Australian Government

Department of Health and Ageing

SENATE COMMUNITY AFFAIRS COMMITTEE INQUIRY INTO PALLIATIVE CARE IN AUSTRALIA

Submission from the
Department of Health and Ageing
April 2012

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LIST OF ABBREVIATIONS

ACP	Advance Care Planning
ACFI	Aged Care Funding Instrument
ACHS	Australian Council on Healthcare Standards
AHCA	Australian Health Care Agreement
AIHW	Australian Institute of Health and Welfare
AMA	Australian Medical Association
APRAC	Australian Palliative Residential Aged Care
CDM	Chronic Disease Management
CACP	Community Aged Care Packages
COMPAC	Community Palliative Aged Care
4C	Cradle Coast Connected Care
CALD	Culturally and Linguistically Diverse
DoHA	Department of Health and Ageing
DHHS	Department of Health and Human Services
EPA	Enduring Power of Attorney
EACH	Extended Aged Care at Home
EACHD	Extended Aged Care at Home Dementia
GP	General Practitioners
IHG	Identified Health Grant
ISO	International Organization for Standardization
LPCGP	Local Palliative Care Grants Program
MBS	Medicare Benefits Schedule
MTRP	Medical Training Review Panel
NEHTA	National E-Health Transition Authority
NHMRC	National Health and Medical Research Council
NPCP	National Palliative Care Program
NPA HHWR	National Partnership Agreement on Hospital and Health Workforce Reform
NSAP	National Standards Assessment Program
NSFATSIH	National Strategic Framework for Aboriginal and Torres Strait Islander Health
NWAHS	North West Area Health Service
NAHSSS	Nursing and Allied Health Scholarship and Support Scheme
PCA	Palliative Care Australia
PaCCSC	Palliative Care Clinical Studies Collaborative
PCC4U	Palliative Care Curriculum for Undergraduates
PCOC	Palliative Care Outcomes Collaboration
PCWG	Palliative Care Working Group
PICAC	Partners in Culturally Appropriate Care
PCEHR	Personally Controlled Electronic Health Record
PBS	Pharmaceutical Benefits Scheme
PEPA	Program of Experience in the Palliative Approach
RACF	Residential Aged Care Facility
RPC	Respecting Patient Choices
RACGP	Royal Australian College of General Practitioners
RPCP	Rural Palliative Care Project
UTAS	University of Tasmania Rural Clinical School

1. INTRODUCTION

Palliative care is defined by the World Health Organization[1] as:

> *'An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment, and treatment of pain and other problems – physical, psychosocial and spiritual.'*

A person receiving palliative care will have an active, progressive and far-advanced disease, with little or no prospect of cure. The aim of palliative care is to achieve the best possible quality of life for the individual patient, their carers and family.

Palliative care:

- affirms life and treats dying as a normal process;
- neither hastens nor postpones death;
- provides relief from pain and other distressing symptoms;
- integrates the physical, psychological, social, emotional and spiritual aspects of care, with coordinated assessment and management of each person's needs;
- offers a support system to help people live as actively as possible until death; and
- offers a support system to help the family cope during the person's illness and in their own bereavement.

Palliative care is provided to people of all ages who are dying. The need for palliative care is not dependent on any specific medical diagnosis, but on the person's needs. Some of the common medical conditions of people requiring palliative care include: cancer, HIV/AIDS, motor neurone disease, muscular dystrophy, multiple sclerosis and end-stage dementia.

Families and carers also receive support from palliative care services. Families provide much of the care for people who are dying, and practical and emotional support for them in this role is critical. Palliative care services can be provided in the home, in community-based settings like nursing homes, palliative care units, and in hospitals. People who are dying need to be able to move freely between these places in response to their medical care and support needs.

The pattern of care will be different for every individual, and may depend on factors like: geography, services in an area, and the needs and desires of the person, family members and friends. In general, palliative care is best provided in close proximity to the person's local environment and community.

Palliative care involves coordination of the skills and disciplines of many service providers. Those involved in palliative care may include:

- specialist providers: medical, nursing and allied health staff who have undertaken further study in palliative care or have significant experience in the area;
- generalist providers: those clinicians (medical, nursing and allied health) working in other areas of the health system who have a professional involvement with people requiring palliative care; and
- support services: including those who assist with the processes of daily living, enhancing quality of life, and/or providing emotional and spiritual support.

[1] Palliative Care. 2007. Cancer control : knowledge into action : WHO guide for effective programmes ; module 5. World Health Organization.

2. NATIONAL PALLIATIVE CARE STRATEGY

The Australian Government first developed a palliative care strategy over a decade ago. The *National Palliative Care Strategy: A National Framework for Palliative Care Service Development (2000)* represented the commitment of the Commonwealth, State and Territory governments to the implementation of palliative care policies, strategies and services that were consistent across the nation.[2]

The updated strategy, *National Palliative Care Strategy 2010: Supporting Australians to Live Well at the End of Life*, was released in 2011, following its endorsement by the Australian Health Ministers Conference (AHMC). The scope of the updated strategy is broad; addressing both palliative care provided in all specialist and general settings as well as end-of-life issues.[3]

The goal areas identified in the strategy focus on the whole of the health and human services sector, in order to meet the rising demand for high quality palliative care across Australia. The four goal areas are:

- Awareness and Understanding;
- Appropriateness and Effectiveness;
- Leadership and Governance; and
- Capacity and Capability.

The implementation of the strategy is being overseen by the interjurisdictional Palliative Care Working Group (PCWG), which became a part of the Australian Health Ministers' Advisory Council (AHMAC) committee structure in 2011.

The PCWG, previously known as the Palliative Care Intergovernmental Forum, was originally established in 1998. It has been the main mechanism through which the Commonwealth, States and Territories work together to ensure that national and local activities in palliative care are consistent and provide the most benefit for the community. The PCWG comprises one representative from the government department in each state and territory responsible for the delivery of palliative care related services.

Since its inception the PCWG has:

1. Provided leadership and national direction on the implementation of the National Palliative Care Strategy.
2. Overseen issues related to palliative care, including, but not limited to, monitoring and evaluation, policy development, quality, implementation, and communication strategies.
3. Worked together to facilitate the integration of high quality palliative care and equitable access to palliative care across the health system.
4. Made recommendations on palliative care in response to new evidence and expert technical advice.
5. Provided a focus for consideration of issues for Aboriginal, Torres Strait Islander and culturally and linguistically diverse people in palliative care programs.
6. Liaised and consulted with relevant experts on palliative care and referred appropriate issues for advice.

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[2] National Palliative Care Strategy 2000. A National Framework for Palliative Care Service Development. Commonwealth Department of Health and Ageing

[3] National Palliative Care Strategy 2010. Supporting Australians to Live Well at the End of Life. Commonwealth Department of Health and Ageing

3. PALLIATIVE CARE NEEDS OF THE POPULATION

Over the past three decades the pattern of life, disease, dying and death has changed dramatically in Australia. Australia's life expectancy at birth is one of the highest in the world, with improvements of life expectancy at birth increasing for both males and females by 6.1 and 4.2 years respectively.[4]

As life expectancy increases so do life limiting conditions such as dementia, cardiovascular and respiratory diseases, and cancers, thus impacting on the pattern of death. Various reports suggest between 25 per cent and 50 per cent of deaths in Australia are anticipated. Based on these reported figures, with approximately 143,500 deaths in Australia[5] each year, it is estimated between 36,000 and 72,000 people may have palliative care needs annually.[6]

Palliative care needs may vary due to the diversity of the Australian population, geography, and availability of services. There are various groups of the population that may have specific palliative care needs, including Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds (CALD), and those living in rural/remote communities.

<u>Aboriginal and Torres Strait Islander issues</u>
The available evidence indicates that Aboriginal and Torres Strait Islander people experience poorer health status and access to appropriate care, particularly in rural and remote locations. *The Health and welfare of Australia's Aboriginal and Torres Strait Islander peoples* (Australian Bureau of Statistics, 2010) reported that the gap between Aboriginal and Torres Strait Islander and non-Indigenous life expectancy (born in 2005-2007) is 11.5 years for males and 9.7 years for females.

Compared with death rates for non-Indigenous Australians, Aboriginal and Torres Strait Islander rates for both males and females were almost 3 times as high overall for almost all causes of deaths[7], with deaths from diseases of the circulatory system, deaths due to external causes, and deaths due to endocrine, nutritional and metabolic diseases accounting for the greatest number.[8]

One of the key principles for the Australian Government's *National Strategic Framework for Aboriginal and Torres Strait Islander Health (NSFATSIH) 2003-2013* is supporting activities to improve the access to, and quality of service delivery (including palliative care where appropriate) for all Aboriginal and Torres Strait Islander people. The NSFATSIH is a framework for action agreed to by all Australian health ministers. Its goal is to ensure that Aboriginal and Torres Strait Islander people enjoy health outcomes equal to that of the general population.

The NSFATSIH sets out the strategic priorities for Governments in addressing Aboriginal and Torres Strait Islander health issues in Australia, and commits governments to strengthening access to culturally sensitive health care service provision (both Indigenous-specific and mainstream) for Aboriginal and Torres Strait Islander people.

The palliative care needs of Aboriginal and Torres Strait Islander people with a life-limiting illness are considered and addressed in all the work progressed under the National Palliative Care Program (NPCP). The NPCP, which is discussed in more detail later in this submission, recognises the need for services which cater sensitively and flexibly to the needs all Australians.

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[4] National Palliative Care Strategy 2010. Supporting Australians to Live Well at the End of Life. Commonwealth Department of Health and Ageing
[5] 3302.0 – Deaths, Australia, Australian Bureau of Statistics, 2010
[6] National Palliative Care Strategy 2010. Supporting Australians to Live Well at the End of Life. Commonwealth Department of Health and Ageing
[7] 4704.0 – The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples, Australian Bureau of Statistics, 2008
[8] 4704.0 – The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples, Australian Bureau of Statistics, October 2010

Within the NPCP, the Local Palliative Care Grants Program (LPCGP) initiative aims to improve access to palliative care services in the local community and provide the vital and compassionate care needed for Australians at the end of their lives.

The LPCGP provides grants to help local groups, church and charitable hospices and health and aged care providers to better provide support to people requiring palliative care and their families in their communities. A number of projects with a focus on palliative care for Aboriginal and Torres Strait Islander people have been funded as part of the LPCGP. More information on these projects is available in **Appendix 1**.

The Government also funds the Program of Experience in the Palliative Approach (PEPA), which aims to improve the quality, availability and access to palliative care for people who are dying, and their families. To achieve this, PEPA's overall objective is to enhance the capacity of health professionals to deliver a palliative care approach through their participation in either clinical placements in specialist palliative care services or interactive workshops.

Since 2007 PEPA's Community Outreach Program has delivered culturally sensitive education to participants. This education is received primarily by Indigenous participants from remote communities working in aged care, respite and resource facilities, remote clinics and Aboriginal community controlled medical services.[9]

Culturally and linguistically diverse (CALD) background issues

Another section of the Australian population with specific palliative care needs is people from culturally and linguistically diverse (CALD) backgrounds. Over the coming decades, immigrants who arrived in Australia during the peak of post-war immigration up to 1971 will become a more significant component of the aged population. This will have considerable implications for the provision of culturally appropriate health and aged services.

An important principle of the Australian Government is that its services are provided on an equitable basis to all Australians. People born from a CALD background can face barriers in accessing appropriate health and aged care services.

The Australian Institute of Health and Welfare's (AIHW) 2007 report *Older Australia at a glance* indicates that one in five older Australians are from a CALD background, and this part of the older population is growing faster than other segments.

Attitudes and approaches regarding care of the dying can vary widely between and within different cultures. In order to provide culturally appropriate palliative care, it is important that issues relating to specific cultural, linguistic and spiritual preferences around death, dying and bereavement are considered.

A variety of government services, initiatives and programs are offered to assist people from CALD backgrounds to access information and culturally appropriate services and care.

Recently, the Australian Government provided funding to the South Australian Partners in Culturally Appropriate Care (PICAC) provider to develop a CALD palliative care training package. This resource is for national application of PICAC providers to provide cultural awareness training to staff in residential and community aged care settings. This training package aims to improve palliative care

[9] www.pepaeducation.com

services for people from CALD backgrounds. More information on government funded programs with a CALD perspective is available at **Appendix 2**.

The Australian Government also provides financial support to government funded aged care homes to access interpreting services. A Translating and Interpreting Service is available 24 hours a day, seven days a week, and provides on-site interpreting services.

Rural and remote issues

Funding has also been provided to the Australian General Practice Network to conduct the Rural Palliative Care Project (RPCP). RPCP aimed to provide improved choice and better access to services in regard to end-of-life care in rural and remote locations through resourcing general practices to provide sustainable models of palliative care service delivery that can be adapted to address the local needs of rural communities.

Since its inception in 2008, the RPCP has increased the capacity of primary health care providers to provide quality palliative care to rural and remote Australia. The project addressed the barriers of remoteness and isolation and sought to build multi-disciplinary teams through integrated systems of communication and education and support for evidenced based best practice palliative care services. It also enhanced the experience of care for the palliative patient and their carers by strengthening the links between specialist palliative care services and mainstream health service delivery.[10]

The objectives for the project were to enhance common understandings of models of palliative care among the participating general practices and key stakeholders, including specialist palliative care services, and to strengthen links between palliative care and mainstream service delivery.

[10] http://www.agpn.com.au/programs/rural-palliative-care-program

4. PALLIATIVE CARE PROVISION

While the Australian Government does not directly fund specialist palliative care service provision, it does provide support in two ways.

Firstly, the Australian Government provides financial assistance to state and territory governments to operate palliative care services, a form of sub-acute care, as part of their health and community service provision responsibilities.[11] Since Medicare was introduced in February 1984, there has been a series of funding agreements through which the Government contributed to the cost of operation of the public hospital system and associated palliative care services.

Through the sub-acute care component of the National Partnership Agreement on Hospital and Health Workforce Reform (NPA HHWR), the Australian Government provided $500 million in June 2009 to expand states and territories' provision of sub-acute care, including palliative care, over the period 2009-10 to 2012-13.

The funding is being used to expand sub-acute care services in each state or territory by five percent annually, or 20 percent over the four years to 2012-13, and to improve the quality and mix of sub-acute care services nationally.

States and territories have prioritised and distributed their funding based on identified needs and gaps in sub-acute care within their respective jurisdiction. In most instances, this has included funding for palliative care beds and/or community based services.

States and territories report annually on service volumes for sub-acute care under the NPA HHWR. These cover public hospital patients and non-admitted public patients. States and territories are still working to improve data collection under the NPA HHWR and variations between the way that palliative care is delivered and reported on, means data cannot be reliably compared at this stage. Reports against annual targets are publicly available on the Productivity Commission website at http://www.pc.gov.au/gsp/national-partnership/hospital-health-agreement

The Australian Government has committed a further $1.623 billion over the four years 2010-11 to 2013-14 through the sub-acute care element of the National Partnership Agreement on Improving Public Hospital Services, for states and territories to deliver and operate at least 1,300 new sub-acute care beds and equivalent services nationally, in residential and community-based settings. The sub-acute services in scope are rehabilitation, palliative care, sub-acute mental health care, Geriatric Evaluation and Management and psychogeriatric services. Based on the approved Implementation Plans, palliative care comprises approximately five per cent of all planned sub-acute care beds and equivalent services.

The allocation of funding to palliative care is a matter for states and territories to assess, based on the needs of their populations and in consultation with relevant sectors.

Secondly, the National Palliative Care Program (NPCP) is an initiative of the Australian Government which aims to improve the access to and quality of palliative care. The NPCP was established in 2002 to help people who are terminally ill access the best care and support available to maintain their dignity and quality of life through a national program of activities to improve palliative care services and enhance support for families and carers. Over the last decade, the Australian Government provided around $180 million to support national initiatives and projects under the NPCP.

[11] National Partnership Agreement on Hospital and Health Workforce Reform. Council of Australian Governments

The NPCP funds initiatives to ensure quality palliative care and to improve access to services for both people who are dying and their families. It does this by offering support in four broad areas:

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

A number of NPCP initiatives are discussed in relevant parts of this submission.

5. PALLIATIVE, HEALTH AND AGED CARE RESOURCES

The Government has funded numerous projects under NPCP to develop palliative care resources such as guidelines, research, performance indicators, and information for patients and their families, carers, general practitioners, other health care professionals and the general public. Some of the organisations and projects funded to develop palliative care resources include:

- Caresearch
- Palliative Care Australia resource development projects
- Aboriginal and Torres Strait Islander palliative care resource kit
- Guidelines for residential and community aged care

Caresearch

Under the National Palliative Care Program (NPCP), Flinders University is funded to host and manage the Palliative Care Knowledge Network, commonly known as Caresearch (www.caresearch.com.au). CareSearch is a website that includes a searchable database of palliative care literature and online forums that allow groups to share research, reports and information. The website provides information resources for researchers and palliative care specialists, along with information for patients and their families, carers, general practitioners, other health care professionals and the general public. More information on Caresearch's page views, site visits, hits and time per visit between July 2011 – January 2012 can be found in **Appendix 3**.

Palliative Care Australia resources

Government funding is provided to Palliative Care Australia (PCA), which is a national peak body that seeks to represent the interests of the palliative care sector in Australia. Under the NPCP, PCA has received financial support from the Department of Health and Ageing (DoHA) since 1997. This funding is intended to provide support for staffing, infrastructure, operational activities and community education.

PCA has been funded to produce many resources, some of which include:

- Towards quality care at the end of life quarterly publication
- PCA e-bulletin (monthly)
- The Standard newsletter (monthly)
- Residential Aged Care Palliative Approach Network newsletter
- Fact Sheets:
  - Facts about morphine and other opioid medicines used in palliative care resource (translated in 21 languages)
  - What is palliative care? (translated in 21 languages)
  - Asking questions can help (translated in 21 languages)
  - What can I say? What can I do?
  - Journeys (palliative care for children and teenagers) resource
  - About the process of Dying: Information for Patients and Carers resource
  - About Pain and Pain Management: Information for Patients and Carers resource

The Government provides funding to PCA to conduct the National Palliative Care Week annually, which is a program of national activities designed to raise awareness of palliative care issues in the community.

Aboriginal and Torres Strait Islander palliative care resource kit

The Wodonga Institute of TAFE was funded to develop a number of practical resources to assist mainstream palliative care services to deliver culturally appropriate palliative care to Aboriginal and Torres Strait Islander people. These resources included:

- Practice principles for staff at all levels who provide care to terminally ill Aboriginal and Torres Strait Islander people in mainstream palliative care services or hospices;
- Education and training resources to support the Practice Principles; and
- A discussion paper on the existing literature relating to Aboriginal and Torres Strait Islander peoples' perspectives on death and dying.

The Wodonga Institute of TAFE received further funding to provide national coordination and support for the implementation of the Indigenous Palliative Care Practice Principles and Educational Resources.

Guidelines for residential and community aged care

The Government also encourages a palliative approach to care delivery in aged care settings. The Government's publication *Guidelines for a Palliative Approach in Residential Aged Care* comprises evidence-based guidelines intended to help practitioners in applying a palliative approach in a residential aged care facility. The guidelines provide a framework for:

- enhancing the care of residents and their families by offering them a palliative approach when appropriate; and
- increasing the knowledge and range of skills of staff in providing the palliative approach in caring for residents and their families.

The Government has funded the development of training resources and modules for the guidelines to assist staff and management of a residential aged care facility to implement, and understand the benefits of, a palliative approach. Palliative Care Australia (PCA) was funded to develop and deliver a series of training resources based on the guidelines. These resources can be used as a self directed learning package or by trainers as a basis to provide education for staff.

Another useful resource is the *Guidelines for a Palliative Approach for Aged Care in the Community Setting*. The guidelines, which have been approved by the National Health and Medical Research Council (NHMRC), are intended as a companion document to the *Guidelines for a Palliative Approach in Residential Aged Care*. The resource was published in 2011 and is aimed at health professionals providing palliative care to older people in the community, including general practitioners, community nurses and organisations providing support for people being care for at home. This resource is supplemented by two booklets in 'plain English', designed for use by care workers and people and their families/friends respectively.

These guidelines explore a palliative approach to care (drawn from in depth literature reviews and expert opinion), how it may be delivered in the community setting, and how family carers may be supported and care planning facilitated. Types of care addressed are physical, spiritual, and social. Needs of particular groups of people are considered, including those of Aboriginal and Torres Strait Islander people; people from diverse cultural and language groups; gay, lesbian, bisexual, transsexual, or intersex people; people living alone; and people having a mental illness, post traumatic stress disorder, or an intellectual disability. The needs of those experiencing motor neurone disease, Parkinson's disease, or dementia are also considered in some depth.[12]

The breadth and depth of the suite of guideline documents serve to emphasise the extensive nature of community care for older people who are frail or unwell, and the extensive skills and knowledge required to both provide appropriate care and support family care provision.

[12] www.caresearch.com.au

The Government has recently commenced work on developing an education and training package for health professionals (General Practitioners, nurses and care workers) to assist them in using the *Guidelines for a Palliative Approach for Aged Care in the Community Setting* in their practice.

It is anticipated that the education and training resources will include, but not be limited to, online training modules, DVDs and guideline summaries.

Other types of projects funded within the four broad areas of the NPCP

Support for Patients, Families and Carers in the Community

- grants to local groups, health and aged care providers, and charitable organisations in the areas of fit out and equipment for palliative care premises, transition to home support, pastoral care and counselling and care planning.

Increased Access to Palliative Care Medicines in the Community

- the Palliative Care Clinical Studies Collaborative which manages multi-site clinical drug trials in order to gather the scientific evidence required to register palliative care medicines on the Australian Register of Therapeutic Goods and listing on the Pharmaceutical Benefits Scheme.

Education, Training and Support for the Workforce

- the Program of Experience in the Palliative Approach (PEPA), a sustainable hands-on training program designed to enhance the capacity of health professionals to deliver a palliative care approach through their participation in either clinical placements in specialist palliative care services or interactive workshops.

Research and Quality Improvement for Palliative Care Services

- a consortium of four universities engaged to form the Australian Palliative Care Outcomes Collaboration (PCOC). PCOC supports services to consistently compare and measure the quality and outcomes they provide, and through this ensure continued quality improvement;
- The Australian Palliative Care Knowledge Network- CareSearch, a one stop shop of evidence-based information and practical resources that serves the needs of patients and their families/carers, clinicians, other health care professionals providing palliative care, and researchers.

An external evaluation of the NPCP projects and activities commenced in 2011-12 and is expected to be completed by 2012-13.

The purpose of the evaluation is to ensure that the projects funded under the NPCP align effectively with the goals of the National Palliative Care Strategy 2010, and to identify future priorities and opportunities in relation to palliative care.

Further information on the National Palliative Care Program, and the projects it funds, is available at: www.health.gov.au/palliativecare

6. RANGE OF PALLIATIVE CARE ARRANGEMENTS

Palliative care is an essential component of health and aged care. This is clearly articulated in the *National Palliative Care Strategy 2010: Supporting Australians to Live Well at the End of Life*, which focuses on the whole of the health and human services sector, in order to meet the rising demand for high quality palliative care across Australia.

With improved medical care and technology, people are living longer. Longevity brings with it shifting patterns of disease, including an increasing demand for complex chronic care associated with dementia, diabetes, and other co-morbidities, as well as palliative care. Traditionally, hospitals have provided most palliative care services, typically to people with acute conditions.

Residential and community aged care

In Australia the number of people aged 85 years and over is projected to more than quadruple from 0.4 million to 1.8 million people, between 2010 and 2050. This is expected to drive a major increase in the demand for aged care service over the next 40 years.

The *Aged Care Act 1997* (the Act) outlines accreditation Standards and outcomes covering comprehensive issues and care outcomes that all aged care homes are required to meet including that providers ensure the comfort and dignity of terminally ill residents is maintained.

In addition, the Quality of Care Principles 1997 under the Act set out the care and services to be provided to residents who receive a high level of residential care. Of particular relevance to palliative care is the requirement that nursing services carried out by a registered nurse, or other professional appropriate to the service are to be provided to residents. Services may include, but are not limited to, establishment and supervision of a complex pain management or palliative care program, including monitoring and managing any side effects.

The Productivity Commission's Report *Caring for Older Australians*, released on 8 August 2011, includes proposals for reform of Australia's aged care system. The report identified palliative care as a core issue.

The Productivity Commission supports the notion that aged care services be tailored to the needs and preferences of the ageing population. The Commission cited estimates that 340,000 older people per year were unnecessarily admitted or readmitted to the acute care hospital system due to a lack of palliative care services and that 31 per cent of transfers from residential aged care facilities to acute care hospitals were potentially avoidable.

The need for better palliative care services, and more effective use of advance care planning, to allow older Australians to die with dignity, have been key themes emerging from the consultations the Government has been conducting with community members and key aged care stakeholders in the context of developing its response to the Productivity Commission's report. While the aged care funding system provides some recognition for complex health care needs including those associated with end-of-life care, it is not designed to support very complex cases historically managed in the acute sector.

There are two distinct but related issues in relation to providing palliative care services for older people, both of which reflect the increasing preference and expectation from consumers to be able to die at home with dignity.

First, like other age groups, older people who are dying and their families can face difficulty accessing the specialist palliative care and support they need, either to be able to die at home, or to be able to access hospice-based care.

Second, palliative and end-of-life care are becoming an increasing part of the business of aged care. Over one third of all deaths annually are of residents of aged care homes, and around 40 per cent of High Care residents die within six months of entering care. Aged care providers are increasingly expected to not only incorporate a palliative approach in the care that is provided, but also to provide increasingly complex end-of-life care. At the same time, there are increasing concerns in the sector that the health and aged care systems need to do more to support this expanding role, particularly in terms of funding and training and education.

Issues related to the delivery of palliative care for aged care recipients are being considered as part of the development of the Government's response to the Productivity Commission's report.

Primary Health Care

A key component of the Australian Government's National Health Reforms is the establishment of a nation-wide network of Medicare Locals.

Medicare Locals are primary health care organisations established to coordinate primary health care delivery and tackle local health care needs and service gaps. They will drive improvements in primary health care and ensure that services are better tailored to meet the needs of local communities.

Medicare Locals will work collaboratively with GPs and other primary health care service providers in their area towards meeting the primary health care needs of their local communities. Medicare Locals will work with local primary health care providers, Local Hospital Networks and communities to ensure that patients, including those that are terminally ill, receive the right care in the right place at the right time.

Medicare Locals will be responsible for working collaboratively with these providers to ensure that primary health care works for the whole of the local population, including, for example, people with chronic or terminal illnesses who require health care and services from multiple providers.

Medicare Benefits Schedule

The Medicare Benefits Schedule (MBS) is a listing of the Medicare services subsidised by the Australian Government. The MBS provides information on the arrangements for the payment of Medicare benefits. These arrangements operate under the *Health Insurance Act 1973* (as amended).

There are number of primary care items on the MBS that can be used for palliative care:

- *Chronic Disease Management (CDM) MBS items 721-732:* To enable GPs to plan and coordinate the health care of patients with chronic or terminal medical conditions, including patients with these conditions who require multidisciplinary, team-based care from a GP and at least two other health or care providers.

- *Individual allied health MBS items 10950-10970:* Patients who have a chronic or terminal medical condition and complex care needs *and* who are managed by their GP using prerequisite CDM items may be eligible for Medicare rebates for a maximum of five allied health services per calendar year.

- *GP case conferencing MBS items 735-758:* To enable GPs to organise or coordinate, or participate in, a case conference for their patients. Case conferences can be undertaken

for patients in the community, for patients being discharged into the community from hospital and for people living in residential aged care facilities.

These MBS items enable medical practitioners to provide planned longer-term care for patients, in collaboration with a wider healthcare team when necessary.

Practice Incentive Program

Through the Practice Incentives Program General Practitioner Aged Care Access Incentive, General Practitioners (GPs) are encouraged to provide increased and continuing services to residents of Commonwealth-funded residential aged care facilities (RACFs).

Incentive payments of:

- $1,500 are available to GPs who provide at least 60 Medicare Benefits Schedule (MBS) services in Commonwealth-funded RACFs, within a financial year; and
- $3,500 are also available to GPs who provide at least 140 MBS services in Commonwealth-funded RACFs, within a financial year.

Pharmaceutical Benefits Scheme

Patients receiving palliative care in their home or other community-based setting, such as a residential care setting, are able to access subsidised medicines for use for palliative care through the Pharmaceutical Benefits Scheme (PBS). This allows patients who receive palliative care at home to have more affordable medicines dispensed through their local community pharmacies, rather than having to travel to hospitals. Access to a broader range of medication and related support services are also available under the Fifth Community Pharmacy Agreement. These services aim to improve the quality use of medicines and reduce the risk of medication associated hospitalisations for patients in receipt of palliative care and include Medication Use Reviews (MedsCheck), Home Medicines Reviews, and Residential Medication Management Reviews.

Medicines for palliative care are listed in a specific section of the PBS Schedule that comprises those medicines recommended for subsidy for palliative care by the Pharmaceutical Benefits Advisory Committee. For the period 2011-2012, a total PBS expenditure of $2.4 million was spent on these medicines. In addition, the palliative care section of the PBS is intended to complement and be used together with the general listings section, which provides access to other drugs used for palliative care.

For the purpose of prescribing under the palliative care section of the PBS, a patient receiving palliative care is defined as: A patient with an active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is the quality of life. This means that any patient with a life-limiting disease can access these medicines, regardless of the type of disease.

A wide range of medicines are available including for pain relief and nausea, and to alleviate distress and medication side-effects. The varying forms of administration available recognise individual patient's needs, such as where alternative forms cannot be tolerated.

Some palliative care listings are Authority Required (Streamlined) listings and certain criteria need to be met to be eligible for PBS subsidy. For example, a palliative care patient has available benzydamine mouth and throat rinse for painful mouth, promethazine tablets and liquid for nausea and vomiting, and glycerol suppositories for constipation. Others require a special telephone authority to be obtained by the prescriber consistent with the conditions outlined in the palliative care section, including medicines to treat pain. This includes opioids and other medicines for pain relief (such as morphine and fentanyl), benzodiazepines for anxiety and insomnia (such as oxazepam

and temazepam) and antiepileptics to prevent epilepsy. Initial authorities can provide a maximum of four months palliative care therapy and there are provisions for continuing treatment where this is needed.

Currently, the co-payment for PBS medicines is $5.80 for concessional patients and up to $35.40 for general patients. The PBS safety net threshold for general patients is currently $1363.30, while the concessional patient threshold is $348.00. After reaching the threshold, general patients usually pay for further PBS prescriptions at the concessional co-payment rate of $5.80, and concessional patients are usually supplied with any further PBS prescriptions without charge for the remainder of the calendar year.

The consumer section of the on-line PBS Schedule identifies palliative care medicines and consumer information for individual medicines.[13] Information about palliative care medicines on the PBS can be found at www.pbs.gov.au

[13] http://www.health.gov.au/internet/main/publishing.nsf/Content/Palliative+Care-1

7. PALLIATIVE CARE WORKFORCE

Workforce composition and size

Palliative care is provided in almost all settings where healthcare is provided including neonatal units, paediatric services, acute hospitals, general practices, residential and community aged care services, and generalist community services.[14]

Specialist palliative care services operate from a variety of settings including specialist inpatient consulting services, specialist inpatient settings, hospices and community based specialist services. Specialist palliative care services have a vital role in providing expert clinical advice – particularly for those with complex symptoms requiring palliation, as well as the provision of direct care for a small number of patients and more broadly the provision of capacity building and support services to the broader health and human services sectors.[15]

The provision of appropriate, high quality care for people at end of life occurs every day across Australia through a palliative approach from general practitioners, community nurses, care workers, family and others, including volunteers.[16]

Data on the whole of workforce that delivers palliative care service is limited. National registration data from the Australian Health Practitioners Regulation Agency in the future may be able to provide more information on nurses who work in the area of palliative care.

The Australian and New Zealand Society of Palliative Medicine estimates that the total number of Palliative Medicine Specialists to service the population of Australia is approximately 128. This number represents those Palliative Medicine Specialists in Australia that self report as being in the 'active in Palliative Medicine' cohort.[17]

In rural areas, services are often delivered in primary care settings through a generalist workforce such as general practice, community nurses and allied health professionals. This often includes consultation with specialists (both medical specialists and nurse specialists). Rural service delivery, in particular, may also involve nurse practitioners in palliative care. Workforce data is therefore more difficult to quantify in rural areas because of the generalist nature of the workforce.

In terms of the workforce delivering sub-acute care, states and territories report annually on service volumes under the National Partnership Agreement on Hospital and Health Workforce Reform (NPA HHWR). These cover public hospital patients and non-admitted public patients. States and territories are still working to improve data collection under the NPA HHWR and variations between the way that palliative care is delivered and reported on, means data cannot be reliably compared at this stage. Annual Reports are publicly available on the Productivity Commission website at www.pc.gov.au/gsp/national-partnership/hospital-health-agreement

Health Workforce Australia is in the process of developing future workforce modelling for doctors, nurses and midwives to predict demand and supply for these professional groups up to 2025. The Report is to be called Health Workforce 2025 - Doctors, Nurses and Midwives.

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[14] National Palliative Care Strategy 2010. Supporting Australians to Live Well at the End of Life. Commonwealth Department of Health and Ageing

[15] ibid

[16] ibid

[17] Australian and New Zealand Society of Palliative Medicine. 2010. Position Statement: Benchmark Number of Specialists in Palliative Medicine. Canberra

Workforce training and education

The Australian Government is committed to supporting and encouraging improvements in the delivery of palliative care and ensuring the best possible end-of-life care is available. Initiatives under the NPCP that support the development of the palliative care workforce and the provision of quality services include the Program of Experience in the Palliative Approach (PEPA), *Guidelines for a Palliative Approach for Aged Care in the Community Setting* (COMPAC Guidelines), the *Guidelines for a Palliative Approach in Residential Aged Care* (APRAC Guidelines), the Palliative Care Curriculum for Undergraduates (PCC4U), and scholarships for nursing and allied health students and professionals.

The PEPA is an initiative to improve the quality, availability and access to palliative care for people who are dying, and their families. To achieve this, PEPA's overall objective is to enhance the capacity of health professionals to deliver a palliative care approach through their participation in either clinical placements in specialist palliative care services or interactive workshops.

PEPA commenced in 2003 and placements were initially offered to generalist nurses and allied health staff from primary health settings in all states and territories. In 2005, PEPA was expanded to include placements for general practitioners (GPs), rural and remote medical staff, and specialist palliative care staff. In 2007 PEPA expanded again and commenced offering placements to Aboriginal Health Workers. A "reverse" PEPA program offers specialist palliative care staff the opportunity to update their skills in clinical areas such as oncology, paediatrics and aged care. They also provide palliative care training to their host site.

From 2003 to 2010, PEPA provided a over 2,000 placements to Registered Nurses, Enrolled Nurses, Assistants in Nursing/Care Workers, Aboriginal Health Workers, Allied Health Professionals, and General Practitioners and/or Rural Medical Practitioners. In 2010-11, PEPA provided 311 placements and conducted 96 workshops to 1,866 participants throughout Australia (refer to Table 5, 6 and 7).

Table 1: PEPA placements from 2003 – 2011

Iteration of PEPA	Total Placements
PEPA 2003-2005 (Nurses, Allied Health & GPs)	271
PEPA 2005-2006 (Nurses, Allied Health & GPs)	608
PEPA Extension (July - Dec 2006)	111
PEPA 2007-2010 (Nurses, Allied Health, GPs & Aboriginal Health Workers)	1076
PEPA 2010-2011	311
TOTAL	**2377**

Table 2: Number of workshops and participants by jurisdiction from 1 July 2010 to 30 June 2011

Jurisdictions	Total # of Workshops	Participants from Aged Care Sector	Participants from Other Sectors	Total Participants
ACT	7	79	42	121
NSW	24	195	308	503
QLD	10	25	168	193
VIC	24	189	265	456
TAS	9	112	49	161
NT	6	24	40	64
SA	7	218	0	218
WA	9	65	85	150
Total	**96**	907	957	**1866**

Table 3: Number of workshops participants by Discipline from 1 July 2010 to 30 June 2011

Participant Discipline	ACT	NT	QLD	NSW	VIC	TAS	SA	WA	Total
Registered Nurses/Div 1	23	7	37	218	90	75	38	15	**503**
Enrolled Nurses/EENs/ Div 2	15	0	1	11	87	14	25	0	**153**
Assistants in Nursing/ Care Workers	49	12	0	33	63	45	0	38	**240**
Aboriginal Health Workers	0	20	15	60	43	4	35	40	**217**
Allied Health Professionals	2	7	112	29	41	6	47	57	**301**
GPs and/or Rural Medical Practitioners	25	1	28	19	0	17	55	0	**145**
Other*	7	17	0	133	132	0	18	0	**307**
Total	**121**	**64**	**193**	**503**	**456**	**161**	**218**	**150**	**1866**

**Includes disability sector and/or health professionals who did not specify discipline and Aboriginal community members*

The Government has developed guidelines in palliative approach for use in the community and residential aged care setting to ensure that the aged population that requires palliative care is receiving the best care possible.

The COMPAC Guidelines provide best practice evidence-based recommendations to those practitioners providing palliative care to older people in the community. The APRAC Guidelines have been developed as a set of guidelines for use by GPs and aged care staff looking after residents with palliative care needs. Both resources have been developed by skilled palliative care experts and approved by the National Health and Medical Research Council, and are designed to enhance the quality of palliative care provided to older people by health professionals.

Another project that supports the development of the palliative care workforce is the PCC4U project. The PCC4U project aims to promote the inclusion of palliative care education in all medical and allied health care training through the provision of student and facilitator learning resources and professional development activities.

The Government has funded the PCC4U project since 2004 to develop, implement and evaluate a set of learning resources in metropolitan and rural universities in Australia.

From 2007 the PCC4U project has conducted a national roll-out concentrated on expanding the number of tertiary institutions and courses using PCC4U materials. In 2010-11, all (then 208) health and allied health courses had been invited to be part of the project. In that period 35% of all courses were currently using the materials, and a further 22% of courses were reviewing the materials or considering the invitation.

The project is currently focusing on continuing to actively promote the uptake of the PCC4U resources in all universities that offer medical, nursing and allied health training, extending and developing networks amongst participating universities, and developing strategies for the ongoing sustainability of the PCC4U project.

The Australian Government also provides scholarships under the Nursing and Allied Health Scholarship and Support Scheme (NAHSSS), including undergraduate, postgraduate, clinical placement and continuing professional development scholarships for nursing and allied health students and professionals. Health professionals working in palliative care are eligible to apply for a scholarship.

The objectives of the NAHSSS are to:

- Increase the health workforce by facilitating the entry of jobseekers and youths interested in pursuing a career in nursing or the allied health professions;
- Facilitate the continued professional development of nurses and allied health professionals; and
- Encourage the pursuit of a health career in both geographic areas and professions where there are shortages.

8. ADEQUACY OF STANDARDS

The majority of settings where palliative care is provided (e.g. acute hospitals, general practices, residential and community aged care services, generalist community services) are required to meet specific standards to maintain and/or improve the quality and safety of health care. In most cases, this is required by law or as a condition of funding.

The Australian Government aims to improve the quality of palliative care provision by investing significantly in relevant projects and by encouraging the use of specific palliative care standards by services in their accreditation and continuous improvement processes.

Palliative Care Australia Standards

The Government provides financial support to Palliative Care Australia (PCA) under the NPCP. This support has included funding to develop and implement standards to improve the quality of palliative care service provision.

PCA first developed its *Standards for Providing Quality Palliative Care for all Australians* (the "PCA Standards") in 1994 in collaboration with the palliative care community. The latest revision of the PCA Standards in 2005 involved a program of wide consultations with consumers and the palliative and end-of-life care sector, which was funded by the Government.

The PCA Standards have been developed for use in a number of ways to support and enhance quality of care for patients who are at the end of their life, their families and carers. Services and providers adopt the PCA Standards on a voluntary basis.[18]

Accreditation services are asked to incorporate the PCA Standards as part of their assessment of palliative care and other services. The PCA Standards have been designed for use alongside other standards for health services (for example the Australian Council of Healthcare Standards – Evaluation and Quality Improvement Program [EQuIP], Quality Improvement Council, Royal Australasian College of General Practitioners, or the Aged Care Accreditation Standards) and therefore do not specifically address areas covered by those standards. The PCA Standards can be used in conjunction with, or as part of service accreditation with these bodies.[19]

In 2007, PCA was funded to undertake National Standards Assessment Program (NSAP). The aim of NSAP is to enable specialist palliative care services to implement quality improvement activities and undertake a self-assessment process against the PCA Standards for providing quality palliative care. The goal of NSAP is to develop a culture of continuous quality improvement within specialist palliative care services to improve delivery of care for palliative patients.

A national roll out for NSAP has been completed with all states and territories eligible and able to participate in the program. There are currently 161 participating services in NSAP, representing greater than 90% of the sector (refer to Figures 1 and 2). This is a significant achievement given that participation is entirely voluntary.

[18] www.palliativecare.org.au
[19] ibid

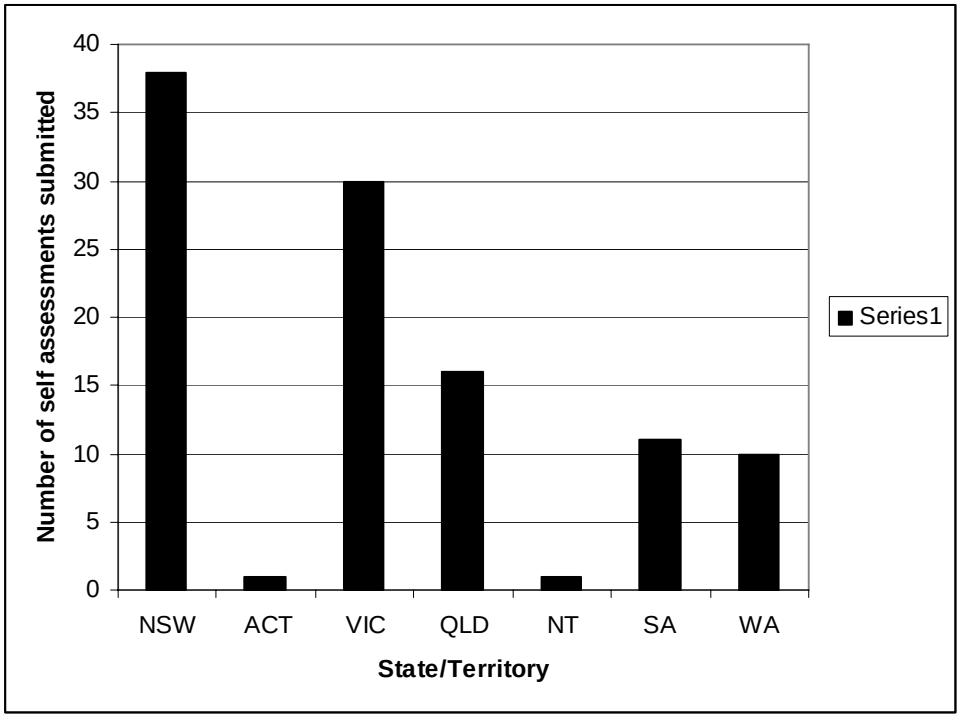

Figure 1: Self assessments submissions by State/Territory

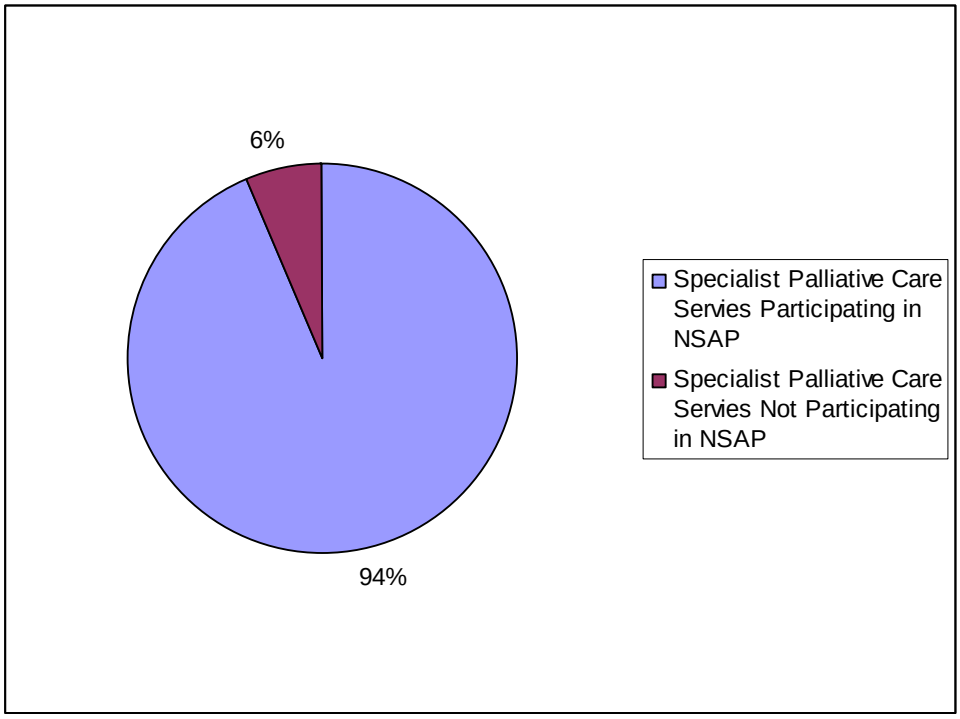

Figure 2: Sector participation

The PCA Standards and the results obtained through the NSAP process can be used to support quality management and improvement activities or benchmarking at a local, state or national level, in conjunction with another Government funded initiative - the Palliative Care Outcomes Collaboration,.

Palliative care services continue to offer positive feedback about NSAP and have stated the program allows their services to focus on actionable improvements, build capacity for quality improvement, identify service gaps and learn new skills (refer to Figure 3).

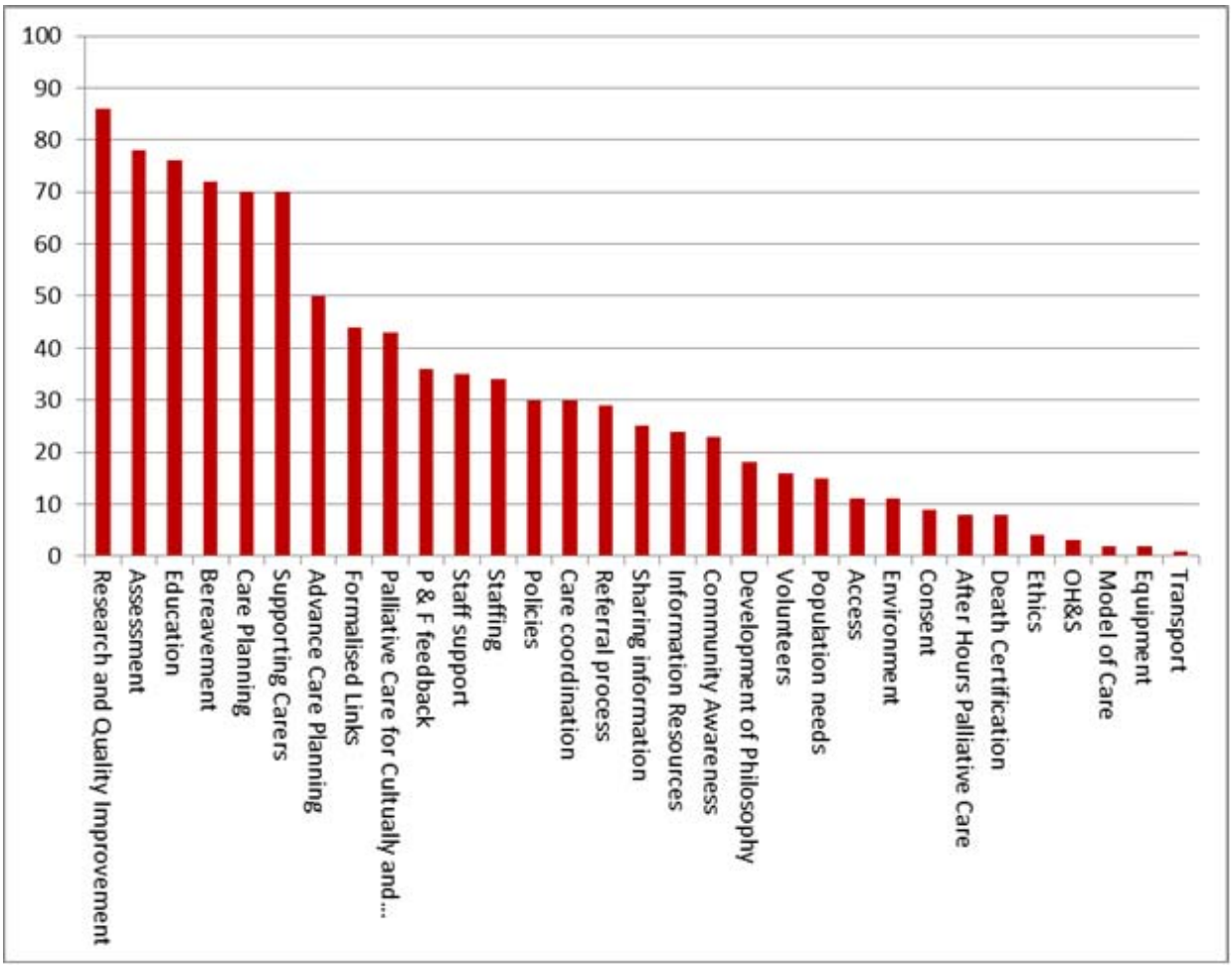

Figure 3: Number of services which reported improvement actions in each category

Aged Care Accreditation Standards

Aged care homes are also required to meet, under the *Aged Care Act 1997* (the Act), the accreditation Standards and 44 outcomes. Expected outcome 2.9 Palliative care requires approved providers to ensure the comfort and dignity of terminally ill residents is maintained.

In addition, the Quality of Care Principles 1997 under the Act set out the care and services to be provided to residents who receive a high level of residential care. Of particular relevance to palliative care is Part 3.8 Nursing services which states that, where required, nursing services carried out by a registered nurse, or other professional appropriate to the service (e.g. medical practitioner, stoma therapist, speech pathologist, physiotherapist or qualified practitioner from a palliative care team) are to be provided to residents. Services may include, but are not limited to, (a) establishment and supervision of a complex pain management or palliative care program, including monitoring and managing any side effects.

Australian Council on Healthcare Standards

The Australian Council on Healthcare Standards (ACHS) is an independent, not-for-profit organisation, which aims to improve the quality and safety of health care. ACHS accredits the

majority of health care organisations in Australia. The health care organisations participating in ACHS quality programs range from major teaching hospitals, corporate offices of private health companies, day surgeries such as endoscopy clinics, nursing agencies, community health centres to divisions of general practice.

Accreditation programs are based on external and independent peer review which is considered international best-practice to improve quality in healthcare. Programs emphasise the importance of consumer participation in healthcare and the need to provide evidence of clinical and organisational outcomes.

The ACHS Clinical Indicator Program is a data analysis and reporting service provided by the ACHS to healthcare organisations. It provides comparative information on the processes and outcomes of healthcare.

The ACHS has information on over 370 clinical indicators with more than 700 health care organisations participating in the ACHS Clinical Indicator Program. Clinical indicators such as the Emergency Medicine version 5 (Pain Management) are relevant to the provision of palliative care and provide valuable information in assessing the performance of health services.

Royal Australian College of General Practitioners Standards

The Royal Australian College of General Practitioners (RACGP) Standards for general practices (4th edition – October 2010) provide a template for quality care and risk management in Australian general practice. A framework for the continuing development of well performing general practice teams and has been designed to keep Australian general practice at the forefront of high quality primary healthcare.

The indicators in the RACGP Standards are set out in five sections: practice services; rights and needs of patients; safety, quality improvement and education; practice management and physical factors. Care relating to particular conditions, including those which may require a palliative approach, is not specifically covered in the Standards but the criteria and associated indicators in the Standards relating to safe and quality uses of medicines, access to care, respectful and culturally appropriate care and consistent evidence-based practice are all relevant to the provision of palliative care by GPs.

International Organization for Standardization

The International Organization for Standardization (ISO) is a non-governmental organisation that is the world's largest developer and publisher of International Standards. ISO is an amalgamation of national standards institute's from 162 countries.

ISO has recently published a new version of IWA 1:2005 Quality management systems – Guidelines for process improvements in health service organizations. The new version has incorporated improvements based on developments in the field and comments by health care providers since the original was published in 2001.

There are several additional standards that have been developed by ISO that may be considered relevant to palliative care in Australia, such as:

- ISO 11.40 series on Hospital equipment including hospital beds, surgical tables, medical garments, medical gloves, containers for sharp disposal, etc;
- ISO 11.120.10 series on Medicaments includes medical prescriptions and medicinal herbs, equipment for pharmaceutical industry;

ISO 11.180.01 series on Aids for disabled and handicapped persons in general, includes Assistive products for personal hygiene;

- ISO 11.180.10 series on Aids and adaptation for moving includes wheelchairs, walking sticks and lifting platforms. Examples of standards included Technical systems and aids for disabled or handicapped persons , Hoists for the transfer of disabled persons and Tips for assistive products for walking;
- ISO 11.180.20 series on Aids for incontinence and ostomy;
- ISO 11.180.40 series on Aids for drinking and eating; and
- ISO 11.180.99 series on other standards related to aids for disabled and handicapped people.

National Palliative Care Program

There are projects funded under the National Palliative Care Program (NPCP) to support quality improvement and benchmarking in palliative care, such as the Palliative Care Outcomes Collaboration (PCOC) and Australian Institute of Health and Welfare (AIHW) data activities.

Funding for the PCOC is provided to support palliative care services to identify and measure the impact of their service delivery on people with a life-limiting illness, their families and carers. It additionally provides a benchmarking service for continuous quality improvement.

PCOC measures a set of quality benchmarks and targets including:

- Time from referral to first contract
- Time in the unstable phase
- Change in pain
- Change in symptoms relative to the national average
- Patient and carer satisfaction

PCOC continues to recruit new services. At December 2011, 117 palliative care services were collecting PCOC data and a further 27 services had agreed to join PCOC. PCOC estimates that the 144 services agreeing to participate in PCOC represents about 81% of inpatient, consultative and community palliative care services nationally.

Table 4: Recruitment status in each PCOC zone as at December 2011

State/Territory	Services collecting data as at Dec 2011	Number agreed to join PCOC	Estimated number of PC services
ACT & NSW	29	31 (88%)	35
QLD	33	35 (80%)	44
SA & NT	14	18 (75%)	24
TAS	5	6 (86%)	7
VIC	24	39 (85%)	46
WA	12	15 (75%)	20
Total	**117**	**144 (81%)**	**176**

The refinement of the PCOC system is an ongoing process. The following table demonstrates the improvements achieved in refining the PCOC system. The table provides a summary of data received

by PCOC between April 2006 and June 2011. The overall number of patients, for example, has increased by 11,726 since the first report; the number of episodes by 14,372 and phases by 35,965. PCOC reports that the majority of services are achieving improvements in quality.

Table 5: Number of services contributing data for each report

Setting	Measure	Issue 1 Apr-Sep 2006 V1	Issue 2 Oct 2006 -Mar 2007 V1	Issue 3 Apr-Sep 2007 V1	Issue 4 Oct 2007-Mar 2008 V2	Issue 5 Jan-June 2008 V2	Issue 6 July-Dec 2008 V2	Issue 7 Jan-June 2009 V2	Issue 8 July-Dec 2009 V2	Issue 9 Jan-June 2010 V2	Issue 10 July-Dec 2010 V2	Issue 11 Jan-June 2011 V2
All services		4	25	28	45	44	61	86	91	95	91	100
Inpatient												
	Patients	733	2840	2956	3878	4893	6174	6861	7350	7200	8213	8890
	Episodes	852	3359	3438	4483	5707	7266	7923	8650	8294	9638	10500
	Phases	1905	6267	6674	9486	11254	15216	17288	19065	18841	23781	26523
Community												
	Patients	1426	1592	1430	2374	2100	2954	3143	4078	4005	5891	5750
	Episodes	2170	1985	1628	2808	2482	3620	3767	4726	4558	7129	6894
	Phases	493	844	4825	7043	7185	8593	7593	9604	8439	13023	11840
Both												
	Patients	2159	4432	4386	6252	6993	9128	9436	10743	10579	13193	13885
	Episodes	3022	5344	5066	7291	8189	10886	11690	13376	12852	16767	17394
	Phases	2398	7111	11499	16529	18439	23809	24881	28669	27280	36804	38363

PCOC's achievements in the reporting period 1 January to 31 December 2011 can be found at **Appendix 4**. PCOC reports that the majority of services are achieving improvements in quality.

In addition, PCOC has produced a summary of services and episodes/phases meeting each of the benchmarks which included a comparison of the results from Report 7 to Report 11. This summary is included in **Appendix 5**.

The Government has funded AIHW to undertake a data mapping project which will help align data collected by PCOC, NSAP and AIHW (under NPCP-funded projects) with the work AIHW is conducting for the Australian Commission on Safety and Quality in Health Care on palliative care quality measures.

9. ADVANCE CARE PLANNING

The Australian Medical Association (AMA) defines 'Advance Care Planning' (ACP) as "a process that allows a competent individual to express their views in relation to future health care decisions when the capacity to express those views is lost."[20] ACP can play a critical role in reducing the stress to families that participate in health care decisions.

An advance care plan may include:

- an Advanced (Health or Care) Directive (or other similar instruments);
- an Enduring Power of Attorney (EPA) (or other similar instruments);
- a letter to the person who will be responsible for this decision-making;
- an entry in the patient medical record;
- a spoken instruction or other communication which clearly enunciates a patient's view; or
- any combination of the above.

Advance care planning is intended to enable individuals to make plans for their future care. The process encourages individuals to reflect on what is important to them, on their beliefs, values, goals and preferences in life, and how they want to be cared for if they reach a point where they cannot communicate decisions about medical care for themselves.

An advance care plan or advance care directive does not constitute euthanasia. Patients may however use advance care planning and advance care directives to record their decisions to refuse medical treatment (including food and drink).

National Framework

State and territory legislation governs advance care planning and directives. Some states and territories have legislated to allow adults to give a formal "advance(d) care directive" (sometimes referred to as a 'living will') regarding their preferences for medical treatment. This legislation typically provides for the protection of medical practitioners and/or other health care providers from criminal charges and civil proceedings when they act in accordance with a patient's expressed wishes. In other jurisdictions, legal advice indicates that under Common Law, any medical treatment can be refused by a competent adult at the time or in advance and any written document about treatment preferences is strongly persuasive, both for medical practitioners and substitute decision makers.

National consultations on a national advance care directives framework were held from 23 August 2010 to 11 October 2010. This was the result of work commissioned by the Australian Health Ministers' Conference (AHMC) in 2008, intended to progress the development of nationally consistent guidelines for advance care directives and related issues concerning end-of-life medical decisions by health professionals. The framework consists of a proposed national terminology, a code for ethical practice and best practice standards for advance care directives.

The National Framework for Advance Care Directives was published in September 2011. This AHMC work is primarily intended to assist state and territory policy makers and planners.

National Health and Hospitals Reform Commission

The National Health and Hospitals Reform Commission final report (June 2009) recommended "that advance care planning be funded and implemented nationally, commencing with all residential aged care services, and then being extended to other relevant groups in the population." In its implementation comments, the Commission recommended that consultations be held with various

[20] *The Role of the Medical Practitioner in Advance Care Planning – 2006,* http://www.ama.com.au/node/2428

stakeholder groups including professional bodies, aged care provider representatives and state/territory departments. This included consulting with aged care providers and state/territory departments about effective advance care planning programs.

Personally Controlled Electronic Health Records and Advance Care Planning

In the 2010 Budget, the Government appropriated $466.7 million over two years to establish a national Personally Controlled Electronic Health Record (PCEHR) system. Significant progress has been made to date with the PCEHR infrastructure, in preparation for the implementation date of 1 July 2012.

The Commonwealth is now funding a total of 12 lead eHealth sites across Australia. The objective of the lead eHealth sites is to provide practical examples of eHealth implementation both in specific geographic areas and also across key health care organisations and practices. The sites have a focus on the high priority consumer cohorts for improving health care services - in particular, the aged, the chronically ill, Aboriginal and Torres Strait Islander people and mothers and babies. The lessons learnt from the experiences of the 12 lead eHealth sites will be used to support the rollout of the national PCEHR system.

The Tasmanian Department of Health and Human Services (DHHS), the Tasmanian North West Area Health Service (NWAHS) and the University of Tasmania Rural Clinical School (UTAS) were selected by the DoHA to develop the Cradle Coast Connected Care (4C) project to provide end-of-life policy lessons for the PCEHR system. The DoHA has a contract in place with DHHS to deliver palliative and supportive care (including advanced care planning for people with lifelimiting disease - advanced cancer, chronic organ failure and the frail aged with/without dementia) in the Cradle Coast region of Tasmania, integrated within an electronic environment.

The 4Cs project will implement training and a framework of care in at least 5 residential aged care facilities incorporating at least 500 elderly residents. In addition, GPs will receive education and training in the 4C system. Once the system is implemented, potentially every member of the North West community who wants to register an ACP within the 4C system, could attend their GP to do so.

Respecting Patient Choices project

The Australian Government has been promoting advance care planning by funding Austin Health in Victoria for the Respecting Patient Choices project since 2003. Respecting Patient Choices (RPC) is a quality assured national standard for advanced care planning in Australia. The project is funded to assist patients across Australia to choose their end of life care and assist them to inform their families, carers and health professionals of the choices that they have made. The essence of RPC is to improve the evidence base that shows the advance care planning process improves the quality of care.

Over the years RPC has developed a comprehensive suite of resources for individuals and health professionals. These resources include:

- training courses
- training manuals
- implementation guidelines
- information booklets and leaflets for consumers (including translations)
- a GP information kit
- the Respecting Patient Choices website

The Respecting Patient Choices website was launched in 2005 and now serves the information needs of health professionals and the Australian community. It provides information about the RPC project and advance care planning to:

- individuals who are preparing their own advance care plans and their families/important others
- members of the general public who are curious about the project
- health care providers who are working with the project
- stakeholders, including government agencies.

The RPC project also completed the world's first randomised, controlled trial of systematised advance care planning in an elderly hospitalised cohort. This trial, which was published in the British Medical Journal in March 2010, showed:

- improved knowledge of and respect for patients' end of life wishes,
- improved perception of quality of care by both patient and family.
- a reduction in clinically significant depression, anxiety and post-traumatic stress in the family of patients who died.

The project is also working with National E-Health Transition Authority (NEHTA) to ensure that personally controlled electronic health records have the capability to store advance care plans and directives. Austin Health is currently funded to continue to work with NEHTA, aged care homes and trial advance care planning for Aboriginal and Torres Strait Islander people and CALD communities, people with dementia and other special needs groups.

Medicare Benefits Schedule

The issue of Medicare Benefits Schedule (MBS) items for advance care planning has previously been considered by the Australian Government. On 20 September 2007, the House of Representatives Standing Committee on Legal and Constitutional Affairs tabled its report entitled *Older people and the law*[21], on the adequacy of current legislative regimes in addressing the legal needs of older Australians in the following specific areas: fraud, financial abuse, general and enduring 'power of attorney' provisions, family agreements, barriers to older Australians accessing legal services, and discrimination.

Recommendation 23 from the Committee was for the Australian Government to include advance health care planning services provided by medical practitioners through the MBS. The Government's response[22] of 26 November 2009 did not accept this recommendation, outlining that Medicare benefits are claimable only for 'clinically relevant' services rendered by an appropriate health practitioner. A 'clinically relevant' service is one which is generally accepted by the profession in question as necessary for the appropriate treatment of the patient.

Where advance health care planning is part of consultations that are clinically relevant to an existing condition for which the medical practitioner is providing appropriate treatment, they are currently covered by the MBS. In relation to older people specifically, recognition of advance health care plans is currently included under Geriatrician Referred Patient Assessment and Management Plan (MBS items 141–147).

Advance health care planning services may not be covered where they are general in nature or unrelated to a current course of treatment. Any change to this requirement would be a substantial change in the intent of the services covered by the MBS.

[21] http://www.aph.gov.au/house/committee/laca/olderpeople/report.htm
[22] http://www.ag.gov.au/www/agd/agd.nsf/Page/Publications_Governmentresponse-OlderPeopleandtheLaw

10. PALLIATIVE CARE RESEARCH, INFORMATION AND DATA

One of the goal areas of the National Palliative Care Strategy is awareness and understanding. This is underpinned by one of the key aims of the National Palliative Care Program - research and quality improvement for palliative care services.

Research

The Palliative Care Clinical Studies Collaborative (PaCCSC) is a research infrastructure funded by the Government comprising a number of partner agencies, which are collaboratively involved in undertaking clinical studies into palliative care medications. PaCCSC has been established to conduct scientific research into the safety and efficacy of a number of medicines for palliative care use. This research may support the registration of a number of medicines used in palliative care on the Australian Register of Therapeutic Goods and subsequently support the listing of these medicines on the Pharmaceutical Benefits Scheme (PBS), allowing for greater community access.

In addition, the National Health and Medical Research Council (NHMRC) manages the National Palliative Care Research Program. The research program provides grants, scholarships and fellowships to improve the quality of palliative care, inform policy development, improve palliative care research capacity and increase the evidence base for good palliative care practice. Grant recipients are health care professions including nurses, allied health professionals, Indigenous health workers, medical practitioners, and clinical researchers who wish to undertake a research project specifically in the field of palliative care.

The objectives of the Palliative Care Research Program are to:

- fund areas of research not previously funded;
- develop innovative service delivery models;
- develop, trial or build on prevention and risk reduction strategies, assessment, treatment or management models;
- improve the knowledge base on populations and population groups;
- support a collaborative approach to research;
- fund non-biomedical research into Palliative Care;
- focus on the practical applications of research.

The NHMRC has been funded to manage the National Palliative Care Research Program since it commenced in 2001 with the first funding round.

Most recently, in 2008, the NHMRC announced the awarding of 16 Research Development Grants, nine priority driven research grants and eleven training awards. The NHMRC is currently monitoring the progress of the grants awarded under this funding round. A number of these projects are not due for completion until 2013.

Information

In 2002, an evidence based palliative care project was funded by the Government which resulted in the development of CareSearch. This web-based resource was established to collate and make available, electronically, Australia's "missing" palliative care literature since 1980. The aim of this project was to promote an evidence based approach to clinical practice and networking of palliative care information.

This concept of was further developed to the point where the CareSearch *Palliative Care Knowledge Network* was launched in 2008. CareSearch is an interactive website that includes a searchable database of palliative care literature and online forums that allow groups to share research, reports

and information. The website also provides information resources for researchers and palliative care specialists, along with information for patients and their families, carers, general practitioners, other health care professionals and the general public.

The Caresearch website is highly regarded as a valuable resource by the palliative care sector and the wider community. Current usage data indicates that the website receives over 40,000 visits and over 200,000 page views each month.

Data

The Australian Institute of Health and Welfare (AIHW) was previously funded by the Department to help develop performance indicators for the National Palliative Care Strategy 2000. AIHW subsequently published annual reports containing performance indicator data.

Most recently, AIHW has produced a scoping report on developing measures for assessing progress in achieving the aims of the *National Palliative Care Strategy 2010*. The scoping report was considered by the interjurisdictional Palliative Care Working Group (PCWG) which reports to Health Policy Priorities Principal Committee as part of the Australian Health Ministers' Advisory Committee structure.

The AIHW assists the PCWG in setting national measures (performance indicators) under the Strategy. It has been engaged to undertake specific work in relation to the *National Palliative Care Strategy 2010.* The work comprises three main streams:

- Data development, including performance indicators, for the Strategy;
- An annual "compendium" report on palliative care data; and
- Support for the PCWG on data matters including secretariat support for its data sub-committee.

The AIHW has also been funded to develop the *Trends in palliative care in Australian hospitals* publication. This report provides information on the extent and nature of palliative care separations in Australian public and private hospitals (**Appendices 6 and 7**).

There is a paucity of data regarding numbers of people in residential care who are receiving palliative care. One estimate may be constructed from the people receiving an Aged Care Funding Instrument (ACFI) assessment who were classified as requiring palliative care involving end-of-life care where ongoing care will involve very intensive clinical nursing and/or complex pain management in the residential care setting. This classification required that palliative care is a directive by Clinical Nurse Consultant or a Clinical Nurse Specialist, as well as clinical pain assessment.

In 2010-11 financial year, 188,826 people received an ACFI assessment, where 8,069 were assessed to require palliative care, suggesting that 4 per cent of aged care residents with ACFI assessment are receiving palliative care treatment. This is only an indicative figure and may only suggest the number of people receiving palliative care services in residential high care services. This does not reflect the residents whose increasing frailty and poor health over time may require them to use palliative care services.

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APPENDIX 1

ABORIGINAL AND TORRES STRAIT ISLANDER PROJECTS

INDIGENOUS PROJECTS

STATE	ORGANISATION	PURPOSE	FUNDING
LOCAL PALLLIATIVE CARE GRANTS PROGRAM (2006-2012)			
Round 1:	***Fit out and equipment/transition to home support - 2005/06 to 2006/07***		
ACT	Clare Holland House - Canberra	The Dennis Davison Hospice Gathering Place	$100,000
NSW	Bega Valley Health Services	Purchase of Palliative Care equipment and equipment to assist with transition to home	$100,000
NT	Central Australian Division of Primary Health Care	Laser therapy for Palliative patients	$77,280
SA	Meningie and Districts Memorial Hospital	Modify existing room and purchase of equipment	$100,000
SA	Port Pirie Regional Health Service	Fit-out of chemotherapy area	$43,800
SA	Southern Cross Care (SA) Inc.	Fit-out / refurbishment of Palliative Care room	$65,880
WA	Kimberley Palliative Care Service	Training package and resource booklet for carers and the community	$39,000
WA	Kimberley Palliative Care Service	Training indigenous health workers	$44,000
		Sub-total	**$569,960**
Round 2:	***Pastoral care, counselling and support - 2005/06 to 2008/09***		
NSW	South East NSW Division of General Practice	"Eurobodalla Education and Grief Support" project - develop a grief and loss education and support program and coordinate training of volunteers as bereavement support group leaders.	$104,479
NT	Territory Palliative Care - Central Australian Team	"Pastoral Care, Counselling and Bereavement Support" project - develop and build the capacity of local pastoral care, counselling and support services for people in the Central Australia and Barkly regions.	$92,000
VIC	Banksia Palliative Care Service	"Pastoral Care Worker" project - promote and coordinate the psycho-social and spiritual care services of palliative patients within culturally and linguistically diverse communities of north-eastern Melbourne.	$115,518
		Sub-total	**$311,997**

Round 3:	***Care planning - 2005/06 to 2008/09***		

NSW	Regional Social Development Group	"Rural and Remote Palliative Care Model" project - develop a cohesive and coordinated palliative care planning model responsive to the needs of rural and remote populations through improving collaboration between sectors and programs.	$244,510
NSW	Riverina Division of General Practice and Primary Health	"Rural Community Palliative Care Packages and Education" project - develop a palliative care package model for rural and Aboriginal target populations supported by an education strategy.	$250,000
NSW	H N McLean Memorial Retirement Village	"Northern New England Palliative Care Planning" project - support residential care and stay at home patients during palliative care	$198,980
NT	Top End Division of General Practice	"Top End Care Planning" project - coordinate case conferencing and promote care planning with appropriate service providers, palliative care patients and their carers	$248,475
SA	Northern Yorke Peninsula Health Service	"Client-Held Record" project - develop a patient record system to be retained by palliative clients	$237,439
WA	Geraldton Palliative Care Service	"Midwest Aged and Indigenous Palliative Care Planning" project - develop processes to facilitate smooth transition of palliative clients from acute care to Residential Aged Care facilities	$154,818
WA	Kimberley Aboriginal Medical Services Council	"Renal Palliative Care" project - integrate a palliative approach into care planning for people with End Stage Renal Disease	$232,862
		Sub-total	**$1,567,084**

Round 4:	***Equipment Purchase, Fit out and Transition care - 2007/08 to 2008/09***		

ACT	ACT Health	Barriers to palliative care discharge in the ACT - to conduct a project to review barriers to effective and timely discharge for palliative care patients in the ACT with a focus on identifying specific barriers for particular population groups, especially Aboriginal and Torres Strait Islander palliative care patients.	$104,479

NT	Department of Health and Community Services	Palliative Care Refurbishment and Upgrade Project 2007-2009 - to establish culturally appropriate palliative care unit primarily for the use of indigenous peoples of the Barkly Region.	$92,000
		Sub-total	**$196,479**

Round 5: Mental Illness, Alzheimer's and other Dementias - 2009/10 to 2010/11

SA	The Lyell McEwin Palliative Care Service	Specialist Mental Health Initiative in Palliative Care (SMIP) - to develop an innovative, integrated model of palliative care for patients with mental health problems, which among other things is clinically useful and culturally sensitive to Aboriginal and Torres Strait Islander people.	$442,063.94
		Sub-total	**$442,063.94**

Round 6: Equipment Purchase and Fit out - 2011/12

NSW	The Uniting Church in Australia Property Trust (NSW) trading as Uniting Care Ageing	Purchase of Equipment for Palliative Care Kits for Loan to Indigenous Patients on the NSW South Coast - to provide improved and flexible access through the Kuranya Palliative Care Equipment Loan Service to palliative care equipment for Indigenous palliative care patients in Eurobodalla and Bega Valley Shires.	$75,048.58
QLD	Queensland Health Cape York Health Service	Weipa Integrated Health Service Palliative Care Services Development Project- to purchase additional equipment for the palliative care unit	$34,373.00
		Sub-total	**$109,421.58**

Indigenous Community Educational Resource - 2009/10 to 2011/12

NSW	The George Institute for International Health	Indigenous Community Educational Resource - to present information on palliative care to Indigenous Australian renal patients in the form of a narrative drama integrated with an informational/instructional component.	$78,000.00
		Sub-total	**$78,000.00**

NATIONAL PALLIATIVE CARE PROGRAM FUNDING

Palliative Care for People Living at Home Initiative (2006-2010)			
NT	Department of Health and Families	Palliative Care for Remote Renal Clients - to examine palliative services for renal clients and their carers where the client requires palliative care and lives at home in a remote community of the Northern Territory, determine the palliative care options for this client group and identify palliative interventions required for those clients located in town undergoing dialysis treatment that wish to return home to their communities for palliative care.	$283,985
		Sub-total	**$283,985.00**

Identification of Palliative Care Resources for Aboriginal and Torres Strait Islander People (2010-2011)			
VIC	Atkinson Kerr and Associates	A consultancy to map and critically assess existing resources which support palliative care for Aboriginal and Torres Strait Islander peoples.	$59,090.90
		Sub-total	**$59,090.90**

Chronic Disease Palliative Care Pathway Trial (2010-2012) - Funding from Palliative Care in the Community			
NT	Department of Health	The project will utilise the outcomes of a previously funded project (see Palliative Care for Remote Renal Clients above) to develop other chronic disease specific pathways, while also embedding the practices initiated under the RPCP into Northern Territory renal services.; and integrate the established pathway into other Chronic Disease pathways	$715,350.00
		Sub-total	**$715,350.00**

TOTAL	**$4,333,431.42**

APPENDIX 2

CULTURALLY AND LINGUISTICALLY DIVERSE PROJECTS

STATE	ORGANISATION	PURPOSE	FUNDING
Local Palliative Care Grants Program (2006-2012)			
Round 1	***Fit out and equipment/transition to home support - 2005/06 to 2006/07***		
NSW	Roman Catholic Church Maitland Diocese	Workforce development, training and retention program	$90,680
NSW	Marco Polo Retirement Village	Fit-out and refurbishment of four Palliative Care rooms	$69,200
NSW	Sydney West Cancer Network	Development and evaluation of a program to support a model of transitional care	$100,000
SA	Southern Cross Care (SA) Inc.	Fit-out and refurbishment of a Palliative Care room	$65,880
SA	Port Pirie Regional Health Service	Fit-out of a chemotherapy area	$43,800
TAS	Tandara Lodge Community Care	Fit-out / refurbishment of a Palliative care room	$34,500
VIC	Assisi Centre Inc.	Fit-out / refurbishment of a Palliative care room	$42,281
		Sub-total	**$446,341**
Round 2	***Pastoral care, counselling and support - 2005/06 to 2008/09***		
NSW	Chinese Australian Services Society Co-op	'Supporting Palliative Care in the Chinese Community' - improve the awareness and knowledge of the Chinese speaking community (and health practitioners treating the community) of the significance of pastoral care, counselling and support for the palliative care patients, family, carers and friends	$120,000
NSW	Greek Welfare Centre	Palliative Care Development Project - CALD Greek community, to be implemented across four geographic regions in NSW with high numbers of residents from Greek speaking background	$79,154
NSW	Sydney West Area Health Service	"Developing Community Partnerships to Facilitate the Pastoral Care, Counselling and Support of the Dying and the Bereaved" project - develop community partnerships to increase the diversity and cultural sensitivity of the provision of pastoral care and bereavement support and develop referral guidelines to improve pastoral care and counselling support services to palliative patients	$119,915

VIC	Banksia Palliative Care Service	"Pastoral Care Worker" project - promote and coordinate the psycho-social and spiritual care services of palliative patients within culturally and linguistically diverse communities of north-eastern Melbourne	$115,518
VIC	Central Gippsland Health Service	"Pastoral Care, Bereavement Counselling and Support Resource Package" - develop multi-media resources to assist in addressing the spiritual, psychological and social support needs of palliative patients and their carers, families and friends	$120,000
		Sub-total	**$554,587**

Round 3 Care planning - 2005/06 to 2008/09

NSW	Regional Social Development Group	"Rural and Remote Palliative Care Model" project - develop a cohesive and coordinated palliative care planning model responsive to the needs of rural and remote populations through improving collaboration between sectors and programs	$244,510
QLD	St Luke's Nursing Service	"Bayside Palliative Care Carers Support Group" project - develop and implement a carer support model to provide peer support, information and clinical support for palliative carers to enable them to participate in the care planning process and enhance the care provided to their care recipient	$205,109
QLD	Uniting Church in Australia Property Trust	Research and evaluate existing models of care and systems with the view to developing a consistent approach to care planning and service delivery for people with a life limiting illness choosing to stay in the community	$250,000
		Sub-total	**$699,619**

Round 5 Mental Illness, Alzheimer's and other Dementias - 2009/10 to 2010/11

SA	Resthaven Incorporated	Coordinated Pathways: Supporting Carers and Families in a Palliative Approach for Care - to develop and trial a framework for a palliative care package that supplements community aged care services to support the older person with dementia, including those from culturally and linguistically diverse backgrounds to die at home, if this is their preference.	**$383,487**
		Sub-total	**$383,487**

Round 6	***Equipment Purchase and Fit out - 2011/12***		
NSW	St Basil's Homes Inc.	St Basil's Palliative Care Enhancement Project - to purchase equipment to support the delivery of palliative care at St Basil's Greek Nursing Home.	**$20,060**

TOTAL	**$2,104,094**

APPENDIX 3

CARESEARCH PAGE VIEWS, SITE VISITS, HITS AND TIME PER VISIT: JULY 2011 – JANUARY 2012

	July 2011	Aug 2011	Sept 2011	Oct 2011	Nov 2011	Dec 2011	29 Jan 2012
Page views	178,559	202,668	204,162	178,867	254,179	278,832	314,089
Visits	51,111	58,089	62,863	64,445	43,471	30,611	33,760
Hits	1,581,166	1,893,926	1,873,120	1,702,509	2,246,220	1,770,676	2,043,771
Time per visits (secs)	187	166	168	138	138	137	137

Source: Smarter Stats available at http://test.caresearch.com.au:9999 (Accessed on 30 January 2012)

APPENDIX 4

PALLIATIVE CARE OUTCOMES COLLABORATION'S (PCOC) ACHIEVEMENTS IN THE REPORTING PERIOD 1 JANUARY TO 31 DECEMBER 2011

- An increase in the number of services collecting PCOC data – now 117 services nationally.

- Report 10, released in March 2011, included data from 91 services for the period July to December 2010 and analysed over 16,767 episodes of care.

- Report 11, released September 2011, included data from 100 services for the period January to June 2011 and analysed over 17,394 episodes of care.

- Four benchmark measures are routinely included in reports to services. A summary table, first included in Report 8, shows the service how they performed on each measure and whether the benchmark was met.

- A workshop style approach to education was trialled primarily in NSW in 2011. Workshops were delivered with the aim of offering staff in palliative care services skill development to enhance their knowledge of the PCOC Assessment Tools.

- The development of a marketing and communications strategy for PCOC resulting in a rebranding exercise which included a new logo, domain name and updated marketing material

PCOC appointed Professor Katy Clark as the PCOC Clinical Director. This is a conjoint appointment , as Professor Clark is also the Director of Palliative Care at Calvary Mater Newcastle which incorporates the Mercy Hospice, Area Director of Palliative Care for the Hunter New England Local Health Network and Associate Professor of Palliative Medicine at the University of Newcastle. Professor Clark has many years' clinical, academic and research experience in palliative medicine. She is published on a variety of topics pertaining to palliative care in particular the symptoms of constipation and dyspnoea and has contributed to a number of textbooks.

APPENDIX 5

PALLIATIVE CARE OUTCOMES COLLABORATION'S (PCOC) PERCENTAGE OF SERVICES MEETING BENCHMARKS

COMPARISON FROM REPORT 7 TO REPORT 11

BENCHMARK MEASURE 1 - TIME FROM REFERRAL TO FIRST CONTACT

Benchmark 1.1: 90% of patients are contacted by a member of the clinical team (either face to face or by phone) the day of, or the day following of referral (including weekends).

	Jan-Jun 09 (Report 7)	Jul-Dec 09 (Report 8)	Jan-Jun 10 (Report 9)	Jul-Dec 10 (Report 10)	Jan-Jun 11 (Report 11)
Episodes meeting benchmark	81%	81%	80%	75%	76%
Services meeting benchmark	49%	45%	49%	41%	42%

BENCHMARK MEASURE 2 - TIME IN THE UNSTABLE PHASE

Benchmark 2.1: 85% or more of patients in their first palliative care phase remain in the unstable phase for less than 7 days.

	Jan-Jun 09 (Report 7)	Jul-Dec 09 (Report 8)	Jan-Jun 10 (Report 9)	Jul-Dec 10 (Report 10)	Jan-Jun 11 (Report 11)
Phases meeting benchmark	62%	66%	67%	72%	77%
Services meeting benchmark	17%	23%	29%	40%	47%

Benchmark 2.2: 90% or more of patients in a subsequent palliative care phase remain in the unstable phase for less than 7 days.

	Jan-Jun 09 (Report 7)	Jul-Dec 09 (Report 8)	Jan-Jun 10 (Report 9)	Jul-Dec 10 (Report 10)	Jan-Jun 11 (Report 11)
Phases meeting benchmark	72%	73%	74%	78%	80%
Services meeting benchmark	13%	20%	23%	39%	44%

Benchmark 2.3: The median time in the unstable phase is 2 days or less.

Services meeting benchmark	Jan-Jun 09 (Report 7)	Jul-Dec 09 (Report 8)	Jan-Jun 10 (Report 9)	Jul-Dec 10 (Report 10)	Jan-Jun 11 (Report 11)
First phase	15%	19%	28%	37%	42%
Subsequent phase	21%	41%	48%	59%	55%

BENCHMARK MEASURE 3 - CHANGE IN PAIN (BOTH PC PSS AND SAS)

Benchmarks 3.1 and 3.3: At least 90% of patients with absent or mild pain at the beginning of their phase of palliative care have absent or mild pain at the end of the phase.

	Jan-Jun 09 (Report 7)	Jul-Dec 09 (Report 8)	Jan-Jun 10 (Report 9)	Jul-Dec 10 (Report 10)	Jan-Jun 11 (Report 11)
PSS Pain					
Phases meeting benchmark	82%	81%	78%	77%	80%
Services meeting benchmark	20%	25%	12%	7%	20%
SAS Pain					
Phases meeting benchmark	82%	81%	79%	78%	80%
Services meeting benchmark	19%	13%	12%	9%	16%

Benchmarks 3.2 and 3.4: At least 60% of patients with moderate or severe pain at the beginning of their phase of palliative care have absent or mild pain at the end of the phase.

	Jan-Jun 09 (Report 7)	Jul-Dec 09 (Report 8)	Jan-Jun 10 (Report 9)	Jul-Dec 10 (Report 10)	Jan-Jun 11 (Report 11)
PSS Pain					
Phases meeting benchmark	38%	41%	47%	49%	50%
Services meeting benchmark	20%	23%	32%	35%	43%
SAS Pain					
Phases meeting benchmark	41%	41%	44%	48%	49%
Services meeting benchmark	12%	16%	24%	9%	35%

BENCHMARK MEASURE 4 - CHANGE IN SYMPTOMS RELATIVE TO THE NATIONAL AVERAGE

Target: 75% of participating services are performing at or above the baseline national average on each measure by the end of 2011.

Percentage of services (with 10 or more valid observations) currently at or above the baseline national average:

	Jan-Jun 09 (Report 7)	Jul-Dec 09 (Report 8)	Jan-Jun 10 (Report 9)	Jul-Dec 10 (Report 10)	Jan-Jun 11 (Report 11)
PCPSS Pain-CAS	54%	63%	66%	73%	76%
SAS Pain-CAS	49%	45%	69%	63%	73%
Other symptoms	67%	68%	76%	78%	80%
Psychological/spiritual	53%	57%	71%	72%	73%
Family/carer	56%	55%	63%	75%	76%
Nausea	46%	51%	58%	67%	76%
Bowels	46%	48%	55%	63%	67%
Breathing	61%	57%	71%	73%	80%

Percentage of phases with a change in symptom score that was better than the baseline national expected change:

	Jan-Jun 09 (Report 7)	**Jul-Dec 09 (Report 8)**	**Jan-Jun 10 (Report 9)**	**Jul-Dec 10 (Report 10)**	**Jan-Jun 11 (Report 11)**
PCPSS Pain-CAS	68%	68%	64%	65%	66%
SAS Pain-CAS	68%	66%	62%	63%	64%
Other symptoms	51%	49%	53%	56%	57%
Psychological/spiritual	59%	58%	61%	64%	65%
Family/carer	48%	48%	50%	54%	56%
Nausea	79%	78%	79%	80%	81%
Bowels	63%	61%	63%	66%	67%
Breathing	68%	66%	70%	71%	72%

APPENDIX 6

AIHW Trends in palliative care in Australian hospitals report

Table 6: Palliative care separations by Indigenous status, selected states and territories[(a)], all hospitals, 2008–09

	Number				
	Male	Female	Total	Percentage	Age-standardised rate[(b)]
Indigenous Australians	354	408	762	1.5	37.2
Other Australians[(c)]	26,569	23,089	49,658	98.5	22.7
Total	**26,923**	**23,497**	**50,420**	**100.0**	**22.9**

(a) Data for Tasmania, the Australian Capital Territory and private hospitals in the Northern Territory are excluded (see *Trends in palliative care in Australian hospitals,* AIHW, Appendix D).

(b) The rates were age standardised to the Australian population as at 30 June 2001 and are expressed per 10,000 persons (see *Trends in palliative care in Australian hospitals,* AIHW, Appendix D).

(c) 'Other Australians' includes separations for non-Indigenous Australians and those for whom the Indigenous status was not reported.

Source: Trends in palliative care in Australian hospitals, AIHW.

Table 7: Palliative care separations by age and sex, all hospitals, 2008–09

	Number of separations			Age-specific rate[(a)]		
Age (years)	Males	Females	Total	Males	Females	Total
0–4	41	37	78	0.6	0.5	0.6
5–9	6	4	10	0.1	0.1	0.1
10–14	12	14	26	0.2	0.2	0.2
15–19	35	35	70	0.5	0.5	0.5
20–24	55	55	110	0.7	0.7	0.7
25–29	53	106	159	0.7	1.4	1.0
30–34	112	144	256	1.5	1.9	1.7
35–39	237	280	517	3.0	3.5	3.2
40–44	398	537	935	5.3	7.0	6.1
45–49	785	901	1,686	10.2	11.4	10.8
50–54	1,294	1,259	2,553	18.3	17.5	17.9
55–59	1,766	1,810	3,576	27.5	27.7	27.6
60–64	2,781	2,055	4,836	48.4	35.8	42.1
65–69	3,128	2,322	5,450	74.3	54.1	64.1
70–74	3,910	2,551	6,461	120.3	73.0	95.8
75–79	4,535	3,151	7,686	178.9	106.7	140.1
80–84	4,665	3,750	8,415	258.1	152.6	197.3
85+	4,124	5,399	9,523	325.1	219.6	255.5
Total[(a)]	**27,937**	**24,410**	**52,347**	**26.5**	**18.9**	**22.2**

(a) Age-specific rates show the number of palliative care separations per 10,000 persons in that age group at 31 December 2008. Rates shown in the 'Total' row are age standardised to the Australian population as at 30 June 2001 (see *Trends in palliative care in Australian hospitals,* AIHW, Appendix D).

Source: Trends in palliative care in Australian hospitals, AIHW.

Table 8: Palliative care separations by remoteness area, all hospitals, 2008–09

Remoteness area[(a)]	Number			Percentage	Age-standardised rate[(b)]
	Male	Female	Total		
Major cities	18,621	17,024	35,645	68.1	23.0
Inner regional	5,909	4,827	10,736	20.5	20.8
Outer regional	2,852	2,113	4,965	9.5	22.0
Remote or very remote	476	382	858	1.6	21.4
Not reported	79	64	143	0.3	. .
Total	**27,937**	**24,410**	**52,347**	**100.0**	**22.5**

(a) Remoteness area was measured using the Australian Standard Geographical Remoteness Area classification (see *Trends in palliative care in Australian hospitals,* AIHW, Appendix E).

(b) The rates were age standardised to the Australian population as at 30 June 2001 and are expressed per 10,000 persons (see *Trends in palliative care in Australian hospitals,* AIHW, Appendix D).

Source: Trends in palliative care in Australian hospitals, AIHW.

APPENDIX 7

AIHW Trends in palliative care in Australian hospitals report

Table 9: Palliative care separations and all separations by principal source of funds, states and territories, public and private hospitals, 2008–09

Principal source of funds	Palliative care separations (%)									Separations for all reasons (%)
	NSW	Vic	Qld	WA	SA	Tas[a,b]	ACT[a]	NT[a]	Total[a]	
Public hospitals										
Public patients[c]	68.1	79.9	92.7	88.9	80.8	78.2	70.1	96.1	76.9	85.6
Private health insurance	23.4	13.1	2.4	6.4	11.5	15.1	20.7	0.1	15.7	9.2
Department of Veterans' Affairs	7.5	6.4	4.5	4.3	7.6	6.4	8.7	3.2	6.6	2.5
Other[d]	1.0	0.6	0.4	0.4	0.0	0.3	0.4	0.5	0.7	2.6
Total[e]	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*
Private hospitals										
Public patients[c]	18.9	0.4	39.4	60.9	9.3	n.p.	n.p.	n.p.	30.7	3.1
Private health insurance	63.0	84.3	44.6	29.6	76.7	n.p.	n.p.	n.p.	53.9	79.2
Department of Veterans' Affairs	14.7	10.5	12.1	9.1	12.0	n.p.	n.p.	n.p.	11.8	6.1
Other[d]	3.4	4.8	3.9	0.3	2.0	n.p.	n.p.	n.p.	2.6	10.9
Total[e]	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*	*n.p.*	*n.p.*	*n.p.*	*100.0*	*100.0*

(a) To ensure confidentiality of information, data for private hospitals in Tasmania, the Australian Capital Territory and the Northern Territory are not shown. 'Total' includes data for all jurisdictions.

(b) Tasmania was unable to identify all patients whose funding source may have been *Self-funded* (a funding source that is included in the *Other* category in this table). Therefore, the number of separations in the *Other* category may be underestimated while the number in the other categories may be overestimated.

(c) The 'Public patients' category includes separations with a funding source of *Australian Health Care Agreements*, *Reciprocal health care agreements*, *Other hospital or public authority* (with a public patient election status) and *No charge raised* (in public hospitals).

(d) 'Other' includes separations with a funding source of *Self-funded*, *Workers compensation*, *Motor vehicle third party personal claim*, *Other compensation (for example, public liability, common law, medical negligence)*, *Department of Defence*, *Correctional facility*, *Other hospital or public authority* (without a public patient election status), *Other* and *No charge raised* (in private hospitals).

(e) 'Total' includes those separations for which the principal source of funds was not reported.

Source: Trends in palliative care in Australian hospitals, AIHW.