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**Australian Institute of  
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# **Palliative care services in Australia 2012**



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*Authoritative information and statistics  
to promote better health and wellbeing*

# **Palliative care services in Australia**

**2012**

Australian Institute of Health and Welfare  
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# Foreword

The pattern of disease seen at the end of life is changing. An increasing proportion of Australians are likely to die from chronic illnesses, and people with such illnesses are more likely to make use of palliative care services. In addition, the growth and ageing of the Australian population is likely to result in increased demand for palliative care services.

This inaugural report, *Palliative care services in Australia 2012*, provides detailed information on the national response of our health and welfare systems to Australians' palliative care needs using 2009–10 data, and where available, 2010–11 data. The AIHW has brought together information from a number of disparate palliative care data sources to produce an inaugural report which aims to give a broad picture of palliative care in Australia; thus providing a 'one-stop shop' of national palliative care service information that can be useful to a broad range of stakeholders. This in turn will facilitate better understanding of the amount and nature of palliative care activity in the Australian health sector and how it is changing over time.

*Palliative care services in Australia 2012* includes information on palliative care-related separations from the Australian Institute of Health and Welfare's National Hospital Morbidity Database (NHMD) and other data sources, including: Bettering the Evaluation and Care of Health survey for general practice; palliative care-specific services from the Medicare Benefits Scheme and Pharmaceutical Benefits Scheme; workforce; and palliative care outcomes from the Palliative Care Outcomes Collaboration.

The Institute is keen to produce *Palliative care services in Australia* on an annual basis and will work with stakeholders to expand the range of palliative care data being reported. The addition of jurisdiction-specific data will be a particular focus as it has the potential to inform readers of the diversity in both the organisation and service delivery arrangements for palliative care services across Australia.

The Institute looks forward to working with stakeholders at all levels to refine the format and content of *Palliative Care Services in Australia* to ensure that it provides a timely evidence base relevant to palliative care services in Australia.

David Kalisch

Director

October 2012

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# Abbreviations

AACR	Australasian Association of Cancer Registries
ABS	Australian Bureau of Statistics
ACHI	Australian Classification of Health Interventions
AChPM	Australasian Chapter of Palliative Medicine
ACFI	Aged Care Funding Instrument
ACT	Australian Capital Territory
ADL	Activities of Daily Living
AIHW	Australian Institute of Health and Welfare
AHCA	Australian Health Care Agreement
AHPRA	Australian Health Practitioner Regulation Agency
ALOS	average length of stay
ANZSPM	Australian and New Zealand Society of Palliative Medicine
ASGC	Australian Standard Geographical Classification
ASR	age-standardised rate
BEACH	Bettering the Evaluation and Care of Health
BEH	behaviour
CHC	Complex Health Care
COPD	chronic obstructive pulmonary disease
DoHA	Australian Government Department of Health and Ageing
DVA	Department of Veterans' Affairs
ERP	estimated resident population
FACHPM	Fellow of the Australasian Chapter of Palliative Medicine
FTE	full-time-equivalent
GP	general practitioner
HITH	hospital-in-the-home
ICD	International Statistical Classification of Diseases and Related Health Problems
ICD-9-CM	International Statistical Classification of Diseases, ninth revision, Clinical Modification
ICD-10-AM	International Statistical Classification of Diseases and Related Health Problems, tenth revision, Australian Modification
IRSAD	Index of Relative Socio-economic Advantage and Disadvantage
IRSD	Index of Relative Socio-economic Disadvantage

MBS	Medicare Benefits Schedule
MHPCU	Mental Health and Palliative Care Unit
METeOR	Metadata Online Registry
NAGATSIHID	National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data
NAPEDCD	Non-admitted Patient Emergency Department Care Database
NCCH	National Centre for Classification in Health
NHHRC	National Health and Hospitals Reform Commission
NHISSC	National Health Information Standards and Statistics Committee
NHMBWG	National Health Ministers' Benchmarking Working Group
NHMD	National Hospital Morbidity Database
NHPC	National Health Performance Committee
NHWDS	National Health Workforce Data Set
NMDS	National Minimum Data Set
NOS	not otherwise specified
NPA HHWR	National Partnership Agreement on Hospital and Health Workforce Reform
NPA IPHS	National Partnership Agreement on Improving Public Hospital Services
NPCP	National Palliative Care Program
NPHEd	National Public Hospital Establishments Database
NSW	New South Wales
NT	Northern Territory
PBAC	Pharmaceutical Benefits Advisory Committee
PBS	Pharmaceutical Benefits Scheme
PCA	Palliative Care Australia
PCOC	Palliative Care Outcomes Collaboration
PEPA	Program of Experience in the Palliative Approach
Qld	Queensland
RACP	Royal Australasian College of Physicians
RACS	residential aged care service
RFE	reason for encounter
RPBS	Repatriation Pharmaceutical Benefits Scheme
SA	South Australia
SEIFA	Socio-Economic Indexes for Areas
SLA	Statistical Local Area

Tas	Tasmania
Vic	Victoria
WA	Western Australia
WHO	World Health Organization

## Symbols

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

# Summary

This inaugural report on palliative care services in Australia provides detailed information on the national responses to the palliative care needs of Australians using a range of AIHW and other national data sources. Broadly, it considers three aspects of palliative care; services, resources and patient outcomes.

## Services provided

Since 2000–01, the number of palliative care separations reported in public and private hospitals has increased by 51% to almost 56,000 in 2009–10.

Over the 5 years to 2010–11, the number of palliative medicine specialist services subsidised through the MBS more than doubled from 19,554 services in 2006–07 to 42,934.

The number of palliative care-specific prescriptions subsidised as part of the PBS/RPBS decreased in the 5 years to 2010–11, whilst the number of prescriptions for analgesics increased.

About 1 in 1,000 of all general practice encounters reported for the Bettering the Evaluation and Care of Health (BEACH) survey of general practice activity in 2010–11 were palliative care-related encounters.

In 2010–11, there were 11,083 residents in aged care with a completed Aged Care Funding Instrument (ACFI) assessment who were assessed as requiring palliative care.

## Resources

Almost \$3 million in MBS benefits was paid for palliative medicine specialist services in 2010–11. Over the 5 years to 2010–11 the amount of benefits paid on palliative medicine specialist services subsidised through the MBS has more than doubled.

About \$2.5 million in PBS/RPBS benefits was paid for medications included on the palliative care schedule in 2010–11. Over the 5 years to 2010–11 the amount of benefits paid on palliative care schedule items increased four-fold, with an average annual change of about 44%.

There were 172 specialist palliative medicine physicians working in Australia in 2009, representing less than 1 in 100 medical practitioners. There were 5,173 nurses working principally in the area of palliative care nursing in 2009, representing about 1 in 50 employed nurses.

## Palliative care outcomes

In 2011 there were a total of 79,253 Palliative Care Outcomes Collaboration (PCOC) phases. Nearly half (43.8%) of all contributing services met the PCOC benchmark 1 (time from referral to contact), where 90% of patients were contacted by a member of the clinical team within 2 days of receipt of referral. Of the 35,389 palliative care episodes in 2011, 81.1% met this benchmark.

More than half (53.3%) of services met benchmark 2.3 (time in unstable phase), where the median length of all unstable phases was 2 days. About 40% of services met benchmark 3.2 (change in pain), where 60% of patients in moderate/severe pain reduced to absent/mild pain at phase end.



# 1 Introduction

The World Health Organization (WHO) estimates that 56 million people die in the world each year and that around 60% of them could have benefited from palliative care (Davies & Higginson 2004). 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 (PCA 2003). It aims to maintain quality of life for the patient, their family and carers (Box 2003).

As a distinct academic discipline, palliative care has been recognised in Australia since the 1980s (Tieman et al. 2005). Indeed, the 1980s saw the start of a community-led call for recognition of the needs of people who are dying and their families, and for services to address these needs (DoHA 2005).

The recognition of palliative care as a distinct medical speciality is even more recent, with the Royal Australasian College of Physicians (RACP) recognising palliative medicine as a speciality in its own right in 1999 (RACP 2012).

Today, 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).

## 1.1 Purpose of this report

Although several Australian data collections contain information relevant to palliative care, the extent and usefulness of these data is variable. This report provides a review of existing national data and presents results of analysis undertaken by the Australian Institute of Health and Welfare (AIHW). The quality and breadth of data items within the various data sources will be considered, along with the usefulness of the data in meeting the information needs of stakeholders.

## 1.2 What are palliative care services?

In describing palliative care, it is important to note that there are a number of different definitions and terminologies which 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'. As such, definitions may vary between states and territories as well as various parts of the sector.

The WHO'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: The World Health Organization definition of palliative care**

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

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.*

## **Demand for palliative care services**

In 2003, Palliative Care Australia (PCA) estimated that between 50 and 90 per cent of cancer patients and between 9 and 16 per cent of non-cancer patients in Australia are referred to palliative care services annually (PCA 2003).

The demand for palliative care services is affected by the incidence of cancer and other chronic progressive diseases in the population. As such, an increased demand for palliative care services is expected to be one of the many consequences of the growth and ageing of Australia's population. In addition, the pattern of disease at the end of life is changing, such that an increasing proportion of people are likely to die from chronic progressive illnesses (AIHW 2010a) – people with such illnesses are likely to make use of palliative care services, increasing demand.

At the same time, there is an increasing focus on the amount and quality of palliative care services. For example, the second National Palliative Care Strategy (DoHA 2010), endorsed by Australian Health Ministers in 2010, articulates a number of priority goal areas which are aimed at meeting 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 National Palliative Care Strategy, each state and territory has a range of initiatives in place to drive improvements in the delivery of palliative care services.

## Supply of palliative care services

In Australia, palliative care is delivered by a range of settings and service types, including:

- specialist palliative care services
- private and public hospitals (with or without hospices)
- residential aged care facilities
- the home and other community settings
- justice health services
- disability services.

The exact model of care provision differs across Australia (DoHA 2005). This diversity stems from factors such as: different state and territory approaches to planning and delivering publicly funded services, local service delivery practices and the structure of the health care system; varying demographics and remoteness; and the demand 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 2010e).

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

- 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.
- 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.

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 Data on palliative care services

One key element of the National Palliative Care Strategy is the collection, analysis and reporting of data to 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 provide high-quality care (AIHW 2008).

## 1.4 Structure and scope of this report

The information presented in this report has been organised around existing national data collections and/or health-care service types. As palliative care is provided in almost all settings where health care is provided, the scope of this report is correspondingly broad.

The second chapter presents information on admitted patient palliative care services, 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 services. Further details on the Admitted Patient Care NMDS methodology presented here can be found in the 2011 publication *Identifying palliative care hospitalisations in admitted patient data: technical paper* (AIHW 2011b) and the *Trends in palliative care in Australian hospitals* publication (AIHW 2011g).

Chapter 3 presents patient demographic, diagnoses and referral information for palliative care-related general practice (GP) encounters, from the 2010–11 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), administered by Medicare Australia. This data provides information on medical (including diagnostic) services and provides an overview of the number and types of services provided by palliative medicine specialists under the MBS and the characteristics of people who received these services.

Palliative care delivered in residential aged care services (RACS) are discussed in Chapter 5. The primary data collection used for this chapter is the Aged Care Funding Instrument (ACFI) data, held by the Department of Health and Ageing (DoHA).

Chapter 6 presents information on palliative care specific PBS subsidised prescriptions. The data source for this is the Pharmaceutical Benefits Scheme (PBS), administered by Medicare Australia.

Resourcing of palliative care is covered in Chapter 7. As there is currently no national data collection which can be used to report on resourcing of palliative care in Australia, a number of different data sources have been used. An overview of government funding of palliative care services in Australia is presented using previously published data. Information on the number of public hospitals with hospice facilities is reported from the National Public Hospital Establishments Database. Information on the palliative care workforce has been derived from two sources: the National Health Workforce Data Set which provides information for specialist palliative medicine physicians, and the AIHW Nursing and Midwifery Labour Force Survey (AIHW 2011d) which provides information on palliative care nurses.

The final chapter on palliative care outcome measures was provided by the Palliative Care Outcomes Collaboration (PCOC) and presents an overview of information on outcomes experienced by patients receiving palliative care.

## 2 Admitted patient palliative care

### 2.1 Introduction

Available data suggest that a substantial proportion of palliative care provided in Australia occurs within the admitted patient setting (PCOC 2010). There are a variety of reasons why a patient will receive palliative care in the admitted patient setting, rather than other settings (Willard & Luker 2006). These include a complex combination of factors 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, the admitted patient setting is often where palliative care patients die (Willard & Luker 2006).

This chapter presents information on episodes of admitted patient palliative care using data on palliative care-related separations as recorded in the National Hospital Morbidity Database (NHMD) for 2009–10 (see Box 2.1). In addition, time series data for the period 2000–01 through to 2009–10 have been presented to show the changes in separations for palliative care over this period. The information included in this chapter 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. This is because the NHMD contains records for each separation, not for each patient. One of the impacts of this is that those patients who separated more than once during a financial year will have more than one record in the database.

Palliative care in the admitted patient setting may be provided in a hospice, in a dedicated palliative care ward or other wards within a hospital. Wherever possible, corresponding data on all separations have been provided for comparison purposes.

In this chapter, a palliative care 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. Two NHMD data items – ‘Care type’ and ‘Diagnosis’ capture information on palliative care, such that if either (or both) has a code of *Palliative care*, that separation is included (see Appendix A for further information). As such, it is important to note that this means that although there may also be other separations within the NHMD which include palliative care services, these separations are not counted due to the fact that palliative care is not recorded as the main care type and/or diagnosis during the separation.

Further details on the methodology used here can be found in the 2011 AIHW publication *Identifying palliative care separations in admitted patient data: technical paper* (AIHW 2011b). In conjunction with the publication of this technical paper, the AIHW also published *Trends in palliative care in Australian hospitals* which provides an overview of the nature and extent of palliative care separations in public and private hospitals across Australia for the period from 1999–00 to 2008–09 (AIHW 2011g).

### Box 2.1: Terms relating to admitted patient care

Information on admitted patients is compiled when an admitted patient (a patient 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** 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 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 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.
- A **same-day separation** occurs when a patient is admitted and separated from the hospital on the same date. An overnight separation occurs when a patient is admitted to and separated from the hospital on different dates.
- 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.
- **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.

This chapter discusses the following five key topics using 2009–10 data:

- the number of admitted patient palliative care 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 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.

## 2.2 Admitted patient palliative care in 2009–10

In 2009–10, there were almost 56,000 palliative care separations reported from public and private hospitals in Australia, accounting for less than 1 in 100 (0.7%) of all hospital separations (8,531,003) (Table 2.1). There was a slightly higher proportion of palliative care separations for males than females (54.2% and 45.8%, respectively) and the age-standardised rate was also higher for males than females (28.0 and 19.4 per 10,000 population, respectively).

**Table 2.1: Palliative care separations by sex and all separations, public and private hospitals, 2009–10**

	Palliative care separations			Separations for all reasons
	Males	Females	Total	
Number	30,328	25,655	55,983	8,531,003
Per cent of palliative care separations	54.2	45.8	100.0	..
Per cent of all separations for all reasons	0.4	0.3	0.7	100.0
Age-standardised rate <sup>(a)</sup>	28.0	19.4	23.2	3,709.3

(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: National Hospital Morbidity Database, AIHW.

People aged 75 years and over accounted for half (49.5%) of all palliative care separations (Table 2.2). The proportion of palliative care separations increases as age increases, with only about one in ten (12%) of the total number of palliative care separations being for patients under 55 years. The average age of those receiving palliative care was 71.9 years with little difference observed between males and females. As would be expected, this is considerably older than the average age of 53.3 years for all separations.

Although there were more palliative care separations for males overall, there were more separations for females for those aged between 25 and 54 years. For those aged 85 years and over, there were 20% more separations for females compared to males.

**Table 2.2: Palliative care separations by age and sex, all separations, public and private hospitals, 2009–10**

Age group	Palliative care separations						Separations for all reasons
	Number			Per cent			
	Males	Females	Total	Males	Females	Total	
0–14 years	117	107	224	0.4	0.4	0.4	6.7
15–24 years	69	61	130	0.2	0.2	0.2	6.5
25–34 years	170	225	395	0.6	0.9	0.7	9.6
35–44 years	640	844	1,484	2.1	3.3	2.7	10.8
45–54 years	2,160	2,304	4,464	7.1	9.0	8.0	12.6
55–64 years	4,862	3,858	8,720	16.0	15.0	15.6	16.3
65–74 years	7,679	5,194	12,873	25.3	20.2	23.0	16.7
75–84 years	9,776	7,241	17,017	32.2	28.2	30.4	14.9
85 years and over	4,855	5,821	10,676	16.0	22.7	19.1	5.9
<b>Total</b>	<b>30,328</b>	<b>25,655</b>	<b>55,983</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>
Average age	71.8	72.1	71.9	..	..	..	53.3

Source: National Hospital Morbidity Database, AIHW.

## 2.3 A profile of palliative care separations in 2009–10

### Where was palliative care provided?

#### Public versus private hospitals

In 2009–10, there were more palliative care separations from public hospitals (85% or 47,345 separations) than private hospitals. This shows a proportional overrepresentation of palliative care in public hospitals, in which 59.4% of all separations occur (Table 2.3). The highest proportion of palliative care separations in public hospitals was seen in New South Wales (92.4%) and Victoria (89.4%). However, in Western Australia, the majority of palliative care separations occurred in private hospitals (60.9%). 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.

The Northern Territory reported the highest age-standardised rate at 57.7 palliative care separations per 10,000 population for public hospitals. This rate was more than double the next highest rate of 24.4 recorded in Victoria. However, note that the total number of palliative care separations was comparatively small in the Northern Territory. Western Australia had the lowest age-standardised rate within public hospitals, at 5.7 palliative care separations per 10,000 population.

Of the five jurisdictions with age-standardised rates able to be reported for private hospitals, Western Australia reported the highest rate (8.9 per 10,000 population) for palliative care separations which was more than four and a half times higher than the rate for New South Wales (1.9 per 10,000 population).

**Table 2.3: Palliative care separations by state and territory, and all separations, public and private hospitals, 2009–10**

	Palliative care separations									Separations for all reasons
	NSW	Vic	Qld	WA	SA	Tas <sup>(a)</sup>	ACT <sup>(a)</sup>	NT <sup>(a)</sup>	Total <sup>(a)</sup>	
<b>Public hospitals</b>										
Number	19,180	14,949	5,953	1,284	3,453	1,074	753	699	47,345	5,069,288
Per cent	92.4	89.4	77.8	39.1	76.2	n.p.	n.p.	n.p.	84.6	59.4
Rate <sup>(b)</sup>	23.6	24.4	13.1	5.7	17.2	17.8	24.0	57.7	19.6	2,214.6
<b>Private hospitals</b>										
Number	1,587	1,775	1,696	1,998	1,081	n.p.	n.p.	n.p.	8,638	3,461,715
Per cent	7.6	10.6	22.2	60.9	23.8	n.p.	n.p.	n.p.	15.4	40.6
Rate <sup>(b)</sup>	1.9	2.8	3.7	8.9	5.2	n.p.	n.p.	n.p.	3.5	1,494.7
<b>All hospitals</b>										
Number	20,767	16,724	7,649	3,282	4,534	n.p.	n.p.	n.p.	55,983	8,531,003
Per cent	100.0	100.0	100.0	100.0	100.0	n.p.	n.p.	n.p.	100.0	100.0
Rate <sup>(b)</sup>	25.6	27.3	16.8	14.6	22.4	n.p.	n.p.	n.p.	23.2	3,709.3

(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: National Hospital Morbidity Database, AIHW.

## How long did patients stay?

In 2009–10, almost all (93.2%) of the palliative care separations involved at least one overnight stay, compared with 40.5% for all separations (AIHW 2011a). Palliative care separations accounted for more than 663,000 patient days with an average length of stay of 11.9 days (Table 2.4). This length of stay is nearly four times longer than the average length of stay of 3.1 days seen for all separations. When only those separations that involved an overnight stay are considered, the difference narrows somewhat to 12.6 days for palliative care separations and 5.9 days for all separations (AIHW 2011a).

The average length of stay per palliative care separation was 11.5 days for males and 12.2 days for females.

**Table 2.4: Palliative care separations, all separations, by sex, patient days and average length of stay (ALOS), public and private hospitals, 2009–10**

	Palliative care separations					Separations for all reasons	
	Same-day <sup>(a)</sup>	Overnight <sup>(b)</sup>		Total		Per cent of overnight separations	ALOS (days)
	Patient days	Patient days	ALOS (days)	Patient days	ALOS (days)		
Males	2,145	347,127	12.3	349,272	11.5	92.9	3.1
Females	1,689	312,480	13.0	314,169	12.2	93.4	3.1
<b>Total</b>	<b>3,834</b>	<b>659,607</b>	<b>12.6</b>	<b>663,441</b>	<b>11.9</b>	<b>93.2</b>	<b>3.1</b>

(a) By definition, the average length of stay (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: National Hospital Morbidity Database, AIHW.

There was little difference observed in the average length of stay between public and private hospitals for Victoria, Western Australia and South Australia (Table 2.5). However, the average length of stay in Queensland was noticeably longer in private hospitals compared to public hospitals (14.2 and 8.7 days, respectively). The average length of stay in public hospitals for overnight separations was highest in South Australia (13.6 days), while in private hospitals, Queensland recorded the highest average length of stay at 15.2 days.

**Table 2.5: Palliative care separations, by state and territory, average length of stay, public and private hospitals, 2009–10**

	Average length of stay (days)								Total <sup>(a)</sup>
	NSW	Vic	Qld	WA	SA	Tas <sup>(a)</sup>	ACT <sup>(a)</sup>	NT <sup>(a)</sup>	
<b>Public hospitals</b>									
Overnight separations	13.0	13.0	9.3	10.4	13.6	12.5	12.0	13.8	12.5
<i>Total separations</i> <sup>(b)</sup>	11.7	12.6	8.7	9.8	13.2	12.2	11.5	13.1	11.7
<b>Private hospitals</b>									
Overnight separations	13.3	13.0	15.2	11.4	13.7	n.p.	n.p.	n.p.	13.4
<i>Total separations</i> <sup>(b)</sup>	13.2	12.7	14.2	9.7	13.1	n.p.	n.p.	n.p.	12.6
<b>All hospitals</b>									
Overnight separations	13.0	13.0	10.7	11.0	13.6	n.p.	n.p.	n.p.	12.6
<b>Total separations</b> <sup>(b)</sup>	<b>11.8</b>	<b>12.6</b>	<b>9.9</b>	<b>9.7</b>	<b>13.2</b>	<b>n.p.</b>	<b>n.p.</b>	<b>n.p.</b>	<b>11.9</b>

(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 average length of stay (ALOS) for same-day separations equal 1 day.

Source: National Hospital Morbidity Database, AIHW.

## Who paid for the care?

Data on the principal source of funding for a separation are also recorded in the NHMD. In 2009–10, the highest proportion of funding attributed to public hospitals for all palliative care separations was for *Public patients* at 76.7%. The next most frequently recorded funding source was *Private health insurance* (16.2%) (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 *Department of Veterans' Affairs* contributing 9.9% and 2.3%, respectively. In private hospitals, *Private health insurance* was the main funding source for all palliative care separations (59.2%).



**Table 2.6: Palliative care separations, all separations, by principal source of funds, states and territories, public and private hospitals, 2009–10**

Principal source of funds	Palliative care separations (per cent)									Separations for all reasons (per cent)
	NSW	Vic	Qld	WA	SA	Tas <sup>(a)(b)</sup>	ACT <sup>(a)</sup>	NT <sup>(a)</sup>	Total <sup>(a)</sup>	
<b>Public hospitals</b>										
Public patients <sup>(c)</sup>	67.3	79.8	92.2	89.0	81.6	79.7	67.6	96.7	76.7	85.1
Private health insurance	24.2	13.6	3.1	5.5	12.9	13.9	22.8	0.4	16.2	9.9
Department of Veterans' Affairs	7.1	6.0	4.2	5.1	5.4	5.7	8.9	2.6	6.2	2.3
Other <sup>(d)</sup>	1.4	0.5	0.5	0.5	0.2	0.2	0.7	0.3	0.9	2.6
<b>Total<sup>(e)</sup></b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>
<b>Private hospitals</b>										
Public patients <sup>(c)</sup>	12.5	0.7	36.4	55.3	9.2	n.p.	n.p.	n.p.	23.5	3.0
Private health insurance	68.7	81.2	47.0	33.9	80.4	n.p.	n.p.	n.p.	59.2	80.0
Department of Veterans' Affairs	16.6	11.9	11.0	10.6	9.3	n.p.	n.p.	n.p.	12.8	5.8
Other <sup>(d)</sup>	2.2	6.2	5.7	0.3	1.2	n.p.	n.p.	n.p.	3.7	10.7
<b>Total<sup>(e)</sup></b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>n.p.</b>	<b>n.p.</b>	<b>n.p.</b>	<b>100.0</b>	<b>100.0</b>

(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: National Hospital Morbidity Database, AIHW.

There was some inter-jurisdictional variability seen in the funding pattern for public hospitals. For *Public patients*, this ranged from 67.3% in New South Wales to 96.7% in the Northern Territory (Table 2.6). In private hospitals, there were inter-jurisdictional differences with funding patterns for *Public patients*, ranging from 55.3% in Western Australia to 0.7% in Victoria. Furthermore, compared with all separations, palliative care separations in private hospitals were more likely to be for *Public patients* (23.5% for palliative care separations compared with 3.0% for all separations) and less likely to be funded by *Private health insurance* (59.2% compared with 80.0%).

## 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 which 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).

Almost half of all palliative care separations ended with the patient's death (48.7%) compared with about 1 in 100 (0.9%) for all separations (Table 2.7). The manner in which palliative care separations ended across both public and private hospitals was similar. However, jurisdictional differences were evident within and across sectors. For example, the proportion of palliative care separations ending with the patient's death was lowest in public hospitals in the Northern Territory (32.5%) and highest in Western Australia (58.9%) and the Australian Capital Territory (58.3%). For private hospitals, Queensland reported the highest percentage of palliative care separations ending with the patient's death (71.4%) which was substantially higher than the national average for the sector (55.2%). Private palliative care patients were more likely to be transferred to another hospital in Western Australia compared to other jurisdictions.

Table 2.7: Palliative care separations all separations, by mode of completing separation, states and territories, public and private hospitals, 2009–10

Mode of completing separation	Palliative care separation (per cent)										Separations for all reasons (per cent)	
	NSW	Vic	Qld	WA	SA	Tas <sup>(a)</sup>	ACT <sup>(a)</sup>	NT <sup>(e)</sup>	Total <sup>(a)</sup>			
<b>Public hospitals</b>												
Discharge or transfer to:												
• an(other) acute hospital	7.4	11.9	5.2	6.2	6.9	8.8	5.8	4.6	8.4	5.9		
• a residential aged care service <sup>(b)</sup>	4.6	4.1	2.2	4.2	7.0	4.0	2.7	3.9	4.2	1.1		
• other health-care accommodation <sup>(c)</sup>	1.8	0.5	1.4	0.5	0.5	0.6	7.0	1.4	1.3	0.4		
Statistical discharge (incl. from leave)	4.9	2.6	7.9	2.1	4.9	6.5	5.6	11.3	4.6	1.6		
Left against medical advice	0.3	0.2	0.2	0.3	0.2	0.0	0.0	2.4	0.3	0.8		
Died	42.6	52.3	52.5	58.9	43.3	43.7	58.3	32.5	47.5	1.2		
Other <sup>(d)</sup>	38.4	28.5	30.6	27.8	37.1	36.4	20.6	43.9	33.7	89.0		
<i>Total<sup>(e)</sup></i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>		
<b>Private hospitals</b>												
Discharge or transfer to:												
• an(other) acute hospital	6.1	11.0	2.3	14.8	7.0	n.p.	n.p.	n.p.	8.2	1.6		
• a residential aged care service <sup>(b)</sup>	3.0	2.7	1.8	1.9	4.8	n.p.	n.p.	n.p.	3.1	0.2		
• other health-care accommodation <sup>(c)</sup>	0.5	0.0	0.2	0.0	0.6	n.p.	n.p.	n.p.	0.5	0.1		
Statistical discharge (incl. from leave)	1.7	0.2	2.5	0.8	0.0	n.p.	n.p.	n.p.	1.2	0.4		
Left against medical advice	0.1	1.9	0.0	0.1	0.0	n.p.	n.p.	n.p.	0.4	0.1		
Died	46.6	53.8	71.4	53.1	52.7	n.p.	n.p.	n.p.	55.2	0.4		
Other <sup>(d)</sup>	42.0	30.5	21.8	29.4	34.9	n.p.	n.p.	n.p.	31.4	97.2		
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>n.p.</i>	<i>n.p.</i>	<i>n.p.</i>	<i>100.0</i>	<i>100.0</i>		

(continued)

**Table 2.7 (continued): Palliative care separations and all separations, by mode of completing separation, states and territories, public and private hospitals, 2009–10**

Mode of completing separation	Palliative care separation (per cent)										Separations for all reasons (per cent)	
	NSW	Vic	Qld	WA	SA	Tas <sup>(a)</sup>	ACT <sup>(a)</sup>	NT <sup>(a)</sup>	Total <sup>(a)</sup>	Total <sup>(a)</sup>		
<b>All hospitals</b>												
Discharge or transfer to:												
• an(other) acute hospital	7.3	11.8	4.6	11.4	6.9	n.p.	n.p.	n.p.	n.p.	n.p.	8.4	4.2
• a residential aged care service <sup>(b)</sup>	4.5	3.9	2.1	2.8	6.5	n.p.	n.p.	n.p.	n.p.	n.p.	4.1	0.8
• other health-care accommodation <sup>(c)</sup>	1.7	0.4	1.2	0.2	0.5	n.p.	n.p.	n.p.	n.p.	n.p.	1.1	0.3
Statistical discharge (incl. from leave)	4.6	2.3	6.7	1.3	3.7	n.p.	n.p.	n.p.	n.p.	n.p.	4.1	1.1
Left against medical advice	0.3	0.4	0.1	0.2	0.2	n.p.	n.p.	n.p.	n.p.	n.p.	0.3	0.5
Died	42.9	52.5	56.7	55.3	45.5	n.p.	n.p.	n.p.	n.p.	n.p.	48.7	0.9
Other <sup>(d)</sup>	38.7	28.7	28.6	28.8	36.6	n.p.	n.p.	n.p.	n.p.	n.p.	33.3	92.3
<b>Total<sup>(e)</sup></b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>n.p.</b>	<b>n.p.</b>	<b>n.p.</b>	<b>n.p.</b>	<b>n.p.</b>	<b>100.0</b>	<b>100.0</b>

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

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

Source: National Hospital Morbidity Database, AIHW.

## 2.4 Characteristics of admitted palliative care patients

The following section presents information on the number and proportion of palliative care separations for various demographic groups. Age-standardised rates are reported to provide an adjustment 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 2011f) and this may affect their use of, and access to, admitted patient palliative care.

There were a total of 812 palliative care separations for Indigenous Australians reported in 2009–10, with the majority (95.4%) occurring in public hospitals (Table 2.8). There were more separations for Indigenous females compared to males, opposite to what is observed for Other Australians. The number of palliative care separations in public hospitals per 10,000 population is one and a half times higher for Indigenous Australians than Other Australians (33.9 and 20.0, respectively). This pattern is also observable for all public hospital separations. However, it is reversed for private hospitals, where the number of palliative care separations per 10,000 population is noticeably higher for Other Australians than Indigenous Australians (3.6 and 1.7, respectively), as is also the case for all private hospitals separations (1,533.2 and 849.1, respectively).

**Table 2.8: Palliative care separations, by Indigenous status, selected states and territories<sup>(a)</sup>, public and private hospitals, 2009–10**

	Palliative care separations					Separations for all reasons	
	Number					Per cent	Rate <sup>(b)</sup>
	Male	Female	Total	Per cent	Rate <sup>(b)</sup>		
<b>Public hospitals</b>							
Indigenous Australians	349	426	775	1.4	33.9	5.8	7,994.8
Other Australians <sup>(c)</sup>	24,360	20,383	44,743	83.4	20.0	94.2	2,150.4
<b>Private hospitals</b>							
Indigenous Australians	16	21	37	0.1	1.7	0.7	849.1
Other Australians <sup>(c)</sup>	4,364	3,736	8,100	15.1	3.6	99.3	1,533.2
<b>Total</b>	<b>29,089</b>	<b>24,566</b>	<b>53,655</b>	<b>100.0</b>	<b>23.8</b>	<b>100.0</b>	<b>3,764.3</b>

(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 the interpretation of these data due to jurisdictional data quality differences. 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: National Hospital Morbidity Database, AIHW.

## Remoteness of patient's usual residence

Most palliative care separations in 2009–10 across both public and private hospital sectors were for patients whose usual residence was in a *Major city* (68.4%) (Table 2.9). The more remote the patients' usual residence, the lower the proportion of palliative care separations reported. However, the age-standardised rate for *Major city* public hospital separations was 20.6 per 10,000 population, which was slightly lower than the rate for *Remote* or *Very remote* (21.4).

A similar pattern emerged for all separations in private hospitals, where the rate per 10,000 population was highest for *Major cities* (1,688.8) and lowest for *Remote* or *Very remote* areas (794.5).

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

**Table 2.9: Palliative care separations, by remoteness of patient's usual residence, public and private hospitals, 2009–10**

Remoteness area <sup>(a)</sup>	Palliative care separations					Separations for all reasons	
	Number			Per cent	Rate <sup>(b)</sup>	Per cent	Rate <sup>(b)</sup>
Male	Female	Total					
<b>Public hospitals</b>							
Major cities	17,327	15,205	32,532	58.1	20.6	62.3	2,060.3
Inner regional	5,172	4,052	9,224	16.5	17.5	21.9	2,405.6
Outer regional	2,643	1,958	4,601	8.2	19.7	11.5	2,722.6
Remote or very remote	479	398	877	1.6	21.4	3.7	3,906.2
Not reported	57	54	111	0.2	..	0.5	..
<i>Total</i>	<i>25,678</i>	<i>21,667</i>	<i>47,345</i>	<i>84.6</i>	<i>..</i>	<i>100.0</i>	<i>..</i>
<b>Private hospitals</b>							
Major cities	3,048	2,703	5,751	10.3	3.6	75.2	1,688.8
Inner regional	1,268	1,053	2,321	4.1	4.3	17.2	1,232.9
Outer regional	306	214	520	0.9	2.2	6.3	991.3
Remote or very remote	18	14	32	0.1	0.8	1.1	794.5
Not reported	10	4	14	0.0	..	0.2	..
<i>Total</i>	<i>4,650</i>	<i>3,988</i>	<i>8,638</i>	<i>15.4</i>	<i>..</i>	<i>100.0</i>	<i>..</i>
<b>Total</b>	<b>30,328</b>	<b>25,655</b>	<b>55,983</b>	<b>100.0</b>	<b>23.5</b>	<b>100.0</b>	<b>3,749.9</b>

(a) Remoteness area was measured using the 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).

Source: National Hospital Morbidity Database, 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.

**Box 2.2: Index of Relative Socio-Economic Disadvantage (IRSD)**

This index is one of four Socio-Economic Indexes for Areas (SEIFAs) developed by the Australian Bureau of Statistics (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 – rather than 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 2009–10, people living in areas classified as having the lowest socioeconomic status (group 1) accounted for a relatively higher proportion of palliative care separations (22.0%) in public hospitals compared with those living in other areas (each of which was 17% or less) (Table 2.10). The rate of palliative care separations was also highest for those living in these areas (24.8 per 10,000 population). Conversely, the rate of palliative care separations was lowest for those living in the highest socioeconomic status areas (16.5). This pattern was also seen for all separations.

A different pattern emerged for palliative care 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 (2,204.8 per 10,000 population).

There were more separations for males than females in each socioeconomic status area with those in the highest socioeconomic status areas showing the least difference between the sexes in the total number of separations.

**Table 2.10: Palliative care separations, by socioeconomic status, public and private hospitals, 2009–10**

Socioeconomic status <sup>(a)</sup>	Palliative care separations					Separations for all reasons	
	Number			Per cent	Rate <sup>(b)</sup>	Per cent	Rate <sup>(b)</sup>
	Male	Female	Total				
<b>Public hospitals</b>							
1 (lowest)	6,910	5,414	12,324	22.0	24.8	26.4	2,909.9
2	5,339	4,247	9,586	17.1	18.5	22.6	2,445.9
3	5,038	4,227	9,265	16.5	20.1	20.6	2,333.4
4	4,376	3,903	8,279	14.8	19.0	16.9	1,980.0
5 (highest)	3,958	3,820	7,778	13.9	16.5	12.9	1,452.1
Not reported	57	56	113	0.2	..	0.6	..
<b>Private hospitals</b>							
1 (lowest)	708	590	1,298	2.3	2.6	13.8	1,021.7
2	673	563	1,236	2.2	2.4	16.0	1,160.3
3	1,108	826	1,934	3.5	4.2	19.4	1,483.8
4	896	832	1,728	3.1	4.0	21.6	1,710.2
5 (highest)	1,255	1,173	2,428	4.3	5.1	29.0	2,204.8
Not reported	10	4	14	0.0	..	0.3	..
<b>Total</b>	<b>30,328</b>	<b>25,655</b>	<b>55,983</b>	<b>100.0</b>	<b>23.5</b>	<b>100.0</b>	<b>3,749.9</b>

(a) Socioeconomic status was measured using the ABS Socio-economic Index for Areas (SEIFA) Index of Relative Socio-economic Disadvantage (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: National Hospital Morbidity Database, 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 2010d; 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 2010b; 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 separations in 2009–10 (59.4%). Of these, secondary site cancer (that is, a malignant tumour that originated from a cancer elsewhere in the body) was assigned to almost 1 in 7 (14.6%) palliative care separations.

Considering additional diagnoses, the proportion of cancer diagnoses increases to three-quarters (75.8%) of palliative care separations, with more than half of these separations (53.1%) 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 separations, by selected diseases, public and private hospitals, 2009–10**

Disease <sup>(a)</sup> (ICD-10-AM codes)	Principal diagnosis only		Principal & additional diagnoses <sup>(c)</sup>	
	Number	Per cent <sup>(b)</sup>	Number	Per cent <sup>(b)</sup>
<b>Cancer<sup>(a)</sup></b>				
Secondary site (C77–C79)	8,192	14.6	29,723	53.1
Lung (C33–C34)	5,552	9.9	8,726	15.6
Bowel (C18–C20)	2,686	4.8	5,079	9.1
Pancreas (C25)	1,736	3.1	2,445	4.4
Prostate (C61)	1,579	2.8	3,510	6.3
Breast (C50)	1,390	2.5	3,194	5.7
Brain (C71)	1,267	2.3	1,503	2.7
Stomach (C16)	932	1.7	1,377	2.5
Non-Hodgkin lymphoma (C82–C85)	759	1.4	1,084	1.9
Liver (C22)	742	1.3	1,094	2.0
Oesophagus (C15)	718	1.3	1,026	1.8
Bladder (C67)	626	1.1	1,109	2.0
Ovary (C56)	593	1.1	1,171	2.1
Kidney (C64)	528	0.9	1,056	1.9
Myeloma (C90)	517	0.9	744	1.3
Mesothelioma (C45)	495	0.9	663	1.2
Acute myeloid leukaemia (C92.0, C92.5–92.5, C93.0 C94.0, C94.2, C94.5)	491	0.9	656	1.2
<i>All cancers (C00–C97, D45, D46, D47.1, D47.3, selected Z codes)</i>	<i>33,278</i>	<i>59.4</i>	<i>42,450</i>	<i>75.8</i>
<b>Diseases other than cancer<sup>(a)</sup></b>				
Heart failure (I50)	1,324	2.4	4,483	8.0
Chronic obstructive pulmonary disease (J40–J44)	1,190	2.1	3,573	6.4
Renal failure (N17–N19)	771	1.4	7,265	13.0
Motor neurone disease (G12.2)	405	0.7	538	1.0
Liver failure (K70.4, K71.1, K72)	339	0.6	1,074	1.9
Dementia and Alzheimer disease (F00 to F03, G30)	227	0.4	2,809	5.0
Parkinson disease (G20, G21, G22)	53	0.1	537	1.0
HIV/AIDS (B20–B24)	12	0.0	83	0.1
Huntingtons disease (G10, F02.2)	9	0.0	21	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 (i.e. 55,983).

(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: National Hospital Morbidity Database, AIHW.

For diseases other than cancer, the next two most frequently reported principal diagnoses were heart failure and chronic obstructive pulmonary disease (COPD) (2.4% and 2.1% of palliative care separations, respectively). Similar to the diagnosis data for cancer, renal failure was found to be relevant to more than nine times as many palliative care 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 separations, followed by heart failure (8.0%) and COPD (6.4%).

## 2.6 Change over time in the amount of activity

In 2000–01, there were almost 37,000 palliative care separations and by 2009–10, this number had increased by 51% to almost 56,000 (Table 2.12). In comparison, the number of all separations increased by 39% over the same period. Apart from a negligible reduction in the number of palliative care separations from 2000–01 to 2001–02, there have been consistent increases in palliative care separations from one year to the next over the 10 year period to 2009–10, which mirrors the pattern observed for all separations over the same time period.

**Table 2.12: Palliative care separations and all separations, public and private hospitals, 2000–01 to 2009–10**

	Palliative care separations				Separations for all reasons	
	Number of separations	Per cent change from previous year	Rate <sup>(a)</sup>	Per cent of all separations	Number of separations	Per cent change from previous year
2000–01	36,980	..	19.3	0.60	6,153,769	..
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

(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: National Hospital Morbidity Database, AIHW.

The age-standardised rate of palliative care separations increased from 19.3 to 23.2 per 10,000 population over the 10-year period to 2009–10. 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 there have been changes in reporting arrangements in some jurisdictions, for example, as to whether a hospital was classified as private or public during the period considered. As such, the following data should be interpreted in 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 separations between 2000–01 and 2009–10, much of this increase occurred in public hospitals with the number of separations increasing by 60% (Table 2.13).

Meanwhile, figures for palliative care separations in private hospitals fluctuated resulting in a net increase of 17% over the 10-year period. This is in contrast to the consistent yearly increase in all private hospital separations, which showed a 52% growth between 2000–01 and 2009–10.

**Table 2.13: Palliative care separations and all separations, public and private hospitals, 2000–01 to 2009–10**

	Palliative care separations				Separations for all reasons	
	Number of separations	Per cent change from previous year	Rate <sup>(a)</sup>	Per cent of all separations	Number of separations	Per cent change from previous year
<b>Public hospitals</b>						
2000–01	29,619	..	15.5	0.76	3,881,875	..
2001–02	28,946	-2.3	14.7	0.73	3,965,512	2.2
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
<b>Private hospitals</b>						
2000–01	7,361	..	3.9	0.32	2,271,894	..
2001–02	7,721	4.9	3.9	0.32	2,432,659	7.1
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

(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: National Hospital Morbidity Database, AIHW.

For public hospitals, an increase in the rate of palliative care separations is evident over time; increasing from 15.5 to 19.6 palliative care 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 palliative care separations in private hospitals.

## Change over time by jurisdiction

The number of palliative care separations recorded in each jurisdiction from 2005–06 to 2009–10 are shown in Table 2.14. Of the five jurisdictions with published figures, Victoria reported the highest average annual increase of 10.6% with comparable increases in both public and private hospitals. Conversely, Western Australia reported an average annual reduction in palliative care separations of 5.7% to 6.7% depending on the sector.

**Table 2.14: Palliative care separations, states and territories, public and private hospitals, 2005–06 to 2009–10**

	Separations (number)					Average annual change (per cent)
	2005–06	2006–07	2007–08	2008–09	2009–10	
<b>Public hospitals</b>						
New South Wales	15,860	16,110	16,726	18,591	19,180	4.9
Victoria	10,033	11,454	12,198	13,362	14,949	10.5
Queensland	3,921	4,405	4,266	5,457	5,953	11.0
Western Australia	1,691	1,318	1,392	1,246	1,284	-6.7
South Australia	3,359	3,088	3,383	3,389	3,453	0.7
Tasmania	860	844	850	916	1,074	5.7
Australian Capital Territory	503	539	649	699	753	10.6
Northern Territory	396	597	632	745	699	15.3
<i>Total</i>	36,623	38,355	40,096	44,405	47,345	6.6
<b>Private hospitals<sup>(a)</sup></b>						
New South Wales	1,191	1,280	1,196	1,211	1,587	7.4
Victoria	1,145	1,211	1,280	1,408	1,775	11.6
Queensland	1,775	2,083	2,433	1,949	1,696	-1.1
Western Australia	2,529	2,459	2,098	2,156	1,998	-5.7
South Australia	918	856	850	906	1,081	4.2
<i>Total<sup>(a)</sup></i>	8,511	9,117	8,535	7,942	8,638	0.4
<b>All hospitals<sup>(a)</sup></b>						
New South Wales	17,051	17,390	17,922	19,802	20,767	5.1
Victoria	11,178	12,665	13,478	14,770	16,724	10.6
Queensland	5,696	6,488	6,699	7,406	7,649	7.6
Western Australia	4,220	3,777	3,490	3,402	3,282	-6.1
South Australia	4,277	3,944	4,233	4,295	4,534	1.5
<b>Total<sup>(a)</sup></b>	<b>45,134</b>	<b>47,472</b>	<b>48,631</b>	<b>52,347</b>	<b>55,983</b>	<b>5.5</b>

(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: National Hospital Morbidity Database, AIHW.

For public hospitals, the average annual increase in palliative care separations was over 10% for Victoria, Queensland, the Australian Capital Territory and the Northern Territory. It

should be noted, though, that numbers of palliative care separations reported by the territories were relatively low.

Among private hospitals, there have been both increases and decreases in the number of palliative care separations over the period, culminating in less than half a per cent average annual increase over the 5 years to 2009–10. Private hospitals in Queensland and Western Australia reported an average negative growth over the same period (1.1 and 5.7%, respectively).

Fluctuations were also noted in the number of palliative care separations per 10,000 population over the 5 years to 2009–10 (Table 2.15). While the national data indicate that there was a consistent increase in the rate for public hospitals over the same period, data for Western Australia and South Australia do not reflect this pattern. The rates for these two jurisdictions were lower in 2009–10 than in 2005–06.

**Table 2.15: Palliative care separations, states and territories, age-standardised rates, public and private hospitals, 2005–06 to 2009–10**

	Age-standardised rates <sup>(a)</sup>				
	2005–06	2006–07	2007–08	2008–09	2009–10
<b>Public hospitals</b>					
New South Wales	21.5	21.4	21.6	23.4	23.6
Victoria	18.2	20.3	21.1	22.4	24.4
Queensland	9.7	10.6	10.0	12.4	13.1
Western Australia	8.6	6.5	6.6	5.7	5.7
South Australia	18.0	16.3	17.5	17.1	17.2
Tasmania	15.2	14.6	14.6	15.3	17.8
Australian Capital Territory	18.2	19.1	22.2	23.1	24.0
Northern Territory	41.8	56.5	57.6	64.7	57.7
<i>Total</i>	16.9	17.3	17.5	18.9	19.6
<b>Private hospitals<sup>(b)</sup></b>					
New South Wales	1.6	1.7	1.5	1.5	1.9
Victoria	2.1	2.1	2.2	2.3	2.8
Queensland	4.4	5.0	5.6	4.4	3.7
Western Australia	12.9	12.1	9.9	9.9	8.9
South Australia	4.9	4.5	4.3	4.5	5.2
<i>Total<sup>(b)</sup></i>	3.9	4.1	3.7	3.4	3.5
<b>All hospitals<sup>(b)</sup></b>					
New South Wales	23.1	23.1	23.2	24.9	25.6
Victoria	20.3	22.5	23.2	24.7	27.3
Queensland	14.2	15.6	15.6	16.7	16.8
Western Australia	21.5	18.6	16.5	15.6	14.6
South Australia	22.9	20.8	21.8	21.5	22.4
<b>Total<sup>(b)</sup></b>	<b>20.8</b>	<b>21.4</b>	<b>21.2</b>	<b>22.2</b>	<b>23.2</b>

(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.

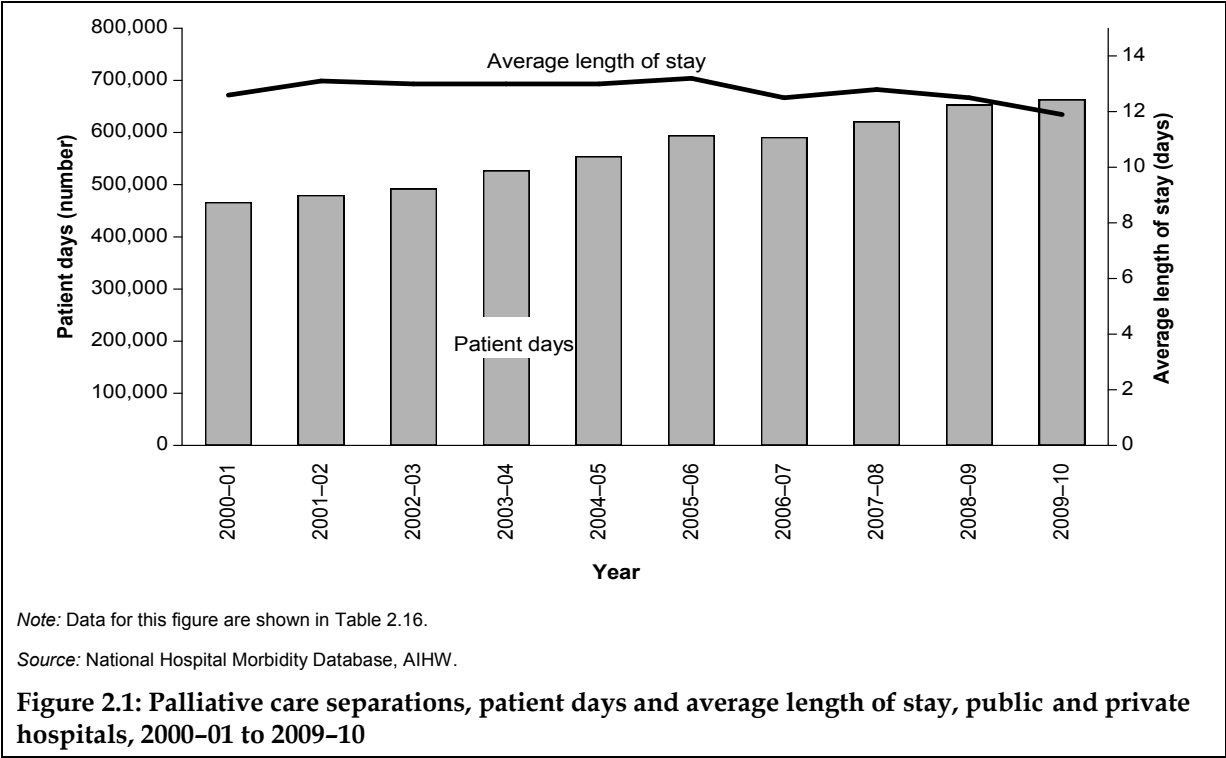
Source: National Hospital Morbidity Database, AIHW.

For private hospitals, the national age-standardised rate of palliative care separations in 2009–10 was lower than the rate in 2005–06 (3.5 and 3.9, respectively). Similar patterns were observed in Queensland and Western Australia where there were fluctuations in the age-standardised rates culminating in lower rates in 2009–10. 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 separations in admitted patient settings has increased between 2000–01 and 2009–10. A total of more than 663,400 patient days were recorded in 2009–10 amounting to a 42% increase in patient days over the 10-year period (Table 2.16).

The average length of stay for palliative care separations remained steady over the 10 years to 2009–10, at around 12 to 13 days (Figure 2.1). This stability in the average length of stay suggests that the observed increase in patient days for palliative care over the years is due to an increase in the number of such separations (see Table 2.16).



**Table 2.16: Palliative care separations, patient days and average length of stay (ALOS), all hospitals, 2000–01 to 2009–10**

	Same-day separations <sup>(a)</sup>	Overnight separations		Total separations		Per cent of overnight separations
	Patient days	Patient days	ALOS (days)	Patient days	ALOS (days)	
2000–01	3,926	462,523	14.0	466,449	12.6	89.4
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

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

Source: National Hospital Morbidity Database, AIHW.

## 2.7 Palliative care and deaths in hospital

Thus far in this chapter, the focus has been on separations for which palliative care was a substantial component of the care provided and they are referred to as ‘palliative care 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 ‘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 2009–10, a total of almost 141,000 people died in Australia (Table 2.17). According to data from the NHMD, about 73,000 of these died as an admitted patient in an Australian hospital.

**Table 2.17: Admitted patient deaths, all hospitals and all deaths, 2000–01 to 2009–10**

	Admitted patient deaths (number)			Total deaths in Australia <sup>(b)</sup> (number)	Admitted patient deaths (excl. HITH) as a per cent of all deaths in Australia
	Total admitted patient deaths	Deaths of HITH admitted patients <sup>(a)</sup>	Admitted patient deaths excluding HITH patients		
2000–01	69,161	..	69,161	128,957	53.6
2001–02	70,671	114	70,557	130,322	54.1
2002–03	71,573	96	71,477	132,460	54.0
2003–04	71,932	106	71,826	133,348	53.9
2004–05	70,799	92	70,707	131,376	53.8
2005–06	71,122	92	71,030	134,053	53.0
2006–07	72,440	86	72,354	135,860	53.3
2007–08	74,365	106	74,259	140,687	52.8
2008–09	74,380	104	74,276	143,630	51.7
2009–10	73,021	113	72,908	140,711	51.8

(a) Data are available from 2001–02 onwards for most states and territories on admitted patients who received hospital-in-the-home (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.

Sources: ABS (2011); National Hospital Morbidity Database, AIHW.

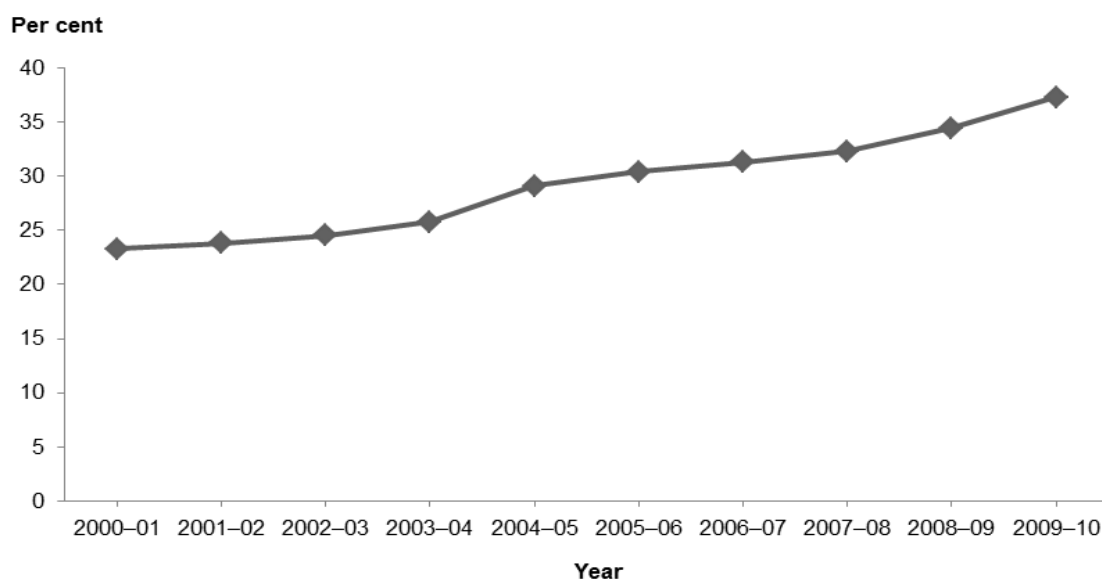
Data on deaths between 2000–01 and 2009–10 are also shown in Table 2.17. The proportion of deaths that occurred within the admitted patient setting ranged from 51.7% to 54.1% over the 10-year period.

Most states and territories have hospital-in-the-home (HITH) programs, under which admitted patients are provided with hospital care in their home as a substitute for hospital accommodation (AIHW 2010d). The place of death of these patients may not have been physically in hospital. After excluding the small number of HITH patients reported, the data indicate that about 73,000 people died in admitted patient care in 2009–10. This equates to just over half (51.8%) of deaths having occurred in an admitted patient setting in an Australian hospital in 2009–10. 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 hospital.

## Palliative care patients and death

In 2000–01, 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 2009–10, more than 1 in 3 (37.3%) 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: National Hospital Morbidity Database, AIHW.

**Figure 2.2: Palliative care patients among those who died as an admitted patient, all hospitals, 2000-01 to 2009-10**

The number of palliative care patients who died during their hospital stay varied by diagnosis (Table 2.18). Approximately 16,500 palliative care patients died with cancer as a principal diagnosis in 2009-10. Of these, more than 7 in 10 (71.3%) received palliative care services during their final hospital separation. This ranged from 80.8% of patients with breast cancer down to 51.5% for those with acute myeloid leukaemia. However, when both principal and additional diagnoses are considered, almost two-thirds (62.3%) 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 COPD showing the lowest (66.1% and 22.4% 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 2009-10. Of these, patients with breast cancer as a principal diagnosis were most likely (80.1%) to have been a palliative care patient during the hospital stay that ended with their death. This was followed by those with brain cancer (78.7%) and prostate cancer (76.4%) 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, just over half (51.5%) of those with an acute myeloid leukaemia as the principal diagnosis were identified as palliative care patients, as were those with Non-Hodgkin lymphoma (55.6%).

**Table 2.18: Palliative care patients among those who died as an admitted patient, by selected diseases, public and private hospitals, 2009–10**

Disease <sup>(a)</sup> (ICD-10-AM codes)	Principal diagnosis only			Principal and additional diagnoses		
	Palliative care patient deaths <sup>(b)</sup>	Total admitted patient deaths	Per cent of palliative care patient deaths <sup>(b)</sup>	Palliative care patient deaths <sup>(b)</sup>	Total admitted patient deaths	Per cent of palliative care patient deaths <sup>(b)</sup>
<b>Cancer site<sup>(a)</sup></b>						
Breast (C50)	670	829	80.8	1,309	1,967	66.5
Brain (C71)	563	715	78.7	626	845	74.1
Prostate (C61)	714	934	76.4	1,332	2,168	61.4
Stomach (C16)	474	623	76.1	644	923	69.8
Pancreas (C25)	958	1,261	76.0	1,217	1,741	69.9
Lung (C33–C34)	2,869	3,858	74.4	3,895	5,988	65.0
Liver (C22)	446	602	74.1	585	884	66.2
Bowel (C18–C20)	1,501	2,098	71.5	2,350	3,679	63.9
Oesophagus (C15)	388	545	71.2	507	780	65.0
Secondary site (C77–C79)	3,472	5,188	66.9	13,450	19,793	68.0
Non-Hodgkin lymphoma (C82–C85)	397	714	55.6	526	1,148	45.8
Acute myeloid leukaemia (C92.0, C92.3–C92.5, C93.0, C94.0, C94.2, C94.4, C94.5)	302	586	51.5	372	783	47.5
<i>All cancers (C00–C97, D45, D46, D47.1, D47.3, selected Z codes)</i>	<i>16,459</i>	<i>23,082</i>	<i>71.3</i>	<i>19,178</i>	<i>30,786</i>	<i>62.3</i>
<b>Diseases other than cancer<sup>(a)</sup></b>						
Motor neurone disease (G12.2)	125	189	66.1	170	339	50.1
Parkinson disease (G20, G21, G22)	33	75	44.0	304	874	34.8
HIV/AIDS (B20–B24)	3	7	42.9	37	82	45.1
Dementia and Alzheimer disease (F00 to F03, G30)	134	314	42.7	1,624	5,638	28.8
Liver failure (K70.4, K71.1, K72)	227	609	37.3	745	2,473	30.1
Huntington disease (G10, F02.2)	5	14	35.7	12	30	40.0
Renal failure (N17–N19)	501	1,445	34.7	4,382	17,949	24.4
Heart failure (I50)	825	3,396	24.3	2,813	13,192	21.3
Chronic obstructive pulmonary disease (J40–J44)	527	2,348	22.4	1,812	7,316	24.8

(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.

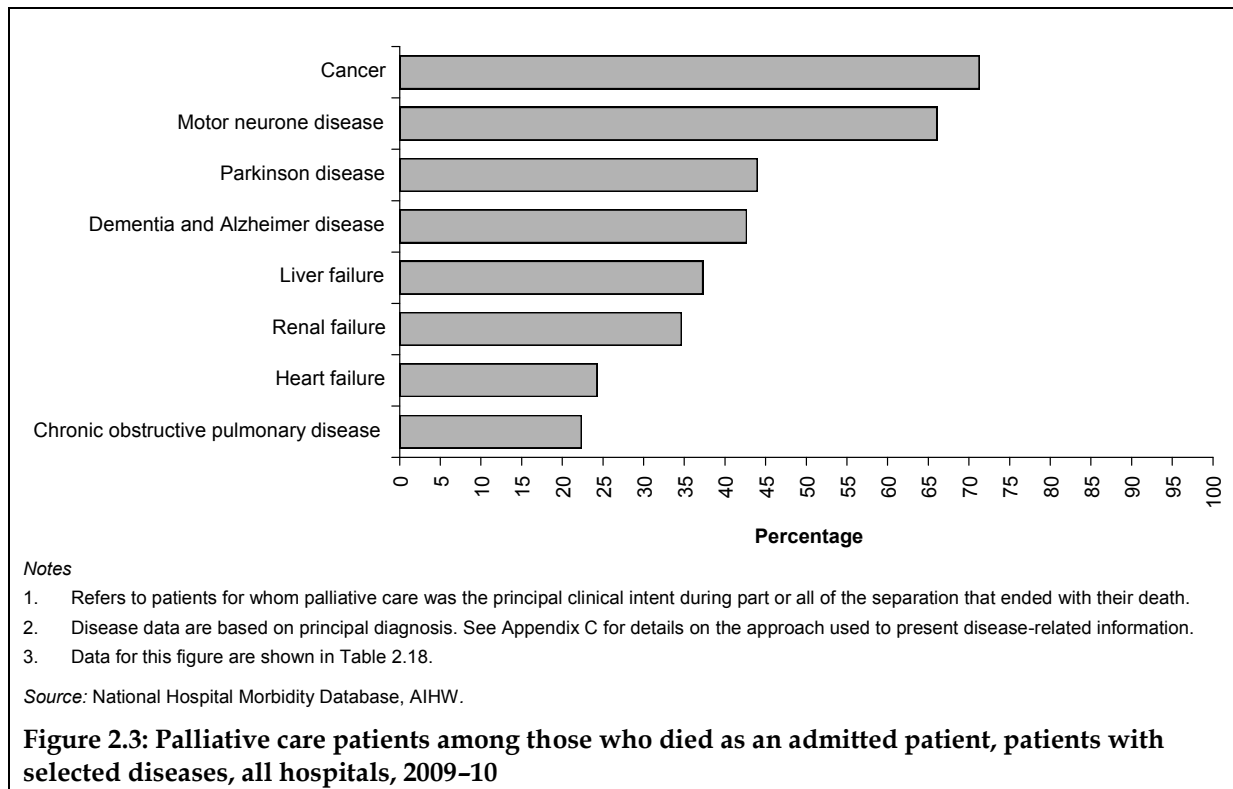
(b) Refers to patients for whom palliative care was the principal clinical intent during part or all of the separation that ended with their death.

Source: National Hospital Morbidity Database, AIHW.

The same patterns remained when both the principal and additional diagnoses were considered. Although the proportions were lower, 45.8% of patients with a principal or additional diagnosis of Non-Hodgkin lymphoma and 47.5% with acute myeloid leukaemia received palliative care during their final hospital stay. Meanwhile, 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 (74.1%) followed by those with cancer of the pancreas or stomach (69.9% and 69.8%, 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).



## 3 Palliative care in general practice

### 3.1 Introduction

In preparing this report it was noted that there is a paucity of routine administrative health data about the role of *general practitioners* (GPs) (see Key concepts) in the treatment and referral of palliative care patients. Unlike data relating to palliative medicine specialists (see Chapter 4), Medicare Benefits Scheme (MBS) data cannot be used to report on those services provided to palliative care patients by GPs. This is due to the fact that the MBS items available to a GP for managing palliative care patients under a ‘GP management plan’ are not palliative care specific – the same MBS items can be used for consultations for any patient with a chronic disease. Nonetheless, there is evidence available from national datasets of the contact GPs have with palliative care patients, for example, the majority of palliative care-related prescriptions are completed by GPs (see Chapter 6).

Another source of information about palliative care-related services provided by GPs is the Bettering the Evaluation and Care of Health (BEACH) survey of general practice activity.

### 3.2 Bettering the Evaluation and Care of Health survey data

The BEACH program is a survey of general practice activity across Australia. The data described in this chapter mainly relate to 95,800 GP *encounters* from a sample of 958 GPs over the period from April 2010 to March 2011, as this is the most recent data period available (Britt et al. 2011). This is described as BEACH 2010–11 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 95,839 (weighted) encounters (Britt et al. 2011).

#### Key concepts

*General practitioners (GPs)* are those medical practitioners who are vocationally registered under Section 3F of the *Health Insurance Act 1973*, 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. 2011).

*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).

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 in Appendix B.

### 3.3 Palliative care-related encounters

In 2010–11, 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 people in 2010–11.

Palliative care-related encounters are difficult to define. Unlike diseases which can be clearly identified using the diagnosis data element, there is no definitive way to identify palliative care-related GP encounters. Since there are four ICPC-2 PLUS palliative care-related codes that can be recorded against three discrete BEACH survey data elements (*Reason for encounter, Diagnosis and Referral*), palliative care-related encounters are identified using all three data elements (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, Diagnosis and Referral*).

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

- Patient reasons for encounter (RFEs)
- Problems managed (Diagnosis)
- 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

It should be noted that the number of encounters during which palliative care was provided could be an underestimate due to varying coding practices by participating GPs.

**Table 3.1: Palliative care related encounters, BEACH, 2010–11**

	2010–11
Total GP encounters that are palliative-care related (per cent)	0.09
Estimated number of palliative-care related encounters <sup>(a)</sup>	108,325
Lower 95% confidence limit	74,226
Upper 95% confidence limit	141,669
Estimated number of palliative-care related encounters per 1,000 population <sup>(a)</sup>	4.8
Lower 95% confidence limit	3.3
Upper 95% confidence limit	6.3

(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 for Non-Referred (GP) Attendances (excluding practice nurse items) as reported by the Department of Health and Ageing (Medicare 2012).

Source: BEACH survey of general practice activity.

## Patient demographics

Table 3.2 presents information on palliative care-related encounters according to the characteristics of those receiving care. The table shows the proportion of palliative care-related encounters for each demographic characteristic, as well as the number of palliative care-related encounters per 1,000 total encounters (that is, both palliative care-related and non-palliative care-related encounters) for that demographic subgroup. In 2010–11 almost three-quarters of patients were aged 65 and over (Table 3.2), and 13.7% were aged less than 55. A higher proportion of GP palliative care-related encounters were for females than males (63.9% and 36.1%, respectively). Around 1% of palliative care-related encounters were recorded as being for Indigenous Australians.

**Table 3.2: Patient demographics for palliative care-related encounters, BEACH 2010–11**

Patient demographics	Per cent of total palliative care-related encounters	Rate (per 1,000 demographic group specific encounters)	95% Confidence Interval		Estimated encounters (per 10,000 population)
			LCL	UCL	
<b>Age group</b>					
Less than 15 years	0	0	0	0	0
15–24 years	0	0	0	0	0
25–34 years	0	0	0	0	0
35–44 years	4.9	0.4	–0.1	0.9	16.6
45–54 years	8.8	0.6	–0.1	1.3	30.9
55–64 years	12.6	0.8	0.3	1.3	52.5
65 years and over	73.7	2.3	1.5	3.1	258.3
<b>Sex</b>					
Male	36.1	0.8	0.4	1.1	..
Female	63.9	1.0	0.6	1.5	..
<b>Indigenous status</b>					
Indigenous Australians	1.2	0.9	–0.9	2.8	..
Non-Indigenous Australians	98.8	1.0	0.7	1.3	..
<b>Remoteness area</b>					
Major cities	55.2	0.7	0.4	1.0	..
Inner regional	29.0	1.3	0.6	2.1	..
Outer regional	11.4	1.3	0.4	2.1	..
Remote and very remote	4.4	2.8	–1.5	7.0	..
<b>Total</b>	<b>100.0</b>	<b>0.9</b>	<b>0.6</b>	<b>1.2</b>	<b>..</b>

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

Source: BEACH survey of general practice activity.

# 4 Services provided by palliative medicine specialists

## 4.1 Introduction

A palliative medicine specialist is defined as a medical specialist, who is a Fellow of the Royal Australasian College of Physicians (RACP) and has completed the RACP training program in palliative medicine, as a Fellow of the Australasian Chapter of Palliative Medicine (FACHPM), or as a Fellow of both (ANZSPM 2008).

The Australian and New Zealand Society of Palliative Medicine (ANZSPM) describe *palliative medicine specialists* (see Key concepts) 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).

This chapter provides information on the number and types of Medicare Benefits Schedule-subsidised (MBS) palliative care-related services provided by palliative medicine specialists under the MBS and the characteristics of patients who received these services. 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).

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

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

Patients referred to palliative medicine specialists usually have complex needs (including physical, social, psychological and emotional needs). These include:

- 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 2005).

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 only relate to palliative care services provided by a palliative medicine specialist that are claimed under the MBS.

### Key concepts

**Palliative medicine specialist:** in order to be eligible for payment of MBS subsidies for palliative care services, a medical practitioner must be a Fellow of the Australasian Chapter of Palliative Medicine (FACHPM).

**MBS-subsidised palliative medicine specialist services:** services provided by a palliative medicine specialist on a fee-for-service basis that are partially 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 in 2010–11. To provide information on changes over time, data are also presented for the reporting periods from 2006–07 to 2010–11. More detailed information on the scope and coverage of the data presented in this chapter is provided in Appendix B.

## 4.2 Characteristics of patients receiving palliative medicine specialist services

Nationally, about 7,700 patients received an MBS-subsidised palliative medicine specialist service during 2010–11 (Table 4.1), which equates to a rate of 34.4 patients per 100,000 population. During this time period, almost 43,000 MBS-subsidised palliative medicine specialist services were provided, an average of 5.6 services per patient (Table 4.1).

**Table 4.1: MBS-subsidised palliative medicine specialist services by numbers of patients and services, 2010–11**

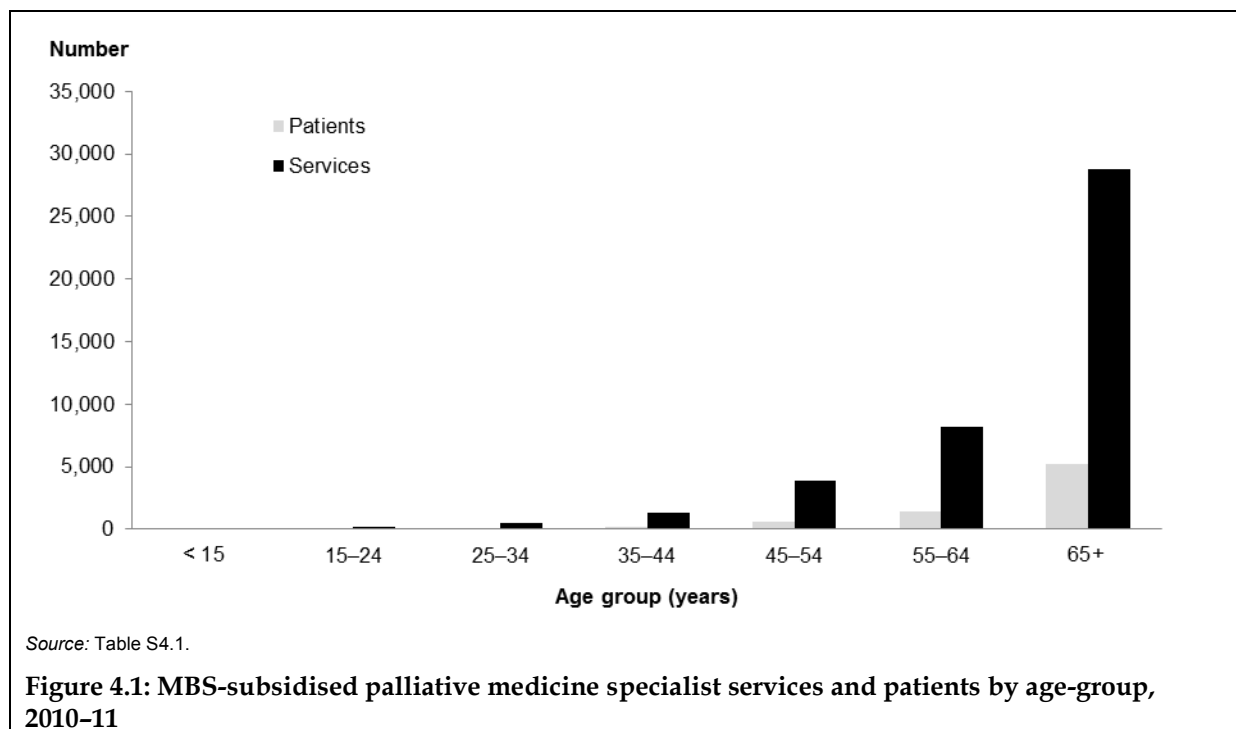
	Patients	Services
Number	7,723	42,934
Rate <sup>(a)</sup>	34.4	191.0

(a) Crude rate is based on the preliminary Australian estimated resident population as at 31 December 2010 and is expressed per 100,000 population (see Appendix C).

Source: MBS data (DoHA).

Of the 7,723 patients receiving an MBS-subsidised palliative medicine specialist service, more than two-thirds (68.2%) were aged 65 years and older with almost 9 in 10 (86.9%) aged 55 years or older (Figure 4.1). For the 65 years and older group, the population rate for 2010–11 was more than three times the rate seen for the 55–64 year age group (172.4 and 56.2 per 100,000 population respectively). Less than 1 in 100 (0.9%) patients receiving MBS-subsidised palliative medicine specialist services were aged 24 years or less in 2010–11 (Table S4.1).





There was almost an equal gender split in those receiving MBS-subsidised palliative medicine specialist services (49.0% for males and 51.0% for females) (Table S4.1).

The highest rate of patients receiving MBS-subsidised palliative medicine specialist services was seen in *Inner regional* areas followed by *Major cities* (36.5 and 35.3 per 100,000 population, respectively) (Table 4.2).

**Table 4.2: Patients receiving MBS-subsidised palliative medicine specialist services by remoteness, 2010-11**

Patient area of residence	Number of patients <sup>(a)</sup>	Per cent of patients <sup>(b)</sup>	Rate <sup>(c)</sup>
Major cities	5,420	70.2	35.3
Inner regional	1,606	20.8	36.5
Outer regional	570	7.4	27.3
Remote	86	1.1	26.3
Very remote	35	0.5	20.1
<b>Total<sup>(c)</sup></b>	<b>7,723</b>	<b>100.0</b>	<b>34.6</b>

(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 whom information was unknown or missing.

(c) Crude rate is based on the preliminary Australian estimated resident population as at 31 December 2010 and is expressed per 100,000 population (see Appendix C).

Source: MBS data (DoHA).

### 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 2010–11 there were about 43,000 MBS-subsidised services provided by palliative medicine specialists. For all MBS-subsidised palliative medicine specialist items, palliative medicine attendances in hospitals or surgery made up the majority at nearly 9 in 10 items (88.0%) in 2010–11 (Table 4.3). Indeed, nearly all of the MBS items claimed against palliative medicine specialist services were for attendances at a hospital, surgery or the patient’s home (93.9%). Palliative medicine specialists were more likely to organise and coordinate case conferences for patients compared with being a participant at such conferences initiated by other care providers.

**Table 4.3: MBS-subsidised palliative medicine specialist services by MBS item group, 2010–11**

MBS item group	Total	Per cent by group	Per cent of total items
<b>Palliative Medicine Attendances</b>			
Attendance in a hospital or surgery	37,776	93.8	88.0
Home visit	2,513	6.2	5.9
<i>Total (palliative medicine attendances)</i>	<i>40,289</i>	<i>100.0</i>	<i>93.9</i>
<b>Palliative Medicine Case Conferences</b>			
Organise and coordinate a community case conference	1,131	42.8	2.6
Participate in a community case conference	801	30.3	1.9
Organise and coordinate a discharge case conference	669	25.3	1.6
Participate in a discharge case conference	44	1.7	0.1
<i>Total (palliative medicine case conferences)</i>	<i>2,645</i>	<i>100.0</i>	<i>6.1</i>
<b>Total items</b>	<b>42,934</b>	<b>..</b>	<b>100.0</b>

Source: Table S4.2.

## MBS-subsidised palliative medicine specialist services by state and territory

Western Australia recorded the highest rate of subsidised palliative medicine specialist services in 2010–11 (592.5 per 100,000 population), which was more than three times the national average rate (191.0) (Table 4.4). The rate of services provided in New South Wales (229.7 per 100,000) was also higher than the national average (191.0 per 100,000). Victoria recorded a lower rate of services than the other states and territories (49.7 per 100,000) which may reflect differences in service delivery arrangements. The Northern Territory had the lowest rate, however only 24 services were recorded.

**Table 4.4: MBS-subsidised palliative medicine specialist services by MBS item group, states and territories<sup>(a)</sup>, 2010–11**

MBS item group	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
<b>Palliative Medicine Attendances</b>									
Attendance in a hospital or surgery	13,452	n.p.	6,925	n.p.	3,487	n.p.	n.p.	n.p.	37,776
Home visit	1,353	n.p.	548	n.p.	452	0	n.p.	0	2,513
<i>Total (palliative medicine attendances)</i>	<i>14,805</i>	<i>n.p.</i>	<i>7,473</i>	<i>9,237</i>	<i>3,939</i>	<i>n.p.</i>	<i>n.p.</i>	<i>n.p.</i>	<i>40,289</i>
<b>Palliative Medicine Case Conferences</b>									
<i>Total (palliative medicine case conferences)</i>	<i>1,902</i>	<i>n.p.</i>	<i>172</i>	<i>541</i>	<i>18</i>	<i>n.p.</i>	<i>n.p.</i>	<i>n.p.</i>	<i>2,645</i>
<b>Total items</b>	<b>16,707</b>	<b>2,776</b>	<b>7,645</b>	<b>9,778</b>	<b>3,957</b>	<b>n.p.</b>	<b>n.p.</b>	<b>24</b>	<b>42,934</b>
Rate <sup>(b)</sup>	229.7	49.7	168.1	592.5	170.8	n.p.	n.p.	10.4	191.0

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

(b) Crude rate is based on the preliminary Australian estimated resident population as at 31 December 2010 and is expressed per 100,000 population (see Appendix C).

Source: Table S4.2.

Palliative medicine case conferences were predominantly recorded for New South Wales in 2010–11 (1,902); with Western Australia and Queensland the only other jurisdictions recording more than 20 case conferences (Table 4.4). For the remainder, the number of case conferences recorded was negligible.

## MBS-subsidised palliative medicine specialist services over time

Over the 5 years to 2010–11, the number of MBS-subsidised palliative medicine specialist services more than doubled (from 19,554 services in 2006–07 to 42,934), equating to an average annual increase of 21.7% (Table 4.5). Substantial growth was noted in the palliative medicine case conferences items. In particular, there was an average annual increase of 247.0% of discharge case conferences organised by palliative medicine specialists lasting less than 30 minutes (Table S4.3). The number of case conferences lasting more than 30 minutes was consistently low over the 5 years to 2010–11, except for discharge case conferences lasting 45 minutes or more.

**Table 4.5: MBS-subsidised palliative medicine specialist services by MBS item group, 2006–07 to 2010–11**

MBS item group	2006–07	2007–08	2008–09	2009–10	2010–11	Average annual change (per cent)
<b>Palliative Medicine Attendances</b>						
Attendance in a hospital or surgery	17,307	21,304	28,878	35,311	37,776	21.5
Home visit	2,146	3,392	2,959	3,170	2,513	4.0
<i>Total (palliative medicine attendances)</i>	<i>19,453</i>	<i>24,696</i>	<i>31,837</i>	<i>38,481</i>	<i>40,289</i>	<i>20.0</i>
<b>Palliative Medicine Case Conferences</b>						
Organise and coordinate a community case conference	n.p.	n.p.	584	916	1,131	n.p.
Participate in a community case conference	37	229	n.p.	n.p.	801	115.7
Organise and coordinate a discharge case conference	33	123	353	550	669	112.2
Participate in a discharge case conference	n.p.	n.p.	n.p.	n.p.	44	n.p.
<i>Total (palliative medicine case conferences)</i>	<i>101</i>	<i>632</i>	<i>1,229</i>	<i>2,013</i>	<i>2,645</i>	<i>126.2</i>
<b>Total items</b>	<b>19,554</b>	<b>25,328</b>	<b>33,066</b>	<b>40,494</b>	<b>42,934</b>	<b>21.7</b>
Rate <sup>(a)</sup>	94	119	153	183	191	..

(a) Crude rate is based on the preliminary Australian estimated resident population as at 31 December 2010 and is expressed per 100,000 population (see Appendix C).

Source: MBS data (DoHA).

## 5 Palliative care in residential aged care

When compared to hospices, where patients are more likely to have a cancer diagnosis, residents in residential aged care facilities are more likely to have a chronic degenerative disease(s) (Grbich et al. 2005). Indeed, it may be that a residential aged care resident is receiving palliative care, not as a consequence of a life-limiting disease *per se*, but due to the fact that they are dying due to the ageing process (NHMRC 2005).

The Australian Government funds residential aged care facilities to provide services to older Australians whose care needs are such that they can no longer remain in their own homes (AIHW 2011e). Residential aged care facilities provide accommodation and aged care services (as a package) 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).

In its final report, the National Health and Hospitals Reform Commission identified residential aged care facilities as one of the settings requiring improved access to specialist palliative care services (NHHRC 2009). Further to this, the Productivity Commission report, *Caring for older Australians*, reported that palliative care is 'core' business of any aged care system (PC 2011).

This chapter presents information on residential aged care residents who have been assessed using the Aged Care Funding Instrument (ACFI) as requiring palliative care (see Key concepts).

### 5.1 Data source

The data presented in this section have been derived from DoHA's Aged and Community Care Data Warehouse which contains information gathered through a number of data collection instruments; in this section, the ACFI has been used (AIHW 2011e).

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

- Activities of Daily Living (ADLs)
- Behaviour (BEH)
- Complex Health Care (CHC) (AIHW 2011e, 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 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 2011e).

### Key concepts

**Palliative care in residential aged care:** residential aged care residents are identified in the ACFI data through care needs being assessed as palliative care in the complex health care domain. 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:** A resident who is admitted to residential aged care for permanent care (long-term care).

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

## 5.2 Characteristics of palliative care residential aged care residents

There were almost 219,000 permanent residential aged care residents in 2010–11 with completed ACFI assessments and about 1 in 20 of these residents had an ACFI assessment indicating the need for palliative care during this reporting period (Table 5.1).

Of the 11,083 permanent residents who were assessed as requiring palliative care in 2010–11, one-third (32.6%) commenced a permanent admission in 2010–11 (Table 5.1).

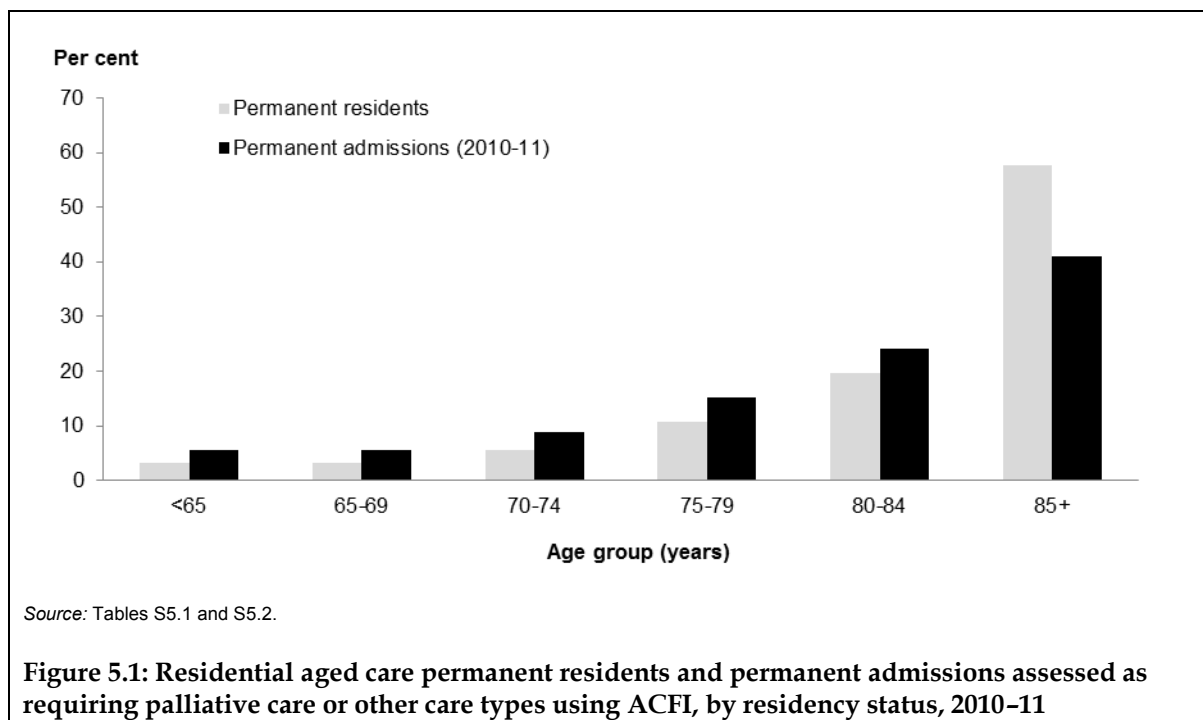
**Table 5.1: Residential aged care permanent admissions and permanent residents assessed as requiring palliative care or other care types using ACFI, 2010–11**

	Palliative care (per cent)	Other care (per cent)	Total (per cent)
Permanent admissions (in 2010–11)	3,618 (32.6%)	52,912 (25.5%)	56,530 (25.9%)
Permanent residents	11,083 (100.0%)	207,590 (100.0%)	218,673 (100.0%)

Source: Tables S5.1 and S5.2.

There was essentially no difference seen in terms of the age profile of permanent residents who required palliative care when compared to residents with other care requirements during 2010–11 (Table S5.1).

Considering those residents who entered permanent care during 2010–11, there was a smaller proportion in the 85 years and older group assessed as requiring palliative care compared to other care types (41% and 51%, respectively) (Table S5.2); whereas the percentage for those assessed as requiring palliative care was higher for permanent residents than for permanent admissions in the remaining age groups (Figure 5.1).



Male residents were more likely to be assessed as requiring palliative care compared to other care types (38.4% and 31.4%, respectively) during 2010-11 (Table 5.2). There was essentially no difference seen across those residents assessed as requiring palliative care and other care types when considering Indigenous status, preferred language, marital status and country of birth (Table S5.3).

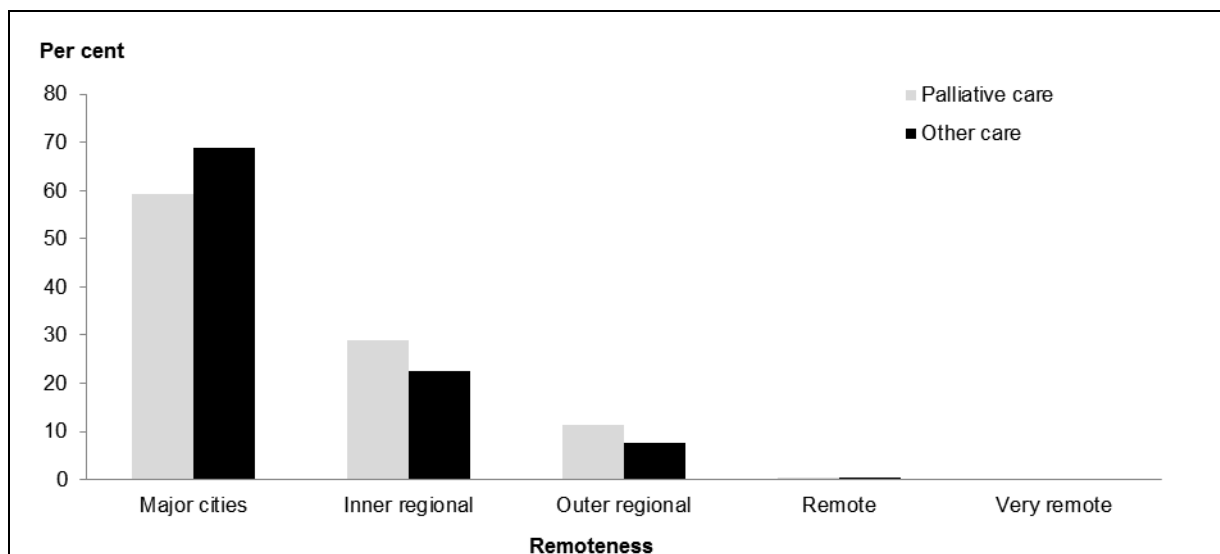
**Table 5.2: Residential aged care permanent residents, assessed as requiring palliative or other care types using ACFI, by gender, 2010-11**

Sex	Palliative care		Other care	
	Number	Per cent	Number	Per cent
Male	4,252	38.4	65,277	31.4
Female	6,831	61.6	142,313	68.6

Source: Table S5.3.

## Geographical distribution of palliative care in residential aged care

A smaller proportion of permanent residents who were assessed as requiring palliative care resided in *Major cities* compared to the proportion of residents with other care types (59.2% and 69.0%, respectively) in 2010-11 (Figure 5.2).



Source: Table S5.3.

**Figure 5.2: Residential aged care permanent residents assessed as requiring palliative care or other care types using ACFI, by geographical remoteness, 2010-11**

## 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 receive palliative care, had death as a mode of separation (Table 5.3). Those residents receiving palliative care were less likely to have a mode of separation of going to hospital, returning to the community, or transferring to another aged care service compared to those residents with other care requirements.



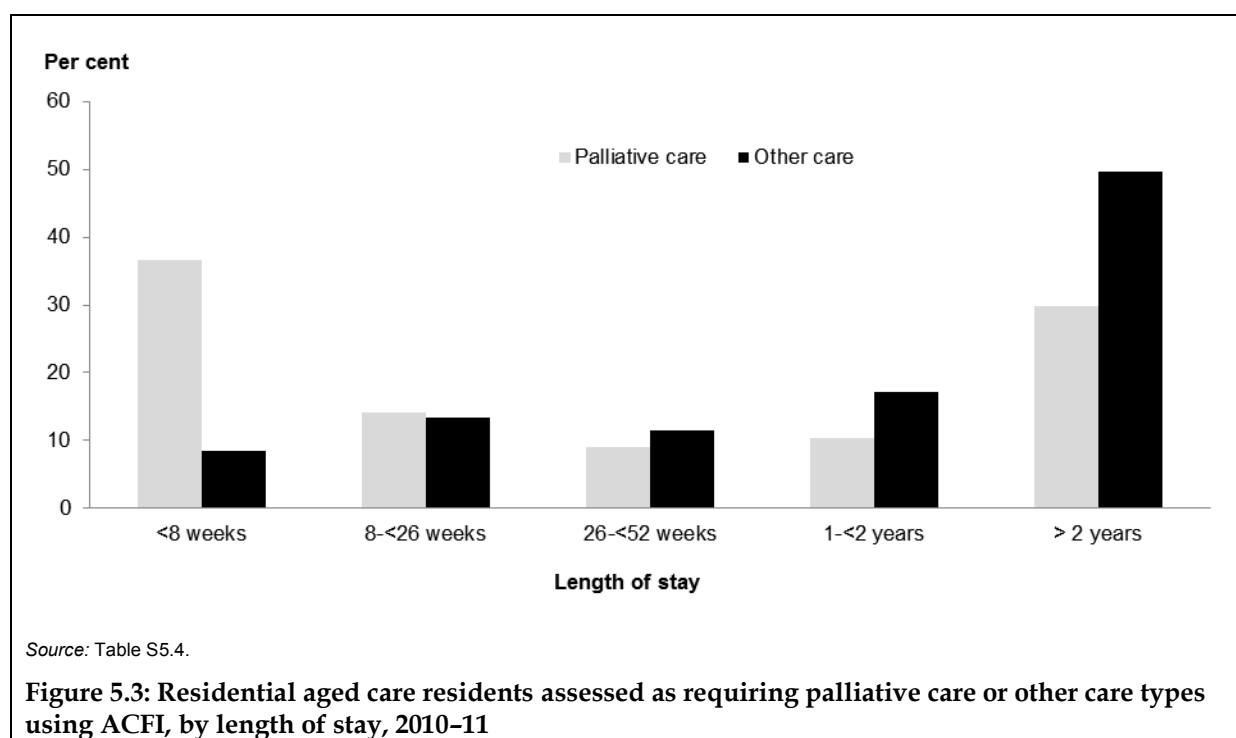
**Table 5.3: Residential aged care residents assessed as requiring palliative care or other care types using ACFI, by mode of separation, 2010–11**

Separation reason	Palliative care		Other care	
	Number	Per cent	Number	Per cent
Death	6,675	97.4	43,890	91.3
To hospital	80	1.2	1,111	2.3
Return to community	46	0.7	1,656	3.4
To another aged care service	26	0.4	882	1.8
Other	23	0.3	542	1.1
<b>All separations</b>	<b>6,850</b>	<b>100.0</b>	<b>48,081</b>	<b>100.0</b>

Source: AIHW analysis of 2010–11 ACFI data.

### 5.3 Length of stay

For those permanent residents separating from a residential aged care facility during the 2010–11 reporting period, residents appraised as requiring palliative care were more likely to have a shorter length of stay compared to other care types (Figure 5.3). For residents with a length of stay of less than 8 weeks, the proportion requiring palliative care was more than four times that for residents receiving other care types (36.7% and 8.4%, respectively) during 2010–11 (Figure 5.3). For a length of stay of less than 4 weeks, the proportion requiring palliative care was almost six times that for other care types (23.8% and 4.2%, respectively) (Table S5.4). This may be due to residents accessing residential aged care in order to manage the end-of-life period.



## Hospital leave

A permanent aged care resident may require hospital leave in order to receive treatment in hospital.

In 2010–11 there was little difference seen in the proportion of residents assessed as requiring palliative care and other care types in terms of hospital leave across geographical categories at the national level (Table 5.4).

**Table 5.4: Residential aged care residents assessed as requiring palliative care or other care types using ACFI, with an episode of hospital leave, 2010–11**

	Palliative care		Other care	
	Number	Per cent	Number	Per cent
Major cities	2,138	66.7	43,316	73.0
Inner regional	753	23.5	11,449	19.3
Outer regional	295	9.2	4,194	7.1
Remote	17	0.5	283	0.5
Very remote	1	0.0	74	0.1
<b>Total</b>	<b>3,204</b>	<b>100.0</b>	<b>59,316</b>	<b>100.0</b>

*Note:* This includes those individuals who were a permanent resident in a residential aged care facility at some time during 2010–11, but who may or may not have been a permanent resident at 30 June 2011.

*Source:* Table S5.5.

# 6 Palliative care-specific 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), which, in many instances, involves the use of various prescription medications.

The purpose of this chapter is to present available information on pharmaceuticals prescribed for palliative care patients. The information is sourced through the Pharmaceutical Benefits Scheme (PBS) and the Repatriation Pharmaceutical Benefits Scheme (RPBS). Under both schemes, Medicare Australia makes payments to subsidise pharmaceutical products regarded as necessary and which are listed in the *Schedule of pharmaceutical benefits* (DoHA 2012c).

In order to improve access to essential and affordable palliative care medications, the Australian Government introduced the *Pharmaceutical Benefits for Palliative Care Schedule*, as a sub-section of the PBS Schedule, in 2004. The palliative care schedule is a list of medications which were recommended for subsidy by the Pharmaceutical Benefits Advisory Committee (PBAC). 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 2012c). 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 schedule. For the purpose of this chapter, only medications in the palliative care listings and medications prescribed by palliative medicine specialists are included in the data and they are collectively referred to as *palliative care-related prescriptions* in the following discussion (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*
- all other medications prescribed by palliative medicine specialists.

### Prescriptions

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 intent of the definition of palliative care-related prescriptions is to capture, as far as possible, medications that were dispensed for palliative care-related reasons. However, it is likely that some medications are included that were prescribed for non-palliative care-related reasons; for example, some medications prescribed by palliative medicine specialists may not

relate directly to the patient's palliative care problems. Similarly, other medications related to palliative care problems might have been excluded; for example, some medications prescribed by general practitioners (GPs) or non-palliative medicine specialists that are not listed in the palliative care schedule may have been prescribed for palliative care-related problems.

In interpreting the information provided in this chapter, 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).

## 6.2 Characteristics of patients receiving palliative care-related prescriptions

Nationally, more than 14,000 patients had a subsidised palliative care-related prescription during 2010–11, which equates to a rate of 64.0 patients per 100,000 population (Table 6.1). In terms of prescriptions, there were almost 29,000 subsidised palliative care-related prescriptions during 2010–11, which equates to a rate of 128.9 per 100,000 population. On average, this equates to two subsidised palliative care-related prescriptions for each patient during 2010–11.

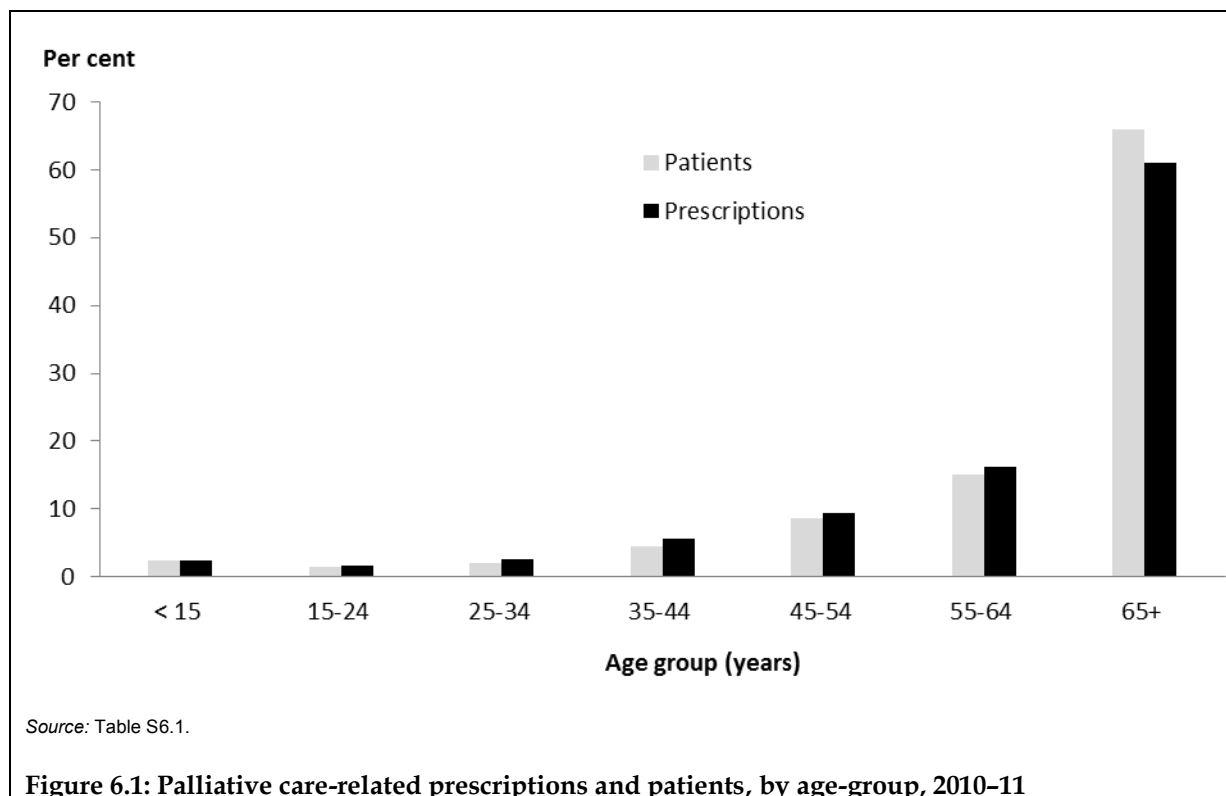
**Table 6.1: Palliative care-related prescriptions: numbers of patients and prescriptions, 2010–11**

	Patients	Prescriptions
Number	14,393	28,982
Rate <sup>(a)</sup>	64.0	128.9

(a) Crude rate is based on the preliminary Australian estimated resident population as at 31 December 2010 and is expressed per 100,000 populations (see Appendix C).

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

Two-thirds of patients prescribed subsidised palliative care-related prescriptions during 2010–11 were aged 65 years or older (65.9%) with more than three-quarters aged 55 years or older (80.9%) (Figure 6.1). For the 65 years and older group, the population rate for 2010–11 was 310.4 per 100,000 population, which was more than three and a half times the rate seen for the 55–64 year age group (84.1 per 100,000). Less than one in twenty patients (3.7%) with palliative care-related prescriptions was aged less than 25 years in 2010–11.



The gender profile for patients who have had subsidised palliative care-related prescriptions was essentially balanced in 2010–11 with 51.8% being female and 48.1% male (Table S6.1). Males and females both averaged two palliative care-related prescriptions for each patient during 2010–11.

The highest rate of patients being prescribed subsidised palliative care-related prescriptions was seen in *Inner regional* areas followed by *Outer regional* areas (82.2 and 71.2 per 100,000 population, respectively) (Table 6.2).

**Table 6.2: Palliative care-related prescriptions: patients by remoteness, 2010–11**

Patient area of residence	Number <sup>(a)</sup>	Per cent <sup>(b)</sup>	Rate <sup>(c)</sup>
Major cities	9,085	63.2	59.2
Inner regional	3,616	25.1	82.2
Outer regional	1,485	10.3	71.2
Remote	154	1.1	47.1
Very remote	45	0.3	25.8
<b>Total</b>	<b>14,393</b>	<b>100.0</b>	<b>64.5</b>

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

(b) The percentages shown do not include prescriptions for which information was unknown or missing.

(c) Crude rate is based on the preliminary Australian estimated resident population as at 31 December 2010 and is expressed per 100,000 populations (see Appendix C).

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

## 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 which are listed on the palliative care schedule of the PBS/RPBS 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 which 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 almost 29,000 subsidised palliative care-related prescriptions in 2010–11 (Table 6.3). The medication type *laxatives* were the most frequently prescribed palliative care-related prescriptions in 2010–11 followed by *psycholeptics* and *anti-epileptics* (28.7%, 22.9% and 20.9%, respectively).

The majority of these prescriptions (84.8%) were prescribed by *general practitioners* (Table 6.3). The next most frequently recorded type of clinician was *other clinicians* followed by *palliative medicine specialists* (12.9% and 2.2%, respectively).

The pattern of the types of medications prescribed varied according to the type of clinician. The most frequently prescribed medications by *general practitioners* were *laxatives* followed by *psycholeptics* (29.7% and 25.0%, respectively). For *palliative medicine specialists* and *other clinicians* the most frequently prescribed medications were *analgesics* (59.1% and 33.0%, respectively) followed by *laxatives* (13.8% and 24.5%, respectively).

**Table 6.3: Palliative care schedule items, by medication type prescribed and prescribing clinician, 2010–11**

Medication type	Prescribing clinician (per cent)			All clinicians	Total (number)
	General practitioners	Palliative medicine specialists	Other clinicians		
Analgesics	13.0	59.1	33.0	16.7	4,828
Anti-emetics and anti-nauseants	3.3	1.1	2.5	3.2	924
Anti-epileptics	21.5	10.6	19.0	20.9	6,068
Anti-inflammatory and anti-rheumatic products	2.5	1.4	3.7	2.6	768
Drugs for functional gastrointestinal disorders	3.1	6.6	4.8	3.4	997
Laxatives	29.7	13.8	24.5	28.7	8,317
Psycholeptics	25.0	6.9	11.5	22.9	6,626
Stomatological preparations	1.7	0.5	0.8	1.6	454
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>..</b>
<b>Total (number)</b>	<b>24,591</b>	<b>650</b>	<b>3,741</b>	<b>..</b>	<b>28,982</b>
Per cent (row)	84.8	2.2	12.9	100.0	..

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

Source: Table S6.2.

## Palliative care-related prescriptions by state and territory

Nationally, there were 128.9 per 100,000 population subsidised palliative care-related prescriptions dispensed in 2010–11. Rates ranged from 97.8 per 100,000 population in the Australian Capital Territory to 197.9 in Tasmania (Table 6.4).

Nationally, *laxatives* had the highest rate of prescription followed by *psycholeptics* and *anti-epileptics* (37.0, 29.5 and 27.0 per 100,000 population, respectively).

**Table 6.4: Palliative care schedule items, by medication type per 100,000 population<sup>(a)</sup>, all clinicians, states and territories, 2010–11**

Medication type	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total (rate) <sup>(a)</sup>	Total (number)
Analgesics	15.7	20.7	26.2	29.9	28.3	15.3	18.8	17.4	21.5	4,828
Anti-emetics and anti-nauseants	2.9	2.7	5.4	6.0	6.8	8.4	3.3	2.6	4.1	924
Anti-epileptics	23.4	42.1	16.0	23.9	27.1	39.1	14.1	15.2	27.0	6,068
Anti-inflammatory and anti-rheumatic products	2.7	3.5	3.5	2.8	3.0	10.6	11.9	3.9	3.4	768
Drugs for functional gastrointestinal disorders	3.9	2.5	7.6	1.9	9.6	1.6	1.1	4.4	4.4	997
Laxatives	36.7	32.9	42.2	22.3	50.8	60.7	33.2	47.0	37.0	8,317
Psycholeptics	27.7	24.2	37.2	27.1	31.6	59.3	15.2	30.0	29.5	6,626
Stomatological preparations	2.0	2.2	2.2	1.0	3.2	2.9	0.3	0.0	2.0	454
<b>Total (rate)<sup>(a)</sup></b>	<b>114.9</b>	<b>130.7</b>	<b>140.2</b>	<b>114.8</b>	<b>160.5</b>	<b>197.9</b>	<b>97.8</b>	<b>120.5</b>	<b>128.9</b>	..
<b>Total (number)</b>	<b>8,355</b>	<b>7,300</b>	<b>6,378</b>	<b>2,661</b>	<b>2,649</b>	<b>1,008</b>	<b>354</b>	<b>277</b>	..	<b>28,982</b>

(a) Crude rate is based on the preliminary Australian estimated resident population as at 31 December 2010 and is expressed per 100,000 populations (see Appendix C).

Source: Table S6.2.

## Palliative care-related prescriptions over time

Nationally, the number of subsidised palliative care-related prescriptions decreased by an average annual rate of about 3% between 2006–07 and 2010–11 (Table 6.5). However, there was notable variability across medication types, ranging from *analgesics*, which had an annual average increase of 41.4% and *anti-inflammatory and anti-rheumatic products*, which had an average annual decrease of 16.1% during this period.

**Table 6.5: Palliative care schedule items, by medication type, all clinicians, 2006–07 to 2010–11**

Medication type	2006–07	2007–08	2008–09	2009–10	2010–11	Average annual change (per cent)
Analgesics	1,208	1,627	3,242	3,827	4,828	41.4
Anti-emetics and anti-nauseants	964	963	935	823	924	-1.1
Anti-epileptics	8,317	7,171	6,686	6,235	6,068	-7.6
Anti-inflammatory and anti-rheumatic products	1,550	1,431	917	698	768	-16.1
Drugs for functional gastrointestinal disorders	1,038	840	936	895	997	-1.0
Laxatives	7,507	11,169	9,258	7,878	8,317	2.6
Psycholeptics	11,829	12,046	9,005	7,840	6,626	-13.5
Stomatological preparations	451	485	426	458	454	0.2
<b>Total</b>	<b>32,864</b>	<b>35,732</b>	<b>31,405</b>	<b>28,654</b>	<b>28,982</b>	<b>-3.1</b>

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



The pattern of prescribing palliative care-related prescriptions on the PBS/RPBS palliative care schedule is likely to be influenced by the fact that about 85% of these prescriptions are prescribed by GPs. Over the 5 years until 2010–11, the number of palliative care-related prescriptions written by GPs decreased by an average annual rate of 5.1% (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 29.4% and 12.3%, respectively).

The prescribing of analgesics included in the PBS/RPBS palliative care schedule showed the largest annual average increase over the 5 year period reported for all clinician types. Palliative medicine specialists had the largest annual average increase followed by other clinicians and GPs (100.0%, 80.6% and 31.7%, respectively) (Table S6.3).

## Palliative care schedule items for pain relief

A sub-analysis of medications prescribed for pain relief indicate that more than two-thirds (69.9%) of medications in this group were opioids with the remainder being paracetamol (Table 6.6). Less than one in ten prescriptions for opioids was a repeat script in 2010–11 compared to almost one-third for paracetamol (9.5% and 31.8%, respectively).

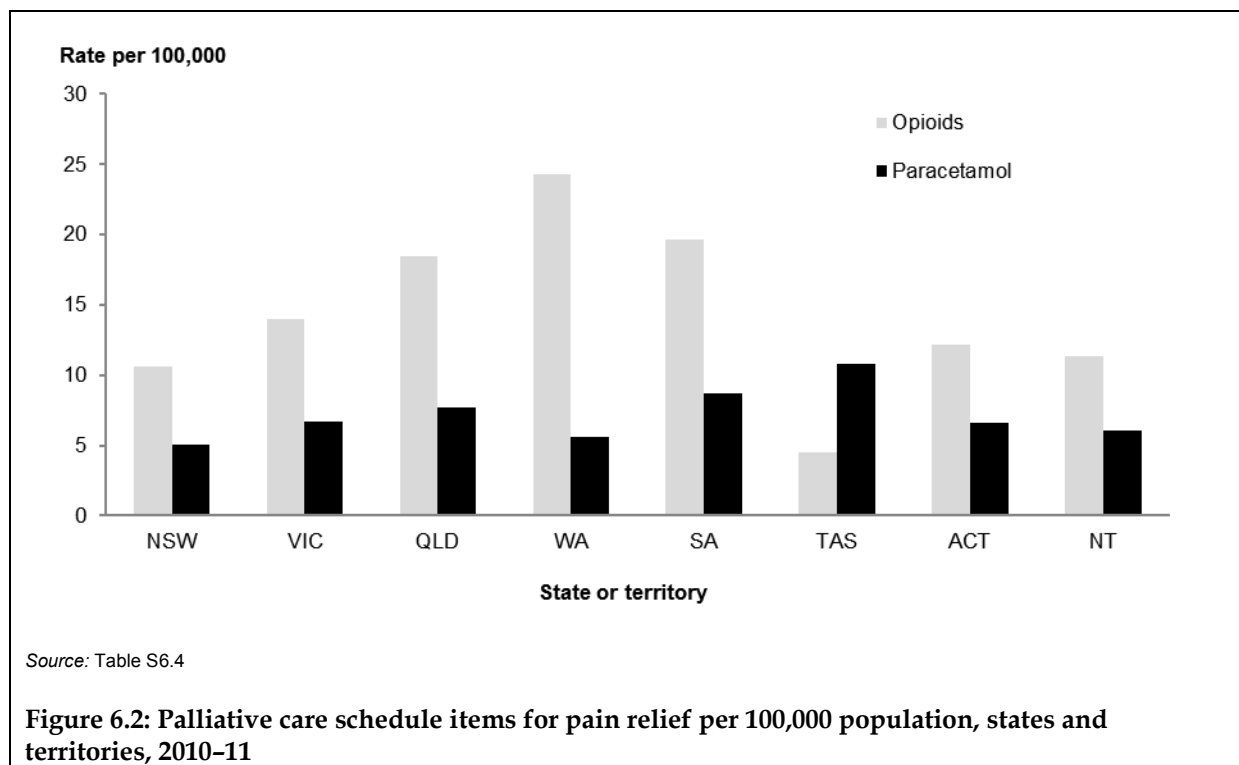
Nationally, there were 21.5 per 100,000 subsidised prescriptions for pain relief medications included on the palliative care schedule in 2010–11, with opioids making up 15.0 per 100,000 population and paracetamol 6.5 per 100,000 (Table S6.4).

**Table 6.6: Palliative care schedule items for pain relief, initial and repeat prescriptions, by medication group, 2010–11**

Medication group	Initial scripts	Repeat scripts	Total	Per cent
<b>Number</b>				
Opioids	3,053	321	3,374	69.9
Paracetamol	992	462	1,454	30.1
<b>Total</b>	<b>4,045</b>	<b>783</b>	<b>4,828</b>	<b>100.0</b>
<b>Per cent</b>				
Opioids	90.5	9.5	100.0	..
Paracetamol	68.2	31.8	100.0	..
<b>Total</b>	<b>83.8</b>	<b>16.2</b>	<b>100.0</b>	<b>..</b>

Source: Table S6.4.

For subsidised palliative care schedule opioid prescriptions, rates ranged from 4.5 per 100,000 in Tasmania to 24.3 for Western Australia. For paracetamol, the rates ranged from 5.0 per 100,000 for New South Wales to 10.8 for Tasmania (Figure 6.2).



### All medications prescribed by palliative specialists

There were more than 23,400 subsidised palliative care schedule prescriptions made by palliative medicine specialists during 2010-11 (Table 6.7). This number includes all PBS/RPBS-subsidised medications prescribed, for 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 which act on the nervous system (which includes analgesics) followed by those which act on the alimentary tract and metabolism (which includes drugs for functional gastrointestinal disorders and laxatives) (56.9% and 17.8%, respectively) (Table 6.7).

**Table 6.7: All PBS/RPBS-subsidised prescriptions made by palliative medicine specialists, by ATC group, 2010-11**

<b>ATC group<sup>(a)</sup></b>	<b>Number</b>	<b>Per cent</b>
Alimentary tract and metabolism	4,164	17.8
Blood and blood forming organs	551	2.4
Cardiovascular system	942	4.0
Dermatologicals	153	0.7
Genito urinary system and sex hormones	75	0.3
Systemic hormonal preparations, excl. sex hormones and insulins	1,290	5.5
Anti-infectives for systemic use	1,314	5.6
Antineoplastic and immunomodulating agents	103	0.4
Musculo-skeletal system	501	2.1
Nervous system	13,340	56.9
Respiratory system	549	2.3
Sensory organs	399	1.7
Various	12	0.1
Other	48	0.2
<b>Total</b>	<b>23,441</b>	<b>100.0</b>

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

# 7 Resourcing of palliative care services

## 7.1 Introduction

This chapter summarises the available information on the resourcing of palliative care services in Australia. It provides a recent history and background information on palliative care funding, including information on the Australian government's expenditure through the Medicare Benefits Schedule (MBS) and the Pharmaceutical Benefits Scheme (PBS) or Repatriation Pharmaceutical Benefits Scheme (RPBS). In addition, information on public hospital establishments with hospice care units is included. Finally, an overview of the palliative care workforce focusing on palliative medicine specialists and palliative care nurses in Australia is provided.

## 7.2 Palliative care funding

This section provides an overview of government funding of palliative care services in Australia. As there is no national data collection to support reporting on funding or expenditure for palliative care, the information presented in this section is limited to available published data on specific programs, such as MBS.

Funding and expenditure are distinct but related concepts, essential to understanding the financial resources utilised by the health system. Funding information relates to the provider of the financial resources, while expenditure information relates to who incurs the expenditure.

### Recent history of palliative care funding

The first National Palliative Care Strategy was introduced and endorsed by Australian health ministers in 2000. This resulted in a number of Australian Government funding initiatives including specific palliative care funding under the National Palliative Care Program (NPCP) (PCA 2010). The Australian Government funds the NPCP to provide accessible and high quality palliative care (DoHA 2012b).

Since this time, Australian Government funding for palliative care has been characterised by a number of interrelated programs including:

- Australian Health Care Agreement (AHCA, 1998–2003) \$151 million (with \$10 million to the Commonwealth for national programs)
- AHCA (2003–2008) \$188m (with \$13m to the Commonwealth for national programs)
- National Palliative Care Program funding, including:
  - Caring Communities Program (2003–2006) \$5m
  - Palliative Care in the Community (2006–2010) \$62.8m
  - Local Palliative Care Grants Program (2005–2009) \$23.1m.

The *Living Longer Living Better* aged care reform package (DoHA 2012d) released by the Australian Government also provides funding of \$19.8 million for specialist palliative care and advance care planning advisory services for aged care providers and general practitioners caring for older people in aged care. An estimated \$1.9 million has also been assigned to the expansion of the existing Program of Experience in the Palliative Approach

(PEPA) program to provide palliative care training for staff in residential aged care facilities and Home Care package services.

## Australian Government funding to states and territories

Funding for palliative care services is provided through a combination of allocations from state and territory budgets and Australian Government funding provided through the National Healthcare Agreement (NHA) to the states and territories (DoHA 2005). Funding provided via the NHA is non-specific, that is, it includes funding for a range of health services of which palliative care service may be a subset. For example, funding of admitted patients beds via public hospital allocations, provision of respite through other health programs, and specialised programs such as pain management, all represent additional investments in palliative care. Against this background it is challenging to identify and quantify the extent and scope of NHA funding spent directly on palliative care services (DoHA 2005).

In addition, funding of palliative care services through National Agreements are often 'bundled up' with other sub-acute care service types including:

- rehabilitation
- sub-acute mental health
- geriatric evaluation and management
- psycho-geriatric.

The recent commitment by the Australian Government of \$500 million over the next 5 years to states and territories for the enhancement of sub-acute care services, under the Council of Australian Governments (COAG) National Partnership Agreement on Hospital and Health Workforce Reform (NPA HHWR) (COAG 2008), will impact on the provision of state and territory sub-acute palliative care services. However, the allocation of sub-acute funding to one or more of the service types is the responsibility of individual state and territory governments (DoHA 2012a). Jurisdiction-specific information on allocation of funding to palliative care services was not available for this report, and so reporting is limited to available information on Australian Government funding. It is, however, envisaged that future reports will include jurisdiction-specific information on state and territory funding allocated to palliative care services.

In addition to the NPA HHWR, the National Health Reform Agreement – National Partnership Agreement on Improving Public Hospital Services (NPA IPHS) provides funding to states and territories to deliver and operate new sub-acute care beds in public hospitals and community settings (COAG 2011). Almost \$50 million was spent on palliative care beds as part of the NPA IPHS as at 30 June 2011 (Table 7.1). It should be noted that this total reflects the funding allocated at a point in time and that jurisdictions may have differing schedules and priorities for funding sub-acute care beds across the various sub-acute service types listed above.

**Table 7.1: National Partnership Agreement on Improving Public Hospital Services: Total funding (\$) allocated to sub-acute care beds in public hospitals and community settings, as at 30 June 2011**

State/territory	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
<b>Funding (\$)</b>	27,893,925	644,515	16,690,000	2,200,000	0	0	86,935	2,075,376	49,860,751

Source: COAG 2011.

## Australian Government expenditure on MBS-subsidised palliative medicine specialist services and palliative care-related medications

This section outlines the Australian Government's funding through the MBS for palliative care-related services provided by palliative medicine specialists, as well as claims processed under the PBS and RPBS for subsidised prescribed medications in 2010–11. 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). Under both PBS/RPBS schemes, the Australian Government also makes payments to subsidise pharmaceutical products regarded as necessary and are listed in the Schedule of pharmaceutical benefits (DoHA 2012c).

Australian Government expenditure on MBS palliative care-related services and PBS/RPBS palliative care-related medications was over \$5.5 million in 2010–11. Almost \$3 million was paid in benefits for MBS-subsidised palliative medicine specialist services in 2010–11 (Table 7.2), equivalent to a rate of \$13,266 per 100,000 population. In terms of palliative care-related prescriptions, about \$2.5 million in benefits was paid for medications included on the palliative care schedule in 2010–11, representing a rate of \$11,276 per 100,000 population.

**Table 7.2: Australian Government expenditure (\$) on MBS palliative care-related services and PBS/RPBS palliative care-related medications, states and territories<sup>(a)</sup>, 2010–11**

State/territory	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
<b>Expenditure (\$)</b>									
Medicare Benefits Schedule	1,212,851	187,245	534,494	657,062	264,094	n.p.	n.p.	1,623	2,981,945
Pharmaceutical Benefits Scheme <sup>(b)</sup>	27,450	510,726	514,652	425,150	265,677	20,808	54,384	15,616	2,534,463
<b>Total<sup>(c)</sup></b>	<b>1,240,301</b>	<b>697,971</b>	<b>1,049,146</b>	<b>1,082,212</b>	<b>529,771</b>	<b>n.p.</b>	<b>n.p.</b>	<b>17,239</b>	<b>5,516,408</b>
<b>Rate (per 100,000 population)<sup>(d)</sup></b>									
Medicare Benefits Schedule	5,396	833	2,378	2,923	1,175	n.p.	n.p.	7	13,266
Pharmaceutical Benefits Scheme <sup>(b)</sup>	10,003	9,144	11,314	18,349	16,098	4,086	15,027	6,793	11,276

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

(b) Refers to benefits paid on palliative care schedule items by prescribing clinician.

(c) The dollar amount may not sum to the total due to rounding.

(d) Crude rate is based on the preliminary Australian estimated resident population as at 31 December 2010 and is expressed per 100,000 population (see Appendix C).

Source: MBS and PBS/RPBS data (DoHA).

## Australian Government expenditure on MBS-subsidised palliative medicine specialist services, states and territories

Table 7.3 disaggregates the \$2.9 million spent by the Australian Government on services provided by palliative medicine specialists through MBS subsidies by jurisdiction.

New South Wales had the highest rate in benefits (\$5,396 per 100,000 population) while the Northern Territory had the lowest (\$7). Just over 90% of total benefits paid were MBS items claimed by palliative medicine specialist's attendances.

**Table 7.3: Medicare benefits paid (\$) on palliative medicine specialist services, by item group, states and territories<sup>(a)</sup>, 2010–11**

MBS item group	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
<b>Palliative medicine attendances</b>									
Attendance in a hospital or surgery	863,620	n.p.	460,586	n.p.	210,372	n.p.	n.p.	n.p.	2,413,876
Home visit	160,346	n.p.	58,516	n.p.	50,826	0	n.p.	0	289,464
<i>Total</i>	<i>1,023,966</i>	<i>n.p.</i>	<i>519,102</i>	<i>586,909</i>	<i>261,197</i>	<i>n.p.</i>	<i>n.p.</i>	<i>n.p.</i>	<i>2,703,340</i>
<b>Palliative medicine case conferences</b>									
<i>Total</i>	<i>188,886</i>	<i>n.p.</i>	<i>15,392</i>	<i>70,153</i>	<i>2,897</i>	<i>777</i>	<i>n.p.</i>	<i>n.p.</i>	<i>278,605</i>
<b>Total items<sup>(b)</sup></b>	<b>1,212,851</b>	<b>187,245</b>	<b>534,494</b>	<b>657,062</b>	<b>264,094</b>	n.p.	n.p.	<b>1,623</b>	<b>2,981,945</b>
Rate <sup>(c)</sup>	5,396	833	2,378	2,923	1,175	n.p.	n.p.	7	13,266

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

(b) The dollar amount may not sum to the total due to rounding.

(c) Crude rate is based on the preliminary Australian estimated resident population as at 31 December 2010 and is expressed per 100,000 population (see Appendix C).

Source: MBS data (DoHA).

Over the 5 years to 2010–11, the MBS benefits paid for palliative medicine specialist services more than doubled (from \$1,205,504 in 2006–07 to \$2,981,946) (Table 7.4). This equates to an average annual increase of 25.4%.

**Table 7.4: Medicare benefits paid (\$) <sup>(a)</sup> on palliative medicine specialist services, Australia, 2006–07 to 2010–11**

MBS item	2006–07	2007–08	2008–09	2009–10	2010–11	Average annual change (per cent)
<b>Palliative medicine attendances</b>						
Attendance in a hospital or surgery	990,828	1,259,518	1,775,859	2,198,438	2,413,876	24.9
Home visit	203,557	340,101	312,898	354,138	289,464	9.2
<i>Total</i>	<i>1,194,385</i>	<i>1,599,619</i>	<i>2,088,758</i>	<i>2,552,576</i>	<i>2,703,340</i>	<i>22.7</i>
<b>Palliative medicine case conferences</b>						
Organise and coordinate a community case conference	n.p.	n.p.	60,651	97,917	123,532	n.p.
Participate in a community case conference	3,211	17,335	n.p.	n.p.	63,544	110.9
Organise and coordinate a discharge case conference	4,827	19,114	56,505	78,329	87,581	106.4
Participate in a discharge case conference	n.p.	n.p.	n.p.	n.p.	3,949	n.p.
<i>Total</i>	<i>11,117</i>	<i>64,343</i>	<i>138,632</i>	<i>217,566</i>	<i>278,605</i>	<i>123.7</i>
<b>Total items<sup>(b)</sup></b>	<b>1,205,502</b>	<b>1,663,962</b>	<b>2,227,390</b>	<b>2,770,142</b>	<b>2,981,945</b>	<b>25.4</b>

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

(b) The dollar amount may not sum to the total due to rounding.

Source: MBS data (DoHA).

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

Over the 5 years from 2006–07 to 2010–11, the benefits paid for palliative care schedule items increased by an annual average of almost 44% (Table 7.5). There was some variability seen across medications with annual average changes ranging from a 16.0% decrease for anti-epileptics to a 163.2% increase for analgesics.

**Table 7.5: PBS/RPBS benefits paid (\$) <sup>(a)</sup> on palliative care schedule items, 2006–07 to 2010–11**

Medication type	2006–07	2007–08	2008–09	2009–10	2010–11	Annual average change (per cent)
<b>Benefits paid (\$)</b>						
Analgesics	41,392	127,590	1,121,677	1,571,594	1,987,303	..
Anti-emetics and anti-nauseants	11,864	12,155	12,943	11,693	13,069	..
Anti-epileptics	149,180	120,443	95,018	81,027	74,439	..
Anti-inflammatory and anti-rheumatic products	26,900	26,198	16,070	13,547	15,867	..
Drugs for functional gastrointestinal disorders	59,195	54,009	72,132	75,276	105,264	..
Laxatives	232,677	334,736	282,494	256,250	295,135	..
Psycholeptics	69,075	73,731	50,696	43,956	37,065	..
Stomatological preparations	4,903	6,332	6,158	7,689	6,322	..
<b>Total</b>	<b>595,187</b>	<b>755,194</b>	<b>1,657,187</b>	<b>2,061,032</b>	<b>2,534,463</b>	<b>43.7</b>
<b>Per cent</b>						
Analgesics	7.0	16.9	67.7	76.3	78.4	163.2
Anti-emetics and anti-nauseants	2.0	1.6	0.8	0.6	0.5	2.4
Anti-epileptics	25.1	15.9	5.7	3.9	2.9	-16.0
Anti-inflammatory and anti-rheumatic products	4.5	3.5	1.0	0.7	0.6	-12.4
Drugs for functional gastrointestinal disorders	9.9	7.2	4.4	3.7	4.2	15.5
Laxatives	39.1	44.3	17.0	12.4	11.6	6.1
Psycholeptics	11.6	9.8	3.1	2.1	1.5	-14.4
Stomatological preparations	0.8	0.8	0.4	0.4	0.2	6.6
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>..</b>

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

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

### All medications prescribed by palliative specialists

This section examines all subsidised prescriptions made by palliative medicine specialists for which palliative care-related prescriptions on the palliative care schedule are a subset. In 2010–11, more than \$1.1 million was paid for subsidised prescriptions made by palliative medicine specialists (Table 7.6). This amount includes benefits paid on all PBS/RPBS subsidised medications prescribed. Analgesics constituted more than three-quarters (78.4%) of this expenditure, followed by laxatives (11.6%).



More than two-thirds of benefits were paid for medications which act on the nervous system (which includes analgesics) followed by those which act on the alimentary tract and metabolism (which includes drugs for functional gastrointestinal disorders and laxatives) (71.4% and 8.6% respectively).

**Table 7.6: All PBS/RPBS benefits paid (\$) <sup>(a)</sup> for prescriptions made by palliative medicine specialists, by ATC group, 2010–11**

<b>ATC group <sup>(b)</sup></b>	<b>Benefits paid (\$)</b>	<b>Per cent</b>
Alimentary tract and metabolism	98,994	8.6
Blood and blood forming organs	43,756	3.8
Cardiovascular system	18,904	1.6
Dermatologicals	2,151	0.2
Genito urinary system and sex hormones	2,470	0.2
Systemic hormonal preparations, excl. sex hormones and insulins	15,425	1.3
Anti-infectives for systemic use	37,892	3.3
Antineoplastic and immunomodulating agents	46,791	4.0
Musculo-skeletal system	35,324	3.1
Nervous system	826,653	71.4
Respiratory system	19,768	1.7
Sensory organs	3,664	0.3
Various	1,122	0.1
Other	4,672	0.4
<b>Total</b>	<b>1,157,585</b>	<b>100.0</b>

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

## 7.3 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 hospitals and time series information on the number of hospice care units in public acute hospitals from 2005–06 to 2009–10. The hospital types reported in this section are public acute hospitals. Information on public hospital resources was derived from the National Public Hospital Establishments Database (NPHEd) (see Appendix B for data source information).

A hospice care unit is a type of specialist unit delivering palliative care services in public acute hospitals. This can include both freestanding hospices and/or palliative care wards. Inter-jurisdictional variability exists regarding how hospices are identified in the NPHEd. It should be noted that information on the number of hospice care units contained in the NPHEd pertains to only a subset of patients receiving palliative care, that is, those patients admitted to a hospice care unit in a public acute hospital. 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, but these may not be identified as a hospice care unit, and are thus not included within the data reported here. In addition, the information derived from 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 2009–10, there were a total of 123 public acute hospitals with a hospice care unit in Australia, with nearly one-third located in New South Wales (Table 7.7). Of the 736 public acute hospital (excluding public psychiatric hospitals) in Australia (AIHW 2011a), 1 in 6 (16.7%) had a hospice care unit. One-quarter (25.0%) of all public acute 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 undercounted.

**Table 7.7: Public acute hospitals with hospice care units, by remoteness area, states and territories, 2009–10**

Remoteness area	NSW <sup>(a)</sup>	Vic <sup>(b)</sup>	Qld	WA	SA <sup>(b)</sup>	Tas	ACT	NT	Total <sup>(d)</sup>
<b>Number</b>									
Major cities	15	15	6	0	5	..	1	..	42
Regional	25	8	5	19	4	1	0	1	63
Remote	0	0	0	11	4	0	0	0	15
<b>Total</b>	<b>40</b>	<b>26</b>	<b>11</b>	<b>30</b>	<b>13</b>	<b>1</b>	<b>1</b>	<b>1</b>	<b>123</b>
<b>Per cent<sup>(c)</sup></b>									
Major cities	24.2	28.8	35.3	0.0	38.5	..	33.3	..	25.0
Regional	18.0	8.4	6.4	51.4	9.3	5.3	0.0	100.0	15.3
Remote	0.0	0.0	0.0	30.6	18.2	0.0	0.0	0.0	9.6
<b>Total<sup>(c)(d)</sup></b>	<b>18.3</b>	<b>17.4</b>	<b>6.6</b>	<b>31.9</b>	<b>16.7</b>	<b>4.3</b>	<b>33.3</b>	<b>20.0</b>	<b>16.7</b>

- (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-enumerated.
- (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) 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.
- (d) Total for public acute hospitals excludes public psychiatric hospitals.

Source: National Public Hospital Establishments Database, AIHW.

### How did hospice units vary across states and territories from 2005–06 to 2009–10?

Table 7.8 presents the number of public acute hospitals with a hospice care unit by state and territory from 2005–06 to 2009–10. It also shows the proportion of all public acute hospitals with a hospice care unit during that period. There was a general increase in the number of public acute hospitals with a hospice care unit between 2005–06 and 2009–10 (from 108 to 123, respectively). New South Wales had the most hospitals with a hospice care unit. The highest increase in the number of public acute hospitals with hospice care units from 2005–06 to 2009–10 was in Western Australia (16 to 30).

**Table 7.8: Public acute hospitals<sup>(a)</sup> with hospice care units, states and territories, 2005–06 to 2009–10**

State/territory	2005–06 <sup>(b)</sup>	2006–07 <sup>(c)</sup>	2007–08	2008–09	2009–10
<b>Number</b>					
NSW	40	44	45	47	40
Vic	23	23	24	23	26
Qld	10	11	9	7	11
WA	16	18	29	29	30
SA	17	16	16	14	13
Tas	1	1	1	1	1
ACT	1	1	1	1	1
NT	0	1	1	1	1
<b>Total</b>	<b>108</b>	<b>115</b>	<b>126</b>	<b>123</b>	<b>123</b>
<b>Per cent<sup>(d)</sup></b>					
NSW	18.1	20.1	20.5	21.5	18.3
Vic	16.2	16.1	16.3	14.9	17.4
Qld	5.8	6.4	5.2	4.2	6.6
WA	17.8	19.1	31.2	31.2	31.9
SA	21.8	20.5	20.5	17.9	16.7
Tas	4.2	4.2	4.2	4.0	4.3
ACT	33.3	33.3	33.3	33.3	33.3
NT	0.0	20.0	20.0	20.0	20.0
<b>Total</b>	<b>14.7</b>	<b>15.6</b>	<b>17.0</b>	<b>16.7</b>	<b>16.7</b>

(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 2005–06, two hospitals in Melbourne were amalgamated.

(c) 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.

(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: National Public Hospital Establishments Database, AIHW.

## 7.4 Workforce

### 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 working 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 (RACP), or the Australasian Chapter of Palliative Medicine (AChPM)

(CareSearch 2012). Many specialist palliative medicine physicians have previously completed training as a GP or in another medical speciality.

The information presented in this section describes the number and characteristics of the workforce of medical practitioners and nurses specialising in palliative care. The AIHW Medical Labour Force Survey (AIHW 2011c) provides information on specialist palliative medicine physicians, while the AIHW Nursing and Midwifery Labour Force Survey (AIHW 2011d) provides information on palliative care nurses. Further details on these data sources are outlined in Appendix B.

### **Key concepts**

In this report, an *employed* health professional is defined 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, 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 only includes 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) is the number of 38-hour-week workloads worked by professionals. 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 comparable figures 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).

## **Specialist palliative medicine physicians**

The information on specialist palliative medicine physicians are estimates derived from the AIHW Medical Labour Force Surveys 2007, 2008 and 2009 (see Box 7.1). This survey collected information on the demographic and employment characteristics of practitioners who were registered in Australia at the time of the survey.

### **Box 7.1: AIHW Medical Labour Force Survey 2009**

The survey was conducted annually until (and including) 2009 by state and territory health authorities, with the questionnaire administered by the registration boards (or councils) in each jurisdiction, usually in conjunction with the registration renewal process. The overall response rate to the 2009 survey was 53.1%. Estimates for some jurisdictions should be interpreted with caution, due to relatively low response rates to the survey and very large declines in the response rate between 2008 and 2009 for Victoria, Queensland, Western Australia, Tasmania and the Northern Territory, as well as low response rates for particular age groups in Queensland.

To enable meaningful comparison in the supply of specialist palliative medicine physicians across Australia over time, *full-time-equivalent* (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 workloads 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.

### **Characteristics of specialist palliative medicine physicians**

Specialist palliative medicine physicians made up less than 1 in 100 (0.2%) of all employed medical practitioners in Australia (AIHW 2012), with an estimated 172 working in Australia in 2009 (Table 7.9).

In 2009, more than half (53.5%) of employed specialist palliative medicine physicians were female. This was more than double the proportion compared with all employed female medical practitioners who were clinician specialists (25.4%) (AIHW 2011c).

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

Specialist palliative medicine physicians worked an average of 38.9 hours per week in 2009 (Table 7.10), which was less than the average hours worked per week by all employed medical practitioners who were specialists (43.7) (AIHW 2011c). The hours worked per week were, on average, lower for females than males (34.5 hours compared with 43.8 hours).

**Table 7.9: Employed specialist palliative medicine physicians<sup>(a)</sup>, demographic characteristics, 2007–2009**

	2007	2008	2009	2009 (per cent)	Average annual change (per cent)
<b>Sex</b>					
Males	87	71	80	46.5	–4.1
Females	91	77	92	53.5	0.5
<b>Age group and sex</b>					
<i>Males</i>					
Less than 35 years	n.p.	n.p.	5	2.9	n.p.
35–44 years	18	11	19	11.0	2.7
45–54 years	32	28	19	11.0	–22.9
55–64 years	27	23	30	17.4	5.4
65 years and over	n.p.	n.p.	8	4.7	n.p.
<i>Females</i>					
Less than 35 years	n.p.	n.p.	—	—	n.p.
35–44 years	34	29	29	16.9	–7.6
45–54 years	29	22	38	22.1	14.5
55–64 years	18	18	19	11.0	2.7
65 years and over	n.p.	n.p.	6	3.5	n.p.
<b>Total<sup>(b)</sup></b>	<b>178</b>	<b>148</b>	<b>172</b>	<b>100.0</b>	<b>–1.7</b>
<b>Average age (years)</b>					
Males	50.5	52.3	51.8	..	1.3
Females	48.5	50.0	50.4	..	1.9
<i>All</i>	49.5	51.1	51.0	..	1.5
<b>All employed medical practitioners</b>	<b>67,208</b>	<b>68,455</b>	<b>72,739</b>	..	<b>4.0</b>

(a) All physicians with a main specialty of palliative medicine.

(b) 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.

**Table 7.10: Employed specialist palliative medicine physicians<sup>(a)</sup>, average hours worked per week, by sex, 2007–2009**

	2007	2008	2009	Average annual change (per cent)
<b>Sex</b>				
Males	47.3	43.1	43.8	–3.8
Females	37.0	36.0	34.5	–3.4
<b>Total</b>	<b>42.1</b>	<b>39.4</b>	<b>38.9</b>	<b>–3.9</b>

(a) All physicians with a main specialty of palliative medicine.

Sources: AIHW Medical Labour Force Surveys, 2007, 2008, 2009.

Nationally, there were 0.8 FTE specialist palliative medicine physicians per 100,000 population in 2009 (Table 7.11). The number of FTE specialist palliative medicine physicians per 100,000 population varied among the states and territories, ranging from 0.4 in

New South Wales to 1.5 for Queensland. No FTE specialist palliative medicine physicians were recorded in the Northern Territory. The average hours worked varied across jurisdictions, ranging from 32.2 hours per week for Victoria to 44.9 hours per week for Western Australia.

**Table 7.11: Employed specialist palliative medicine physicians<sup>(a)</sup>, average hours worked per week, FTE and FTE per 100,000 population, states and territories, 2009**

State/territory	Number of specialist palliative medicine physicians	Average hours worked per week	FTE number	FTE per 100,000 population <sup>(b)</sup>
NSW	30	36.8	29	0.4
Vic	48	32.2	41	0.7
Qld	60	41.8	66	1.5
WA	13	44.9	15	0.7
SA	15	41.3	16	1.0
Tas	n.p.	n.p.	n.p.	n.p.
ACT	n.p.	n.p.	n.p.	n.p.
NT	—	—	—	—
<b>Total<sup>(c)</sup></b>	<b>172</b>	<b>38.9</b>	<b>176</b>	<b>0.8</b>

(a) All physicians with a main specialty of palliative medicine.

(b) Crude rate is based on the preliminary Australian estimated resident population as at 31 December 2009 and is expressed per 100,000 populations (see Appendix C).

(c) 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: AIHW Medical Labour Force Survey, 2009.

Almost 9 out of 10 (86.6%) FTE specialist palliative medicine physicians (for whom region was reported) worked mainly in *Major cities* (Table 7.12) during 2009. 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* (1.0), followed by *Outer regional* (0.5) and *Inner regional* (0.3) areas.



**Table 7.12: Employed specialist palliative medicine physicians<sup>(a)</sup> by remoteness area<sup>(b)</sup>, average hours worked per week, 2009**

Remoteness area of main job <sup>(b)</sup>	Number	Average hours worked per week	FTE number	FTE per 100,000 population <sup>(c)</sup>
Major cities	149	38.0	149	1.0
Inner regional	11	50.9	15	0.3
Outer regional	10	39.7	10	0.5
Remote and very remote	0	0.0	0	0.0
Not reported	2	40.0	2	n.p.
<b>Total<sup>(d)</sup></b>	<b>172</b>	<b>38.9</b>	<b>176</b>	<b>0.8</b>

(a) All physicians with a main specialty of palliative medicine.

(b) Remoteness area is derived from the postcode of the respondent's location of main job. These data should be treated with caution due to the large number of Not reported values for remoteness area, relative to the number of values reported in *Outer regional* and *Remote and very remote* regions.

(c) Crude rate is based on the preliminary Australian estimated resident population as at 31 December 2009 and is expressed per 100,000 populations (see Appendix C).

(d) 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: AIHW Medical Labour Force Survey, 2009.

## Changes in the specialist palliative medicine physicians

The size and characteristics of the specialist palliative medicine physician workforce, including the hours worked, changed in the period from 2007 to 2009. During this period, the number of employed specialist palliative medicine physicians declined by an annual average of 1.7% (Table 7.9).

Between 2007 and 2009, the number of male specialist palliative medicine physicians decreased by an annual average of 4.1%, while female specialist palliative medicine physicians increased by an annual average of 0.5%. However, for the age group 55 to 64 years, the number of male specialist palliative medicine physicians increased by an annual average of 5.4%, while the number of female specialist palliative medicine physicians in the same age group increased by an annual average of 2.7%. The proportion of specialist palliative medicine physicians who were female increased from 51.1% in 2007 to 53.5% in 2009 (Table 7.9).

The average hours worked by specialist palliative medicine physicians per week has declined by an annual average of 3.9% over the past 3 years (Table 7.10), with the number of hours worked per week decreasing for both males and females by annual averages of 3.8% and 3.4%, respectively.

The supply of specialist palliative medicine physicians, measured as FTE per 100,000 population, increased in some, but not all, jurisdictions in 2009. Queensland had the highest the rate of FTE specialist palliative medicine physicians of all the jurisdictions at 1.5 FTE per 100,000 population (Table 7.11).

## Palliative care nurses

In this report, a palliative care nurse is defined based on a self-identified principal area of nursing activity, rather than the qualification of the nurse. An *employed* registered or enrolled nurse with a principal area of activity in their main nursing job of palliative care is considered to be a palliative care nurse.

### **Box 7.2: AIHW Nursing and Midwifery Labour Force Survey**

Information on the palliative care nursing workforce is derived from responses to the AIHW Nursing and Midwifery Labour Force Survey, with these responses weighted to available nursing registration data from each state and territory. As described in Appendix B, this is a survey of all enrolled and registered nurses in Australia conducted by the state and territory departments of health, in conjunction with nursing registration boards and the AIHW. The survey collects information on the demographic characteristics of nurses, the hours they worked, their qualifications, their place of work and their main area of nursing activity in the week before the survey. Estimates for some jurisdictions should be interpreted with caution due to relatively low response rates to the survey (refer to Appendix B for further information).

In this section of the chapter, some comparisons are made between employed palliative care nurses and all employed nurses. Detailed data on the total nursing labour force are available from *Nursing and midwifery labour force 2009* (AIHW 2011d).

### **Characteristics of the palliative care nursing workforce**

Of the almost 277,000 nurses employed in Australian in 2009, about 1 in 50 (5,173; 1.9%) worked principally in the area of palliative care nursing. The usual minimum education requirements for registration as a nurse are a 3-year degree or equivalent when studied full-time. Enrolled nurses, whose minimum educational requirement is a 1-year diploma or equivalent, usually work under the direction of registered nurses to provide basic care. In 2009, 71.0% of nurses working principally in palliative care and 81.3% of all employed nurses in Australia were registered nurses, with the remainder being enrolled nurses (AIHW 2011d).

Nurses working in palliative care are slightly older on average when compared with nurses in the general workforce (AIHW 2011d). The average age of employed palliative care nurses in 2009 was 47.4 years (Table 7.13), compared with 44.3 years for all employed nurses (AIHW 2011d). Male nurses working in palliative care nursing in 2009 were slightly younger, on average, than their female counterparts (46.1 years compared with 47.5 years).

In general, nursing is a female-dominated profession, with only about 1 in 10 (9.6%) of all nurses employed in Australian in 2009 being male (AIHW 2011d). Male nurses made up about 1 in 20 (5.8%) of employed palliative care nurses in 2009 (Table 7.13).

**Table 7.13: Employed palliative care nurses, demographic characteristics, 2007–2009**

	2007	2008	2009	2009 (per cent)	Average annual change (per cent)
Registered nurses	3,796	3,723	3,672	71.0	–1.7
Enrolled nurses	1,636	1,509	1,501	29.0	–4.2
<b>Sex</b>					
Males	294	261	298	5.8	0.8
Females	5,138	4,971	4,875	94.2	–2.6
<b>Sex and age group</b>					
<i>Males</i>					
Less than 25 years	4	4	11	0.2	60.4
25–34 years	42	20	25	0.5	–23.7
35–44 years	97	76	92	1.8	–2.8
45–54 years	104	100	102	2.0	–1.1
55–64 years	45	57	61	1.2	17.1
65 years and over	n.p.	n.p.	n.p.	n.p.	n.p.
<i>Females</i>					
Less than 25 years	305	205	144	2.8	–31.3
25–34 years	682	517	583	11.3	–7.5
35–44 years	1,048	1,075	971	18.8	–3.7
45–54 years	1,762	1,801	1,773	34.3	0.3
55–64 years	1,146	1,215	1,242	24.0	4.1
65 years and over	195	158	161	3.1	–9.2
<b>Total<sup>(a)</sup></b>	<b>5,432</b>	<b>5,232</b>	<b>5,173</b>	<b>100.0</b>	<b>–2.4</b>
<b>Average age (years)</b>					
Males	44.4	46.8	46.1	..	1.9
Females	46.2	47.1	47.5	..	1.4
<i>All</i>	46.1	47.1	47.4	..	1.4
<b>All employed nurses</b>	<b>263,331</b>	<b>269,909</b>	<b>276,751</b>	..	<b>2.5</b>

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

Source: AIHW Nursing and Midwifery Labour Force Surveys, 2007, 2008 and 2009.

Palliative care nurses worked an average of 33.0 hours per week in 2009 (Table 7.14). The hours worked per week were, on average, lower for females than males (32.6 hours compared with 38.7 hours). There was little difference between registered nurses and enrolled nurses (33.0 hours compared with 32.9 hours).

**Table 7.14: Employed palliative care nurses, average hours worked per week, by sex, 2007–2009**

	2007	2008	2009	Average annual change (per cent)
Registered nurses	33.5	33.1	33.0	-0.7
Enrolled nurses	32.2	33.4	32.9	1.1
<b>Sex</b>				
Males	36.2	38.3	38.7	3.4
Females	32.9	32.9	32.6	-0.5
<b>Total</b>	<b>33.1</b>	<b>33.2</b>	<b>33.0</b>	<b>-0.2</b>

Sources: AIHW Nursing and Midwifery Labour Force Survey, 2007, 2008, 2009.

Nurses working in palliative care areas are not evenly distributed among the states and territories or the regions of Australia. In 2009, there were 20.5 FTE palliative care nurses per 100,000 population in Australia, with Tasmania and Victoria reporting the highest rates of 31.0 and 30.3 FTE per 100,000 population, respectively (Table 7.15).

**Table 7.15: Employed palliative care nurses, average hours worked per week, and FTE number and FTE per 100,000 population<sup>(a)</sup>, states and territories, 2009**

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Number	1,383	1,962	401	583	565	176	60	43	5,173
Average hours worked per week	34.1	32.0	33.2	32.6	32.4	33.8	36.9	37.0	33.0
FTE number	1,240.9	1,652.3	350.8	500.3	481.8	156.2	58.2	42.1	4,492.8
FTE per 100,000 population	17.4	30.3	7.9	22.3	29.7	31.0	16.5	18.6	20.5
<b>All nurses</b>									
FTE per 100,000 population	1,005.0	1,166.9	1,043.4	1,008.0	1,468.8	1,279.7	1,167.9	1,800.1	1,104.8

(a) Crude rate is based on the preliminary Australian estimated resident population as at 31 December 2009 and is expressed per 100,000 populations (see Appendix C).

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

Source: AIHW Nursing and Midwifery Labour Force Survey, 2009.

Information on the supply of palliative care nurses by remoteness area (derived from the location of the respondent's main nursing job as reported in the survey) is provided in Table 7.16. The figures are underestimates for each individual region as nurses who did not provide information on the location of their main job could not be allocated to a region. The figure for the total FTE per 100,000 population is calculated based on all employed nurses with a known region.

For nurses who reported information on the location of their main job, the number of FTE palliative care nurses per 100,000 population is highest in *Inner regional* areas (26.1 FTE per 100,000 population in 2009) and in *Outer regional* areas (21.2 FTE per 100,000 population). *Major cities*, *Remote* and *Very remote* regions had lower rates than the national rate of 20.5 FTE per 100,000 population (16.1 and 11.8 FTE per 100,000 population, respectively for palliative care nurses) (Table 7.16).

**Table 7.16: Employed palliative care nurses, average hours worked per week, and FTE and FTE per 100,000 population, by remoteness area<sup>(a)</sup>, 2009**

Remoteness area of main job <sup>(a)</sup>	Palliative care nurses				All nurses
	Number	Average hours worked per week	FTE number	FTE per 100,000 population <sup>(b)</sup>	FTE per 100,000 population <sup>(b)</sup>
Major cities	2,786	33.1	2,427	16.1	996.6
Inner regional	1,312	32.7	1,129	26.1	1,140.6
Outer regional	504	32.9	437	21.2	1,094.8
Remote and very remote	67	33.3	59	11.8	1,215.9
Not reported	505	32.3	429	..	..
<b>Total<sup>(c)</sup></b>	<b>5,173</b>	<b>33.0</b>	<b>4,493</b>	<b>20.5</b>	<b>1,104.8</b>

(a) Remoteness area is derived from the postcode of the respondent's location of main job. These data should be treated with caution due to the large number of *Not reported* values for remoteness area, relative to the number in *Outer regional* and *Remote and very remote* areas.

(b) Crude rate is based on the preliminary Australian estimated resident population as at 31 December 2009 and is expressed per 100,000 populations (see Appendix C).

(c) 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: AIHW Nursing and Midwifery Labour Force Survey, 2009.

## Changes in the palliative care nursing workforce

The size and characteristics of the palliative care nursing workforce changed in the period from 2007 to 2009. The number of FTE nurses working in palliative care decreased by an annual average of 2.4% (Table 7.13) compared with a 2.5% increase for all employed nurses in Australia (Tables 7.13).

Demographic characteristics of the palliative care nursing workforce also changed over this time. While the number of males and females in this workforce remained relatively similar from 2007 to 2009, there was an average annual increase of 0.8% for male nurses and a 2.6% decrease for females (Table 7.13). The number of palliative care nurses who were registered nurses slightly decreased over the same period, with an annual decrease of 1.7% for registered nurses compared with a decrease of 4.2% for enrolled nurses (Table 7.13).

As with the general nursing population (AIHW 2011d), the palliative care nursing workforce is ageing, with the average age increasing from 46.1 years in 2007 to 47.4 years in 2009 (Table 7.13). This reflects a 1.4% average annual increase in the average age of palliative care nurses since 2007. The proportion of all palliative care nurses aged 55 years and over also increased from 24.7% in 2007 to 27.1% in 2009.

While there was a small decrease in the average hours that employed palliative care nurses worked per week from 2007 to 2009 (Table 7.14), the decrease in the number of palliative care nurses resulted in decreased supply over the same period (from 22.5 FTE per 100,000 population in 2007 to 20.5 in 2009) (Table 7.17).

**Table 7.17: Employed palliative care nurses, FTE number and FTE per 100,000 population, 2007–2009**

	2007	2008	2009	Average annual change (per cent)
FTE Registered nurses	3,346.8	3,242.6	3,188.8	–2.4
FTE Enrolled nurses	1,386.0	1,326.3	1,300.0	–3.2
<b>Total FTE number<sup>(a)</sup></b>	<b>4,731.6</b>	<b>4,570.8</b>	<b>4,492.8</b>	<b>–2.6</b>
FTE per 100,000 population <sup>(b)</sup>	22.5	21.3	20.5	–4.5

(a) Numbers may not sum to the total due to the estimation process and rounding.

(b) Crude rate is based on the preliminary Australian estimated resident population as at 31 December 2009 and is expressed per 100,000 populations (see Appendix C).

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

Sources: AIHW Nursing and Midwifery Labour Force Surveys, 2007, 2008, 2009.

There is inter-jurisdictional variability in estimates of FTE palliative care nurses and FTE per 100,000 population in the period from 2007 to 2009 (Table 7.18). As outlined in Appendix B, at least part of this variation may be due to changes in the survey methodology and variations in response rates, and thus jurisdictional differences should be interpreted with caution.

**Table 7.18: Employed palliative care nurses, FTE number and FTE per 100,000 population, states and territories, 2007–2009**

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
<b>FTE number</b>									
2007	1,188.4	1,531.8	818.8	446.2	498.1	149.4	61.1	32.9	4,731.6
2008	1,262.3	1,350.8	727.0	445.0	511.1	154.0	67.7	47.0	4,570.8
2009	1,240.9	1,652.3	350.8	500.3	481.8	156.2	58.2	42.1	4,492.8
<b>Average annual change (per cent)</b>	<b>2.2</b>	<b>3.9</b>	<b>–34.6</b>	<b>5.9</b>	<b>–1.6</b>	<b>2.3</b>	<b>–2.4</b>	<b>13.2</b>	<b>–2.6</b>
<b>FTE per 100,000 population<sup>(a)</sup></b>									
2007	17.2	29.3	19.5	21.1	31.4	30.3	17.9	15.3	22.5
2008	18.0	25.4	16.9	20.4	31.9	30.9	19.6	21.3	21.3
2009	17.4	30.3	7.9	22.3	29.7	31.0	16.5	18.6	20.5
<b>Average annual change (per cent)</b>	<b>0.6</b>	<b>1.7</b>	<b>–36.3</b>	<b>2.7</b>	<b>–2.8</b>	<b>1.2</b>	<b>–4.0</b>	<b>10.3</b>	<b>–4.5</b>

(a) Crude rate is based on the preliminary Australian estimated resident population as at 31 December 2009 and is expressed per 100,000 populations (see Appendix C).

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

Source: AIHW Nursing and Midwifery Labour Force Surveys, 2007, 2008, 2009.

# 8 Palliative Care Outcomes

## 8.1 Introduction

The Palliative Care Outcomes Collaboration (PCOC) was established in mid-2005 and is funded under the National Palliative Care Program supported by the Australian Government Department of Health and Ageing. The goal of the PCOC is to utilise standardised validated clinical assessment tools to benchmark and measure outcomes in palliative care and assist palliative care service providers to improve practice and meet the Palliative Care Australia (PCA) *Standards for Providing Quality Palliative Care*. Participation by palliative care services in PCOC is voluntary. However, PCOC estimates that over three-quarters of patients seen by specialist palliative care services are included in the collection.

## 8.2 The PCOC Data set

The current PCOC data set (Version 2) was developed following consultation with palliative care services and approval by PCOC's Scientific and Clinical Advisory Committee (SCAC). This data collection was introduced from 1 July 2007.

The items included in the current PCOC data set serve the dual purpose of:

- Defining a common clinical language to allow communication between palliative care providers.
- 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 107 specialist palliative care services reported to PCOC in 2011, which included data for a total of 27,201 patients accessing specialist palliative care services.

The information presented in this chapter refers to palliative care service data reported to PCOC for the 1 January to 31 December 2011 reporting period. The three levels of PCOC data items are presented here, including *patient*, *episode* 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 *community/ambulatory* care. Inpatient episodes of care are those for which the *patient* was admitted for an overnight stay. This includes those patients who are admitted and die on the day of their admission. Ambulatory/community patients refer to those patients who receive palliative care either in their home, a residential aged care facility or an outpatient clinic.

## Key concepts

*Patient level* data relate to patient demographics.

*Episode level* data items provide information relating to 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 in describing the clinical condition of a patient which in turn contributes to a patient's care plan. These assessment tools include: 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.

PCOC provides analysis of each service's data and compares this to the national average. The items at the phase level are used to quantify patient outcomes and are the focus of the PCOC Benchmarks.

A *patient* is defined as a person for whom a palliative care service accepts responsibility for assessment and/or treatment as evidenced by the existence of a medical record (PCOC V2 Data Definitions and Guidelines) (PCOC 2009). Family/carers are included in this definition if interventions relating to them are recorded in the patient medical record. It should be noted that the number of patients reported to PCOC refers to patients who may receive services both within the *inpatient* and *community/ambulatory* 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.

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.

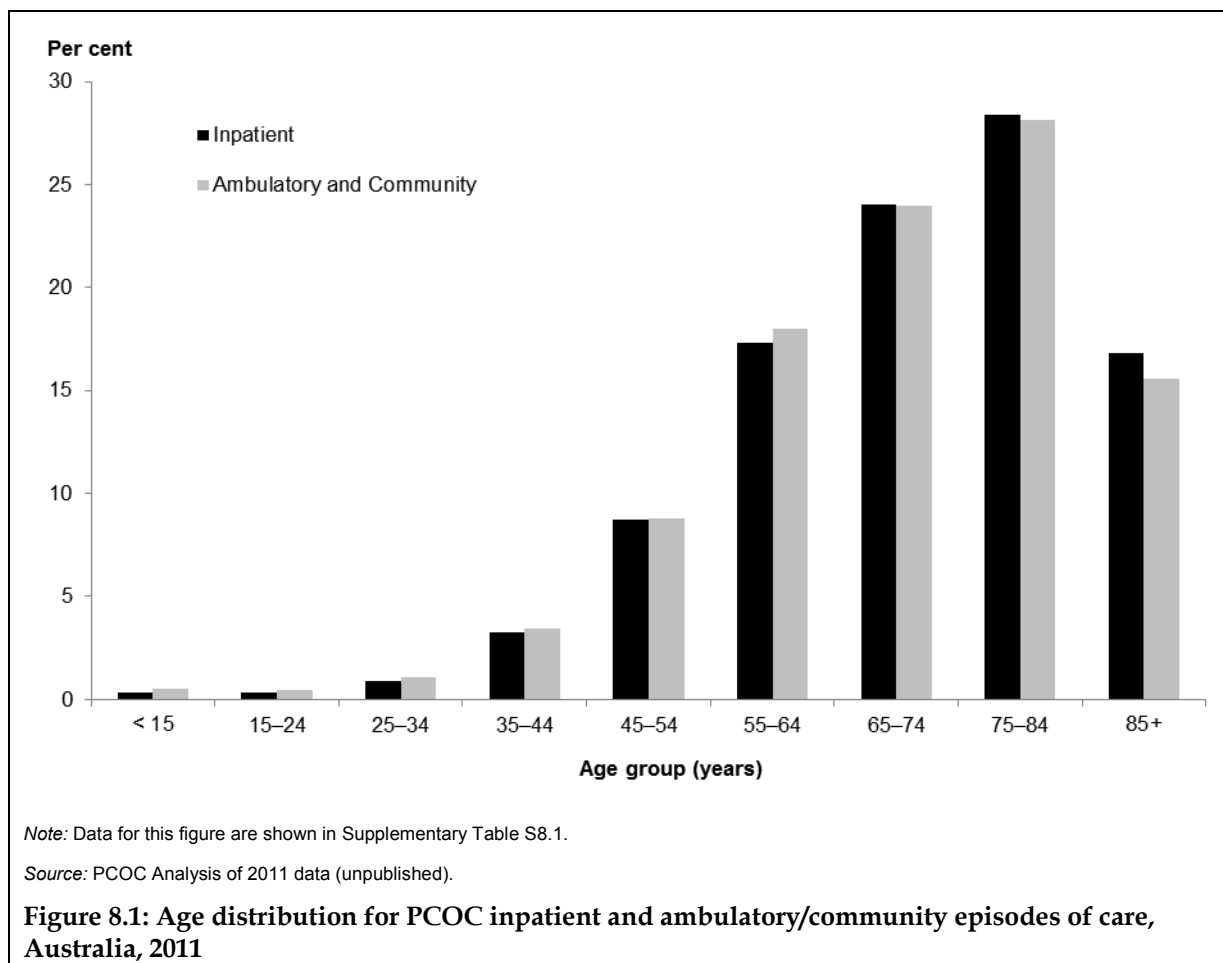
## 8.3 Patient characteristics

### Age and sex

In 2011 there were 35,389 episodes of care reported to PCOC, of which more than half (59.5%; 21,058) were inpatient episodes. The provision of palliative care by age group for 2011 is shown in Figure 8.1. People aged 65 to 84 years accounted for about half of all episodes (52.3%), while those aged 45 to 64 years accounted for 1 in 4 (26.3%), and those aged over 85 years about 1 in 6 (16.3%). People aged 25 to 44 years accounted for almost 1 in 20 (4.3%), while those aged 24 years or younger made up less than 1 in 100 (0.8%).

The average age for all patients reported to PCOC during this period was 70.4 years with a median age of 72.0 years for all services (the median is the middle value in a set of ranked observations, see Glossary). There were 19,217 males reported accounting for 54.3% of episodes and 16,143 females (45.6%).





## 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 2011, English was the most frequently reported main language spoken at home (90.9% of episodes). This was followed by Italian (2.2%), Greek (1.3%) and Cantonese (0.7%) (Table 8.1). Similar patterns were seen in the 2006 Census (ABS 2007a) for the general population where 78.5% of the Australian population were recorded as speaking English, followed by Italian (1.6), Greek (1.3%) and Cantonese (1.2%).

The main country of birth was Australia for 66.2% of PCOC episodes of palliative care. This was followed by England (7.3%), Italy (4.1%) and Greece (2.0%) (Table 8.2). For the general population, a slightly different distribution is evident, with Australia and England being the top two countries of birth (70.9% and 4.3%, respectively) followed by New Zealand (2.0%) and China (1.0) (ABS 2007a).

**Table 8.1: PCOC palliative care episodes, by top four languages spoken, 2011**

Palliative care episodes			General population <sup>(a)</sup>		
Main language	Number	Per cent	Main language	Number	Per cent of total persons 2006 Census
English	29,203	90.9	English	15,581,333	78.5
Italian	701	2.2	Italian	316,890	1.6
Greek	408	1.3	Greek	252,220	1.3
Cantonese	217	0.7	Cantonese	244,553	1.2
All other languages	1,608	5.0	..	..	..
<b>Total<sup>(b)(c)</sup></b>	<b>35,389</b>	<b>100.0</b>	..	..	..

(a) Data refers to main responses for 'Language spoken at home' Australia 2006 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 was missing and/or not reported.

Source: PCOC analysis of 2011 data (unpublished) and ABS 2007a.

**Table 8.2: PCOC palliative care episodes, by country of birth, 2011**

Palliative care episodes			General population		
Country of birth	Number	Per cent	Country of birth	Number	Per cent of total persons 2006 Census
Australia	21,847	66.2	Australia	14,072,944	70.9
England	2,406	7.3	England	856,939	4.3
Italy	1,355	4.1	New Zealand	389,468	2.0
Greece	669	2.0	China <sup>(a)</sup>	206,591	1.0
All other countries	6,733	20.4	..	..	..
<b>Total<sup>(b)(c)</sup></b>	<b>35,389</b>	<b>100.0</b>	..	..	..

(a) Excludes Special Administrative Regions (SAR's) and Taiwan Province.

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

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

Source: PCOC Analysis of 2011 data (unpublished) and ABS 2007a.

## Diagnosis

Table 8.3 shows that most palliative care episodes (84.7%) were characterised by a malignant diagnosis while 15.3% had non-malignant diagnoses during 2011 (Table 8.3). The most frequently recorded diagnoses were neoplasms of the lung (16.5%), colorectal cancer (9.2%) and breast cancer (6.7%) (Table 8.4).

**Table 8.3: PCOC palliative care episodes, by cancer diagnosis, 2011**

<b>Diagnosis</b>	<b>Number</b>	<b>Per cent</b>
Malignant	29,340	84.7
Non-malignant	5,292	15.3
<b>Total<sup>(a)(b)</sup></b>	<b>35,389</b>	<b>100.0</b>

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

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

Source: PCOC analysis of 2011 data (unpublished).

**Table 8.4: PCOC palliative care episodes, by three most common cancer diagnoses, 2011**

<b>Diagnosis</b>	<b>Number</b>	<b>Per cent<sup>(a)</sup></b>
Neoplasm of the lung	5,843	16.5
Colorectal cancer	3,262	9.2
Breast cancer	2,365	6.7
<b>Total</b>	<b>35,389</b>	<b>. .</b>

(a) The percentage shown was calculated using total number of episodes as the denominator.

Source: PCOC analysis of 2011 data (unpublished).

## **Socio-economic status**

This section presents information on PCOC palliative care episodes based on the socio-economic status of the usual residence of the patient. Socio-economic status is generally associated with access to material resources, educational opportunities and health status (AIHW 2010a). The ABS Socio-Economic Indexes for Areas (SEIFA) measures different aspects of socio-economic conditions by geographic areas using a range of indexes (ABS 2012). This section uses the ABS Index of Relative Socio-economic Advantage and Disadvantage (IRSAD) to indicate socio-economic status.

From January to December 2011, those people living in areas classified as having the lowest socio-economic status (group 1) accounted for about 1 in 10 of PCOC palliative care episodes (9.5%) (Table 8.5). The highest proportion of episodes, almost one-third, was seen for those patients living in the highest socio-economic status area (31.7%). There was little difference in proportions between inpatient and ambulatory/community settings.

**Table 8.5: PCOC palliative care episodes by socio-economic status, 2011**

SEIFA quintile	Inpatient		Ambulatory/Community		Total	
	Number	Per cent	Number	Per cent	Number	Per cent
1 (lowest)	1,809	9.2	1,373	9.8	3,182	9.5
2	2,508	12.7	1,798	12.9	4,306	12.8
3	3,877	19.7	2,376	17.0	6,253	18.6
4	5,336	27.1	3,912	28.0	9,248	27.5
5 (highest)	6,144	31.2	4,530	32.4	10,674	31.7
<b>Total<sup>(a)(b)</sup></b>	<b>21,058</b>	<b>100.0</b>	<b>14,331</b>	<b>100.0</b>	<b>35,389</b>	<b>100.0</b>

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

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

Source: PCOC Analysis of 2011 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 2011. Closed episodes are those that end because:

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

The average number of days for each episode of care in the inpatient setting was 12.4 days, with a median of 7 days during 2011. The difference between the average and the median number is noteworthy, reflecting a 'skewed' distribution for inpatient palliative care episodes on one side of the average. This finding was also seen for the ambulatory/community setting with the average episode length in ambulatory/community settings being nearly double the episode length of inpatient palliative care; an average number of 34.9 days and a median of 19 days.

Table 8.6 shows the average number of elapsed days for inpatient and ambulatory/community care settings during 2011. 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, 2011**

	Inpatient	Ambulatory/Community
Average number of days	12.4	34.9
Median number of days	7	19

Source: PCOC analysis of 2011 data (unpublished).

Nearly three-quarters (73.0%) of inpatient episodes lasted for up to 14 days, of which 21.8% were 1–2 days and 21.7% were 8–14 days (Table 8.7). This pattern differed for the ambulatory/community setting, where the episode length increased as the days spent in care increased; nearly 60% of palliative care episodes were 15 days or longer (Table 8.7).

**Table 8.7: PCOC, elapsed days in palliative care, closed episodes, inpatient and ambulatory/community care setting, 2011**

Elapsed Days	Inpatient		Ambulatory/Community		Total	
	Number	Per cent	Number	Per cent	Number	Per cent
1–2 days	4,550	21.8	2,138	15.6	6,688	19.4
3–4 days	2,780	13.3	723	5.3	3,503	10.1
5–7 days	3,385	16.2	996	7.3	4,381	12.7
8–14 days	4,526	21.7	1,712	12.5	6,238	18.0
15–21 days	2,215	10.6	1,207	8.8	3,422	9.9
22–30 days	1,432	6.9	1,200	8.8	2,632	7.6
31–60 days	1,497	7.2	2,205	16.1	3,702	10.7
61–90 days	299	1.4	1,200	8.8	1,499	4.3
> 90 days	164	0.8	2,333	17.0	2,497	7.2
<b>Total</b>	<b>20,848</b>	<b>100.0</b>	<b>13,714</b>	<b>100.0</b>	<b>34,562</b>	<b>100.0</b>

Source: PCOC analysis of 2011 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, the patient may transition back and forth between phases during an episode and there may be more than one phase of care within the episodes.

### Key concepts

The five *palliative care phases* are:

- 1. Stable:** 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, the family/carer situation is relatively stable and no new issues are apparent.
- 2. Unstable:** An urgent change in the plan of care or emergency treatment is required due to at least one of the following:
  - the patient experiences a new problem that was not anticipated in the existing plan of care
  - the patient experiences a rapid increase in the severity of a current problem
  - the patient's family/carers circumstances change suddenly impacting on patient care.

(continued)

3. **Deteriorating:** The care plan is addressing anticipated needs but requires periodic review because the patient's overall functional status is declining and the patient experiences a gradual worsening of existing problem and/or experiences a new but anticipated problem. The family/carers experience gradual worsening distress that impacts on the patient's care.
4. **Terminal:** Death is likely within days.
5. **Bereaved/ post death support:** The patient has died. Bereavement support provided to family/carers is documented in the deceased patient's clinical record.

Table 8.8 presents information on the number and type of palliative care phases. There were a total of 79,253 PCOC palliative care phases reported in 2011, with more than two-thirds (67.7%) occurring in inpatient palliative care. Of these, just over one-quarter (27.7%) were in an unstable phase. Of the 25,595 phases reported in the ambulatory and community care setting, 37.4% were stable, followed by deteriorating (36.1%) and unstable (16.8%).

The average phase length (elapsed days) was highest for the stable phase at 6.9 days in the inpatient setting, while in the ambulatory and community care setting the stable phase had the highest average number of elapsed days at 22.6 days, followed by deteriorating (15.8 days) (Table 8.9).

**Table 8.8: PCOC, phase counts by palliative care phase and setting, 2011**

Palliative care phase	Inpatient		Ambulatory/Community		Total	
	Number	Per cent	Number	Per cent	Number	Per cent
Stable	14,095	26.3	9,584	37.4	23,679	29.9
Unstable	14,863	27.7	4,296	16.8	19,159	24.2
Deteriorating	13,683	25.5	9,247	36.1	22,930	28.9
Terminal	8,318	15.5	2,244	8.8	10,562	13.3
Bereaved	2,699	5.0	224	0.9	2,923	3.7
<b>Total</b>	<b>53,658</b>	<b>67.7</b>	<b>25,595</b>	<b>32.3</b>	<b>79,253</b>	<b>100.0</b>

Source: PCOC analysis of 2011 data (unpublished).

**Table 8.9: PCOC, average phase length (elapsed days) by palliative care phase type and setting, 2011**

Phase	Inpatient days	Ambulatory/Community days
Stable	6.9	22.6
Unstable	3.9	8.6
Deteriorating	5.4	15.8
Terminal	2.2	2.9
Bereaved	1.1	2.2

Source: PCOC analysis of 2011 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 spent in an unstable phase (defined as the development of a new unexpected problem or a rapid increase in the severity of existing problems, either of which requires an urgent change in management or emergency treatment).
3. Change in pain.

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

Nearly half (43.8%) of all PCOC contributing services met benchmark 1, where 90% of patients were contacted by a member of the clinical team within 2 days of receipt of referral (Table 8.10). Of the 35,389 palliative care episodes in 2011, 81.1% met this benchmark.

In relation to benchmark 2.3, the median length of all unstable phases was 2 days, with more than half (53.3%) of services meeting this benchmark (Table 8.10). There was a slight difference between the inpatient and ambulatory/community setting with the median being 2 days in the inpatient setting and 3 days in the ambulatory/community setting (Table S8.2).

Around 14–15% of services met benchmarks 3.1 and 3.3 (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), while 41.2% and 31.0% of services met benchmarks 3.2 and 3.4, respectively (60% of patients in moderate/severe pain have reduced to absent/mild pain at phase end) (Table 8.1).

### **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 or 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.

There are three benchmarks related to this measure and each is reflective of whether the patient is assessed in the unstable phase at the start of the episode (that is *the first phase in their episode* of care) or assessed in the unstable phase following the first phase of their episode (that is *not the first phase in their episode* of care). It was agreed that the median time for a patient to remain in the unstable should be 2 days or less regardless of when it occurs during the episode.

#### **Outcome measure 3: Change in pain**

Pain management is acknowledged as the 'core business' for palliative care services and so 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 include:

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, 2011**

Outcome Measure	Benchmark scores
<b>1: Time from referral to first contact for the episode</b>	
<b>Benchmark 1.1:</b> 90% of patients are contacted by a member of the clinical team on the day of, or the day after referral	<ul style="list-style-type: none"> <li>• 43.8% of services met benchmark (Inpatient + Ambulatory/Community combined)</li> <li>• 81.1% of episodes met benchmark (Inpatient + Ambulatory/Community combined)</li> </ul>
<b>2: Time in Unstable Phase</b>	
<b>Benchmark 2.1:</b> 85% in their first phase remain unstable for less than 7 days	<ul style="list-style-type: none"> <li>• 45.3% of services meet benchmark</li> <li>• 78.5% of patient phases satisfied the benchmark criteria</li> </ul>
<b>Benchmark 2.2:</b> 90% in a subsequent phase remain unstable for less than 7 days	<ul style="list-style-type: none"> <li>• 42.2% of services met this benchmark</li> <li>• 81.7% of patient phases satisfied the benchmark criteria</li> </ul>
<b>Benchmark 2.3:</b> the median time in the unstable phase is <b>2 days</b> or less.	<ul style="list-style-type: none"> <li>• 53.3% of services met this benchmark</li> <li>• The median length of all unstable patient phases was 2 days</li> </ul>
<b>3: Change in Pain</b>	
<b>Benchmark 3.1:</b> 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	<ul style="list-style-type: none"> <li>• 14.1% of services met this benchmark</li> <li>• 80.1% of patient phases satisfied the benchmark criteria</li> </ul>
<b>Benchmark 3.2:</b> 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	<ul style="list-style-type: none"> <li>• 41.2% of services met this benchmark</li> <li>• 52.1% of patient phases satisfied the benchmark criteria</li> </ul>
<b>Benchmark 3.3:</b> 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	<ul style="list-style-type: none"> <li>• 15.0% of services met this benchmark</li> <li>• 80.7% of patient phases satisfied the benchmark criteria</li> </ul>
<b>Benchmark 3.4:</b> 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	<ul style="list-style-type: none"> <li>• 31.0% of services met this benchmark</li> <li>• 49.9% of patient phases satisfied the benchmark criteria</li> </ul>

Source: PCOC analysis of 2011 data (unpublished).

# Supplementary tables

Table S2.1: Palliative care separations, by age and sex, all hospitals, 2009–10

Age group (years)	Number of separations			Age-specific rate <sup>(a)</sup>		
	Males	Females	Total	Males	Females	Total
0–4	72	81	153	1.0	1.2	1.1
5–9	18	12	30	0.3	0.2	0.2
10–14	27	14	41	0.4	0.2	0.3
15–19	29	21	50	0.4	0.3	0.3
20–24	40	40	80	0.5	0.5	0.5
25–29	65	92	157	0.8	1.1	1.0
30–34	105	133	238	1.4	1.8	1.6
35–39	220	328	548	2.7	4.0	3.4
40–44	420	516	936	5.5	6.7	6.1
45–49	784	907	1,691	10.1	11.4	10.7
50–54	1,376	1,397	2,773	19.1	19.0	19.1
55–59	2,058	1,741	3,799	31.6	26.2	28.9
60–64	2,804	2,117	4,921	47.2	35.5	41.3
65–69	3,500	2,470	5,970	79.5	55.0	67.2
70–74	4,179	2,724	6,903	123.9	75.5	98.9
75–79	4,807	3,367	8,174	188.0	113.9	148.3
80–84	4,969	3,874	8,843	267.1	155.5	203.2
85+	4,855	5,821	10,676	364.9	229.3	276.0
<b>Total<sup>(a)</sup></b>	<b>30,328</b>	<b>25,655</b>	<b>55,983</b>	<b>28.0</b>	<b>19.4</b>	<b>23.2</b>

(a) Age-specific rates show the number of palliative care separations per 10,000 population in that age group at 31 December 2009. Rates shown in the 'Total' row are age-standardised to the Australian population as at 30 June 2001 (see Appendix C).

Source: National Hospital Morbidity Database, AIHW.

**Table S2.2: Palliative care patients among those who died as an admitted patient, public and private hospitals, 2000-01 to 2009-10**

	Admitted patient deaths (number)		Per cent palliative care patients <sup>(a)</sup>
	Palliative care patients <sup>(a)</sup>	Total admitted patient deaths	
2000-01	16,096	69,161	23.3
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

(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: National Hospital Morbidity Database, AIHW.

**Table S4.1: MBS-subsidised palliative medicine specialist services, by patient demographic characteristics and number of services received, 2010–11**

Patient demographics	Number of patients	Per cent of patients	Rate <sup>(a)</sup>	Number of services	Per cent of services <sup>(a)</sup>	Rate <sup>(b)</sup>	Services per patient
<b>Age group</b>							
Less than 15 years	29	0.4	0.7	n.p.	n.p.	n.p.	n.p.
15–24 years	40	0.5	1.3	n.p.	n.p.	n.p.	n.p.
25–34 years	60	0.8	1.9	484	1.1	15.0	8.1
35–44 years	233	3.0	7.3	1,345	3.1	42.4	5.8
45–54 years	650	8.4	21.3	3,884	9.0	127.2	6.0
55–64 years	1,444	18.7	56.2	8,233	19.2	320.7	5.7
65+ years	5,267	68.2	172.4	28,741	66.9	940.6	5.5
<b>Total</b>	<b>7,723</b>	<b>100.0</b>	<b>34.4</b>	<b>42,934</b>	<b>100.0</b>	<b>191.0</b>	<b>5.6</b>
<b>Sex</b>							
Male	3,784	49.0	33.5	22,070	51.4	195.5	5.8
Female	3,939	51.0	35.2	20,864	48.6	186.5	5.3
<b>Total</b>	<b>7,723</b>	<b>100.0</b>	<b>34.4</b>	<b>42,934</b>	<b>100.0</b>	<b>191.0</b>	<b>5.6</b>

(a) Percentages may not add to total due to rounding.

(b) Rates were directly age-standardised, with the exception of age, which is a crude rate, as detailed in Appendix C. Crude rate is based on the preliminary Australian estimated resident population as at 31 December 2010 and is expressed per 100,000 population (see Appendix C).

Source: MBS data (DoHA).

Table S4.2: MBS-subsidised palliative medicine specialist services, by MBS item, states and territories<sup>(a)</sup>, 2010–11

MBS item	MBS item no.	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
<b>Palliative Medicine Attendances</b>										
Attendance in a hospital or surgery, initial visit	3005	2,212	n.p.	n.p.	n.p.	n.p.	148	n.p.	n.p.	6,395
Attendance in a hospital or surgery, subsequent visit	3010	10,895	1,998	5,211	7,721	2,483	n.p.	n.p.	n.p.	30,055
Attendance in a hospital or surgery, subsequent visit , minor	3014	345	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	0	1,326
Initial home visit	3018	580	n.p.	n.p.	n.p.	172	0	n.p.	0	n.p.
Subsequent home visit	3023	773	n.p.	n.p.	n.p.	280	0	0	0	1,508
Subsequent home visit , minor	3028	0	n.p.	n.p.	0	0	0	0	0	n.p.
<b>Palliative Medicine Case Conferences</b>										
Organise and coordinate a community case conference 15–<30 minutes	3032	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	1,117
Organise and coordinate a community case conference 30–<45 minutes	3040	n.p.	0	0	0	n.p.	0	0	0	7
Organise and coordinate a community case conference >=45 minutes	3044	n.p.	0	0	0	n.p.	0	0	0	7
Participate in a community case conference 15–<30 minutes	3051	n.p.	0	n.p.	n.p.	0	0	n.p.	n.p.	791
Participate in a community case conference 30–<45 minutes	3055	n.p.	0	n.p.	n.p.	n.p.	0	0	0	n.p.
Participate in a community case conference >=45 minutes	3062	0	0	0	n.p.	n.p.	n.p.	0	0	n.p.
Organise and coordinate a discharge case conference 15–<30 minutes	3069	n.p.	0	n.p.	n.p.	n.p.	n.p.	0	0	n.p.
Organise and coordinate a discharge case conference 30–<45 minutes	3074	n.p.	0	n.p.	n.p.	0	0	0	0	n.p.
Organise and coordinate a discharge case conference >=45 minutes	3078	n.p.	0	n.p.	154	n.p.	0	0	0	191
Participate in a discharge case conference 15–<30 minutes	3083	n.p.	0	0	0	0	0	0	0	37
Participate in a discharge case conference 30–<45 minutes	3088	n.p.	0	n.p.	n.p.	0	0	0	0	n.p.
Participate in a discharge case conference >=45 minutes	3093	0	0	n.p.	0	0	0	0	0	n.p.
<b>Total items</b>		<b>16,707</b>	<b>2,776</b>	<b>7,645</b>	<b>9,778</b>	<b>3,957</b>	<b>n.p.</b>	<b>n.p.</b>	<b>24</b>	<b>42,934</b>

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

Source: MBS data (Medicare Australia 2011 and DoHA).

Table S4.3: MBS-subsidised palliative medicine specialist services, by MBS item, 2006–07 to 2010–11

MBS item	MBS item no.	2006–07	2007–08	2008–09	2009–10	2010–11	Average annual change (per cent)
<b>Palliative Medicine Attendances</b>							
Attendance in a hospital or surgery, initial visit	3005	2,773	3,605	4,981	5,806	6,395	23.2
Attendance in a hospital or surgery, subsequent visit	3010	13,267	16,564	23,079	28,066	30,055	22.7
Attendance in a hospital or surgery, subsequent visit , minor	3014	1,267	1,135	818	1,439	1,326	1.1
Initial home visit	3018	n.p.	n.p.	n.p.	1,221	n.p.	20.3
Subsequent home visit	3023	1,666	2,441	1,945	1,915	1,508	-2.5
Subsequent home visit , minor	3028	n.p.	n.p.	n.p.	34	n.p.	10.7
<b>Palliative Medicine Case Conferences</b>							
Organise and coordinate a community case conference 15–<30 minutes	3032	n.p.	n.p.	n.p.	n.p.	1,117	n.p.
Organise and coordinate a community case conference 30–<45 minutes	3040	n.p.	n.p.	n.p.	n.p.	7	n.p.
Organise and coordinate a community case conference >=45 minutes	3044	n.p.	n.p.	n.p.	n.p.	7	n.p.
Participate in a community case conference 15–<30 minutes	3051	n.p.	n.p.	n.p.	n.p.	791	n.p.
Participate in a community case conference 30–<45 minutes	3055	n.p.	n.p.	n.p.	n.p.	n.p.	36.8
Participate in a community case conference >=45 minutes	3062	n.p.	n.p.	n.p.	n.p.	n.p.	-12.0
Organise and coordinate a discharge case conference 15–<30 minutes	3069	n.p.	n.p.	85	n.p.	n.p.	247.0
Organise and coordinate a discharge case conference 30–<45 minutes	3074	20	29	60	52	n.p.	21.1
Organise and coordinate a discharge case conference >=45 minutes	3078	n.p.	67	208	229	191	109.1
Participate in a discharge case conference 15–<30 minutes	3083	n.p.	n.p.	0	n.p.	37	87.4
Participate in a discharge case conference 30–<45 minutes	3088	0	0	0	0	n.p.	..
Participate in a discharge case conference >=45 minutes	3093	0	n.p.	n.p.	0	n.p.	..
<b>Total items</b>		<b>19,554</b>	<b>25,328</b>	<b>33,066</b>	<b>40,494</b>	<b>42,934</b>	<b>21.7</b>
Rate <sup>(a)</sup>		93.7	119.3	152.8	182.8	191.0	19.5

(a) Crude rate is based on the preliminary Australian estimated resident population as at 31 December 2010 and is expressed per 100,000 population (see Appendix C).

Source: MBS data (Medicare Australia 2011 and DoHA).

**Table S5.1: Residential aged care residents, by care type, sex and age group, 2010–11**

<b>Age group and sex</b>	<b>Palliative care</b>	<b>Other care</b>	<b>Total</b>	<b>Per cent</b>
<b>Females</b>				
Less than 65 years	177	3,298	3,475	2.3
65–69 years	163	2,911	3,074	2.1
70–74 years	294	5,735	6,029	4.0
75–79 years	588	11,765	12,353	8.3
80–84 years	1,219	26,305	27,524	18.5
85 years and over	4,390	92,299	96,689	64.8
<i>Total females</i>	<i>6,831</i>	<i>142,313</i>	<i>149,144</i>	<i>100.0</i>
<b>Males</b>				
Less than 65 years	170	3,928	4,098	5.9
65–69 years	188	3,290	3,478	5.0
70–74 years	333	5,247	5,580	8.0
75–79 years	607	8,362	8,969	12.9
80–84 years	963	13,900	14,863	21.4
85 years and over	1,991	30,550	32,541	46.8
<i>Total males</i>	<i>4,252</i>	<i>65,277</i>	<i>69,529</i>	<i>100.0</i>
<b>Persons</b>				
Less than 65 years	347	7,226	7,573	3.5
65–69 years	351	6,201	6,552	3.0
70–74 years	627	10,982	11,609	5.3
75–79 years	1,195	20,127	21,322	9.8
80–84 years	2,182	40,205	42,387	19.4
85 years and over	6,381	122,849	129,230	59.1
<b>Total persons</b>	<b>11,083</b>	<b>207,590</b>	<b>218,673</b>	<b>100.0</b>
Per cent	5.1	94.9	100.0	..

Source: AIHW analysis of 2010–11 ACFI data.

**Table S5.2: Residential aged care permanent admissions, by care type, sex and age group, 2010–11**

<b>Age group and sex</b>	<b>Palliative care</b>	<b>Other care</b>	<b>Total</b>	<b>Per cent</b>
<b>Females</b>				
Less than 65 years	94	847	941	2.7
65–69 years	85	776	861	2.5
70–74 years	128	1,783	1,911	5.5
75–79 years	238	3,729	3,967	11.4
80–84 years	402	7,543	7,945	22.8
85 years and over	789	18,397	19,186	55.1
<i>Total females</i>	<i>1,736</i>	<i>33,075</i>	<i>34,811</i>	<i>100.0</i>
<b>Males</b>				
Less than 65 years	107	952	1,059	4.9
65–69 years	112	943	1,055	4.9
70–74 years	194	1,583	1,777	8.2
75–79 years	311	2,835	3,146	14.5
80–84 years	467	4,872	5,339	24.6
85 years and over	691	8,652	9,343	43.0
<i>Total males</i>	<i>1,882</i>	<i>19,837</i>	<i>21,719</i>	<i>100.0</i>
<b>Persons</b>				
Less than 65 years	201	1,799	2,000	3.5
65–69 years	197	1,719	1,916	3.4
70–74 years	322	3,366	3,688	6.5
75–79 years	549	6,564	7,113	12.6
80–84 years	869	12,415	13,284	23.5
85 years and over	1,480	27,049	28,529	50.5
<b>Total persons</b>	<b>3,618</b>	<b>52,912</b>	<b>56,530</b>	<b>100.0</b>
Per cent	6.4	93.6	100.0	..

Source: AIHW analysis of 2010–11 ACFI data.



**Table S5.3: Residential aged care residents, by care type and demographic characteristics, 2010–11**

	Palliative care		Other care	
	Number	Per cent	Number	Per cent
<b>Sex</b>				
Females	6,831	61.6	142,313	68.6
Males	4,252	38.4	65,277	31.4
<b>Indigenous status</b>				
Indigenous	63	0.6	1,434	0.7
Non-Indigenous	11,020	99.4	206,156	99.3
<b>Preferred language</b>				
English speaking	10,254	92.5	187,860	90.5
Non-English speaking	829	7.5	19,730	9.5
<b>Country of birth</b>				
Australia	8,164	73.7	149,006	71.8
Overseas	2,919	26.3	58,584	28.2
<b>Remoteness area</b>				
Major cities	6,557	59.2	143,234	69.0
Inner regional	3,209	29.0	46,952	22.6
Outer regional	1,255	11.3	15,934	7.7
Remote	55	0.5	1,147	0.6
Very remote	7	0.1	323	0.2
<b>Marital status</b>				
Widowed	5,709	51.5	109,832	52.9
Married	3,647	32.9	58,951	28.4
Single	743	6.7	18,454	8.9
Divorced	658	5.9	13,621	6.6
Separated	207	1.9	3,796	1.8
Unknown	119	1.1	2,936	1.4
<b>Total</b>	<b>11,083</b>	<b>100.0</b>	<b>207,590</b>	<b>100.0</b>

Source: AIHW analysis of 2010–11 ACFI data.

**Table S5.4: Residential aged care residents, by care type and length of stay, 2010–11**

Length of stay	Palliative care		Other care	
	Number	Per cent	Number	Per cent
0–<4 weeks	1,629	23.8	2,036	4.2
4–<8 weeks	881	12.9	2,028	4.2
8–<13 weeks	442	6.5	2,191	4.6
13–<26 weeks	520	7.6	4,214	8.8
26–<39 weeks	367	5.4	2,951	6.1
39–<52 weeks	257	3.8	2,583	5.4
1–<2 years	707	10.3	8,247	17.2
2–<3 years	535	7.8	6,217	12.9
3–<4 years	418	6.1	4,701	9.8
4–<5 years	278	4.1	3,449	7.2
5–<8 years	508	7.4	5,886	12.2
8+ years	308	4.5	3,578	7.4
<b>Total</b>	<b>6,850</b>	<b>100.0</b>	<b>48,081</b>	<b>100.0</b>

Source: AIHW analysis of 2010–11 ACFI data.

**Table S5.5: Residents who were permanent residents at some time between 1 July 2010 and 30 June 2011, by care type, with hospital leave to 30 June 2011**

	Major cities	Inner regional	Outer regional	Remote	Very remote	All regions
<b>Palliative care</b>						
NSW	701	270	51	2	0	1,024
Vic	553	218	50	2	..	823
Qld	434	118	87	6	0	645
WA	217	37	26	1	1	282
SA	174	19	26	4	0	223
Tas	..	91	48	0	0	139
ACT	59	0	..	..	..	59
NT	..	..	7	2	0	9
<b>Total</b>	<b>2,138</b>	<b>753</b>	<b>295</b>	<b>17</b>	<b>1</b>	<b>3,204</b>
<b>Other care types</b>						
NSW	15,873	4,402	1,249	52	0	21,576
Vic	10,728	2,881	668	11	..	14,288
Qld	7,526	2,484	1,165	103	35	11,313
WA	3,914	622	302	41	22	4,901
SA	4,590	440	536	39	0	5,605
Tas	..	618	173	10	2	803
ACT	685	2	..	..	..	687
NT	..	..	101	27	15	143
<b>Total</b>	<b>43,316</b>	<b>11,449</b>	<b>4,194</b>	<b>283</b>	<b>74</b>	<b>59,316</b>

Source: AIHW analysis of 2010–11 ACFI data.

**Table S6.1: Palliative care schedule items: numbers of patients and prescriptions, by age and gender, 2010–11**

Patient characteristics	Number of patients	Per cent of patients	Rate <sup>(a)</sup>	Number of prescriptions	Per cent of prescriptions	Rate <sup>(a)</sup>	Prescriptions per patient
<b>Age group</b>							
Less than 15 years	334	2.3	7.9	675	2.3	15.9	2.0
15–24 years	208	1.4	6.6	492	1.7	15.6	2.4
25–34 years	291	2.0	9.0	751	2.6	23.3	2.6
35–44 years	652	4.5	20.5	1,637	5.6	51.6	2.5
45–54 years	1,246	8.7	40.8	2,742	9.5	89.8	2.2
55–64 years	2,160	15.0	84.1	4,682	16.2	182.4	2.2
65 years and over	9,485	65.9	310.4	17,699	61.1	579.2	1.9
<b>Sex</b>							
Male	6,916	48.1	61.8	13,738	47.4	122.8	2.0
Female	7,460	51.8	66.1	14,940	51.5	132.4	2.0
<b>Total<sup>(b)</sup></b>	<b>14,393</b>	<b>100.0</b>	<b>64.0</b>	<b>28,982</b>	<b>100.0</b>	<b>128.9</b>	<b>2.0</b>

(a) Crude rate is based on the preliminary Australian estimated resident population as at 31 December 2010 and is expressed per 100,000 populations (see Appendix C).

(b) The totals include patients for which gender and/or age-group was not available and so summing the columns will not equal the total numbers.

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

Table S6.2: PBS/RPBS palliative care schedule items, by prescribing clinician, states and territories, 2010–11

Medication type	Clinician type	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Analgesics	General practitioners	964	712	744	370	252	72	60	35	3,209
	Palliative medicine	57	28	200	58	36	n.p.	n.p.	n.p.	384
	Other clinicians <sup>(a)</sup>	118	414	246	264	179	n.p.	7	n.p.	1,235
Anti-emetics and anti-nauseants	General practitioners	195	137	212	130	90	42	10	6	822
	Palliative medicine	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	7
	Other clinicians <sup>(a)</sup>	16	16	33	8	19	n.p.	n.p.	n.p.	95
Anti-epileptics	General practitioners	1,600	2,009	622	424	371	187	39	35	5,287
	Palliative medicine	21	n.p.	15	17	9	n.p.	n.p.	n.p.	69
	Other clinicians <sup>(a)</sup>	80	338	92	113	68	10	n.p.	n.p.	712
Anti-inflammatory and anti-rheumatic products	General practitioners	164	140	144	52	42	47	22	8	619
	Palliative medicine	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	9
	Other clinicians <sup>(a)</sup>	30	54	10	12	8	n.p.	21	n.p.	140
Drugs for functional gastrointestinal disorders	General practitioners	256	108	285	24	84	n.p.	n.p.	10	773
	Palliative medicine	16	n.p.	6	n.p.	11	n.p.	n.p.	n.p.	43
	Other clinicians <sup>(a)</sup>	12	31	56	18	64	n.p.	n.p.	n.p.	181
Laxatives	General practitioners	2,409	1,574	1,692	405	754	284	114	78	7,310
	Palliative medicine	29	9	14	13	11	n.p.	n.p.	n.p.	90
	Other clinicians <sup>(a)</sup>	232	254	212	98	74	13	n.p.	30	917
Psycholeptics	General practitioners	1,898	1,229	1,572	548	491	295	53	65	6,151
	Palliative medicine	19	6	10	5	5	n.p.	n.p.	n.p.	45
	Other clinicians <sup>(a)</sup>	95	114	109	74	25	7	n.p.	n.p.	430
Stomatological preparations	General practitioners	133	104	94	23	52	14	n.p.	n.p.	420
	Palliative medicine	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	3
	Other clinicians <sup>(a)</sup>	9	15	5	n.p.	n.p.	n.p.	n.p.	n.p.	31
<b>Total</b>		<b>8,355</b>	<b>7,300</b>	<b>6,378</b>	<b>2,661</b>	<b>2,649</b>	<b>1,008</b>	<b>354</b>	<b>277</b>	<b>28,982</b>

(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, 2006–07 to 2010–11**

Medication type	2006–07	2007–08	2008–09	2009–10	2010–11	Average annual change (per cent)
<b>General practitioners</b>						
Analgesics	1,068	1,298	2,188	2,490	3,209	31.7
Anti-emetics and anti-nauseants	893	874	840	715	822	-2.0
Anti-epileptics	7,320	6,302	5,837	5,512	5,287	-7.8
Anti-inflammatory and anti-rheumatic products	1,371	1,253	808	618	619	-18.0
Drugs for functional gastrointestinal disorders	855	691	770	774	773	-2.5
Laxatives	7,059	10,493	8,624	7,264	7,310	0.9
Psycholeptics	11,318	11,491	8,448	7,417	6,151	-14.1
Stomatological preparations	396	443	384	422	420	1.5
<b>Total</b>	<b>30,280</b>	<b>32,845</b>	<b>27,899</b>	<b>25,212</b>	<b>24,591</b>	<b>-5.1</b>
<b>Palliative medicine specialists</b>						
Analgesics	24	114	225	338	384	100.0
Anti-emetics and anti-nauseants	13	39	17	14	7	-14.3
Anti-epileptics	50	44	79	73	69	8.4
Anti-inflammatory and anti-rheumatic products	7	14	7	5	9	6.5
Drugs for functional gastrointestinal disorders	41	49	42	22	43	1.2
Laxatives	59	90	63	57	90	11.1
Psycholeptics	34	34	40	39	45	7.3
Stomatological preparations	n.p.	8	n.p.	11	n.p.	-6.9
<b>Total</b>	<b>232</b>	<b>392</b>	<b>476</b>	<b>559</b>	<b>650</b>	<b>29.4</b>
<b>Other clinicians<sup>(a)</sup></b>						
Analgesics	116	215	829	999	1,235	80.6
Anti-emetics and anti-nauseants	58	50	78	94	95	13.1
Anti-epileptics	947	825	770	650	712	-6.9
Anti-inflammatory and anti-rheumatic products	172	164	102	75	140	-5.0
Drugs for functional gastrointestinal disorders	142	100	124	99	181	6.3
Laxatives	389	586	571	557	917	23.9
Psycholeptics	477	521	517	384	430	-2.6
Stomatological preparations	51	34	39	25	31	-11.7
<b>Total</b>	<b>2,352</b>	<b>2,495</b>	<b>3,030</b>	<b>2,883</b>	<b>3,741</b>	<b>12.3</b>

(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, 2010–11

Medication type	Script type	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
<b>Opioids</b>						<b>Number</b>				
Fentanyl	Initial scripts	602	608	642	454	274	n.p.	25	n.p.	2,626
	Repeat scripts	47	64	37	70	13	n.p.	n.p.	n.p.	238
Methadone hydrochloride	Initial scripts	63	70	79	34	35	13	10	5	309
	Repeat scripts	18	18	20	n.p.	n.p.	n.p.	n.p.	n.p.	62
Morphine sulphate	Initial scripts	39	16	51	n.p.	n.p.	6	n.p.	n.p.	118
	Repeat scripts	5	6	10	n.p.	n.p.	n.p.	n.p.	n.p.	21
<i>Total</i>		774	782	839	562	324	23	44	26	3,374
<b>Other analgesics and antipyretics</b>										
Paracetamol	Initial scripts	259	272	234	82	83	33	n.p.	n.p.	992
	Repeat scripts	106	100	117	48	60	22	n.p.	n.p.	462
<i>Total</i>		365	372	351	130	143	55	24	14	1,454
<b>Total pain relief items</b>		<b>1,139</b>	<b>1,154</b>	<b>1,190</b>	<b>692</b>	<b>467</b>	<b>78</b>	<b>68</b>	<b>40</b>	<b>4,828</b>
<b>Opioids</b>						<b>Rate<sup>(a)</sup> per 100,000 population</b>				
Fentanyl	Initial scripts	8.3	10.9	14.1	19.6	16.6	n.p.	6.9	n.p.	11.7
	Repeat scripts	0.6	1.1	0.8	3.0	0.8	n.p.	n.p.	n.p.	1.1
Methadone hydrochloride	Initial scripts	0.9	1.3	1.7	1.5	2.1	2.6	2.8	2.2	1.4
	Repeat scripts	0.2	0.3	0.4	n.p.	n.p.	n.p.	n.p.	n.p.	0.3
Morphine sulphate	Initial scripts	0.5	0.3	1.1	n.p.	n.p.	1.2	n.p.	n.p.	0.5
	Repeat scripts	0.1	0.1	0.2	n.p.	n.p.	n.p.	n.p.	n.p.	0.1
<i>Total</i>		10.6	14.0	18.4	24.3	19.6	4.5	12.2	11.3	15.0
<b>Other analgesics and antipyretics</b>										
Paracetamol	Initial scripts	3.6	4.9	5.1	3.5	5.0	6.5	n.p.	n.p.	4.4
	Repeat scripts	1.5	1.8	2.6	2.1	3.6	4.3	n.p.	n.p.	2.1
<i>Total</i>		5.0	6.7	7.7	5.6	8.7	10.8	6.6	6.1	6.5
<b>Total pain relief items</b>		<b>15.7</b>	<b>20.7</b>	<b>26.2</b>	<b>29.9</b>	<b>28.3</b>	<b>15.3</b>	<b>18.8</b>	<b>17.4</b>	<b>21.5</b>

(a) Crude rate is based on the preliminary Australian estimated resident population as at 31 December 2010 and is expressed per 100,000 populations (see Appendix C).

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

**Table S7.1: Medicare benefits paid (\$) on palliative medicine specialist services, by schedule item, states and territories<sup>(b)</sup>, 2010–11**

MBS item	MBS item number	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
<b>Palliative Medicine Attendances</b>										
Attendance in a hospital or surgery, initial visit	3005	251,235	67,898	158,340	153,648	58,197	15,990	11,274	555	717,138
Attendance in a hospital or surgery, subsequent visit	3010	601,734	109,217	292,026	420,264	137,315	81,558	12,735	986	1,655,833
Attendance in a hospital or surgery, subsequent visit , minor	3014	10,650	3,354	10,220	31	14,860	124	1,666	0	40,904
Initial home visit	3018	86,786	5,217	23,582	8,199	25,623	0	147	0	149,554
Subsequent home visit	3023	73,560	1,446	34,740	4,767	25,203	0	0	0	139,716
Subsequent home visit , minor	3028	0	0	194	0	0	0	0	0	194
<b>Palliative Medicine Case Conferences</b>										
Organise and coordinate a community case conference 15–<30 minutes	3032	119,047	114	928	214	228	228	226	0	120,983
Organise and coordinate a community case conference 30–<45 minutes	3040	469	0	0	0	617	0	0	0	1,086
Organise and coordinate a community case conference >=45 minutes	3044	197	0	0	0	1,265	0	0	0	1,463
Participate in a community case conference 15–<30 minutes	3051	46,940	0	11,292	3,824	0	0	80	82	62,218
Participate in a community case conference 30–<45 minutes	3055	230	0	261	228	115	0	0	0	834
Participate in a community case conference >=45 minutes	3062	0	0	0	158	179	155	0	0	492
Organise and coordinate a discharge case conference 15–<30 minutes	3069	11,946	0	887	29,630	296	394	0	0	43,154
Organise and coordinate a discharge case conference 30–<45 minutes	3074	151	0	898	5,361	0	0	0	0	6,410
Organise and coordinate a discharge case conference >=45 minutes	3078	6,799	0	398	30,624	197	0	0	0	38,018
Participate in a discharge case conference 15–<30 minutes	3083	2,991	0	0	0	0	0	0	0	2,991
Participate in a discharge case conference 30–<45 minutes	3088	115	0	391	115	0	0	0	0	621
Participate in a discharge case conference >=45 minutes	3093	0	0	337	0	0	0	0	0	337
<b>Total items<sup>(c)</sup></b>		<b>1,212,851</b>	<b>187,245</b>	<b>534,494</b>	<b>657,062</b>	<b>264,094</b>	<b>98,448</b>	<b>26,128</b>	<b>1,623</b>	<b>2,981,945</b>
Rate <sup>(d)</sup>		5,395.9	833.0	2,377.9	2,923.2	1,174.9	438.0	116.2	7.2	13,266.4

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

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

(c) The dollar amount may not sum to the total due to rounding.

(d) Crude rate is based on the preliminary Australian estimated resident population as at 31 December 2010 and is expressed per 100,000 population (see Appendix C).

Source: MBS data (Medicare Australia 2011 and DoHA).



Table S7.2: Medicare benefits paid (\$) (a) on palliative medicine specialist services, by schedule item, Australia, 2006–07 to 2010–11

MBS item	MBS item number	2006–07	2007–08	2008–09	2009–10	2010–11	Average annual change (per cent)
<b>Palliative Medicine Attendances</b>							
Attendance in a hospital or surgery, initial visit	3005	284,807	376,276	535,885	637,175	717,138	26.0
Attendance in a hospital or surgery, subsequent visit	3010	670,254	850,652	1,215,702	1,517,584	1,655,833	25.4
Attendance in a hospital or surgery, subsequent visit, minor	3014	35,767	32,591	24,273	43,679	40,904	3.4
Initial home visit	3018	65,376	132,384	143,718	178,719	149,554	23.0
Subsequent home visit	3023	138,063	207,595	188,623	173,253	139,716	0.3
Subsequent home visit, minor	3028	119	122	557	2,165	194	13.2
<b>Palliative Medicine Case Conferences</b>							
Organise and coordinate a community case conference 15–<30 minutes	3032	1,998	26,179	57,993	96,580	120,983	179.0
Organise and coordinate a community case conference 30–<45 minutes	3040	650	473	1,041	312	1,086	13.7
Organise and coordinate a community case conference >=45 minutes	3044	209	926	1,618	1,025	1,463	62.7
Participate in a community case conference 15–<30 minutes	3051	2,159	16,272	20,665	40,423	62,218	131.7
Participate in a community case conference 30–<45 minutes	3055	237	441	344	238	834	37.0
Participate in a community case conference >=45 minutes	3062	815	623	300	499	492	11.9
Organise and coordinate a discharge case conference 15–<30 minutes	3069	275	2,525	8,124	26,255	43,154	254.0
Organise and coordinate a discharge case conference 30–<45 minutes	3074	2,732	4,057	8,598	7,603	6,410	23.8
Organise and coordinate a discharge case conference >=45 minutes	3078	1,821	12,532	39,783	44,471	38,018	113.8
Participate in a discharge case conference 15–<30 minutes	3083	222	152	0	159	2,991	91.5
Participate in a discharge case conference 30–<45 minutes	3088	0	0	0	0	621	..
Participate in a discharge case conference >=45 minutes	3093	0	164	168	0	337	..
<b>Total items</b> <sup>(b)</sup>		<b>1,205,502</b>	<b>1,663,962</b>	<b>2,227,390</b>	<b>2,770,142</b>	<b>2,981,945</b>	<b>25.4</b>

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

(b) The dollar amount may not sum to the total due to rounding.

Source: MBS data (DoHA).

**Table S8.1: PCOC palliative care episodes by inpatient and ambulatory/community setting, 2011**

Age group (years)	Inpatient		Ambulatory/Community		All patients	
	Number	Per cent	Number	Per cent	Number	Per cent
< 15	63	0.3	76	0.5	139	0.4
15–24	63	0.3	65	0.5	128	0.4
25–34	194	0.9	157	1.1	351	1.0
35–44	684	3.3	491	3.4	1,175	3.3
45–54	1,833	8.7	1,261	8.8	3,094	8.7
55–64	3,645	17.3	2,581	18.0	6,226	17.6
65–74	5,054	24.0	3,433	24.0	8,487	24.0
75–84	5,979	28.4	4,033	28.1	10,012	28.3
85+	3,534	16.8	2,234	15.6	5,768	16.3
<b>Total<sup>(a)(b)</sup></b>	<b>21,058</b>	<b>100.0</b>	<b>14,331</b>	<b>100.0</b>	<b>35,389</b>	<b>100.0</b>

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

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

Source: PCOC analysis of 2011 data (unpublished).

**Table S8.2: Summary of PCOC palliative care outcome benchmark results, by palliative care setting, 2011**

<b>Benchmark</b>	<b>All services</b>	<b>Inpatient setting</b>	<b>Ambulatory/Community setting</b>
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	<ul style="list-style-type: none"> <li>• 43.8% of services met benchmark</li> <li>• 81.1% of patient episodes met benchmark</li> </ul>	<ul style="list-style-type: none"> <li>• 65.9% of services met benchmark</li> <li>• 93.2% of patient episodes met benchmark</li> </ul>	<ul style="list-style-type: none"> <li>• 21.4% of services met benchmark</li> <li>• 60.9% of patient phases satisfied the benchmark criteria</li> </ul>
2.1: Time in unstable phase—unstable phases that are the first phase in an episode of care. To meet this benchmark, at least 85% of these unstable phases must last for less than 7 days	<ul style="list-style-type: none"> <li>• 45.3% of services met benchmark</li> <li>• 78.5% of patient phases satisfied the benchmark criteria</li> </ul>	<ul style="list-style-type: none"> <li>• 63.4% of services met benchmark</li> <li>• 78.5% of patient phases satisfied the benchmark criteria</li> </ul>	<ul style="list-style-type: none"> <li>• 25.0% of services met benchmark</li> <li>• 59.6% of patient phases satisfied the benchmark criteria.</li> </ul>
2.2: Time in unstable phase—that are not the first phase in an episode of care. To meet this benchmark, at least 90% of these unstable phases must last for less than 7 days.	<ul style="list-style-type: none"> <li>• 42.2% of services met benchmark</li> <li>• 81.7% of patient phases satisfied the benchmark criteria</li> </ul>	<ul style="list-style-type: none"> <li>• 58.1% of services met benchmark</li> <li>• 81.7% of patient phases satisfied the benchmark criteria</li> </ul>	<ul style="list-style-type: none"> <li>• 25.0% of services met benchmark</li> <li>• 68.1% of patient phases satisfied the benchmark criteria</li> </ul>
2.3: Time in all unstable phases, regardless of where they occur in the episode. To meet this benchmark, the median length of all unstable phases must be 2 days or less.	<ul style="list-style-type: none"> <li>• 53.3% of services met benchmark</li> <li>• The median length of all unstable patient phases was 2 days</li> </ul>	<ul style="list-style-type: none"> <li>• 56.6% of services met benchmark</li> <li>• The median length of unstable patient phases for inpatient services was 2 days</li> </ul>	<ul style="list-style-type: none"> <li>• 45.6% of services met benchmark</li> <li>• The median length of unstable patient phases for ambulatory and community services was 3 days</li> </ul>
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.	<ul style="list-style-type: none"> <li>• 14.1% of services met benchmark</li> <li>• 80.1% of patient phases satisfied the benchmark criteria</li> </ul>	<ul style="list-style-type: none"> <li>• 22.2% of services met benchmark</li> <li>• 81.9% of patient phases satisfied the benchmark criteria</li> </ul>	<ul style="list-style-type: none"> <li>• 13.5% of services met benchmark</li> <li>• 76.3% of patient phases satisfied the benchmark criteria</li> </ul>
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.	<ul style="list-style-type: none"> <li>• 41.2% of services met benchmark</li> <li>• 52.1% of patient phases satisfied the benchmark criteria</li> </ul>	<ul style="list-style-type: none"> <li>• 43.1% of services met benchmark</li> <li>• 50.7% of patient phases satisfied the benchmark criteria</li> </ul>	<ul style="list-style-type: none"> <li>• 47.1% of services met benchmark</li> <li>• 56.3% of patient phases satisfied the benchmark criteria</li> </ul>

(continued)

**Table S8.2 (continued): Summary of PCOC palliative care outcome benchmark results by palliative care setting, January–December 2011**

<b>Benchmark</b>	<b>All services</b>	<b>Inpatient setting</b>	<b>Ambulatory/Community setting</b>
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.	<ul style="list-style-type: none"> <li>• 15.0% of services met benchmark</li> <li>• 80.7% of patient phases satisfied the benchmark criteria</li> </ul>	<ul style="list-style-type: none"> <li>• 28.0% of services met benchmark</li> <li>• 82.2% of patient phases satisfied the benchmark criteria</li> </ul>	<ul style="list-style-type: none"> <li>• 8.0% of services met benchmark</li> <li>• 77.5% of patient phases satisfied the benchmark criteria</li> </ul>
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.	<ul style="list-style-type: none"> <li>• 31.0% of services met benchmark</li> <li>• 49.9% of patient phases satisfied the benchmark criteria</li> </ul>	<ul style="list-style-type: none"> <li>• 32.4% of services met benchmark</li> <li>• 48.0% of patient phases satisfied the benchmark criteria</li> </ul>	<ul style="list-style-type: none"> <li>• 42.0% of services met benchmark</li> <li>• 56.5% of patient phases satisfied the benchmark criteria</li> </ul>

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

Source: PCOC analysis of 2011 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 a technical paper (AIHW 2011b). A summary of the key findings from that technical paper follows.

## ‘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 2010b):

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

In addition to 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; furthermore, 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 2010d; 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 2010d; 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 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 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.  
[emphasis added]

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.

Note 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 (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 for some of these separations, palliative care may have been the clinical intent for *part* (not all) of the separation, 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’.

Note that, at its March 2011 meeting, the Palliative Care Working Group 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 a survey undertaken by the University of Sydney. For each year's data collection, a random sample of about 1,000 general practitioners (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 2010–11 BEACH survey can be obtained from *General practice activity in Australia 2010–11* (Britt et al. 2011).

### Medical Labour Force Survey

The AIHW Medical Labour Force Survey collected information on the demographics, employment characteristics, work locations and work activity of medical practitioners who were registered at the time of the survey. Prior to 2010, the survey was conducted annually by state and territory health authorities, with the questionnaire administered by the registration boards (councils) in each jurisdiction, usually in conjunction with the registration renewal process. Since 2010, a similar survey is conducted through the Australian Health Practitioner Regulation Agency in partnership with the Medical Board of Australia, and administered at the time of registration renewal with the National Registration and Accreditation Scheme.

The same basic survey questionnaire was used across jurisdictions, although there were some variations in the design of the AIHW Medical Labour Force Survey. While the core data items (such as labour force status) had been collected in the survey since its inception, there had been changes to the questionnaire and estimation methods over time. While every effort was made to maintain a comparable time series, this was not always possible. As a result, some care should be taken in comparing data from earlier years with 2009.

The overall response rate to the 2009 survey was 53.1%. The national rate has gradually declined over time, from the 78.6% response rate achieved in 1999. Estimates for some jurisdictions should be interpreted with caution, due to low national response rates and large decreases between 2008 and 2009 for Victoria, Queensland, Western Australia, Tasmania and the Northern Territory, as well as low response rates for particular age groups in Queensland.

For more information on the scope, coverage, methodology and data issues relating to the Survey, see the explanatory notes section at <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737420500>.

# National Hospital Morbidity Database

The data source for the chapter on admitted patient palliative care was the National Hospital Morbidity Database (NHMD). These data pertain to admitted patients in public and private hospitals in Australia. Some of these hospitals have hospices affiliated with them.

The NHMD includes administrative data, demographic information on patients, and clinical information including diagnoses and procedures performed. This annual collection is compiled and maintained by the AIHW, using data supplied by state and territory health authorities. Information from almost all hospitals in Australia is included in the database: from public acute and public psychiatric hospitals, private acute and psychiatric hospitals, and from private free-standing day hospital facilities (AIHW 2011a).

At the time that the analyses were completed for this report, the NHMD contained data for the years from 1993–94 to 2009–10. Around 1998–99, hospitals across Australia began to implement a change in the classification system used to code diagnoses (i.e. from ICD-9-AM to ICD-10-AM). The first full year for which national data are available using ICD-10-AM is 1999–00.

## 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 they 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 active cancer treatment 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 Palliative Care Outcomes Collaboration (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 2009–10, 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. Most of the private facilities that did not report to the NHMD were free-standing day hospital facilities. For 2009–10, complete data were not provided by a few private free standing day hospitals in the Australian Capital Territory and Northern Territory.

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 2009–10 and earlier, see the annual *Australian hospital statistics* reports (e.g. AIHW 2011a, 2010b).



Hospitals may be re-categorised as public or private between or within years (see AIHW 2011a 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 (e.g. AIHW 2009, 2010b, 2011a) and further information about the NHMD can be obtained from those publications. Metadata information for the National Minimum Data Sets 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 information) 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).

## **National Public Hospital Establishments Database**

The National Public Hospital Establishments Database (NPHEd) 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. The collection covers hospitals within the jurisdiction of the state and territory health authorities only. Hence, public hospitals not administered by the state and territory health authorities (hospitals operated by the DoHA, Department of Defence or correctional authorities, for example, and hospitals located in offshore territories) are not included.

The collection is based on the NMDS for public hospital establishments. Information is included on the hospital's resources, expenditure, average available bed numbers, peer group, and the statistical local area and remoteness area of its location. Essentially all public hospitals were included for 2009–10. Also included is information on their average available bed numbers, peer group and the statistical local area and remoteness area of their location.

For more information on the data collection method and other relevant data issues, refer to the NPHEd data quality statement at

<<http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737421911>>.

## Public hospital establishments data analyses

### Public hospital peer groups

The AIHW worked with the National Health Ministers' Benchmarking Working Group (NHMBWG) and the National Health Performance Committee (NHPC) to develop a national public hospital peer group classification for use in presenting data on costs per casemix-adjusted separation. The aim was to allow more meaningful comparison of the data than comparison at the jurisdiction level would allow. This classification is currently under review.

The peer groups were designed to explain variability in the average cost per casemix-adjusted separation. They also group hospitals into broadly similar groups in terms of their range of admitted patient activity and geographical location. The peer group names are broadly descriptive of the types of hospitals included in each category.

The peer group classification is summarised in Table B1. Details of the derivation of the peer groups are in Appendix 11 of *Australian hospital statistics 1998–99* (AIHW 2000). From 2001–02, the method was adjusted slightly, replacing the rural, remote and metropolitan area classification with the 2001 Australian Standard Geographical Classification (ASGC) remoteness areas for the geographical component of the peer grouping.

A flow chart can be found in *Australian hospital statistics 2002–03* (AIHW 2004a; Figure A4.1) to illustrate the assignment of peer groups for almost all hospitals. However, on the advice of jurisdictions, hospitals may be assigned a different peer group due to special circumstances, such as the opening or closing of a hospital during the year.

Although not specifically designed for purposes other than the cost per casemix-adjusted separation analysis, the peer group classification is recognised as a useful way to categorise hospitals for other purposes, including the presentation of other data.

The peer group to which each public hospital was assigned for 2009–10 is included in Table B1. In some cases, the establishments defined as hospitals for the cost per casemix-adjusted separation analysis differ from those defined as hospitals for the elective surgery waiting times data or those defined for counts of hospitals. In these cases, their peer groups may also differ, and these differences are indicated in Table B1. Table B2 presents the coverage of hospitals in the NHMD by hospital sector and states and territories in 2009–10.

### 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 (NAPEDCD). These data have been provided as state or territory and Statistical Local Area (SLA), a small area unit within the Australian Bureau of Statistics (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 Australian Standard Geographical Classifications.

The ASGC's remoteness structure categorises geographical areas in Australia into remoteness areas, described in detail on the ABS website <[www.abs.gov.au](http://www.abs.gov.au)>.

The classification is as follows:

- *Major cities*
- *Inner regional*
- *Outer regional*
- *Remote*
- *Very remote.*

**Table B1: Public hospital peer group classification**

Peer group	Subgroup	Code	Definition
Principal referral and Specialist women's and children's hospitals	Principal referral	A1	Major city hospitals with >20,000 acute casemix-adjusted separations, and Regional hospitals with >16,000 acute casemix-adjusted separations per annum.
	Specialist women's and children's	A2	Specialised acute women's and children's hospitals with >10,000 acute casemix-adjusted separations per annum.
Large hospitals	Major city	B1	Major city acute hospitals treating more than 10,000 acute casemix-adjusted separations per annum.
	Regional and Remote	B2	Regional acute hospitals treating >8,000 acute casemix-adjusted separations per annum, and Remote hospitals with >5,000 casemix-adjusted separations.
Medium hospitals	Group 1	C1	Medium acute hospitals in Regional and Major city areas treating between 5,000 and 10,000 acute casemix-adjusted separations per annum.
	Group 2	C2	Medium acute hospitals in Regional and Major city areas treating between 2,000 and 5,000 acute casemix-adjusted separations per annum, and acute hospitals treating <2,000 casemix-adjusted separations per annum but with >2,000 separations per annum.
Small acute hospitals	Regional	D1	Small Regional acute hospitals (mainly small country town hospitals), acute hospitals treating <2,000 separations per annum, and with less than 40% non-acute and outlier patient days of total patient days.
	Remote	D3	Small Remote hospitals (<5,000 acute casemix-adjusted separations but not 'multi-purpose services' and not 'small non-acute'). Most are <2,000 separations.
Sub-acute and non-acute hospitals	Small non-acute	D2	Small non-acute hospitals, treating <2,000 separations per annum, and with more than 40% non-acute and outlier patient days of total patient days.
	Multi-purpose services	E2	
	Hospices	E3	
	Rehabilitation	E4	
	Mothercraft	E5	
Unpeered and other hospitals	Other non-acute	E9	For example, geriatric treatment centres combining rehabilitation and palliative care, with a small number of acute patients.
		G	Prison medical services, dental hospitals, special circumstance hospitals, Major city hospitals with <2,000 acute casemix-adjusted separations, hospitals with <200 separations etc.
Psychiatric hospitals		F	

## Geographical location of hospital

The remoteness area of each public hospital was determined on the basis of its SLA. For 2009–10, the geographical location was updated to align with the ABS's ASGC Remoteness Structure 2006.

**Table B2: Coverage of hospitals in the National Hospital Morbidity Database, by hospital sector, states and territories, 2009–10**

	Public acute hospitals	Public psychiatric hospitals	Private free-standing day hospital facilities	Other private hospitals
NSW	Complete	Complete	Complete	Complete
Vic	Complete	Complete	Complete	Complete
Qld	Complete	Complete	Complete	Complete
WA	Complete	Complete	Complete	Complete
SA	Complete	Complete	Complete	Complete
Tas	Complete	Complete	Complete	Complete
ACT	Incomplete	Not applicable	Incomplete	Complete
NT	Complete	Not applicable	Incomplete	Complete

*Note:* Complete—all facilities reported data to the National Hospital Morbidity Database. Incomplete—some facilities did not provide data to the National Hospital Morbidity Database; see text for more details. Not applicable—there are no facilities in this sector for this state or territory.

## Nursing and midwifery labour force survey

The AIHW Nursing and Midwifery Labour Force Survey collected information on the demographic and employment characteristics of nurses who were registered or enrolled in Australia at the time of the survey. Up until and including 2009, this survey was done annually by state and territory health authorities, with the questionnaire administered by the registration boards (or councils) in each jurisdiction, usually in conjunction with the registration renewal process. Future reports will be based on the similar survey being run through the Australian Health Practitioner Regulation Agency, which is implementing the National Registration and Accreditation Scheme in partnership with the Nursing and Midwifery Board of Australia.

The overall response rate to the 2009 survey was 44.4%. The national rate has declined over time, from the 78.1% response rate achieved in 1999. Estimates for some jurisdictions for some years should be interpreted with caution, due to the relatively low response rate to the survey. In particular, Western Australia and the Northern Territory had very low response rates in 2005 (26.9% and 13.7%, respectively). Estimates for the Northern Territory for 2005 are not separately published, due to the very low response rate to the survey in that jurisdiction (13.7%).

Interpretation of responses for the Northern Territory is made difficult, due to the high turnover of nurses moving to and from that jurisdiction.

For more information on the data collection method and other relevant data issues, see the explanatory notes section at: <[www.aihw.gov.au/workforce/](http://www.aihw.gov.au/workforce/)>.

## 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.

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](http://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 2009, 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 (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 the chapter on admitted patient palliative care, ABS deaths data on the total number of Australian deaths that occurred during the specified financial years are shown (ABS 2011). 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 Medicare Benefits Schedule (MBS) and provides this information to 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 B3 lists all MBS items that have been defined as palliative medicine specialist services.

**Table B3: MBS-subsidised palliative medicine specialist services items**

<b>MBS item</b>	<b>MBS group &amp; subgroup</b>	<b>MBS item number</b>
<b>Palliative Medicine Attendances</b>		
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
<b>Palliative Medicine Case Conferences</b>		
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 Australian Bureau of Statistics estimated resident population (ERP) at the midpoint of the data range (for example, rates for 2009–10 data were calculated using ERP at 31 December 2010, while rates for 2010 calendar year data were calculated using ERP at 30 June 2010). Rates for 2010–11 data were calculated using preliminary ERP at 31 December 2011.

Crude rates for Indigenous status, country of birth and remoteness area data were calculated using ERP 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 (e.g. 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 at 31 December 2009.

## 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 five-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 purpose, the ABS population estimates at the mid-point of the respective financial year were used to indicate the size of the population 'at risk'. For example, for analyses of the 2009–10 data, the ABS population estimates for 31 December 2009 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 is used when analysing 2010–11 data.

**Table C1: Summary of approaches used to calculate age-standardised rates<sup>(a)</sup>**

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

(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 from one analysis to another.

## Average annual rates of change

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

$$\text{Average rate of change} = ((P_n/P_o)^{1/N} - 1) \times 100$$

where  $P_n$  = value in the later time period

$P_o$  = 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 that are presented may be influenced by factors not considered in that particular analysis. This should be considered when examining the results. While undertaking multivariate analyses would be a useful extension of some of the analyses presented in this report, completing such analyses 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 cancer patients mirrors 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 their cancer (such as chemotherapy or the insertion of a drug delivery device) are 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), but they were reclassified as invasive with the publication of the ICD classification that dealt specifically with neoplasms (WHO 2000).

- (ii) Those with a *principal* diagnosis from Chapter 21 of ICD-10-AM (that is, ICD-10-AM ‘Z’ codes) that was *directly* related to receiving health services or treatment for cancer as follows:

- Observation for suspected malignant neoplasm (Z03.1)
- Follow-up examination after treatment for malignant neoplasms (Z08)
- Special screening examination for neoplasm (Z12)
- Prophylactic surgery (Z40)
- Radiotherapy session (Z51.0)
- Pharmacotherapy session for neoplasm (Z51.1)
- Convalescence following radiotherapy (Z54.1)
- Convalescence following chemotherapy (Z54.2)
- Family history of malignant neoplasm (Z80)
- Personal history of malignant neoplasm (Z85).

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

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

**and**

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

Source: AIHW & AACR 2010.

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, Table 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 2010 *Cancer in Australia: an overview* report (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 in that table.

**Table C2: Diagnosis codes used to identify specific diseases other than cancer<sup>(a)</sup>**

Specific disease	Diagnosis codes (ICD-10-AM)	Source for code specification
Chronic obstructive pulmonary disease (COPD)	J40–J44	WHO 2008
Dementia and Alzheimer disease	F00–F03, G30	AIHW 2010d
Heart failure	I50	AIHW 2010d
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 2010d, Begg et al. 2007
Multiple sclerosis	G35	AIHW 2010d, Begg et al. 2007
Muscular dystrophy	G71.0	Begg et al. 2007
Parkinson disease	G20, G21, G22	AIHW 2010d
Renal failure	N17–N19	AIHW 2010d

(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).

## A principal diagnosis of *Palliative care*

In the 2009–10 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 but this is not applicable 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 2009 to 30 June 2010), this means that all patients that 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 2009–10, but who were admitted before 1 July 2009, will be generally counterbalanced by the patient days for patients still in hospital on 30 June 2010 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 (NHISSC) and the National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID) – was used in the admitted patient palliative care chapter 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 Australian Standard Geographical Classification (ASGC) was developed by the ABS for the collection and dissemination of geographically classified statistics.

In this report, the ASGC Remoteness Areas were used to assign areas across Australia to a remoteness category (ABS 2007b). This classification divides all areas of Australia into five categories – namely, *Major cities*, *Inner regional*, *Outer regional*, *Remote* and *Very remote* (AIHW 2004b). Information on the quality of the data in the NHMD on the usual residence of the patient can be found in Appendix 1 of *Australian hospital statistics 2009–10* (AIHW 2011a).

### Index of Relative Socio-economic Advantage and Disadvantage (IRSAD) and the Index of Relative Socio-economic Disadvantage (IRSD)

The Index of Relative Socio-economic Advantage and Disadvantage (IRSAD) and the Index of Relative Socio-economic Disadvantage (IRSD) are two of four Socio-Economic Indexes for Areas (SEIFAs) developed by the Australian Bureau of Statistics (ABS 2008). Each of the indexes summarises a different aspect of the socio-economic conditions in an area and were created using a different set of information (ABS 2008). Broadly, they 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 (ICD)

The International Statistical Classification of Diseases and Related Health Problems (ICD), which was developed by the World Health Organization (WHO), is the international standard for coding morbidity and mortality statistics. It was designed to promote international comparability in the collection, processing, classification and presentation of 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, 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, which is referred to as the ICD-10-AM (NCCH 2008b), is based on ICD-10. ICD-10 was modified for the Australian setting by the NCCH to make it more relevant to Australian clinical practice. Compatibility with ICD-10 at the higher levels (that is, up to 4 character codes) of the classification has been maintained. 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 that 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.

# 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](http://www.aihw.gov.au)>.

**Aged Care Funding Instrument (ACFI):** The ACFI is a resource allocation instrument and focuses on three domains that discriminate care needs among residents. The ACFI 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:** observations about events that are routinely recorded or required by law to be recorded. Such events include 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** 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. 2011).

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

**General practitioners (GPs)** are those medical practitioners who are vocationally registered under Section 3F of the *Health Insurance Act 1973*, 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:** provision of care to hospital admitted patients in their place of residence as a substitute for hospital accommodation. Place of residence may be permanent or temporary (METeOR identifier: 270305).

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

**International Statistical Classification of Diseases and Related Health Problems (ICD):** 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 is calculated by subtracting the date the patient is admitted from the date of separation and deducting days 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:** services provided by a palliative medicine specialist on a fee-for-service basis that are partially 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, then the median is the middle value. When there is an even number of observations, then 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:** status at separation of person (discharge, transfer or death) and place to which 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: 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:** residential aged care residents are identified in the ACFI data through 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** 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 separation:** a 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:** in order to be eligible for payment of MBS subsidies for palliative care services, a medical practitioner must be a fellow of the Fellowship of the Australasian Chapter of Palliative Medicine (FACHPM).

**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** 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 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 is created (Also see *Care type* and *Episode of care*).

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Palliative care services in Australia 2012 is the first in a planned series of annual reports providing a detailed picture of the national response to the palliative care needs of Australians. Details from a range of data sources for 2009–10, and where available 2010–11, are presented, as are changes over time.

There were almost 56,000 palliative care separations reported in public and private hospitals in 2009–10.

Almost \$3 million in Medicare Benefits Schedule payments was paid for palliative medicine specialist services in 2010–11.