

Palliative Care Strategic Framework 2010-2013

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Functional Sub group Clinical/ Patient Services - Medical Treatment
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Summary The NSW Palliative Care Strategic Framework builds on and replaces the NSW Palliative Framework (2001). The Palliative Care Strategic Framework sets five priorities for service development over the next four years:

- 1) Improving NSW palliative care service planning & delivery;
- 2) Implementing the Standards for Providing Quality Palliative Care for all Australians;
- 3) Improving palliative care workforce capacity and training;
- 4) Improving palliative care data ; and
- 5) Strengthening evidence based practice.

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Applies to Area Health Services/Chief Executive Governed Statutory Health Corporation, Board Governed Statutory Health Corporations, Affiliated Health Organisations, Affiliated Health Organisations - Declared, Public Health System Support Division

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Director-General

This Policy Directive may be varied, withdrawn or replaced at any time. Compliance with this directive is **mandatory** for NSW Health and is a condition of subsidy for public health organisations.

NSW PALLIATIVE CARE STRATEGIC FRAMEWORK

PURPOSE

The *NSW Palliative Care Strategic Framework* builds on and replaces the *NSW Palliative Care Framework* (2001).

The *Strategic Framework* is aligned with the goals of the *National Palliative Care Strategy*. The *Strategic Framework* sets out five priority areas for strengthening palliative care services in NSW.

The Statewide Centre for Improvement of Palliative Care (SCIP) has been established to provide leadership for palliative care service planning and to support the implementation of the *Strategic Framework*. This work will be aided by the Palliative Care Service Development Officer Network (SDO). A Service Development Officer position has been established in each AHS. These positions were approved in 2006 with recurrent funding.

MANDATORY REQUIREMENTS

The *Strategic Framework* sets out the priority areas for strengthening palliative care services in NSW. The values and operating statements articulate the way forward, and are supported by five planning priorities.

- Priority 1: Improving NSW palliative care service planning & delivery
- Priority 2: Implementing the Standards for Providing Quality Palliative Care for all Australians
- Priority 3: Improving the palliative care workforce capacity
- Priority 4: Improving palliative care data
- Priority 5: Strengthening evidence based practice

Area Health Services are required to develop *Palliative Care Service Plans*, with support and guidance from SCIP. Each Area *Palliative Care Service Plan* should reflect the priorities of the *NSW Palliative Care Strategic Framework*. Areas must lodge their plans with SCIP, which will review them as necessary in partnership with the Department of Health to ensure they align with the *Strategic Framework*.

SCIP will also take a lead role in developing the *NSW Palliative Care Service Development Plan* and work in partnership with the Children's Hospital at Westmead on the *NSW Paediatric Palliative Care Service Development Plan*. The *NSW Palliative Care Service Development Plan* for paediatric and non paediatric patients will also be used to align *Area Health Service Palliative Care Service Plans*.

IMPLEMENTATION

The *Strategic Framework* will be implemented through the *NSW Palliative Care Service Development Plan* and the *NSW Paediatric Palliative Care Service Development Plan*. Strategies from these plans will be incorporated into *NSW Area Health Service Palliative Care Service Plans*. Implementation at an AHS level is being supported by the Palliative Care Service Development Officer Network.

The Palliative Care Advisory Group (PCAG) will provide advice during the implementation process, and the *Palliative Care Strategic Framework* will be reviewed in 2013.

REVISION HISTORY

Version	Approved by	Amendment notes
January 2010 (PD2010_003)	Director-General	Replaces the <i>NSW Palliative Care Framework</i> (2001) not released as a policy. Issues 2009 version.

ATTACHMENTS

1. NSW Palliative Care Strategic Framework

NSW Palliative Care Strategic Framework 2010-2013

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Foreword

In the last 50 years the experience of dying has changed in Australia. Australians are living longer than ever before and are also experiencing significant periods of illness and disability due to chronic health conditions that bring with them an array of physical, psychological and social challenges.

Current demographic and epidemiological data identifies population trends that are likely to increase the demand for palliative care. The key drivers behind the growth in demand include population ageing and changes in community expectations for health care service provision.

Most Australians die from exacerbation of a chronic or long-standing condition; in other words, their death is 'expected' and care provision will become primarily focussed on quality of life in the later stages of disease progression. Accordingly, palliative care has to be recognised as core business for health services.

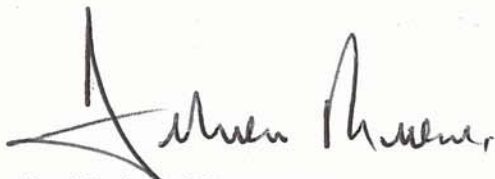
Palliative care services provide coordinated medical, nursing and allied health care, delivered whenever possible in the environment of the person's choice. Palliative care involves the provision of physical, psychological, emotional and spiritual support for patients and their families, friends and carers. It aims to respect the dignity, needs and wishes of the person who is dying with specific attention given to the needs of different cultural and religious groups.

Although it is commonly linked with cancer by people unfamiliar with its practice, palliative care is in fact broader than this and is defined as 'care provided for all people of all ages who have a life limiting illness, with little or no prospect of cure, and for whom the primary treatment goal is quality of life'.

There is increasing recognition that in many cases, palliative care can be more effectively and efficiently provided in the community setting. Providing more support for dying-in-place will help to meet patient and carer needs and preferences, and at the same time help to manage demand for acute care services.

The *NSW Palliative Care Strategic Framework 2010 – 2013* provides a model for the development and strengthening of palliative care service provision, both specialist and generalist, over the next four years. It has been prepared in consultation with representatives from State and Commonwealth Governments, service providers, clinicians, academics, consumer groups, and state advocacy groups.

Over the next four years, NSW Health will work towards achieving our vision for the future of palliative care in NSW – *that the palliative care needs of patients, their carers and their families across NSW are met by: responsive, multidisciplinary health care services working in partnership.*



Prof Debora Picone AM
Director-General, NSW Health

22/11/09

1. Introduction

1.1 Scope and purpose of the document

The *NSW Palliative Care Strategic Framework* builds on and replaces the *NSW Palliative Care Framework (2001)*.

The *Strategic Framework* is aligned with the goals of the National Palliative Care Strategy around: awareness and understanding; quality and effectiveness; and partnerships in care.

Within the context of the State Plan and the State Health Plan, the *Strategic Framework* sets out five priority areas for strengthening palliative care services in NSW.

These five priorities of the *Strategic Framework* will be reflected in the *NSW Palliative Care Service Development Plan* and the *NSW Paediatric Palliative Care Service Development Plan*. Strategies from these plans will be incorporated into *AHS Palliative Care Services Plans*.

The Statewide Centre for Improvement of Palliative Care (SCIP) has been established to provide leadership for palliative care service planning and to support the implementation of the *Strategic Framework*.

In 2006, the NSW Department of Health approved \$1.49 million recurrent funds for the establishment a Palliative Care Service Development Officer (SDO) position in each AHS. These officers will form a network of officers across the state and play an integral part in the implementation of the strategic direction for NSW Palliative Care services.

1.2 What is palliative care?

According to the World Health Organisation:

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 people 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.*
- *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.¹*

In addition the World Health Organisation defines palliative care for children as:

- *the active total care of the child's body, mind and spirit, and also involves giving support to the family.*
- *It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.*
- *Health providers must evaluate and alleviate a child's physical, psychological and social distress.*
- *Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of the available community resources; it can be successfully implemented even if resources are limited.*
- *It can be provided in tertiary care facilities, in community health centres and even in children's homes.²*

1.3 Causes of death in NSW

Deaths from all causes has decreased by 22% in men over the last ten years and by 19% in women, however the rate of decline in deaths from potentially avoidable causes was 36% in men and 32% in women which coincides with ongoing reductions in risky behaviours such as smoking, sedentary behaviour and risk-drinking, which lead to disease.³

In 2006, there were 739.6 male deaths per 100,000 and 494.5 female deaths per 100,000 deaths from all causes in NSW.

The largest contributor to these deaths was cardiovascular diseases 248.9 deaths per 100,000 males and 176 deaths per 100,000 females.

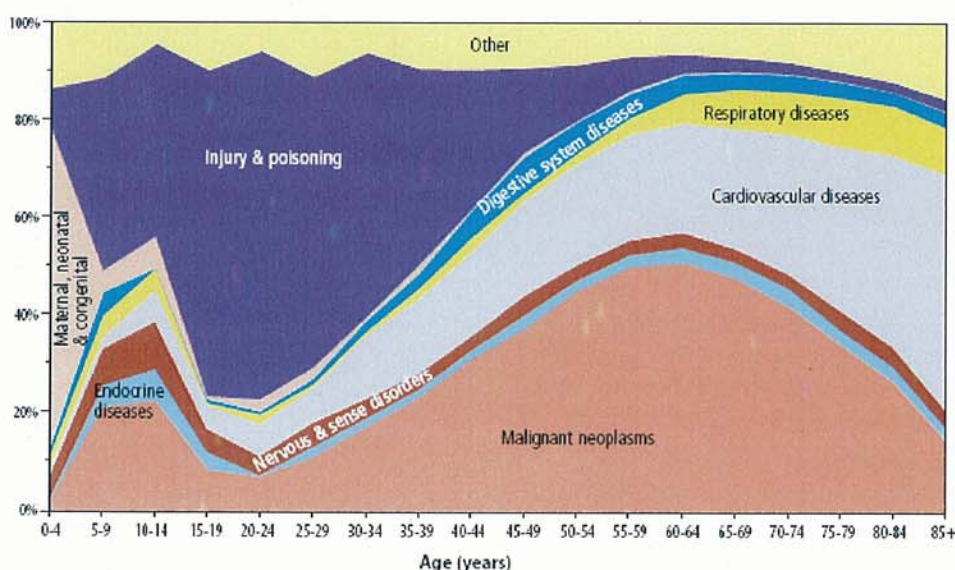


Figure 1.3.1: Percentage contribution of leading causes of death by age, NSW 2006⁴

The second most significant cause of death in NSW in 2006 was the estimated 13,099 deaths caused by various types of cancer.

In the same year a further 34,654 new cases of cancer were diagnosed and reported. Improved treatments for cancer have led to lower mortality rates. In 2006 the lowest mortality rate was recorded, since 1972 when the NSW Cancer Registry was established, falling 16% in males and 11% in females.

Despite these statistics cancer patients comprise approximately 85-90% of the palliative care service caseload. The decreasing number of deaths from cancer, combined with the increasing number of deaths from non-malignant causes, indicates the need for a review of existing models of care and funding arrangements to ensure equitable access to needs based palliative care.

1.4 Palliative care services in NSW

Palliative Care services are provided across a range of healthcare settings from hospital to community care.

According to the *Descriptive Overview of Palliative Care Services in NSW*⁶, in 2007 there were a total of 367.87 full-time equivalent (FTE) palliative care staff in NSW comprising:

- 89 FTE medical staff, including 43.6 staff specialists;
- 178.8 FTE nursing staff, including 57.4 clinical nurse consultants (CNCs) and 119.4 community-based Community Nurse Specialists (CNSs) / registered nurses; and
- 100 allied health staff, including 27 social workers and 26.6 bereavement counsellors.

A total of 348 designated palliative care beds were identified, of which 277 were in metropolitan areas, and 71 were in regional and rural NSW. The total figure excluded acute care beds in public hospitals used by patients being managed by palliative care teams.

Dedicated palliative care institutions (hospices) exist in only two Area Health Services in NSW. Principal referral hospitals are concentrated in large urban areas.

The *Descriptive Overview of Palliative Care Services in NSW* identified that outside of the Hunter New England AHS, there was only one palliative care staff specialist in regional / rural NSW. People living in rural and remote areas of Australia generally experience higher mortality than those from metropolitan areas due to geographic isolation, socioeconomic disadvantage, shortage of health care providers, less access to health services, greater exposure to injury risks, and larger Aboriginal populations with a higher prevalence of health risk factors and diseases.

1.4.1 Palliative care service models

In 2003, the NSW Department of Health commissioned the Palliative Care Association of NSW to conduct a review of palliative care services. The review revealed a high degree of variability in the structure and resourcing of palliative care services across the NSW health service.

A *primary palliative care service* refers to the group of services, which cover the continuum of care required for all people who are experiencing a life limiting illness with little or no prospect of cure. This incorporates general practitioners, community nurses and allied health staff and other specialists services (e.g. medical oncology, aged care) working in the community, residential aged care facilities or acute care hospitals. These are the first contact carers at the time of diagnosis. These service/professionals may have existing relationships with the patient, or be providing interventional care in conjunction with more palliative approaches.

A *specialist palliative care service* includes clinicians with recognised skills, knowledge and experience in palliative care. This level of service is appropriate for patients with a life limiting illness whose condition has progressed beyond curative treatment, or patients who choose not to pursue curative treatment.

The person with the illness, their family, friends and caregivers are all recognised as people to whom care is provided.

The specialist team at a minimum includes:

- Director of Palliative Care on an area basis
- Medical practitioner with qualifications and/or experience in palliative medicine
- Clinical Nurse Consultant with qualifications in palliative care nursing
- Nurse Practitioner (Palliative Care)
- Social worker with palliative care expertise
- Formalised access to bereavement support
- Formalised access to pastoral care.

The role of the specialist palliative care service supports and complements the care provided by primary care services. In particular, specialist palliative care services provide care for patients with complex or unstable symptoms or to meet other high level needs associated with a life-limiting illness.

Specialist palliative care services provide interdisciplinary assessment, consultation and when required ongoing care for patients in conjunction with their primary care service providers and the patient's caregivers. Specialist care may be episodic and ongoing partnerships with primary care providers are necessary to ensure the development of a single system of care with seamless referral and case management of patients.

Metropolitan Service Model

Currently, a typical palliative care service model in a metropolitan AHS comprises:

- Patient beds either in acute or sub-acute public hospitals or in a third schedule hospital;
- Inpatient consultations in all hospitals in the AHS (including private hospitals);
- A community medical and / or nursing service.

Rural Service Model

A typical rural palliative care service model comprises:

- A team of nurses covering vast distances;
- Fly in/out doctors funded through the Medical Specialist Outreach Assistance Program (MSOAP). MSOAP provides for an agreement between the treating doctor and AHS;
- no inpatient palliative care facilities.

Paediatric Services

Paediatric palliative care services are currently provided by metropolitan Children's Hospitals – Children's Hospital Westmead, Sydney Children's Hospital and John Hunter Children's Hospital. Each of these hospitals offer integrated palliative care services providing care at home, in hospital and respite/hospice care through the statewide children's hospice.

1.5 NSW Role Delineation Framework for Palliative Care

The *NSW Role Delineation Framework for Palliative Care (2007)* was developed to provide a consistent and common language for describing and differentiating palliative care services. Thus the Role Delineation Framework outlines the relationship between specialist and primary care services, and defines three levels of specialist palliative care services in terms of their resources and capability.

The Role Delineation Framework describes the complexity of clinical activity and specifies the staff profile, support services and other requirements recommended to ensure that effective, high quality services are available to meet the needs of patients and their carers and families.

Table 1 describes the complexity of clinical activity undertaken by specialist palliative care services.

Table 1: Specialist Palliative Care

Level	Clinical Activity Undertaken
1	<p>Provide a specialist palliative care consultation and direct care service to patients whose needs exceed the capability and resources of primary care providers.</p> <ul style="list-style-type: none"> – Provides specialist palliative care for patients and their families where assessed needs exceed the resources capability of primary care providers. – Provides assessment and care consistent with the needs of the patient, caregiver and family and within available service capability and resources. – Provides consultation and support to primary care services managing the care of people with life-limiting illness in community, acute care hospitals and residential aged care facilities. – Provides ongoing care to patients with complex, unstable conditions not restricted to physical symptoms but including psycho-emotional, social and spiritual problems. – Provide 24/7 specialist support and advice for registered patients and carers, including patients in residential aged care facilities and acute care hospitals. – Provides education to primary care providers. – Participates in education programs to develop specialist palliative care skills. – Participates in research and quality activities. – Has access to designated/dedicated inpatient palliative care beds.
2	<p>As per Level 1 but also:</p> <ul style="list-style-type: none"> – Provide support and consultation to Level 1 services within local area for patients who have complex problems (physical, emotional, social or spiritual). – Provide or contribute to education to support Level 1 specialist providers as appropriate – Participates and/or provides leadership in collaborative research activities. – Capability for registrar training under supervision of Fellow.
3	<p>As per Level 2 but also:</p> <ul style="list-style-type: none"> – Provide for the needs of patients with complex end of life care issues/problems referred either directly or through Specialist Level 1 or 2 services. – Provide consultation-based service for Level 2 Palliative Care Services outside of local area (e.g. for rural or remote area services) through formal network agreements.

As Figure 1.5.1 demonstrates, the majority of the population will experience a relatively uncomplicated, although potentially distressing trajectory following the point of diagnosis (Group A). Those patients mainly receive primary health care service.

Some patients may experience episodes of increased distress associated with physical, emotional or social consequences of their illness (Group B). These episodes are of variable duration and intensity but require additional support or intervention from professionals skilled in palliative care. When appropriately managed these patients are frequently stabilised and may be referred back to primary care services for ongoing care.

A smaller subset of people (Group C) will experience problems of high intensity, complexity and/or frequency. The needs of these patients generally exceed the capacity of primary services. These patients will receive direct care from the specialist service, although the primary care service will remain involved.

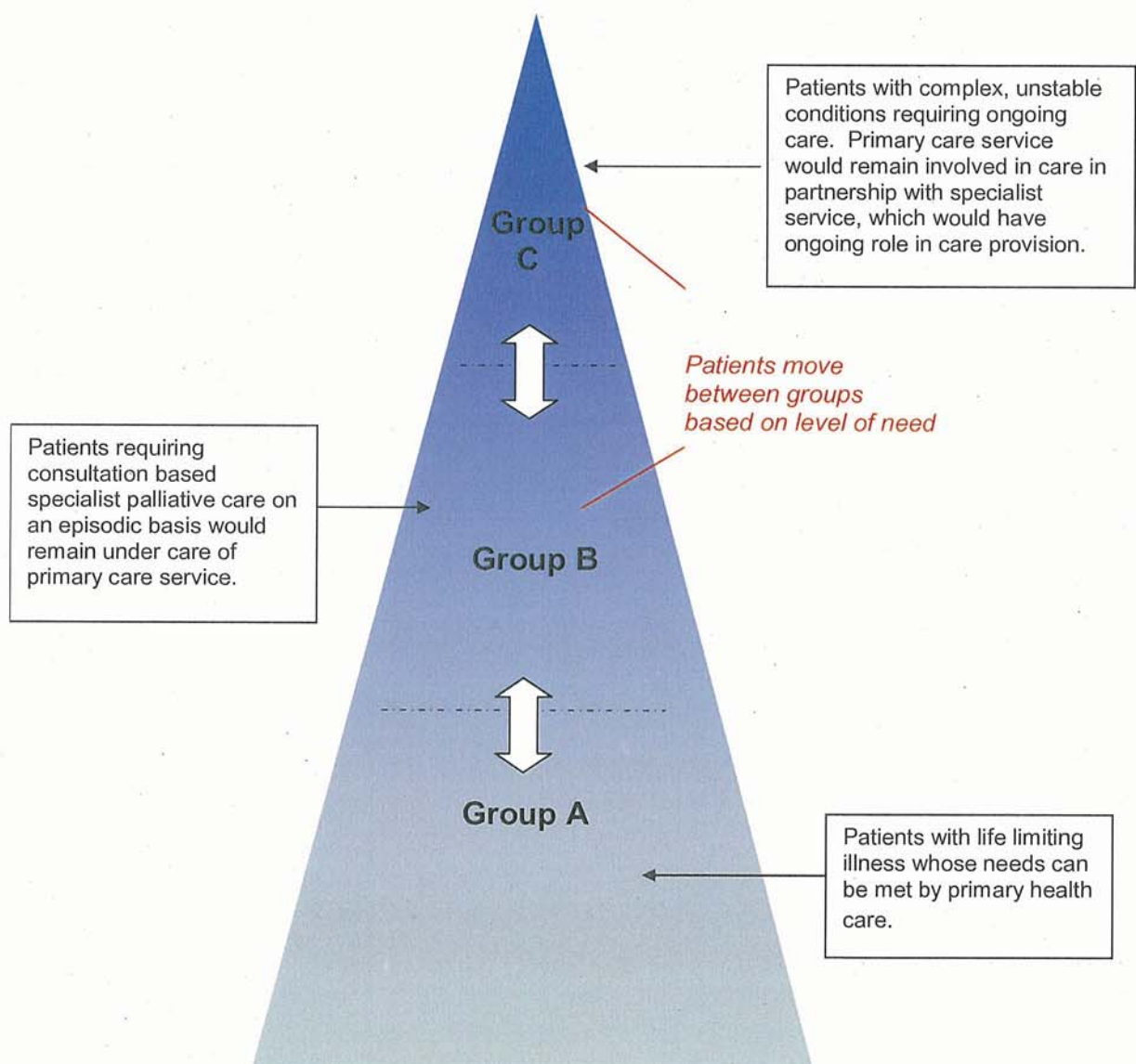


Figure 1.5.1: Health care services and patients with a life limiting illness

1.6 Challenges in the provision of palliative care in NSW

The challenges in the provision of palliative care in NSW are many and varied. A summary of some of the more significant challenges are outlined in this section, as well as addressed through the priorities outlined in section four.

The *Descriptive Overview of Palliative Care Services in NSW (2007)* identified the following information deficits:

- lack of an integrated data collection system in relation to palliative care service delivery; and
- very little information able to be reported in relation to expenditure on palliative care.

For regional and rural AHSs there are particular challenges. As previously noted, the number of designated palliative care beds in regional / rural AHSs is relatively low, with some regions experiencing GP shortages, and in general there are no locally based medical palliative care specialists. To address this shortfall, medical specialists from metropolitan AHS make fortnightly or monthly visits to some regional/rural areas.

The *Descriptive Overview* noted that all regional/rural AHS have specialist palliative care nurses who provide support and advice to local community nurses and general practitioners.

These arrangements for rural areas will be difficult to sustain in the long term, and need either to be formalised or alternative long-term sustainable solutions identified to meet the required standards.

Workforce recruitment and retention, especially with regard to the medical workforce, is already a significant issue. There is a need to enhance workforce capacity to ensure access to services across NSW.

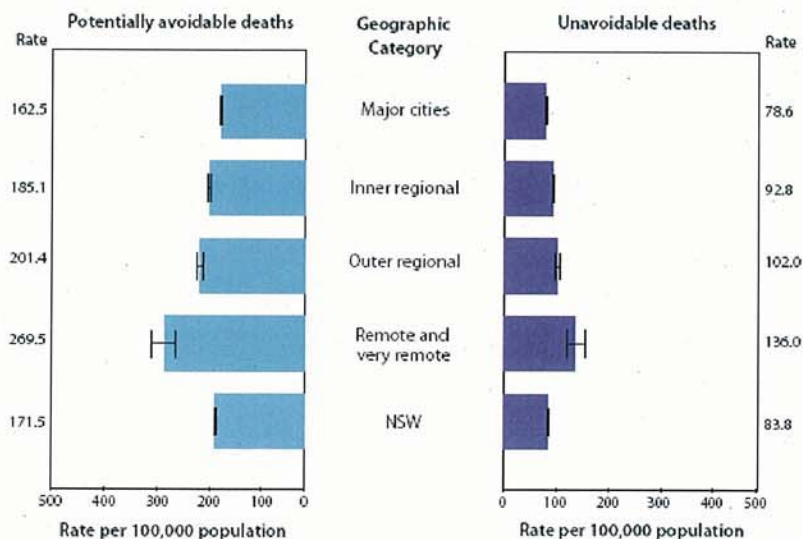


Figure 1.6.1: Potentially avoidable and unavoidable deaths by remoteness, persons aged under 75 years, NSW 2002 – 2006 combined⁶

2. The Policy Context

2.1 National policy

In October 2000 the Australian Health Ministers' Advisory Council (AHMAC) endorsed the *National Palliative Care Strategy*.⁷ This strategy is a partnership between the Australian government, state and territory governments, palliative care service providers and community-based organisations, and sets out the Australian Government's strategy for palliative care.

The Strategy guides the development and implementation of palliative care policies, strategies and services and provides a framework that promotes consistency across Australian jurisdictions in terms of the quality and delivery of palliative care that is accessible to all people who are dying.

The *National Palliative Care Strategy* has three goals:

1. 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 of care.
2. To support continuous improvement in the quality and effectiveness of all palliative care service delivery across Australia.
3. To promote and support partnerships in the provision of care for people who are dying and their families, and the infrastructure for that care, to support delivery of high quality, effective palliative care across all settings.

Under the Council of Australian Governments (COAG) *National Partnership Agreement on Hospital and Health Workforce Reform*, the Commonwealth will provide \$165.6M over 4 years (2009/10 to 2012/13) to NSW to enhance subacute care services. The National Partnership Agreement for Subacute Care includes Palliative Care, Rehabilitation, Geriatric Evaluation and Management, and Psychogeriatric Care.

A five per cent increase in the number of services provided per year has been identified as a headline target under the Agreement. Other measures reflect access, workforce capacity, patient outcomes, quality, continuity of care, timeliness of care and efficiency.

The fourth edition of the *Standards for Providing Quality Palliative Care for all Australians*⁸ (the Standards) was released in 2005, and aims to support quality management and improvement activities or benchmarking at a local and state level.

The Standards are intended to be read in conjunction with the Palliative Care Australia publications *A Guide to Palliative Care Service Development: A population based approach*⁹ and *Palliative Care Service Provision in Australia: A Planning Guide*¹⁰. Together, the three documents intend to provide consistent advice and direction to States and Territories with respect to palliative care.

The National Standards Assessment Program (NSAP) provides a mechanism for services to undertake a standardised self assessment against the Standards, and a process by which they can report the outcomes for the purposes of meeting jurisdictional requirements or benchmarking.

2.2 NSW policy

2.2.1 Palliative care policy

The *NSW Palliative Care Framework 2001* set out a number of directions for both Area Health Services and the NSW Department of Health to pursue. Continuing work in progress includes: development and implementation of data collection systems, quality standards and outcome measures, and an evaluation of the progress made under the Framework, with a view to further developing palliative care policy.

The *NSW Palliative Care Strategic Framework* replaces the *NSW Palliative Care Framework 2001*. The *Strategic Framework* will build upon the work achieved under the 2001 Framework, and will also reflect current national palliative care policy and priorities.

The *NSW Role Delineation Framework*¹¹, published as a Guideline in 2007 (GL2007_022), provides both a mechanism to ensure integration of specialist and primary palliative care providers, and a guideline for the resourcing and responsibilities of the three levels of specialist palliative care service providers. Application of the *Role Delineation Framework* will improve equity of access to palliative care services, provide a single system of care incorporating both specialist and primary care providers, and ensure resources are allocated according to level of need.

Two further policy tools will be developed to give focus to the application of the *Strategic Framework* in service planning. The *NSW Palliative Care Service Development Plan* will be developed to align with the *Strategic Framework* to provide guidance to AHS for implementation. The *NSW Paediatric Palliative Care Service Development Plan* will also guide the development, implementation and evaluation of services for paediatric palliative care patients in a way that is tied to the priorities articulated in the *Strategic Framework*.

Each AHS will need to develop their own *AHS Palliative Care Services Plan* to identify strategies for implementing the *Service Development Plan* and the *Paediatric Service Development Plan*.

An overview of the national and state policy context can be found below in Figure 2.2.1 (overleaf).

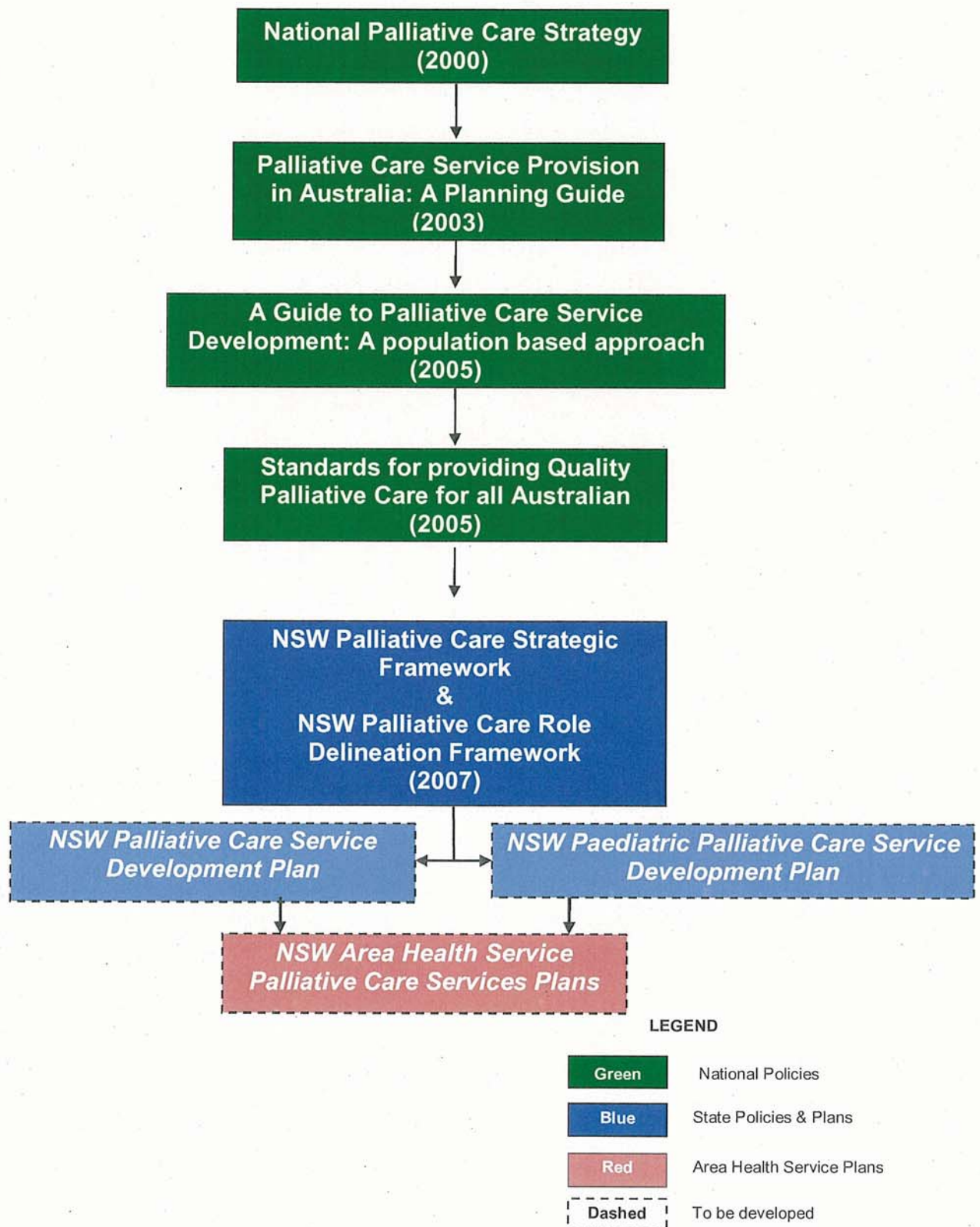


Figure 2.2.1 National, State and AHS Palliative Care Policy Flow Chart

2.2.2 The broader NSW policy context

NSW Health's key goals are to: keep people healthy; provide the health care that people need; deliver high quality services; and manage health services well. The Strategic Framework will assist the NSW health system to achieve its key strategic directions with respect to palliative care services.

The *NSW State Plan*¹² is the NSW Government's long term plan to deliver the best possible services to the people of NSW. The *NSW State Plan* is supported by the *State Health Plan*¹³, which reflects the health priorities in the State Plan and addresses the challenges that lie ahead using the seven Strategic Directions identified during the consultation for *Future Directions for Health in NSW – Towards 2025*.¹⁴

The expected contribution of the Strategic Framework towards implementation of the *NSW State Plan* and the *State Health Plan* is set out in Table 1 and Table 2.

Table 1: State Plan

Priority	State Plan Priority	How the Strategic Framework will contribute
Healthy Communities	Improve and maintain access to quality healthcare in the face of increasing demand	Improved access to healthcare services for people receiving end of life and palliative care. Improved linkages between primary, community and specialist care services for people receiving palliative care.
	Improved survival rates and quality of life for people with potentially fatal or chronic illness	Improved quality of life for people receiving end of life and palliative care.
	Reduced potentially preventable hospital admissions	Enhanced capacity to provide palliative care in the home / community setting including residential aged care facilities.

Table 2: State Health Plan

Strategic Direction	State Health Plan Strategic Direction	How the Strategic Framework will contribute
SD2	Create better experiences for people using health services	Improved end of life and palliative care service delivery outcomes. Greater support for the carers and family members of people receiving end of life and palliative care.
SD3	Strengthen primary health and continuing care in the community	Improved capacity to deliver end of life and palliative care services in the community.
SD4	Build regional and other partnerships for health	Improved linkages, both within the NSW Health system and with external service providers, for people receiving end of life and palliative care.
SD5	Make smart choices about the costs and benefits of health services	Decreased number of avoidable hospital admissions. Improved support services and treatment options for people who choose to die at home.
SD6	Build a sustainable health workforce	Improved support structure and workforce development initiatives for specialist and generalist palliative care health professionals.

2.2.3 Supporting policies and strategies

The *Palliative Care Strategic Framework* also takes into account, and supports the implementation of, the following key NSW Health documents:

*Caring Together: the Health Action Plan for NSW*¹⁵ is the NSW Government's response to the Special Commission of Inquiry into Acute Care Services in NSW Public Hospitals. Creating a stronger, more flexible and sustainable health system are primary concerns of *Caring Together*. This requires not only improving hospital services, but also community-based services – and how these services integrate.

Key areas for action will include role delineation; clinical innovation; improved teaching training and research; improved use of clinical and other information; quality and safety frameworks, better coordination between hospital and community based care and strong local partnerships.

NSW Health is developing a strategy to improve community-based health service delivery across NSW in response to the Community Health Review 2008. Taking into account health reforms nationally, and the further implementation phases of *Caring Together*, the strategy will outline important actions to improve primary health care services across NSW.

The *Integrated Primary and Community Health Policy 2007 – 2012*¹⁶ (PD2006_106) is a five-year plan to provide comprehensive and well-coordinated primary and community health care for the people of NSW. It aims to ensure that the activities of the primary and community health sector are integrated, both internally and with other parts of the NSW health system. Implementation of this policy will improve access to, and continuity of, service provision for people including those with a life-limiting illness, their carers and their families.

The *NSW Carers Action Plan 2007-2012*¹⁷ (PD2007_018) sets out five priorities for action to improve the quality of life for carers and the people they care for, these are:

- 1) Carers are recognised, respected and valued
- 2) Hidden carers are identified and supported
- 3) Services for carers and the people they care for are improved
- 4) Carers are partners in care
- 5) Carers are supported to combine caring and work.

Implementation of the *NSW Carers Action Plan* will lead to better support for carers of palliative care patients.

NSW Health has produced 3 policy guidelines to ensure best practice in end-of-life care. *Using Advance Care Directives (NSW)* (GL2005_056)¹⁸, *Guidelines for End-of-Life Care and Decision-Making* (GL2005_057)¹⁹ and *CPR - Decisions Relating to No Cardiopulmonary Resuscitation Orders* (GL2008_018)²⁰ provide guidance for NSW Health staff in supporting patients and family to plan for future treatment choices and making end-of-life care decisions, including withholding of CPR. NSW Health is committed to implementing Advance Care Planning, the process by which a person plans ahead for health care related decisions in the event they do not have the capacity to make those decisions or communicate for themselves.

The *NSW Cancer Plan 2007-2010*²¹ focuses on five high priorities that are most likely to improve cancer results and will reduce the effects of cancer in the NSW community.

The NSW Department of Human Services – Ageing, Disability and Home Care's *Palliative Care Policy*²² provides guidance to staff in supporting clients in accommodation support services who have been diagnosed with a progressive

advanced disease or terminal illness, including guidance on accessing appropriate palliative care services from NSW Health.

An evaluation of this document has been recently undertaken and it is expected that DADHC will review and reissue the Policy in due course. The revised Policy will be a useful resource to NSW Health staff who provide palliative care services to DADHC clients.

NSW Health is mindful of the need to provide culturally appropriate palliative care services. *Aboriginal Health Strategic Plan (1999)* provides strategies to improve health outcomes for Aboriginal and Torres Strait Islander peoples and to address the issues raised in the Aboriginal health planning process in New South Wales.

The *Aboriginal Health Strategic Plan* is to be implemented in conjunction with the *Aboriginal Workforce Development Strategic Plan 2003* which forms part of the NSW Health response to address significant inequities, and to address key workforce issues for Aboriginal people employed by NSW Health.

3. A framework for planning

The *NSW Palliative Care Strategic Framework* sets out the priority areas for strengthening palliative care services in NSW. The values and operating statements articulate the way forward, and are supported by five planning priorities.

VISION FOR CHANGE

Palliative care needs of patients, their carers and their families across NSW are met by responsive, multidisciplinary health care services working in partnership

VALUES

- **Equity** – ensuring equal access to palliative care services for people with equal need, irrespective of personal characteristics such as gender, cultural background or place of residence
- **Access** – providing responsive, culturally and linguistically appropriate end of life and palliative care services, made available locally whenever possible
- **Community engagement** – the participation of patients, carers and communities in decision-making.
- **Responsiveness** – to local population needs through palliative care service funding, planning and provision
- **Partnerships** – developing & maintaining links with other providers who play an important role in the delivery of end of life and palliative care services
- **Multidisciplinary and evidence-based approaches** – multidisciplinary teams delivering evidence-based end of life and palliative care services to achieve optimal outcomes for patients and carers

OPERATING STATEMENTS

1. Patients, their carers and their families will be the central focus of service provision
2. Providers will work in partnership with patients, their carers and their families to enhance coordination of palliative care service delivery
3. Palliative care will be provided in a setting appropriate to patient, carer and family needs and wishes
4. The choice to die-in-place will be supported whenever possible
5. Patients carers and their families will need to make well informed decisions about the management of their health care needs
6. There will be enhanced capacity to deliver multidisciplinary end of life and palliative care services
7. There will be enhanced access to appropriate levels of primary and specialist care based on need and in accordance with agreed referral criteria
8. Palliative care services will be provided on the basis of need, regardless of the patient's age or diagnosis
9. Interventions will be based on sound evidence, be efficient and cost-effective, and will be more consistent across NSW
10. There will be a consistent approach to service funding, planning and delivery across NSW, particularly with respect to the availability of core palliative care services
11. Palliative care services will be delivered by a skilled and well trained workforce

PLANNING PRIORITIES

- Priority 1: Improving NSW palliative care service planning & delivery**
Priority 2: Implementing the Standards for Providing Quality Palliative Care for all Australians
Priority 3: Improving the palliative care workforce capacity
Priority 4: Improving palliative care data
Priority 5: Strengthening evidence based practice

4. The planning priorities

4.1 Improving NSW palliative care service planning & delivery

The *Palliative Care Service Provision in Australia: a Planning Guide*²³ outlines the minimum professional staffing needs required to ensure that palliative care is provided to those people with life-limiting illnesses who need it. Mapping AHS staff against the indicative numbers suggested in the guide will provide a reference that will assist the implementation of the *Role Delineation Framework* and will support AHS planning.

The *Role Delineation Framework* provides a clearer statewide planning approach, with shared understanding of the needs of the entire population of patients with life-limiting conditions, including their needs for primary and specialist palliative care.

Although developed in 2007, the application of the *Role Delineation Framework* has been limited. Its status as a guideline has contributed to its limited application, as has the absence of a reliable methodology.

With the *Palliative Care Service Development Plan*, the Statewide Centre for Improvement of Palliative Care (SCIP) will work in conjunction with AHSs to apply the *Role Delineation Framework* through their *AHS Palliative Care Services Plans* and provide ongoing education around its application. Ideally, AHS plans will also align closely with the *NSW Cancer Plan 2007–2010*²⁴.

Strategies from the *NSW Paediatric Palliative Care Development Plan* will also be incorporated into *AHS Palliative Care Services Plans*.

With information derived from applying these tools each AHS will be able to develop clear policies on access to services and referral criteria. It should also be possible to define resource links across AHS boundaries to ensure patients are able to move between care providers based on assessed clinical need with little disruption to their clinical care or support. This may include the development of standard referral protocols and service level agreements between AHSs.

Strong collaborative partnerships and referral networks are necessary between Justice Health and Area Health Services to ensure that appropriate palliative care services are provided to the prison population.

Further review of palliative care service delivery funding and resources is required to support equitable service provision and access across NSW. Determining palliative care expenditure at the AHS level is expected to be challenging, particularly with respect to community-based and outpatient services, where in most instances only a limited range of data/information is available.

Achieving greater clarity about palliative care funding requirements is a prerequisite for consistent and sufficient dedicated palliative care services across NSW, in line with population need. Improved data collection, reporting and analysis will assist clearer understanding of existing services, resources and to identify opportunities for improvement (see also 4.4 Improving palliative care data).

4.2 Implementing the Standards for Providing Quality Palliative Care for all Australians

The *Standards for Providing Quality Palliative Care for all Australians 2005* (Appendix 1) were developed by Palliative Care Australia for use by services and providers.

The Standards were designed to support innovation and quality improvement. The Standards were developed to complement assessment processes for accreditation. In the absence of a methodology for implementation the Standards have not been broadly applied.

The *National Standards Assessment Program* (NSAP) will enable services to undertake a multi-disciplinary self-assessment using standardised tools and processes to determine their performance in relation to the Standards.

They were specifically designed to be used in conjunction with other standards for health services, including:

- The Australian Council of Healthcare Standards – Evaluation and Quality Improvement Program (EQulP)
- Quality Improvement Council
- Royal Australasian College of General Practitioners
- Aged Care Accreditation Standards

AHSs will be required to incorporate the Standards into their *Palliative Care Service Development Plans*, for accreditation. The Standards are to be incorporated so each AHS can report on quality of care as well as performance.

In implementing the standards NSW Health will be mindful of the need to provide palliative care services that are culturally appropriate for Aboriginal and Torres Strait Islanders and Culturally and Linguistically Diverse people.

4.3 Improving palliative care workforce capacity and training

An appropriately skilled workforce is essential to enhance the availability and accessibility of palliative care services.

Palliative care education and training is currently provided in academic and health service settings. The Australian Department of Health and Ageing has developed a Program of Experience in the Palliative Approach (PEPA) which provides workshops and workforce placements, workplace learning and support networks designed to develop the palliative skills of primary health care workers.

Meeting the demand for appropriately skilled health care workers, particularly in rural, remote and outer metropolitan areas, is a challenge being faced across the NSW health system. The *NSW Health Workforce Action Plan 2005*²⁵ sets out actions to be taken at the statewide level to address these challenges.

With respect to palliative care, strategies to address workforce capacity may include:

- Promoting and enhancing palliative care education and training opportunities
- Promoting and valuing palliative care skills in health care staff working in all service settings

- Applying the *NSW Role Delineation Framework* and the *National Palliative Care Standards* to ensure that palliative care staff are working within a supportive, high-quality service structure
- Providing opportunities for palliative care staff to engage in research work
- Providing recognition and support for the role of volunteers in palliative care.

The role of the AHS Palliative Service Development Officer in each AHS includes liaison and collaboration with the Statewide Centre for the Improvement of Palliative Care (SCIP) and the NSW Department of Health. These Officers will play an important role in the identification of strategies for workforce development in each AHS.

The development of a statewide network of palliative care services, linked to implementation to the *Role Delineation Framework*, will facilitate the identification and development of further strategies for workforce capacity and training.

4.4 Improving palliative care data

A review of palliative care data currently collected as well as available data collection systems is required. Comprehensive data collection will form an integral part of the *NSW Palliative Care Service Development Plan* providing data to inform improvements in palliative care service planning and deliver and to facilitate improved service standards.

There are significant limitations to the availability of data / information regarding palliative care service provision, particularly in the community setting. Currently, there is no single, high-quality data collection system in place for primary and community health services, and consequently there is no reliable information regarding palliative care interventions, activity or expenditure.

The NSW Department of Health is currently working on developing the NSW Primary, Community and Outpatient Care Data Collection. Once operational, this data collection will provide a more comprehensive picture of palliative care service provision than is currently available. Information from this data collection will assist in identifying gaps and variations in service provision, and enable improved palliative care service planning.

Consideration will also be given to the Australian Government sponsored palliative care data collection systems. These include the Australian National Subacute and Non-Acute Patient Classification (SNAP) and Palliative Care Outcomes Collaboration (PCOC). Improved data collection is a key output of the National Partnership Agreement on Subacute Care.

Palliative care is one of five case types that form the SNAP classification system, which is supported by Synaptix¹ in designated in-patient units. It is a statewide collection, which allows for benchmarking of functional outcomes across services, planning of services and providing appropriate funding and a greater understanding of the diversity that exists within sub-acute and non-acute care. SNAP data:

- Identifies the cost of this type of care for appropriate resource allocation
- Establishes a requirement for clinical data to be collected consistently, so allowing comparison between services
- Helps with service planning and clinical benchmarking
- Provides the potential to track patients through the continuum of care and show activity within services.

¹ A data collection tool

Data derived from the SNAP classification system will provide a more accurate description of palliative care service provision within the subacute/non-acute setting than is currently available. In turn, this data will provide valuable information to assist in the allocation of resources for end of life and palliative care services.

In addition the Commonwealth Department of Health and Ageing funded a consortium of universities to operate PCOC which is a voluntary quality initiative aiming to assist palliative care service providers to improve practice. PCOC collects information from voluntary participating services about the palliative care service, the person receiving care, administrative details about the period of care and clinical characteristics. PCOC data enables better planning and management of services to meet population needs.

4.5 Strengthening evidence based practice

Strengthening palliative care evidence based practice is an essential part of continuing quality improvement of palliative care and ensuring best practice by both palliative care services and generalist health services.

Improving palliative care research in NSW is closely linked to the ongoing development of Level 3 specialist palliative care services. These services will need to engage with academic institutions and primary care providers to develop research programs to improve quality, clinical management and continuity of care.

Developing Level 3 specialist palliative care services as research centres will increase research opportunities for all palliative care staff. At the same time, Level 3 services can act as a focus for educational and training activities.

The NSW Department of Health will examine strategies for improving the dissemination of research findings. A statewide network of Palliative Care Service Development Officers will facilitate the dissemination of research findings.

5. Implementation and Monitoring

5.1 Implementation of the Framework

The *Strategic Framework* will be implemented through the *NSW Palliative Care Service Development Plan* and the *NSW Paediatric Palliative Care Service Development Plan*. Strategies from these plans will be incorporated into *AHS Palliative Care Services Plans*.

Implementation at an AHS level is being supported by recurrent annual funding of \$1.49M to employ Palliative Care Service Development Officers.

The Statewide Centre for Improvement of Palliative Care will report on progress under the *Strategic Framework* and report twice annually to the Department of Health. These reports will include:

- Progress against indicators identified in the *NSW Palliative Care Service Development Plan* and SCIP's annual work plan
- Relevant activities including key highlights and challenges
- When finalised provide summary reports on AHS progress against *AHS Palliative Care Services Plans*.

The Palliative Care Advisory Group (PCAG) will provide a consultative mechanism during the implementation process and provide advice where required.

The Palliative Care Strategic Framework will be reviewed in 2013.

6. Acronyms

AHMAC	Australian Health Ministers Advisory Council
AHAC	Area Health Advisory Council
AHS	Area Health Service
AN-SNAP	Australian National Subacute and Non Acute Patient Classification
CHW	Children's Hospital at Westmead
CNC	Clinical Nurse Consultant
CNS	Clinical Nurse Specialist
DADHC	Department of Ageing, Disability and Home Care
EOI	Expression of Interest
EQulP	Evaluation and Quality Improvement Program
FTE	Full Time Equivalent
HACC	Home and Community Care
NMDS	National Minimum Data Set
NSAP	National Standards Assessment Program
NSW	New South Wales
NSWOG	NSW Oncology Group
NSWRDF	New South Wales Role Delineation Framework
PCA	Palliative Care Association of Australia
PCAG	Palliative Care Advisory Group
PCDWG	Palliative Care Data Working Group
PCIF	Palliative Care Intergovernmental Forum
PCNSW	Palliative Care NSW
PCOC	Palliative Care Outcomes Collaboration
PEPA	Program of Experience in the Palliative Approach
PHCPB	Primary Health and Community Partnerships Branch
QUT	Queensland University of Technology
SCIP	Statewide Centre for the Improvement of Palliative Care

7. Appendix

7.1 Standards for Providing Quality Palliative Care for all Australians

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

- 1 World Health Organisation, n.d. *Palliative care*. World Health Organisation, accessed 20 July 2009. <http://www.who.int/cancer/palliative/definition>.
- 2 World Health Organisation, n.d. *Palliative care*. World Health Organisation, accessed 20 July 2009. <http://www.who.int/cancer/palliative/definition>.
- 3 Population Health Division. The health of the people of New South Wales - Report of the Chief Health Officer. Sydney: NSW Department of Health. Available at: www.health.nsw.gov.au/publichealth/chorep/. Accessed September 2009.
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- 5 Hardwick, J & Gilbert, R., 2007. *Descriptive Overview of Palliative Care Services in NSW*. Sydney: Cancer Institute NSW.
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- 7 Commonwealth Department of Health and Aged Care, 2000. *National Palliative Care Strategy*. Canberra: Commonwealth Department of Health and Age Care.
- 8 NSW Health Department, 2001. *New South Wales Palliative Care Framework*. Sydney: NSW Health Department.
- 9 Palliative Care Australia, 2005. *Palliative Care Service Provision in Australia: A Planning Guide*. Deakin West, ACT: Palliative Care Australia.
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- 11 NSW Department of Health, 2007. *Palliative Care Role Delineation Framework (GL2007_022)*. Sydney: NSW Department of Health.
- 12 NSW Government, 2009. *State Plan: A New Direction for NSW*. Sydney: NSW Government.
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- 16 NSW Department of Health, 2007. *Integrated Primary and Community Health Policy 2007 – 2012*. Sydney: NSW Department of Health.
- 17 NSW Department of Health, 2007. *NSW Carers Action Plan 2007 -2012*. Sydney: NSW Department of Health.
- 18 NSW Department of Health, 2004 *Using Advance Care Directives (NSW)*
- 19 NSW Department of Health, 2005 *Guidelines for End-of-Life Care and Decision-Making*
- 20 NSW Department of Health, 2008 *CPR – Decisions Relating to No Cardiopulmonary Resuscitation*

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- ²¹ Cancer Institute NSW, 2006. *NSW Cancer Plan 2007–2010*. Sydney: Cancer Institute NSW.
- ²² Department of Ageing, Disability and Home Care *DADHC Palliative Care Policy*. NSW, DADHC.
- ²³ Palliative Care Australia, 2003, *Palliative Care Service Provision in Australia: a Planning Guide* www.palliativecare.org.au/Portals/46/resources/PalliativeCareServiceProvision.pdf
- ²⁴ Cancer Institute NSW, 2006. *NSW Cancer Plan 2007–2010*. Sydney: Cancer Institute NSW.
- ²⁵ NSW Department of Health, 2005. *NSW Health Workforce Action Plan*. Sydney: NSW Department of Health.