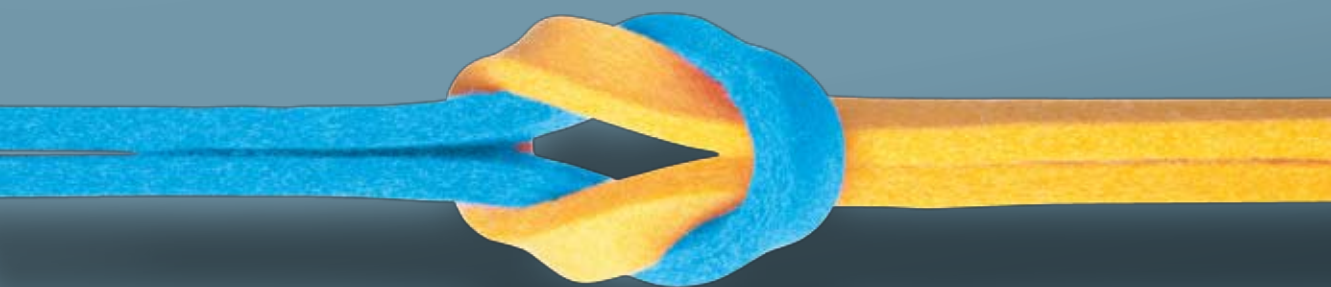


# HEALTH SYSTEM REFORM AND CARE AT THE END OF LIFE: A GUIDANCE DOCUMENT

EXECUTIVE SUMMARY

MAY 2010



NATIONAL EOL FRAMEWORK FORUM

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## **Acknowledgments**

A number of individuals have generously contributed to the development of this Guidance document. Coming from different specialties and interests, they share a common vision for quality care at the end of life for all Australians. Their contribution is gratefully acknowledged.

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## 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.

## GUIDE TO USING THE GUIDANCE DOCUMENT

**Section 1 (Purpose and methodology)** has provided 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 on 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.

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

## 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 systemic 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, aging 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

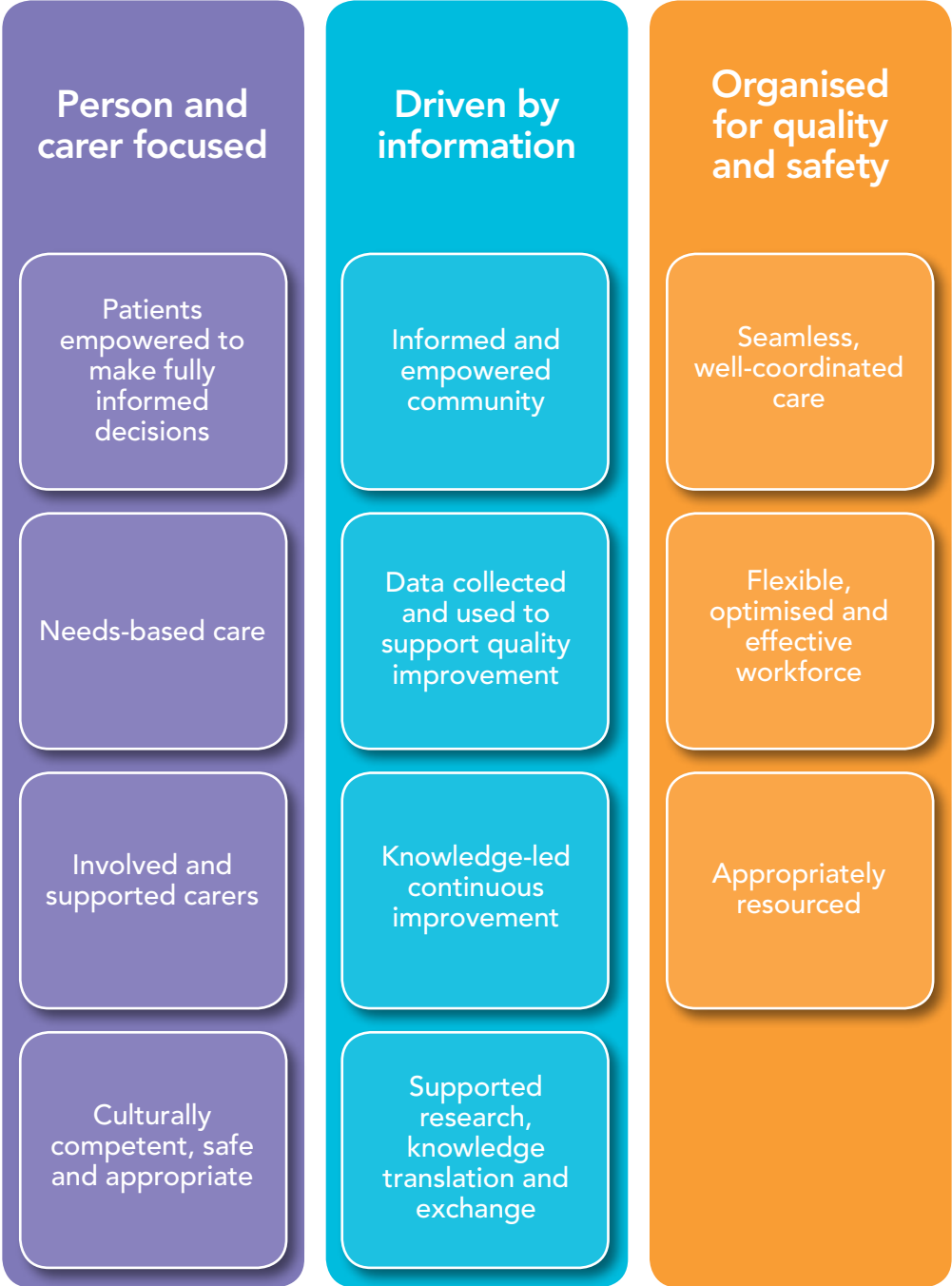
recommendations and massive scope of the endeavour. The aim of this Guidance document is to provide governments—federal, state and territory—policy makers, planners and service providers with advice and a pathway forward to establish strategic short, medium and longer term priorities that will result 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 p.8), 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

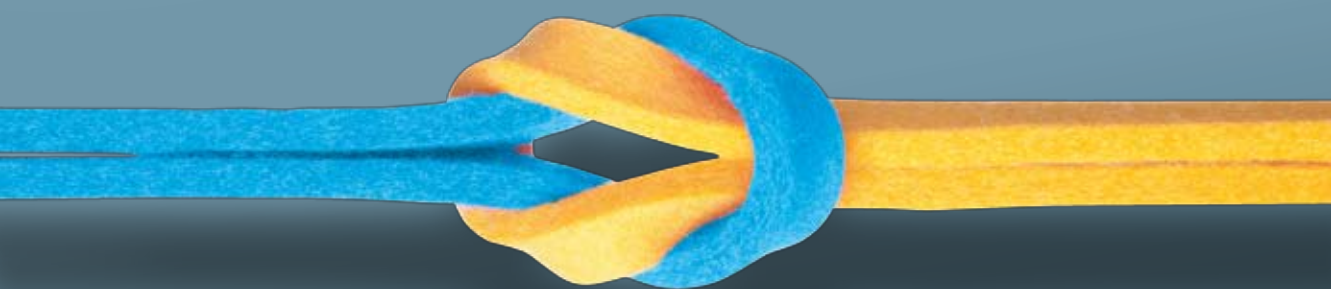
(‘patient and carer focused’, ‘driven by information’ and ‘organised for quality and safety’), 11 guidance domains and 61 specific guidance elements. It has been designed to guide action to improve the health care system’s ability to deliver high-quality care to people in all health care settings who 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.

# THE NATIONAL END OF LIFE GUIDANCE FRAMEWORK



# GUIDANCE DOMAINS AND ELEMENTS



## 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.