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Palliative care services in Australia 2013

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Palliative care services in Australia

2013

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Please note that there is the potential for minor revisions of data in this report. Please check the online version at <www.aihw.gov.au> for any amendments.

Contents

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Abbreviations

ABS	Australian Bureau of Statistics
ACFI	Aged Care Funding Instrument
ACT	Australian Capital Territory
AIHW	Australian Institute of Health and Welfare
ALOS	average length of stay
ASGC	Australian Standard Geographical Classification
BEACH	Bettering the Evaluation and Care of Health
DoHA	Australian Government Department of Health and Ageing
DVA	Australian Government Department of Veterans' Affairs
FTE	full-time-equivalent
GP	general practitioner
HITH	hospital-in-the-home
ICD	International Statistical Classification of Diseases and Related Health Problems
ICD-10-AM	International Statistical Classification of Diseases and Related Health Problems, 10th revision, Australian Modification
ICPC	International Classification of Primary Care
IRSAD	Index of Relative Socio-Economic Advantage and Disadvantage
IRSD	Index of Relative Socio-Economic Disadvantage
MBS	Medicare Benefits Schedule
METeOR	Metadata Online Registry
NHMD	National Hospital Morbidity Database
NHWDS	National Health Workforce Data Set
NMDS	National Minimum Data Set
NPHED	National Public Hospital Establishments Database
NSAP	National Standards Assessment Program
NSW	New South Wales
NT	Northern Territory
PBS	Pharmaceutical Benefits Scheme
PCA	Palliative Care Australia
PCOC	Palliative Care Outcomes Collaboration
PCPSS	Palliative Care Problem Severity Score
Qld	Queensland

RPBS	Repatriation Pharmaceutical Benefits Scheme
RUG-ADL	Resource Utilisation Groups—Activities of Daily Living
SA	South Australia
SAS	Symptom Assessment Scale
SEIFA	Socio-Economic Indexes for Areas
Tas	Tasmania
Vic	Victoria
WA	Western Australia

Symbols

—	nil or rounded to zero
. .	not applicable (category/data item does not apply)
n.a.	not available
n.o.s.	not otherwise specified
n.p.	not published because of small numbers, confidentiality or other concerns about the quality of the data

Summary

This report on Australian palliative care services is the second in this series. It provides detailed information on the national response to the palliative care needs of Australians using a range of Australian Institute of Health and Welfare (AIHW) and other national data sources.

Service provision

There were 54,466 palliative care-related separations from public and private hospitals in Australia in 2010–11, with patients aged 75 years and over accounting for nearly half (49.5%) of these. There was a 49% increase in palliative care-related separations between 2001–02 and 2010–11.

In 2010–11, palliative care separations accounted for 0.6% of all separations, but 37.2% of patients who died as an admitted patient had been a palliative care patient during their final separation. Approximately 16,500 palliative care patients died with cancer as a principal diagnosis.

There were just over 221,000 permanent residential aged care residents in 2011–12 with completed Aged Care Funding Instrument (ACFI) assessments; almost 1 in 20 of these residents had an ACFI assessment indicating the need for palliative care during this reporting period.

Resources and outcomes

Nationally, about 9,600 patients received a palliative medicine specialist service subsidised through the Medicare Benefits Schedule (MBS) during 2011–12 for which approximately $3.5 million was paid in benefits. Over the 5 years to 2011–12 benefits paid for all palliative medicine specialist services has more than doubled.

Nationally, more than 19,000 patients had a palliative care–related prescription subsidised through the Pharmaceutical Benefits Scheme (PBS) during 2011–12, which equates to a rate of 85.8 patients per 100,000 population. The medication type laxatives were the most frequently dispensed palliative care-related prescriptions in 2011–12, followed by analgesics and anti-epileptics (37.3%, 22.2% and 14.5%, respectively).

Specialist palliative medicine physicians made up nearly 4 in every 1,000 (0.38%) employed medical specialists in Australia, with an estimated 92 working in Australia in 2011. In 2011, more than half (56.6%) of employed specialist palliative medicine physicians were female. This was more than double the proportion of all employed female medical practitioners who practice other clinical specialities (25.6%).

There were 108 specialist palliative care services that reported to the Palliative Care Outcomes Collaboration in 2012—an increase of 1 service since 2011. More than 30,400 patients accessed specialist palliative care services in 2012, an increase of 11.8% from 2011 (27,201). Just over one-third (36.0%) of services met benchmark 3.2, where 60% of patients in moderate/severe pain at phase start were reduced to absent/mild pain at phase end.

1 Introduction

Palliative care services in Australia 2013 is the latest in the Australian Institute of Health and Welfare's (AIHW's) series of annual palliative care reports. It describes the activity and characteristics of Australia's palliative care services and provides information on a range of palliative care services in Australia in a centralised and accessible form.

The latest year reported for most information in this report is 2011–12, with the exception of chapters 2 and 9, which include 2010–11 data. Where appropriate and possible, time series data are also reported.

1.1 Definition of palliative care

The World Health Organization's definition of palliative care has been adopted by national palliative care data committees and peak representative bodies as the national definition for Australia (see Box 1.1).

Box 1.1: World Health Organization's definition of palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems 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.

Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Source: WHO 2002.

Nonetheless, it is important to note that there are a number of different definitions and terminologies of palliative care that have been applied, both within Australia and internationally. For example, 'hospice', 'end-of-life care' and 'specialist palliative care' have all been used interchangeably with 'palliative care'. Hence, definitions may vary between states and territories as well as within the sector.

1.2 Background on palliative care in Australia

As a distinct academic discipline, palliative care has been recognised in Australia since the 1980s (Tieman et al. 2005). That decade saw the start of a community-led call to recognise the needs of people who were dying and their families, and to provide services to address these needs (DoHA 2005). Today, there is an increasing focus on the amount and quality of palliative care services. With the growth and ageing of Australia's population, and an increase of chronic and generally incurable illnesses, the types of patient groups requiring palliative care has widened (AIHW 2010a).

How is palliative care delivered in Australia?

Palliative care is provided in almost all settings where health care is provided, including neonatal units, paediatric services, acute hospitals, general practices, residential and community aged care services, and generalist community services. Specialist palliative care services operate from a variety of settings, including specialist inpatient consulting services, specialist inpatient settings, hospices and community-based specialist services (DoHA 2010).

The exact model of care provision differs across Australia (DoHA 2005). Each state and territory has articulated an approach to palliative care in its jurisdiction (Australian Government 2012). The states and territories have different approaches to planning and delivering publicly funded services, different local services delivery practices and differently structured health-care systems. They also have varying demographics and remoteness profiles, and varying demands for particular types of services. In recent years, there has been a focus on expanding the practice of specialist palliative care teams to support primary palliative care providers, often through consultative or consortium arrangements (AIHW 2010d).

In addition, a range of health professionals, other workers, carers and volunteers provide palliative care services:

- nurses, including registered and non-registered nurses with and without specialised palliative care qualifications
- medical practitioners, including specialist palliative care physicians, hospital-based specialist palliative care trainees, hospital-based non-specialists and general practitioners (GPs)
- health professionals, including psychologists, physiotherapists, occupational therapists and pharmacists
- other occupations, including personal care assistants, social workers, chaplains, pastoral carers and music therapists
- volunteers
- carers, including both formal and informal carers.

While palliative care can be provided to patients in a variety of settings, a distinction is commonly made between care provided in hospitals (which includes hospices or dedicated palliative care wards) and the community (such as in the patient's home or in residential aged care facilities).

1.3 National policies for palliative care

National Palliative Care Strategy

State and territory governments and the Australian Government have committed to improving the palliative care needs of Australians through the *National Palliative Care Strategy 2010: supporting Australians to live well at the end of life* (the strategy). The strategy was endorsed by Australian Health Ministers in 2010 to promote a coordinated and consistent approach to the delivery of high-quality palliative care across Australia. The strategy acknowledges that responsibility for providing palliative care services ultimately rests with the states and territories, and that each state and territory has an articulated approach to palliative care in its jurisdiction (Australian Government 2012). The strategy aims to enhance and build on the work occurring within jurisdictions.

The strategy outlines a number of priority 'goal areas' and 'measures of success' which aim to meet the identified demand for high-quality palliative care services across Australia. These 'goal areas' encompass building and enhancing the capacity of all relevant sectors to provide quality, appropriate and effective palliative care to all Australians who require it. In addition to the strategy, each state and territory has a range of initiatives in place to improve the delivery of palliative care services.

In October 2012, the Senate Community Affairs References Committee released its report into palliative care in Australia (Australian Government 2012). The committee made 38 recommendations relating to palliative care, including the need for improved access to information about services. Noting the lack of comprehensive palliative care data, the committee's report highlighted the need for consistent data collection practices to become fixed in the clinical environment and for systems to be set up to enable palliative care data to be accurately measured.

The collection, analysis and reporting of palliative care data will assist policy makers, palliative care providers, researchers and the general public to better understand the amount and nature of palliative care activity in the Australian health-care sector. Reliable, accurate and comprehensive data about health-care services can improve the quality of care and lead to better health outcomes through:

- highlighting areas in need of more or different types of services
- highlighting inequalities and inequities in access and outcomes of care
- helping to assess the uptake of guidelines and evidence-based practices and to evaluate the effects these practices have on patient outcomes, as well as other consequences
- helping to detect barriers to and facilitators of the uptake of best-practice patterns of care
- helping to recognise changes in practice and consequent changes in outcomes
- informing evidence-based policy and strategy decisions
- providing practitioners with information and the ability to make appropriate decisions and to provide high-quality care (AIHW 2008).

1.4 Report structure

This report for 2013 follows a similar structure to that of the 2012 report:

- The introductory chapter (Chapter 1) defines palliative care, presents background information on palliative care services in Australia and outlines the major features of the current policy framework and government initiatives in providing palliative care services.
- The main body of the report consists of nine chapters. Chapter 2 presents information on palliative care services provided in hospital, using the Admitted Patient Care National Minimum Data Set (NMDS) held by the AIHW. This is the most developed data collection currently available for reporting on palliative care activity.
- Chapter 3 presents patient demographics, diagnoses and referral information for palliative care-related general practice encounters from the 2011–12 Bettering the Evaluation and Care of Health (BEACH) survey, a national survey of GP activity.
- Attendances by palliative medicine specialists are discussed in Chapter 4. The data source for this chapter is the Medicare Benefits Schedule (MBS), which is administered by Medicare Australia. These data provide information on medical (including diagnostic) services and present an overview of the number and types of services provided by palliative medicine specialists under the MBS, as well as the characteristics of people who received these services.
- Palliative care delivered in residential aged care services is discussed in Chapter 5. The primary data collection used for this chapter is the Aged Care Funding Instrument (ACFI) data, held by the Australian Government Department of Health and Ageing (DoHA).
- Chapter 6 presents information on Pharmaceutical Benefits Scheme (PBS) subsidised prescriptions that are palliative care-specific. The data source for this is the PBS, which is administered by Medicare Australia.
- Chapter 7 provides information on the palliative care workforce derived from the National Health Workforce Data Set (NHWDS), which provides information for specialist palliative medicine physicians.
- Palliative care outcome measures are discussed in Chapter 8. This chapter was developed in conjunction with the Palliative Care Outcomes Collaboration (PCOC) and presents an overview of information on outcomes experienced by patients receiving palliative care.
- Chapter 9 includes information on various palliative care facilities and programs, including hospice care units in public hospitals from the National Public Hospital Establishments Database (NPHED), as well as Community Nursing services for clients of the Australian Government Department of Veteran's Affairs (DVA).
- Supplementary tables provide additional data to the information presented in some chapters.
- The appendixes provide specific codes used to define 'palliative care-related' encounters and separations in particular chapters of this report (Appendix A), information on the data sources used (Appendix B), technical notes on data presentation and calculation of rates (Appendix C), information on the classifications used (Appendix D) and Palliative Care Outcomes Collaboration (PCOC) benchmark revisions (Appendix E).

It should be noted that while the aim of this report is to provide a comprehensive view of the broad range of palliative care-related services provided in Australia, achieving this aim is driven to a large extent by the availability of good-quality comparable national data. Consequently, there are some overlaps and gaps in the information on services provided in this report.

2 Admitted patient palliative care

2.1 Introduction

This chapter presents information on episodes of **admitted patient** palliative care occurring in hospitals using data on **palliative care-related separations** from the National Hospital Morbidity Database (NHMD) for 2010–11 (see Key concepts).

It should be noted that NHMD data for the 2011–12 year were available when this report was prepared. However, delays in receiving data clearance from all jurisdictions within the required time frame precluded use of these data in this report.

The information from the NHMD indicates the number of **separations** for which palliation was a substantial component of the care provided, not the number of people who received such care. Data are not available on the number of separations accrued by an individual, so all the tabulations in this chapter are in terms of separation events, not patients. Time series data for the period 2001–02 through to 2010–11 have been presented to show the changes in separations for palliative care over this period. Wherever possible, corresponding data on all separations have been provided for comparison purposes.

Admitted patient palliative care may be provided in a hospice, in a dedicated palliative care ward or other wards within a hospital, and is often where palliative care patients receive care (Willard & Luker 2006). A range of complex factors contribute to this, such as patient and carer preference, rapid and sometimes unexpected deterioration, availability of carers and other health-care services, or the inability to manage at home when there is no access to admitted patient care (Glare et al. 2003). In addition, some terminal conditions may require a level of palliative care that hospitals are best equipped to provide. Consequently, a substantial proportion of palliative care in Australia is provided within the admitted patient setting (PCOC 2010).

This chapter discusses the following five key topics using 2010–11 data:

- the number of admitted patient palliative care-related separations
- the demographic and clinical characteristics of patients who received palliative care
- the nature of the palliative care service, including what care was provided and the main funding source
- change over time in the number of admitted patient palliative care-related separations and the **average length of stay** in hospital
- the proportion of people who died while in admitted patient care who were palliative care patients.

In this chapter, a palliative care-related separation is defined as an episode of admitted patient care for which the principal clinical intent was palliation during all or part of that episode. There are two NHMD data items—'**Care type**' and 'Diagnosis'—used to capture information on palliative care, such that if either (or both) has a code of 'palliative care', that separation is included as being in scope (see Appendix A for further information). It is important to note that this means that, although there may also be other separations within the NHMD that include palliative care services, these separations are not counted, as palliative care is not recorded as the main care type and/or diagnosis during that separation.

Key concepts

Information on admitted patients is compiled when a patient (a person who undergoes a hospital's formal admission process) completes an episode of admitted patient care and 'separates' from the hospital. This is because most of the data on the use of hospitals by admitted patients are based on information provided at the end of the patients' episodes of care, rather than at the beginning. The length of stay and the procedures carried out are then known and the diagnostic information is more accurate.

- **Separation** refers to the episode of admitted patient care, which can be a total hospital stay (from admission to discharge, transfer or death) or a portion of a hospital stay (beginning or ending in a change of type of care; for example, from acute care to rehabilitation). 'Separation' also means the process by which an admitted patient completes an episode of care by being discharged, dying, transferring to another hospital or changing type of care.
- **Care type** refers to the overall nature of a clinical service provided to an admitted patient during an episode of care. Examples of care types are Acute care, Rehabilitation care, Palliative care and Geriatric evaluation and management.
- **Palliative care-related separations** are defined, for the purposes of this report, as those separations for which palliative care was a substantial component of the care provided. Such separations were identified as those for which the principal clinical intent of the care was palliation during part or all of the separation, as evidenced by a code of Palliative care for the 'Care type' and/or 'Diagnosis' data items in the NHMD.
- **Admitted patients** are patients who undergo a hospital's formal admission process to receive treatment and/or care.
- The **principal diagnosis** is the diagnosis established after study to be chiefly responsible for occasioning the patient's episode of admitted patient care. An additional diagnosis is a condition or complaint that either coexists with the principal diagnosis or arises during the episode of care.
- **Additional diagnosis** refers to conditions or complaints either coexisting with the principal diagnosis or arising during the episode of care.
- **Patient day** means the occupancy of a hospital bed (or chair in the case of some same-day patients) by an admitted patient for all or part of a day. The **length of stay** for an overnight patient is calculated by subtracting the date the patient is admitted from the date of separation and deducting any days the patient was 'on leave'.
- **Average length of stay** refers to the average number of patient days for admitted patient episodes. Patients admitted and separated on the same day are allocated a length of stay of 1 day.

2.2 Admitted patient palliative care in 2010–11

In 2010–11, there were 54,466 palliative care-related separations reported from public and private hospitals in Australia, accounting for fewer than 1 in 100 (0.6%) of all hospital separations (8,852,550) (Table 2.1). There was a higher proportion of palliative care-related separations for males than females (54.1% and 45.9%, respectively) and the age-standardised rate was also higher for males than females (26.8 and 18.5 per 10,000 population, respectively).

Table 2.1: Palliative care-related separations by sex and all separations, public and private hospitals, 2010–11

	Palliative care-related separations			Separations for all reasons
	Males	Females	Total	
Number	29,446	25,020	54,466	8,852,550
Per cent of palliative care-related separations	54.1	45.9	100.0	. .
Per cent of all separations for all reasons	0.3	0.3	0.6	100.0
Age-standardised rate[(a)]	26.8	18.5	22.1	3,809.4

(a) The rates were age-standardised to the Australian population as at 30 June 2001 and are expressed per 10,000 population (Appendix C).

Source: NHMD, AIHW.

The proportion of palliative care-related separations is higher at older ages, with only about 1 in 10 (11.0%) of the total number of palliative care-related separations being for patients aged under 55 (Table 2.2). People aged 75 and over accounted for nearly half (49.5%) of all palliative care-related separations; the average age of these patients was 72.1, with little gender difference observed. Unsurprisingly, this is older than the average age of 53.8 for all separations.

Although there were more palliative care-related separations for males overall, there were more separations for females for all those aged between 25 and 54. For all those aged 85 and over, there were 20.1% more separations for females than males.

Table 2.2: Palliative care-related separations by age and sex, all separations, public and private hospitals, 2010–11

	Palliative care-related separations						Separations for all reasons
	Number			Per cent			
Age group (years)	Males	Females	Total	Males	Females	Total	Per cent
0–14	80	81	161	0.3	0.3	0.3	6.6
15–24	103	90	193	0.3	0.4	0.4	6.4
25–34	176	201	377	0.6	0.8	0.7	9.4
35–44	621	787	1,408	2.1	3.1	2.6	10.5
45–54	1,915	2,073	3,988	6.5	8.3	7.3	12.5
55–64	4,902	3,895	8,797	16.6	15.6	16.2	16.4
65–74	7,409	5,159	12,568	25.2	20.6	23.1	17.1
75–84	9,395	6,917	16,312	31.9	27.6	29.9	14.9
85+	4,845	5,817	10,662	16.5	23.2	19.6	6.2
Total	**29,446**	**25,020**	**54,466**	**100.0**	**100.0**	**100.0**	**100.0**
Average age	71.9	72.3	72.1	. .	. .	. .	53.8

Note: Total may not add due to rounding.

Source: NHMD, AIHW.

2.3 Profile of palliative care-related separations in 2010–11

Where was palliative care provided?

Public versus private hospitals

In 2010–11, there were more palliative care-related separations recorded from public hospitals (83.9% or 45,713 separations) than from private hospitals, showing proportional over-representation of palliative care in public hospitals, in which 59.6% of all separations occur (Table 2.3). The highest proportion in public hospitals was seen in New South Wales (91.2%) and Victoria (90.3%); in Western Australia, the majority of palliative care-related separations occurred in private hospitals (65.2%). It should be noted that the differences across jurisdictions are likely to be due to a range of factors, including differences in the characteristics of the population, health-care systems and service delivery practices.

The Northern Territory reported the highest age-standardised rate at 58.5 palliative care-related separations per 10,000 population for public hospitals, more than double the next highest rate of 25.7 in Victoria. However, the total number of palliative care-related separations was comparatively small in the Northern Territory. Western Australia had the lowest age-standardised rate within public hospitals, at 5.4 palliative care-related separations per 10,000 population.

For the five jurisdictions able to report on private hospitals, Western Australia reported the highest rate (10.0 per 10,000 population) for palliative care-related separations which was more than five and a half times higher than the rate for New South Wales (1.8).

Table 2.3: Palliative care-related separations by state and territory, and all separations, public and private hospitals, 2010–11

	Palliative care-related separations									Separations for all reasons
	NSW	Vic	Qld	WA	SA	Tas[(a)]	ACT[(a)]	NT[(a)]	Total[(a)]	
Public hospitals										
Number	15,433	16,047	6,599	1,234	3,499	1,388	743	770	45,713	5,279,132
Per cent	91.2	90.3	79.4	34.8	78.7	n.p.	n.p.	n.p.	83.9	59.6
Rate[(b)]	18.6	25.7	14.4	5.4	17.1	22.0	23.2	58.5	18.6	2,285.0
Private hospitals										
Number	1,496	1,733	1,715	2,317	945	n.p.	n.p.	n.p.	8,753	3,573,418
Per cent	8.8	9.7	20.6	65.2	21.3	n.p.	n.p.	n.p.	16.1	40.4
Rate[(b)]	1.8	2.7	3.7	10.0	4.5	n.p.	n.p.	n.p.	3.5	1,524.4
All hospitals										
Number	16,929	17,780	8,314	3,551	4,444	n.p.	n.p.	n.p.	54,466	8,852,550
Per cent	100.0	100.0	100.0	100.0	100.0	n.p.	n.p.	n.p.	100.0	100.0
Rate[(b)]	20.4	28.4	18.1	15.4	21.6	n.p.	n.p.	n.p.	22.1	3,809.4

(a) To ensure confidentiality of information, data for private hospitals in Tasmania, the Australian Capital Territory and the Northern Territory are not shown. 'Total' includes data for all jurisdictions.

(b) The rates were age-standardised to the Australian population as at 30 June 2001 and are expressed per 10,000 population (see Appendix C).

Source: NHMD, AIHW.

How long did patients stay?

In 2010–11, almost all (93.8%) palliative care-related separations involved at least one overnight stay, compared with 42.2% for all separations (AIHW 2012a). Palliative care-related separations accounted for more than 653,000 **patient days**, with an average length of stay (ALOS) of 12.0 days (Table 2.4)—four times as long as the ALOS of 3.0 days for all separations. When only those separations that involved an overnight stay are considered, the difference narrows somewhat to 12.7 days for palliative care-related separations and 5.8 days for all separations (AIHW 2012a).

The ALOS per palliative care-related separation was 11.6 days for males and 12.4 days for females.

Table 2.4: Palliative care-related separations, all separations, by sex, patient days and ALOS, public and private hospitals, 2010–11

	Palliative care-related separations						Separations for all reasons
	Same-day[(a)]	Overnight[(b)]		Total			
Sex	Patient days	Patient days	ALOS (days)	Patient days	ALOS (days)	Per cent of overnight separations	ALOS (days)
Males	1,851	340,623	12.3	342,474	11.6	93.7	3.0
Females	1,553	309,553	13.2	311,106	12.4	93.8	3.1
Total	**3,404**	**650,176**	**12.7**	**653,580**	**12.0**	**93.8**	**3.0**

(a) By definition, the ALOS for same-day separations equals 1 day.

(b) Overnight separations are those in which the patient was admitted and discharged on a different day, and thus the separations involved at least one overnight stay.

Source: NHMD, AIHW.

There was little difference observed in the ALOS between public and private hospitals for all jurisdictions except Queensland, the Australian Capital Territory and the Northern Territory (Table 2.5). The ALOS in Queensland was noticeably longer in private hospitals than in public hospitals (15.7 and 8.6 days, respectively). The ALOS in public hospitals for overnight separations was highest in South Australia (15.9 days), while, in private hospitals, Queensland recorded the highest ALOS at 16.0 days.

Table 2.5: Palliative care-related separations, by state and territory, ALOS, public and private hospitals, 2010–11

	ALOS (days)								
	NSW	Vic	Qld	WA	SA	Tas[(a)]	ACT[(a)]	NT[(a)]	Total[(a)]
Public hospitals									
Overnight separations	12.8	12.7	9.2	11.6	15.9	14.3	12.7	13.5	12.5
Total separations[(b)]	*11.7*	*12.4*	*8.6*	*10.8*	*15.4*	*14.0*	*12.2*	*12.6*	*11.8*
Private hospitals									
Overnight separations	13.4	13.2	16.0	11.4	14.5	n.p.	n.p.	n.p.	13.7
Total separations[(b)]	*13.3*	*13.0*	*15.7*	*9.5*	*13.6*	n.p.	n.p.	n.p.	*12.9*
All hospitals									
Overnight separations	12.9	12.8	10.7	11.5	15.6	n.p.	n.p.	n.p.	12.7
Total separations[(b)]	**11.8**	**12.4**	**10.1**	**9.9**	**15.0**	**n.p.**	**n.p.**	**n.p.**	**12.0**

(a) To ensure confidentiality of information, data for private hospitals in Tasmania, the Australian Capital Territory and the Northern Territory are not shown. 'Total separations' includes data for all jurisdictions.

(b) 'Total separations' include same-day and overnight separations. By definition, the ALOS for same-day separations equals 1 day.

Source: NHMD, AIHW.

Who paid for the care?

Data on the principal source of funding for a separation are also recorded in the NHMD. In 2010–11, the highest proportion of funding attributed to public hospitals for all palliative care-related separations was for *Public patients* at 77.3%; the next most frequently recorded funding source was *Private health insurance* (15.6%) (Table 2.6). In comparison, for all separations in public hospitals, the proportion of funding attributed to *Public patients* was higher at 85.1%, with *Private health insurance* and the *Australian Government Department of Veterans' Affairs* contributing 10.0% and 2.2%, respectively. In private hospitals, *Private health insurance* was the main funding source for all palliative care-related separations (58.3%).

Table 2.6: Palliative care-related separations, all separations, by principal source of funds, states and territories, public and private hospitals, 2010–11

Principal source of funds	NSW	Vic	Qld	WA	SA	Tas[(a)(b)]	ACT[(a)]	NT[(a)]	Total[(a)]	Separations for all reasons (per cent)
	Palliative care-related separations (per cent)									
Public hospitals										
Public patients[(c)]	66.4	79.6	90.4	88.7	83.1	79.4	69.2	98.3	77.3	85.1
Private health insurance	23.3	14.6	5.5	4.9	12.3	13.8	21.1	0.1	15.6	10.0
DVA	6.9	5.3	3.9	5.8	4.6	6.0	9.3	1.2	5.6	2.2
Other[(d)]	3.3	0.6	0.2	0.5	0.1	0.5	0.4	0.4	1.4	2.7
Total[(e)]	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**
Private hospitals										
Public patients[(c)]	11.6	0.4	35.0	55.9	6.7	n.p.	n.p.	n.p.	24.4	2.9
Private health insurance	70.6	79.7	47.9	34.8	77.8	n.p.	n.p.	n.p.	58.3	80.3
Department of Veterans' Affairs	14.0	11.3	10.9	9.1	9.8	n.p.	n.p.	n.p.	11.4	5.5
Other[(d)]	3.8	8.7	3.1	0.1	5.7	n.p.	n.p.	n.p.	4.7	11.3
Total[(e)]	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**n.p.**	**n.p.**	**n.p.**	**100.0**	**100.0**

(a) To ensure confidentiality of information, data for private hospitals in Tasmania, the Australian Capital Territory and the Northern Territory are not shown. 'Total' includes data for all jurisdictions.

(b) Tasmania was unable to identify all patients whose funding source may have been Self-funded (a funding source that is included in the 'Other' category in this table). Therefore, the number of separations in the 'Other' category may be underestimated while the number in the other categories may be overestimated.

(c) The 'Public patients' category includes separations with a funding source of National Healthcare Agreement, Reciprocal health-care agreements, Other hospital or public authority (with a public patient election status) and No charge raised (in public hospitals).

(d) 'Other' includes separations with a funding source of Self-funded, Workers compensation, Motor vehicle third party personal claim, Other compensation (for example, public liability, common law, medical negligence), Department of Defence, Correctional facility, Other hospital or public authority (without a public patient election status), Other and No charge raised (in private hospitals).

(e) 'Total' includes those separations for which the principal source of funds was not reported.

Source: NHMD, AIHW.

The funding pattern for public hospitals differed among jurisdictions. For *Public patients*, this ranged from 66.4% in New South Wales to 98.3% in the Northern Territory (Table 2.6). For private hospitals with funding patterns for *Public patients,* this ranged from 55.9% in Western Australia to 0.4% in Victoria. Furthermore, compared with all separations, palliative care-related separations in private hospitals were more likely to be funded by *Public patients* (24.4%)—compared with 2.9% for all separations—and less likely to be funded by *Private health insurance*—58.3% compared with 80.3%.

How was the care completed?

The 'mode of completing a separation' provides information on the status of a patient at the end of the separation; for example, whether the person died, and, if not, their destination after discharge from hospital. A *statistical discharge* is one type of separation that can be assigned to those patients for whom the intent of the care changed during their stay within a hospital. The *Other* option includes those who were discharged to their own accommodation, their usual residence (which could be a residential aged care service), or a welfare institution (such as a prison, hostel or group home providing primarily welfare services).

More than half of all palliative care-related separations ended with the patient's death (51.2%) compared with about 1 in 100 (0.8%) for all separations (Table 2.7). The manner in which palliative care-related separations ended across both public and private hospitals was similar. However, jurisdictional differences were evident within and across sectors. For states or territories that were able to be reported on, the proportion of palliative care-related separations ending with the patient's death was lowest in public hospitals in the Northern Territory (31.6%) and highest in the Australian Capital Territory (63.5%) and Western Australia (62.8%). For private hospitals, Queensland reported the highest percentage of separations ending with the patient's death (71.3%), which was higher than the national average for the sector (55.3%). Private palliative care patients were more likely to be transferred to another hospital in Western Australia compared with other jurisdictions.

Table 2.7: Palliative care-related separations and all separations, by mode of completing separation, states and territories, public and private hospitals, 2010–11

	Palliative care-related separations (per cent)									Separations for all reasons (per cent)
Mode of completing separation	**NSW**	**Vic**	**Qld**	**WA**	**SA**	**Tas(a)**	**ACT(a)**	**NT(a)**	**Total(a)**	
Public hospitals										
Discharge or transfer to:										
• an(other) acute hospital	6.9	11.9	6.2	7.1	6.5	7.3	3.2	3.9	8.4	6.0
• a residential aged care service(b)	4.1	4.1	2.3	5.4	6.3	3.2	1.5	1.4	4.0	1.1
• other health-care accommodation(c)	1.7	0.5	1.7	0.2	0.3	0.8	8.3	1.4	1.2	0.3
Statistical discharge (incl. from leave)(d)	4.0	3.5	8.3	2.6	5.8	9.8	3.4	15.7	4.9	1.7
Left against medical advice	0.3	0.3	0.2	0.2	0.3	0.1	0.0	4.5	0.3	0.8
Died	49.7	51.8	52.2	62.8	42.9	44.2	63.5	31.6	50.4	1.2
Other(e)	33.2	27.9	29.1	21.7	37.9	34.7	20.1	41.4	30.8	88.8
Total(f)(g)	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*
Private hospitals										
Discharge or transfer to:										
• an(other) acute hospital	6.2	11.3	1.7	16.5	5.1	n.p.	n.p.	n.p.	8.6	1.6
• a residential aged care service(b)	2.5	3.5	2.3	2.4	5.0	n.p.	n.p.	n.p.	3.1	0.2
• other health-care accommodation(c)	0.6	0.0	0.8	0.1	1.6	n.p.	n.p.	n.p.	0.7	0.3
Statistical discharge (incl. from leave)(d)	0.9	0.3	2.2	1.2	0.0	n.p.	n.p.	n.p.	1.1	0.5
Left against medical advice	0.0	1.0	0.0	0.1	0.0	n.p.	n.p.	n.p.	0.2	0.1
Died	48.8	54.0	71.3	51.2	49.5	n.p.	n.p.	n.p.	55.3	0.4
Other(e)	41.0	30.0	21.7	28.4	38.8	n.p.	n.p.	n.p.	31.0	97.0
Total(f)(g)	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*	*n.p.*	*n.p.*	*n.p.*	*100.0*	*100.0*

(continued)

Table 2.7 (continued): Palliative care-related separations and all separations, by mode of completing separation, states and territories, public and private hospitals, 2010–11

Mode of completing separation	Palliative care separations (per cent)									Separations for all reasons (per cent)
	NSW	Vic	Qld	WA	SA	Tas[(a)]	ACT[(a)]	NT[(a)]	Total[(a)]	
All hospitals										
Discharge or transfer to:										
• an(other) acute hospital	6.9	11.9	5.3	13.3	6.2	n.p.	n.p.	n.p.	8.5	4.2
• a residential aged care service[(b)]	4.0	4.1	2.3	3.4	6.0	n.p.	n.p.	n.p.	3.8	0.8
• other health-care accommodation[(c)]	1.6	0.5	1.5	0.1	0.6	n.p.	n.p.	n.p.	1.1	0.3
Statistical discharge (incl. from leave)[(d)]	3.7	3.2	7.0	1.7	4.6	n.p.	n.p.	n.p.	4.3	1.2
Left against medical advice	0.3	0.3	0.2	0.1	0.2	n.p.	n.p.	n.p.	0.3	0.5
Died	49.6	52.0	56.1	55.3	44.3	n.p.	n.p.	n.p.	51.2	0.8
Other[(e)]	33.9	28.1	27.6	26.1	38.1	n.p.	n.p.	n.p.	30.8	92.1
Total[(f)(g)]	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**n.p.**	**n.p.**	**n.p.**	**100.0**	**100.0**

(a) To ensure confidentiality of information, data for private hospitals in Tasmania, the Australian Capital Territory and the Northern Territory are not shown. 'Total' includes data for all jurisdictions.

(b) Excluding those for whom a residential aged care service was the usual place of residence.

(c) Includes psychiatric hospitals and mothercraft hospitals.

(d) A statistical discharge refers to an administrative process that completes an admitted patient episode of care when there is a change in the clinical intent of treatment (for example, from acute care to palliative care). For each statistical discharge, there should be a corresponding statistical admission—that is, a new episode of care with a different care type created.

(e) Includes discharge to own accommodation, usual residence or a welfare institution (such as a prison, hostel or group home providing primarily welfare services).

(f) Includes those separations for which the mode of completing the separation was not reported.

(g) Total may not add due to rounding.

Source: NHMD, AIHW.

2.4 Characteristics of admitted palliative care patients

The following section presents information on the number and proportion of palliative care-related separations for various demographic groups. Age-standardised rates are reported to adjust for relative population sizes and age structures.

Indigenous status

Aboriginal and Torres Strait Islander people are disadvantaged relative to other Australians across a range of health-related and socioeconomic indicators (AIHW 2011c) and this may affect their use of, and access to, admitted patient palliative care.

There was a total of 831 palliative care-related separations for Indigenous Australians reported in 2010–11, with the majority (95.8%) occurring in public hospitals (Table 2.8). There were more separations for Indigenous males than females, similar to what is observed for Other Australians. The number of palliative care-related separations in public hospitals per 10,000 population is about one and a half times as high for Indigenous Australians as for Other Australians (36.2 and 18.6, respectively). This pattern is also seen for all public hospital separations. However, it is reversed for private hospitals, where the number of palliative care-related separations per 10,000 population is noticeably as high for Other Australians as for Indigenous Australians (3.5 and 1.6, respectively); this is also the case for all private hospitals separations (1,534.6 and 919.6, respectively).

Table 2.8: Palliative care-related separations, by Indigenous status, selected states and territories[(a)], public and private hospitals, 2010–11

	Palliative care-related separations					Separations for all reasons	
	Number						
	Male	Female	Total	Per cent	Rate[(b)]	Per cent	Rate[(b)]
Public hospitals							
Indigenous Australians	402	394	796	1.5	36.2	5.8	8,359.4
Other Australians[(c)]	23,248	19,538	42,786	82.6	18.6	94.2	2,172.6
Private hospitals							
Indigenous Australians	17	18	35	0.1	1.6	0.8	919.6
Other Australians[(c)]	4,325	3,846	8,171	15.8	3.5	99.2	1,534.6
Total	**27,992**	**23,796**	**51,788**	**100.0**	**22.4**	**100.0**	**3,794.7**

(a) Only Indigenous status data for New South Wales, Victoria, Queensland, Western Australia, South Australia and public hospitals in the Northern Territory have been included in this table as they are the only jurisdictions for which the data are considered to be of sufficient quality for reporting. However, caution should be used in interpreting these data due to differences in data quality between jurisdictions. The data do not necessarily represent the national trend (see Appendix C).

(b) The rates were age-standardised to the Australian population as at 30 June 2001 and are expressed per 10,000 population (see Appendix C).

(c) 'Other Australians' includes separations for non-Indigenous Australians and those for whom the Indigenous status was not reported.

Source: NHMD, AIHW.

Remoteness of patient's usual residence

Most palliative care-related separations in 2010–11 across both public and private hospital sectors were for patients whose usual residence was in *Major cities* (65.4%) (Table 2.9). Of all palliative care episodes, the more remote the patients' usual residence, the lower the proportion of palliative care-related separations reported. However, the age-standardised rate for *Major cities* public hospital separations was 18.4 per 10,000 population, which was lower than the rate for *Remote or very remote* (23.4).

A similar pattern emerged for all separations in private hospitals, where the rate per 10,000 population was highest for *Major cities* (1,703.8) and lowest for *Remote or very remote* areas (820.4).

Males accounted for a greater proportion of the palliative care-related separations than females in all remoteness categories.

Table 2.9: Palliative care-related separations, by remoteness area of patient's usual residence, public and private hospitals, 2010–11

	Palliative care-related separations					Separations for all reasons	
	Number						
Remoteness area[a]	**Male**	**Female**	**Total**	**Per cent**	**Rate**[b]	**Per cent**	**Rate**[b]
Public hospitals							
Major cities	15,795	14,057	29,852	54.8	18.4	37.2	2,111.9
Inner regional	5,585	4,388	9,973	18.3	18.4	13.1	2,497.1
Outer regional	2,823	2,050	4,873	8.9	20.9	6.8	2,819.2
Remote or very remote	580	357	937	1.7	23.4	2.2	4,005.2
Not reported	42	36	78	0.1	. .	0.4	. .
Total	*24,825*	*20,888*	*45,713*	*83.9*	. .	*59.6*	. .
Private hospitals							
Major cities	2,946	2,825	5,771	10.6	3.5	30.2	1,703.8
Inner regional	1,392	1,088	2,480	4.6	4.6	7.1	1,289.1
Outer regional	245	194	439	0.8	1.9	2.5	997.7
Remote or very remote	26	21	47	0.1	1.2	0.4	820.4
Not reported	12	4	16	0.0	. .	0.1	. .
Total	*4,621*	*4,132*	*8,753*	*16.1*	. .	*40.4*	. .
Total[c]	**29,446**	**25,020**	**54,466**	**100.0**	**22.4**	**100.0**	**3,840.7**

(a) Remoteness area was measured using the Australian Bureau of Statistics (ABS) Australian Standard Geographical Classification Remoteness Areas (see Appendix D).

(b) The rates were age-standardised to the Australian population as at 30 June 2001 and are expressed per 10,000 population (see Appendix C).

(c) Total may not add due to rounding.

Source: NHMD, AIHW.

Socioeconomic status

Socioeconomic status is generally associated with access to material resources, educational opportunities and health status (AIHW 2010a). In this report, the Index of Relative Socio-Economic Disadvantage (IRSD) was used to indicate socioeconomic status (see Box 2.1 for further information).

Box 2.1: Index of Relative Socio-Economic Disadvantage

The IRSD is one of four Socio-Economic Indexes for Areas (SEIFA) developed by the ABS (ABS 2008). It is based on factors such as average household income, education levels, unemployment rates, occupation and housing characteristics. Note that the IRSD, like the other SEIFA indexes, is an area-based measure of socioeconomic status—not a person-based measure—in which small areas of Australia are classified on a continuum from disadvantaged to affluent. This information is used as a proxy for the socioeconomic status of people living in those areas and may not be correct for each person living in that area. In this report, the first socioeconomic status group (labelled '1') corresponds to geographical areas containing the 20% of the population with the lowest socioeconomic status according to the IRSD, and the fifth group corresponds to the 20% of the population with the highest socioeconomic status (see Appendix D for more information).

In 2010–11, people living in areas classified as having the lowest socioeconomic status (group 1) accounted for a relatively higher proportion of palliative care-related separations (22.5%) in public hospitals than those living in other areas (each group of which was 18% or less) (Table 2.10). The rate of palliative care-related separations was also highest for those living in these areas (24.0 per 10,000 population). Conversely, the rate of palliative care-related separations was lowest for those living in the highest socioeconomic status areas (13.9), with this pattern being seen for all separations.

A different pattern emerged for palliative care-related separations in private hospitals, where, as expected, the rate was highest for those living in the highest socioeconomic status (group 5) (5.1 per 10,000 population). This pattern was also seen for all separations for this group (2,204.9 per 10,000 population).

There were more separations for males than females in nearly all socioeconomic status areas, with those in the higher socioeconomic status areas showing the least difference between the sexes in the total number of separations.

Table 2.10: Palliative care-related separations, by socioeconomic status, public and private hospitals, 2010–11

Socioeconomic status[(a)]	Palliative care-related separations					Separations for all reasons	
	Number						
	Male	Female	Total	Per cent	Rate[(b)]	Per cent	Rate[(b)]
Public hospitals							
1 (Lowest)	6,744	5,526	12,270	22.5	24.0	15.5	2,930.0
2	5,379	4,334	9,713	17.8	18.2	13.6	2,508.5
3	4,868	3,899	8,767	16.1	18.5	12.5	2,409.3
4	4,382	3,835	8,217	15.1	18.3	10.1	2,002.6
5 (Highest)	3,409	3,257	6,666	12.2	13.9	7.6	1,467.7
Not reported	43	37	80	0.1	. .	0.4	. .
Private hospitals							
1 (Lowest)	611	557	1,168	2.1	2.3	5.3	986.7
2	691	594	1,285	2.4	2.4	6.9	1,239.5
3	1,211	938	2,149	3.9	4.5	7.8	1,494.3
4	842	771	1,613	3.0	3.6	8.7	1,707.4
5 (Highest)	1,254	1,268	2,522	4.6	5.1	11.6	2,204.9
Not reported	12	4	16	0.0	. .	0.1	. .
Total	**29,446**	**25,020**	**54,466**	**100.0**	**22.2**	**100.0**	**3,840.5**

(a) Socioeconomic status was measured using the ABS SEIFA IRSD (see Appendix D).

(b) The rates were age-standardised to the Australian population as at 30 June 2001 and are expressed per 10,000 population (see Appendix C).

Source: NHMD, AIHW.

2.5 What was the diagnosis?

Diseases based on diagnosis

The **principal diagnosis** is 'the diagnosis established after study to be chiefly responsible for occasioning an episode of admitted patient care' (AIHW 2012b; NCCH 2010). **Additional diagnoses** are 'conditions or complaints either coexisting with the principal diagnosis or arising during the episode of admitted patient care', and one or more additional diagnoses can be assigned to the care episode (AIHW 2012a; NCCH 2010). In addition to showing the most frequently recorded cancer types, information on nine other diseases considered to be amenable to palliative care (DoHA 2010; McNamara et al. 2006) is also shown (Table 2.11).

Cancer was the most frequently recorded principal diagnosis for palliative care-related separations in 2010–11 (58.1%) and, of these, secondary site cancer (that is, a malignant tumour originating from a cancer elsewhere in the body) was assigned to 1 in 7 (14.9%) of these separations.

Considering additional diagnoses, the proportion of cancer diagnoses increases to three-quarters (74.2%) of palliative care-related separations, with more than half of these separations (53.4%) having secondary site cancer recorded as a diagnosis. These findings mirror those from other research, which has consistently found that cancer patients comprise the majority of those using palliative care services (Currow et al. 2008).

Table 2.11: Palliative care-related separations, by selected diseases, public and private hospitals, 2010–11

	Principal diagnosis only		Principal and additional diagnoses[c]	
Disease[a] (ICD-10-AM codes)	**Number**	**Per cent[b]**	**Number**	**Per cent[b]**
Cancer[a]				
Secondary site (C77–C79)	8,107	14.9	29,066	53.4
Lung (C33–C34)	5,080	9.3	8,127	14.9
Bowel (C18–C20)	2,534	4.7	4,698	8.6
Pancreas (C25)	1,596	2.9	2,278	4.2
Prostate (C61)	1,515	2.8	3,389	6.2
Breast (C50)	1,253	2.3	2,993	5.5
Brain (C71)	1,216	2.2	1,467	2.7
Stomach (C16)	872	1.6	1,371	2.5
Liver (C22)	776	1.4	1,153	2.2
Oesophagus (C15)	777	1.4	1,179	2.2
Non-Hodgkin lymphoma (C82–C85)	663	1.2	985	1.8
Bladder (C67)	546	1.0	1,015	1.2
Ovary (C56)	537	1.0	1,084	2.0
Kidney (C64)	527	1.0	1,018	1.9
Mesothelioma (C45)	500	0.9	633	1.2
Myeloma (C90)	456	0.8	724	1.3
Acute myeloid leukaemia	434	0.8	594	1.1
(C92.0, C92.3–92.5, C93.0 C94.0, C94.2, C94.4, C94.5)				
All cancers (C00–C97, D45, D46, D47.1, D47.3, selected Z codes)	*31,603*	*58.1*	*40,428*	*74.2*
Diseases other than cancer[a]				
Heart failure (I50)	1,481	2.7	4,698	8.6
Chronic obstructive pulmonary disease (J40–J44)	1,305	2.4	3,595	6.6
Renal failure (N17–N19)	1,006	1.9	7,080	13.0
Motor neurone disease (G12.2)	471	0.9	589	1.1
Liver failure (K70.4, K71.1, K72)	364	0.7	1,206	2.2
Dementia and Alzheimer disease (F00 to F03, G30)	218	0.4	2,552	4.7
Parkinson disease (G20, G21, G22)	50	0.1	430	0.8
HIV/AIDS (B20–B24)	15	0.0	79	0.1
Huntington disease (G10, F02.2)	7	0.0	18	0.0

(a) Data on the most common cancer types recorded for palliative care separations are shown, as are data on selected other diseases. See Appendix C for details on the approach used to present disease-related information.

(b) The per cent is based on the total number of palliative care separations (that is, 54,466).

(c) When both principal and additional diagnoses are considered, the sum of the separations may exceed the total number of palliative care separations since patients may have had more than one diagnosis recorded during any one separation.

Source: NHMD, AIHW.

For diseases other than cancer, the next two most frequently reported principal diagnoses were heart failure and chronic obstructive pulmonary disease (2.7% and 2.4% of palliative care separations, respectively). As seen with cancer, renal failure was found to be relevant to more than six times as many palliative care-related separations when both the principal and additional diagnoses were considered, compared with when only the principal diagnosis was examined.

In terms of the specified non-cancer diseases, a principal or an additional diagnosis of renal failure was reported for more than 1 in 10 (13.0%) of the palliative care-related separations, followed by heart failure (8.6%) and chronic obstructive pulmonary disease (6.6%).

2.6 Change over time in the amount of activity

In 2001–02, there were almost 37,000 palliative care-related separations; by 2010–11, this number increased by 49% to almost 54,500 (Table 2.12). In comparison, the number of all separations increased by 38% over the same period. Between 2001–02 and 2009–10, there was a steady increase in the number of palliative care-related separations but, in 2010–11, there was a 2.7 per cent decrease in the number from the previous year.

Table 2.12: Palliative care separations and all separations, public and private hospitals, 2001–02 to 2010–11

	Palliative care separations				Separations for all reasons	
Year	**Number of separations**	**Per cent change from previous year**	**Rate(a)**	**Per cent of all separations**	**Number of separations**	**Per cent change from previous year**
2001–02	36,667	–0.8	18.7	0.57	6,398,171	4.0
2002–03	37,996	3.6	18.9	0.57	6,644,984	3.9
2003–04	40,435	6.4	19.7	0.59	6,841,225	3.0
2004–05	42,622	5.4	20.2	0.61	7,018,850	2.6
2005–06	45,134	5.9	20.8	0.62	7,311,983	4.2
2006–07	47,472	5.2	21.4	0.62	7,602,917	4.0
2007–08	48,631	2.4	21.2	0.62	7,873,945	3.6
2008–09	52,347	7.6	22.2	0.64	8,148,448	3.5
2009–10	55,983	6.9	23.2	0.66	8,531,003	4.7
2010–11	54,466	–2.7	22.1	0.62	8,852,550	3.8

(a) The rates were age-standardised to the Australian population as at 30 June 2001 and are expressed per 10,000 population (see Appendix C).

Source: NHMD, AIHW.

Additional analysis of the data showed that this reduction was largely due to a drop in the number of palliative care-related separations for New South Wales. Between 2009–10 and 2010–11, the number of palliative care-related separations in New South Wales reduced by 19.5% for public hospitals and 5.7% for private hospitals (Table 2.14). Further investigation showed that this reduction was principally due to an administrative change by New South Wales Health to the coding of health data relating to palliative care-related hospital separations. Specifically, New South Wales changed the coding of palliative care-related separations after July 2010, whereby a separation was captured only when both *care type* and diagnosis code (Z51.5) were assigned to a patient. It should be noted, however, that the practices around the use of the Z51.5 diagnosis code and the palliative care type are not explicitly defined in the International Statistical Classification of Diseases and Related Health Problems, 10th revision, Australian Modification (ICD-10-AM) coding standards.

Before this date, several New South Wales hospitals were using the diagnosis code (without a care type of palliative care) to indicate that a patient was seen by the palliative care team. This change in practice led to lower numbers of palliative care-related separations being reported for 2010–11 compared with those for previous years. As New South Wales accounts for a large proportion of the total separations data (31.1% in 2010–11), 2010–11 data in particular should be treated with caution and are likely to represent an underestimate in terms of the long-term trends.

There was no similar change in coding practice identified for the other states and territories. In spite of the decrease in the number of palliative care separations from 2009–10 to 2010–11, the age-standardised rate of palliative care separations increased from 18.7 to 22.1 per 10,000 population over the 10-year period to 2010–11. This indicates that there was a 'real' increase in the number of admitted patient palliative care separations that goes beyond the increase explained by population growth and an ageing population.

Change over time by sector

In considering palliative care activities by sector over time, it should be noted that reporting arrangements have changed in some jurisdictions—for example, as to whether a hospital was classified as private or public during the period considered. The following data should therefore be interpreted in the light of such variations (see Appendix 2 of *Australian hospital statistics* [AIHW 2011a] for further information).

While there has been an overall increase in the number of admitted patient palliative care-related separations between 2001–02 and 2010–11, much of this increase occurred in public hospitals, with the number of separations increasing by 58% (Table 2.13).

Figures for palliative care-related separations in private hospitals fluctuated, resulting in a net increase of 13% over the same 10-year period. This contrasts with the consistent yearly increase in all private hospital separations, which showed a 47% growth between 2001–02 and 2010–11.

Table 2.13: Palliative care-related separations and all separations, public and private hospitals, 2001–02 to 2010–11

	Palliative care-related separations				Separations for all reasons	
Year	Number of separations	Per cent change from previous year	Rate[(a)]	Per cent of all separations	Number of separations	Per cent change from previous year
Public hospitals						
2001–02	28,946	. .	14.7	0.73	3,965,512	. .
2002–03	30,093	4.0	15.0	0.74	4,090,969	3.2
2003–04	32,542	8.1	15.8	0.77	4,200,517	2.7
2004–05	35,522	9.2	16.9	0.83	4,276,425	1.8
2005–06	36,623	3.1	16.9	0.82	4,466,076	4.4
2006–07	38,355	4.7	17.3	0.82	4,661,280	4.4
2007–08	40,096	4.5	17.5	0.85	4,744,060	1.8
2008–09	44,405	10.7	18.9	0.91	4,891,023	3.1
2009–10	47,345	6.6	19.6	0.93	5,069,288	3.6
2010–11	45,713[(b)]	–3.4	18.6	0.87	5,279,132	4.1
Private hospitals						
2001–02	7,721	. .	3.9	0.32	2,432,659	. .
2002–03	7,903	2.4	3.9	0.31	2,554,015	5.0
2003–04	7,893	–0.1	3.8	0.30	2,640,708	3.4
2004–05	7,100	–10.0	3.4	0.26	2,742,425	3.9
2005–06	8,511	19.9	3.9	0.30	2,845,907	3.8
2006–07	9,117	7.1	4.1	0.31	2,941,637	3.4
2007–08	8,535	–6.4	3.7	0.27	3,129,885	6.4
2008–09	7,942	–6.9	3.4	0.24	3,257,425	4.1
2009–10	8,638	8.8	3.5	0.25	3,461,715	6.3
2010–11	8,753	1.3	3.5	0.24	3,573,418	3.2

(a) The rates were age-standardised to the Australian population as at 30 June 2001 and are expressed per 10,000 population (see Appendix C).

(b) The decrease in the numbers of separations between 2001–02 and 2010–11 is likely to be largely attributable to changes in coding of health data relating to palliative care-related hospital separations in New South Wales.

Source: NHMD, AIHW.

For public hospitals, an increase in the rate is evident over time—increasing from 14.7 to 18.6 palliative care-related separations per 10,000 population. In contrast, the rate of palliative care separations in private hospitals fluctuated within a narrow range over the years reported, ranging from a low of 3.4 to a high of 4.1 per 10,000 population. Overall, there was no discernible trend over the 10-year period in the rate of separations in private hospitals.

Change over time by jurisdiction

The number of palliative care-related separations recorded in each jurisdiction from 2006–07 to 2010–11 are shown in Table 2.14. Of the five jurisdictions with published figures, Victoria reported the highest average annual increase in all hospitals of 8.9%, with comparable increases in both public and private hospitals. Conversely, New South Wales reported an average annual reduction in palliative care-related separations of 1.1% in public hospitals and 0.7% in all hospitals; this is likely to be largely attributable to changes in reporting arrangements (see earlier discussion on changes to palliative care coding practices in New South Wales). Western Australia also reported a reduction of 1.5% to 1.6%, depending on the sector. Meanwhile, for public hospitals, the average annual increase in palliative care-related separations was over 10% for Queensland and Tasmania, higher than the national average of 4.5%.

Table 2.14: Palliative care-related separations, states and territories, public and private hospitals, 2006–07 to 2010–11

	Separations (number)					Average annual change (per cent)
	2006–07	2007–08	2008–09	2009–10	2010–11	
Public hospitals						
New South Wales	16,110	16,726	18,591	19,180	15,433	–1.1
Victoria	11,454	12,198	13,362	14,949	16,047	8.8
Queensland	4,405	4,266	5,457	5,953	6,599	10.6
Western Australia	1,318	1,392	1,246	1,284	1,234	–1.6
South Australia	3,088	3,383	3,389	3,453	3,499	3.2
Tasmania	844	850	916	1,074	1,388	13.2
Australian Capital Territory	539	649	699	753	743	8.4
Northern Territory	597	632	745	699	770	6.6
Total	*38,355*	*40,096*	*44,405*	*47,345*	*45,713*	*4.5*
Private hospitals[(a)]						
New South Wales	1,280	1,196	1,211	1,587	1,496	4.0
Victoria	1,211	1,280	1,408	1,775	1,733	9.4
Queensland	2,083	2,433	1,949	1,696	1,715	–4.7
Western Australia	2,459	2,098	2,156	1,998	2,317	–1.5
South Australia	856	850	906	1,081	945	2.5
Total[(a)]	*9,117*	*8,535*	*7,942*	*8,638*	*8,753*	*–1.0*
All hospitals[(a)]						
New South Wales	17,390	17,922	19,802	20,767	16,929	–0.7
Victoria	12,665	13,478	14,770	16,724	17,780	8.9
Queensland	6,488	6,699	7,406	7,649	8,314	6.4
Western Australia	3,777	3,490	3,402	3,282	3,551	–1.5
South Australia	3,944	4,233	4,295	4,534	4,444	3.0
Total[(a)]	**47,472**	**48,631**	**52,347**	**55,983**	**54,466**	**3.5**

(a) To ensure confidentiality of information, data for private hospitals in Tasmania, the Australian Capital Territory and the Northern Territory are not shown. 'Total' includes data for all jurisdictions.

Source: NHMD, AIHW.

Among private hospitals, there have been both increases and decreases in the number of palliative care-related separations over the period, culminating in a 1.0% average annual decrease over the 5 years to 2010–11. Private hospitals in Queensland and Western Australia reported an average negative growth over the same period (–4.7% and –1.5%, respectively), while Victoria, New South Wales and South Australia reported an increase in the number of palliative care-related separations (9.4%, 4.0% and 2.5%, respectively).

Fluctuations were also noted in the number of palliative care-related separations per 10,000 population over the 5 years to 2010–11 (Table 2.15). While the national data indicate that the rates for 2010–11 were lower than those for the previous year over the same period, data for Victoria and Queensland do not reflect this pattern. The rates for these two jurisdictions were higher in 2010–11 than in 2006–07.

Table 2.15: Palliative care-related separations, states and territories, age-standardised rates, public and private hospitals, 2006–07 to 2010–11

	Age-standardised rates[(a)]				
	2006–07	**2007–08**	**2008–09**	**2009–10**	**2010–11**
Public hospitals					
New South Wales	21.4	21.6	23.4	23.6	18.6
Victoria	20.3	21.1	22.4	24.4	25.7
Queensland	10.6	10.0	12.4	13.1	14.4
Western Australia	6.5	6.6	5.7	5.7	5.4
South Australia	16.3	17.5	17.1	17.2	17.1
Tasmania	14.6	14.6	15.3	17.8	22.0
Australian Capital Territory	19.1	22.2	23.1	24.0	23.2
Northern Territory	56.5	57.6	64.7	57.7	58.5
Total	*17.3*	*17.5*	*18.9*	*19.6*	*18.6*
Private hospitals[(b)]					
New South Wales	1.7	1.5	1.5	1.9	1.8
Victoria	2.1	2.2	2.3	2.8	2.7
Queensland	5.0	5.6	4.4	3.7	3.7
Western Australia	12.1	9.9	9.9	8.9	10.0
South Australia	4.5	4.3	4.5	5.2	4.5
Total[(b)]	*4.1*	*3.7*	*3.4*	*3.5*	*3.5*
All hospitals[(b)]					
New South Wales	23.1	23.2	24.9	25.6	20.4
Victoria	22.5	23.2	24.7	27.3	28.4
Queensland	15.6	15.6	16.7	16.8	18.1
Western Australia	18.6	16.5	15.6	14.6	15.4
South Australia	20.8	21.8	21.5	22.4	21.6
Total[(b)]	**21.4**	**21.2**	**22.2**	**23.2**	**22.1**

(a) The rates were age-standardised to the Australian population as at 30 June 2001 and are expressed per 10,000 population (see Appendix C).

(b) To ensure confidentiality of information, data for private hospitals in Tasmania, the Australian Capital Territory and the Northern Territory are not shown. 'Total' includes data for all jurisdictions.

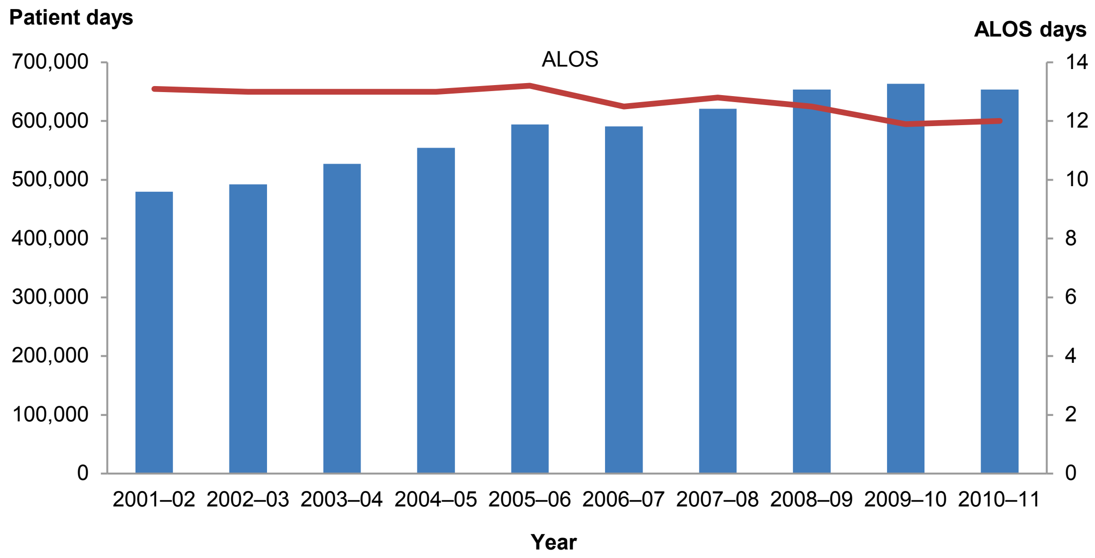
Source: NHMD, AIHW.

For private hospitals, the national age-standardised rate of palliative care-related separations in 2010–11 was lower than the rate in 2006–07 (3.5 and 4.1, respectively). Similar patterns were observed in Queensland and Western Australia where there were fluctuations in the age-standardised rates, culminating in lower rates in 2010–11. This is consistent with the pattern shown in the average annual change data for these two jurisdictions.

Change over time in length of stay

The number of patient days for palliative care-related separations in admitted patient settings has increased between 2001–02 and 2010–11 by 36% to a total of 653,600 patient days (Table 2.16).

The ALOS for palliative care-related separations remained steady over the 10 years to 2010–11, at around 12 to 13 days (Figure 2.1). This stability in the ALOS suggests that the observed increase in the number of patient days for palliative care over the years is due to an increase in the number of such separations (see Table 2.16).



Note: Data for this figure are shown in Table 2.16.

Source: NHMD, AIHW.

Figure 2.1: Palliative care-related separations, patient days and ALOS, public and private hospitals, 2001–02 to 2010–11

Table 2.16: Palliative care-related separations, patient days and ALOS, all hospitals, 2001–02 to 2010–11

	Same-day separations[(a)]	Overnight separations		Total separations		
Year	Patient days	Patient days	ALOS (days)	Patient days	ALOS (days)	Per cent of overnight separations
2001–02	3,200	476,683	14.2	479,883	13.1	91.3
2002–03	3,237	489,222	14.1	492,459	13.0	91.5
2003–04	3,337	523,982	14.1	527,319	13.0	91.7
2004–05	2,892	551,542	13.9	554,434	13.0	93.2
2005–06	3,364	591,014	14.1	594,378	13.2	92.5
2006–07	4,290	586,957	13.6	591,247	12.5	91.0
2007–08	3,304	617,695	13.6	620,999	12.8	93.2
2008–09	3,381	650,087	13.3	653,468	12.5	93.5
2009–10	3,834	659,607	12.6	663,441	11.9	93.2
2010–11	3,404	650,176	12.7	653,580	12.0	93.8

(a) By definition, the ALOS for same-day separations equals 1 day.

Source: NHMD, AIHW.

2.7 Palliative care and deaths in hospital

The focus of this chapter so far has been on separations for which palliative care was a substantial component of the care provided; these separations are referred to as 'palliative care-related separations '. The following section presents data on a subset of these separations—those that ended with the patient's death. To aid understanding, the term 'palliative care patients' will be used in this section since the number of separations is equivalent to the number of patients in this subset. Some admitted patients who died in hospital but were not identified as being 'palliative care patients' may also have received some palliation during the separation that ended with their death. However, as elsewhere in this chapter, the focus is on those separations for which palliation was a substantial component of the care provided.

Place of death

In 2010–11, just over 145,000 people died in Australia (Table 2.17). According to data from the NHMD, nearly 75,000 of these died as an admitted patient in an Australian hospital.

Table 2.17: Admitted patient deaths, all hospitals and all deaths, 2001–02 to 2010–11

	Admitted patient deaths (number)				
Year	Total admitted patient deaths	Deaths of HITH admitted patients[(a)]	Admitted patient deaths excluding HITH patients	Total deaths in Australia[(b)] (number)	Admitted patient deaths (excl. HITH) as a per cent of all deaths in Australia
2001–02	70,671	114	70,557	130,323	54.1
2002–03	71,573	96	71,477	132,462	54.0
2003–04	71,932	106	71,826	133,350	53.9
2004–05	70,799	92	70,707	131,378	53.8
2005–06	71,122	92	71,030	134,059	53.0
2006–07	72,440	86	72,354	135,865	53.3
2007–08	74,365	106	74,259	140,700	52.8
2008–09	74,380	104	74,276	143,682	51.7
2009–10	73,021	113	72,908	140,956	51.7
2010–11	74,861	129	74,732	145,053	51.5

(a) Data are available from 2001–02 onwards for most states and territories on admitted patients who received HITH care. These data are not complete; for example, for all of the years considered, New South Wales and Tasmania did not provide information on HITH activity.

(b) Deaths in Australia by date of occurrence.

Note: HITH = Hospital-in-the-home.

Sources: ABS 2012a; NHMD, AIHW.

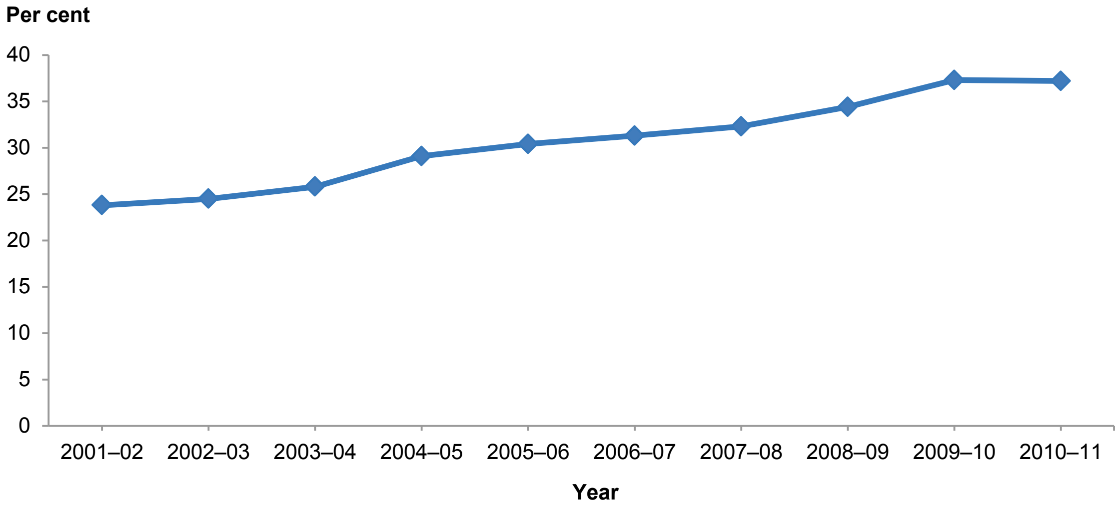
Data on deaths between 2001–02 and 2010–11 are also shown in Table 2.17. The proportion of deaths that occurred within the admitted patient setting ranged from 51.5% to 54.1% over the 10-year period.

Most states and territories have HITH programs, under which admitted patients are provided with hospital care in their home as a substitute for hospital accommodation (AIHW 2012b). The physical place of death of these patients may not have been in hospital. After excluding the small number of HITH patients reported, the data indicate that about 74,700 people died in admitted patient care in 2010–11. This equates to just over half (51.5%) of deaths having occurred in an admitted patient setting in an Australian hospital in 2010–11.

This proportion includes deaths that occurred in hospices that were affiliated with hospitals. However, the NHMD does not include data on the number of deaths that occurred in a hospice, unless the hospice is identified as a separate establishment.

Palliative care patients and death

In 2001–02, more than 1 in 5 (23.3%) admitted patients had been a palliative care patient during the separation that ended with their death (Figure 2.2). Over the following years, this proportion has steadily increased such that by 2010–11 more than 1 in 3 (37.2%) people who died as an admitted patient had been a palliative care patient during their final separation.



Notes

1. Refers to patients for whom palliative care was the principal clinical intent during part or all of the separation that ended with their death.
2. Data for this figure are shown in Supplementary Table S2.2.

Source: NHMD, AIHW.

Figure 2.2: Palliative care patients among those who died as an admitted patient, all hospitals, 2001–02 to 2010–11

The number of palliative care patients who died during hospitalisation varied by diagnosis (Table 2.18). Approximately 16,500 palliative care patients died with cancer as a principal diagnosis in 2010–11. Of these patients, 81.0% had brain cancer while 55.0% had Non-Hodgkin lymphoma. However, when both principal and additional diagnoses are considered, almost two-thirds (62.0%) of those with a cancer diagnosis received palliative care services during their final separation. Of those patients with a non-cancer diagnosis who died as admitted patients, a principal diagnosis of motor neurone disease saw the highest proportion of patients receiving palliative care, and chronic obstructive pulmonary disease the lowest (71.2% and 24.0%, respectively) (Table 2.18).

Table 2.18 also presents data on those cancer sites for which there were 500 or more admitted palliative care patient deaths (based on the principal diagnosis) in 2010–11. Of these, patients with brain cancer as a principal diagnosis were most likely (81.0%) to have been a palliative care patient during the hospital stay that ended with their death. This was followed by those with breast cancer (79.0%) and stomach cancer (77.2%) as the principal diagnosis. Conversely, patients with a blood or lymphatic system cancer were least likely to have been a palliative care patient during the separations that ended with their death. Specifically, over half (55.0%) of those with Non-Hodgkin lymphoma as the principal diagnosis were identified as palliative care patients.

Table 2.18: Palliative care patients among those who died as an admitted patient, by selected diseases, public and private hospitals, 2010–11

	Principal diagnosis only			Principal and additional diagnoses		
Disease[(a)] (ICD-10-AM codes)	No. of palliative care patient deaths[(b)]	Total admitted patient deaths	Per cent of palliative care patient deaths[(b)]	No. of palliative care patient deaths[(b)]	Total admitted patient deaths	Per cent of palliative care patient deaths[(b)]
Cancer site[(a)]						
Brain (C71)	621	767	81.0	678	891	76.1
Breast (C50)	661	837	79.0	1,277	1,970	64.8
Stomach (C16)	477	618	77.2	643	921	69.8
Prostate (C61)	744	967	76.9	1,396	2,200	63.5
Bladder (C67)	320	429	74.6	508	815	62.3
Oesophagus (C15)	416	560	74.3	571	856	66.7
Lung (C33–C34)	2,758	3,742	73.7	3,800	6,009	63.2
Pancreas (C25)	955	1,299	73.5	1,218	1,805	67.5
Liver (C22)	455	622	73.2	588	932	63.1
Colorectal (C18–C20)	1,468	2,033	72.2	2,268	3,538	64.1
Secondary site (C77–C79)	3,616	5,406	66.9	13,792	20,633	66.8
Non-Hodgkin lymphoma (C82–C85)	374	680	55.0	519	1,127	46.1
All cancers (C00–C97, D45, D46, D47.1, D47.3, selected Z codes)	*16,435*	*23,112*	*71.1*	*19,136*	*30,856*	*62.0*
Diseases other than cancer[(a)]						
Motor neurone disease (G12.2)	153	215	71.2	190	380	50.0
HIV/AIDS (B20–B24)	7	10	70.0	42	91	46.2
Huntington disease (G10, F02.2)	4	8	50.0	10	20	50.0
Dementia and Alzheimer disease (F00 to F03, G30)	138	308	44.8	1,515	5,117	29.6
Parkinson disease (G20, G21, G22)	31	76	40.8	258	805	32.0
Renal failure (N17–N19)	663	1,864	35.6	4,365	18,261	23.9
Liver failure (K70.4, K71.1, K72)	234	685	34.2	815	2,885	28.2
Heart failure (I50)	947	3,626	26.1	2,992	14,005	21.4
Chronic obstructive pulmonary disease (J40–J44)	557	2,319	24.0	1,873	7,207	26.0

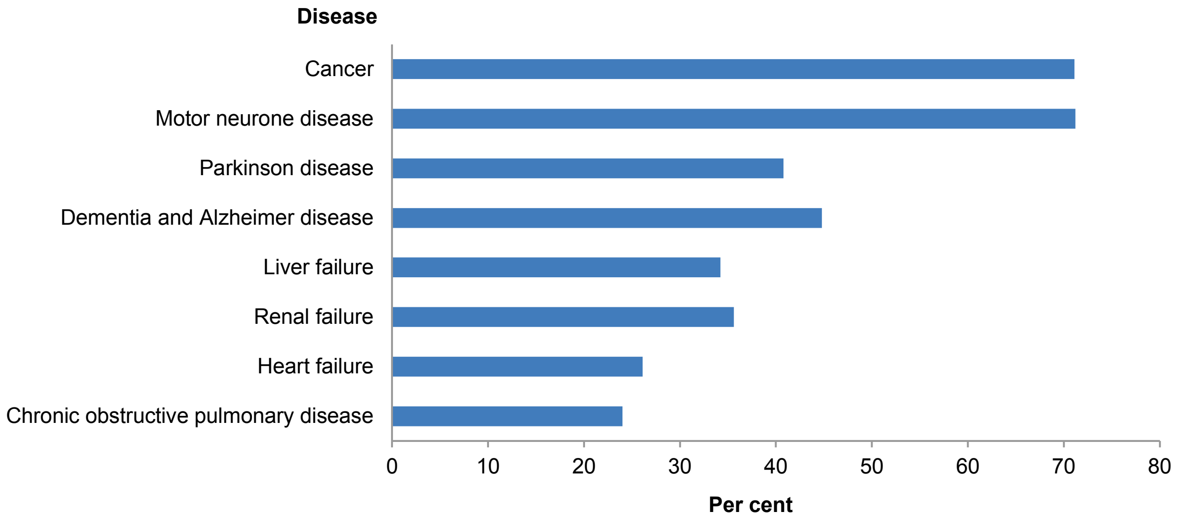
(a) Data for the cancer sites with 500 or more admitted patient deaths (based on the principal diagnosis) are shown, as are data on selected other diseases. See Appendix C for details on the approach used to present disease-related information.

(b) Refers to patients for whom palliative care was the principal clinical intent during part or all of the separation that ended with their death.

Source: NHMD, AIHW.

The same patterns remained when both the principal and additional diagnoses were considered. Patients with a principal or additional diagnosis of brain cancer were substantially more likely to have been a palliative care patient during their last separation (76.1%), followed by those with cancer of the stomach and pancreas (69.8% and 67.5%, respectively).

Although palliative care is closely associated with cancer patients, other diseases are also amenable to palliative care, with nine such diseases considered in this section (Table 2.18 and Figure 2.3).



Notes

1. Refers to patients for whom palliative care was the principal clinical intent during part or all of the separation that ended with their death.
2. Disease data are based on principal diagnosis. See Appendix C for details on the approach used to present disease-related information.
3. Data for this figure are shown in Table 2.18.

Source: NHMD, AIHW.

Figure 2.3: Palliative care patients among those who died as an admitted patient, patients with selected diseases, all hospitals, 2010–11

3 Palliative care in general practice

3.1 Introduction

It has been previously noted that there is a lack of data relating to palliative care services and patient outcomes (see AIHW 2012c for more information). One of the main limitations in reporting on general practice activity for palliative care is the lack of a Medicare item that is specific to palliative care-related treatment provided by **general practitioners (GPs)**.

The Medicare Benefits Schedule (MBS) includes specific items for palliative medicine specialist services (delivered by palliative medicine specialists) for which it will reimburse a proportion of the MBS fee (see Chapter 4); however, there are no equivalent palliative care specific items that can be used by GPs. This means that GPs are likely to be using other MBS items, such as those for chronic disease management, when providing patients with palliative care support. Consequently, the extent of palliative care-related services delivered by GPs cannot be established from existing Medicare data.

Despite the critical importance of the GPs' role in the health-care system broadly, and in palliative care specifically, there is currently no nationally consistent primary health-care data collection that can support reporting on the provision of care by GPs.

This chapter presents information on **palliative care-related encounters** provided by GPs using data from the BEACH survey of general practice activity, which is currently the only available data source that can support this reporting. Given that BEACH is a sample survey of GPs and their encounters with patients, it is subject to the inherent limitations of a survey methodology including questions about how representative the survey is of the target population. Consequently, the following results should be used very cautiously in light of these known limitations.

3.2 Bettering the Evaluation and Care of Health survey data

The data described in this chapter relate to 98,400 GP **encounters** from a sample of 984 GPs over the period from April 2011 to March 2012; this is the most recent reporting period available (Britt et al. 2012). This is described as BEACH 2011–12 in this chapter.

The GP encounters covered by the survey represent about 0.1% of all GP encounters over that time. After post-stratification weighting (to ensure that national general practice activity patterns are reflected), the data include 99,030 (weighted) encounters (Britt et al. 2012). The survey provides information on the reasons patients visited the GP, the problems managed and the types of management provided for each problem.

Further information about this survey and the data can be found at Appendix B.

Key concepts

General practitioners (GPs) are those medical practitioners who are vocationally registered under Section 3F of the *Health Insurance Act 1973* (Cwlth), or are Fellows of the Royal Australian College of General Practitioners or trainees for vocational registration.

Encounter refers to any professional interchange between a patient and a GP; it includes both face-to-face encounters and indirect encounters where there is no face-to-face meeting but where a service is provided (for example, a prescription or referral) (Britt et al. 2012).

International Classification of Primary Care (ICPC-2) PLUS refers to the terminology used in BEACH to secondarily code patient reasons for encounter, problems managed, and non-pharmacological management actions recorded in free tests by participating GPs. The PLUS terminology is classified according to the ICPC-2. It is also used by health professionals to record these aspects of electronic health records during delivery of primary care or general practice (Family Medicine Research Centre 2013).

Palliative care-related encounters are identified in the BEACH survey using the BEACH coding system's four ICPC-2 PLUS palliative care-related codes (see Box 3.1).

3.3 Palliative care-related encounters

In 2011–12, about 1 in 1,000 of all GP encounters reported for the BEACH data were palliative care-related encounters (see Box 3.1) (Table 3.1). This corresponds to approximately 5 encounters per 1,000 population in 2011–12.

It should be noted that palliative care-related encounters are difficult to define. Palliative care is not a medical diagnosis in its own right, but rather a process related to a stage in managing an illness. That is, typically, GPs record the problems they manage as part of the palliative care process (for example, cancer)—not the palliative care process itself. In cases where the patient's health is gradually deteriorating and there is no specific problem being dealt with, palliative care would be recorded as the problem managed. As such, the number of encounters presented in this chapter is likely to be an underestimate of the total amount of palliative care-related encounters by GPs.

Palliative care-related encounters in this chapter have been identified using the four **International Classification of Primary Care (ICPC-2 PLUS)** palliative care-related codes that are recorded against three discrete BEACH survey data elements (*Reason for encounter, Diagnosis* and *Referral)* (see Box 3.1).

Box 3.1: Defining a palliative care-related encounter

Palliative care-related GP encounters were identified via the four ICPC-2 PLUS palliative care-related codes that were recorded against three BEACH survey data elements (*Reason for encounter, Problems managed* and *Referral*).

The following data elements in BEACH are classified according to the ICPC-2 PLUS:

- Patient reasons for encounter
- Problems managed
- Referral.

The following four ICPC-2 PLUS palliative care-related codes have been used by GPs to identify palliative care-related GP encounters:

A28011	Limited function/Disability NOS (Not Otherwise Specified) palliative care
A46020	Palliative care consultation
A67015	Referral; hospice
A68004	Referral; palliative care.

Table 3.1: Estimated number of palliative care-related encounters, BEACH, 2011–12

Total GP encounters that are palliative-care related (per cent)	0.1%
Estimated number of palliative-care related encounters[(a)]	119,000
Lower 95% confidence limit	85,000
Upper 95% confidence limit	153,000
Estimated number of palliative-care related encounters per 1,000 population[(a)]	5.3
Lower 95% confidence limit	3.8
Upper 95% confidence limit	6.8

(a) The estimated number of encounters is based on the proportion of encounters in the BEACH survey of general practice activity that are palliative care-related, multiplied by the total number of Medicare services item numbers for Non-Referred (GP) Attendances (excluding practice nurse items) as reported by the DoHA (Medicare 2012).

Source: Family Medicine Research Centre, University of Sydney analysis of BEACH Survey 2011–12 data.

Patient demographics

Table 3.2 presents information on palliative care-related encounters according to patient characteristics. The table shows the proportion of palliative care-related encounters for each demographic characteristic, and the estimated number of palliative care-related encounters per 1,000 total encounters (that is, both palliative care-related and non-palliative care-related encounters). In 2011–12, more than three-quarters of palliative care encounters were with people aged 65 and over (Table 3.2), and 7.9% with those aged under 55. Females accounted for a greater proportion of GP palliative care-related encounters (54.0%) than males (46.0%), but there was no difference between the sexes in the likelihood of palliative care encounters (about 1% of encounters with both males and females). Just over 2% of palliative care-related encounters were recorded as being with Indigenous Australians.

Table 3.2: Patient demographics for palliative care-related encounters, BEACH 2011–12

Patient demographics	Per cent of total palliative care-related encounters	Rate (per 1,000 demographic group- specific encounters)	95% LCL	95% UCL
Age group (years)				
<15	1.1	0.0	0.0	0.1
15–24	0.0	0.0	0.0	0.0
25–34	0.0	0.0	0.0	0.0
35–44	3.4	0.1	0.0	0.3
45–54	3.4	0.2	0.0	0.4
55–64	10.3	0.7	0.1	1.3
65+	81.6	2.7	1.9	3.6
Sex				
Male	46.0	1.0	0.6	1.4
Female	54.0	0.9	0.6	1.3
Indigenous status				
Indigenous Australians	2.4	1.0	0.0	2.5
Non-Indigenous Australians	97.6	1.0	0.7	1.3
Remoteness area				
Major cities	49.4	0.7	0.4	1.0
Inner regional	41.4	2.2	1.2	3.2
Outer regional	6.9	0.6	0.1	1.1
Remote and very remote	2.3	1.2	0.0	2.7
Total	**100.0**	**1.0**	**0.7**	**1.2**

Note: LCL = lower confidence limit; UCL = upper confidence limit.

Source: Family Medicine Research Centre, University of Sydney analysis of BEACH Survey 2011–12 data.

4 Services provided by palliative medicine specialists

4.1 Introduction

This chapter provides information on the number and types of MBS-subsidised palliative care-related services provided by **palliative medicine specialists** (see Key concepts) under the MBS and the characteristics of patients who received these services. A palliative medicine specialist can be defined as either a medical specialist who is a Fellow of the Royal Australasian College of Physicians and has completed the College's training program in palliative medicine, or a Fellow of the Australasian Chapter of Palliative Medicine, or a Fellow of both (ANZSPM 2008).

The Australian and New Zealand Society of Palliative Medicine describes palliative medicine specialists as the 'general physicians of end of life care, able to coordinate a wide array of palliative treatment options (including chemotherapy, radiotherapy, surgical options, pharmacological options) and psychosocial care, based on a knowledge of the disease, burden versus benefits of palliative therapeutics and the wishes of patient and family' (ANZSPM 2009).

In order to be eligible to claim subsidies under the MBS, referrals to palliative medicine specialist services are required to be made through primary care providers. These include:

- GPs
- community or hospital-based doctors (including specialists), nurses and allied health staff
- staff of residential aged care.

Those patients who are referred to palliative medicine specialists usually have high-level and complex needs (physical, social, psychological, emotional needs), including:

- an exacerbation of a previously stable symptom, and/or
- identified needs (physical, social, emotional or spiritual) that exceed the capacity (knowledge, resources, facilities) of the primary care providers (PCA 2005a).

Further information on the specific MBS items and item groups for palliative medicine specialist can be found in the *Medicare Benefits Schedule book* (DoHA 2011).

In considering the information presented in this chapter, it should be noted that a patient may access more than one type of **MBS-subsidised palliative medicine specialist service** during the reporting period; each service presented in this chapter is counted separately. In addition, the data relate only to when palliative care services provided by a palliative medicine specialist are being claimed under the MBS. In other words, the number of patients receiving palliative medicine services are likely to be an underestimate of total palliative care activity. This is because a range of medical specialists (such as geriatricians and oncologists) also frequently attend to terminally ill patients and provide palliative care, without the service being eligible to be claimed as a palliative care-related service in the MBS (Parker et al. 2008).

Key concepts

Palliative medicine specialist is a medical practitioner who, in order to be eligible for payment of MBS subsidies for palliative care services, must be a Fellow of the Royal Australasian College of Physicians who has completed the College training program in palliative medicine, or a Fellow of the Australasian Chapter of Palliative Medicine, or a Fellow of both (ANZSPM 2008).

MBS-subsidised palliative medicine specialist services are services provided by a palliative medicine specialist on a fee-for-service basis that are partly or fully funded under the Australian Government's Medicare program. These services cover patient attendances (or consultations) provided in different settings, as well as services such as case conferencing. These item groups, along with the relevant MBS item numbers, are listed in Appendix Table B3.

The information presented in this chapter relates to MBS-subsidised palliative medicine specialist services processed by Medicare Australia in the 2011–12 financial year. To provide information on changes over time, data are also presented for the reporting periods from 2007–08 to 2011–12. More detailed information on the scope and coverage of the data presented in this chapter is provided at Appendix B.

4.2 Characteristics of patients receiving palliative medicine specialist services

Nationally, about 9,600 patients received an MBS-subsidised palliative medicine specialist service during 2011–12 (Table 4.1), which equates to a rate of 42.6 patients per 100,000 population. During this time period, almost 49,600 MBS-subsidised palliative medicine specialist services were provided, equating to an average of 5.2 services per patient (Table 4.2).

Table 4.1: MBS-subsidised palliative medicine specialist services: numbers of patients and services, 2011–12

	Patients	Services
Number	9,584	49,586
Rate[(a)]	42.6	220.5

(a) Crude rates are based on the preliminary Australian estimated resident population as at 31 December 2011 and are expressed per 100,000 population (see Appendix C).

Source: DoHA analysis of MBS data, unpublished.

Of the 9,584 patients receiving an MBS-subsidised palliative medicine specialist service, more than two-thirds (69.1%) were aged 65 and older, with almost 9 in 10 (87.5%) aged 55 or older (Table 4.2). For the 65 and older group, the population rate for 2011–12 was more than three times the rate seen for the 55–64 age group (210.6 and 68.0 per 100,000 population, respectively). Fewer than 1 in 50 (1.9%) patients receiving MBS-subsidised palliative medicine specialist services were aged 24 or less in 2011–12 (Table 4.2).

There was almost an equal gender split in those receiving MBS-subsidised palliative medicine specialist services (48.2% for females and 51.8% for males) (Table 4.2).

Table 4.2: MBS-subsidised palliative medicine specialist services: patient demographic characteristics and number of services received, 2011–12

Patient demographics	Number of patients	Per cent of patients	Rate[(a)]	Number of services[(b)]	Per cent of services	Rate[(a)]	Number of services per patient
Age group (years)							
<15	31	0.3	0.7	86	0.2	2.0	2.8
15–24	37	0.4	1.2	169	0.3	5.5	4.6
25–34	72	0.8	2.2	371	0.7	11.5	5.2
35–44	280	2.9	8.8	1,563	3.2	49.3	5.6
45–54	787	8.2	25.8	4,114	8.3	134.7	5.2
55–64	1,759	18.4	68.0	9,407	19.0	363.7	5.3
65+	6,618	69.1	210.6	33,876	68.3	1,078.0	5.1
Total	9,584	100.0	42.6	49,586	100.0	220.5	5.2
Sex							
Male	4,962	51.8	44.4	24,154	48.7	216.0	4.9
Female	4,622	48.2	40.9	25,432	51.3	225.0	5.5
Total	**9,584**	**100.0**	**42.6**	**49,586**	**100.0**	**220.5**	**5.2**

(a) Rates were directly age-standardised, with the exception of age, which is a crude rate, as detailed at Appendix C. Crude rates are based on the preliminary Australian estimated resident population as at 31 December 2011 and are expressed per 100,000 population (see Appendix C).

(b) The number and per cent of patients will not sum to the total since a patient may receive a service in more than one age group in the course of the year but will be counted only once in the total.

Source: DoHA analysis of MBS data, unpublished.

4.3 Types of MBS-subsidised palliative medicine specialist services

In interpreting the information presented here, it should be noted that a patient may have received several MBS-subsidised palliative medicine specialist services during the reporting period. Broadly, the MBS-subsidised palliative medicine specialist services can be categorised into the following groups:

- Palliative medicine attendances
  - Attendances at hospital or surgery
  - Home visits
- Palliative medicine case conferences
  - Organise and coordinate a community case conference
  - Participate in a community case conference
  - Organise and coordinate a discharge case conference
  - Participate in a discharge case conference.

In 2011–12 there were about 49,600 MBS-subsidised services provided by palliative medicine specialists. Palliative medicine attendances in hospitals or other locations made up the majority (86.6%) of all MBS-subsidised palliative medicine specialist items in 2011–12 (Table 4.3). Indeed, nearly all of the MBS items claimed by palliative medicine specialists were for attendances at a hospital, surgery or the patient's home (92.7%). Palliative medicine specialists were more likely to organise and coordinate case conferences for patients than to participate at such conferences initiated by other care providers.

Table 4.3: MBS-subsidised palliative medicine specialist services: MBS item groups, 2011–12

MBS item groups	Total (number)	Per cent by group	Per cent of total items
Palliative medicine attendances			
Attendance in a hospital or surgery	42,921	93.4	86.6
Home visit	3,039	6.6	6.1
Total	*45,960*	*100.0*	*92.7*
Palliative medicine case conferences			
Organise and coordinate a community case conference	1,720	47.4	3.5
Participate in a community case conference	1,143	31.5	2.3
Organise and coordinate a discharge case conference	718	19.8	1.4
Participate in a discharge case conference	45	1.2	0.1
Total	*3,626*	*100.0*	*7.3*
Total	**49,586**	. .	**100.0**

Source: DoHA analysis of MBS data, unpublished.

MBS-subsidised palliative medicine specialist services by state and territory

The rate of subsidised palliative medicine specialist services in 2011–12 varied among states and territories. A number of states and territories could not be reported. This is due to cell suppression being applied to ensure that any data release takes into account privacy and legal requirements. Cells have been suppressed across a number of jurisdictions, with all cells suppressed for the Australian Capital Territory and the Northern Territory, consistent with the policies of the DoHA.

For those states for which data could be reported, Tasmania recorded the highest rate (482.5 per 100,000 population), which was more than double the national average rate (220.5) (Table 4.4). Victoria had the lowest rate at 114.4 per 100,000 population.

Palliative medicine case conferences were predominantly recorded for New South Wales in 2011–12 (2,649), followed by Western Australia, Queensland and Victoria (Table 4.4). For the remaining jurisdictions, the number of case conferences recorded was negligible.

Table 4.4: Palliative medicine specialist services subsidised through Medicare by schedule item, states and territories[(a)], 2011–12

MBS item groups	NSW	Vic	Qld	WA	SA	Tas	ACT[(b)]	NT[(b)]	Total
Palliative medicine attendances									
Attendance in a hospital or surgery	13,033	6,075	8,517	n.p.	n.p.	n.p.	n.p.	n.p.	42,921
Home visit	1,556	119	881	n.p.	n.p.	n.p.	n.p.	n.p.	3,039
Total	*14,589*	*6,194*	*9,398*	*9,217*	*n.p.*	*2,466*	*n.p.*	*n.p.*	*45,960*
Palliative medicine case conferences									
Organise and coordinate a community case conference	1,664	n.p.	13	n.p.	n.p.	n.p.	n.p.	n.p.	1,720
Participate in a community case conference	904	n.p.	168	n.p.	n.p.	n.p.	n.p.	n.p.	1,143
Organise and coordinate a discharge case conference	65	168	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	718
Participate in a discharge case conference	16	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	45
Total	*2,649*	*181*	*217*	*561*	*n.p.*	*n.p.*	*n.p.*	*n.p.*	*3,626*
Total (number)	**17,238**	**6,375**	**9,615**	**9,778**	**3,780**	**2,469**	**n.p.**	**n.p.**	**49,586**
Rate[(c)]	237.8	114.4	213.1	409.6	229.8	482.5	n.p.	n.p.	220.5

(a) State and territory is based on the postcode of the mailing address of the patient as recorded by Medicare Australia.

(b) To ensure confidentiality of information, data for palliative medicine specialist services in the Australian Capital Territory and the Northern Territory are not shown. ‘Total’ includes data for all jurisdictions.

(c) Crude rates are based on the preliminary Australian estimated resident population as at 31 December 2011 and are expressed per 100,000 population (see Appendix C).

Source: DoHA analysis of MBS data, unpublished.

In 2011–12 the highest rate of patients receiving MBS-subsidised palliative medicine specialist services was recorded in *Major cities*, followed by *Inner regional* areas (247.8 and 205.2 per 100,000 population, respectively) (Table 4.5).

Table 4.5: MBS-subsidised palliative medicine specialist services: services by remoteness area, 2011–12

MBS item groups	Major cities	Inner regional	Outer regional	Remote	Very remote	Total
Palliative medicine attendances						
Attendance in hospital or surgery	32,477	8,136	n.p.	n.p.	0	42,921
Home visit	2,370	597	n.p.	n.p.	n.p.	3,039
Total	*34,847*	*8,733*	*2,114*	*n.p.*	*n.p.*	*45,960*
Palliative medicine case conferences						
Organise and coordinate a community case conference	1,659	n.p.	n.p.	n.p.	n.p.	1,720
Participate in a community case conference	1,090	n.p.	n.p.	n.p.	n.p.	1,143
Organise and coordinate a discharge case conference	n.p.	n.p.	n.p.	n.p.	n.p.	718
Participate in a discharge case conference	n.p.	n.p.	n.p.	n.p.	n.p.	45
Total	*3,430*	*145*	*31*	*n.p.*	*n.p.*	*3,626*
Total items (number) [(a)]	**38,277**	**8,878**	**2,146**	**223**	**n.p.**	**49,586**
Rate[(b)]	247.8	205.2	105.8	68.2	—	221.9

(a) Number may not sum to total due to unknown or missing data.

(b) Crude rates are based on the preliminary Australian estimated resident population as at 31 December 2011 and are expressed per 100,000 population (see Appendix C).

Source: DoHA analysis of MBS data, unpublished.

MBS-subsidised palliative medicine specialist services over time

Over the 5 years to 2011–12, the total number of MBS-subsidised palliative medicine specialist services almost doubled (from 25,328 services in 2007–08 to 49,586), equating to an average annual increase of 18.3% (Table 4.6). As a population rate, this represents an 86.0% increase between 2007–08 and 2011–12, from 119.3 per 100,000 to 221.9.

During this same period, the number of palliative medicine attendances increased at an average annual rate of 16.8%, whereas palliative medicine case conferences increased at 54.8%.

Table 4.6: Palliative medicine specialist services subsidised through Medicare by schedule item, 2007–08 to 2011–12

MBS item groups	2007–08	2008–09	2009–10	2010–11	2011–12	Average annual change (per cent)
Palliative medicine attendances						
Attendance in a hospital or surgery	21,304	28,878	35,311	37,776	42,921	19.1
Home visit	3,392	2,959	3,170	2,513	3,039	–2.7
Total	*24,696*	*31,837*	*38,481*	*40,289*	*45,960*	*16.8*
Palliative medicine case conferences						
Organise and coordinate a community case conference	n.p.	n.p.	n.p.	1,131	1,720	57.9
Participate in a community case conference	229	291	545	801	1,143	49.5
Organise and coordinate a discharge case conference	123	353	550	669	718	55.4
Participate in a discharge case conference	n.p.	n.p.	n.p.	44	45	96.8
Total	*632*	*1,229*	*2,013*	*2,645*	*3,626*	*54.8*
Total items (number)	**25,328**	**33,066**	**40,494**	**42,934**	**49,586**	**18.3**
Rate[(a)]	119.3	152.8	182.8	191.0	221.9	. .

(a) Crude rates are based on the preliminary Australian estimated resident population as at 31 December 2011 and are expressed per 100,000 population (see Appendix C).

Source: DoHA analysis of MBS data, unpublished.

Australian Government expenditure on MBS-subsidised palliative medicine specialist services

This section outlines the Australian Government's funding through the MBS for palliative care-related services provided by palliative medicine specialists in 2011–12. Benefits paid are based on the MBS, with the schedule allocating a unique item number to each service, as well as indicating the scheduled payment amount. Further information on the specific MBS items and item groups for palliative medicine specialists can be found in the *Medicare Benefits Schedule book* (DoHA 2011).

Approximately $3.5 million was paid in benefits for MBS-subsidised palliative medicine specialist services in 2011–12 (Table 4.7)—equivalent to a rate of $15,908 per 100,000 population, or about $373 per patient. Table 4.7 disaggregates the $3.5 million spent by the Australian Government on services provided by palliative medicine specialists through MBS-subsidies by jurisdiction. For those states for which reporting was possible, New South Wales had the highest rate in benefits ($18,223 per 100,000 population). Nearly 90% of total benefits paid were MBS items claimed for palliative medicine specialist attendances.

Table 4.7: Medicare benefits paid on palliative medicine specialist services, by item group, states and territories[(a)], 2011–12 ($)

MBS item groups	NSW	Vic	Qld	WA	SA	Tas	ACT[(b)]	NT[(b)]	Total
Palliative medicine attendances									
Attendance in a hospital or surgery	863,636	418,570	593,473	n.p.	n.p.	n.p.	n.p.	n.p.	2,840,124
Home visit	187,557	14,111	94,790	n.p.	n.p.	n.p.	n.p.	n.p.	355,900
Total	*1,051,193*	*432,681*	*688,263*	*n.p.*	*n.p.*	*151,016*	*n.p.*	*n.p.*	*3,196,024*
Palliative medicine case conferences									
Organise and coordinate a community case conference	183,946	n.p.	2,069	n.p.	n.p.	n.p.	n.p.	n.p.	190,731
Participate in a community case conference	72,617	n.p.	14,172	n.p.	n.p.	n.p.	n.p.	n.p.	92,972
Organise and coordinate a discharge case conference	11,620	17,300	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	91,751
Participate in a discharge case conference	1,387	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	5,532
Total	*269,569*	*18,735*	*21,472*	*68,562*	*n.p.*	*n.p.*	*n.p.*	*n.p.*	*380,986*
Total[(c)]	**1,320,762**	**451,416**	**709,735**	**663,465**	**255,288**	**151,318**	**n.p.**	**n.p.**	**3,577,010**
Rate[(d)]	18,223	8,098	15,726	27,792	15,519	29,571	n.p.	n.p.	15,908

(a) State and territory is based on the postcode of the mailing address of the patient as recorded by Medicare Australia.

(b) To ensure confidentiality of information, data for palliative medicine specialist services in the Australian Capital Territory and the Northern Territory are not shown. 'Total' includes data for all jurisdictions.

(c) Totals may not add due to rounding.

(d) Crude rates are based on the preliminary Australian estimated resident population as at 31 December 2011 and are expressed per 100,000 population (see Appendix C).

Source: DoHA analysis of MBS data, unpublished.

Over the 5 years to 2011–12, the MBS benefits paid for all palliative medicine specialist services more than doubled (from $1,663,962 in 2007–08 to $3,577,010) (Table 4.8). This equates to an average annual rate increase of 21.1%.

During this same period, the benefits paid for palliative medicine attendances increased at an average annual rate of 18.9%, whereas the benefits paid for palliative medicine case conferences increased at a rate of 56.0% (Table 4.8).

Table 4.8: Medicare benefits paid on palliative medicine specialist services, Australia, 2007–08 to 2011–12 ($)

MBS item	2007–08	2008–09	2009–10	2010–11	2011–12	Average annual change (per cent)
Palliative medicine attendances						
Attendance in a hospital or surgery	1,259,518	1,775,859	2,198,438	2,413,876	2,840,124	22.5
Home visit	340,101	312,898	354,138	289,464	355,900	1.1
Total	*1,599,619*	*2,088,758*	*2,552,576*	*2,703,340*	*3,196,024*	*18.9*
Palliative medicine case conferences						
Organise and coordinate a community case conference	n.p.	n.p.	n.p.	123,532	190,731	. .
Participate in a community case conference	17,335	21,308	41,161	63,544	92,972	52.2
Organise and coordinate a discharge case conference	19,114	56,505	78,329	87,581	91,751	48.0
Participate in a discharge case conference	n.p.	n.p.	n.p.	3,949	5,532	. .
Total	*64,343*	*138,632*	*217,566*	*278,605*	*380,986*	*56.0*
Total items[(a)]	**1,663,962**	**2,227,390**	**2,770,142**	**2,981,945**	**3,577,010**	**21.1**

(a) Totals may not add due to rounding.

Source: DoHA analysis of MBS data, unpublished.

5 Palliative care in residential aged care

The Australian Government funds residential aged care services for older Australians whose care needs are such that they can no longer remain in their own homes (AIHW 2011d). Residential aged care services provide accommodation and services to people requiring ongoing health and nursing care due to chronic impairments and a reduced degree of independence in activities of daily living. They provide nursing, supervision or other types of personal care required by the residents (PC 2011).

Research indicates that, over the last 20 years, the proportion of people dying who are aged care residents is increasing (Giles et al. 2003). Further, the Productivity Commission report *Caring for older Australians* stated that palliative care is 'core business' for any aged care system (PC 2011).

Residential aged care services face unique difficulties in administering palliative care, with residents often having dementia and/or communication difficulties and multiple diagnoses (NHMRC 2006). When compared with hospices, where patients are more likely to have a cancer diagnosis, residents in aged care services are more likely to have a diagnosis of a chronic degenerative disease(s) (Grbich et al. 2005).

This chapter presents information on aged care residents who have been assessed using the ACFI as requiring palliative care.

5.1 Data source

The data on **palliative care in residential aged care** (see Key concepts) presented in this section have been derived from the DoHA's Aged and Community Care Data Warehouse, which contains information gathered via a number of data collection instruments. For the analyses presented in this section, data collected from the ACFI has been used (AIHW 2011d).

An ACFI appraisal is completed by residential aged care services in order to determine a resident's care needs. The results of the assessment are used to allocate funding, based on a resident's need for care across three care domains:

- Activities of Daily Living
- Cognition and Behaviour
- Complex Health Care (AIHW 2011d; DoHA 2009).

ACFI appraisals include information on:

- up to three mental or behavioural diagnoses
- up to three other medical diagnoses
- five questions about the need for assistance with activities of daily living: nutrition, mobility, personal hygiene, toileting, and continence
- five questions on the need for assistance with a resident's cognition and behaviour: cognitive skills, wandering, verbal behaviour, physical behaviour, and depression
- two questions on the need for assistance with the use of medication and complex health-care procedures (AIHW 2011d).

Key concepts

Palliative care in residential aged care is care provided to residential aged care residents identified in the complex health-care domain of the ACFI as requiring palliative care. This appraisal process identifies residents requiring a palliative care program where ongoing care will involve very intensive clinical nursing and/or complex pain management in the residential care setting.

Permanent resident is a resident who is admitted to residential aged care for permanent care (long-term care).

Permanent admission is an admission to residential aged care for expected long-term care during the reporting period.

5.2 Characteristics of residential aged care residents receiving palliative care

There were just over 221,000 permanent residential aged care residents in 2011–12 with completed ACFI appraisals and almost 1 in 20 of these residents had an ACFI appraisal indicating the need for palliative care (Table 5.1).

Of the almost 12,300 **permanent residents** appraised as requiring palliative care during 2011–12, about one-third (31.8%) commenced a **permanent admission** in 2011–12 (Table 5.1).

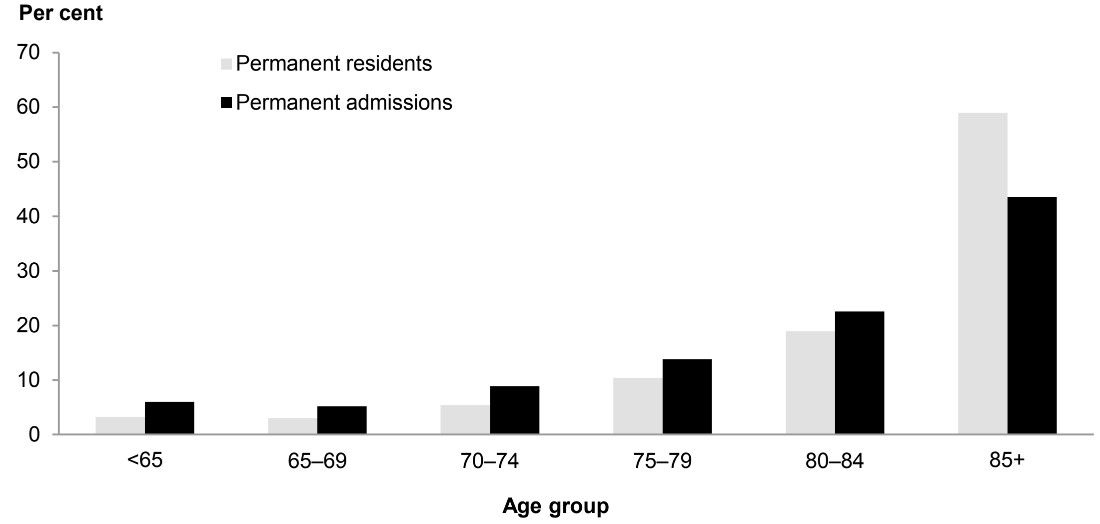
Table 5.1: Residential aged care permanent admissions and permanent residents appraised as requiring palliative care or other care types by number and per cent, 2011–12

	Palliative care	Other care	Total
Permanent admissions (in 2011–12)	3,908 (31.8%)	52,809 (25.3%)	56,717 (25.6%)
Permanent residents	12,298 (100.0%)	208,864 (100.0%)	221,162 (100.0%)

Sources: Supplementary tables S5.1 and S5.2.

There was essentially no difference in the age profile between permanent residents who required palliative care and residents with other care requirements during 2011–12 (Supplementary Table S5.1).

For residents who entered permanent care during 2011–12, there was a smaller proportion in the 85 and older age group who were appraised as requiring palliative care compared with other care types (43.5% and 51.8%, respectively) (Supplementary Table S5.2). The percentage for those appraised as requiring palliative care was higher for permanent residents than for permanent admissions in the remaining age groups (Figure 5.1).



Sources: Supplementary tables S5.1 and S5.2.

Figure 5.1: Residential aged care permanent residents and permanent admissions appraised as requiring palliative care, by age group, 2011–12

Male residents were more likely to be appraised as requiring palliative care than female residents (9.1% and 5.4%, respectively) during 2011–12 (Table 5.2). There was essentially no difference in Indigenous status, marital status and country of birth between those residents appraised as requiring palliative care and those requiring other care types (Supplementary Table S5.3).

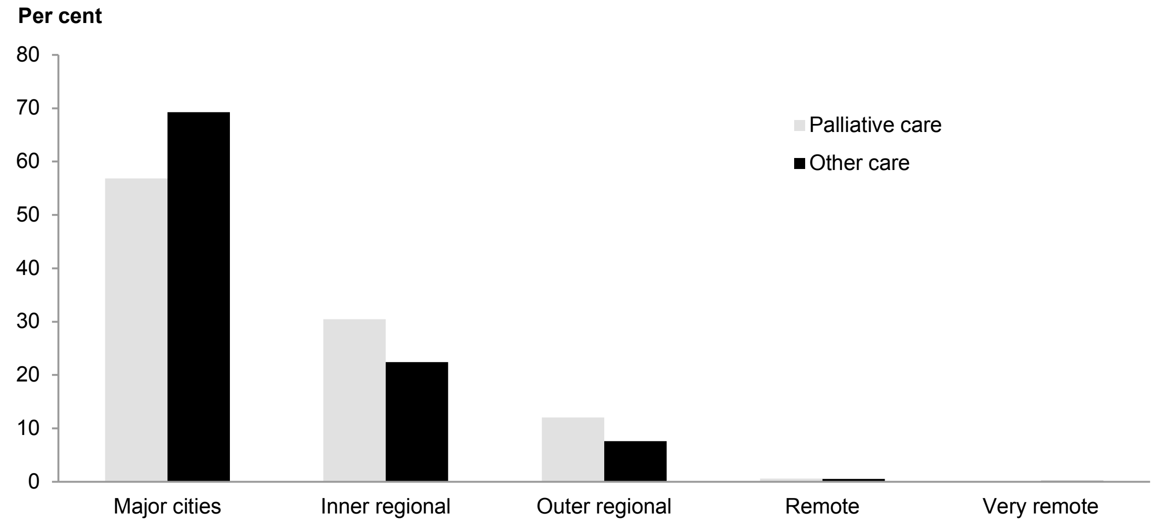
Table 5.2: Residential aged care permanent residents, appraised as requiring palliative or other care types, by sex, 2011–12

	Palliative care		Other care	
Sex	**Number**	**Per cent**	**Number**	**Per cent**
Male	4,709	38.3	66,520	31.8
Female	7,589	61.7	142,344	68.2

Source: Supplementary Table S5.3.

Geographical distribution of palliative care in residential aged care

A smaller proportion of permanent residents appraised as requiring palliative care resided in *Major cities* compared with residents with other care types (56.8% and 69.2%, respectively) in 2011–12 (Figure 5.2).



Source: Supplementary Table S5.3.

Figure 5.2: Residential aged care permanent residents appraised as requiring palliative care or other care types, by remoteness area, 2011–12

The rate per 100,000 population of residential aged care residents appraised as requiring palliative care varied across remoteness areas. Rates of palliative care within aged care were generally highest in *Inner regional* areas for those aged 65 and over; similarly high rates were seen for *Outer regional* areas for those aged 75 and over. Overall, the rate of palliative care within aged care increased with age (for example, 39 per 100,000 for those aged 65–69 increasing to 781 per 100,000 for those aged 85+). A similar pattern was seen in admissions. Other care types within aged care did not show the same pattern across remoteness areas, with the rate generally trending towards lower rates of other care with increasing remoteness (Supplementary tables S5.4 and S5.5).

There were higher rates of palliative care in aged care in Tasmania (246 per 100,000) than in the other states and territories (55 for Australia overall). This pattern was also reflected in admissions requiring palliative care, but was not evident for residents or admissions involving other care types (Supplementary tables S5.6 and S5.7).

Diagnoses

The majority of aged care residents appraised as requiring either palliative or other care in 2011–12 had been diagnosed with diseases other than cancer. However, around one-quarter of aged care residents receiving palliative care had been diagnosed with cancer, with the most frequently recorded types of cancer being other malignant tumours (22.9%), lung cancer (18.1%) and prostate cancer (13.5%) (Table 5.3). The most frequently recorded non-cancer disease categories of those assessed as requiring palliative care were circulatory system (29.6%), other (17.5%), and musculoskeletal (13.7%) (Supplementary Table S5.8).

Table 5.3: Diagnosed diseases in ACFI appraised permanent residential aged care residents, 2011–12

	Palliative care		Other care	
Disease	Number	Per cent	Number	Per cent
Cancer	3,138	25.5	7,219	3.5
Other diseases	9,160	74.5	201,646	96.5

Source: Supplementary Table S5.8.

Separation mode

A separation from residential aged care occurs when a resident leaves and does not re-enter the same or another residential aged care service within 2 days. The reasons for separation (called the separation mode) are categorised as:

- death
- return to community
- admission to hospital
- move to another aged care service
- other.

Unsurprisingly, the majority of residents, whether or not they received palliative care, had death as the mode of separation (Table 5.4). Those residents receiving palliative care were less likely to have a mode of separation of going to hospital, returning to the community, or moving to another aged care service than those residents with other care needs.

Table 5.4: Residential aged care residents appraised as requiring palliative care or other care types, by mode of separation, 2011–12

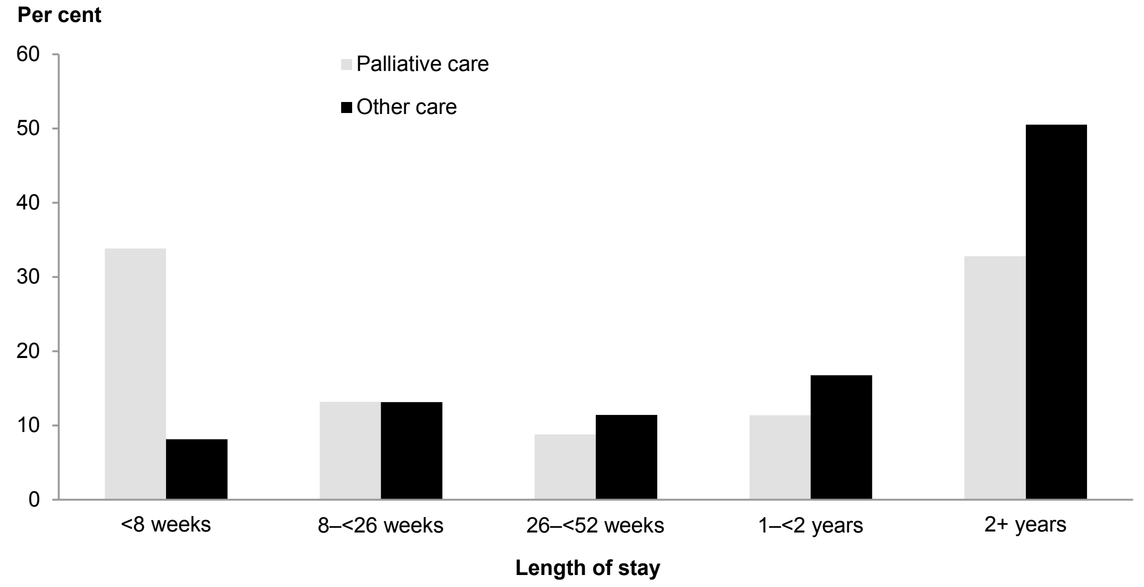
	Palliative care		Other care	
Separation reason	Number	Per cent	Number	Per cent
Death	7,644	97.9	43,909	91.5
Admission to hospital	44	0.9	1,744	2.1
Return to community	71	0.6	1,018	3.6
Move to another aged care service	25	0.3	818	1.7
Other	22	0.3	517	1.1
All separations	7,806	100.0	48,006	100.0

Source: AIHW analysis of 2011–12 ACFI data.

5.3 Length of stay

For permanent residents separating from a residential aged care facility during the 2011–12 reporting period, those appraised as requiring palliative care were more likely to have a shorter length of stay than other care types (Figure 5.3). For residents with a length of stay of less than 8 weeks, the proportion of residents requiring palliative care was more than four times that for residents receiving other care types (33.8% and 8.2%, respectively) during 2011–12 (Figure 5.3). When considering a length of stay of less than 4 weeks, the difference was over five times (21.4% and 4.1%, respectively) (Supplementary Table S5.9).

These findings may be due to individuals accessing residential aged care in order to manage the end-of-life period.



Source: Supplementary Table S5.9.

Figure 5.3: Residential aged care residents assessed as requiring palliative care or other care types using ACFI, by length of stay, 2011–12

Hospital leave

A permanent aged care resident may require hospital leave in order to receive treatment in hospital. In 2011–12, for residents requiring palliative care, two-thirds (66.3%) were in *Major cities* compared with almost three-quarters (73.0%) for other care types (Table 5.5).

Table 5.5: Residential aged care residents appraised as requiring palliative care or other care types using ACFI, with an episode of hospital leave, by remoteness area, 2011–12

	Palliative care		Other care	
Remoteness	**Number**	**Per cent**	**Number**	**Per cent**
Major cities	2,288	66.3	44,570	73.0
Inner regional	819	23.7	11,677	19.1
Outer regional	324	9.4	4,397	7.2
Remote	n.p.	n.p.	336	0.6
Very remote	n.p.	n.p.	64	0.1
Total	**3,452**	**100.0**	**61,044**	**100.0**

Note: This includes those individuals who were a permanent resident in a residential aged care facility at some time during 2011–12, but who may or may not have been a permanent resident as at 30 June 2012.

Source: Supplementary Table S5.10.

6 Palliative care-related medications

6.1 Introduction

Prescription medications are an important component of care for palliative patients. One of the attributes of palliative care is to 'provide relief from pain and other distressing symptoms' (WHO 2002); in many instances, this involves using prescription medications.

This chapter presents information on pharmaceuticals prescribed for palliative care patients. The information is sourced through the PBS and the Repatriation Pharmaceutical Benefits Scheme (RPBS). Under both schemes, Medicare Australia makes payments to subsidise pharmaceutical products listed in the *Schedule of Pharmaceutical Benefits* (DoHA 2012b).

In order to improve access to essential and affordable palliative care medications, the Australian Government introduced, in 2004, the *Pharmaceutical Benefits for Palliative Care Schedule,* as a subsection of the PBS Schedule. The palliative care schedule is a list of medications recommended for subsidy by the Pharmaceutical Benefits Advisory Committee. These medications may be prescribed for patients with 'active, progressive and far-advanced diseases for whom the prognosis is limited and the focus of care is quality of life' (DoHA 2012b). In practice, this means that any patient with a life-limiting disease can access these medications, regardless of the type of disease.

Apart from those medications listed on the palliative care schedule, patients receiving palliative care can also access medications in the general listings of the PBS/RPBS schedules. Only medications in the palliative care listings and medications prescribed by palliative medicine specialists are discussed in this chapter; these are referred to as **palliative care-related prescriptions** (see Key concepts).

Key concepts

Palliative care-related prescriptions are defined in this section as:

- medications listed in the *Pharmaceutical Benefits for Palliative Care Schedule* and/or
- all other medications prescribed by palliative medicine specialists.

The information on prescriptions in this chapter is sourced from the PBS/RPBS and refers to medications prescribed by medical practitioners and subsequently dispensed in community pharmacies (or, for Section 100 drugs, by hospital pharmacies). Consequently, it is a count of medications dispensed rather than a count of the prescriptions written by medical practitioners.

The definition of palliative care-related prescriptions captures, as far as possible, medications that were dispensed for palliative care-related reasons. However, it is likely that some medications that were prescribed for non-palliative care-related reasons are included; that is, some medications prescribed by palliative medicine specialists may not relate directly to the patient's palliative care. Similarly, other medications related to palliative care might have been excluded; for example, medications that are not listed in the palliative care schedule that were prescribed by GPs or non-palliative medicine specialists as part of palliative care.

The data used to create this chapter relate to the number of prescriptions recorded on the PBS. When interpreting the information presented in this chapter, it is useful to note that individual prescriptions will vary in the number of doses, the strength of each individual dose and the type of preparation (such as tablets or injections). This level of detail is not presented in this chapter.

6.2 Characteristics of patients receiving palliative care-related prescriptions

Nationally, more than 19,000 patients had a subsidised palliative care-related prescription during 2011–12, which equates to a rate of 85.8 patients per 100,000 population (Table 6.1). There were over 36,000 subsidised palliative care-related prescriptions during 2011–12, which equates to a rate of 161.3 per 100,000 population. On average, this equates to 1.9 subsidised palliative care-related prescriptions for each patient during 2011–12.

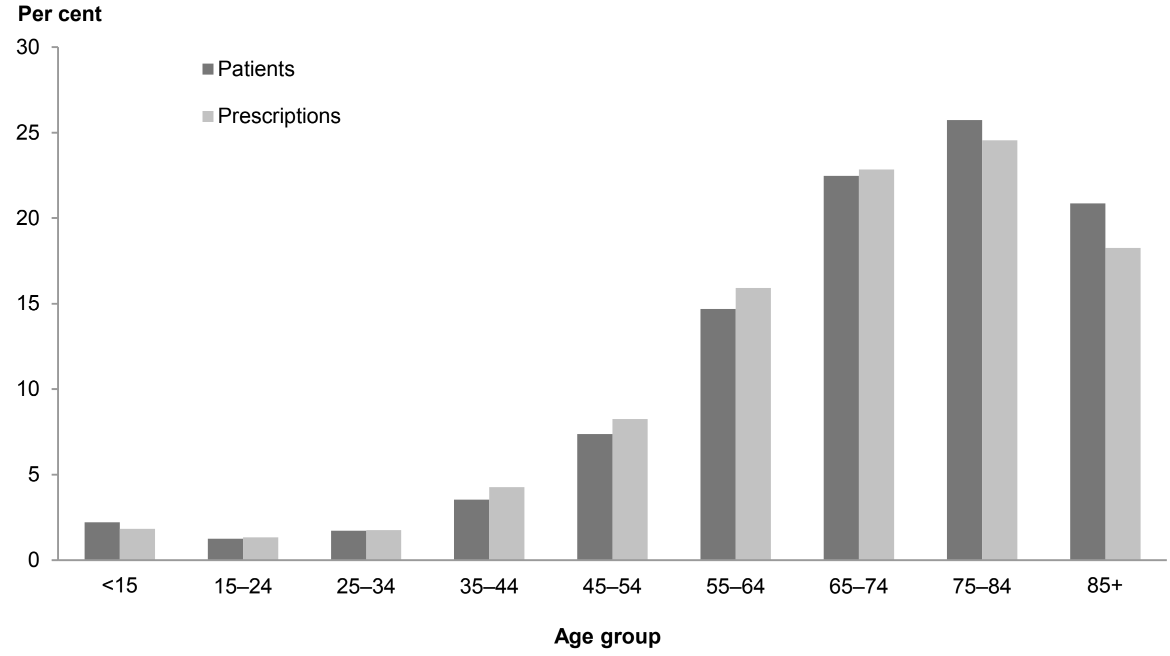
Table 6.1: Palliative care schedule items: numbers of patients and prescriptions, 2011–12

	Patients	Prescriptions
Number	19,293	36,263
Rate[(a)]	85.8	161.3

(a) Crude rates are based on the preliminary Australian estimated resident population as at 31 December 2011 and are expressed per 100,000 population (see Appendix C).

Source: DoHA analysis of PBS/RPBS data, unpublished.

Around 1 in 5 (20.9%) patients prescribed subsidised palliative care-related prescriptions during 2011–12 were aged 85 or older, with almost half (46.6%) aged 75 or older (Figure 6.1). For the 85 and older group, the population rate for 2011–12 was 975.0 per 100,000 population, which was almost twice as high as the rate for the 75–84 age group (493.0 per 100,000). Fewer than 1 in 20 patients (3.4%) with palliative care-related prescriptions was aged under 25 in 2011–12.



Source: Supplementary Table S6.1.

Figure 6.1: Palliative care schedule items, prescriptions and patients, by age-group, 2011–12

The gender profile of patients who had subsidised palliative care-related prescriptions was essentially balanced in 2011–12 (52% female and 48% male) (Supplementary Table S6.1). Males and females both averaged 1.9 palliative care-related prescriptions for each patient during 2011–12.

The highest rate of patients being dispensed subsidised palliative care-related prescriptions was in *Inner regional* areas, followed by *Outer regional* areas (114.8 and 109.6 per 100,000 population, respectively) (Table 6.2).

Table 6.2: Palliative care patients, by remoteness area, 2011–12

Patient area of residence	Number[(a)]	Per cent[(b)]	Rate[(c)]
Major cities	11,779	61.1	76.2
Inner regional	4,968	25.8	114.8
Outer regional	2,223	11.5	109.6
Remote	238	1.2	72.8
Very remote	75	0.4	39.5
Total	**19,293**	**100.0**	**85.8**

(a) The number of patients may not sum to the total due to unknown or missing data.

(b) The percentages shown do not include patients for which remoteness area was unknown or missing.

(c) Crude rates are based on the preliminary Australian estimated resident population as at 31 December 2011 and are expressed per 100,000 population (see Appendix C).

Source: DoHA analysis of PBS/RPBS data, unpublished.

6.3 Types of palliative care-related prescriptions and prescribing clinicians

This section presents information on the number and type of PBS/RPBS subsidised palliative care-related prescriptions and the prescribing clinician. A range of health professionals are able to prescribe medications that are listed on the palliative care schedule, including palliative medicine specialists, other medical specialists, GPs and nurse practitioners.

In interpreting this information, it should be noted that a patient may have received several subsidised palliative care-related prescriptions during the reporting period.

Broadly, the palliative care-related prescriptions that are included in the PBS/RPBS palliative care schedule can be categorised into the following groups:

- analgesics
- anti-emetics and anti-nauseants
- anti-epileptics
- anti-inflammatory and anti-rheumatic products
- drugs for functional gastrointestinal disorders
- laxatives
- psycholeptics
- stomatological preparations.

There were over 36,000 subsidised palliative care-related prescriptions in 2011–12 (Table 6.3). Laxatives were the most frequently dispensed palliative care-related prescription in 2011–12, followed by analgesics and anti-epileptics (37.3%, 22.2% and 14.5%, respectively).

The majority of palliative care-related prescriptions (82.5%) were written by GPs (Table 6.3). The next most frequently recorded type of clinician was other clinicians, followed by palliative medicine specialists (15.3% and 2.2%, respectively).

The pattern of the types of medications dispensed varied according to the type of clinician. The most frequently dispensed medications by GPs and by other clinicians were laxatives (38.8% and 32.3%, respectively), followed by analgesics (19.6% and 31.8%, respectively). The most frequently dispensed medications by palliative medicine specialists were analgesics, followed by laxatives (55.5% and 14.1%, respectively).

Table 6.3: Palliative care schedule items, by medication type prescribed and prescribing clinician, 2011–12

	Prescribing clinician (per cent)				
Medication type	**GPs**	**Palliative medicine specialists**	**Other clinicians**	**All clinicians (per cent)**	**Total (number)**
Analgesics	19.6	55.5	31.8	22.2	8,056
Anti-emetics and anti-nauseants	4.5	1.4	3.4	4.3	1,551
Anti-epileptics	15.1	9.1	12.0	14.5	5,267
Anti-inflammatory and anti-rheumatic products	2.8	0.5	4.4	3.0	1,084
Drugs for functional gastrointestinal disorders	2.9	12.9	6.3	3.7	1,329
Laxatives	38.8	14.1	32.3	37.3	13,516
Psycholeptics	14.1	5.6	8.1	13.0	4,715
Stomatological preparations	2.1	0.8	1.7	2.1	745
Total (per cent)	**100.0**	**100.0**	**100.0**	**100.0**	**. .**
Total (number)	**29,933**	**780**	**5,550**	**. .**	**36,263**
Per cent (row)	82.5	2.2	15.3	100.0	. .

Note: 'Other clinicians' includes medical specialists from other disciplines, and nurse practitioners.

Source: Supplementary Table S6.3.

Palliative care-related prescriptions by state and territory

Nationally, there were 161.3 per 100,000 population subsidised palliative care-related prescriptions dispensed in 2011–12. Rates ranged from 99.3 per 100,000 population in the Australian Capital Territory to 250.3 per 100,000 population in Tasmania (Table 6.4).

Nationally, laxatives had the highest rate of prescriptions, followed by analgesics and anti-epileptics (60.1, 35.8 and 23.4 per 100,000 population, respectively).

Table 6.4: Palliative care schedule items, by medication type per 100,000 population[(a)], all clinicians, states and territories, 2011–12

Medication type	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total (rate)[(a)]	Total (number)
Analgesics	28.9	35.5	42.2	39.8	44.4	48.5	25.1	24.5	35.8	8,056
Anti-emetics and anti-nauseants	5.5	5.3	9.4	8.1	8.5	12.7	6.7	5.6	6.9	1,551
Anti-epileptics	18.2	37.3	12.9	24.2	27.0	36.9	7.6	20.7	23.4	5,267
Anti-inflammatory and anti-rheumatic products	5.0	5.3	3.7	4.1	4.1	9.6	9.2	4.3	4.8	1,084
Drugs for functional gastrointestinal disorders	3.8	3.6	12.8	2.8	9.8	6.8	1.1	2.6	5.9	1,329
Laxatives	58.6	56.1	73.4	41.2	67.2	96.0	38.0	46.0	60.1	13,516
Psycholeptics	18.9	18.1	23.9	24.0	25.7	34.6	10.0	21.1	21.0	4,715
Stomatological preparations	3.5	3.2	3.6	1.8	4.3	5.3	1.6	0.0	3.3	745
Total (rate)[(a)]	**142.3**	**164.4**	**182.0**	**146.1**	**190.9**	**250.3**	**99.3**	**124.8**	**161.3**	. .
Total (number)	**10,316**	**9,166**	**8,213**	**3,488**	**3,141**	**1,281**	**368**	**290**	. .	**36,263**

(a) Crude rates are based on the preliminary Australian estimated resident population as at 31 December 2011 and are expressed per 100,000 population (see Appendix C).

Source: Supplementary Table S6.2.

Palliative care-related prescriptions over time

Nationally, the number of subsidised palliative care-related prescriptions decreased between 2007–08 and 2010–11, but there was a 25.0% increase between 2010–11 and 2011–12 (Table 6.5). However, during this period, there was notable variability across medication types, ranging from analgesics (which had an annual average increase of 49.2%) to psycholeptics (which had an average annual decrease of 20.9%).

Table 6.5: Palliative care schedule items, by medication type, all clinicians, 2007–08 to 2011–12

Medication type	Number					Average annual change (per cent)
	2007–08	2008–09	2009–10	2010–11	2011–12	
Analgesics	1,627	3,242	3,827	4,828	8,056	49.2
Anti-emetics and anti-nauseants	963	935	823	924	1,551	12.7
Anti-epileptics	7,171	6,686	6,235	6,068	5,267	–7.4
Anti-inflammatory and anti-rheumatic products	1,431	917	698	768	1,084	–6.7
Drugs for functional gastrointestinal disorders	840	936	895	997	1,329	12.2
Laxatives	11,169	9,258	7,878	8,317	13,516	4.9
Psycholeptics	12,046	9,005	7,840	6,626	4,715	–20.9
Stomatological preparations	485	426	458	454	745	11.3
Total	**35,732**	**31,405**	**28,654**	**28,982**	**36,263**	**0.4**

Source: DoHA analysis of PBS/RPBS data, unpublished.

The prescription pattern of medications from the PBS/RPBS palliative care schedule is likely to be influenced by GPs prescribing over 80% of these prescriptions. Over the 5 years until 2011–12, the number of palliative care-related prescriptions written by GPs decreased by an average annual rate of 2.3% (Supplementary Table S6.3). In contrast, the number of palliative care-related prescriptions prescribed by palliative medicine specialists and other clinicians increased (annual average changes of 18.8% and 22.1%, respectively).

The prescription of analgesics included in the PBS/RPBS palliative care schedule showed the largest average annual increase over the 5-year period reported for all clinician types. Other clinicians had the largest annual average increase, followed by GPs and palliative medicine specialists (69.2%, 45.8% and 39.6%, respectively) (Supplementary Table S6.3).

Palliative care schedule items for pain relief

An analysis of medications prescribed for pain relief indicate that over half (55.4%) of medications in this group were paracetamol, with the remainder being opioids (Table 6.6). Fewer than 1 in 20 prescriptions for opioids was a repeat script in 2011–12, compared with almost 1 in 5 for paracetamol (3.2% and 19.0%, respectively).

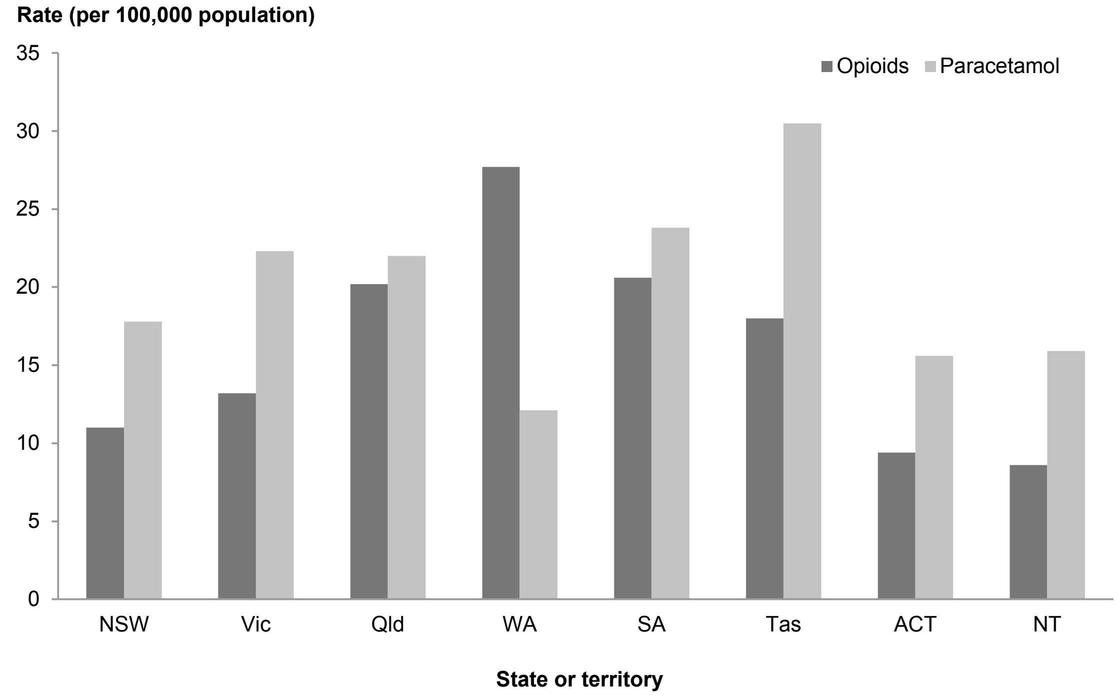
Nationally, there were 35.8 per 100,000 population subsidised prescriptions for pain relief medications included on the palliative care schedule in 2011–12, with opioids making up 16.0 per 100,000 population and paracetamol 19.8 per 100,000 population (Supplementary Table S6.4).

Table 6.6: Palliative care schedule items for pain relief, initial and repeat prescriptions, by medication group, 2011–12

Medication group	Initial scripts	Repeat scripts	Total	Per cent
		Number		
Opioids	3,338	256	3,594	44.6
Paracetamol	2,929	1,533	4,462	55.4
Total	**6,267**	**1,789**	**8,056**	**100.0**
		Per cent		
Opioids	92.9	7.1	100.0	. .
Paracetamol	65.6	34.4	100.0	. .
Total	**77.8**	**22.2**	**100.0**	**. .**

Source: Supplementary Table S6.4.

For subsidised palliative care schedule opioid prescriptions, rates ranged from 8.6 per 100,000 population for the Northern Territory to 27.7 for Western Australia. For paracetamol, the rates ranged from 12.1 per 100,000 population for Western Australia to 30.5 for Tasmania (Figure 6.2).



Source: Supplementary Table S6.4.

Figure 6.2: Palliative care schedule items for pain relief per 100,000 population, states and territories, 2011–12

All medications prescribed by palliative medicine specialists

There were about 26,200 subsidised prescriptions written by palliative medicine specialists during 2011–12 (Table 6.7). This number includes all PBS/RPBS-subsidised medications prescribed, of which palliative care-related prescriptions on the palliative care schedule are a subset.

Nationally, the most frequently prescribed groups of medications by palliative medicine specialists were those that act on the nervous system (includes analgesics), followed by those that act on the alimentary tract and metabolism (includes drugs for functional gastrointestinal disorders and laxatives) (56.3% and 17.6%, respectively) (Table 6.7).

Table 6.7: All PBS/RPBS-subsidised prescriptions made by palliative medicine specialists, by ATC group, 2011–12

ATC group[(a)]	Number	Per cent
Alimentary tract and metabolism	4,620	17.6
Blood and blood forming organs	895	3.4
Cardiovascular system	1,101	4.2
Dermatologicals	206	0.8
Genito urinary system and sex hormones	70	0.3
Systemic hormonal preparations, excl. sex hormones and insulins	1,409	5.4
Anti-infectives for systemic use	1,642	6.3
Antineoplastic and immunomodulating agents	134	0.5
Musculo-skeletal system	543	2.1
Nervous system	14,742	56.3
Respiratory system	486	1.9
Sensory organs	247	0.9
Various	37	0.1
Other	72	0.3
Total	**26,204**	**100.0**

(a) In the Anatomical Therapeutic Chemical (ATC) classification system, the active substances are divided into different groups according to the organ or system on which they act and their therapeutic, pharmacological and chemical properties (WHO 2011).

Source: DoHA analysis of PBS/RPBS data, unpublished.

Australian Government expenditure on PBS/RPBS-subsidised palliative care-related medications

This section outlines the Australian Government's funding through the PBS/RPBS for claims processed under the PBS and RPBS for subsidised prescribed medications in 2011–12. Under both the PBS and RPBS schemes, the Australian Government subsidises pharmaceutical products regarded as necessary and that are listed in the schedule of pharmaceutical benefits (DoHA 2012b).

During 2011–12, about $3.0 million in benefits for medications included on the palliative care schedule was paid nationally, representing a rate of $13,592 per 100,000 population or about $158 per patient (Table 6.8). Jurisdictional rates ranged from $25,640 per 100,000 population for Western Australia to and equivalent rate of $3,535 for the Northern Territory.

Nationally, analgesics constituted more than three-quarters (76.7%) of this expenditure, followed by laxatives (14.1%). The proportion of benefits paid for analgesics ranged from 91.7% for Western Australia to 46.9% for Tasmania.

Table 6.8: PBS/RPBS benefits paid on PBS/RPBS palliative care-related medications, states and territories[(a)], 2010–11

Medication type	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
					Benefits paid ($)				
Analgesics	597,558	388,644	520,898	561,148	227,383	24,095	20,811	4,031	2,344,567
Anti-emetics and anti-nauseants	4,900	3,430	5,670	2,241	3,302	826	401	134	20,903
Anti-epileptics	15,343	22,253	6,150	6,226	4,977	2,012	287	479	57,726
Anti-inflammatory and anti-rheumatic products	7,879	6,330	2,186	1,782	744	976	1,509	63	21,469
Drugs for functional gastrointestinal disorders	39,741	22,441	53,828	7,714	17,826	4,062	767	575	146,953
Laxatives	143,412	96,094	101,950	29,652	33,884	18,045	3,681	2,710	429,428
Psycholeptics	7,064	5,346	5,657	2,866	2,238	914	168	222	24,475
Stomatological preparations	3,301	3,119	1,935	455	1,248	481	65	—	10,605
Total[(b)]	**819,197**	**547,657**	**698,272**	**612,084**	**291,601**	**51,411**	**27,689**	**8,214**	**3,056,126**
					Per cent				
Analgesics	72.9	71.0	74.6	91.7	78.0	46.9	75.2	49.1	76.7
Anti-emetics and anti-nauseants	0.6	0.6	0.8	0.4	1.1	1.6	1.4	1.6	0.7
Anti-epileptics	1.9	4.1	0.9	1.0	1.7	3.9	1.0	5.8	1.9
Anti-inflammatory and anti-rheumatic products	1.0	1.2	0.3	0.3	0.3	1.9	5.5	0.8	0.7
Drugs for functional gastrointestinal disorders	4.9	4.1	7.7	1.3	6.1	7.9	2.8	7.0	4.8
Laxatives	17.5	17.5	14.6	4.8	11.6	35.1	13.3	33.0	14.1
Psycholeptics	0.9	1.0	0.8	0.5	0.8	1.8	0.6	2.7	0.8
Stomatological preparations	0.4	0.6	0.3	0.1	0.4	0.9	0.2	0.0	0.3
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**
Rate[(c)]	**11,303**	**9,824**	**15,472**	**25,640**	**17,726**	**10,047**	**7,469**	**3,535**	**13,592**

(a) State/territory is based on the postcode of the mailing address of the patient as recorded by Medicare Australia.

(b) Totals may not add due to rounding.

(c) Crude rates are based on the preliminary Australian estimated resident population as at 31 December 2011 and are expressed per 100,000 population (see Appendix C).

Source: DoHA analysis of PBS/RPBS data, unpublished.

Expenditure on PBS/RPBS-subsidised palliative care-related medications over time

Over the 5 years from 2007–08 to 2011–12, the benefits paid for palliative care schedule items increased by an annual average of almost 42% (Table 6.9). There was variability between medication types, with annual average changes ranging from a 24.1% decrease for psycholeptics to a 107.0% increase for analgesics.

Over the 5 years to 2011–12, there was some change in the relative proportion that each medication type made to the total amount of benefits paid. Analgesics increased from about 17% to about 77% over the 5 years, whereas laxatives and anti-epileptics decreased from about 44% and 16%, respectively, to 14% and 2%, respectively.

Table 6.9: PBS/RPBS benefits paid[(a)] on palliative care schedule items, 2007–08 to 2011–12

Medication type	2007–08	2008–09	2009–10	2010–11	2011–12	Annual average change (per cent)
			Benefits paid ($)			
Analgesics	127,590	1,121,677	1,571,594	1,987,303	2,344,567	107.0
Anti-emetics and anti-nauseants	12,155	12,943	11,693	13,069	20,903	14.5
Anti-epileptics	120,443	95,018	81,027	74,439	57,726	–16.8
Anti-inflammatory and anti-rheumatic products	26,198	16,070	13,547	15,867	21,469	–4.9
Drugs for functional gastrointestinal disorders	54,009	72,132	75,276	105,264	146,953	28.4
Laxatives	334,736	282,494	256,250	295,135	429,428	6.4
Psycholeptics	73,731	50,696	43,956	37,065	24,475	–24.1
Stomatological preparations	6,332	6,158	7,689	6,322	10,605	13.8
Total	**755,194**	**1,657,187**	**2,061,032**	**2,534,463**	**3,056,126**	**41.8**
			Per cent			
Analgesics	16.9	67.7	76.3	78.4	76.7	. .
Anti-emetics and anti-nauseants	1.6	0.8	0.6	0.5	0.7	. .
Anti-epileptics	15.9	5.7	3.9	2.9	1.9	. .
Anti-inflammatory and anti-rheumatic products	3.5	1.0	0.7	0.6	0.7	. .
Drugs for functional gastrointestinal disorders	7.2	4.4	3.7	4.2	4.8	. .
Laxatives	44.3	17.0	12.4	11.6	14.1	. .
Psycholeptics	9.8	3.1	2.1	1.5	0.8	. .
Stomatological preparations	0.8	0.4	0.4	0.2	0.3	. .
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**. .**

(a) All figures are in Australian dollars in current prices (that is, unadjusted for inflation).

Source: DoHA analysis of PBS/RPBS data, unpublished.

All medications prescribed by palliative medicine specialists

The information presented in this section relates to all PBS/RPBS-subsidised prescriptions made by palliative medicine specialists during 2011–12 (Table 6.10). This number includes all medications prescribed, of which palliative care-related prescriptions on the palliative care schedule are a subset.

Nearly 70% of the benefits were paid for medications that act on the nervous system (includes analgesics). This was followed by those that act on the alimentary tract and metabolism (includes drugs for functional gastrointestinal disorders and laxatives), which constitutes nearly 9% of the total benefits paid by ATC group (Table 6.10).

Table 6.10: All PBS/RPBS benefits paid[(a)] for prescriptions made by palliative medicine specialists, by ATC group, 2011–12

ATC group[(b)]	Benefits paid ($)	Per cent
Alimentary tract and metabolism	112,017	8.9
Blood and blood forming organs	72,602	5.8
Cardiovascular system	22,210	1.8
Dermatologicals	2,752	0.2
Genito urinary system and sex hormones	1,846	0.1
Systemic hormonal preparations, excl. sex hormones and insulins	17,280	1.4
Anti-infectives for systemic use	51,963	4.1
Antineoplastic and immunomodulating agents	50,219	4.0
Musculo-skeletal system	32,316	2.6
Nervous system	876,094	69.5
Respiratory system	15,171	1.2
Sensory organs	3,157	0.3
Various	949	0.1
Other	2,539	0.2
Total	**1,261,116**	**100.0**

(a) All figures are in Australian dollars in current prices (that is, unadjusted for inflation).

(b) In the Anatomical Therapeutic Chemical (ATC) classification system, the active substances are divided into different groups according to the organ or system on which they act and their therapeutic, pharmacological and chemical properties (WHO 2011).

Source: DoHA analysis of PBS/RPBS data, unpublished.

7 Workforce

7.1 Introduction

The palliative care workforce is characterised by a variety of health professionals including specialist palliative medicine physicians, nurses, GPs, pharmacists, medical specialists such as oncologists and geriatricians, as well as other health workers, support staff and volunteers.

Medical practitioners **employed** (see Key concepts) in palliative care complete specialist training to become specialist palliative medicine physicians. Specialist palliative medicine physicians are required to have completed several more years of training after their initial medical training, such as advanced training in palliative medicine through the Royal Australasian College of Physicians or the Australasian Chapter of Palliative Medicine (CareSearch 2012). Many of these physicians have previously completed training as a GP or in another medical specialty.

The information presented in this chapter describes the number and characteristics of the workforce of palliative care medical practitioners. The annual AIHW Labour Force Surveys for medical practitioners and nurses and midwives were replaced from July 2010 onwards by the NHWDS, from data collected under the National Registration and Accreditation Scheme for health professionals. Data for palliative care nurses were not collected as part of the 2011 survey but will be available from the 2013 survey onwards. The most recent published figures for palliative care nurses for 2009 are available in the report *Palliative care services in Australia 2012* (AIHW 2012c). Estimates of the medical workforce before 2010 were derived from the responses to the AIHW Medical Labour Force Survey. Further details on these data sources are outlined at Appendix B.

Key concepts

Employed health professional is defined in this report as one who:

- worked for a total of 1 hour or more, principally in the relevant profession, for pay, commission, payment in kind or profit, mainly or only in a particular state or territory during a specified period (the week before the survey), or
- usually worked but was away on leave (with some pay) for less than 3 months, on strike or locked out, or rostered off.

This includes those involved in clinical and non-clinical roles; for example, education, research and administration. 'Employed' people are referred to as the 'workforce' in this chapter. This includes only practitioners whose main speciality is palliative care and excludes those medical practitioners practising palliative care as a second or third speciality and those who were on extended leave for more than 3 months or who were not employed.

Full-time equivalent (FTE) represents the number of 38-hour-week workloads worked by professionals. The FTE is calculated by multiplying the number of employed professionals in a specific category by the average total hours worked by employed people in that category, and dividing by 38. The figures for FTE per 100,000 population provide a standardised measure of supply of professionals. The standard of a 38-hour working week was used in this report to provide figures comparable with previously published data.

Total hours are the total hours worked per week in the profession, including paid and unpaid work. Average total weekly hours are calculated only for those people who reported their hours (that is, those who did not report them are excluded).

7.2 Specialist palliative medicine physicians

The information on specialist palliative medicine physicians provides estimates derived from the AIHW Medical Labour Force Surveys 2007 to 2009 and the Medical Workforce Survey 2010 and 2011 (see Box 7.1). These surveys collected information on the demographic and employment characteristics of practitioners who were registered in Australia at the time of the survey.

Box 7.1: Medical Workforce Survey 2011

In 2010, the National Registration and Accreditation System for health professionals was introduced and the AIHW Medical Labour Force Survey was replaced with the Medical Workforce Survey.

The overall response rate to the Medical Workforce Survey 2011 was 85.3%, which was higher than for any previous AIHW Medical Labour Force Survey. New South Wales, South Australia and Victoria had the highest response rates at 87.7%, 86.7% and 85.9%, respectively. The Northern Territory had the lowest response rate at 82.4%.

To meaningfully compare the supply of specialist palliative medicine physicians across Australia over time, FTE figures are provided in addition to the number of specialist palliative medicine physicians and the average ***total hours*** worked (see Key concepts). The FTE measures the number of 38-hour-week worked by specialist palliative medicine physicians, regardless of how many worked full time or part time. Population standardised FTE figures (FTE per 100,000 population) are also reported, as these take into account differences in the size of the relevant populations between regions and over time. The AIHW labour force surveys and current NHWDS workforce surveys have different collection and estimation methodologies, questionnaire designs and response rates. As a result, care should be taken in comparing historical data from the AIHW labour force surveys and data from the NHWDS.

Characteristics of specialist palliative medicine physicians

Specialist palliative medicine physicians made up nearly 4 in every 1,000 (0.38%) employed medical specialists in Australia, with an estimated 92 working in Australia in 2011 (Table 7.1). Nationally, in 2011, there were 71 vocational trainees under the Australian Chapter of Palliative Medicine’s 3-year training program and 44 physician adult medicine advanced trainees undertaking training in palliative care with the Royal Australasian College of Physicians (DoHA 2012a).

In 2011, more than half (56.5%) of employed specialist palliative medicine physicians were female. This was more than double the proportion of all employed female medical practitioners who practice as other types of clinician specialists (25.6%) (AIHW 2013).

The average age of specialist palliative medicine physicians was 51, with female physicians being younger, on average, than their male counterparts.

Specialist palliative medicine physicians worked an average of 39.5 total hours per week in 2011 (Table 7.2), which was less than the average hours worked per week by all employed medical practitioners who were specialists (44.7) (AIHW 2013). The hours worked per week were, on average, lower for females than males (36.4 hours and 43.5 hours, respectively).

Table 7.1: Employed specialist palliative medicine physicians, demographic characteristics, 2007–2011[(a)]

Demographic characteristic	2007	2008	2009	2010[(b)]	2011	2011 (per cent)
Sex (number)						
Males	84	69	74	28	40	43.5
Females	79	73	79	31	52	56.5
Age group (years) and sex						
Males						
<35	5	n.p.	5	n.p.	—	—
35–44	18	11	18	n.p.	5	5.4
45–54	31	26	15	7	9	9.8
55–64	25	23	29	11	20	21.7
65+	5	n.p.	8	6	6	6.5
Females						
<35	n.p.	—	—	n.p.	n.p.	n.p.
35–44	29	28	29	10	18	19.6
45–54	24	18	25	13	17	18.5
55–64	17	18	19	n.p.	13	14.1
65+	n.p.	8	6	n.p.	n.p.	n.p.
Total[(c)]	**163**	**142**	**153**	**59**	**92**	**100.0**
Average age (years)						
Males	50.4	52.5	51.9	55.8	56.1	. .
Females	48.9	50.2	50.2	48.3	47.6	. .
All	*49.6*	*51.3*	*51.0*	*51.9*	*51.3*	. .
All employed medical practitioners (number)	**62,425**	**68,455**	**72,739**	**53,646**	**78,833**	**. .**

(a) From 2007 to 2009, labour force survey data contained 54 categories for specialty. The 2010 and 2011 NHWDS data contain 23 categories for specialty. Data may not be comparable across years.

(b) Excludes Queensland and Western Australia.

(c) The number for each variable may not sum to the total due to the estimation process and rounding.

Sources: AIHW Medical Labour Force Surveys, 2007, 2008, 2009; NHWDS: medical practitioners 2010, 2011.

Table 7.2: Employed specialist palliative medicine physicians, average number of total hours worked per week, type and sex, 2007–2011[(a)]

Sex	2007	2008	2009	2010[(b)]	2011
Males	46.9	43.2	44.1	42.8	43.5
Females	37.1	35.6	31.8	35.1	36.4
Total	**42.3**	**39.3**	**37.9**	**38.8**	**39.5**

(a) From 2007 to 2009, labour force survey data contained 54 categories for specialty. The 2010 and 2011 NHWDS data contain 23 categories for specialty. Data may not be comparable across years.

(b) Excludes Queensland and Western Australia.

Sources: AIHW Medical Labour Force Surveys, 2007, 2008, 2009; NHWDS: medical practitioners 2010, 2011.

Nationally, there were 0.4 **full-time-equivalent** (FTE) specialist palliative medicine physicians per 100,000 population in 2011 (Table 7.3). The number of FTE specialist palliative medicine physicians per 100,000 population among the states and territories ranged from 0.3 in Victoria and Western Australia to 0.5 for New South Wales and South Australia. No FTE specialist palliative medicine physicians were recorded in the Northern Territory. The average hours worked varied across jurisdictions, ranging from 33.0 hours per week for Victoria to 46.6 hours per week for Queensland.

Table 7.3: Employed specialist palliative medicine physicians, average total hours worked per week, FTE and FTE per 100,000 population, states and territories, 2011

State or territory	Number of specialist palliative medicine physicians	Average total hours worked per week	FTE number	FTE per 100,000 population[(a)]
New South Wales	39	38.8	40	0.5
Victoria	19	33.0	17	0.3
Queensland	14	46.6	17	0.4
Western Australia	6	38.3	6	0.3
South Australia	7	42.4	8	0.5
Tasmania	n.p.	n.p.	n.p.	n.p.
Australian Capital Territory	n.p.	n.p.	n.p.	n.p.
Northern Territory	—	—	—	—
Total[(b)]	**92**	**39.5**	**95**	**0.4**

(a) Crude rates are based on the preliminary Australian estimated resident population as at 30 June 2011 and are expressed per 100,000 population (see Appendix C).

(b) The number for each variable may not sum to the total due to the estimation process and rounding.

Note: FTE number is based on a 38-hour standard working week.

Source: NHWDS: medical practitioners 2011.

Almost 9 out of 10 (85.9%) FTE specialist palliative medicine physicians worked mainly in the *Major cities* (Table 7.4) during 2011. Once population sizes for each remoteness area were taken into account, the FTE specialist palliative medicine physicians per 100,000 population was highest for *Major cities* (0.5), followed by *Outer regional* (0.3) and *Inner regional* (0.2) areas.

Table 7.4: Employed specialist palliative medicine physicians by remoteness area, average total hours worked per week, 2011

Remoteness area of main job	Number	Average total hours worked per week	FTE number	FTE per 100,000 population[(a)]
Major cities	79	39.2	81	0.5
Inner regional	8	42.8	9	0.2
Outer regional	5	39.2	5	0.3
Remote and very remote	—	—	—	—
Total[(b)]	**92**	**39.5**	**95**	**0.4**

(a) Crude rates are based on the preliminary Australian estimated resident population as at 30 June 2011 and are expressed per 100,000 population (see Appendix C).

(b) The number for each variable may not sum to the total due to the estimation process and rounding.

Note: FTE number is based on a 38-hour standard working week.

Source: NHWDS: medical practitioners 2011.

8 Palliative care outcomes

8.1 Introduction

The Palliative Care Outcomes Collaboration (PCOC) was established in mid–2005 and is funded by the Australian Government. The goal of the PCOC is to use standardised, validated clinical assessment tools to benchmark and measure patient outcomes in palliative care and to assist palliative care service providers to improve practice and meet the Palliative Care Australia (PCA) *Standards for Providing Quality Palliative Care*. While participation by palliative care services in the PCOC is voluntary, the PCOC estimates that over three-quarters of patients seen by palliative care services are included in the collection.

8.2 Palliative Care Outcomes data set

Data using Version 1 of the PCOC data set were collected between January 2006 and January 2007. Version 2 of the data set was implemented from July 2007, and Version 3 has been progressively implemented since July 2012 (PCOC 2012). The items included in the PCOC data set serve the dual purpose of:

- defining a common clinical language to allow palliative care providers to communicate
- facilitating the routine collection of nationally consistent palliative care data for the purpose of reporting and benchmarking to drive quality improvement.

What data are reported?

There were 30,405 patients accessing specialist palliative care services in 2012, an increase of 11.8% from 2011 (27,201). There were 108 specialist palliative care services that reported to the PCOC in 2012—an increase of 1 service since 2011.

The information presented in this chapter refers to palliative care service data reported to the PCOC for the 1 January to 31 December 2012 reporting period. The three levels of PCOC data items are presented here; namely **patient level**, **episode level** and **phase level** care data (see Key concepts).

The information provided on total number of days for **episodes of care** is categorised by two broad types of care—inpatient and ambulatory/community care. Inpatient episodes of care are those for which the intent of the admission was for the patient to be in hospital overnight. This includes those patients who were admitted and died on the day of their admission. Ambulatory/community patients refer to those patients who received palliative care either in their home, a residential aged care facility, an outpatient clinic or day only. It should be noted that the number of patients reported to the PCOC refers to patients who may receive services both within the inpatient and ambulatory/community settings. Hence, as these two categories are not mutually exclusive, the same patient can have an inpatient episode and then subsequent ambulatory/community episodes and may be counted for both service settings.

Key concepts

Patient level data relate to patient demographics.

Episode level data items provide information on the reasons why and how a palliative care episode starts/ends; the level of support a palliative care patient received, both before and after an episode; and (where applicable) the setting in which the patient died.

Phase level data items describe a palliative care patient's stage of illness, functional impairment and their levels of pain and symptom distress. There are five assessment tools used to describe the clinical condition of a patient, which, in turn, contribute to a patient's care plan. These assessment tools are phase of care, palliative care problem, severity, Australia-modified Karnofsky, and Resource Utilisation Groups—Activities of Daily Living (RUG–ADL) which provide measures of quality and outcomes of care.

The PCOC analyses each service's data and compares these with the national average. The items at the phase level are used to quantify patient outcomes and are the focus of the PCOC benchmarks.

An **episode of care** is a period of contact between a patient and a service where palliative care is provided in one setting. An episode is initiated on the day the patient is assessed, either face-to-face or via telephone, and an agreed plan of care between the patient and/or carer and the service is commenced.

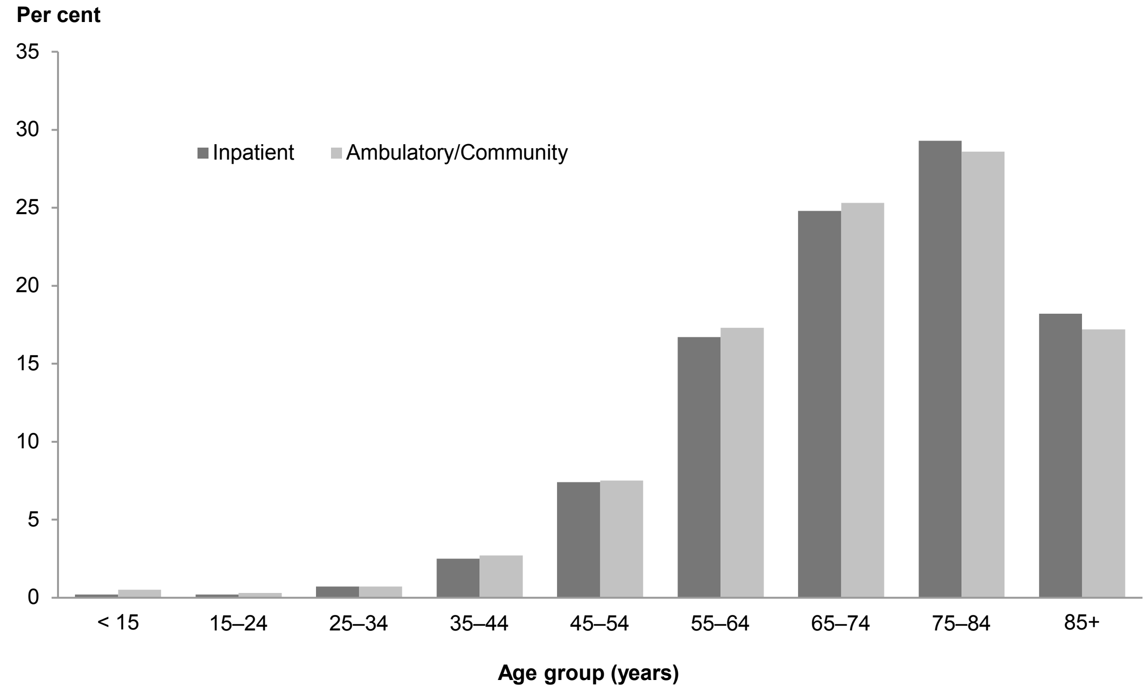
8.3 Patient characteristics

Age and sex

In 2012, there were 39,177 episodes of care reported to the PCOC, of which more than half (56.3%; 22,069) were **inpatient** episodes. The provision of palliative care by age group for 2012 is shown in Figure 8.1. People aged 65 to 84 accounted for over half of all episodes (54.0%), while those aged 45 to 64 accounted for almost 1 in 4 (24.3%) and those aged 85 and over, 1 in 6 (17.7%). People aged 25 to 44 accounted for fewer than 1 in 20 (3.3%), while those aged 24 or younger made up fewer than 1 in 100 (0.6%).

The average age for all patients reported to the PCOC during this period was 71.7, with a median age of 73.0 for all services. There were 20,880 male palliative care patients in 2012, accounting for 53.4% of episodes and 18,235 female patients (46.6% of episodes).

The age and sex characteristics of patients in the 2012 PCOC data are essentially unchanged from the 2011 results.



Note: Data for this figure are shown in Supplementary Table S8.1.

Source: PCOC Analysis of 2012 data (unpublished).

Figure 8.1: Age distribution for PCOC inpatient and ambulatory/community episodes of care, Australia, 2012

Language spoken and country of birth

Information on 'main language spoken at home' provides information on the diversity of the palliative care patient population. This information may also be useful in providing a greater understanding of the cultural needs of a service, such as interpreter access. In 2012, English was the most frequently reported main language spoken at home (91.7% of episodes). This was followed by Italian (1.8%), Greek (1.2%) and Cantonese (0.6%) (Table 8.1). A different distribution to these findings was seen in the 2011 Census (ABS 2013), where 76.8% of the Australian population were recorded as speaking English, followed by Mandarin (1.6%), Italian (1.4%) and Arabic (1.3%).

The main country of birth was Australia for 64.1% of PCOC episodes of palliative care. This was followed by England (7.4%), Italy (3.9%) and Greece (2.1%) (Table 8.2). As with main language spoken at home, a slightly different distribution is seen for the general population, with Australia and England being the top two countries of birth (69.8% and 4.2%, respectively) followed by New Zealand (2.2%) and China (1.5%) (ABS 2013).

Table 8.1: PCOC palliative care episodes, by top four languages spoken at home, 2012

Palliative care episodes			General population[a]		
Main language	Number[b]	Per cent[c]	Main language	Number	Per cent of total persons 2011 Census
English	33,445	91.7	English	16,509,291	76.8
Italian	652	1.8	Mandarin	336,410	1.6
Greek	422	1.2	Italian	299,834	1.4
Cantonese	229	0.6	Arabic	287,174	1.3
All other languages	1,707	4.7	. .	. .	. .
Total	**39,177**	**100.0**	**. .**	**. .**	**. .**

(a) Data refer to main responses for 'Language spoken at home', Australia 2011 Census.

(b) Numbers may not add to the totals due to not-reported data.

(c) The percentages shown do not include episodes for which data were missing or not reported.

Sources: PCOC analysis of 2012 data (unpublished); ABS 2013.

Table 8.2: PCOC palliative care episodes, by country of birth, 2012

Palliative care episodes			General population		
Country of birth	Number[a]	Per cent[b]	Country of birth	Number	Per cent of total persons 2011 Census
Australia	24,517	64.1	Australia	15,017,847	69.8
England	2,820	7.4	England	911,593	4.2
Italy	1,480	3.9	New Zealand	483,398	2.2
Greece	795	2.1	China[c]	318,969	1.5
All other countries	8,660	22.6	. .	. .	. .
Total[b][c]	**39,177**	**100.0**	**. .**	**. .**	**. .**

(a) Numbers may not add to the totals due to not-reported data.

(b) The percentages shown do not include episodes for which data were missing or not reported.

(c) Excludes Special Administrative Regions and Taiwan Province.

Sources: PCOC Analysis of 2012 data (unpublished); ABS 2013.

Diagnosis

More than 4 in 5 episodes (83.0%) were characterised by a cancer diagnosis, while about 1 in 6 (17.0%) had a non-cancer diagnosis (Table 8.3). The three most frequently recorded diagnoses were neoplasms of the lung (16.7%), colorectal cancer (9.2%) and other gastro-intestinal cancers (7.1%) (Table 8.4).

The diagnosis profile of patients included in the 2012 data is essentially unchanged from that seen in 2011.

Table 8.3: PCOC palliative care episodes, cancer and non-cancer diagnosis, 2012

Diagnosis	Number[(a)]	Per cent[(b)]
Cancer	31,572	83.0
Non-cancer	6,445	17.0
Total	**39,177**	**100.0**

(a) Numbers may not add to the total due to not-reported data.

(b) The percentages shown do not include episodes for which data were missing and/or not reported.

Source: PCOC analysis of 2012 data (unpublished).

Table 8.4: PCOC palliative care episodes, three most frequently recorded cancer diagnoses, 2012

Diagnosis	Number[(a)]	Per cent[(b)]
Neoplasm of the lung	6,529	16.7
Colorectal cancer	3,616	9.2
Other gastro-intestinal cancer	2,762	7.1
Total	**39,177**	. .

(a) Numbers may not add to the total due to not-reported data.

(b) The percentage shown was calculated using total number of episodes where diagnosis was reported as the denominator.

Source: PCOC analysis of 2012 data (unpublished).

Socio-economic status

This section presents information on PCOC episodes based on the socioeconomic status of the usual residence of the patient. Socioeconomic status is generally associated with access to material resources, educational opportunities and health status (AIHW 2010a). The ABS SEIFA measure various aspects of socioeconomic conditions by geographic areas using a range of indexes (ABS 2012d). This section uses the ABS Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD).

From January to December 2012, those people living in areas classified as having the lowest socioeconomic status (quintile 1) accounted for 1 in 7 PCOC episodes (14.2%) (Table 8.5). The highest proportion of episodes, almost one-third, was seen for those patients living in the highest socioeconomic status area (31.7%), with this quintile proportionally over-represented in both the inpatient and ambulatory/community settings. Overall, there was little difference in proportions between inpatient and ambulatory/community settings.

Table 8.5: PCOC palliative care episodes by socioeconomic status, 2012

	Inpatient		Ambulatory/Community		Total	
SEIFA quintile	Number[(a)]	Per cent[(b)]	Number[(a)]	Per cent[(b)]	Number[(a)]	Per cent[(b)]
1 (Lowest)	2,881	13.5	2,544	15.1	5,425	14.2
2	3,186	15.0	1,939	11.5	5,125	13.5
3	4,060	19.1	3,123	18.6	7,183	18.9
4	4,687	22.0	3,607	21.5	8,294	21.8
5 (Highest)	6,474	30.4	5,588	33.3	12,062	31.7
Total	**21,288**	**100.0**	**16,801**	**100.0**	**39,177**	**100.0**

(a) Numbers may not add to the total due to not-reported data.

(b) The percentage shown was calculated using total number of episodes where diagnosis was reported as the denominator.

Source: PCOC Analysis of 2012 data (unpublished).

8.4 Episode length

The following information refers to closed episodes within the inpatient and ambulatory/community care setting reported to PCOC for 2012. Closed episodes are those that end because either the:

- principal clinical intent of the care changes and the patient is no longer receiving palliative care
- patient is formally separated from the service for palliative care
- patient dies.

The average number of days for each episode of care in the inpatient setting was 11.9 days, with a median of 7 days during 2012 (Table 8.6). The difference between the average and the median number is noteworthy, reflecting a 'skewed' distribution for inpatient palliative care episodes due to those episodes of longer duration. This finding was also seen for the ambulatory/community setting.

Table 8.6 shows the average number of elapsed days during 2012 for inpatient and ambulatory/community care settings. The elapsed days represent the number of days between the start and end of an episode and do not take into account leave days. Within the ambulatory/community setting, the elapsed days do not reflect the number of times the palliative care team visited the patient. In addition, the contributions of bereavement phases have been excluded from the calculations used to generate the elapsed episode level data.

Table 8.6: PCOC, average number of elapsed days by palliative care setting, 2012

	Inpatient	Ambulatory/Community
Average number of days	11.9	36.9
Median number of days	7	21

Source: PCOC analysis of 2012 data (unpublished).

There were 37,582 closed episodes reported to the PCOC for 2012 compared with 34,562 for 2011 (an increase of about 8.7%). Nearly three-quarters (70.3%) of inpatient episodes lasted between 1 and 14 days, with 18.8% lasting 1–2 days and 20.6% lasting 8–14 days (Table 8.7). This pattern differed for the ambulatory/community setting, where the number of episodes increased as the days spent in care increased; 61.0% of palliative care episodes were 15 days or longer (Table 8.7).

Table 8.7: PCOC, closed episodes by number of elapsed days in palliative care inpatient and ambulatory/community care settings, 2012

	Inpatient		Ambulatory/Community		Total	
Elapsed days	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
Same-day	830	3.8	1,172	7.3	2,002	5.3
1–2 days	4,066	18.8	1,118	7.0	5,184	13.8
3–4 days	3,056	14.1	834	5.2	3,890	10.4
5–7 days	3,622	16.8	1,202	7.5	4,824	12.8
8–14 days	4,446	20.6	1,909	11.9	6,355	16.9
15–21 days	2,230	10.3	1,369	8.6	3,599	9.6
22–30 days	1,482	6.9	1,313	8.2	2,795	7.4
31–60 days	1,453	6.7	2,653	16.6	4,106	10.9
61–90 days	260	1.2	1,378	8.6	1,638	4.4
> 90 days	158	0.7	3,031	19.0	3,189	8.5
Total	**21,603**	**100.0**	**15,979**	**100.0**	**37,582**	**100.0**

Source: PCOC analysis of 2012 data (unpublished).

8.5 Palliative care phases

The **palliative care phase** describes the stage of the patient's illness within an episode of care and provides a clinical indication of the level of care required (see Key concepts). It should be noted that palliative care phases are not necessarily sequential and that the patient may transition back and forth between phases during an episode; there may also be more than one phase of care within an episode.

Key concepts

The five **palliative care phases** are:

1. **Stable Phase Start:** Patient problems and symptoms are adequately controlled by an established plan of care; further interventions to maintain symptom control and quality of life have been planned and the family/carer(s) situation is relatively stable and no new issues are apparent.

   Stable Phase End: The needs of the patient and or family/carer(s) increase, requiring changes to the existing plan of care.
2. **Unstable Phase Start:** An urgent change in the plan of care or emergency treatment is required because the patient experiences a new problem that was not anticipated in the existing plan of care; and/or the patient experiences a rapid increase in the severity of a current problem; and/or the circumstances of the patient's family/carer(s) change suddenly, impacting on patient care.

(continued)

Unstable Phase End: The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom crisis has fully resolved but there is a clear diagnosis and plan of care (that is, the patient is stable or deteriorating) and/or death is likely within days (that is, the patient is now terminal).

3. **Deteriorating Phase Start:** The care plan is addressing anticipated needs but requires periodic review because the patient's overall functional status is declining; the patient experiences a gradual worsening of existing problem and/or experiences a new but anticipated problem and/or the family/carer(s) experience gradually worsening distress that impacts on the patient's care.

   Deteriorating Phase End: The patient condition plateaus (that is, the patient is now stable) or there is an urgent change in the care plan or emergency treatment and/or the family/carer(s) experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (that is, the patient is now unstable) or death is likely within days (that is, the patient is now terminal).
4. **Terminal Phase Start:** Death is likely within days.

   Terminal Phase End: The patient dies or the patient condition changes and death is no longer likely within days (that is, the patient is now stable or deteriorating).
5. **Bereaved/post death support Phase Start:** The patient has died. Bereavement support provided to the family/carer(s) is documented in the deceased patient's clinical record.

   Bereaved/post death support Phase End: Case closure.

Table 8.8 presents information on the number and type of palliative care phases. There was a total of 90,127 PCOC palliative care phases reported in 2012, with almost two-thirds (62.4%) occurring in inpatient palliative care. Of these, over one-quarter (27.0%) were in a deteriorating phase. Of the 33,912 phases reported in the ambulatory/community care setting, 39.4% were deteriorating, followed by stable (38.0%) and unstable (13.3%).

The average phase length (elapsed days) was highest for the stable phase at 7.5 days in the inpatient setting; in the ambulatory/community care setting, the stable phase had the highest average number of elapsed days (at 21.1 days), followed by deteriorating (15.5 days) (Table 8.9). These characteristics are essentially unchanged from the 2011 results presented in the 2012 report.

Table 8.8: PCOC, phase counts by palliative care phase and setting, 2012

	Inpatient		Ambulatory/Community		Total	
Palliative care phase	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
Stable	13,821	24.6	12,893	38.0	26,714	29.6
Unstable	14,849	26.4	4,518	13.3	19,367	21.5
Deteriorating	15,163	27.0	13,359	39.4	28,522	31.6
Terminal	9,247	16.4	2,825	8.3	12,072	13.4
Bereaved	3,135	5.6	317	0.9	3,452	3.8
Total (row)	**56,215**	**62.4**	**33,912**	**37.6**	**90,127**	**100.0**

Source: PCOC analysis of 2012 data (unpublished).

Table 8.9: PCOC, average phase length (elapsed number of days) by palliative care phase type and setting, 2012

Phase	Inpatient days	Ambulatory/Community days
Stable	7.5	21.1
Unstable	3.3	7.4
Deteriorating	5.3	15.5
Terminal	2.2	3.0
Bereaved	1.2	2.8

Source: PCOC analysis of 2012 data (unpublished).

8.6 Palliative care outcome measures and benchmarks

In 2009, the PCOC, in collaboration with participating palliative care services, developed a set of national palliative care outcome benchmarks. The purpose of benchmarking is to drive palliative care service innovation and provide participating services with the opportunity to compare their service nationally. In this section, three of PCOC's outcome measures are presented, with the national performance against each benchmark summarised (see Box 8.1 for information on the three outcome measures and Table 8.10 for benchmark definitions). These outcome measures cover:

1. time from referral to first contact
2. time patient spent in an unstable phase
3. change in pain.

Table 8.10 presents results compared with benchmarks for the three measures of palliative care outcomes, while Supplementary Table S8.2 shows the same benchmark results by palliative care setting (inpatient and ambulatory/community).

Nearly half (45.8%) of all PCOC contributing providers met benchmark 1.1, where 90% of patients were contacted by a member of the clinical team within 2 days of receipt of referral (Table 8.10). Almost three-quarters (74.3%) of inpatient episodes met this benchmark in 2012, compared with almost 1 in 5 ambulatory/community services.

Around 1 in 10 services (11.1%) met benchmark 2.1 (Table 8.10); there was a slight difference between the inpatient and ambulatory/community setting, with 16.0% of inpatient services and 11.1% of ambulatory/community services meeting this benchmark (Supplementary Table S8.2).

Benchmarks 3.1 and 3.3 (that is, 90% of phases that started with absent/mild pain at the start of the phase remain in absent/mild pain at the end of the phase) were met by 20.0% and 14.6% of all services, respectively, while 36.0% and 25.0% of services, respectively, met benchmarks 3.2 and 3.4 (that is, moderate/severe pain has reduced to absent/mild pain at phase end for 60% of patients (Table 8.10).

Box 8.1: Summary of outcome measures 1–3

Outcome measure 1: Time from referral to first contact for the episode

'Time from referral to first clinical contact' relates to the responsiveness of palliative care services in terms of patient needs. This measure is the time (in days) between the referral date and the date of first clinical contact or episode start date (whichever occurs first) and is measured for all episodes of care and across all settings of care. Although definitional issues relating to this measure exist, this benchmark still provides a useful measure of service responsiveness.

Outcome measure 2: Time in unstable phase

This outcome measure relates to the number of patients in the 'unstable phase' and the number of days they remain in an unstable phase during their episode of care. The unstable phase, by nature of its definition, alerts clinical staff to the need for urgent or emergency intervention. This phase shows the effectiveness of the intervention(s) implemented for a specific new problem or the exacerbation of an existing problem. Those patients determined as being in the unstable phase should have their problem(s) managed and under control within this period of time, regardless of the setting of care.

This measure was originally associated with three benchmarks. However, following consultation at the 2012 PCOC benchmarking workshops, these were replaced with one consolidated benchmark. Further detail can be found at Appendix E.

Outcome measure 3: Change in pain

Pain management is acknowledged as the 'core business' for palliative care services; hence, measuring patient distress from pain is considered an important outcome for palliative care services. Two of the five assessment tools used in PCOC are used to measure pain: the Symptom Assessment Scale (SAS) is a patient-rated tool and the Palliative Care Problem Severity Score (PCPSS) is a clinician-rated tool.

Palliative care patients are assessed at two levels of outcomes for pain. These are:

1. Patients with absent/mild pain at phase start
2. Patients with moderate/severe pain at phase start.

Ideally, those patients with absent/mild pain at the beginning of the phase should be maintained with absent/mild pain at the end of the phase. Similarly, patients in moderate/severe pain at the start of a phase should be able to achieve mild/absent pain at the end of the phase.

Any change in pain is measured by the difference in pain score from the beginning of a phase to the end of a phase and is calculated using both PCPSS and SAS pain measures.

Table 8.10: Summary of PCOC palliative care outcome benchmark results, 2012

Outcome measure	Benchmark scores
1: Time from referral to first contact for the episode	
Benchmark 1: 90% of patients are contacted by a member of the clinical team on the day of, or the day after, referral	• 45.8% of services met benchmark (Inpatient + Ambulatory/Community combined) • 74.3% of episodes met benchmark (Inpatient + Ambulatory/Community combined)
2: Time in unstable phase	
Benchmark 2[(a)]: 90% of patients are in the unstable phase for 3 days or less	• 11.1% of services met benchmark • 67.3% of patient phases satisfied the benchmark criteria
3: Change in pain	
Benchmark 3.1: 90% of patients with absent/mild pain at phase start remain in absent/mild pain at phase end as rated by the clinician on the PCPSS tool	• 20.0% of services met this benchmark • 84.5% of patient phases satisfied the benchmark criteria
Benchmark 3.2: 60% of patients in moderate/severe pain at phase start must be reduced to absent/mild pain at phase end as rated by the clinician on the PCPSS tool	• 36.0% of services met this benchmark • 51.5% of patient phases satisfied the benchmark criteria
Benchmark 3.3: 90% of patients with absent/mild pain at the beginning of a phase remain in absent or mild pain at phase end as rated by the patient on the SAS tool	• 14.6% of services met this benchmark • 83.5% of patient phases satisfied the benchmark criteria
Benchmark 3.4: 60% of patients with moderate/severe pain at phase start must reduce to absent/mild pain at phase end as rated by the patient on the SAS tool	• 25.0% of services met this benchmark • 47.7% of patient phases satisfied the benchmark criteria

(a) This benchmark was updated in 2012 and has replaced the former benchmarks 2.1, 2.2 and 2.3. See Appendix E.

Source: PCOC analysis of 2012 data (unpublished).

9 Palliative care facilities and services

This chapter summarises available information on various palliative care facilities and programs, including hospice care units in public hospitals, as well as Community Nursing services for DVA clients.

9.1 Hospice units in public hospitals

This section presents an overview of the number of hospice care units provided across public hospitals in Australia. It also provides information on the number of specialised services provided across public acute hospitals, and time series information on the number of hospice care units for these hospitals from 2006–07 to 2010–11. The hospital types reported in this section relate only to public acute hospitals. Information on public hospital resources was derived from the NPHED (see Appendix B for data source information).

A hospice care unit is a type of specialist unit delivering palliative care services and can include both free-standing hospices and/or palliative care wards. There is inter-jurisdictional variability regarding how hospices are identified in the NPHED. In considering the information presented in this section, it should also be noted that palliative care services may be delivered in other specialist care units within a hospital, which are unlikely to be identified as a hospice care unit and so not included within the data reported here. In addition, the information derived from the NPHED does not include all hospice services in Australia—for example, those private health-care providers/hospitals providing hospice care services are not in scope for this data collection.

In 2010–11, there was a total of 136 public acute hospitals with a hospice care unit in Australia, with over one-third located in New South Wales (Table 9.1). Of the 735 public acute hospitals (excluding public psychiatric hospitals) in Australia (AIHW 2012a), more than 1 in 6 (18.5%) had a hospice care unit. Just over one-quarter (26.0%) of all hospitals with hospice care units were located in *Major cities*. Data on specialised services were not available for a small number of hospitals, so the services may be under-counted.

Table 9.1: Public acute hospitals with hospice care units, by remoteness area, states and territories, 2010–11

Remoteness area	NSW[(a)]	Vic[(b)]	Qld	WA	SA[(b)]	Tas	ACT	NT	Total[(c)]
					Number				
Major cities	16	16	6	0	5	0	1	0	44
Regional	33	8	5	20	4	1	0	1	72
Remote	3	0	0	10	4	0	0	0	17
Total	**52**	**27**	**11**	**30**	**13**	**1**	**1**	**1**	**136**
					Per cent[(d)]				
Major cities	25.8	30.2	35.3	0.0	38.5	. .	33.3	. .	26.0
Regional	23.7	8.4	6.4	54.1	9.3	5.6	0.0	100.0	17.5
Remote	17.6	0.0	0.0	28.6	18.2	0.0	0.0	0.0	11.0
Total[(c)(d)]	**23.9**	**18.0**	**6.6**	**32.3**	**16.7**	**4.5**	**33.3**	**20.0**	**18.5**

(a) Data for a small number of hospitals in New South Wales were not available; therefore, the number of services is likely to be under-counted.

(b) Data for Victoria and South Australia may underestimate the number of specialised services as some small multi-campus rural services were reported at network rather than campus level. Consequently, if two campuses within the group had a specialised type of service, they were counted as one.

(c) Total for public acute hospitals excludes public psychiatric hospitals.

(d) Calculations were made using number of public acute hospitals with a hospice care unit as the numerator and total number of public acute hospitals as the denominator.

Source: NPHED, AIHW.

How did hospice units vary across states and territories from 2006–07 to 2010–11?

Table 9.2 presents the number of public acute hospitals with a hospice care unit by state and territory from 2006–07 to 2010–11, reported as a proportion of all public acute hospitals. There was a general increase in the number of hospitals with a hospice care unit between 2006–07 and 2010–11 (from 115 to 136, respectively). New South Wales had the most hospitals with a hospice care unit, while the largest increase in the number of public acute hospitals with hospice care units from 2006–07 to 2010–11 was seen in Western Australia (18 to 30). It should be noted that differences across jurisdictions are likely to be due to a range of factors, including differences in the characteristics of the population, health-care systems and service delivery practices.

Table 9.2: Public acute hospitals(a) with hospice care units, states and territories, 2006–07 to 2010–11

State/territory	2006–07(b)	2007–08	2008–09	2009–10	2010–11
			Number		
New South Wales	44	45	47	40	52
Victoria	23	24	23	26	27
Queensland	11	9	7	11	11
Western Australia	18	29	29	30	30
South Australia	16	16	14	13	13
Tasmania	1	1	1	1	1
Australian Capital Territory	1	1	1	1	1
Northern Territory	1	1	1	1	1
Total	**115**	**126**	**123**	**123**	**136**
			Per cent(c)		
New South Wales	20.1	20.5	21.5	18.3	23.9
Victoria	16.1	16.3	14.9	17.4	18.0
Queensland	6.4	5.2	4.2	6.6	6.6
Western Australia	19.1	31.2	31.2	31.9	32.3
South Australia	20.5	20.5	17.9	16.7	16.7
Tasmania	4.2	4.2	4.0	4.3	4.5
Australian Capital Territory	33.3	33.3	33.3	33.3	33.3
Northern Territory	20.0	20.0	20.0	20.0	20.0
Total	**15.6**	**17.0**	**16.7**	**16.7**	**18.5**

(a) The number of hospitals reported can be affected by administrative and/or reporting arrangements and is not necessarily a measure of the number of physical hospital buildings or campuses.

(b) In 2006–07, there were two new public hospitals created in Western Australia, which covered contracted public hospital services previously provided by two private hospitals.

(c) Calculations were made using number of public acute hospitals with a hospice care unit as the numerator and total number of public acute hospitals as the denominator.

Source: NPHED, AIHW.

9.2 Private acute and psychiatric hospitals

This section includes data on private hospitals, including facilities and specialised services for acute and psychiatric hospitals. These data were derived from the Private Health Establishments Collection (ABS 2012b), which is sourced from the annual survey collecting information relating to private hospital activities in Australia.

There were 279 private acute and psychiatric hospitals across Australia in 2010–11 (ABS 2012c). Of these hospitals, 29 (10.4%) had hospice units recorded (Table 9.3). The number of average available beds in hospice units was 215, with an estimated 25,800 patient days and an average length of stay of 4.6 days (ABS 2012c).

Table 9.3: Characteristics of hospice care units in private acute and psychiatric hospitals in 2010–11

Hospitals with hospice care units (number)	Average available beds (number)	Patient days (number)	Average length of stay (days)
29	215	25,748	4.6

Source: ABS 2012c.

9.3 Veteran's Community Nursing program

The DVA offers a range of health-care services, such as Community Nursing services, to entitled veterans and war widows/widowers at DVA's expense. The DVA Community Nursing Program aims to meet an entitled person's assessed clinical and/or personal care needs in their own home (DVA 2012). These services are delivered primarily by organisations contracted by DVA (SCRGSP 2013).

There were nearly 31,000 DVA clients receiving Community Nursing services in Australia in 2011–12 (SCRGSP 2013). Of these clients, nearly 4% received palliative care (Table 9.4). The highest proportion of DVA clients receiving palliative care was in New South Wales (34.3%) and Victoria (27.5%), while Tasmania had the lowest (2.1%). It should be noted that differences across jurisdictions are likely to be due to a range of factors, including differences in population size and characteristics.

Table 9.4: Number of DVA clients receiving palliative care from Community Nursing services(a)(b) in 2011–12

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Number	401	322	253	57	113	25	n.p.	n.p.	**1,170**
Per cent(c)	34.3	27.5	21.6	4.9	9.7	2.1	n.p.	n.p.	**100.0**

(a) DVA Community Nursing services are provided under a casemix model using a 28-day claiming cycle, with clients classified into categories based on care interventions. As a substantial proportion of clients receive services for well under 12 months, the 'average hours per 28-day claim period' more accurately reflects the average service levels received by clients. In addition, these figures are estimated as some data on hours provided are not available.

(b) Due to the very small number of clients, some Australian Capital Territory client numbers have been included with those for New South Wales and some Northern Territory client numbers have been included with those for South Australia.

(c) Per cent may not sum to 100.0% due to rounding.

Source: SCRGSP 2013.

9.4 Palliative care standards

The PCA has developed the Standards for Providing Quality Palliative Care for all Australians (the Standards, see Box 9.1) in collaboration with the palliative care sector (PCA 2005b). The National Standards Assessment Program (NSAP), funded by the Australian Government, has been designed as a quality improvement program for participating specialist palliative care services which who undertake self-assessment and monitoring against the Standards.

Box 9.1: The Standards

There are 13 Standards and 88 Quality Elements that constitute PCA's National Standards. Services conduct a self-assessment against the Standards using specifically developed quality elements and then record whether that Standard is rated as a high-, medium- or low-level improvement priority. Full details of the NSAP program can be found on the PCA website: <http://www.palliativecare.org.au/Standards/NSAP.aspx>.

1. Care, decision making and care planning are each based on a respect for the uniqueness of the patient, their caregiver(s) and family. The patients, their caregiver(s) and families' needs and wishes are acknowledged and guide decision making and care planning.
2. The holistic needs of the patient, their caregiver(s) and family are acknowledged in the assessment and care planning processes, and strategies are developed to address those needs, in line with their wishes.
3. Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient, their caregiver(s) and family.
4. Care is coordinated to minimise the burden on the patient, their caregiver(s) and family.
5. The primary caregiver(s) is/are provided with information, support and guidance about their role according to their needs and wishes.
6. The unique needs of dying patients are considered, their comfort maximised and their dignity preserved.
7. The service has an appropriate philosophy, values, culture, structure and environment for the provision of competent and compassionate palliative care.
8. Formal mechanisms are in place to ensure that the patient, their caregiver(s) and family have access to bereavement care, information and support services.
9. Community capacity to respond to the needs of people who have a life limiting illness, their caregiver(s) and family is built through effective collaboration and partnerships.
10. Access to palliative care is available for all people based on clinical need and is independent of diagnosis, age, cultural background or geography.
11. The service is committed to quality improvement and research in clinical and management practices.
12. Staff and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development.
13. Staff and volunteers reflect on practice and initiate and maintain effective self-care strategies.

Source: NSAP 2013.

Table 9.5 presents the five Standards most frequently rated as a high improvement priority in cumulative results between 2010 and 2012. In 2012, 125 specialist palliative care services participated in the NSAP. Standard 1 (person-centred care planning) was rated as a high improvement priority by 42% of participating services, followed by Standard 8 (bereavement care) with 38% of services.

Table 9.5: Participating services rating Standards as a high improvement priority, 2010 to 2012

		Services rating Standards as high priority (per cent)		
Standard		**2010**	**2011**	**2012**
1	Person-centred care planning	32	36	42
8	Bereavement care	38	35	38
11	Quality improvement/Research	34	28	31
6	Needs of dying patient	26	27	27
2	Holistic needs of the patient	21	21	26
Number of services		**68**	**107**	**125**

Source: NSAP unpublished (PCA 2013).

Supplementary tables

Table S2.1: Palliative care separations, by age and sex, all hospitals, 2010–11

Age group (years)	Number of separations			Age-specific rate[(a)]		
	Males	Females	Total	Males	Females	Total
0–4	35	56	91	0.5	0.8	0.6
5–9	27	20	47	0.4	0.3	0.3
10–14	18	5	23	0.3	0.1	0.2
15–19	54	43	97	0.7	0.6	0.7
20–24	49	47	96	0.6	0.6	0.6
25–29	82	94	176	1.0	1.2	1.1
30–34	94	107	201	1.2	1.4	1.3
35–39	259	340	599	3.3	4.2	3.8
40–44	362	447	809	4.7	5.7	5.2
45–49	700	793	1,493	9.1	10.1	9.6
50–54	1,215	1,280	2,495	16.6	17.2	16.9
55–59	2,030	1,719	3,749	31.0	25.7	28.3
60–64	2,872	2,176	5,048	47.2	35.4	41.3
65–69	3,364	2,344	5,708	72.8	50.1	61.4
70–74	4,045	2,815	6,860	117.5	77.0	96.6
75–79	4,624	3,071	7,695	180.5	103.0	138.8
80–84	4,771	3,846	8,617	253.1	152.6	195.6
85+	4,845	5,817	10,662	358.8	224.2	270.3
Total[(a)]	**29,446**	**25,020**	**54,466**	**26.8**	**18.5**	**22.1**

(a) Age-specific rates show the number of palliative care separations per 10,000 population in that age group at 31 December 2011. Rates shown in the 'Total' row are age-standardised to the Australian population as at 30 June 2001 (see Appendix C).

Source: NHMD, AIHW.

Table S2.2: Palliative care patients among those who died as an admitted patient, public and private hospitals, 2001–02 to 2010–11

	Admitted patient deaths (number)		
Year	Palliative care patients[(a)]	Total admitted patient deaths	Per cent palliative care patients[(a)]
2001–02	16,792	70,671	23.8
2002–03	17,552	71,573	24.5
2003–04	18,587	71,932	25.8
2004–05	20,625	70,799	29.1
2005–06	21,649	71,122	30.4
2006–07	22,672	72,440	31.3
2007–08	24,012	74,365	32.3
2008–09	25,552	74,380	34.4
2009–10	27,270	73,021	37.3
2010–11	27,865	74,861	37.2

(a) Refers to patients for whom palliative care was the principal clinical intent during part or all of the separations that ended with their death.

Source: NHMD, AIHW.

Table S5.1: Number of residential aged care residents, by care type, sex and age group, 2011–12

Age group (years) and sex	Palliative care	Other care	Total	Per cent
Females				
< 65	186	3,133	3,319	2.2
65–69	177	3,013	3,190	2.1
70–74	320	5,730	6,050	4.0
75–79	635	11,607	12,242	8.2
80–84	1,317	25,608	26,925	18.0
85+	4,954	93,253	98,207	65.5
Total females	*7,589*	*142,344*	*149,933*	*100.0*
Males				
< 65	217	3,816	4,033	5.7
65–69	191	3,484	3,675	5.2
70–74	348	5,377	5,725	8.0
75–79	645	8,386	9,031	12.7
80–84	1,012	13,820	14,832	20.8
85+	2,296	31,637	33,933	47.6
Total males	*4,709*	*66,520*	*71,229*	*100.0*
Persons				
< 65	403	6,949	7,352	3.3
65–69	368	6,497	6,865	3.1
70–74	668	11,107	11,775	5.3
75–79	1,280	19,993	21,273	9.6
80–84	2,329	39,428	41,757	18.9
85+	7,250	124,890	132,140	59.7
Total persons	**12,298**	**208,864**	**221,162**	**100.0**
Per cent	5.6	94.4	100.0	. .

Source: AIHW analysis of 2011–12 ACFI data.

Table S5.2: Number of residential aged care permanent admissions, by care type, sex and age group, 2011–12

Age group (years) and sex	Palliative care	Other care	Total	Per cent
Females				
< 65	97	724	821	2.4
65–69	98	816	914	2.7
70–74	149	1,707	1,856	5.4
75–79	226	3,544	3,770	11.0
80–84	403	7,427	7,830	22.8
85+	898	18,317	19,215	55.8
Total females	*1,871*	*32,535*	*34,406*	*100.0*
Males				
< 65	137	1,011	1,148	5.1
65–69	105	996	1,101	4.9
70–74	199	1,618	1,817	8.1
75–79	315	2,793	3,108	13.9
80–84	478	4,819	5,297	23.7
85+	803	9,037	9,840	44.1
Total males	*2,037*	*20,274*	*22,311*	*100.0*
Persons				
< 65	234	1,735	1,969	3.5
65–69	203	1,812	2,015	3.6
70–74	348	3,325	3,673	6.5
75–79	541	6,337	6,878	12.1
80–84	881	12,246	13,127	23.1
85+	1,701	27,354	29,055	51.2
Total persons	**3,908**	**52,809**	**56,717**	**100.0**
Per cent	6.9	93.1	100.0	. .

Source: AIHW analysis of 2011–12 ACFI data.

Table S5.3: Residential aged care residents, by care type and demographic characteristics, 2011–12

	Palliative care		Other care	
Demographic characteristic	**Number**	**Per cent**	**Number**	**Per cent**
Sex				
Females	7,589	61.7	142,344	68.2
Males	4,709	38.3	66,520	31.8
Indigenous status				
Indigenous	79	0.6	1,497	0.7
Non-Indigenous	12,219	99.4	207,367	99.3
Country of birth				
Australia	9,013	73.3	148,558	71.1
Overseas	3,285	26.7	60,306	28.9
Remoteness area				
Major cities	6,987	56.8	144,598	69.2
Inner regional	3,745	30.5	46,872	22.4
Outer regional	1,484	12.1	15,933	7.6
Remote	72	0.6	1,132	0.5
Very remote	10	0.1	329	0.2
Marital status				
Never married	875	7.1	18,620	8.9
Widowed	6,147	50.0	108,880	52.1
Divorced	824	6.7	14,441	6.9
Separated	204	1.7	3,873	1.9
Married	4,131	33.6	60,427	28.9
Unknown	117	1.0	2,623	1.3
Total	**12,298**	**100.0**	**208,864**	**100.0**

Source: AIHW analysis of 2011–12 ACFI data.

Table S5.4: Residential aged care residents, rate per 100,000 population[(a)], by care type, age group and remoteness area, 2011–12

Age group (years)	Major cities	Inner regional	Outer regional	Remote	Very remote	All regions
			Palliative care			
<65	2	3	3	2	1	2
65–69	37	48	34	8	0	39
70–74	79	122	115	95	0	93
75–79	194	293	334	106	165	229
80–84	442	702	733	363	167	525
85+	641	1,114	1123	491	221	781
Total	**10**	**20**	**15**	**3**	**1**	**12**
			Other care types			
<65	35	40	35	36	35	36
65–69	738	620	527	376	540	682
70–74	1,593	1,506	1,371	1,264	1,269	1,544
75–79	3,691	3,594	3,001	2,463	2,361	3,585
80–84	9,080	8,906	7,879	5,106	5,004	8,884
85+	31,326	32,114	26,799	17,098	11,074	30,967
Total	**936**	**1,083**	**786**	**346**	**173**	**936**

(a) Crude rates are based on the preliminary Australian estimated resident population as at 30 June 2011 and are expressed per 100,000 population (see Appendix C).

Source: AIHW analysis of 2011–12 ACFI data.

Table S5.5: Residential aged care admissions, rate per 100,000 population[(a)], by care type, age group and remoteness area, 2011–12

Age group (years)	Major cities	Inner regional	Outer regional	Remote	Very remote	All regions
			Palliative care			
<65	1	1	2	1	0	1
65–69	21	27	16	0	0	21
70–74	40	70	52	35	33	48
75–79	85	119	131	70	0	97
80–84	177	260	229	0	83	199
85+	382	552	445	131	221	422
Total	**15**	**26**	**19**	**5**	**2**	**18**
			Other care types			
<65	9	10	8	8	7	9
65–69	196	197	160	96	62	190
70–74	467	478	428	295	167	462
75–79	1,161	1,162	971	721	494	1,136
80–84	2,813	2,838	2,350	1,500	1,001	2,759
85+	6,814	7,195	5,913	3,177	1,883	6,783
Total	**234**	**282**	**201**	**79**	**31**	**237**

(a) Crude rates are based on the preliminary Australian estimated resident population as at 30 June 2011 and are expressed per 100,000 population (see Appendix C).

Source: AIHW analysis of 2011–12 ACFI data.

Table S5.6: Residential aged care residents, rate per 100,000 population[(a)], by care type, age group and state or territory, 2011–12

Age group (years)	NSW	VIC	QLD	WA	SA	TAS	ACT	NT	Total
				Palliative care					
<65	2	2	2	2	3	8	1	1	2
65–69	39	30	35	29	40	122	44	0	37
70–74	94	78	80	85	62	395	21	83	91
75–79	208	206	207	231	166	1,040	191	53	227
80–84	477	513	515	593	326	1,881	387	507	525
85+	1,519	1,823	1,615	1,966	1,071	7,069	1,821	1,357	1,755
Total	**53**	**56**	**45**	**49**	**44**	**246**	**36**	**9**	**55**
				Other care types					
<65	40	35	34	28	40	36	24	34	36
65–69	694	672	649	548	639	658	508	610	657
70–74	1,535	1,484	1,529	1,449	1,582	1,414	1,369	2,154	1,514
75–79	3,600	3,523	3,656	3,256	3,743	2,830	3,021	5,302	3,549
80–84	8,879	8,861	9,254	8,280	9,310	7,813	8,069	9,459	8,890
85+	30,116	30,241	30,987	28,622	32,194	25,925	28,626	28,054	30,238
Total	**998**	**964**	**841**	**724**	**1216**	**909**	**624**	**253**	**929**

(a) Crude rates are based on the preliminary Australian estimated resident population as at 31 December 2011 and are expressed per 100,000 population (see Appendix C).

Source: AIHW analysis of 2011–12 ACFI data.

Table S5.7: Residential aged care admission, rate per 100,000 population[(a)], by care type, age group and state or territory, 2011–12

Age group (years)	NSW	VIC	QLD	WA	SA	TAS	ACT	NT	Total
				Palliative care					
<65	1	1	1	1	2	4	0	0	1
65–69	23	17	19	18	16	67	7	0	21
70–74	52	35	48	37	32	190	21	28	47
75–79	101	78	81	101	97	315	59	53	96
80–84	215	160	190	159	177	677	174	0	199
85+	432	354	323	362	413	1,513	384	302	412
Total	**20**	**15**	**13**	**13**	**21**	**70**	**10**	**2**	**17**
				Other care types					
<65	10	9	8	7	11	12	6	10	9
65–69	189	182	186	144	190	225	184	181	183
70–74	455	450	465	382	490	495	460	552	453
75–79	1,172	1,078	1,133	1,044	1,207	919	983	1,697	1,125
80–84	2,801	2,732	2,885	2,513	2,847	2,549	2,148	2,449	2,761
85+	6,658	6,655	6,719	6,363	6,577	6,336	6,413	6,184	6,623
Total	**255**	**243**	**212**	**182**	**295**	**255**	**157**	**67**	**235**

(a) Crude rates are based on the preliminary Australian estimated resident population as at 31 December 2011 and are expressed per 100,000 population (see Appendix C).

Source: AIHW analysis of 2011–12 ACFI data.

Table S5.8: Number of diagnosed diseases in ACFI assessed permanent residential aged care clients, 1 July 2011 to 30 June 2012

Disease	Palliative care	Other care
Cancers		
Brain	194	323
Breast	256	847
Colorectal (bowel)	376	1,254
Head and neck	153	268
Leukaemia	82	243
Lung	569	554
Non-Hodgkin lymphoma	55	173
Other malignant tumours	719	1,027
Prostate	423	1,319
Skin	108	677
Stomach	76	120
Other neoplasms (including tumours and tumours of uncertain or unknown behaviour)	127	414
Total cancers	*3,138*	*7,219*
Other diseases		
Blood	98	1,091
Circulatory system	2,707	50,005
Congenital malformations	16	272
Digestive system	234	4,627
Ear	67	3,030
Endocrine	536	17,457
Genitourinary	641	10,357
Infectious/parasitic	26	502
Injury/poisoning/external	306	7,483
Musculoskeletal	1,252	38,229
Nervous system/Parkinson disease	632	13,180
Respiratory system	666	8,778
Skin	98	2,598
Vision	278	9,678
Other	1,603	34,359
Total other diseases	*9,160*	*201,646*
Total	**12,298**	**208,865**

Source: AIHW analysis of 2011–12 ACFI data.

Table S5.9: Residential aged care residents, by care type and length of stay, 2011–12

	Palliative care		Other care	
Length of stay	**Number**	**Per cent**	**Number**	**Per cent**
0–<4 weeks	1,667	21.4	1,976	4.1
4–<8 weeks	973	12.5	1,939	4.0
8–<13 weeks	463	5.9	2,240	4.7
13–<26 weeks	568	7.3	4,060	8.5
26–<39 weeks	394	5.0	2,964	6.2
39–<52 weeks	293	3.8	2,517	5.2
1–<2 years	888	11.4	8,054	16.8
2–<3 years	700	9.0	6,334	13.2
3–<4 years	487	6.2	4,766	9.9
4–<5 years	377	4.8	3,673	7.7
5–<8 years	624	8.0	5,881	12.3
8+ years	372	4.8	3,602	7.5
Total	**7,806**	**100.0**	**48,006**	**100.0**

Source: AIHW analysis of 2011–12 ACFI data.

Table S5.10: Residents who were permanent residents at some time between 1 July 2011 and 30 June 2012 with hospital leave, by care type, state and territory and remoteness area, 30 June 2012

	Major cities	Inner regional	Outer regional	Remote	Very remote	All regions
Palliative care						
New South Wales	700	312	61	3	—	1,076
Victoria	636	196	63	2	—	897
Queensland	427	122	90	6	1	646
Western Australia	297	51	26	2	1	377
South Australia	173	15	14	4	—	206
Tasmania	—	123	66	—	—	189
Australian Capital Territory	55	—	—	—	—	55
Northern Territory	—	—	4	2	—	6
Total	**2,288**	**819**	**324**	**19**	**2**	**3,452**
Other care types						
New South Wales	16,292	4,508	1,254	38	—	22,092
Victoria	11,066	2,829	661	15	—	14,571
Queensland	7,699	2,611	1,272	136	36	11,754
Western Australia	4,142	686	351	53	18	5,250
South Australia	4,626	466	562	44	—	5,698
Tasmania	1	576	158	5	1	741
Australian Capital Territory	744	1	—	—	—	745
Northern Territory	—	—	139	45	9	193
Total	**44,570**	**11,677**	**4,397**	**336**	**64**	**61,044**

Source: AIHW analysis of 2011–12 ACFI data.

Table S6.1: Palliative care schedule items: numbers of patients and prescriptions, by age and gender, 2011–12

Patient characteristics	Number of patients[(a)]	Per cent of patients	Rate[(b)]	Number of prescriptions[(a)]	Per cent of prescriptions	Rate[(b)]	Number of prescriptions per patient
Age group (years)							
<15	426	2.2	10.1	666	1.8	15.7	1.6
15–24	241	1.2	7.9	478	1.3	15.6	2.0
25–34	331	1.7	10.3	639	1.8	19.8	1.9
35–44	683	3.5	21.5	1,546	4.3	48.8	2.3
45–54	1,424	7.4	46.6	2,997	8.3	98.1	2.1
55–64	2,836	14.7	109.7	5,776	15.9	223.3	2.0
65–74	4,338	22.5	251.8	8,285	22.8	481.0	1.9
75–84	4,964	25.7	493.0	8,905	24.6	884.4	1.8
85+	4,027	20.9	975.0	6,624	18.3	1,603.8	1.6
Sex							
Male	9,240	47.9	82.6	17,208	47.5	153.9	1.9
Female	10,030	52.0	88.7	18,708	51.6	165.5	1.9
Total[(b)]	**19,293**	**100.0**	**85.8**	**36,263**	**100.0**	**161.3**	**1.9**

(a) Numbers may not add to the totals due to missing or not-reported data.

(b) Crude rates are based on the preliminary Australian estimated resident population as at 31 December 2011 and are expressed per 100,000 population (see Appendix C).

Source: PBS/RPBS palliative care schedule data (DoHA).

Table S6.2: PBS/RPBS palliative care schedule items, by prescribing clinician, states and territories, 2011–12

Medication type	Clinician type	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Analgesics	GPs	1,781	1,379	1,337	582	483	186	69	43	5,860
	Palliative medicine	77	34	182	66	43	25	6	0	433
	Other clinicians[(a)]	235	565	387	302	205	37	18	14	1,763
Anti-emetics and anti-nauseants	GPs	360	237	366	172	123	60	21	12	1,351
	Palliative medicine	0	0	3	2	5	1	0	0	11
	Other clinicians[(a)]	35	58	55	20	12	4	4	1	189
Anti-epileptics	GPs	1,247	1,736	489	460	372	160	19	47	4,530
	Palliative medicine	10	5	25	16	10	5	0	0	71
	Other clinicians[(a)]	61	340	68	101	62	24	9	1	666
Anti-inflammatory and anti-rheumatic products	GPs	294	191	150	86	53	40	16	8	838
	Palliative medicine	0	0	1	0	3	0	0	0	4
	Other clinicians[(a)]	69	104	17	12	11	9	18	2	242
Drugs for functional gastrointestinal disorders	GPs	240	145	338	45	90	15	2	5	880
	Palliative medicine	13	8	59	5	6	9	1	0	101
	Other clinicians[(a)]	26	47	179	18	65	11	1	1	348
Laxatives	GPs	3,868	2,563	2,860	762	938	406	127	89	11,613
	Palliative medicine	24	5	27	21	8	18	7	0	110
	Other clinicians[(a)]	356	560	426	200	159	67	7	18	1,793
Psycholeptics	GPs	1,249	880	949	500	383	172	37	49	4,219
	Palliative medicine	25	3	10	2	3	1	0	0	44
	Other clinicians[(a)]	93	125	121	72	37	4	0	0	452
Stomatological preparations	GPs	239	123	145	41	62	27	5	0	642
	Palliative medicine	0	1	2	0	3	0	0	0	6
	Other clinicians[(a)]	14	57	17	3	5	0	1	0	97
Total		**10,316**	**9,166**	**8,213**	**3,488**	**3,141**	**1,281**	**368**	**290**	**36,263**

(a) ‘Other clinicians’ includes medical specialists from other disciplines, and nurse practitioners.

Source: PBS/RPBS palliative care schedule data (DoHA).

Table S6.3: Palliative care schedule items by medication type, by prescribing clinician, 2007–08 to 2011–12

	Number					Average annual change (per cent)
Medication type	**2007–08**	**2008–09**	**2009–10**	**2010–11**	**2011–12**	
			GPs			
Analgesics	1,298	2,188	2,490	3,209	5,860	45.8
Anti-emetics and anti-nauseants	874	840	715	822	1,351	11.5
Anti-epileptics	6,302	5,837	5,512	5,287	4,530	–7.9
Anti-inflammatory and anti-rheumatic products	1,253	808	618	619	838	–9.6
Drugs for functional gastrointestinal disorders	691	770	774	773	880	6.2
Laxatives	10,493	8,624	7,264	7,310	11,613	2.6
Psycholeptics	11,491	8,448	7,417	6,151	4,219	–22.2
Stomatological preparations	443	384	422	420	642	9.7
Total	**32,845**	**27,899**	**25,212**	**24,591**	**29,933**	**–2.3**
			Palliative medicine specialists			
Analgesics	114	225	338	384	433	39.6
Anti-emetics and anti-nauseants	39	17	14	7	11	–27.1
Anti-epileptics	44	79	73	69	71	12.7
Anti-inflammatory and anti-rheumatic products	14	7	5	9	4	–26.9
Drugs for functional gastrointestinal disorders	49	42	22	43	101	19.8
Laxatives	90	63	57	90	110	5.1
Psycholeptics	34	40	39	45	44	6.7
Stomatological preparations	8	3	11	3	6	–6.9
Total	**392**	**476**	**559**	**650**	**780**	**18.8**
			Other clinicians[(a)]			
Analgesics	215	829	999	1,235	1,763	69.2
Anti-emetics and anti-nauseants	50	78	94	95	189	39.4
Anti-epileptics	825	770	650	712	666	–5.2
Anti-inflammatory and anti-rheumatic products	164	102	75	140	242	10.2
Drugs for functional gastrointestinal disorders	100	124	99	181	348	36.6
Laxatives	586	571	557	917	1,793	32.3
Psycholeptics	521	517	384	430	452	–3.5
Stomatological preparations	34	39	25	31	97	30.0
Total	**2,495**	**3,030**	**2,883**	**3,741**	**5,550**	**22.1**

(a) 'Other clinicians' includes medical specialists from other disciplines, and nurse practitioners.

Source: PBS/RPBS palliative care schedule data (DoHA).

Table S6.4: Palliative care schedule items for pain relief, states and territories, 2011–12

Medication type	Script type	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Opioids						**Number**				
Fentanyl	Initial scripts	610	579	718	547	295	36	31	5	2,821
	Repeat scripts	49	32	23	56	2	0	3	0	165
Methadone hydrochloride	Initial scripts	84	72	103	44	31	38	0	9	381
	Repeat scripts	18	16	5	8	0	1	0	4	52
Morphine sulphate	Initial scripts	30	29	56	4	6	8	1	2	136
	Repeat scripts	9	7	7	2	5	9	0	0	39
Total		*800*	*735*	*912*	*661*	*339*	*92*	*35*	*20*	*3,594*
Other analgesics and antipyretics										
Paracetamol	Initial scripts	835	855	644	189	258	96	27	25	2,929
	Repeat scripts	458	388	350	100	134	60	31	12	1,533
Total		*1,293*	*1,243*	*994*	*289*	*392*	*156*	*58*	*37*	*4,462*
Total pain relief items		**2,093**	**1,978**	**1,906**	**950**	**731**	**248**	**93**	**57**	**8,056**
Opioids						**Rate[a] per 100,000 population**				
Fentanyl	Initial scripts	8.4	10.4	15.9	22.9	17.9	7.0	8.4	2.2	12.5
	Repeat scripts	0.7	0.6	0.5	2.3	0.1	0.0	0.8	0.0	0.7
Methadone hydrochloride	Initial scripts	1.2	1.3	2.3	1.8	1.9	7.4	0.0	3.9	1.7
	Repeat scripts	0.2	0.3	0.1	0.3	0.0	0.2	0.0	1.7	0.2
Morphine sulphate	Initial scripts	0.4	0.5	1.2	0.2	0.4	1.6	0.3	0.9	0.6
	Repeat scripts	0.1	0.1	0.2	0.1	0.3	1.8	0.0	0.0	0.2
Total		*11.0*	*13.2*	*20.2*	*27.7*	*20.6*	*18.0*	*9.4*	*8.6*	*16.0*
Other analgesics and antipyretics										
Paracetamol	Initial scripts	11.5	15.3	14.3	7.9	15.7	18.8	7.3	10.8	13.0
	Repeat scripts	6.3	7.0	7.8	4.2	8.1	11.7	8.4	5.2	6.8
Total		*17.8*	*22.3*	*22.0*	*12.1*	*23.8*	*30.5*	*15.6*	*15.9*	*19.8*
Total pain relief items		**28.9**	**35.5**	**42.2**	**39.8**	**44.4**	**48.5**	**25.1**	**24.5**	**35.8**

(a) Crude rates are based on the preliminary Australian estimated resident population as at 31 December 2011 and are expressed per 100,000 population (see Appendix C).

Source: PBS/RPBS palliative care schedule data (DoHA).

Table S8.1: PCOC palliative care episodes by inpatient and ambulatory/community setting, 2012

Age group (years)	Inpatient		Ambulatory/Community		All patients	
	Number[(a)]	Per cent[(b)]	Numbers[(a)]	Per cent[(b)]	Number[(a)]	Per cent[(b)]
<15	53	0.2	87	0.5	140	0.4
15–24	48	0.2	45	0.3	93	0.2
25–34	152	0.7	127	0.7	279	0.7
35–44	545	2.5	455	2.7	1,000	2.6
45–54	1,640	7.4	1,276	7.5	2,916	7.4
55–64	3,681	16.7	2,957	17.3	6,638	16.9
65–74	5,473	24.8	4,336	25.3	9,809	25.0
75–84	6,468	29.3	4,888	28.6	11,356	29.0
85+	4,008	18.2	2,936	17.2	6,944	17.7
Total	**22,068**	**100.0**	**17,107**	**100.0**	**39,175**	**100.0**

(a) Numbers may not add to the totals due to missing or not-reported data.

(b) The percentages shown do not include episodes for which data were missing and/or not reported.

Source: PCOC analysis of 2012 data (unpublished).

Table S8.2: Summary of PCOC palliative care outcome benchmark results, by palliative care setting, 2012

Benchmark	All services	Inpatient setting	Ambulatory/Community setting
1.1: Time from referral to first contact. To meet this benchmark, 90.0% of patients must be contacted within 2 days of receipt of referral.	• 45.8% of services met benchmark • 74.3% of patient episodes met benchmark	• 73.8% of services met benchmark • 90.6% of patient episodes met benchmark	• 18.2% of services met benchmark • 52.3% of patient phases satisfied the benchmark criteria
2.1[(a)]: Time in unstable phase. To meet this benchmark, at least 90% of these unstable phases must last for 3 days or less.	• 11.1% of services met benchmark • 67.3% of patient phases satisfied the benchmark criteria	• 16.0% of services met benchmark • 70.5% of patient phases satisfied the benchmark criteria	• 11.1% of services met benchmark • 56.6% of patient phases satisfied the benchmark criteria.
3.1: Change in pain—patients who have absent or mild pain at the start of their phase of palliative care, as rated via the PCPSS clinical tool. To meet this benchmark, 90% of these phases must end with the patient still experiencing only absent or mild pain.	• 20.0% of services met benchmark • 84.5% of patient phases satisfied the benchmark criteria	• 33.3% of services met benchmark • 86.1% of patient phases satisfied the benchmark criteria	• 11.1% of services met benchmark • 82.5% of patient phases satisfied the benchmark criteria
3.2: Change in pain—patients who have moderate or severe pain at the start of their phase of palliative care, as rated via the PCPSS clinical tool. To meet this benchmark, 60% of these phases must end with the patient's pain reduced to being absent or mild.	• 36.0% of services met benchmark • 51.5% of patient phases satisfied the benchmark criteria	• 43.8% of services met benchmark • 52.0% of patient phases satisfied the benchmark criteria	• 22.2% of services met benchmark • 50.5% of patient phases satisfied the benchmark criteria

(continued)

Table S8.2 (continued): Summary of PCOC palliative care outcome benchmark results by palliative care setting, January–December 2012

Benchmark	All services	Inpatient setting	Ambulatory/Community setting
3.3: Change in pain—patients who have absent or mild pain at the start of their phase of palliative care, as rated via the SAS clinical tool. To meet this benchmark, 90% of these phases end with the patient still experiencing only absent or mild pain.	• 14.6% of services met benchmark • 83.5% of patient phases satisfied the benchmark criteria	• 29.3% of services met benchmark • 84.9% of patient phases satisfied the benchmark criteria	• 5.7% of services met benchmark • 81.5% of patient phases satisfied the benchmark criteria
3.4: Change in pain—patients who have moderate or severe pain at the start of their phase of palliative care, as rated via the SAS clinical tool. To meet this benchmark, 60% of these phases must end with the patient's pain reduced to being absent or mild.	• 25.0% of services met benchmark • 47.7% of patient phases satisfied the benchmark criteria	• 27.3% of services met benchmark • 48.5% of patient phases satisfied the benchmark criteria	• 15.1% of services met benchmark • 46.2% of patient phases satisfied the benchmark criteria

(a) This benchmark was updated in 2012 and has replaced the former benchmarks 2.1, 2.2 and 2.3. See Appendix E for further information.

Note: Only relevant services/patients are included in percentages.

Source: PCOC analysis of 2012 data (unpublished).

Appendix A: Identifying palliative care separations

The aim of Chapter 2 in this report is to quantify and describe separations in admitted patient settings for which palliation was a substantial component of the care provided. Two NHMD data items—'Care type' and 'Diagnosis'—capture information on palliative care. The question is whether these two data items should be used to identify palliative care separations. The AIHW explored this question in some detail with the findings released in the technical paper *Identifying palliative care separations in admitted patient data: technical paper* (AIHW 2011b).

'Care type' data item

A 'Care type' is assigned for each admitted patient separation, with any one separation equal to either a total hospital stay (from admission to discharge, transfer or death) or to a portion of a hospital stay beginning or ending in a change of care type (for example, from a 'Care type' of *Acute care* to a 'Care type' of *Palliative care*). Such a change in 'Care type' leads to a statistical discharge (for the stated example, this would result in the end of the *Acute care* separation) and a corresponding statistical admission (for example, the start of the *Palliative care* separation).

One of the response options in the NHMD 'Care type' data item is *Palliative care*, with *Palliative care* defined as follows (AIHW 2012a):

> Palliative care is care in which the clinical intent or treatment goal is primarily quality of life for a patient with an active, progressive disease with little or no prospect of cure. It is usually evidenced by an interdisciplinary assessment and/or management of the physical, psychological, emotional and spiritual needs of the patient; and a grief and bereavement support service for the patient and their carers/family. It includes care provided:
>
> - in a palliative care unit
> - in a designated palliative care program, or
> - under the principal clinical management of a palliative care physician or, in the opinion of the treating doctor, when the principal clinical intent of care is palliation.

'Diagnosis' data items

As well as the information on the provision of palliative care collected via the 'Care type' data item, information on palliative care is also recorded in the NHMD under the 'Diagnosis' data items. In Australian hospitals, a principal diagnosis is assigned during each separation; one or more additional diagnoses may also be assigned. The principal diagnosis is 'the diagnosis established after study to be chiefly responsible for occasioning an episode of admitted patient care' (AIHW 2012b; NCCH 2010). Additional diagnoses are 'conditions or complaints either coexisting with the principal diagnosis or arising during the episode of admitted patient care'; such diagnoses give information on the 'conditions that were significant in terms of treatment required, investigations needed and resources used during the episode of care' (AIHW 2012b; NCCH 2010).

The classification that has been used nationally to assign diagnosis codes since 1999–00 is the ICD-10-AM (see Appendix D); one of the codes in that classification—namely Z51.5—is *Palliative care*. While diagnosis codes usually describe a disease, injury or poisoning, they can also be used in certain instances to indicate the specific care or service provided for a current condition or other reasons for separation (AIHW 2009). This is the case when *Palliative care* is recorded as a diagnosis code.

A specific ICD-10-AM coding standard—namely standard '0224'—applies to the recording of *Palliative care* as a diagnosis (NCCH 2008a). This coding standard has two parts: a definition of palliative care, and classification rules. The definition of *Palliative care* in the coding standard—and thus the one used to assign *Palliative care* as a diagnosis—is the same as the definition used for the 'Care type' data item. That is, as for 'Care type', *Palliative care* as a diagnosis is defined to include the care provided be it in a palliative care unit; in a designated palliative care program; or under the principal clinical management of a palliative care physician or, in the option of the treating doctor, when the principal clinical intent of care is palliation. The classification rules in the coding standard provide an additional instruction (which does not apply when assigning *Palliative care* as the 'Care type') on when palliative care should be assigned as a diagnosis code as follows (NCCH 2008a):

> Palliative care should be assigned (as an additional diagnosis code) when the intent of care at admission is 'for palliation' *or if at any time during the admission* the intent of care becomes 'for palliation' and the care provided to the patient meets the definition above. [Italics added for emphasis.]

Thus, while the clinical intent of the entire separation is considered to be palliation when *Palliative care* is assigned as a 'Care type', when a diagnosis code of *Palliative care* is assigned, palliation may have been the clinical intent during either *part* or all of the separation.

It should be noted that, based on the collection and coding rules, it could be argued that there should not be any separations in which palliation was the clinical intent of care for just *part* of the separation. That is, since the 'Care type' data item is meant to describe the clinical intent of the entire separation, when the clinical intent of a separation changes to become palliation (and thus a diagnosis code of *Palliative care* is assigned), a statistical discharge from the original care type should occur, along with a corresponding statistical admission with a 'Care type' of *Palliative care*. Thus, for every separation in which a diagnosis of *Palliative care* is recorded, one might also expect a corresponding 'Care type' of *Palliative care*.

Data from the NHMD indicate that such a one-to-one correspondence is not observed in the Australian admitted patient data. There were clear jurisdictional differences in the level of congruence between the coding of 'Care type' and diagnosis items.

Identifying palliative care separations

For the purposes of this report, palliative care separations are identified using both 'Care type' and 'Diagnosis' information such that if either (or both) has a code of *Palliative care*, that separation is included as a palliative care separation (see AIHW 2011b for further information). This approach allows one to identify those separations in admitted patient settings for which a substantial component of the care was palliation. To make it clear that palliative care may have been the clinical intent for *part* (not all) of the separation for some of these separations, a palliative care separation is described in this report as 'a separation for which the principal clinical intent of the care was palliation during part or all of that separation'. At its March 2011 meeting, the Palliative Care Working Group of the Australian

Health Ministers’ Advisory Council endorsed the use of both ‘Care type’ and ‘Diagnosis’ information to identify those separations in admitted patient settings for which palliative care was a substantial component of the care provided.

Appendix B: Data sources

The data sources used to complete the analyses detailed in this report are described in this section.

Bettering the Evaluation and Care of Health survey

The BEACH survey of general practice activity is undertaken by the Family Medicine Research Centre at the University of Sydney. For each year's data collection, a random sample of about 1,000 GPs each report details of 100 consecutive GP encounters of all types on structured encounter forms. Each form collects information about the consultations (for example, date and type of consultation), the patient (for example, date of birth, sex, and reasons for encounter), the problems managed and the management of each problem (for example, treatment provided, prescriptions and referrals). Data on patient risk factors, health status and GP characteristics are also collected.

Additional information on the 2011–12 BEACH survey can be obtained from *General practice activity in Australia 2011–12* (Britt et al. 2012).

Medical Workforce Survey

In 2010, the National Registration and Accreditation Scheme was introduced and the AIHW Medical Labour Force Survey was replaced with the Medical Workforce Survey. The new national health workforce surveys are administered to all registered health practitioners by the Australian Health Practitioners Regulation Agency and are included as part of the registration renewal process. It should be noted that the workforce surveys are voluntary. The Medical Workforce Survey is used to provide nationally consistent estimates of the medical workforce. It provides data not readily available from other sources, such as on the type of work done by, and job setting of, medical practitioners; the number of hours worked in a clinical or non-clinical role, and in total; and the numbers of years worked in, and intended to remain in, the health workforce. The survey also provides information on those registered medical practitioners who are not undertaking clinical work or who are not employed. The information from the National Registration and Accreditation Scheme workforce surveys, combined with the Scheme's registration data items, comprises the NHWDS.

The overall response rate to the Medical Workforce Survey in 2011 was 85.3%, which was higher than any previous AIHW Medical Labour Force Survey (Table A2, AIHW 2013). New South Wales, South Australia and Victoria had the highest response rates at 87.7%, 86.7% and 85.9%, respectively. The Northern Territory had the lowest response rate at 82.4%.

Responses to the surveys have been weighted to benchmark figures to account for non-response based on registration data supplied by the Australian Health Practitioner Regulation Agency. For medical practitioners, the benchmarks used are the number of medical practitioners registered by state and territory (using principal address), by main specialty of practice by sex and age group.

'NHWDS: medical practitioners' is a combination of data collected through the medical practitioner registration renewal process. Some of the data, such as specialties, are based on registration data at the time specified in the extract. Other data, such as employment status and hours worked, are based on a survey component. As such, differences between 'NHWDS: medical practitioners' and other data sources may arise from differences in timing, response biases and collection methods. (See National Health Workforce Data Set: medical practitioners 2011: National Health Workforce Data Set, 2011; Data Quality Statement which can be accessed on the AIHW website:

< http://meteor.aihw.gov.au/content/index.phtml/itemId/510913>.

Past and present surveys have different collection and estimation methodologies, questionnaire designs and response rates. As a result, care should be taken in comparing historical data from the AIHW Labour Force Surveys with data from the NHWDS.

A detailed description of the Medical Workforce Survey 2011, including a summary of changes from the previous AIHW Medical Labour Force Survey, is provided at Appendix A of the *Medical workforce 2011* report (AIHW 2013).

National Hospital Morbidity Database

The data source for the chapter on admitted patient palliative care was the NHMD. These data pertain to admitted patients in public and private hospitals in Australia. Some of these hospitals have hospices affiliated with them. The data supplied are based on the NMDS for admitted patient care and include demographic, administrative and 'length of stay' data, as well as data on the diagnoses of the patients, the procedures they underwent in hospital and external causes of injury and poisoning.

In 2010–11, diagnoses and external causes of injury and poisoning were recorded using the seventh edition of the ICD-10-AM. Procedures were recorded using the seventh edition of the Australian Classification of Health Interventions.

The counting unit for the NHMD is the 'separation'. Separation is the term used to refer to the episode of admitted patient care, which can be a total hospital stay (from admission to discharge, transfer or death) or a portion of a hospital stay that begins or ends in a change of type of care (for example, from acute care to rehabilitation).

The NHMD contains records from 1993–94 to 2011–12. For each reference year, the NHMD includes records for admitted patient separations between 1 July and 30 June.

Episode-based data

The NHMD is episode based, with the term 'separation' used to refer to an episode of admitted patient care. Each record in the NHMD is based on a single phase of treatment for an admitted patient, with such phases classified in the 'Care type' data item as *Acute care*, *Palliative care*, *Rehabilitation care, Newborn* and other types of care. When a patient receives only one type of care during a hospital stay (such as only acute care or only palliative care), the length of stay for that separation is equal to the total length of time the patient spent in hospital during that stay. However, where patients receive different types of care during one hospital stay (for example, a person may be admitted for acute care but then later reclassified as a palliative care patient), the patient may be statistically discharged from the hospital after the first type of care and then statistically admitted into a second phase of care. Thus, patients may have two or more separations during any one hospital stay. Since each record within the NHMD is based on an episode of care, the separation count is a count of episodes, not persons. Data from the PCOC suggest that a relatively small proportion (14%) of patients in Australia have two or more separations for palliative care within a 12-month period (Currow et al. 2008).

Coverage

For each of the years considered in this report, the coverage of the NHMD has been very good. For 2010–11, coverage for the NHMD was essentially complete: data from all public hospitals were included except for a small mothercraft hospital in the Australian Capital Territory. As well, the great majority of private hospitals were also included, with the exceptions being the private day hospital facilities in the Australian Capital Territory, the single private free-standing day hospital facility in the Northern Territory, and a small private hospital in Victoria.

Due to the lack of complete private hospital data, the counts of the total number of private sector separations shown in this report are slight underestimates of the actual counts. For further details on coverage of the NHMD collection in 2010–11, and earlier, see the annual *Australian hospital statistics* reports (for example, AIHW 2012a, 2011a, 2010b).

Hospitals may be re-categorised as public or private between or within years (see AIHW 2012a for further information). This should be taken into account when comparing data by sector over time.

Standard admitted patient care data exclusions

As per the standard practice when analysing admitted patient data in the NHMD, the data presented in this report exclude those records for which the 'Care type' data item was reported as *Newborn (unqualified days only)*, *Hospital boarder* or *Posthumous organ procurement*.

Further information

Comprehensive hospital statistics from the NHMD are released by the AIHW on an annual basis (for example, AIHW 2009, 2010b, 2011a, 2012a) and further information about the NHMD can be obtained from those publications. Metadata information for the NMDSs that are the basis for the AIHW National Hospital Databases are published in the AIHW's online metadata repository—METeOR, and the *National health data dictionary*, which can be accessed on the AIHW website:

<http://meteor.aihw.gov.au/content/index.phtml/itemId/181162>.

<http://www.aihw.gov.au/publication-detail/?id=6442468385>.

In those reports, information from the 'Care type' data item only (and not 'Diagnosis') has been used to identify palliative care separations. Thus, the information on palliative care separations presented there will not match the information presented in this report (see Appendix A for additional information on the identification of palliative care separations).

The Data Quality Statement for this database is available online at
<http://www.aihw.gov.au/publication-detail/?id=6442468385>.

National Public Hospital Establishments Database

The NPHED is based on the NMDS for Public hospital establishments. It holds establishment-level data for each public hospital in Australia, including public acute hospitals, psychiatric hospitals, drug and alcohol hospitals and dental hospitals in all states and territories. Hence, public hospitals not administered by the state and territory health authorities (hospitals operated by correctional authorities, for example, and hospitals located in offshore territories) are not included. The collection does not include data for private hospitals.

The NPHED includes information on hospital resources (beds, staff and specialised services), recurrent expenditure (including depreciation), non-appropriation revenue, and services to non-admitted patients. The NPHED holds data from 1993–94 to 2011–12.

For more information on the data collection method and other relevant data issues, refer to the NPHED Data Quality Statement at:

<http://meteor.aihw.gov.au/content/index.phtml/itemId/511361>.

Data on geographical location

Data on geographical location are collected on hospitals in the NPHED, and on the area of usual residence of patients in the NHMD and the Non-Admitted Patient Emergency Department Care Database. These data have been provided as state or territory and Statistical Local Area (a small area unit within the ABS Australian Standard Geographical Classification (ASGC)) and/or postcode, and have been aggregated to remoteness areas.

The *Remoteness area of hospital* presented in this section was based on the ABS 2006 ASGC.

The ASGC's remoteness structure categorises geographical areas in Australia into remoteness areas, described in detail on the ABS website <www.abs.gov.au>.

Some examples of localities in different remoteness categories include:

- *Major cities*, which include most capital cities, as well as major urban areas such as Newcastle, Geelong and the Gold Coast
- *Inner regional*, which includes towns such as Hobart, Launceston, Mackay and Tamworth
- *Outer regional*, which includes towns such as Darwin, Whyalla, Cairns and Gunnedah
- *Remote*, which includes towns such as Alice Springs, Mount Isa and Esperance
- *Very remote*, which includes towns such as Tennant Creek, Longreach and Coober Pedy.

Geographical location of hospital

The remoteness area of each public hospital was determined on the basis of its Standard Geographical Classification. For 2010–11, the geographical location was updated to align with the ABS's ASGC Remoteness Structure 2006.

National Standards Assessment Program

PCA has developed the National Palliative Care Standards in collaboration with the palliative care sector. The NSAP has been designed as a quality improvement program for participating specialist palliative care services which undertake self-assessment and monitoring against the 4th edition of the PCA *Standards for providing quality palliative care for all Australians* (PCA 2005b) (the Standards).

Participating services are asked to self-assess against the Standards' quality elements and then assign 'high', 'medium' or 'low' levels of priority to their perceived need for improvement against each of the 13 Standards. Services are also asked to provide action plans for quality improvement, which are subjected to thematic coding by the NSAP to identify categories of quality improvement action across Australia. The current report provides the aggregated results from all 126 services submitting cycle 1 results over NSAP's first 3 years (to 30 June 2012).

Additional information on the NSAP can be obtained from the *NSAP national quality report* (available on the NSAP website <www.nsap.palliativecare.org.au>).

Palliative Care Outcomes Collaboration

The PCOC is a national program using standardised validated clinical assessment tools to benchmark and measure outcomes in palliative care. Participation in the PCOC is voluntary and open to all palliative care service providers across Australia. Representation is sought from public and private health sectors, rural and metropolitan areas, and inpatient and ambulatory settings. The PCOC data set includes the following clinical assessment tools: Palliative Care Phase, PCPSS, SAS, Australia-modified Karnofsky Performance Status Scale, and RUG-ADL. The PCOC aims to assist services to improve the quality of the palliative care it provides through the analysis and benchmarking of patient outcomes.

The national figures used in this report reflect all palliative care services which submitted data for the January–December 2012 period. A full list of these services can be found at <www.pcoc.org.au>.

Population data

Throughout this report, estimated resident population data were used to derive age-standardised rates. The population data were sourced from the ABS and the most up-to-date estimates available at the time of analysis were used. Rates for 2011–12 data were calculated using preliminary estimated resident population data at 31 December 2012.

To derive estimates of the resident population, the ABS uses the 5-yearly Census of Population and Housing data as follows:

- All respondents to the Census are coded in relation to their state or territory, statistical local area and postcode of usual residence; overseas visitors are excluded.
- An adjustment is made for persons missed in the Census (approximately 2%).
- Australians temporarily overseas on Census night are added to the usual residence Census count.

The resulting numbers provide an estimate of the resident population in the Census year. In the following years, the Census numbers are adjusted by taking into account indicators of population change, such as births, deaths and net migration. More information on the process used to derive population estimates is available from the ABS website <www.abs.gov.au>.

For the Indigenous rates presented in this report, 'Series B' of the projected Indigenous experimental resident population estimates for 30 June 2010, as released by the ABS, was used (ABS 2009).

Mortality data

The registration of deaths has been compulsory in Australia since the mid-1850s and this information is registered with the relevant state and territory Registrar of Births, Deaths and Marriages. Since 1906, the Commonwealth Statistician has both compiled the information collected by the Registrars and published national death information. The information on deaths from the Registrars is coded nationally by the ABS according to rules set forward in various versions of the International Statistical Classification of Diseases and Related Health Problems (ICD). In the ABS deaths data, information is available in terms of the year in which a person *died* and the year in which the death was *registered*.

In chapter 2, ABS deaths data on the total number of Australian deaths that occurred during the specified financial years are shown (ABS 2012a). These mortality data were based on the year of *death* as this aligns with the information on deaths of admitted patients as recorded in the NHMD.

Medicare Benefits Schedule data

Medicare Australia collects data on the activity of all providers making claims through the MBS and provides this information to the DoHA. Information collected includes the type of service provided (MBS item number) and the benefit paid by Medicare Australia for the service. The item number and benefits paid by Medicare Australia are based on the *Medicare Benefits Schedule book* (DoHA 2011). Services that are not included in the MBS are not included in the data.

Table B1 lists all MBS items that have been defined as palliative medicine specialist services.

Table B1: MBS-subsidised palliative medicine specialist services items

MBS item	MBS group and subgroup	MBS item number
Palliative medicine attendances		
Attendance in a hospital or surgery, initial visit	Group A48	3005
Attendance in a hospital or surgery, subsequent visit	Group A48	3010
Attendance in a hospital or surgery, subsequent visit, minor	Group A48	3014
Initial home visit	Group A48	3018
Subsequent home visit	Group A48	3023
Subsequent home visit, minor	Group A48	3028
Palliative medicine case conferences		
Organise and coordinate a community case conference 15–<30 minutes	Group A48	3032
Organise and coordinate a community case conference 30–<45 minutes	Group A48	3040
Organise and coordinate a community case conference >=45 minutes	Group A48	3044
Participate in a community case conference 15–<30 minutes	Group A48	3051
Participate in a community case conference 30–<45 minutes	Group A48	3055
Participate in a community case conference >=45 minutes	Group A48	3062
Organise and coordinate a discharge case conference 15–<30 minutes	Group A48	3069
Organise and coordinate a discharge case conference 30–<45 minutes	Group A48	3074
Organise and coordinate a discharge case conference >=45 minutes	Group A48	3078
Participate in a discharge case conference 15–<30 minutes	Group A48	3083
Participate in a discharge case conference 30–<45 minutes	Group A48	3088
Participate in a discharge case conference >=45 minutes	Group A48	3093

The MBS data presented in this report relate to services provided on a fee-for-service basis for which MBS benefits were paid. The year is determined from the date the service was processed by Medicare Australia, rather than the date the service was provided. The state or territory is determined according to the postcode of the patient's mailing address at the time of making the claim. In some cases, this will not be the same as the postcode of the patient's residential address.

Appendix C: Technical notes

Population rates

Crude rates were calculated using the ABS estimated resident population at the midpoint of the data range (for example, rates for 2010–11 data were calculated using the estimated residential population as at 31 December 2010, while rates for the 2011 calendar year data were calculated using the estimated residential population as at 30 June 2011). Rates for 2011–12 data were calculated using preliminary estimated residential population as at 31 December 2012.

Crude rates for Indigenous status, country of birth and remoteness area data were calculated using the estimated residential population as at 30 June of the relevant year.

Age-specific rates

Age-specific rates provide information on the incidence of a particular event in a specified age group relative to the total number of people 'at-risk' of that event in the same age group. It is calculated by dividing the number of events occurring in each specified age group by the corresponding population in the same group, and then multiplying the result by a constant (for example, 10,000) to derive the rate.

In this report, age-specific rates are reported in Chapter 2; they are expressed per 10,000 persons and were based on ABS population estimates as at 31 December 2010.

Age-standardised rates

A crude rate provides information on the number of events (for example, palliative care separations) relative to the population 'at-risk' (for example, the entire population) in a specified period. No age adjustments are made when calculating such a rate. Since the likelihood of a palliative care separation is associated with age, crude rates are not suitable for making comparisons across time or groups when differences by age structure exist. More meaningful comparisons can be made by using age-standardised rates, with such rates adjusted for age in order to facilitate comparisons between populations that have different age structures.

There are two standardisation methods commonly used to adjust for age: direct and indirect. The direct standardisation approach is used in this report. To calculate age-standardised rates, age-specific rates (grouped in 5-year intervals) were multiplied against a constant population (namely, the Australian population as at 30 June 2001). This effectively removes the influence of age structure on the rate and it is described as the age-standardised rate.

For data analysis purposes, the ABS population estimates at the midpoint of the respective financial year were used to indicate the size of the population 'at-risk'. For example, for analyses of the 2010–11 data, the ABS population estimates for 31 December 2010 were used. However, in some instances, estimates for December were not available according to a particular characteristic (such as Indigenous status). In such instances, as shown in Table C1, population estimates for 30 June of the respective financial year were used. Likewise, the same approach was used when analysing 2011–12 data.

Table C1: Summary of approaches used to calculate age-standardised rates[(a)]

Characteristic	Applicable date for population estimates	Highest age group
Sector of hospital (public or private) Sex State or territory of separation State or territory of usual residence	31 December of the respective financial year	85 years and over
Indigenous status	30 June of the respective financial year	75 years and over
Remoteness area Socioeconomic status	30 June of the respective financial year	85 years and over

(a) All of the age-standardised rates were calculated using the direct standardisation method and 5-year age groups. The rates were age-standardised to the Australian population as at 30 June 2001 and expressed per 10,000 population.

For most of the ABS population estimate series, the highest age group for which data are available is '85 years and over'. However, for some estimates—including the projected Indigenous population—the highest age group for which data are made available is '75 years and over' (see Table C1).

Note that owing to the differences in approaches used to calculate the age-standardised rate for different analyses, the rates shown throughout this report for Australia (labelled as the 'Total') may differ slightly between analyses.

Average annual rates of change

Average annual rates of change or growth rates have been calculated as geometric rates:

$$\text{Average rate of change} = ((Pn/Po)^{(1/n)} - 1) \times 100$$

where Pn = value in the later time period

Po = value in the earlier time period

n = number of years between the two time periods.

Descriptive analyses

The details provided in this report are based on descriptive analyses, not multivariate analyses. Because of this, the results presented may be influenced by factors not considered in that particular analysis. This should be considered when examining the results. While completing multivariate analyses would be a useful extension of some of the analyses presented in this report, this goes beyond the scope of this report.

Disease-related information

Information on the number of separations by particular diseases is presented in two ways in this report. The first is based only on the principal diagnosis such that the number of separations for which a certain disease was coded as the principal diagnosis is counted. The second is based on the principal diagnosis and any additional diagnoses such that the number of separations for which a certain disease was coded as either the principal diagnosis or an additional diagnosis is counted. While only one principal diagnosis can be assigned for any one separation, one or more additional diagnoses may also be assigned.

Information relating to cancer

The ICD-10-AM diagnosis codes used in the admitted patient chapter to identify patients with a cancer diagnosis mirror the approach used in *Cancer in Australia: an overview* (see Appendix I in AIHW & AACR 2010). This approach takes into account that, for some cancer-related separations, the treatment relating to the person's cancer (such as chemotherapy or the insertion of a drug delivery device) is recorded as the principal diagnosis, rather than the specific form of cancer the person had, as per ICD-10-AM coding standards (NCCH 2008a). Thus, in this report, three different criteria are used to identify those separations with a principal diagnosis of cancer; these are summarised in Box C1.

Box C1: 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); 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.

The same approach as outlined in Box C.1 was used to identify those separations that had a principal or an additional diagnosis code of cancer. However, for those analyses, only the first two criteria are needed to identify those with cancer since the third one is redundant (that is, the relevant separations would already have been captured via the first criterion).

Thus, separations that met one of the following two criteria were considered to have a principal or additional diagnosis of cancer:

- a principal or additional diagnosis code of C00–C97, D45, D46, D47.1 or D47.3 from the 'Neoplasms' chapter of ICD-10-AM
- a principal or additional diagnosis from Chapter 21 of ICD-10-AM that was *directly* related to receiving health services or treatment for cancer as follows: Z03.1, Z08, Z12, Z40, Z51.0, Z51.1, Z54.1, Z54.2, Z80 or Z85.

Information relating to other specific diseases

Some diagnoses for palliative care patients are shown at a specific disease level in this report (for example, see tables 2.11 and 2.18). The best way to group ICD-10-AM codes to identify some diseases (such as bowel cancer, dementia and chronic obstructive pulmonary disease) is not always straightforward, as different approaches are used in the literature. Regarding the cancer site groupings, the process used in the *Cancer in Australia 2010: an overview* (AIHW & AACR 2010) is mirrored in this report. For the non-cancer diseases, the ICD-10-AM codes used to identify the relevant palliative care patients are shown in Table C2; the source of information for the code specification used is also shown.

Table C2: Diagnosis codes used to identify specific diseases other than cancer[a]

Specific disease	Diagnosis codes (ICD-10-AM)	Source for code specification
Chronic obstructive pulmonary disease	J40–J44	WHO 2008
Dementia and Alzheimer disease	F00–F03, G30	AIHW 2012b
Heart failure	I50	AIHW 2012b
HIV/AIDS	B20–B24	Becker et al. 2006, WHO 2008
Huntington disease	G10, F02.2	Begg et al. 2007
Liver failure	K70.4, K71.1, K72	. .
Motor neurone disease	G12.2	AIHW 2012b, Begg et al. 2007
Multiple sclerosis	G35	AIHW 2012b, Begg et al. 2007
Muscular dystrophy	G71.0	Begg et al. 2007
Parkinson disease	G20, G21, G22	AIHW 2012b
Renal failure	N17–N19	AIHW 2012b

(a) The diagnosis codes used to identify specific cancer sites are based on the approach used in *Cancer in Australia: an overview* (AIHW & AACR 2010).

Principal diagnosis of *Palliative care*

In the 2010–11 NHMD, there was one separation for which the principal (rather than an additional) diagnosis was recorded to be *Palliative care* (ICD-10-AM code of Z51.5). Usually, the first additional diagnosis will be used in place of the *Palliative care* code when reporting the principal diagnosis; however, this does not apply in this circumstance because there was no additional diagnosis recorded for this separation.

Patient day statistics

Patient day statistics can be used to provide information on hospital activity that, unlike separation statistics, accounts for differences in length of stay. As the NHMD contains records for patients ceasing separation during a specific reporting period (such as

1 July 2010 to 30 June 2011), this means that all patients who ceased separation during the reporting period are included, regardless of whether or not they were *admitted* during that period. Thus, not all patient days reported will have occurred during the reporting period. However, it is expected that, in general, patient days for patients who ceased separation in 2010–11, but who were admitted before 1 July 2010, will be generally counterbalanced by the patient days for patients still in hospital on 30 June 2011 who will cease separation in future reporting periods.

Quality of Indigenous status data

The AIHW report entitled *Indigenous identification in hospital separations data: quality report* (AIHW 2010c) presented the latest findings on the quality of Indigenous identification in Australian hospital separations data, based on studies of Indigenous identification in public hospitals conducted during 2007 and 2008. The results of the studies indicated that, overall, the quality of Indigenous identification in hospital separations data had improved over time but that the quality of Indigenous identification still varied substantially between jurisdictions. Since levels of Indigenous identification were estimated to be 80% or higher for New South Wales, Victoria, Queensland, Western Australia, South Australia and the Northern Territory (public hospitals only), the report recommended that hospitals data from those jurisdictions were of sufficient quality for analysis for the reporting periods from 2004–05 onwards. This recommendation—which was endorsed by the National Health Information Standards and Statistics Committee and by the National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data—was used in chapter 2 when examining differences by Indigenous status.

Thus, the conclusions drawn from the comparisons by Indigenous status are relevant to the jurisdictions considered, and may not necessarily be representative of the two excluded jurisdictions (namely, Tasmania and the Australian Capital Territory).

Appendix D: Classifications

This section describes the classification systems referred to in this report.

Australian Standard Geographical Classification Remoteness Areas

The ASGC was developed by the ABS to collect and disseminate geographically classified statistics.

In this report, the ASGC Remoteness Areas were used to assign areas across Australia to a remoteness category (ABS 2007). This classification divides all areas of Australia into five categories—namely, *Major cities*, *Inner regional*, *Outer regional*, *Remote* and *Very remote* (AIHW 2004). Information on the quality of the data in the NHMD on the usual residence of the patient can be found in Appendix 2 of *Australian hospital statistics 2010–11* (AIHW 2012a).

Index of Relative Socio-economic Advantage and Disadvantage and the Index of Relative Socio-Economic Disadvantage

The IRSAD and the IRSD are two of four SEIFAs developed by the ABS (ABS 2008). Each of the indexes summarises a different aspect of the socioeconomic conditions in an area and each was created using a different set of information (ABS 2008). Broadly, the indexes are based on factors such as average household income, education levels, unemployment rates, occupation and housing characteristics. The IRSAD and IRSD are area-based (not person-based) measures of socioeconomic status in which small areas of Australia are classified on a continuum from disadvantaged to affluent. This information is used as a proxy for the socioeconomic status of people living in those areas and may not be correct for each person living in that area. In this report, the first socioeconomic status group (labelled '1') corresponds to geographical areas containing the 20% of the population with the lowest socioeconomic status according to the IRSAD and the IRSD, and the fifth group (labelled '5') corresponds to the 20% of the population with the highest socioeconomic status.

International Statistical Classification of Diseases and Related Health Problems

The ICD, which was developed by the World Health Organization, is the international standard for coding morbidity and mortality statistics. It was designed to promote international comparability in collecting, processing, classifying and presenting these statistics. The ICD is periodically reviewed to reflect changes in clinical and research settings (WHO 2011).

The version currently in use in Australia for the coding of causes of death, the ICD-10 (WHO 1992), was endorsed in May 1990 and officially came into use in WHO member states from 1994. Further information on the ICD is available from the WHO website at <http://www.who.int/classifications/icd/en/>.

ICD-10-AM

The Australian Modification of ICD-10, referred to as the ICD-10-AM (NCCH 2008b), is based on the ICD-10. The ICD-10 was modified for the Australian setting by the National Centre for Classification in Health to make it more relevant to Australian clinical practice. Compatibility with the ICD-10 at the higher levels (that is, up to 4-character codes) of the classification has been maintained. The ICD-10-AM has been used for classifying diagnoses in hospital records in all Australian states and territories since 1999–00 (AIHW 2000).

The ICD-10-AM disease classification is hierarchical, with a small number of summary disease chapters which are divided into a large number of more specific disease groupings (represented by 3-character codes). Most of the 3-character disease groupings can be divided into an even larger number of very specific disease categories represented by 4- and 5-character codes.

Appendix E: PCOC benchmark revisions

The PCOC's first set of national benchmarks was developed in consultation with participating services in 2009 and included in PCOC's 6-monthly benchmarking reports from Report 8, which covered July to December 2009. Included in this set were three benchmarks for time spent in the unstable phase:

- *Benchmark 2.1*: 85% of patients remain in the unstable phase for fewer than 7 days—first phase of episode
- *Benchmark 2.2*: 90% of patients remain in the unstable phase for fewer than 7 days—not first phase of episode
- *Benchmark 2.3*: the median time in the unstable phase is 2 days or less.

Stakeholders at PCOC's 2012 benchmarking workshops suggested that benchmarks 2.1 and 2.2 be combined, as the distinction between first phase and not first phase did not provide any additional information. It was also suggested that the 'fewer than 7 days' time frame did not represent best practice and should be reduced.

To investigate these suggestions, the PCOC analysed data for July to December 2009 (Report 8) and January to June 2012 (Report 13). This analysis showed that setting the benchmark at 90% for a length of the unstable phase of 3 days or less resulted in a similar level of performance for the top 10 services as was achieved for benchmarks 2.1 and 2.2 in both time periods. It was therefore deemed appropriate to replace benchmark 2.1 and 2.2 with 'Benchmark 2: 90% of patients are in the unstable phase for 3 days or less.'

Table E1 compares the percentage of all services and patient phases that meet the original and revised benchmarks.

Table E1: Per cent of all service and patient phases that meet benchmark 2.1, 2.2 and revised benchmark 2, by report

	Benchmark 2.1		Benchmark 2.2		Benchmark 2.0
	Report 8	Report 13	Report 8	Report 13	Report 13
Patient phases	66	83	73	84	66
Services	23	54	20	45	12

Source: PCOC analysis of 2012 data (unpublished).

In light of the new benchmark 2, the PCOC decided benchmark 2.3 (median time in the unstable phase for 2 days or less) was redundant and subsequently removed it from the suite of PCOC benchmarks.

The amalgamated benchmark will be implemented as of PCOC's Report 14, covering July to December 2012.

Glossary

This section provides a general description of the terms used in this report. The terms have been defined in the context of this report; some terms may have other meanings in other contexts. Where applicable, the identification number from the Metadata Online Registry (METeOR) is shown after the definition of the term. METeOR is Australia's central repository for health, community services and housing assistance metadata. METeOR can be viewed on the AIHW website at <www.aihw.gov.au>.

Aged Care Funding Instrument: a resource allocation instrument which focuses on three domains that discriminate care needs among residents. The Instrument assesses core needs as a basis for allocating funding.

Additional diagnosis: a condition or complaint either coexisting with the principal diagnosis or arising during the episode of care (METeOR identifier 333832).

Administrative database: the recording—either routinely or as required by law—of observations about events such as births, deaths, hospital separations and cancer incidence. The National Hospital Morbidity Database is an example of an administrative database.

Admitted patient: a person who undergoes a hospital's formal admission process to receive treatment and/or care. Such treatment or care is provided over a period of time and can occur in hospital and/or in the person's home (as a 'hospital-in-the-home' patient) (METeOR identifier 268957).

Average length of stay: the average number of patient days for admitted patient episodes. Patients admitted and separated on the same day are allocated a length of stay of 1 day.

Care type: the overall nature of a clinical service provided to an admitted patient during an episode of care. The 'Care type' categories applicable for admitted patient care are listed below (METeOR identifier 270174).

- acute care
- rehabilitation care
- palliative care
- geriatric evaluation and management
- psychogeriatric care
- maintenance care
- newborn care
- other admitted patient care.

Encounter: any professional interchange between a patient and a general practitioner; it includes both face-to-face encounters and indirect encounters where there is no face-to-face meeting but where a service is provided (for example, a prescription or referral) (Britt et al. 2012).

Episode of care: the period of admitted patient care between a formal or statistical admission and a formal or statistical discharge, characterised by only one care type (METeOR identifier 268956) (Also see *Care type*, *Separation* and *Statistical discharge*).

Establishment type: the type of establishment (defined in terms of legislative approval, service provided and patients treated) for each separately administered establishment. Establishment types include acute care hospitals, psychiatric hospitals, alcohol and drug treatment centres and hospices (METeOR identifier: 269971).

Funding source for hospital patient: the expected principal source of funds for an admitted patient episode or non-admitted patient service event (METeOR identifier: 339080).

General practitioners: medical practitioners who are vocationally registered under Section 3F of the Health Insurance Act, or are Fellows of the Royal Australian College of General Practitioners or trainees for vocational registration.

Hospital: a health-care facility established under Commonwealth, state or territory legislation as a hospital or a free-standing day procedure unit and authorised to provide treatment and/or care to patients (METeOR identifier: 268971).

Hospital-in-the-home care: the provision of care to hospital admitted patients in their place of residence as a substitute for hospital accommodation. The place of residence may be permanent or temporary (METeOR identifier: 270305).

Indigenous status: a measure of whether a person identifies as being of Aboriginal and/or Torres Strait Islander origin (METeOR identifier: 291036).

International Statistical Classification of Diseases and Related Health Problems: the World Health Organization's internationally accepted classification of diseases and related health conditions. The Australian Modification of the tenth revision of the ICD (namely, ICD-10-AM) has been used in all Australian jurisdictions for the coding of admitted patient data since 1999–00 (see Appendix D).

Length of stay: the length of stay of an overnight patient, which is calculated by subtracting the date the patient is admitted from the date of separation and deducting days that the patient was on leave. A same-day patient is allocated a length of stay of 1 day (METeOR identifier: 269982).

MBS-subsidised palliative medicine specialist services: the services provided by a palliative medicine specialist on a fee-for-service basis that are partly or fully funded under the Australian Government's Medicare program. These services cover patient attendances (or consultations) provided in different settings as well as services such as case conferencing.

Median: the value in a set of ranked observations that divides the data into two parts of equal size. When there are an odd number of observations, the median is the middle value. When there is an even number of observations, the median is calculated as the mean of the two central values.

Mode of admission: the mechanism by which a person begins an episode of admitted patient care (METeOR identifier: 269976).

Mode of separation: the status at separation of a person (through discharge, transfer or death) and the place to which the person is released (where applicable) (METeOR identifier: 270094).

Overnight-stay patient: a patient who, following a clinical decision, receives hospital treatment for a minimum of 1 night (that is, who is admitted to and separated from the hospital on different dates).

Palliative care: care in which the clinical intent or treatment goal is primarily quality of life for a patient with an active, progressive disease with little or no prospect of cure. It is usually evidenced by an interdisciplinary assessment and/or management of the physical, psychological, emotional and spiritual needs of the patient; and a grief and bereavement support service for the patient and their carers/family. It includes care provided as follows: in a palliative care unit; in a designated palliative care program; and under the principal clinical management of a palliative care physician or, in the opinion of the treating doctor, when the principal clinical intent of care is palliation (also see *Care type*).

Palliative care in residential aged care: care provided for residential aged care residents identified in the ACFI data through their care needs being appraised as palliative care in the complex health-care domain. This appraisal process identifies residents undergoing a palliative care program where ongoing care will involve very intensive clinical nursing and/or complex pain management in the residential care setting.

Palliative care-related encounters: encounters that are identified using the BEACH coding system's four ICPC-2 PLUS palliative care-related codes against three data elements: *Reason for encounter, Diagnosis* and *Referral* (which are used by GPs to record a reason for encounter). A palliative care-related encounter includes one or more of these ICPC-2 PLUS codes which are recorded for one or more of the three data elements.

Palliative care-related separation: a hospital separation for which the principal clinical intent of the care was palliation during all or some of that separation (also see *Palliative care*).

Palliative medicine specialist: a medical practitioner who is a Fellow of the Australian Chapter of Palliative Medicine. This membership is required in order for the practitioner to be eligible for payment of MBS subsidies for palliative care services.

Patient days: the total number of days for patients who were admitted for an episode of care and who separated during a specified reference period. A patient who is admitted and separated on the same day is allocated 1 patient day (METeOR identifier: 270045).

Permanent admission: an admission to residential aged care for expected long-term care during the reporting period.

Permanent resident: a resident who is admitted to residential aged care for permanent care (long-term care).

Principal diagnosis: the diagnosis established after study to be chiefly responsible for occasioning an episode of admitted patient care (METeOR identifier 333838).

Private hospital: a privately owned and operated institution, catering for patients who are treated by a doctor of their own choice. Patients are charged fees for accommodation and other services provided by the hospital and relevant medical and paramedical practitioners. Acute care and psychiatric hospitals are included, as are private free-standing day hospital facilities (also see *Establishment type*).

Procedure: a clinical intervention that is surgical in nature, carries a procedural risk, carries an anaesthetic risk, requires specialised training and/or requires special facilities or equipment available only in the acute care setting (METeOR identifier: 361687).

Public hospital: a hospital controlled by a state or territory health authority. Public hospitals offer free diagnostic services, treatment, care and accommodation to all eligible patients (also see *Establishment type).*

Same-day: an admitted patient who is admitted and separates on the same date. Such patients are allocated a length of stay of 1 day.

Separation: the term used to refer to the episode of admitted patient care, which can be a total hospital stay (from admission to discharge, transfer or death) or a portion of a hospital stay beginning or ending in a change of type of care (for example, from acute care to rehabilitation). 'Separation' also means the process by which an admitted patient completes an episode of care by being discharged, dying, transferring to another hospital or changing type of care.

Statistical admission: an administrative process that begins an admitted patient episode of care when there was a change in the clinical intent of treatment (for example, from acute care to palliative care) (also see *Care type, Episode of care* and *Statistical discharge*).

Statistical discharge: an administrative process that completes an admitted patient episode of care when there is a change in the clinical intent of treatment (for example, from acute care to palliative care). For each statistical discharge, there should be a corresponding statistical admission—that is, a new episode of care with a different care type created (also see *Care type* and *Episode of care*).

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Related publications

This report, *Palliative care services in Australia 2013*, is part of an annual series. The earlier edition can be downloaded for free from the AIHW website <http://www.aihw.gov.au/publication-detail/?id=10737423073>. The website also includes information on ordering printed copies.

The following AIHW publications relating to palliative care might also be of interest:

- AIHW 2011. Identifying admitted patient palliative care hospitalisations: technical paper. Cat. no. HWI 113. Canberra: AIHW.
- AIHW 2011. Trends in palliative care in Australian hospitals. Cat. no. HWI 112. Canberra: AIHW.

Palliative care services in Australia 2013 is the second in a planned series of annual reports providing a detailed picture of the national response to the palliative care needs of Australians. Information from a range of data sources from 2011–12 and where indicated, 2010–11 are presented, as are changes over time. There were almost 24,500 palliative care-related separations reported in public and private hospitals in 2010–11. Almost $3.5 million in Medicare Benefits Schedule payments was paid for palliative medicine specialist services in 2011–12.