Revisit review of South Australia's Palliative Care Services Plan 2009-16: Statistical addendum

August 2019

Health Performance Council

Government of South Australia
Health Performance Council

Recommended citation

Health Performance Council, *Revisit review of South Australia's Palliative Care Services Plan 2009-16: Statistical addendum*, Government of South Australia, Adelaide, 2019.

SA Health information asset classification

Public–I2–A1

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Acknowledgment of the Aboriginal peoples of South Australia

The Health Performance Council acknowledges the Aboriginal peoples of South Australia and their ongoing contributions to and participation in the life of South Australia. We acknowledge and respect their spiritual relationship with their respective countries.

We also acknowledge the diversity of Aboriginal people in South Australia. Our Australian continent is known to have been inhabited for at least 55,000 years. The first inhabitants comprised over 270 different Aboriginal language/cultural groups across Australia, with 40 independent groups living in South Australia. Each group occupied its own territory and had its own unique culture, beliefs, laws, language, stories, ceremonies and art (Reconciliation SA, 2017). Aboriginal peoples in their diversity have demonstrated resilience and have made significant contributions to South Australia despite the ongoing effects of colonisation and dispossession.

Executive summary

Background

This report forms a statistical addendum to complement the Health Performance Council's *Revisit review of South Australia's Palliative Care Services Plan 2009-16* (HPC 2018). The 2018 revisit review is a comprehensive policy review and presents a range of statistical measures in relation to end-of-life care in South Australia.

The primary purpose of this addendum is to look at long-term trends and outcomes in public hospital utilisation in the months before a person's death in South Australia. It supplements and expands on the quantitative analysis in the 2018 report.

Findings

South Australia's **population** of over 1.7 million people is structurally older than the other mainland Australian states and territories—and the proportion of aged persons is projected to increase.

There are more than 14,000 **deaths** in South Australia every year. The **average age of death** in South Australia is around 78 years. This compares to the average age of death for Aboriginal persons in the state of around 55 years.

The **leading cause of death** in South Australia is neoplasms—mostly cancers of the bronchus, lung, prostate and breast. Diseases of the circulatory system—mostly heart disease, heart attack, heart failure and stroke—are the second-highest contributors to the state's death rate. Third are diseases of the respiratory system—mostly chronic obstructive pulmonary disease and pneumonia.

Higher-than-average **rates of death** from cancer and circulatory disease are observed in areas correlated with lower socioeconomic status—Adelaide's northern and southern suburbs and the regional areas of the Mid-North, the Riverland and the Limestone Coast.

Trends in the **place of death** have moved gradually over the last decade.

- A decline in the percentage of people who die in **hospital** corresponds with an increase in the proportion of persons who die at **home or in aged care**.
- The place of death varies by **hospital utilisation**. Those who are public hospital inpatients but not coded or diagnosed in-hospital as palliative care in the 12 months prior to death are more likely to die in a residential aged care facility, a nursing home or their own private residence. Those who receive at least one coding or diagnosis of in-hospital palliative care are more likely to die in hospital.

An in-hospital palliative care coding or diagnosis does not identify whether the inpatient had contact with a palliative care service, and does not distinguish between levels of involvement if it had occurred. It is crucial to make a distinction between 'coded or diagnosed as palliative care' and 'received palliative care'. Note that deaths in hospital include deaths on any ward, not only on wards that are hospice-specialised.

Population groups show variation in the rates of palliative care services.

- In relation to **sex**, a higher proportion of males than females are coded or diagnosed as palliative care while public hospital inpatients in the 12 months prior to death.
- In terms of **age**, those aged 65 to 79 years record the highest rate of in-hospital coding or diagnosis as palliative care.
- The rate is higher for non-Aboriginal people than **Aboriginal people**.
- The rate for those from **culturally and linguistically diverse** (CALD) backgrounds and non-CALD backgrounds is also similar.
- The proportion of **metropolitan** Adelaide residents who are coded or diagnosed as palliative care while public hospital inpatients in the 12 months prior to death is similar to that in regional South Australia.
- Those living in lower **socioeconomic areas** are coded or diagnosed in-hospital as palliative care at a higher rate of services than those who live in other areas.

Most **in-hospital palliative care** is provided by the public hospital system.

- The last ten years have seen the volume of **palliative care hospitalisations** (inpatient separations) at public hospitals increase.
- Average number of **intensive care unit and ventilation hours** recorded per palliative care hospitalisation have also increased.
- It is unclear to what extent observed trends may be due to changes in data standards or improved data capture and quality.
- **Entry** into palliative care in the public hospital system as an inpatient is most often through the emergency department.

Hospital treatment is a feature of the last 12 months of life for most people.

- In the last 12 months of life, the majority of people will be admitted to a public hospital as an **inpatient** on average around five times.
- Around one in ten of those hospitalised will be coded or diagnosed as **palliative care** during their admission as public hospital inpatients.

There is **unmet need** for palliative care within South Australia.

- This report uses **two methods to test** the extent to which the South Australian population is serviced by palliative care, looking at patients with non-malignant conditions as well as cancer.
- Both methods identify unmet need for palliative care in the state but provide different **estimates of unmet need: 18% and 55%**.
- Both estimates reflect **only data of deaths in public hospitals**, and so are limited. Without access to private hospital data or community health datasets it is impossible to say whether the people identified as not receiving palliative care may have been provided a service from outside the public hospital system.

In South Australia, around one in 13 people who die does so from disease and age combinations considered amenable to healthcare, defined as '**avoidable deaths**'.

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Introduction

The Health Performance Council considers the provision of quality, consumer-centred end-of-life care an important measure of a humane 21st-century society and an essential element of that society's healthcare system. The Council considers end-of-life care optimises the quality of life as well as the quality of death.

South Australia faces growing demand in end-of-life care services, including palliative care. The state's population is relatively older compared to the national average; and the proportion of aged persons is projected to increase. More than 14,000 people die every year in South Australia—more than a quarter from cancer, a disease associated with high levels of hospitalisation and palliative care in the final months of life. Fewer people are dying in hospital with more people dying at home or in residential aged care. The majority of inpatient palliative care is provided by the public hospital system and the volume of public hospital-based inpatient palliative care activity is growing. Limited modelling suggests a level of unmet need for palliative care in the community. Further investigation into demand and unmet need is required.

Purpose of this report

This report forms a statistical addendum to complement the Council's *Revisit review of South Australia's Palliative Care Services Plan 2009-16* (HPC 2018). The 2018 revisit review is a comprehensive policy review and presents a range of statistical measures in relation to end-of-life care in South Australia. This addendum supplements and expands on the quantitative analysis in the 2018 revisit review—with attention to additional detail by geographies and by specific and vulnerable population groups.

The primary purpose of this addendum is to look at long-term trends and outcomes in public hospital utilisation in the months before a person's death in South Australia. This analysis relies on access to linked deaths registry and hospital activity datasets (admitted patient hospitalisations and emergency department presentations) that unfortunately could not be sourced in time to include in the 2018 report.

It is beyond the scope of this report to be an exhaustive source of intelligence on the cultural and geographical diversity of, and unmet need for, end-of-life care in South Australia. It is intended as a short 'bite-sized' statistical report, presenting a range of summary measures in relation to end-of-life care in South Australia, across the following themes:

1. Demographics of an ageing population
2. A profile of death—causes, geography and place
3. Palliative care access and equity
4. Palliative care outcomes
5. Growth in hospital-based palliative care
6. Estimates of unmet need for palliative care
7. Quality of palliative care.

Technical notes on the data including data quality statements and validation processes, a glossary, and a list of references, are provided at the back of this report.

Election commitments

This report has been prepared in the context of the South Australian government's election commitments. It aims to assist SA Health with end-of-life care planning and policy direction.

To address growing and unmet demand for end-of-life care, the South Australian government has committed $16m to:

- extend community outreach palliative care services from the current weekday service to a 24-hour, 7-days-a-week service
- undertake a state-wide assessment of unmet need for palliative care
- renew palliative care services with the establishment of a statewide clinical network for palliative care as part of a Commission on Excellence and Innovation in Health
- deliver a new Palliative Care Services Plan.

When delivered, the government's new Palliative Care Services Plan will succeed the *Palliative Care Services Plan 2009-16*. The 2009-16 plan was reviewed by the Council in 2013 (HPC 2013) (midpoint review) and again in 2018 (HPC 2018) (revisit review).

Findings from the review of the Palliative Care Services Plan 2009-16

In the 2018 revisit review the Council found that achievement of the 2009-16 plan to expand and reshape end-of-life care services in South Australia was uneven. While excellence in end-of-life care existed throughout South Australia's public health system, within local health networks and work units, and in particular among highly regarded and compassionate staff, key objectives of the plan had been achieved only in part. The Council found lack of progress due to contested resources and confusion about the plan's intent.

Lack of action has resulted in less community-based care than was promised, high levels of hospitalisation and acute care treatments, pressure on carers, disruption, delays, and inconsistent quality of care. Consumers cannot be sure they are more likely now than before the plan was introduced to receive the palliative care they want, where they want it. SA Health is impacted with pressure on staff, financial and other resources in many parts of the system

Delivering future improvements will depend on consistent quality of care and efficiencies between all levels of government, the private sector and non-government organisations.

The Health Performance Council

The Health Performance Council is the South Australian government's statutory ministerial advisory body established under the *Health Care Act 2008* to provide advice to the Minister for Health and Wellbeing on the performance of the health system, health outcomes for South Australians and specific population groups, and the effectiveness of community and individual engagement.

The Council publishes four-yearly reviews of South Australian health system performance, case studies and other monitoring reports. These are available for download via the Council's website: hpcsa.com.au.

Acknowledgements

The Council acknowledges the contribution of SA-NT DataLink; SA Health; the South Australian Department of Consumer & Business Services—Births, Deaths and Marriages; Palliative Care SA; and the SA Health Data and Analysis Group which contributed data, feedback and advice to this report.

The Council also takes this opportunity to again thank members of the project advisory group who contributed to the 2018 revisit review.

1. Demographics of an ageing population

There are more than 1.7 million people resident in South Australia, representing 6.9% of Australia's total population of 25.0 million. More than 42,000 people, or 2.5% of the South Australian resident population are Aboriginal persons. Around 70% of the state's population resides in metropolitan Adelaide and 30% are from rural or remote areas. Over the decade 2008-18 South Australia's population grew by an average 0.9% per annum, around half of Australia's 1.7% average annual population growth rate over the same period. Among SA Health's local health networks (LHNs), the fastest growing region in South Australia during the period was the Barossa Hills Fleurieu LHN with a 1.4% average annual population growth rate, while the population in the Flinders and Upper North LHN declined slightly over the same period (-0.3% average per annum) (ABS 2019).

The life expectancy of a baby born in South Australia in 2015-17 is 82.3 years (80.3 years for males and 84.5 years for females). Life expectancy is slightly higher in the Australian Bureau of Statistics' statistical area of Greater Adelaide (82.8 years) compared to the rest of South Australia at 81.5 years (ABS 2018c).

Around one in five (18.1%) South Australians is aged 65 years or over, and around one in forty (2.6%) is aged 85 years or over. South Australia has a relatively older population compared to the other states and territories, ranking second highest (after Tasmania) for percentage of population aged 65 years or over and highest for percentage of population aged 85 years or over. The Yorke and Northern LHN records the highest proportion of population aged 65 years or over (25.0%), while the Central Adelaide LHN has the highest percentage of those aged 85 years or over (3.2%) (ABS 2018b). Fewer than one in twenty (4.6%) Aboriginal persons in South Australia are aged 65 years or over (ABS 2016).

The proportion of aged persons in the South Australian community is projected to increase over the next four decades, with over a quarter (25.2%) of the state's population aged 65 years or over, and 5.6% aged 85 years or over, by the year 2060 (ABS 2013b).

Table 1: Population of South Australia by SA Health local health network, 2018 and 2017

SA Health local health network (LHN) of usual residence	2018 population	2017 population aged 65+ years	2017 population aged 85+ years
	persons	%	%
Northern Adelaide	402,441	14.5%	1.8%
Central Adelaide	464,692	18.3%	3.2%
Southern Adelaide	367,837	18.2%	2.8%
Metropolitan Adelaide	**1,234,970**	**17.1%**	**2.6%**
Barossa Hills Fleurieu	200,663	20.6%	2.4%
Eyre and Far North	40,446	17.9%	2.2%
Flinders and Upper North	44,314	15.4%	1.7%
Limestone Coast	66,863	18.9%	2.5%
Riverland Mallee Coorong	72,339	21.6%	2.7%
Yorke and Northern	76,827	25.0%	3.1%
Country South Australia	**501,452**	**20.5%**	**2.5%**
SOUTH AUSTRALIA	**1,736,422**	**18.1%**	**2.6%**
AUSTRALIA	*24,992,860*	*15.4%*	*2.0%*

Sources: ABS 2018b, ABS2018c, ABS 2019

2. Profile of death

There were 14,004 deaths registered in South Australia during 2017 (13,888 South Australian residents and 116 non-South Australian residents or residents of unknown region). This converts to an age-standardised death rate of 5.5 deaths per 1,000 population (SA-NT DataLink 2019). There were 222 deaths of Aboriginal persons in 2017, corresponding to an age-standardised death rate of almost double that of the overall rate, at 9.2 deaths per 1,000 population (ABS 2018a).

Adjusting for age, the Flinders and Upper North LHN recorded the highest death rate of 7.0 deaths per 1,000 population. The Southern Adelaide and Barossa Hills Fleurieu LHNs recorded the equal lowest age-standardised death rates of 5.0 deaths per 1,000 population (SA-NT DataLink 2019).

The average age of death in South Australia in 2017 was 78.2 (75.3 years for males and 81.1 years for females). The average age of death of Aboriginal persons in South Australia during 2017 was more than two decades lower, at 54.5 years (52.1 years for Aboriginal males and 57.8 years for Aboriginal females). The Central Adelaide LHN recorded the state's highest average age of death (80.3 years), while Flinders and Upper North recorded the lowest at 73.1 years (SA-NT DataLink 2019).

Table 2: Deaths in South Australia by SA Health local health network, 2017

SA Health local health network (LHN) of usual residence	2017 deaths	2017 crude death rate	2017 age adjusted death rate	2017 average age at death
	no.	per 1000 popn.	per 1000 popn.	years
Northern Adelaide	2,724	6.8	5.9	75.4
Central Adelaide	4,088	8.9	5.4	80.3
Southern Adelaide	2,758	7.6	5.0	79.0
Metropolitan Adelaide	**9,570**	**7.8**	**5.4**	**78.5**
Barossa Hills Fleurieu	1,509	7.6	5.0	78.8
Eyre and Far North	344	8.5	6.3	76.5
Flinders and Upper North	367	8.2	7.0	73.1
Limestone Coast	566	8.5	5.7	78.0
Riverland Mallee Coorong	663	9.2	5.8	76.7
Yorke and Northern	869	11.3	6.2	78.0
Country SA	**4,318**	**8.7**	**5.7**	**77.6**
Non-South Australian resident or unknown LHN	*116*			
SOUTH AUSTRALIA	**14,004**	**8.1**	**5.5**	**78.2**
AUSTRALIA	*160,909*	*6.6*	*5.7*	*81.9 (median)*

Age-adjusted rates are standardised to the Australian 2001 population for consistency with the Australian Bureau of Statistics
Sources: SA-NT DataLink 2019 (South Australian figures), ABS 2018a (Australian figures)

Cause of death

Neoplasms (mostly cancers of the bronchus, lung, prostate and breast) were the leading cause of death in South Australia in 2016, responsible for 151.3 deaths per 100,000 population (age standardised). Diseases of the circulatory system (mostly heart disease, heart attack, heart failure and stroke) recorded the second-highest age-standardised death rate (131.0). This is followed by diseases of the respiratory system (mostly chronic obstructive pulmonary disease and pneumonia) at 46.0 deaths per 100,000 population (age standardised). Dementia and Alzheimer's disease were two of the top 20 individual causes of death in South Australia in terms of percentage of deaths in 2016, reflecting an increasingly ageing population (SA-NT DataLink 2019).

The average age at death of people whose cause of death was neoplasms (cancer) was 74.2 years, compared to 82.9 years for people who died as a result of diseases of the circulatory system and 81.5 years for people who died as a result of diseases of the respiratory system (SA-NT DataLink 2019).

Table 3: All grouped causes of death in South Australia, 2016

Grouped cause of death (ICD-10 chapter)	2016 deaths	2016 crude death rate	2016 age adjusted death rate	2016 average age at death
	no.	per 100k popn.	per 100k popn.	years
CHAPTER I Certain infectious and parasitic diseases (A00-B99)	221	12.9	9.0	77.4
CHAPTER II Neoplasms (C00-D48)	**3,553**	**207.4**	**151.3**	**74.2**
CHAPTER III Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism (D50-D89)	40	2.3	1.6	79.3
CHAPTER IV Endocrine, nutritional and metabolic diseases (E00-E90)	555	32.4	21.8	79.9
CHAPTER V Mental and behavioural disorders (F00-F99)	918	53.6	32.1	87.7
CHAPTER VI Diseases of the nervous system (G00-G99)	879	51.3	34.5	81.1
CHAPTER VII Diseases of the eye and adnexa (H00-H59)	0	0	0	n.a.
CHAPTER VIII Diseases of the ear and mastoid process (H60-H95)	n.p.	n.p.	n.p.	n.p.
CHAPTER IX Diseases of the circulatory system (I00-I99)	**3,482**	**203.3**	**131.0**	**82.9**
CHAPTER X Diseases of the respiratory system (J00-J99)	**1,193**	**69.7**	**46.0**	**81.5**
CHAPTER XI Diseases of the digestive system (K00-K93)	492	28.7	20.1	76.4
CHAPTER XII Diseases of the skin and subcutaneous tissue (L00-L99)	47	2.7	1.7	82.9
CHAPTER XIII Diseases of the musculoskeletal system and connective tissue (M00-M99)	112	6.5	4.2	83.0
CHAPTER XIV Diseases of the genitourinary system (N00-N99)	237	13.8	8.7	85.6
CHAPTER XV Pregnancy, childbirth and the puerperium (O00-O99)	n.p.	n.p.	n.p.	n.p.
CHAPTER XVI Certain conditions originating in the perinatal period (P00-P96)	28	1.6	1.8	0
CHAPTER XVII Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)	37	2.2	2.0	36.5
CHAPTER XVIII Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99)	207	12.1	9.3	68.6
CHAPTER XX External causes of morbidity and mortality (V01-Y98)	769	44.9	37.7	62.0
Missing/uncodified cause of death	*665*			
TOTAL DEATHS	**13,440**	**784.7**	**540.7**	**78.3**

n.a. not applicable

n.p. not published. Small cell data has been suppressed to protect privacy of individuals

Chapter XIX (injury, poisoning and certain other consequences of external causes) is not listed as it refers to the nature of injury and is not relevant to underlying causes of death. This is consistent with Australian Bureau of Statistics' published data on causes of death.

2017 data not available at time of publication

Source: SA-NT DataLink 2019

Table 4: Top 20 individual causes of deaths in South Australia, 2013-2016

Top 20 individual causes of death in South Australia and ICD-10 code	2013 deaths	2014 deaths	2015 deaths	2016 deaths	
	no.	no.	no.	no.	%
1. Chronic ischaemic heart disease (I25)	1,031	988	919	885	6.6%
2. Unspecified dementia (F03)	718	805	770	719	5.3%
3. Acute myocardial infarction (I21)	748	808	740	611	4.5%
4. Malignant neoplasm of bronchus and lung (C34)	646	657	675	605	4.5%
5. Other chronic obstructive pulmonary disease (J44)	529	564	561	528	3.9%
6. Alzheimer's disease (G30)	387	429	435	469	3.5%
7. Stroke, not specified as haemorrhage or infarction (I64)	438	430	444	366	2.7%
8. Malignant neoplasm of prostate (C61)	252	282	265	262	1.9%
9. Malignant neoplasm of breast (C50)	245	223	273	247	1.8%
10. Heart failure (I50)	204	231	260	239	1.8%
11. Pneumonia, organism unspecified (J18)	202	254	234	224	1.7%
12. Malignant neoplasm of pancreas (C25)	219	233	255	219	1.6%
13. Non-insulin-dependent diabetes mellitus (E11)	176	179	212	214	1.6%
14. Unspecified diabetes mellitus (E14)	180	209	182	179	1.3%
15. Malignant neoplasm, without specification of site (C80)	211	210	210	176	1.3%
16. Atrial fibrillation and flutter (I48)	132	144	155	173	1.3%
17. Other ill-defined and unspecified causes of mortality (R99)	66	61	176	162	1.2%
18. Unspecified fall (W19)	129	137	150	162	1.2%
19. Vascular dementia (F01)	115	121	122	146	1.1%
20. Malignant neoplasm of colon (C18)	175	153	169	141	1.0%
Other	*6,096*	*6,320*	*6,356*	*6,713*	*49.9%*
TOTAL DEATHS	**12,899**	**13,438**	**13,563**	**13,440**	**100.0%**

Data has been sorted in descending order on number of 2016 deaths

2017 data not available at time of publication

Source: SA-NT DataLink 2019

Deaths by geography

Variations in cancer and circulatory disease death rates are seen across South Australia when mapped by Australian Bureau of Statistics' Statistical Area 2 (SA2) geography. Higher-than-average rates are observed in northern and southern metropolitan Adelaide areas. Higher-than-average rates are also observed in the Mid-North, Riverland and Limestone Coast areas of Country South Australia (SA-NT DataLink 2019). These areas are correlated with lower socioeconomic status.

The three SA2s of Elizabeth, Morphett Vale–East and Christies Beach recorded the highest death rates from neoplasms (ie. cancer) in South Australia during 2016 (271.2, 257.1, 256.2 deaths per 100,000 population, age standardised, respectively). The SA2 of "Port Pirie Region" (as distinct from the SA2 of "Port Pirie") was the highest ranked country SA2 for deaths from cancer at 252.5 per 100,000 population (SA-NT DataLink 2019). Figure 1 contains further detail.

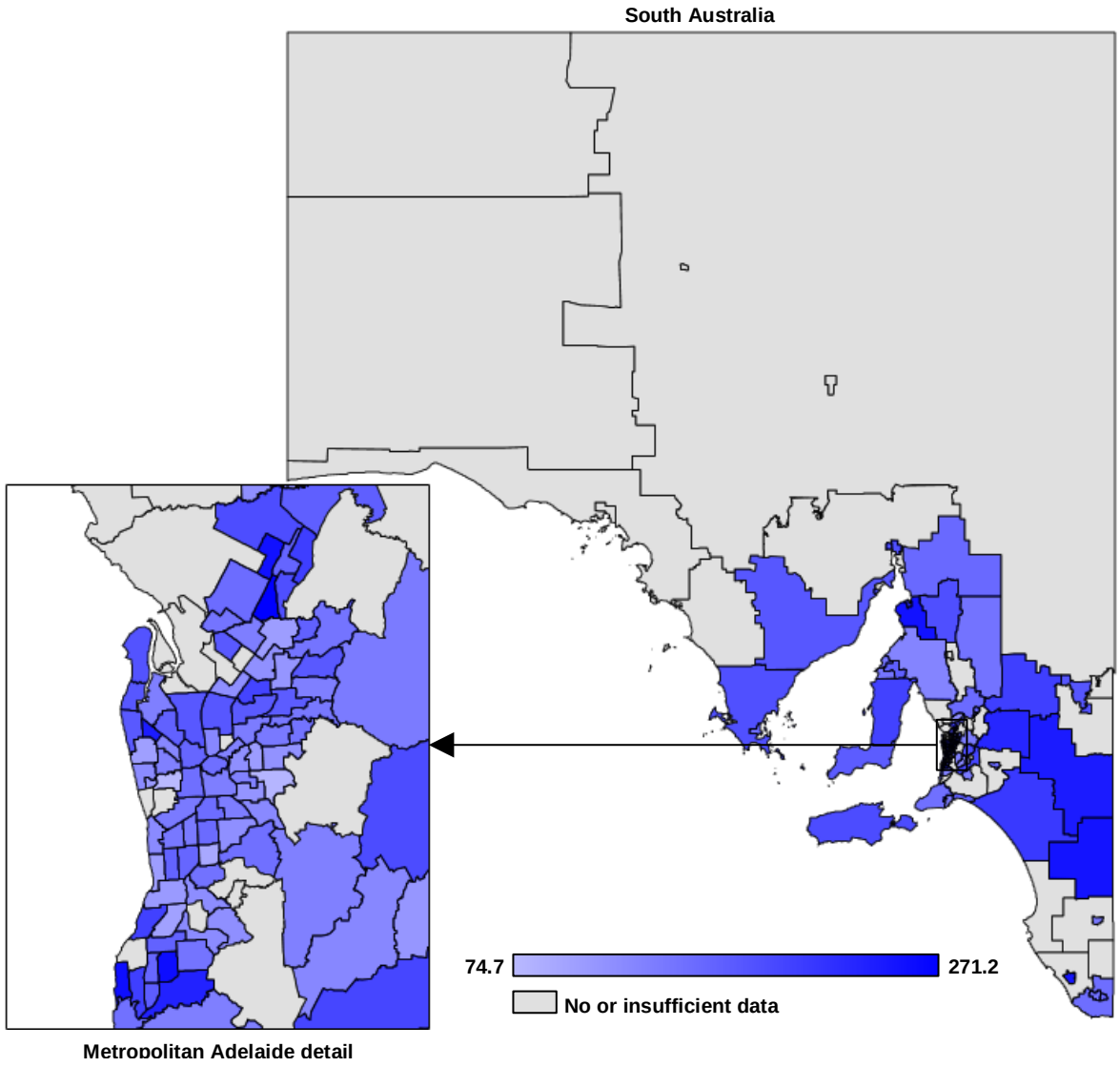
The SA2s of Waikerie, Hackham–Onkaparinga Hills and Penola recorded the three highest death rates from circulatory disease in South Australia during 2016 (290.8, 270.0, 257.0 deaths per 100,000 population, age standardised, respectively) (SA-NT DataLink 2019). Figure 2 contains further detail.

There was insufficient data to support mapping other causes of death at the SA2 level.

LOCAL HEALTH NETWORK INFORMATION:

For a more detailed breakdown of cause of death by SA Health local health network, refer to Appendix C of this report.

Figure 1: Cancer deaths per 100,000 population (age standardised) by SA2, 2016



Highest 10 SA2s for cancer deaths in South Australia, 2016

1. Elizabeth (271.2 cancer deaths per 100,000 population, age standardised)
2. Morphett Vale–East (257.1)
3. Christies Beach (256.2)
4. Davoren Park (252.9)
5. Port Pirie Region* (252.5)
6. Tatiara (251.5)
7. Millicent (249.8)
8. Karoonda–Lameroo (242.4)
9. Royal Park–Hendon–Albert Park (241.3)
10. Hackham–Onkaparinga Hills (234.6)

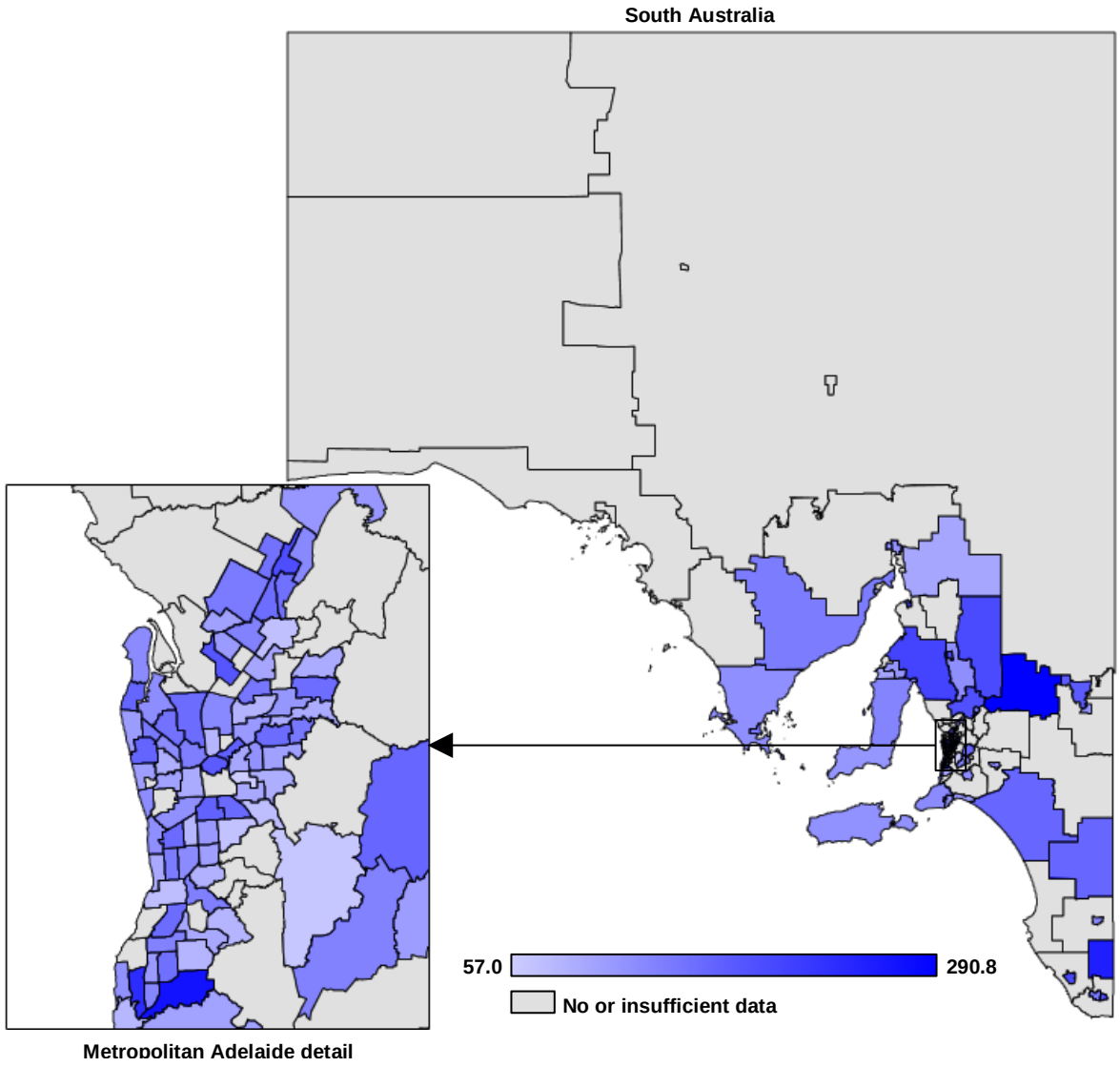
* Distinct from “Port Pirie” SA2 in Figure 2

Small cell data has been suppressed to protect privacy of individuals

Age-adjusted rates are standardised to the Australian 2001 population for consistency with the Australian Bureau of Statistics

Source: SA-NT DataLink 2019

Figure 2: Circulatory disease deaths per 100,000 population (age standardised) by SA2, 2016



Highest 10 SA2s for circulatory disease deaths in South Australia, 2016

1. Waikerie (290.8 circulatory disease deaths per 100,000 population, age standardised)
2. Hackham–Onkaparinga Hills (270.0)
3. Penola (257.0)
4. Christie Downs (240.4)
5. Port Pirie* (216.7)
6. Renmark (214.0)
7. Wakefield–Barunga West (213.6)
8. Millicent (210.3)
9. Goyder (207.0)
10. Clare (204.4)

* Distinct from “Port Pirie Region” SA2 in Figure 1

Small cell data has been suppressed to protect privacy of individuals

Age-adjusted rates are standardised to the Australian 2001 population for consistency with the Australian Bureau of Statistics

Source: SA-NT DataLink 2019

Deaths by place

Trends in place of death have moved gradually over the last decade in South Australia. During the period 2007-17 there was a gradual decline in the percentage of people who died in hospital, down from 48.2% of all deaths to 42.9%. Reported numbers of deaths in hospital include deaths on any ward, not only on wards that are hospice-specialised. Over the same time period there has been a corresponding increase in the proportion of persons who died in residential aged care facilities (RACFs) or nursing homes, up from 26.7% to 30.6%. The proportion of deaths at home (defined here as private residential address—it is recognised that for many people a RACF or nursing home is their home) has also been trending up, from 17.2% of all deaths in 2007 to 19.2% in 2017 (SA-NT DataLink 2019).

LOCAL HEALTH NETWORK INFORMATION:

For a more detailed breakdown of place of death by SA Health local health network, refer to Appendix D of this report.

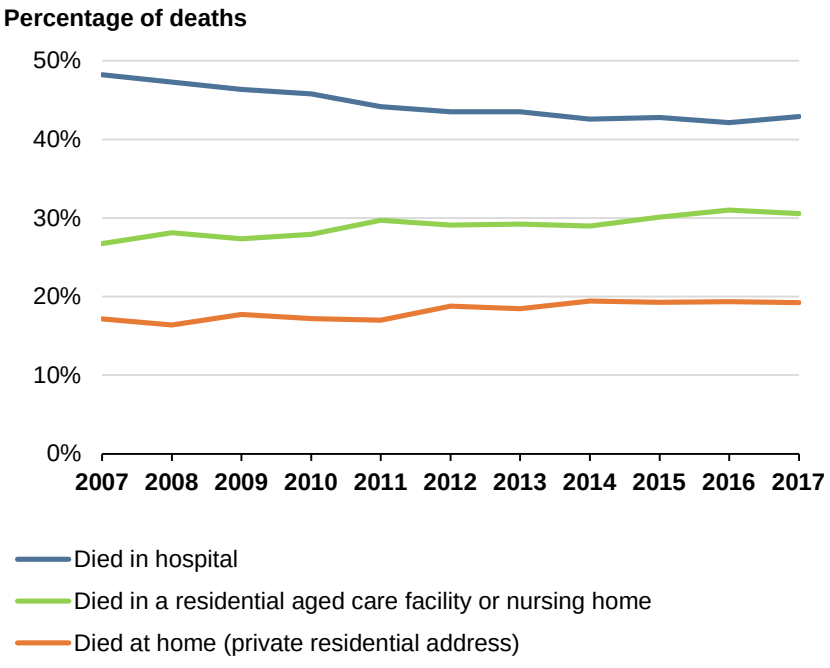
Table 5: Place of death in South Australia, 2007 vs. 2017

Place of death	2007 deaths		2017 deaths	
	no.	%	no.	%
Hospice	612	5.0%	551	3.9%
Hospital	5,934	48.2%	6,008	42.9%
Hostel or lodge	305	2.5%	428	3.1%
Mental health facility	20	0.2%	n.p.	n.p.
Private residential address (ie. home)	2,112	17.2%	2,695	19.2%
Rehabilitation facility	12	0.1%	n.p.	n.p.
Residential aged care facility or nursing home	3,291	26.7%	4,281	30.6%
Other supported accommodation	20	0.2%	22	0.2%
TOTAL DEATHS	**12,306**	**100.0%**	**14,004**	**100.0%**

n.p. not published. Small cell data has been suppressed to protect privacy of individuals

Source: SA-NT DataLink 2019

Figure 3: Place of death in South Australia, 2007-17



Not all places of death are shown

Source: SA-NT DataLink 2019

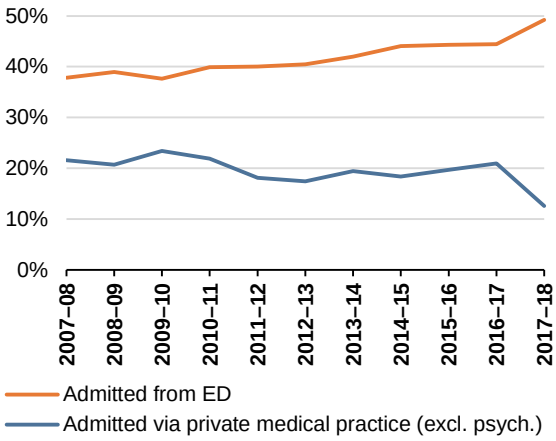
3. Palliative care access and equity

Access

In 2017-18, the majority (49.2%) of palliative care hospitalisation activity (inpatient separations) was admitted from emergency departments (EDs). Smaller percentages were referred from private medical practices (12.6%), transferred from other hospitals (12.3%) or were administrative admissions (10.5%) (SA Health 2019).

An administrative admission occurs when an inpatient's 'episode of care' (the overall nature of a clinical service provided to them as an admitted patient) changes during their hospital stay (for example, their care type changes from acute to palliative). Also note that a person can have multiple hospitalisations over a 12-month period, so these figures won't align with person-level results summarised in other parts of this report.

Figure 4: Percentage of palliative care hospitalisations (inpatient separations) by top two sources of referral, 2007-08 to 2017-18



Includes public and private hospitals
Source: SA Health 2019

The trend in palliative care hospitalisations (inpatient separations) that were admitted via emergency departments has been increasing since 2007-08, up from 37.8%. There has been a corresponding decline in the percentage of palliative care hospitalisations (inpatient separations) referred from private medical practices, down from 21.6% (SA Health 2019).

It is unclear to what extent observed trends may be due to changes in data standards or improved data capture and quality.

Table 6: Palliative care hospitalisations (inpatient separations) by source of referral, 2007-08 vs. 2017-18

Source of referral (ie. inpatient admitted from)	2007-08 hospitalisations		2017-18 hospitalisations	
	no.	%	no.	%
Administrative admission*	370	8.7%	661	10.5%
Community health service	204	4.8%	263	4.2%
Emergency department	1,601	37.8%	3,098	49.2%
Inter-hospital transfer	525	12.4%	775	12.3%
Outpatient department	277	6.5%	238	3.8%
Private medical practice (excluding psychiatrist)	913	21.6%	794	12.6%
Residential aged care facility	17	0.4%	38	0.6%
Other/unknown	*326*	*7.7%*	*425*	*6.8%*
Total palliative care hospitalisations (inpatient seps.)	**4,233**	**100.0%**	**6,292**	**100.0%**

Includes public and private hospitals

* An administrative admission follows an administrative separation. It occurs when the type of treatment and/or care has changed on an ongoing basis (eg. the episode of care has changed from acute to palliative) within the one hospital stay

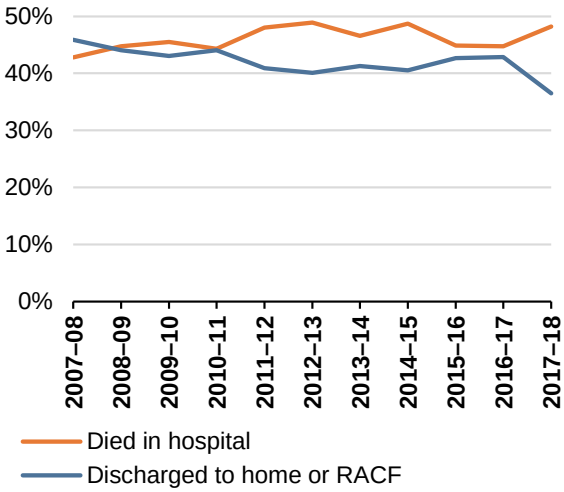
Source: SA Health 2019

In 2017-18, the majority (48.2%) of palliative care hospitalisation inpatients died in hospital. Smaller proportions were discharged to their homes (32.6%), transferred other hospitals (8.0%), were administrative separations (6.6%), or were discharged to residential aged care facilities (3.8%) (SA Health 2019).

An administrative separation occurs when an inpatient's 'episode of care' (the overall nature of a clinical service provided to them as an admitted patient) changes during their hospital stay (for example, their care type changes from acute to palliative) but they have not been formally 'separated' (discharged, transferred or died).

The trend in palliative care hospitalisations (inpatient separations) that end with the patient dying in hospital has increased since 2007-08, up from 42.8%. There has been a corresponding decline in the percentage of palliative care hospitalisations (inpatient separations) discharged to home (down from 39.0%) or discharged to residential aged care facilities (down from 6.9%) (SA Health 2019).

Figure 5: Percentage of palliative care hospitalisations (inpatient separations) by top two types of separation, 2007-08 to 2017-18



Includes public and private hospitals
Source: SA Health 2019

It is unclear to what extent observed trends may be due to changes in data standards or improved data capture and quality.

Table 7: Palliative care hospitalisations (inpatient separations) by type of separation, 2007-08 vs. 2017-18

Type of separation (ie. inpatient discharged to)	2007-08 hospitalisations		2017-18 hospitalisations	
	no.	%	no.	%
Administrative separation*	112	2.6%	418	6.6%
Died in hospital	1,812	42.8%	3,033	48.2%
Home	1,650	39.0%	2,053	32.6%
Residential aged care facility	293	6.9%	242	3.8%
Transferred to another hospital/healthcare accommodation	357	8.4%	504	8.0%
Other/unknown	*9*	*0.2%*	*42*	*0.7%*
Total palliative care hospitalisations (inpatient seps.)	**4,233**	**100.0%**	**6,292**	**100.0%**

Includes public and private hospitals

* An administrative separation occurs when the type of treatment and/or care has changed on an ongoing basis (eg. the episode of care has changed from acute to palliative) but the patient has not been formally separated from the reporting hospital

Source: SA Health 2019

Equity

Of the 13,440 persons who died in South Australia in 2016, 9,729 had been hospitalised as public hospital inpatients on at least one occasion in the 12 months prior to their death. Of this cohort, 3,112 persons (23.2% of all deaths) were coded or diagnosed as palliative care as part of their inpatient episode of care on at least one occasion in the 12 months prior to death. Some disparities are observed when this data is broken down by specific population group (SA-NT DataLink 2019).

An in-hospital palliative care coding or diagnosis does not identify whether the inpatient had contact with a palliative care service, and does not distinguish between levels of involvement if it had occurred. It is crucial to make a distinction between 'coded or diagnosed as palliative' and 'received palliative care'.

A higher proportion of males than females who died in South Australia in 2016 were coded or diagnosed in-hospital as palliative care on at least one occasion as public hospital inpatients in the 12 months prior to their deaths (25.1% and 21.1% respectively) (SA-NT DataLink 2019).

Table 8: Palliative care in 12 months prior to death by sex, 2016

Sex	2016 deaths	Hospitalised (public hospital inpatient) in 12 months prior to death	Coded/diagnosed as palliative care while public hospital inpatient in 12 months prior to death	
	persons	persons	persons	% of deaths
Males	6,873	5,214	1,726	25.1%
Females	6,567	4,515	1,386	21.1%
All persons	**13,440**	**9,729**	**3,112**	**23.2%**

A small number of death records with unknown sex status have been added to the males cohort to protect privacy of individuals
Source: SA-NT DataLink 2019

The proportions of persons who died in South Australia in 2016 and were coded or diagnosed in-hospital as palliative care on at least one occasion as a public hospital inpatient in the 12 months prior to death are similar for the 30 to 64 years (31.5%) and 65 to 79 years (31.9%) age cohorts. The proportion is lowest for the 18 to 29 years age cohort (11.7%), while proportions for the under 18 years (18.6%) and 80 years-and-over (17.6%) cohorts are also similar (SA-NT DataLink 2019).

Table 9: Palliative care in 12 months prior to death by age cohort, 2016

Age cohort	2016 deaths	Hospitalised (public hospital inpatient) in 12 months prior to death	Coded/diagnosed as palliative care while public hospital inpatient in 12 months prior to death	
	persons	persons	persons	% of deaths
Less than 18 years	102	57	19	18.6%
18-29 years	111	48	13	11.7%
30-64 years	2,024	1,462	638	31.5%
65-79 years	3,318	2,621	1,058	31.9%
80 years and over	7,885	5,541	1,384	17.6%
All persons	**13,440**	**9,729**	**3,112**	**23.2%**

Source: SA-NT DataLink 2019

The percentage of persons who died in South Australia in 2016 and coded or diagnosed in-hospital as palliative care on at least one occasion as public hospital inpatients in the 12 months prior to death varies by SA Health local health network (LHN), from 33.8% in the Flinders and Upper North LHN down to 16.8% in the Yorke and Northern LHN (SA-NT DataLink 2019).

However, in aggregate, the rates for metropolitan Adelaide residents (23.1%) and Country SA residents (23.5%) are similar (SA-NT DataLink 2019).

Table 10: Palliative care in 12 months prior to death by SA Health local health network, 2016

SA Health local health network (LHN) of resident	2016 deaths	Hospitalised (public hospital inpatient) in 12 months prior to death	Coded/diagnosed as palliative care while public hospital inpatient in 12 months prior to death	
	persons	persons	persons	% of deaths
Northern Adelaide	2,532	1,968	812	32.1%
Central Adelaide	3,989	2,601	705	17.7%
Southern Adelaide	2,680	1,957	607	22.6%
Metropolitan Adelaide	**9,201**	**6,526**	**2,124**	**23.1%**
Barossa Hills Fleurieu	1,426	1,036	356	25.0%
Eyre and Far North	323	259	75	23.2%
Flinders and Upper North	317	260	107	33.8%
Limestone Coast	553	430	141	25.5%
Riverland Mallee Coorong	636	493	143	22.5%
Yorke and Northern	852	639	143	16.8%
Country SA	**4,107**	**3,117**	**965**	**23.5%**
Non-South Australian resident or unknown LHN	*132*	*86*	*23*	*17.4%*
SOUTH AUSTRALIA	**13,440**	**9,729**	**3,112**	**23.2%**

Source: SA-NT DataLink 2019

In this report, the Health Performance Council respectfully uses the term ‘Aboriginal’, rather than ‘Indigenous’, to refer to people who identify as Aboriginal, Torres Strait Islander, or both. The Council recognises Aboriginal and Torres Strait Islander people as two separate groups. However, this document refers to Aboriginal persons in recognition that Aboriginal people are the original inhabitants of South Australia. The Council also acknowledges the complexity and diversity of the Aboriginal communities of South Australia, recognising each has its own beliefs and practice.

The percentage of persons who died in South Australia in 2016 and were coded or diagnosed in-hospital as palliative care on at least one occasion as a public hospital inpatient in the 12 months prior to death is higher for non-Aboriginal persons (23.2%) than Aboriginal persons (20.4%) (SA-NT DataLink 2019).

Table 11: Palliative care in 12 months prior to death by Aboriginal status, 2016

Aboriginal status	2016 deaths	Hospitalised (public hospital inpatient) in 12 months prior to death	Coded/diagnosed as palliative care while public hospital inpatient in 12 months prior to death	
	persons	persons	persons	% of deaths
Aboriginal persons	181	139	37	20.4%
Non-Aboriginal persons	13,259	9,590	3,075	23.2%
All persons	**13,440**	**9,729**	**3,112**	**23.2%**

A small number of death records with unknown Aboriginal status have been added to the non-Aboriginal persons cohort to protect privacy of individuals

Source: SA-NT DataLink 2019

In this report, the Health Performance Council defines persons from culturally and linguistically diverse (CALD) backgrounds in this report as those born in non-main English-speaking countries. That is, countries *other than* Australia, New Zealand, the United Kingdom, Ireland, the United States of America, Canada and South Africa.

The percentage of persons who died in South Australia in 2016 and coded or diagnosed in-hospital as palliative care on at least one occasion as public hospital inpatients in the 12 months prior to death is similar for persons from CALD and non-CALD backgrounds (24.1% and 23.2%, respectively). (SA-NT DataLink 2019).

Table 12: Palliative care in 12 months prior to death by culturally and linguistically diverse status, 2016

Culturally and linguistically diverse (CALD) status	2016 deaths	Hospitalised (public hospital inpatient) in 12 months prior to death	Coded/diagnosed as palliative care while public hospital inpatient in 12 months prior to death	
	persons	persons	persons	% of deaths
CALD persons	2,279	1,710	550	24.1%
Non-CALD persons	10,466	7,544	2,426	23.2%
Unknown status	695	475	136	19.6%
All persons	**13,440**	**9,729**	**3,112**	**23.2%**

Source: SA-NT DataLink 2019

In this report, the Health Performance Council classifies the socioeconomic status (SES) of geographic areas in South Australia using the *Socio-Economic Index for Areas (SEIFA) Index of Relative Socio-economic Disadvantage (IRSD) by Statistical Area Level 2 (SA2)*, published by the Australian Bureau of Statistics (ABS 2013a).

Lowest-SES areas are those in the lowest quintile (bottom 20%) of SA2s ordered by SEIFA IRSD. South Australian SA2s ranked by the Council in this report as lowest SES quintile are:

Metropolitan Adelaide: Christie Downs, Davoren Park, Elizabeth, Elizabeth East, Enfield - Blair Athol, Hackham West–Huntfield Heights, Morphett Vale–West, Parafield Gardens, Paralowie, Port Adelaide, Royal Park–Hendon–Albert Park, Salisbury, Salisbury North, Smithfield–Elizabeth North, The Parks, Virginia–Waterloo Corner, Woodville–Cheltenham.

Country South Australia Anangu Pitjantjatjara Yankunytjatjara (APY) Lands, Barmera, Berri, Ceduna, Coober Pedy, Millicent, Murray Bridge, Peterborough–Mt Remarkable, Port Augusta, Port Pirie, Renmark, Waikerie, Wallaroo, Western, Whyalla.

Proportionally, more people who live in areas classified in the lowest quintile of socioeconomic status in terms of relative disadvantage are likely to be coded or diagnosed in-hospital as palliative care on at least one occasion as a public hospital inpatient in the 12 months prior to death (28.4%) than those in other areas (21.9%) (SA-NT DataLink 2019).

Table 13: Palliative care in 12 months prior to death by socioeconomic status of area, 2016

Socioeconomic status (SES) quintile of area of resident	2016 deaths	Hospitalised (public hospital inpatient) in 12 months prior to death	Coded/diagnosed as palliative care while public hospital inpatient in 12 months prior to death	
	persons	persons	persons	% of deaths
Lowest SES quintile	2,718	2,163	771	28.4%
Low to highest SES quintiles	9,624	6,800	2,110	21.9%
Non-South Australian resident or unknown SA2	*1,098*	*766*	*231*	*21.0%*
All persons	**13,440**	**9,729**	**3,112**	**23.2%**

Sources: ABS 2013 and SA-NT DataLink 2019

4. Palliative care outcomes

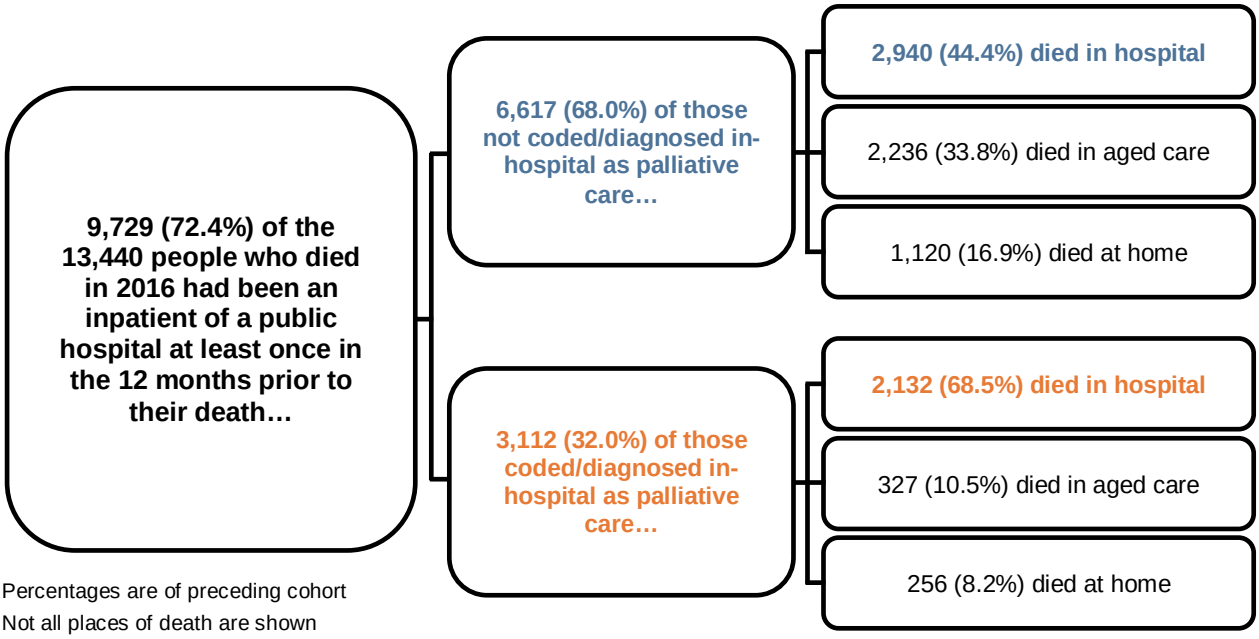
This section looks at public hospital utilisation (emergency department presentations and inpatient separations) in the 12 months before a person's death in South Australia. The 12-month period is arbitrary, however focus groups have noted that this time period is when major clinical and social needs emerge (Davidson et al 2003).

Of the 13,440 people who died in South Australia in 2016, 9,729 (72.4%) had been inpatients in a South Australian public hospital at least once in the 12 months prior to their death. Of this cohort, around two-thirds (68.0%) were not coded or diagnosed in-hospital as palliative care. The remaining 32.0% were coded or diagnosed as palliative care while inpatients on at least one occasion in the 12 months prior to death (SA-NT DataLink 2019).

The place-of-death outcomes between the palliative and non-palliative groups are quite different. Those who had been inpatients but not coded or diagnosed in-hospital as palliative care in the 12 months prior to death were more likely (50.7%) to die in a residential aged care facility, a nursing home or their own private residence. Those who had received at least one episode of in-hospital palliative care coding or diagnosis as a public hospital inpatient in the 12 months before death were more likely (68.5%) to die in hospital (SA-NT DataLink 2019).

An in-hospital palliative care coding or diagnosis does not identify whether the inpatient had contact with a palliative care service, and does not distinguish between levels of involvement if it had occurred. It is crucial to make a distinction between 'coded or diagnosed as palliative' and 'received palliative care'. Deaths in hospital include deaths on any ward, not only on wards that are hospice-specialised.

Figure 6: Place of death in South Australia where person was a public hospital inpatient in the last 12 months of life, 2016

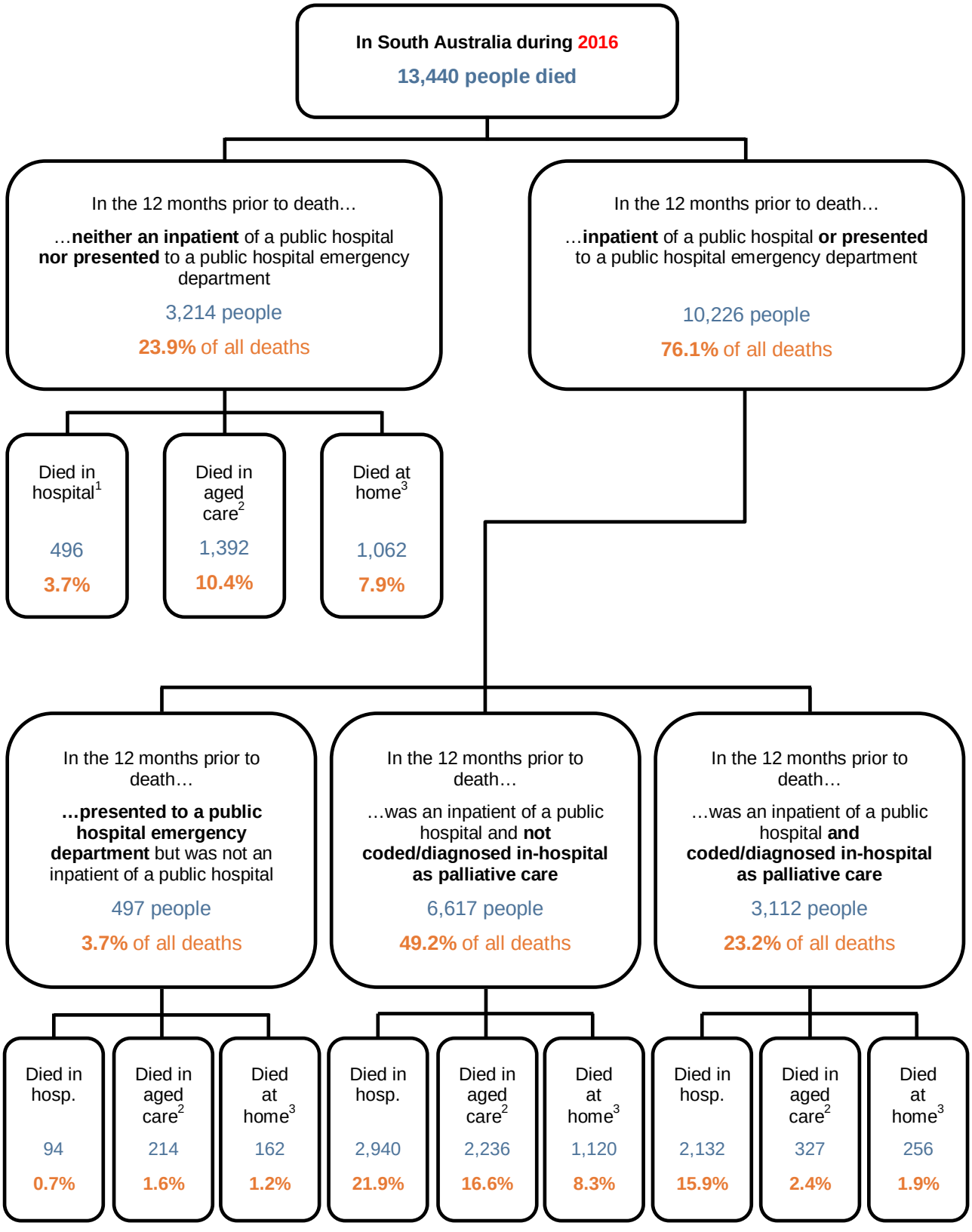


Percentages are of preceding cohort
Not all places of death are shown
2017 data not available at time of publication
Source: SA-NT DataLink 2019

Figure 7 presents a more complete picture of public hospital utilisation (including emergency department presentations and inpatient separations) in the 12 months before a person's death in South Australia, linked to their place of death. In 2016, 50.4% of people died in a residential aged care facilities, nursing homes or their own private residences. A further 42.1% died in hospitals, while the remaining 7.5% died in other accommodation such as hospices, hostels and lodges (SA-NT DataLink 2019).

Figure 8 compares 2016 to 2009-10, reproducing results from the Health Performance Council's 2013 end-of-life care report. In 2009-10 a combined 45.5% of people died in residential aged care facilities, nursing homes or their own private residences, while 46.4% died in hospitals (HPC 2013, p. 24).

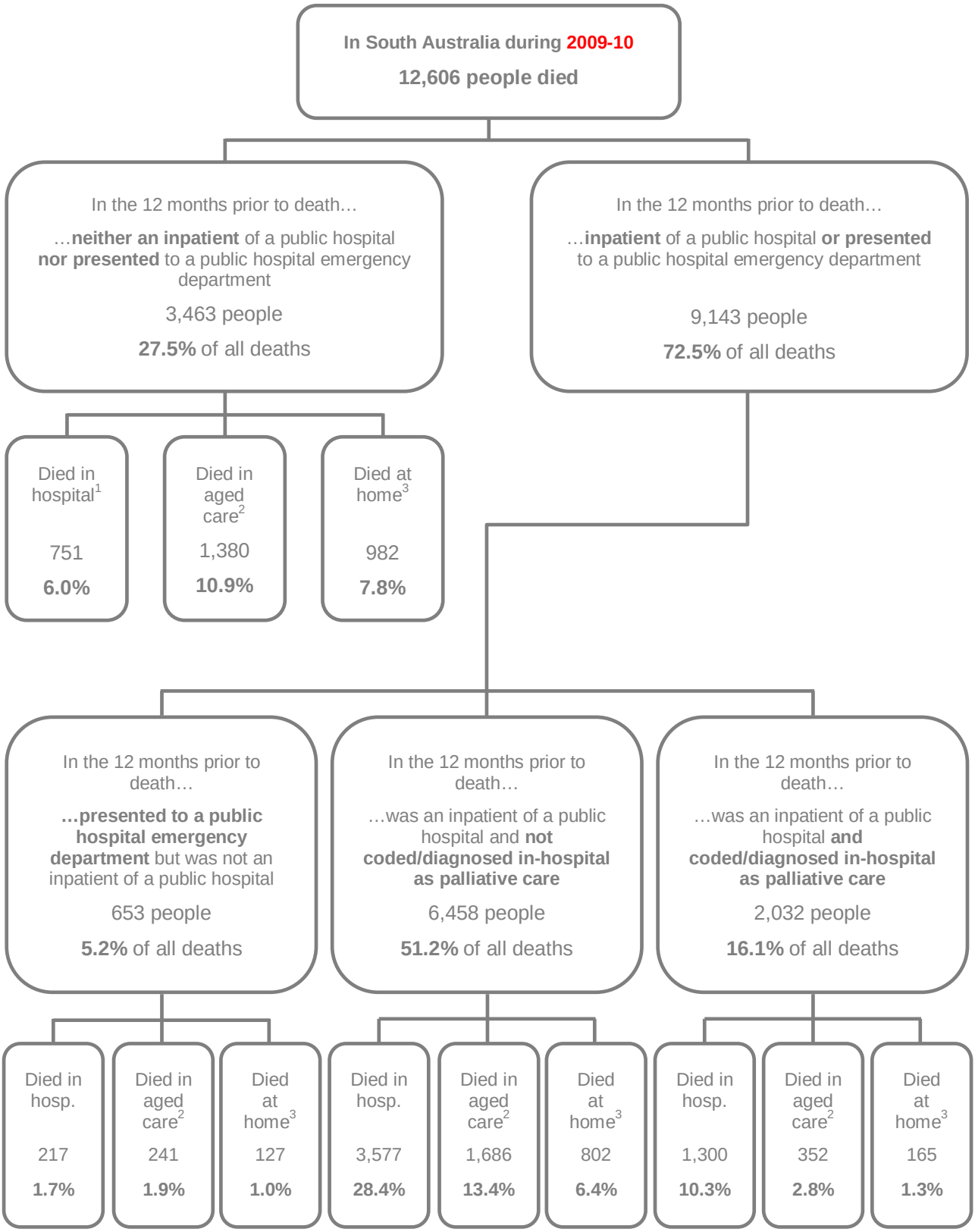
Figure 7: Place of death in South Australia by public hospital utilisation, 2016



1. Death is recorded at a public or private hospital location but there is no public emergency department or public hospital inpatient record for the 12 months prior to death. Person may have been a patient of a private hospital or deceased and was transferred to a public or private hospital for pronouncement of death.
2. Residential aged care facility or nursing home
3. Private residential address

2017 data not available at time of publication
Percentages are of all deaths in South Australia in 2016 (13,440)
Not all places of death are shown. Deaths in hospital include deaths on any ward, not only on wards that are hospice-specialised.
Source: SA-NT DataLink 2019

Figure 8: Place of death in South Australia by public hospital utilisation, 2009-10



1. Death is recorded at a public or private hospital location but there is no public emergency department or public hospital inpatient record for the 12 months prior to death. Person may have been a patient of a private hospital or deceased and was transferred to a public or private hospital for pronouncement of death.
2. Residential aged care facility or nursing home
3. Private residential address

Percentages are of all deaths in South Australia in 2009-10 (12,606)
Not all places of death are shown. Deaths in hospital include deaths on any ward, not only on wards that are hospice-specialised.
Source: HPC 2013

5. Growth in hospital-based palliative care

The majority of in-hospital palliative care activity recorded for admitted patients in South Australia is provided by the public hospital system. In 2017-18 there were 6,284 palliative care hospitalisations (inpatient separations coded or diagnosed as palliative care) in South Australia—5,440 (86.6%) at public hospitals and 844 (13.4%) at private hospitals (SA Health 2019). Note that a person can have multiple hospitalisations over a 12-month period, so these figures do not align with person-level results summarised in other parts of this report.

The period 2007-08 to 2017-18 has seen the volume of palliative care hospitalisations (inpatient separations coded or diagnosed as palliative care) at public hospitals increase 62.1%, from 3,356 to 5,440. Over the same time period, the number of palliative care hospitalisations at private hospitals in South Australia has remained relatively steady, decreasing from 851 in 2007-08 to 844 in 2017-18 (SA Health 2019). The Australian Institute of Health and Welfare reports a 25.6% increase in palliative care-related hospitalisations between 2012-13 and 2016-17 (AIHW 2019a).

The average length of stay for a palliative care hospitalisation (inpatient separations coded or diagnosed as palliative care) has diverged between public and private hospitals in South Australia. In 2017-18 the average length of stay for a palliative care hospitalisation in public hospitals was 10.5 days, a 28.2% decline from 2007-08. The average length of stay remained steady within private hospitals (SA Health 2019). The Australian Institute of Health and Welfare reports that Australia-wide palliative care-related hospitalisations accounted for an average length of stay of 10.2 days (AIHW 2019a).

The average number of intensive care unit (ICU) hours in public and private hospitals, and ventilation hours in public hospitals, per palliative care hospitalisation (inpatient separation), have also been trending up over the period 2007-08 to 2017-18 (SA Health 2019).

It is unclear to what extent observed trends may be due to changes in data standards or improved data capture and quality.

Figure 9: Palliative care hospital utilisation in South Australia, 2007-08 to 2017-18

Fig. 9.1: Number of palliative care hospitalisations (inpatient separations)

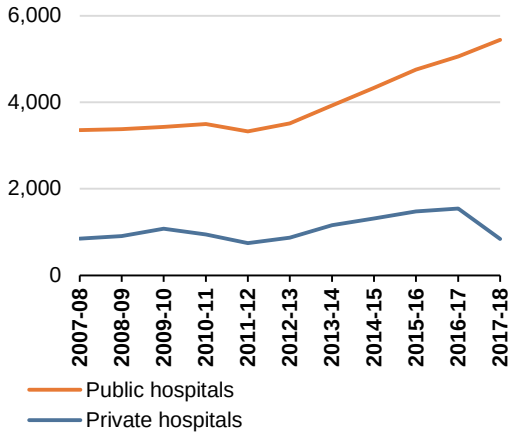


Fig. 9.2: Average length of stay (days) for a palliative care hospitalisation (inpatient separation)

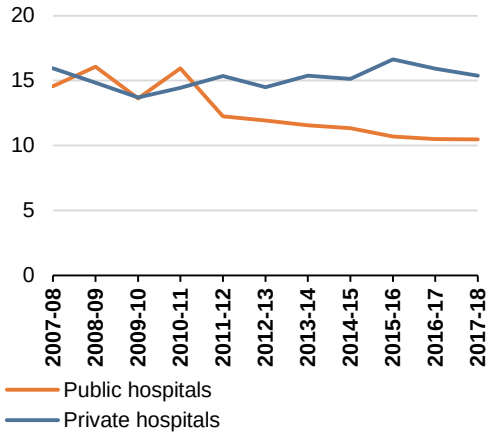


Fig. 9.3: Average intensive care unit hours per palliative care hospitalisation (inpatient separation)

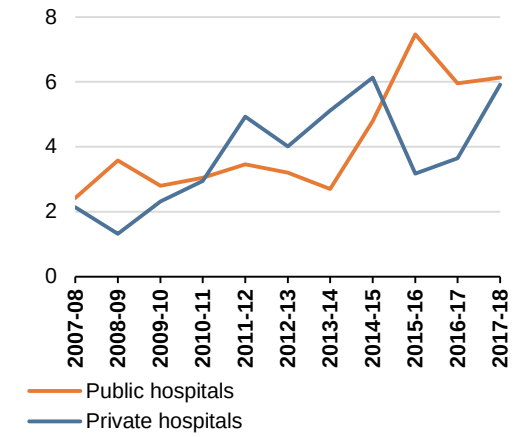
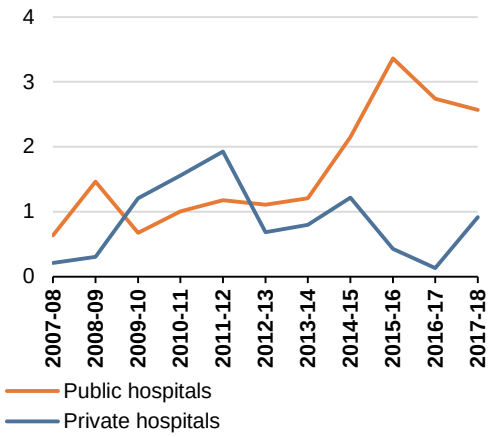


Fig. 9.4: Average ventilation hours per palliative care hospitalisation (inpatient separation)



Source: SA Health 2019

6. Unmet need for palliative care

Historically focusing on patients with cancer, palliative care services have, more recently, attempted to include patients with other conditions. Extending palliative care services to patients with non-malignant conditions is not straightforward. There have been concerns about the delivery of such services and difficulty in identifying the point at which palliative care is required. Nevertheless, there is a case to be made for the extension of these services. The symptoms of patients with malignant conditions may be more severe, yet those with non-malignant conditions are generally more prolonged. In many instances the need for palliative care for people dying of non-malignant conditions is as great as the needs of those with malignant conditions. (Rosenwax et al 2005).

Selected methods

This section uses linked deaths and public hospital inpatient activity data to test the extent to which the South Australian population is serviced by palliative care—patients with non-malignant conditions as well as cancer. This is used as a basis for estimating unmet need for palliative care.

Two methods for estimating unmet need for palliative care are applied here:

1. 'Rosenwax design', applying the 'mid-range criteria'
2. 'Murtagh design', which is a refining of the Rosenwax approach.

These approaches produce different outcomes in estimating level of unmet need and have limitations which are important to note and are described below.

Other methods and future work

There are several approaches possible in estimating the size of a potential palliative care population. For timeliness reasons, applying them all is out of the scope of this report.

Appendix E summarises numbers of deaths in South Australia in 2016 by cause of death and whether persons had been hospitalised as a public hospital inpatient in the 12 months prior to death—with and without a coding or diagnosis in-hospital for palliative care. This data has been provided to researchers to assist in deriving their own estimates of levels of unmet need for palliative care in the community.

Other possible areas for future work to directly measure unmet need for palliative care could include building ongoing use of existing data sources and mixed methods approaches which include: listening to patients, their families and carers; and seeking the views of harder-to-reach and vulnerable population groups.

Rosenwax design

An approach used by the University of Western Australia to estimate the size of a potential palliative care population is applied here to quantify unmet need. The Rosenwax method proposes three different sets of criteria to estimate the need for palliative care in a population (Rosenwax et al 2005):

1. a minimal estimate based on ten specific disease groups recognised through expert consensus as likely to need palliative care
2. a mid-range estimate that identifies people who were hospitalised (as an inpatient separation) in the 12 months prior to death with the reason for admission (based on principal and secondary diagnoses) matching the cause of death
3. a maximal estimate that includes *all* deaths apart from sudden deaths.

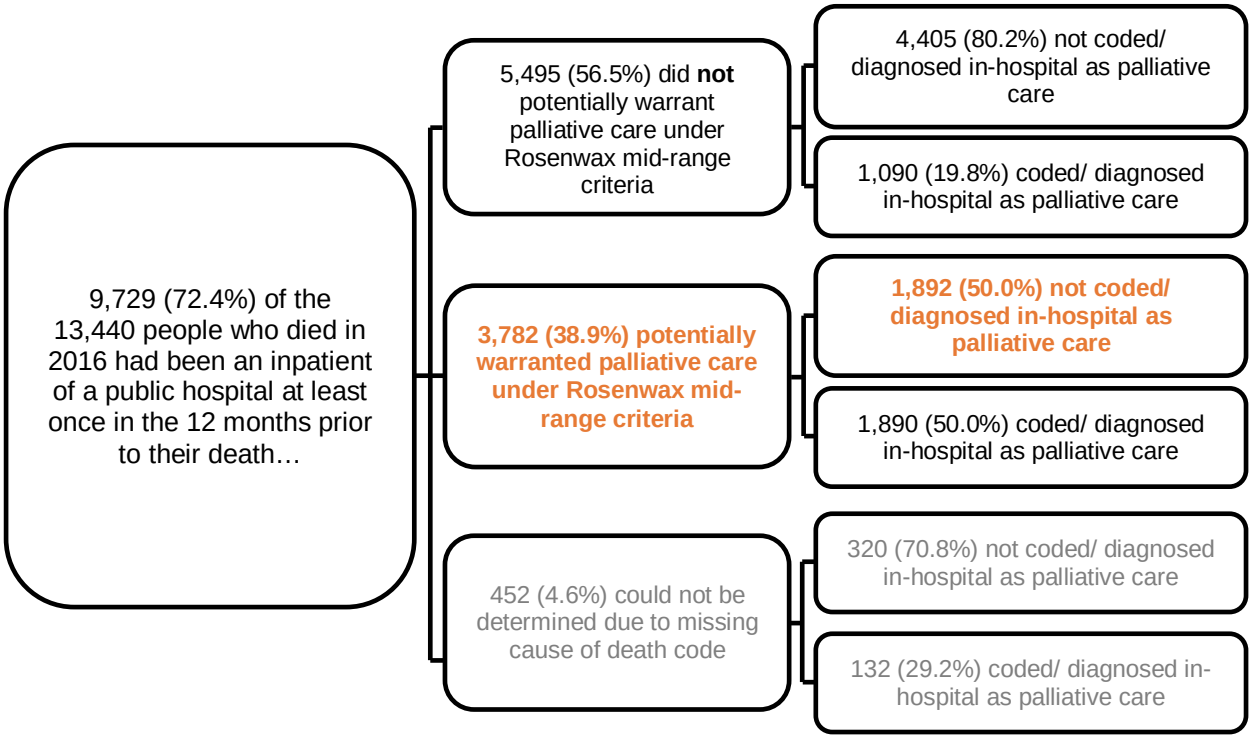
The Council has adopted the Rosenwax mid-range criteria (method 2) in the following analysis.

Applying the Rosenwax mid-range criteria to linked data provided by SA-NT DataLink identifies 3,782 people who died in 2016 who potentially warranted palliative care in the 12 months prior to death. Of this cohort, 1,892 (50.0%) were **not** coded or diagnosed in-hospital as palliative care. Conversely, 1,090 people were identified under the model who did **not** potentially warrant palliative care, **but were coded or diagnosed in-hospital as palliative care** (SA-NT DataLink 2019).

The gap between the 3,112 people who died in 2016 and were coded or diagnosed in-hospital as palliative care in the 12 months prior to death, and the 3,782 people identified as *warranting* palliative care under the *Rosenwax design* (670 persons), expressed as a percentage of all potentially warranted, indicates **an estimated level of unmet need of 18%**.

However, a recognised limitation with this analysis is it only links deaths with public hospital activity data. Without access to linked private hospital data or community health datasets it is impossible to say whether the people identified may have received palliative care from outside the public hospital system.

Figure 10: Potential unmet need for in-hospital palliative care using the Rosenwax mid-range design



Percentages are of preceding cohort
2017 data not available at time of publication
Source: Rosenwax et al 2005 and SA-NT DataLink 2019

Murtagh design

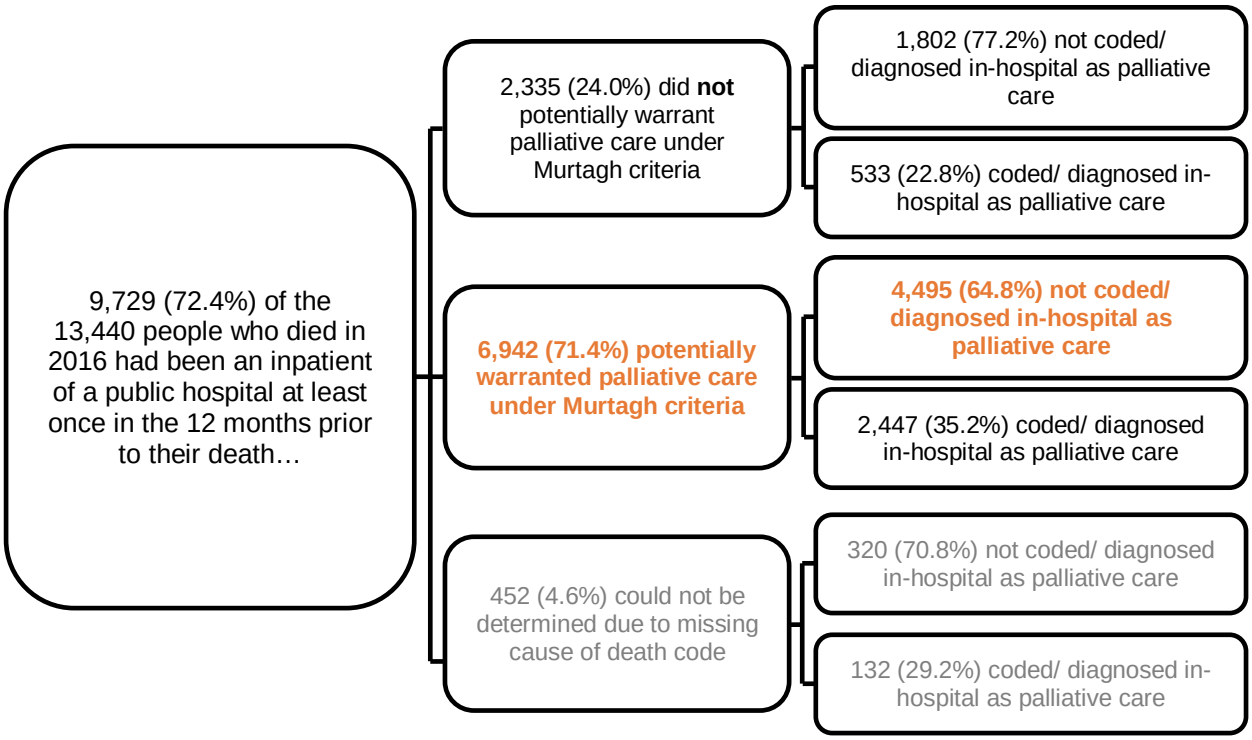
The other approach selected by the Health Performance Council to estimate the size of a potential palliative care population refines the Rosenwax design. The Murtagh design applied here to quantify unmet need is based on the views of an expert panel and applies a detailed breakdown of disease classification (ICD-10) codes with the inclusion or extension of a number of life-limiting illnesses[1] (Murtagh et al 2014).

Applying the Murtagh criteria to linked data provided by SA-NT DataLink identifies 6,942 people who died in 2016 who potentially warranted palliative care in the 12 months prior to death. Of this cohort, 4,495 (64.8%) were **not** coded or diagnosed in-hospital as palliative care. Conversely, applying the Murtagh criteria identifies 533 people who did **not** potentially warrant palliative care, **but were coded or diagnosed in-hospital as palliative care** (SA-NT DataLink 2019).

The gap between the 3,112 people who died in 2016 and were coded or diagnosed in-hospital as palliative care in the 12 months prior to death, and the 6,942 people identified as *warranting* palliative care under the *Murtagh design* (3,830 persons), expressed as a percentage of all potentially warranted, indicates an **estimated level of unmet need of 55%.**

However, as with applying the Rosenwax design, a recognised limitation with this analysis is it only links deaths with public hospital activity data. Without access to linked private hospital data or community health datasets it is impossible to say whether the people identified may have received palliative care from outside the public hospital system.

Figure 11: Potential unmet need for in-hospital palliative care using the Murtagh design



Percentages are of preceding cohort

2017 data not available at time of publication

Source: Murtagh et al 2014 and SA-NT DataLink 2019

[1] All cancer deaths (ICD-10: C00-C97)—malignant neoplasms only included; Non-cancer (ICD-10: I00-I52, I60-I69, N17, N18, N28, C64, I12, I13, K70-K77, J06-J18, J20-J22, J40-J47 and J96, G10, G20, G35, G122, G903, G231, F01, F03, G30, R54, B20-B24).

Unmet need at the local health network level

Applying the Rosenwax mid-range criteria by SA Health local health network (LHN) identifies a potentially higher level of unmet need for palliative care in Country SA in percentage terms (27%) compared to metropolitan Adelaide (13%). Unmet need for palliative care is highest in the Yorke and Northern LHN (44%). The Rosenwax design identifies a *negative* unmet need (-2%) in the Northern Adelaide LHN, indicating slightly more people were coded or diagnosed as palliative care while inpatients of public hospitals in the 12 months prior to death than was potentially warranted (SA-NT DataLink 2019).

Table 14: Potential unmet need for in-hospital palliative care by local health network using the Rosenwax design

SA Health local health network (LHN) of resident	Coded/diagnosed as palliative care while public hospital inpatient in 12 months prior to death	Potentially warranted palliative care under Rosenwax mid-range criteria	Estimated level of unmet need under Rosenwax mid-range criteria
	persons	persons	%
Northern Adelaide	812	793	-2%
Central Adelaide	705	866	19%
Southern Adelaide	607	770	21%
Metropolitan Adelaide	**2,124**	**2,429**	**13%**
Barossa Hills Fleurieu	356	441	19%
Eyre and Far North	75	115	35%
Flinders and Upper North	107	109	2%
Limestone Coast	141	180	22%
Riverland Mallee Coorong	143	219	35%
Yorke and Northern	143	255	44%
Country SA	**965**	**1,319**	**27%**
Non-South Australian resident or unknown LHN	*23*	*34*	*32%*
SOUTH AUSTRALIA	**3,112**	**3,782**	**18%**

Sources: Rosenwax et al 2005 and SA-NT DataLink 2019

Applying the Murtagh criteria by SA Health local health network (LHN) again identifies a potentially higher level of unmet need for palliative care in Country SA in percentage terms (58%) compared to metropolitan Adelaide (54%). Unmet need for palliative care identified under the Murtagh design is highest in the Yorke and Northern LHN (70%) and lowest in the Flinders and Upper North LHN (41%) (SA-NT DataLink 2019).

Table 15: Potential unmet need for in-hospital palliative care by local health network using the Murtagh design

SA Health local health network (LHN) of resident	Coded/diagnosed as palliative care while public hospital inpatient in 12 months prior to death	Potentially warranted palliative care under Murtagh criteria	Estimated level of unmet need under Murtagh criteria
	persons	persons	%
Northern Adelaide	812	1,395	42%
Central Adelaide	705	1,807	61%
Southern Adelaide	607	1,410	57%
Metropolitan Adelaide	**2,124**	**4,612**	**54%**
Barossa Hills Fleurieu	356	762	53%
Eyre and Far North	75	184	59%
Flinders and Upper North	107	180	41%
Limestone Coast	141	306	54%
Riverland Mallee Coorong	143	370	61%
Yorke and Northern	143	469	70%
Country SA	**965**	**2,271**	**58%**
Non-South Australian resident or unknown LHN	*23*	*59*	*61%*
SOUTH AUSTRALIA	**3,112**	**6,942**	**55%**

Sources: Murtagh et al 2014 and SA-NT DataLink 2019

7. Quality of palliative care

In South Australia, around one in 13 persons who die do so from diseases considered amenable to healthcare, defined as 'avoidable deaths'. The majority of people who die spend their last year of life going in and out of hospital, on average around five times as public hospital inpatients. Around one in ten will be coded or diagnosed as palliative care while an admitted patient. On average, the duration from their last hospitalisation to death is just over 40 days.

However, these outcomes vary by disease type and by public hospital. This section compares patterns of palliative care for persons dying from different serious illnesses and receiving services at different public hospitals in South Australia. Data is provided in the context of monitoring healthcare in the months prior to death as in other areas of healthcare: quality and safety.

Selected methods

Quality can be measured in terms of overuse—for example, acute care provided that is not warranted or avoidable ; and underuse—for example, palliative care not provided for non-malignant diseases. Outcomes for this measure are summarised in Table 14.

Safety can be measured in terms of distribution of utilisation and outcomes by facility. Outcomes for this measure are summarised in Table 15.

Other methods and future work

There are several approaches possible in monitoring palliative quality of care. For timeliness reasons, this report cannot evaluate them all.

Other possible areas for future work to measure quality of palliative hospital care could include looking at return users to emergency departments; 30-day, 60-day and 90-day mortality rates; hospital standardised mortality ratios (HSMRs) and Australian National Sub-Acute and Non-Acute Patient (AN-SNAP) data. Feedback from consumers, carers and their families can also inform this assessment.

Avoidable mortality

Work by Ellen Nolte and Martin McKee for the Nuffield Trust looks at deaths that should not occur in the presence of effective and timely healthcare—so called 'avoidable' mortality—as a method of monitoring health system performance. The Nuffield Trust identifies 34 causes of death and age combinations considered amenable to healthcare (Nolte, McKee 2004).

Applying the Nolte and McKee criteria to linked data identifies 1,034 people who died in South Australia in 2016 and whose cause of death, considering age, is potentially 'avoidable'. Of this cohort, 720 (69.6%) persons had been hospitalised (as an inpatient separation) at least once in the 12 months prior to death in the public hospital system and 259 of those (36.0%) had been coded or diagnosed in-hospital as palliative care (SA-NT DataLink 2019).

The highest number of deaths in 2016 for disease and age combinations considered amenable to healthcare comprised:

1. ischaemic heart disease, ages 0-74 years—377 deaths; 202 persons hospitalised as public hospital inpatients at least once in the 12 months prior to death with 24 (11.9%) who were coded or diagnosed as palliative care while public hospital inpatients at least once in the 12 months prior to death
2. malignant neoplasm of colon and rectum, ages 0-74 years—152 deaths; 128 hospitalised in 12 months prior to death with 89 (69.5%) receiving in-hospital palliative care
3. malignant neoplasm of breast, ages 0-74 years—141 deaths, 106 hospitalised in the 12 months prior to death, with 70 (66.0%) receiving in-hospital palliative care.

Table 16: Hospital utilisation in the 12 months prior to death by avoidable deaths, 2016

	Cause of death and age combinations considered amenable to healthcare –'avoidable deaths'			2016 deaths	Hospitalised (public hosp. inpatient) in 12 months prior to death	Coded or diagnosed as palliative care while public hosp. inpatient in 12 months prior to death
	Cause of death	ICD-10 code(s)	Age (years)	persons	persons	persons
1	Intestinal infections	A00-A09	0-14	0	0	0
2	Tuberculosis	A15-A19, B90	0-74	n.p.	0	0
3	Other infectious (diphtheria, tetanus, poliomyelitis)	A36, A35,A80	0-74	0	0	0
4	Whooping cough	A37	0-14	0	0	0
5	Septicaemia	A40-A41	0-74	30	29	n.p.
6	Measles	B05	0-14	0	0	0
7	Malignant neoplasm of colon and rectum	C18-C21	0-74	152	128	89
8	Malignant neoplasm of skin	C44	0-74	11	10	n.p.
9	Malignant neoplasm of breast	C50	0-74	141	106	70
10	Malignant neoplasm of cervix uteri	C53	0-74	n.p.	n.p.	n.p.
11	Malignant neoplasm of cervix uteri and body of the uterus	C54, C55	0-44	0	0	0
12	Malignant neoplasm of testis	C62	0-74	n.p.	n.p.	n.p.
13	Hodgkin's disease	C81	0-74	n.p.	n.p.	n.p.
14	Leukaemia	C91-C95	0-44	n.p.	n.p.	n.p.
15	Diseases of the thyroid	E00-E07	0-74	n.p.	n.p.	n.p.
16	Diabetes mellitus	E10-E14	0-49	14	n.p.	n.p.
17	Epilepsy	G40-G41	0-74	13	10	n.p.
18	Chronic rheumatic heart disease	I05-I09	0-74	n.p.	n.p.	n.p.
19	Hypertensive disease	I10-I13, I15	0-74	10	n.p.	n.p.
20	Ischaemic heart disease	I20-I25	0-74	377	202	24
21	Cerebrovascular disease	I60-I69	0-74	121	100	20
22	All respiratory diseases (excl. pneumonia and influenza)	J00-J09,J20-J99	1-14	n.p.	n.p.	0
23	Influenza	J10-J11	0-74	n.p.	n.p.	n.p.
24	Pneumonia	J12-J18	0-74	38	27	n.p.
25	Peptic ulcer	K25-K27	0-74	n.p.	n.p.	0
26	Appendicitis	K35-K38	0-74	0	0	0
27	Abdominal hernia	K40-K46	0-74	n.p.	0	0
28	Cholelithiasis & cholecystitis	K80-K81	0-74	n.p.	n.p.	n.p.
29	Nephritis and nephrosis	N00-N07, N17-N19 N25-N27	0-74	19	16	n.p.
30	Benign prostatic hyperplasia	N40	0-74	0	0	0
31	Maternal deaths	O00-O99	All	n.p.	n.p.	n.p.
32	Congenital cardiovascular anomalies	Q20-Q28	0-74	n.p.	n.p.	n.p.
33	Perinatal deaths, all causes excluding stillbirths	P00-P96, A33, A34	All	28	19	n.p.
34	Misadventures to patients during surgical and medical care	Y60-Y69, Y83-Y84	All	n.p.	n.p.	n.p.
Deaths considered amenable to healthcare				**1,034**	**720**	**259**
*Deaths considered **not** amenable to healthcare*				*12,406*	*9,009*	*2,853*
TOTAL				**13,440**	**9,729**	**3,112**

n.p. not published. Small cell data has been suppressed to protect privacy of individuals.

2017 data not available at time of publication

Sources: Nolte, McKee 2004 and SA-NT DataLink 2019

Hospital utilisation prior to death

There were 13,440 people who died in South Australia during 2016. Of these, 9,729 were hospitalised as a public hospital inpatient at least once—on average 4.6 times—in the 12 months prior to their death. Proportionally, 9.9% of hospitalisations (inpatient separations) in the 12 months prior to death for people who died in 2016 were palliative, that is coded or diagnosed as palliative care during admission (10.5% in the major metropolitan Adelaide public hospitals and 8.1% in the major Country SA public hospitals). (SA-NT DataLink 2019).

The public hospitals most frequently used for inpatient services by people who died in 2016 were the Port Augusta Hospital and Regional Health Service (8.2 hospitalisations per person in 12 months prior to death), the Mount Gambier and Districts Health Service (4.2) and the Women's and Children's Hospital (4.0) (SA-NT DataLink 2019). Table 17 includes renal dialysis in the hospital utilisation data. A relatively small number of persons receiving a large number of renal dialysis services over the 12-month period prior to death may skew some averages.

Over a quarter (27.0%) of Modbury Hospital hospitalisations (inpatient separations) in the 12 months prior to death were palliative (coded or diagnosed as palliative care during admission), followed by the Repatriation General Hospital (19.9%) and the Women's and Children's Hospital (19.1%) (SA-NT DataLink 2019).

Table 17: Hospital utilisation in the 12 months prior to death by public hospital, 2016

Admitting South Australian public acute hospital in 12 months prior to death	Hospitalisations (inpatient separations) in 12 months prior to death	Hospitalisations (inpatient separations) in 12 months prior to death that were palliative
	average no. per person over 12-month period	% of hospitalisations during 12-month period
Major metropolitan Adelaide public hospitals		
Flinders Medical Centre	3.4	6.0%
Lyell McEwin Hospital	3.0	13.8%
Modbury Hospital	1.9	27.0%
Noarlunga Hospital	3.2	6.6%
The Queen Elizabeth Hospital	3.4	9.6%
Repatriation General Hospital	2.3	19.9%
Royal Adelaide Hospital	2.8	7.9%
Women's and Children's Hospital	4.0	19.1%
Total major metro. public hospitals	**4.0**	**10.5%**
Major Country SA public hospitals		
Gawler Health Service	2.0	16.8%
Mt Gambier and Districts Health Service	4.2	6.7%
Pt Augusta Hospital & Regional Health Service	8.2	3.6%
Pt Lincoln Health Service	3.4	9.2%
Pt Pirie Regional Health Service	3.2	11.5%
Riverland General Hospital	3.5	2.3%
Whyalla Hospital and Health Service	3.6	12.9%
Total major country public hospitals	**3.9**	**8.1%**
Non-major public hospitals	**3.0**	**8.0%**
TOTAL	**4.6**	**9.9%**

Source: SA-NT DataLink 2019

Appendix A: Palliative care data under the Community Nursing Services Agreement

Up until 30 June 2018, SA Health negotiated with the Royal District Nursing Service of South Australia (RDNS SA) for the provision of specialised community nursing services to support individuals with long-term complex care requirements. The community nursing program supported a flexible, holistic approach to ensure that patients with longer term complex-care requirements received clinically appropriate services as an alternative to a hospital admission. Patients could be referred to the program from either the community or the acute sector.

The program included providing community-based palliative nursing care to people within the home environment.

SA Health provided the Health Performance Council with monthly extracts of community nursing services palliative care client data for analysis. Summary results for the final three financial years are presented below.

Between 1 July 2015 and 30 June 2018, RDNS SA provided care to 2,017 people (1,112 male, 897 female and 8 unknown) under its community-based palliative nursing care program. The average age of those in the program was 71.0 years (71.6 years for males and 70.5 years for females) (SA Health 2018).

Over the period, there was a total of 54,654 *in-home* community-based palliative nursing care visits under the program, or about 1,518 per month across the program over the 36 months of data analysed. Similarly, there were 8,307 *out-of-home* visits, or approximately 231 per month (SA Health 2018).

At an individual level, a person received community-based palliative nursing care services under the RDNS SA program for an average duration of 2.7 months—every month receiving an average of 10.2 in-home visits and 1.5 out-of-home visits during that time. The average duration of an in-home visit was 56 minutes, while the average duration of an out-of-home visit was 13 minutes (SA Health 2018).

People were referred to the program primarily through the three metropolitan Adelaide local health network palliative care services (Southern Adelaide, Central Adelaide and Northern Adelaide), Flinders Medical Centre, the Metropolitan Referral Unit and The Queen Elizabeth Hospital (SA Health 2018).

Palliative assessment, client care and support provided to people admitted under the program over the period 1 July 2015 to 30 June 2018 was predominantly related to symptom and pain management, hygiene and pressure area care, and bowel care and constipation management (SA Health 2018).

Figure 12: RDNS SA community-based palliative nursing care activity, 2015-16 to 2017-18

Figure 12.1: Number of palliative care visits under the Community Nursing Agreement

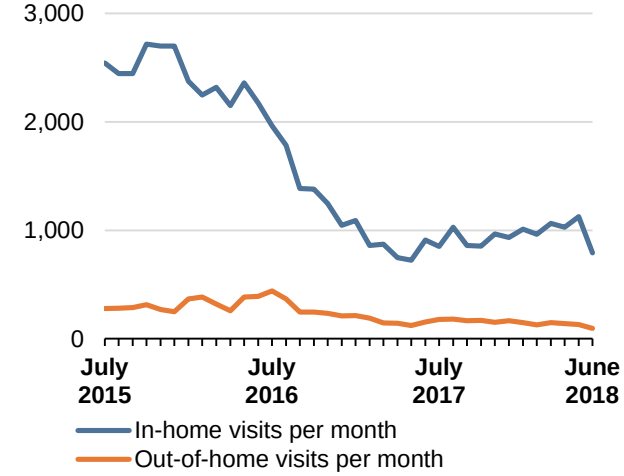
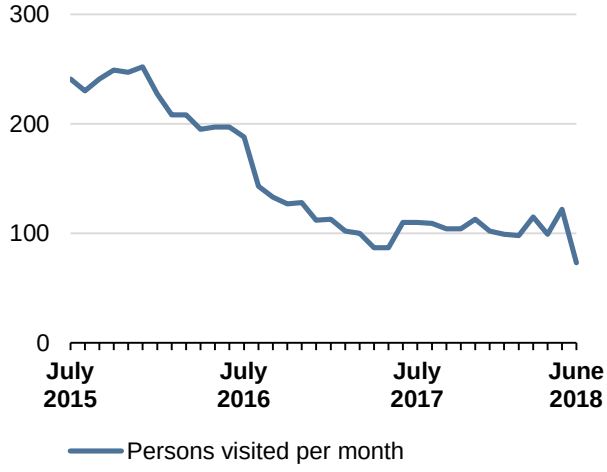


Figure 12.2: Number of persons seen under the Community Nursing Agreement



Source: SA Health 2018

Appendix B: Population and deaths by Aboriginal status and local health network, 2016

Table 18: Population and deaths by Aboriginal status and SA Health local health network, 2016

SA Health local health network (LHN)	2016 population			2016 deaths		
	Aboriginal persons	Total population	% Aboriginal persons	Aboriginal deaths	Total deaths	% Aboriginal deaths
Northern Adelaide	8,020	388,407	2.1%	34	2,532	1.3%
Central Adelaide	4,948	445,361	1.1%	15	3,989	0.4%
Southern Adelaide	4,182	355,304	1.2%	20	2,680	0.7%
Metropolitan Adelaide	**17,150**	**1,189,072**	**1.4%**	**69**	**9,201**	**0.7%**
Barossa Hills Fleurieu	2,278	192,414	1.2%	n.p.	1,421	n.p.
Eyre and Far North	4,348	38,887	11.2%	30	323	9.3%
Flinders and Upper North	4,283	43,912	9.8%	41	317	12.9%
Limestone Coast	1,222	64,781	1.9%	n.p.	545	n.p.
Riverland Mallee Coorong	2,568	69,533	3.7%	n.p.	631	n.p.
Yorke and Northern	1,965	74,992	2.6%	n.p.	846	n.p.
Country South Australia	**16,664**	**484,519**	**3.4%**	**95**	**4,107**	**2.3%**
Non-South Australian resident or unknown LHN	254	2,864	8.9%	17	132	12.9%
SOUTH AUSTRALIA	**34,068**	**1,676,455**	**2.0%**	**181**	**13,440**	**1.3%**

n.p. not published. Small cell data has been suppressed to protect privacy of individuals.

Crude rates. Percentages have not been age-adjusted.

Source: ABS 2017 (population figures) and SA-NT DataLink 2019 (deaths figures)

Appendix C: Cause of death by local health network, 2016

Table 19: Leading causes of death by SA Health local health network, 2016

SA Health local health network (LHN) of usual residence	Top 3 causes of death and ICD-10 code	2016 deaths	2016 deaths
		persons	% by LHN
Northern Adelaide	1. Chronic ischaemic heart disease (I25)	172	6.8%
	2. Unspecified dementia (F03)	159	6.3%
	3. Malignant neoplasm of bronchus and lung (C34)	136	5.4%
	Other	*2,065*	*81.5%*
	Total Northern Adelaide	**2,532**	**100.0%**
Central Adelaide	1. Chronic ischaemic heart disease (I25)	270	6.8%
	2. Acute myocardial infarction (I21)	218	5.5%
	3. Unspecified dementia (F03)	197	4.9%
	Other	*3,304*	*82.8%*
	Total Central Adelaide	**3,989**	**100.0%**
Southern Adelaide	1. Chronic ischaemic heart disease (I25)	169	6.3%
	2. Unspecified dementia (F03)	162	6.0%
	3. Malignant neoplasm of bronchus and lung (C34)	118	4.4%
	Other	*2,231*	*83.3%*
	Total Southern Adelaide	**2,680**	**100.0%**
METROPOLITAN ADELAIDE	1. Chronic ischaemic heart disease (I25)	611	6.6%
	2. Unspecified dementia (F03)	518	5.6%
	3. Acute myocardial infarction (I21)	397	4.3%
	Other	*7,675*	*83.5%*
	Total metropolitan Adelaide	**9,201**	**100.0%**
Barossa Hills Fleurieu	1. Chronic ischaemic heart disease (I25)	79	5.5%
	2. Malignant neoplasm of bronchus and lung (C34)	72	5.0%
	3. Acute myocardial infarction (I21)	71	5.0%
	Other	*1,204*	*84.5%*
	Total Barossa Hills Fleurieu	**1,426**	**100.0%**
Eyre and Far North	1. Unspecified dementia (F03)	23	7.1%
	2. Malignant neoplasm of bronchus and lung (C34)	17	5.3%
	3. Chronic ischaemic heart disease (I25)	17	5.3%
	Other	*266*	*82.3%*
	Total Eyre and Far North	**323**	**100.0%**
Flinders and Upper North	1. Other chronic obstructive pulmonary disease (J44)	24	7.6%
	2. Chronic ischaemic heart disease (I25)	22	6.9%
	3. Malignant neoplasm of bronchus and lung (C34)	13	4.1%
	Other	*258*	*81.4%*
	Total Flinders and Upper North	**317**	**100.0%**
Limestone Coast	1. Malignant neoplasm of bronchus and lung (C34)	38	6.9%
	2. Chronic ischaemic heart disease (I25)	33	6.0%
	3. Acute myocardial infarction (I21)	25	4.5%
	Other	*457*	*82.6%*
	Total Limestone Coast	**553**	**100.0%**
Riverland Mallee Coorong	1. Chronic ischaemic heart disease (I25)	56	8.8%
	2. Acute myocardial infarction (I21)	38	6.0%
	3. Malignant neoplasm of bronchus and lung (C34)	33	5.2%
	Other	*509*	*80.0%*
	Total Riverland Mallee Coorong	**636**	**100.0%**
Yorke and Northern	1. Chronic ischaemic heart disease (I25)	56	6.6%
	2. Acute myocardial infarction (I21)	50	5.9%
	3. Unspecified dementia (F03)	43	5.0%
	Other	*703*	*82.5%*
	Total Yorke and Northern	**852**	**100.0%**
COUNTRY SOUTH AUSTRALIA	1. Chronic ischaemic heart disease (I25)	263	6.4%
	2. Malignant neoplasm of bronchus and lung (C34)	207	5.0%
	3. Acute myocardial infarction (I21)	203	4.9%
	Other	*3,434*	*83.7%*
	Total Country South Australia	**4,107**	**100.0%**
Non-South Australian resident or unknown region		*132*	
TOTAL DEATHS IN SOUTH AUSTRALIA	1. Chronic ischaemic heart disease (I25)	885	6.6%
	2. Unspecified dementia (F03)	719	5.3%
	3. Acute myocardial infarction (I21)	611	4.5%
	Other	*11,225*	*83.5%*
	Total deaths in South Australia	**13,440**	**100.0%**

2017 data not available at time of publication

Source: SA-NT DataLink 2019

Appendix D: Place of death by local health network, 2017

Table 20: Where people died by SA Health local health network, 2017

SA Health local health network (LHN) of usual residence	Top 3 locations of death	2017 deaths	2017 deaths
		persons	% by LHN
Northern Adelaide	1. Hospital	1,238	45.4%
	2. Residential aged care facility or nursing home	818	30.0%
	3. Private address (ie. home)	564	20.7%
	Other	*104*	*3.8%*
	Total Northern Adelaide	**2,724**	**100.0%**
Central Adelaide	1. Hospital	1,585	38.8%
	2. Residential aged care facility or nursing home	1,361	33.3%
	3. Private address (ie. home)	759	18.6%
	Other	*383*	*9.4%*
	Total Central Adelaide	**4,088**	**100.0%**
Southern Adelaide	1. Residential aged care facility or nursing home	990	35.9%
	2. Hospital	946	34.3%
	3. Private address (ie. home)	525	19.0%
	Other	*297*	*10.8%*
	Total Southern Adelaide	**2,758**	**100.0%**
METROPOLITAN ADELAIDE	1. Hospital	3,769	39.4%
	2. Residential aged care facility or nursing home	3,169	33.1%
	3. Private address (ie. home)	1,848	19.3%
	Other	*784*	*8.2%*
	Total metropolitan Adelaide	**9,570**	**100.0%**
Barossa Hills Fleurieu	1. Hospital	630	41.7%
	2. Residential aged care facility or nursing home	487	32.3%
	3. Private address (ie. home)	289	19.2%
	Other	*103*	*6.8%*
	Total Barossa Hills Fleurieu	**1,509**	**100.0%**
Eyre and Far North	1. Hospital	246	71.5%
	2. Residential aged care facility or nursing home	51	14.8%
	3. Private address (ie. home)	47	13.7%
	Other	*0*	*0.0%*
	Total Eyre and Far North	**344**	**100.0%**
Flinders and Upper North	1. Hospital	205	55.9%
	2. Private address (ie. home)	91	24.8%
	3. Residential aged care facility or nursing home	59	16.1%
	Other	*12*	*3.3%*
	Total Flinders and Upper North	**367**	**100.0%**
Limestone Coast	1. Hospital	319	56.4%
	2. Private address (ie. home)	91	16.1%
	3. Residential aged care facility or nursing home	90	15.9%
	Other	*66*	*11.7%*
	Total Limestone Coast	**566**	**100.0%**
Riverland Mallee Coorong	1. Hospital	360	54.3%
	2. Residential aged care facility or nursing home	151	22.8%
	3. Private address (ie. home)	132	19.9%
	Other	*20*	*3.0%*
	Total Riverland Mallee Coorong	**663**	**100.0%**
Yorke and Northern	1. Hospital	418	48.1%
	2. Residential aged care facility or nursing home	270	31.1%
	3. Private address (ie. home)	153	17.6%
	Other	*28*	*3.2%*
	Total Yorke and Northern	**869**	**100.0%**
COUNTRY SOUTH AUSTRALIA	1. Hospital	2,178	50.4%
	2. Residential aged care facility or nursing home	1,108	25.7%
	3. Private address (ie. home)	803	18.6%
	Other	*229*	*5.3%*
	Total Country South Australia	**4,318**	**100.0%**
Non-South Australian resident or unknown region		*116*	
TOTAL DEATHS IN SOUTH AUSTRALIA	1. Hospital	6,010	42.9%
	2. Residential aged care facility or nursing home	4,281	30.6%
	3. Private address (ie. home)	2,695	19.2%
	Other	*1,018*	*7.3%*
	Total deaths in South Australia	**14,004**	**100.0%**

Small cell counts have been altered slightly to protect privacy of individuals without affecting overall results

Deaths in hospital include deaths on any ward, not only on wards that are hospice-specialised

Source: SA-NT DataLink 2019

Appendix E: Deaths by cause of death and hospital utilisation

Table 21: Number of deaths in South Australia in 2016 and public hospital utilisation in the 12 months prior to death

Cause of death and ICD-10 code	2016 deaths	Hospitalised (public hospital inpatient) in 12 months prior to death	Coded or diagnosed as palliative care while public hospital inpatient in 12 months prior to death
	persons	persons	persons
Chronic ischaemic heart disease (I25)	885	553	69
Unspecified dementia (F03)	719	339	45
Acute myocardial infarction (I21)	611	386	41
Malignant neoplasm of bronchus and lung (C34)	605	531	337
Other chronic obstructive pulmonary disease (J44)	528	431	117
Alzheimer's disease (G30)	469	258	29
Stroke, not specified as haemorrhage or infarction (I64)	366	238	41
Malignant neoplasm of prostate (C61)	262	213	108
Malignant neoplasm of breast (C50)	247	186	110
Heart failure (I50)	239	185	30
Pneumonia, organism unspecified (J18)	224	166	33
Malignant neoplasm of pancreas (C25)	219	184	116
Non-insulin-dependent diabetes mellitus (E11)	214	164	42
Unspecified diabetes mellitus (E14)	179	122	14
Malignant neoplasm, without specification of site (C80)	176	146	75
Atrial fibrillation and flutter (I48)	173	131	32
Unspecified fall (W19)	162	147	36
Other ill-defined and unspecified causes of mortality (R99)	162	65	0
Vascular dementia (F01)	146	101	14
Malignant neoplasm of colon (C18)	141	119	69
Parkinson disease (G20)	138	87	14
Malignant neoplasm of rectosigmoid junction (C19)	134	102	75
Malignant neoplasm of liver and intrahepatic bile ducts (C22)	133	111	72
Other interstitial pulmonary diseases (J84)	126	108	32
Other sepsis (A41)	125	116	27
Sequelae of cerebrovascular disease (I69)	125	74	10
Intentional self-harm by hanging, strangulation and suffocation (X70)	121	45	0
Aortic aneurysm and dissection (I71)	115	73	11
Malignant neoplasm of oesophagus (C15)	113	96	58
Nonrheumatic aortic valve disorders (I35)	112	83	n.p.
Chronic kidney disease (N18)	103	87	27
Malignant neoplasm of brain (C71)	96	85	48
Malignant neoplasm of kidney, except renal pelvis (C64)	96	84	55
Malignant melanoma of skin (C43)	93	74	36
Malignant neoplasm of bladder (C67)	91	74	40
Cerebral infarction (I63)	88	84	36
Malignant neoplasm of other and ill-defined digestive organs (C26)	86	74	44
Malignant neoplasm of stomach (C16)	85	66	51
Myeloid leukaemia (C92)	81	72	37
Multiple myeloma and malignant plasma cell neoplasms (C90)	75	60	32
Intracerebral haemorrhage (I61)	73	64	15
Other and unspecified types of non-Hodgkin lymphoma (C85)	72	57	28
Alcoholic liver disease (K70)	71	60	20
Cardiomyopathy (I42)	68	48	11
Spinal muscular atrophy and related syndromes (G12)	66	53	29
Malignant neoplasm of ovary (C56)	64	52	32
Hypertensive heart disease (I11)	59	33	n.p.
Fall on same level from slipping, tripping and stumbling (W01)	57	54	17
Malignant neoplasm of rectum (C20)	56	45	23
Paralytic ileus and intestinal obstruction without hernia (K56)	55	47	19
Fibrosis and cirrhosis of liver (K74)	51	49	21

Cause of death and ICD-10 code	2016 deaths	Hospitalised (public hospital inpatient) in 12 months prior to death	Coded or diagnosed as palliative care while public hospital inpatient in 12 months prior to death
	persons	persons	persons
Mesothelioma (C45)	50	45	27
Emphysema (J43)	50	39	n.p.
Subarachnoid haemorrhage (I60)	50	38	n.p.
Lymphoid leukaemia (C91)	48	41	18
Other disorders of urinary system (N39)	48	33	n.p.
Other degenerative diseases of nervous system, not elsewhere classified (G31)	46	25	n.p.
Asthma (J45)	45	35	n.p.
Other peripheral vascular diseases (I73)	45	33	13
Other diseases of digestive system (K92)	42	32	n.p.
Other cerebrovascular diseases (I67)	42	29	n.p.
Other nontraumatic intracranial haemorrhage (I62)	41	36	12
Exposure to unspecified factor (X59)	41	36	n.p.
Vascular disorders of intestine (K55)	41	34	n.p.
Pneumonitis due to solids and liquids (J69)	41	34	n.p.
Influenza due to other identified influenza virus (J10)	41	32	n.p.
Other acute ischaemic heart diseases (I24)	40	32	n.p.
Other malignant neoplasms of skin (C44)	39	31	17
Essential [primary] hypertension (I10)	37	24	n.p.
Complications and ill-defined descriptions of heart disease (I51)	36	16	n.p.
Myelodysplastic syndromes (D46)	34	32	12
Malignant neoplasm of corpus uteri (C54)	34	29	20
Disorders of lipoprotein metabolism and other lipidaemias (E78)	33	17	n.p.
Accidental poisoning by and exposure to narcotics and psychodysleptics [hallucinogens], not elsewhere classified (X42)	33	14	n.p.
Unspecified kidney failure (N19)	32	19	n.p.
Non-follicular lymphoma (C83)	31	28	16
Hypertensive renal disease (I12)	30	18	n.p.
Acute renal failure (N17)	28	25	n.p.
Unspecified acute lower respiratory infection (J22)	28	18	n.p.
Other pulmonary heart diseases (I27)	27	24	n.p.
Hypertensive heart and renal disease (I13)	27	20	n.p.
Other respiratory disorders (J98)	27	18	n.p.
Osteomyelitis (M86)	26	25	10
Phlebitis and thrombophlebitis (I80)	26	14	0
Malignant neoplasm of other connective and soft tissue (C49)	25	20	14
Accidental poisoning by and exposure to other and unspecified drugs, medicaments and biological substances (X44)	25	n.p.	0
Malignant neoplasm of other and unspecified urinary organs (C68)	24	22	16
Delirium, not induced by alcohol and other psychoactive substances (F05)	24	21	n.p.
Diverticular disease of intestine (K57)	24	20	n.p.
Other degenerative diseases of basal ganglia (G23)	24	18	n.p.
Insulin-dependent diabetes mellitus (E10)	23	14	n.p.
Other general symptoms and signs (R68)	23	11	n.p.
Cardiac arrest (I46)	22	15	n.p.
Pulmonary embolism (I26)	22	14	n.p.
Cellulitis (L03)	21	17	n.p.
Other diseases of oesophagus (K22)	21	17	n.p.
Obesity (E66)	21	15	n.p.
Bronchiectasis (J47)	21	14	n.p.
Car occupant injured in collision with fixed or stationary object (V47)	21	12	n.p.
Intentional self-poisoning by and exposure to other and unspecified drugs, medicaments and biological substances (X64)	21	10	n.p.
Leukaemia of unspecified cell type (C95)	19	16	n.p.
Other neoplasms of uncertain or unknown behaviour of lymphoid, haematopoietic and related tissue (D47)	19	16	n.p.
Hepatic failure, not elsewhere classified (K72)	18	16	n.p.
Multiple sclerosis (G35)	18	12	n.p.

Cause of death and ICD-10 code	2016 deaths	Hospitalised (public hospital inpatient) in 12 months prior to death	Coded or diagnosed as palliative care while public hospital inpatient in 12 months prior to death
	persons	persons	persons
Malignant neoplasm of other and unspecified parts of tongue (C02)	17	16	n.p.
Malignant neoplasm of uterus, part unspecified (C55)	17	14	10
Amyloidosis (E85)	17	14	n.p.
Other disorders of fluid, electrolyte and acid-base balance (E87)	17	13	n.p.
Nonrheumatic mitral valve disorders (I34)	17	10	n.p.
Other cardiac arrhythmias (I49)	17	n.p.	0
Car occupant injured in collision with car, pick-up truck or van (V43)	17	n.p.	n.p.
Malignant neoplasm of larynx (C32)	16	16	11
Cholecystitis (K81)	16	15	n.p.
Malignant neoplasm of cervix uteri (C53)	16	14	10
Other disorders of brain (G93)	16	14	n.p.
Other gastroenteritis and colitis of infectious and unspecified origin (A09)	16	14	n.p.
Mental and behavioural disorders due to use of alcohol (F10)	16	11	n.p.
Other rheumatoid arthritis (M06)	16	10	n.p.
Malignant neoplasm of gallbladder (C23)	15	13	n.p.
Rheumatic mitral valve diseases (I05)	15	n.p.	n.p.
Other diseases of liver (K76)	14	14	n.p.
Other diseases of intestine (K63)	14	12	n.p.
Endocarditis, valve unspecified (I38)	14	12	n.p.
Other inflammatory liver diseases (K75)	13	13	n.p.
Chronic viral hepatitis (B18)	13	12	n.p.
Neoplasm of uncertain or unknown behaviour of oral cavity and digestive organs (D37)	13	10	n.p.
Multiple valve diseases (I08)	13	10	n.p.
Epilepsy (G40)	13	n.p.	n.p.
Duodenal ulcer (K26)	13	n.p.	n.p.
Intentional self-poisoning by and exposure to other gases and vapours (X67)	13	n.p.	0
Malignant neoplasm of tonsil (C09)	12	12	n.p.
Malignant neoplasm of small intestine (C17)	12	11	n.p.
Other diseases of biliary tract (K83)	12	10	n.p.
Inhalation and ingestion of food causing obstruction of respiratory tract (W79)	12	10	0
Other arthrosis (M19)	12	n.p.	0
Acute pancreatitis (K85)	11	11	n.p.
Other diseases of anus and rectum (K62)	11	11	0
Unspecified protein-energy malnutrition (E46)	11	n.p.	n.p.
Car occupant injured in collision with heavy transport vehicle or bus (V44)	11	n.p.	0
Malignant neoplasm of other and unspecified parts of mouth (C06)	10	10	n.p.
Intentional self-poisoning by and exposure to antiepileptic, sedative-hypnotic, antiparkinsonism and psychotropic drugs, not elsewhere classified (X61)	10	n.p.	n.p.
Paraplegia and tetraplegia (G82)	10	n.p.	n.p.
Osteoporosis with pathological fracture (M80)	10	n.p.	n.p.
Cerebral palsy (G80)	10	n.p.	n.p.
Other hypothyroidism (E03)	10	n.p.	n.p.
Pedestrian injured in collision with car, pick-up truck or van (V03)	10	n.p.	n.p.
Viral infection of unspecified site (B34)	10	n.p.	n.p.
Senility (R54)	10	n.p.	0
Huntington disease (G10)	10	n.p.	0
…			
Other causes of death (aggregated to suppress small cell data)	*1,612*	*1,157*	*338*
TOTAL	**13,440**	**9,729**	**3,112**

n.p. not published. Small cell data has been suppressed to protect privacy of individuals.

Coded or diagnosed as palliative care while a public hospital inpatient does not identify whether the inpatient had contact with a palliative care service, and does not distinguish between levels of involvement if it had occurred. It is crucial to make a distinction between ‘coded or diagnosed as palliative care’ and ‘received palliative care’.

2017 data not available at time of publication

Source: SA-NT DataLink 2019

Notes on the data

This report sources data from publicly available datasets and publications as well as internal government enterprise datasets provided with the approval of their custodians. The Health Performance Council applies standardised business counting rules to data sourced from enterprise systems where applicable. Data sources, definitions and other technical information are provided so that results can be replicated.

It is standard Council practice to validate its reports prior to publication with data custodians, relevant experts and key stakeholders to sense-check findings, and confirm robustness of method, accuracy of findings and clarity of presentation.

Linked data

This addendum relies heavily on analysis of linked datasets via an SA-NT DataLink application—registered deaths in South Australia with national codified cause of death, linked to South Australian public hospital inpatient and South Australian public hospital emergency department records associated with those deceased individuals. Linkage between the datasets is possible at the individual person level using unique, de-identified 'project specific linkage keys' provided by SA-NT DataLink. SA NT DataLink produces these keys based on probabilistic matching of demographic information recorded on the relevant datasets (NB. only SA-NT DataLink has access to this demographic information—the Health Performance Council cannot see names or addresses). However, changing personal and system circumstances as people interact with health services over many years, often sporadically, can mean that a unique linkage key doesn't always correspond to the same person. The Health Performance Council recognises this as an unquantifiable bias in the analysis.

Missing data and under-reporting

The Health Performance Council takes the opportunity here to address gaps, shortcomings and areas for improvement in systemic end-of-life care data collections. One finding of the Council's 2018 revisit review is a paucity of data, systematic reporting, evidence-based evaluation, and evidence-based policy and planning related to end-of-life-care in South Australia.

Private hospital data

Of particular note is the lack of availability of private hospital activity data for linkage analysis. This topic has been an ongoing and priority concern of the Council for many years—and one that has shown frustratingly little progress. For its end-of-life care case study reports, SA-NT DataLink provided the Council with an anonymised, person-level dataset of deaths in South Australia that can be linked to patient-level public hospital inpatient activity and public hospital emergency department activity. Private hospitals, however, do not provide activity data to SA-NT DataLink. The lack of private hospital data for linkage analysis is a major, albeit unavoidable, omission in this report.

Residential aged care services

The Council's application to SA-NT DataLink also included a request for a linkable dataset of residential aged-care services. However, SA-NT DataLink advised that this dataset would not be accessible within project timeframes and so it was excluded from the application. Residential aged-care services were excluded from the Council's 2013 end-of-life care study (HPC 2013) for similar timeliness reasons. The Council recognises that this represents another major gap in the analysis.

Specific population groups

Despite the quality assurances of data providers and others, the Health Performance Council recognises that there is data missing, under-reported and mis-reported in administrative datasets that can and do impact the analysis in this report. The Council can only report self-identified data as-is.

For example, the Council recognises that not all Aboriginal people are correctly identified in the data and acknowledges that not all Aboriginal people choose to identify themselves or their loved ones every time they interact with government services. Aboriginal leaders have told the Council that many Aboriginal health consumers do not identify as Aboriginal for fear of discrimination. Aboriginal leaders have also told the Council that health service providers frequently fail to ask about the Aboriginal status of health consumers, even where collection of this status field is mandatory. The Council will work to report on systemic racism in the health system as part of its forward review program.

The issue of integrity, variability and quality of self-reported data in administrative datasets applies to other specific population groups as well—often for fear of discrimination—such as culturally and linguistically diverse people and aged persons.

Glossary

AGE STANDARDISATION: Age standardisation is a way of allowing comparisons between two (or more) populations with different age structures, for a variable related to age. The age standardised estimates are not useful on their own, but the comparison between two (or more) age standardised estimates can remove the confounding effects of age. Deaths data in this report has been age standardised to the 2001 Australian population to maintain consistency with Australian Bureau of Statistics' published results.

AVOIDABLE MORTALITY: Avoidable mortality has been proposed as a measure of performance of a health system and as a measure of quality of healthcare service delivery. Avoidable deaths are deaths from causes that should not occur in the presence of timely and effective interventions. This is also referred to as 'amenable mortality', 'treatable mortality' or 'preventable mortality'.

EPISODE OF CARE: The majority of patients enter hospital for a specific condition, receive a specific service and are then discharged. However, there are other patients whose treatment pattern is more complex. These patients enter hospital and undergo two or more phases of treatment within the one hospital stay. These different phases of treatment are referred to as an episode of care and are designed to reflect the changing diagnosis and/or treatment of the patient. It does not refer to each individual bed day. An episode of care ends when the care type changes or the patient separates from hospital. An episode of care is a phase of treatment within a single stay in hospital.

HOSPITALISATION: See 'separation'.

ICD-10 CAUSES OF DEATH: Causes of death are coded to an international standard, called the International Statistical Classification of Diseases and Related Health Problems (ICD). Coding causes of death to an international standard enables the comparability of statistics over time and between countries. The ICD is revised periodically and currently in its tenth revision (ICD-10). The coding produces an underlying cause—the disease or condition which initiated the sequence of events resulting in death—and, for most deaths, associated causes (any other diseases or conditions that contributed to the death but were not the underlying cause).

ICD-10 CHAPTERS: Once coded, causes of death are categorised into disease groupings, or "ICD chapters".

ICU: Hospital intensive care unit.

LOCAL HEALTH NETWORK: Local health networks (LHNs) are SA Health-defined geographical areas that manage the delivery of public hospital services and other community-based health services within a region. LHNs are supported by governing councils to monitor and provide advice on improving clinical care outcomes within the LHN, with a particular focus on local service integration, performance the safety and quality of services and consumer engagement. There are ten LHNs in South Australia, four in metropolitan Adelaide and six in Country SA.

PALLIATIVE CARE: The World Health Organisation (WHO) defines palliative care as follows:

> *Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.* (PCA 2018, p. 6)

In alignment with the WHO definition, Palliative Care Australia (PCA), the national peak body for palliative care, defines palliative care in the contemporary Australian context as:

> *Palliative care is person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary treatment goal is to optimise the quality of life.* (PCA 2018, p. 6)

The Council embraces PCA's emphasis on quality of life, the health and wellbeing of patients and those associated with them, and the broader aspects of care—which go beyond the clinical to incorporate the psychosocial and spiritual needs of consumers, their families and carers.

This report applies the term **palliative care hospitalisation** (coded or diagnosed as palliative care while a hospital inpatient) using the Australian Institute of Health and Welfare (AIHW) definition:

> *The intent of care at hospital inpatient admission is 'for palliation' (based on episode of care), or if at any time during the inpatient admission the intent of care becomes 'for palliation', and the care provided to the inpatient is palliative care (based on the inpatient's hospital-coded episode of care diagnoses fields)* (AIHW 2019b).

An in-hospital palliative care coding or diagnosis does not identify whether the inpatient had contact with a palliative care service, and does not distinguish between levels of involvement if it had occurred. It is crucial to make a distinction between 'coded or diagnosed as palliative care' and 'received palliative care'.

PERINATAL MORTALITY: The Australian Bureau of Statistics defines perinatal mortality as "all fetal (stillbirth) deaths of at least 20 weeks' gestation *or* at least 400 grams birth weight, and neonatal deaths (all live born babies who die within 28 days of birth, regardless of gestation or weight)".

SEPARATION: This report uses the term 'hospitalisation' in place of the more technical term 'hospital inpatient separation'—a completed episode of care of an admitted patient, generally concluding with their discharge from hospital (mostly to their place of residence), transfer to another healthcare facility or in-hospital death. It can also refer to **'administrative separation'** where the type of treatment and/or care has changed on an ongoing basis (eg. the episode of care has changed from acute to palliative) but the person continues as an inpatient.

STATISTICAL AREAS LEVEL 2 (SA2): Defined by the Australian Bureau of Statistics, an SA2 is a medium-sized general purpose area. An SA2 generally has a population in the range of 3,000 to 25,000 persons and represents a community that interacts together socially and economically.. There are 2,310 SA2 regions covering the whole of Australia without gaps or overlaps.

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