



ACI NSW Agency
for Clinical
Innovation

Framework for the Statewide Model for Palliative and End of Life Care Service Provision



ACKNOWLEDGEMENTS

The Palliative Care Network Executive Committee:

Dr Ghauri Aggarwal (Co-Chair)	Dr Theresa Jacques
Ms Sue Hanson (Co-Chair)	Associate Professor Craig Lewis
Mr Geoffrey Berry	Professor Liz Lobb
Dr Andrew Broadbent	Ms Coral Marks
Associate Professor Richard Chye	Ms Jenny McKenzie
Mr Peter Cleasby	Dr Yvonne McMaster
Mr Joshua Cohen	Ms Sarah Ramsey
Mr Nick Goryl	Dr Rob Wilkins
Ms Janeane Harlum	Ms Stefanie Williams

AGENCY FOR CLINICAL INNOVATION

Level 4, Sage Building
67 Albert Avenue
Chatswood NSW 2067

PO Box 699
Chatswood NSW 2057
T +61 2 9464 4666 | F +61 2 9464 4728

E info@aci.health.nsw.gov.au | www.aci.health.nsw.gov.au

Produced by: ACI Palliative Care Network

For enquiries contact:

Rob Wilkins, ACI Palliative Care Network Manager
Phone: (02) 9464 4637

SHPN: (ACI) 130041
ISBN 978 1 74187 807 3

Further copies of this publication can be obtained from the
Agency for Clinical Innovation website at: www.aci.health.nsw.gov.au

Disclaimer: Content within this publication was accurate at the time of publication.

This work is copyright. It may be reproduced in whole or part for study or training purposes subject to the inclusion of an acknowledgment of the source. It may not be reproduced for commercial usage or sale. Reproduction for purposes other than those indicated above, requires written permission from the Agency for Clinical Innovation.

© Agency for Clinical Innovation 2013

Published: May 2013
HS13-029

CONTENTS

FOREWORD	2
SECTION 1: THE CASE FOR CHANGE.....	3
1. Context.....	3
2. Introduction	3
3. What is a Model of Care?.....	4
4. Taking a Framework approach to service delivery	4
5. Vision and Scope.....	4
End of life	4
End of life care	5
Palliative care.....	5
6. The need for palliative and end of life care in NSW	5
7. An integrated framework for palliative and end of life care including specialist palliative care services and primary health services.....	6
8. Linking services to ensure seamless care at the end of life	8
9. Understanding current gaps in provision of services in NSW	9
10. The benefits of palliative and end of life care	10
Enhanced quality of life, management of pain and other symptoms	10
Improved efficiency in the health system	10
SECTION 2: A STATEWIDE FRAMEWORK FOR PALLIATIVE AND EOL CARE	11
11. A Framework for the Future	11
12. Principles underpinning the Framework	12
13. Roles and Partnerships in Implementing the Framework.....	13
14. Priority Action Areas.....	14
15. Where to from here – a road map for improvement.....	14
Supported and informed Patients, Families and Carers.....	14
Supportive and Supported Primary Care Providers, Medical Specialists and Service Providers.....	14
Local needs-based access to specialist palliative care for all people in NSW	14
Integrated and networked primary, aged and specialist palliative care services	14
Process Flow Chart for developing a Model of Care	15
16. References	16

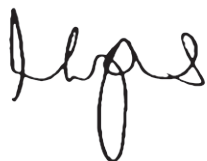
FOREWORD

The NSW Agency for Clinical Innovation (ACI) is the primary agency for promoting innovation, engaging clinicians and designing and implementing new models of care. In late 2012, the NSW Minister for Health and Minister for Medical Research, the Honourable Jillian Skinner MP launched the NSW Government plan to increase access to palliative care 2012 – 2016. The Plan calls for new models of care that foster partnerships and establish linkages across services and sectors to develop an integrated network of primary care, specialist palliative care, aged care and community services.

The ACI was tasked with the responsibility of developing these new models of care to improve patient outcomes.

This Framework is the first step in developing a statewide model for palliative and end of life care. It describes some of the complexities faced in providing quality palliative and end of life care across a range of acute, sub-acute, primary care and community settings, including the home. As a road map for improvement, the Framework will guide the work of the ACI as it engages clinicians, patients, carers, health service managers, researchers and others.

I look forward to supporting the ACI Palliative Care Network as it continues to develop a model of care that ensures everyone in NSW has access to quality care as they approach the end of their life.



Dr Nigel Lyons,
ACI Chief Executive

SECTION 1: THE CASE FOR CHANGE

1. Context

In 2011, there were 146,932 deaths in Australia, 50,661 of which were in NSW (ABS, 2013). It is broadly accepted that approximately 75% of deaths follow an anticipated course.

Palliative and End of Life Care (PEoLC) aims to enhance quality of life by managing pain and other distressing symptoms for people as they approach and reach the end of life and by providing emotional, practical, social and spiritual support to the patient, family members or carers. PEoLC can be provided in a variety of settings, such as the home (including a Residential Aged Care Facility), hospital or a local clinic. Specialist Palliative Care can be provided to patients with complex needs directly or on a consultancy basis, either in the hospital or community setting.

There has been broad acceptance supported by evidence throughout the health system, including the NSW Government plan to increase access to palliative care 2012 – 2016, that the reach of PEoLC to the people of NSW is limited under current structural and resourcing arrangements.

2. Introduction

This is a high-level Framework that will inform the development of a comprehensive Model of Care for equitable Palliative and End of Life Care Service Provision in NSW. This Framework will identify and articulate:

1. The need for taking a Framework approach to service delivery
2. The scope and vision of the Framework and the subsequent Model of Care
3. The need for palliative and end of life care in NSW
4. Current challenges that will inform our work
5. Principles that underpin the Framework

6. An integrated service framework including levels of specialist palliative care services and primary health services
7. Structural arrangements and an analysis of current service gaps
8. The benefits of palliative and end of life care in NSW
9. Roles and relationships for implementing the Framework
10. Priority action areas
11. Where to from here – a road map for improvement.

In short, this Framework lays the groundwork in developing a comprehensive Model of Care for Palliative and End of Life Care Service Provision. It describes some of the complexities, challenges and shortcomings in providing such care in a range of clinical, community and home settings for specialist palliative care providers, primary care providers including general practitioners and generalist community teams, residential aged care providers, carers and family members.

In an ideal world, developing solutions to these challenges requires a thorough understanding of the root causes for all of the challenges and problems facing palliative and end of life care service provision. However, a great deal of evidence-based work to improve the availability and quality of palliative and end of life care has occurred and continues to do so. This Framework harnesses these evidence-based solutions, literature reviews, learnings from pilot programs and practitioner insights that have been developed prior to the commencement of this work. Building on past efforts and developing partnership approaches to current developmental work in this area will be pivotal to the success of an effective model of care.

The NSW Agency for Clinical Innovation (ACI) is the primary agency in NSW for engaging clinicians in clinical improvement, including the design and implementation of new models of care. The ACI's clinical networks provide a framework for clinicians and consumers to meet across regional and service boundaries with a mandate to drive improvements in care through

innovation in clinical practice. They harness the clinical and practical knowledge of clinicians and patients to research, design and deliver best practice models of care built around the needs of patients.

3. What is a Model of Care?

The ACI develops flexible, evidence-based and patient-focused models of care, adopting the Western Australia Department of Health (2012) definition:

A Model of Care... broadly defines the way health services are delivered. It outlines best practice care and services for a person or population group or patient cohort as they progress through the stages of a condition, injury or event. It aims to ensure people get the right care, at the right time, by the right team and in the right place.

Agency for Clinical Innovation, 2013.

Models of care can be adapted to the various settings found in the NSW health system across metropolitan, regional, rural and remote NSW. When designing a new Model of Care, the aim is to bring about improvements in service delivery. Developing Models of Care is considered a key change management process and broadly follows a project management methodology (ACI, 2013). In Australia and globally, there are multiple definitions of Models of Care. Davidson et al's (2006) definition provides a relevant description of the components required to develop a Model for Palliative and End of Life Care: "An overarching design for the provision of a particular type of health service that is shaped by a theoretical basis, EBP [evidence-based practice] and defined standards" (Davidson et al, 2006).

4. Taking a Framework approach to service delivery

All people approaching the end of their life require some level of support and access to a range of health and other support services. The range and depth of services required is obviously dependent on the nature and length of the illness. A large cohort of people with a life-limiting illness can and should be supported by generalist primary health services in a range of settings: at home; in a Residential Aged Care Facility; at local medical clinics; or in hospital.

Palliative Care NSW Policy Statement, 2012, p.1.

Taking a framework approach to service delivery achieves three key outcomes by:

- Describing a 'network' of services to support people approaching and reaching the end of life
- Describing minimum expected levels of accessibility of PEOLC services to the people of NSW
- Ensuring best practice care is provided safely and meets required standards and quality.

Ultimately this Framework "shapes and guides" (Davidson et al, 2006) the development of the Model of Care: "Using a building analogy, the *framework* is the brace and girders that support the model" (Ibid p.49). It provides a roadmap for service development and improvement and draws from extensive practitioner consultations in the development of previous state planning and strategy documents, research-based evidence, policies and existing frameworks, including the newly released NSW Government plan to increase access to palliative care 2012 – 2016. Specifically, this Framework includes evidence or strategic direction from:

- *NSW Government plan to increase access to palliative care 2012 – 2016* (NSW Ministry of Health, 2012)
- *Supporting Australians to Live Well at the End of Life; National Palliative Care Strategy 2010* (Commonwealth of Australia, 2010)
- *A Guide to Palliative Care Service Development: A Population based approach* (PCA, 2005)
- *Palliative Care New South Wales Policy Statement* (PCNSW, 2012)
- *NSW Palliative Care Role Delineation Framework* (NSW Ministry of Health, 2007).

5. Vision and Scope

The vision for this Framework and the Model of Care for PEOLC Service Provision that will emerge from it is to ensure that all NSW residents have access to quality care based on assessed need as they approach and reach the end of their life.

The scope of this Framework is inclusive of both palliative and end of life care.

End of life

In this document we have used the term end of life to mean that period of time when a person is living with an advanced, progressive life-limiting illness.

Estimating when someone will die is very difficult. It is more useful to identify those for whom increasing disability and illness will lead to their death sometime in the next year.

The 'surprise' question (Lynn et al, 2000) "Would you be surprised if the person died in the next 12 months or so?" is used to identify those people who will benefit from the kind of services that help people live well while dying. These services include advance care planning, comfort care, psychological and spiritual support.

End of life care

In this document end of life care is used to describe care provided to people approaching the end of life by all health professionals, regardless of where they work in the health and aged care systems.

End of life care is an integral component of aged care services, medical and surgical care, management of chronic and complex illness, intensive care, accident and emergency care and paediatrics amongst others. All health professionals should be competent to provide care to people who are approaching the end of their life or dying.

Palliative care

In this document palliative care is used to describe designated specialist services provided by an interdisciplinary team of specialist palliative care professionals whose substantive work is with people approaching the end of life.

6. The need for palliative and end of life care in NSW

There is substantial evidence of the burden of unmet need for palliative and end of life care.

A number of current population challenges in providing PEoLC based on assessed need to all NSW residents have been identified and include:

- **The rapidly escalating demand for palliative and end of life care.** As the population ages and an increasing number of people approach or reach the end of their life, a significant burden on communities, social, aged and health care services to provide appropriate levels of support and care will occur.
- **Changing demographics of the NSW population.**

By 2049-2050 health expenditure on people over 65 is expected to increase seven-fold. For those aged over 85 years the increase is expected to be 12-fold. At the same time the number of working people (i.e. tax payers) available to support each retiree is expected to fall from 5 people today to 2.7 people in 2049-2050.

- **Concurrent health, aged and social care system pressures.** More than half of all deaths occur in a hospital (AIHW, 2011) although studies have repeatedly shown that most people would prefer to die at home if possible (Hillman, 2010). With the annual number of deaths predicated to increase from 143,900 per annum in 2011 to more than 320,000 in 2056 (ABS, 2009) there will need to be significant changes to the organisation and delivery of health care to continue to provide care even at the current level. For those older people living in residential care 88% will remain there until the end of their life.
- **Workforce capacity to provide Palliative and End of Life Care services.** Across generalist, primary care and specialist workforces there remain significant challenges in both workforce size and competency to address the needs of the community in relation to palliative and end of life care. There are significant challenges in our ability to provide sufficient qualified specialist staff, particularly medical and nursing staff and equitable and consistent access to allied health care professionals. Limited education and training for primary care workers, and availability of general practitioners and community support workers does and will continue to challenge attempts to establish primary care led models of care.
- **Gaps in access to care for regional, rural and remote communities.** The NSW Government Plan to increase access to palliative care 2012 – 2016 ('the Government Plan') identifies gaps in the delivery of palliative and end of life care for some regional, rural or remote communities (NSW Ministry of Health, 2012: 13-14). Delivery of high quality, sustainable and equitable services to these communities has been and will continue to be a challenge as these communities age and experience changes in their demographic profile.
- **Addressing the unique needs of some population groups or communities.** There are some groups in the community who have special needs in relation to palliative and end of life care. These include people with dementia, children and adolescents, indigenous Australians and those from different cultural or linguistic backgrounds. The needs of these specific groups are often particularly difficult to meet within the current service models and arrangements.

The Government Plan acknowledges the gaps in PEoLC service provision to the people of NSW. Of the 13,000 people in NSW who die of cancer each year, two-thirds receive specialist palliative care. Importantly, the report further identifies that of those people who die of conditions other than cancer where death is predictable, only about 10 per cent will receive specialist palliative care. (NSW Ministry of Health, 2012: 13)

Palliative Care New South Wales' (PCNSW) Policy Statement (2012) was produced in consultation with a broad range of stakeholders, including those involved in the delivery of palliative and end of life care. This statement highlights the significant gaps in geographic reach as well as to those with a non-cancer diagnosis:

The quality of care is largely dependent on where one lives and/or the nature of one's illness.... There is also inequitable service provision for consumers who have non-cancer life-limiting illnesses such as dementia, renal failure, heart failure, end stage respiratory disease and many others. One contributing reason is that palliative care services have historically been linked to cancer funding models and services. (Palliative Care NSW, 2012, p.1)

Access to specialist and primary care services for palliative and end of life care is not equitable across NSW, with people in regional and rural areas particularly affected.

Not all specialist palliative care services have direct access to a palliative care physician – a gap that is further pronounced in rural and regional NSW.

Three key priorities have been identified across a range of policy and strategic documents including the *National Palliative Care Strategy 2010 – Supporting Australians to Live Well at the End of Life* (Commonwealth of Australia, 2010); the NSW Government plan to increase access to palliative care 2012-2016 (Ministry of Health, 2012):

- 1. Caring appropriately for people approaching the end of life** – identification of preferred place of care, better care coordination, patient focused, goal directed care and advance care planning and access to competent and supported primary care providers
- 2. Caring for people with complex needs related to life-limiting illnesses** – needs based assessment and referral, management of refractory pain or other symptoms, management of complex social or psychological distress
- 3. Care for those who are dying** – impeccable symptom management, communication and care and support for the family.

7. An integrated framework for palliative and end of life care including specialist palliative care services and primary health services

A population based approach proposes that the target population be conceptualised as falling within three broad sub-groups, based on the complexity of their needs (Figure 1, see next page).

The *Guide to Palliative Care Service Development* developed by Palliative Care Australia (2005) provides a generic template for a collaborative, inclusive model that incorporates care provided by primary and specialist providers.

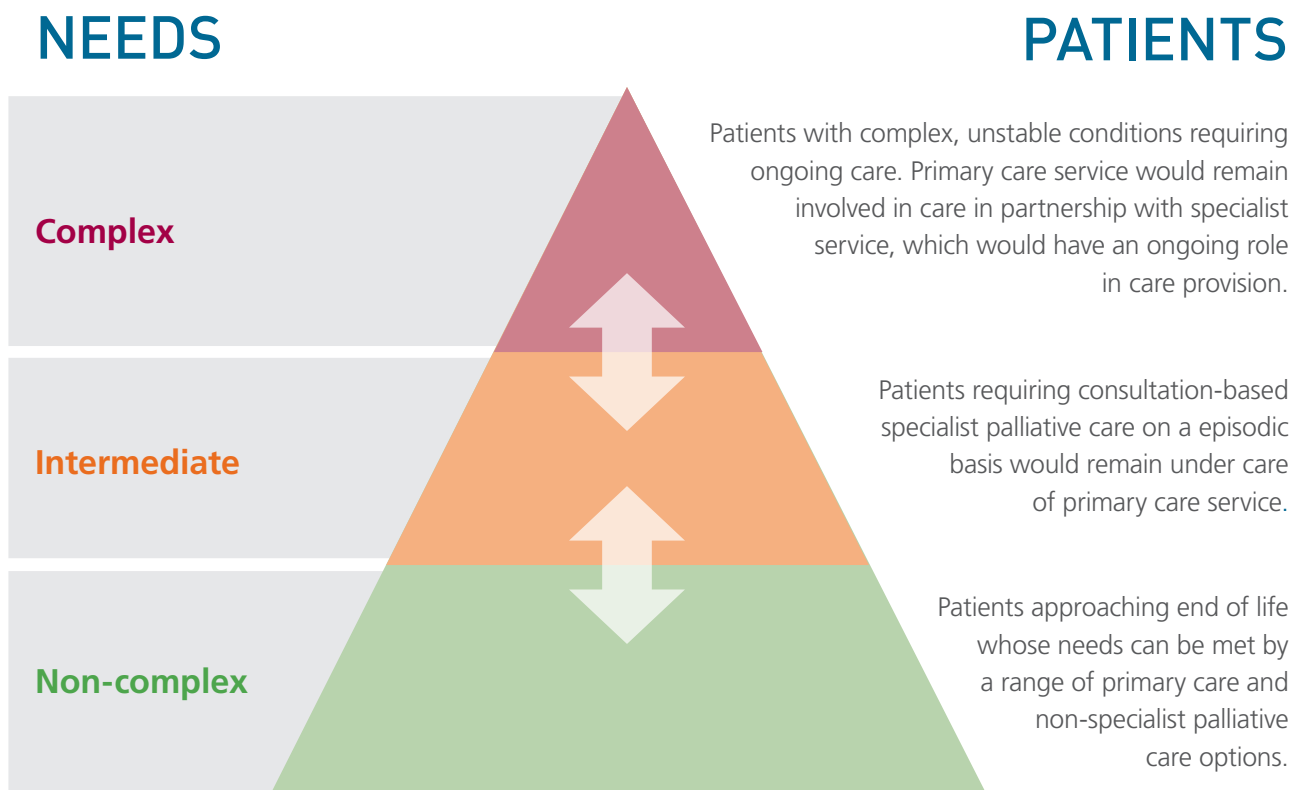
Primary care providers in the context of the planning framework include general practitioners, community and hospital based doctors, nurses, including specialists in other areas of practice, allied health staff and staff of residential aged care services whose substantive work is not in palliative care (PCA, 2005). Collectively, these primary providers represent the first contact carers at the time of diagnosis.

The NSW Palliative Care Role Delineation Framework (NSW Ministry of Health, 2007) provides a consistent and common language to describe and differentiate specialist palliative care services. The Framework also describes the relationship between specialist palliative and primary care services and defines three levels of specialist palliative care services in terms of their resources and capabilities.

Importantly, this framework also directs our work towards a range of non-palliative care specialist clinical and community settings where patients with a life-limiting illness are routinely cared for. A growing body of evidence is revealing the extensive use of inpatient services and emergency departments in the last year of life by people whose deaths are clinically expected (Forero et al, 2012; Rosenwax, et al 2011). These settings also include Intensive Care, Aged Care settings and Geriatrics Units. Home settings are also an important setting of care associated with enhanced "quality of death" (EIU, 2011) and is a key focus in the NSW Government plan to increase access to palliative care 2012-2016 (NSW Ministry of Health, 2012).

Specialist palliative care services support and complement the care provided by primary care services. These specialist services provide care for patients

Figure 1: Level of Need within the Population of Patients Approaching and Reaching the End of Life



with complex or unstable symptoms or meet other high level needs associated with a life-limiting illness. Specialist palliative care staff will, in general, have formal qualifications in palliative care (medical, nursing or allied health) or adequate experience where there is an absence of a formal training program.

Each level of specialist palliative care service describes and reflects the complexity of clinical activity undertaken by a service 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, carers and families.

Specialist Palliative Care Level 1 provide a specialist palliative care consultation and direct care service to patients whose needs exceed the capability and resources of primary care providers. Level 1 specialist palliative care should be available locally as a minimum for all patients approaching and reaching the end of their life.

Specialist Palliative Care Level 2 provide a specialist palliative care service with the additional capabilities of:

- providing support and consultation to Level 1 services within a local area for patients who have complex problems;
- providing or contributing to education to support Level 1 specialist providers as appropriate;
- participating and/or providing leadership in collaborative research activities; and
- have a capability for registrar training under supervision of a Fellow.

Specialist Palliative Care Level 3 provide for the needs of patients with complex end of life care issues referred either directly or indirectly through Specialist level 1 or 2 services. Additionally, level 3 services

- provide consultation-based services for Level 2 palliative care services outside of local area (eg for rural or remote locations) through formal network agreements;
- undertake a lead role in education and research in palliative care and has formal links with academic units;
- have conjoint appointments of senior clinical staff; and
- have a capability for registrar training under supervision of a Fellow.

8. Linking services to ensure seamless care at the end of life

Quality end-of-life care is realised when strong networks exist between specialist palliative care providers, primary generalist providers, primary specialists, and support care providers and the community – working together to meet the needs of the people (PCA, 2008b) requiring care as they approach and reach the end of their life.

Primary generalist providers and primary specialists include general practitioners, generalist community nurses and allied health staff and other specialist services or professions (eg medical oncology, aged care, geriatrics etc) working in community, residential aged care facilities or acute care hospitals. (NSW Ministry of Health, 2007)

The key responsibilities for primary care providers in providing PEOLC are outlined below.

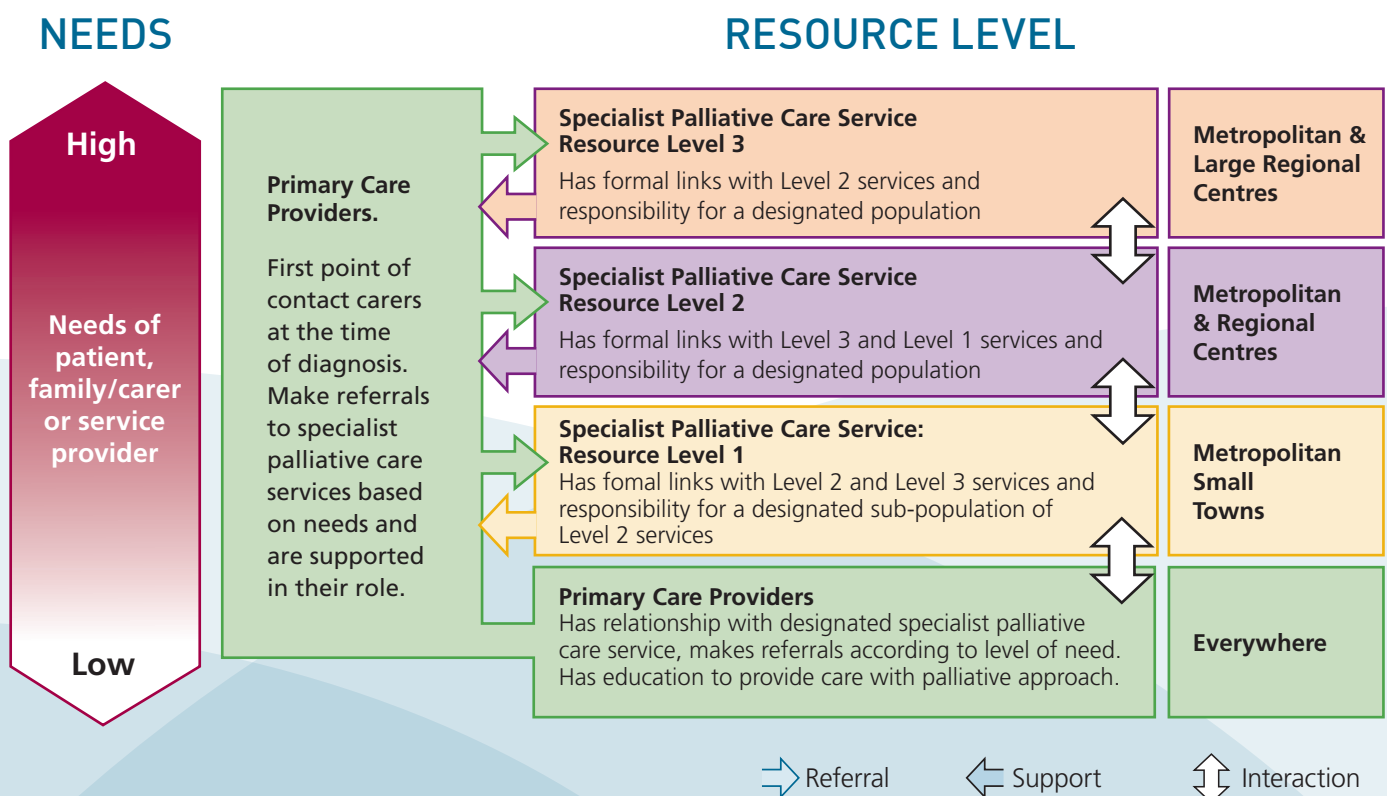
- To provide supportive care, including pain and symptom control, social, spiritual and emotional support, education and bereavement risk assessment for patients, care givers and family members.

- Primary care provides ongoing support, from diagnosis to death of the patient and support to caregivers and family members. Where primary care services are primarily responsible for care of patients approaching and reaching the end of their life, they should ensure that formal links have been established with allied health, home care and other support services required to meet the patient, caregiver and family’s needs.

In the context of providing PEOLC, primary care providers have a responsibility to:

- Undertake a holistic assessment of patients diagnosed with a life limiting illness at the point of diagnosis and on an ongoing basis;
- Implement and undertake best practice referral policy and procedures; and
- Meet primary care standards for competency in the management of patients approaching and reaching the end of their life. These standards should include competency in pain and symptom management, emotional and spiritual assessment and support, and support for loss and grief.

Figure 2: A networked approach for the care of people approaching and reaching the end of life in NSW



Source: Adapted from the Framework for Palliative Care Service Planning (PCA, 2005).

The key responsibilities for specialist palliative care services in providing PEOLC are to:

- Undertake comprehensive interdisciplinary assessment of patients referred to the service, their caregivers and family members;
- Establish formal links and referral pathways and processes with primary care services and other specialist services (such as oncology or geriatric services) that may be required to meet patient needs;
- Develop formal links with other tertiary acute care services;
- Provide consultative assessment and care based on patient, carer and family need in consultation with primary care providers; and
- Provide ongoing care for patients, carers and families with complex needs in partnership with primary care providers.

Figure 2 illustrates a networked approach to quality end-of-life care among patients, families, carers, primary care providers and specialist palliative care services.

9. Understanding current gaps in provision of services in NSW

The *NSW Government Plan to Increase Access to Palliative Care 2012–2016* describes a number of gaps in the provision of PEOLC to the people of NSW. These include gaps in:

- care provided by specialist palliative care services for people who die of cancer or of other conditions where death is predictable in the last year of life across NSW
- access to care for regional, rural and remote communities
- access to care from GPs, particularly after hours; and
- access to federally funded services such as Home and Community Care and aged care packages.

Figure 3 (see next page) from *The NSW Government Plan to Increase Access to Palliative Care 2012–2016* illustrates the scarcity of specialist palliative care services with direct access to a specialist palliative care physician in rural and regional NSW.

Additionally, the plan identifies a number of gaps that prevent people from being able to die at home. These include:

- limited availability of specialist and primary community palliative care services in rural areas and in some metropolitan areas;
- lack of 24-hour or after-hours advice and support;
- fewer incentives for GPs to provide home visits or extended consultations;
- lack of adequate support to provide coordinated and high quality palliative care in aged care facilities; and
- lack of coordination between hospital and community-based services to allow people to move quickly and easily from home to hospital and back again as their needs change.

Access to education, practice training and ongoing professional development for:

- new health professionals;
- specialists in other fields;
- primary care providers; and
- specialist palliative care providers

is an identified gap and ongoing need for a skilled and knowledgeable workforce to provide PEOLC.

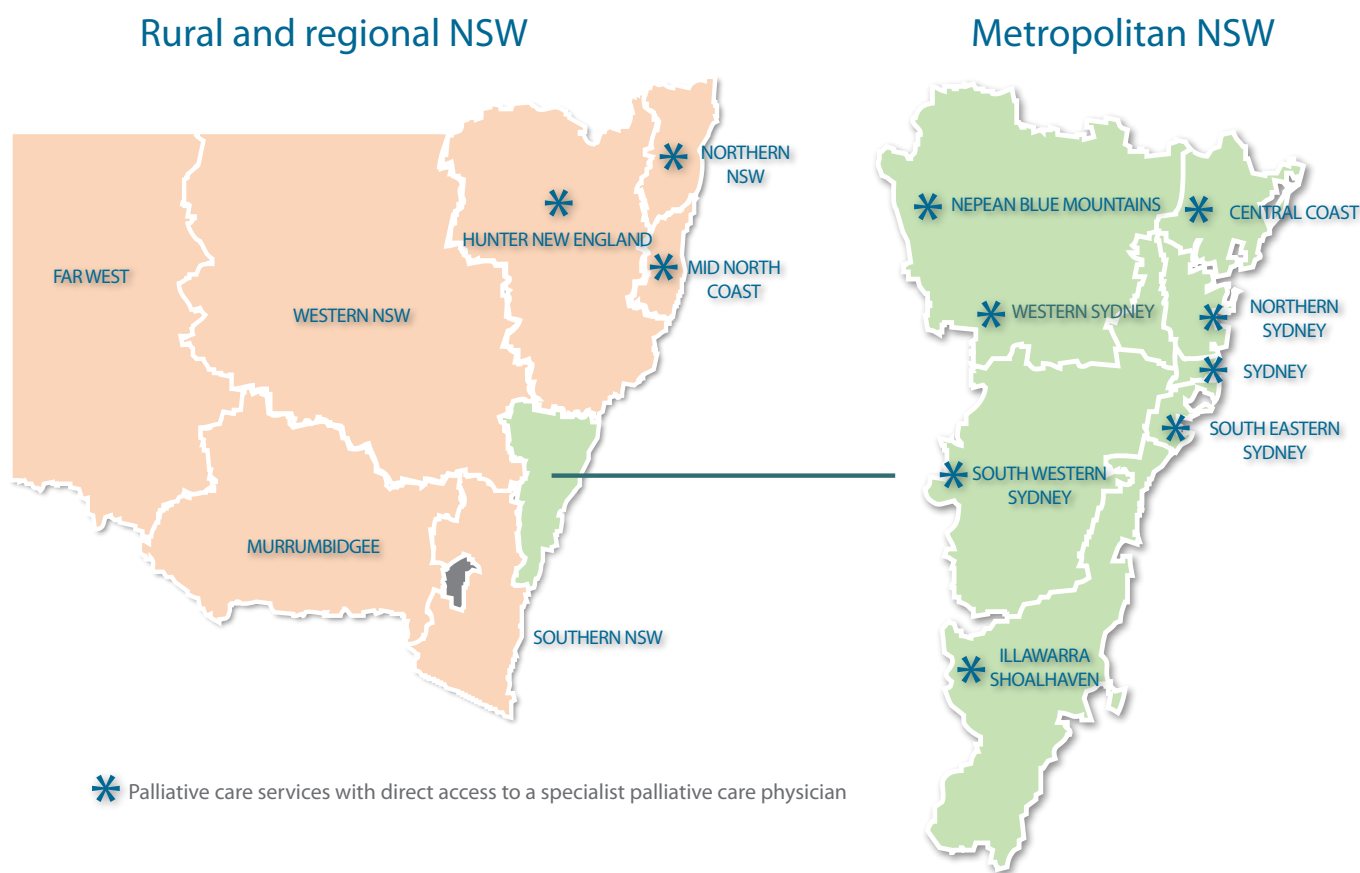
The need to redesign and reinvest in professional health education is echoed in many other state, national and international health system contexts. An independent commission of 20 academic leaders from around the world recommended comprehensive reform in the training of healthcare professionals in a Lancet report entitled *Health Professionals for a new century: transforming education to strengthen health systems in an interdependent world*. The Commission concluded that more equitable and better performing health systems require a greater emphasis on transformative learning:

Put simply, the education of health professionals in the 21st Century must focus less on memorising and transmitting facts and more on promotion of the reasoning and communication skills that will enable the professional to be an effective partner, facilitator, adviser and advocate.

(Frenk et al, 2010)

Promoting increased access to and supporting the development of innovative palliative care education, practice training and ongoing professional development for all professions will be integral to an effective PEOLC Model of Care.

Figure 3: Palliative care services with direct access to a specialist palliative care physicians (NSW Ministry of Health, 2012: 8)



10. The benefits of palliative and end of life care

Palliative care enhances communication, quality of life, symptom control, patient satisfaction, and resource utilization.

(Rocque & Cleary, 2013)

Enhanced quality of life, management of pain and other symptoms

Palliative care interventions consistently demonstrate improvement in patients' pain, control of symptoms, anxiety and relieve caregiver burden (Higginson et al (2010); Gomes B, et al (2009) and Lorenz et al (2008).

Palliative care consultancy services significantly improve the quality of end of life care instead of providing patients with unwanted, futile and distressing interventions, even when death is imminent. (Palliative Care Victoria, 2010).

Improved efficiency in the health system

Improved access to palliative and end of life care can improve the effectiveness and the efficiency of health services for the dying, and the health system as a whole. It can avoid inappropriate and preventable hospital admissions. It can also help to minimise or avoid investigations, treatments and procedures that offer no improvement in quality of life (PCNSW, 2012).

Specialist palliative care has been shown to reduce unwarranted hospital admissions (Higginson, I. et al, 2010; Gomes B. et al, 2009). The overall cost of home-based palliative care is lower than in-patient care (Gomes B. et al, 2009)

The UK National Audit Office found average savings of 30% for patients receiving palliative care in their last year of life, due to their reduced use of acute care resources (Hatzianreou, E. Et al, UK National Audit Office, 2008, p.19).

SECTION 2: A STATEWIDE FRAMEWORK FOR PALLIATIVE AND EOL CARE

11. A Framework for the Future

The development and implementation of sustainable approaches to the delivery of care to people approaching and reaching the end of life will require the collaborative and concerted effort of a wide range of community, aged and health care providers. Agreed and consistent principles that underpin this collaborative effort will provide a compass for future development of models of care, service partnerships and strategic development.

This section outlines the principles, activities, roles and partnerships that underpin the Statewide Framework and the Model of Care that will emerge from it. It sets out a road-map for service improvement by highlighting priority action areas and acknowledges the breadth of work and practitioner consultation undertaken in these areas.

12. Principles underpinning the Framework

Principle	What it means	Ideas and Programs to leverage from recommended through Consultations
Patient and family centred Care	Care that is delivered in accordance with the wishes of the patient and family	<ul style="list-style-type: none"> • Advance Care Planning tools • Education and Support for carer communication • Goals of Care
Population and Needs based care	<p>Services are planned based on population distribution and disparities in health status between different population groups and clinical cohorts are addressed</p> <p>Networked care provided on the basis of assessed patient and carer needs</p>	<ul style="list-style-type: none"> • Population based planning tools for EoL • Tools to support recognition of EoL and dying • Consistent, validated clinical assessment tools • Care navigation pathways and tools • Consistent referral and discharge criteria
Care as close to home as possible	All people approaching the end of their life in NSW should be able to access care as close to their home as possible	<ul style="list-style-type: none"> • Available and supported GP services • 24/7 access to advice and support • Local access to L1 SPCS • Available social support services • Support for carers
Accessible	People approaching the end of their life have access to local primary care, needs based access to level one specialist palliative care services and networked access to Level 2 or 3 services based on assessed need	<ul style="list-style-type: none"> • State-wide network plan for SPCS that may include the use of Pop-Up Models, Nurse led models • Protocols for accessing services
Equitable	Access to needs based care regardless of age, diagnosis, geography, culture	<ul style="list-style-type: none"> • Networked services • Models of care designed around patient journeys • Patient and family focused models of care
Integrated	Primary services, specialist acute services and specialist palliative care services are integrated to enable seamless patient transfer based on needs assessment and clear referral and access protocols	<ul style="list-style-type: none"> • State-wide SPCS Network plan • Needs based assessment tools • Access protocols • Record linkage • Minimum Data Set development • From 1 July 2013, Medicare Locals will be responsible for ensuring comprehensive face-to-face after-hours services are available across their catchments according to population need (NHPA, 2013)
Safe and effective	<p>Care meets the Australian Safety and Quality Goals for Health Care:</p> <ul style="list-style-type: none"> • That people receive health care without experiencing preventable harm • That people receive appropriate evidence-based care • That there are effective partnerships between consumers and healthcare providers and organisations at all levels of healthcare provision, planning and evaluation. 	<ul style="list-style-type: none"> • Health services regularly participate in quality improvement programs including the: • National Safety and Quality Health Service Standards • National Standards Assessment Program (NSAP) • Palliative Care Outcomes Collaborative (PCOC)

13. Roles and Partnerships in Implementing the Framework

Implementing the proposed framework will require that everybody plays their part – from patients, their families and carers through to specialist palliative care and other aged, community and health care professionals and services.

Who is involved	What is their Role
Patients	Actively participate in their care plan
Families and carers	Are supported throughout the care process including bereavement support and included in care planning
Primary care providers	Provide the first line of care to the greatest cohort of people approaching and reaching end of life. These include general practitioners, nurses, allied health professionals as well as community workers and staff of residential aged care facilities and are most often located in the community
Other medical specialists and services	End of life care provided by specialists whose substantive work is not in palliative care. For example, oncologists, geriatricians, staff in intensive care units and Emergency departments
Local palliative care services	Provide care for patients with complex or unstable symptoms or meet other high level needs associated with end of life care. They may provide episodic or ongoing partnerships with primary care providers in caring for a patient
Networked palliative care services	Have the capacity to provide a coordinated and sustained coverage of palliative and end of life care – particularly for those living in rural or regional areas of NSW. Networking arrangements can include formalised partnerships, pop-up models, consultative arrangements

The Quality Systems Assessment (QSA) program, within the NSW Clinical Excellence Commission (CEC), is based on a risk management framework which aims to evaluate the systems and processes which organisations have in place to control risks to patient safety using self assessment and independent verification. The QSA program aims to develop and conduct quality system assessments of public health organisations (PHOs)

including the fourteen Local Health Districts (LHD), St Vincent's Health Network, The Sydney Children's Hospital Network, NSW Ambulance Service and Justice Health and recommend improvements.

The QSA collected data in 2012 in relation to palliative and end of life care that will assist with the planning, implementation and evaluation of the upcoming model of care.

14. Priority Action Areas

The following have been identified as priority action areas to improve the care and support of people who are approaching and reaching the end of life in NSW.

- Supported and informed patients, families and carers
- Supportive and supported primary care providers, medical specialists and other service providers
- Local needs-based access to L1 specialist palliative care services for all NSW people
- Networked needs-based access to L2 or L3 specialist palliative care service advice and support
- Integrated and networked primary, aged and specialist palliative care services
- Education for new and existing health professionals

Each of these areas is discussed in more detail in the following section.

15. Where to from here – a road map for improvement

Supported and informed Patients, Families and Carers

- Work in partnership across government, non-government and community services to better understand and meet the needs of patients, families and carers

Potential ways forward include:

- Mapping, describing and showcasing care planning tools (including Advance Care Planning) that support the inclusion of patient, family and carer involvement and communication in decision-making and goals of care
- Mapping, describing and showcasing effective models of or approaches to bereavement support

Supportive and Supported Primary Care Providers, Medical Specialists and Service Providers

- Understanding the challenges and needs of primary care providers including general practitioners and residential aged care facilities
- Understanding the challenges and needs of other medical specialists and service providers (e.g. oncologists, geriatricians, ICU, Emergency)

Potential ways forward include:

- Investigating the development of common pathways and protocols
- Providing or supporting education and training.

Local needs-based access to specialist palliative care for all people in NSW

- As a priority address gaps in access to Level 1 specialist palliative care services across the state

Potential ways forward include:

- Promoting or developing needs-based assessment criteria and referral tools

Integrated and networked primary, aged and specialist palliative care services

- Ensuring coordination and integration of services across settings.

Potential ways forward include:

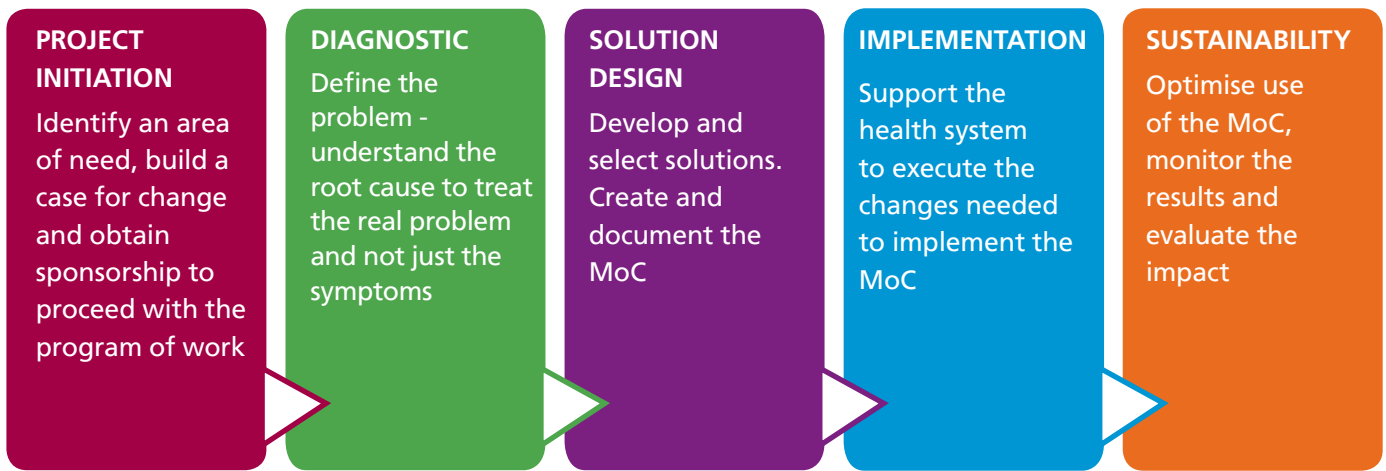
- Providing an overview of where services are currently
- Setting out the principles for networking – Service Level Agreements, resourcing within establishment of Level 2 and Level 3 services, minimum resources, 24/7 accessibility
- Describing potential infrastructure requirements – IT, telehealth
- Scoping patient journeys, mapping and redesign
- Review of the capacity and support needs of primary care providers in providing palliative and end of life care
- Review of the capacity and support needs of residential aged care facilities in providing palliative and end of life care.

Process Flow Chart for developing a Model of Care

This Framework completes the **Project Initiation** phase of the Model of Care development process. It identifies the Scope and Vision of the program; outlines the need for, benefits of and burden of unmet need for palliative and end of life care in NSW. Furthermore, the Framework sets the groundwork for further developing the Model of Care by identifying the principles, service definitions and structural arrangements that are required for the delivery of effective, accessible and efficient care to those people

in NSW who are approaching or reaching the end of life, their families and carers. The Framework also identifies service gaps and proposed ways forward by drawing on ideas presented in research, policy, guidelines and frameworks and consultations with a range of clinicians, service managers, researchers and consumers.

Further investigation into the root causes within these priority areas is required to complete the Diagnostic Phase of Model of Care development. Following this, the Solution Design phase takes these prioritised issues and builds a more comprehensive range of solutions that are implementable across a range of settings.



16. References

- Agency for Clinical Innovation, 2013. Understanding the process to develop a Model of Care; a practical guide on how to develop a Model of Care at the Agency for Clinical Innovation. http://www.aci.health.nsw.gov.au/___data/assets/pdf_file/0009/181935/How-to-develop-a-MoC-20.03.2013.pdf#zoom=100
- Australian Bureau of Statistics, 2009. Release of Deaths, Australia Cat No 3302.0 Canberra: ABS.
- Australian Bureau of Statistics, 2013. Underlying cause of death, All causes, New South Wales 2011, Cat No 3303.0. Canberra: ABS.
- Australian Commission on Safety and Quality in Health Care, 2012. Australian Safety and Quality Goals for Health Care. <http://www.safetyandquality.gov.au/wp-content/uploads/2012/08/Goals-Overview.pdf>
- Australian Institute of Health and Welfare, 2011. Trends in palliative care in Australian hospitals. Cat. no. HWI 112. Canberra: AIHW.
- Commonwealth of Australia, 2010. National Palliative Care Strategy 2010: *Supporting Australians to Live Well at the End of Life*. Canberra: Commonwealth of Australia
- Davidson, P. et al, 2006. Beyond the Rhetoric: What do we mean by a 'Model of Care'? Australian Journal of Advanced Nursing. Volume 23 Number 3, pp. 47-55.
- Economist Intelligence Unit. The Quality of death: ranking end-of-life care across the world. London: EIU, 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf
- Forero, R. et al, 2012. A Literature Review on Care at the End-of-Life in the Emergency Department. Emergency Medicine International. Volume 2012, Article ID 486516. Hindawi Publishing Corporation.
- Frenk, J. et al, 2010. Health Professionals for a new century: transforming education to strengthen health systems in an Interdependent world. The Lancet Dec 2010 v 376.
- Gomes B. et al, 2009. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers (Protocol). Cochrane Database of Systematic Reviews 2009, Issue 2.)
- Government of Western Australia, Department of Health, 2012. <http://www.agedcare.health.wa.gov.au/home/moc.cfm>
- Hatziandreu, E. et al, UK National Audit Office, 2008. The Potential Cost Savings of Greater Use of Home and Hospice-based End of Life Care in England, Rand Corporation.
- Higginson I. et al, 2010. What is the evidence that palliative care teams improve outcomes for cancer patients and their families? Cancer J, 2010 Sep-Oct; 16(5) 423-35.
- Hillman, K. 2010, "Dying safely", *International journal for quality in health care: Journal of the International Society for Quality in Health Care / ISQua*, vol. 22, no. 5, pp. 339-340.
- Lynn J., Schuster JL, Kabcenell A. 2000. Improving Care for the end of life: A sourcebook for Health Care Managers and Clinicians. Oxford University Press: New York.
- National Health Performance Authority, 2013. Healthy Communities: Australians' experience with primary health care in 2010–11. Sydney: Commonwealth of Australia
- NSW Department of Health, 2007. Palliative Care Role Delineation Framework. Sydney: NSW Department of Health.
- NSW Ministry of Health, 2012. The NSW Government plan to increase access to palliative care 2012 – 2016. Sydney: NSW Ministry of Health.
- Palliative Care Australia, 2003. Palliative Care Service Provision in Australia: A Planning Guide. Palliative Care Australia.
- Palliative Care Australia, 2005. A Guide to Palliative Care Service Development: A population based approach. Palliative Care Australia.
- Palliative Care Australia, 2008a. Palliative and End of Life Care – Glossary of Terms, Palliative Care Australia, Canberra, Australia.
- Palliative Care Australia, 2008b. Palliative Care Australia Strategic Plan 2008 - 2011. Palliative Care Australia.
- Palliative Care New South Wales, 2012. Palliative Care in NSW - Palliative Care NSW Policy Statement: *providing informed input to the development of palliative care policy in NSW*. <http://palliativecare.nsw.org.au/site/wp-content/uploads/2012/05/PCNSW-Policy-Statement-FINAL1.pdf>
- Rocque, G. and Cleary, J. 2013. Palliative care reduces morbidity and mortality in cancer. *Nat. Rev. Clin. Oncol.* 10, 80–89

