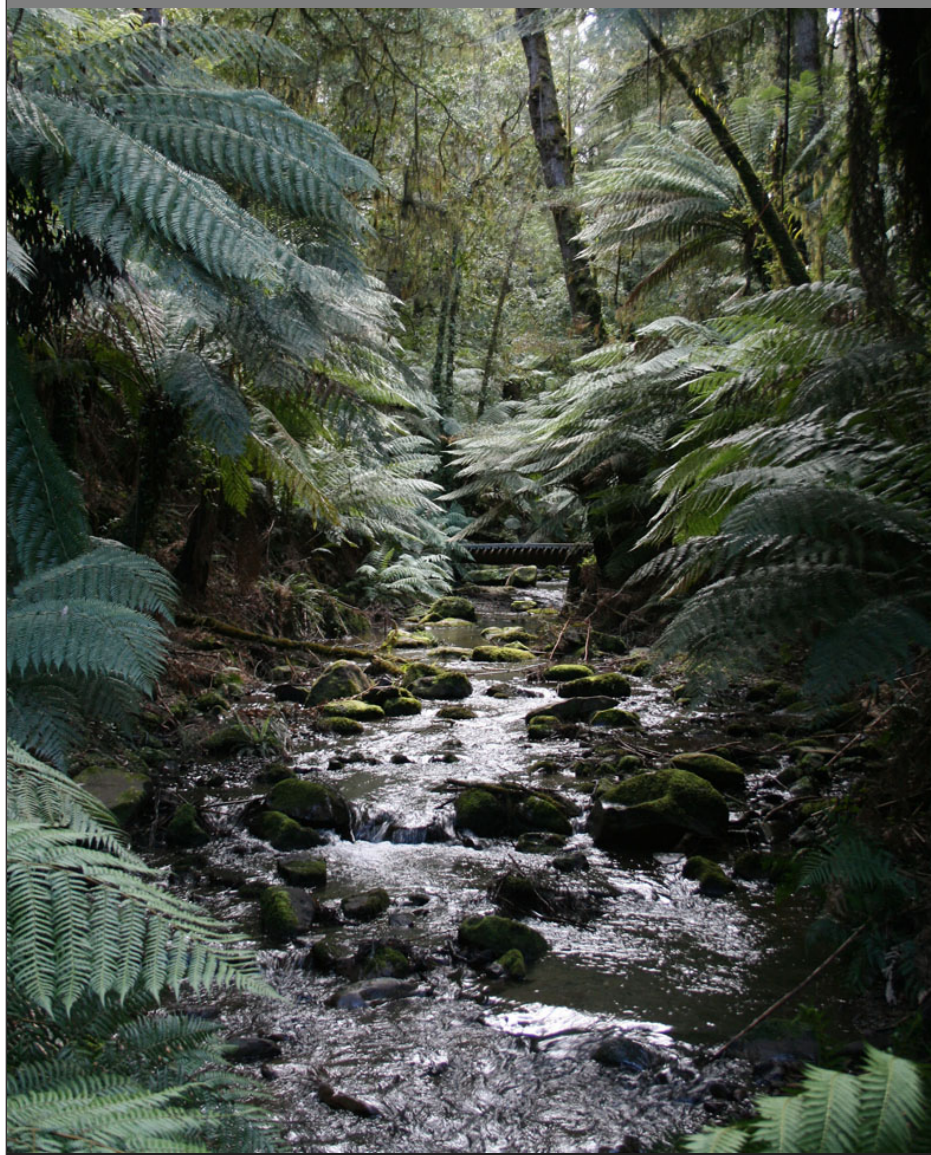


# **EVALUATION OF THE NATIONAL PALLIATIVE CARE STRATEGY 2010 FINAL REPORT**



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FINAL  
PREPARED FOR COMMONWEALTH DEPARTMENT OF HEALTH

**URBIS**

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# ACRONYMS

ACDs	Advance Care Directives
ACI	The Agency for Clinical Innovation
ACP	Advance Care Planning
AHMAC	Australian Health Ministers' Advisory Council
AHMC	The former Australian Health Ministers' Conference
AIHW	Australian Institute of Health and Welfare
ANZSPM	Australian and New Zealand Society of Palliative Medicine
BAPC	Better Access to Palliative Care
CALD	Culturally and Linguistically Diverse
COAG	Council of Australian Governments
DHBs	District Health Boards
DNR	Do Not Resuscitate
EIU	Economist Intelligence Unit
GP	General Practitioner
HSE	Health Service Executive
ICGP	Irish College of General Practitioners
MBS	Medical Benefits Schedule
MOOC	Massive Open Online Course
NHS	National Health Service
NMDS	Admitted Patient Care National Minimum Data Set
NPCP	National Palliative Care Projects
NSAP	National Standards Assessment Program
OTDs	Overseas Trained Doctors
PA	Palliative Approach Toolkit
PaCCSC	Palliative Care Clinical Studies Collaborative
PBS	Pharmaceutical Benefits Scheme
PCA	Palliative Care Australia
PCC	Palliative Care Council of New Zealand
PCC4U	Palliative Care Curriculum for Undergraduates
PCETC	Palliative Care Education and Training Collaborative
PCIF	Palliative Care Intergovernmental Forum
PCIG	Palliative Care Interest Group

PCOC	Palliative Care Outcomes Collaboration
PCWG	Palliative Care Working Group
PEPA	Program of Experience in the Palliative Approach
RACFs	Residential Aged Care Facilities
RNs	Registered Nurses
RPC	Respecting Patient Choices
UK	United Kingdom
WHO	World Health Organisation

## OTHER

“the Framework”	<i>Palliative Care Services - Five Year/Medium Term Development Framework</i>
“the Commission”	Australian Commission on Safety and Quality in Health Care
“the Committee”	Commonwealth Senate Community Affairs References Committee
“the Strategy”	<i>National Palliative Care Strategy 2010 – Supporting Australians to Live Well at the End of Life</i>

# EXECUTIVE SUMMARY

Australia ranks high in international comparisons of national palliative care provision, which is attributed, among other things, to a strong national strategy to guide policy and service development. The *National Palliative Care Strategy 2010 – Supporting Australians to Live Well at the End of Life* (the Strategy) builds on the first national strategy in 2000, was endorsed by the former Australian Health Ministers' Conference (AHMC)<sup>1</sup> and has provided guidance to all jurisdictions in developing and implementing policies and services.

The Commonwealth Department of Health commissioned Urbis to conduct an evaluation of the Strategy. The evaluation has been informed by an evidence review as well as national consultation through workshops, in-depth interviews, and an online submission portal.

This report presents the findings of the evaluation as well as considerations for optimising the potential of the current Strategy as a strategic national framework.

Overall, the evaluation has found that the Strategy's existence contributes to an authorising environment for the continued expansion and improvement of palliative care service delivery across the health system. The fact that it is a national document, endorsed by all jurisdictions, gives weight to the four strategic goal areas which is reported to be helpful in aligning service development priorities to regional and national directions.

Evaluation participants were able to identify many achievements within the palliative care sector since 2010. The extent to which these achievements are directly attributable to the Strategy varies, with the projects and activities funded under the National Palliative Care Projects (NPCP) most visibly aligned with the Strategy.

Analysis of international palliative care strategies suggests that effective strategies contain the following elements:

- Governance
- Integration of services
- Patient-centred care
- Systems and processes
- Workforce capability.

All of these elements are present within the Strategy; however, the lack of defined baseline measures, measurable performance indicators, and an accountability framework has hindered the Strategy's effectiveness.

In considering future directions for a national strategy for palliative care, the literature suggests the following factors should be considered:

- the alignment between national and jurisdictional policy, planning and funding
- the policy directions required to:
  - maintain the high level of palliative care services currently available to Australians
  - ensure the supply of well-trained medical, nursing and other health professionals
  - improve consistency of access and quality across the country
  - increase the appropriateness of services to respond to the needs of sectors of the population (e.g. Aboriginal and Torres Strait Islander peoples, migrants, different religious groups, people from culturally and linguistically diverse backgrounds)
- the needs of an ageing population expected to live for longer periods with one or more chronic diseases, including cancer
- the particular needs of children in the provision of paediatric palliative care

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<sup>1</sup> The AHMC is now known as the COAG Health Council.

- the importance of increasing the public comfort with thoughtful and considered discussion of death and dying.

Australia has a strong foundation based on decades of investment and leadership in palliative care policy, research and services. Continued leadership, commitment and investment will be required to ensure that all Australians are able to achieve a good death.

Urbis suggests that the following actions could be considered by the Commonwealth to increase the influence of the Strategy going forward.

1. The fact that there is little reference to the Strategy in many jurisdictional strategies and plans suggests that the Strategy has not been effective in aligning state, territory and Commonwealth planning and policies. The loss of an effective inter-jurisdictional mechanism for planning and policy development has also hindered the development of a nationally consistent approach to service delivery. Urbis suggests that a priority for the future is to work with the Palliative Care Interest Group (PCIG) to consider national objectives for improving consistency across the country and for ensuring that states and territories are able to reduce duplication of effort. This should include consideration of mechanisms for engaging more closely with AHMC.
2. The evaluation has found that the lack of accountability and measurement within the Strategy has hindered its effectiveness. In order to provide national leadership in the direction of policy development the document requires strengthening in terms of what it is seeking to achieve and how achievements can be demonstrated. This is essential to provide a policy lever for maintaining the quality and expansion of palliative care services, addressing workforce shortages, and improving consistency of access and service delivery. Urbis suggests that an action or implementation plan should be developed to guide implementation of the Strategy going forward, with identified objectives, actions, responsibilities, and indicators.
3. The Australian Institute of Health and Welfare (AIHW) analyses the Admitted Patient Care National Minimum Data Set (NMDS), along with other national data sources, for its annual report on palliative care services. The lack of effective indicators in the Strategy has highlighted the need for consideration of a nationally consistent data set that could provide insight into the provision, quality and effectiveness of palliative care services. Benchmark indicators for service performance have already been identified through the National Standards Assessment Program (NSAP) and the Palliative Care Outcomes Collaboration (PCOC). Recognising the lengthy process required to identify appropriate data indicators and work with jurisdictions to assess feasibility for an NMDS, it would be useful to work with the AIHW to identify a possible way forward to improve data collection for the purpose of monitoring the Strategy's effectiveness.
4. There is currently no efficient mechanism for collecting data regarding palliative care service provision in community and primary care settings. Given the expected increase in palliative care service delivery in non-specialist settings, it would be useful to work with the AIHW to identify a possible way forward to improve data collection for these services.
5. There is a need for the Strategy to be more closely aligned with other national strategic frameworks, such as the one currently being developed for chronic disease, the aged care reform package, future iterations of the National Carer Strategy, and the National Disability Insurance Scheme. Within the life of the current Strategy, it would be beneficial to explore ways in which the Strategy can be revised to accommodate the significant policy developments that have occurred since 2010.
6. The need for public awareness and understanding of the process of death and dying continues to be identified as a barrier for managing pain and symptoms for many people at the end of life. The Strategy has identified this as a priority, and progress has been made both through the Advance Care Planning (ACP) activities funded under the NPCP and through a number of community-led initiatives. The Strategy identified social marketing and health promotion campaigns as a means of raising awareness nationally, and consideration should be given to what such a campaign might achieve and how this might be implemented.
7. There remain significant barriers to access to palliative care services for a number of people within the population, particularly for Aboriginal and Torres Strait Islander peoples. While some progress has been made in raising awareness of palliative care services in culturally appropriate ways, the cultural security of palliative care services varies significantly. The Strategy does not focus on groups which have traditionally not accessed palliative care services; developing culturally-specific activities to address the

needs of Aboriginal and Torres Strait Islander peoples may help to improve access to services for those who need it.

8. Similarly, there is little detail in the Strategy regarding the needs of people from a range of vulnerable populations, including the homeless, people living with disabilities, new migrants and people from culturally and linguistically diverse (CALD) backgrounds. It would be valuable to consider whether national strategic direction would assist to improve the availability of services for these and other people at the end of life.
9. *Capacity and Capability* was the goal area with the longest list of actions and the least ability to measure progress. Identifying tangible and practical activities to support jurisdictions and educational institutions to address workforce shortages and capacity issues would be useful. Continued funding for research and information dissemination projects, as well as for those providing education and training opportunities, will continue to strengthen capacity among the existing workforce.
10. In summary, Urbis considers that the current Strategy should be updated to reflect the above considerations. The current Strategy has no defined end point and, as a result, does not provide a clear timeframe for delivering outcomes or define accountability and performance measurement. Stakeholders strongly believed that the Strategy requires updating to reflect the changing environment since 2010 and to improve the Strategy's position as a mechanism to drive national, jurisdictional and service delivery activity, in order to ensure that the Australian health system is able to meet the increasing needs for high quality palliative care.

# INTRODUCTION

## 1.1. THE NATURE OF PALLIATIVE CARE

Palliative care as a medical discipline began in the mid-20<sup>th</sup> century in London with the ground-breaking work of Dame Cicely Saunders, a medical practitioner who launched the modern hospice movement with a focus on providing palliation of symptoms for cancer patients who had reached the limit of what curative treatment could achieve. Palliative care as a health speciality has since grown to encompass a holistic approach to the needs of a patient at the end of life as well as the needs of immediate family and carers, and includes not just the management of a patient's physical symptoms, but also their psychosocial and spiritual well-being. In Australia, the World Health Organisation's (WHO) definition of palliative care has been generally accepted as the standard (see box 1 below).

### BOX 1 – WHO DEFINITION OF PALLIATIVE CARE

Palliative care is 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.

Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Source: (World Health Organization, 2016)

The Australian Institute of Health and Welfare (2014) notes that the term “palliative care” is often used interchangeably with terms such as “end of life care” and “specialist palliative care”. The use of such terms continues to be debated, however at the present it appears that the term “end of life care” is gaining prominence to refer to the approach taken in caring for people who are living with a life-limiting illness, with palliative care considered as a specific component of the larger approach to the last period of an individual's life (NHS England, 2014). Palliative care can be delivered in many settings and by a variety of professionals, including specialists as well as generalist clinicians (Gardiner et al., 2011) including general practitioners, community nurses, allied health professionals and personal and social carers including volunteers.

Specialist palliative care can be delivered in settings such as general hospital wards, dedicated palliative care hospital wards, hospices and the community (Australian Institute of Health and Welfare, 2014), and palliative care teams will include at least one professional with advanced training in palliative medicine (Gomes et al., 2013).

## 1.2. PALLIATIVE CARE IN AUSTRALIA

Palliative care has been recognised as a specialised field within the Australian health care system since the 1980s (Department of Health and Ageing, 2000).

In the last few decades, palliative care has become available within almost every health care setting, including neonatal units, paediatric services, general practices, acute hospitals, residential and community aged care services, and generalist community services. Palliative care is also provided through specialist palliative care services which operate from a variety of settings, including specialist inpatient consulting services, specialist inpatient settings, hospices and community-based specialist services (Department of Health and Ageing, 2010).

Data show that the demand for palliative care services has increased over time. Recent data published by the Australian Institute for Health and Welfare indicate that:

- in 2014-2015, MBS-subsidised palliative medicine specialist services were estimated at \$5.3 million, an increase of nearly 80% over the previous five years
- in 2014, 32,800 patients accessed palliative care services from 101 Palliative Care Outcomes Collaboration (PCOC) participating palliative care providers, an increase of 4% from 2013
- in 2013-2014, there were nearly 62,200 palliative care hospitalisations, of which nearly half (51%) were people aged 75 and over, this represented an 11% increase compared with 2009-2010 (Australian Institute of Health and Welfare, 2016).

The increase in demand reflects international trends and has been influenced by an ageing population as well as changing understanding of the nature of palliative care. The development and implementation of national, state and territory palliative care policies, strategies and initiatives over the last two decades will also have influenced the increase of palliative care services, including the establishment of the National Palliative Care Program, the release of two national palliative care strategies and the 2015 National Consensus Statement. A summary of each of these initiatives is provided below.

### 1.2.1. The National Palliative Care Projects (NPCP)

In the 1990's, the Australian Government provided funding for palliative care through Medicare Hospital Grants and the Palliative Care Program (PCP). Most of the PCP funding was allocated to the state and territory governments to improve the quality of life of people suffering a terminal illness and to help states and territories develop options for future delivery of palliative care services.

The development of the first National Palliative Care Strategy: *A National Framework for Palliative Care Service Development 2000* commenced in 1998. The Palliative Care Intergovernmental Forum (PCIF) was appointed to assist in the development of the first Strategy and comprised of representatives from the Australian Government and all state and territory jurisdictions.

In 2002, the Australian Government provided funding for the National Palliative Care Program to support the first Strategy. The National Palliative Care Program implemented initiatives and activities to support improvements in the quality of palliative care. The name of the program has recently changed to the National Palliative Care Projects (NPCP).

The aims of the NPCP are to improve access to, and the quality of, palliative care services. The NPCP seeks to do this through funding and support for a wide range of discrete projects, both large-scale institutional projects and small-scale grant-funded projects to health-related services for targeted palliative care support. The projects are primarily focused on research, education, training, quality improvement and advance care planning (Department of Health, n.d.).

### 1.2.2. The National Palliative Care Strategy

The first National Palliative Care Strategy was launched in 2000. This Strategy was endorsed by the Australian Health Ministers' Advisory Council and marked a national commitment from the Commonwealth, all states and territories, palliative care service providers and community-based organisations to develop and implement palliative care policies, strategies and services (Department of Health and Ageing, 2010).

Ten years later, within the midst of major governance and funding health care reforms to address the needs of a changing and ageing population, the revised National Palliative Care Strategy 2010 was released (Department of Health and Ageing, 2010). With the revised Strategy, all Australian governments continued their commitment to further enhance the development and implementation of palliative care. The new Strategy replaced the former three national goals with five national goal areas for the Australian health and human services sector as outlined in Table 1.

TABLE 1 – NATIONAL PALLIATIVE CARE STRATEGY 2010 GOAL AREAS

Goal Area	Number	Goal
Awareness and Understanding	Goal 1	To significantly improve the appreciation of dying and death as a normal part of the life continuum
	Goal 2	To enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to, palliative care services
Appropriateness and Effectiveness	Goal 3	Appropriate and effective palliative care is available to all Australians based on need
Leadership and Governance	Goal 4	To support the collaborative, proactive, effective governance of national palliative care strategies, resources and approaches
Capacity and Capability	Goal 5	To build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care

### 1.2.3. A national consensus in end-of-life care

In 2013, the Australian Commission on Safety and Quality in Health Care (the Commission) undertook scoping and consultation work “in an effort to understand the complexity of issues and barriers affecting the delivery of safe and high-quality end-of-life care in acute facilities” (Australian Commission on Safety and Quality in Health Care, 2013). This resulted in a background paper, *Safety and quality of end-of-life care in acute hospitals*, to provide a platform for discussion to improve the provision of end-of-life care in the acute setting.

The Commission identified key areas for improvements, including the need for:

- an increase in open discussions and conversations about death and dying
- a shared understanding and more clarity in terminology (e.g. “palliative care”, “advance care planning”) among the health workforce, patients and their families to avoid miscommunication and variability in practice
- improvements in acute care systems to address end-of-life care issues during a patient’s journey
- a stronger focus on assessing the quality of end-of-life care when evaluating deaths in acute care (instead of primarily reviewing whether deaths were expected or potentially preventable).

The Commission emphasised the need for a national consensus statement to articulate the standard of end-of-life care that patients, carers and families should expect in acute hospitals.

This led to the release of the National Consensus Statement on End-of-Life Care in 2015 (the Consensus Statement), endorsed by all Australian Health Ministers (Australian Commission on Safety and Quality in Health Care, 2015).

The Consensus Statement outlines ten essential elements for the delivery of high quality and safe end-of-life care as summarised in the table below.

The Consensus Statement provides clinicians, health service executives and managers, policy-makers, educators and training providers with principles as a guide to improve the provision of end-of-life care.

The Commission recognises that these elements will be relevant for a range of settings, but that in some settings the *National Standards for Providing Quality Palliative Care for All Australians* (Palliative Care Australia, 2005) will be more appropriate in providing guidance to support the quality and safety of care. The

Consensus Statement and the National Standards provide complementary frameworks to guide the development of systems that “foster a collaborative approach between acute and specialist palliative care services” (Australian Commission on Safety and Quality in Health Care, 2015).

TABLE 2 – OVERVIEW OF THE 10 ESSENTIAL ELEMENTS IN THE CONSENSUS STATEMENT

	Key elements	Key goals
Patient centred care	1. Patient Centred Care	Patients are part of decision making about end-of-life care
	2. Teamwork	Clinicians work together to provide end-of-life care
	3. Goals of care	Clear goals improve the quality of end-of-life care
	4. Using triggers	Triggers identify when patients need end-of-life care
	5. Responding to concerns	Clinicians get help to rapidly respond to patient suffering
Organisational prerequisites	6. Leadership and governance	Policies and systems for end-of-life care
	7. Education and training	Clinicians have the skills and knowledge to provide end-of-life care
	8. Supervision and support	Clinicians providing end-of-life care are supported
	9. Evaluation and feedback	The quality of end-of-life care is measured and improved
	10. Supporting systems	Systems align with NSQHS Standards to improve outcomes

Source: Australian Commission on Safety and Quality in Health Care, 2015

### 1.3. EVALUATION OF THE NATIONAL PALLIATIVE CARE STRATEGY 2010

Urbis was engaged by the Department of Health to undertake an evaluation of the National Palliative Care Strategy 2010 – Supporting Australians to Live Well at the End of Life (the Strategy). In particular, the evaluation focused on:

- the role of the Strategy as a strategic national document
- the extent to which the Strategy has been effective in providing aspirational goals for governments
- the value of the Strategy as an enabler of policy and service development
- achievements that can be attributed to the Strategy
- opportunities for future improvement
- new or emerging priorities to be considered for the future.

This report provides an analysis of the evaluation findings, and is structured as follows:

- Chapter 2 – Methodology
- Chapter 3 – An overview of the literature review
- Chapter 4 – Findings from the consultation and evidence review
- Chapter 5 – Discussion
- Chapter 6 – Considerations for the future.

## 2. METHODOLOGY

### 2.1. OVERVIEW OF EVALUATION APPROACH

Table 3 below outlines the approach taken to complete the evaluation including the research activities relevant to each phase of the project.

TABLE 3 – EVALUATION STRUCTURE

Evaluation phase	Timeline	Research activities
Phase 1: inception and project planning	April 2016	<ul style="list-style-type: none"><li>• inception meeting with the Department</li><li>• project plan and consultation strategy</li></ul>
Phase 2: initial analysis	May-June 2016	<ul style="list-style-type: none"><li>• key informant interviews</li><li>• evidence review</li></ul>
Phase 3: national consultation	July-August 2016	<ul style="list-style-type: none"><li>• 11 half-day workshops across Australia</li><li>• stakeholder interviews</li><li>• public online submission process</li></ul>
Phase 4: analysis and reporting	August-September 2016	<ul style="list-style-type: none"><li>• preparation of draft and final reports</li></ul>

### 2.2. EVIDENCE REVIEW

Urbis conducted a review of the published literature, as well as a review of other available program and service documentation. This review focused on the issues associated with policy implementation, current trends and challenges for the development of palliative care services and strategic national approaches to palliative care service development.

Chapter three of this report provides an overview of the review of literature, and many of the findings of the review are reflected throughout this evaluation report. The full literature review is also provided as a separate document.

### 2.3. NATIONAL CONSULTATION

The national consultation phase of the evaluation occurred between May and August 2016. The purpose of this phase was to provide an opportunity for people to reflect on the success of the Strategy. Several consultation methods (described below) were employed to ensure that as many people as possible were provided an opportunity to contribute to the evaluation.

The national consultation involved workshops and in-depth interviews with a wide range of stakeholders. Urbis sought the perspectives of people living and working in a range of settings, including carers and consumers; Commonwealth, state and territory government representatives; health service policy makers; palliative care clinicians and support workers; representatives of funded projects under the NPCP; academics and researchers; representatives of health services including Primary Health Networks and Aboriginal Medical Services; and representatives of peak bodies. Table 4 provides a summary of the national consultation fieldwork conducted as a part of the evaluation.

TABLE 4 – NATIONAL CONSULTATION FIELDWORK

Evaluation Fieldwork	Outcome
Key informant interviews	7 telephone and face-to-face interviews, with 9 individuals
Workshops	11 half day workshops in 10 locations in all state and territories, with a total of 148 participants
Public online submission portal	20 completed written submissions
Stakeholder interviews	35 in-depth interviews (telephone and face-to-face)

### 2.3.1. Communication and stakeholder engagement strategy

Urbis developed a communications and stakeholder engagement strategy in consultation with the Department. This strategy was developed to provide an open and transparent process that would allow stakeholders multiple avenues for participation in the evaluation.

The Department provided Urbis with contact details for stakeholders and Urbis liaised directly to invite stakeholders to participate in key informant interviews, workshops, in-depth interviews and/or provide a written submission via a public online portal.

Recognising that Aboriginal and Torres Strait Islander Australians have not accessed palliative care services to the same extent as the general Australian population, a specific strategy to consult with Aboriginal and Torres Strait Islander policy representatives, health providers and community members was devised. Individual interviews were conducted with nine Aboriginal health providers and a small workshop in Canberra was attended by four people.

### 2.3.2. Key informant interviews

Nine key informants were interviewed in the initial stages of the project to understand the strategic and policy context of the Strategy, as well as their early perspectives regarding success.

A brief interview guide was developed, covering the critical areas of the evaluation to consider, the documentation and evidence available to inform the evaluation, the critical people to consult and the key barriers and enablers of the Strategy.

### 2.3.3. Stakeholder interviews

A wide range of stakeholders were provided an opportunity to contribute feedback to the evaluation through in-depth interviews (n=44), mainly conducted via telephone. Many stakeholders chose to attend a local workshop rather than participate in an individual interview, although some stakeholders were involved in both an interview and their local workshop.

The purpose of these interviews was to explore more deeply the ways in which local services and organisations have engaged with the Strategy, the impact of the Strategy on local service development and implementation, key achievements of the Strategy, as well as opportunities for future improvement and new or emerging priorities to be considered for the future.

All interviews were conducted in confidence using a tailored interview guide aligned with the workshop questions for consistency. Interviews were conducted face to face where possible, or by telephone, and were recorded manually or with digital recorder with consent from the participant. Key findings from the stakeholder interviews are included within Chapter 4 of this report.

### 2.3.4. Workshops in each jurisdiction

Urbis conducted a series of half-day workshops in each state and territory in July and August 2016.

The workshops provided an opportunity to hear from participants regarding the influence of the Strategy at local, regional and national levels, recognising that states and territories hold authority in planning and designing their palliative care services.

As with the in-depth interviews, the workshops included discussions on the ways in which local services and organisations have engaged with the Strategy, the impact of the Strategy on local service development and

implementation, key achievements of the Strategy, as well as opportunities for future improvement and new or emerging priorities to be considered for the future. Table 5 below provides a summary of the schedule and attendees for all workshops.

TABLE 5 – HALF DAY WORKSHOPS

Date	Location	Attendance
5 July 2016	Sydney	29
14 Jul 2016	Adelaide	14
19 July 2016	Darwin	13
20 July 2016	Melbourne	23
26 July 2016	Brisbane	17
27 July 2016	Townsville	4
27 July 2016	Hobart	5
28 July 2016	Perth	18
4 August 2016	Wagga Wagga	6
4 August 2016	Canberra (Indigenous focus)	4
5 August 2016	Canberra	15
Total workshop participants		148

The participants who attended the 11 workshops included a range of representatives from the palliative care and health sectors:

- state-funded and private palliative care service managers, clinicians, and support workers
- palliative care peak bodies
- state or territory government health services
- local consumer and carer organisations
- commonwealth agency representatives
- funded programs under the National Palliative Care Projects
- Primary Health Networks and primary care clinicians
- palliative care researchers and academics
- NGO community service providers
- Aboriginal health services.

Representatives of the Commonwealth Department of Health attended five workshops as observers.

### 2.3.5. Public submissions

A public online submission portal was developed to invite feedback from the general public, stakeholders who were unavailable to take part on the day of the workshop, those based in rural or remote locations and those who wished to provide more detailed feedback in addition to taking part in a workshop and/or in-depth interview.

The public submission form contained a series of open and reflective questions and was based on the questions explored in the workshops.

The submission website was available during July and August 2016.

20 completed responses were submitted through the online submissions portal or directly to Urbis. Data were analysed and triangulated with other consultation data sources.

## **2.4. ANALYSIS**

The data sources for the evaluation comprised the following:

- evidence review, including a review of the literature and a review of program and policy documentation
- stakeholder consultations, including perspectives gained through workshops, interviews and written submissions.

Findings from the evidence review are included throughout this evaluation report and are also provided as a separate review report.

Key points from the workshops were collected during the meeting using tailored templates, which were then aggregated and compared across all workshops.

In-depth interviews with stakeholders were audio-recorded and transcribed for analysis.

Written submissions, interview transcripts, workshop findings, and findings from the evidence review were analysed thematically and iteratively during a half-day team workshop, at which the emerging themes and the structure for this report were agreed.

### 3. NATIONAL STRATEGIES FOR PALLIATIVE CARE

Palliative care is available in some form to a majority of the world's population, and many countries around the world have developed national strategic frameworks to guide the development and quality of palliative care services (Economist Intelligence Unit, 2015). This chapter explores international best practice and the role of national frameworks in guiding palliative care service development and delivery.

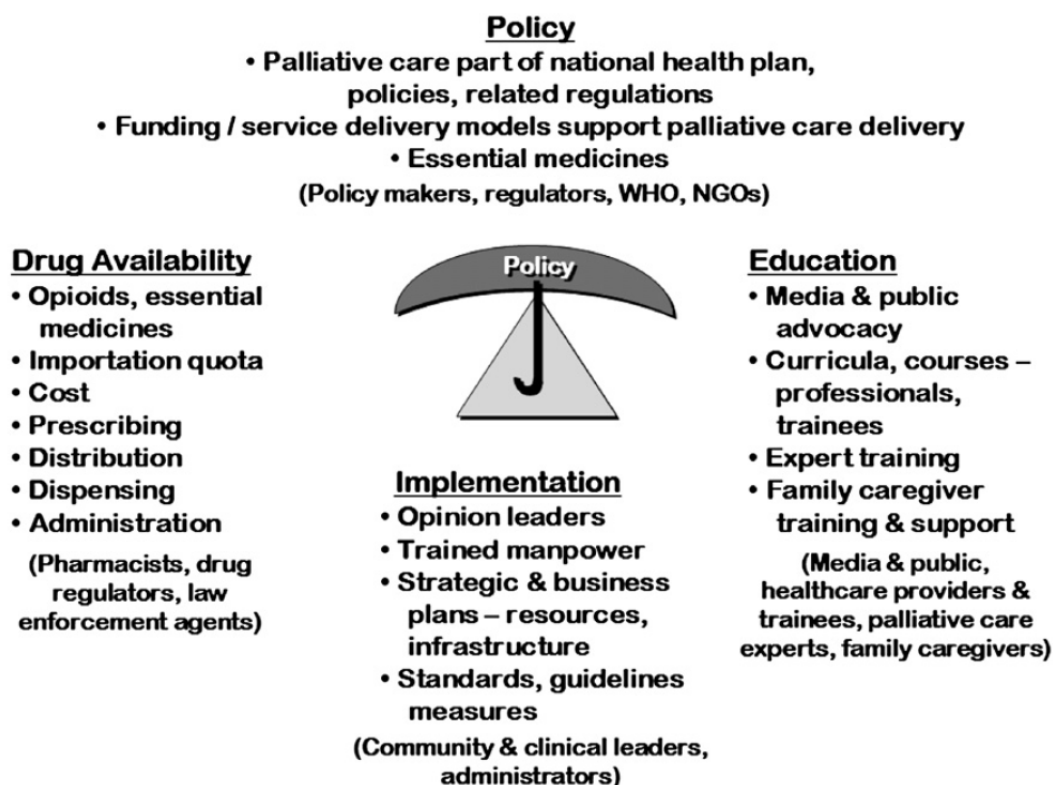
#### 3.1. BENCHMARKS IN INTERNATIONAL PRACTICE

In 1990, the WHO formally recognised the importance of palliative care by establishing a Public Health Strategy on Palliative Care, which included advice and guidelines to governments on how to develop and implement national palliative care programs. This led to the development of a public health model which comprises the following four key domains as a framework for effectively integrating and improving palliative care (European Association for Palliative Care, 2014):

- appropriate policies
- availability of education and training
- availability of drugs
- implementation across all levels of society.

These domains are illustrated in the figure below.

FIGURE 1 – WHO PUBLIC HEALTH MODEL OF PALLIATIVE CARE



Source: European Association for Palliative Care, 2014.

More recently, in 2014 the first international resolution on palliative care called upon WHO and member states to strengthen palliative care “as a core component of health systems”, particularly within primary and community care settings (World Health Organization, 2015). This development led to WHO's commitment to improve palliative care in the following areas:

- “integrating palliative care into all relevant global disease control and health system plans
- developing guidelines and tools on integrated palliative care across disease groups and levels of care, addressing ethical issues related to the provision of comprehensive palliative care
- supporting Member States in improving access to palliative care medicines through improved national regulations and delivery systems
- promoting increased access to palliative care for children (in collaboration with UNICEF)
- monitoring global palliative care access and evaluating progress made in palliative care programmes
- encouraging adequate resources for palliative care programmes and research, especially in resource-limited countries building evidence of models of palliative care that are effective in low- and middle-income settings” (World Health Organization, 2015).

Another important international initiative is the Quality of Death Index, developed by the Economist Intelligence Unit (EIU) (Economist Intelligence Unit, 2015). In 2010, the EIU developed an index to assess the availability, affordability and quality of end-of-life in 40 countries. The methodology enabled EIU to rank the quality of the provision of palliative care at a country level, with an initial report released in 2010.

A follow-up report was released in 2015, expanded to 80 countries, reflecting around 85% of the world's population (Economist Intelligence Unit, 2015). Most Western countries were included in both study years, including Australia, the US, New Zealand, Canada, the UK, the Netherlands and other European countries.

Both study reports provide insights into international best practice regarding palliative care development and implementation strategies and policies. The reports also set out emerging new developments and challenges internationally, as well as examples of successful community-based initiatives and activities.

The indicators used to rank countries in the provision of palliative care are instructive as they suggest the fundamental components of effective palliative care; these are shown in the table below.

TABLE 6 – INDICATORS FOR THE QUALITY OF DEATH INDEX

Palliative and healthcare environment	<ul style="list-style-type: none"> <li>• Healthcare spending</li> <li>• Presence and effectiveness of government-led national palliative care strategy</li> <li>• Availability of research-based policy evaluation</li> <li>• Capacity to deliver palliative care services</li> </ul>
Human resources	<ul style="list-style-type: none"> <li>• Availability of specialised palliative care workers</li> <li>• General medical knowledge of palliative care</li> <li>• Certification for palliative care workers</li> <li>• Number of doctors per 1,000 palliative care-related deaths</li> <li>• Number of nurses per 1,000 palliative care-related deaths</li> </ul>
Affordability of care	<ul style="list-style-type: none"> <li>• Availability of public funding for palliative care</li> <li>• Financial burden to patients for available palliative care services</li> <li>• National pension scheme coverage of palliative care services</li> </ul>
Quality of care	<ul style="list-style-type: none"> <li>• Presence of accreditation and monitoring standards for organisations</li> <li>• Availability of opioid painkillers</li> <li>• Availability of psychosocial support for patients and families</li> <li>• Presence of Do Not Resuscitate (DNR) policy</li> <li>• Shared decision making</li> <li>• Use of patient satisfaction surveys</li> </ul>
Community engagement	<ul style="list-style-type: none"> <li>• Public awareness of palliative care</li> <li>• Availability of volunteer workers for palliative care.</li> </ul>

In the 2010 and 2015 reports, Australia was highly regarded in the quality of palliative care as demonstrated by its ranking as one of the top three countries in almost every indicator (Economist Intelligence Unit, 2015). The reports' value lies in the international comparison and the analysis of what elements are required at a strategic and systemic level to ensure that palliative care services are able to provide effective and accessible care.

## 3.2. INTERNATIONAL BEST PRACTICE

As noted earlier, the Quality of Death Index provides insights in international best practice regarding palliative care development and implementation strategies and policies. Evidence suggests that countries with high quality of death ratings shared several key characteristics, including:

- “a strong and effectively implemented national palliative care policy framework
- high levels of public spending on healthcare services
- extensive palliative care training resources for general and specialised medical workers
- generous subsidies to reduce the financial burden of palliative care on patients
- wide availability of opioid analgesics
- strong public awareness of palliative care.” (Economist Intelligence Unit, 2015).

Countries other than Australia that were also ranked highly on these characteristics included the United Kingdom, the Republic of Ireland, the Netherlands and New Zealand. The sections below provide a snapshot of recent key activities undertaken in these four countries.

### 3.2.1. The United Kingdom

In 2010 and 2015, the United Kingdom (UK) ranked highest in the EIU Quality of Death Index. Strengths of the UK palliative care system included:

- comprehensive national policies
- extensive integration of palliative care into the National Health Service (NHS)
- a movement towards integrating hospice care more deeply into the healthcare system
- a strong hospice movement, much of it supported by charitable funding
- strong government engagement (Economist Intelligence Unit, 2015).

The WHO also viewed the national palliative care approach in the UK as good practice, particularly in relation to the inclusiveness reflected in the 2008 national strategy: *“a whole-system and care-pathway approach is a key feature of the End of Life Care Strategy. Services are for everyone, regardless of diagnosis and care setting”* (World Health Organization, 2011:14). Another strength of the national approach, as identified by the WHO, was the evidence-based approach, with themes in the strategy based on the best available research evidence from a range of key service providers and relevant programs, including voluntary hospices and the NHS End of Life Care Programme (2004-2007).

At the time of writing, the UK delivers palliative care under a national framework, released in 2015 (*Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*). This framework was developed by the National Palliative and End of Life Care Partnership, aimed at local health and social care and community leaders (NHS England, 2016).

The framework replaces the Department of Health's 2008 Strategy for End of Life Care and responds to increased emphasis on local decision making in the delivery of palliative care services.

An important key element in the framework is to integrate specialist-level palliative care services as an “integral part” of the overall provision of care.

As set out in Table 7, the framework comprises six overarching “ambitions” which lead towards one overarching vision.

TABLE 7 – AMBITIONS FRAMEWORK

Key ambitions	Overarching vision
1. Each person is seen as an individual	<i>“I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).”</i>
2. Each person gets fair access to care	
3. Maximising comfort and wellbeing	
4. Care is coordinated	
5. All staff are prepared to care	
6. Each community is prepared to help	

Source: NHS England, 2016.

The most notable aspect of this framework is that it is constructed from the perspective of the patient, rather than the service system. This is unique as far as is known among countries, but perhaps demonstrates the continuing evolution of the health system from service-centric to patient-centric.

### 3.2.2. The Netherlands

The Netherlands were also highly regarded by the EIU in terms of a strong and effective presence of a government-led palliative care strategy.

In 2014, the Dutch Government committed a total of 51 million euros to a new national palliative care program from 2014 to 2020. The program was developed by ZonMw (The Netherlands Organisation for Health Research and Development) and endorsed by the Dutch Ministry of Health, Welfare and Sport in 2014 (Ross, 2015).

Compared to previous national programs, the current program is viewed as “wider and more comprehensive” by including a focus on coherence between practice, education and research (Ross, 2015).

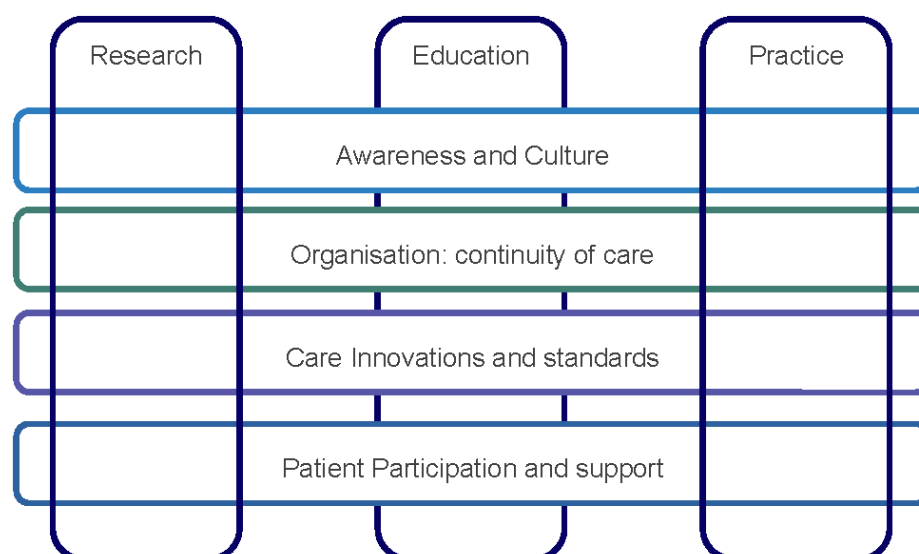
The program aims to accelerate “improvements in care practice”, and envisions that “palliative care should be:

- based on the needs and wishes of patients and their families
- part of regular healthcare provision
- arranged as close to home as possible” (ZonMw, 2015).

The program is underpinned by the NPPZ matrix (National Palliative Care Program), which were identified by key experts and stakeholders as essential elements in quality palliative care (ZonMw, 2015).

The matrix encompasses three activities: research, education and practice. These activities are set out across four key themes: awareness and culture, organisation - continuity of care, care innovations and standards and patient participation and support (see Figure 2).

FIGURE 2 – THE NPPZ MATRIX



Source: ZonMw, 2015

The program describes overarching goals to be achieved by 2020, and more specific goals to be reached for the first two years of the program (2015-2016).

### 3.2.3. Republic of Ireland

The Republic of Ireland is also highly regarded in the Quality of Death Index in relation to governance and national strategies. At the time of writing, Ireland's most recent national strategy was the *Palliative Care Services - Five Year/Medium Term Development Framework* (the Framework) for the period 2009-2013. While the timeframe of this framework appears to have lapsed, several initiatives in the last decade indicate continuing strong governance involvement and leadership in shaping and directing the provision of palliative care.

Firstly, with the 2009-2013 Framework, the Government committed to 41 palliative care priorities to address the four service provision categories: home care deficits, specialist in-patient bed deficits, capital developments and acute hospital support (also see Table 8).

TABLE 8 – FOUR SERVICE PROVISION CATEGORIES WITHIN THE FRAMEWORK FOR 2009-2013

National Actions for Palliative Care Service Provision	Completion Timeframe				
	2009	2010	2011	2012	2013
	Number of National Palliative Care Actions per year				
Priorities relating to <i>Home Care</i> Deficits	4	2	2	2	2
Priorities relating to <i>Specialist In-Patient Bed</i> Deficits	2	2	1	1	0
Priorities relating to <i>Capital Developments</i>	1	0	2	2	10
Priorities relating to <i>Acute Hospital Support</i>	0	0	3	3	2
Total	7	4	8	8	14

Source: (Health Service Executive, 2009)

Another important development in the Irish palliative care system is the partnership between the Irish Hospice Foundation, the Irish College of General Practitioners (ICGP) and the Health Service Executive (HSE) in 2009 to jointly develop a program to support the development of primary palliative care in Ireland. This collaboration was formed in recognition of a growing awareness that most people prefer to receive palliative care services in the home (The Irish Hospice Foundation, 2011).

### 3.2.4. New Zealand

At the time of writing, the most recent national palliative care strategy in New Zealand dates from 2001, and as stated by the New Zealand Palliative Care Council, appears to have lapsed (Trainor & Naylor, 2012). However, New Zealand is highly regarded in terms of the presence of a governance-led national approach in palliative care (Economist Intelligence Unit, 2015). Recent key activities suggest that a national approach on palliative care is evident, particularly in the release of two national frameworks, discussed below:

#### Palliative care outcomes framework

In 2012 the Palliative Care Council of New Zealand (PCC) developed a national palliative care outcomes framework, in consultation with the Ministry of Health and Hospice New Zealand. The framework was developed as a resource to inform the development of a new national strategy to replace the 2001 strategy, and in recognition of a lack of strategic direction in the provision of palliative care.

The framework uses the principles of outcomes management, an approach *“to planning and managing projects that helps organisations to be clear about what their projects are doing, as well as what they are changing”* (Trainor & Naylor, 2012:8). Importantly, this approach enables organisations to demonstrate value for investment which is particularly relevant for accountability when public funds are spent.

The overarching aim of the framework is to allow organisations to monitor progress and outcomes, and to measure whether desired outcomes have been achieved. The framework provides a strategic view and sets out desired outcomes and impact of activities for the palliative care sector.

Whilst the framework has been developed by national leading bodies in palliative care, the document appears to be an optional resource for organisations to use.

#### Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand

In the same year (2012) as the release of the palliative care outcomes framework, the New Zealand Ministry of Health also released a framework for the provision of integrated adult palliative care. This framework was developed in recognition of a *“common lack of understanding about what makes up specialist palliative care services, which affected the strategic development of palliative care services”* (Ministry of Health, 2012:V).

With the framework, the Ministry of Health aimed to differentiate services by level of complexity to reach more consistent access to and purchasing of palliative care services.

The framework informed the refinement of the Specialist Palliative Care Service Specifications, used by District Health Boards (DHBs) to purchase services. The framework identified the following two key recommendations specifically for DHBs:

- DHBs should use the framework to inform strategic planning and development of palliative care services
- DHBs should consider population palliative care needs during regional clinical service planning.

Funders and policy makers can use the framework to inform strategic planning and purchasing of accessible and equitable palliative care services.

It is also important to note that New Zealand ranked highest in the 2015 EIU Quality of Death Index in terms of community engagement. This indicator assessed a nation's performance in public awareness raising of palliative care, and supporting volunteer workers in palliative care delivery. This finding appeared to be a result of the strategic plan of Hospice New Zealand (2013-2015), which formulates community engagement as one of the five key goals (Hospice New Zealand, 2014).

### 3.3. EMERGING CHALLENGES

Around the world, countries are facing a growing and ageing population, leading to increasing demands on health care systems. This single demographic change, coupled as it is with increases in longevity and longer periods of failing health, will put heightened pressure on palliative care services in the future (Economist Intelligence Unit, 2015).

In light of this, the EIU states that for wealthy nations, a shift in culture is needed to focus more on managing long-term illness in palliative care, rather than on curing illness. This will require a change in health investment and planning as the traditional model of acute hospital care will need to be augmented by different service environments, including home-based care, respite and short stay care, nursing home care, and hospice care. This shift will take time and will require considerable planning and investment as well as public education of the changing role of the health system within society. While this transition will be costly, there is evidence of the comparatively lower cost of providing community-based care as opposed to acute care, and in the potential to reduce acute hospital stays and avoid unplanned emergency room visits (Economist Intelligence Unit, 2015).

The EIU identified a range of interventions that could assist in improving the quality of care, including:

- creating a legislative framework that provides for easier access to painkillers such as opioids and training healthcare workers to administer these drugs
- creating mechanisms that make palliative care more affordable for those that need it
- integrating some level of palliative care training into the education of all healthcare professionals
- increasing access to home- and community-based palliative care
- providing support for the families and voluntary workers who can extend access to care
- increasing public awareness of palliative care
- encouraging more open conversations about death and dying (Economist Intelligence Unit, 2015).

While Australia ranks highly among the countries surveyed by the EIU, these interventions remain applicable to the Australian context. A summary of emerging challenges, for Australia but also common globally, is provided below.

#### 3.3.1. A changing Australian population

Between 2009 and 2014, the Australian population increased yearly by around 400,000 people (Krockenberger, 2015). Forecasts indicate that this trend will continue in the coming decades. Based on an estimated population of 22.7 million people in 2012, it is expected that the Australian population will increase to between 36.8 and 48.3 million people by 2061 (Australian Bureau of Statistics, 2013).

With a growing population, Australia's life expectancy has also increased steadily in the last decades, and it is expected to continue in the future. For instance, male life expectancy was estimated at 55 years between 1901 and 1910, compared to 80 years in the period 2009-2011. Life expectancy for females increased from 59 years to 84 years between the same periods (Australian Bureau of Statistics, 2013).

It is also expected that the proportion of older Australians (aged 65 years and over) will increase in the future. In 2012, older Australians represented 14% of Australia's population, and forecasts predict an increase to 22% in 2061 and to 25% in 2101 (Australian Bureau of Statistics, 2013).

A growing and ageing population is predicted to lead to increasing demands on the Australian health system, as advances in technology and understanding are assisting people to live longer with a range of debilitating but not life-threatening chronic diseases (Department of Health and Ageing, 2010).

According to the definition of the Australian Institute of Health and Welfare (AIHW), chronic diseases cover a wide spectrum and can range from mild to more severe conditions, including cardiovascular conditions, cancers, mental illness, diabetes and respiratory diseases (Australian Institute of Health and Welfare, 2016). This broad definition is reflected in the significant high rate of chronic diseases as the leading cause of death as, according to the AIHW, chronic diseases accounted for 90% of all deaths in Australia in 2011 (Australian Institute of Health and Welfare, 2014).

This high rate could partly be explained by including cancer in the definition of chronic diseases, particularly when considering that cancer is already a common diagnosis for which Australians receive palliative care. In 2013-2014, cancer was the most common principal diagnosis (53%) for Australian palliative care hospitalisations, and forecasts predict a sharp rise in the incidence rate of diagnosed cancer in the future. More specifically, the Australian Institute of Health and Welfare estimated that between the years 2007 and 2020, the prevalence of diagnosed cancer will rise by nearly 40% (from 108,368 to around 150,000 respectively) (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, 2010; Australian Institute of Health and Welfare, 2012).

Within this context, it is not surprising that chronic diseases have a significant impact on the Australian health system. For example, in 2008-2009, the Australian health system expenditure included \$7.74 billion for cardiovascular disease, \$6.38 billion for mental health, \$5.67 billion for musculoskeletal conditions and \$4.95 billion for cancer (Willcox, 2014).

### **3.3.2. Challenges within the Australian Palliative Care system**

In 2012, the Commonwealth Senate Community Affairs References Committee (the Committee) reviewed the Australian palliative care system, and highlighted important challenges facing the Australian Government in the provision of palliative care.

The Committee recognised these challenges were partly a result of the complex and multidisciplinary nature that the provision of palliative care generally requires. Palliative care is not only applicable for older people, but for Australians from all age groups who face a life-limiting illness. Moreover, disease trajectories associated with a variety of life-limiting illnesses require flexibility in service delivery approach, and may take place in a variety of settings, such as hospitals, residential aged care facilities and within the home.

In addition, recipients of palliative care may include others beyond the individual with a life limiting illness, such as carers and family members, reinforcing the requirement for a tailored approach for each palliative care patient.

Overall outcomes of the Inquiry showed many successful palliative care activities and initiatives had been undertaken, but that the palliative care system delivery “as a whole” was fragmented, and complex in nature. Importantly, the report raised concerns in relation to variation in the quality of palliative care available to Australians, as well as a level of unmet need for Australians who require palliative care.

A total of 38 recommendations were formulated, mainly in relation to strengthen and improve governance and funding, system and processes and workforce capability. A summary of key issues identified by the Committee is provided below.

### **The palliative care funding model**

Funding of the Australian health system is governed by a range of agreements negotiated between the members of the Council of Australian Governments (COAG); the Commonwealth and the states and territories share responsibility in funding and providing health care services.

Under the current system, the Commonwealth provides funding to the states and territories for the provision of palliative care, while the states and territories take responsibility for the delivery of palliative care. The Committee suggested that the Australian palliative care funding framework is a contributor to inconsistencies in the standard of the provision of palliative care.

Importantly, the Committee found there were no appropriate mechanisms in place to review how states and territories allocate government funding. In particular, stakeholders who participated in the Inquiry commonly raised a need for more transparency in the allocation of “bundled” funding.

The Committee highlighted the need for more flexibility in funding arrangements given the diverse settings in which palliative care may be provided. It also recognised the need for appropriate mechanisms to enhance transparency in palliative care funding, especially to determine whether services are provided with appropriate levels of funding to meet local need.

The evidence provided to the Committee suggested the need for greater inclusion of the community sector in formal funding arrangements. The Committee found evidence of lower costs for community-based palliative care compared to a hospital setting, and stakeholder feedback highlighted a strong preference among Australians to die at home or in a community setting (including residential aged care), suggesting the need for a greater focus on community-based services (Senate Community Affairs References Committee, 2012).

It should be noted that the Committee does not consider dying at home as a *better* option than in the hospital, but it does emphasise that peoples' preferences should be met where possible.

## **Dying outside a hospital setting**

As noted previously, evidence suggested that peoples' preferences in palliative care services were not always being met, particularly in relation to the setting in which people prefer to die (e.g. dying at home rather than in hospice). Recent literature also shows that in Australia, receiving palliative care in a hospital setting is much more common than in the home (Carers Australia, 2014; Swerissen & Duckett, 2014). The Committee recommends an increase in the capacity to support palliative care in the home and other community settings (e.g. aged care facilities) and to reduce the demand on transfers to the hospital system. Ultimately, this change is expected to improve the patient experience, as well as the experience of the carers and family members involved.

## **The palliative care workforce**

The Committee identified an undersupply in the Australian palliative care workforce. During the Inquiry, the Australian and New Zealand Society of Palliative Medicine (ANZSPM) recommended a ratio of one specialist per 100,000 population, while the 2014 Australian palliative care workforce only comprised half of this number (this accounted for a total of 192 palliative medicine physicians).

In addition, there has been little increase in the number of palliative medicine physicians over time. Data published by the AIHW indicate that between 2009 and 2014, the total number of specialist palliative medicine physicians in Australia only increased by 20 specialists in total (Australian Institute of Health and Welfare, 2016; Australian Institute of Health and Welfare, 2012).

An undersupply of the palliative care nursing workforce is also reflected in national data. Between 2009 and 2014, national data indicates a decrease in the palliative care nursing workforce. In 2009, around 5,173 nurses worked principally in the area of palliative care nursing compared to 3,269 in 2014 (around 1,900 nurses less than in 2009). However, these numbers should be considered with caution, due to possible changes in required qualifications for nurses working in palliative care.

The Committee stressed that in anticipation of an ageing and growing population, a larger national palliative care workforce is needed. The Committee strongly recommended greater awareness and knowledge of the principles of palliative care across the entire health workforce, and not just among specialist palliative care providers. This should be facilitated through undergraduate and postgraduate curriculums, as well as through the provision of ongoing training and education of health professionals, especially within the nursing workforce.

## **Accessing care**

Many stakeholders who participated in the Inquiry described the palliative care system as fragmented, and identified this fragmentation as a barrier for patients and families in accessing the services they need. Also, there was evidence of variation in care available between states and territories, and the Inquiry highlighted a growing concern in disparity of care provision between urban and rural settings.

The Committee found evidence of difficulties patients and families may have in accessing the right support and treatment services, as well as accessing the right equipment that is needed for the patient.

Evidence also suggested difficulties in accessing care may be even more profound among younger individuals. The Committee noted many palliative care services were offered within aged care settings, and that younger people who do not meet the age requirements of government-funded programs are at risk of "falling through the cracks".

## **Culturally appropriate care**

The Committee identified cultural appropriateness of care as an issue, particularly within Aboriginal and Torres Strait Islander settings. Evidence suggested a lack of cultural knowledge around death and dying among the Australian health workforce, as well as providing appropriate points of access to care for Aboriginal and Torres Strait Islander people. In addition, the Committee recognised the need for more culturally and linguistically appropriate services to people from migrant and ethnic communities, recognising the likely increase in migration in the 21<sup>st</sup> century.

## Support for family and carers

Evidence before the Committee also highlighted the need for improvement in services for carers. This included improvements in service access to support and information, as well as enhancement of respite services and bereavement support after a patient's death. The Committee also identified education and training as an area for improvement, particularly when considering the involvement of volunteers in various community palliative care settings.

In addition, the Committee acknowledged the *“crucial role played by carers in relieving additional healthcare cost burdens on governments and society”* (Senate Community Affairs Reference Committee, 2012:82). In light of this, the Committee recommended changes in funding models to better reflect the unpaid hours that carers spend on the delivery of palliative care.

## Advance care planning

The Committee recognised the value of advance care planning to enable individuals to take control of their own circumstances during the last stages of their life. The Committee found a lack of consistency between jurisdictions in regard to governing advance care directives (ACDs), resulting in different adaptations of ACDs across the country. Ultimately, these legal differences between jurisdictions were found to have affected the uptake of advance care planning.

Interestingly, the Committee referred to the National Framework for Advance Care Directives, which was launched in 2011 to work towards a mutual recognition of ACDs across jurisdictions through nationally agreed terminology. However, at the time of the Inquiry, evidence suggested the work undertaken under the Framework had not gone far enough.

Within this context, the Committee identified a strong need for nationally consistent legislation for advance care directives to enhance the uptake of advance care planning. It also suggested the need for a Government-funded national awareness campaign around advance care planning and directives.

Findings also highlighted the need for more education and training in issues relating to advance care planning. In particular, the limited funding available for staff was noted, including staff who are expected to provide education to others, both service providers and service users. In light of this, some of the Committee's recommendations included the integration of advance care training as a component of the aged care accreditation standards, as well as an increase in funding to the Respecting Patient Choices project to support the development of training providers.

## 3.4. SUMMARY

Overall, the literature review has found that Australia provides high quality palliative care services which are generally accessible and affordable, when compared to other countries. Australia ranks second only to the UK in an international comparison of the provision of palliative care. This is something to be acknowledged and celebrated.

The key elements for good palliative care, identified throughout the literature, and in the EIU's analysis, are all present within the Australian health system:

- jurisdictional policy frameworks
- public spending on health services
- training for general and specialist health workers
- a form of national or social insurance to reduce the financial burden for families
- availability of analgesics
- public awareness.

At the same time, there are opportunities for improvement in relation to a number of continuing and emerging challenges facing Australia, and other countries; these must be addressed if Australia is to continue to provide the level and quality of service which will be required in the future. These challenges can be summarised as follows:

- stakeholders reported that inconsistent public investment and service provision across all jurisdictions, and between metropolitan and rural locations, hindered access to palliative care for segments of the population
- a continuing reticence within society to discuss death and dying, coupled with varying levels of awareness of what palliative care services can offer to people at the end of life
- an acknowledged undersupply of specialist palliative care clinicians, and unknown levels of understanding of the palliative approach amongst generalist clinicians
- the ageing population, who will be living for longer with life-limiting illnesses, creating a corresponding increase in the demand for palliative care services.

Australia has a strong foundation based on decades of investment and leadership in palliative care policy, research and services. Continued leadership, commitment and investment will be required to ensure that all Australians are able to achieve a good death.

## 4. FINDINGS

### 4.1. INTRODUCTION TO FINDINGS

Since the introduction of the Strategy in 2010, progress has been made in relation to all goal areas. A brief summary of headline findings is presented in Table 9 below, reflecting the data collected through the evidence review and consultation with 148 workshop participants and 44 interview participants.

Palliative care is a diverse and complex sector, with policy responsibilities at both the Commonwealth and State levels. While a number of achievements are evident across states and territories in line with the Strategy, the extent to which they can be directly attributed to the Strategy is unclear. That is, participants were often not able to attribute the extent to which the Strategy provided policy direction or drivers for the development or continuation of relevant initiatives. The question of attribution is discussed further in section 4.1.3, when discussing the extent to which the Strategy has provided direction and an authorising environment for policy and service improvement.

Stakeholders reported numerous examples of positive outcomes from the projects and activities funded under the NPCP, many of which are cited in this chapter. The NPCP represents the Commonwealth's continuing investment in improving the quality of palliative care, through support for research and evidence dissemination, education and training, and the development of resources and information tools. While not funded under the Strategy, the NPCP is intended to align with the goals of the Strategy, and this evaluation will consider the NPCP's contribution to furthering the goals of the Strategy.

TABLE 9 – SUMMARY OF KEY FINDINGS UNDER THE STRATEGY GOAL AREAS

Goal area	Key findings
Awareness and understanding	<p>Increase in general community awareness of palliative and end-of-life care</p> <p>Increase in grassroots-driven awareness raising and localised initiatives, noting this is “patchy” and less prevalent in some communities than others, where reluctance to discuss and taboo continue to surround death and dying</p> <p>Increase in awareness of Advance Care Planning</p> <p>Increase understanding among health professionals of the palliative approach</p>
Appropriateness and effectiveness	<p>Promotion of nationally consistent guidelines through the National Consensus Statement and Palliative Care Australia's National Palliative Care Standards</p> <p>Improvement in data collection, notably through the Palliative Care Outcomes Collaboration (PCOC), though data issues remain</p> <p>Inconsistent improvement in access to palliative care across the country</p>
Leadership and governance	<p>Some evidence that the Strategy is used as a leverage tool to create an authorising environment for improved palliative care</p> <p>Some consistency across governments in approach to palliative care and other health priorities, notably chronic disease and aged care</p> <p>At its establishment the Strategy had high-value governance structures, the benefits of which have dissipated since the disbanding of the Palliative Care Working Group</p>
Capacity and capability	<p>Significant investment in workforce capability and capacity development in both specialist and generalist settings</p> <p>Innovative service models occurring in some places</p>

The subsequent sections of this chapter present findings regarding progress under each of the Strategy's goal areas, including the identification of achievements that can be attributed to the Strategy itself, noting the challenge of attribution, as discussed above.

### 4.1.1. Awareness and understanding

Goal 1: To significantly improve the appreciation of dying and death as a normal part of the life continuum.

Goal 2: To enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to, palliative care services.

#### Community awareness

During the life of the Strategy, most stakeholders reported an increase in the general community's awareness of palliative and end-of-life care. In all states and territories, participants provided examples of activities and projects undertaken at the local, jurisdictional and national level which had contributed to progress against the two awareness and understanding goals.

At the national level, the program of activity surrounding National Palliative Care Week is considered to provide a positive contribution to community awareness and understanding. National Palliative Care Week activity has typically included a range of events, expos, launches and forums supported by a media and PR campaign. Despite noting the positive contribution of the National Palliative Care Week, many stakeholders believe more could be done to boost awareness and understanding of palliative care via public communications.

At the local level, a range of community-led initiatives are providing spaces for people to discuss death and dying. The GroundSwell Project, a not-for-profit organisation, was mentioned by a number of stakeholders as providing a positive contribution to the improvement in death literacy in the community. The GroundSwell Project has established *Dying to Know Day* as a national day of action to encourage local events relating to death literacy, many of which approach the topic via community development activities. Stakeholders also commented on the growth in Australia of global movements such as “death cafes”, which are events that provide opportunities for people to come together locally to discuss death, dying and bereavement. These take a number of forms, and include events which have light-hearted names to help reduce the stigma around dying, such as “Die-alogue Café”, “Death by chocolate” and “Death over dinner”.

*There aren't end points and I think that is and remains a very key challenge particularly for government which wants to be able to tick things off and move things on. I think so much has progressed in genuinely improving the community conversation and I think one of the nice areas is there are more organisations that are taking those conversations forward. It's not just palliative care there are broader community groups who are now saying actually this is really important to us. (NPCP grant recipient)*

A number of Department of Health-funded projects including those under the NPCP were identified to have contributed positively to an increase in information available about palliative care. CareSearch is valued as a key enabler of palliative care awareness and understanding through the provision of palliative care information and advice to a range of audiences including consumers and health professionals. This includes the Dying2Learn MOOC (Massive Open Online Course) run by CareSearch, which had over 1,100 students enrolled for its first course.

Advance Care Planning (ACP) was given a prominent place in the Strategy, which has reportedly heightened awareness of the need to promote the uptake of ACP among clinicians. Stakeholders familiar with the National Advance Care Planning Conference valued the range of information and resources developed through research and projects funded by the Commonwealth, including Respecting Patient Choices. ACP was seen broadly as an important tool to assist with planning at the end of life stages, with a few stakeholders using the analogy that a “good death” plan is just as important as a “good birth” plan.

Another frequently cited project contributing to palliative care understanding was the Decision Assist project, also funded by the Department, which aims to provide advice and support to health professionals (primarily GPs) and aged care staff regarding palliative care and advance care planning. Decision Assist<sup>2</sup> is managed by a consortium led by Austin Health and includes a telephone advice line, a website with information including clinical guidelines and other resources, and tele-health apps. This program was considered to be a

<sup>2</sup> See <https://www.caresearch.com.au/caresearch/tabid/3104/Default.aspx>

good example of an enabler to improve awareness and understanding of palliative care for health professionals and the aged care sector.

*The decision assist program I think has been the most innovative thing that's been offered. (palliative care clinician)*

The lack of available data to measure and track the uptake and the use of ACPs by patients and health professionals was noted by some stakeholders as a barrier to the achievement of the action items relating to ACP. It is also of note that stakeholders cited the potential risk of focusing on ACP without embedding the systems needed to respect consumers' wishes at the point of implementation. An example of this was when the ACP document and service delivery are not aligned, risking a significant impact on trust in the system. Improvements in practitioners' knowledge and capacity to implement effective palliative approaches are discussed below and in section 4.1.4.

The Strategy's strong focus on awareness and understanding represented a significant change in the direction of palliative care policy when it was released in 2010. One stakeholder with expertise in death literacy commented that the prominence of these goals in the Strategy has enabled a shift towards discussions around death and dying and positioning the concept of a "good death". A number of stakeholders noted that demographic factors, such as the ageing Australian population and the increase in length of time that people may now live with chronic and life-limiting disease, are likely contributing to an increased awareness in palliative care and end-of-life decision making.

However, stakeholders believed that there are still significant barriers to changing attitudes towards death and dying in Australia. There are still some population groups where stakeholders believe that the reach of awareness and understanding initiatives has been less successful, notably Aboriginal and Torres Strait Islander Australians, and people from culturally and linguistically diverse (CALD) backgrounds.

Aboriginal and Torres Strait Islander palliative care practitioners noted the importance of being explicit about aims for Aboriginal and Torres Strait Islander people within the Strategy in order to drive improvement. The lack of specific reference to issues facing Aboriginal and Torres Strait Islander peoples at the end of life and the barriers to accessing care led some people to reflect that the Strategy development process had not included sufficient engagement with Indigenous Australians.

There remains a significant lack of understanding and awareness among health professionals, according to some evaluation participants, regarding the emotional and social needs, as well as physical needs, of Aboriginal and Torres Strait Islander peoples at the end of life. Greater sensitivity is required among specialist palliative care providers regarding the importance of dying on country, the importance of family involvement, and cultural protocols around death and dying.

*End of life is a sacred part of our life and it isn't for everybody to know. [Health professionals] need to know it is an incredibly sacred time. (Indigenous outreach worker)*

At the same time, reportedly Aboriginal health worker training does not include mandatory palliative care modules, and this means that many health workers are not aware of what services and assistance may be available to people as they approach the end of life. Aboriginal evaluation participants did suggest that awareness of the Strategy itself was low among Aboriginal and Torres Strait Islander health providers and that this suggested that awareness among Indigenous communities would be low as well.

## **Professional awareness**

Activity under this goal area has also produced an increase in education among the generalist health and human services workforce about the importance of a palliative approach at the end of life.

*I do think that there is a greater awareness and understanding of palliative care. I think that there has been a greater attention to building capacity across a number of those different sectors that we talked about and I suppose overall that I would see it as now recognised as part of health care that isn't just nice to have, it's something mainstream now more than what it was even in 2010. (academic)*

There is some evidence that this approach is being embedded throughout a health professional's education and work life. The coordinated approach to undergraduate education, particularly through the Palliative Care Curriculum for Undergraduates (PCC4U) project, is a clear step towards embedding the palliative approach as part of all health professionals' awareness and understanding, and was commended by stakeholders.

The Program of Experience in the Palliative Approach (PEPA) was frequently mentioned by stakeholders as a program that provides practicing health professionals with valuable work experience opportunities. Over 3,500 health professionals have participated in PEPA since 2003<sup>3</sup>, and while PEPA appears to be highly regarded by stakeholders, the extent to which this and other educational initiatives reach those who are most in need of education is unclear, as it may be that people undertaking the training are already those with an interest in palliative care and a desire to improve their practice. Likewise, while new additions into the medical and health curricula will raise awareness and understanding among new graduates, the extent to which older health practitioners are expanding their knowledge of palliative care is unclear. Cumulatively, it seems reasonable that over time this will raise the overall levels of awareness among the medical and health professions overall.

Initiatives to increase awareness and understanding prioritise the importance of professionals' death literacy and their ability to talk to patients about death and how to approach it, such as ACP. As a result, a number of stakeholders could point to increased awareness in the acute setting of the palliative approach. Stakeholders in NSW and the NT pointed particularly towards improvements in the attitudes of oncologists in relation to palliative care.

Stakeholders also identified an increase in knowledge among other health specialities, with an understanding that palliative care was not simply for people with cancer, but was relevant for other disease profiles, including dementia and chronic disease. When the Strategy was written, the emphasis on non-malignant disease was an innovation in palliative care in Australia, expanding the approach from its traditional place in cancer care.

Professional events such as the Australian Palliative Care Conference were also discussed as activities that have contributed positively towards improving awareness and understanding amongst health care professionals.

However, stakeholders reported inconsistency in the increase in knowledge and understanding, and that over-medicalisation at the end of life persists at all levels of health provision. Often this is because there is lack of understanding that appropriate pain and symptom management can be provided without continuing aggressive treatment.

In particular, several stakeholders commented on the role of paramedics, often the frontline staff responding to a patient who needs additional support. Some stakeholders stressed the need for greater knowledge and awareness among paramedics and support for them to make decisions. In direct contrast, some stakeholders held the view that paramedics should not exercise discretion about, for example, whether to transfer a palliative patient from home to hospital, even when an ACD or DNR order is in place.

Additionally, some stakeholders mentioned that overseas trained doctors (OTDs), especially those with different cultural norms around death and dying, were not necessarily aware of the palliative approach as endorsed in Australia, particularly with regard to the use of opioids and other medications for pain and symptom management. This is potentially an area of risk given the important role that OTDs play in the delivery of primary care particularly in rural areas, and as providers of after-hours GP services. Stakeholders noted that the Strategy has value in providing a reference point for cultural and practice norms for doctors newly arrived to Australia.

Examples and further opportunities to collaborate with partners outside of the health sector were discussed, for example with the community development sector to understand how change occurs at the community level. In some cases collaborative work is already underway, and in others, the value of such work is seen by stakeholders as an opportunity. One stakeholder commented that clinical staff and health professionals have an important role to play in delivering high quality care; however, they are not necessarily best placed to effectively drive community awareness activities.

*...it's really, really hard for health and medical people to think in community development terms. So I think co-creation models are really important but there would be a priority need to help people develop an understanding of how to do co-creation in the community. (palliative care advocate)*

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<sup>3</sup> See <http://www.pepaeducation.com/about/outcomes-research.aspx>

TABLE 10 – PROGRESS AGAINST ACTION AREAS

Action areas	Progress
1. Develop a comprehensive, evidence based, multi-modal and targeted national public awareness strategy to promote death as a normal part of living and promote the services and options available for people nearing the end of life.	Public awareness activities have been undertaken by a wide range of organisations and community groups but not as a comprehensive and national approach.
2. Promote collaborative integration of health and human services and increase the visibility of end of life issues, palliative care and roles and responsibilities.	All jurisdictions have undertaken activities which align with this statement. It is unclear the extent to which this activity was driven by the Strategy.
3. Provide mechanisms to ensure palliative care providers across the continuum are aware of, and provide, culturally appropriate palliative care and end of life support including care preferences, spiritual requirements and bereavement expression.	All jurisdictions have undertaken activities which align with this statement. It is unclear the extent to which this activity was driven by the Strategy.  The Commonwealth (through the NPCP) has supported Cabrini Health in the development of an online resource for the ethical conduct of religious and cultural advance care planning.
4. Support the national roll out of Advance Care Planning across all sectors (primary, acute, aged care) including addressing any barriers to uptake.	All jurisdictions have undertaken activities which align with this statement. The Commonwealth supported the development of a National Framework for Advance Care Directives in 2011, and provides funding for a number of projects to support ACP, including Respecting Patient Choices, Decision Assist, HammondCare's training package for nurses, CareSearch and Cabrini Health's online resource noted above.
5. Encourage the integration of palliative care training within all health undergraduate and relevant post-graduate curricula.	Palliative Care Education and Training Collaborative (PCETC) (previously PCC4U) continues to work with universities to increase the visibility of palliative care within the undergraduate curricula. Flinders University was funded under the NPCP to develop education modules for the acute hospital setting.

#### 4.1.2. Appropriateness and effectiveness

Goal 3: Appropriate and effective palliative care is available to all Australians based on need.

##### National policy

Stakeholders noted that a key contribution to achieving appropriate and effective palliative care was the development of consistent national approaches to palliative and end-of-life care. Among these was the publication of the *National Consensus Statement: Essential elements for safe and high-quality end-of-life care* published by the Australian Commission on Safety and Quality in Health Care in 2014. This document sets out guidelines for end-of-life care in acute health settings. A few stakeholders also noted the position statement from the Australian & New Zealand Society of Palliative Medicine as an enabler to achieving the goal of appropriateness and effectiveness in acute settings. These documents were perceived by stakeholders to broadly align with the Strategy under the goal area, however it was not clear to stakeholders if these alignments were due to deliberate policy actions at the national level, or due to the Strategy having a broad focus.

Stakeholders identified Palliative Care Australia's *National Palliative Care Standards* and the *National Standards Assessment Program* for specialist palliative care providers as contributing to the appropriateness and effectiveness goal. The long-established voluntary and reflective assessment program allows specialist palliative care providers to benchmark service delivery.

### **Data and accountability**

The importance of collecting data to measure appropriate and effective care was discussed by stakeholders. Stakeholders noted that the Strategy did not include baseline measures, which made identification of improvements difficult and unmeasurable. Consequently, there is no consistent national data collection relating to palliative care, covering all jurisdictions and palliative care settings, and there is no responsibility for data collection for reporting under the Strategy at a consistent, national level.

There have been some steps towards creating data systems. Key programs and achievements towards monitoring appropriate and effective care included the continuing work of the PCOC, and regular reports produced by the AIHW. These programs primarily collect and report on data regarding specialist palliative care services and admitted patients in acute settings.

Despite improvements in data collection and the positive contribution of PCOC and AIHW data, there are considerable gaps in the data collected for palliative care services and occasions that hinder the ability of the sector to monitor and deliver appropriate and effective care. PCOC is a voluntary participation program benchmarking specialist palliative care providers, and while there are increasing numbers of participating hospitals (115 services in 2015<sup>4</sup>), there are many more services that do not participate. In addition, there continues to be a considerable lack of data in primary and community settings, and for non-admitted palliative care patients.

The lack of consistency across jurisdictions and sections of the palliative care sector mean that there are multiple benchmarks to assess appropriateness and effectiveness, which may result in different outcomes depending on the selection made. Each jurisdiction collects and measures community service delivery differently. This is a barrier to the development of a national data set and the ability to assess appropriate and effective service delivery in community settings. In the absence of mechanisms and indicators for community settings, it reinforces the specialist view of palliative care, given that current measurements such as PCOC focus on specialist settings.

### **Appropriate and effective service delivery**

Notwithstanding the data issues and the lack of baseline data, which make it difficult to determine if there have been improvements in access to and quality of palliative care, stakeholders consistently pointed to improvements in palliative care delivery, albeit with variation across jurisdictions.

Stakeholders identified examples where palliative care was being provided on the basis of need, and service delivery improvements enabled people to access effective palliative care regardless of where they were based. Tasmania, for example, has developed a service model with palliative care beds in regional hospitals, providing patients with the confidence to stay at home for longer because potential transfer into hospital is easier at a later stage of disease. In Queensland, a stakeholder gave the example of a child able to die at home with their family, despite being cut off from any health service assistance other tele-health support for several months due to flooding.

The Agency for Clinical Innovation (ACI) in New South Wales has developed a *Blueprint for improvement* to improve the integration of palliative care services across the state, and to embed a palliative approach more deeply within all aspects of the health service. This aligns with other initiatives currently being funded or trialled by the NSW Ministry of Health to increase palliative care service reach and capacity across the state. These initiatives align with the goals of the Strategy without necessarily being driven by the Strategy.

However, in most states (including those mentioned above), stakeholders highlighted an inconsistent approach to palliative care based on geographical location. It is important to note that this was not merely a rural/urban divide, but included cases where people in different suburbs of the same city had different access to palliative care on the basis of local service systems. This suggests that a consistent framework for palliative care has some merit, but must be supported by accountability measures that drive systemic reform.

Additionally, states and territories noted an inconsistent approach to palliative care for Aboriginal and Torres Strait Islander people. While resources for Aboriginal palliative care have increased in some areas, there remains a gap in knowledge and understanding among the community and professionals, and a service

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<sup>4</sup> See <http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow207619.pdf>

system that did not support effective access to care. Without adequate cultural knowledge among practitioners, the palliative care system cannot provide appropriate support for Aboriginal and Torres Strait Islander people. Some areas are trialling Aboriginal “patient navigators” to support individuals and families navigate service system pathways. Stakeholders also noted the importance of having service systems that respond to requests to return to country during the palliative care process.

A further issue raised was the high degree of pressure placed upon health professionals working in Aboriginal palliative care, given the relatively low number of professionals and their roles both as community figures and health professionals.

TABLE 11 – PROGRESS AGAINST ACTION AREAS

Action areas	Progress
1. Continue to support a continuous improvement approach to meet national standards for palliative care provision and work with national standards bodies to incorporate appropriate standards.	PCA continues to support the NSAP and the use of their National Standards in quality improvement. The Consensus Statement is new from 2015 but is expected to influence quality improvement over time.
2. Support the evolution of innovative models of palliative care service provision.	Jurisdictions are trialling a range of service models, including provision of home-based services. It is unclear the extent to which this activity was driven by the Strategy.
3. Support the development of integrated/ coordinated models of palliative care service provision.	Jurisdictions are trialling a range of service models, including provision of home-based services. It is unclear the extent to which this activity was driven by the Strategy.
4. Develop a national template with triggers for referral to specialist palliative care services that can be customised for their own setting.	There is no evidence that this has been developed.
5. Support the national roll out of an integrated care pathway across all sectors (primary, acute, aged care), including addressing any barriers to uptake.	There is no evidence that this has been developed.
6. Incorporate specific references to palliative care and the end of life phase in all relevant national and state plans, frameworks and clinical guideline documents.	Jurisdictions have made efforts to expand the understanding of palliative care and end-of-life care. However, the extent to which this activity was driven by the Strategy is unclear. Palliative care and the end of life phase are not mentioned in <i>all</i> relevant documents as stated here.
7. Develop an appropriate mechanism to review national outcome data from relevant standards and accreditation processes to drive further improvements across specialist palliative care services.	PCOC, NSAP, and reports produced by the Australian Institute of Health and Welfare (AIHW) provide data on palliative care, though this is primarily data regarding specialist palliative care services and admitted patients in acute settings. Additionally, PCOC and NSAP are voluntary so do not represent a national data set.
8. Support a national bereavement care framework collaboration. Undertake longitudinal research into bereavement in palliative care.	There is no evidence that this has been developed.
9. Management of storage and release of the deceased body.	This is a matter for jurisdictions, and it is unclear to what extent activity in this area is driven by the Strategy.

### 4.1.3. Leadership and governance

Goal 4: To support the collaborative, proactive, effective governance of national palliative care strategies, resources and approaches.

Stakeholders noted the value of the Strategy in highlighting palliative care as a priority at the national level. There was value in bringing key stakeholders from states and territories together to agree on a national approach to palliative and end of life care.

*I think a national strategy is important. I think it's important just in the symbolism of the Commonwealth government as well as state government and the whole queuing of our system just so there is an interest and a need for direction policy, leadership, and that needs to come from government as much as anybody. I think that's important, the fact that there is a strategy that's important just in itself... I think there's a lot of value add that comes as a consequence that you have these nationally agreed to and national programs that we can thank the Commonwealth for being part of. (palliative care clinician)*

#### Impact on State and Territory strategies

As noted in the Strategy, the delivery of most palliative care services is not underpinned by a nation-wide approach, but is the responsibility of the individual states and territories: “Each State and Territory has an articulated approach to palliative care in their jurisdiction” (Department of Health and Ageing, 2010:5).

This approach allows states and territories to deliver palliative care services that tap into specific needs and settings within their regions. However, the extent to which the Strategy has influenced states and territories in an ongoing way is less clear. As highlighted by the Senate Community Affairs References Committee, the Strategy's approach has resulted in variations in delivery models and services implemented in each state and territory.

The states and territories differ greatly in terms of their own strategic approaches to palliative care. The following points outline some of these different approaches:

- Jurisdictions with a current palliative care strategy are New South Wales, South Australia, the ACT and Queensland. With the exception of Queensland, the strategies in these jurisdictions are expected to end in 2016 or 2017. So far, there are no indications of how and when each jurisdiction will replace or renew its current strategy.
- In June 2016, the Victorian Government released a new palliative care strategy to replace the former strategy which was relevant for the period 2011-2015. The new strategy (Victoria's end of life and palliative care framework) aims to align with the National Consensus Statement (see Section 3.1.3). Interestingly, the new strategy includes a section on Measurement and accountability, which outlines the Victorian Government's commitment to measure progress across the strategy's priority areas. Data from information systems will be used to monitor progress, which includes client and carer experience survey data, benchmark data on patient outcomes and documented evidence of advance care plans in patient records (Health and Human Services, 2016).
- The Tasmanian Government released in 2015 a draft of a new state-wide palliative care framework to replace its former 2004 framework. However, there are no further updates available that indicate the release of a formal renewed framework.
- Prior to the release of the Strategy, the Western Australian Government released a palliative care strategy in 2008. This document appears to be superseded, particularly by the release of the State Government's 2016 End-of-Life Framework. This framework sets out a state-wide model for the provision of coordinated end-of-life care by formulating a set of key goals for health professionals. It also describes gaps and challenges in the current service delivery of palliative care, but it does not clearly outline how these gaps and challenges can be overcome in the coming years.

- To date, the Northern Territory does not have a palliative care strategy in place. The most recent strategy dates back to 2005, which ended in 2009<sup>5</sup>. However, across the NT health sector, some health strategies are currently relevant, including action areas in the delivery of palliative care, such as the Chronic Conditions Prevention Management Strategy 2010-2020, the 2010 Northern Territory Aboriginal Palliative Care Model and the Renal Service Framework 2012-2017.

As a document, the Strategy appears to be a resource that has only partly informed some of the state and territory frameworks and strategies. For example, only the State Government of Queensland, Tasmania, the ACT and Western Australia refer directly to the Strategy as a resource that informed the development of a state-wide palliative care approach. On the contrary, the National Consensus Statement developed by the Australian Commission on Safety and Quality in Health Care appears to have been more influential in guiding the development of the most recent palliative care strategy for the State Government of Victoria.

Notwithstanding this limited visibility, the jurisdictional strategies share similarities in overarching goal areas with the Strategy, particularly in relation to ensuring the delivery of appropriate and effective care to all Australians. Broadly speaking, common themes in jurisdictional focus areas and objectives include:

- accessibility of appropriate services, including the provision of cultural and linguistically appropriate services (relates to Strategy goal area Appropriateness and Effectiveness)
- identification and awareness of patient needs in relation to end-of-life care, including patients with chronic diseases (relates to Strategy goal area Awareness and Understanding)
- awareness and uptake of end-of-life care planning (relates to Strategy goal area Awareness and Understanding)
- mechanisms to review and monitor outcomes, and to predict future needs and requirements (relates to Strategy goal area Appropriateness and Effectiveness )
- service linkage and smoother continuous care across the full health care spectrum (relates to Strategy goal area Appropriateness and Effectiveness)
- building a strong and sustainable workforce across different sectors and settings (relates to Strategy goal area Capacity and Capability).

The goal area Leadership and Governance appears to be less visible in the jurisdictional strategies, which could partly be a result of the national focus within the associated action areas in order “*to support the collaborative, proactive, effective governance of national palliative care strategies, resources and approaches*” (Department of Health and Ageing, 2010:14).

## Authorising environment

Several stakeholders noted that the Strategy had provided them with an authorising environment in which to implement State-level activities. In some cases, this was through strategies and initiatives that are explicitly aligned with the Strategy (for example, Tasmania’s Better Access to Palliative Care (BAPC) Project<sup>6</sup>), and funded under the NPCP.

In other cases, the Strategy has provided legitimacy for State and Territory actions, as one stakeholder put it, a “facilitatory document”. Additionally, stakeholders highlighted the value of the NPCP and suggested that, while the funded projects are distinct from the Strategy, they are consistent and reinforce one another. One peak body noted that the existence of the Strategy is a visible reminder of palliative care priorities, to guide their own work and also when seeking funding for projects.

In addition to vertical policy integration between levels of government, several stakeholders noted the value of the Strategy for integrating palliative care with other policy frameworks across government, such as chronic disease, carers, disability and aged care, and suggested there was room for improvement in aligning the Strategy with other national frameworks.

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<sup>5</sup> Please note that the Renal Service Framework 2012-2017 refers to the Northern Territory Palliative Care Service Plan 2010-2020 as a supported document. However, this document seems not to be publically available.

<sup>6</sup> See:  
[http://www.dhhs.tas.gov.au/\\_\\_data/assets/pdf\\_file/0003/176448/Better\\_Access\\_to\\_Palliative\\_Care\\_Program\\_Presentation\\_Nov\\_2014.pdf](http://www.dhhs.tas.gov.au/__data/assets/pdf_file/0003/176448/Better_Access_to_Palliative_Care_Program_Presentation_Nov_2014.pdf)

## Governance and accountability

Stakeholders commented on the absence of accountability measures in the Strategy. However, they believed that the Palliative Care Working Group (PCWG) had been a valuable focal point for the communication and dissemination of information. Program managers that were involved in national policy dialogues noted that the PCWG encouraged collaboration, and provided the opportunity to share experiences and avoid unnecessary duplication.

Stakeholders considered that the coordinating body served an important purpose at the national level due to the challenge of encouraging jurisdictions to collaborate where state priorities and frameworks take precedence over national discussions on policy development and key definitions within the sector. In particular, they noted the value of a national document in outlining key definitions around palliative and end of life care. As governance of the Strategy has drifted, so has common understanding of key terms in the sector.

Stakeholders with knowledge of the PCWG commented that the secretariat and its governance mechanisms worked well to encourage dialogue between jurisdictional palliative care program managers. As a result of its discontinuation, there are currently few options for progressing cross-jurisdictional policy changes. Although the PCWG has been replaced by the Palliative Care Interest Group (PCIG), this is an informal group with no formal mechanisms for engagement with the Australian Health Ministers' Advisory Council (AHMAC), and many stakeholders considered that AHMAC's leadership is important to maintain momentum for palliative care service and policy development.

*The palliative care intergovernmental forum has been dissolved so the ability for the Commonwealth and the states to meet together, assess new progress, set common goals, work collaboratively is suddenly much harder. And although that group has now reformed informally, it's only an informal process and you know the palliative care intergovernmental forum was a strong and useful forum as far as I could see. (NPCP grant recipient)*

In addition to the value of the PCWG for advancing policy, it was noted as an important focal point for advocacy in the sector, both for clinicians and consumers.

*[The] intergovernmental forum was a very good place to be hearing what was happening in at a department level in each state or territory around end of life care, the way they're structuring things, the way they're engaging things in life cares for example where Victoria and WA are spending quite a bit of time together and it's very hard to understand or engage the departments in the other states in this area so we trying not to build and develop things in a vacuum but you end up having to do your own thing and so yeah, the cohesion gets lost and I saw value in meeting. (palliative care clinician)*

TABLE 12 – PROGRESS AGAINST ACTION AREAS

Action areas	Progress
1. Strengthen the role of the Palliative Care Working Group (PCWG) by establishing a work plan and formal reporting responsibilities to the Australian Health Ministers' Advisory Council (AHMAC).	The PCWG has been disbanded. Its successor, the PCIG, has no formal relationship with AHMAC.
2. Ensure mechanisms for formal communication, engagement and linkages throughout the sector to address: <ul style="list-style-type: none"> <li>• Research collaboration, funding, priorities and dissemination of outcomes</li> <li>• Clinical leadership</li> <li>• Consumer engagement</li> <li>• Leadership across all areas of health and human services for end of life issues</li> <li>• Coordination between national program providers</li> <li>• Priority setting and tracking of project funding with a focus on consolidating outcomes from previous projects</li> <li>• National measurement of both palliative care service provision and quality, and the implementation and outcomes of this Strategy</li> <li>• Workforce</li> <li>• Palliative care in the health context.</li> </ul>	<p>Commonwealth funding through the NPCP has provided a mechanism to progress some of these elements, particularly those projects focused on:</p> <ul style="list-style-type: none"> <li>• research and information dissemination (PCOC, PaCCSC, CareSearch, AIHW)</li> <li>• consumer engagement through ACP (RPC, Cabrini Health's online portal for ethical conduct of ACP)</li> <li>• leadership and advocacy (PCA)</li> <li>• reporting on clinical quality and outcomes (PCOC, PaCCSC, NSAP, AIHW)</li> <li>• workforce education and training (PCETC, HammondCare's training package for practice nurses, Flinders' education modules, Carers Australia's training project for counsellors, Children's Health Queensland's paediatric palliative care collaborative.</li> </ul> <p>Jurisdictions have also undertaken activities to progress workforce planning and development, and integration of palliative care within the health system. The extent to which this activity was driven by the Strategy is unclear.</p>

#### 4.1.4. Capacity and capability

Goal 5: To build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care.

This goal area had the most action statements of any of the four goal areas. Most of these were ambitious, system-level action statements and in the absence of assigned responsibility and reporting, it is difficult to attribute achievements to the Strategy. This section reports the range of activities identified by evaluation participants as furthering progress towards the goal of improving capacity and capability across health and human services.

## Capacity and capability of palliative care services, in all settings

There have been a number of activities undertaken by the Commonwealth, states and territories that have represented investment in workforce capability and capacity development in both specialist and generalist settings. This includes continued investment in the projects and activities under the NPCP that are directed towards increasing knowledge and skill among GPs, nurses and other generalist health providers. Of these, PEPA was generally acknowledged across all states and territories as providing a highly-regarded experiential training opportunity; this was reported as helping to increase clinical capacity by those who were familiar with the program. As noted above, to date PEPA has provided training to over 3,500 health professionals working in a range of community and acute settings.

Recognising the growing needs of Australia's ageing population, stakeholders identified an increasing role for palliative care services in residential aged care facilities (RACFs). Reportedly, the level of palliative knowledge and training within the aged care sector varies considerably between, and within, facilities as well as states. Stakeholders identified examples of capacity and capability improvement, such as the introduction of a small number of nurse practitioners in aged care facilities in South Australia and the introduction of core competencies for those wishing to obtain a Certificate III in Individual Support in Tasmania. Additionally, the Palliative Approach (PA) Toolkit from CareSearch provides a step by step approach for implementing palliative approach in RACFs, and this resource was considered by a number of stakeholders to be useful.

With the advent of aged care reforms over the last decade, reportedly people are entering RACFs at an older age, and in poorer health, than previously. Stakeholders raised concerns regarding the availability of clinical support within RACFs generally, as there is a recognised shortage of registered nurses (RNs) in the aged care sector, and often facilities do not employ RNs after hours. Consequentially, people who could be safely cared for in an aged care facility with nursing support are often transferred to hospital at the end of their life due to lack of workforce capacity and capability "in place".

*Aged care is a perfect example, however the situation is now more dire with few RNs being employed in aged care facilities, high turnover of staff, lack of skilled staff and lack of awareness of dying and palliative care needs. People enter aged care facilities now with little time left to live (3-6 months in many cases) and yet the staff are not skilled in palliative care and round the clock pain medication cannot be given as there are no RNs available. (palliative care service manager)*

A majority of stakeholders discussed the need to strengthen community and needs-based models of care in order to build capacity and capability in the sector. In particular, service providers noted that the rhetoric around integrated care models is typically strong, however in reality models are not funded adequately at the service delivery level. This often results in home and community care falling short of expectations and patients returning to acute settings. Integrated service models require upskilling in a range of professions, for example, social workers, and this is not seen as a priority among providers to make integrated service models a reality.

The role of allied health professionals in palliative care was also widely acknowledged. While recognising the need to increase numbers of palliative care medical and nursing specialists, many stakeholders also pointed to the importance of physiotherapists, dietitians, and social workers in assisting people to live as well as possible for as long as possible.

Stakeholders also emphasised the importance of acknowledging the burden on family carers and the need for appropriate services and support, particularly in the home setting. The representative of one carers' organisation noted the perceived tendency to conflate volunteers and carers in the Strategy. Each of these groups have an important role to play, however their roles are distinctive and should be recognised so that the needs of each group can be adequately addressed.

Several innovative service models were discussed by stakeholders at a jurisdictional or local level. Service models described included integrated partnership models with Primary Health Networks and GPs, home-based models, and programs that improve the capacity of ambulance services attending RACFs. Home- and community-based models, in particular, have grown in recent years in recognition that many people would prefer to remain at home for as long as possible. Stakeholders noted that much of the development of service models occurs under the direction of jurisdictional policy frameworks that cannot be clearly attributed to the Strategy.

## Capacity and capability development through research

Research is a priority under the Strategy, and has been most obviously progressed through the long-standing research projects supported by the NPCP, such as the PCOC, the PaCCSC, and CareSearch.

*The Strategy has underpinned the continuation of internationally leading initiatives, which have been able to develop significant impacts due to a consistent funding approach over a period of time... These initiatives have allowed the development of whole of sector, national approach, underpinned by evaluation and data to improve palliative care service performance and the evidence which underpins this, and also the capacity of new graduates to contribute to palliative care. These initiatives have been able to institute longer term change; and are much preferred approach than single projects which have little opportunity for national impact without a sustainability plan. (academic)*

One of these initiatives, the PaCCSC, brings together 14 palliative care services across Australia to conduct clinical trials with a focus on effectiveness and outcomes of palliative medications<sup>7</sup>. The work of PaCCSC has reportedly been influential in changing clinical practice by providing a rigorous evidence-base, including both clinical research trials and economic analysis, on the efficacy of pharmaceuticals for palliative symptom management, and is well respected internationally. As at 2014, PaCCSC had initiated over two dozen studies and had “recruited over 1,300 individuals to nine phase III clinical trials. This is the world’s largest phase III study group in palliative care” (PaCCSC, 2014:5).

Some stakeholders believed, however, that investment in research does not necessarily translate into improvements in the service system due to a disconnect between research and clinical settings, and that while Australia undertook world-leading research, the influence on clinical practice varies across the country. While PaCCSC involves 14 palliative care services (PaCCSC, 2014), PCOC has 115 services enrolled in its benchmarking program (PCOC, 2015), and NSAP has had 178 services participating in its voluntary self-assessment program (PCA, 2016), there are still many services around Australia that are not engaged in national quality or benchmarking programs or clinical trials.

Some jurisdictions have attempted to bridge this gap. For example, in Tasmania, the Better Access to Palliative Care project funds joint clinical/academic positions in a collaboration between the state government and university, providing these professionals with exposure in both environments and the opportunity to share lessons.

*In terms of capacity and capability we’ve seen the sector come a long way. You know it’s only 2002 when the research strategy kicked off as part of the national strategy that we’ve seen genuine competitive funding coming into the palliative care sector; that’s a very short time and that capacity continues to build in research. I don’t think we have enough strong clinical leaders in the sector. I think we’ve got some good clinical leaders but I think it’s an area where we have not invested enough and good clinical leaders don’t just happen, you do have to invest in them and I would like to see in the next strategy a greater emphasis on being able to build that clinical leadership capacity. (academic)*

## Capacity and capability development through workforce planning

A number of the action areas under this goal related to increasing the palliative care specialist workforce, and to improving the capability of other health professionals to provide palliative care, for instance those working in general practice, cardiology, neurology, and renal medicine.

*The ideal is that we endorse and resource end of life care and palliative care. The risk is if it starts to be seen as an either/or then health contractors start to say “well we don’t need to resource a specialist palliative care service for this new hospital that we’re planning because end of life care is everybody’s business and any clinician should be able to provide good end of life care”. That’s as great a risk as how I think the practice used to be, of generalist clinicians saying “well, palliative care is the remit of specialist care services so I’m not providing any palliative care or any end of life care to this patient, I will refer them to the palliative care team when the time is right”. Either of those are pretty risky propositions, it only works if you combine the two and you’re confident that yes, all clinicians or the majority of clinicians where it’s appropriate can recognise the need for end of life care and can provide basic end of life care and can refer to a specialist palliative care service when and if it’s necessary. (state health department representative)*

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<sup>7</sup> See <https://www.flinders.edu.au/clinical-change/research/palliative-care-clinical-studies-collaborative-paccsc.cfm>

This quotation summarises well the general assessment of most evaluation participants: palliative care is everyone's business but there is a need for specialist knowledge in palliative pain and symptom management and oversight of holistic care to ensure that quality of life is maintained for as long as possible.

State and territory governments at all levels have been engaged in planning for expanded palliative care service provision, recognising the increasing demand for services. The extent to which the Strategy has contributed to workforce planning for future palliative care services is unclear, as is summarised in the table below.

TABLE 13 – PROGRESS AGAINST ACTION AREAS

Action areas	Progress
<p>1. Identify and recommend improved funding models that explicitly promote flexibility to meet the needs of the patient and their family. This may include:</p> <ul style="list-style-type: none"> <li>• Funding based on assessed need</li> <li>• Funded care packages, including rapid access/rapid response options</li> <li>• Fund holding by appropriate providers, including aged care services, to be able to navigate and source appropriate care regardless of location, outside the aged care assessment process.</li> </ul>	<p>A number of jurisdictions have undertaken activities to explore improved funding models. It is unclear the extent to which this activity was driven by the Strategy.</p>
<p>2. Explore new and enhanced roles for aged care providers in palliative care.</p>	<p>There is evidence of jurisdictions trialling integrated models of community-based palliative care. It is unclear the extent to which this activity was driven by the Strategy.</p>
<p>3. Undertake further research and ongoing monitoring of the relative cost of care and cost effectiveness of care models in the last year of life, particularly savings to be gained through appropriate hospital avoidance for clients approaching the end of their life.</p>	<p>Many jurisdictions have monitored costs of care models, including home-based care models. It is unclear the extent to which this activity was driven by the Strategy.</p>
<p>4. Undertake further work to identify, classify and cost specialist palliative care clients and their care.</p>	<p>Many jurisdictions have monitored costs of care for specialist palliative care services. It is unclear the extent to which this activity was driven by the Strategy.</p>
<p>5. Provide enhanced, coordinated support for carers, volunteers, communities of carers and carer respite.</p>	<p>The NPCP projects such as those related to ACP and the CareSearch portal have resources specifically for consumers and carers.</p> <p>Some jurisdictions are supporting local initiatives to support carers and communities. It is unclear the extent to which this activity was driven by the Strategy.</p>
<p>6. Provide coordinated, flexible local care delivery for people at the end of life regardless of where they live and address any barriers.</p>	<p>This is a matter for jurisdictions, and it is unclear to what extent activity in this area is driven by the Strategy.</p>
<p>7. Further improve the skill and confidence of the generalist workforce to work with people with palliative care needs.</p>	<p>Several of the NPCP projects provide resources and training for generalist clinicians: PEPA provides training placements for the generalist workforce; CareSearch enables access to a broad range of clinical guidelines, research, and training resources; the Palliative Care Training and Information online portal offers an online education and training package for health workers; the Children's Health Queensland paediatric palliative care collaborative develops educational resources for generalist and community-based health providers.</p>

Action areas	Progress
8. Enhance online palliative care support and resources through the development of “communities of interest”.	It is not clear what the “communities of interest” comprise, however online resources have been developed as part of the NPCP.
9. Promote the existence of online palliative care resources to all health and human service providers with links to service specific and disease specific websites.	A number of resources have been developed as part of the NPCP, however it is not clear how or whether they are being promoted.
10. Work with Health Workforce Australia to ensure adequate numbers of skilled palliative care specialist providers across all disciplines.	Health Workforce Australia no longer exists, with many of its functions now undertaken by the Department. Workforce planning remains a priority but progress under the Strategy is not able to be assessed.
11. Work with the Community Services and Health Industry Skills Council to include end of life and palliative care competencies in all care worker training packages.	There is no evidence that this has been progressed.
12. Enhance and legitimise the role of specialist consultancy services in providing direct clinical advice, education and training, advocacy for end of life issues and training places.	Many jurisdictions support an explicit consultancy role for specialist palliative care providers. It is unclear the extent to which this activity was driven by the Strategy.
13. Work with National eHealth Transition Authority and other relevant agencies to ensure that the capacity exists to record and track Advance Care Planning within electronic health records and appropriate systems.	My Health Record includes capacity to upload Advance Care Plans online. However, the extent to which these are acted upon by health professionals varies by jurisdiction.
14. Work with private health insurers to develop sustainable models of quality palliative care in the private sector.	There is no evidence that this has been progressed.
15. Continue to develop the role of the general practitioner in palliative care through supportive approaches including: <ul style="list-style-type: none"> <li>the development of those with a special interest</li> <li>the development of practice nurse roles in palliative care</li> <li>incorporation of Advance Care Planning in enhanced primary care planning</li> <li>appropriate support for general practitioners who are providing an active role in a client's palliative care, including providing telephone support and home visits.</li> </ul>	The NPCP has continued to provide support for GPs through a number of projects including PEPA, Respecting Patient Choices and Decision Assist, CareSearch, the Palliative Care Training and Information online portal, the paediatric palliative care national education quality improvement collaborative, development of an online resource for the ethical conduct of religious and cultural advance care planning, and The Palliative Care and Advance Care Planning in General Practice – A training package for Practice Nurses.

## 4.2. SUMMARY

*I think the goal areas are really good but I think where it probably falls down is operationalising those or providing some direction of what that might look like and who's jurisdiction it falls into is unclear and so I think there is a tendency to say that's Commonwealth and their responsibility to lead these elements where some of those things are actually grass roots issues that need to be tackled at that level. (palliative care clinician)*

Evaluation participants consider the Strategy's existence to signal the importance of palliative care and a palliative approach with the Australian health system. Stakeholders who had been working in palliative care for a long time and were familiar with the first strategy considered that the 2010 Strategy had built on the significant achievements that had been achieved in the 1990s, and consolidated under the 2000 Strategy.

A number of achievements and indicators of progress in the palliative care sector were identified by evaluation participants. Notable among these is the greater awareness and uptake of ACP, and continued education and training among health professionals to promote the palliative approach among non-specialists. The continued Commonwealth investment in research, quality improvement and outcomes benchmarking, was noted in every workshop as a significant achievement which enhances clinical knowledge and practice. Other participants noted the indications of a greater willingness to talk about death within the general community (spurred, among other things, by the rise of “death cafes” and other social events, and the topic of euthanasia).

At the same time, it is evident through analysis of the Strategy as well as through consultation and documentation review that the Strategy’s lack of robust indicators, time frames or accountability mechanisms has rendered it less effective than it might have been in providing direction to the sector. The need for leadership and governance was emphasised as essential for ensuring that Australia can maintain and enhance the quality of palliative care services.

The next chapter discusses the implications of the evaluation findings.

## 5. DISCUSSION

*We had a national palliative care strategy that had been endorsed by all the states and territories as far back as 2000. That was a huge step forward and I think the real issue with the new [2010] strategy was could we maintain momentum for many of the innovations that were brought about in that decade... We had gone from being a very disparate community both in clinical care where many services had grown up organically to a much more structured approach, not as structured as it needs to be in the cut and thrust of service delivery in 2016 but we've come a long way. (NPCP grant recipient)*

Overall, Australia performs very well with regard to the provision of high quality palliative care services, when ranked internationally. Ranking second out of the 80 countries surveyed by the EIU (2015), Australia scores highest in the categories of “human resources” (availability of medical and health professionals, training and education) and “affordability”.

The key elements for good palliative care, identified throughout the literature, and in the EIU’s analysis, are all present within the Australian health system:

- jurisdictional policy frameworks
- public spending on health services
- training for general and specialist health workers
- a form of national or social insurance to reduce the financial burden for families
- availability of analgesics
- public awareness.

In many ways, Australia already offers a model for other countries to follow given the considerable investment over many years by all jurisdictions in these elements of care and, particularly, in the investment through the NPCP in research programs which have created an evidence-base to inform clinical practice in palliative care. These research programs are reported to have had a strong influence nationally and internationally.

The literature suggests that there are a number of common elements which are features of effective national strategic frameworks for palliative care (Economist Intelligence Unit, 2015; European Association of Palliative Care, 2014; World Health Organization, 2011). These elements are present in other national strategies or frameworks, and within such models as the WHO public health model and the EIU indicators. These are also present in the National Palliative Care Strategy 2010.

For instance, when compared to the WHO’s model for palliative care (see Figure 1 in section 3.1 of this report), Australia demonstrates strong performance against the four components of the model, as outlined in the table below:

TABLE 14 – AUSTRALIAN COMPARISON TO WHO’S PALLIATIVE CARE MODEL

Components of WHO’s model for palliative care	Australian evidence
Policy framework	Existence of National Strategy 2010 as well as jurisdictional frameworks; previous existence of the PCWG
Drug availability	Pharmaceutical Benefits Schedule; strong policy, legislative and regulatory frameworks for the provision of pharmaceuticals; the work of the PaCCSC and other research projects testing drug efficacy
Implementation	Demonstration of growing investment in palliative care services at national and jurisdictional levels over several decades; the existence of professional and advocacy bodies such as the Australian and New Zealand Society for Palliative Medicine, Palliative Care Nurses Association, and Palliative Care Australia; the NPCP projects
Education	Demonstration of investment in medical, nursing and other health professional education and training; the NPCP projects supporting health professional training; projects supporting public awareness and advance care planning

In evaluating the Strategy, the Urbis team has analysed the Strategy against the common elements found across the literature regarding strategic frameworks for palliative care, to determine the strengths of the current framework and the opportunities for future development. Table 15 below summarises the features present in effective national strategies and the extent to which they are present in the current Australian Strategy.

TABLE 15 – FEATURES OF A NATIONAL PALLIATIVE CARE STRATEGY

	<b>A strategy that...</b>	<b>Present in 2010 strategy</b>
Governance	<p>enables the development and promotion of national palliative care features strong government engagement in the development and promotion of palliative care</p> <p>enables a cohesive national approach with high quality of care across the nation, regardless of location or remoteness of services</p> <p>enables the development of appropriate mechanisms to regularly review and update the national approach</p> <p>ensures transparency in funding, including the allocation and review of funding.</p>	Partly (funding is not included, and while governance and leadership are noted, there is not a cohesive national approach to action)
Integration of services	<p>allows a whole-of-system approach for integrated care across the entire health care setting and other relevant sectors</p> <p>fosters strong engagement of local communities in the delivery of palliative care</p> <p>supports palliative care in the home and other community settings.</p>	Yes
Patient-centred care	<p>increases awareness and the uptake of advance care planning</p> <p>fosters inclusiveness in the delivery of palliative care services, regardless of diagnosis or illness, age group, care setting, cultural background, location and income</p> <p>provides affordable palliative care services to those who need it</p> <p>integrates support and services to carers and volunteers, including training and education, and bereavement support.</p>	Yes
System and processes	<p>works towards a central coordinating facility of single point of access</p> <p>enhances rapid access to care (24/7) in local communities</p> <p>enables clear processes and systems for timely identification of patients who may require palliative care.</p>	Partly (this is devolved to the states/territories)
Workforce capability	<p>integrates palliative care in undergraduate and graduate curriculums</p> <p>provides ongoing training and education of the principles of palliative care across the entire health workforce and other relevant sectors.</p>	Yes

This chapter will discuss each of these elements in turn.

## 5.1. GOVERNANCE

The evaluation team has found that the existence of a national strategy is valued by policy makers, health service managers and palliative care providers, consumers and carers. As noted in chapter 4, the Strategy creates an “authorising environment”, providing evidence of the priority governments place on the development and improvement of palliative care services. The fact that, as a National Strategy, all jurisdictions have endorsed the document, also provides weight to the document as a foundation for the development of new policies, programs, and activities that may improve service delivery at a local, regional or national level.

Australia has had a national strategic direction for palliative care since 2000, and all jurisdictions are actively engaged in the development of policy and services to meet the increasing need for palliative care specialist

services, and for a palliative approach to become more widespread throughout the primary, community and tertiary levels of the health system.

The Commonwealth has demonstrated leadership in its continued funding and support for a range of projects and activities that may benefit palliative care policies and services across the country. In turn, most jurisdictions have developed their own strategies and have supported the development of local services and activities to improve the awareness of, access to, and provision of palliative care services.

Evaluation participants considered that the four goal areas of the Strategy themselves were reasonable, primarily because they were so broad that all priorities could be located within one or more of the areas. For many, this breadth is a strength as it allows jurisdictions and services room to address local priorities as needed while still remaining aligned with the national strategic direction. For others, however, this breadth itself signalled a lack of national strategic direction.

There are a number of action areas under each of the focus areas, and it is here that the Strategy's primary weakness is evident: there is no defined responsibility or accountability within the Strategy for ensuring that the stated actions will be undertaken. The Commonwealth, through the NPCP, has funded projects that have progressed many of the action areas. However, many of the areas are not clearly defined, nor is it clear who might have accountability for action, the extent to which each has been met cannot clearly be measured. In the words of one evaluation participant, the Strategy *"has no teeth"*.

Consultation participants consistently noted the lack of a Palliative Care Working Group by which to draw these disparate activities together to improve information sharing and the development of a nationally consistent approach. It is notable that the Strategy includes, as a Measure of Success, *"the inclusion of PCWG in formal reporting requirements to AHMAC"* (p.14). It is not clear why the PCWG was disbanded, and its successor, the PCIG, does not seem to have been able to achieve the influence which stakeholders clearly desire and which was intended in the 2010 Strategy. While the nature of AHMAC reporting structures is outside the scope of this evaluation, it seems evident that the lack of a national inter-jurisdictional governing structure has impeded the potential for the Strategy to become a unifying document for a nationally consistent approach to the development of palliative care policies and services. Greater collaboration and coordination of services may also assist that proportion of Australians who may be required to travel across boundaries (for instance, NT residents who travel to South Australia for treatment, NSW residents who may travel to Victoria for treatment, and so forth).

The second flaw of the Strategy is related to the first, and lies in the "Measures for Success" under each goal area. As noted in chapter 4, these indicators for success are largely unmeasurable. For many of them, there is no baseline data nor is there any national or jurisdictional means of collecting indicators which might provide evidence of achievement. Many stakeholders considered that the lack of an implementation plan for the Strategy has hindered its effectiveness; theoretically, such a document could have defined roles of responsibility, lines of accountability and reporting structures, and might have defined performance indicators for the Commonwealth and other jurisdictions.

Notwithstanding this lack of clarity, the evaluation has found that the Commonwealth, through its oversight of the NPCP, has contributed to the formation of national resources and approaches as implied in the goal statement under the area of Leadership and Governance: to *"support the collaborative, proactive, effective governance of national palliative care strategies, resources and approaches."* The suite of projects and activities funded under the NPCP, with its combination of long-standing research and clinical projects and shorter-term activities to develop resources and other tools, has contributed significantly to the strong evidence-based approach taken by Australia, as noted by many stakeholders and by international benchmarks.

Stakeholders in all jurisdictions indicated that greater leadership and governance is essential to draw together all the disparate activities occurring in each state and territory as well as through the NPCP. While the mechanism for this governance role is to be determined, stakeholders did agree that the PCWG had played an important role in bringing together the jurisdictions and enabling a forum to work collaboratively across borders, while the role of the PCIG has been less clear and its impact less apparent.

## 5.2. INTEGRATION OF SERVICES

The consultations across Australia identified a wide range of activity undertaken by state-based health services, private and not-for-profit organisations and health providers, peak bodies, consumer organisations, and local communities. Some of this activity has been directed at a state or territory-wide level, while other initiatives have risen organically within local communities. Very little of this, it appears, has been driven by the Strategy but, as noted in chapter 4, has appeared to be auspiced by the strategies or policy frameworks

of each jurisdiction. This is not surprising given the structure of the Australian health system, as the responsibility for service delivery rests with the states and territories.

The understanding of when and for whom palliative care is appropriate has changed considerably over decades. Once the sole responsibility of cancer services, palliative care is now recognised as a stage of care for people living with chronic diseases (both malignant and non-malignant), dementia, and aged care. While the Strategy references the expanding understanding of palliative care, it was developed before some other more recent national strategic and legislative frameworks, such as those for chronic disease, aged care, and disability, and those referencing carers and social services. Stakeholders widely agreed that there is a need at the national level for greater alignment and cross-referencing of policies across service settings, including primary, community and acute settings, given that palliative care should now be, in the words of a number of stakeholders, “*everyone’s business*”.

Stakeholders did note the progress that has been made with regard to extending the palliative approach out of specialist palliative care services and into the acute setting as well as into primary and community care. Stakeholders noted that in 2010 the place of palliative care within the “generalist” setting had not been clearly defined; however, since then many of the states and territories have made efforts to support the extension of palliative care outside of the specialist palliative care setting, and to recognise the role that GPs, generalist physicians and nurses, and specialists in other disciplines play in supporting palliative and end of life care.

This suggests that there are further opportunities for future strategic directions for palliative care to include greater integration across service settings, including public, private and not-for-profit services working at all levels of the health service. In addition, there is an opportunity to build a more cohesive strategic framework by aligning this Strategy more closely to those strategies related to chronic disease, aged care, disability, and potentially other social service areas.

### **5.3. PATIENT-CENTRED CARE**

Of the emerging issues facing Australia as a whole, the ageing of the population is possibly the most pressing, given the AIHW’s conclusion that 90% of deaths are now due to chronic disease (noting as above that this includes cancer as a chronic disease, itself an indication of a significant shift in treatment and understanding over time). Grassroots movements to “normalise” death as an aspect of life are reportedly contributing to a small but significant rise in people’s awareness of the process of dying and this, combined with ongoing media discourse regarding euthanasia, have the potential to increase the extent to which people consider and make choices about end of life care.

Australia shares fourth place in the EIU survey in the category of “community engagement”, which is of concern as raising public awareness was a goal of the 2010 Strategy. While awareness of and engagement with advance care planning appears to have increased, as evidenced by the literature and also by the increased visibility within jurisdictional strategic frameworks, the general willingness of the public to discuss matters of death and dying may be an area for further improvement.

ACP has been one of the notable successes during the life of the Strategy, although the extent to which this is attributable to the Strategy is not clear. Certainly, the support from the NPCP has ensured that a number of national projects have continued to raise awareness of, and develop resources to support, advance care planning among clinicians as well as the community. As an example of putting the patient’s desires at the centre of care planning, ACP certainly suggests that there has been progress under the strategic focus area of Awareness and Understanding.

As noted above, the integration of a palliative approach into the wider health system has increased over time, which provides access to palliative care for many more patients regardless of diagnosis or care setting. Stakeholders generally agreed that there was room for improvement in the level of understanding among health professionals outside of the palliative care speciality, including GPs, community nurses, general physicians and specialists in other medical disciplines. NPCP projects such as PEPA and PCC4U (most people continue to use these acronyms rather than the more recent PCETC), CareSearch, and PaCCSC were credited with raising awareness among health professionals, and increasing visibility of palliative care within the clinical educational curricula. While not a short-term solution, such investments have demonstrated the potential over time of helping to embed greater understanding and confidence in adopting a palliative approach wherever required in health settings, rather than only within specialist palliative care settings.

## 5.4. SYSTEMS AND PROCESSES

As noted above, there is potential at jurisdictional and national levels to improve integration of palliative care services with other elements of the health system as well as with the aged care and disability sectors. While this will largely be the responsibility of the states and territories, the Commonwealth also has a role to play given its responsibilities for primary health care, Aboriginal Medical Services, and aged care, as well as management of the NDIS. Many stakeholders felt that the Strategy should provide more of a platform for encouraging cross-jurisdictional discussions which could help mitigate the areas of the health system that are traditionally siloed due to the state-federal divide.

It is worth noting as well the role of the Commonwealth in management of the Medical Benefits Schedule (MBS) and the Pharmaceutical Benefits Scheme (PBS). Comments did arise during consultation with regard to the disincentive for GPs to engage with palliative care services, including home visits, given the limitations in rebates for attendance regarding preparing care plans, care management or coordinating care with other health professionals. (Stakeholders did acknowledge the MBS items for chronic disease management however these hide palliative care activity under a broader category so it is not possible to quantify palliative care activity actually undertaken by GPs.) Likewise, the use of opioid and other S8 drugs in palliative care does require a level of expertise which many GPs do not possess, and is an area where pharmacists as well as specialist palliative care providers can assist, although there is no easy funding mechanism to encourage GPs to participate in this kind of inter-professional engagement.

One of the major weaknesses of the Strategy, according to stakeholders, is the lack of measurable indicators by which to monitor the progress of the Strategy. No baseline measures were set and no indicators were defined which might indicate progress. Indeed, many of the Strategy's Measures of Success, as noted above, are too broad to be measurable in any case. Many stakeholders felt that future Strategies should include clearly defined measures that can be monitored against baseline data.

Further, some stakeholders did suggest that performance indicators should be embedded in federal funding agreements so that the jurisdictions will be required to report national progress with regard to palliative care service performance. This suggestion is not likely to take place in the near future; however, given the likely growth of investment in palliative care and end of life services across all levels of the health system, it will be important in the future to consider mechanisms for assessing effectiveness and quality of service delivery and patient outcomes.

## 5.5. WORKFORCE CAPABILITY

All goals of the Strategy 2010 contain an element of increasing workforce capacity and capability, and there is evidence that the NPCP projects and activities have contributed to increasing workforce capability through their focus on clinical research and evidence dissemination, education and training, and development and dissemination of resources and tools.

There is a recognised shortfall of palliative care specialists nationally. Using a 2007 analysis undertaken by the Australasian Chapter of Palliative Medicine, the Australian and New Zealand Society of Palliative Medicine (ANZSPM) reported that there is an expected workforce shortage of 97 palliative care medical specialists (ANZSPM, 2010). Given the ageing of the nursing and allied workforce generally, it is to be expected that there will be a need for increasing numbers of professionals able to provide palliative and end of life care. This includes the many allied health professionals who contribute to comprehensive palliative care, including social workers, pharmacists, dieticians, physiotherapists, counsellors and psychologists.

The Strategy acknowledges the need to undertake a range of approaches to address workforce capability, and identifies many actions that, as noted in chapter 4, have not been achieved, are not measurable, or where it is not clear who if anyone has taken action.

Workforce planning for palliative care services is the responsibility of states and territories, as well as the Commonwealth, and all jurisdictions will have their own workforce planning in place. However, it is not clear that any of this activity is either related to, or influenced by, the Strategy. Future Strategies, in addressing workforce capability issues, will need to define clearly what aspect of workforce capability can be influenced by the Strategy and identify what outcomes the Strategy is seeking to achieve.

## 5.6. THE ROLE OF THE NATIONAL PALLIATIVE CARE PROJECTS

As the National Palliative Care Projects are the Commonwealth's investment in furthering the Strategy 2010, it is of interest to note that the suite of projects also align across the elements of good strategic practice identified in the literature (leaving out "governance" as more appropriate for the strategic rather than the project level), as indicated Table 16.

TABLE 16 – ALIGNMENT OF THE NATIONAL PALLIATIVE CARE PROJECTS WITH STRATEGIC BEST PRACTICE

National Palliative Care Projects	Integration of services	Patient-centred care	Systems and processes	Workforce capability
The Palliative Care Education and Training Collaborative (PCETC)		▲	▲	▲
Palliative Care Training and Information Online Portal		▲	▲	▲
Palliative Care Outcomes Collaboration (PCOC)		▲	▲	▲
Palliative Care Australia	▲	▲	▲	
Respecting Patient Choices	▲	▲	▲	▲
Paediatric Palliative Care National Education and Quality Improvement Collaborative		▲	▲	▲
Listen, Acknowledge, Respond		▲	▲	▲
Training Counsellors for Carers of Palliative Patients	▲	▲		▲
Online Religious and Culturally Sensitive Advance Care Planning	▲	▲	▲	▲
Australian Institute of Health and Welfare (AIHW)			▲	
The Australian Palliative Care Knowledge Network – CareSearch		▲	▲	▲
The Palliative Care Clinical Studies Collaborative (PaCCSC)		▲	▲	▲
Palliative Care and Advance Care Planning in General Practice – A training package for Practice Nurses	▲	▲	▲	▲

While the scope of this evaluation included review of the contribution of the projects to the Strategy, the scope did not include a detailed evaluation of the individual projects. The evaluation team was asked to consider the extent to which the NPCP's projects contributed to achievements under the Strategy and, overall, the evaluation team considers that the suite of projects funded by the Commonwealth has made a demonstrable and significant contribution towards furthering the goals of the Strategy, without being specifically identified within the Strategy or, indeed, having any articulated accountability within the Strategy. In addition, the combination of long-term investments in large-scale research projects with shorter-term educational and resource activities is considered to provide structures for rigorous knowledge development as well as flexibility in responding to evolving educational and training needs.

## 5.7. SUMMARY

It is clear that progress has been made in the goal areas of the Strategy, although it is not possible to assess the extent to which the Strategy itself has been a driving force for progress. The limitations of this evaluation lie in the lack of baseline data or measurable indicators by which to assess progress. The lack of an implementation plan or a monitoring framework within the Strategy has hampered the ability to assess progress and to identify in detail the barriers or enablers to implementation of the Strategy's ambitious action agenda.

The palliative care sector in Australia is, on the whole, well developed and mature, and the evaluation team considers that many of the achievements noted within this report have been possible due to the extensive commitment across all jurisdictions and at all levels of the health system. As noted previously, it is unclear the extent to which these achievements are driven or auspiced by the national strategic framework. It is possible that the existence of the Strategy itself has created an authorising environment in which continuous improvement of palliative care in Australia can occur. Given the already strong performance of the Australian palliative care services by international assessment, the following chapter considers how the Strategy may be strengthened for the future.

## 6. CONSIDERATIONS FOR THE FUTURE

*The things that make a better death are so simple...It's basic knowledge about good pain control and conversations with people about the things that matter – that could transform many more deaths.* (quoted in Economist Intelligence Unit, 2015:13)

By international comparisons Australia performs well in embedding palliative care as a speciality and the palliative approach into the national health system, and has developed an exceptional reputation for high quality palliative care. At the same time, there are opportunities for improvement.

The importance of a national policy framework cannot be underestimated, as evidenced by the impact of such frameworks on the development of palliative care services internationally. Australia's policy framework is mature; however, the fact that only half of the jurisdictions appear to reference the Strategy in their own policies suggests that there is room for greater alignment in policy direction between the Commonwealth, states and territories.

The EIU report (2015) specifically notes the lack of national consistency in service provision, due to the devolution of responsibility for service delivery to the states and territories. This can lead to differentials in public spending on palliative care services and the level of public education regarding good end-of-life care.

Likewise, while Australian public expenditure on palliative care is generous by international standards, it is clear that in a straightened economic climate there is a risk that investment in specialist and generalist education and training, and the funding of specialist palliative care positions, may not grow to meet the needs of the population in the future. This will require attention, particularly in light of the expected increase in demand for services by an ageing population.

In considering future directions for a national strategy for palliative care, the literature suggests the following factors should be considered:

- the alignment between national and jurisdictional policy, planning and funding
- the policy directions required to:
  - maintain the high level of palliative care services currently available to Australians
  - ensure the supply of well-trained medical, nursing and other health professionals
  - improve consistency of access and quality across the country
  - increase the appropriateness of services to respond to the needs of sectors of the population (e.g. Aboriginal and Torres Strait Islander peoples, migrants, different religious groups)
- the needs of an ageing population expected to live for longer periods with one or more chronic diseases, including cancer
- the particular needs of children in the provision of paediatric palliative care
- the importance of increasing the public comfort with thoughtful and considered discussion of death and dying.

Australia has a strong foundation based on decades of investment and leadership in palliative care policy, research and services. Continued leadership, commitment and investment will be required to ensure that all Australians are able to achieve a good death.

The current Strategy has no defined end point. Urbis suggests that the following actions could be considered by the Commonwealth to increase the influence of the Strategy going forward.

1. The fact that there is little reference to the Strategy in many jurisdictional strategies and plans suggests that the Strategy has not been effective in aligning state, territory and Commonwealth planning and policies. The loss of an effective inter-jurisdictional mechanism for planning and policy development has also hindered the development of a nationally consistent approach to service delivery. Urbis suggests that a priority for the future is to work with the PCIG to consider national objectives for improving consistency across the country and for ensuring that states and territories are able to reduce duplication of effort.

2. The evaluation has found that the lack of accountability and measurement within the Strategy has hindered its effectiveness. In order to provide national leadership in the direction of policy development the document requires strengthening in terms of what it is seeking to achieve and how achievements can be demonstrated. This is essential to provide a policy lever for maintaining the quality and expansion of palliative care services, addressing workforce shortages, and improving consistency of access and service delivery. Urbis suggests that an action or implementation plan should be developed to guide implementation of the Strategy going forward, with identified objectives, actions, responsibilities, and indicators.
3. The AIHW analyses the Admitted Patient Care National Minimum Data Set (NMDS), along with other national data sources, for its annual report on palliative care services. The lack of effective indicators in the Strategy has highlighted the need for consideration of a nationally consistent data set that could provide insight into the provision, quality and effectiveness of palliative care services. Benchmark indicators for service performance have already been identified through NSAP and PCOC. Recognising the lengthy process required to identify appropriate data indicators and work with jurisdictions to assess feasibility for an NMDS, it would be useful to work with the AIHW to identify a possible way forward to improve data collection for the purpose of monitoring the Strategy's effectiveness.
4. There is currently no efficient mechanism for collecting data regarding palliative care service provision in community and primary care settings. Given the expected increase in palliative care service delivery in non-specialist settings, it would be useful to work with the AIHW to identify a possible way forward to improve data collection for these services.
5. There is a need for the Strategy to be more closely aligned with other national strategic frameworks, such as the one currently being developed for chronic disease, the aged care reform package, future iterations of the National Carer Strategy, and the National Disability Insurance Scheme. Within the life of the current Strategy, it would be beneficial to explore ways in which the Strategy can be revised to accommodate the significant policy developments that have occurred since 2010.
6. The need for public awareness and understanding of the process of death and dying continues to be identified as a barrier for managing pain and symptoms for many people at the end of life. The Strategy has identified this as a priority, and progress has been made both through the ACP activities funded under the NPCP and through a number of community-led initiatives. The Strategy identified social marketing and health promotion campaigns as a means of raising awareness nationally, and consideration should be given to what such a campaign might achieve and how this might be implemented.
7. There remain significant barriers to access to palliative care services for a number of people within the population, particularly for Aboriginal and Torres Strait Islander peoples. While some progress has been made in raising awareness of palliative care services in culturally appropriate ways, the cultural security of palliative care services varies significantly. The Strategy does not focus on groups which have traditionally not accessed palliative care services; developing culturally-specific activities to address the needs of Aboriginal and Torres Strait Islander peoples may help to improve access to services for those who need it.
8. Similarly, there is little detail in the Strategy regarding the needs of people from a range of vulnerable populations, including the homeless, people living with disabilities, and new migrants. It would be valuable to consider whether national strategic direction would assist to improve the availability of services for these and other people, at the end of life.
9. Capacity and Capability was the goal area with the longest list of actions and the least ability to measure progress. Identifying tangible and practical activities to support jurisdictions and educational institutions to address workforce shortages and capacity issues would be useful. Continued funding for the clinical research and information dissemination projects, as well as for those providing education and training opportunities, will continue to strengthen capacity among the existing workforce.
10. In summary, Urbis considers that the current Strategy should be updated to reflect the above considerations. The current Strategy has no defined end point and, as a result, does not provide a clear timeframe for delivering outcomes or define accountability and performance measurement. Stakeholders strongly believed that the Strategy requires updating to reflect the changing environment since 2010 and to improve the Strategy's position as a mechanism to drive national, jurisdictional and service delivery activity, in order to ensure that the Australian health system is able to meet the increasing needs for high quality palliative care.

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