



ACI NSW Agency
for Clinical
Innovation



**Palliative &
End of Life Care**

A Blueprint for Improvement

REPORT

Fact of Death Analysis 2011/12

Use of NSW public hospital services in the last year of life by NSW residents

Health Economics and Evaluation Team, and Palliative Care Network

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Table of Contents

Section 1	Executive Summary	1
	1.1 Hospitalisations	2
	1.2 Presentations to Emergency Departments	2
	1.3 Deaths	2
	1.4 Cost	2
	1.5 Background	2
Section 2	Introduction	3
Section 3	Methodology	4
Section 4	Results	5
	4.1 Hospitalisations	5
	4.1.1 Palliative care service type	9
	4.1.2 AIHW specific ICD-10-AM diseases and conditions	10
	4.1.3 Cancer ICD-10-AM diagnosis codes	11
	4.1.4 AIHW conditions and Cancer in the same admission ICD-10-AM diagnosis codes	12
	4.1.5 Receiving Health Services/Treatment for Cancer ICD-10-AM diagnosis codes	13
	4.1.6 Other relevant diseases and conditions 'grey area'	14
	4.2 Emergency Department presentations	14
	4.3 Analysis by Local Health District	16
Section 5	Discussion and Next Steps	17
Appendix 1	Data Linkage Flow Chart	18
	ICD-10-AM diagnosis codes for hospitalisations	20
Appendix 2	Admitted Patient Tables and Figures	21
Appendix 3	Emergency Department Tables and Figures	36
Appendix 4	Codes and Classifications	42
Appendix 5	Footnotes	44

Section 1

Executive Summary

There were 49,801 deaths in NSW in 2011/12.

This paper examines the hospital service use of the 38,282 people (77% of all who died in that period) who were hospitalised at least once between 1 July 2010 and 30 June 2012,¹ which roughly equates to the last year of their lives.

It also analyses the use of the emergency department (ED) by the 37,907 people (76% of all who died in that period) who presented to an ED at least once between 1 July 2010 and 30 June 2012.

1.1 Hospitalisations

For people in their last year of life, there were about 165,000 hospitalisations using 1.4 million bed-days (51% of the bed-days from emergency admissions and 49% from planned admissions).

The average number of admissions among this cohort was 4.3 admissions per person.

About 27% (10,463) of the hospitalised cohort had only one admission.

About 37% of the hospitalised cohort had between two and four admissions, and about 24% had more than 10 hospitalisations. Many of this latter group had end-stage renal disease. The greatest number of admissions was 204.

More than a third of admissions (39%) were day-only. For those who stayed overnight, the average length of stay (ALOS) was 13 days, which is three times longer than the average for all patients.

Among those hospitalised, 7% received designated palliative care services. The ALOS was 11 days, and about 23% of admissions for those receiving designated palliative care services were on an emergency basis.

People with cancer were more likely than people with other diagnoses to receive designated palliative care services on admission. The most common non-cancer-related reasons for admission to designated palliative care services were *congestive heart failure, pneumonitis due to food and vomit, pneumonia, unspecified, and stroke, not specified as haemorrhage or infarction*.

1.2 Presentations to emergency departments

Of the 49,801 people who died in NSW in 2011/12, 37,907 (76%) presented to an ED at least once between 1 July 2010 and 30 June 2012.

There were around 105,000 presentations – about 54% resulted in people being admitted and 46% did not.

About three-quarters (76%) of these admitted emergency presentations were in people aged 70 and over.

The total cost of emergency presentations was approximately \$89 million (see Table 14).

1.3 Deaths

Of those admitted to hospital at some time in their last year of life, 61% died in hospital (15% in their first and only admission, and 46% in a subsequent admission) and 39% outside hospital.

For those who died outside hospital, the average survival time from last hospitalisation to death was 84 days.

1.4 Cost

The total cost of hospitalisations and non-admitted emergency presentations was about \$1 billion (Table 1 below). Of the total cost, around \$977 million was for inpatient admitted care and \$32.5 million was for non-admitted presentation to ED. The average price per separation was \$7482.

Table 1: Total ABF funding of the palliative and end of life care cohort

	Costs
ED presentations (non-admitted)	\$32,505,369
Hospitalisations [#]	\$977,417,084
Total	\$1,009,922,453
[#] This includes all of the admitted patient and end of life cohort (includes palliative care and exclusions).	

There significant cost and service utilisation in providing hospital services to people in their last year of life is likely to grow significantly as the population ages.

1.5 Background

This paper is the second iteration of the *Fact of death analysis*. The first version was published in 2013 and focused on issues for the Agency for Clinical Innovation (ACI) Palliative Care Network to consider in terms of refining the patient cohort, as well as analysis of the latest available linked data. This analysis had its origins in the **Australian Institute of Health and Welfare's report *Palliative care services in Australia 2012***, where a list of 11 specific diseases/conditions and cancer ICD-10-AM diagnosis codes (see Tables 38 and 39, Appendix 4) were used to identify part of the patient cohort of this analysis.

This updated analysis:

- reflects Network feedback on the 2013 analysis
- includes updates in the NSW health administrative datasets – the APDC and the deaths data in the Registry of Births, Deaths and Marriages [RBDM]
- includes ED data, as requested by the Network
- helps policymakers understand the demand for palliative and end of life care.

This 'fact of death' exploratory analysis examines healthcare utilisation patterns and trends using linked death, admitted patients and ED datasets for people who died in the 12 months from 1 July 2011 to 30 June 2012, which is seen by the Network as a suitable baseline for comparison. Cause of death data for that period should be available late in 2015. Unfortunately there is little robust data relating to community-based palliative care service provision.

The Network is currently developing an online *Blueprint for improvement* that will provide a flexible evidence-based guide for health services in NSW to meet the needs of people approaching and reaching the end of life, their families and their carers. This analysis complements the *Blueprint*.

Section 2

Introduction

This paper provides an analysis of the utilisation trends and costs associated with people who have been hospitalised and/or presented to an ED in the year before their deaths. This broad palliative and end of life care cohort will generally be referred to as the 'patient cohort' throughout this document. Data linkage was used in this report to identify those people who died (fact of death) and were hospitalised and/or presented to an ED a year prior to their deaths. The paper is intended to support the online *Blueprint for improvement* developed by the Palliative Care Network.

Significant data was extracted to help gain an understanding of the patient cohort in terms of service provided, utilisation of services and cost. This analysis focuses on the data that is relevant to analysing inpatient and ED utilisation and cost.

Section 3

Methodology

All NSW and interstate residents of all ages who died in 2011/2012 and presented to EDs and/or were admitted to NSW public facilities a year prior to their deaths were included in this analysis.

Key components of the methodology were as follows:

- Extraction of death data from the RBDM and linked to the Admitted Patient Data Collection (APDC) and Emergency Department Data Collection (EDDC) and Activity Based Funding (ABF) data. Cause of death data was also linked to the patient cohort.
- Data from the RBDM and cause of death were for the 2011/12 financial year, and data from the APDC and EDDC were from the 2010/11 and 2011/12 datasets.³
- Records that fell outside the patient cohort were excluded.

This paper presents the analysis from linked data in the following six patient sub-cohorts:

- Australian Institute of Health and Welfare (AIHW)-specific conditions and diseases⁶
- palliative care service type
- cancer
- overlapping cancer and AIHW conditions
- receiving health services/treatment for cancer, diagnosis codes
- other diseases/conditions 'grey areas' for inclusion or exclusion (See Table 39 in Appendix 4).

Admitted patient and ED deaths attributed to injury and or poisoning were excluded from this analysis.

In 2011/12, there were 49,801 registered deaths in NSW. Of these:

- 38,282 (77%) people who died were hospitalised at least once⁴
- 37,907 (76%) people who died presented to ED at least once⁵
- 32,760 (66%) people who died presented to ED and were admitted at least once.

Appendix 1 contains further detail on the methodology.

Section 4

Results

4.1 Hospitalisations

The following table provides a summary of the hospitalisations, bed-days and estimated ABF funding by the seven sub-cohorts, with and without exclusions. This approach could not be replicated for ED presentations due to the nature and complexity of ED data systems.

	<i>Hospitalisations</i>	<i>Bed-days</i>	<i>NWAU</i>	<i>Cost</i>	<i>Average cost per separation</i>
Cancer	25,059	199,683	42,505	\$198,540,855	\$7,923
Receiving health services/treatment for cancer	2,494	20,069	3,549	\$16,577,379	\$6,647
AIHW conditions	38,905	436,482	71,538	\$334,153,998	\$8,589
AIHW conditions and cancer (overlap)*	4,866	67,261	15,082	\$70,448,022	\$14,478
Other grey area	33,544	365,829	35,301	\$164,890,971	\$4,916
Subtotal	104,868	1,089,324	167,975	\$784,611,225	\$7,482
Exclusions (trauma, injury, etc.)	48,613	173,057	19,314	\$90,215,694	\$1,856
Total excluding palliative care	153,481	1,262,381	187,289	\$874,828,884	\$5,700
Palliative care services	11,313	120,692	N/A	\$102,588,200	\$9,068
Grand total	164,794	1,383,073	187,289	\$977,417,084	\$5,931
Total (with palliative care and without exclusions)	116,181	1,210,016	167,975	\$887,199,425	\$7,636

*Hospitalisations where a patient is admitted for cancer and an AIHW condition.
Palliative care services cost based on per diem rate for 2011/12.
#Note that the total cost and average cost per separation is underestimated due to missing national weighted activity units (NWAUs).

There was a relatively low use of admitted coded palliative care services. Inpatient coded palliative care services were more likely to be provided to people with cancer.

Of the 164,794 hospitalisations:

- overall 7% received palliative care services
- 15% were hospitalised with cancer, of whom 23% received palliative care services
- 2% received health services/treatment for cancer, of whom 7% received palliative care services
- 24% were hospitalised with one or more AIHW conditions, of whom 4% received palliative care services
- 13% of hospitalisations had two or more (up to six) AIHW conditions
- 3% were hospitalised with AIHW conditions and cancer in the same admission, of whom 19% received palliative care services.

Those who did not receive palliative care services, or were hospitalised with cancer and/or AIHW conditions, were classified as 'other grey area' – these represented 20% of all hospitalisations (Figure 4).

More than half of the hospitalisations had an emergency status (54%⁷).

Day-only admissions represented 39% of all hospitalisations.

The median age of the cohort who were hospitalised was 78. More than two-thirds (70%) of those hospitalised were aged 70 and over. The group most likely to be admitted following an emergency presentation was people aged 80+. Those aged 85+ had the highest age-specific death rate, which was 9672 per 100,000 deaths.

Table 3 provides a summary of key hospitalisation data.

Table 3: Hospitalisation statistics	
Deaths	
Number of deaths	38,282
Sex (% male)	20,217 (52.8%)
Aboriginal Torres Strait Islander (%)	601 (1.6%)
Died in hospital (%)	23,474 (61.3%)
Hospitalisations	
Total number of hospitalisations	164,794
Minimum number of hospitalisations	1
Maximum number of hospitalisations	204
Day-only admissions (%)	64,586 (39.2%)
Total bed-days	1,383,073
ALOS (days)	8
ALOS (days excluding day-only admissions)	13
Median age (years)	78
Hospitalised for palliative care services (%)	11,313 (6.9%)
Survival time from last hospitalisation	
Total days	1,207,179
Average days	84 days
NWAU	187,289
Total \$ (excluding palliative care; see Table 1)	\$874,826,844
Average NWAU per separation	\$5700

The following figure (Figure 1) shows the proportion of hospitalisations used by each sub-cohort.

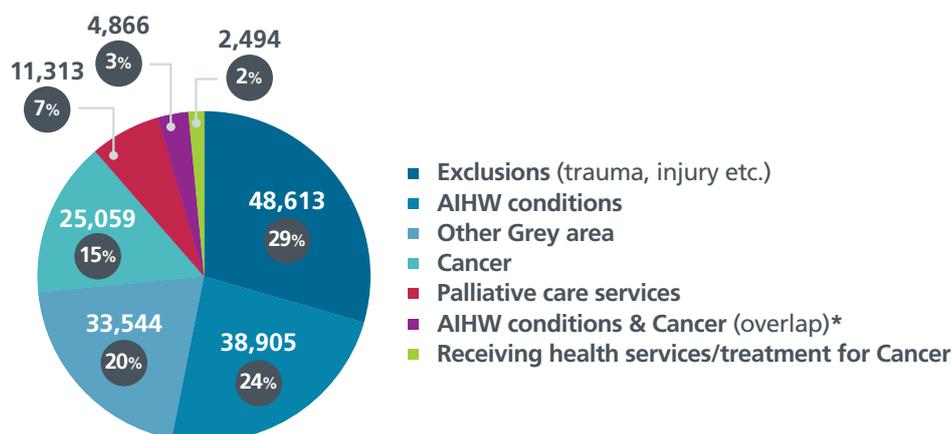


Figure 1: Reasons for admission

A large proportion of people died in hospital – nearly 61% of the deaths that are in the scope of this analysis (15% in their first and only admission, and 46% in a subsequent admission) and 39% outside hospital (13% died after having only one admission and 26% died after subsequent admissions).

Around 7% of hospitalisations were for palliative care. When the 'exclusions' are removed (as shown in Table 4 on page 9), around 10% of hospitalisations were for palliative care.

The ALOS was eight days, which is nearly double the ALOS for all patients. When day-only admissions are excluded (so only patients with at least an overnight stay are included) the ALOS increased to 13 days.

Figure 2 shows the number of times patients were admitted in the last year of life.

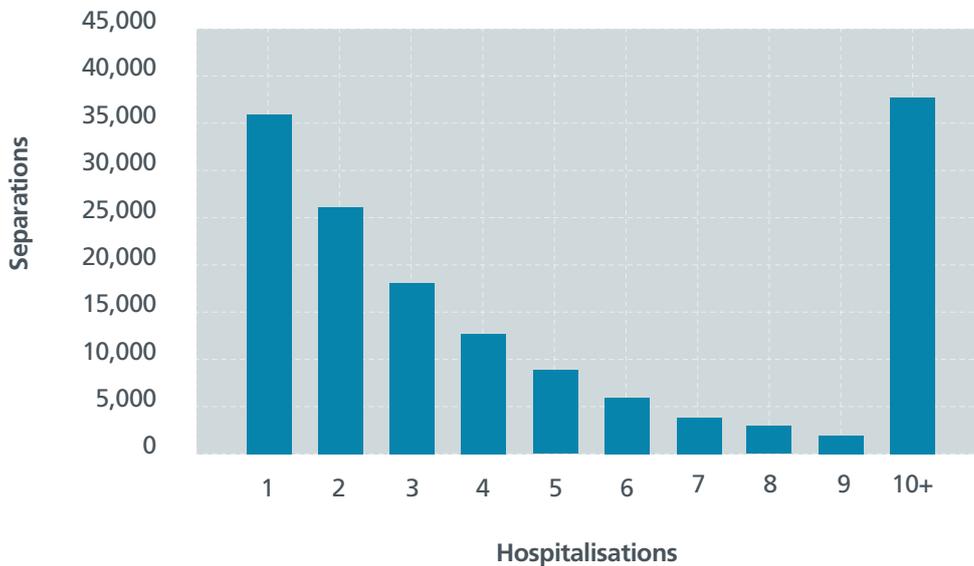


Figure 2: Multiple hospitalisations

A significant majority (72%) of patients hospitalised in their last year of life had multiple (two or more) hospitalisations.

On average, patients that were in their last year of life were hospitalised just over four times each (Figure 2).

Around 24% of patients had more than 10 hospitalisations – a large proportion of this group were people with end-stage renal disease. Further analysis of the multiple admissions will occur in the next stage.

Separate tables containing demographic factors and survival times from last hospitalisation by five-year age groups are available upon request.

Of note is the following.

- The average *survival time* from last hospitalisation to death, excluding those who died in hospital, was 84 days.
- Fewer than 2% of the patient cohort was of Aboriginal and Torres Strait Islander background. This figure is relatively low and most likely under representative of this population given that this population group are 2.5 times more likely to be hospitalised than people who are not of an Aboriginal and Torres Strait Islander background⁸.

Tables 15–19 in Appendix 2 provide information on *admission type* and *separation mode*. Of note is the following.

Day-only admissions were included in the dataset and represented over a third of (39%) of all hospitalisations. *Extracorporeal dialysis* was the most common reason for same day admissions, representing 54% of all day-only hospitalisations, followed by *anaemia, unspecified*, and *chest pain, unspecified* (Table 15, Appendix 2).

The most common reason for admission for overnight hospitalisations were *congestive heart failure, care involving use of rehabilitation procedure, unspecified*, and *pneumonia, unspecified*, which represented 11% of all overnight hospitalisations (Table 15, Appendix 2).

More than half of the hospitalisations had an emergency status (54%). The top five reasons for an emergency admission were *congestive heart failure, pneumonia, unspecified, chronic obstructive pulmonary disease (COPD) with acute lower respiratory infection, urinary tract infection, site not specified, and pneumonitis due to food and vomit*. These top five reasons represented 16% of all emergency admissions (Table 18, Appendix 2, shows the top 20).

Two-thirds of separations were discharged by the hospital (63%) and 6% had a type change separation. This included discharges to palliative care, as well as other forms of sub-acute care.

The figure below shows the number of bed-days by broad age group.

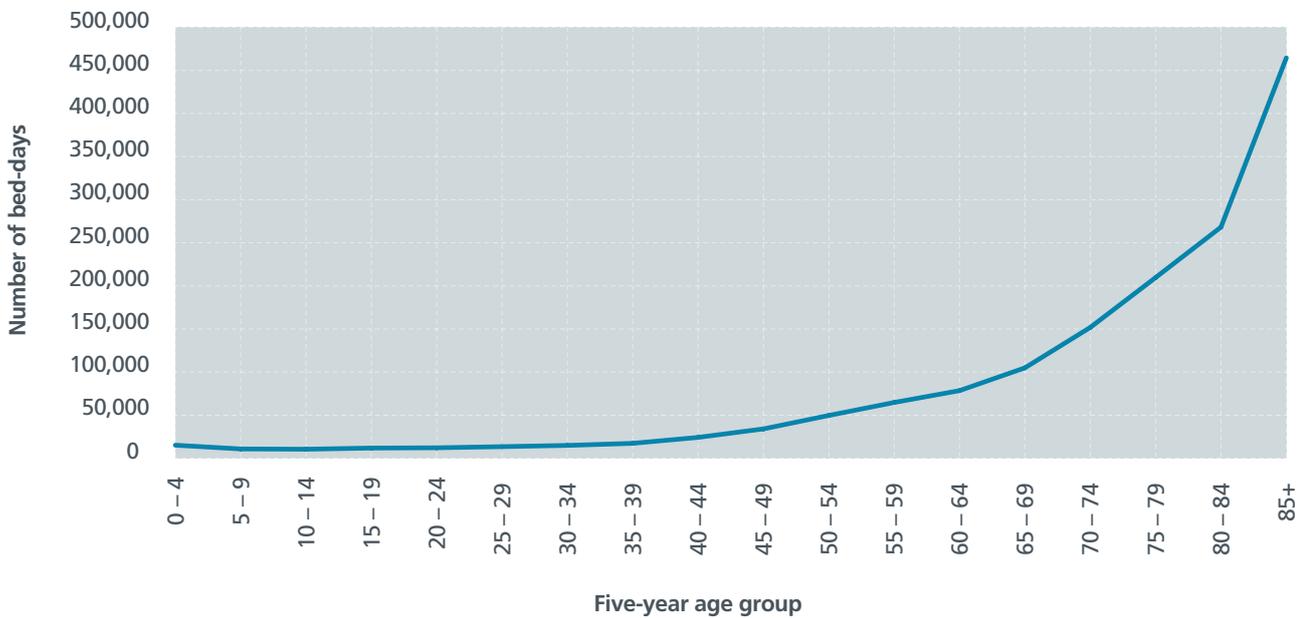


Figure 3: Number of bed-days by five-year age group

The majority of bed-days for people in their last year of life were for people aged over 65 years (79% of bed-days). Over two-thirds (70%) of bed-days were those aged 70 and over and those aged 85+ were most likely to be admitted following an ED presentation.

The number of bed-days increases as the age increases; hence, the elderly have the greatest number of bed-days. This was the same for total costs, which were higher in the oldest age groups. However, the average cost per separation was highest in those aged 5-9, which was \$26,041.

Of the 38,282 deaths, nearly two-thirds (61%) died in hospital and the oldest age group (85+) had the highest age-specific death rate (age group at last hospitalisation used to calculate rate), which was 9672 per 100,000 deaths.

Tables detailing hospitalisation utilisation and age-specific death rates and survival time from last separation by five-year age groups are available upon request.

4.1.1 Palliative care service type

A total of 8404 people died after a total of 11,313 hospitalisations for palliative care. Palliative care services in the acute care setting represented approximately 7% of all hospitalisations from the patient cohort.

About 23% of the hospitalisations were on an emergency basis.

A majority of the hospitalisations were overnight (88%), and the ALOS was 11 days. The total number of bed-days for this sub-cohort was 120,692 bed-days.

The median age on separation was 75.

Most admissions were cancer-related. The most common non-cancer-related reasons for admission were congestive heart failure, pneumonitis due to food and vomit, pneumonia and stroke (Table 20, Appendix 2). The most common Australian refined diagnosis-related group (AR-DRG) was *respiratory neoplasms without catastrophic complications* and comorbidities, which represent approximately 11% of all hospitalisations for people receiving palliative care service. The top 25 AR-DRGs were dominated by cancer (Table 21, Appendix 2).

The total cost for patients who received palliative care services in NSW public hospitals in 2011/12 was \$102.6 million, based on a per diem rate of \$850. The average cost per separation was \$9068 (Table 5).

Table 4: Hospitalisation statistics for those who received palliative care services	
Deaths	
Number of deaths	8,404
Sex (% male)	4,531 (53.8%)*
Aboriginal Torres Strait Islander (%)	121 (1.4%)
Died in hospital (%)	6,806 (80.9%)
Hospitalisations	
Total number of hospitalisations	11,313
Minimum number of hospitalisations	1
Maximum number of hospitalisations	155
Day-only admissions (%)	1,360 (12.0%)
Emergency (%)	2,541 (22.5%)
Total bed-days	120,692
ALOS (days)	11
Median age (years)	75

Table 5: Received/had palliative care services – cost per diem rate, 2011/12				
<i>Total separations</i>	<i>Per diem rate</i>	<i>Bed-days</i>	<i>Total cost</i>	<i>Average per separation</i>
11,313	\$850	120,692	\$102,588,200	\$9,068

* Note that the total cost and average cost per separation is underestimated due to missing NWAUs

4.1.2 AIHW specific ICD-10-AM diseases and conditions

A total of 17,372 people died after 38,905 hospitalisations for AIHW-specific diseases and conditions for which they were not assessed and/or did not receive palliative care in hospital, representing 24% of the patient cohort (Figure 1).

The majority were emergency admissions (76%).

About 4% of all related AIHW-specific disease and condition hospitalisations received palliative care services (Table 6).

Bed-days used were 436,482 and ALOS was 11 days.

The median age was 82 (Table 6).

About 42% of this sub-cohort died in hospital.

Congestive heart failure was the most common diagnosis, representing around 11% of all hospitalisations with AIHW condition(s) (Table 23, Appendix 2). The most common AR-DRG is *chronic obstructive airways disease without catastrophic complications or comorbidities (CC)*, which represent approximately 8% of all hospitalisations for people with AIHW condition(s) (Table 24, Appendix 2).

The total price for ABF funding for patients hospitalised with AIHW conditions/diseases who were not assessed or did not receive palliative care was \$334 million, which is 38% of the total palliative and end of life cohort. The average cost per separation was \$8589 (Table 7).

Table 6: Hospitalisation statistics for those admitted with AIHW conditions/diseases only (excluding palliative care services)	
Deaths	
Number of deaths	17,372
Sex (% male)	8,992 (51.8%)
Aboriginal Torres Strait Islander (%)	257 (1.5%)
Died in hospital (%)	7,345 (42.3%)
Hospitalisations	
Total number of hospitalisations (excluding palliative care)	38,905
Number with palliative care services	1,507 (3.7%)
Minimum number of hospitalisations	1
Maximum number of hospitalisations	204
Day-only admissions (%)	5,990 (15.4%)
Emergency (%)	29,587 (76.0%)
Total bed-days	436,482
ALOS (days)	11
Median age (years)	82

Table 7: ABF funding (NWAU) for hospitalisation with AIHW diseases/condition that have not been assessed and could have benefitted from palliative care service, 2011/12					
<i>Total separations (excluding palliative care)</i>	<i>Total NWAU 2013</i>	<i>Bed-days</i>	<i>NSW cost 2013</i>	<i>Total cost</i>	<i>Average per separation*</i>
38,905	71,538	436,482	\$4,671	\$334,155,030	\$8,589
* Note that the total cost and average cost per separation is underestimated due to missing NWAUs					

4.1.3 Cancer ICD-10-AM diagnosis codes

A total of 10,581 people died after 25,059 hospitalisations for cancer that were not assessed and/or did not receive palliative care in hospital. This represents 15% of the patient cohort.

About two-thirds were emergency admissions (64%).

The median age was 71 (Table 8).

Bed-days used were 199,683 and ALOS was 8days.

About 23% of all cancer-related hospitalisations received palliative care services (Table 8).

About 24% of this sub-cohort died in hospital.

The total cost in 2011/12 for patients hospitalised with cancer disease who were not assessed or did not receive palliative care was about \$198.5 million and the average cost per separation was \$7,923 (Table 9).

The most common reasons for admission were *secondary malignant neoplasm of bone and bone marrow*, *secondary malignant neoplasm of brain and cerebral meninges* and *malignant neoplasm of bronchus or lung unspecified*, which represented 11% of all cancer hospitalisations (Table 25, Appendix 2). The most common AR-DRGs were *respiratory neoplasms without catastrophic CC* and *lymphoma and non-acute leukaemia same day* (Table 26, Appendix 2).

Table 8: Hospitalisation statistics for those admitted with cancer as the reason for admission that were not assessed or did not receive palliative care service, 2011/12

Deaths	
Number of deaths	10,581
Sex (% male)	6,157 (58.2%)
Aboriginal Torres Strait Islander (%)	161 (1.5%)
Died in hospital (%)	2,537 (24.0%)
Hospitalisations	
Total number of hospitalisation (excluding palliative care)	25,059
Number with palliative care services	7,439 (22.9%)
Minimum number of hospitalisations	1
Maximum number of hospitalisations	149
Day only admissions (%)	6,896 (27.5%)
Emergency (%)	15,935 (63.6%)
Total bed-days	199,683
ALOS (days)	8
Median age (years)	71

Table 9: ABF funding (NWAU) for those admitted with cancer that were not assessed or did not receive palliative care service, 2011/12

<i>Total separations (excluding palliative care)</i>	<i>Total NWAU 2013</i>	<i>Bed-days</i>	<i>NSW cost 2013</i>	<i>Total cost</i>	<i>Average per separation*</i>
25,059	42,505	199,683	\$4,671	\$198,542,465	\$7,923

* Note that the total cost and average cost per separation is underestimated due to missing NWAUs

4.1.4 AIHW conditions and cancer in the same admission ICD-10-AM diagnosis codes

A total of 3698 people died after a total of 4866 hospitalisations those with AIHW conditions and cancer in the same admission and were not assessed and/or did not receive palliative care in hospital. This represents 3% of the hospitalisations for the patient cohort.

The majority were emergency admissions (81%).

The median age was 76 (Table 10).

Bed-days used were 67,261 and ALOS was 14 days.

About 19% of this sub-cohort received palliative care services (Table 10).

About 36% of this sub-cohort died in hospital.

The total cost in 2011/12 for patients hospitalised with an AIHW condition and cancer in the same admission, and who were not assessed or did not receive palliative care was about \$70.5 million and the average cost per separation was \$14,478 (Table 11).

The most common reasons for admission were *acute renal failure, unspecified, COPD with acute lower respiratory infection* and *pneumonia, unspecified*, which represented 13% of all AIHW conditions and cancer hospitalisations (Table 27, Appendix 2). The most common AR-DRGs were *respiratory neoplasms with catastrophic CC*, *respiratory infections/inflammations with catastrophic CC* and *chronic obstructive airway disease with catastrophic CC* (Table 28, Appendix 2).

Table 10: Hospitalisation statistics for those admitted with AIHW condition(s) and cancer in the same admission as the reason for admission that were not assessed or did not receive palliative care service, 2011/12

Deaths	
Number of deaths	3,698
Sex (% male)	2,290 (61.9%)
Aboriginal Torres Strait Islander (%)	55 (1.5%)
Died in hospital (%)	1,324 (35.8%)
Hospitalisations	
Total number of hospitalisations (excluding palliative care)	4,866
Number with palliative care services	1,171 (19.4%)
Minimum number of hospitalisations	1
Maximum number of hospitalisations	157
Day-only admissions (%)	306 (6.3%)
Emergency (%)	3,940 (81.0%)
Total bed-days	67,261
ALOS (days including day-only)	13.8
Median age (years)	76

Table 11: ABF funding (NWAU) for those admitted with AIHW condition(s) and cancer in the same admission that were not assessed or did not receive palliative care service, 2011/12

<i>Total separations (excluding palliative care)</i>	<i>Total NWAU 2013</i>	<i>Bed-days</i>	<i>NSW cost 2013</i>	<i>Total cost</i>	<i>Average per separation</i>
4,866	15,082	67,261	\$4,671	\$70,446,607	\$14,477

4.1.5 Receiving health services/treatment for cancer ICD-10-AM diagnosis codes

A total of 1589 people died after 2,494 hospitalisations among people receiving health services/treatment for cancer who were not assessed and/or did not receive palliative care in hospital, representing 2% of the patient cohort resulting in 1589 deaths.

More than half of these admissions were emergencies (54%).

About 7% of those receiving health services/treatment for cancer received palliative care services (Table 12).

Bed-days were 20,069 and ALOS was 8 days.

The median age at separation was 75 (Table 12).

Around 13% of this sub-cohort died in hospital.

The most common reasons for admission were pharmacotherapy session for neoplasm, follow-up examination after surgery for malignant neoplasm and *pneumonia, unspecified*, which represented 24% of all hospitalisations receiving health services/treatment for cancer (Table 29, Appendix 2). The most common AR-DRGs were *chemotherapy, endoscopy with diagnoses of other contacts with health services, same day* and *other digestive system diagnoses without catastrophic or severe CC* (Table 30, Appendix 2).

The total cost in 2011/12 for patients receiving health services/treatment for cancer, and who were not assessed or did not receive palliative care in NSW public hospitals, was \$16.6 million and the average cost per separation was \$6647 (Table 13).

Table 12: Hospitalisation statistics for those receiving health services/treatment for cancer that were not assessed or did not receive palliative care service, 2011/12

Deaths	
Number of deaths	1,589
Sex (% male)	996 (62.7%)
Aboriginal Torres Strait Islander (%)	17 (1.1%)
Died in hospital (%)	213 (13.4%)
Hospitalisations	
Total number of hospitalisations (excluding palliative care)	2,494
Number with palliative care services	197 (7.3%)
Minimum number of hospitalisations	1
Maximum number of hospitalisations	145
Day-only admissions (%)	1,078 (43.2%)
Emergency (%)	1,337 (53.6%)
Total bed-days	20,069
ALOS (days including day-only)	8
Median age (years)	75

Table 13: ABF funding (NWAU) for those receiving health service/treatment for cancer that were not assessed or did not receive palliative care service, 2011/12

<i>Total separations (excluding palliative care)</i>	<i>Total NWAU 2013</i>	<i>Bed-days</i>	<i>NSW cost 2013</i>	<i>Total cost</i>	<i>Average per separation</i>
2,494	3,549	20,069	\$4,671	\$16,577,945	\$6,647

4.1.6 Other relevant diseases and conditions 'grey area'

There were 33,544 hospitalisations for those in the 'grey area' inclusion underlying diagnosis category (based on ICD-10-AM diagnosis code), excluding those who received palliative care services, who had cancer and/or had and AIHW-specific diseases/conditions, which represents 20% of the total hospitalisation in this patient cohort.

There is uncertainty around the inclusion/exclusion of these categories as some sub-cohorts may be amenable to palliative care and others to end of life care. Advice from the Network is sought around this issue.

The top three principal diagnosis codes used for this sub-cohort were pneumonia, unspecified, urinary tract infection, site not specified, and anaemia, unspecified (Table 31, Appendix 2). The top three AR-DRGs were red blood cell disorders without catastrophic or severe CC, arrhythmia, cardiac arrest and conduction disorders without catastrophic or severe CC and other digestive system diagnoses without catastrophic or severe CC (Table 32, Appendix 2).

The total cost for ABF funding in 2011/12 for patients hospitalised with other relevant diseases and conditions 'grey area' in NSW public hospitals was \$165 million and the average cost per separation was \$4916 (Table 2).

4.2 Emergency department presentations

The following summarises data for people who presented to ED between 1 July 2010 and 30 June 2012 in the year prior to their death.

- In 2012, there were 37,907 persons who died in NSW and presented to ED and were either admitted or discharged from ED at least once prior to their deaths.
- There were 104,794 presentations to an ED in the year prior to a person's death. A significant majority of patients who presented to ED in their last year of life had multiple presentations.
- On average, patients that were in their last year of life presented to ED around three times each. Around 47% of patients had between two and four presentations and around 3% had 10 or more presentations (Figure 5). This includes all presentations for those who were admitted to hospital and those who were not admitted and were discharged from ED.
- The maximum number of ED presentations for a patient was 89, i.e., one patient presented to ED 89 times prior to their death.
- The main source of ED referral (i.e. if the patient was referred elsewhere) was self, family, friends, which represented over two-thirds (68%, 70,985 presentations) of all ED presentations.
- The majority mode of arrival was via State Ambulance vehicle and private car, which represented 67% (70,460) and 28% (29,212) of total ED presentations.
- Of the total ED presentations, approximately 2145 people were dead on arrival and 1913 people died in ED, which represented 6% and 5%, respectively, of total deaths. The median age for these people who were dead on arrival or died in ED was 65.
- Of the total ED presentations, more than half (54%), 56,867 presentations were admitted to hospital (Figure 4, derived from linked data).⁹
- A majority (76%) of the ED presentations admitted to hospital were in those aged 70 and over (Figure 21, Appendix 2).

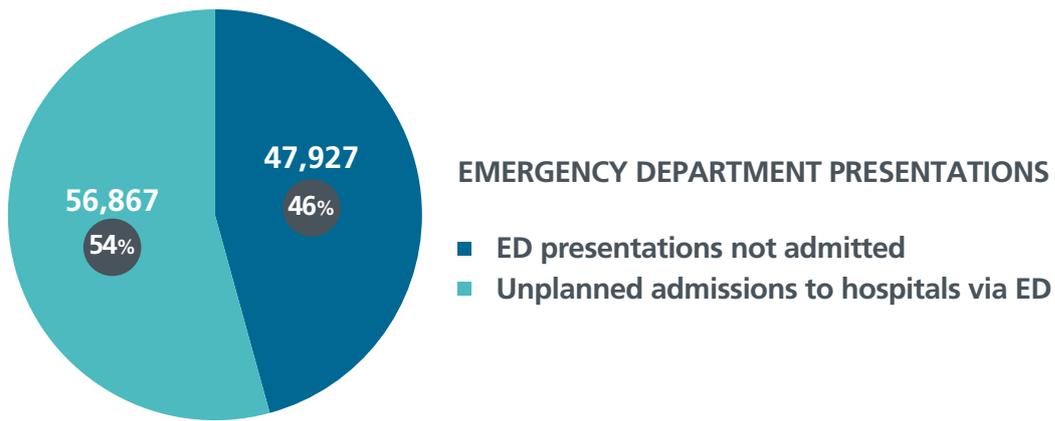


Figure 4: Number of ED presentations and presentations that were admitted

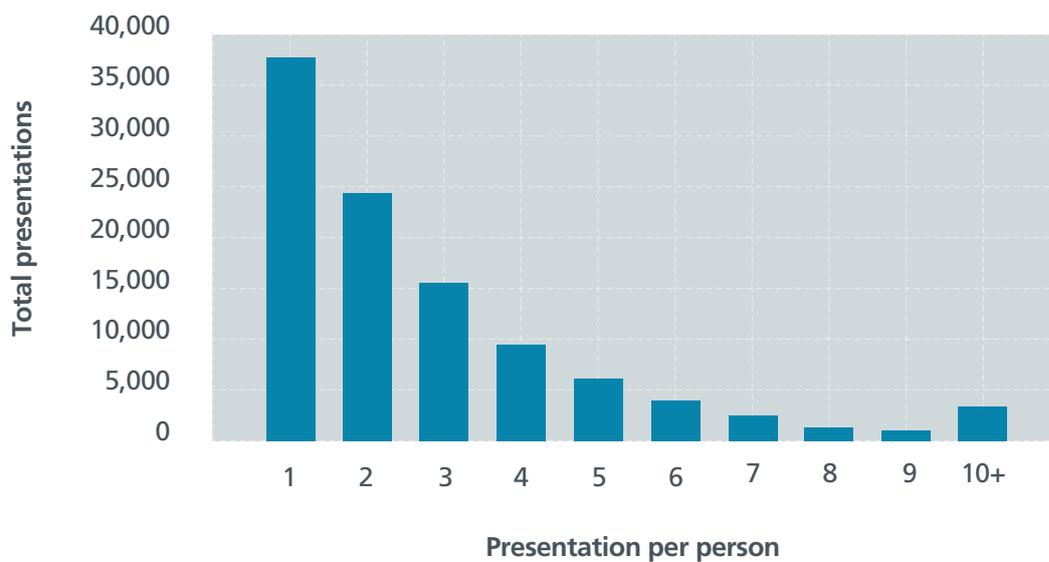


Figure 5: Multiple ED presentations in the last year of life

Tables 33–35 in Appendix 3 list the top 20 ICD-9, ICD-10 and Systematized Nomenclature of Medicine – Clinical Terms (SNOMED-CT) terms for patients that presented to an ED and were either admitted, sent home or died¹⁰.

The total ABF funding for the palliative and end of life cohort for patients presenting to ED, regardless of whether they were admitted or not, was \$89 million and the average cost per presentation was \$850. Of the total ABF funding, \$56.5 million was for ED presentations that were admitted to hospital, which is included in the admitted inpatient cost, and \$32.5 million for ED presentations not admitted. Those ED presentations not admitted are not included in the admitted inpatient cost and have been added to the final grand total cost highlighted in the executive summary (Table 1). Nearly two-thirds of the total ABF funding was from ‘other grey area’, which cost \$59 million (Table 14, below).

Table 14: Palliative and end of life cohort for patients presenting to ED and ABF funding summary by breakdown using ICD-10 (refer to Table 36; Appendix 3)

	Activity					ABF Funding		
	<i>ED presentations admitted</i>	<i>(%) of total</i>	<i>ED presentations not admitted</i>	<i>(%) of total</i>	<i>Grand total</i>	<i>ED presentations admitted</i>	<i>ED presentations not admitted</i>	<i>Grand total</i>
AIHW conditions	4,467	(66%)	2,321	(34%)	6,788	\$4,481,785	\$2,062,083	\$6,543,869
Cancer	1,223	(65%)	659	(35%)	1,882	\$1,165,195	\$535,208	\$1,700,403
Exclusions	6,213	(42%)	8,726	(58%)	14,939	\$5,484,486	\$4,369,575	\$9,854,061
Other grey area	36,969	(57%)	28,412	(43%)	65,381	\$37,644,688	\$20,987,884	\$58,632,572
Receiving health services /treatment for cancer	10	(59%)	7	(41%)	17	\$8,754	\$4,922	\$13,676
<i>Diagnoses and SNOMED terms that did not map to ICD-10-AM</i>	7,985	(51%)	7,802	(49%)	15,787	\$7,738,019	\$4,545,697	\$12,283,716
Grand Total	56,867	(54%)	47,927	(46%)	104,794	\$56,522,928	\$32,505,369	\$89,028,297

*The NWAU price weight of 4,583 applied

4.3 Analysis by Local Health District

Detailed individual LHD summaries will be provided to each LHD separately.

Section 5

Discussion and Next Steps

This dataset was large and complex, with more than 8 million linked records. It is a 'fact of death' analysis that meant that it was not possible to ascertain whether the reason for being hospitalised for a particular disease(s)/condition(s) was the ultimate cause of death.

The cause of death data will be added as a separate chapter in mid-late 2015.

The 2011/12 data analysed in this paper is baseline data as it aligns with the (soon to be updated) cause of death data and it was a year before changes were being made to the NSW ABF.

5.1 Proposed next steps

- Add the cause of death data analysis, which will be added once data is available around mid-2015.
- Add updated data. This could also include projections of demand and cost over the next 10 years, i.e. modelling of a business as usual approach. This would enable comparison of a business as usual approach to 'do something' options, that is the implementation of the *Blueprint*, and should be included in the evaluation strategy.¹¹

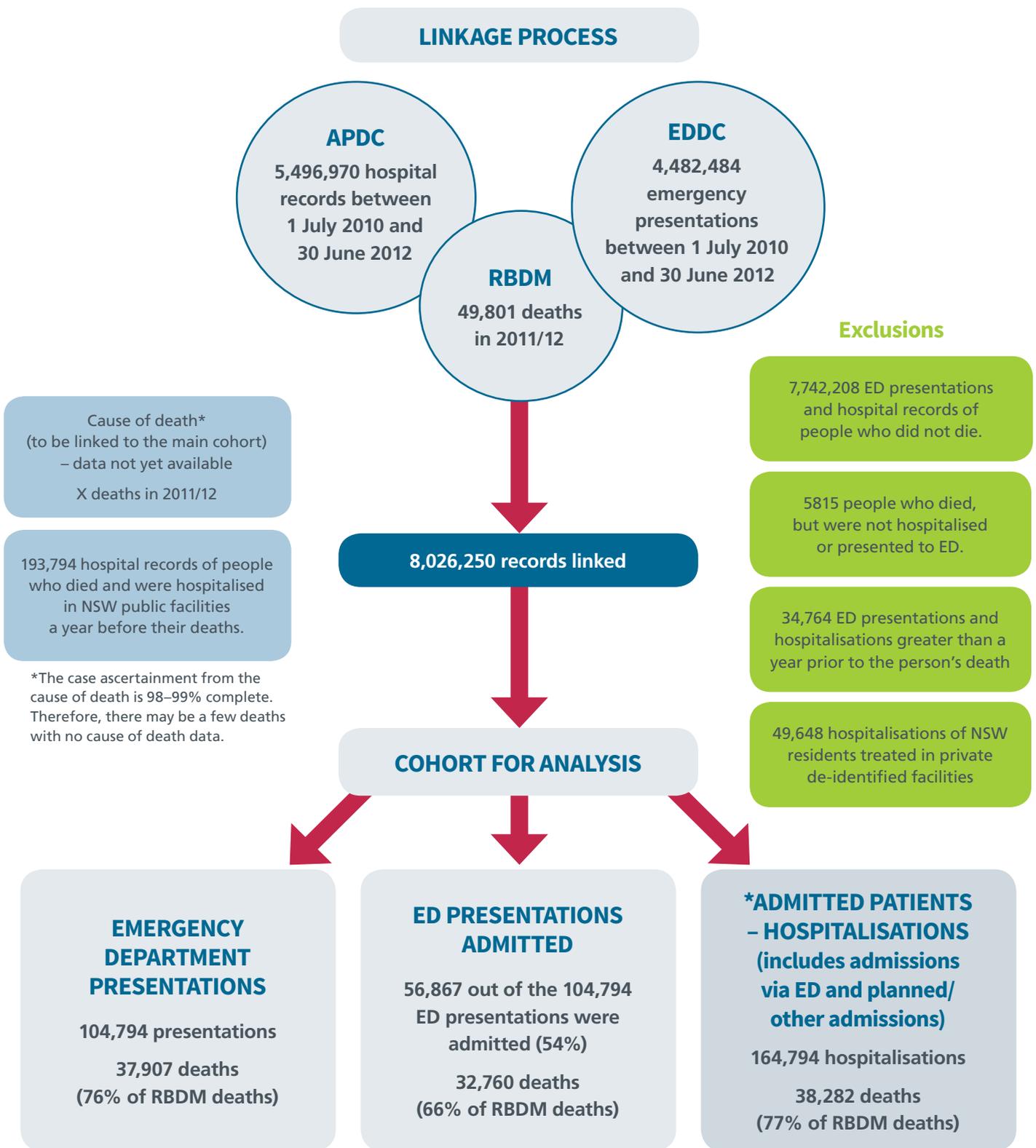
Appendix 1

Data Linkage Flow Chart

Figures 6 and 7 illustrate the process of linking the data to extract patient cohorts.



Figure 6: Data linkage between APDC, EDDC and RBDM



There are three main cohorts in this analysis (as seen above) – bearing in mind there will be overlaps between cohorts.

- Emergency presentations:** Patients who presented to ED and were discharged from ED (ED presentations only) and those who were admitted to hospital.
- ED presentations admitted:** Patients who presented to ED and were then admitted to a ward/unit.
- Admitted patients – Hospitalisation* (main cohort for analysis):** Patients who were hospitalised regardless of whether they came via ED or were planned/other admissions i.e. all hospitalisations.

Figure 7: Data linkages between APDC, EDDC and RBDM – flow chart

Out of the 49,801 deaths in the RBDM:

- 38,282 (77%) of persons who died in NSW during 2012 were hospitalised at least once between 1 July 2010 and 30 June 2012. An additional 49,648 hospitalisations for NSW residents treated in private facilities were excluded.
- 37,907 (76%) of persons who died in NSW during 2012 presented to EDs at least once between 1 July 2010 and 30 June 2012.
- 32,760 (66%) of persons who died in NSW during 2012 presented to ED and were admitted at least once between 1 July 2010 and 30 June 2012.

Cause of death data is not yet available and will be added as a separate chapter.

ICD-10-AM diagnosis codes for hospitalisations

Data for those who were hospitalised have been analysed according to the following six sections.

- 1. AIHW-specific diagnosis and condition codes:**
A list of 10 diagnosis codes from the AIHW report *'Palliative care services in Australia 2012'* was used to identify specific diseases other than cancer coded as either the principal or additional diagnosis (see Appendix 3, Table 23).
- 2. Cancer diagnosis codes** (see Appendix 3, Table 45).
- 3. AIHW-specific diagnosis/conditions and cancer diagnosis codes:** People who were admitted with both an AIHW diagnosis/condition and cancer.
- 4. Receiving health services/treatment for cancer:** People who were receiving health services/treatment for their cancer (See Appendix 3, Table 45).
- 5. Palliative care type:** Those who had a 'palliative care type' service.
- 6. Other relevant diagnosis 'grey area of interest':** Reasons for admission will also be identified and investigated, where appropriate. This will be the 'grey area of interest' of the patient cohort. Certain ICD-10-AM principal diagnosis codes will be excluded (see Appendix 3, Table 24).

The subgroup exclusions were included in the analysis for the consideration and interest of the Palliative Care Network. These exclusions were based on principal ICD diagnosis codes for people who were admitted for other reasons other than any of the six main subgroups, such as trauma or acute injury (see Appendix 3, Table 46).

In 2011/12, there were 49,801 registered deaths in NSW. There were also 5,496,970 hospital records extracted from the APDC dataset and 4,482,484 records extracted from the EDDC dataset between 1 July 2010 and 30 June 2012. This produced over 8 million linked records. The following were excluded from analysis:

- 7,742,208 hospital and ED records for those who did not die.
- 5815 of people who died, but were **not** hospitalised and/or did not present to ED within a year prior to their deaths.
- 34,764 ED presentations and hospitalisations greater than a year prior to the persons' death.
- 49,648 of hospitalisations of NSW residents treated in private de-identified facilities.

Three cohorts were further refined and then analysed (shown in the flow chart above). However, the main cohort of this analysis were the patients who were hospitalised/admitted.

The analysis is a **'fact of death'** analysis and is based on a combination of variables from the APDC, such as ICD-10-AM diagnosis codes, palliative care type and AR-DRG codes and from the EDDC, such as ICD-10-AM, ICD-9-clinical modification (CM) diagnosis codes and SNOMED-CT to explore and identify ED presentation and hospitalisation utilisation and activity. Cause of death data will be linked to the main patient cohort to *briefly* describe the patterns of death and what particular disease(s)/condition(s) the person died from. However, this data is not yet available, but will be added as a separate chapter once data is available.

An approximation of the age-specific death rates was calculated by using the age group of the person's last hospitalisation prior to their death. The age-specific death rate at death was also calculated from the cause of death data.

Appendix 2

Admitted Patient Tables and Figures

Table 15: Top 20 principal diagnosis (reason for admission) – Overnight versus same day hospitalisations

Overnight		Same Day	
<i>Principal diagnosis (reason for admission)</i>	<i>Separations</i>	<i>Principal diagnosis (reason for admission)</i>	<i>Separations</i>
Congestive heart failure	4,080	Extracorporeal dialysis	35,122
Care involving use of rehabilitation procedure, unspecified	3,686	Anaemia, unspecified	1,287
Pneumonia, unspecified	3,398	Chest pain, unspecified	510
COPD with acute lower respiratory infection	2,974	Ascites	490
Urinary tract infection, site not specified	2,199	Cataract, unspecified	472
Person awaiting admission to residential aged care service	2,156	Pneumonia, unspecified	459
Pneumonitis due to food and vomit	1,982	Myelodysplastic syndrome, unspecified	428
Secondary malignant neoplasm of bone and bone marrow	1,785	Congestive heart failure	419
Acute subendocardial myocardial infarction	1,307	Pharmacotherapy session for neoplasm	411
Malignant neoplasm of bronchus or lung, unspecified	1,263	Cardiac arrest, unspecified	397
Acute renal failure, unspecified	1,250	Urinary tract infection, site not specified	369
COPD with acute exacerbation, unspecified	1,247	Syncope and collapse	323
Septicaemia, unspecified	1,197	Constipation	312
Unspecified acute lower respiratory infection	1,042	Nausea and vomiting	267
Cellulitis of lower limb	1,013	Septicaemia, unspecified	261
Secondary malignant neoplasm of brain and cerebral meninges	1,011	Dyspnoea	255
Cerebral infarction, unspecified	919	Iron deficiency anaemia, unspecified	252
Other and unspecified intestinal obstruction	839	Acute myeloid leukaemia, without mention of remission	244
Atrial fibrillation and flutter	808	Atrial fibrillation and flutter	240
Malignant neoplasm of upper lobe, bronchus or lung	783	Fitting and adjustment of urinary device	234
Subtotal	34,939	Subtotal	42,752
Missing	154	Missing	27
TOTAL (overnight)	100,208	TOTAL (overnight)	64,586

Table 16: Number of separations per persons (multiple hospitalisations)

<i>Multiple hospitalisations</i>	<i>No. of separations</i>
1	38,282
2	27,819
3	19,579
4	13,607
5	9,388
6	6,390
7	4,398
8	3,110
9	2,224
10+	39,997
Total	164,794

Table 17: Number of hospitalisations by emergency status

<i>Emergency status</i>	<i>No. of separations</i>
Emergency	88,806
Non-emergency/planned	55,195
Urgency not assigned	20,788
Grand Total	164,794

Table 18: Top 20 principal diagnoses (reason for admissions) for hospitalisations with an emergency status

Hospitalisations with an emergency status	
<i>Principal diagnosis (reason for admission)</i>	<i>Separations</i>
Congestive heart failure	3,851
Pneumonia, unspecified	3,397
COPD with acute lower respiratory infection	2,861
Urinary tract infection, site not specified	2,279
Pneumonitis due to food and vomit	1,870
COPD with acute exacerbation, unspecified	1,336
Septicaemia, unspecified	1,249
Acute subendocardial myocardial infarction	1,241
Secondary malignant neoplasm of bone and bone marrow	1,208
Acute renal failure, unspecified	1,122
Unspecified acute lower respiratory infection	1,097
Anaemia, unspecified	1,034
Cellulitis of lower limb	957
Atrial fibrillation and flutter	888
Other and unspecified intestinal obstruction	828
Malignant neoplasm of bronchus or lung, unspecified	781
Cerebral infarction, unspecified	779
Constipation	777
Syncope and collapse	768
Chest pain, unspecified	763
Subtotal	29,086
Missing	00
TOTAL	88,806

Table 19: Number of hospitalisations by mode of separation

<i>Mode of separation</i>	<i>No. of hospitalisations</i>	<i>(%)</i>
Discharge by hospital	103,462	(62.8%)
Death without autopsy	22,103	(13.4%)
Transfer to other hospital	16,701	(10.1%)
Type change separation	10,241	(6.2%)
Transfer to nursing home	7,559	(4.6%)
Death with autopsy	1,673	(1.0%)
Discharge own risk	1,077	(0.7%)
Transfer to palliative care unit/hospice	733	(0.4%)
Transfer to other accommodation	725	(0.4%)
Discharge on leave	387	(0.2%)
Transfer to public psychiatric hospital	104	(0.1%)
Missing/blank	29	(0.0%)
TOTAL	164,794	(100%)

*Death totals (those that died in hospital) will not match the totals from the summary Table 1 – the mode of separation may not always be accurate.

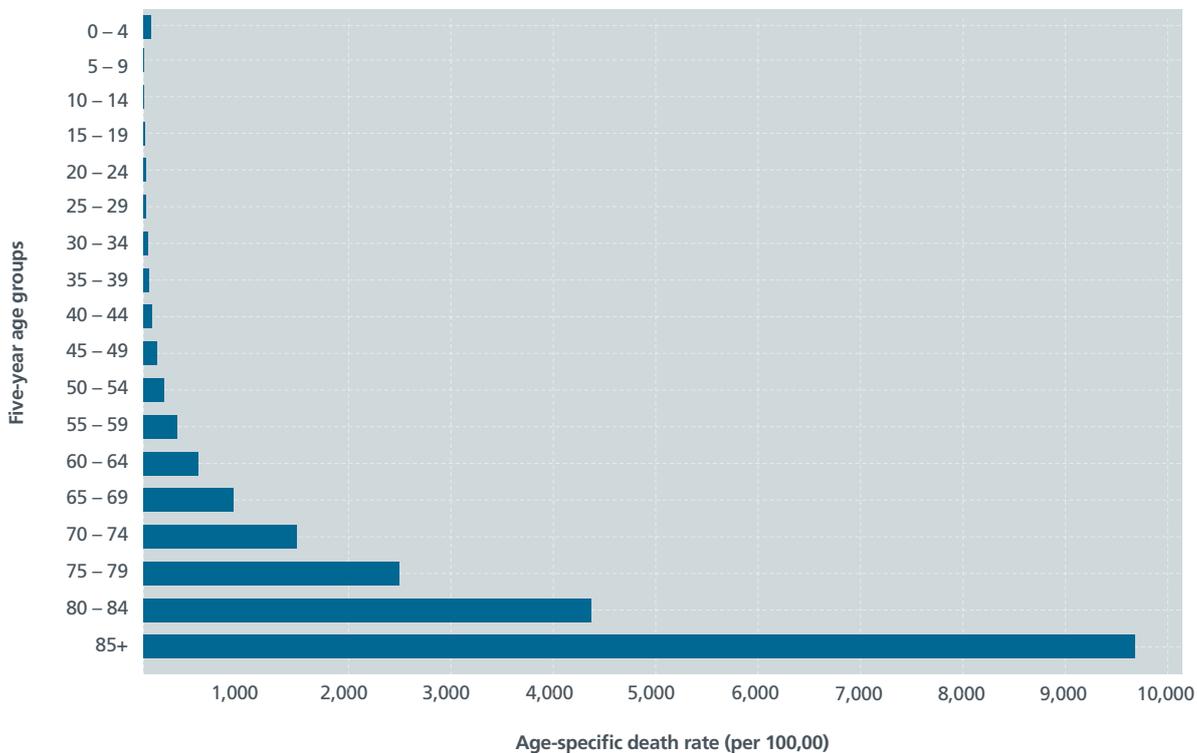


Figure 8: Age-specific death rates at last hospitalisation by five-year age groups

Table 20: Top 20 principal diagnoses for those who received/had palliative care services

<i>Principal diagnosis (reason for admission)</i>	<i>Separations</i>
Malignant neoplasm of bronchus or lung, unspecified	762
Malignant neoplasm of prostate	444
Secondary malignant neoplasm of bone and bone marrow	435
Malignant neoplasm of breast, unspecified part	356
Malignant neoplasm of upper lobe, bronchus or lung	308
Malignant neoplasm of pancreas, part unspecified	284
Secondary malignant neoplasm of brain and cerebral meninges	259
Malignant neoplasm of rectosigmoid junction	254
Congestive heart failure	224
Pneumonitis due to food and vomit	196
Malignant neoplasm of ovary	179
Secondary malignant neoplasm of liver	170
Pneumonia, unspecified	162
Secondary malignant neoplasm of lung	154
Liver cell carcinoma	149
Malignant neoplasm of lower lobe, bronchus or lung	149
Malignant neoplasm of kidney, except renal pelvis	142
Malignant neoplasm of head of pancreas	132
Malignant neoplasm of bladder, unspecified	129
Stroke, not specified as haemorrhage or infarction	123
Subtotal	5,011
Missing	164
TOTAL	11,313

Table 21: Top 25 AR-DRGs and cost per diem rate for those who received/had palliative care services, 2011/12

<i>AR-DRG</i>	<i>No. of separations</i>	<i>Bed-days</i>	<i>ALOS</i>
Respiratory neoplasms without catastrophic CC	1207	12,193	10.1
Digestive malignancy without catastrophic CC	836	9,595	11.5
Malignancy of hepatobiliary system, pancreas without catastrophic CC	687	7,130	10.4
Respiratory neoplasms with catastrophic CC	513	7421	14.5
Digestive malignancy with catastrophic CC	422	6,510	15.4
Malignant breast disorders with CC	394	5,330	13.5
Nervous system neoplasm with catastrophic or severe CC	301	4,506	15.0
Malignancy, male reproductive system with catastrophic or severe CC	291	3,571	12.3
Musculoskeletal malignant neoplasms without catastrophic CC	284	3,498	12.3
Kidney and urinary tract neoplasms with catastrophic or severe CC	267	2,900	10.9
Malignancy of hepatobiliary system, pancreas with catastrophic CC	253	3,374	13.3
Lymphoma and non-acute leukaemia without catastrophic CC	244	2,480	10.2
Malignancy, female reproductive system without catastrophic CC	236	2,773	11.8
Stroke and other cerebrovascular disorders, died or transferred <5 days	226	503	2.2
Nervous system neoplasm without catastrophic or severe CC	213	2,365	11.1
Respiratory infections/inflammations with catastrophic CC	202	1,262	6.2
Heart failure and shock without catastrophic CC	185	1,294	7.0
Musculoskeletal malignant neoplasms with catastrophic CC	184	3,196	17.4
Other neoplastic disorders with CC	161	2,243	13.9
Skin malignancy without catastrophic CC	157	1,712	10.9
Malignancy, male reproductive system without catastrophic or severe CC	156	1,317	8.4
Respiratory infections/inflammations with severe or moderate CC	142	821	5.8
Chronic obstructive airways disease without catastrophic CC	136	1,156	8.5
Ear, nose, mouth and throat malignancy without catastrophic or severe CC	132	1,965	14.9
Septicaemia without catastrophic CC	108	678	6.3
TOTAL	7937	89,793	11.3

Table 22: ABF funding (NWAU) for AIHW diseases/conditions by the specific AIHW disease/condition, 2011/12

Specific disease/condition	Diagnosis codes (ICD-10-AM)	All separations			Separations as reason for admission (principal diagnosis)		
		Did not have/receive palliative care services	Received palliative care services	Total	Did not have/receive palliative care services	Received palliative care services	Total
COPD	J40–J44	10,422	689	11,111	4,970	192	5,162
Dementia and Alzheimer's disease	F00–F03, G30	8,725	437	9,162	681	49	730
Heart failure	I50	14,654	768	15,422	5,024	270	5,294
HIV/AIDS	B20–B24	107	16	123	2	0	2
Huntington's disease	G10, F02.2	27	5	32	5	2	7
Liver failure	K70.4, K71.1, K72	1,687	213	1,900	566	71	637
Motor neurone disease	G12.2	301	71	372	108	62	170
Multiple sclerosis	G35	80	10	90	10	4	14
Muscular dystrophy	G71.0	4,746	15	4,761	2	10	12
Parkinson's disease	G20, G21, G22	1,363	94	1,457	143	17	160
Renal failure	N17–N19	19,563	1,106	20,669	1,742	219	1,961
	Totals	61,675	3424	65,099*	13,253	896	14,149

*Totals will not match the total from the summary table as a person can have one or more of the diagnosis codes in their episode of care – an interaction of disease and comorbidities

Table 23: Top principal diagnoses for those who were admitted with AIHW conditions and were not assessed or did not receive palliative care services

<i>Principal diagnosis (reason for admission)</i>	<i>No. of separations</i>
Congestive heart failure	4,119
COPD with acute lower respiratory infection	2,838
Extracorporeal dialysis	1,907
Pneumonia, unspecified	1,609
Care involving use of rehabilitation procedure, unspecified	1,541
COPD with acute exacerbation, unspecified	1,328
Person awaiting admission to residential aged care service	1,126
Pneumonitis due to food and vomit	1,010
Acute renal failure, unspecified	973
Urinary tract infection, site not specified	902
Acute subendocardial myocardial infarction	743
Left ventricular failure	609
Septicaemia, unspecified	609
Unspecified dementia	458
Cellulitis of lower limb	421
Atrial fibrillation and flutter	353
Unspecified acute lower respiratory infection	339
Fracture of intertrochanteric section of femur	329
Fracture of subcapital section of femur	308
COPD, unspecified	291
Subtotal	21,813
TOTAL	38,905

Table 24: Top 20 AR-DRG and ABF funding (NWAU) by volume for those who were admitted with AIHW condition(s) and were not assessed and did not receive palliative care services, 2011/12

<i>AR-DRG</i>	<i>No. of separations</i>	<i>Bed-days</i>
Chronic obstructive airways disease without catastrophic CC	2,988	18,119
Heart failure and shock without catastrophic CC	2,881	21,023
Haemodialysis	1,907	1,908
Respiratory infections/inflammations with catastrophic CC	1,770	18,364
Heart failure and shock with catastrophic CC	1,711	20,786
Other factors influencing health status	1,432	43,441
Chronic obstructive airways disease with catastrophic CC	1,257	12,717
Rehabilitation with catastrophic CC	1,201	24,975
Respiratory infections/inflammations with severe or moderate CC	868	5,038
Dementia and other chronic disturbances of cerebral function	825	26,191
Kidney and urinary tract infections with catastrophic or severe CC	749	6,948
Septicaemia with catastrophic CC	724	7,584
Renal failure with catastrophic CC	485	7,263
Respiratory system diagnosis with non-invasive ventilation	476	5,881
Other digestive system diagnoses with catastrophic or severe CC	463	3,301
Tracheostomy with ventilation >95 hours without catastrophic CC or tracheostomy/ventilation >95 hours with catastrophic CC	460	10,543
Renal failure without catastrophic or severe CC	454	2,853
Cellulitis with catastrophic or severe CC	430	5,006
Circulatory disorders with acute myocardial infarction (AMI) without invasive cardiac investigative procedure with catastrophic CC	424	4,705
Circulatory Disorders with AMI without Invasive cardiac investigative procedure without catastrophic CC	412	1,757
Subtotal	21,917	248,403
TOTAL	38,905	436,482

Table 25: Top 20 principal diagnoses for those who were admitted with cancer and were not assessed or did not receive palliative care services

<i>Principal diagnosis (reason for admission)</i>	<i>No. of separations</i>
Secondary malignant neoplasm of bone and bone marrow	1,306
Secondary malignant neoplasm of brain and cerebral meninges	785
Malignant neoplasm of bronchus or lung, unspecified	597
Anaemia, unspecified	582
Malignant neoplasm of upper lobe, bronchus or lung	553
Secondary malignant neoplasm of pleura	537
Myelodysplastic syndrome, unspecified	524
Secondary malignant neoplasm of liver	501
Acute myeloid leukaemia, without mention of remission	477
Pneumonia, unspecified	455
Care involving use of rehabilitation procedure, unspecified	442
Agranulocytosis	388
Secondary malignant neoplasm of retroperitoneum and peritoneum	387
Large cell (diffuse) non-Hodgkin's lymphoma	324
Malignant neoplasm of prostate	322
Malignant neoplasm of lower lobe, bronchus or lung	313
Nausea and vomiting	308
Secondary malignant neoplasm of lung	299
Other and unspecified intestinal obstruction	275
Malignant neoplasm of head of pancreas	251
Subtotal	9,626
TOTAL	25,059

Table 26: Top 20 AR-DRG and ABF funding (NWAU) by volume for those who were admitted with cancer and were not assessed and did not receive palliative care services, 2011/12

<i>AR-DRG</i>	<i>No. of separations</i>	<i>Bed-days</i>
Respiratory neoplasms without catastrophic CC	1,480	8,476
Lymphoma and non-acute leukaemia, same day	983	981
Digestive malignancy without catastrophic CC	899	4,191
Musculoskeletal malignant neoplasms without catastrophic CC	855	6,179
Malignancy of hepatobiliary system, pancreas without catastrophic CC	847	4,030
Lymphoma and non-acute leukaemia without catastrophic CC	766	5,411
Respiratory neoplasms with catastrophic CC	609	6,162
Acute leukaemia without catastrophic CC	574	2,125
Nervous system neoplasm with catastrophic or severe CC	538	4,944
Other digestive system diagnoses with catastrophic or severe CC	499	2,796
Red blood cell disorders without catastrophic or severe CC	466	796
Nervous system neoplasm without catastrophic or severe CC	400	2,262
Other factors influencing health status	336	5,714
Digestive malignancy with catastrophic CC	333	3,189
Reticuloendothelial and immunity disorders with catastrophic or severe CC	329	2,854
Musculoskeletal malignant neoplasms with catastrophic CC	309	4,207
Respiratory infections/inflammations with catastrophic CC	305	2,764
Respiratory infections/inflammations with severe or moderate CC	261	1,729
Major small and large bowel procedures with catastrophic CC	257	4,632
Red blood cell disorders with catastrophic or severe CC	250	1,150
Subtotal	11,296	74,592
TOTAL	25,059	199,683

Table 27: Top 20 principal diagnoses for those who were admitted with AIHW condition(s) and cancer in the same admission and were not assessed or did not receive palliative care services

<i>Principal diagnosis (reason for admission)</i>	<i>No. of separations</i>
Acute renal failure, unspecified	262
COPD with acute lower respiratory infection	209
Pneumonia, unspecified	185
Secondary malignant neoplasm of bone and bone marrow	148
Congestive heart failure	124
Malignant neoplasm of bronchus or lung, unspecified	116
Malignant neoplasm of upper lobe, bronchus or lung	111
Septicaemia, unspecified	99
Multiple myeloma, without mention of remission	92
Secondary malignant neoplasm of liver	85
Urinary tract infection, site not specified	84
Secondary malignant neoplasm of pleura	75
Acute myeloid leukaemia, without mention of remission	74
Malignant neoplasm of lower lobe, bronchus or lung	69
COPD with acute exacerbation, unspecified	68
Secondary malignant neoplasm of retroperitoneum and peritoneum	67
Anaemia, unspecified	60
Liver cell carcinoma	60
Malignant neoplasm of prostate	52
Large cell (diffuse) non-Hodgkin's lymphoma	51
Subtotal	2,091
TOTAL	4,866

Table 28: Top 20 AR-DRG and ABF funding (NWAU) by volume for those who were admitted with AIHW condition(s) and cancer in the same admission and were not assessed and did not receive palliative care services, 2011/12

<i>AR-DRG</i>	<i>No. of separations</i>	<i>Bed-days</i>
Respiratory neoplasms with catastrophic CC	223	2,433
Respiratory infections/inflammations with catastrophic CC	204	2,342
Chronic obstructive airways disease with catastrophic CC	161	1,720
Renal failure with catastrophic CC	158	1,902
Respiratory neoplasms without catastrophic CC	154	1,183
Malignancy of hepatobiliary system, pancreas with catastrophic CC	153	1,654
Lymphoma and non-acute leukaemia with catastrophic CC	149	2,254
Septicaemia with catastrophic CC	149	1,968
Digestive malignancy with catastrophic CC	124	1,388
Chronic obstructive airways disease without catastrophic CC	118	843
Tracheostomy with ventilation >95 hours without catastrophic CC or tracheostomy/ventilation >95 hours with catastrophic CC	104	3,004
Lymphoma and non-acute leukaemia without catastrophic CC	93	620
Musculoskeletal malignant neoplasms with catastrophic CC	91	1,360
Renal failure with severe CC	80	598
Kidney and urinary tract infections with catastrophic or severe CC	79	942
Heart failure and shock with catastrophic CC	78	903
Major small and large bowel procedures with catastrophic CC	77	1,578
Red blood cell disorders with catastrophic or severe CC	75	466
Disorders of liver except malignancy, cirrhosis, alcoholic hepatitis with catastrophic or severe CC	68	490
Other digestive system diagnoses with catastrophic or severe CC	68	588
Subtotal	2,406	28,236
TOTAL	4,866	67,261

Table 29: Top 20 principal diagnoses for those receiving health service/treatment for cancer and were not assessed or did not receive palliative care services

<i>Principal diagnosis (reason for admission)</i>	<i>No. of separations</i>
Pharmacotherapy session for neoplasm	414
Follow-up examination after surgery for malignant neoplasm	125
Pneumonia, unspecified	55
Care involving use of rehabilitation procedure, unspecified	49
Other and unspecified intestinal obstruction	46
COPD with acute lower respiratory infection	45
Anaemia, unspecified	37
Urinary tract infection, site not specified	36
Secondary malignant neoplasm of bone and bone marrow	34
Congestive heart failure	32
Pleural effusion, not elsewhere classified	29
Unspecified haematuria	29
Acute renal failure, unspecified	27
Septicaemia, unspecified	24
Secondary malignant neoplasm of brain and cerebral meninges	23
Gastrointestinal haemorrhage, unspecified	22
Pneumonitis due to food and vomit	22
Constipation	21
Oesophageal obstruction	20
COPD with acute exacerbation, unspecified	19
Subtotal	1,109
TOTAL	2,494

Table 30: Top 20 AR-DRG and ABF funding (NWAU) by volume for those receiving health services/treatment for cancer and were not assessed and did not receive palliative care services, 2011/12

<i>AR-DRG</i>	<i>No. of separations</i>	<i>Bed-days</i>
Chemotherapy	413	420
Endoscopy with diagnoses of other contacts with health services, same day	123	123
Other digestive system diagnoses without catastrophic or severe CC	46	98
Other factors influencing health status	44	1,207
Respiratory infections/inflamations with catastrophic CC	40	634
Chronic obstructive airways disease without catastrophic CC	39	254
Transurethral procedures except prostatectomy without CC	33	45
Rehabilitation with catastrophic CC	32	685
Respiratory infections/inflamations with severe or moderate CC	30	228
Gastrointestinal obstruction without catastrophic or severe CC	29	85
Abdominal pain or mesenteric adenitis	28	99
Operating room procedures with diagnoses of other contacts with Health services without catastrophic or severe CC	28	28
Other gastroscopy, same day	28	28
Kidney and urinary tract signs and symptoms without catastrophic or severe CC	27	54
Respiratory neoplasms without catastrophic CC	27	127
Septicaemia with catastrophic CC	27	337
Other digestive system diagnoses with catastrophic or severe CC	26	196
Other factors influencing health status, same day	26	26
Red blood cell disorders without catastrophic or severe CC	26	38
Chronic obstructive airways disease with catastrophic CC	24	282
Subtotal	1,096	4,994
TOTAL	2,494	20,069

Table 31: Top 20 principal diagnosis codes in underlying diagnosis categories of inclusions

<i>Underlying diagnosis category</i>	<i>Principal diagnosis</i>	<i>No. of separations</i>
Diseases and disorders of the respiratory system	Pneumonia, unspecified	1,382
Diseases and disorders of the kidney and urinary tract	Urinary tract infection, site not specified	1,277
Diseases and disorders of the blood and blood forming organs and immunological disorders	Anaemia, unspecified	1,084
Diseases and disorders of the respiratory system	Pneumonitis due to food and vomit	844
Diseases and disorders of the circulatory system	Chest pain, unspecified	634
Diseases and disorders of the respiratory system	Unspecified acute lower respiratory infection	609
Diseases and disorders of the circulatory system	Acute subendocardial myocardial infarction	603
Diseases and disorders of the circulatory system	Atrial fibrillation and flutter	587
Diseases and disorders of the nervous system	Cerebral infarction, unspecified	581
Diseases and disorders of the circulatory system	Syncope and collapse	549
Factors influencing health status and other contacts with health services	Ascites	510
Diseases and disorders of the digestive system	Constipation	480
Diseases and disorders of the digestive system	Gastrointestinal haemorrhage, unspecified	465
Diseases and disorders of the digestive system	Gastroenteritis and colitis of unspecified origin	452
Diseases and disorders of the nervous system	Stroke, not specified as haemorrhage or infarction	434
Infectious and parasitic diseases	Septicaemia, unspecified	406
Diseases and disorders of the digestive system	Other and unspecified intestinal obstruction	395
Diseases and disorders of the circulatory system	Cardiac arrest, unspecified	385
Diseases and disorders of the respiratory system	Pleural effusion, not elsewhere classified	356
Diseases and disorders of the digestive system	Nausea and vomiting	350
Subtotal		12,383
TOTAL		33,544
*Excluded were those who received palliative care service and/or had cancers and/or had an AIHW principal diagnosis.		

Table 32: Top 25 AR-DRGs for those inclusions in the underlying diagnosis category

<i>AR-DRG</i>	<i>No. of separations</i>	<i>Bed-days</i>
Red blood cell disorders without catastrophic or severe CC	1,450	2,341
Arrhythmia, cardiac arrest and conduction disorders without catastrophic or severe CC	1,133	2,707
Other digestive system diagnoses without catastrophic or severe CC	1,131	2,989
Kidney and urinary tract infections without catastrophic or severe CC	853	3,490
Respiratory infections/inflammations with severe or moderate CC	844	5,057
Chest pain	842	2,848
Respiratory infections/inflammations without CC	783	3,220
Circulatory disorders with AMI without invasive cardiac investigative procedures without catastrophic CC	767	3,100
Stroke and other cerebrovascular disorders, died or transferred <5 days	763	1,223
Respiratory infections/inflammations with catastrophic CC	714	6,823
Stroke and other cerebrovascular disorders with catastrophic CC	564	8,013
Abdominal pain or mesenteric adenitis	505	1,173
Syncope and collapse without catastrophic or severe CC	501	1,335
Oesophagitis and gastroenteritis without catastrophic or severe CC	490	1,450
Kidney and urinary tract infections with catastrophic or severe CC	464	3,893
Septicaemia without catastrophic CC	452	6,902
Miscellaneous metabolic disorders without catastrophic or severe CC	441	1,180
Other respiratory system diagnosis without CC	406	1369
Stroke and other cerebrovascular disorders with severe CC	398	3,646
Dementia and other chronic disturbances of cerebral function	389	154,920
Kidney and urinary tract signs and symptoms without catastrophic or severe CC	388	1,725
Other digestive system diagnoses with catastrophic or severe CC	372	2,307
Gastrointestinal haemorrhage without catastrophic or severe CC	367	942
Signs and symptoms, same day	365	364
Respiratory signs and symptoms without catastrophic or severe CC	360	767
Subtotal	15,742	223,784
TOTAL	33,544	365,829

Appendix 3

Emergency Department Tables and Figures

The top three diagnoses (admitted and non-admitted) for facilities with:

- ICD-9-CM classification system were *observation and evaluation for suspected conditions not found – observations following other accident, symptoms involving respiratory system and other chest symptoms – dyspnoea and respiratory abnormalities – other* and *Other disorders of urethra and urinary tract – urinary tract infection, site not specified*, which represented 13% of all ICD-9 diagnoses.
- ICD-10-AM classification system were *unspecified fall, other, unspecified abdominal pain* and *dyspnoea*, which represented 9% of all ICD-10 diagnoses.
- SNOMED-CT system were *dyspnoea (finding), pneumonia (disorder) and congestive heart failure (disorder)*, which represented 5% of SNOMED-CT terms.

For ease of analysis we have mapped (what could be mapped) SNOMED-CT terms and ICD-9 to ICD-10 and have grouped diagnosis and terms (similar to the summary hospitalisation table in the executive summary). Out of the 104,794 ED presentations, around 15% (15,787 presentations; mainly SNOMED terms) did not map to ICD-10-AM (Table 33).

More than half of the SNOMED concepts that could not be mapped to ICD-10-AM were 'disorder' (37%) and 'finding' (20%). Of the 'disorder' concepts that could not be mapped to ICD-10-AM, the top five most common terms were cancer-related disorders, including *malignant neoplastic disease, neoplastic pleural effusion, secondary malignant neoplasm of brain, malignant tumour of oesophagus and chemotherapy sickness*. Of the 'finding' concepts that could not be mapped to ICD-10-AM, the top five most common terms were *dead, informal referral – signposted to other agency, patient status determination, deceased, under care of palliative care physician and pain from metastases*.

Of those that mapped to ICD-10-AM (85% of all ED presentations), a majority (62%) of presentations were 'other grey area' (Table 34). The most common diagnosis for 'other grey area' were *dyspnoea, pneumonia unspecified* and *septicaemia unspecified* (Table 34), which represented 14% of all ED presentations for 'other grey area'.

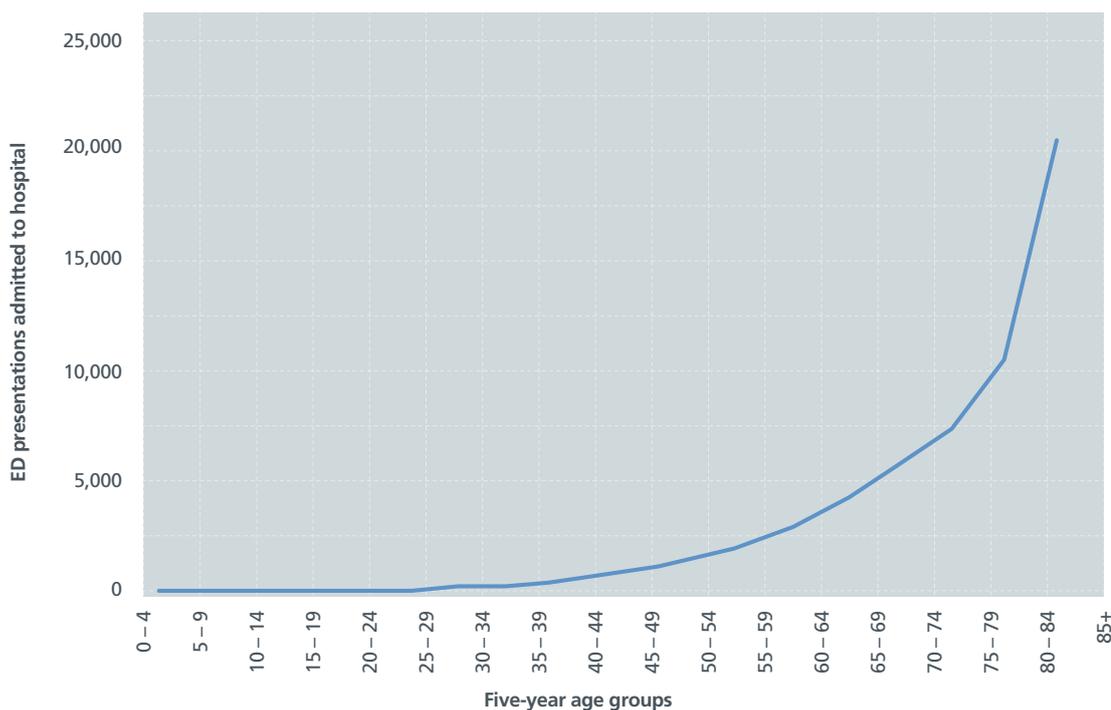


Figure 9: Number of ED presentations admitted to hospital by five-year age groups

Table 33: SNOMED-CT concepts for those diagnoses and SNOMED terms that could not map to ICD-10-AM

<i>SNOMED-CT concepts (Diagnoses and SNOMED terms that could not map to ICD10-AM)</i>	<i>Number of ED presentations (%)</i>
Disorder	5,884 (37.3%)
Finding	3,108 (19.7%)
Procedure	690 (4.4%)
Situation	501 (3.2%)
Morphologic abnormality	343 (2.2%)
Qualifier value	211 (1.3%)
Observable entity	139 (0.9%)
Regime/therapy	104 (0.7%)
Event	71 (0.4%)
Physical object	69 (0.4%)
Dead on arrival	68 (0.4%)
Body structure	52 (0.3%)
Discharge status = dead	45 (0.3%)
Substance	20 (0.1%)
Property	17 (0.1%)
Malignant, clinical disorder	15 (0.1%)
Navigational concept	14 (0.1%)
Other SNOMED concepts (<10 ED presentations)	71 (0.4%)
Missing (diagnosis and SNOMED terms)	4,365 (27.6%)
TOTAL	15,787 (100%)

Table 34: Top 20 ICD-10-AM diagnosis codes for 'other grey area'

<i>Other grey area</i>	<i>Number of ED presentations</i>
Dyspnoea	1,848
Pneumonia, unspecified	1,833
Septicaemia, unspecified	1,407
Urinary tract infection, site not specified	1,403
Chest pain, unspecified	1,213
Tendency to fall, not elsewhere classified	1,137
Other and unspecified abdominal pain	1,052
Cardiac arrest, unspecified	936
Anaemia, unspecified	852
Cardiovascular disease, unspecified	778
Unspecified acute lower respiratory infection	745
Syncope and collapse	705
Volume depletion	700
Gastrointestinal haemorrhage, unspecified	676
Disorientation, unspecified	668
Other and unspecified intestinal obstruction	609
Pleural effusion, not elsewhere classified	598
Nausea and vomiting	594
Pneumonitis due to food and vomit	585
Atrial fibrillation and flutter	527
Subtotal	18,866
TOTAL	36,969

Table 35: Top 20 ICD-9-CM ED presentations

<i>Top 20</i>	<i>ICD-9-CM code and description</i>	<i>ED presentations</i>
1	V71.4 Observation and evaluation for suspected conditions not found – observation following other accident	470
2	786.09 Symptoms involving respiratory system and other chest symptoms – dyspnoea and respiratory abnormalities – other	291
3	599.0 Other disorders of urethra and urinary tract – urinary tract infection, site not specified	269
4	789.0 Other symptoms involving abdomen and pelvis – abdominal pain	222
5	428.0 Heart failure – congestive heart failure	206
6	496 Chronic airway obstruction, not elsewhere classified	206
7	786.50 Symptoms involving respiratory system and other chest symptoms – chest pain, unspecified	165
8	519.8 Other diseases of respiratory system – other diseases of respiratory system, not elsewhere classified	140
9	780.2 General symptoms – syncope and collapse	132
10	285.9 Other and unspecified anaemias – anaemia, unspecified	117
11	682.6 Other cellulitis and abscess – leg, except foot	103
12	298.9 Other nonorganic psychoses – unspecified psychosis	102
13	724.5 Other and unspecified disorders of back – backache, unspecified	94
14	719.45 Other and unspecified disorders of joints – pain in joint, pelvic region and thigh	91
15	780.3 General symptoms – convulsions	88
16	486 Pneumonia, organism unspecified	87
17	564.0 Functional digestive disorders, not elsewhere classified – constipation	84
18	482.9 Other bacterial pneumonia – bacterial pneumonia, unspecified	82
19	820.8 Fracture of neck of femur – unspecified part of neck of femur, closed	79
20	578.9 Gastrointestinal haemorrhage – haemorrhage of gastrointestinal tract, unspecified	78
	Subtotal	3,106
	TOTAL	8,031

Table 36: Top 20 ICD-10-AM ED presentations

<i>Top 20</i>	<i>ICD-9-CM code and description</i>	<i>ED presentations</i>
1	Unspecified fall	587
2	Other and unspecified abdominal pain	559
3	Dyspnoea	496
4	Chest pain, unspecified	473
5	Pneumonia, unspecified	419
6	Respiratory disorder, unspecified	419
7	Other specified general symptoms and signs	383
8	Septicaemia, unspecified	351
9	Congestive heart failure	330
10	Nausea and vomiting	327
11	Urinary tract infection, site not specified	318
12	Stroke, not specified as haemorrhage or infarction	299
13	Syncope and collapse	297
14	Disorientation, unspecified	263
15	COPD with acute lower respiratory infection	225
16	Volume depletion	217
17	Fracture of neck of femur, part unspecified	210
18	Anaemia, unspecified	208
19	Follow-up examination after unspecified treatment for other conditions	189
20	Constipation	180
	Subtotal	6,750
	TOTAL	18,691

Table 37: Top 20 SNOMED ED presentations

<i>Top 20</i>	<i>SNOMED term</i>	<i>ED presentations</i>
1	Dyspnoea (finding)	2,376
2	Pneumonia (disorder)	1,685
3	Congestive heart failure (disorder)	1,578
4	Chronic obstructive lung disease (disorder)	1,564
5	Dead on arrival at hospital (finding)	1,374
6	Urinary tract infectious disease (disorder)	1,345
7	Chest pain (finding)	1,280
8	Abdominal pain (finding)	1,272
9	Falls (finding)	1,253
10	Systemic infection (disorder)	1,237
11	Anaemia (disorder)	965
12	Cerebrovascular accident (disorder)	911
13	Dehydration (disorder)	795
14	Cardiac arrest (disorder)	732
15	Fracture of neck of femur (disorder)	694
16	Constipation (disorder)	681
17	Pleural effusion (disorder)	658
18	Cellulitis (disorder)	652
19	Aspiration pneumonia (disorder)	600
20	Backache (finding)	566
	Subtotal	22,218
	TOTAL	73,844

Appendix 4

Codes and Classifications

Table 38: AIHW-specific ICD-10 diagnosis and condition codes

<i>Specific disease</i>	<i>Diagnosis codes (ICD-10-AM)</i>	<i>Source for code specification</i>
COPD	J40–J44	World Health Organization 2008
Dementia and Alzheimer's disease	F00–F03, G30	AIHW 2010d
Heart failure	I50	AIHW 2010d
HIV/AIDS	B20–B24	Becker et al. 2006, WHO 2008
Huntington's disease	G10, F02.2	Begg et al. 2007
Liver failure	K70.4, K71.1, K72	—
Motor neurone disease	G12.2	AIHW 2010d, Begg et al. 2007
Multiple sclerosis	G35	AIHW 2010d, Begg et al. 2007
Muscular dystrophy	G71.0	Begg et al. 2007
Parkinson's disease	G20, G21, G22	AIHW 2010d
Renal failure	N17–N19	AIHW 2010d

Source: *Palliative care services in Australia 2012*, AIHW

AIHW cancer diagnosis codes – approach used to identify separations with a principal diagnosis of cancer

In this report, separations that met one of the following three criteria were considered to have a principal diagnosis of cancer.

- (i) Those with a *principal* diagnosis code of C00–C97, D45, D46, D47.1 or D47.3 from the 'Neoplasms' chapter of ICD-10-AM. Note that some ICD-10-AM 'D' codes are included in this list of invasive neoplasms (that is, cancers) since the related diseases – such as polycythaemia vera (D45) – were not considered to be invasive at the time of the publication of ICD-10 (WHO 1992), but they were reclassified as invasive with the publication of the ICD classification that dealt specifically with neoplasms (WHO 2000).
- (ii) Those with a *principal* diagnosis from Chapter 21 of ICD-10-AM (that is, ICD-10-AM 'Z' codes) that was directly related to receiving health services or treatment for cancer as follows:
 - Observation for suspected malignant neoplasm (Z03.1)
 - Follow-up examination after treatment for malignant neoplasms (Z08)
 - Special screening examination for neoplasm (Z12)
 - Prophylactic surgery (Z40)
 - Radiotherapy session (Z51.0)
 - Pharmacotherapy session for neoplasm (Z51.1)
 - Convalescence following radiotherapy (Z54.1)
 - Convalescence following chemotherapy (Z54.2)
 - Family history of malignant neoplasm (Z80)
 - Personal history of malignant neoplasm (Z85).

(iii) Those with a *principal* diagnosis from Chapter 21 of ICD-10-AM (that is, ICD-10-AM 'Z' codes) that could be related to the receipt of health services or treatment for cancer as follows:

- Prophylactic immunotherapy (Z29.1)
- Other prophylactic chemotherapy (Z29.2)
- Follow-up care involving plastic surgery of head and neck (Z42.0)
- Follow-up care involving plastic surgery of breast (Z42.1)
- Adjustment and management of drug delivery or implanted device (Z45.1)
- Adjustment and management of vascular access device (Z45.2).

and

an *additional* diagnosis code of C00–C97, D45, D46, D47.1 or D47.3 from the 'Neoplasms' chapter of ICD-10-AM.

Source: AIHW & AACR 2010

Table 39: Other relevant diagnosis codes – Inclusions and exclusions		
<i>Underlying diagnosis category</i>	<i>ICD-10-AM principal diagnosis code</i>	<i>Inclusion/exclusion</i>
Certain Infectious and parasitic Diseases	A00-B99	Inclusion
Neoplasm (Cancer)	C00-D48	Inclusion
Blood and Immunity Disorders	D50-D89	Inclusion
Endocrine, nutritional and metabolic diseases	E00-E90	Inclusion
Mental and behaviour disorders	F00-F99	Exclusion
Diseases of the nervous system	G00-G99	Inclusion
Eye conditions	H00-H59	Exclusion
Ear Conditions	H60-H95	Exclusion
Diseases of the circulatory system (heart and blood vessels)	I00-I99	Inclusion
Diseases of the respiratory system	J00-J99	Inclusion
Diseases of the digestive system	K00-K93	Inclusion
Diseases of the skin and subcutaneous tissue	L00-L99	Exclusion
Diseases of the musculoskeletal system and connective tissue	M00-M99	Inclusion
Diseases of the genitourinary system (kidneys, urinary system and genitals)	N00-N99	Inclusion
Pregnancy and childbirth	O00-O59	Exclusion
Conditions originating in the parental period	P00-P96	Exclusion
Congenital and chromosomal abnormalities	Q00-Q99	Exclusion
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	R00-R99	Inclusion
Injuries and poisonings	S00-T98	Exclusion
External Causes	V01-Y98	Exclusion
Factors influencing health status	Z00-Z99 except when Z51.5 is an additional diagnosis	Exclusion
Special purposes (used for SARS outbreak)	U00-U49 and U80-U89	Exclusion

*Source: Centre for Epidemiology and Evidence, NSW Ministry of Health

Appendix 5

Footnotes

- ¹ The fact of death (between 1 July 2011 and 30 June 2012) was linked to the NSW Admitted Patient Data Collection (APDC)/ NSW Emergency Department Data Collection (EDDC) dataset between 1 July 2010 and 30 June 2012 (two financial years) to account for those who died mid-late 2011 and were possibly hospitalised mid-late 2010 (i.e. a year prior to their death).
- ² This will be further articulated in the evaluation plan.
- ³ The extended data was to account for the hospitalisations of those who died in the beginning of July 2011 and could have been hospitalised in the previous financial year (as early as July 2010).
- ⁴ Includes those who came via ED.
- ⁵ Includes those who were admitted.
- ⁶ These specific ICD-10-AM diagnosis codes were used by the AIHW (*AIHW palliative care services report*) as a way of identifying specific conditions/diseases that are more likely to benefit/require palliative and end of life care, including chronic obstructive pulmonary disease, dementia and Alzheimer's disease, heart failure, HIV/AIDS, Huntington's disease, liver failure, motor neurone disease, multiple sclerosis, muscular dystrophy, Parkinson's disease and renal failure.
- ⁷ Emergency status is a variable in the APDC dataset, which is meant to describe whether the admission was emergency, non-emergency/planned or urgency not assigned. For accuracy, linked data between the APDC and EDDC was used to determine how many ED presentations were than admitted to hospital (Chapter 4.3). Admissions with an emergency status were approximately 54% and the proportion of emergency presentations admitted (using linked data) was around 56%. Hence the emergency status variable is quite accurate.
- ⁸ The health of Aboriginal people of NSW, Report of the Chief Health Officer, 2012
- ⁹ The mode of separation also shows the number of presentations that were admitted and the numbers were higher (67% of ED presentations were admitted). However, for the purposes of this analysis, linked data between the APDC and EDDC was analysed to show the actual numbers of ED presentations that were then admitted into the hospital/facility (dates between records were matched).
- ¹⁰ It is important to note that EDs across NSW public facilities use different classification/terminology systems to describe ED presentations. Some facilities still use classifications systems, such as ICD-9-CM and ICD-10-AM, and a majority now use SNOMED-CT (clinical terminology systems). There can be up to two ED diagnosis records for each ED presentation. This is because incoming records can contain a primary and an additional diagnosis code.
- ¹¹ Inpatient and RDBM data could not be linked to community data. It is hoped that the diagnostic undertaken by a private consulting firm will fill the knowledge gap in community service provision.