

**HEALTH SYSTEM REFORM
AND CARE AT THE END OF LIFE:
A GUIDANCE DOCUMENT**



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ABBREVIATIONS

ABS—Australian Bureau of Statistics

ACFI—Aged Care Funding Instrument

AIHW—Australian Institute of Health and Welfare

ACSQHC—Australian Commission on Safety and Quality in Health Care

CPE—continuing professional education

COAG—Council of Australian Governments

COPD—chronic obstructive pulmonary disease

GP—general practitioner

HACC—Home and Community Care

MBS—Medicare Benefits Schedule

MND—Motor Neurone Disease

NHHRC—National Health and Hospitals Reform Commission

NHMRC – National Health and Medical Research Council

NHS—National Health Service

NSAP—National Standards Assessment Program

PCOC—Palliative Care Outcomes Collaboration

PBS—Pharmaceutical Benefits Scheme

RACF—Residential aged care facilities

TAFE—technical and further education

TERMINOLOGY

For the purposes of this Guidance document, the following terms and definitions apply:

Palliative care—Palliative care is specialist care provided on the basis of a needs assessment for all people living with, and dying from a life limiting illness and for whom the primary goal is quality of life.

End of life care—End of life care is provided to people who are living with, and who are impaired by, a life limiting illness. It is not limited by prognosis or diagnosis. End of life care includes support and services delivered by all health care professionals.

Primary care—Refers to health care in the community accessed directly by consumers and/or services provided outside of hospital. It includes care provided by general practitioners, nursing and other services such as community health services, pharmacists, Aboriginal health workers, physiotherapists, podiatrists, dental care, and other registered practitioners.

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

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

Consumer: is a collective term used to describe people who may require access to a health care service at some time in the future.

Patient: is used to describe individuals who are accessing palliative and end of life care.

Person: is used to describe individuals (who may or may not require or be accessing care).

Carer(s)—Is used to refer to family members, relatives or friends who provide unpaid support to consumers receiving palliative or end of life care. 'Caregiver' is used only when it is referred to in source documents.

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GUIDE TO USING THE GUIDANCE DOCUMENT

Section 1 (Purpose and methodology) provides an introduction to the Guidance document and its development.

Section 2 (Values driven reform) describes the values and standards that underpin the delivery of palliative and end of life care and drive the reform process.

Section 3 (Dying differently—understanding complexity at the end of life) discusses the complexity of consumer experience at the end of life, and provides information about the demographics of death. It outlines common patient journeys at the end of life as patients manage the complexities of the health care system.

Section 4 (Current issues and challenges) discusses current issues and challenges to providing good quality care and the key messages that emerged from the consultations.

Section 5 (Care at the end of life—international directions) discusses the international directions in reform of end of life care.

Section 6 (Health care reform at the end of life—national directions) sets out the national directions in health reform at the end of life arising from the major system-wide reform processes of the National Health and Hospitals Reform Commission, the National Primary Health Care Strategy and the Australian Commission for Safety and Quality in Health Care.

Section 7 (Guidance for the health care system—moving towards an integrating system of end of life care) provides a framework for an integrating system of palliative and end of life care. The national end of life Guidance components are described and specific guidance is provided on the necessary system-wide preconditions and steps required to achieve quality care for all Australians as they approach the end of life.

Section 8 (Implementing the end of life Guidance) sets out the responsibilities for implementing the Guidance.

EXECUTIVE SUMMARY

Health System Reform and Care at the End of Life: A Guidance Document represents a shared vision for the development of high-quality palliative and end of life care in Australia. This Guidance document was informed by a variety of evidence sources and consultations, but the main impetus was from the National EoL Framework Forum held in Canberra in October 2009, which brought together a broad based group with experience and expertise in palliative and end of life care across a range of care settings (see acknowledgements).

Additional input was provided from a workshop held as part of the National Palliative Care Conference in September 2009 as well as a National End of Life Forum in March 2008. These meetings were part of a series of national consultations on end of life care that formed a continuing 'conversation' between the various stakeholders, structured around the central question:

What would a reformed health care system that could deliver high-quality care at the end of life for all look like?

The development of the Guidance document has also been informed by targeted reviews of key national reform processes currently underway in Australia and related health literature along with international literature from the US, Ireland, the United Kingdom, Canada and France.

The need for a comprehensive end of life guidance document was seen as critical given the numerous reform processes and strategy development arrangements currently underway across the Australian health and community care sectors. By providing the best informed advice, government, policy makers and service providers will be able to set priorities for end of life care so that Australia doesn't fall behind other developed nations in this area.

Evidenced-based policy and practice is an important step along the path to achieving high-quality care. However, currently there is little systematic data available about patient's experiences and the outcomes of end of life care. Without timely information, it is not possible to undertake informed decision making about service delivery or assess the impact of any efforts at improvement. Further, broad health system reform calls for care centred around each individual patient and improving person-centred care for all people at the end of life requires that we develop systems that support and enable

high-quality, safe care of individual patients. Grounding the development of these systems in the experience of patients and understanding the common illness trajectories may help health professionals, patients, their families and carers to better prepare for their journey at the end of life.

While palliative care began to be recognised as a mainstream health service in the mid 1980s and has been shown to improve the experience and care of patients, end of life care within Australia has had a comparatively lower profile. The health care system is designed to provide short-term, episodic care for mainly acute illness and there is an understanding that more needs to be done to improve the experience of people as they approach the end of their life to ensure that care is both appropriate and adequate. The proposed national health care reforms present an opportunity to review how systems of care might better enable a more dignified, peaceful and respectful death.

Challenges to achieving this at present exist at all levels from the individual patient level to communities, health professionals and care systems. For example, there is limited community and professional awareness of end of life issues and a societal reluctance to talk about death, which limits discussion about important issues such as dying at home and stopping futile treatments. Also the lack of a shared and common language used by health professionals to describe the needs and service provision of people approaching the end of life creates unnecessary confusion in planning palliative and end of life services.

Another barrier to achieving quality care is the inability of health professionals to recognise and appropriately treat those who are dying. Advances in medical care mean that we can do more to treat illnesses and the majority of people now die in acute care settings with many being actively treated right up to the moment of their death. Part of the difficulty lies in our lack of understanding of the indistinct boundaries between chronic and complex health care problems, ageing and dying.

The provision of specialist palliative care services in Australia and many other countries has mainly been for people dying of cancer. Providing appropriate care and services for patients who are dying from non-malignant diseases is a significant priority. The overarching principle of a needs-based system is providing care on the basis of need rather than diagnosis.

Special needs groups present particular challenges; for example the complex cognitive, emotional and social considerations that accompany dementia. Similarly, for people with Motor Neurone Disease it is difficult to predict the prognosis at the time of its diagnosis, which presents problems for planning palliative and end of life care. It is important to recognise that the higher and more complex a person's needs, the more appropriate it is to involve palliative care specialists regardless of the clinical setting. The importance of recognising who may benefit from specialist palliative care services needs to gain increasing awareness in both residential care settings and at the primary care level with general practitioners.

The delivery of care to people who are dying is essential in all types of care settings including acute wards, emergency departments, hospices, nursing homes and home care. However many of the problems associated with the provision of complex cases of end of life care relate to barriers that occur at the interfaces between these settings as well as between services and health care professionals. It is important that patients and their families and carers are given an informed choice based on an understanding of their realistic options and likely outcomes of various treatment modalities. An emerging approach in developing effective communications between all consumers and health professionals is the process of advance care planning.

Each community is unique and models of care need to be flexible and responsive to local circumstances, such as access to services for rural and remote patients as well as sensitivity to culturally diverse populations. The evidence suggests that there are profound cross cultural differences in end of life decision making concerning autonomy, advance care planning, truth telling and communication in general. For example a culture-centred, person-focused approach to end of life care is needed for Aboriginal and Torres Strait Islander Australians to accommodate their spiritual and cultural needs.

A major challenge to the equitable access to palliative and end of life services is the poor distribution of health professionals, particularly in rural and remote regions. Accessibility means being able to see the right health professional at the right time in the right place. It is essential that services are able to be accessed at any time in the 24/7 cycle, including the consistent use of referral 'triggers' to assist in timely review as a patient's circumstances change.

A number of workforce changes are occurring to the skill mix of health professionals caused by new team based and shared care models. These changing dynamics require additional training and education for health care workers in areas such as professional resistance and poor interpersonal relationships that are often an inherent barrier to teamwork. The National Health and Hospitals Reform Commission (NHHRC) has recommended a new framework for the education of health professionals that includes agreed competencies that will in the future include palliative and end of life care competencies.

Building the capacity of the workforce will require support and empowerment to take on the challenge of continuous learning from the undergraduate to the professional level.

Aligning and clearly communicating the actions that need to be undertaken by all of those who share the responsibility for reform is fundamental to achieving the goal of a 'good death' for all Australians. What we value as essential for a 'good death'—such as respect, dignity and autonomy—should also be at the core of the process of reform. Values are difficult to embed in the design of health care systems but they allow us to create shared aspirations in a way that political agendas may not. It is proposed that the values that underpin the *Standards for providing quality palliative care for all Australians* (4th Edition) be used as the benchmark against which the reforms included in this Guidance document can be tested and judged.

The recommendations in this Guidance document are well grounded in the three sets of parallel reform processes established through the: NHHRC; National Primary Health Care Strategy; and the Australian Commission on Safety and Quality in Health Care (ACSQHC). Common themes emerge from these reform processes including: services need to be matched to people's needs, including the most appropriate setting to receive those services; services should be delivered in an integrated way across sectoral boundaries; continuity of care is critical, particularly in management of chronic conditions; building capacity and competence in primary health care is a priority, particularly involving multidisciplinary approaches; and improving safety and quality based on information, evidence and continuous improvement.

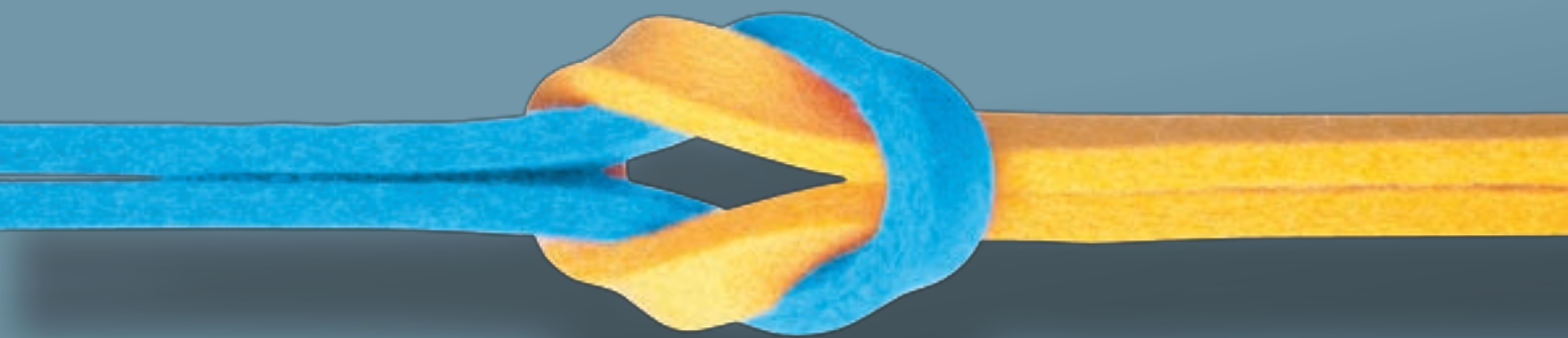
As the health care system begins a complex process of reform, it can be difficult for individual service providers or policy makers to discern the first steps from the plethora of reform recommendations and massive scope of the endeavour. The aim of this Guidance document is to provide governments—federal, state and territory—policy makers, planners and service providers with advice and a pathway forward to establish strategic short, medium and longer term priorities that will result in better care for all people approaching the end of life regardless of their diagnosis, prognosis, setting of care or geographical location. It provides practical guidance on strategic and operational service development as well as the refocusing of current quality and service development activities.

This advice is organised in the following National End of Life Guidance Framework (see the figure on page 6), which has been adapted from the ACSQHC's National Safety and Quality Framework to ensure close alignment with its broad directions.

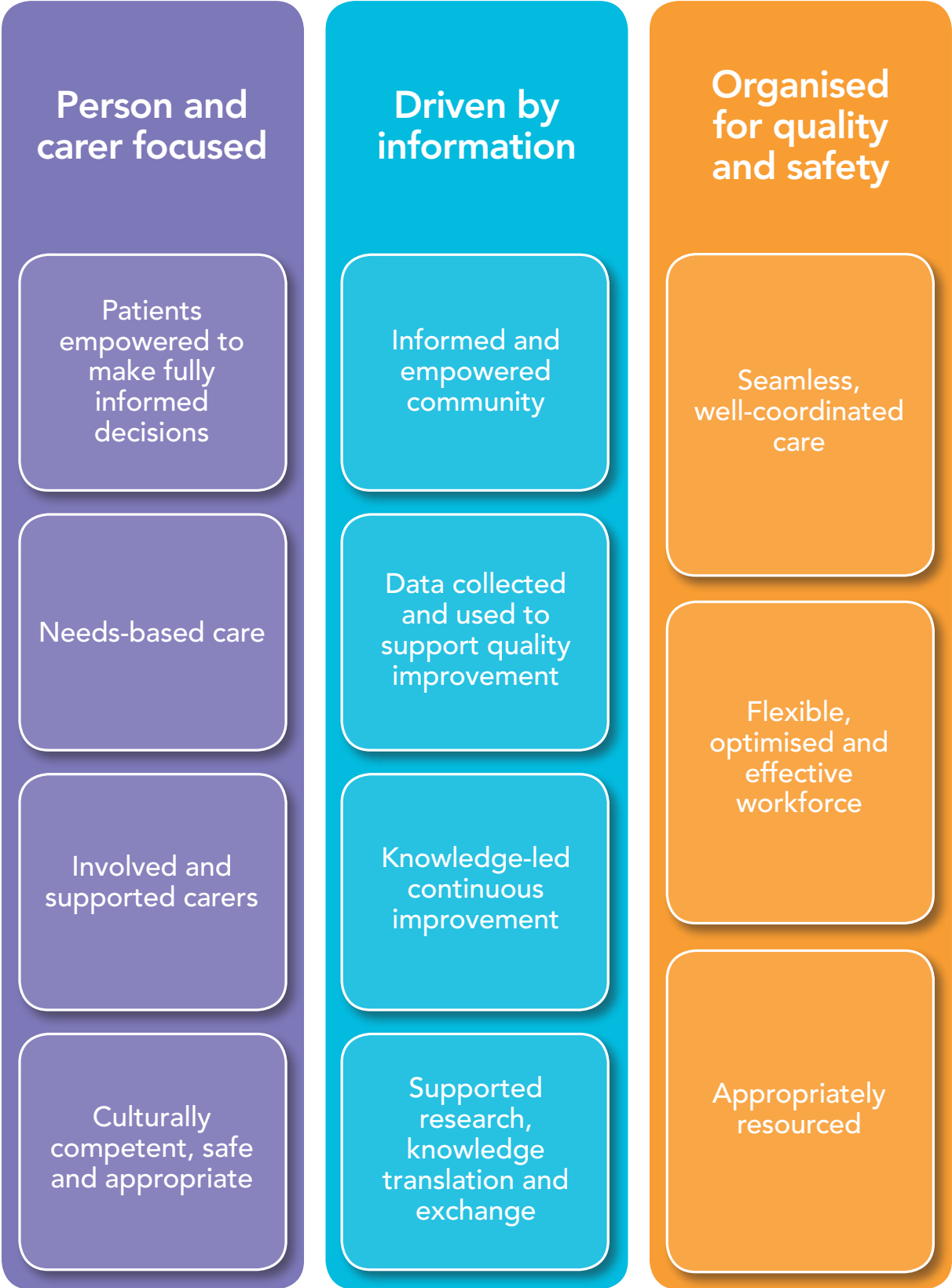
The Guidance takes the form of three overarching priorities or constructs ('patient and carer focused', 'driven by information' and 'organised for quality and safety'), 11 guidance domains and 61 specific guidance elements. It has been designed to guide action to improve the health care system's ability to deliver high-quality care to people in all health care settings who are approaching the end of life. The guidance elements articulate the preconditions for system-wide reform in the context of the directions that have emerged out of the national reform agenda and need to be used alongside other national quality and reform documents including *Primary Health Care Reform in Australia* (2009) and *A Healthier Future for all Australians* (2009).

It is intended that the Guidance document will promote a 'continuing conversation' on high-quality care at the end of life among consumers, carers, students, health professionals, managers, researchers and policy makers.

GUIDANCE DOMAINS AND ELEMENTS



THE NATIONAL END OF LIFE GUIDANCE FRAMEWORK



Guidance Domain 1: Patients empowered to make fully informed decisions

Specific guidance elements:

- 1.1 Develop and implement policies, procedures and tools to support consumer and carer involvement in end of life care planning commencing from the early stages of a life limiting illness.
- 1.2 Develop and implement a national approach to the implementation of advance care planning across the health and aged care systems.
- 1.3 Develop a nationally led, systematic process to develop and disseminate evidence-based, consumer-friendly education and information to support people to make decisions about the location and type care and resources they need as they approach the end of their life.

Guidance Domain 2: Needs-based care

Specific guidance elements:

- 2.1 Develop a national systematic approach to the development of criteria for the recognition of people approaching the end of life.
- 2.2 Introduce standardised, validated assessment tools to determine patient and carer needs at the end of life.
- 2.3 Develop and implement streamlined, consistent holistic assessment of end of life needs across primary, aged care and specialist services.
- 2.4 Develop disease cluster referral triggers that align consumer need and the common trajectories of people approaching the end of life.
- 2.5 Develop and implement a standardised, systematic approach to the implementation of end of life care pathways for acute care, community and aged care settings.

Guidance Domain 3: Involved and supported carers

Specific guidance elements

- 3.1 Support the vital role of carers through the development and dissemination of educational programs, information and access to timely advice regarding end of life care.
- 3.2 Provide access to residential and flexible at home respite care arrangements to assist carers sustain their role in caring for someone approaching the end of life.
- 3.3 Develop and implement appropriate tools to routinely assess and support the health of carers.
- 3.4 Ensure that carers are engaged in care decisions and communications to the extent they wish to be and subject to the consent of the patient.
- 3.5 Directly consult with carers in the processes of policy and services development and evaluation to ensure that their specific needs and experiences related to end of life care are adequately and accurately reflected and acknowledged.
- 3.6 Ensure that carers are provided with resources to enable them to undertake their role providing care to someone approaching the end of life.
- 3.7 Provide access to bereavement support for all carers and families.

Guidance Domain 4: Culturally competent, safe and appropriate

Specific guidance elements

- 4.1 Ensure that cultural and spiritual competence and safety related to end of life care is incorporated into multidisciplinary education programs at all levels.
- 4.2 Ensure that policies, procedures and processes of care respect and reflect different cultural and ethnic values, beliefs and practices that surround death, dying and end of life care.
- 4.3 Support the development and provision of culturally appropriate health information and resources in a range of community languages and access to trained interpreters.
- 4.4 Build relationships between Indigenous and non-Indigenous health care providers that facilitate understanding of cultural differences and care needs at the end of life for Aboriginal and Torres Strait Islander people.
- 4.5 Ensure there are policies, procedures and mechanisms to support 'return to country' for Indigenous Australians who are approaching the end of their life.
- 4.6 Support the strengthening of the role of Indigenous health workers to connect health professionals and services with local communities to support improved end of life care.

Guidance Domain 5: Informed and empowered community

Specific guidance elements:

- 5.1 Strengthen consumer participation and voice in:
 - a) end of life policy and service development;
 - b) community capacity building initiatives; and
 - c) quality review.
- 5.2 Develop a national awareness raising strategy that guides and integrates community awareness, consumer health literacy and community capacity building initiatives in end of life care.
- 5.3 Promote open discussion of death and dying through health and legal professional, education and awareness programs.

Guidance Domain 6: Data collected and used to support quality improvement

Specific guidance elements:

- 6.1 Inventory the data needs related to end of life care of the different stakeholders—government (Commonwealth and state/territory), clinical services (specialist, primary and aged care), funders, clinicians and the wider community.
- 6.2 Collect and use routine data on patient and service level activity and outcomes to support improvement and monitor performance in end of life care.
- 6.3 Ensure that data on safety and quality of care at the end of life is collated, compared and provided back to clinical services and clinicians in a timely fashion to expedite quality and quality improvement cycles.
- 6.4 Develop and support the use of nationally standardised measurement tools.
- 6.5 Enable end of life data linkages between various data collections and repositories held at clinical, national and jurisdictional level.

Guidance Domain 7: Knowledge-led continuous improvement

Specific guidance elements:

- 7.1 Implement, monitor and report on performance against national standards for end of life care across all care settings (specialist palliative care, primary and community care, aged care and acute care).
- 7.2 Report on strategies to improve safety and quality of care at the end of life and the actions taken in response to identified quality and safety issues.
- 7.3 Develop and implement strategies that support the translation and diffusion of evidence and knowledge in relation to the needs and effective care of people approaching the end of life.
- 7.4 Reduce unjustified variation in practice by disseminating evidence and implementing best practice clinical guidelines for palliative and end of life care.

Guidance Domain 8: Supported research, knowledge translation and exchange

Specific guidance elements:

- 8.1 Adopt a national approach to the synthesis and dissemination of clinical evidence/knowledge and research related to end of life to expedite its translation into practice.
- 8.2 Prioritise and invest in clinical and health service research in palliative and end of life care.
- 8.3 Provide dedicated resources for the regular dissemination of research outcomes related to end of life to health services and clinicians.
- 8.4 Develop a national approach to the collection and reporting of patient and family reported outcomes related to end of life.
- 8.5 Enhance the spread of innovation in palliative and end of life care by supporting health service and health professional participation in breakthrough collaboratives, clinical forums, health roundtables etc.
- 8.6 Invest in the development of knowledge transfer methodologies between researchers, health care professionals and policy makers.

Guidance Domain 9: Seamless, well-coordinated care

Specific guidance elements:

- 9.1 Build the capacity and competence of integrated primary and community care services to provide end of life care and support to people approaching the end of their life.
- 9.2 Develop strong partnerships and networks between primary care providers, aged care services, disease specific organisations and services, and specialist palliative care services to support needs-based service delivery for people approaching the end of life.
- 9.3 Ensure 24/7 access to primary care and specialist palliative care services for patients who are approaching the end of their life.
- 9.4 Network specialist palliative care services within defined regions and in accordance with role and capability frameworks.
- 9.5 Expand specialist palliative care outreach services to support the care of people dying at home and in residential aged care facilities.
- 9.6 Utilise emerging technologies (eg. telehealth networks) to enhance communication and support for clinicians, patients and families in rural and remote areas.
- 9.7 Establish referral and advice networks between primary care, aged care and specialist palliative services.
- 9.8 Implement strategies, including the nomination of a case coordinator for the coordination of care for all patients with complex needs at the end of life to assist with navigation, transition and utilisation of services.
- 9.9 Ensure the availability of affordable medication and equipment in appropriate care settings where needed to provide care at the end of life, and ensure that staff are credentialed in their use.

Guidance Domain 10: Flexible, optimised and effective workforce

Specific guidance elements:

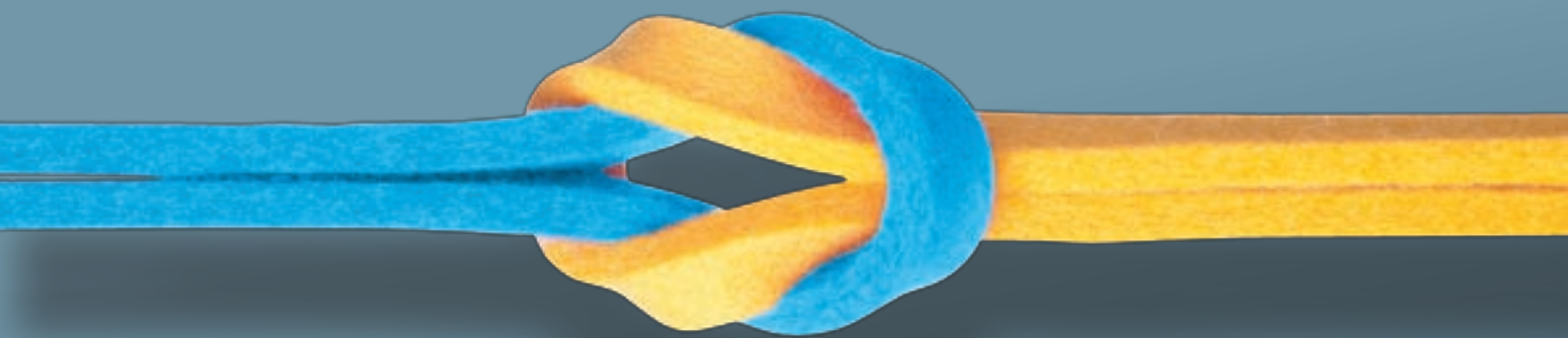
- 10.1 Collect and report standardised national data on the size, skill mix and demographics of the specialist palliative care workforce.
- 10.2 Ensure all primary care and aged care providers have staff trained in advance care planning.
- 10.3 Ensure that all health care professionals whose role interfaces with end of life care have the knowledge and skills to provide care to people who are approaching the end of their life.
- 10.4 Include cross-cultural considerations in death and dying in all undergraduate and specialist palliative care curricula.
- 10.5 Incorporate specific content related to end of life care and needs of ethnic minority and other marginalised groups and Aboriginal and Torres Strait Islander populations, in all undergraduate and specialist palliative care curricula.
- 10.6 Develop and disseminate a nationally consistent set of core competencies for palliative and end of life care to underpin continuing professional education.
- 10.7 Collaborate with Health Workforce Australia to facilitate optimal development and distribution of specialist palliative care and skilled primary care and aged care workforces.
- 10.8 Develop national standards for recruitment, training, supervision and support of volunteers providing care at the end of life.

Guidance Domain 11: Adequately resourced

Specific guidance elements:

- 11.1 Adopt flexible funding arrangements to enable rural and remote communities to access end of life care resources and services to meet their needs.
- 11.2 Develop resourcing formulas that incorporate assessment of local population end of life care needs, cost of service delivery and that support the achievement of desired outcomes.
- 11.3 Ensure public and private funding that is directly linked to care of people who are approaching the end of their life irrespective of the settings of care.
- 11.4 Ensure affordable access to equipment and medications necessary to provide care at the end of life in the community.
- 11.5 Ensure that residential aged care facilities are accurately and adequately resourced to reflect the cost of delivery of end of life care to residents, and support for families and carers.

SECTION 1
PURPOSE AND METHODOLOGY



SECTION 1—PURPOSE AND METHODOLOGY

How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of our society as a whole and it is a litmus test for health and social services.¹

End of Life Strategy, Department of Health NHS (2008)

Hospices and the care of the dying have a long history in Australia with the first services provided by the Sisters of Charity and the Little Company of Mary in the last decades of the nineteenth century.² Building on the strong foundation established by the hospices and earlier palliative care pioneers, palliative care began to be recognised as a mainstream health service in the mid 1980s. Palliative care has achieved much in improving the experience and care of people approaching the end of their life. Access to palliative care services has been shown to improve the experience and outcomes for patients, their carers and family.³ Ongoing investment by Commonwealth and state and territory governments has now ensured some level of access to palliative care services in all States and Territories. More recently there has been significant investment in building the capacity of primary care services to provide care for people approaching the end of life.⁴

While these efforts have enhanced accessibility and quality of care, there is still much to be done before all Australians have access to needs-based high-quality care as they approach the end of their life. For most people, the time they spend living with an illness that will end in death is not spent in either a hospice or in the care of palliative care services, but rather in the community and acute care hospitals. Also people are increasingly dying from chronic illnesses where their need for care may span many years, or even decades. The health system is poorly designed to meet the needs of these patients, who

either fall through the gaps or receive inappropriate and ineffective care.⁵

There is an emerging understanding that more needs to be done to improve the experience of people as they approach the end of their life.⁶ While some people do die as they might have wished and/or experience excellent care in hospitals, hospices, residential aged care facilities (RACFs) and at home, many do not.

End of life care within Australian health and social policy and services has had a relatively low profile. The health system in the main is designed to treat and cure disease and to provide short-term, episodic care of acute illness. Acute care systems are focused on providing treatment and cure—increasing survival and reducing mortality. For patients who are dying this can result in the delivery of care that is either inappropriate or inadequate. It can also create significant moral distress for health professionals working in these systems and who recognise that the care they provide in some cases is not what they would want for themselves or for their families.⁷

As the Australian health care system undertakes reform, it is timely to address the fundamental questions about how we care for people who are dying.

The recent work of the National Health and Hospitals Reform Commission (NHHRC)⁸, has thrown a spotlight on the health and social system's responsibility for the care of people who are approaching the end of their life. While the

1 Department of Health NHS 2008, *End of Life Care Strategy: Promoting high quality care for all adults at the end of life. Executive Summary*, London.

2 Lewis, MJ 2007, *Medicine and Care of the Dying. A modern history*, Oxford University Press. New York.

3 Currow, DC et al. 2008, 'Comfort in the last 2 weeks of life: relationship to accessing palliative care services', *Support Cancer Care*, vol. 16(11), pp. 1255–63.

4 Australian Government Department of Health and Ageing website: <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-program.htm> (accessed 12 May 2009)

5 Lynn, J 2005, *Living long in fragile health: The new demographics shape end of life care*. In *Improving end of life care: Why has it been so difficult?*, Hastings Centre Report, Special Report 35: No.6, pp. S14–S18.

6 Covinsky, KE et al. 1994, 'The impact of serious illness on patients' families. SUPPORT Investigators. Study to understand prognoses and preferences for outcomes and risks of treatment.' *JAMA*, vol. 272(23), pp. 1839–44.

7 Hillman, K 2009, *Vital Signs: Stories from intensive care*, University of New South Wales Press, Sydney.

8 Australian Government National Health and Hospitals Reform Commission 2009, *A Healthier Future for all Australians—Final Report*, June 2009.

proposed reforms could be seen to be responses to the challenges—both economic and demand for access—facing the hospital and acute care system, they present an opportunity to review and reconsider how systems of care might better enable a dignified, peaceful and respectful death.

Reform in the area of end of life care can be shaped and driven by values that define what it is that we hold to be essential components of a 'good death'.⁹ Values can be subtle, multi-faceted and complex. They can be hard to systematically embed in the design of health care systems and hard to operationalise in the practical day-to-day work of providing care. But they allow us to cross political and sectoral boundaries and create common and shared aspirations in a way that pragmatic and political agendas may not. Those things that we collectively value as essential for a good death—respect, autonomy, dignity—should be at the core of the process of reform of care for those who are dying.¹⁰

This Guidance document proposes the values that underpin the *Standards for providing palliative care for all Australians (4th Edition)*¹¹ as the benchmark against which the proposed reforms can be tested and judged.

Working together to meet the need for care of people approaching the end of their life means that the unique and complementary contribution of all who have a role to play must be recognised, coordinated and resourced.¹² Specialist palliative care services and practitioners are required and will continue to be required to:

- meet the needs of people with complex problems;
- provide education and support to others providing end of life care; and
- contribute to the ongoing development and dissemination of knowledge that will improve care.

Specialist palliative care services need to be organised and resourced to ensure that they can meet these demands. All people with a life-limiting

illness require as an absolute minimum access to health services and professionals that have knowledge and skills in end of life care. The fundamental role that acute care, aged care and primary care services play in meeting the needs of people at the end of life should be supported to ensure that they are adequately prepared and resourced and that networks between their services and specialist palliative care services are established and formalised.

Providing care and supporting people as they approach the end of their life is a broad social responsibility. It falls on individuals, communities, health and social care systems, educators and employers. Aligning and clearly communicating the actions that will need to be undertaken by all of those who share this responsibility and share aspirations for reform is fundamental to achieving the goal of a 'good death' for all Australians.

Purpose

As the wider health care system begins a process of overdue reform and reorganisation it can be difficult for individual services or policy makers to discern the essential first steps. The sheer volume of reform recommendations and the massive scope of the endeavour can be overwhelming for the very individuals who can make it a reality. The Guidance set out in this document proposes a pathway forward for those who are concerned and accountable for the care of people who are approaching the end of life. It draws together the general reform directions and applies them to the specific objective of improving end of life care.

It has been designed to guide practical action to improve the health system's ability to deliver high-quality care to people approaching the end of life in all health care settings. This Guidance should be used by policy makers, planners and service providers alongside the national quality and reform documents to:

- form the basis for strategic and operational service development and improvement plans and priorities;

9 Smith, RA 2000, 'A good death'. *BMJ*, vol 320, pp. 129–130.

10 Murray, TH 2009, *Connecting American Values with Health Reform*, Hastings Centre http://www.thehastingscenter.org/uploadFiles/Publications/Primers/Connecting_American_Values.pdf. (accessed Feb 2010).

11 Palliative Care Australia 2005, *Standards for providing palliative care for all Australians (4th Edition)*, Canberra.

12 Palliative Care Australia 2005, *A guide to palliative care service development: A population based approach*, Canberra.

- provide a mechanism for refocusing current quality and service development activities and reviewing investments in health services delivery; and
- promote discussion with consumers, clinicians, managers, researchers and policy makers.

The various Guidance elements articulate the preconditions for system-wide reform that are necessary to achieve best practice in end of life care and propose an agenda for ongoing improvement.

Developing the Guidance document

The development of the Guidance has been informed by a range of information and evidence sources (Figure 1).

The embedded values of the national palliative care standards were used to guide the development of the Guidance elements. These values have represented the aspirations for quality care at the end of life that have been held by patients, communities and health professionals in Australia for more than a decade. They were reconfirmed in a national consultation on the standards in 2004 and also as part of the consultations undertaken for the PCC4U undergraduate palliative care curriculum project.¹³

The Guidance has been significantly influenced by the major national reform processes that are currently underway in Australia, along with related literature on health and end of life reform issues. International end of life reform documents and related literature were also reviewed in preparing the Guidance document.

In addition, feedback received from a series of national consultations on end of life care was reviewed and used to shape and develop the Guidance elements. These consultations were broadly structured around the central question:

What would a reformed health care system that could deliver high-quality care at the end of life for all look like?

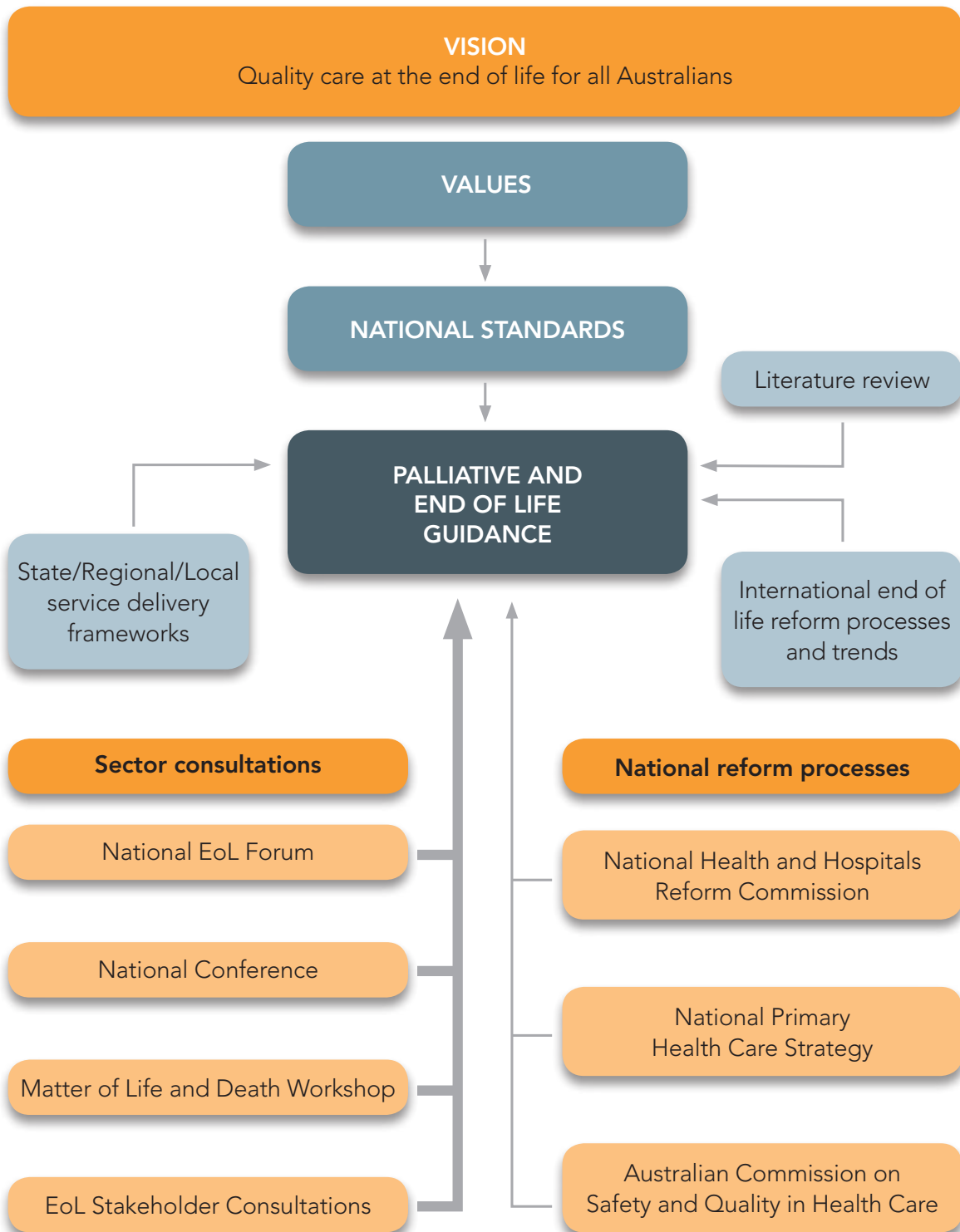
The principal consultation was undertaken with a broad-based group with experience and expertise in palliative and end of life care in October 2009 and March 2010 (National EoL Framework Forum). This National Forum has provided the impetus and imprimatur to develop this Guidance document. Additional input has been provided from a workshop held as part of the National Palliative Care Conference in September 2009 as well as a National End of Life Forum in March 2008.¹⁴

Figure 1 (opposite) shows the process and sources that were used to inform the development of the Guidance.

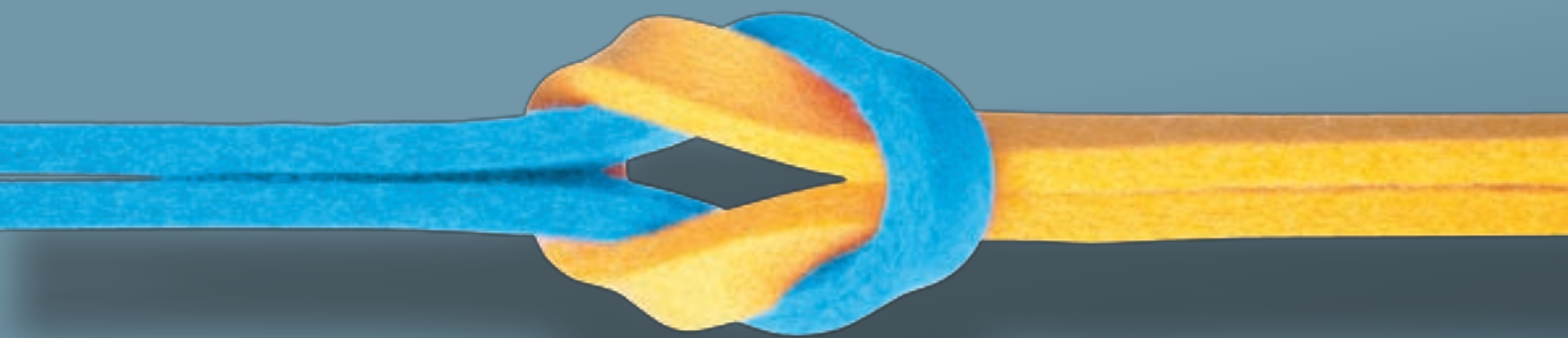
¹³ CPCRE 2005, *Principles for including palliative care in undergraduate curriculum*, The National Palliative Care Program.

¹⁴ The National End of Life Forum was held in Canberra in March 2008 and was attended by over 100 participants. The invited speakers, Dr Joanne Lynn, Prof Michael Ashby, Prof Patricia Davidson and others outlined the challenges of delivering high-quality care to all patients as they approached the end of their life, particularly to older people, those with chronic and complex care needs and those in acute care settings. Participants workshopped strategies that would improve care across a range of health care settings, including aged care, primary care, acute care and specialist palliative care.

Figure 1: The development of the Guidance



SECTION 2
VALUES DRIVEN REFORM



SECTION 2: VALUES DRIVEN REFORM

Understanding what is at stake in a public policy debate is as vital as it can be elusive.

Thomas H. Murray PhD, President, Hastings Centre¹⁵

Linking end of life care values to health system reform

In the midst of a process of widespread and rapid reform, primarily driven by concerns about the ongoing funding and sustainability of the hospital and acute care sector, there is a need to remain focused on what matters most about the care of those approaching the end of life. When it is recognised that the goal of care at the end of life is to preserve and protect the person's dignity and autonomy, to respect their choices and preferences, and to provide care that is both compassionate and competent, we are compelled to think broadly about the direction and nature of the reforms necessary to achieve those goals. Embedding our values in the reform process allows us to create a language that crosses sectoral boundaries and creates an imperative that can be shared by all. Care becomes a partnership between patients, carers, communities and professionals built around shared values.

In Australia we have clearly defined the values that are essential components of high-quality care at the end of life. They were initially described in 1999 and have been endorsed by consumers¹⁶ and health professionals.¹⁷ These values set out what patients, families and health care practitioners believe matters most in the delivery of care to people approaching the end of life. Together they provide a roadmap for quality care—a set of rights and responsibilities that can act as a reference standard for the reform journey and its outcomes.

We believe that quality care at the end of life is provided by health care workers who:

- endeavour to maintain the **dignity** of the patient, their caregiver and family;
- work within the strengths and limitations of the patient, their caregiver and family to **empower** them in managing their own situation;

- act with **compassion** towards the patient, their caregivers and family;
- consider **equity** in the accessibility of services and in the allocation of resources;
- demonstrate **respect** for the patient, their caregivers and family;
- **advocate** on behalf of the expressed wishes of patients, caregivers, families and communities;
- are committed to the pursuit of **excellence** in the provision of care and support; and
- are **accountable** to patients, caregivers, families and communities.

These values—dignity, empowerment, compassion, equity, respect, advocacy, excellence and accountability—should underpin the reform of the health care system. Indeed, the success of the reform process could be measured by the extent to which these values are upheld.

Standards for providing quality palliative care for all Australians¹⁸

The national palliative care standards have been based on the foundation values described above and set out the reasonable expectations of quality in the delivery of care to those approaching the end of life (Figure 2).

The national standards have been adopted by all states and territories to guide the development of palliative and end of life services. They provide a practical and accessible mechanism for communicating and monitoring the quality of care provided to patients and their families and carers.

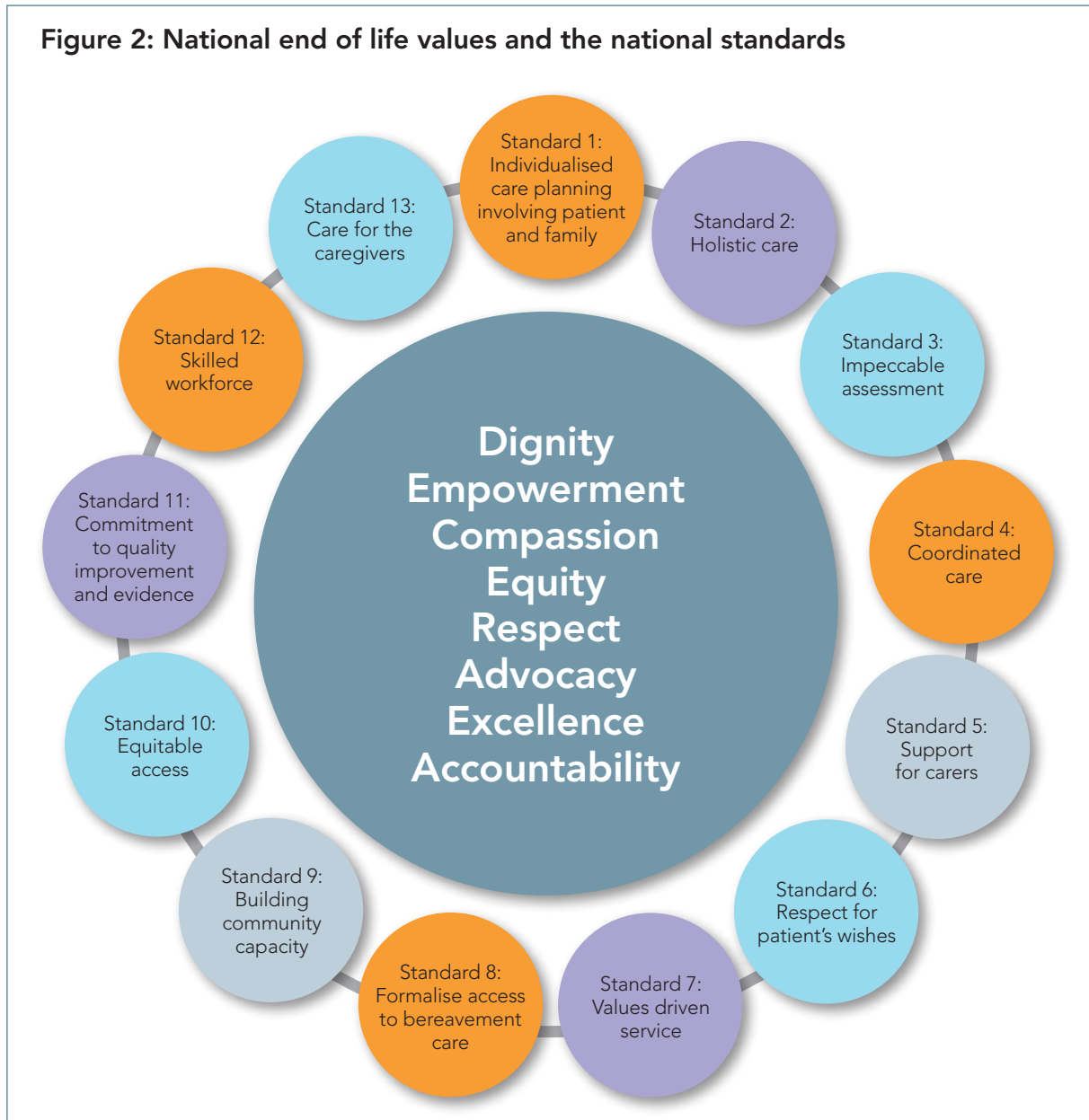
¹⁵ Murray, TH 2009, *op. cit.*

¹⁶ Palliative Care Australia 1999, *Palliative Care Standards* (3rd Edition), Canberra.

¹⁷ CPCRE 2005, *op. cit.*

¹⁸ Palliative Care Australia 2005, *Standards for providing quality palliative care for all Australians* (4th Edition), *op. cit.*

Figure 2: National end of life values and the national standards



There are 13 national standards in the *Standards for providing quality palliative care for all Australians* (4th Edition) as follows:

Standard 1

Care, decision making and care planning are each based on a respect for the uniqueness of the patient, their caregivers and family. The patient, their caregivers and their family's needs and wishes are acknowledged and guide decision making and care planning.

Standard 2

The holistic needs of the patient, their caregivers and family are acknowledged in the assessment and care planning processes and strategies are developed to address those needs in line with their wishes.

Standard 3

Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient, their caregivers and family.

Standard 4

Care is coordinated to minimise the burden to the patient, their caregivers and family.

Standard 5

The primary caregiver is provided with information, support and guidance about their role according to their needs and wishes.

Standard 6

The unique needs of dying patients are considered, their comfort maximised and their dignity preserved.

Standard 7

The service has an appropriate philosophy, values, culture, structure and environment for the provision of competent and compassionate palliative care.

Standard 8

Formal mechanisms are in place to ensure that the patient, their caregivers and family have access to bereavement care, information and support services.

Standard 9

Community capacity to respond to the needs of people who have a life limiting illness, their caregivers and family is built through effective collaboration and partnerships.

Standard 10

Access to palliative care is available for all people based on clinical need and is independent of diagnosis, age, cultural background or geography.

Standard 11

The service is committed to quality improvement and research in clinical and management practices.

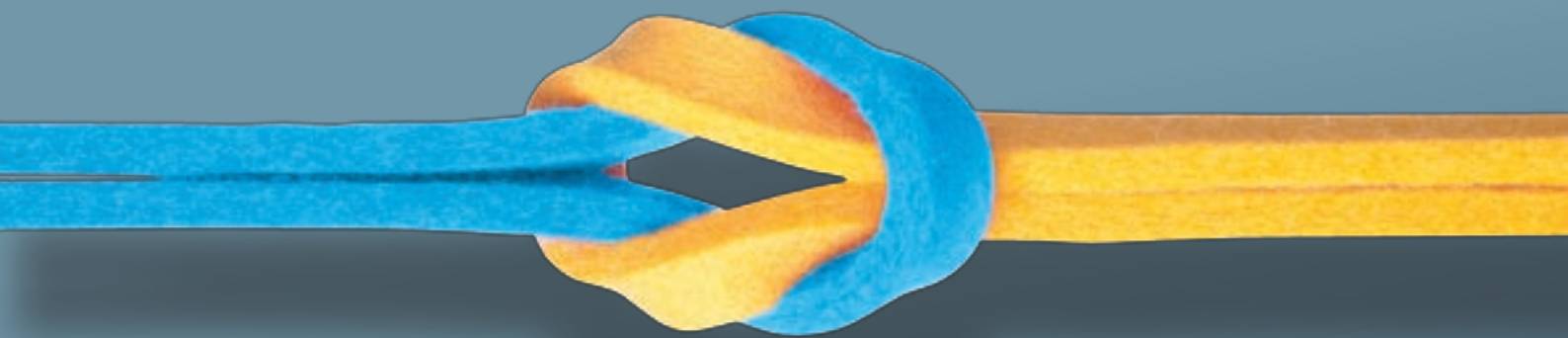
Standard 12

Staff and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development.

Standard 13

Staff and volunteers reflect on practice and initiate and maintain effective self care strategies.

SECTION 3
DYING DIFFERENTLY
UNDERSTANDING COMPLEXITY
AT THE END OF LIFE



SECTION 3: DYING DIFFERENTLY—UNDERSTANDING COMPLEXITY AT THE END OF LIFE

Understanding death in Australia

In 2008 there were 143 946 deaths registered in Australia.¹⁹ It is estimated that almost three quarters of these deaths could have been anticipated as they followed a period of chronic illness caused by conditions such as cancer or heart disease.²⁰

The patterns of death in relation to age, cause of death and place of death have changed radically in the past 100 years. There has also been a remarkable change in how people approach and are cared for at the end of life. One hundred years ago people usually died at home, cared for and supported by family, friends and community. They were more likely to die suddenly following a short, acute illness—commonly infection or injury. Many people died at a young age either during childhood or early adulthood.

Nowadays people are most likely to die in a hospital or other institutional setting.^{21,22} They are more likely to be elderly, to die as a consequence of the end stages of advanced chronic illness and be less likely to have family or community supports available to them. Projections of the demand for care at the end of life suggest that the trend towards institutional care will increase as the number of people dying each year grows in absolute terms, and as the proportion of elderly people in the community exceeds the availability of carers.

This section explores the nature of death and dying in Australia in the first decade of the new millennium and the outlines the projections for the next 20–30 years.

Who dies?

Number of deaths

Of the 143 946 deaths in Australia in 2008 just over half (73 548) were male and 70 398 were female. This represented an increase of 4.4 per cent compared with the number of deaths registered in 2006.²³

The steady increase in the number of deaths over time reflects an increase in the overall size of the population, and in particular a proportional increase in the number of older people. With the continued ageing of the population the number of deaths is projected to continue to increase through the remainder of the century.²⁴ It is projected that by 2056 the death rates will more than double to over 320 000 registered deaths per annum.²⁵

Age

Decedents aged over 65 account for 79 per cent of all deaths, and those aged over 80 for just over half of all deaths (51%). The median age at death was 77.9 years for males and 83.9 years for females.²⁶ While the majority of deaths occurred in older people, younger people also experience life limiting illnesses.

Culturally and Linguistically Diverse

Australia's overseas born population accounted for 30 per cent of deaths registered in 2008 (43 100 deaths), despite making up only 26 per cent of the resident population. This is due to the older age structure of the overseas-born population (with a median age of 45.7 years in 2008) compared with the Australian-born population (with a median age of 33.2 years).

Recent data published by the Palliative Care Outcomes Collaborative (PCOC) suggests that almost one third (32.1%) of patients seen by specialist palliative care services were born overseas.²⁷

Aboriginal and Torres Strait Islanders

There were 2500 deaths registered in Australia in 2008 where the deceased person was identified as being of Aboriginal, Torres Strait Islander or both origins (Indigenous). It is believed that there is under-reporting of Indigenous status.²⁸

19 ABS 2009: 2008 Deaths Australia, Cat No. 3302.0.

20 Palliative Care Australia 2008, <http://www.palliativecare.org.au/Portals/46/PCA%20submission%20to%20NHHCRC.pdf> (accessed 12 May 2010)

21 Foreman, LM et al. 2006, 'Factors predicative of preferred place of death in the general population of South Australia'. *Palliative Medicine*, vol. 20, pp. 447–53.

22 Tabor, B et al. 2007, *Place of Death of people with cancer in NSW*. Cancer Institute NSW.

23 ABS 2009, *op. cit.*

24 *ibid.*

25 *ibid.*

26 *ibid.*

27 Palliative Care Outcomes Collaborative 2009, *National Report on Palliative Care in Australia—January–June 2009*.

28 ABS and AIHW 2005, *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples*.

Table 1: Numbers of deaths in Australia 2008 (ABS Cat 3303.0)

State	No of deaths	Median age (M)	Median age (F)	No. Indigenous deaths	Indigenous deaths as % of all deaths
NSW	48 782	78.3	84.0	559	1.15
VIC	35 497	78.5	84.2	97	0.27
QLD	27 335	77.0	83.4	562	2.06
SA	12 616	79.0	84.5	141	1.12
WA	12 752	76.3	83.7	605	4.74
TAS	4 219	78.1	83.3	24	0.57
NT	1 041	61.5	61.5	467	44.86
ACT	1 697	78.1	83.0	16	0.94
AUST	143 946	77.9	83.9	2 472	1.72

Life expectancy for Indigenous Australians is on average 17 years less than for non-Indigenous Australians. Life expectancy for Indigenous males was 59.4 years in 1996–2001 and 64.8 years for females. This is compared with 76.6 years for all males in 1998–2000 and 82.0 for all females. These Indigenous life expectancies are similar to those of Australians overall a century ago.

Compared with death rates for non-Indigenous Australians, Indigenous rates for both males and females were:

- almost three times as high overall
- three times as high for infants
- five times as high for those aged 35–54
- higher in all other age groups.

Death rates for Indigenous Australians are among the highest in the world. For Indigenous Australians aged 25–45, death rates are 5–8 times those of non-Indigenous Australians leading to a life expectancy 19 years less than non-Indigenous Australians for this group.²⁹ Indigenous people are less likely to use health care facilities of all types except where there are well established Indigenous health services. This means that major conditions such as cancers often come to medical attention late in the course of the illness. The services offered by Indigenous health care providers may have fewer

links with mainstream services and be less aware of what palliative care can offer.

What do people die of?

The pattern of the causes of death is also changing. In the early 20th century the major causes of death were infection and injury. At the commencement of the 21st century the pattern had changed to one that was characterised by chronic illnesses—cancer, heart, respiratory and renal disease and the diseases of old age.

Today chronic illness makes up more than 70 per cent of Australia’s overall disease burden. This is expected to increase to 80 per cent by 2020.³⁰

As people approach the end of their life they are faced with multiple, chronic and complex medical problems. In 2008 a mean of 3.2 causes contributing to death were reported for each person registered.³¹ At least 70 per cent of people will be living with one or more chronic illnesses by the age of 65.³²

In 2008 the major cause of death was diseases of the heart and circulatory system.³³ The incidence of cardiovascular disease is projected to increase by 14 per cent by 2021 and by 51 per cent for cancers.

29 Hayman, N 2003, ‘Indigenous health today’. *RACP News*, vol. 22, pp. 5–6.

30 Vos, Tet al. 2005, *Australian burden of disease and injury study: projected health care costs report*, University of Queensland and AIHW, Brisbane.

31 ABS 2010. *2008 Causes of Death*. Cat No. 3303.0.

32 Tsisis, P 2009, ‘Chronic disease management and the home-care alternative in Ontario Canada’. *Health Services Management Research*; vol. 22, pp. 136–9.

33 ABS 2010, *op. cit.*

In 2008 the four leading causes of death were³⁴:

- heart and circulatory disease—48 456 people or 34 per cent of all deaths.
- cancer—42 418 deaths or 30 per cent of all deaths. One-in-three people can expect to develop cancer by age 85.
- end stage organ failure (end stage of chronic renal, or respiratory disease or diabetes)—17 160 people or 12 per cent of all deaths.
- dementia and Alzheimer's Disease—8 171 people or 6 per cent of all deaths. Deaths from dementia related illness have increase 138 per cent since 1999.

Compared with causes of death for non-Indigenous Australians, the causes of death for Indigenous males and females respectively were:

- 7.5 and 10.5 times as high for endocrine, nutritional and metabolic diseases
- 5.3 and 7.3 times as high for diseases of the genitourinary system
- 2.7 and 3.2 times as high for injuries and poisoning
- 2.9 and 2.5 times as high for diseases of the circulatory system
- higher for a range of other broad causes as well.³⁵

Where do Australians die?

Most people will say that they want to die at home.³⁶ However, the reality is that most people will eventually die in an institutional setting.³⁷ Many factors influence the actual place of death for an individual, and for some their desire to remain at home will change as their illness progresses.

A number of studies about place of death have reached similar conclusions. A 2007 NSW study found that nearly two-thirds of cancer patients died in public hospitals and less than 20 per cent died at home.³⁸

In South Australia researchers undertaking a similar study found that 75 per cent of cancer patients died in hospital or hospice and only 15.8 per cent died at home.³⁹ Research in Western Australia examining deaths from all causes (excluding sudden and accidental deaths) found that over one-third of people die in their usual place of residence, and close to two-thirds died in some form of institutional setting.⁴⁰

As the Australian population ages we can expect that more people will require residential aged care and many will die there. The population of residential aged care facilities is expected to increase by 70 per cent in the next 30 years.⁴¹ Currently, almost one-third of people who are admitted to a residential aged care facility as high care residents will die within six months of admission⁴², and 61 per cent will die within one year.⁴³ By 2020 half of all deaths are expected to occur in residential aged care facilities.⁴⁴

Patient journeys at the end of life

The broad health system reform agendas call for care centred around each individual patient. Improving person-centred care for all people at the end of life requires that we develop systems that support and enable high-quality, safe care of individual patients. Grounding the development of these systems in the experience of patients and understanding the common characteristics of their journeys is critical to achieving the reform goal of a person-centred system of care.

Failure to develop system-wide approaches to improving care at the end of life will continue to allow unacceptable variation in the quality of care and experience. Lynn argues that although each patient's journey at the end of life is unique and individual, people do have similar needs that can be predicted and that should be planned for.⁴⁵ Lynn calls this 'mass customisation'.

34 *ibid*.

35 ABS and AIHW 2005, *op. cit*.

36 Foreman, LM et al. 2006, *op. cit.*, pp. 447.

37 McNamara, B et al. 2004, *Who receives specialist palliative care in Western Australia—and who misses out*, University of Western Australia.

38 Tabor, B et al. 2007, *Place of death of people with cancer in NSW*. Sydney. Cancer Institute NSW.

39 Hunt, RW et al. 2001, 'Where patients with cancer die in South Australia 1990–1999: a population based review'. *MJA*, vol. 175, pp. 526–9.

40 McNamara, B et al. 2004, *op. cit*.

41 Giles, LC et al. 2003, 'Disability in older Australians: projections for 2006–2031'. *MJA*, vol. 179, pp. 130–133.

42 AIHW 2008, *Residential aged care in Australia 2006–2007: A statistical overview*.

43 Hudson, R and O'Connor, M 2007, *Palliative and Aged Care: A guide to practice*, Ausmed Publications.

44 Sheenan, D and Schirm, V 2003, 'End-of-life care of older adults'. *American Journal of Nursing*, vol. 103, pp. 48–58.

45 Lynn, J 2005, *op. cit*.

The mass customisation approach conceptualises the problem of end of life not as a problem of decision making by the patient and clinician, but as one of system design and reform. It allows the design of systems to match the size of the population and to meet their predictable needs.

It is grounded in the observation that most illnesses follow fairly stereotypical pathways over the last months and years of life. Lynn has described three common illness trajectories that define care needs over time.⁴⁶

These illness trajectories have been conceptually based on longitudinal, qualitative studies.⁴⁷ More research is needed to understand how awareness of trajectories can be translated into improvements in outcomes for people approaching the end of their life. Nevertheless, thinking about reform in terms of these illness trajectories provides a broad framework for understanding timeframes and patterns of probable needs and patterns of interactions with health and social services.

Understanding these common illness trajectories and their characteristics may also help health professionals and patients, their families and carers better plan and prepare for their journey at the end of life.

While illness trajectories provide a conceptual overview of the characteristic course of chronic, progressive illness at the end of life, individual patient journeys may vary widely. People may die at any stage along each trajectory and the rate of progression may also vary. Other disease and social or family circumstances may arise and change priorities or needs. Some diseases may follow all or none of the described trajectories. Each individual journey at the end of life is different and careful assessment and good communication is necessary to achieve the desired outcome of a timely, dignified and peaceful death.

The three common illness trajectories proposed by Lynn are described below:

Trajectory 1

Trajectory 1 is characterised by a short period of evident decline over a period of weeks or months. Good function may be maintained for some time, with a few weeks or months of rapid decline as the illness becomes overwhelming and leads to death.

Generally there is time to anticipate needs and plan for end of life care. While many diseases follow this course, it is typical of the major cancers. This trajectory meshes well with traditional palliative care services that concentrate on providing comprehensive care over the last weeks or months of a person's life. About 20 per cent of people will follow this trajectory.

Trajectory 2

Trajectory 2 is characterised by long-term limitation of function with intermittent severe, acute episodes. Patients with heart failure or chronic obstructive pulmonary disease (COPD) are usually ill for many years. They frequently experience acute and often severe exacerbation of their physical symptoms. These exacerbations are frequently associated with admission to hospital and intensive treatment.

If patients survive an episode, they may well return home without much progression of their everyday disabilities. Patients usually survive many such episodes but at some point, rescue attempts fail.

The timing of death is often a surprise in this group, despite their long-term chronic illness. Although many illnesses can follow this course, chronic heart failure and emphysema are the most common. About 25 per cent of people will follow this trajectory.

Trajectory 3

Those who escape cancer and organ failure as they age will be likely to die of either dementia or generalised frailty.⁴⁸

This trajectory is characterised by progressive disability from a baseline of already low cognitive or physical function. Gradual decline in functional capacity combined with the impact of often minor physical events—for example a fall or a respiratory or urinary infection—can prove fatal. Approximately 40 per cent of people will follow this trajectory.

The three characteristic trajectories described above are roughly sequential in relation to the ages afflicted, with illness trajectory 1 (cancer) peaking around age 65, fatal chronic organ system failure (trajectory 2) about a decade later and frailty and dementia (trajectory 3) afflicting those who live past their mid eighties.

It is recognised that some people (approximately 15 per cent) will have illnesses that will not follow any of

46 *ibid.*

47 Murray, SA et al. 2005, 'Illness trajectories and palliative care'. *BMJ*, vol, 330, pp. 1007–1011. Downloaded from www.bmj.com (accessed 2 June 2008).

48 *ibid.*

the three trajectories described by Lynn, particularly those that are rapidly progressive such as Motor Neurone Disease (MND). These present unique challenges (see Section 4).

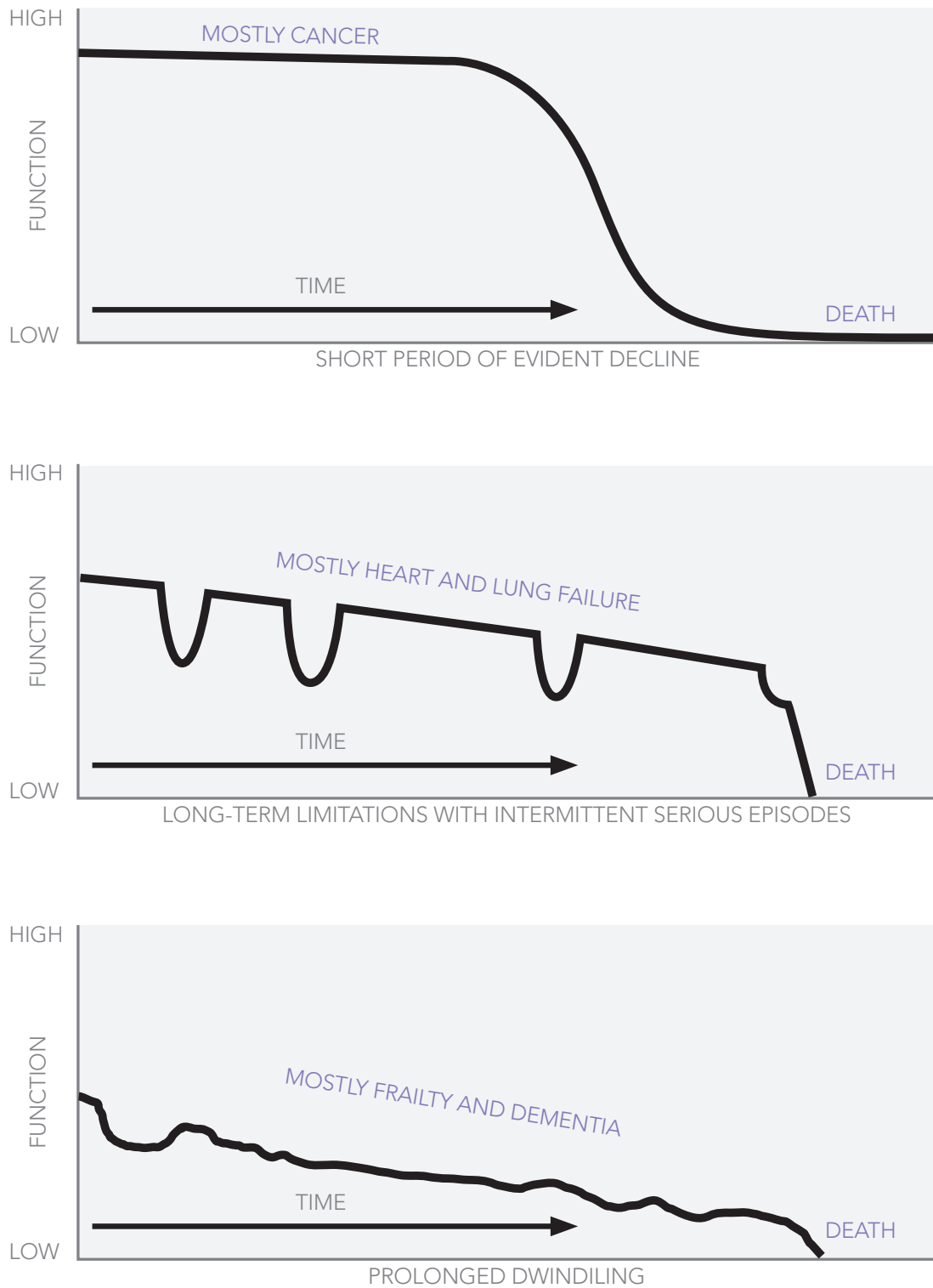
Lynn proposes that society could build care arrangements around these three patterns of experience and need.⁴⁹ This anticipatory planning approach does not rest on the premise that good care arises solely from the prudent choices of individual doctors and patients. It proposes that good care starts with a health care system arranged to serve the needs of the majority of patients rather than one that requires tailoring to meet the need of every individual patient or clinician. Good care should be built into the system to ensure that even when individuals have not or are unable to specify

choices or preferences they will still receive quality care because the system has been designed to ensure that they will.

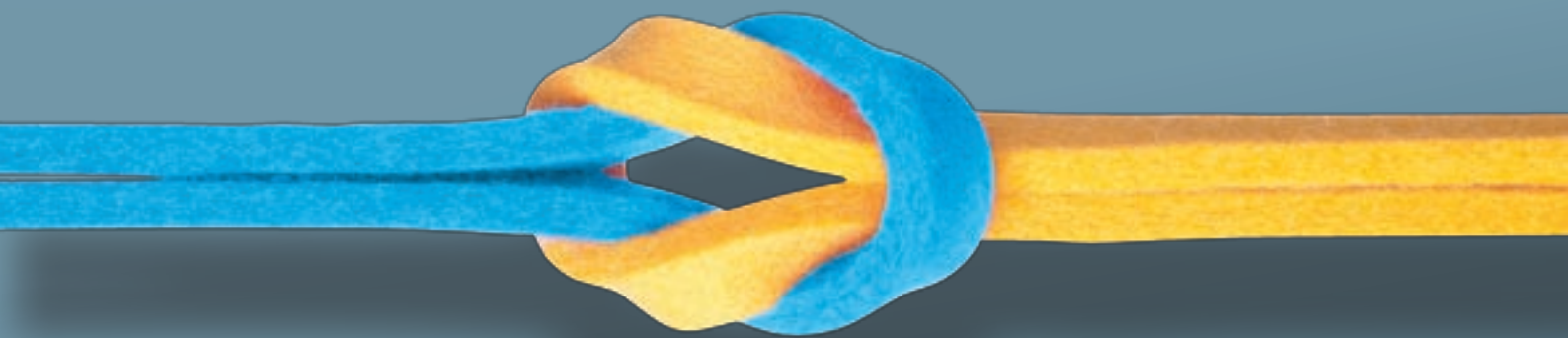
While each person's journey is different, there are common patterns of symptoms, experiences and in the need for, and use of, health care services. The key to caring well for people as they approach end of life is to understand how they are likely to die and to plan appropriately at the individual consumer and system levels. Lynn's approach does not remove or reduce an individual's autonomy or the need to communicate and plan well with people as they approach the end of their life. Rather it adds system support for those elements and needs that we can predict from the accumulated knowledge about end of life experiences

Figure 3: Illness trajectories at the end of life

(Lynn J and Adamson DM. (2003) *Living well at the end of life: Adapting health care to serious chronic illness in old age*. Rand Health. Santa Monica CA)



SECTION 4
CURRENT ISSUES
AND CHALLENGES



SECTION 4: CURRENT ISSUES AND CHALLENGES

The health system has changed radically over the past half century. Advances in medical care mean that we can now do more to treat illnesses and conditions that were once more immediately fatal. Consequently we live longer and die differently from those who lived 50 or 60 years ago. The current misalignment between the orientation of the health system and the needs of people approaching the end of life creates challenges in ensuring that patients, and their families and carers, have the best possible experience.

These challenges exist at all levels from the individual patient level to communities, health professionals and care systems. In part they emerge as a consequence of our difficulty in facing the reality of death, talking about death and dying and communicating with those who are approaching the end of their life. These challenges also arise from whole of health system structural impediments that are associated with health system fragmentation and a complexity of funding responsibilities and performance accountabilities between governments.⁵⁰ They are further compounded by little common understanding or agreement between states/territories—or within the sector—as to the most effective ways to provide palliative and end of life services.

This section provides a brief, selected overview of the current key issues and challenges faced by consumers, carers, clinicians, researchers and policy makers in providing good-quality care to people approaching the end of their life. Individually these are complex issues, each worthy of detailed and systematic review. However, that is not the purpose of their incorporation in this document. The selection of issues and challenges presented here has been based on the key messages that emerged out of the consultations conducted at the National Conference and the National Forum and that are reflected by the evidence in the literature. The intention is to provide a context for understanding the proposed Guidance elements, particularly as an introduction for those whose substantive work has not been end of life care.

Breaking taboos—talking about dying

Key consultation messages:

- *The language of death and dying needs to be placed back in everyday conversations.*
- *Make it normal to talk about death and dying.*
- *Promote a culture change and a flexible system that would 'allow' health professionals to engage in conversations about death and dying.*
- *Palliative and end of life care can provide a meaningful response to some people's fear of death and the deeply held anxieties this evokes, i.e. a sense of vulnerability, helplessness, insignificance and uncertainty.*
- *The reality of dying—can't guarantee a 'good death' but should be able to guarantee 'good care'.*
- *Need to improve public awareness of death and dying issues.*
- *Make end of life care everybody's business.*

Limited community and professional awareness of end of life issues and obstacles to discussing death and dying in the wider community still present important challenges to making high-quality end of life care accessible when needed. Our society is often characterised as 'death denying' and this has been exacerbated in recent decades as life expectancy increases and we distance ourselves from death.⁵¹ Denial is considered an impediment to effective care at the end of life as it limits open discussion about important issues such as the dying process itself, dying at home, stopping futile treatments, advance care planning and awareness of and control of symptoms.⁵²

While the difficulties in discussing death equally affect patients, families and health professionals, it is the attitude of health professionals that may be the greater impediment. The biomedical perspective of many health professionals emphasises the physical self, and often does not align with broader psychosocial and spiritual components that are usually more important to patients and families.⁵³

50 Australian Government National Health and Hospitals Reform Commission 2009, *op. cit.*, pp. 3.

51 Department of Health, Social Services and Public Safety 2009, *Palliative and End of Life Care Strategy for Northern Ireland Consultation Document*.

52 Zimmermann, C 2007, 'Death denial: obstacle or instrument for palliative care? An analysis of clinical literature'. *Social Health Illness*, vol. 29, pp. 297–314.

53 Steinhäuser, KE et al. 2000, 'Factors considered important at the end of life by patients, family, physicians, and other care providers'. *JAMA*; vol. 284; pp. 2476–82.

The pervasive curative medical model combined with mismatched perspectives and attitudes creates barriers to open communication about end of life issues and impending death. Health professionals need to be skilled in talking about this difficult subject, even when patients may not be able to.⁵⁴

According to Perkins:

*When crisis hits, physicians should provide guidance; should help make decisions despite the inevitable uncertainties; should share responsibility for those decisions; and above all, should courageously see patients and families through the fearsome experience of dying.*⁵⁵

Changing deeply rooted mores is not a short-term proposition but requires a deep understanding of the psychosocial and cultural issues involved. A major cultural and behavioural shift in how palliative and end of life care is viewed and accepted in a multicultural society will be required to enable increased community and professional awareness.⁵⁶ Increased awareness should increase our capacity to engage in open discussion about options and preferences.

Aligning understanding

Key consultation messages:

- *there is no common understanding regarding palliative care and end of life.*
- *there is no agreed definition of palliative care.*
- *rhetorical framework developed and agreed.*

The societal reluctance to talk about death and dying is compounded by the lack of a shared and common language used by health professionals to describe needs and service provision for people approaching end of life. Lack of clarity regarding when end of life care begins in the context of increasingly complex medical conditions and treatments acts as a barrier to referral and care planning.

Jargon has evolved as health professionals struggle to define and differentiate different types of services

provided by both specialist and non-specialist palliative and end of life care professionals across a range of settings, for example specialist palliative care, end of life care, supportive care, non-specialist care, and palliative approach. Some of these terms are used interchangeably and in many cases incorrectly. Language variation creates the opportunity for misunderstandings and limits the way different providers contribute to care and recognise care provided by others. Jargon also creates unnecessary confusion in policy development and planning for palliative and end of life services.

Recognising patients who are dying

Key consultation messages:

- *the acute care sector needs to 'recognise' dying.*
- *we need to develop a model to determine when end of life begins.*
- *we need to ensure that there is a focus on improving end of life symptom management.*
- *we need to explicitly recognise alternative paradigms to the medical model and the imperative to treat in health services.*

One of the fundamental barriers to achieving quality care at the end of life arises from the inability or unwillingness of health professionals to recognise those who are dying and treat them appropriately. At present up to 70 per cent of people die in acute care hospitals and many are actively treated right up until the moment of their death.⁵⁷ Not all of these deaths are expected deaths, but many could have been anticipated.

Health professionals have the ability and the strongly held desire to treat and cure. Our systems of care and training limit our capacity to recognise that a person is dying—a journey that may have begun decades earlier with the emergence of chronic health problems, but where the inevitable and natural process of physiological decline has recently accelerated.

Part of the difficulty in recognising a person is dying lies in our lack of understanding of the indistinct

54 Knauff, E et al. 2005, 'Barriers and facilitators to end-of-life care communication for patients with COPD'. *CHEST*, vol. 127; p. 2188-96.

55 Perkins, HS 2007, 'Controlling death: the false promise of advance directives'. *Ann Intern Med*, vol. 147, pp. 51-7.

56 Department of Health, Social Services and Public Safety 2009, *op. cit.*

57 Hillman, K 2009, *op. cit.*

boundary between chronic and complex health care problems, ageing and dying. While reliable and detailed statistics on death exist, for example the age at which we can expect to die, the place and cause of death, there is little to assist in understanding the experience of dying and its milestones. We are poorly educated to understand what the journey of dying entails. How consumer and carer experiences are interpreted to improve care and how health care systems can be redesigned and reformed so that we provide the same quality of care to those we expect might die as we provide for those we expect will survive.

A recent study undertaken in Ireland⁵⁸ examined the care provided to 3000 patients who died within four days of admission. The majority of these patients were classified as an emergency admission. The study found that almost half of these patients were not expected to survive on admission. Two-thirds were assessed as having a severe or incapacitating illness and nearly one quarter were moribund on admission.⁵⁹ The majority were aged over 65 years.

The study identified a number of deficiencies in the care provided to these patients and these included:

- poor communication and team working;
- lack of multidisciplinary care;
- poor end of life care planning;
- lack of involvement of palliative care teams;
- inadequate consent to treatment;
- deficiencies in diagnosis;
- delay in assessment and treatment;
- failure to adapt level of care to health status of patient.

Some of the patients in the study who were not expected to survive on admission were admitted to an intensive care unit. Almost a quarter of clinicians participating in the study reported that no discussion had taken place on the withdrawal of treatment before the patient's death—including in those cases where it was expected on admission that the patient would not survive.

In a recent review of hospital access block, inappropriately aggressive treatment of patients who are clearly dying, the management of end of life care patients in acute care hospitals because of poor end of life care planning and the lack of planning for treatment failure (especially after hours) in frail medical patients with complex conditions, were considered contributory factors in demand for hospital emergency department services and hospital overcrowding.⁶⁰

Hillman⁶¹ describes the journey of many patients in intensive care at the end of their life and questions the adequacy of current systems and processes of care to deal with the complex problems surrounding medical and personal decision making at the end of life. The stories presented by Hillman put a human face to the statistics produced by the Irish study discussed above and speak to the common challenges facing health care systems internationally.

Reform is needed at a systems level to ensure that all health professionals understand the journey that most individuals will make to the end of their lives and the ways they will experience it. First and foremost will be the ability to recognise when that phase has begun. Health systems and care processes must be designed to incorporate and respond appropriately to that recognition. While these issues have been recognised for some time^{62,63} it is only recently that there has more direct expression of this in the context of Australian and international acute care hospitals.⁶⁴

Recognising people who need care at the end of life

Key consultation messages:

- *ensure continuity of care for all patients.*
- *the need to define the end of life target population.*
- *quality end of life needs to be accessible to people with non-malignant conditions.*
- *the need to develop better clinical models for transition to palliative care.*

58 NCEPOD 2009. *Caring to the end? A review of the care of patients who died in hospital within four days of admission. National Confidential Enquiry into Patient Outcome and Death, Ireland.*

59 The study used the American Society of Anaesthesiologists health status score to classify patients.

60 *ibid.*

61 Hillman, K 2009, *op. cit.*

62 Mills, M et al. 1994, 'Care of dying patients in hospital'. *BMJ*, vol. 309, pp. 583–6.

63 Glare, PA et al. 2003, 'The interface between palliative medicine and specialists in acute-care hospitals: boundaries, bridges and challenges' *MJA*, vol. 179, pp. S29–S31.

64 For example, see Kuehn, BM 2007. 'Hospitals embrace palliative care'. *JAMA*, vol. 298, pp. 1263–5.

A fundamental tenet of ensuring quality care for all is the ability to recognise patient and carer needs for appropriate care as they approach the end of life. The provision of specialist palliative care services in Australia, and many other countries, has traditionally been to people with malignant diseases. It has become widely acknowledged that the needs of many people dying of non-malignant conditions (for example dementia, Motor Neurone Disease (MND), multiple sclerosis), and the needs of their carers, could significantly benefit from access to care aimed at supporting them as they approach the end of life.^{65,66,67}

Providing care on the basis of needs rather than diagnosis is the overarching principle of a needs-based system of care, but this has not been the general experience in Australia. A needs-based approach focuses on a range of symptoms and psychosocial domains targeted at the maintenance of quality of life at the end of life. The approach to management of these symptoms is the same, regardless of diagnosis.⁶⁸ Persons living with progressive chronic conditions (such as peripheral vascular disease, malignancies, chronic renal and liver disease, congestive heart failure, COPD, dementia) all fall under the target population.

The failure to provide end of life care to much of the broader non-malignant disease target population is likely to be the result of a complexity of reasons, including prognostic accuracy for chronic diseases, a curative culture, lack of communication, lack of appropriate assessment tools and lack of time.⁶⁹ Many of these require a long-term culture change perspective.

An additional dimension to the recognition of who may benefit from end of life care is to ensure that the care offered is appropriate to the individual and carer's level of need. The higher and more complex a person's needs are, the more appropriate it is to involve specialist palliative care teams in any care setting.⁷⁰ Despite the high number of people dying

in hospitals, end of life care is not yet fully integrated into the various clinical systems and structures of the hospital. The Irish study of deaths within four days of admission to hospital is illustrative of this, reporting that there was no involvement of the palliative care team in 81 per cent of cases reviewed.⁷¹

Similar system-wide challenges exist at a primary care level with the need to achieve a better system and structural alignment between GPs and specialist palliative care services. The importance of the appropriate recognition of who may benefit from end of life care, needs to gain increasing priority in residential aged care facilities, in particular.

Providing high-quality care at the end of life is among the most complex challenges for general practitioners (GPs).⁷² Patient symptoms may be severe, family issues complex and the GP's own beliefs and fears about death and dying challenging.

A number of barriers to ensuring that GPs are well equipped to provide care to people as they approach the end of their life have been identified. These include: differences in structural and resource models for general practice (community based, self-employed and paid on a fee for service basis) and specialist medicine (commonly hospital based and salaried out of public funds)⁷³; lack of time and remuneration; lack of training, knowledge and resources, and experience in palliative medicine; and unwillingness to provide homecare and after-hours visits.⁷⁴

Despite these barriers there is evidence that the proactive involvement of GPs enable more terminally ill patients to die at home and that this is the preference of patients and their carers.⁷⁵ It has been anecdotally reported that there is underutilisation of Enhanced Primary Care Medicare items that would support case conferencing and care planning.

65 McNamara, B et al. 2004, *op. cit.*, pp. 2.

66 Murray, S and Sheikh, A 2008, 'Care for all at the end of life'. *BMJ*, vol. 336, pp. 958.

67 Skilbeck, J and Payne, S 2005, 'End of life care: a discursive analysis of specialist palliative care nursing'. *Journal of Advanced Nursing*, vol. 51, pp. 325–34.

68 Fischer, J 2006, 'Palliating symptoms other than pain'. *Australian Family Physician*, vol. 35, pp. 766–70.

69 Yohannes, A 2007, 'Palliative care provision for patients with chronic obstructive pulmonary disease'. *Health and Quality of Life Outcomes*, vol. 5, pp. 17.

70 Palliative Care Australia 2005, *A Guide to Palliative Care Service Development: A population based approach*, *op. cit.*

71 NCEPOD 2009, *op. cit.*

72 Mitchell, GK et al. 2008, 'Do case conferences between general practitioners and specialist palliative care services improve quality of life? A randomized controlled trial'. *Palliative Medicine*, vol. 22, pp. 19.

73 *ibid.*

74 Rhee, JJO et al. 2008, 'Attitudes and barriers to involvement in palliative care by Australian urban general practitioners'. *Journal of Palliative Medicine*, vol. 11, pp. 980–5.

75 *ibid.*

Engaging consumers, families and carers

Key consultation messages:

- ensure that people understand that their opinion matters.
- patients and their families and carers must be involved at all levels in the system.
- ensure that patients and families are provided with information to make an informed choice regarding the realistic options available and the probable outcomes of a course of treatment from an early stage.
- ensure that goals of care are defined in partnership with patients and carers upon admission to hospitals and care facilities.
- facilitate the ability of patients and their families to make decisions based on their preferences for care at the end of life.
- facilitate real choices around individual and family preferences about place of death and support those choices.
- invest in consumer controlled options for end of life care planning.
- ensure that people understand that active treatment is an individual choice.
- end of life and advance care planning needs to be an ongoing conversation, facilitated at all (individual/family/health professional) levels.

Putting individuals, and their families and carers at the centre of care will enable them to engage with the health care system and make decisions about their own health.⁷⁶

An important issue for patients and families approaching end of life is for an informed choice based on an understanding of the realistic options that may be available and the likely outcomes of various treatment modalities. It is critical that preferences and needs are clearly understood by consumers, their carers and health care professionals. There is also a requirement to ensure

that an individual's autonomy is maintained and this extends to the right to refuse medical treatment.⁷⁷ Health professionals are obliged to ensure that attempts at curative or life-prolonging treatment are not futile and that there is clear communication about the probabilities and consequences of any interventions. Further there is significant concern that we have lost the notion of death as a normal part of life because it has been institutionalised and medicalised.⁷⁸ As discussed earlier, reluctance to talk about death, further exacerbates positive consumer and carer engagement at the end of life.

End of life care, like health care in general, needs to be approached as a collaboration between individuals, carers and health care professionals and this extends to ensuring that false hopes and expectations are not engendered, where the evidence clearly indicates that a particular course is likely to have a significant negative impact on the quality of life of patients and their carers.⁷⁹ An emerging approach in developing effective communications between health care providers and patients and families is the process of advance care planning.

A further significant issue is the need for more explicit recognition of the role of family carers both as informal carers and as an integral part of an individual's care team, particularly in the context of support in community settings.⁸⁰ The presence of carers is fundamental to the ability of patients to have a choice at the end of life. There is also an increasing recognition that there is an inextricable relationship between the wellbeing of carers and patients and that in some cases the needs of the carers may exceed that of patients.⁸¹

There is a mixture of individual and systematic factors that are barriers to supporting the needs of carers. These include the availability of psychological support, information, help with personal, nursing and medical care of the patient, out of hours support, respite, domestic and financial help.⁸² The lack of clear communication with the care team is one of the most consistent issues raised by carers as a barrier in Australian studies^{83,84} and aligns with international experience.

76 Australian Government Department of Health and Ageing 2009, *Primary Health Care Reform in Australia: Report to Support Australia's First National Primary Health Care Strategy*, pp. 42.

77 AMA 2006, Code of Ethics, <http://www.ama.com.au/codeofethics> (accessed 12 May 2010)

78 Smith, RA 2000, *op. cit.*, pp. 129–30.

79 Lynn, J 2008, 'Reliable comfort and meaningfulness'. *BMJ*; vol. 336, pp. 959.

80 O'Connor, L et al. 2009, 'Absolutely fabulous—but are we? Carers' perspectives on satisfaction with a palliative homecare service'. *Collegian*, vol. 16, pp. 201–9.

81 Higginson, I et al. 1990, 'Palliative care: views of patients and their families'. *BMJ*, vol. 301, pp. 277–81.

82 Grande, G et al. 2009, 'Supporting lay carers in end of life care: current gaps and future priorities'. *Palliative Medicine*; vol. 23, pp. 339–44.

83 Aoun, S 2006, 'Assessment of the Supportive and Palliative Care Needs of People with Neurodegenerative Disorders' http://www.health.qld.gov.au/cpcrc/pdf/Newsletter/2006_march.pdf (accessed 12 May 2010).

84 O'Connor, L et al. 2009, *op. cit.*

However, a recent comprehensive review of the carer literature has highlighted that while the adverse effects of caring have been extensively researched, there is little empirical evidence as to how carers can be better supported to prevent problems, and the remedial model predominates.⁸⁵

Right care, right time, right place

Key consultation messages:

- *provide the right care, at the right time at the right place.*
- *ensure appropriate services are available around the clock.*
- *ensure that appropriate medication is available and affordable in all settings.*
- *ensure that services are available, known as available, planned (as far as possible), coordinated, effectively led and equitable.*
- *develop enabling strategies to ensure all people have access to palliative care regardless of socio-economic status or location.*
- *articulate additional requirements for services in regional and remote areas.*
- *ensure that the responsibility for bereavement care is determined and available to all.*

Inadequate access to palliative and end of life care is associated with poorer and suboptimal consumer and carer outcomes. Accessibility essentially means being able to see the right health professional, at the right time, in the right place and in a manner that is culturally appropriate and affordable.⁸⁶ In non-specialist inpatient settings it means ensuring that there is access to medications, nurses and GPs, emergency respite, equipment, therapies and psychosocial support when needed.

This may involve the redesign of both the way services relate to each other, particularly at the interface between care settings (see section on integrated/seamless care) and may also mean the more effective use of all members of the palliative care team within each of the care settings. Health care services should be accessible and based on need to all people who require care, regardless of their diagnosis, prognosis, age, culture, geography, socio-economic status or care setting.⁸⁷

While we may not be able to change some real challenges posed by geography for instance, our goal should be to change those aspects of service delivery and funding models that block rather than facilitate access to care. Models of care and service approaches need to be flexible to accommodate the wide range of symptom related and psychosocial needs across all care settings and geographic locations, and be culturally appropriate.

One of the key issues around access is that a person's condition can change rapidly and at any time in the 24/7 cycle and it is essential that services are able to be accessed quickly. Emerging evidence shows that the provision of 24/7 services can avoid unnecessary hospital admissions and can enable more people at the end of their life to live and die in the place of their choice.⁸⁸ Furthermore, the consistent use of referral 'triggers' is being increasingly utilised to assist in promoting timely referral to palliative care services as well as provide opportunities for intervention and review as circumstances change.^{89,90} This is particularly important in the recognition of symptoms and psychosocial needs in non-palliative care specialist settings, such as acute hospital wards and primary and aged care settings.⁹¹

Affordable access to many non-Pharmaceutical Benefits Scheme (PBS) medicines remains an issue. According to a report co-authored by National Prescribing Service and Palliative Care Australia in 2009: 'In hardship cases, particularly in rural areas,

85 Grande, G et al. 2009, *op. cit.*

86 Australian Government Department of Health and Ageing 2009, *Primary Health Care Reform in Australia: Report to Support Australia's First National Primary Health Care Strategy*, *op. cit.*, pp. 29

87 Palliative Care Australia 2005, *A Guide to palliative care service development: A population based approach*, *op. cit.*

88 Department of Health NHS 2008, *op. cit.*, pp. 13.

89 SA Health 2009, *Palliative Care Services Plan 2009–2016*, pp. 34.

90 One of the best known examples of this approach has been the development and use of prognostic indicators as part of the Gold Standards Framework that enables better identification of patients at the end of life so as to trigger better assessment and planning and provision of care related to their needs. The National Gold Standards Framework Centre 2008, *Prognostic Indicator Guidance* March. http://www.goldstandardsframework.nhs.uk/Resources/Gold%20Standards%20Framework/PIG_Paper_Final_revised_v5_Sept08.pdf (accessed 12 May 2010) In the Australian context, there is a needs assessment tool for use with advanced cancer patients, see Wallner, A 2008. 'Development of a palliative care needs assessment tool (PC-NAT) for use by multidisciplinary health professionals'. *Palliative Medicine*, vol. 22, pp. 956–64.

91 Irish Hospice Foundation 2009, *Hospice friendly Hospitals: Draft Quality Standards for end of life care in hospitals. A consultation document*, Dublin, pp. 54.

this means these drugs are often not used. In some circumstances, lack of access to non-PBS drugs in the community can result in hospitalisation in order to access certain medications.⁹² Further, some drugs are only subsidised through outpatient clinics of public hospitals and there is anecdotal evidence that *ad hoc* 'workaround' strategies are sometimes utilised to maintain access to these in the community.

The fundamental principle should be that people who would benefit from care at the end of life should have access to services that match their need.

Cultural appropriateness

Key consultation messages:

- ensure planning is approached in a culturally informed, competent and appropriate way.
- ensure care is reflective of different cultural world views—knowledge, values, beliefs and practices.
- improve cultural competency and cultural safety of systems to provide care at the end of life.
- provide resources to allow 'return to country' for Indigenous people.
- address racial and ethnic disparities in health outcomes.
- incorporate cultural competency and safety into palliative and end of life education programs at all levels.

A key determinant of the ability to access services appropriately in the Australian context is the influence of culture and ethnicity on end of life care, both from the perspective of consumer and carer choices, and the cultural competencies of health care providers. The evidence suggests that there are profound cross-cultural differences in end of life decision making around autonomy, advance care planning and truth telling, communication and

attitudes to medication, among others^{93,94,95} which require the application of individual and professional cultural competence, systematically supported by organisation-level commitment.⁹⁶

For culturally and linguistically diverse communities emerging paradigms require significant shifts in thinking about how services are delivered:

A more fundamental requirement for genuine and sustainable reform of health care institutions is to move beyond the prescriptive approach of cultural generalisations to take account of social, economic, attitudinal, linguistic and cultural factors that create barriers to equitable access to care.⁹⁷

It is clear that culture is a specific dimension of a person-focused approach.

Similarly a culture-centred, person-focused approach to end of life care is required for Aboriginal and Torres Strait Islander Australians. There is a need to acknowledge more openly our failures in providing quality end of life care that is culturally appropriate to Aboriginal and Torres Strait Islander Australians, and to develop strategies and programs that respect and accommodate their spiritual and cultural beliefs. Contemporary models of palliative and end of life care in Australia, which are dominated by western traditions and the biomedical paradigm, should integrate Aboriginal and Torres Strait Islander traditions, values and cultural practice relating to palliation and end of life transitions.⁹⁸ At the heart of this is respect of culture:

Indigenous and non-Indigenous health care providers should build relationships that facilitate understanding of cultural differences that influence aspirations relating to end of life care. The reciprocal process of respect can enhance palliative care services, offering additional approaches to patient and family care. At the same time, Indigenous communities gain equal access to service and treatment options available to other Australians.⁹⁹

92 National Prescribing Service and Palliative Care Australia 2009, *Achieving quality use of medicines in the community for palliative and end of life care*, Canberra.

93 Johnstone, M-J and Kanitsaki, O 2009, 'Ethics and advance care planning in a culturally diverse society'. *J Transcult Nurs*, vol. 20, pp. 405.

94 Lickiss, JN 2003, 'Approaching death in multicultural Australia'. *MJA*, vol. 179, pp. S14–S16.

95 Kanth, F 2006, *Cultural competence in End of Life Care for Asian Indian Immigrants*, 8 September, research presentation, Dalhousie University, Canada.

96 National Health and Medical Research Council 2005, *Cultural Competency in Health: A guide for policy, partnerships and participation*, has a comprehensive discussion about structural and organisational change required to developed systematic and sustained cultural competence.

97 Krouskos, D 2009, 'Equity—A view from the multicultural frontline'. *EoL*, vol. 1(2), pp. 14–5.

98 Palliative Care Australia 2010, *Interim Position Statement—Improving access to quality care at the end of life for Aboriginal and Torres Strait Islander Australians* <http://www.palliativecare.org.au/Portals/46/Policy/PCA%20interim%20position%20statement%209-12-9%20ATSI.pdf> (accessed 12 May 2010)

99 Prior, D 2009, 'Bridging the gap of inequities—Indigenous Australians'. *EoL*, vol. 1(2), pp. 12–3.

One major issue affecting our ability to provide care at the end of life is communication. A failure to understand or appreciate the cultural practices of Aboriginal and Torres Strait Islander peoples leads to inappropriate and inadequate health care. Research has found 'Communication would improve if health professionals learned to listen to the [Aboriginal and Torres Strait Islander] story and let it shape the structure of their own biomedical perceptions. Both staff and patients need to recognise that their understandings come from their own backgrounds, and are therefore saturated in their own histories, languages and culture.'¹⁰⁰

This is compounded by the Aboriginal and Torres Strait Islander people being under-represented in the health workforce and among those with higher education health qualifications. In 2004, it was estimated that to achieve the same proportion of Aboriginal and Torres Strait Islander people working as health professionals as non-Indigenous people, it would require a further 2000 Aboriginal Health Workers to be trained.¹⁰¹

Aboriginal and Torres Strait Islander doctors, nurses, psychologists and social workers play an important role in the provision of care at the end of life. Aboriginal and Torres Strait Islander Home and Community Care (HACC) workers and Aboriginal Health Workers play a key role in providing appropriate community based care and in liaising with other health care professionals involved in planning and delivering end of life services.¹⁰²

There is great need for more Aboriginal and Torres Strait Islander people working in these settings.

Aboriginal and Torres Strait Islander peoples have different cultures and histories and in many instances different needs. Nevertheless, both groups are affected by the problems that face them as unique Australians. The differences must be acknowledged and may need to be addressed by locally developed specific strategies.¹⁰³

Fragmentation across care settings

Key consultation messages:

- ensure continuity of care for all patients.
- ensure that services work together rather than in parallel (e.g. residential aged care and palliative care).
- develop and implement collaborative models of care.
- investment in GP led care will reduce frequency of hospital admission and improve quality of life.
- improve information transfer between services.
- develop and implement end of life care pathways and criteria, within and between sectors with a particular need in acute settings.
- ensure care coordinators are available for all patients.

*For all health consumers, but especially those with multiple chronic conditions and complex care needs, their interactions with the health care system need to be well integrated with effective and coordinated transitions between different health services and health providers and continuity of care.*¹⁰⁴

The delivery of care to people who are dying is integral to all health care settings (acute wards, emergency departments, hospices, nursing homes and home care). The provision of systems of care need to be well coordinated and seamless to ensure consumers can navigate the health care system to meet their needs for care and this is nowhere more important than for patients and carers at the end of life, where there is a real risk of needless suffering, care preferences being compromised and sub-optimal outcomes.¹⁰⁵

100 Cass, A et al. 2002, 'Sharing the true stories: improving communication between Aboriginal patients and health care workers'. *MJA*, vol. 176, no. 20, pp. 466–70.

101 National Rural Health Alliance 2006, *The health of Aboriginal and Torres Strait Islander Australians*, Canberra.

102 Sullivan, K et al. 2003, *National Indigenous palliative care needs study: final report*, prepared for the Australian Government Department of Health and Ageing, Canberra.

103 National Aboriginal Community Controlled Health Organisation 2008, *Our guiding principles*, Canberra. <http://www.naccho.org.au/aboutus/principles.html> (accessed 7 July 2009)

104 Australian Government Department of Health and Ageing 2009, *Primary Health Care Reform in Australia*, op. cit., pp.64.

105 National Consensus Project for Quality Palliative Care 2009, *Clinical Guidelines for quality palliative care*, 2nd Edition, pp. 9.

Transitions between hospitals, hospices, nursing homes and home care are potentially high-risk events for patients when those transitions between sites of care are poorly managed. Many of the problems associated with the effective provision of end of life care, and indeed the management of complex and chronic cases in general, relate to barriers that occur at the interfaces between settings, between services and between health care professionals. In short, we have an absolute, non-negotiable obligation to get the interfaces 'right'.

The need to support quality improvement through data

Key consultation messages:

- importance of best-quality end of life care when dying and outcome driven services.
- importance of a government commitment through national health care agreements for the inclusion of agreed national indicators for end of life care.
- invest in data systems to support quality of care, including standard datasets, indicators and feedback.
- develop defined metrics for quality of care at the end of life.

*We believe that our future health system should be driven by a strong focus on continuous learning and being able to apply new best knowledge to improve the delivery and organisation of health services.*¹⁰⁶

In line with the principle of a consumer-focused approach, the measurement of quality needs to relate directly to an understanding of what quality means in terms of consumer outcomes and consumer, family and carer experiences of end of life care. Developing this understanding is crucial for policy and service design. Evidence from overseas has shown that relationships with the treatment team are critical, such as trust in the treating doctor,

effective communication and coordination of care, along with avoidance of unwanted life support. It also shows that a tailored patient-specific approach may be required as what matters in terms of quality can vary with individual circumstances.¹⁰⁷

Evidence-based policy and practice is fundamental to achieving high-quality care. Currently there is very little systematic data available about the quality and outcomes of end of life care or consumer experiences, reflecting the general dearth of information in the health system as a whole. We are at the early stages of developing a systematic understanding of quality and outcomes through national projects funded by the Department of Health and Ageing.

The Palliative Care Outcomes Collaboration (PCOC) is a voluntary quality initiative that assists palliative care service providers to improve care through the collection and reporting of routine patient data. The latest PCOC report included data from 86 services nationally.¹⁰⁸ PCOC reports are produced on a six-monthly basis. Six reports have been released over the past three years.

The National Standards Assessment Program (NSAP) is a national, standardised assessment program based on the National Palliative Care Standards.¹⁰⁹ Currently Cycle 1 assessment is being undertaken by 150 specialist palliative care services nationally. The NSAP provides a benchmarked report of service level performance against the national standards and matched clinical services, and identifies opportunities for improvement. Reports are provided to services on the completion of their assessment. The NSAP assessment is undertaken on a two-yearly cycle to align with accreditation schedules.

Without relevant, timely information and data it is not possible to undertake informed decision making about service delivery, assess current practice or indeed enable assessment of the impact of improvement efforts. High-quality information is a key lever for change.¹¹⁰

¹⁰⁶ Australian Government National Health and Hospitals Reform Commission 2009. *op. cit.*, pp. 202.

¹⁰⁷ Heyland, DK et al. 2006, 'What matters most in end-of-life-care: perceptions of seriously ill patients and their family members'. *CMAJ*, vol. 174, pp. 627-33.

¹⁰⁸ Palliative Care Outcomes Collaborative 2009, *op. cit.*

¹⁰⁹ Palliative Care Australia website: <http://www.standards.palliativecare.org.au/Default.aspx?tabid=1794> (accessed 12 May 2010).

¹¹⁰ Department of Health NHS 2008, *op. cit.*, pp. 14.

The appropriate workforce to meet contemporary health care needs

Key consultation messages:

- facilitate education to ensure that there is a paradigm shift in attitudes by health professionals.
- optimise the workforce skill mix (including carers and volunteers).
- integrate palliative care into all health professional undergraduate curricula.
- develop a generic learning resource for all health providers on early/difficult conversations on planning for the end of life.
- facilitate development of GP skills around proactive end of life planning and use of medicines.
- review the educational requirements of the aged care sector.
- facilitate ongoing training of health professionals working in the aged care sector.
- facilitate a common understanding among interdisciplinary teams on goals of end of life care.

The planning of our future health workforce requirements is a bit like Swiss cheese (riddled with gaps and incomplete, poorly coordinated information). Meanwhile, the education of our health workforce still tends to reinforce professional boundaries and does not adequately foster team-based collaborative models of care. There is growing support to strengthen and redesign how we train our health professionals.¹¹¹

The challenges in meeting the future development needs of the specialist palliative care and wider health care workforce to provide high-quality care to people approaching the end of life can be considered to be a subset of the broader challenges of developing a sustainable, skilled and adaptable workforce to meet the health needs of the Australian community.

Changes to the demographics and patterns of disease are currently leading to the development of new workforce planning and development strategies. These give recognition to the need to be grounded in evidence-based population needs approaches (socio-economic, health status, disease and risk factors, age, ethnicity, geography etc.) combined with more consumer-focused contemporary models of care.^{112,113}

A number of factors are also increasingly leading to a re-examination of roles, responsibilities, scope of practice and skill mix of health care professionals, including:

- inherent relationship changes caused by new team-based and shared-care models¹¹⁴;
- workforce shortages and support for better utilising the full capacity of existing health professionals.¹¹⁵

This will require the proactive but sensitive management of barriers to change, and in particular professional resistance and poor interpersonal relationships that are often an inherent barrier to teamwork.¹¹⁶

These changing workforce dynamics require support in training and education. While there has been some improvement in recent years through national programs like Palliative Care Curriculum for Undergraduates (PCC4U), there is still considerable concern that undergraduate education may not adequately prepare the health workforce for end of life care. Considerable variation also exists in the nature, scope and approaches to the delivery of education at both undergraduate level and in continuing professional education.¹¹⁷

The growing complexity of care provided in the community also requires education and training of students and health professionals to be better incorporated at all levels, in appropriately resourced, interdisciplinary, community based settings.¹¹⁸

111 Australian Government National Health and Hospitals Reform Commission 2009, *op. cit.*

112 Segal, L 2009, 'Issues facing the future health care workforce: the importance of demand modelling'. *Australia and New Zealand Health Policy*, vol. 6, pp.12.

113 Australian Health Workforce Advisory Committee 2005, *A Models of Care Approach to Health Workforce Planning*, Health Workforce Information Paper 1.

114 Crawford, GB and Price, SD 2003, 'Team working: palliative care as a model of interdisciplinary practice'. *MJA*; vol. 179, pp. S32-S34.

115 See Scott, IA 2009, 'Health care workforce crisis in Australia: too few or too disabled?'. *MJA*, vol. 190, pp. 689-92; Australian Government Department of Health and Ageing 2009, *Primary Health Care Reform in Australia*, *op. cit.*, pp.115.

116 Tang, M 2009, 'Multidisciplinary teams in cancer care: pros and cons'. *Cancer Forum*, vol. 33(3), pp. 208-12.

117 National Palliative Care Program 2005, *Principles for including palliative care in undergraduate curricula*.

118 Australian Government Department of Health and Ageing 2009, *Primary Health Care Reform in Australia*, *op. cit.*, pp. 117.

Finally a range of challenges exist with regard to workforce availability and distribution. A major challenge to the equitable access to palliative care services is the poor distribution of health professionals, particularly in rural and remote regions. System-wide issues such as inability to take leave, limited availability of locums; lack of inter-professional support and other lifestyle and professional considerations all impact on workforce availability.

There is a larger risk that the overall growth in the available workforce may be insufficient to meet needs. Australia has about half the palliative care medicine specialists it needs under current referral patterns, with unmet need being by far the greatest outside of metropolitan areas. Data for NSW shows that the number of palliative medicine specialists outside of the Greater Sydney Metropolitan Area is about one third per 100 000 of the state average.¹¹⁹ This has significant implications for the development of flexible models such as shared care or hub and spoke models in non-metropolitan areas as they rely on specialist medical care to be proximate within a geographical service region.

Palliative care nurses have the same age profile issues as the rest of the workforce.^{120,121} and industry dynamics, such as the enormous growth in GP practice nurses over the last decade may impact on further availability.

In primary and aged care settings the availability of GPs is a generic problem with about half the number being available to regional, rural and remote areas compared to metropolitan areas (although availability in some outer metropolitan areas is an issue as well). People living in outer regional centres have access to about a half as many allied health professionals as people in metropolitan centres.¹²² These shortages are further exacerbated by logistical challenges of servicing highly dispersed populations.¹²³

Adequate and appropriate resourcing

Key consultation messages:

- provide for equitable resourcing of end of life care.
- increase capacity of primary care practitioners through palliative care items in member benefit schemes (MBS)—that will facilitate home visits, case conferencing, care coordination, telephone support/coordination.
- review current residential aged and community care funding.
- improve support for carers including respite.
- invest in funding of successful projects to facilitate the sustainability of improvements already made.
- develop adequate funding models based on population data.
- promote the need for an accurate reflection of time requirements to deliver a high-quality service to be built into the financing of models of care.

The provision of high-quality care at the end of life is not possible without adequate, appropriate, and equitable resourcing. Inadequate resourcing also fundamentally affects workforce distribution and this in turn affects the ability of patients and carers to gain access to a service, often resulting in suboptimal outcomes.

A particular area of concern is the resourcing of appropriate models of care to support end of life care for older people in general, and aged care facilities in particular. Funding for aged care under the Aged Care Funding Instrument (ACFI) needs to recognise the real cost of providing end of life care and support in aged care facilities, including support for families and carers. This is further exacerbated by the current incoherent mix of federal and state/territory funding for palliative care services for residents of aged care facilities that

119 ANZSPM 2009, *Benchmark Number of Specialists in Palliative Medicine*, Position Statement.

120 Victorian Government Department of Human Services 2006, *Palliative Care Workforce. A supply and demand study*.

121 SA Health 2010, *op. cit.*

122 Australian Government Department of Health and Ageing 2009, *Primary Health Care Reform in Australia*, *op. cit.*, pp. 114.

123 *ibid*, pp. 31.

reinforces the maintenance of professional silos and works against the integration of both GPs and specialist palliative care providers into the primary care team. There are also disincentives to the uptake of out of hospital palliative and end of life care services by private health insurers, particularly the availability of publicly funded services to private patients. Funding and other resources need to support flexible models of care, rather than create barriers to them.

Special needs populations

Key consultation messages:

- importance of including marginalised groups (e.g. Indigenous, rural remote, prisons).
- articulation of what extra measures are needed to address needs in regional and remote locations.
- identify low access marginalised groups and apply enabling strategies.

Children

While many of the above issues are as relevant to improving the delivery of services for children as they are for adults, the end of life care needs of children and their families are nevertheless unique and require special consideration in the development of system-wide reform and care models. The majority of families choose to care for their children at home, and there are usually profound effects on all dimensions of family life, with often long-term care regimes that can be complex and isolating.¹²⁴ Further, children with non-malignant terminal illness also may not receive equal access to care. The resources available to this medically fragile group compare poorly with those available to children with cancer. This is largely due to the public sympathy towards children with cancer.¹²⁵

There are significant variations in the models of paediatric palliative care provided across Australia.¹²⁶ Factors that have influenced the development of paediatric palliative care services include:

- variability in the demand for paediatric palliative care services;
- variability in the complexity of prognosis of conditions;
- differing family choices;
- range of service providers; and
- availability of trained paediatric palliative care staff.

Dementia

One of the three trajectories in section 3 describes the clinical course of dementia that will affect an increasing number of patients and their carers in the future. While the final stages of dementia have similarities to some other commonly recognised end of life conditions, its treatment is often more difficult due to the complex medical, cognitive, emotional, ethical and social considerations that accompany it.¹²⁷ Often the extent of physical suffering and the use of burdensome interventions is not well understood and often people with dementia are subjected to interventions such as tube feeding or hospitalisation for pneumonia that may be of limited benefit and not consistent with quality end of life care.¹²⁸ There is also strong evidence of the under-recognition of pain in people with dementia.¹²⁹ A recent critical literature review highlighted four common challenges in delivering effective palliative care to older people with dementia; difficulties associated with diagnosing terminal phase; issues relating to communication; medical interventions and the appropriateness of palliative care intervention.¹³⁰

124 Monterosso, L et al. 2007, 'Supportive and Palliative Care needs of children and families in Western Australia: evidence to guide the development of a palliative care service'. *Palliative Medicine*, vol. 21, pp. 689-96.

125 New Zealand Ministry of Health 1994. *Children and young people with a terminal illness*, Wellington.

126 Australian Government Department of Health and Ageing 2003, *Paediatric Palliative Care Service Model Review Final Report*, Rural Health and Palliative Care Branch.

127 Chang, E et al. 2006, *Palliative Care Dementia Interface: Enhancing Community Capacity Project Final Report*, University of Western Sydney.

128 Mitchell, SL et al. 2009, 'The clinical course of advanced dementia'. *N Eng J Med*, vol. 361, pp. 1539-38.

129 Alzheimer's Australia 2006, *Palliative Care and Dementia*.

130 Birch, D and Draper, J 2008, 'A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia'. *J Clin Nursing* vol. 17, pp. 1144-63.

Some of the strongest anecdotal evidence about system failure to care appropriately for people with dementia as they approach the end of life is found at the transitions between care sectors. Inappropriate transfers into unfamiliar environments such as busy emergency departments, coupled with invasive procedures may leave patients disoriented, confused and anxious resulting in further complications and behavioural changes that these settings are generally ill-equipped to deal with.

Motor Neurone Disease (MND)

Motor Neurone Disease (MND) is an eventually fatal condition with treatments that, at present, offer only the potential to slow the disease process. It is a complex disease of progressive loss and increasing disability with an average life expectancy of two to three years. Prognosis at diagnosis is difficult to predict with certainty which raises itself as one of the significant barriers in achieving equitable access to palliative and end of life care. Palliative care services are often reluctant to take on MND patients due to the uncertain course of the disease and consequent concerns about the high demand for care that MND patients will have on limited resources, a view also supported by the literature. People diagnosed with MND or their families can also be reluctant to accept the terminal nature of MND and resist discussions about palliative care.¹³¹

While there is still only limited research in Australia the outcomes of a recent project¹³² have highlighted some further challenges faced by people living with MND and their carers, including:

- there is no existing framework that can be implemented to integrate the palliative care of people with MND into the overall care received.
- palliative care workers did not feel confident in their level of knowledge regarding MND and people with MND had a distorted understanding of the service that palliative care offered.
- the relative rarity and the progression of the disease made coordinating care between numerous agencies difficult.
- the lack of appropriate and timely respite which causes considerable emotional, psychological and physical demands.

Rural and remote issues

Many of the challenges facing metropolitan or urban communities are also shared by rural and remote communities but often are present to a greater degree through reasons of geography, cost and service availability. Many of these issues (e.g. lack of specialists, nurses and allied health workforce) are generic to the health system and require system-wide funding changes and integrated multi-stakeholder strategies to change the disincentives that currently limit access to services.¹³³ While the defining characteristic of rural health remains its geography (and related issues of access to health care services) rural and remote Australia is also sociologically, culturally, economically and spiritually different from metropolitan areas, as well as internally diverse.¹³⁴

There is a lack of research literature on the issues that impact on the provision of end of life care in rural areas¹³⁵ and remote communities.¹³⁶ There is however, some evidence that rural and remote Australians receive poorer palliative care than those in urban areas. Population based admission rates to palliative care services are 30–50 per cent lower in regional and remote locations than in metropolitan areas; GPs are more time pressured and deal with more complex cases and communication between

131 Birks, C 2009, 'MND—A condition falling between the cracks' *EoL*, vol. 1(1), pp. 20–22.

132 Victorian Government Department of Human Services 2008, *Motor Neurone Disease and Palliative Care: Interim Report on the MND Pathway Project*. In July 2007, the MND Pathway Project was established to develop a framework to assist people living with MND to access palliative care services, and to assist palliative care services manage and support people living with MND. <http://www.health.vic.gov.au/palliativecare/mnd-report.pdf> (accessed 12 May 2010).

133 Australian Government National Health and Hospitals Reform Commission 2009, op. cit. pp. 89.

134 AIHW 2001, *It's different in the bush—a comparison of general practice activity in metropolitan and rural areas of Australia, 1998–2000*, Canberra.

135 White, K et al. 2004, *Development of a model for palliative care in rural and remote communities: the 'pop-up model'*, National SARRAH Conference (26–28 August 2004), Alice Springs, NT.

136 White, K et al. 2004, 'Out of sight out of mind: reframing remoteness in providing palliative care in remote Australia'. *Collegian*, vol. 11(3), pp. 29–33.

specialist services and primary care providers can be problematic.¹³⁷ There are particular problems in accessing services after hours and on weekends with the associated issues of difficulties in assessing the patient's condition and uncertainties around symptom management. Limited choices for home care are impacted by families having limited knowledge about service availability and economic and physical barriers associated with distance. Access to allied health services, such as bereavement counselling and occupational therapists, are also challenging.¹³⁸ Rural palliative care nurses also have difficulties in providing 24-hour care over vast distances.¹³⁹ Access to appropriate palliative and end of life care is further exacerbated in communities with significant numbers of Aboriginal and Torres Strait Islander people (see earlier discussion on cultural appropriateness).

There is significant agreement across the literature that rural and remote communities are not homogenous; each community is unique and there are different social constructs relating to rural and remote communities, such as self-reliance and independence that needs to be factored into how palliative and end of life care services are planned for and provided. This indicates that models of care need to be flexible and responsive to local circumstances and community capacity with the ability to leverage the well coordinated relationships often found between rural and remote primary health care providers.¹⁴⁰ The evidence suggests that a population-based approach to palliative care service development based on local need and capacity is the most appropriate framework for the delivery of effective and efficient palliative care in rural and regional areas.¹⁴¹

137 Australian Government Department of Health and Ageing 2003, *Research Study Into the Educational Training and Support Needs of General Practitioners in Palliative Care*.

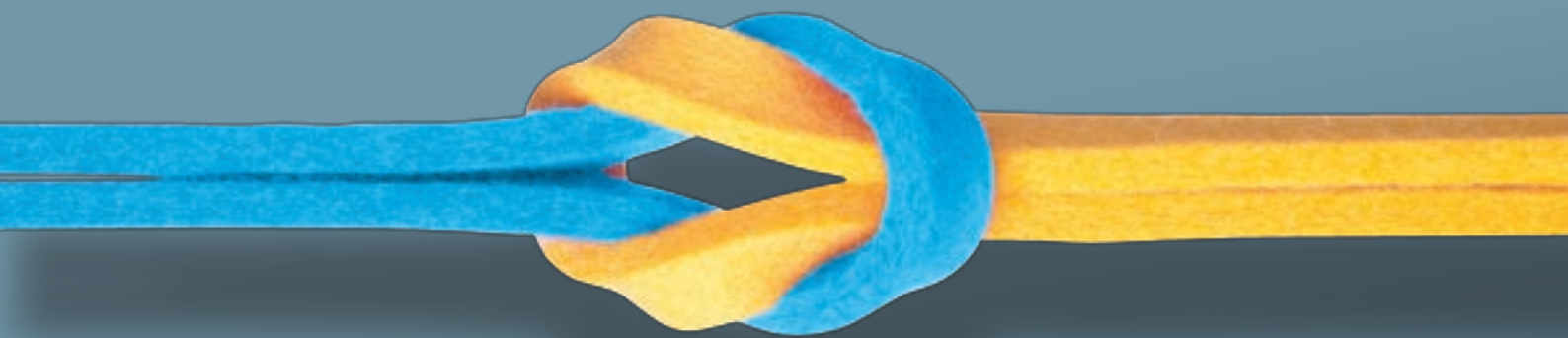
138 White, K et al. 2004, *op. cit.*

139 Australian Government Department of Health and Ageing 2003, *op. cit.*

140 White, K et al. 2004, *op. cit.*; Australian Government National Health and Hospitals Reform Commission 2009, *op. cit.*

141 Phillips, J et al. 2006, 'Enhancing palliative care delivery in a regional community in Australia'. *Aust Health Rev*, vol. 30 pp. 370–9.

SECTION 5
REFORMING CARE
AT THE END OF LIFE
INTERNATIONAL DIRECTIONS



SECTION 5: REFORMING CARE AT THE END OF LIFE—INTERNATIONAL DIRECTIONS

In recent years there has been a substantial amount of work undertaken in a variety of countries to further develop end of life care strategies from both whole-of-system and/or clinical perspectives. The need to develop an overarching framework to support system-wide improvement in care for people approaching the end of their life has been recognised as a national development priority in the UK¹⁴², Canada¹⁴³, and France. Some of the major work in the US¹⁴⁴ and Ireland¹⁴⁵ has revolved around the development of standards, more akin to the national standards work that has been undertaken in Australia.

In the UK end of life care was identified as one of the eight principal care pathways for the National Health Service (NHS) Next Stage Review, establishing care for people at the end of life on the NHS agenda. The Canadian consensus-based strategy on palliative and end of life care sets out a wide ranging agenda to achieve quality outcomes for those approaching the end of their life, regardless of the setting of care and underpins broad structural change in the delivery of palliative care services. In France a national palliative care development program for 2008–2012¹⁴⁶ was implemented in June 2008 with three primary goals: development of hospital palliative care structures and home care services, including the development of networks to support end of life care in aged care and disability services: education and research for all health care workers, and support for volunteers and the general public. It aims to develop a new culture around palliative and end of life care in France.

In the US there has been significant focus on the development of guidelines and in particular the National Consensus Project¹⁴⁷ which produced the first set of national guidelines for the delivery of quality palliative care in 2004 and forged an agreement on the elements of quality of care, and the more recent development of clinical guidelines through the Institute for Clinical Systems Improvement.

The RAND Organisation also provided a landmark study in 1994 of the experience of people who were dying in hospital.¹⁴⁸ In Ireland¹⁴⁹, the Health Information and Quality Authority has endorsed a national standards program that establishes the benchmarks for best practice in relation to end of life care provision in hospitals and other care environments. There has also been seminal work on the integration of end of life approaches into non-malignant chronic disease management.

Below are outlined some of the directions that have been developed in these countries and collectively they represent a significant body of work produced by governments, quality improvement or peak organisations in the last two years in response to the challenges faced in their service delivery environments. These studies and reports will contribute to the Guidance provided in this document and should inform the review of Australia's National Palliative Care Strategy, now over 10 years old. While it is not intended to overview all major international developments in end of life strategy, we believe that what is highlighted below is representative of the major directions that we need to be cognisant of when further considering any guidance for policy and service development in Australia.

The international context—directions and models

England

In 2008 the NHS developed the *End of Life Care Strategy*¹⁵⁰ that was aligned with the broader NHS reform agenda focused on devolving funding, decision making and service development to more local jurisdictions (Primary Care Trusts). It was recognised that the quality of care was generally variable and the strategy was to bring about a stepped change.

142 Department of Health NHS 2008, *op. cit.*

143 Health Canada 2007, *Canadian strategy on palliative and end of life care. Final report.*

144 National Consensus Project for Quality Palliative Care 2009, *op. cit.*

145 Irish Hospice Foundation 2009, *op. cit.*

146 Hirsch, G 2009, SFAP: 'France is witnessing major developments in palliative care'. *European Journal of Palliative Care*, vol. 16(2), pp. 100–1.

147 National Consensus Project for Quality Palliative Care 2009, *op. cit.*

148 Covinsky, KE et al. 1994, *op. cit.*

149 Irish Hospice Foundation 2009, *op. cit.*

150 Department of Health NHS 2008, *op. cit.*

The key areas addressed by the strategy are:

- engagement with local communities to raise the profile of end of life care.
- identifying people approaching the end of life with emphasis in health professional skills development in this area.
- the development of care plans that reflect people's needs, wishes and preferences that are reviewed as circumstances change and are available across settings.
- coordination of care in accordance with the care plan and the delivery of high-quality services across all sectors and at all times.
- rapid access to care that responds to a rapid change in a person's condition and that is made available in the community 24/7, avoiding unnecessary emergency admissions and facilitating people to die in their place of choice.
- the adoption of the Liverpool Care Pathway or similar tools across a range of settings and a range of conditions.
- involving and supporting carers, including the provision of information about the likely progress of a person's condition and services that are available, as well as having their own needs assessed.
- embedding education and training, including continuing professional development in curricula at all levels and for all staff groups.
- recognition that good information and measurement of end of life care provision is a key lever for change and this will require measurement of structure process and outcomes of care.

Ireland

There have been two seminal works that are overviewed here, *Palliative Care for All*¹⁵¹ and *Draft Quality Standards for End of Life in Hospitals*.¹⁵²

Palliative Care for All specifically addresses the needs of patients with diseases other than cancer and reflected the Irish experience that this group of patients are not being responded to in a consistent manner; and that research has indicated that people with chronic obstructive pulmonary disease (COPD), dementia and heart failure (the initial focus of the

study) can experience equal and sometimes greater palliative care needs than people with malignant conditions.

The report is developed in the context of the emergence of chronic disease management programs and the opportunity this provides to address the palliative care needs of all people with a life limiting illness throughout the patient journey. The report is based on the premise that creating an understanding of the disease trajectories of life-limiting chronic illness can provide direction for the delivery of non-specialist and specialist palliative care within the disease-specific management framework, delivered on the basis of need. A similar premise is used in the development of this policy Guidance document.

The report had the following key general considerations across the domains of policy, education, service models and research:

- specialist palliative care is to be provided on the basis of need, not diagnosis.
- it is vital that the changing nature of palliative care needs is addressed at all levels of formal and informal palliative care education.
- international evidence indicates that people with life-limiting non malignant diseases benefit most when palliative care service models are based on a collaborative and/or shared care approach between the disease-specific specialist, primary care staff and palliative care specialists.
- it is recognised that the majority of patients can have their palliative care needs addressed by primary care and disease specific services where there is appropriate training and support from a specialist palliative care service.
- the use of standardised eligibility criteria for entry and exit from specialised services can assist in providing clarity and equity of access for those with specialist palliative care needs.
- disease-specific triggers need to be developed to assist in identifying the need for referral.
- there is a dearth of evidence-based service models and clinical interventions relating to palliative care for people with non-malignant diseases and research is required.

151 Irish Hospice Foundation 2008, *Palliative Care for All. Integrating Palliative Care into Disease Management Frameworks*.

152 Irish Hospice Foundation 2009, *op. cit.*

The report also addresses a range of specific recommendations for each of the target diseases.

Perhaps some of the most instructive aspects of work to develop standards for the end of life care in Irish hospitals are the analyses of the difficulties faced by those hospitals.¹⁵³ There are some similarities that are apparent with our hospital systems:

- an absence of an end of life care strategy.
- the physical environment in many hospitals currently not supporting the delivery of high-quality end of life care because of the lack of private space.
- poorly developed integration of hospital systems relating to end of life care.
- underdevelopment of widespread application of a palliative care approach by all health care professionals.
- a shortage of specialist palliative care services.
- inequality of access to specialist palliative care services.
- the excessive pressure on emergency departments.
- an inherent tension between the acute/curative and the supportive/comfort providing elements of an acute hospital.
- poor public engagement in discussions regarding issues such as preferences at end of life, resuscitation, life support, organ donation.
- sometimes a reluctance on the part of health care professionals to discuss prognosis in advanced life-limiting illness and to refer to specialist palliative care services accordingly and a reluctance on the part of patients and carers to avail of these services (sometimes due to a lack of accurate information).
- a reluctance on the part of some consultants to 'share care' with others.
- negative public perceptions of palliative care as indicative that no further active treatment is possible.
- quality of care depending on the person delivering the service rather than on systems of service provision.

- lack of adequate community based resources to support the choice to die at home.

United States

A number of key policy and guidance documents produced in the United States in recent years are focused on the development of clinical guidelines for various aspects of palliative and end of life care.

*RAND Health SUPPORT Study*¹⁵⁴

One of the first large studies of the experience of people who were dying in hospital illuminated a number of facts about dying that had not been previously understood. While the study was undertaken in the United States, its findings reflect anecdotal evidence about end of life experience in Australia. The key findings were that:

- many patients suffer substantially in the lead-up to their death.
- the patients, their families and their professional caregivers did not see adverse symptoms or aggressive treatments as serious shortcomings of the health system.
- statistical models *could* accurately predict the likelihood of survival for two or for six months, both for individual patients and for groups of patients.
- knowing reliable predictions concerning the survival of the patient did not influence patients, family members, physicians or nurses: they continued to follow usual treatment patterns.
- prognoses remain ambiguous even every close to death. For example the median person dying of heart failure today had a predicted 50 per cent chance yesterday to live another six months.
- good care for the dying means taking care of many who will live for a long time with their serious illnesses.
- counselling about the possible alternatives for care and encouraging decision making that implemented patient preferences among available options had no effect on patterns of care.

The course of care is much more strongly associated with the service supply and habit patterns of the local care system than with the particular preferences or prognosis of the individual patient.

¹⁵³ Irish Hospice Foundation 2009, *op. cit.*

¹⁵⁴ Covinsky, KE et al. 1994, *op. cit.*

Health Care Guideline: Palliative Care¹⁵⁵

This guideline is targeted at assisting primary and specialty care providers in *identifying and caring for adult patients* with a potentially life-limiting, life-threatening or chronic, progressive illness who may benefit from palliative care. Secondary objectives were:

- to improve the effectiveness and comfort level of the primary care provider in communicating the necessity and benefits of palliative care with those patients with a progressive, debilitating illness.
- to improve the assessment of the identified patient's palliative care needs utilising the seven domains of palliative care.
- to increase palliative care planning with patients who have been identified in the early stages of a progressive debilitating disease.
- to improve the continual reassessment and adjustment of the patient's palliative care plan as conditions warrant, utilising the seven domains of care.
- to increase the completion, documentation and ongoing utilisation of advance directives for patients with a progressive, debilitating illness.

The guideline was developed as an algorithm with evidence-based notations for each of its 22 components. In developing the guideline the following issues related to clinical systems improvement were highlighted:

- palliative care planning should begin early in the patient's journey of a progressive, debilitating illness.
- health care providers should initiate palliative care conversations with their patients.
- health care providers should complete a systematic review and document patients' goals for care and advance directives.
- suffering is common in this patient population and the recognition, assessment, and management of both physical and non-physical areas of suffering that are important to the patient is vital.
- communication difficulties among health care providers, patients, and families can hamper quality of care and patient well-being. Setting realistic goals of care and providing realistic hope are essential.

- in the delivery of palliative care, aggressive interventions may continue with an increased focus on symptom management.
- health care providers play an important role in the grief and bereavement processes by supporting the patient and family throughout the course of illness and following the family after the patient's death.

Improving Palliative Care in Nursing Homes¹⁵⁶

A significant study undertaken by the Centre to Advance Palliative Care was developed in response to the recognition that the number of frail elderly in the US will triple or quadruple over the next 20 years and that as the number of persons living with severe, debilitating illnesses increases over the coming decade, so too will the numbers living and dying in nursing homes. At the same time untreated and under-treated pain in nursing homes is well documented.

The study sets out the case for improving palliative care delivery in nursing homes, the challenges and the models that work in the US context. While nursing homes strive to deliver quality care and a wide scope of services to their residents, limited financial resources, the changing resident population and high staff turnover constitute significant ongoing challenges.

The following key findings distilled from this project's research are perhaps instructive because of their resonance with the Australian experience:

- advance care planning and pain and symptom management are targets consistently identified by nursing homes as goals for improvement. A concerted effort is needed to identify and test strategies that meet these goals.
- transitions between hospitals and nursing homes are high-risk events for residents, and project interviews revealed that transitions between sites of care are poorly managed. Communication, documentation, reconciliation of pharmaceutical regimens and care plans are often inadequate or in conflict.
- participants interviewed for this study reported that several programs rely on partnerships to sustain palliative care programs in their nursing homes. Successful partnerships between hospices and/or palliative care teams and nursing homes require size, patience and flexibility. Although some services will eventually

¹⁵⁵ Institute for Clinical Systems Improvement 2009, *Health Care Guideline: Palliative Care*.

¹⁵⁶ Center to Advance Palliative Care 2007, *Improving Palliative Care in Nursing Homes*. http://www.capc.org/support-from-capc/capc_publications/nursing_home_report.pdf (accessed Feb 2010).

be financially self-sustaining, partners need to be able to contribute time to building the relationship, training and skill building without a revenue source.

- training nursing home staff has limited impact in homes with high turnover. Regular on-site access for frontline nursing assistant staff to informal teaching and shared care planning with palliative care providers will be an effective way to improve palliative care in nursing homes.

Canada

*Canadian Strategy on Palliative and End-of-Life Care*¹⁵⁷

The Canadian Strategy on Palliative and End-of-Life Care was established in 2002 and was completed in 2007. A consensus on five key areas, resulting in the establishment of five Working Groups was reached and key accomplishments that are relevant to policy and program work in the Australian context are outlined below.

Best practices and quality care:

- collaborating on the development of an accreditation process for palliative and end-of-life care in Canada, including national standards and measurement tools, completed by the Canadian Council on Health Services Accreditation.
- collaborating on the development of national norms of practice for paediatric hospice palliative care.
- developing *A Model for Volunteer Best Practice and Collaboration in Canadian Hospice Palliative Care* to serve as a framework to enhance the quality of service of volunteers in interdisciplinary palliative care teams.

Education for formal caregivers:

- identifying the core palliative and end-of-life care competencies that apply to physicians, nurses, social workers, pharmacists and pastoral care workers at the undergraduate and post-graduate levels. This led to further engagement with physicians, nurses and social workers to develop discipline-specific competencies.
- collaborating to ensure that by 2008, all undergraduate medical students and clinical post-graduate trainees at Canada's medical schools would receive education in palliative and end-of-life care and graduate with competencies in these areas.

Public information and awareness:

- developing a Hospice Palliative Care Public Awareness Raising Framework.
- developing a synthesis report called on the information needs of informal caregivers.
- developing a glossary of terms utilised as part of advance care developing and undertaking work on cross cultural considerations.

Research:

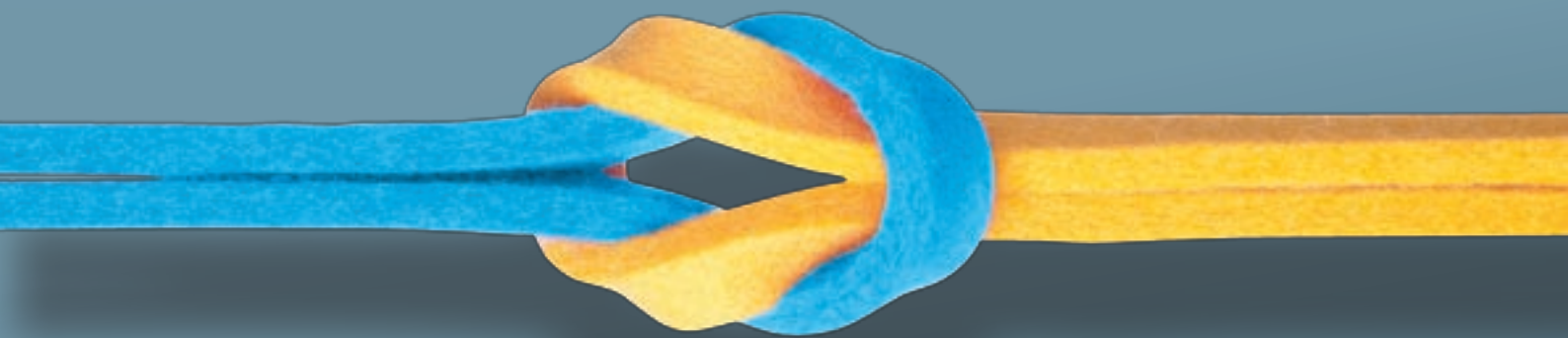
- collaborating on the development and implementation of a virtual network of palliative and end-of-life care researchers housed on a website that includes palliative and end-of-life care research tools and resources.
- supporting initiatives to explore knowledge translation and exchange.
- collaborating with the growing community of researchers addressing terminal illnesses other than cancer.
- supporting a training program to help graduate-level students who want to build a career in palliative research.

Surveillance:

Developing a system for collecting and using information about who needs palliative and end of life care, who receives it, and how to measure its quality including:

- collaborating on a two-phase pilot project to test a method for and assess the feasibility of collecting standardised data on palliative care patients across Canada.
- supporting an extensive literature review on ways to measure the performance of palliative and end-of-life care programs and services. This resulted in an inventory of performance measures that palliative program administrators can use to assess the quality of their services.
- facilitating a national meeting to assess the data needs of different stakeholders, including clinicians, program administrators and government officials, to inform the policy, planning and evaluation of palliative and end-of-life care services

SECTION 6
HEALTH CARE REFORM
AT THE END OF LIFE
NATIONAL DIRECTIONS



SECTION 6: HEALTH CARE REFORM AT THE END OF LIFE— NATIONAL DIRECTIONS

In the decade since the development of the National Palliative Care Strategy¹⁵⁸, there has been a lack of major national work undertaken to drive the system-wide reform that is required to deliver an integrated cross-sectoral approach to and the care of people approaching the end of life. The exceptions to this have been the redevelopment of National Palliative Care Standards and the development of Caresearch.¹⁵⁹ Only in the last year has there been recognition through the NHHRC that the care of people approaching their end of life should be a significant part of the whole-of-health system reform agenda. This section highlights the elements of the NHHRC's reform proposals and those contained in the National Primary Health Care Strategy and the work undertaken by the Australian Commission for Safety and Quality in Health Care that support system-wide improvement in the delivery of care at the end of life.

National reform agenda in Australia

In most senses the issues and challenges associated with the provision of care at the end of life are a microcosm of the issues and challenges that face the whole health system, so it is important that the general directions of health reform are understood and these provide the broad context to this Guidance document.

Since the election of the Rudd Labor Government in 2007 with a significant platform to reform Australia's health delivery system in cooperation with the states and territories, there have been a number of landmark initiatives to shape the nature of this reform. The most significant of these have been the establishment of the National Health and Hospitals Reform Commission (NHHRC) to report on what will be required to transform Australia's health system to meet the emerging needs of Australians in the 21st Century. The Commission has produced two key reports that have set the reform agenda for negotiations with the states and territories through the Council of Australian Governments (COAG):

- *beyond the Blame Game* (April 2008)
- *a Healthier Future For All Australians—Final Report of the National Health and Hospitals Reform Commission* (June 2009).

Another significant element of the national health reform agenda has been the release of *Building a 21st Century Primary Health Care Strategy* (August 2009) that provides a roadmap to guide future policy and practice in primary health care in Australia.

In parallel with these two streams of work has been the work undertaken by the Australian Commission on Safety and Quality in Health Care that is developing a future national model for safety and quality accreditation.

All these reform agendas, to the extent that they will have a major influence on the way government restructures and resources health care in the future, could also have a profound effect on the way care is delivered at the end of life.

NHHRC reforms and end of life care

The Final Report of the NHHRC concludes that the case for health reform is compelling. It summarises this case in the following terms:

While the Australian health system has many strengths, it is a system under growing pressure, particularly as the health needs of our population change. We face significant challenges, including large increases in demand for and expenditure on health care, unacceptable inequities in health outcomes and access to services, growing concerns about safety and quality, workforce shortages, and inefficiency.

Further, we have a fragmented health system with a complex division of funding responsibilities and performance accountabilities between different levels of government. It is ill-equipped to respond to these challenges.¹⁶⁰

The report identifies three overarching reform goals, all of which are relevant to the care of people at the end of life.

158 Australian Government Department of Health and Aged Care 2000, *National Palliative Care Strategy*.

159 There have been a number of other major projects, all funded by the Commonwealth Government—APRAC, PCOC, Rural Palliative Care Program, PEPA, PCC4U—and these have generally focused on reforms within care delivery sectors or components such as education and training.

160 Australian Government National Health and Hospitals Reform Commission 2009, *op. cit.*, pp.3.

1. Tackling major access and equity issues.

Within this, four priorities are particularly relevant:

- improve health outcomes of Aboriginal and Torres Strait Islander people:
 - particularly, train and recognise an Indigenous health workforce;
- redress ethnic disparities in health and care outcomes;
- support for people living in rural and remote areas;
- timely access to quality care in public hospitals:
 - particularly care in emergency departments.

2. Redesigning our health system to meet emerging challenges

Within this, the following design elements have particular relevance:

- support for people living in rural and remote areas;
- connect and integrate health and aged care services;
- redesigning health services around people to make sure that they can access the right care in the right setting;
- integrating multidisciplinary primary health care services and improving access in the community including establishing primary health care organisations;
- better continuity and coordinated care for people with more complex health problems;
- better use of specialists in the community, including shared management of patients with chronic and complex health needs;
- ‘next generation’ of Medicare;
- bringing together state-funded primary health care services and medical services to create a comprehensive primary health care platform;
- reshaping the MBS to promote the continuity and integration of care through collaborative team models of care.

3. Creating an agile and self-improving health system

Within this, three levers of reform have particular relevance:

- strengthened consumer engagement and voice;
 - building health literacy
 - empowering consumers to make fully informed decisions
- modern learning and supported workforce;
 - developing a new competency based framework for education and training which moves towards a flexible and multidisciplinary approach
- knowledge-led continuous improvement, innovation and research.

In addition to the strategic elements highlighted above there are a range of structural enablers that will facilitate whole-of-system changes, such as a ‘one health system’ bringing a range of functions together at the national level and person controlled electronic health records.

The NHHRC report also identified four specific recommendations on caring for people at the end of life:

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

treatment, and their right to decline treatment, noting that in some states/territories this is complemented by supporting legislation that relates more specifically to end of life and advance care planning decisions.

Primary Care Strategy and end of life care

Building a 21st Century Primary Health Care Strategy sets out an ambitious high-level agenda that attempts to address a range of structural problems that are inherent in our health system. These are summarised in the Strategy in the following way:

... primary health care in Australia tends to operate as a disparate set of services, rather than an integrated service system—it is difficult for primary health care to respond effectively to changing pressures (such as demographic change, changes in the burden of disease, emerging technologies and changing clinical practice) and to coordinate within and across the various elements of the broader health system to meet the needs of the individual patient.

For individuals, the primary health care services they access and the resulting quality of care can depend on where they live, their particular condition and particular service providers involved, as much as their clinical needs and circumstances. Many patients, particularly those with complex needs, can either be left to navigate a complex system on their own or, even when supported by their GP, can be effected by gaps in information flows and limited ability to influence care decisions in other services.¹⁶¹

The strategy sets out four priority directions for change, of which three are directly relevant to the care of people at the end of life:

- Improving access and reducing inequity—services matched to people’s needs and delivered across an integrated system:
 - more uniform quality care across the country;
 - actively addressing service gaps and the needs of specific population subgroups;
- service delivery and funding arrangements supporting flexible service delivery models.
- Better management of chronic conditions:
 - flexible responses tailored to local service systems and needs;
 - services that include comprehensive and multidisciplinary team care, ‘as needed’ care coordination, sharing of information within and across providers, and self-management support including through diagnostic support tools.
- Improving quality, safety, performance and accountability—a framework and improved mechanisms for measurement and feedback driving transparency and quality improvement:
 - individuals to have enough information about health providers, facilities and services to make informed choices about their care;
 - patient care based on best available evidence;
 - access to information on safety, quality and performance will drive continuous quality health care outcomes improvement.

Australian Commission for Safety and Quality in Health Care (ACSQHC) and end of life care—focus on quality

The national quality and safety framework has been developed by the ACSQHC to provide a mechanism to coordinate the wide variety of sector-specific strategies that address quality and safety issues. The framework spans the whole health system—public and private, primary and hospital settings. The framework is expected to be used:

- as the basis for strategic and operational safety and quality plans;
- to provide a mechanism to refocus current quality improvement activities, reviewing investments for safety and quality and designing goals for health service improvement; and
- to promote discussion with consumers, clinicians, managers, researchers and policy-makers about how they might best contribute to safety and quality improvement.

¹⁶¹ Australian Government Department of Health and Ageing 2009. *Building a 21st Century Primary Health Care System: A Draft of Australia’s First National Primary Health Care Strategy*, op. cit., pp. 9.

The national quality and safety framework proposes three key areas of direction (called constructs) for health services. Within each of these there are a range of strategies, some of which are directly relevant to palliative and end of life care¹⁶²:

'Consumer focused care'

- Develop service models which improve access to health care for patients. This would involve:
 - developing incentives and models that enable patients to access health care when they need it;
 - use of information technology to support access to quality care;
 - designing training and service models to provide access to skilled health professionals in rural and remote areas;
 - establishing formal links and support mechanisms between specialist tertiary units and rural services;
 - reducing the need for people to access health through targeted prevention programs that focus on the social determinants of health;
 - maintain affordability of health care, especially for those patients with multiple, ongoing and complex conditions;
 - making essential allied health and dental service available to all.
- Increase health literacy. This would involve:
 - supporting patients and consumers to take greater responsibility for their health care and obtain and use information that is available to them;
 - training clinicians to recognise that encouraging questions makes health care safer and assists clinicians to identify and support patients with lower health literacy;
 - screening for those with lower health literacy;
 - making facilitated support groups available;
 - ensuring educational curricula contain modules that will help students achieve a basic level of health literacy.

- Involve patients so they can make decisions about their care and plan their lives. This would involve:
 - ensuring patients, consumers and providers have access to trusted information to support decision making. This includes information on evidence, patient experiences and patient outcomes;
 - clearly and compassionately communicating with patients about what will happen during care and recovery;
 - providing patients with written records of consultations and take-home information;
 - providing patients and consumers with information in languages and formats that meet their needs, and using interpreters and visual aids when necessary to support decision making and explain care processes;
 - teaching essential skills for communicating and shared decision making in health care curricula;
 - ensuring that health services have effective mechanisms in place for patient, consumer and carer feedback.
- Provide care that is culturally responsive, competent, appropriate and safe. This would involve:
 - providing clinicians with education in cultural safety;
 - making cultural advice and interpreter services available to clinicians;
 - ensuring training opportunities for clinicians to work with Indigenous and other culturally and linguistically diverse populations;
 - paying special attention to the care of the vulnerable.
- Enhance continuity of care. This would involve:
 - organising primary care services so that all patients and consumer have access to a regular doctor or place of care and phone advice when it is needed;
 - funding models and contracts to support access.

162 Australian Commission on Safety and Quality in Health Care 2009, Discussion Paper on achieving the directions established in the proposed National Safety and Quality Framework.

- Provide case management for complex care. This would involve:
 - ensuring that patients with multiple, ongoing and complex conditions receive appropriate case management;
 - considering case management as an essential component of clinical care;
 - fully exploiting electronic communication to support care;
 - working with other agencies to reduce the impact of socio-economic disadvantage or mental illness.
- Facilitate patient-centred models. This would involve:
 - ensuring all health professionals are focused on achieving the best outcomes and experiences for patients;
 - routinely using multidisciplinary models of care.

‘Driven by information’

- Reduce unjustified variation in the standards of care. This would involve:
 - embedding guidelines in clinical practice;
 - systematic monitoring of compliance with guidelines and safety protocols;
 - making available a comprehensive suite of Australian guidelines;
 - ensuring that guidelines are up-to-date, authoritative and accessible; that they contain relevant indicators and that they are actively disseminated;
 - obtaining endorsement for guidelines from major professional bodies.
- Collect and use data to support safety and quality. This would involve:
 - ensuring individual practitioners have timely access to relevant data about the quality of care they provide and the outcomes of their patients;
 - public and private health services analysing their own data to monitor quality and improve systems of care;
 - policy makers accessing national data collections and indicators including MBS, PBS, case-mix data collections, clinical registries and ABS data collections;
 - all clinical registries working towards offering timely institutional or provider level data.
- Learn from patients’ and carers’ experiences. This would involve:
 - regularly conducting, reporting and using patient experience surveys to improve the patient’s experience of health care;
 - piloting patient experience surveys that measure the quality of the patient journey and interactions across different settings of care.
- Encourage and apply research that will improve safety and quality. This would involve:
 - dedicating a substantial quantum of medical research funding to safety and quality priorities and to implementation and evaluation research;
 - regularly determining quality research priorities and using the priorities to guide funding;
 - enhancing the organisation of care delivery through a systematic research program that informs funders, policy makers and research users;
 - making methods for successful implementation and spread of new clinical research findings the subject of detailed investigation.
- Continually monitor the effects of health care interventions. This would involve:
 - ensuring clinical trials are of sufficiently long duration and designed to meet the specific needs of people who receive these treatments in Australia;
 - linking data from existing data sets to enable treatment outcomes of Australian patients to be tracked over time;
 - accompanying approval for medications and treatments with a plan to systematically collect data about their effects and patient outcomes.

'Organised for safety'

- Restructure funding models to support comprehensive, appropriate care. This would involve:
 - progressively changing funding structures to address known safety and quality issues, and to encourage effective care;
 - developing sophisticated analyses of health care effectiveness (including economic analyses) to support the restructure of funding models.

Council of Australian Governments response to National Reform Agenda

The Council of Australian Governments (COAG), led by the Australian Government, in April 2010 began a process of responding to the above health reform reports and initiatives, through the development of a National Health and Hospitals Network.¹⁶³ These reforms promise to be 'the most far-reaching structural reforms to the health system since the introduction of Medicare'.¹⁶⁴

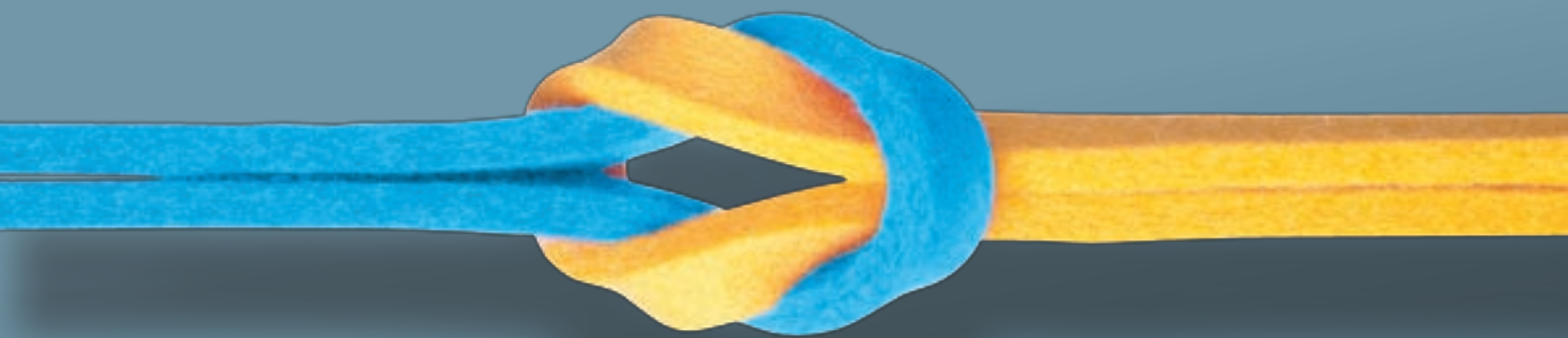
The most significant initiatives that lay the structural foundation for long-term improvements in palliative and end of life services are the following:

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

163 Australian Government 2010, *A National Health and Hospitals Network: Further Investments in Australia's Health*.

164 *ibid.* pp. iii.

SECTION 7
GUIDANCE FOR THE
HEALTH CARE SYSTEM
MOVING TOWARDS AN
INTEGRATING SYSTEM
OF END OF LIFE CARE



SECTION 7: GUIDANCE FOR THE HEALTH CARE SYSTEM— MOVING TOWARDS AN INTEGRATING SYSTEM OF END OF LIFE CARE

It is clear that any guidance that can be provided around achieving our vision for integrating care at the end of life needs to be well grounded in the three sets of parallel reform processes described in the previous section. Our sector recognises that many of the directions outlined in these sets of reforms will require a fundamental structural change within the health system that can only be achieved in the medium-to-long term through concerted cooperation between Commonwealth, state and territory governments and through a strong determination by health professionals and consumers to reorient the delivery of health services towards a consumer needs focus.

Aligning guidance on palliative and end of life care with national reform processes

The common themes that emerge across these three broad and overlapping areas of reform have a particular resonance when looking at the challenges in delivering consistent services to achieve quality care at the end of life for all. These common reform themes include:

- services need to be matched to people's needs, including the most appropriate setting to receive those services;
- services should be delivered in an integrated way across sectoral boundaries;
- continuity of care is critical; particularly in the management of chronic conditions;
- building capacity and competence in primary health care is a priority; particularly involving multidisciplinary approaches;
- improving quality based on information, evidence and continuous improvement.

These are aligned with the reforms that are required to achieve good-quality care at the end of life.

The Guidance that is provided in this document will be aligned with these whole-of-system directions and aims to positively contribute to their achievement. With regard to this it has been observed on a number of occasions that good palliative care services, which by definition should already be delivered within a multidisciplinary team and across a range of health care settings, provide an exemplar to the rest of the health system on a number of levels.¹⁶⁵ Furthermore, it is often said that the way we care for the dying is a litmus test for how we as a society care for all sick and vulnerable people¹⁶⁶ and hence prioritising 'getting it right' needs no apology.¹⁶⁷

Figure 4 provides an integrating framework that shows the alignment between the three major national reform process directions. We have integrated these into an overarching framework that relates closely to, but modifies to suit end of life issues the three broad priorities or constructs established by ACSQHC¹⁶⁸ as follows:

- 'Consumer and carer focused'

This means providing care that is respectful of and responsive to individual needs, values and preferences. It means a partnership between consumers, carers and their health care providers. Processes of care are designed to optimise the consumer experience.

- 'Driven by information'

This means enhancing knowledge and understanding about; end of life issues in the community; how services are provided; and the outcomes of these. Data is collected and analysed to support improvements and in understanding consumer and carer experiences

- 'Organised for quality and safety'

This means that quality and safety are high priorities in the design of health care. Organisational structures, work processes and funding models recognise and reward taking responsibility for well-coordinated quality care.

165 Good, P 2003, 'Advances in Palliative Care relevant to the wider delivery of healthcare'. *MJA*; vol. 179, pp. S44–S46; Crawford, GB and Price SD 2003, *op. cit.*; Center to Advance Palliative Care 2008 *op. cit.*

166 Department of Health NHS 2008, *op. cit.*, pp.10.

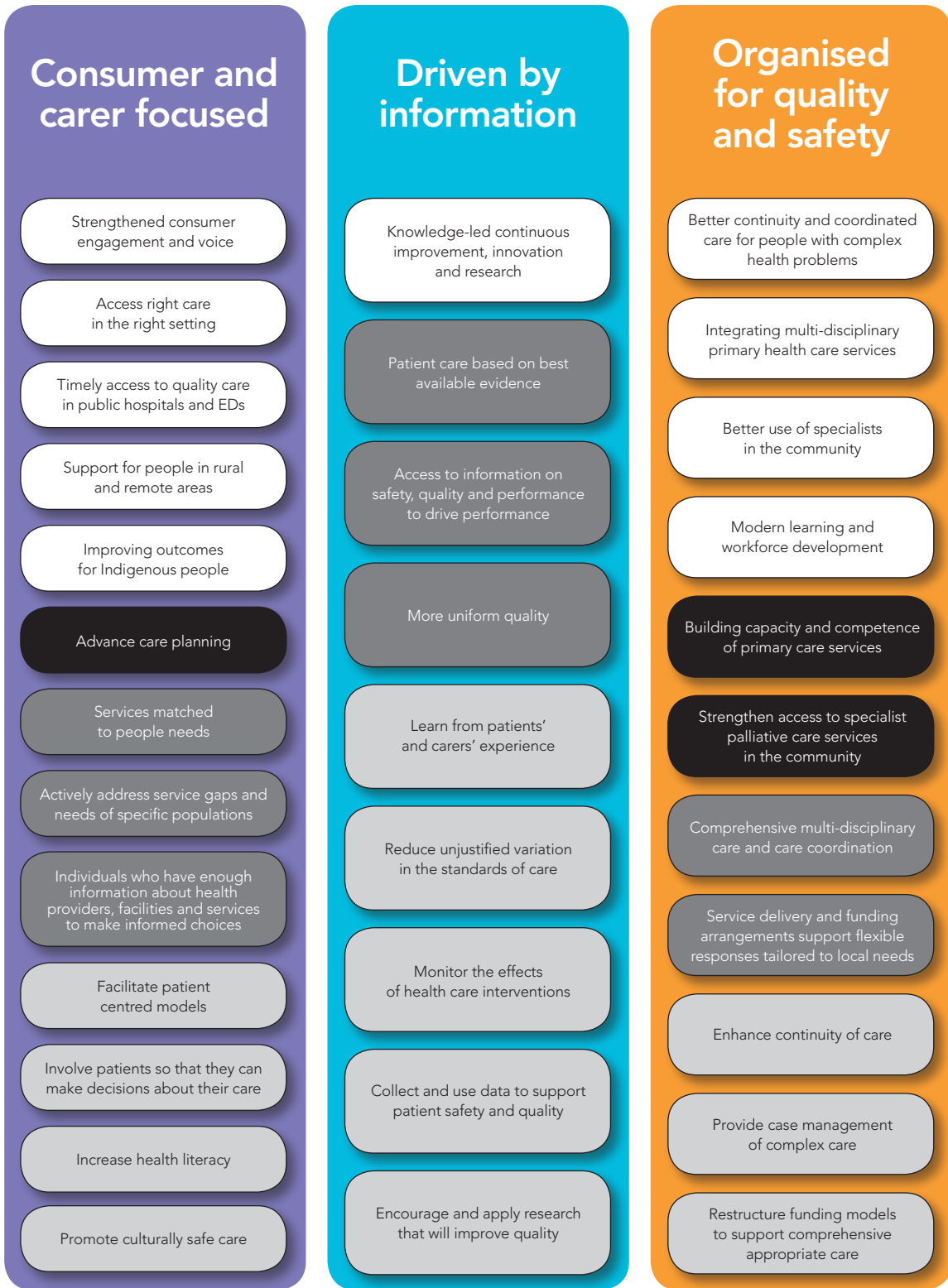
167 Murray, SA and Sheikh, A 2008, *op. cit.*

168 Australian Commission on Safety and Quality in Health Care 2009, *op. cit.*

Figure 4: Aligning national reform directions related to end of life care

Key:

NHHRC
 Primary Care Strategy
 ACSQHC
 NHHRC Palliative Care Specific



The ACSQHC's overarching framework will also be used to frame the Guidance domains and their constituent Guidance elements developed in this section.

National end of life care guidance framework

The national end of life Guidance framework is comprised of three key constructs:

- 'Person and carer focused'
- 'Driven by information'
- 'Organised for quality and safety'.

These constructs have been derived from the ACSQHC proposed National Quality and Safety Framework.¹⁶⁹

Each construct contains a number of domains and there are a number of guidance elements within each domain. There are 11 domains and 61 guidance elements within the framework.

Figure 5 below represents the Guidance framework constructs and its domains. Guidance elements developed within each of the domains articulate the key system-level changes that are required and that should be considered preconditions to achieving the delivery of quality care at the end of life to patients and their families.

Figure 5: National end of life Guidance framework comprising three key constructs and 11 domains



¹⁶⁹ Australian Commission on Safety and Quality in Health Care 2009, op.cit.

Care that is 'Person and carer focused'

*Putting individuals, and their families and carers at the centre of care is fundamental in designing health system changes.*¹⁷⁰

Putting individuals at the centre of care is similarly fundamental in the development of an integrated, person focused¹⁷¹ system that delivers quality care at the end of life for all.

Many factors impact on the ability for any health system to deliver person-focused care. The Picker Institute has identified eight factors that relate to the ability to achieve patient-focused care:

- respect for patient-centred values, preferences and expressed needs;
- coordination and integration of care;
- information, communication and education;
- physical comfort;
- emotional support and alleviation of fear and anxiety;
- involvement of family and friends;
- transition and continuity; and
- access to care.¹⁷²

We would also add to this list the necessity to achieve a partnership between consumers, their carers and health care providers. Knowing the person over time in their family and community contexts also greatly facilitates person focused care.¹⁷³ These factors highlight the self evident fact that it is the inter-relationships between various elements that make up a system of care that will either facilitate or hinder the achievement of an integrated person-focused outcome. Most of these factors are highlighted throughout the various Guidance elements in this section.

The first construct, 'Person and carer focused', has four domains as follows:

Guidance Domain 1: Patients empowered to make fully informed decisions

The importance of developing effective communications between patients, families and their care team is paramount. One of the major

communication tools to emerge in recent years has been advance care planning. Advance care planning provides for an ongoing conversation between patients, their families and carers and the health care team that can be used as a mechanism to take control of decisions that affect an individual's care. It is linked with the broader imperative of raising community awareness about death and dying.

Ideally, advance care planning discussions need to be entered into at an early stage of a progressive debilitating disease or terminal illness. It should facilitate a discussion about the goals of care at any stage in the patient journey and in any setting. In an integrated and person-focused system, information provided by the care team that is competent in having such discussions, will facilitate a mutual understanding of people's care preferences and needs to occur in each care setting and can be either a formal process (such as an advance care directive) or an informal process. Any advance care planning process also needs to recognise that preferences might change, particularly as the phase or circumstances of a person's illness changes.

Guidance Domain 1: Patients empowered to make fully informed decisions

Specific guidance elements:

- 1.1 *Develop and implement policies, procedures and tools to support consumer and carer involvement in end of life care planning commencing from the early stages of a life-limiting illness.*
- 1.2 *Develop and implement a national approach to the implementation of advance care planning across the health and aged care systems.*
- 1.3 *Develop a nationally led, systematic process to develop and disseminate evidence-based, consumer-friendly education and information to support people to make decisions about the location and type of care and resources they need as they approach the end of their life.*

170 Australian Government Department of Health and Ageing 2009. *Primary Health Care Reform in Australia*, op. cit., pp. 42.

171 Patient-focused or patient-centred care in the context of this paper includes the broader family and carers that provide support and with whom the patient has a significant relationship.

172 Commonwealth Department of Health and Ageing 2009. *Primary Health Care Reform in Australia*, op. cit., p. 42.

173 Stange, KC and Ferrer, RL 2009. 'The Paradox of Primary Care' *Ann Fam Med*; vol. 7, pp. 293-9.

Guidance Domain 2: Needs-based care

Patients and carers who would benefit from care at the end of life should have access to services to match their need. It is now generally accepted that services should be tailored to individual needs with the majority of patients not having complex needs and being able to be dealt with by a multidisciplinary primary care team. Others will require specialist service input to deal with sporadic exacerbations of symptoms, while the minority of patients with complex symptoms will require care plans to be developed and implemented by specialist palliative care providers in conjunction with the contextual knowledge of a primary care team.^{174,175,176} The more complex the needs, the higher the degree of responsiveness that may be required by service providers. Patients and families with complex needs may require a care plan that guides the delivery of services across all sectors and at all times.

Further, there is recognition that people with a wide range of progressive chronic conditions would also equally benefit from palliative and end of life care. Management of end of life care needs to be incorporated into disease management frameworks and pathways supported by additional training of chronic disease specialist teams. Ensuring access to palliative care requires the development of collaborative approaches across primary, aged, sub-acute and acute sectors and the use of standardised eligibility and discharge criteria for both malignant and non-malignant diseases.¹⁷⁷

Guidance Domain 2: Needs-based care

Specific guidance elements:

- 2.1 *Develop a national systematic approach to the development of criteria for the recognition of people approaching the end of life.*
- 2.2 *Introduce standardised, validated assessment tools to determine patient and carer needs at the end of life.*
- 2.3 *Develop and implement streamlined, consistent holistic assessment of end of life needs across primary, aged care and specialist services.*
- 2.4 *Develop disease cluster referral triggers that align consumer need and the common trajectories of people approaching the end of life.*
- 2.5 *Develop and implement a standardised, systematic approach to the implementation of end of life care pathways for acute care, community and aged care settings.*

Guidance Domain 3: Involved and supported carers

Carers play an integral role in the ability of the health system to deliver high-quality care at the end of life. In many respects they are 'co-workers' in a health care team¹⁷⁸ and need to be supported in a variety of ways both during and after the death of the person they are caring for. Carers have varying needs depending on individual circumstances and a well-performing system needs to be able to take these into account in the development of patient care plans so as to involve and support carers at various stages along the end of life pathway.¹⁷⁹

174 Palliative Care Australia 2005. *A Guide to Palliative Care Service Development: A population based approach*, op. cit.

175 Mitchell, GK et al. 2008. op. cit.

176 Irish Hospice Foundation 2008. op. cit., pp. 38.

177 Irish Hospice Foundation 2008. op. cit., pp. 3.

178 Department of Health NHS 2008. op. cit., pp. 107.

179 *ibid.*

Guidance Domain 3: Involved and supported carers

Specific guidance elements

- 3.1 *Support the vital role of carers through the development and dissemination of educational programs, information and access to timely advice regarding end of life care.*
- 3.2 *Provide access to residential and flexible at home respite care arrangements to assist carers sustain their role in caring for someone approaching the end of life.*
- 3.3 *Develop and implement appropriate tools to routinely assess and support the health of carers.*
- 3.4 *Ensure that carers are engaged in care decisions and communications to the extent they wish to be and subject to the consent of the patient.*
- 3.5 *Directly consult with carers in the processes of policy and services development and evaluation to ensure that their specific needs and experiences related to end of life care are adequately and accurately reflected and acknowledged.*
- 3.6 *Ensure that carers are provided with resources to enable them to undertake their role providing care to someone approaching the end of life.*
- 3.7 *Provide access to bereavement support for all carers and families.*

Guidance Domain 4: Culturally competent, appropriate and safe

There is a need for health care providers to engage in culturally competent and safe practice by recognising the way in which culture and language influence and frame responses to beliefs and understandings about death and dying; the provision of information, truth telling and consent; professional and interpersonal relationships; and the provision of services.¹⁸⁰ A key aspect of this is leadership and accountability for cultural competence and responsiveness¹⁸¹ within local end of life specialist and primary care teams that is linked to an understanding of the cultural and linguistic profile of the consumer base in their service

catchment, which may include immigrant, refugee, asylum seeker and Indigenous populations.¹⁸²

Cultural competence and culturally safe practice needs to be integrated into learning at all levels. Of particular importance will be the need to effectively address the delivery of end of life services to immigrant, refugee, and asylum seeker populations and Indigenous communities, requiring a fundamental shift in the capacity of the health workforce to meet their needs. This needs to include a greater recognition of the key role of ethnic liaison and aboriginal health workers with research beginning to demonstrate significant success in improving access to care and patient experiences when associated with utilisation of these key roles.¹⁸³ There is also a need to increase the representation of Indigenous people in the health workforce, including the tertiary trained sector.¹⁸⁴

Guidance Domain 4: Culturally competent, appropriate and safe

Specific guidance elements

- 4.1 *Ensure that cultural and spiritual competence and safety related to end of life care is incorporated into multidisciplinary education programs at all levels.*
- 4.2 *Ensure that policies, procedures and processes of care respect and reflect different cultural and ethnic values, beliefs and practices that surround death, dying and end of life care.*
- 4.3 *Support the development and provision of culturally appropriate health information and resources in a range of community languages and access to trained interpreters.*
- 4.4 *Build relationships between Indigenous and non-Indigenous health care providers that facilitate understanding of cultural differences and care needs at the end of life for Aboriginal and Torres Strait Islander people.*
- 4.5 *Ensure there are policies, procedures and mechanisms to support 'return to country' for Indigenous Australians who are approaching the end of their life.*
- 4.6 *Support the strengthening of the role of Indigenous health workers to connect health professionals and services with local communities to support improved end of life care.*

180 SA Health 2009. *op. cit.*, p.58.

181 Australian Government National Health and Hospitals Reform Commission 2009, *op. cit.*, pp. 29.

182 SA Health 2009. *op. cit.*

183 McGrath, PD et al. 2007. 'The case for Aboriginal Health Workers in palliative care'. *Australian Health Review*, vol. 31(3), pp. 430-9; Taylor, KP 2009, 'Exploring the impact of an Aboriginal Health Worker on hospitalised Aboriginal experiences: lessons from cardiology'. *Australian Health Review*, vol. 33(4), pp. 549-57.

184 Australian Government Department of Health and Ageing 2009. *Primary Health Care Reform in Australia*, *op. cit.*, pp. 126.

Care that is 'Driven by information'

Information needs exist at all levels in the health care system as consumers, carers, clinicians, researchers and policy makers all have information needs. Providing access to information to meet these needs is central to an ability to deliver high-quality accessible care.

Information includes all forms of data, research evidence and consumer focused literature that can be used to guide and support decision making. This Guidance construct focuses on the key areas of information to consumers and the community, the collection and use of data to support improvement, the translation of data and evidence into knowledge that drives improvement and the need to support the ongoing generation of research based knowledge.

In the second construct, 'Driven by information', there are four domains as follows:

Guidance Domain 5: Informed and empowered community

Interventions designed to inform, educate and involve patients in their health care improve experiences and clinical outcomes.¹⁸⁵

Strengthening community participation in policy development and quality review and building community capacity to be effective advocates and fully participant partners in the delivery of care systems to meet their needs will result in more person and carer centred care.

Raising awareness and improving health literacy will support consumers to make informed decisions about their health care needs as they approach the end of life. Health literacy is defined as 'the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions'.¹⁸⁶ It has been reported that 59 per cent of Australians have low levels of health literacy.¹⁸⁷

Promoting open discussion of death and dying amongst the general community and consumers will

support their capacity to become involved in decision making regarding care preferences and choices at the end of life. Open discussion among health and legal professionals will also serve to create a greater understanding of the needs of people as they approach the end of life and will be instrumental in reducing legal impediments and professional barriers to the delivery of appropriate high-quality care to people who are dying.

Guidance Domain 5: Informed and empowered community

Specific guidance elements:

- 5.1 *Strengthen consumer participation and voice in:*
 - a) *end of life policy and service development;*
 - b) *community capacity building initiatives; and*
 - c) *quality review.*
- 5.2 *Develop a national awareness raising strategy that guides and integrates community awareness, consumer health literacy and community capacity building initiatives in end of life care.*
- 5.3 *Promote open discussion of death and dying through health and legal professional, education and awareness programs.*

Guidance Domain 6: Data collected and used to support quality improvement

Engaging jurisdictions, services and individual health professionals in the development of relevant data is a critical aspect of achieving an effective systematic and sustainable approach to support improvement and drive change. Ensuring health practitioners and services have timely access to relevant data about the quality of care they provide and the outcomes for patients and their families is vital.¹⁸⁸

¹⁸⁵ Culter, A and Ellins, J 2007, 'Effectiveness of strategies for informing, educating and involving patients'. *BMJ*, vol. 335, pp. 24-7.

¹⁸⁶ Fineberg, H 2004, *Health Literacy*, Institute of Medicine, National Academies Press.

¹⁸⁷ ABS 2008. *Health Literacy, Australia, 2006*, Cat. No. 4233.0, Canberra.

¹⁸⁸ Australian Commission on Safety and Quality in Health Care 2009, *op.cit.*, p 20.

In broad terms a systematic approach would cover the three key levels of data and information needs working in parallel:

- System level data and information—necessary to inform national policy;
- Service level data—activity and outcome data of importance to service for quality improvement purposes and jurisdictional service planning e.g. access, equity, quality and performance management;
- Clinical data—important to provide evidence to improve clinical care to patients and carers and assess clinical performance.

Guidance Domain 6: Data collected and used to support quality improvement

Specific guidance elements:

- 6.1 *Inventory the data needs related to end of life care of the different stakeholders—government (Commonwealth and state/territory), clinical services (specialist, primary and aged care), funders, clinicians and the wider community.*
- 6.2 *Collect and use routine data on patient and service level activity and outcomes to support improvement and monitor performance in end of life care.*
- 6.3 *Ensure that data on safety and quality of care at the end of life is collated, compared and provided back to clinical services and clinicians in a timely fashion to expedite quality and quality improvement cycles.*
- 6.4 *Develop and support the use of nationally standardised measurement tools.*
- 6.5 *Enable end of life data linkages between various data collections and repositories held at clinical, national and jurisdictional level.*

Guidance Domain 7: Knowledge-led continuous improvement

Unjustifiable variation in the way that end of life care services are resourced, structured and delivered across Australia means that not all patients receive the best quality care. Australian palliative care outcomes data collected via Palliative Care Outcomes Collaborative (PCOC) suggests that there is considerable unjustified variation in palliative care outcomes experienced by patients and carers.¹⁸⁹

The national palliative care standards set out the reasonable expectations of quality for all services delivering care to people at the end of life.¹⁹⁰

Understanding the causes of variation and implementing improvement actions to address these issues will bring about system level improvement and reduction in unacceptable and unjustifiable variation.

System-wide improvement requires an integrated and strategic approach to the diffusion and spread of innovation and evidenced based care.¹⁹¹

Guidance Domain 7: Knowledge-led continuous improvement

Specific guidance elements:

- 7.1 *Implement, monitor and report on performance against national standards for end of life care across all care settings (specialist palliative care, primary and community care, aged care and acute care).*
- 7.2 *Report on strategies to improve safety and quality of care at the end of life and the actions taken in response to identified quality and safety issues.*
- 7.3 *Develop and implement strategies that support the translation and diffusion of evidence and knowledge in relation to the needs and effective care of people approaching the end of life.*
- 7.4 *Reduce unjustified variation in practice by disseminating evidence and implementing best practice clinical guidelines for palliative and end of life care.*

189 Palliative Care Outcomes Collaborative 2009, op.cit.

190 Palliative Care Australia 2005. *Standards for providing quality palliative care for all Australians (4th Edition)* op. cit.

191 Massoud, MR et al. 2006, *A Framework for Spread: From local improvements for system-wide change*, IHI Innovations Series white paper, Cambridge, Massachusetts: Institute for Healthcare Improvement.

192 Australian Government National Health and Hospitals Reform Commission 2009, op cit., pp. 140

Guidance Domain 8: Supported research, knowledge translation and exchange

A critical aspect of knowledge-led continuous improvement is the ability to get evidence as it develops to health professionals at the coalface if we are to effect real improvements in consumer and carer outcomes. This requires structures and processes that support this process. We already have an excellent repository of evidence available through Caresearch. The challenge is to develop a range of processes and methodologies that can encourage knowledge transfer of evidence into everyday practice in an effective and pragmatic manner.¹⁹² This requires a commitment to invest in the development of knowledge transfer methodologies between researchers, health care professionals and policy makers.¹⁹³

Guidance Domain 8: Supported research, knowledge translation and exchange

Specific guidance elements:

- 8.1 *Adopt a national approach to the synthesis and dissemination of clinical evidence/ knowledge and research related to end of life to expedite its translation into practice.*
- 8.2 *Prioritise and invest in clinical and health service research in palliative and end of life care.*
- 8.3 *Provide dedicated resources for the regular dissemination of research outcomes related to end of life to health services and clinicians.*
- 8.4 *Develop a national approach to the collection and reporting of patient and family reported outcomes related to end of life.*
- 8.5 *Enhance the spread of innovation in palliative and end of life care by supporting health service and health professional participation in breakthrough collaboratives, clinical forums, health roundtables etc.*
- 8.6 *Invest in the development of knowledge transfer methodologies between researchers, health care professionals and policy makers.*

Care that is 'Organised for quality and safety'

Quality and safety must be seen as a high priority in the design of health care.¹⁹⁴ Improving the quality of care at the end of life will require evaluation and redesign of models of care, workforce and approaches to funding.

Organising care to improve safety will also require that clinicians, managers and governments recognise and enact their individual and collective responsibilities for quality and safety. Education can improve quality and safety of care, and care improves when individuals, organisations and teams are encouraged to reflect on and learn from their experience. A well-trained and supported workforce is necessary for the provision of high-quality, safe care—as is a supportive work environment.

In the construct, 'Organised for quality and safety', there are four domains as follows:

Guidance Domain 9: Provide seamless, well-coordinated care

There are a number of critical dimensions to developing well-coordinated and seamless end of life care. Foremost is the development of protocols and a shared understanding of pathways to provide linkages between sectors and health care professionals. There is wide-spread agreement that a high value health care system needs to be built around a primary care focus with the primary medical responsibility being borne by the GP, supplemented by specialist teams on the basis of complexity of need. Evidence suggests that specialists are central to shared management of care and have a critical role in the assessment, complex care planning and consultancy support and advice to patients and their primary health care teams.^{195,196}

Furthermore, the development of strong partnerships between local and regional primary care services, aged care services and specialist services is necessary to achieve sustainable and responsive services focused on population needs.

¹⁹³ The uptake of breakthrough collaborative methodologies developed by the Institute for Healthcare Improvement is one way of creating a practical structure through which clinical and service based palliative care teams can learn from each other and draw on evidence and specific expertise to facilitate successful improvement and change.

¹⁹⁴ Australian Commission on Safety and Quality in Health Care 2009, *op. cit.*

¹⁹⁵ Australian Government National Health and Hospitals Reform Commission 2009, *op. cit.*, pp. 103.

¹⁹⁶ Irish Hospice Foundation 2008, *op. cit.*, pp. 11

¹⁹⁷ Harris, M et al. 2009, *op. cit.*

¹⁹⁸ Palliative Care Australia 2008, *Palliative and End of Life Care Glossary of Terms Edition 1*, *op. cit.*

While there are examples of such partnerships emerging in the Australian context, a systematic change will be needed involving service redesign, changed financing/incentive arrangements and changed accountabilities, along the lines of the recommendations of NHHRC. These delivery models and partnerships would be based on the need to be structured around the patient journey.

Well-coordinated, person focused care also requires a range of health professionals working together as a team and is increasingly being recognised as a key strategy to effective care in chronic and more complex cases.¹⁹⁷ Palliative care, by definition, presupposes the operation of a team approach.¹⁹⁸ Well functioning interdisciplinary teams facilitate care planning, streamline referral processes, improve treatment access, prevent unnecessary duplication of investigations and enhance continuity of care leading to a better quality of life.¹⁹⁹

Importantly in palliative care, interdisciplinary teams provide support not only for physical symptoms, but also for a range of psychosocial symptoms, facilitating a more holistic approach to developing individualised care and providing a valuable model for whole-of-system person focused health reform.²⁰⁰ Effective communication between team members is critical to creating positive team dynamics, and clarifying roles and responsibilities. It is clear from both published and anecdotal evidence that the quality of personal interactions between members is a key determinant of successful collaborations supported by the efforts and leadership of committed individuals.^{201,202}

199 Tang, M 2009, *op. cit.*

200 Good, P 2003, *op. cit.*

201 Harris, M et al. 2009, *op. cit.*

202 Tang, M 2009, *op. cit.*

Guidance Domain 9: Provide seamless, well-coordinated care

Specific guidance elements:

- 9.1 *Build the capacity and competence of integrated primary and community care services to provide end of life care and support to people approaching the end of their life.*
- 9.2 *Develop strong partnerships and networks between primary care providers, aged care services, disease specific organisations and services, and specialist palliative care services to support needs- based service delivery for people approaching the end of life.*
- 9.3 *Ensure 24/7 access to primary care and specialist palliative care services for patients who are approaching the end of their life.*
- 9.4 *Network specialist palliative care services within defined regions and in accordance with role and capability frameworks.*
- 9.5 *Expand specialist palliative care outreach services to support the care of people dying at home and in residential aged care facilities.*
- 9.6 *Utilise emerging technologies (e.g. telehealth networks) to enhance communication and support for clinicians, patients and families in rural and remote areas.*
- 9.7 *Establish referral and advice networks between primary care, aged care and specialist palliative services.*
- 9.8 *Implement strategies, including the nomination of a case coordinator for the coordination of care for all patients with complex needs at the end of life to assist with navigation, transition and utilisation of services.*
- 9.9 *Ensure the availability of affordable medication and equipment in appropriate care settings where needed to provide care at the end of life, and ensure that staff are credentialed in their use.*

Guidance Domain 10: Flexible, optimised and effective workforce

Moving towards an integrating system to provide care at the end of life will require health care professionals to have the necessary knowledge, skills, attitudes and behaviours related to care of the dying. The NHHRC is recommending a new framework for education and training of health professionals that:

- moves towards a flexible, multidisciplinary approach to how we educate and train health professionals; and
- incorporates an agreed competency based framework as part of a broad teaching and learning curriculum for all health professionals.

Such a framework would support the future development of palliative and end of life care competencies. Building up the capacity of the workforce will also require support and empowerment to take on the challenge of continuous learning, research and innovation.

A key principle is the imperative of developing a workforce with skills and competencies that are able to support the emerging models of care that reflect both changing population needs as well as evolving health service delivery structures, and that meet consumer quality and safety standards.²⁰³

As death is a normal part of the life cycle and an important part of our health system is providing services for those at the end of life, it follows that a baseline goal is that all health care professionals require, as a minimum, knowledge and skills to provide care at the end of life. This means that basic training in palliative care principles and practice should be built into all undergraduate and postgraduate health care curricula.

The national palliative care standards require that health professionals are appropriately qualified for the level of service offered. In practice, health care professionals will be involved with dying patients to varying extents depending on which part of the health care continuum, specialty or setting they operate within. As a result a range of undergraduate, post graduate and continuing professional education and training approaches are required to flexibly cater for differing circumstances. This will require different levels of competency and knowledge with appropriate minimum competencies being applied to match the requirements at each level. Additionally the articulation of core learning domains will further assist in developing a consistent approach to cross sectoral and cross discipline learning.²⁰⁴

A further important element in continuing professional development in particular is the development of flexible approaches to the delivery of CPE and support for palliative care in primary care practice. However, these approaches however need to be based on effective learning methodologies. Interdisciplinary learning is emerging as an effective strategy in primary and aged care, particularly when it can be delivered within local and regional networks involving health professionals who will then continue to collaborate in a team care environment. Strategies that develop capabilities in self-directed learning are also integral to the delivery of quality services.²⁰⁵

Finally, volunteers play a particularly unique role in end of life care and make a significant contribution in supporting patients and their carers in a range of settings. Appropriate training, ongoing supervision and support to maximise the integration of volunteers into the care team²⁰⁶, and national standards for volunteer training, supervision and support and a consistent approach to volunteer engagement are required.

203 Australian Health Workforce Advisory Committee 2005, *op. cit.*

204 The following five domains are being utilised as part of the PCC4U program targeted at incorporating palliative care into undergraduate curricula:

- principles of palliative care
- communication in palliative care
- principles for clinical assessment and intervention in palliative care
- optimising function in palliative care
- coping with dying and bereavement.

Variants of these domains are also found in postgraduate and CPE courses.

205 Cairns, W and Yates, PM 2003, 'Education and training in palliative care'. *MJA*; vol. 179, pp. S26–S28.

206 The Victorian Department of Human Services has developed standards for palliative care volunteers that can be utilised as template for a national approach.

Guidance Domain 10: Flexible, optimised and effective workforce

Specific guidance elements:

- 10.1 *Collect and report standardised national data on the size, skill mix and demographics of the specialist palliative care workforce.*
- 10.2 *Ensure all primary care and aged care providers have staff trained in advance care planning.*
- 10.3 *Ensure that all health care professionals whose role interfaces with end of life care have the knowledge and skills to provide care to people who are approaching the end of their life.*
- 10.4 *Include cross-cultural considerations in death and dying in all undergraduate and specialist palliative care curricula.*
- 10.5 *Incorporate specific content related to end of life care and needs of ethnic minority and other marginalised groups and Aboriginal and Torres Strait Islander populations, in all undergraduate and specialist palliative care curricula.*
- 10.6 *Develop and disseminate a nationally consistent set of core competencies for palliative and end of life care to underpin continuing professional education.*
- 10.7 *Collaborate with Health Workforce Australia to facilitate optimal development and distribution of specialist palliative care and skilled primary care and aged care workforces.*
- 10.8 *Develop national standards for recruitment, training, supervision and support of volunteers providing care at the end of life.*

Guidance Domain 11: Appropriately resourced

It is clear that substantial reforms in resourcing services providing care at the end of life will not occur in isolation from the broader national health funding reforms that are currently being advocated. The national issues that strike a particular resonance with what will be required to support palliative and end of life care in the future are:

- the need to reduce the current fragmented service delivery and funding arrangements and increase local flexibility to identify and better

address inequities in access and the needs of under-served populations.²⁰⁷

- the reshaping and development of a comprehensive primary care platform that is driven by a robust evidence base and also promotes continuity and integration of care through collaborative team models.²⁰⁸

While supporting these principles it will be also be important to ensure that in developing future resourcing arrangements, financial incentives are designed to facilitate system and cultural change within the sector.

In addition to the big picture changes that may be required, there are more specifically-targeted proposals that will be of particular benefit to and enable effective palliative care delivery. Importantly, the NHHRC has recognised 'the need to build the capacity and competence of primary health care services to provide generalist palliative care support for their terminally ill patients, supported by additional investment in specialist palliative care services to allow better access to care for people at home'.²⁰⁹

Guidance Domain 11: Appropriately resourced

Specific guidance elements:

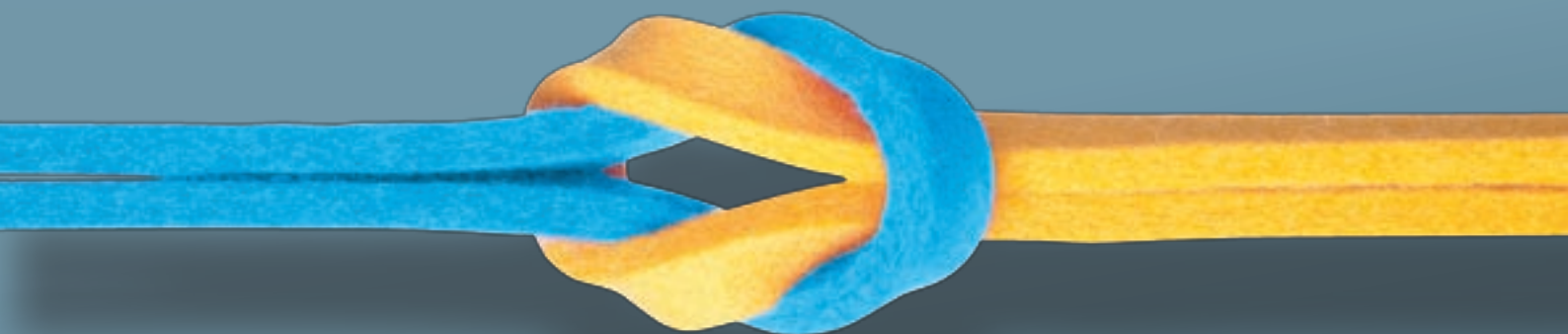
- 11.1 *Adopt flexible funding arrangements to enable rural and remote communities to access end of life care resources and services to meet their needs.*
- 11.2 *Develop resourcing formulas that incorporate assessment of local population end of life care needs, cost of service delivery and that support the achievement of desired outcomes.*
- 11.3 *Ensure public and private funding that is directly linked to care of people who are approaching the end of their life irrespective of the settings of care.*
- 11.4 *Ensure affordable access to equipment and medications necessary to provide care at the end of life in the community.*
- 11.5 *Ensure that residential aged care facilities are accurately and adequately resourced to reflect the cost of delivery of end of life care to residents, and support for families and carers.*

207 Australian Government Department of Health and Ageing 2009. *Primary Health Care Reform in Australia*, op. cit., pp.131

208 Australian Government National Health and Hospitals Reform Commission 2009, op. cit., pp. 7.

209 *ibid*, pp. 6.

SECTION 8 IMPLEMENTING
THE END OF LIFE GUIDANCE



SECTION 8: IMPLEMENTING THE END OF LIFE GUIDANCE

Improving care at the end of life is everybody's business.

All levels of government, specialist and generalist clinical services, individual clinicians and the community will need to work together to bring about the reforms that are set out in this Guidance.

There is already a significant amount of work that has been undertaken in relation to many of the Guidance elements. It was beyond the scope of this document to inventory all this work and develop a status map that would demonstrate progress towards achievement of the Guidance elements. It is recommended that a comprehensive inventory of the investments made to date in the Guidance areas be undertaken as an immediate first step to inform implementation and further development.

Aligning and clearly communicating the actions that will need to be taken by all those who share the responsibility to improve care at the end of life for all Australians, and who share the aspirations for reform will be fundamental to achieving the goal of a 'good death' for all.

This section makes recommendations for leadership and accountability to commence the conversation and decision making regarding collaborative implementation of the guidance elements. These accountabilities have been recommended to conform to the existing accountability relationships and structures of the health system and will need to evolve as the broader health system reforms are implemented.

Where it is determined that a national, standardised approach should be taken, leadership has been designated to the Commonwealth. Issues that more closely relate to operational implementation or service delivery should be led by states and territories. Clearly, regardless of the nominal leadership role, implementation of this Guidance will require all key stakeholders, funders and services to work together to develop common solutions and evidence-based approaches to improvement.

CARE THAT IS 'PERSON AND CARER FOCUSED'

Guidance Domain 1: Patients empowered to make fully informed decisions

Element	Guidance	Lead by	Involves
1.1	Develop and implement policies, procedures and tools to support consumer and carer involvement in end of life care planning commencing from the early stages of a life-limiting illness.	Commonwealth	All clinical services, patient groups, consumer advocacy groups, carers
1.2	Develop and implement a national approach to the implementation of advance care planning across the health and aged care systems	Commonwealth	States and territories, legal and health professionals, consumers, carers
1.3	Develop a nationally led, systematic process to develop and disseminate evidence-based, consumer-friendly education and information to support people to make decisions about the location and type care and resources they need as they approach the end of their life.	Commonwealth	States and territories, Caresearch, health and aged care services, patient groups, consumer advocacy groups, carers

Guidance Domain 2: Needs-based care

Element	Guidance	Lead by	Involves
2.1	Develop a national systematic approach to the development of criteria for the recognition of people approaching the end of life.	Commonwealth	States and territories, clinicians, researchers
2.2	Introduce standardised, validated assessment tools to determine patient and carer needs at the end of life.	Commonwealth	States and territories, specialist palliative care services, aged care services, primary care services, palliative care research community
2.3	Develop and implement streamlined, consistent holistic assessment of end of life needs across primary, aged care and specialist services.	Commonwealth	States and territories, consumer and peak bodies, Caresearch, health and aged care services, palliative care research community
2.4	Develop disease cluster referral triggers that align consumer needs and the common trajectories of people approaching the end of life.	Commonwealth	Palliative care research community, specialist palliative care, aged care and primary care services, patient groups, consumer advocacy groups, carers
2.5	Develop and implement a standardised, systematic approach to the implementation of end of life care pathways for acute care, community and aged care settings.	Commonwealth	Specialist palliative care, aged care and primary care services, consumer and peak bodies

Guidance Domain 3: Involved and supported carers

Element	Guidance	Lead by	Involves
3.1	Support the vital role of carers through the development and dissemination of educational programs, information, and access to timely advice regarding end of life care.	Commonwealth	States and territories, all clinical services, consumer advocacy groups, carers
3.2	Provide access to residential and flexible at home respite care arrangements to assist carers sustain their role in caring for someone approaching the end of life.	States and territories, Commonwealth	Commonwealth, all clinical services, consumer advocacy groups, carers, HACC
3.3	Develop and implement appropriate tools to routinely assess and support the health of carers of people approaching the end of life.	Commonwealth	Palliative care research community, all clinical services, consumer advocacy groups, carers
3.4	Ensure that carers are engaged in care decisions and communications to the extent they wish to be and subject to the consent of the patient.	All clinical services	Consumers, patients, carers
3.5	Directly consult with carers in the processes of policy and services development and evaluation to ensure that their specific needs and experiences related to end of life care are adequately and accurately reflected and acknowledged.	Commonwealth	States and territories, all clinical services, consumer advocacy groups, carers
3.6	Ensure that carers are provided with resources to enable them to undertake their role providing care to someone approaching the end of life.	Commonwealth	States and territories, all clinical services, consumer advocacy groups, carers
3.7	Provide access to bereavement support for all carers and families.	States and territories	All clinical services, consumer advocacy groups, carers

Guidance Domain 4: Culturally competent, safe and appropriate

Element	Guidance	Lead by	Involves
4.1	Ensure that cultural and spiritual competence and safety related to end of life care are incorporated into multidisciplinary education programs at all levels.	States and territories	Universities, education providers, all clinical services
4.2	Ensure that policies, procedures and processes of care respect and reflect different cultural and ethnic values, beliefs and practices that surround death, dying and end of life care.	States and territories	Commonwealth, all clinical services
4.3	Support the development and provision of culturally appropriate health information and resources in a range of community languages and access to trained interpreters.	Commonwealth	States and territories, all clinical services, ethnic communities' councils
4.4	Build relationships between Indigenous and non-Indigenous health care providers that facilitate understanding of cultural differences and care needs at the end of life for Aboriginal and Torres Strait Islander people.	All clinical services	States and territories, Commonwealth, Aboriginal and Torres Strait Islander community health organisations
4.5	Ensure there are policies, procedures and mechanisms to support 'return to country' for Indigenous Australians who are approaching the end of their life.	States and territories	Commonwealth, All clinical services, Aboriginal and Torres Strait Islander community health organisations
4.6	Support the strengthening of the role of Indigenous health workers to connect health professionals and services with local communities to support improved end of life care.	States and territories	All clinical services, Aboriginal and Torres Strait Islander community health organisations

CARE THAT IS 'DRIVEN BY INFORMATION'

Guidance Domain 5: Informed and empowered community

Element	Guidance	Lead by	Involves
5.1	Strengthen consumer participation and voice in: <ul style="list-style-type: none"> • end of life policy and service development; • community capacity building initiatives; and • quality review. 	Commonwealth	States and territories, all clinical services, patient groups, consumer advocacy groups, carers
5.2	Develop a national awareness raising strategy that guides and integrates community awareness, consumer health literacy and community capacity building initiatives in end of life care.	Commonwealth	States and territories, consumer and peak bodies, health and aged care services
5.3	Promote open discussion of death and dying through health and legal professional, education and awareness programs.	Commonwealth	States and territories, consumer and peak bodies Caresearch, health and aged care services

Guidance Domain 6: Data collected and used to support quality improvement

Element	Guidance	Lead by	Involves
6.1	Inventory the data needs related to end of life care of the different stakeholders—government (Commonwealth and state/territory), clinical services (specialist, primary and aged care), funders, clinicians and the wider community.	Commonwealth	AIHW, states and territories, all clinical services, patient groups, consumer advocacy groups, carers
6.2	Collect and use routine data on patient and service level activity and outcomes to support improvement and monitor performance in end of life care.	All clinical services	Commonwealth, states and territories
6.3	Ensure that data on safety and quality of care at the end of life is collated, compared and provided back to clinical services and clinicians in a timely fashion to expedite quality and quality improvement cycles.	National quality programs	Commonwealth, states and territories
6.4	Develop and support the use of nationally standardised measurement tools.	National quality programs	Palliative care researchers, states and territories, all clinical services
6.5	Enable end of life data linkages between various data collections and repositories held at clinical, national and jurisdictional level.	Commonwealth	States and territories, clinical repositories

Guidance Domain 7: Knowledge-led continuous improvement

Element	Guidance	Lead by	Involves
7.1	Implement, monitor and report on performance against national standards for end of life care across all care settings (specialist palliative care, primary and community care, aged care and acute care).	Commonwealth	National quality programs, states and territories, all clinical services
7.2	Report on strategies to improve safety and quality of care at the end of life and the actions taken in response to identified quality and safety issues.	All clinical services	National quality programs, states and territories
7.3	Develop and implement strategies that support the translation and diffusion of evidence and knowledge in relation to the needs and effective care of people approaching the end of life.	National quality programs	Commonwealth, states and territories, palliative care research community, all clinical services
7.4	Reduce unjustifiable variation in practice by disseminating evidence and implementing best-practice clinical guidelines for palliative and end of life care.	National quality programs	Commonwealth, states and territories, all clinical services

Guidance Domain 8: Supported research, knowledge translation and exchange

Element	Guidance	Lead by	Involves
8.1	Adopt a national approach to the synthesis and dissemination of clinical evidence/knowledge and research related to end of life to expedite its translation into practice.	National quality programs	Commonwealth, states and territories
8.2	Prioritise and invest in clinical and health service research in palliative and end of life care.	Commonwealth	NHMRC, grants bodies, research funders, states and territories, universities, health services
8.3	Provide dedicated resources for the regular dissemination of research outcomes related to end of life to health services and clinicians.	Commonwealth	NHMRC, grants bodies, research funders, states and territories
8.4	Develop a national approach to the collection and reporting of patient and family reported outcomes related to end of life care.	Commonwealth	States and territories, all clinical services, patient groups, consumer advocacy groups, carers
8.5	Enhance the spread of innovation in palliative and end of life care by supporting health service and health professional participation in breakthrough collaboratives, clinical forums, health roundtables etc.	States and territories	All clinical services
8.6	Invest in the development of knowledge transfer methodologies between researchers, health care professionals and policy makers.	Commonwealth	NHMRC, palliative care research community, health professionals, states and territories

CARE THAT IS 'ORGANISED FOR QUALITY AND SAFETY'

Guidance Domain 9: Seamless, well-coordinated care

Element	Guidance	Lead by	Involves
9.1	Build the capacity and competence of integrated primary health and community care services to provide end of life care and support to people approaching the end of their life.	Commonwealth	States and territories, primary care, aged care and community services
9.2	Develop strong partnerships and networks between primary care providers, aged care services, disease specific organisations and services, and specialist palliative care services to support needs-based service delivery for people approaching the end of life.	States and territories	Specialist palliative care providers, primary care providers, aged care services, disease specific organisations,
9.3	Ensure 24/7 access to primary care and specialist palliative care services for patients who are approaching the end of their life.	States and territories	Specialist palliative care services, primary and community care services, aged care services
9.4	Network specialist palliative care services within defined regions and in accordance with role and capability frameworks.	States and territories	Specialist palliative care services
9.5	Expand specialist palliative care outreach services to support the care of people dying at home and in residential aged care facilities.	States and territories	Specialist palliative care services approved providers of residential aged care, GPs
9.6	Utilise emerging technologies (e.g. telehealth networks) to enhance communication and support for clinicians, patients and families in rural and remote areas.	States and territories	Specialist palliative care services, primary care services, GPs
9.7	Establish referral and advice networks between primary care, aged care and specialist palliative care services.	States and territories	Specialist palliative care services, primary care services
9.8	Implement strategies, including the nomination of a case coordinator, for the coordination of care for all patients with complex needs at the end of life to assist with navigation, transition and utilisation of services.	States and territories	Specialist palliative care services, all clinical services
9.9	Ensure the availability of affordable medication and equipment in appropriate care settings where needed to provide care at the end of life, and ensure that staff are credentialed in their use	States and territories	All clinical services

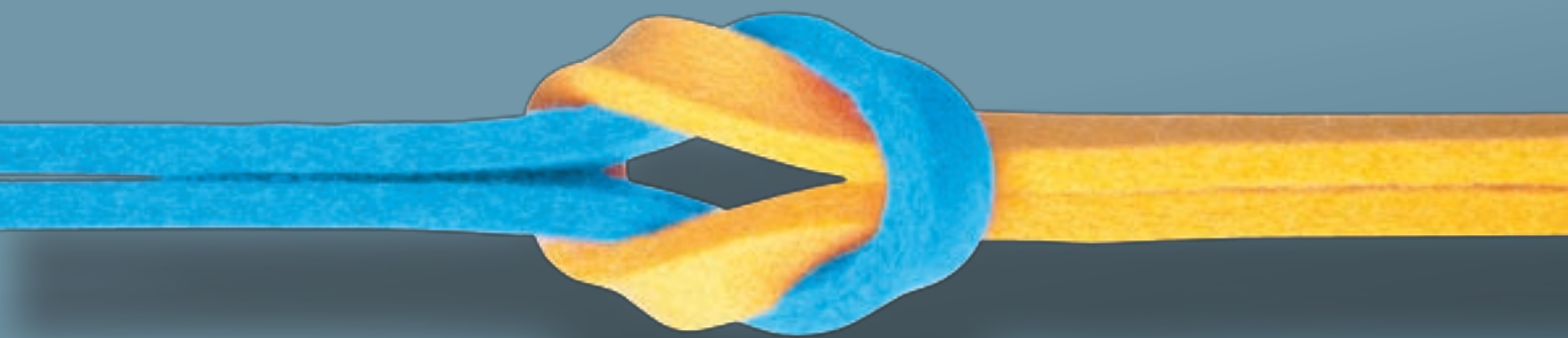
Guidance Domain 10: Flexible, optimised and effective workforce

Element	Guidance	Lead by	Involves
10.1	Collect and report standardised national data on the size, skill mix and demographics of the specialist palliative care workforce.	Commonwealth	States and territories
10.2	Ensure all primary care and aged care providers have staff trained in advance care planning.	Commonwealth	Primary care providers, approved providers of residential aged care
10.3	Ensure that all health care professionals whose role interfaces with end of life care have the knowledge and skills to provide care to people who are approaching the end of their life.	Commonwealth	Universities, TAFE, all education providers
10.4	Include cross-cultural considerations in death and dying in all undergraduate and specialist palliative care curricula.	Universities	Health education providers, TAFE,
10.5	Incorporate specific content related to end of life care and needs of ethnic minority and other marginalised groups and Aboriginal and Torres Strait Islander populations, in all undergraduate and specialist palliative care curricula.	Commonwealth	Universities, TAFE, all education providers
10.6	Develop and disseminate a nationally consistent set of core competencies for palliative and end of life care to underpin continuing professional education.	Commonwealth	Universities, TAFE, all education providers
10.7	Collaborate with Health Workforce Australia to facilitate optimal development and distribution of specialist palliative care and skilled primary care and aged care workforces.	Commonwealth	Health Workforce Australia, universities, states and territories
10.8	Develop national standards for recruitment, training, supervision and support of volunteers providing care at the end of life.	Commonwealth	States and territories, specialist palliative care services, peak bodies, patient groups, consumer advocacy groups, carers

Guidance Domain 11: Adequately resourced

Element	Guidance	Lead by	Involves
11.1	Adopt flexible funding arrangements to enable rural and remote communities to access end of life care resources and services to meet their needs.	Commonwealth	States and territories
11.2	Develop resourcing formulas that incorporate assessment of local population end of life care needs, cost of service delivery and that support the achievement of desired outcomes.	Commonwealth	States and territories
11.3	Ensure public and private health care funding that is directly linked to care of people who are approaching the end of their life irrespective of the settings of care.	Commonwealth	States and territories
11.4	Ensure affordable access to equipment and medications necessary to provide care at the end of life in the community.	Commonwealth	States and territories
11.5	Ensure that residential aged care facilities are accurately and adequately resourced to reflect the cost of delivery of end of life care to residents, and support for families and carers.	Commonwealth	Approved providers of residential aged care

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