10. PALLIATIVE CARE

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Key points

- Palliative care is defined by the World Health Organization as '... an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual'.
- Palliative care is a critical component of cancer care and may be delivered through inpatient, outpatient and community-based settings. Of those people referred to specialised hospice and palliative care services, over 85% have cancer as their primary diagnosis and approximately 60% of people who die from cancer are referred to palliative care services.
- The *National palliative care strategy* has been in place in Australia for the past decade and is underpinned by a strategic framework with defined standards and performance indicators. Specific initiatives aimed at improving access to, and quality of, palliative care are funded by the government through the National Palliative Care Program.
- Several major national and state and territory policy documents have been issued in the past 10 years. Policy and planning guides have been developed by the peak national palliative care advocacy group Palliative Care Australia and most states and territories.
- Information on palliative care service provision comes from a range of sources; however, a complete national picture is not available and the nature and amount of information provided on service provision varies across states and territories.
- A national palliative care data collection project identified 334 palliative care agencies and 280 (84%) of these provided details of services provided.
- An online registry of palliative care services compiled by Palliative Care Australia provides a list of service providers (name and contact details) by state and territory or postcode; further developments are intended to allow specification of the type of palliative care service provided by each registered organisation.
- The CareSearch palliative care knowledge network, funded by the Department of Health and Ageing, is a significant online resource of evidence-based information for the palliative care community;
- One hundred and forty-eight Fellows of the Chapter of Palliative Medicine were listed on the website of the Royal Australasian College of Physicians as of October 2008.
- Nurses are a key component of the palliative care workforce, particularly in community-based palliative care.
- Four agreed performance indicators covering partnerships, strategic plans, feedback and standards are used to assess palliative care services against Palliative Care Australia standards.
- The Palliative Care Outcomes Collaboration (based at the University of Wollongong) is running a national program supporting palliative care services to consistently compare and measure the quality and outcomes they provide, and through this ensure continued quality improvement.

10.1 Overview

This chapter defines palliative care and summarises major national state and territory palliative care policies and plans as they apply to cancer control. National, state and territory data on the palliative care workforce and services and other ongoing data collection initiatives are described.

10.2 Definitions

The World Health Organization defines palliative care as:

> '… an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.' (World Health Organization 2008)

The application of this definition may be variable. In a 2004 report on national palliative care information collection, the Australian Institute of Health and Welfare stated that:

> 'While most palliative care providers in Australia would aim to apply the above definition in their day-to-day care, different approaches are used to achieve this, depending on the type of agency delivering the care, the setting, the geographical location and the individual circumstances of the patient. This has resulted in many different models of care being applied across agencies and even within agencies. No final agreement on how to describe these models of care has been reached, however work on this topic is being undertaken by Palliative Care Australia.' (Australian Institute of Health and Welfare 2004)

A *palliative care provider* is any medical, nursing or allied health professional who provides primary care with a palliative approach to people with life-limiting illnesses (Palliative Care Australia 2003).

A *specialist palliative care provider* is a medical, nursing or allied health professional who provides care to people with a life-limiting illness as the dominant part of their work, and, in the case of medical practitioners, is appropriately credentialled.

Specialised palliative care services provide interdisciplinary, consultative and ongoing care for people with life-limiting illnesses, support for primary carers and family members, and support and education for end-of-life care. Care settings include community, home, hospitals, aged care homes, hospices and palliative care units. Services employ specialist palliative care professionals who have qualifications or experience in palliative care (Palliative Care Australia 2008c).

10.3 Australian palliative care policy and programs

Palliative care is a critical component of cancer care. In Australia a systematic national palliative care program has been funded for the past two decades (Currow et al. 2008). Specialist hospice and palliative care services span inpatient, outpatient and community care and consultations with a palliative care specialist. In Australia more than 85% of people referred for palliative and/or hospice care have a primary diagnosis of cancer and 60% of people who die from cancer are

referred to specialist palliative care services (Currow et al. 2008). In 2005, there were 38,838 deaths from cancer (Australian Institute of Health and Welfare 2008d).

The *National palliative care strategy*, agreed by the Australian Health Ministers' Advisory Council, has been in place since 2000, underpinned by a national strategic framework (Commonwealth Department of Health and Aged Care 2000). The National Palliative Care Program, developed within the goals of the *National palliative care strategy* supports specific palliative care initiatives (Australian Government Department of Health and Ageing 2008b). The program is funded by the Australian Government Department of Health and Ageing.

10.3.1 National palliative care committees and programs

This section provides a brief overview of the key committees and programs involved in developing and implementing palliative care strategies and programs in Australia. The policies and strategies overseen by these groups are described in section 10.3.2.

Palliative Care Intergovernmental Forum

The Palliative Care Intergovernmental Forum, consisting of representatives of all states and territories and the Australian Government Department of Health and Ageing, is the main mechanism by which Australian governments work together to coordinate activities and policy development relating to palliative care. The forum oversees implementation of the *National palliative care strategy* and related initiatives. The forum has been influential in progressing initiatives around palliative care workforce, standards and performance indicators (Australian Institute of Health and Welfare 2004).

National Palliative Care Program

The National Palliative Care Program is an initiative of the Department of Health and Ageing. It aims to improve access to, and quality of, palliative care by offering support in four broad areas (Australian Government Department of Health and Ageing 2008b). These are:

- support for patients, families and carers in the community;
- increased access to palliative care medicines in the community;
- education, training and support for the workforce; and
- research and quality improvement for palliative care services.

Some of the projects funded within these program areas include:

- the Palliative Care Research Program, managed on behalf of the Department by the National Health and Medical Research Council, aims to improve the quality of palliative care, inform policy development, improve clinical practice and develop researcher capacity, by funding priority driven research grants, training awards and research development grants;
- a consortium of four universities engaged to form the Australian Palliative Care Outcomes Collaboration with the aim of supporting palliative care services to consistently compare, benchmark and measure the quality and outcomes they provide, and through this ensure continued quality improvement;

- the Palliative Care Clinical Studies Collaborative, which manages multisite clinical drug trials in order to gather the scientific evidence required to register palliative care medicines on the Australian Register of Therapeutic Goods and subsequently to be listed on the Pharmaceutical Benefits Scheme if appropriate;
- grants to organisations to enable: equipment for, and fit out of, palliative care premises; pastoral care, counselling and support to patients and families; step-down and transition-to-home support; and care planning for patients living at home;
- the Program of Experience in the Palliative Approach: a sustainable hands-on work placement training program for health professionals in a specialist palliative care service of their choice;
- The Palliative Care Curriculum for Undergraduates, developed in conjunction with the University of Queensland, to provide education and resources for health professionals;
- the CareSearch palliative care knowledge network is an online resource consolidating evidence-based information and practical resources for researchers and palliative care specialists, patients and their families, carers, general practitioners and other health professionals. The website has been developed and is monitored by multidisciplinary health professionals specialising in end of life care;
- development of palliative care needs assessment tools to enable people with the most complex needs to have access to the most comprehensive services (Australian Government Department of Health and Ageing 2008b);
- development of *Guidelines for a palliative approach in residential aged care* and development and implementation of *Guidelines for a palliative approach for aged care in the community setting* (National Health and Medical Research Council 2006).

Palliative Care Medicines Working Group

As part of the National Palliative Care Program, the Palliative Care Medicines Working Group has been established to look at efficient access to and quality use of medicines at the end stages of a person's life.

This group works with the Therapeutic Goods Administration, the Pharmaceutical Benefits Advisory Committee and pharmaceuticals sponsors to evaluate priority palliative care medicines for listing on the Pharmaceutical Benefits Scheme (PBS).

Key achievements of the working group include: developing a framework to support the listing of palliative medicines through the PBS, including a palliative care section within the PBS Schedule; PBS listing for a number of medicines not previously available; and simplifying the prescribing requirements for general practitioners for narcotic analgesics (Australian Government Department of Health and Ageing 2008d).

Ongoing projects include expanding health professional communication networks and considering the educational needs of pharmacists and staff in residential aged care facilities (Australian Government Department of Health and Ageing 2008d).

Palliative Care Clinical Studies Collaborative

This collaborative research group has 10 sites around Australia supported by a coordinating site (Flinders University) and a Management Advisory Board.

Between the sites, a number of phase 3 and phase 4 clinical studies relating to palliative medicines are underway or in the advanced stages of preparation. The studies aim to improve the evidence base for quality palliative care. (Australian Government Department of Health and Ageing 2008d).

Palliative Care Australia

Palliative Care Australia is the national peak body representing the interests and aspirations of all who share the ideal of quality care at the end of life for all (Palliative Care Australia 2008a). It represents jurisdictional palliative care service providers and members of the general community.

The purpose of Palliative Care Australia is to:

- provide a national advocacy platform for palliative care;
- raise the profile of palliative care;
- collaborate on the development of national policies, standards and service improvement initiatives;
- collaborate with the Australian Government Department of Health and Ageing to implement projects funded by the Australian Government such as the *National palliative care strategy*, and
- improve the understanding and availability of services across Australia (Palliative Care Australia 2008a).

Membership of Palliative Care Australia comprises:

- Palliative Care New South Wales (Palliative Care Association of New South Wales 2007)
- Palliative Care Queensland (Palliative Care Queensland 2007)
- Palliative Care Victoria (Palliative Care Victoria 2007)
- Australian Capital Territory Palliative Care Society (ACT Palliative Care Society 2008)
- Palliative Care Western Australia (Palliative Care WA 2007)
- Palliative Care Council of South Australia (Palliative Care Council of South Australia 2007)
- Tasmanian Association for Hospice and Palliative Care (Tasmanian Association for Hospice and Palliative Care 2008)
- Palliative Care Northern Territory (Palliative Care Northern Territory 2008)
- Australian and New Zealand Society of Palliative Medicine (Australian and New Zealand Society of Palliative Medicine 2007).

National Standards Assessment Program

Funded by the Australian Government, this program aims to support policy goals set out in the National Palliative Care Program and *National palliative care strategy*, to improve the quality of palliative care (Palliative Care Australia 2008d). The program is being implemented during 2007–

2010 and is tasked with developing, in consultation with key stakeholders, the processes, tools, procedures and resources to enable specialist palliative care services to implement quality assurance activities and to be assessed in accordance with the National Palliative Care Standards (see section 10.3.2). The program also aims to meet Australian Government priority areas, as expressed in the National Palliative Care Program, in education, training and support for the palliative care workforce and research and quality improvement for palliative care services. The program's processes are aligned with the accreditation principles and practices outlined by the Australian Commission on Safety and Quality in Health Care (Palliative Care Australia 2008d).

Palliative Care Data Working Group

The Palliative Care Data Working Group is a subgroup of the Palliative Care Intergovernmental Forum and was established to promote data consistency and quality in palliative care (Australian Institute of Health and Welfare 2008c). The working group provides advice to the forum and consults with key stakeholders such as the Health Data Standards Committee. Its membership consists of representatives from the Australian Government Department of Health and Ageing, all states and territories, the Australian Institute of Health and Welfare, Palliative Care Australia, the Palliative Care Outcomes Collaboration and the Australian Government Department of Veterans' Affairs. The working group provides guidance and advice to the Australian Institute of Health and Welfare in relation to the collection and reporting of data on the National Palliative Care Performance Indicators (see section 10.3.2) (Australian Institute of Health and Welfare 2008b).

10.3.2 National palliative care policy and strategies

Directions for palliative care in Australia are enunciated in four major national policy, strategic or planning statements. These documents are outlined in this section and the main policy themes relevant to palliative care for people with cancer are highlighted. An overview of state and territory policy relating to palliative care is provided in section 10.3.3. It should be noted that national, state and territory policy statements refer to the full spectrum of palliative care, with people with cancer and their families comprising a large proportion of the palliative care workload.

National palliative care services framework

In 2000, the Australian Health Ministers' Advisory Council endorsed a national palliative care strategy, providing a framework for palliative care service delivery in Australia. The intent of the *National palliative care strategy: a framework for palliative care service development* was to guide:

> '… the development and implementation of palliative care policies, strategies and services that are consistent across Australia, and the delivery of quality palliative care that is accessible to all people who are dying. The Strategy [has] three goals:
>
> 1. Awareness and understanding: To improve community and professional awareness and understanding of, and professional commitment to, the role of palliative care practices in supporting the care needs of people who are dying and their families.
>
> 2. Quality and effectiveness: To support continuous improvement in the quality and effectiveness of all palliative care service delivery across Australia.
>
> 3. Partnerships in care: To promote and support partnerships in the provision of care for people who are dying and their families, and the infrastructure for that care, and to support

delivery of high quality, effective palliative care across all settings.' (Commonwealth Department of Health and Aged Care 2000)

National Palliative Care Performance Indicators

All states and territories have agreed to four national performance indicators, and measurement of activity against these indicators provides information on the extent to which key areas of the strategy have been implemented by palliative care agencies. The performance indicators measure the extent to which agencies:

- develop written plans for palliative care incorporating palliative care elements;
- undertake routine formal assessment against Palliative Care Australia standards;
- actively collect feedback from people with cancer, consumers and staff relating to services; and
- develop formal working partnerships with other service providers or organisations (Australian Institute of Health and Welfare 2008b).

Palliative Care Australia guidelines

Palliative Care Australia has developed two key documents to guide palliative care service delivery in Australia:

- *Palliative care service provision in Australia: a planning guide* provides population-based guidelines for clinical staffing of palliative care services at national, state, territory, regional and local levels (Palliative Care Australia 2003). Palliative Care Australia has indicated that this guide is due for revision.
- *A guide to palliative care service development: a population-based approach* is a needs-based framework for palliative care service planning to allow planners to consider the requirements per 100,000 population, in addition to the particular needs of different subsets of patients (Palliative Care Australia 2005a).

Palliative care standards

Palliative Care Australia developed the current 2005 *Standards for providing quality palliative care for all Australians* in collaboration with the Australian Government Department of Health and Ageing and the Palliative Care Intergovernmental Forum. These set out the relationship between primary care providers and specialist palliative care services and provide criteria for all services involved in the provision of care to people with a life-limiting illness (Palliative Care Australia 2005b). A survey conducted by the Australian Institute of Health and Welfare in 2007 suggested that the standards are not routinely taken up by palliative care services, with almost 90% of services indicating that they do not routinely undertake formal assessment against the standards (Australian Institute of Health and Welfare 2008b).

10.3.3 State and territory plans, strategies and reports

Most states and both territories have produced strategic planning or framework documents for the development of palliative care services. An overview of activity is provided below.

New South Wales

The *NSW palliative care framework: a guide for the provision of palliative care in NSW* (NSW Department of Health 2001) is being revised and is due to be finalised in January 2009. The framework's focus will be on identifying key issues in palliative care delivery. A New South Wales services development plan is being developed in parallel to look at how the framework will be implemented. This development plan (due for completion in mid-2009) will be complemented by individual plans for each area health service addressing implementation at the local level.

Victoria

Victoria's policy for palliative care is *Strengthening palliative care: a policy for health and community care providers 2004–09* (Victorian Government Department of Human Services 2004). An evaluation of the principles and actions outlined in the policy commenced in September 2008 and is expected to conclude in August 2009. The evaluation findings will be used to inform the development of the *Strengthening palliative care policy 2010–2015*, which is expected to be launched in May 2010 (Victorian Government Department of Human Services 2008).

Queensland

Palliative care for people with cancer receiving inpatient care in Queensland is covered in the document *Queensland cancer control: strategic directions 2005–2010,* which outlines strategies to ensure all patients have access to quality integrated palliative care services. Strategies include developing a statewide framework for palliative care for the public and private sectors, which will include clearly defined service networks, incorporating protocols for referral, access and treatment; planning and developing palliative service capacity to meet population needs; using the statewide framework to inform planning and service delivery at a local level; developing a partnership approach to establishing inpatient palliative care facilities; and supporting research into palliative care (Queensland Health 2006).

As of December 2008, Queensland Health had not developed a separate statewide palliative care services plan. However palliative care service provision is planned at a local level through the health service districts (C. Christiansen, Queensland Health, pers. comm. 19 January 2009).

Western Australia

In 2005, the Western Australian Department of Health, in consultation with the Palliative Care Advisory Group, commissioned the Western Australian Centre for Cancer and Palliative Care to review the state's palliative care services. The report, *Palliative care in Western Australia* (WA Centre for Cancer and Palliative Care 2005) outlines current service provision, including the relationships between services and service role delineation, and identifies future service needs and options for coordinating service delivery across the state. The report makes recommendations relating to service governance, including models of service provision, standards, protocols and pathways and workforce planning and development; the location and features of palliative care units; metropolitan inpatient bed allocations; and service delivery for special groups, including Aboriginal and Torres Strait Islander people, those from culturally and linguistically diverse backgrounds and rural and remote communities. Progress in implementing this framework includes developing a model of care for paediatric palliative care and a rollout across the state of an end-of-life standard of care.

South Australia

The *Strategic plan for palliative care services1998–2006* (South Australian Department of Health 1998) provides planning guidelines for developing and enhancing palliative care services, with a focus on equity of access, quality of care, and ease of transition within and between hospital, hospice (inpatient and day patient) and community-based settings.

Tasmania

The *Tasmanian palliative care plan 2002–2005* focused on sustainable workforce capacity, enhancing public awareness, patient support and strengthening partnerships (Tasmanian Government Department of Health and Human Services 2001). A palliative care clinical network is being established as a result of this plan. Following a review of palliative care services in 2004 (Eagar et al. 2004), the plan is being updated and is expected to be completed in 2009.

Australian Capital Territory

The *ACT palliative care strategy 2007–2011* (ACT Health 2007) aims to provide overarching direction for the delivery of palliative care services across ACT Health. The strategy has six aims for improving palliative care service provision, each with a number of proposed actions. The aims focus on improving community education, awareness and participation, further developing a comprehensive Australian Capital Territory palliative care service, strengthening provision of primary care through the palliative approach, strengthening specialist palliative care services, further developing a skilled workforce and improving information management and data collection.

Northern Territory

The Northern Territory *Palliative care strategy 2005–2009* (NT Government Department of Health and Community Services 2005) identifies major priority areas for palliative care, and acknowledges the difficulty of providing palliative care in remote areas and the need to provide culturally appropriate care for Aboriginal and Torres Strait Islander people. It emphasises improved access to palliative care services. It also covers access to a flexible service model to ensure a holistic continuum of care, the need for support services for people in rural and remote areas and the development of a skilled and competent workforce. A health-promoting framework that incorporates education, advice and support and sound data collection is an integral part of this document, as is continuous evaluation and an evidence base to inform service delivery and development.

10.3.4 Issues in palliative care policy

Australian services are set up to provide palliative care for people with all types of life-limiting diseases, not just those with cancer. As far as could be determined, the only palliative care services concentrating exclusively (or almost exclusively) on people with cancer are those based in the largest multidisciplinary cancer centres, such as the Peter MacCallum Cancer Centre in Melbourne.

The major policy statements described above focus on role delineation in palliative care, defined according to the degree of specialisation and breadth of service, either from the perspective of service organisation and provision or patient needs. Role delineation is intended to ensure that the

most highly specialised services are accessible to the patients who need them most, and that specialists can practise in an environment where there is a comprehensive high level of expertise. The Palliative Care Needs-Assessment Project is directly addressing this process.

In addition to oncology expertise, palliative care service providers require knowledge in fields as diverse as neurology, cardiology, acquired immune deficiency syndrome (AIDS), immunology and respiratory medicine. This highlights the need to bring together disease-specific specialists and palliative care providers.

A report on palliative care in Victoria in 2002-2003 found that over 85% of people requiring community-based palliative care had been diagnosed with cancer (Currow et al. 2008). Available data suggest that many patients who are likely to benefit from appropriate palliative care do not receive it. Overall, it is likely that demand for palliative care will increase as the population ages, the incidence of chronic diseases and complex health conditions increases, and the value of palliative care is increasingly recognised.

10.4 Australian palliative care services

10.4.1 Scope

In 2006-2007 there were 28,273 palliative care separations from Australian hospitals, with an average length of stay of 11.7 days. The majority (77%) of separations were from public hospitals. The proportion of separations for 2006-2007 that were for people with a principal diagnosis of cancer was not available by December 2008. However, for 2005-2006, 73% of the 25,741 hospital separations had a principal diagnosis of cancer. No national data are currently available on the number of palliative care services delivered in non-admitted settings, such as community health services (Australian Institute of Health and Welfare 2008a). This section outlines current estimates in relation to patient and service requirements for delivery of palliative care in Australia.

Historically, palliative care services were offered mainly to people who refused aggressive treatment. However, approaches have developed significantly in the last decade. Now many people benefit from services provided by specialised palliative care teams, and people with cancer may be referred to a palliative care service before all other treatment options have been exhausted, in line with the World Health Organization definition once progressive life-limiting disease is first recognised (World Health Organization 2008).

Palliative Care Australia's *Palliative care service provision in Australia: a planning guide* recommends that 90% of people dying from cancer and 50% of people dying from other causes should be referred for assessment by a palliative care service, while 70% and 30% respectively will require ongoing palliative care consultations (Palliative Care Australia 2003).

Two recent studies have investigated the use of specialist palliative care services in Australia. Currow et al. interviewed people in over 3000 households and found that over 66% of people who died with cancer accessed a specialist palliative care service. Of the population who had someone close to them die, 15% did not know whether a specialist palliative care service had been used. This group was significantly more likely to be very young or very old, never married, less educated and of non-English speaking background than others in the study. The study demonstrated a trend of increasing access to specialist palliative care services with increasing socio-economic

status. McNamara et al. found that those who died of cancer were significantly less likely to receive care in a specialist palliative care service if they were single or widowed, elderly or lived in a region other than a major city (Currow, Abernethy & Fazekas 2004; McNamara et al. 2004).

The *Guide to palliative care service development* identifies the target group for palliative care services as patients with a progressive and advancing life-limiting illness, their carers and family. For population-based service planning, the guide proposes that this target group be divided into three subgroups (see Figure 10.1) (Palliative Care Australia 2005a).

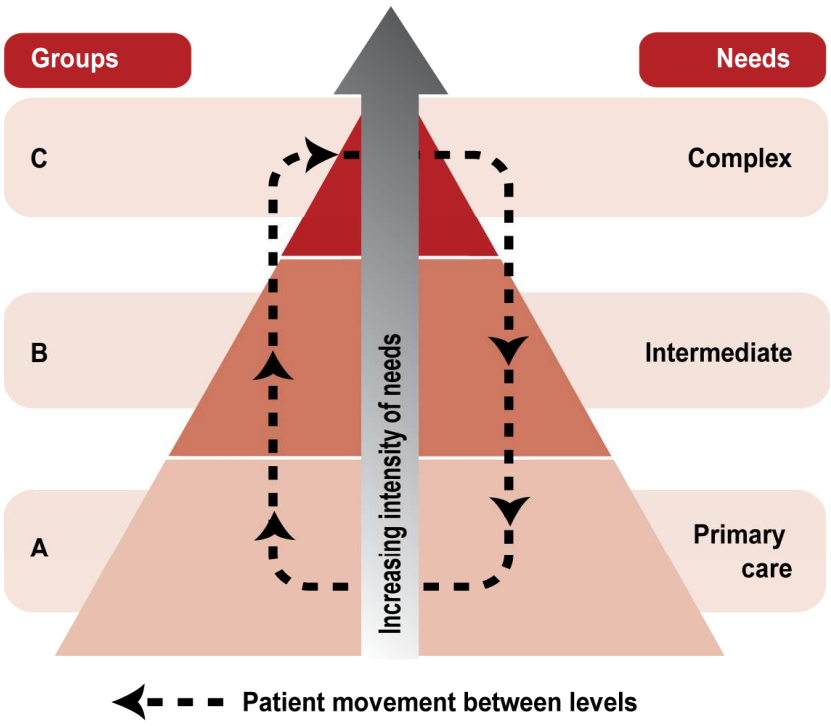
1. patients who do not require access to specialist care to meet their needs: this comprises almost two-thirds of all those whose death is expected;

2. patients who have temporary exacerbations of pain or other symptoms requiring access to specialist palliative care services; these patients will continue to receive care from their primary care provider; and

3. patients with the greatest need, often with complex physical, social, psychological and/or spiritual needs who do not respond to established protocols of care.

Figure 10.1

Conceptual model of level of need within the population of patients with a life-limiting illness



Note: primary care will play a key role at each level

Source: *A guide to palliative care service development: a population based approach*. Canberra, ACT: Palliative Care Australia (Palliative Care Australia 2005a)

Table 10.1 describes the various levels of service required to meet population needs and sets out a role delineation framework of service capabilities for variously resourced specialist services.

Table 10.1

Capabilities and typical resource profiles for each level of palliative care

Level	Capability	Typical resource profile(a)
Primary care	Clinical management and care coordination including assessment, triage and referral using a palliative approach for patients with uncomplicated needs associated with a life-limiting illness and/or end of life care. Has formal links with a specialist palliative care provider for referral, consultation and access to specialist care as necessary.	General medical practitioner, nurse practitioner, registered nurse, generalist community nurse, Aboriginal health worker, allied health staff. Specialist health care providers in other disciplines would be included at this level.
Specialist palliative care level 1	Palliative care for patients, primary carers and families whose needs exceed the capability of primary care providers. Provides assessment and care consistent with needs and provides consultative support, information and advice to primary care providers. Has formal links to primary care providers and level 2 and/or 3 specialist palliative care providers to meet the needs of patients, carers and families with complex problems. Has quality and audit program.	Multidisciplinary team including medical practitioner with skills and experience in palliative care, clinical nurse specialist/consultant, allied health staff, pastoral care and volunteers. A designated staff member, if available, coordinates a volunteer service.
Specialist palliative care level 2	As for level 1, able to support higher resource level due to population base (eg regional area). Provides formal education programs to primary care and level 1 providers and the community. Has formal links with primary care providers and level 3 specialist palliative care services for patients, primary carers and families with complex needs.	Interdisciplinary team including medical practitioner and clinical nurse specialist/ consultant with specialist qualifications. Includes designated allied health and pastoral care staff.
Specialist palliative care level 3	Provides comprehensive care for the needs of patients, primary carers and families with complex needs. Provides local support to primary care providers, regional level 1 and/or 2 services including education and formation of standards. Has a comprehensive research and teaching role. Has formal links with local primary care providers and with specialist palliative care providers level 1 and 2, and relevant academic units including professorial chairs where available.	Interdisciplinary team including a medical director and clinical nurse consultant/nurse practitioner and allied health staff with specialist qualifications in palliative care.

a Primary care will play a key role at each level

Source: Reproduced from *A guide to palliative care service development: a population based approach.* Canberra, ACT: Palliative Care Australia (Palliative Care Australia 2005a)

Australian palliative care services have evolved over the past 30 years. The formation of key palliative care organisations and the development of the *National palliative care strategy* have promoted a more coordinated approach to service development. For example, Palliative Care Australia's 2003 population-based planning guide on staffing levels required to provide palliative care services in Australia (see Table 10.2) was the first blueprint to guide palliative care service planning (Currow & Nightingale 2003; Palliative Care Australia 2003).

Table 10.2

Estimated minimum staffing levels for professional support of interdisciplinary palliative care in the community, acute care settings and palliative care units by discipline, expressed as full-time equivalent staff

Discipline/ staff category	Community-based services[a]	Acute-care hospital consultative service[b]	Designated palliative care beds[c]
Palliative care specialist [d]	1.5	1.5	1.5
Registrar [d]	1.0	1.0	1.0
Resident medical officer	0	0	0.25
Liaison psychiatry	0.25	0.25	0.25
Clinical nurse consultant [d]	1.0	0.75	0
Registered and enrolled nurses [d]	0	0	6.5 hours per patient per day
Discharge liaison	0	0.25	0
Psychology	0.25	0.1	0.1
Social work	0.5	0.25	0.25
Bereavement support	0.25	0.1	0.1
Pastoral care	0.25	0.25	0.25
Speech pathology	0.2	0.2	0.2
Dietitian	0.2	0.2	0.2
Physiotherapy	0.4	0.2	0.2
Occupational therapy	0.4	0.2	0.2
Pharmacist	0	0.25	0.1
Other therapies [e]	0.5	0	0.25

a Full-time equivalent staff per 100,000 population served

b Full-time equivalent staff per 125 hospital beds

c Full-time equivalent staff per 6.7 beds, whether in an acute care setting or in a freestanding palliative care unit or hospice (6.7 palliative care beds per 100,000 population would be needed)

d Assumes that these roles in the community are consultative, with well-resourced primary clinical care (general practitioners and community nurses)

e Includes combinations of music, art, complementary, narrative and diversional therapies

Sources: *Palliative care service provision in Australia: a planning guide* Canberra, ACT: Palliative Care Australia (Palliative Care Australia 2003); 'A planning guide': Developing a consensus document for palliative care service provision *Med J Aust* 179(6 Suppl): S23-S25 (Currow & Nightingale 2003)

10.4.2 Extent of palliative care services

Data collection activities from administrative health regions and palliative care agencies support the calculation of the four National Palliative Care Performance Indicators. State and territory members of the Palliative Care Data Working Group identified 334 agencies for inclusion in the national palliative care agency data collection (Australian Institute of Health and Welfare 2008b). Questionnaires were sent to these agencies and 280 (84%) returned completed questionnaires. Table 10.3 shows the distribution of responding agencies across the states and territories.

Table 10.3

Palliative care services participating in the national palliative care agency data collection by state and territory, Australia, 2007

State/territory	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aus
Number of services	74	52	111	18	18	3	2	2	280

Source: *National palliative care performance indicators: results of the 2007 performance indicator data collection.* Cat. No. HWI 99.Canberra, ACT: Australian Institute of Health and Welfare (Australian Institute of Health and Welfare 2008b)

Of the remaining agencies, 16 (5%) did not complete survey questionnaires for various reasons such as having been amalgamated into a larger organisation or not having any palliative care patients. No response was received from 38 agencies.

Palliative Care Australia has developed a publicly available online searchable database of palliative care services, listing the names and contact details of palliative care services by state, territory or postcode (see Table 10.4) (Palliative Care Australia 2008b). As part of the updating process for the Palliative Care Australia website, the listed agencies are asked to identify the types of palliative care services offered (after-hours, day care, education, home care, etc). The database does not currently specify staffing levels or characteristics of the palliative care workforce.

Table 10.4

Palliative care services listed in the Palliative Care Australia Palliative Care Service Directory

	Number of services by state								
Type of service	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	All states
Specialist palliative care service providers	61	63	37	29	21	5	2	2	220
Primary care/end of life service providers	25	21	110	24	5	1	–	4	191
Community support agencies	12	2	11	2	4	8	1	2	42

Source: *National palliative care service directory.* http://pallcare.gky.com.au/c/pc?a=apps&ap=bd (viewed 9 December 2008) (Palliative Care Australia 2008b)

Palliative Care Australia's 2006 *Submission to Senate Community Affairs Committee private health insurance bill 2006 (provisions) and related bills* (Palliative Care Australia 2006) also presented figures on palliative care services, as follows:

- approximately one-third of all patients receiving palliative care die at home, and up to 90% of terminally ill patients spend most of their final year of life at home (Palliative Care Australia 1999)
- a significant factor causing unwanted hospital admission is insufficient coordination of, or support by, health care services to maintain home care (McNamara et al. 2004)
- access to home-based palliative care services is varied. Services are often under-resourced and over-stretched with waiting periods for access (Box 2003)

- in New South Wales, one study estimated a 17.3% increase in demand for palliative care services between 1998 and 2006, compared to an overall population increase of 7% (NSW Department of Health 2001).

10.4.3 Palliative care workforce

Fellows of the Chapter of Palliative Medicine

Since 1988 the Royal Australasian College of Physicians has had a separate specialist advisory committee in palliative medicine and a training program for Fellows. Palliative care was recognised as a medical specialty in July 2005 and Medical Benefits Schedule items for palliative medicine were approved (items 3005 to 3093). Training for palliative medicine specialists in Australia is overseen by the Combined Palliative Medicine Education Committee of the college's Australasian Chapter of Palliative Medicine. Table 10.5 lists the number of Fellows as of October 2008. The list is not necessarily complete as it contains only those Fellows who agreed to be listed on the college's website.

Table 10.5

Numbers of Fellows of the Chapter of Palliative Medicine listed on the Royal Australasian College of Physicians website by state and territory, 2008

State/territory	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
No. Fellows	59	30	21	11	10	10	3	4	148

Source: List of palliative care fellows. http://www.racp.edu.au/page/about-the-racp/structure/australasian-chapter-of-palliative-medicine/list-of-palliative-medicine-fellows (Royal Australasian College of Physicians 2008)

No data are available on the extent of involvement of medical practitioners who are not specialists in palliative care.

Nurses

Nurses form a significant part of the palliative care workforce. In the report on palliative care services in Victoria published in 2004, 74.4% of community-based care was provided by nurses (Victorian Government Department of Human Services 2004).

Palliative care is recognised as a speciality in nursing, but it is not mandatory for nurses working in the area to have specialist qualifications. Palliative Care Nurses Australia is a national organisation for nurses employed in palliative care, launched in 2005. Initial funding was provided by Palliative Care Australia. National palliative care nursing conferences are held bi-annually (Palliative Care Nurses Australia 2008). The Royal College of Nursing, Australia has a position statement on the role of the palliative care nurse (Royal College of Nursing Australia 2000). This position statement, currently under review, states:

> 'Palliative care nursing is a key component in the multidisciplinary approach to care necessary to meet the complex needs of individuals and their families/carers facing life threatening illnesses. Care is directed towards easing the symptoms associated with end-

stage illnesses and the fears, anxieties, grief and concerns of both clients and their families/carers.'

Allied health professionals

Optimal palliative care usually requires the support of a multidisciplinary team. Pharmacists, occupational therapists, physiotherapists, dietitians, speech pathologists, social workers and mental health professionals have significant roles within the team.

Carers and personal assistants

The wider workforce of personal care assistants and aged care workers are frequently involved in providing supportive care at the end of life, as many patients are elderly and/or have a disability and live in residential care settings.

Programs to support the palliative care workforce

The Program of Experience in the Palliative Approach is a national program funded by the Australian Government through the National Palliative Care Program. The program provides supervised clinical placements in palliative care for a broad range of health care professionals, including nurses; general practitioners, especially in rural and remote areas; allied health professionals; and Aboriginal and Torres Strait Islander health care workers. The program also supports the integration of learning into practice and provides post-placement support to develop knowledge and skills in this specialised area. Between January and June 2008, 137 clinical placements were completed, with 44 placements in progress across all jurisdictions. Funding is available to support 1030 placements and 162 workshops up to June 2010 (Program of Experience in the Palliative Approach 2008).

Another initiative of the Department of Health and Ageing through the National Palliative Care Program is the Palliative Care Curriculum for Undergraduates developed in conjunction with the University of Queensland. This program and associated resources, including *Palliative care: a learning resource for health care students,* provide education for undergraduate nurses and other health professionals (Australian Government Department of Health and Ageing 2008c). Of the 191 health courses at Australian universities, 60 were implementing this curriculum as of late-2007.

10.4.4 Hospital data

Hospital separations data for palliative care for 2006–2007 are provided in Table 10.6. These data show that there were 28,273 separations for palliative care, of which 77% were in public hospitals. However, few conclusions about patterns of service provision can be drawn from these data because they include palliative care separations for conditions other than cancer. Note also that palliative care services provided to people with cancer may be recorded under the original diagnosis rather than under palliative care; palliative care services delivered in non-admitted settings are not included; and hospice data are only included for hospices that are part of a hospital.

Table 10.6

Hospital separations data for palliative care by state and territory and public/private hospital, 2006–2007

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Public hospital	8 452	5 182	4 405	1 318	1 324	360	476	268	21 785
Private hospital	440	508	2 083	2 459	125	–	–	–	6 488
Total	**8 892**	**5 690**	**6 488**	**3 777**	**1 449**	–	–	–	**28 273**

Note : a dash represents data not published

Source: *Australian hospital statistics 2006–2007*. Health Services Series No.31. Cat. No. 55. Canberra, ACT: Australian Institute of Health and Welfare (Australian Institute of Health and Welfare 2008b)

10.4.5 Medicare data

Medicare procedures for palliative care items for 2007 are summarised in Table 10.7. The distribution of palliative care items by state and territory is summarised in Figure 10.2, and the distribution by age is summarised in Figure 10.3. The data do not distinguish the palliative care procedures that were specifically for cancer and only refer to private billing for services. Billing through Medicare only represents a very small percentage of the services provided by palliative care physicians.

There were 23,005 services billed to Medicare for palliative medicine specialists (see Table 10.). As could be expected, the number of palliative care procedures increases with age, particularly after the age of 30 years, with the greatest proportion among those over 50 years of age.

Medicare funded palliative care procedures for New South Wales were three times higher than for other jurisdictions; this is likely to reflect variations in billing practice.

Table 10.7

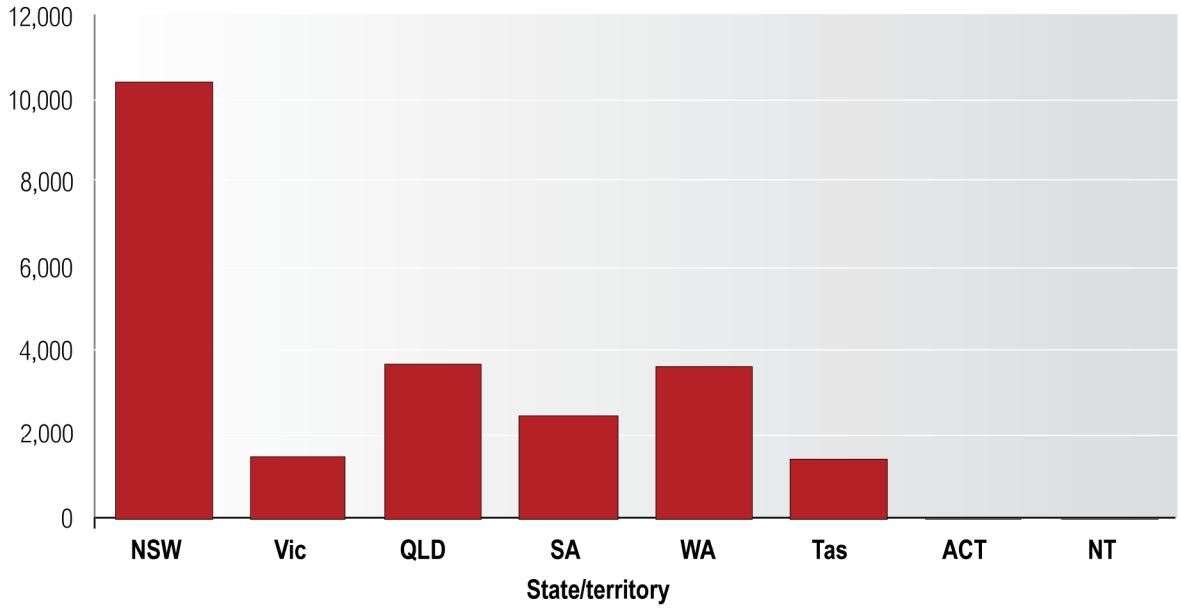
Medicare procedures for palliative care for calendar year 2007

Item description	Item number	Frequency
Palliative medicine specialist attendance in a hospital or surgery	3005	3119
Palliative medicine specialist attendance in a hospital or surgery, subsequent visit	3010	15 589
Palliative medicine specialist attendance in a hospital or surgery, subsequent visit, minor	3014	1509
Palliative medicine specialist attendance, home visit	3018	721
Palliative medicine specialist attendance, home visit, subsequent visit	3023	2067
Palliative medicine specialist attendance, home visit, subsequent visit, minor	3028	0
Organise and coordinate a community case conference palliative medicine specialist 15-30 m	3032	55
Organise and coordinate a community case conference palliative medicine specialist 30-45 m	3040	7
Organise and coordinate a community case conference palliative medicine specialist >=45 m	3044	5
Participate in a community case conference palliative medicine specialist 15-30 m	3051	140
Participate in a community case conference palliative medicine specialist 30-45 m	3055	3
Participate in a community case conference palliative medicine specialist >=45 m	3062	6
Organise and coordinate a discharge case conference palliative medicine specialist 15-30 m	3069	10
Organise and coordinate a discharge case conference palliative medicine specialist 30-45 m	3074	29
Organise and coordinate a discharge case conference palliative medicine specialist >=45 m	3078	14
Participate in a discharge case conference palliative medicine specialist 15-30 m	3083	1
Participate in a discharge case conference palliative medicine specialist 30-45 m	3088	0
Participate in a discharge case conference palliative medicine specialist >=45 m	3093	1
Total case conferences – palliative medicine specialist		**271**
Total palliative medicine specialist attendances		**23 005**

Source: *Medicare group reports.* https://www.medicareaustralia.gov.au/statistics/mbs_group.shtml (viewed March 2008) (Australian Government Department of Health and Ageing 2008a)

Figure 10.2

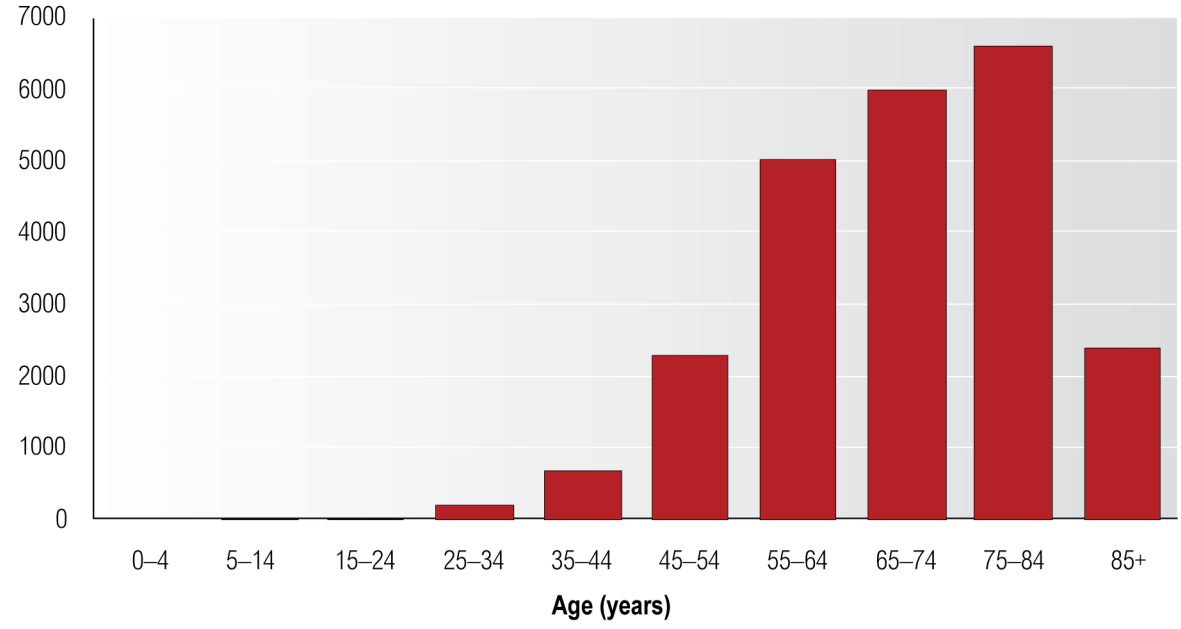
Medicare procedures for palliative care by state/territory, Australia, 2007



Source: *Medicare group reports*. https://www.medicareaustralia.gov.au/statistics/mbs_group.shtml (viewed 5 December 2008) (Australian Government Department of Health and Ageing 2008a)

Figure 10.3

Medicare procedures for palliative care by age, Australia, 2007



Source: *Medicare group reports*. https://www.medicareaustralia.gov.au/statistics/mbs_group.shtml (viewed 5 December 2008) (Australian Government Department of Health and Ageing 2008a)

10.4.6 State and territory data on palliative care

Some data on palliative care service organisation, delivery and utilisation can be obtained by examining Victorian, South Australian and Western Australian data collections and reports.

Victoria

Strengthening palliative care: a policy for health and community care providers 2004–09 (Victorian Government Department of Human Services 2004), provides a profile of inpatient and community-based palliative care in the state. With regard to inpatient palliative care, the report notes that:

> 'Of all people admitted to public hospitals for more than one day in 2002–03, only 1% died in the hospital ... Of these deaths, only 3071 patients (0.26% of all separations) died in a designated palliative care unit in a hospital. The average length of stay for patients in a designated palliative care unit was 17.1 days in a metropolitan hospital and 13.7 days in a rural hospital. Of all patients admitted to a designated palliative care unit, 66.7% died in the unit... Of patients admitted to a designated palliative care unit, 83.3% were over the age of 60 years.'

These data indicate that patients spend two to three weeks in a palliative care unit on average, whether they die during the course of an admission or are discharged. Patients are not admitted to palliative care units solely for end of life care, but for brief admissions for symptom control or for more extended management.

With regard to community-based palliative care, the report cites Department of Human Services data highlighting the duration of therapeutic contact (more than three months on average), the preponderance of cancer cases, and the extensive role of nurses. In 2002–2003:

> '... 7228 patients accessed community palliative care services... Of these, 52.9% were male and 76.4% were over the age of 60 years. The average length of... [contact] was 97.7 days. Malignancy was the reported diagnosis in 87% of the cases. Clinical consultancy or care was provided in 23.6% of contacts, and spiritual or emotional support or counselling was provided in 20% of contacts. Nurses provided 74.4% of services. Fifty-one per cent of patients cared for through community palliative care services died in hospital.'

South Australia

In 2004, Currow, Abernethy and Fazekas (Currow, Abernethy & Fazekas 2004) published the results of a face-to-face health survey of a random sample comprising 4400 South Australian households. A total of 3027 interviews were conducted, representing a 70% response rate. This study is referred to in section 10.4.1.

In an earlier study, Hunt et al. (Hunt et al. 2002) observed that, among patients who died from invasive cancer in South Australia, the proportion who had 'palliative care involvement' rose from 55.8% in 1990 to 68.2% in 1999. The likelihood of 'palliative care involvement' did not vary greatly with age among those aged less than 80 years, but decreased after the age of 80, and it did not vary greatly with gender or socio-economic status. Patients with lung cancer, liver cancer and upper gastro-intestinal cancers were most likely to have had 'palliative care involvement'.

Western Australia

The report *Palliative care in Western Australia* (WA Centre for Cancer and Palliative Care 2005) highlights the following findings for palliative care activity in the Perth metropolitan area.

- In 2003–2004, approximately 55% of separations for palliative care services were from tertiary hospitals. Thirty per cent were from hospices and private palliative care units and 15% were from non-tertiary (acute) hospitals.
- From 2001–2002 to 2003–2004, palliative care separations from tertiary hospitals increased from 1158 in 2001–2002 to 1350 in 2003–2004, an increase of almost 17% in three years. Over the same period, there was relatively little change (a 5% increase) in separations from other facilities that provide inpatient palliative care. Overall, there was an increase of 11% in three years.

(Inpatient data did not clearly distinguish palliative care activity from other separations for Princess Margaret Hospital and King Edward Memorial Hospital. Data from these hospitals are excluded from the figures given above.)

Based on the findings, a projected benchmark of 8.4 palliative care beds per 100,000 population was recommended for Western Australia. This would lead to a total requirement of some 148 public- and private-sector beds in the state by 2015–2016, allowing for population growth and ageing. The recommended benchmark is higher than the current Palliative Care Australia benchmark of 6.7 beds per 100,000 population, which would lead to a requirement of some 117 beds. The latter projection does not take population ageing into account.

10.5 Monitoring the quality of palliative care

The Palliative Care Outcomes Collaboration (PCOC) was established with three years' funding from the Australian Government to compile a clinical dataset of palliative care services to improve access to and the quality of palliative care services offered. It is a collaboration between four centres, based at the Centre for Health Service Development, University of Wollongong (University of Wollongong 2007).

The four zones and partners are:

- PCOC Central (Centre for Health Service Development, University of Wollongong, NSW);
- PCOC West (Western Australian Centre for Cancer & Palliative Care, Curtin University of Technology, Perth);
- PCOC South (Flinders Medical Centre, Flinders University of South Australia, Adelaide); and
- PCOC North (Institute of Health and Biomedical Innovation, Queensland University of Technology, Brisbane).

PCOC is a voluntary initiative that aims to support a national benchmarking system to assist palliative care service providers to improve practice and meet the *Standards for providing quality palliative care for all Australians*. The data collection activities focus on instances of care, including details about the palliative care service, the person receiving care, administrative details about the period of care, and clinical characteristics. The program also includes regular patient and caregiver

surveys. Three consolidated reports have been produced as of December 2008 (Currow et al. 2008). For the purpose of this audit PCOC provided data on participating palliative care services (*n*=200) (see Table 10.8).

Table 10.8

Description of palliative care services (by state or territory) in Palliative Care Outcomes Collaboration (PCOC) database, as of October 2008

	Palliative care service	NSW	Vic	Qld	WA	SA	Tas	ACT	NT
	Public/NGO	31	86	28	12	20	3	2	1
	Private	1	1	10	5	1	2	0	–
	Unspecified								
	Total	32	87	38	17	21	5	2	1
	Inpatient	23	31	33	16	4	3	1	1
	Community	26	39	17	9	20	4	1	1
	Consultative	29	16	22	5	5	1	2	–
	Metro	11	20	13	9	7	1		1
	Regional/rural/remote	21	67	25	15	26	4	2	1

NGO: non-government organisation

Note: these numbers are a mix of specialist and some primary care palliative care services. With the exception of Victoria, most of the services qualify as specialist palliative care services; in Victoria, the numbers are for all palliative care services, many of which are primary care.

Source: compiled from data provided by PCOC coordinators, personal communications, October 2008

The majority of services described are public rather than private, and many provide inpatient as well as community and/or consultative services. There is also a relatively even spread between metropolitan, regional and rural services, but very few provide remote access to palliative care. Further breakdowns of the data into types and numbers of patients for each service were not available at this stage.

The most recent report on palliative care performance indicators (Australian Institute of Health and Welfare 2008c) collected data from 280 hospital- and community-based agencies receiving government funding across Australia. Of these:

- 174 agencies (62%) reported that they mostly provided care in community settings: these were most commonly primary palliative care agencies that delivered care in private residences and residential aged care settings, and had hospitals and palliative care agencies as partners.
- 67 agencies (24%) mostly provided care in inpatient settings: these were most commonly primary palliative care agencies that delivered care in inpatient settings and had community nursing agencies and hospitals as partners.
- 39 agencies (14%) provided care in both settings: these were most commonly specialist palliative care agencies that delivered care in private residences and inpatient settings other than designated palliative care units, and had community nursing agencies and hospitals as partners.

The performance indicators and reported results are provided in Table 10.9.

Table 10.9

Performance indicator data from the survey of palliative care agencies, Australia, 2008

Performance indicator	Agencies meeting the indicator (%)
Performance indicator 1: strategic plans: the proportion of administrative health regions that have a written plan for palliative care that incorporates palliative care elements	63
Performance indicator 2: standards: the proportion of palliative care agencies that routinely undertake or undergo formal assessment against the current Palliative Care Australia standards	11
Performance indicator 3: feedback: the proportion of palliative care agencies that actively collect feedback from clients and staff (within the workforce) relating to services and service delivery	66
Performance indicator 4: partnerships: the proportion of palliative care agencies that have formal working partnerships with other service providers or organisations	89

Source: *National palliative care performance indicators: results of the 2007 performance indicator data collection*. Cat. No. HWI 99.Canberra, ACT: Australian Institute of Health and Welfare (Australian Institute of Health and Welfare 2008c)

10.6 Summary

A systematic national palliative care program has been funded in Australia for the past two decades and several national, state and territory policy documents have been produced in the last ten years. Data on the distibution and types of palliative care services are limited. However, available data suggest that palliative care services are of high quality, but that greater integration with cancer services is needed.

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