figure 3) as well as the hospital use data presented later in this report. Most deaths over 75 years are from other causes.

View the supplementary workbook and Appendix 2 for more information on the:

- cause of death tables with details of the conditions are contained within each of these chapters and sub-chapters (supplementary workbook)
- top causes of death in babies and children under four years with the leading cause being conditions originating in the perinatal period (Figure 34).

Advances in medical diagnosis and interventions have contributed to increased life expectancy for Australians. Progress in life expectancy has had an unintended consequence on the dying experience, shifting a large proportion of end-of-life care into institutions, such as hospitals and residential aged care facilities.³

Around half of all deaths in Australia occur in hospitals, with rates relatively unchanged over the last decade.¹ For permanent residents of aged care facilities, the most common reason for separation from the facility for their last care episode was due to death. This accounted for around 95%, or 54,000 people, in 2013–14. Less than half of these people had lived for less than 12 months in the residential care facility.³

Information about where Australians die, their preferred place of death and the end-of-life support they received is fragmented. No standardised data set or master record is maintained.³

Of the 412,856 deaths in NSW during the reporting period, 190,519 were in hospital (public or private) representing 46.1% of all deaths. Figure 5 illustrates the leading cause of death in a hospital were neoplasms (40.7%) while the leading cause of death not in a hospital were diseases of the circulatory system (34.7%).





Note: Aboriginal status is based on Enhanced Reporting of Aboriginality (ERA)

The leading cause of death for people who identify as Aboriginal or Torres Strait Islander and their place of death was consistent with the overall trends. However, there is a greater percentage of deaths resulting from external causes of morbidity and mortality and other causes.

See Appendix 2 for more information on the top cause of death by place of death for all people (Figure 35).

Life-limiting illnesses

A life-limiting illness is an illness that can't be cured and will result in death. Life-limiting illnesses can include cancer, motor neurone disease, end-stage kidney disease and dementia.¹¹ Some, but not all, chronic conditions are life-limiting. This is explored because people with life-limiting illness and multi-morbidities are associated with poorer quality of life, increased use of health services and hospitalisation, and polypharmacy.¹² This group may also have considerable palliative care needs associated with the cumulative impact of their disease symptoms and functional impairments.¹³

Figure 6. Number and percent of people who died by life-limiting illness and year, NSW residents 2012-2019



Figure 6 illustrates that of the people who died:

- 69,134 (16.7%) had a diagnosis of cancer only
- 67,459 (16.3%) had a diagnosis of cancer and one or more non-cancer morbidities (including chronic obstructive pulmonary disease [COPD], heart failure, renal failure and neurodegenerative disease)
- more males (17%) had a diagnosis of cancer and organ failure than females (11%)
- 133,987 (32.5%) had one or more (most common) non-cancer morbidities (COPD, heart failure, renal failure and neurodegenerative disease) see Appendix 2, Table 3
- 129,338 (31.3%) had no selected diagnosis
- more females (35%) had no selected diagnosis than males (28%).

The life-limiting diagnosis at death profile shown in Figure 7 has remained substantially unchanged. As people aged, so did the prevalence of life-limiting illnesses. Figure 8 shows that males have a higher prevalence of a diagnosis of cancer or cancer and organ failure than females.



Figure 7. Percent of people who died by life-limiting illness and age, NSW residents 2012-2019

Figure 8. Percent of people who died by life-limiting illness and sex, NSW residents 2012-2019



View Appendix 2 for a more detailed table on most common life-limiting diagnosis for people who died in NSW between 2012 and 2019 (Table 3).

Palliative care use

Palliative care aims to prevent and relieve suffering and improve the quality of life of people (adults, children and their families) facing problems associated with life-limiting illness. In this report inpatient palliative care use (hospitalisations) refers to those episodes of admitted patient care where palliative care was a component of the care provided during all, or part of the episode, and were identified as:

- hospitalisations with care type coded as 'Palliative Care' in which the primary clinical purpose of care is palliative care and care is provided in a palliative care unit or by a palliative care specialist, and/or
- hospitalisations with a diagnosis code of palliative care, Z51.5, recorded in primary or any of 50 additional diagnoses.¹

Nationally, hospital separations with a palliative care component (about 57,000 separations) account for less than 0.6% of all hospital separations. However, they make up nearly one-third (32%) of all deaths in hospitals.³

This section of the report presents data on people who received palliative care during their admission to hospital in NSW within the last year of life. Of all patients who died, 26.9% accessed inpatient palliative care services.





Report findings

- Palliative care use is greatest among people aged 50-89 years as a proportion of total deaths (Figure 9).
- The overall trend of palliative care use across all life-limiting illnesses is increasing (Figure 10).

- Of those people who accessed palliative care, the number of people dying out of hospital is increasing from 3.5% to 5.4%, accounting for 18% to 20% of all palliative care recipients (Figure 10).
- Use of palliative care is higher for those people who died with a cancer diagnosis (Figure 11).
- The median times of the start of palliative care to death remains unchanged (Figure 12).
- Where a cancer diagnosis is present, palliative care is started earlier (8-18 days). For noncancer patients the median time to the start of the palliative care intervention to death was four to five days (Figure 12).

Figure 10. Percent of people who died who received inpatient palliative care within their last year of life by place of death and year, NSW residents 2012-2019



Figure 11. Percent of people who died who received inpatient palliative care within their last year of life by life-limiting illness and year, NSW residents 2012-2019



Figure 12. Median days-to-death from start of inpatient palliative care by life-limiting illness and year, NSW public and private hospitals 2012-2019



View Appendix 2 for more information on:

- the percentage of people with most common life-limiting diagnosis and their palliative care utilisation (Table 3)
- palliative care start time by life-limiting illness (Figure 36).

Emergency department presentations

Emergency department presentations are defined as patients who died and presented to ED within their last year of life and were discharged from ED and/or admitted to hospital. Several Australian studies have looked at ED use in the last year of life.

One study found 70% of the cohort had at least one emergency presentation and on their last day of life, 4% had been seen in an ED.¹⁴ Another study reported that 83% of these ED presentations required care in the ED that could not be delivered in another setting.¹⁵ The two most common reasons for presenting to ED were shortness of breath (35%) and pain (28%).

The next figures profile the patient presenting to ED and their use. Of the 412,856 people who died, there were 957,161 ED presentations. Most dying people (80.5%) presented to the ED at least once in their last year of life (Figure 13). Figure 14 highlights that those people who died, and were older, were less likely to have an ED presentation, and even less likely to have multiple ED presentations.









Figure 15. Percent of people who died who had an ED presentation within their last year of life by frequency of presentations and sex, NSW residents 2012-2019



Of all the people who had ED presentations:

- 95,214 (23.1%) presented to EDs more than four times (Figure 13)
- the number of frequent ED users (i.e. four or more ED presentations) has increased from 20% to 25% (range: 4-325 and IQR: 4-7). See Figure 13 and supplementary data tables
- males are 26% more likely to be frequent users than females 20% (Figure 15)
- the more life-limiting illnesses a person is diagnosed with, the more often they present to the ED (Figure 16)
- organ failure appears in the top four illness/es combinations resulting in frequent user presentations (Figure 16)
- multiple ED presentations were higher for those people living in rural LHDs than metropolitan LHDs (supplementary data tables).

Figure 16. Percent of people who died who had an ED presentation within their last year of life by frequency of presentation and life-limiting illness, NSW residents 2012-2019



The frequency and urgency of ED presentations within the last year of life of NSW people who died were reported in Figure 17. The data suggests that the number of ED presentations increased by 30,472 over the period. Also, the proportion of more urgent ED presentations classified as triage category 1-3 (resuscitation to urgent) increased from 65% in 2012 to 74% in 2019.





These next figures explore the nature of the ED presentation.

Reasons why people attended ED

- They most commonly presented with diseases of the respiratory system, diseases of the circulatory system and injury, poisoning and other external causes (Figure 18 and Figure 19).
- They were more likely to present, and present more frequently, the closer they got to death. Presentations within the last month before death were more than double that of two months before death and accounted for 27.4% of all ED presentations (Figure 20).
- People with a life-limiting diagnosis of cancer, organ failure, or cancer and organ failure, were the highest users of ED within the last 12 months of life (Figure 21).

Figure 18. Percent of ED presentation within last year of life for people who died by principal diagnosis and age, NSW public hospitals 2012-2019



Figure 19. Number and percent of ED presentation within last year of life for people who died by principal diagnosis and sex, NSW public hospitals 2012-2019



Supplementary data tables show

- Those aged 65 and over represent 72.6% of all ED presentations in the last year of life.
- Of all ED presentations, 633,356 (66.2%) were admitted to hospital, 322,110 (33.7%) were discharged and 1,695 (0.2%) were dead on arrival.
- Those aged 65 and over were more likely (68.6%) to be admitted following their ED presentation.





Figure 21. Percent of cohort (people who died who had an ED presentation within their last year of life) and ED presentation within the last year of life by life-limiting illness, NSW public hospitals 2012-2019



This report has found that 80.5% of patients visited an ED in their last year of life, many repeatedly. Of these, 66.2% were admitted to hospital. Of those ED presentations admitted to hospital, threequarters (75.7%) were people aged 70 and over.

View supplementary data tables for more information on long tables of principal diagnosis at the time of admission.

Hospital admissions

On average people who die use more hospital services in their last year of life than the rest of the population in a single year. They have an average of 2.6 admissions per person in their last year of life compared with 0.1 admissions per person per year among those not in the last year of life.¹⁶ A study found 96% of people who died spent time in hospital.¹⁴ There was also a spike in hospitalisations in the last 108 days of life for people who died of cancer and the last 83 days of life for people who died of non-cancer conditions. Those with cancer spent less time in hospital than those with other diagnoses.

Hospital admissions in this analysis refers to people who died after they were hospitalised, regardless of whether they came via the ED (unplanned) or had planned/other admissions. This analysis includes only acute overnight admissions (that is, no sub-acute admissions or same-day admissions).





The supplementary data tables and Figure 22 illustrate that of the 412,856 people who died:

- 304,946 (73.9%) had at least one acute overnight hospital admission in their last year of life, of which 81.9% were aged 65 and over and 33.8% were aged 85 and over
- 49,078 (11.9%) had three admissions in their last year of life, of which 84.9% were aged 65 and over
- females represented 44.9% of the total hospital admissions for the period
- there were 855,780 acute overnight admissions, averaging 2.8 admissions per patient
- average length of stay per patient was 17.4 days and 661,329 (77.3%) of these acute admissions were unplanned.

Only 29% of females and 24% of males who died **did not have** an overnight hospital admission in their last year of life (supplementary data tables).

The supplementary data tables and Figure 23 show the number of people admitted to a NSW hospital with four or more admissions is 82,014 (19.9%), almost double the number who had three admissions 49,078 (11.9%). Of this, 80.4% were aged 65 and over and 29.4% aged 85 and over.

Figure 23 also shows the number of people with four or more admissions is increasing over time (median 5, range 4-62, interquartile range 4-6).





The most common life-limiting illnesses attributable to people with multiple hospital admissions was consistent with the frequent ED user. People with a life-limiting diagnosis of cancer, organ failure, or cancer and organ failure, accounted for the most hospital admissions within the last 12 months of life (Figure 24). However, where a neurodegenerative disease is diagnosed in combination with organ failure and/or cancer, this small cohort contribute to a large proportion of multiple hospital admissions (Figure 26).

Figure 24. Percent of people who died who had an acute overnight admission within their last year of life by frequency of admission and life-limiting illness, NSW residents 2012-2019



Figure 25 demonstrates that hospital admissions increase as people get closer to death with admissions in the last month before death more than double that of two months to death. This accounted for 26.9% of all admissions. This trend is consistent with ED presentations. Hospital admissions for people living in rural LHDs are higher than metropolitan LHDs (supplementary data tables).

Figure 25. Number and percent of acute overnight admission within last year of life for people who died by life-limiting illness and months-to-death, NSW public and private hospitals 2012-2019



Figure 26. Percent of cohort (people who died who had an acute overnight admission within their last year of life) and acute overnight admissions within the last year of life by lifelimiting illness, NSW public and private hospitals 2012-2019



People with a life-limiting diagnosis of cancer accounted for 405,359 (47.4%) of acute hospital overnight admissions within the last year of life. Meanwhile, neurodegenerative diseases accounted for only 4.8% of all acute hospital overnight admissions within the last year of life (Figure 26).

The principal diagnosis for admission trend is steady across the time series (Figure 27). The principal diagnosis for admission by age data suggests that diseases of the circulatory system, injury, poisoning and other external causes, as well as diseases of the genitourinary system increase with age (Figure 28). The pattern of principal diagnoses was consistent between males and females (Figure 29).



Figure 27. Number and percent of acute overnight admission within last year of life for people who died by principal diagnosis and year, NSW public and private hospitals 2012-2019

Figure 28. Percent of acute overnight admission within last year of life for people who died by principal diagnosis and age, NSW public and private hospitals 2012-2019



Figure 29. Number and percent of acute overnight admission within last year of life for people who died by principal diagnosis and sex, NSW public and private hospitals 2012-2019



View Appendix 2 for more information on the principal diagnosis for admission by life-limiting illness (Figure 37).

Intensive care admissions

Several Australian-based studies have explored intensive care admissions in the last year of life. Mitchell et al. found that almost one-third of patients had an ICU admission before death and 71% of these were invasively ventilated.¹⁷

This population-based study on the use of hospital-based services (including ICU admissions) found that 12% percent of people who died had an ICU admission with median stay of three days.¹⁸

"Time in an ICU in the last year of life was most common for younger decedents, perhaps suggesting more ICU services were being directed towards people with the most years of life to gain. ICU admissions were less common for people who died from cancer, potentially due to these decedents often having a less precipitous decline in health towards the end-of-life and potentially having a stage of illness that resulted in their condition being less amenable to ICU interventions".¹⁸

The data illustrates for the following key points.

- There were 70,222 ICU admissions between 57,715 patients. This represented 13.9% of all patients who died and were admitted to a NSW hospital in their last year of life (supplementary data tables).
- There were 1.22 admissions per ICU admitted patient and the average length of stay was 5.3 days (supplementary data tables).
- ICU admissions are greatest in the younger population, such as children under four years of age, and the rate of use is 42.6% (Figure 30).
- ICU admissions are most common for people with organ failure (Figure 31).
- An intensive care admission within the last year of life is associated with a greater likelihood of dying in hospital but not necessarily during the intensive care admission (Figure 31).

Figure 30. Percent of people who died who had an ICU admission within their last year of life by age and sex, NSW residents 2012-2019



Figure 31. Percent of people who died who had an ICU admission within their last year of life by place of death and life-limiting illness, NSW residents 2012-2019



Surgery admissions

Surgical admission data is inclusive of only NSW public hospital admissions. The data illustrates for the following key points.

- There were 106,072 surgical admissions between 82,270 patients, representing 26.9% of all patients who died and were admitted to a NSW hospital in the last year of life (supplementary data tables).
- There were 1.12 admissions per surgical admitted patient and the average surgical admission length of stay was 14 days (supplementary data tables).
- There is no correlation between surgical admissions and age or gender. Surgical admissions are equally prevalent in the younger and older age groups (Figure 32).
- Surgical admissions are most common for people with cancer (Figure 33).

Figure 32. Percent of people who died who had a surgical admission to a NSW public hospital within their last year of life by age and sex, NSW residents 2012-2019



Figure 33. Percent of people who died who had a surgical admission to a NSW public hospital within their last year of life by place of death and life-limiting illness, NSW residents 2012-2019



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Appendix 1: Data and methods

Data source

Data was extracted from the de-identified record-linked NSW Admitted Patient Data Collection (APDC), Emergency Department Data Collection (EDDC), Registry of Births Deaths and Marriages (RBDM), and Cause of Death Data (COD), accessed via the Hospital Performance Dataset (HoPeD), NSW Ministry of Health Secure Analytics for Population Health Research and Intelligence.⁷ The Cause of Death Unit Record File (COD URF) forms part of the Hospital Performance Dataset and is provided by the Australian Coordinating Registry for COD URF on behalf of Australian Registries of Births, Deaths and Marriages, Australian Coroners and the National Coronial Information System. Record linkage was carried out by the Centre for Health Record Linkage (www.CheReL.org.au) using probabilistic methods.

Cohort

The cohort included in this report is all NSW residents who died between 2012 and 2019 and whose death was registered in NSW. The registration included the underlying cause of death with information on those patients who presented to an emergency department and/or were admitted to a public or private hospital in the year prior to their death. Reporting place of death was limited to whether the patient died in NSW hospitals (public or private) or not.

Aboriginal status

Aboriginal and Torres Strait Islander people were identified using the Enhanced Reporting of Aboriginality (ERA) variable provided in the record-linked HoPeD datasets.¹⁹

Hospital use

Hospital use included in this report comprised all NSW public and private hospitals ED presentations and hospital admissions (or separations). A patient may be admitted to hospital following an ED presentation. A hospital separation is the process by which an episode of care for an admitted patient stops. A separation may be formal or statistical. Formal separation includes discharge, transfer or death of a patient. Statistical separation is care type change (e.g. from acute to rehabilitation) for a patient with formal hospital admission.

From 15 June 2017 the NSW Health Admission Policy indicates a patient treated in, and discharged from an ED only, is not an admitted patient and must not be recorded as such. These patients must be recorded and counted as ED non-admitted attendees. Subsequently, ED-only admissions are no longer considered a proper admission and, therefore, gradually disappeared in the APDC.²⁰ In order to preserve the consistency of trends over time, ED-only admissions were removed from the data in this report.

Cause of death and principal diagnosis

Underlying cause of death and principal diagnosis at ED presentations and hospital admissions were identified and reported using diagnoses related codes recorded in hospital data, based on International Statistical Classification of Diseases and Related Health Problems,10th Revision, Australian Modification (ICD-10-AM).²¹ For ED data where the codes were in Systematized

Nomenclature of Medicine-Clinical Terms, Australian modification (SNOMED-CT AU), they were mapped into ICD codes.^{22, 23} Diagnoses codes were grouped based on the chapters of ICD codes (20 chapters) and where appropriate, the chapters with higher numbers were reported and the remaining chapters were collapsed and presented as "other".

Length of stay and days in hospital

Length of stay (LOS) of an admitted patient in hospital, excluding leave days, measured in days. Separations with LOS greater than 365 days were excluded in calculation of LOS related measures. For same day admissions, LOS was set to 1. Days spent in hospital is sum of LOSs of one or more separations.

Triage category of ED presentations

All ED presentations are assigned a triage category (the Australian Triage Scale Category, ATS). The ATS was developed by the Australasian College for Emergency Medicine and is used to describe clinical urgency of an ED presntation.²⁴ Five categories are:

- Resuscitation: people with life-threatening condition requiring immediate treatment
- Emergency: people with imminently life-threatening condition
- Urgent: people with potentially life-threatening condition
- Semi-urgent: people with potentially serious condition
- Non-urgent: people with less urgent condition.

Frequent hospital user

People were categorised based on their count of ED presentations and acute overnight separations within their last year of life. Four groups were defined as people with one, two, three, and four or more ED presentations (or acute overnight separations).

Life-limiting illnesses

Life-limiting illnesses are illnesses that are expected to directly cause death. People with lifelimiting illness can benefit from palliative care. Palliative care aims to give the best possible quality of life to someone living with life-limiting illnesses so that they live their life as fully and as comfortably as possible.²⁵ Life-limiting illnesses amenable to palliative care include cancer, organ failure and neurodegenerative diseases. In this report a modified list of diagnoses proposed by Murtagh et al. was adopted.^{26, 27} Illnesses were identified using related codes recorded in hospital admissions data, based on ICD-10-AM, within the last two years of life.²¹ The illnesses and associated ICD-10-AM codes are summarised in Table 2.

Diagnoses group		ICD-10-AM codes	
Cancer		C00-C97, D45, D47.1, D47.3, Z03.1, Z51.0, Z51.1, Z54.1	
Organ failure			
 Heart 		111.0, 113.0, 113.2, 150	
-	Respiratory	J40-J44	
-	Renal	N17-N19, I12.0, I13.1, I13.2	
-	Liver	K70.4, K71.1, K72	
Neurodegene	rative diseases	F00-F03, G10, G12.2, G20, G21, G22, G30	

Table 22. Life-limiting illnesses and related ICD-10-AM codes

Palliative care use

People with life-limiting illness may require care in a hospital setting, such as a hospital ward (specialist palliative care ward or other areas of the hospital). In this report inpatient palliative care use (hospitalisations) refers to those episodes of admitted patient care where palliative care was a component of the care provided during all or part of the episode and were identified as:

- hospitalisations with care type coded as "Palliative Care" in which the primary clinical purpose of care is palliative care and care is provided in a palliative care unit or by a palliative care specialist; and/or
- hospitalisations with a diagnosis code of palliative care, Z51.5, is recorded in primary or any of 50 additional diagnoses.¹

Surgery admission

Surgery admissions were identified using the allocated Australian Refined Diagnosis Related Group (AR-DRG) codes. An admission in which the numeric component of the AR-DRG code is between 01 to 39 (vs. 40-99) was considered as a surgical admission. Reporting was limited to surgeries performed in NSW public hospitals only because AR-DRG codes were not available for private hospitals over the studied period.

Appendix 2: Additional figures and tables

Cause and place of death

Figure 34. Percent of children aged 0-4 years who died by cause of death, NSW residents 2012-2019



Figure 35. Percent of people who died by cause of death and place of death, NSW residents 2012-2019



Life-limiting illness and palliative care

Table 3. Number and percent of people who died who received inpatient palliative care bytop life-limiting illness, NSW residents 2012-2019

Top life-limiting illnesses*		People who died		Inpatients who accessed palliative care	
		%	N	%	received inpatient palliative care
Cancer and respiratory failure	7,788	1.9%	4,751	4.3%	61.0%
Cancer	69,134	16.7%	40,773	36.7%	59.0%
Cancer and renal failure	23,045	5.6%	12,999	11.7%	56.4%
Cancer, respiratory failure and renal failure	3,005	0.7%	1,566	1.4%	52.1%
Cancer and heart failure	5,153	1.2%	2,389	2.2%	46.4%
Cancer, respiratory failure, renal failure and heart failure	3,103	0.8%	1,333	1.2%	43.0%
Cancer and renal failure	7,375	1.8%	3,132	2.8%	42.5%
Cancer and neurodegenerative diseases	5,311	1.3%	1,917	1.7%	36.1%
Heart failure, respiratory failure and renal failure	9,584	2.3%	2,281	2.1%	23.8%
Heart failure and renal failure	21,530	5.2%	4,987	4.5%	23.2%
Heart failure, renal failure and neurodegenerative diseases	4,615	1.1%	1,054	0.9%	22.8%
Heart failure and respiratory failure	6,085	1.5%	1,267	1.1%	20.8%
Renal failure and neurodegenerative diseases	10,146	2.5%	2,091	1.9%	20.6%
Respiratory failure and renal failure	4,481	1.1%	918	0.8%	20.5%
Respiratory failure	10,159	2.5%	1,858	1.7%	18.3%
Renal failure	23,634	5.7%	4,310	3.9%	18.2%
Heart failure and neurodegenerative diseases	3,676	0.9%	646	0.6%	17.6%
Heart failure	12,435	3.0%	2,037	1.8%	16.4%
Neurodegenerative diseases	27,642	6.7%	4,284	3.9%	15.5%
TOTAL	412,856	100%	111,083	100%	26.9%

* Top life-limiting illnesses were limited to those with highest rates of receiving inpatient palliative care, and minimum 3,000 deaths.

Figure 36. Percent of people who died who received inpatient palliative care by life-limiting illness and start of inpatient palliative care, NSW public and private hospitals 2012-2019



Hospital admissions

Figure 37. Percent of acute overnight admission within last year of life by life-limiting illness and principal diagnosis, NSW public and private hospitals 2012-2019

