



Palliative Care NSW

## **PALLIATIVE CARE IN NSW**

Palliative Care NSW Policy Statement:  
providing informed input to the development  
of palliative care policy in NSW

**Palliative Care**  
New South Wales



## Foreword

The NSW health system is currently experiencing significant change as a result of reforms at both the national and state level.

Palliative Care NSW is concerned to ensure that these reforms result in improved and more equitable access for care for people in NSW approaching and reaching the end of their life.

To that end, PCNSW has released this Policy Statement canvassing the significant challenges in delivering equitable, quality palliative care in NSW, and possible solutions to those challenges.

This Policy Statement reflects feedback received in response to our Discussion Paper, which was released in November 2011.

Palliative Care NSW wishes to thank those members and stakeholders who took the time to prepare submissions on the Discussion Paper, and who participated in regional consultative meetings over recent months. Your input has been invaluable in ensuring this Policy Statement properly reflects the real and practical experience of those involved in the delivery of palliative care in a range of different care settings.

We consider this Statement to be a 'living document' and welcome your comments at any time. If you have any comments, please send them to:

Post: Executive Officer, Palliative care NSW  
PO Box 487, Strawberry Hills NSW 2012

Or

Email: [info@palliativecarensw.org.au](mailto:info@palliativecarensw.org.au)

**Peter Cleasby, President**

Palliative Care New South Wales

## Terminology

In many areas of public policy, the development of clear and well-articulated policy positions is often stymied by confusion or disagreement about the use of terms. This has been the case in the palliative care sector where there remains differences in the definitions used for key terms across the key strategies and frameworks applied at the national and state level.

These differences derive from a diverse range of views in the sector about their use and meaning. These issues are discussed in detail in Section 3 of this Statement.

For the purposes of this Policy Statement, PCNSW has adopted the following definitions of key terms.

**Aged Care:** refers to services offered specifically for older people, including residential aged care and home/community care provided through specific packages such as Community Aged Care Packages (CACPs) and Extended Aged Care in the Home (EACH). They are normally considered a sub-set of primary care services.

**Community Support Services:** includes bereavement services, Home and Community Care (HACC) and home care services, community transport services, occupational therapy, pain clinics, social work and respite services.

**Health Promoting Palliative Care:** is a philosophic approach to health services that focuses on enabling a person to live as well as they can up until the time they die.

A health promotion approach to palliative care involves the entire community and the work becomes more in tune with social needs that support prevention, harm minimisation and early intervention. In this way we create a community better equipped to understand how to support those experiencing the difficulties associated with dying, death, loss, bereavement and caring for others.

**Life-limiting illness:** is a progressive illness for which there is little or no prospect of cure. It therefore can be expected to shorten a person's life. This differs from chronic illnesses where, even though there may be a significant impact on the person's quality of life, there is a less direct relationship between the chronic illness and the person's death.

**Non-specialist palliative care:** is palliative care specifically provided by medical practitioners and other healthcare providers that is within their scope of practice and capacity. Non-specialist palliative care providers include General Practitioners, Hospital medical teams, community care and aged care providers.

**Palliative Care:** is the active care of people with a life limiting illness, focussing on comfort, function and support from the time it is recognised that the person has a progressive disease that will lead to their death. In this document palliative care is care provided by a range of services and teams including Specialist Palliative Care.

**Patient(s) and Consumer(s):** the following terms have been used in this document to describe the various ways that people engage with health services:

**Consumer:** is a collective term used to describe people who may require access to a health care service, either now or at some time in the future. It can include the person with an illness, or their family or carers. The services accessed by a consumer cover the full range of health and community support services.

**Patient:** is used to describe individuals who are accessing palliative care in a medical setting.

**Carer(s):** Is used to refer to family members, relatives or friends who provide unpaid support to consumers receiving palliative care.

**Primary Care:** refers to health care accessed directly by consumers and/or services provided outside of hospital. It includes care provided by general practitioners (GPs), community nursing and other services such as community health services, pharmacists, Aboriginal health workers, physiotherapists, podiatrists, dental care, and other registered practitioners. Note that the NSW Role Delineation Framework (GL2007\_22) used the term primary care provider to mean non-specialist palliative care provider.

**Specialist Palliative Care:** is palliative care specifically provided by clinicians who are appropriately qualified and whose full time focus is palliative care. Usually Specialist Palliative Care will be provided by multidisciplinary Palliative Care Teams. Specialist Palliative Care is provided on an assessed needs basis for patients with complex or unstable symptoms or with 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 non-specialist palliative care providers and the patient's caregivers. Specialist Palliative Care may be episodic and ongoing partnerships with non-specialist providers are necessary to ensure the development of a single system of care with seamless referral and case management of patients. Specialist Palliative Care is the foundation stone upon which quality best practice palliative care is identified and provided across the NSW health care system.

# Table of Contents

<b>1.</b>	<b>Executive Summary</b>	<b>1</b>
1.1	Palliative Care in Context	1
1.2	Challenges in Service Delivery	1
1.3	Recommendations – A Call to Action	2
<b>2.</b>	<b>Introduction</b>	<b>7</b>
2.1	About Us	7
2.2	Our Vision	7
2.3	Why do we need a Policy Statement?	8
2.4	Policy Framework	9
<b>3.</b>	<b>What is Palliative Care</b>	<b>10</b>
3.1	Lack of consensus about the use of terms	10
3.2	Palliative Care Service Providers	10
3.3	Health Promoting Palliative Care	12
3.4	Types of Palliative Care Services	12
3.5	Review of the Role Delineation Framework	13
3.6	Scope of the Policy Statement	13
<b>4.</b>	<b>Why is Palliative Care Important?</b>	<b>14</b>
4.1	The Community – consumers, carers and families	14
4.2	The Health System	14
<b>5.</b>	<b>National Health Reform and Palliative Care</b>	<b>17</b>
5.1	The NHHRC Final Report	17
5.2	The Primary Care Strategy	18
5.3	Australian Commission for Safety and Quality in Health Care	18
5.4	COAG's Response to the National Reform Agenda	18
<b>6.</b>	<b>Moving Towards an Integrated System of End of Life Care</b>	<b>19</b>
<b>6.1</b>	<b>Care that is Person and Carer Focused</b>	<b>19</b>
6.1.1	Making Informed Decisions about Care	19
	Advance Care Planning in NSW	19
	Advance Care Planning – National Issues	21
	One stop information point	21
6.1.2	Flexible needs-based care	21
	Access to Services in all Care Settings	21
	Standardised Assessment Tools	23
	Extinction of Life	23
	Grief and Bereavement Support	23
6.1.3	Carers and Volunteers	23
	A Partnership with Health Services	24
	Respite Services	24
24/7	Access to Information/support services	24
	Inequity in Services for Carers	25
	Volunteer Coordination and Training	25
6.1.4	Culturally Appropriate Care	25

<b>6.2</b>	<b>Care that is Driven by Information</b>	<b>26</b>
6.2.1	Community Awareness	26
6.2.2	Quality Improvement	27
	National Standards	27
	Data Collection and Analysis	27
	Research and leadership	28
<b>6.3</b>	<b>Care that is Organised for Quality and Safety</b>	<b>29</b>
	Mapping Palliative Care Services	29
6.3.1	Coordinated integrated care	30
	NSW Role Delineation Framework	30
	Networking and Referrals Between Services	30
	Case Management and Access to Support	31
	Rural and Remote Challenges	31
	Aged Care Sector	32
6.3.2	Workforce	34
6.3.3	Resourcing and funding models	35
	Funding Models	35
	Activity Based Funding	36
<b>7.</b>	<b>Institutional Arrangements and Consultation</b>	<b>37</b>
<b>7.1</b>	<b>The NSW Ministry of Health Governance</b>	<b>37</b>
7.1.1	Funding and performance management under a devolved model	37
7.1.2	Palliative Care Strategic Policy	38
<b>7.2</b>	<b>Consultative Mechanisms</b>	<b>38</b>
	<b>Attachment A</b>	<b>40</b>
	<b>Attachment B</b>	<b>43</b>
	<b>Endnotes</b>	<b>44</b>

# 1. Executive Summary

## 1.1 Palliative Care in Context

Palliative Care NSW (PCNSW) is the peak body for palliative care in NSW, representing the interests of health care professionals, people with a life-limiting illness and their carers and families.

Our vision is that every person in NSW who is diagnosed with a condition that will result in their death in the foreseeable future will have access to quality palliative and end of life care that addresses their physical, psychosocial and spiritual needs.

All people approaching the end of their life, along with their family and carers, 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.

For the purposes of this Statement, we refer to all these services as “palliative care” and those services apply from the time of a person’s diagnosis with a life-limiting 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.

Specialist Palliative Care is the cornerstone of the broader set of palliative care services. A Level 3 Specialist Palliative Care Service for example includes a multi-disciplinary team of clinicians, nurses and allied health professionals with recognised skills, knowledge and experience in palliative care and a higher level of expertise in complex symptom control, loss, grief and bereavement.<sup>i</sup>

## 1.2 Challenges in Service Delivery

Not all people approaching the end of life require Specialist Palliative Care. But all people in NSW deserve quality health care that allows them to live as well as they can until their death.

At present, every person in NSW **does not** have access to quality care as they approach and reach the end of life. The quality of care is largely dependent on where one lives and/or the nature of one’s illness.

Even within the metropolitan area of Sydney, access to palliative care varies enormously between suburbs. Regional and rural areas have particular challenges in providing the full range of services, and in particular in accessing Specialist Palliative Care Services when required.

There is also inequitable service provision for consumers who have non-cancer related 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. While palliative care services have increasingly provided services to non-cancer patients over recent decades, the historical cancer based funding model has not been reviewed and amended to meet the increased (and increasing) demands of non-malignant causes of death.

Poor models of service delivery for palliative care reflect the challenges facing the health sector more generally. These challenges are currently the subject of reform at the national and State levels. Current service models, with a silo approach to funding, budgeting and service provision, mitigates against an optimal and flexible model of care. There is little incentive and significant barriers for services to work collaboratively to meet the needs of consumers. This is exacerbated by out-dated performance measures that focus on process indicators, mostly in a hospital setting, rather than outcomes measures based on the consumer’s experience across the whole range of health services.

Equitable access to palliative care is therefore not simply a result of the challenge of servicing regional or remote communities. It is the result of skewed funding models, inadequate resourcing across health areas, and fragmented and inconsistent approaches to service delivery.



PCNSW welcomes the development of a rigorous Activity Based Funding framework for palliative care, as this has been an underfunded area in all jurisdictions, in both inpatient and community settings. Historic underfunding in palliative care service provision is partly due to the ad-hoc development of palliative care services and partly due to current and past difficulties quantifying the need for end of life care on a population basis. This has resulted in significant variation in resource capability to meet the specialist care needs across the state. Specialist Palliative Care Funding is historically linked to cancer populations, and there has been no formal recurrent adjustment to fund the provision of these services to the non-cancer population which is estimated to be up to 40% of demand.

PCNSW also welcomed the announcement by the NSW Minister for Health and Medical Research, the Hon Jillian Skinner MP, in August 2011 that the NSW Ministry of Health would undertake an exercise to map current palliative care services against population needs; investigate population planning tools to assist in future planning; examine workforce capability, including the training and resources available to support volunteers.

The outcomes of this exercise are critical to understanding the range of services currently available, and the gaps in those services.

We understand that the mapping exercise is being framed around the *NSW Role Delineation Framework 2007*. However, the definitions of services remain a contentious issue within the sector (see Section 3). The Mapping exercise may well provide useful insights into improvements to the definition and delineation of services.

### 1.3 Recommendations – A Call to Action

Throughout this Policy Statement, PCNSW has identified a range of opportunities to improve the quality and safety of palliative care services within NSW. These recommendations are listed below.

#### **Recommendation 1:**

That the review of the NSW Palliative Care Role Delineation Framework which is due in November 2012<sup>ii</sup> revises the definitions of palliative care services in light of lessons learned from the Palliative Care Services Mapping Exercise.

#### **Recommendation 2:**

That PCNSW, work in collaboration with Alzheimer's Australia and the Australian Government Department of Health and Ageing to make 'The Dementia Journey' available at a national level.

#### **Recommendation 3:**

That the NSW Ministry of Health fund PCNSW to widely promote and distribute 'The Dementia Journey' to consumers, relevant health care professionals and aged care services across NSW.

#### **Recommendation 4:**

That the NSW Ministry of Health fund PCNSW to undertake a project to develop, in consultation with other relevant stakeholders, a generic Advance Care Planning Guidance Kit. The Guidelines would draw on lessons learned through the development of the 'The Dementia Journey'.

#### **Recommendation 5:**

That any state or national legislation for Advance Care Planning provide for flexibility given the reality that people may change their minds during the course of their illness. Further, that the NSW Ministry of Health work to prevent situations where the existence of an Advance Care Plan becomes a barrier to appropriate clinical assessment and care being provided in NSW facilities or by NSW services.

#### **Recommendation 6:**

That the NSW Ministry of Health fund PCNSW to provide a one-stop information point for the community about palliative care, referral pathways, advance care planning and directives.

**Recommendation 7:**

That the NSW Ministry of Health finalise as a matter of urgency its review of the Policy Directive "Assessment of the Extinction of Life and Certification of Death" (PD2005\_488) and ensure that the revised requirements are clearly communicated to relevant health services, including the ambulance service.

**Recommendation 8:**

That a planned and negotiated process is undertaken by the NSW Ministry of Health to enable Specialist Palliative Care Services to provide 24/7 support in all NSW LHDs.

**Recommendation 9:**

That the NSW Ministry of Health ensures that there is adequate funding and support for a Volunteer Coordinator position in every palliative care service that recruits and trains volunteers or have identified the potential to do so.

**Recommendation 10:**

That PCNSW be funded by the NSW Ministry of Health to develop a state wide mandatory Palliative Care Volunteer training resource to support existing services, especially those in non-metropolitan areas and that annual volunteer training courses be conducted in rural and regional areas.

**Recommendation 11:**

That further research be undertaken into the cultural needs of Aboriginal people and Culturally And Linguistically Diverse communities, and the impact of different attitudes towards death and dying in the provision of palliative care to inform policy and service development.

**Recommendation 12:**

That Palliative Care Australia work in collaboration with the Australian Government Department of Health and Ageing to develop a national media campaign designed to raise community awareness about how to live with a life limiting-illness, face death and cope with loss and bereavement.

**Recommendation 13:**

That death, dying and the role of palliative care be integrated into the personal development syllabus of all NSW schools and the development of the Australian Curriculum.

**Recommendation 14:**

That the NSW Ministry of Health and all Local Health Districts commit to the adoption of the National Standards for Providing Quality Palliative Care in all appropriate care settings in NSW.

**Recommendation 15:**

That following consultation with the broad spectrum of Specialist Palliative Care Services the NSW Ministry of Health determine a minimum Palliative Care data set and support its collection within all NSW Specialist Palliative Care Services;

That LHDs be held responsible for ensuring local capacity to collect and report this data.

**Recommendation 16:**

That PCOC consider adjustments to both its data set and processes to allow increased uptake in community and consultative palliative care services.

**Recommendation 17:**

That all Level 3 Specialist Palliative Care Services be supported to be centres of research excellence in palliative care. As a first step, the palliative care mapping exercise undertaken by the NSW Ministry of Health should include within its scope palliative care research capacity and activity in order to assess progress in achieving the aim of transforming all Level 3 services into well-functioning research centres. This activity should include an assessment of the research activity and capacity of Level 2 services.

**Recommendation 18:**

That the NSW Ministry of Health review opportunities to improve resourcing for non-cancer palliative care research across all care settings. Areas of special concern include community care, coordination of care and the needs of culturally and linguistically diverse groups.

**Recommendation 19:**

That the State-wide Centre for Improvement in Palliative Care (SCIP) undertake an evaluation of the effectiveness of the dissemination of palliative care research findings through the Palliative Care Service Development Officer Network.

**Recommendation 20:**

That the NSW Ministry of Health clarify and confirm that the Treasury managed funds indemnity for investigator led research in palliative care covers all aspects of the health system where this care is delivered, including the community and residential aged care.

**Recommendation 21:**

That the Ministry of Health establish mechanisms to examine the palliative care service delivery possibilities of all eHealth developments and that systems to allow cross Specialist Palliative Care Service access to electronic medical records be facilitated where improvements in service access and provision can be demonstrated.

**Recommendation 22:**

That policies, processes and guidelines for the allocation and funding of “fly-in fly-out” palliative medicine support comprising a Specialist Palliative Care physician at minimum to regional and remote communities be reviewed and formalised on a state-wide basis.

**Recommendation 23:**

That the NSW Ministry of Health undertake a feasibility study for establishing a state wide Palliative care After Hours Advice Line, either through a single Level 3 Specialist Palliative Care Service, or on a regional basis through all Level 3 Specialist Palliative Care Services.

**Recommendation 24:**

That the Australian Government adopt the recommendations of the Productivity Commission with respect to aged care, and in particular:

- the replacement of the current system of discrete care packages across community and residential care with a single integrated and flexible system of entitlements. The System would cover services including palliative care;
- a flexible funding model that supports individual choice and ensures that people are assisted to die in the place of their choice, with the people they wish to be present;
- the Australian Government ensure that residential and community care providers receive appropriate payments for delivering palliative care;
- that Advance Care Directives form part of a person’s electronic health record; and
- that palliative care be a basic competency for aged care workers.

**Recommendation 25:**

That the NSW Ministry of Health:

- strongly engage with the Australian Department for Health and Ageing in the proposed review of barriers to the provision of short term intensive health care services in the aged care setting;
- facilitate consultation with PCNSW and Specialist Palliative Care Services as part of the review process;
- include in the scope of the review:
  - the ratio of Senior Registered Nurses to residents in Residential Aged Care Facilities;
  - access to and storage of medications needed to care for residents with life-limiting illness within the aged care setting;
  - access to specialist equipment, including oxygen, within aged care settings.

**Recommendation 26:**

That the NSW Ministry of Health prepare a “Palliative Care Workforce Strategy” based on supply and demand analyses arising from the current palliative care mapping exercise. The Strategy should:

- Identify workforce resources required across services (general, specialist and community);
- Address existing and anticipated workforce shortages in Specialist Palliative Medicine
- Address succession planning concerns amongst Rural Specialist Palliative Care Nurses
- Aim to ensure that palliative care is a basic competency for acute care workers, aged care workers and disability care workers.

**Recommendation 27:**

That the NSW Ministry of Health ensures, through their Service Level Agreements with Local Health Districts, that funding is provided to maintain effective access to Palliative Care Service Development Officer services in each Local Health District.

**Recommendation 28:**

That by 2015:

- revised and updated palliative care training curricula be in place in appropriate faculties of tertiary teaching institutions; and
- the Palliative Care Curriculum for Undergraduates (PCC4U – [www.pcc4u.org](http://www.pcc4u.org)) be in place in all appropriate faculties of tertiary teaching<sup>iii</sup>.

**Recommendation 29:**

Without pre-empting the outcomes of the NSW palliative care service mapping exercise, based on current estimates of the workforce shortage, PCNSW recommends:

- That the NSW Government provide an increase in recurrent funding for Specialist Palliative Care services to allow capacity to meet demand across all care settings (including hospital consultation teams).
- That the NSW Government review and adjust the existing funding arrangements to better meet costs of fly-in and telemedicine support from metropolitan level 3 services.

**Recommendation 30:**

In conjunction with the palliative care mapping exercise announced by the Minister in August 2011, the NSW Ministry of Health should:

- Ensure that the mapping accurately identifies not only the resources allocated to specialist, generalist and community services (as set out in the Role Delineation Framework), but also sets out the funding models underpinning the provision of each service;
- Review the current Specialist Palliative Care Service funding model to reflect the changing demand pattern for palliative care services and changing service role, (ie to reflect increased cancer related demand plus demand for palliative care service for people who have non-malignant life-limiting illness, and to better reflect the growing need specialist consultancy advice for generalist end of life care providers;
- Ensure that Specialist Palliative Care Hospital Consultations Teams are discreetly funded and available in all major rural, regional and metropolitan public hospitals'
- Formalise funding models and support structures for regional and remote access to Specialist Palliative Care Services (eg fly in/fly out programs, teleconferencing etc).

**Recommendation 31:**

That the NSW Ministry of Health ensure a suitable level of consultation with Palliative Care Services is undertaken to allow an informed determination to be made as to the future funding arrangements for Specialist Palliative Care provision across acute, sub-acute and community care settings under the healthcare reform agreements.

**Recommendation 32:**

That the Service Agreements between the Ministry of Health and Local Health Districts (LHDs) clearly specify:

- The minimum Specialist Palliative Care services to be funded or purchased, in all care settings;
- The strategies, targets and goals to be achieved in relation to palliative care services;
- Measures to be used to monitor the performance of services (including outcomes for consumers and carers) in relation to palliative care and these include that CEO performance is linked to palliative care standards achieved in their LHD.

**Recommendation 33:**

That the NSW Ministry of Health review current palliative care related consultative mechanisms in relation to Specialist and non-specialist Palliative Care and establish an on-going policy and strategic consultative/advisory body with a documented terms of reference covering palliative and life care issues, including Specialist Palliative Care, that is separate to the anticipated ACI Palliative Care Network. That the consultative arrangements ensure representation from peak bodies representing health service professionals in palliative, end of life and aged care services, health consumers, carers and disease-specific organisations.

## 2. Introduction

### 2.1 About Us

Palliative Care New South Wales (PCNSW) is a not-for-profit, non-government organisation and is the peak body for palliative care in NSW. We represent the interests of health care professionals who work in end of life care across the full range of care settings, including Specialist Palliative Care Services. We also seek to represent the interests of people with a life-limiting illness and their carers and families.

PCNSW is governed by a Management Committee elected by our members. Committee members serve on a voluntary basis.

We have two full-time paid staff. Our funding is sourced through a small NGO grant from the NSW Ministry of Health, membership fees and income from events like our biennial State Conference and Gala Awards dinner.

During the development of this Policy Statement, PCNSW received a number of written submissions from our members and other interested stakeholders. We also conducted a number of consultations with service providers. While our policy positions have been informed by these inputs, this Policy Statement reflects the views of Palliative Care NSW, and not necessarily those of any of the organisations or individuals who provided such input.

### 2.2 Our Vision

PCNSW's vision is that every person in NSW who is diagnosed with a condition that will result in their death in the foreseeable future will have access to quality care that addresses their physical, psychosocial and spiritual needs.

Quality care is realised when strong networks exist between Specialist Palliative Care Services, non-specialist services, and community support services, enabling them to work together to promote optimal quality and safe care for consumers in any care setting, be it the home, a Residential Aged Care Facility, a hospital or hospice.

In achieving this vision, PCNSW:

- provides informed input into the development of policy;
- provides information and education to our members;
- provides a range of information services to consumers, patients, their families and/or carers;
- raises awareness of palliative care and the Association within
  - the community
  - the health sector, and
  - Government;
- Promotes excellence in the provision of palliative care in NSW.

Further information about what we do and how we are governed is available on our website at [www.palliativecarenewsw.org.au](http://www.palliativecarenewsw.org.au).

## 2.3 Why do we need a Policy Statement?

This Policy Statement has been prepared to help achieve our aim of providing informed input to the development of palliative care policy in NSW.

The aim of the Policy Statement is to articulate, from PCNSW's perspective, the issues and challenges that impact on the delivery of quality palliative care including, Specialist Palliative Care, to the NSW community. It also proposes recommendations for future policy directions.

In doing so we aim to support the goals of the NSW Ministry of Health<sup>iv</sup> which are to:

- Keep people healthy;
- Provide the health care that people need;
- Deliver high quality services; and
- Manage health services well.

This Policy Statement:

- Discusses what palliative care is, (see Section 3);
- Explains why quality palliative care is important to:
  - The community – people with a life-limiting illness, their families and carers
  - The health system (see Section 4);
- Examines recent reform initiatives at the national and State level, and their relevance to palliative care service provision (see Section 5);
- Identifies the constraints or barriers in the delivery of care and makes recommendations about priorities for future policy directions impacting on palliative care in NSW (see Section 6);
- Comments on the current reforms to the governance of the NSW health sector and the need for on-going and effective communication and consultation with health care service providers, consumers and carers (see Section 7).

“... providing appropriate care and support ... has the potential to significantly enhance the quality of life of the dying, while reducing unnecessary demand for hospital and acute care services”.

PCNSW believes it is both important and timely to articulate policy issues around palliative care as the national health care system and the NSW Ministry of Health undergoes significant reform. With the health care system facing considerable challenges and increasing demands, there is an imperative for reform and change. PCNSW is concerned to ensure that the interests and needs of people who are dying, along with their carers and families, are given due consideration as part of the reform process.

This is a challenging proposition for a health care system which, in the main, is designed to “treat and cure disease and to provide short-term, episodic care of acute illness”<sup>v</sup>. PCNSW is of the view that there are opportunities to improve the client focus of services for people who are approaching or have reached the end of their life, while achieving improvements in the productivity and efficiency of health care and allied services.

In short, providing appropriate care and support, particularly through better resourcing and coordination of primary care and community services, has the potential to significantly enhance the quality of life of the dying, while reducing unnecessary demand for hospital and acute care services.

## 2.4 Policy Framework

This Policy Statement draws upon a number of recent national and State-based publications about the delivery of palliative and end of life care. These include:

- the *National Palliative Care Strategy*, released by the Australian Government in 2010<sup>vi</sup>. The strategy has four “goal areas”:
  - Awareness and Understanding
  - Appropriateness and Effectiveness
  - Leadership and Governance
  - Capacity and Capability
- *Health Care Reform and Care at the End of Life: A Guidance Document*<sup>vii</sup> (hereinafter referred to as the **National Guidance Document**), published by Palliative Care Australia on behalf of the End of Life Forum in 2010<sup>viii</sup>. The National Guidance Document provides a useful framework for considering the range of policy issues in palliative care, drawing on a range of recent recommendations for health reform by the National Health and Hospitals Reform Commission (NHHRC), the National Primary Care Strategy, and the Australian Commission for Safety and Quality in Health Care (ACSQHC).
- the *NSW Palliative Care Framework 2010-2013*<sup>x</sup>, which sets five priorities for service development over four years:
  - Improving NSW palliative care service planning and delivery;
  - Implementing the National Standards;
  - Improving palliative care workforce capacity and training;
  - Improving palliative care data;
  - Strengthening evidence based practice.
- The NSW Role Delineation Framework 2007<sup>x</sup> which was developed to provide consistent and common language to describe and differentiate palliative care services.

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. It also outlines appropriate access to support services at different levels. It expands on the three components of palliative care delivery outlined in the NSW Palliative Care Framework:

- Generalist providers,
- Specialist providers, and
- Community support services.

The framework allows these sectors to conceptualise how patients can readily move between services when care needs escalate or when needs are stabilised.



## 3. What is Palliative Care

### 3.1 Lack of consensus about the use of terms

Despite a myriad of policy documents providing definitions of terms around palliative and end of life care, including the guidance of the NSW Role Delineation Framework, there remains confusion and misunderstanding of what palliative care is. This is not just within the broader community, but also within the health system.

The core of the confusion, and the heart of the debate about the use of terms, seems to be whether it is only **Specialist** Palliative Care Services that provide “Palliative Care”, or whether all services meeting the needs of a person with a life-limiting illness can be considered as “palliative care”.

The responses to our Discussion Paper revealed two broad camps:

- Those who believe that the definition of palliative care should be limited to that care provided by Specialist Palliative Care Services. Other care required or accessed by people with a life-limiting illness, or their family and carers, should be called something else, like “end-of-life” care; and
- Those who argue that palliative care is a general term for all those services required to support a person with a life-limiting illness, including generalist services, community support services, and specialist medical services, including Specialist Palliative Care Services. Many oppose the use of the term “end-of-life care” as a means to describe all services required from the point of diagnosis, as there is a growing trend in international research to use the term “end-of-life pathways” to mean those services provided at the last stages of life.

The lack of agreement on this basic point is, itself, an impediment to delivering a coherent and consistent approach to care for people with a life-limiting illness:

- Some consumers or their families may resist seeking access to palliative care services early in the diagnosis of a life limiting illness as they may perceive palliative care as being relevant only in the last days or weeks of life. They may also fear that seeking Specialist Palliative Care Services means that treatments to extend life will be withdrawn, or that measures will be taken to actively shorten the person’s life. It is important to emphasise that palliative care practice intends neither to hasten nor postpone death. In fact, palliative care may be applicable early in the course of an illness in conjunction with other therapies that are intended to prolong life, such as chemotherapy or dialysis<sup>vi</sup>.
- Within the health system, similar misperceptions may prevent clinicians from referring patients to Specialist Palliative Care Services, particularly early in the diagnosis of the illness, even where the complex nature of the person’s illness would demand such specialist assistance. Conversely, Specialist Palliative Care Service providers expressed concern about an increasing trend for primary care providers and clinicians in hospital and acute settings to view the care for the dying as a “specialist” area and to therefore refer “all” dying patients to Specialist Palliative Care Services even where the nature of the illness does not require specialist input. It is important that non-specialist services see care for the dying as a continuum of their care. While such referrals to Specialist Palliative Care services may be appropriate, it is important that primary care providers and non-palliative care medical teams in acute and sub-acute settings, are not deskilled, or discouraged, from dealing with the needs of the dying.

### 3.2 Palliative Care Service Providers

In 2003, the NSW Ministry of Health commissioned PCNSW<sup>vii</sup> to conduct a review of palliative care services in NSW. That review revealed significant variability in the structure and resourcing of services. It also revealed a need to develop a consistent and common language to describe palliative care services.

As a result, in 2007, the NSW Ministry of Health published a Guideline titled: *NSW Palliative Care Role Delineation Framework*. The Framework notes that palliative care can be provided by a range of health care professionals, with Specialist Palliative Care Services playing an essential provider and supportive role.

The Framework essentially describes all the care provided to a person with a life-limiting illness as palliative care, with three components of delivery:

- Generalist providers;
- specialist providers; and
- community support services.

The Framework uses the term “primary palliative care service” as 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, and includes General Practitioners (GPs), community nursing and allied health services”.

The Framework notes that a “Specialist Palliative Care Service” includes clinicians with recognised skills, knowledge and experience in palliative care.

The Framework also provides a classification of three levels of Specialist Palliative Care Service.

- **Level 1:** provides Specialist Palliative Care consultation and direct care service to patients whose needs exceed the capability and resources of primary care providers. Level 1 services should be available locally as a minimum for all patients. Importantly they should provide 24/7 specialist support and advice for registered patients, including those in RACFs and acute hospitals;
- **Level 2:** as for Level 1, but also provides support and consultation to level 1 services and participates in collaborative research and training activities;
- **Level 3:** as for level 2, provides consultation-based service for Level 2 services outside the local area (eg for rural and remote area services).

The detailed role delineation framework for Level 1-3 services, including the implications for indicative staffing profiles, is at Attachment A.

This Framework is also reflected in the NSW Palliative Care Strategic Framework 2010-2013.

Given these definitions by the NSW Ministry of Health, and the balance of views provided in feedback to our Discussion Paper, PCNSW has adopted the following definitions for the purpose of this Policy Statement:

**Palliative Care:** is the active care of people with a life limiting illness, focussing on comfort, function and support from the time it is recognised that the person has a progressive disease that will lead to their death. In this document Palliative Care is care provided by a range of services and teams including Specialist Palliative Care.

**Specialist Palliative Care:** is palliative care specifically provided by clinicians who are appropriately qualified and whose full time focus is palliative care. Usually Specialist Palliative Care will be provided by multidisciplinary Palliative Care Teams. Specialist Palliative Care is provided on an assessed needs basis for patients with complex or unstable symptoms or with 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 non-specialist palliative care providers and the patient’s caregivers. Specialist Palliative Care may be episodic and ongoing partnerships with non-specialist providers are necessary to ensure the development of a single system of care with seamless referral and case management of patients. Specialist Palliative Care is the foundation stone upon which quality best practice palliative care is identified and provided across the NSW health care system.

Direct access to Specialist Palliative Care Services is not necessarily required for all people with a life limiting illness.

**Primary Care:** refers to health care accessed directly by consumers and/or services provided outside of hospital. It includes care provided by general practitioners (GPs), community nursing, services in residential aged care facilities, and other services such as community health services, pharmacists, Aboriginal health workers, physiotherapists, podiatrists, dental care, and other registered practitioners.

**Non-specialist palliative care:** is palliative care specifically provided by medical practitioners and other healthcare providers that is within their scope of practice and capacity. Non-specialist palliative care providers include General Practitioners, Hospital medical teams, community care and aged care providers.

**Community Support Services:** include bereavement services; Home and Community Care (HACC) and home care services, occupational therapy, pain clinics, social work and respite services.

**Life-limiting Illness:** is an illness for which there is little or no prospect of cure. It therefore can be expected to shorten a person's life. This differs from chronic illnesses where, even though there may be a significant impact on the person's quality of life, there is a less direct relationship between the chronic illness and the person's death<sup>xiii</sup>.

### 3.3 Health Promoting Palliative Care

Palliative Care NSW supports the construct of Health Promoting Palliative Care. This concept has developed since the publication of the Ottawa Charter following the First International Conference on Health Promotion held in Canada in 1986.

While dealing with the broader context of health systems, PCNSW believes that the concepts of the Ottawa charter should underpin palliative care service planning and provision.

It is possible to live and die in ways which are harmful and unhealthy – equally it is possible to live and die in ways which are healthy and which minimise harms to individuals and groups.

Dying and death is not just a biomedical process. It is also a social phenomenon. People who live with life-limiting illnesses, their families and carers, spend most of their time in the broader community, and only a short time as patients or consumers interacting with the health system. Health promotion in the context of end of life care recognises that optimising health is not reliant on the health system alone. It encompasses a range of other social, economic, psychological and spiritual aspects.

The policies and practices of a range of institutions within our society (government, non-government and private enterprise) can have profound effects – some harmful – on the experiences of people living with a life-limiting illness, their families and carers. Equally it is possible to reform policies and practices so that organisations are more sensitive to the needs of consumers.

Many people in our community have no experience dealing with the effects of serious illness, death and bereavement. When they are confronted with such challenges, people may benefit from information and education that equips them with the skills and knowledge they need to cope with loss and to support others.

The areas of public health and health promotion offer powerful ways in which to conceptualise and respond to problems and opportunities which confront communities dealing with the end of life, loss and grief.<sup>xiv</sup> Importantly, the discussion about the types of services required for consumers, carers and families set out below is founded on the Health Promoting concept.

Palliative Care NSW believes that adopting a Health Promoting approach to Palliative care will assist persons with limiting illnesses live as well as they can until their death.

### 3.4 Types of Palliative Care Services

Given the broad definition of palliative care services outlined above, and in the context of “Health Promoting Palliative Care”, the type and extent of services that may be needed by people with a life-limiting illness, or their carers and families, can include:

- assessment, management and review of pain and other distressing symptoms;
- support that helps people live as actively as possible until death. This might include, for people living in a home setting, access to equipment (such as oxygen, wheel chairs, walkers, ergonomic beds, commodes, hand rails and so on) as well as community support services, such as home help and access to community transport;
- access to services that support the consumer's psychological, spiritual and cultural needs;
- support to help carers and family cope during the person's illness and in bereavement. This can include access to information and counselling services and respite care. Home help support for the person, as described above, also provides a form of support to families and carers as they also provide respite for carers.

Such services are provided by a range of service providers, in a range of care settings<sup>xv</sup>.

The settings in which services might be provided are as varied as the living circumstances of the consumers themselves. Services (primary and specialist) may be delivered where the consumer is, which may be in:

- the home (of the consumer or their carer)
- in a Residential Aged Care Facility (RACF);
- acute and sub-acute hospitals;
- Palliative Care units (sometimes known as “hospices”).

The services provided to a particular consumer, and the setting in which they are provided, may (and usually does) change often throughout the period in which the consumer receives palliative care. It is not a linear trajectory. A person may move between their home, an acute inpatient facility or designated Palliative Care Unit many times in the course of their illness.

As illustrated by the NSW Palliative Care Role Delineation Framework, Specialist Palliative Care Services provide direct care when indicated. The provision of consultation and support services to other care providers allows Specialist Palliative Care to be the foundation for quality care provision across all care settings.

### 3.5 Review of the Role Delineation Framework

In August 2011, the NSW Minister for Health and Medical Research, the Hon Jillian Skinner MP, announced that the NSW Ministry of Health would undertake an exercise to map current palliative care services against population needs; investigate population planning tools to assist in future planning; examine workforce capability, including the training and resources available to support volunteers. PCNSW warmly welcomes the Minister’s announcement and emphasises the importance of this work in underpinning effective and efficient investment in services into the future.

PCNSW understands that this revision is being undertaken in accordance with the definition of services in the Role Delineation Framework, and that its scope is limited to the existing Specialist Palliative Care Services. PCNSW recognises that the existing service level differentiation does not accurately capture the specialist clinician based service provision occurring in many rural and regional LHDs.

PCNSW notes that it is critically important to ensure the mapping exercise be undertaken in the context of developing further clarity around role delineation across all palliative care services. Implications for the models of care, and resourcing of services, are discussed further in Section 6.3.1 *Coordinated and Integrated Care*.

However, the mapping exercise is likely to throw further light, or potentially further debate, about the delineation and definition of roles across all palliative care services. PCNSW notes that the NSW Role Delineation Framework is scheduled for a routine review in November 2012. This provides an opportunity to revise the Framework in light of lessons learned from the mapping exercise. PCNSW, having developed the original RDF, would welcome the opportunity to undertake this review.

#### **Recommendation 1:**

**That the review of the NSW Palliative Care Role Delineation Framework which is due in November 2012<sup>xvi</sup> revises the definitions of palliative care services in light of lessons learned from the Palliative Care Services Mapping Exercise.**

### 3.6 Scope of the Policy Statement

PCNSW believes that the needs of people with life-limiting illnesses and their families or carers can only be met if all relevant services are drawn upon if and when necessary. It is not an “either/or” option. Both specialist and primary care may play a part in the effective treatment and care for the dying, and need to be used in collaboration with each other.

The scope of this Policy Statement therefore covers all services needed by consumers affected by a life-limiting illness, including, but not limited to, Specialist Palliative Care Services.

## 4. Why is Palliative Care Important?

The provision of effective, efficient and seamless palliative care services can provide clear and significant benefits to both:

- The Community – consumers, carers and families; and
- The Health System.

### 4.1 The Community – consumers, carers and families

There is compelling evidence that the demand for palliative care will increase significantly over coming decades:

- Over 70,000 NSW citizens die each year;
- However, improvements in health care over recent decades have resulted in people living longer. The number of people aged over 85 is expected to increase by more than 56% between 2006 and 2016. However, they are living longer with more complex health issues e.g. dementia, diabetes, cardiovascular, respiratory and musculoskeletal problems. Caring for this greater number of older people with increasingly complex healthcare needs is becoming increasingly demanding and costly;
- The World Health Organisation predicts that by 2020 chronic disease (i.e. an illness that is long-lasting or recurrent such as diabetes, arthritis, some types of heart disease or cancer) will account for almost 75% of all deaths; this trend is reflected in Australia;
- The demand for palliative care services is expected to increase by at least 4.6% annually in NSW.

Palliative Care enhances quality of life for people with a life-limiting illness and their families:

- Physically, by relieving pain and discomfort and by controlling other symptoms such as nausea, constipation and lethargy which can be associated with a life-limiting illness, including as a side effect of associated treatments;
- Psychologically, by helping to alleviate any fear or anxiety that may be associated with death and dying. By treating people with dignity and respect during these difficult times, patients, carers and their families can arrive at a sense of acceptance, confident that they will live well until they die;
- Spiritually, by acknowledging and dealing with the spiritual aspects of death. People's needs vary widely as death approaches, but they commonly include the need to understand what is happening, resolve issues with family and friends, achieve a sense of completion emotionally and spiritually, and come to terms with significant life changes;
- Socially, by reducing feelings of isolation through the engagement of volunteers and local support networks in the appropriate cultural context.

Studies in the US have shown that families of patients who have benefited from palliative care and have received bereavement counselling have much better experiences during the terminal phase of their loved one's illness, have an acceptance of death and lower rates of depression six months after the death. A further study of patients receiving treatment for metastatic lung cancer who also received early palliative care support revealed that they may live longer and with better quality of life, including decreased depression<sup>xvii</sup>.

### 4.2 The Health System

The effective and efficient delivery of palliative care services, particularly under community based models of care, has the potential to significantly reduce the pressure on the acute care system:

- Provision of sub-acute beds for palliative care patients enables transfer of appropriate patients away from acute beds;
- Improved resources for community palliative care, including through Residential Aged Care Facilities, increases community (non-hospital) stays;
- Acute inpatient palliative care hospital consultation teams facilitate better end of life care, discharge or transfer out of the acute care system where possible, as well as reducing the use of clinically futile treatments. This can be facilitated through timely Advance Care Planning discussions.

Improved access to a more holistic range of end-of life and palliative care services has the potential to improve both the effectiveness and the efficiency of healthcare services for the dying, and the healthcare system as a whole. It can avoid inappropriate and preventable admissions to emergency and acute services. It can also help to minimise or avoid investigations, treatments and procedures that offer no improvement in quality of life. Effective models of care can therefore improve:

- *Efficiency* of health service delivery through more cost-effective use of health resources;
- *Effectiveness* of health services by providing better outcomes for patients and their families.

A 2011 study conducted by Palliative Care Australia found that 74% of Australians surveyed who had thought about where they would like to die indicated they would prefer to die at home<sup>xviii</sup>. In reality, only 16% of people die at home, with 20% dying in hospices, 10% in aged care facilities and the remainder (over 50%) dying in hospital.

While it may not always be appropriate or possible to die at home, any initiatives that decrease the number of unnecessary deaths in hospitals have the twin benefit of meeting the desires of consumers, and reducing pressure on the costs of the health system.

A conservative analysis of available data indicates that the cost of community based palliative care services can be between 50% and 300% less expensive than care in an acute bed or intensive care bed:

- An ICU Bed costs around \$4000 per patient, per day, or \$1.5M per bed per year, according to Professor Ken Hillman, who says “at least half of my ICU patients shouldn’t be there ... Dying in ICU is a very cruel, awful way to die.”<sup>xix</sup> Senior Intensive Care Specialist Dr Peter Saul says “in terms of health costs, our final year of life is our most expensive. Almost all of this expense is in the last few weeks. Dying in an ICU costs more than most of us have ever paid in contributions to the Medicare levy. Nor is it a particularly pleasant experience. Evidence suggests that as many as half the people admitted to an ICU at the end of life would have chosen otherwise had they been given the choice.”<sup>xx</sup>
- An Acute Hospital Bed costs around \$1100 per day on average;
- Ambulance callouts cost between \$300 and \$5000;
- The cost of community based palliative care varies depending on where it is provided and the particular needs of the consumer, but it has been broadly estimated at between \$200 per day (for a person in an Aged Care Facility) and \$600 per day (for an Inpatient Palliative Care Facility).

Appropriate palliative care can therefore play a pivotal role in improving both the effectiveness and efficiency of health services, and reducing the pressure on acute care services.

In sum, investment in appropriately structured, funded and coordinated palliative care can:

- help prevent the types of distressing, often lengthy, costly and unnecessary acute hospital admissions at the end of a consumer’s life;
- create better experiences for people using health services, and opportunities for people to live and die in settings of their own choosing;
- achieve significant financial savings, especially by freeing up acute hospital resources.

## **Andrea's story – Saving Acute Care Resources**

Andrea is 79 and has breast cancer that has extended into her bones. She is being treated with chemotherapy in an attempt to extend her life and minimise symptoms, but the cancer has spread so far it is not curable.

Andrea has been registered with a Community Palliative Care Service. In her region, she is fortunate that this service provides 24 hour access to specialist advice and home visit services. Few regions in NSW, even in metropolitan areas, provide such a service. Her symptoms are becoming more complex, particularly as an elderly person with other health issues.

Andrea is living at home alone, but her daughter lives nearby. One night, at home, she feels dizzy and nauseous. As Andrea was registered with the Community Palliative Care Service, her daughter Jill calls the Palliative Care team, knowing they would be able to help. Calling for an ambulance would otherwise have been her only option. Andrea is too frail and ill for Jill to take her to hospital on her own.

A Palliative Care nurse arrives within an hour, examines Andrea and reviews her medications. The Nurse calls Andrea's GP on the "after hours" call line and they agree to a revised medication regimen. The nurse up-dates Andrea's medical files, settles Andrea, and reassures her daughter but notes that they should call again if the symptoms worsen.

Andrea's symptoms ease and she stays at home and recovers well from the episode.

The support of the Palliative Care system:

- Provided reassurance to Andrea and her daughter;
- Allowed Andrea to stay at home safely, comfortable in her own bed;
- Prevented the unnecessary use and cost of an ambulance;
- Prevented the unnecessary use and cost of accessing an Emergency Department.



## 5. National Health Reform and Palliative Care

PCA's National Guidance Document sets out the most significant recent initiatives shaping the nature of health care reform in Australia<sup>xxi</sup>. These include:

- The establishment of the National Health and Hospitals Reform Commission (NHHRC) which has to date produced two key documents that have set the reform agenda for negotiations under the Council of Australian Governments (COAG) framework;
- The release of *Building a 21st Century Primary Health Care Strategy* by the Commonwealth Department of Health and Ageing that provides a roadmap to guide future policy and practice in primary health care in Australia;
- The development of a future model for safety and quality accreditation by the Australian Commission on Safety and Quality in Health Care (ACSQHC).

### 5.1 The NHHRC Final Report

The Final Report of the National Health and Hospitals Reform Commission (NHHRC) concluded that, while the Australian health system has many strengths, it “is a system under growing pressure, particularly as the health needs of our population change<sup>xxii</sup>.” The challenges include: increasing demand for, and expenditure on, care; unacceptable inequities in health outcomes and access to services; growing concerns about safety; workforce shortages; and inefficiencies.

The report also notes the fragmented nature of the health system with complex funding arrangements and accountabilities between different levels of government.

The NHHRC Report identified three main goals:

- Tackling major access and equity issues;
- Redesigning the health system to meet emerging challenges; and
- Creating an agile and self-improving health system.

Key themes underpinning these goals, and which are particularly relevant to end of life care, include:

- the connection and integration of health and aged care services;
- the ability of patients to receive the right care in the right setting;
- integrating multi-disciplinary primary health care services and improving access to services in the community;
- better coordination and continuity of care for people with more complex health problems;
- strengthened consumer engagement and empowerment.

The NHHRC made four recommendations relating specifically to palliative care, notably:

- building the capacity and competence of the primary health care services, including Comprehensive Primary Health Care Centres and Services, to provide generalist palliative care support for dying patients. This will require greater educational support and improved collaboration and networking with Specialist Palliative Care service providers;
- strengthening access to specialist Palliative Care services for all relevant patients across a range of settings, with special emphasis on people living in residential aged care facilities and rural areas;
- Additional investment in specialist Palliative Care services to support greater availability of these services to people living at home in the community, where specialist assistance is required;
- advance care planning that is funded and implemented nationally, commencing with all residential aged care services. This will require a national approach to education and training of health professionals including greater awareness of the common law right of people to make decisions on their health treatment, including their right to decline treatment.



## 5.2 The Primary Care Strategy

The *Building a 21<sup>st</sup> Century Primary Health Care Strategy* also notes that Australia's primary health care services "operate as a disparate set of services, rather than an integrated service system<sup>xxiii</sup>". The services received by patients therefore depend as much on where they live, their particular condition and the particular service providers involved, as their clinical needs and circumstances. Patients with complex needs are often left to navigate the system themselves, are hampered by gaps in information, and therefore have a limited ability to influence decisions about their care.

The Strategy aims to:

- Improve access and reduce inequity;
- Better manage chronic conditions; and
- Improve quality, safety, performance and accountability.

The Strategy echoes similar themes to the NHHRC in relation to the need to match services to patient needs, build multi-disciplinary teams, improve information sharing, and drive continuous improvement based on evidence.

## 5.3 Australian Commission for Safety and Quality in Health Care

The ACSQHC has developed a national quality and safety framework to address safety and quality issues within the health system<sup>xxiv</sup>. The framework proposes three key areas of direction for health services:

- Consumer focused care, that is;
- Driven by information, and
- Organised for safety.

Again, similar themes emerge through the ACSQHC report, including the need to develop models of service delivery that improve access to health care for patients; to enable patients to get access to the right care when they need it; improve health literacy that supports patients in taking greater responsibility for their health care and that involves patients in their health care decisions; enhancing the continuity of care; and using data and evidence to drive performance.

The ACSQHC particularly emphasises the need to reduce unjustified variation in the standard of care through embedding guidelines in clinical practice and monitoring their compliance.

## 5.4 COAG's Response to the National Reform Agenda

COAG began the process of responding to these proposed health reforms with the announcement in April 2010 of the development of a National Health and Hospitals Network<sup>xxv</sup>.

PCA's National Guidance Document provides a summary of what it considers to be the most significant initiatives in the COAG announcement with respect to palliative care. PCA argues these initiatives would lay the foundations for long-term improvements in palliative and end of life services. They include<sup>xxvi</sup>:

- The Commonwealth taking full funding and policy responsibility for GP and primary health care services in Australia;
- The establishment of primary health care organisations with strong links to local communities, allied health professionals and service providers including Aboriginal Medical Services to:
  - Improve access to services and drive integration across GP and primary health care services so that patients can conveniently access the full range of services they need;
  - Facilitate allied health care and other support for people with chronic conditions;
  - Identify groups of people missing out on primary health care, or services that a local area needs, and respond to these gaps;
  - Work with hospital networks to assist patient transition in and out of hospital.
- Major investments to train more health professionals, including GPs and specialists and allied health professionals, in rural and regional areas;
- Improving incentives for GPs to provide more services in aged care.

## 6. Moving Towards an Integrated System of End of Life Care

The National Guidance Document argues that “our vision for integrating care at the end of life needs to be well grounded in the three sets of parallel reform processes”: that is the NHHRC Report, the Primary Care Strategy and the ACSQHC Report. PCNSW endorses this approach.

The Guidance Document proposes a national end of life care framework based around three main constructs that are derived from the ACSQHC model ie:

- Person and Carer Focused
- Driven by Information
- Organised for Safety and Quality.

The following discussion is framed around these three key constructs, and draws upon the outcomes of research and analysis undertaken as part of the national reform process, as discussed in Section 5. Our recommendations set out below also draw on submissions received from our members and other key stakeholders in the preparation of this Policy Statement.

At the time of writing this Statement, the NSW health system was experiencing significant change and reform, with the transition of the Department of Health into a Ministry for Health, and a realigned range of functions for the “four pillars” that provide key centralised policy and strategic direction under the proposed reforms.

While the Director-General’s paper, *Future Arrangements for Governance of NSW Health*, provides some guidance as to the roles and functions of these agencies, it is not completely clear to PCNSW as to which agency may take the lead in particular policy and strategic matters. Recommendations referring to “NSW Health” should therefore be considered to mean the Ministry of Health and the four pillars collectively.

### 6.1 Care that is Person and Carer Focused

Providing care that is person and carer focused means designing and delivering services that are respectful and responsive to individual needs, values and preferences. Contemporary approaches to the delivery of health promoting systems of care recognise that “putting individuals and their families and carers at the centre of care is fundamental in designing health system changes<sup>xxvii</sup>”.

For this to occur:

- Individuals, their families and carers must be empowered to make fully informed decisions;
- Service should match the need of clients;
- Carers need to be involved and supported as co-workers in the health care team; and
- Health care providers must engage in culturally competent, appropriate and safe practice.

#### 6.1.1 Making Informed Decisions about Care

##### Advance Care Planning in NSW

Advance Care Planning means planning for care in advance of one’s condition worsening to the point where a person is unable to make decisions for themselves.

It is how you take control of your future.

PCNSW supports the broad approach of the *Advance Planning for Quality Care at End of Life Strategic and Implementation Framework* by the NSW Ministry of Health, to improving advance care planning and quality end of life care.

Advance Care Planning needs to be seen as an on-going “conversation” with the person experiencing a life-limiting illness. Their views on whether they wish to be given treatment, particularly in the latter phases of their illness, will be influenced by the nature of the particular episode and the likelihood that it may be successful in extending life while maintaining a desired level of quality of life. This is a complex and challenging area for a person to work through. Any system that tries to entrench that decision in “black and white”, legalistic documents that are resistant to regular review and change will undermine the effective take up of Advance Care Planning.

Communication skills are crucial for the health professional who has these discussions with the person, and for those who are providing care to someone with an advance directive in future medical events, also reassess their views at that time, and ensure they are still holding the same views as their written document.

It is expected that the introduction of Electronic Health Records will assist in formalising Advance Care Planning, while facilitating flexibility in doing so. PCNSW strongly supports investment in the introduction of electronic health records.

Within NSW, there are a variety of Advance Care Planning tools, and the education and training around their use. This creates some confusion around the principles and practices associated with Advance Care Planning. A single set of Guidelines for Advance Care Planning which distinguish between the planning process and the plans themselves would help support the take-up of Advance Care Planning, as well as reduce confusion or uncertainty around its purpose.

During 2011, PCNSW, in collaboration with Alzheimer’s Australia NSW, developed a kit of information for people with dementia and their families to help them to plan for their health care outcomes in advance. The kit, entitled ‘*The Dementia Journey*’, was developed using project funding from Department of Health and Ageing.

PCNSW believes that ‘*The Dementia Journey*’ has the potential to be a useful resource across Australia.

#### **Recommendation 2:**

**That PCNSW, work in collaboration with Alzheimer’s Australia and the Australian Government Department of Health and Ageing to make ‘*The Dementia Journey*’ available at a national level.**

Within NSW, ‘*The Dementia Journey*’ has proved to be a much in demand resource. While it is available electronically on the PCNSW web site, users have expressed a strong preference for a printed version, given the quality of the printed version’s design, and the reality that many people who would benefit from the kit do not have access to the internet. There is also an opportunity to more effectively promote the adoption and use of the tool kit.

#### **Recommendation 3:**

**That the NSW Ministry of Health fund PCNSW to widely promote and distribute ‘*The Dementia Journey*’ to consumers, relevant health care professionals and aged care services across NSW.**

The experience and knowledge acquired through preparing ‘*The Dementia Journey*’ means that PCNSW is well placed to develop a more generic set of Guidelines on Advance Care Planning. Further illness-specific kits could then be developed tailoring the Guidelines to particular illness types.

#### **Recommendation 4:**

**That the NSW Ministry of Health fund PCNSW to undertake a project to develop, in consultation with other relevant stakeholders, a generic Advance Care Planning Guidance Kit. The Guidelines would draw on lessons learned through the development of the ‘*The Dementia Journey*’.**

Carer involvement in advance care planning is vital. It is particularly important to ensure that the impact of any decision on the carer is considered, and to ensure that the carer understands and can support the decisions of the consumer. Involving carers in advance care planning, with the consent of the care recipient, is an important part of working with carers as partners in care.

Carers NSW would therefore be an important partner in developing the Advance Care Planning Kit, along with GPNSW, Medicare Locals and RACFs.

## Advance Care Planning – National Issues

PCNSW supports the introduction of a consistent national framework for Advance Care Planning. At the moment, Australian States and Territories have adopted different approaches and legal frameworks around Advance Care Planning. Movement toward a nationally consistent approach would help reduce confusion and inefficiencies in supporting Advance Care Planning and could potentially lead to better take up of Advance Care Planning.

PCNSW notes that some jurisdictions underpin Advance Care Planning concepts with legislation that regulates its use. NSW at present does not.

Should legislation be introduced in NSW, PCNSW supports, in principle, the notion of uniform national legislation to avoid inconsistencies of approach between jurisdictions. However, PCNSW remains concerned to ensure that any legislation allows sufficient flexibility to address the reality that people tend to change their minds as an illness or condition progresses. Further, PCNSW call upon the NSW Ministry of Health to work to prevent situations where the existence of an Advance Care Plan becomes a barrier to appropriate clinical assessment and care being provided.

### Recommendation 5:

**That any state or national legislation for Advance Care Planning provide for flexibility given the reality that people may change their minds during the course of their illness. Further, that the NSW Ministry of Health work to prevent situations where the existence of an Advance Care Plan becomes a barrier to appropriate clinical assessment and care being provided in NSW facilities or by NSW services.**

### One stop information point

PCNSW currently receives numerous requests from people with life-limiting illnesses and their carers and families seeking general information about palliative care and for advice on when and how to access relevant services.

However, PCNSW has limited resources and capacity to develop resource and referral material, and to provide staff to deliver information services. Funding is required to establish and provide a one stop information point for consumers, carers and families in NSW to access information about palliative care, referral pathways, advance care planning and directives and bereavement care.

This service is not intended to replicate medical referrals or case management processes. It would operate on a standard business hours basis, with recorded messages referring clients to appropriate after hours “crisis” hot lines. It would also aim to complement existing “issue-specific” information services offered by organisations such as cancer help lines, MND help lines, MS help lines, and carer help lines.

### Recommendation 6:

**That the NSW Ministry of Health fund PCNSW to provide a one-stop information point for the community about palliative care, referral pathways, advance care planning and directives.**

## 6.1.2 Flexible needs-based care

### Access to Services in all Care Settings

The significant reforms to health services at both the National and State levels have recognised the need to move away from traditional models of care which are heavily focused on institutionally based service provision. The past focus on institutional based models of care has diminished the system’s capacity to provide “person-centred care”, particularly in a community setting.

The lack of community based services, including access to home visits by GPs and limited community nursing resources, means that consumers are often forced to access services via acute hospital settings (eg emergency departments) even though this may be a more expensive form of service delivery for the health system.

While the rebalancing of models of care and funding arrangements is a challenge for the health sector as a whole, it is particularly relevant in the context of palliative care.

PCNSW's vision is that every person in NSW who is diagnosed with a condition that will result in their death in the foreseeable future will have access to quality palliative and end of life care that addresses their physical, psychosocial and spiritual needs. That care should allow people to live and die, as far as reasonably practicable, in the setting of their choice.

As discussed in Section 4, access to flexible models of care that enable people to stay out of acute care settings as much as possible has the potential to both improve the quality of life of consumers, and to reduce the cost burden on the health system.

The need to develop more coordinated and integrated models of care is discussed further in Section 6.3.1. Implications for reforms to funding models are discussed at Section 6.3.3.

### **Case Study – Utilising Community Palliative Care Services**

Bill is 67 and has metastatic bowel cancer. He was referred to a Community Nursing Service for ongoing support and Palliative Care six months ago. Bill and his wife have stated very clearly that Bill's wish is to die at home.

When Bill first met the Community Nurses they explained how the Palliative Care system works in his local area:

- That the Community Nurses visit him and his wife on a regular, agreed upon frequency
- The Community Nurses are supported by Specialist Palliative Care Nurses who accompany the Community Nurse on visits when required and play a vital role in the planning and delivery of his care.
- The Community Nurse also explained the importance of Bill being registered or "linked" with the local Palliative Care Unit (PCU). This registration gave Bill and his wife access to after-hours phone support, written resources and an offer to visit the PCU
- By being registered he would then be able to receive a suite of multi-disciplinary palliative care services including medical reviews at an outpatient clinic or home visit as needed
- This also ensured that his clinical information was already with the PCU and if his condition required inpatient care his admission to the PCU could be direct rather than initially presenting to the local ED and then being transferred

Bill developed ascites (excess fluid in the peritoneal cavity), increased pain, breathlessness and both he and his wife were increasingly anxious. The Community Nurse discussed his deteriorating condition with the Palliative Care Nurse and they arranged for Bill's GP do a home visit that afternoon. The GP then spoke with the Medical Director of the local PCU who agreed to admit Bill in to the PCU for review of his symptoms and possible draining of his ascites. Bill's son drove his parents to the PCU that afternoon.

## Standardised Assessment Tools

An individual's palliative and end of life care will involve multiple providers over time. It is recognized as good clinical practice to utilise standardised assessment tools wherever and whenever appropriate. PCNSW believes that the NSW Health System would benefit from increased use of such instruments in routine clinical care. PCNSW believes that agreement on a common suite of symptom assessment instruments, including a non-verbal pain assessment chart, could be an early agenda item for the yet to be formed Palliative Care Clinical Network.

## Extinction of Life

Access to flexible and needs based services is not the only impediment to facilitating a person's desire to die at home.

In May 2008, PCNSW released a Discussion Paper on *The Extinction of Life: Obtaining death certificates for palliative care patients dying at home*. The Paper raised concerns about the increasing confusion surrounding the legal obligation to report deaths to police where a doctor is not available to legally certify the death of a palliative care patient at home.

PCNSW concluded that a factor contributing to the confusion in this area is the NSW Policy Directive "Assessment of the Extinction of Life and Certification of Death" (PD2005\_488) which is ambiguous about legislative requirements and has led to a "risk averse" approach to reporting deaths to the Coroner. That is, many services, including the ambulance service, believe they have a legal obligation to report **any** home death to the Coroner. This is not required by law. Only "suspicious" deaths require reporting to the coroner, and therefore an obligation to call the police.

The ambulance service therefore instructs its employees to report **any** home death to the police. This has led to circumstances where, following an expected home death, the deceased patient's home has been turned into a crime scene, causing unnecessary and inappropriate distress to grieving family members and carers.

A full discussion of the issues surrounding the NSW Ministry of Health Directive is set out in our Discussion Paper on *The Extinction of Life* and is available on our website at [palliativecare.nsw.org.au](http://palliativecare.nsw.org.au).

### Recommendation 7:

**That the NSW Ministry of Health finalise as a matter of urgency its review of the Policy Directive "Assessment of the Extinction of Life and Certification of Death" (PD2005\_488) and ensure that the revised requirements are clearly communicated to relevant health services, including the ambulance service.**

Resolution of this important issue requires no funding resources. In fact, it has the potential to reduce the cost of unnecessary police resources.

## Grief and Bereavement Support

People facing a life-limiting illness and those close to them can experience profound and complex feelings of loss, anger, grief and depression. Effective risk assessment and appropriate support is required before death and during bereavement to avert significant detriment to well-being and long term negative personal and social impacts.

### 6.1.3 Carers and Volunteers

Family and friends who voluntarily care for people living with a life-limiting illness obviously play a critical part in improving the quality of care for that person.

They also greatly reduce the demands on the health system and community support budgets where, in the absence of a voluntary carer, government resources would be called upon to support a greater part of the person's needs.

It is therefore in the interests of both consumers and the health care system that carers be given adequate support to enable them to provide such valuable care.

That support needs to address the wellbeing of both the carer and the care recipient. Carer support needs to be person-centred and flexible in order to accommodate the range of caring situations and to meet the individual needs of the diversity of carers. Support for carers is most effective when it is delivered in line with the principles of the *NSW Carers Charter*. In particular, support for carers should be timely, responsive, appropriate and accessible.

## A Partnership with Health Services

Carers of people who are dying often feel disempowered and undervalued in their role as a carer, and report many difficulties in being recognised as a 'key party' in the care and support of the care recipient. Services and support for the care recipient must also reflect the principles of the Charter, for instance, by respecting the relationship between carers and persons requiring care, and also by recognising the unique knowledge of carers.

With consent from the care recipient, services and health professionals must work in partnership with carers in order to ensure the best possible outcomes for the care recipient. Having carers recognised as partners in care is a Priority for Action under the *NSW Carers Action Plan*.

## Respite Services

Carers must be recognised as having their own individual needs within and beyond their caring role. This means carers may require assistance such as respite to maintain other aspects of their life, such as other family responsibilities, paid employment, and recreational and social activities.

Some carers of people with life-limiting illnesses find it particularly difficult to access respite where the person requiring care has high level or complex needs. This may mean that paid care workers will need a higher level of training and experience, reducing the choice of potential service providers.

More flexibility is needed with regard to when and where respite is available. For instance, respite hours which can accommodate paid employment may allow a carer to continue employment. In the context of palliative care, access to in-home respite may be the only form of respite possible due to the condition of the care recipient.

Consideration should also be given to different ways of enabling or providing flexible and effective respite options, such as the option to cash out respite entitlements or employ family members. This may be particularly appropriate in the context of support for Aboriginal carers or carers in rural and remote areas.

## 24/7 Access to Information/support services

Supporting a person who needs palliative care is not a simple task for carers, families and friends. It can involve everything from attending to daily physical tasks of showering, assisting with travel and preparation of meals to the provision of emotional and spiritual support and counselling. It can also include assisting with the administration of complex drugs and other treatments.

Improved access to up-to-date information on supporting a person who needs palliative care is needed and should be available in a range of community languages.

Carers need access to 24/7 support services covering both:

- Access to medical advice/assistance for the person they are caring for. This may be through a Specialist Palliative Care Service, if the person is a registered client, or through after hours medical services, such as Family Care Medical Services
- Access to support and counselling for themselves – to address their own concerns and needs.

Specialist Palliative Care Services currently do not have the resources to meet the demand for 24/7 support in all NSW LHDs.

### **Recommendation 8:**

**That a planned and negotiated process is undertaken by the NSW Ministry of Health to enable Specialist Palliative Care Services to provide 24/7 support in all NSW LHDs.**



## Inequity in Services for Carers

Currently, many carers are frustrated by the inflexibility of many services, which can make them inaccessible or of limited benefit.

There is also a lack of specific services for people with a life-limiting illness who have high care needs, but who are under the age of 65 and who don't have dementia.

## Volunteer Coordination and Training

Voluntary work is integral to the provision of palliative care. Palliative Care Volunteers offer compassionate, 'neutral' support to those living with a terminal illness. They complement and enhance the care being provided by professional staff both in the Hospital and in the Community. They also provide support and respite for carers.

- It is critically important, however, that the activities of volunteers be effectively coordinated with professional services, and that volunteers be given appropriate training in the provision of their services. This is particularly important given the recent amendments to work health and safety legislation in NSW that now makes it clear that organisations engaging volunteers have a clear duty of care to ensure the safety of volunteers in the course of their work, as well as the safety of the people they support<sup>xxviii</sup>.
- Coordination and training is usually managed by dedicated Volunteer Coordinators within Specialist Palliative care Services. Over recent years, funding for paid Volunteer Coordinator positions for palliative care has been cut in some areas, resulting in additional challenges in training and managing volunteers. It also reduces the Services' capacity to recruit valuable volunteer resources.

### Recommendation 9:

**That the NSW Ministry of Health ensures that there is adequate funding and support for a Volunteer Coordinator position in every palliative care service that recruits and trains volunteers or who have identified the potential to do so.**

### Recommendation 10:

**That PCNSW be funded by the NSW Ministry of Health to develop a state wide mandatory Palliative Care Volunteer training resource to support existing services, especially those in non-metropolitan areas and that annual volunteer training courses be conducted in rural and regional areas.**

## 6.1.4 Culturally Appropriate Care

There are significant cultural differences in dealing with issues of death, dying and bereavement and a need to engage appropriately with communities to ensure they have access to culturally respectful palliative care services.

In particular, there is currently a lack of culturally appropriate respite services for Aboriginal peoples. An increase in the number of culturally sensitive services for Aboriginal people is especially important as the population has higher rates of disease while Aboriginal and Torres Strait Islander carers are more likely to need assistance with core activities themselves. This affects the capacity of the carer to provide care and their own needs for services and support.

Aboriginal and Torres Strait Islander people may have different cultural understandings which impact on the types of services they are willing to access. This includes different understandings of concepts such as kinship and family relationships, place, healing, communication styles and death and dying. These differences are particularly significant in the context of palliative care.

The possibility of direct employment of family members to provide care services should be considered in some situations as an option for Aboriginal and Torres Strait Islander people with a life limiting illness and their carer.

### Recommendation 11:

**That further research be undertaken into the cultural needs of Aboriginal people and Culturally And Linguistically Diverse communities, and the impact of different attitudes towards death and dying in the provision of palliative care to inform policy and service development.**



## 6.2 Care that is Driven by Information

The delivery of quality care is needs to be driven by information. There are two key aspects to this:

- Information required by consumers, including an awareness of the issues around death and dying, and information about their health care choices;
- Information required by health care services to ensure service provision is driven by a strong evidence base.

### 6.2.1 Community Awareness

It is self-evident that everyone ultimately faces the prospect of death. Yet, as a community, we shy away from what are seen as “difficult” conversations about death and dying. This means that many of us remain ill-prepared for the prospect of facing an illness that cannot be cured or for caring for a loved one who is living with a life-limiting illness. It also means that people who have life-limiting illnesses and their carers can often feel isolated from the others in the community who find it difficult to cope with the complex emotions associated with death and dying.

A number of organisations have been actively attempting to engage the community in discussions about death and dying. Palliative Care Australia, with support from the State based associations such as PCNSW, seeks to raise awareness of this issue, particularly during National Palliative Care Week.

However, much more needs to be done to lift the veil on one of the last “taboo” subjects in the area of public health.

PVNSW is strongly of the view that community engagement will only be forthcoming through a well-resourced, national campaign similar to those adopted for AIDS awareness, or road safety. Such a campaign needs to be based on human experiences and demonstrate why it is important for people to have a healthy approach to understanding the process of death and dying and to discussing issues around death and dying within the community.

#### **Recommendation 12:**

**That Palliative Care Australia work in collaboration with the Australian Government Department of Health and Ageing to develop a national media campaign designed to raise community awareness about how to live with a life limiting-illness, face death and cope with loss and bereavement.**

Exposure to the death of a love one or friend can occur at any time in a person’s life. Yet little or no emphasis is given to this in the personal development curricula for children at school.

#### **Recommendation 13:**

**That death, dying and the role of palliative care be integrated into the personal development syllabus of all NSW schools and the development of the Australian Curriculum.**

## 6.2.2 Quality Improvement

### National Standards

National standards for the delivery of palliative care were first developed in 1994. The *Standards for Providing Quality Palliative Care for All Australians* are based upon a set of values that have been endorsed by consumers and health care professionals<sup>xxix</sup>. The values set out the things that patients, families and health care professionals believe are most important in the delivery of care to people reaching the end of their lives. The values state that quality care is provided by health workers who:

- Endeavour to maintain the **dignity** of the patients, their caregivers and family;
- Work within the strengths and limitations of the person, their caregivers and family to **empower** them in managing their own situation;
- Act with **compassion** towards the patient, their caregivers and family;
- Consider **equity** in the accessibility of services and in the allocation of resources;
- Demonstrate **respect** for the patient, their caregivers and family;
- **Advocate** on behalf of the expressed wishes of patients, caregivers, families and communities;
- Are committed to the pursuit of **excellence** in the provision of care and support; and
- Are **accountable** to patients, caregivers, families and communities.

Flowing from these values are 13 specific standards for Palliative care services. The standards are available from the PCA website: [www.pallcare.org.au](http://www.pallcare.org.au).

The National Standards set out the capability and services expected of health services, including primary care services, and Level 1, 2 and 3 Specialist Palliative Care Services. These capabilities reflect the structure of services set out in the NSW *Role Delineation Framework* which is defined in Section 3.2.

Despite having standards in place for almost two decades, much more needs to be done to support their application across all services in NSW. The poor adoption of the standards appears to be due to a number of factors, including:

- Limited data and information about the capability and range of palliative care services provided by health services, including Specialist Palliative Care Services;
- Lack of resourcing for Specialist Palliative Care Services, and inflexible models of care that means the Role Delineation Framework cannot be implemented in practice. This issue is discussed further in Section 6.3.

#### Recommendation 14:

**That the NSW Ministry of Health and all Local Health Districts commit to the adoption of the National Standards for Providing Quality Palliative Care in all appropriate care settings in NSW.**

### Data Collection and Analysis

The collection and analysis of data by services and individual health professionals is critical to managing a quality and continuously improving end of life and palliative care service.

System level data is necessary to inform national and state health policies.

Service level data is required for quality improvement and service planning.

Clinical data is necessary to provide the evidence needed to improve clinical care.

Two key initiatives sponsored by the Australian Government has been the National Sub-acute and Non-acute Patient Classification (NSAP) program, and the Palliative Care Outcomes Collaboration (PCOC).

Palliative care is one of the case types in the NSAP classification system designed to identify the cost of care and allow consistency in data collection for the purpose of benchmarking and service planning across the State.

Palliative Care Outcomes Collaborative (PCOC) is a federally funded voluntary quality initiative which aims to assist providers collect clinically relevant data with a view to improved practice and outcomes..

Notwithstanding the challenges associated with data collection, feedback from NSW palliative care services suggests that the both NSAP and PCOC are useful and important tools to develop better data and understanding around palliative care.

Anecdotal evidence suggests that participating services do not consistently code clinical events within the 'phases of care' criteria used by PCOC so that benchmarking and validation is impaired. Further, non-participating services have indicated that they feel they lack the service capacity and/or the data collection infrastructure to consider participation.

Improving coding practices is an expensive and time-consuming process for service providers who also need to believe in the clinical or service benefit associated with data acquisition. At present, funding is provided to develop the tool, but not to the resources necessary to administer it. PCNSW recognises that a consistent framework for an agreed data collection for Specialist Palliative Care Services in NSW is lacking, and this is impacting on the ability of government to make informed decisions around Palliative Care demand, service provision and service distribution.

#### **Recommendation 15:**

**That following consultation with the broad spectrum of Specialist Palliative Care Services the NSW Ministry of Health determine a minimum Palliative Care data set and support its collection within all NSW Specialist Palliative Care Services;**

**That LHDs be held responsible for ensuring local capacity to collect and report this data.**

PCNSW recognises that the PCOC data set will need to be part of the consultation and decision making process in Recommendation 15. The role/purpose of PCOC has changed significantly since it was introduced in 2005. At that time PCOC was about collecting outcomes data to support investment decisions with respect to Specialist Palliative Care Services. Subsequently, a benchmarking function was included. The service improvement element has remained problematic because the client populations and service models within and around the participating services are so very different. PCOC is now focused on quality improvement and is trying to teach services how they can use the data in a reflective process to understand where their outcomes are sub-optimal. However, while the PCOC data set is well established for inpatient palliative care units there is some question as to the appropriateness of these measures in consultation and/or community only settings.

#### **Recommendation 16:**

**That PCOC consider adjustments to both its data set and processes to allow increased uptake in community and consultative palliative care services.**

### **Research and leadership**

Appropriate support and increased capacity for research into palliative and end of life care is critical to ensure best-practice evidence based care.

Currently, clinical research is undertaken by a number of bodies and collaborative groups at the national and State level. The major research collaborative in palliative care in NSW, *Improving Palliative Care through Clinical Trials* (ImPaCCT), is governed by a Management Advisory Committee and supported through a coordinator based at UNSW and is funded until June 2013 by the Cancer Institute of NSW. Recurrent funding is not ensured and needs to be.

ImPaCCT was set up to support and complement the work of the national collaborative research group, *Palliative Care Clinical Studies Collaborative*.

Collaborative groupings at both national and state levels offer great potential for advancing NSW's research agenda by encouraging the sharing and transfer of expertise, enabling recruitment for research activity across multiple sites, and ensuring the dissemination of findings through their associated networks.

The NSW Palliative Care Strategic Framework aims to strengthen evidenced based practice, by developing Level 3 Specialist Palliative Care Services as research centres.

PCNSW endorses this goal, and in particular that research into improved quality of care should be a routine element of the functions of Level 3 Services.

**Recommendation 17:**

**That all Level 3 Specialist Palliative Care Services be supported to be centres of research excellence in palliative care. As a first step, the palliative care mapping exercise undertaken by the NSW Ministry of Health should include within its scope palliative care research capacity and activity in order to assess progress in achieving the aim of transforming all Level 3 services into well-functioning research centres. This activity should include an assessment of the research activity and capacity of Level 2 services.**

Feedback from the palliative care research community indicates that the balance of research funding remains skewed towards research into cancer related illnesses. Given the increasing contribution of non-malignant illnesses to the demand for Palliative care services, this imbalance needs to be addressed.

**Recommendation 18:**

**That the NSW Ministry of Health review opportunities to improve resourcing for non-cancer palliative care research across all care settings. Areas of special concern include community care, coordination of care and the needs of culturally and linguistically diverse groups.**

The NSW Palliative Care Strategic Framework also commits the NSW Ministry of Health to examine strategies to improve the dissemination of research findings, and proposes that this be facilitated by the Palliative Care Service Development Officers.

**Recommendation 19:**

**That the State-wide Centre for Improvement in Palliative Care (SCIP) undertake an evaluation of the effectiveness of the dissemination of palliative care research findings through the Palliative Care Service Development Officer Network.**

LHD Human Research Ethics Committees, LHD Research Governance Offices, the NSW Ministry of Health and Treasury Managed Funds need to develop a better, broader understanding of the aims of palliative care research to allow for collaborative, national palliative care research (eg by addressing indemnity issues), research into areas that non-Palliative Care clinicians might find taboo (eg the dying process such as respiratory secretions or terminal agitation) and in non-hospital settings (eg at home and in residential aged care).

**Recommendation 20:**

**That the NSW Ministry of Health clarify and confirm that the Treasury managed funds indemnity for investigator led research in palliative care covers all aspects of the health system where this care is delivered, including the community and residential aged care.**

## 6.3 Care that is Organised for Quality and Safety

### Mapping Palliative Care Services

As indicated in the discussions above, additional palliative care service capacity is required to address unmet need, particularly in rural areas and the growth corridors of metropolitan Sydney.

Access to after-hours palliative care services, including emergency medication, consultancy advice, telephone support and callout is restricted and leads to patient and family distress, as well as inappropriate and unnecessary admission to hospital.

However, the lack of data on current needs, and of the services currently available, makes it difficult (if not impossible) to clearly assess to resources required, and to deliver efficiencies through more appropriate, flexible, and needs based delivery of care.

As a first step in determining the extent of resources required, PCNSW welcomes the announcement by the NSW Minister for Health, the Hon Jillian Skinner, in August 2011 that “Health NSW will map current palliative care services against population needs; investigate population planning tools used in other jurisdictions to assist in future service planning; examine the current workforce and identify any gaps, and examine training and resources available to support volunteers, carers and health workers”.

PCNSW also welcomed the opportunity to participate in the oversight of this initiative through our representation, along with other consumer and service provider representative organisation, on the Palliative Care Expert Advisory Group (PCEAG).

PCNSW understands that the collection of data for the mapping exercise is structured around the nomenclature and definition provided in the NSW Palliative Care Role Delineation Framework. That framework was developed in 2007 and is scheduled for review in 2012.

As discussed in Section 3, PCNSW is of the view that the review of the Role Delineation Framework should consider incorporating a clearer delineation between generalist and community “end of life” care services and Specialist Palliative Care Services. This could assist in reducing confusion around the wide range of care services that may be available to assist consumers, carers and families as a person approaches and reaches the end of life and the provision of Specialist Palliative Care services for those with more complex needs (recommendation 1). All palliative care services need to be mapped and assessed as part of this exercise.

Opportunities to improve care that is organised for quality and safety are likely to be strongly influenced by the outcomes of the NSW Ministry of Health mapping exercise. The discussion below aims to identify those priority issues that PCNSW believes need to be addressed following the outcomes of the mapping exercise.

### **6.3.1 Coordinated integrated care**

#### **NSW Role Delineation Framework**

As discussed in Section 3.2, the NSW Palliative care Strategic Framework 2010-13 is predicated on the NSW Role Delineation for Palliative care (2007) which outlines the relationship between specialist and non-specialist services and defines three levels of Specialist Palliative care Services in terms of their resources and capability.

Quality Palliative Care relies on the flexibility of the system to enable “patients” to move seamlessly between services according to their need.

The Framework broadly categories patients into three Groups:

- Group A: patients with a life-limiting illness whose needs can be met by non-specialist care services;
- Group B: Patients requiring consultation-based Specialist Palliative Care on an episodic basis but remain under the care of non-specialist services; and
- Group C: Patients with complex, unstable conditions requiring on-going care. Non-specialist services would remain involved in care in partnership with Specialist Palliative Care services, which would have an on-going role in care provision.

Importantly, all Groups may receive care in a variety of settings (the home, Residential Aged Care Facilities or in acute and sub-acute hospitals).

PCNSW remains broadly supportive of this model. However, notwithstanding the aspirations of the NSW Palliative Care Strategic Framework, it has not been successfully implemented in practice. Inflexibility in models of care, particularly between hospital and community based services, and perverse outcomes from poorly structured funding models mean that consumers do not move seamlessly through the system, do not receive appropriate care in a timely and responsive fashion, and the health care system is paying for inappropriate and more costly services than necessary to meet the needs of the community. Historic funding variations are also present across NSW and are not linked to population need and demand.

## Networking and Referrals Between Services

Significant improvement is needed in the networking of non-specialist services and Specialist Palliative Care Services, and in the timely referral of clients across these services.

The adoption of consistent standards across services, as discussed in Section 6.2.2 would assist in this process. Further, variance in referral criteria between Specialist Palliative Care Services needs to be addressed, although local resourcing and service structures may necessitate some restrictions.

More seamless movement between services, and greater collaboration amongst services, may be strengthened by opportunities presenting through new technologies and investment in eHealth systems and the National Broadband Network infrastructure. Strategies to address after-hours access to palliative care advice and support may be more possible through eHealth capacities.

### Recommendation 21:

**That the Ministry of Health establish mechanisms to examine the palliative care service delivery possibilities of all eHealth developments and that systems to allow cross Specialist Palliative Care Service access to electronic medical records be facilitated where improvements in service access and provision can be demonstrated.**

Improved management information systems within and across services could support multidisciplinary teams and provide a more seamless service to consumers of services. Improved management Information Systems could also support standards assessment and reporting for data collections such as PCOC.

## Case Management and Access to Support

The dying are best supported by a steady, reliable, consistent contact with the people who will care for them right up until the end. Our aim should be to have some “same faces” supporting the dying and their loved one’s from the time of the diagnosis, through to the final stages of life. Where multiple services are providing care a central case manager / care coordinator is critical in providing a point of continuity for the care recipients. PCNSW notes that there is a wide range of models of community service provision in NSW and does not advocate for any single one example. PCNSW does call on all community service providers, specialist and primary, to recognise the importance of this role and to ensure work allocations permit suitable time for its fulfilment.

## Rural and Remote Challenges

PCNSW recognises and accepts that a range of health and community service may not be accessible for people living in rural or remote areas. This represents a huge challenge in a number of policy areas. However, as in other areas of policy, we need to develop a population, needs based model that sets out the expectation of the levels of resourcing and servicing that can reasonably be expected across all regions in NSW. This would also provide a sound basis for the equitable provision of care for all people in NSW.

PCNSW’s objective is to harness the collective resources of services across the state to provide support to communities in regional and remote areas.

Opportunities with improving communication technologies and, particularly with the rollout of the National Broadband Network, must be grasped for the benefit of people living (and dying) in rural and remote NSW.

This must be complemented by targeted and structured processes for “fly-in fly-out” consultations by Specialist Palliative care Service to rural and remote areas.

### Recommendation 22:

**That policies, processes and guidelines for the allocation and funding of “fly-in fly-out” palliative care service comprising a Specialist Palliative Care physician and nurse at minimum to regional and remote communities be reviewed and formalised on a state-wide basis.**

For those people living in their own homes, or even in Residential Aged care Facilities, the lack of after-hours support services, particularly in regional and rural areas, mean that it is often necessary to access ambulance and acute care services, when this could possibly be averted.

**Recommendation 23:**

**That the NSW Ministry of Health undertake a feasibility study for establishing a state wide Palliative care After Hours Advice Line, either through a single Level 3 Specialist Palliative Care Service, or on a regional basis through all Level 3 Specialist Palliative Care Services.**

### Aged Care Sector

The challenges posed by the ageing population in Australia, and the pressure it brings to health and aged care budgets, has been well publicised in recent times.

PCNSW acknowledges the important work undertaken by the Productivity Commission and supports the thrust of the recommendations it made in its report, *Caring for Older Australians* in August 2011:

**Recommendation 24:**

**That the Australian Government adopt the recommendations of the Productivity Commission with respect to aged care, and in particular:**

- **the replacement of the current system of discrete care packages across community and residential care with a single integrated and flexible system of entitlements. The System would cover services including palliative care;**
- **a flexible funding model that supports individual choice and ensures that people are assisted to die in the place of their choice, with the people they wish to be present;**
- **the Australian Government ensure that residential and community care providers receive appropriate payments for delivering palliative care;**
- **that Advance Care Directives form part of a person's electronic health record; and**
- **that palliative care be a basic competency for aged care workers.**

PCNSW welcomes the recent Australian Government announcement of an aged care reform package that responds, in part, to the issues raised by the Productivity Commission. In particular, PCNSW welcomes the:

- \$19.8 million for Specialist Palliative Care and advance care planning advisory services for aged care providers and GPs caring for older people to build better links between aged care and palliative care services;
- \$1.9 million for the expansion of the existing Program of Experience in the Palliative Approach (PEPA) to provide palliative care training for staff in residential aged care facilities and Home Care package services;
- \$58.5 million for projects with a focus on prevention of hospitalisation for older Australians and improved access to complex health care through a number of initiatives:
  - improved access to complex health care services including palliative and psycho-geriatric care for aged care recipients;
  - support for aged care providers to enter into partnerships with public and private sector health care providers and medical insurers for the delivery of short term, more intensive health care services;
  - improvements to the care and support provided to older Australians by supporting research translation and better evidence-based practice across the Home Care and residential care sectors, to test and promote innovations in service delivery and integrated care models; and
  - improvements to the health and well-being of older Australians by providing support for multidisciplinary care for care recipients in both residential and community settings and the opportunity to test the use of video consultations to improve access to GPs for residents in aged care homes.



PCNSW notes, however, that there are many other barriers to ensuring that residents in aged care facilities with life-limiting illnesses receive appropriate care without the need for unnecessary hospital admission to deal with short-term periods of instability. PCNSW therefore also welcomes the Australian Government's announcement that funding will be made available to assess and develop options to address barriers to the provision of short term intensive health care services in the aged care setting, including both in-reach services from the hospital sector and diversification of the aged care sector into providing a broader range of health care services.

The Australian Government notes that consultation with states and territories and with Local Hospital Networks will be an integral part of this process.

#### **Recommendation 25:**

##### **That the NSW Ministry of Health:**

- **strongly engage with the Australian Department for Health and Ageing in the proposed review of barriers to the provision of short term intensive health care services in the aged care setting;**
- **facilitate consultation with PCNSW and Specialist Palliative Care Services as part of the review process;**
- **include in the scope of the review:**
  - **the ratio of Senior Registered Nurses to residents in Residential Aged Care Facilities;**
  - **access to and storage of medications needed to care for residents with life-limiting illness within the aged care setting;**
  - **access to specialist equipment, including oxygen, within aged care settings.**

#### **Case Study –Interface with a Residential Aged Care Facility**

Mrs G is 87 years old and widowed with two children. One has a long standing psychiatric history and cognitive impairment and the other estranged from his sibling and mother. Mrs G has a history of advanced dementia, congestive cardiac failure and a stage 4 pressure area on her sacrum. Mrs G had been living in a Residential Aged Care Facility (RACF) for the past 5 years.

Mrs G had been transferred from the RACF to the Emergency Department (ED) 7 times in the past 12 months for dehydration, urinary tract infections and sepsis. In one admission she spent 5 days in ICU following surgery to debride her sacral wound. As Mrs G's GP was not contactable after hours and there was no Advance Care Directive, the RACF had no choice but to transfer Mrs G to the ED each time she became acutely unwell.

An allied health professional referred Mrs G to a Palliative Care service after meeting with her daughter. Mrs G was transferred the next day. Her daughter accompanied her to the Palliative Care Unit and stayed with her for the 3 days before Mrs G died comfortably. Social Workers were able to assist her daughter with the practicalities of dealing with her mother's death as well as refer her to a bereavement service.

Because Mrs G did not have a malignant diagnosis, the RACF incorrectly exempted her from a referral to Palliative Care. If Mrs G had been referred to Palliative Care earlier:

- many transfers to the Emergency Department would probably have been avoided;
- she would have been more likely to have been cared for in the RACF;
- consultative advice from a Specialist Palliative Care Service would have been available at no charge to the RACF. In most regions (predominantly metro) this is available 24 hours a day.



### 6.3.2 Workforce

The ageing population will impact on workforce shortages at a time when the demands on health care services will be at their greatest. Investment is needed now to ensure an appropriately qualified, skilled and experienced workforce is available when and where it is needed into the future.

A range of workforce initiatives are required, including:

- Further development of the capacity of Specialist Palliative Care Services to meet current and future demand;
- Further development of capacity in the palliative approach in disability and aged care services;
- Increased availability of scholarships for the rural Specialist Palliative Care workforce.

#### **Recommendation 26:**

**That the NSW Ministry of Health prepare a “Palliative Care Workforce Strategy” based on supply and demand analyses arising from the current palliative care mapping exercise. The Strategy should:**

- **Identify workforce resources required across services (general, specialist and community);**
- **Address existing and anticipated workforce shortages in Specialist Palliative Medicine**
- **Address succession planning concerns amongst Rural Specialist Palliative Care Nurses**
- **Aim to ensure that palliative care is a basic competency for acute care workers, aged care workers and disability care workers**

The NSW Ministry of Health currently provides recurrent funding for the appointment of Palliative Care Service Development Officers (PCDSOs) in each former Area Health Service. With the reform of the NSW Health portfolio, it is important that the service provided by such positions be available to Palliative Care Services in each of the new Local Health Districts. It is currently not clear whether this is being addressed as part of the transitional arrangements but PCNSW has received reports that some LHDs feel they have lost access to PCDSO services.

#### **Recommendation 27:**

**That Health NSW ensures, through their Service Level Agreements with Local Health Districts, that funding is provided to maintain effective access to Palliative Care Service Development Officer services in each Local Health District.**

Given the reliance on primary care services in providing services to people with life-limiting illness, it is imperative that all healthcare workers have some knowledge of, and training in, issues dealing specifically with palliative and end of life care

#### **Recommendation 28:**

**That by 2015:**

- **revised and updated palliative care training curricula be in place in appropriate faculties of tertiary teaching institutions; and**
- **the Palliative Care Curriculum for Undergraduates (PCC4U – [www.pcc4u.org](http://www.pcc4u.org)) be in place in all appropriate faculties of tertiary teaching<sup>xxx</sup>.**

### 6.3.3 Resourcing and funding models

#### Recommendation 29:

Without pre-empting the outcomes of the NSW palliative care service mapping exercise, based on current estimates of the workforce shortage, PCNSW recommends:

- That the NSW Government provide an increase in recurrent funding for Specialist Palliative Care services to allow capacity to meet demand across all care settings (including hospital consultation teams).
- That the NSW Government review and adjust the existing funding arrangements to better meet costs of fly-in and telemedicine support from metropolitan level 3 services.

#### Funding Models

Historically, palliative care service funding has been linked to funding for cancer services.

Modern cancer treatments have seen an increase in the symptom burden during the palliative phase adding to the complexity of palliative care needs for many cancer patients. More people are now dying from end stage organ failure and dementia, and management of these disease trajectories are significantly more complex. It necessitates more coordination of multi-disciplinary care, and more need for Specialist Palliative Care contribution.

Over the past 15 years palliative care has been moving from being only a cancer related service. However, the historical cancer based funding model has not been reviewed and amended to meet either the increasing numbers of cancer patients or the demand from non-cancer groups. In 2010, ischaemic heart disease and cerebrovascular disease were the two leading causes of death in Australia. Dementia and Alzheimer's disease is now the third, respiratory cancers fourth. Despite this, cancer patients still comprise around 85-90% of the palliative care service caseload in NSW<sup>xxxi</sup>, although one metropolitan LHD reports a 40% non-cancer load. Palliative Care Australia estimates that non-cancer referrals should be 35% of Specialist Palliative Care service demand.

This has resulted in inequitable service provision for consumers who have non-cancer related terminal illnesses such as dementia, renal failure, heart failure, end stage respiratory disease and many others.

There are a number of related anomalies or inconsistencies in funding models that impact on the efficient and effective delivery of palliative care:

- Inconsistency in funding models resulting in great variance in the availability of Specialist Palliative Care Consultation teams to improve the quality of end of life care in NSW acute hospitals. There is strong narrative evidence to indicate that NSW Public Hospitals are not always safe places to die;
- Absence of any formal recurrent adjustment to funding to support the provision of Specialist Palliative Care services to the growing non-cancer population.
- In rural and regional areas a significant number of services operate without formal agreements for specialist medical support. This is most often provided on a good will basis by fly in/fly out Palliative care medical specialists from metropolitan services. This is not a sustainable model and needs to be reviewed;
- The funding and delivery mechanisms for acute and sub-acute inpatient care and community based services vary markedly between area health services. In areas where in-patient and community based services are delivered through different agencies or services, funding anomalies can significantly impede effective care. For instance, sub-acute in-patient funding may only cover the basic costs of the bed, and not any other services or treatments that may be required for the patient;
- Similarly, aged care funding is structured on the assumption of "stable" care requirements. If a resident becomes "unstable" there is no provision for funding to provide necessary services, even where they could be most effectively delivered at the Aged Care Facility. As a result, ACFs often have to transfer a resident to hospital to access necessary treatment.

### **Recommendation 30:**

In conjunction with the palliative care mapping exercise announced by the Minister in August 2011, the NSW Ministry of Health should:

- Ensure that the mapping accurately identifies not only the resources allocated to specialist, generalist and community services (as set out in the Role Delineation Framework), but also sets out the funding models underpinning the provision of each service;
- Review the current Specialist Palliative Care Service funding model to reflect the changing demand pattern for palliative care services and changing service role, (ie to reflect increased cancer related demand plus demand for palliative care service for people who have non-malignant life-limiting illness, and to better reflect the growing need specialist consultancy advice for generalist end of life care providers;
- Ensure that Specialist Palliative Care Hospital Consultations Teams are discreetly funded and available in all major rural, regional and metropolitan public hospitals'
- Formalise funding models and support structures for regional and remote access to Specialist Palliative Care Services (eg fly in/fly out programs, teleconferencing etc).

### **Activity Based Funding**

The move to Activity Based Funding presents special challenges to palliative care. We are aware that the Palliative Care Outcomes Collaborative (PCOC) has developed and incorporated a surrogate casemix model but understand that this has not been validated adequately to support robust cost studies. Anecdotal evidence suggests that participating services do not consistently code clinical events within the 'phases of care' criteria used by PCOC so that benchmarking and validation is impaired.

Any future Activity Based Funding framework should seek to accurately measure the cost of good practice and account for indirect care activity like clinician-to-clinician consultation, telephone advice, coordination of volunteers, provision of education, and health promotion. An inpatient funding model exclusively based on cost weights may not cover the infrastructure and indirect care costs of Specialist Palliative Care services. Palliative care clinicians from a range of settings should be involved in the development of any framework. There is a theoretical risk that downward pressures on length of stay and cost of care will create a disincentive for the maintenance of consultation type services in the hospital sector despite the evidence supporting the valuable contributions Palliative Care Hospital Consultation Teams make to care outcomes.

### **Recommendation 31:**

**That the NSW Ministry of Health ensure a suitable level of consultation with Specialist Palliative Care Services is undertaken to allow an informed determination to be made as to the future funding arrangements for Palliative Care provision across acute, sub-acute and community care settings under the healthcare reform agreements.**

## 7. Institutional Arrangements and Consultation

### 7.1 The NSW Ministry of Health Governance

In August 2011, the Minister for Health and Medical Research released a report by the NSW Ministry of Health Director-General relating to *Future Arrangements for Governance of NSW Health*.

The reforms constitute a major reform of NSW Health institutional arrangements.

PCNSW understands that the key features of the reforms include:

- Devolution of accountability for managing all aspect of hospital and health service delivery to Local Health Districts (LHDs);
- Transition of the Department of Health into the Ministry of Health with accountability (amongst other things) for statewide planning, purchasing and performance monitoring of health services;
- Strengthening of the “four pillars” in their respective areas of health care design, standards, reporting, education and associated policy.

These reforms offer considerable opportunity, but as with any transformational change, also pose significant challenges.

PCNSW applauds the underlying rationale of the proposed governance arrangements that recognises the need to reform our health system to reflect the shift in disease burden from acute to chronic conditions. It acknowledges that our current systems, designed in the 1950s with a focus on acute care delivered through hospitals on an episodic basis, struggles to meet the need to coordinate consumer/patient care across a range of care settings.

PCNSW notes however that, in addition to the increasing burden of chronic disease, the system is also facing increased demands in relation to the complexity and challenges associated with people facing a life-limiting illness.

PCNSW supports the move toward more flexible and responsive local services that can engage with consumers and the community in the design of services.

However, a challenge in the reform process is to ensure that the central agencies (the Ministry and the four pillars) have the competence and capacity to drive evidence-based policy, planning and performance management that ensures equitable access to quality health services across the state.

A devolved model demands a strong centre.

#### 7.1.1 Funding and performance management under a devolved model

While recognising a desire to end the “micro-management” of local health services by a centralised bureaucracy, PCNSW remains concerned that a devolved model of funding may result in a lack of transparency and accountability for funding palliative care services. PCNSW is of the strong view that the Service Agreements between the new Ministry of Health and the Local Health Districts must incorporate clear and transparent mechanisms to collect and report of data around funding, resourcing and delivery of palliative and end-of-life care within each LHD.

This is particularly important given the traditional cultural focus of the institutional health model on treatment and cure, rather than on the needs of people facing life-limiting illness for which there is no cure.

#### **Recommendation 32:**

**That the Service Agreements between the Ministry of Health and Local Health Districts (LHDs) clearly specify:**

- **The minimum Specialist Palliative Care Services to be funded or purchased, in all care settings;**
- **The strategies, targets and goals to be achieved in relation to all palliative care service provisions;**
- **Measures to be used to monitor the performance of services (including outcomes for consumers and carers) in relation to palliative care are articulated and these include that CEO performance is linked to palliative care standards achieved in their LHD.**

## 7.1.2 Palliative Care Strategic Policy

PCNSW understands that the role of the new Ministry of Health will include:

- Provision of advice to the Minister on policy, legislation and governance arrangements;
- Planning for future capacity, including specialised services;
- Securing resources to deliver health services;
- Negotiating Service Agreements with LHDs stimulating system-wide initiatives that improve quality and efficiency;
- Ensuring clinicians are involved in service planning; and
- Regulatory functions in relation to public health.

The Ministry will look to the Pillars as the focal point for clinical engagement and will transfer some clinical planning, design and review functions to the Pillars.

The roles of the four pillars will be:

- **Clinical Excellence Commission (CEC):** quality, safety and leadership in clinical governance with the LHDs;
- **Agency for Clinical Innovation (ACI):** primary agency for engaging clinical service networks and designing and implementing new models of care;
- **Bureau of Health Information:** primary source of quality information to the community, healthcare professionals and policymakers;
- **Health Education and Training Institute (HETI):** clinical and non-clinical leadership development, including undergraduate and vocational training as well as post-graduate training.

Over recent years, the Statewide Centre for Improvement of Palliative Care (SCIP) has been charged with leadership for palliative care service planning and to support the implementation of the NSW Palliative Care Strategic Framework.

SCIP was located within the Sydney South West Area Health Service and has been supported by the Palliative Care Service Development Officer Network, with an SDO position within each AHS.

PCNSW understands that the roles and functions of SCIP will transfer to the Agency for Clinical Innovation. PCNSW strongly supports this move.

## 7.2 Consultative Mechanisms

Over recent years, the Palliative Care Advisory Group (PCAG) has provided the key forum for consultation and advice to Government on the implementation of the Palliative Care Strategic Framework. PCNSW has chaired this group from its inception. PCAG has not formally met since 2011 due to uncertainty around structural changes at the state level.

A time limited consultative group, the Palliative Care Expert Advisory Group (PCEAG) was established in 2011 to oversee the preparation of the Palliative Care “mapping project” announced by the Minister of Health in August 2011 and to provide advice on Palliative Care demand and service gaps in NSW. PCNSW was a member of this group. PCEAG concluded its work in April 2012 with a final report sent to the Minister.

It has been stated that a Palliative Care Clinical Network will be established within the Agency for Clinical Innovation. Clinical Networks within the ACI “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.” It would appear that this group would not have a direct policy or service strategic role.

PCNSW is concerned to ensure that appropriate, long term consultative mechanisms are established within the new framework of the Health Reforms to provide policy and strategic advice beyond clinical practice related guidance.

The consultative mechanism(s) need to be:

- linked to the appropriate structures within the reformed health system;
- acknowledged as canvassing the complete range of palliative care services and requirements (including Specialist Palliative Care services); and
- including representation from peak bodies representing service providers, health consumers, and disease-specific representative organisations.

**Recommendation 33:**

**That the NSW Ministry of Health review current palliative care related consultative mechanisms in relation to Specialist and non-specialist Palliative Care and establish an on-going policy and strategic consultative/ advisory body with a documented terms of reference covering palliative and life care issues, including Specialist Palliative Care, that is separate to the anticipated ACI Palliative Care Network. That the consultative arrangements ensure representation from peak bodies representing health service professionals in palliative, end of life and aged care services, health consumers, carers and disease-specific organisations.**

## Attachment A

### NSW Role Delineation Framework: Level 1-3 Services Resource Capability Matrix

Level	Capability Statement	Resources
<p><b>Specialist Palliative Care Level 1</b></p>	<p>Level 1 Specialist Palliative Care services 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 with life-limiting illness.</p> <ul style="list-style-type: none"> <li>• Provides specialist palliative care for patients and their families where assessed needs exceed the resources capability of primary care providers.</li> <li>• Provides assessment and care consistent with the needs of the patient, caregiver and family and within available service capability and resources.</li> <li>• 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.</li> <li>• Provides ongoing care to patients with complex, unstable conditions not restricted to physical symptoms but including psycho-emotional, social and spiritual problems.</li> <li>• Provide 24/7 specialist support and advice for registered patients and carers, including patients in residential aged care facilities and acute care hospitals.</li> <li>• Provides education to primary care providers.</li> <li>• Participates in education programs to develop specialist palliative care skills.</li> <li>• Participates in research and quality activities.</li> <li>• Has access to designated/dedicated inpatient palliative care beds.</li> </ul>	<p><b>Indicative Staffing:</b></p> <ul style="list-style-type: none"> <li>• Director of Palliative Care on an area basis.</li> <li>• Medical practitioner with qualifications and/or experience in palliative medicine.</li> <li>• Clinical Nurse Consultant with qualifications in palliative care nursing.</li> <li>• Nurse Practitioner (Palliative Care).</li> <li>• Social worker with palliative care expertise.</li> <li>• Formalised access to bereavement support.</li> <li>• Formalised access to pastoral care.</li> </ul> <p><b>Links:</b></p> <ul style="list-style-type: none"> <li>• Formalised network links to primary care providers and Level 2 and/or 3 Specialist Palliative Care providers</li> <li>• Formalised links with residential aged care facilities.</li> <li>• Formalised links with core support services (see Support Service List) to ensure access to expanded multi-disciplinary care where required to meet individual patient's needs.</li> </ul>

## Attachment A

### NSW Role Delineation Framework: Level 1-3 Services Resource Capability Matrix

Level	Capability Statement	Resources
<b>Specialist Palliative Care Level 2</b>	<p>As for Level 1 Specialist Palliative Care Services (above).</p> <p>In addition a Level 2 service would;</p> <ul style="list-style-type: none"> <li>• Provide support and consultation to Level 1 services within local area for patients who have complex problems (physical, emotional, social or spiritual).</li> <li>• Provide or contribute to education to support Level 1 specialist providers as appropriate.</li> <li>• Participates and/or provides leadership in collaborative research activities.</li> <li>• Capability for registrar training under supervision of Fellow.</li> </ul>	<p><b>Indicative Staffing:</b></p> <ul style="list-style-type: none"> <li>• Director of Palliative Care on an Area basis.</li> <li>• Medical specialist(s) with specialist qualifications in palliative medicine (Fellow of Chapter of Palliative Medicine) and/or</li> <li>• Medical practitioner(s) with specialist qualifications in Palliative Medicine.</li> <li>• Clinical Nurse Consultant with specialist qualifications in palliative care.</li> <li>• Nurse Practitioner (Palliative Care).</li> <li>• Clinical nurse specialists / Registered nurses with formal qualifications in palliative care</li> <li>• Specialist allied health staff with a direct report to Director Palliative Care, including but not limited to: <ul style="list-style-type: none"> <li>– Social work</li> <li>– Pastoral care</li> <li>– Physiotherapist</li> <li>– Bereavement support</li> <li>– Pharmacist</li> </ul> </li> <li>• Volunteer/ Volunteer Co-ordinator</li> </ul> <p><b>Links:</b></p> <ul style="list-style-type: none"> <li>• Must have formal links with primary care providers in their local area and with Level 3 Specialist palliative care service for patients with complex needs.</li> <li>• May have links to a Level 1 Palliative Care service.</li> <li>• Has formal links with Universities as appropriate to role and function.</li> </ul>



## Attachment A

### NSW Role Delineation Framework: Level 1-3 Services Resource Capability Matrix

Level	Capability Statement	Resources
<b>Specialist Palliative Care Level 3</b>	<p>As for Level 2 Specialist Palliative Care Service (above).</p> <p>In addition a Level 3 service would;</p> <ul style="list-style-type: none"> <li>• 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.</li> <li>• 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.</li> <li>• Undertake lead role in education and research in palliative care. Has formal links with academic units.</li> <li>• Con-joint appointment of senior clinical staff.</li> <li>• Capability for registrar training under supervision of Fellow</li> </ul>	<p><b>Staffing:</b></p> <ul style="list-style-type: none"> <li>• Director of Palliative Care on an Area basis.</li> <li>• Medical specialist(s) with specialist qualifications in palliative medicine (Fellow of Chapter of Palliative Medicine) and/or</li> <li>• Medical practitioner(s) with specialist qualifications in Palliative Medicine.</li> <li>• Clinical Nurse Consultant with qualifications in palliative care.</li> <li>• Clinical Nurse Specialist(s) with qualifications and experience in palliative care nursing.</li> <li>• Registered nurses with experience/ qualifications in palliative care.</li> <li>• Expanded specialist allied health staff with a direct report to Director Palliative Care, including but not limited to: <ul style="list-style-type: none"> <li>• Speech therapist</li> <li>• Dietician</li> <li>• Pastoral Care with experience/ qualifications in a field relevant to palliative care.</li> <li>• Volunteer/ Volunteer Coordinator.</li> </ul> </li> </ul> <p><b>Links:</b></p> <ul style="list-style-type: none"> <li>• Formal links with primary palliative care providers (local). Formal links with Level 1-2 specialist palliative care services to provide consultation based care and referral for patients with complex needs.</li> <li>• Formal links to other tertiary services/ specialties e.g. anaesthetics, pain service.</li> <li>• Links to University, Schools of Medicine, Nursing and Allied health. Conjoint appointment of senior clinical staff.</li> </ul>

## Attachment B

### Organisations and individuals that provided feedback to the Policy Statement Discussion Paper

1. Improving Palliative Care through Clinical Trials (ImPaCCT) NSW
2. The Palliative Care Clinical Studies Collaborative (PaCCSC)
3. Aged and Community Services Association of NSW & ACT
4. Motor Neurone Disease NSW
5. Life Circle/Cancer Council NSW
6. Calvary Health Care Sydney
7. Southern NSW Local Health District
8. Hunter New England Palliative Care Clinical Stream
9. Carers Australia NSW
10. Cancer Voices NSW
11. Coral Marks
12. James Couston
13. Yvonne McMaster

Thank you to the service providers and other individuals who met with us in our face to face consultations in the Lismore area, the Hunter region, Wollongong and Western Sydney.

## Endnotes

- i. NSW Department of Health 2007, *Palliative Care Role Delineation Framework GL2007\_022*, p3.
- ii. The cover page to the Guideline stipulates a review date for the Palliative Care Role Delineation framework as November 2012.
- iii. See Palliative care Austr: National Palliative Care Consensus Statement 2011, Priority 5.
- iv. NSW Department of Health 2007, *A New Direction for NSW: State Health Plan Towards 2010*, Sydney, p4.
- v. Palliative Care Australia: *Health System Reform and Care at the End of Life: A Guidance Document*, 2010, Canberra, p 14.
- vi. Australian Government Department of Health and Ageing: *Supporting Australians to Live Well at the End of Life, National Palliative Care Strategy 2010*
- vii. Palliative Care Australia: *Health System Reform and Care at the End of Life: A Guidance Document*, 2010, Canberra.
- viii. Palliative Care Australia (PCA) is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life for all. Palliative Care NSW is a member of PCA, along with other State and Territory Palliative care associations.
- ix. NSW Department of Health 2010, *Palliative Care Strategic Framework 2010-2013 PD2010\_003*
- x. NSW Department of Health 2007, *Palliative Care Role Delineation Framework GL2007\_022*
- xi. Palliative Care Australia: *Standards for Providing Quality Palliative Care for all Australians*, 2005, p10.
- xii. Then known as the NSW Association for Palliative Care. The Association changed its name to Palliative Care NSW in 2007
- xiii. Palliative Care Australia 2005, p11.
- xiv. Input in part from Palliative Care WA
- xv. Palliative Care Australia 2005, pp11-12.
- xvi. The cover page to the Guideline stipulates a review date for the Palliative Care Role Delineation framework as November 2012.
- xvii. NEMJ 363(8):733-42
- xviii. Palliative Care Australia, 2011. Media Release "We Need to Talk About Dying – Survey", <http://www.palliativecare.org.au/Portals/46/National%20Palliative%20Care%20Week%20Media%20release.pdf>
- xix. Hillman, K. "Address at Launch of National Palliative Care Week 2010." Palliative Care Australia, Parliament House, 26 May 2010
- xx. Saul, P. "We need to talk of death in our perfect health storm." Sydney Morning Herald, 30 March, 2009
- xxi. Palliative Care Australia 2010, p54.
- xxii. National Health and Hospitals Reform Commission: *A Healthier Future for All Australians – Final Report*, June 2009, p3.
- xxiii. Australian Government Department of Health and Ageing: *Building a 21st Century Primary Health Care System: A Draft of Australia's First National Primary Health Care Strategy*, 2009, p9.
- xxiv. Australian Commission on Safety and Quality in Health Care: *Discussion Paper on achieving the directions established in the proposed National Safety and Quality Framework*, 2009.
- xxv. Australian Government: *A National Health and Hospitals Network: Further Investment in Australia's Health*, 2010
- xxvi. Palliative Care Australia 2010, p59.
- xxvii. Australian Government Department of Health and Ageing 2009, *Primary Health Care Reform in Australia*, p42
- xxviii. *Work Health and safety Act 2011, Section 7(h)*.
- xxix. Palliative Care Australia 2010, p20.
- xxx. See Palliative care Austr: National Palliative Care Consensus Statement 2011, Priority 5.
- xxxi. NSW Department of Health 2010, *Palliative Care Strategic Framework 2010-2013 PD2010\_003*, p5



Palliative Care NSW