

Statewide strategy for end-of-life care 2015

May 2015

Acknowledgments

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Preface

Modern medical care has been very successful in improving both the quantity and quality of life for many, many people. However, in spite of all the gains, there is now a growing recognition amongst clinicians and community members that modern technologies (that can delay dying) do not always maintain or enhance the quality of the life being lived — this can be true for patients of any age. Everyone will die and there will come a time for each one of us that further attempts at life prolongation will become futile, burdensome and potentially unwanted. Many people are now choosing to concentrate on the quality rather than the quantity of the remainder of their lives. Health services must accommodate these realities and continue to provide appropriate care for people until they die.

In Australia, and indeed in most developed countries, improvements in the provision of care at the end of life have tended to lag behind most other fields of practice. This has occurred for a number of reasons, but not least because the focus of attention has been on life prolongation and the treatment of disease. Fortunately, over the past few decades the care of people who are nearing the end of their life has been recognised as a core component of modern health services.

Clinicians have a variety of means by which they can identify many of the patients who are likely to deteriorate in the near future, or may have entered the last year of their life. These assessments should be an integral component of routine practice and the results of such assessments communicated to patients and their carers. This information provides the opportunity for patients to make the choices that will determine how they, and their families, will experience the time remaining before they die.

With support from clinicians, the community is starting to participate in advance care planning that enables them to document their choices for their future healthcare and maximise the likelihood that those choices will be respected. This can be done at any time of life but is of particular importance as people become frail with age, and/or are identified as having a life-limiting illness.

As clinicians we have a responsibility to provide patients with appropriate care at the end of their life, or to refer to those who can. The best outcomes are achieved when we work collaboratively with other specialties and across health settings to provide the best possible advice about what can be realistically achieved, and help patients to make wise choices from the options that are available to them.

As health managers, we can work to ensure that we provide the services appropriate to the needs of our patients.

As members of our community we can all participate in the growth of our society by encouraging open conversation with our family and friends about death and dying, and the choices that we might wish to make towards the end of our life.

The quality of care provided to people at the end of their life is one of the key indicators of the values of a community.

Dr Will Cairns OAM

Chair, Statewide Palliative Care Sub-Clinical Network 2015

Summary

High-quality end-of-life care can help people to achieve the best possible quality for their life as they approach death. This strategy is aimed at helping people who are dealing with failing health, helping clinicians dealing with death and dying in the health system, and in caring for people of all ages as they face the end of their life.

The strategy was developed in collaboration with Queensland clinicians and a range of key stakeholders. The outcomes of previous planning activity were considered together with contemporary information to develop the strategy which is aligned with the principal themes of the *Blueprint for better healthcare in Queensland* and objectives in of the *Department of Health Strategic Plan 2012–2016* (2013 update).

Four service directions have been developed:

1. Knowledge of end-of-life care throughout public health organisations is expanded and includes a comprehensive awareness of the benefits in the planning and delivery of end-of-life care and availability of supporting services/resources within and between health services.
2. Earliest possible identification of patients who will or are anticipated to have shortened life expectancy as a result of known health conditions is routinely achieved, together with timely Advanced Care Planning (ACP) and the initiation of coordinated planning of end-of-life care.
3. End-of-life-care delivered in Queensland public services consistently responds to the needs of patients throughout their illnesses and meets established clinical safety and quality standards.
4. The strategic capability and configuration of end-of-life care services in Queensland is strengthened to maximise system health service delivery and performance so as to provide access to appropriate services for the projected population, while making the most effective use of available resources.

The strategy recognises the pivotal role of individuals being empowered to undertake ACP and to make informed decisions about their own healthcare, and the role of all health professionals in the identification of patient needs and supporting the delivery of high-quality end-of-life care.

The Department of Health (DoH) anticipates Hospital and Health Services (HHSs), and other providers will need to work collaboratively to implement this strategy. The DoH will monitor, evaluate, report and share progress towards achievement of the service directions outlined in this strategy.

Part A: The strategy

1. Introduction

High-quality end-of-life care can help people achieve the best possible quality of their life as they approach their death. The statewide strategy for end-of-life care (2015) has been developed to strengthen the capacity of Queensland health services to respond to the needs of those with a progressive life-limiting illness (at any life stage) through the delivery of services that prioritise patient goals for quality of life as key components of care.

The strategy is intended to integrate end-of-life care as a core element of health services in Queensland. End-of-life care should be delivered based on an assessment of need considering but not limited by diagnosis, prognosis, setting of care or anticipated illness trajectory. The strategy describes the components of end-of-life care across the full range of levels of care from a palliative approach through to general and specialist palliative care. It identifies key service directions to guide planning and service development to meet future demand.

Addressing health system limitations that have been identified as barriers will enhance the provision of individualised care of consistent quality. The strategy aims to strengthen health services to deliver end-of-life care in Queensland. Through a range of actions at the system and local levels, patients, their families and carers will benefit through greater access to preferred services, relief from suffering, and improved quality of life before death.

Public health services have the leading responsibility for implementing this strategy. The engagement and collaboration with the full range of service providers is considered essential to achieving success in the long term.

1.1. Defining end-of-life care

Terminology associated with end-of-life care is applied in various ways throughout literature and key policy documents with variances evident in care type, level of need and phase (duration). End-of-life care refers to healthcare services aimed at meeting the health needs of people (including infants and children) whose life expectancy is anticipated to be shortened as a result of known life-limiting conditions, and where the primary intent of care may have shifted from life prolongation to a focus on quality of life.

Quality end-of-life care supports patients throughout the course of assessment and progression of a life-limiting illness and includes bereavement support for the family of the deceased.¹ Whenever possible, end-of-life care should be instigated well before death is imminent. It does not seek to hasten death and may incorporate treatment that prolongs life.²

In this strategy, the care phase associated with end-of-life is therefore inherently linked from the point the need is identified, and the patient and clinician engage in discussions about this care phase, to the point of death (for which the process may take less than a day or sometimes even years) and includes bereavement support.

Effective management of end-of-life care that meets the multi-dimensional needs of those people facing life-limiting illnesses is dependent on complex relationships between patients, their families and carers, healthcare professionals and health services.

'End-of-life care helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support'.³

End-of-life care encompasses care inclusive of the following:

- **A palliative approach** recognises that curative and life-prolonging interventions are becoming less effective and focuses more on comfort-focused care, the reduction of suffering and the promotion of an understanding of loss and bereavement. This approach can be adopted by all health professionals and incorporates a concern for the full range of needs of the dying patient and their family. The underlying perspective of the palliative approach is that death, dying and bereavement are an integral part of life.⁴
- **Palliative care** which aims at improving the quality of life of patients and their families facing the problems associated with life-limiting illness, through the prevention and relief of suffering by early identification and assessment and treatment of pain and other problems, including physical, psychosocial and spiritual issues.⁵
- **Complementary care** which provides self-help and support to the patient and their family and carers and includes charitable and other volunteer care as well as non-clinical therapies e.g. massage therapy.

End-of-life care is delivered through the collaboration of specialist and generalist palliative care providers with other supportive care providers, patient's family and other carers. Care providers include:

- **Support care providers** including assistants in nursing, healthcare workers, volunteers, non-clinical therapists and family members.
- **Non-specialist palliative** care providers including (but not limited to) general practitioners and healthcare professionals in acute hospital, and healthcare workers with knowledge of basic palliative care principles.⁶
- **Specialist palliative care** providers include specialised teams with specific skill and training in dealing with complex problems, including the management of pain and symptoms, loss, grief and bereavement.⁶ Specialist care teams have a leading role in supporting and building general palliative care capacity within health services, organisations and the community at large.

Central to the practice of high-quality end-of-life care are the concepts of:

- holistic care that addresses the physical, psychological, social and spiritual needs of the patient and their caregivers
- a focus on quality of life
- minimising the impact of invasive healthcare interventions or investigations
- respecting patient choice and autonomy.

1.2. Policy context

Contemporary international policy standards clearly establish a mandate for strengthened end-of-life care delivery arrangements and services across health systems. In 2013, the World Health Assembly adopted a resolution on the inclusion of palliative care in all health systems, at all levels of care and to the whole population.⁷ In January 2014, the Executive Board of the World Health Organisation published policy directions recognising the need for end-of-life care/palliative care to be provided 'in accordance with the principles of universal health coverage', and incorporating palliative care into all health systems.⁸ These were endorsed by the World Health Assembly in April 2014.

Despite being identified as a 'priority area' in international and Australian policy documents, services aimed at meeting end-of-life care needs are commonly described in contemporary literature as 'neglected fields', 'suffering an identity problem' or simply 'forgotten' compared to other contemporary core health services. Emerging policy dialogue within Australia suggests that a transition towards more contemporary models of end-of-life care embedded within and throughout health service systems is necessary. Established policy and frameworks to guide service delivery for end-of-life care in Australia and Queensland (outlined in Appendix 1) have informed the development of this strategy.

1.3. Population context

The pattern of death has changed over the past 100 years and, with this, there have been changes in how people approach the end of their life.⁹ Though many people report they would rather die at home, it is more likely than not that they will be admitted to hospital as they approach the terminal phase of their life, and will die in a hospital or other institutional setting. This is prevalent where there is a late recognition of deteriorating health or a prevailing culture particularly where death and dying are not openly discussed.¹⁰

Contemporary health services—particularly in the acute care setting—are predominantly orientated towards the prolongation of life and treatment of disease. Comparatively less effort is directed towards supporting those dealing with the reality of inevitable death from a life-ending illness, including providing people with a realistic understanding of their disease progression. Optimal health service delivery arrangements may be constrained by:

- a general societal reluctance to deal with death and dying
- lack of awareness of benefits and components of end-of-life care
- health/medical systems narrowly focussed on curative interventions and 'doing more'
- a lack of mechanisms that encourage the integration of services.

Many people die in an acute hospital setting and undergo extensive treatment in the year(s) leading up to their death. Recent scientific research outcomes have estimated the population-based need for palliative and end-of-life care at anywhere between half and almost all of those who die.^{11,12,13} The World Health Organisation has estimated that each year in the world, approximately 377 adults (those aged 15 years and over) and 63 children per 100,000 population will need end-of-life care.¹⁴

The number of people who died in Australia in 2012 was almost 150,000, with approximately 50 per cent of these dying during an admission to an acute hospital facility.¹⁵ The context in Queensland is similar. In the 2011–12 financial year approximately 14,700 people died whilst a patient in a Queensland hospital, which is close to half of the total Queensland resident deaths in

that year.¹⁶ For children and young people under the age of 20, there are approximately 400–500 deaths each year, with approximately two thirds of these occurring in hospital settings.¹⁷ The majority of these deaths are in the perinatal period.

2. The strategy

The Statewide strategy for end-of-life care (2015) promotes service delivery by healthcare professionals and services throughout the health system in response to the level of need, regardless of the professional stream of the carer or the setting of the service delivery provider. The strategy recognises the pivotal role of individuals being empowered to make informed decisions about their own healthcare, and the role of all health professionals in the identification of patient needs and supporting the delivery of high-quality end-of-life care.

The DoH anticipates HHSs, and other providers, will work collaboratively to implement this strategy. The DoH will monitor, evaluate, report and share progress towards achievement of the service directions.

2.1. Service directions

The four overarching key service directions are collectively aimed at achieving the intent of the strategy—to strengthen the capability and capacity of Queensland health services to respond to the needs of those living with life-limiting illnesses and dying. Achieving change in end-of-life care provision will require concerted ongoing action from all levels of Queensland public health service organisations and from almost all healthcare professionals.

Within each service direction, a number of objectives and action proposals are outlined to establish a more proactive approach to end-of-life care throughout the health system. Each objective should be interpreted as applicable across all health and service delivery settings, regardless of the level of clinical need.

The actions outlined are intended to support the achievement of the objectives for the duration of the strategy. A range of system level actions will require implementation by the DoH (Health Service and Clinical Innovation Division (HSCI) and Health Commissioning Queensland (HCQ). Each HHS has the discretion to elect to implement service level actions or to identify and implement others that best address locally identified needs. As elements of the service directions are interrelated, many actions within the individual service directions may contribute to the achievement of others.

Service direction 1

Knowledge of end-of-life care throughout public health organisations is expanded and includes a comprehensive awareness of the benefits of the planning and delivery of end-of-life care and availability of supporting services/resources within and between health services.

Limited conversations about death and dying and a lack of recognition of quality end-of-life care were identified as recurrent themes throughout the development of this strategy. A lack of knowledge and awareness in both the community and among health professionals creates challenges to making high-quality end-of-life care accessible.⁹

There is a need to raise the priority accorded to end-of-life care issues and services across Queensland. All health professionals deal with dying patients in their work. A greater level of understanding and recognition of death and dying (including ACP) is required within society and by all healthcare services—this is integral in the delivery of this strategy. Normalising the inevitability of death and enhancing an awareness of quality end-of-life healthcare will deliver improvements to the ways people experience the end of their life.¹⁸

The intent of this service direction is to support heightened general awareness and a greater understanding of the benefits of end-of-life care, to encourage open conversations, and to address instances where perceptions about care may impede optimal service delivery. New approaches to meeting the educational needs of clinicians across health settings are required.

Objectives

- 1.1 Members of the broader community are aware of the benefits and indications for end-of-life care to support quality of life for those living with conditions anticipated to shorten life expectancy.^a
- 1.2 End-of-life care is recognised by healthcare professionals and providing organisations as a core component of health service delivery and is delivered across all service settings for all age groups.
- 1.3 Healthcare professionals are aware of the core components of end-of-life care and how and when it may benefit patients in their care throughout all stages of illness.
- 1.4 Healthcare professionals are knowledgeable and supported in their role in the delivery of end-of-life care (regardless of level of clinical need and/or setting of care).
- 1.5 Patients who have life-limiting conditions (and their families and carers) have a clear understanding of their clinical condition, prognosis, and the likelihood (or not) of benefits being realised from healthcare interventions (including the perinatal period where there is an identified foetal anomaly or life-limiting condition, and in early childhood).
- 1.6 Patients (and their families and carers) have an understanding about how and when they may benefit from specialist palliative care.
- 1.7 Patients (and their families and carers) understand what health service types and supports are available and how to access these.

Service actions	Responsibility
1 (a) Lead the development of an overarching public awareness strategy designed to address key content areas that can be implemented via social media and other mediums, considering: <ul style="list-style-type: none"> • key general messages appropriate for repeating on a regular basis (cycle) e.g. ‘speak to your general practitioner about your healthcare preferences/advanced care planning’ • particular issues that may require more comprehensive public engagement e.g. tool kit for advanced care planning • collaborative communications with external service providers/peak bodies • targeted campaigns e.g. culturally appropriate communication for Aboriginal and Torres Strait Islander people. 	DoH
1 (b) Determine an appropriate response to address knowledge deficits regarding the existing Queensland legislative framework around end-of-life issues e.g. provide/develop a suite of resources for health professionals.	DoH

^a Achievement of this objective is beyond Queensland Health’s direct ability to influence.

1 (c)	Evaluate the effectiveness of available educational programs and re-focus design and approach (if necessary) to target the highest educational needs (and achieve highest audience volumes).	DoH
1 (d)	Prioritise (and consider making mandatory) routine/regular access to educational opportunities and training resources in end-of-life-care decision making for all healthcare professionals including junior medical, nursing and allied workforces.	HHS
1 (e)	Establish resource hubs to advance end-of-life care initiatives e.g. core nucleus of experienced clinical leads who can teach and mentor, expert inter-professional working groups.	HHS

Service direction 2

Earliest possible identification of patients who will or are anticipated to have shortened life expectancy as a result of known health conditions is routinely achieved, together with timely Advanced Care Planning (ACP) and the initiation of co-ordinated planning of end-of-life care.

The possibility of a health condition(s) being life-limiting and incurable needs to be recognised early, so patient's end-of-life care needs can be identified and addressed. Clinicians have a variety of means by which they can identify patients who are likely to deteriorate in the near future. Planning for this possibility will reduce the likelihood of the need for abrupt transfers or 'last minute' referrals to palliative care in the last days of life (unless deterioration is sudden and unexpected).

Assessment as to when end-of-life care should begin is an iterative process. Organisations need to implement processes which further early recognition by health professionals and/or patients that life expectancy is likely to be shortened by a diagnosed health condition. Where health professionals have limited capacity to manage end-of-life and specialist palliative care needs (including sensitive communications), timely referrals to specialist palliative care teams need to be considered as standard practice. Patients need to be supported by health services to discuss their goals and preferences and actively participate in decision making.

The intent of this service direction is to maximise the potential for optimal quality of care for patients approaching the end of their life by giving time to consider what may be complex health and personal issues. Early identification also increases the chance of clinicians having sufficient lead time to work with patients, their families and carers, to develop and plan care aligned with patient preferences, and to gain consent for ongoing care.

Objectives

- 2.1 Healthcare professionals routinely practice optimal early recognition of life-limiting conditions and initiate care planning (or referral to specialist care) with patients.
- 2.2 The patient's values and goals of care are established (through ACP) and communicated within plans of care as early as possible.
- 2.3 Patients whose life expectancy is known, or expected, to be limited by health condition(s) are supported by healthcare providers to consider goals of their healthcare and the identification of preferences with maximum lead time to support realisation of goals.
- 2.4 Healthcare professionals are supported with evidence-based resources to aid in the early identification of those who may benefit from end-of-life care.
- 2.5 Inter-professional teams are effective in responding to the best interests of patients with a life-limiting condition supported by available expertise.

	Service actions	Responsibility
2 (a)	Establish evidence-based tools to support health professionals in the early identification of patients nearing the end of their life (e.g. adaption of NHS Supportive and Palliative Care Indicators Tool—SPICt, use of the ‘surprise question’).	DoH
2 (b)	Progress and expand the uptake of advanced care planning activities across all service settings for all ages and life stages (including provision of supporting materials that guide people to incorporate key information required to support realisation of goals).	DoH
2 (c)	Implement mechanisms for improving clinical practice and promoting the benefits of end-of-life care e.g. introduce ‘how’ a person died to all mortality reviews, examining appropriate responses for deteriorating patients (i.e. care of the dying audit).	HHS
2 (d)	Introduce processes and interventions, including early referral pathways, within organisational entry points to identify patients who may benefit from early intervention of end-of-life care e.g. emergency departments, outpatient departments, intensive care services, paediatrics and perinatal services.	HHS
2 (e)	Maintain records of established goals of care and communications, which are accessible to inter-professional team members.	HHS
2 (f)	Establish service pathways between organisations for the transition of children and adolescents to adult services.	HHS

Service direction 3

End-of-life-care delivered in Queensland public services consistently responds to the needs of patients throughout their illnesses and meets established clinical safety and quality standards.

The provision of quality care which respects the dignity of people at the end of their life involves the unique and complementary contribution of all health professionals. End-of-life care recognises the dying person as well as their family and carers as beneficiaries of care. Whilst there is recognised benefit for all patients from a specialist palliative care assessment, a large proportion of patients will be able to be managed at the end of their life through a palliative approach, delivered by other specialist and general clinicians, with intermittent support from specialist palliative care.¹⁹ The overarching principle of end-of-life care delivery is, wherever possible, based on the personal preferences of the patient (often documented through ACP).

Evidence suggests patients and their families and carers want to talk about end-of-life care and early conversations empower patients to set treatment goals (ACP),²⁰ and that when this occurs, preferences for healthcare are more likely to be realised.²¹ The intent of this service direction is to promote patient access to evidence-based end-of-life care of high clinical quality, which prioritises quality of life (rather than quantity), and considers the needs of carers and families. Through the delivery of high-quality care, the delivery of interventions with minimal or no clinical benefit can be minimised.

Objectives

- 3.1 End-of-life care is planned so as to be responsive to the needs of patients throughout the course of their illness and is inclusive of the management of pain and other physical symptoms as well as psychological, social, spiritual and practical support.
- 3.2 End-of-life care is accessible in parallel with active/curative and other supportive treatments for those with life-limiting conditions.
- 3.3 Patients have the opportunity to develop and participate in a documented planning process (ACP) to establish consent with the goals of their care incorporating personal preferences (e.g. place of care at time of death, treatment limitations) with the flexibility to be adapted as their condition changes.
- 3.4 Inter-professional teams clearly identify who is taking the lead responsibility for initiating and coordinating care for each patient.
- 3.5 Healthcare providers collaborate in the provision of care to those who are nearing the end of their life including escalation/referral to specialist care providers including palliative and allied healthcare specialist, when appropriate, for complex care.
- 3.6 Families and carers are involved and supported in their roles when looking after someone who is nearing the end of their life, and in bereavement.
- 3.7 Practices aimed at responding to the needs of deteriorating patients incorporate mechanisms for recognising the need for end-of-life care.

Service actions	Responsibility
3 (a) Develop system level clinical policy initiatives, implementation arrangements and staff resources to support safe and high-quality service delivery e.g. management of deteriorating patient processes, patient charter, clinical pathways and supporting materials aimed towards phases of care.	DoH
3 (b) Implement available incentives which reward good practice e.g. quality improvement payment for enabling patient choice about care.	DoH
3 (c) Implement service models that maximise opportunities for patient choice through the early identification and establishment of care goals in conjunction with the patient, their family or carers, and medical and nursing professionals (and reduce treatments of minimal or no clinical benefit).	HHS
3 (d) Implement strategies to enable ease of access to palliative care beds in acute health facilities, particularly during exacerbations of symptoms and the terminal phase and to mitigate the need for emergency assistance after hours.	HHS
3 (e) Establish mechanisms to provide specialist health and psychosocial support for families and carers, including options for respite and bereavement support, through the implementation of early referral to services and routine risk assessments.	HHS
3 (f) Assess care provision and patient satisfaction through actively involving patients, families and carers in evaluations of care, and the use of standardised benchmarking tools where available and appropriate.	HHS

Service direction 4

The strategic capability and configuration of end-of-life care services in Queensland is strengthened to maximise system health service delivery and performance so as to provide access to appropriate services for the projected population, while making the most effective use of available resources.

In Queensland, end-of-life care and health services are provided in a number of models, predominantly through the delivery of specialist and generalist palliative care services. However at the system and local levels, significant gaps and barriers (associated with service models, services types and geography) have been identified throughout planning and review processes. In some instances, current services are reliant on very small specialist teams and workers, which are not considered sustainable models for the long term. In others, though services may exist, there is a lack of capacity for flexibility and coordination between services.

Existing arrangements are not sufficient to meet anticipated future demand from an ageing population with complex health needs, as well as from younger populations where improvements in medical outcomes have led to increases in life expectancy but with more complex clinical problems. Each HHS requires palliative care services established at the highest CSCF level possible and appropriate to provide sustainable care models that meet local needs of communities.

Health and related enabling services, in particular information and communication technology, will need to be configured to effectively combine the range of service types aimed at the full breadth of end-of-life care needs (not limited to inpatient specialist palliative care). Effective linkages between services across all settings are required to create a system that can be more responsive to individual needs.

System-wide change is required to effectively position existing services for development to meet future need. This service direction promotes a more strategic approach to service delivery arrangements in the future, which maximises the use of available resources to improve end-of-life care services.

Objectives

- 4.1 Integrated end-of-life care services are accessible as close as possible to where people reside within Queensland.
- 4.2 End-of-life care services are networked at statewide and local levels to function effectively within and between HHS, including with external service providers.
- 4.3 Each HHS has a service model with capability across full range of end-of-life care service types across settings with capacity to respond to local population needs.
- 4.4 Each HHS has capacity for coordination of available specialist resources towards addressing complex needs, while providing capacity-building support to other services and care providers to meet basic and non-complex needs across general services.
- 4.5 Service enabling infra-structure expansions (workforce, assets capital infrastructure, information management and resourcing) are aligned with need to support safe and effective inter-professional practice across service settings.

Service actions		Responsibility
4 (a)	Establish system organisational arrangements to oversee system clinical improvements, including the provision of strategic clinical advice and input into issues pertaining to statewide service delivery	DoH
4 (b)	Review and evaluate the effectiveness of existing statewide services (including services that are contracted to external providers).	DoH
4 (c)	Explore and implement viable funding mechanisms e.g. incentivise the delivery of quality end-of-life care.	DoH
4 (d)	Strengthen and/or formalise relationships with general practitioners, community based palliative care services and organisations to promote an integrated and coordinated approach to end-of-life care, especially for patients in isolated or remote areas.	HHS
4 (e)	Develop and upscale specialist palliative care inpatient and consulting service capacity, to provide daily coverage and accessibility throughout health services (to highest appropriate CSCF level for community).	HHS
4 (f)	Coordinate effective interagency responses for children and young people to facilitate access to short breaks/family respite and medical equipment.	HHS
4 (g)	Undertake local end-of-life care needs analysis at the catchment level in partnership with non-government and community based service providers to develop plans to meet future need (as part of local health service planning).	HHS
Information communication and technology		Responsibility
4 (h)	Promote patient uptake of the Personally Controlled Electronic Health Record (PCEHR) to support end-of-life care (e.g. to promote effective clinical handover within Queensland Health services).	HHS
4 (i)	Leverage capability in the PCEHR such that clinicians can access this record along with other related health records.	DoH
4 (j)	Trial the addition of end-of-life care information (including ACP) and related documents into Queensland Health's integrated electronic medical record system.	DoH

3. Implementation, monitoring and review

3.1. Implementation

Under the *Hospital and Health Boards Act 2011* (the Act), the responsibility to 'undertake further service planning that aligns with the statewide plans' rests with each HHS.²² Health service planning at the local level will assist HHSs to respond to local health service needs and will establish a platform for negotiation with the DoH around particular community issues not addressed within the strategy.

Local health service plans should align with the service directions and service objectives in the strategy. For the actions suggested in the strategy, each HHS is positioned to consider the suitability of these for their local population and make decisions regarding whether to adopt the actions, or develop others designed to meet the service directions and objectives.

Risks to successful implementation

The success of the strategy relies on each HHS determining an approach to implementing local plans and actions aligned with the service directions. The key risks of not having effective local plans in place include:

- sub-optimal patient care
- inability to achieve service benchmarks for timely access, quality and safety
- inability to meet health service demand for the ageing population
- inability to accurately inform service enablers, including workforce, support service and information technology requirements
- inability to plan the allocation of future resources.

Resource implications

The process of planning did consider resource implications of the strategy. Service actions were prioritised based on the basis of cost neutrality, however service development will require resourcing over time through organisational budgetary processes.

3.2. Monitoring and review

Monitoring, evaluating, reporting and reviewing implementation of the strategy, including reporting on and reviewing progress towards achieving the identified objectives is required. These processes also allow changes in direction during the implementation of the strategy to ensure ongoing relevance and provide information upon which future service planning may be based.

Monitoring and evaluation

Under the Act, the DoH is responsible for the monitoring of service performance and HHSs are required to provide service performance data to the DoH. This will involve collection and analysis of available data at a number of points in time—before, during and after implementation. Where possible, evaluation will consider the extent of strategy implementation and the extent of health services development.

Measures of progress

There are limited data available currently from corporate systems (or other existing reporting mechanisms) suitable for system evaluation in this clinical setting. In addition, available measures would require consideration alongside other information (not currently available at a system level), and should not be considered as definitive measures of quality or improvement in isolation. In the initial years, it is recommended that an approach to evaluating progress be designed around information that can be drawn from existing sources, combined with additional qualitative information to be sought from HHS and clinical networks (where possible). Additional measures of progress may become accessible over time as development is progressed.

Signs of success proposed in the base year

Based on information currently available, the following measures are to be used as base indicators of progress towards meeting the intent of the service directions:

1. The proportion of overnight stays where patients (adults) have been given the opportunity to contemplate developing an ACP (with a documented outcome). For children, the proportion of overnight hospital stays where patients (and families) have been given the opportunity to contemplate/develop an ACP (with a documented outcome).

2. Palliative care service capability and development towards the highest appropriate CSCFv3.1 level to address community needs by HHS (self-assessment).

These measures are based on current data collection process, which may be subject to change. The need to develop and strengthen evaluative indicators is identified as work to be progressed within the strategy, and revised/additional measures may be available to support evaluation in the coming years.

Reporting and review

Reporting on the progress of implementation (i.e. reporting on the criteria of success via the monitoring and evaluation process detailed above) is required on an annual basis where data is reported and available. In addition, review points are planned for the third year (2017), fifth year (2019) and tenth year (2024). These review points should consider the progress that has been made in the development of system level indicators of performance subsequent to the base year.

Reviews will take into consideration not only the progress to date but also any changes to the key elements informing the development of the original strategy, including any significant changes in health need, health services, and the service environment. Based on the outcomes of the review, a revision of this strategy may be considered to ensure the service directions remain current and continue to provide for the identified needs and the actions being implemented are achieving the objectives.

Part B: Supporting information

1. Background to the strategy

Purpose

The need for a statewide strategy to guide end-of-life care and service delivery was jointly identified by the Palliative Care Sub-Network of the Statewide General Medicine Clinical Network and the Queensland Department of Health. The end-of-life care project was tasked to deliver a statewide health service strategy to guide public health services in Queensland to plan and implement service enhancements for end-of-life care services, either directly or through partnerships with private sector and/or non-government organisations over a 10-year planning horizon.

The scope of the end-of-life care strategy project focused on planning care for people for whom it would be expected that their increasing disability and/or life-limiting illness would lead to their death. The early recognition of people who would benefit from quality end-of-life care was identified as a key priority area.

The project was informed by submissions into national and state inquiries on palliative and end-of-life care and work previously undertaken by Queensland clinical specialist working groups, the Palliative Care Sub-Network, and relevant statewide plans and planning projects.

The project was designed to:

- address the needs of the adult and paediatric population
- promote the provision of a coordinated approach to the delivery of end-of-life care and the integration of multidisciplinary models of care across the care continuum
- improve health service delivery arrangements with the primary focus on public sector health services
- identify key priority areas for the delivery of end-of-life services and formulate strategic directions for Chief Executives of HHSs
- review and build on previous service planning activities undertaken within the Palliative Care Sub-Network and by the Department of Health as part of broader planning activities
- support the long-term delivery of safe and sustainable health services in line with Commonwealth and Queensland Government strategic directions, whilst being responsive to the changing patterns of health service demand in the HHS over time.

Exclusions

The project scope did not include:

- service planning for private sector and/or non-government organisations though opportunities for coordination, collaboration and partnerships with such services was not excluded
- detailed objectives and actions for the enabling and support functions (workforce, funding, support services such as assets, infrastructure and information management)
- the development of specific tools, clinical pathways or models of care (although these may be identified as appropriate actions within the strategy)

- local implementation actions at HHS level to achieve the service directions and objectives set out in the strategy—localised planning will assist each HHS to respond to the specific needs of their HHS and may inform their negotiations with the DoH
- enabling and support functions at a HHS level (workforce, funding, support services, assets, infrastructure and information management)
- actions or strategies specifically tailored to particular clinical services e.g. respiratory, cardiac services
- active interventions instituted in order to deliberately end life.

Methodology

Following a submission from the planning team, the proposal for a strategy to inform quality end-of-life care in Queensland was endorsed by the Executive Management Team (the department). The strategy was subsequently developed based on the integrated health service planning process outlined in the Queensland Health Guide to Health Service Planning version 2 (2012). The project governance arrangements were established in collaboration with key stakeholders in HHSs, the DoH and external (to Queensland Health) organisations. Initial profiling of the end-of-life care environment to inform the strategy included overviews of:

- themes and trends in end-of-life care research and policy at state, national and international levels—scanning of research and policy was ongoing throughout the project
- health status and death rates of Queensland residents to inform the potential need for end-of-life care services
- historical patterns of inpatient care coded as palliative in Queensland public and private hospitals
- current and future Queensland population demographics.

All data was sourced from endorsed corporate databases. Submissions to and consultations undertaken during the project included a broad range of Queensland Health clinical and non-clinical staff as well as non-government and external (to Queensland Health) organisations.

Targeted consultations within Queensland Health included those palliative care, intensive care, cardiac, renal, diabetes and geriatric care providers, as well as workforce planning, healthcare purchasing, and information and communication technology.

A range of interrelated health service issues and needs were identified from consultations. Analysis included validation of issues against available evidence and the development broad themes within the health service delivery context to inform service directions. Strategy development then focussed on issues within the influence of public health services to address in order to develop objectives and actions.

2. Profiling for end-of-life care

Research themes

There is national and international recognition of the need for a reconfiguration of health services to integrate end-of-life care into existing health services and engaging the broader community in supporting those in need of care.⁷ Fundamentally however, a lack of clarity in defining and confusion of the term ‘end-of-life’ (e.g. with terminal care and care of the dying) may impact on the

population which requires this care. Whilst the national palliative care strategy states the 'average time people are on end-of-life care is 37 hours', others suggest, using the same terminology, that provision of end-of-life care should not be assigned a particular time period or based on a diagnosis or prognosis.

Despite definitional issues, a shared purpose for end-of-life care revolves around the concepts of:

- high societal discomfort and grief surrounding the death of a child
- holistic care that addresses the physical, psychological, social and spiritual needs of the patient and their caregivers, not just physical needs
- ensuring the highest quality of life possible
- limiting invasive and unnecessary healthcare interventions or investigations²⁶
- ensuring respect for patient choice and the patient remaining in control as much as possible as they approach death^{26,28,}
- supporting patients' families and caregivers.

Inequitable access to end-of-life care is evident for some populations and is generally based on ethnic and cultural variables. In Australia, inequitable access is prominent in rural and remote communities, Aboriginal and Torres Strait Islander populations, as well as non-cancer patients and older people living in residential aged care facilities.^{16,}

Identifying deterioration and diagnosing when a patient is/may be moving into the end phase of their life is recognised as complex and challenging for many clinicians. Barriers that contribute to delays in initiating end-of-life care include:

- a disconnect between the aims of modern medicine to cure and the acceptance of death as a likely outcome
- a cultural/societal fear of initiating conversations and discussing death (by both health professionals and the general public)
- impact of health financing mechanisms that do not fund service models such as 'consultation–liaison' and 'shared care' practices.

Though the use of triggers and/or tools has been identified as a possible way of assisting in this process, the comfort and wishes of the patient and the potential futility of treatment have been identified as the two most important factors in deciding the commencement of end-of-life care.

Advance care planning aims to encourage people to consider, discuss and document their future wishes for care. Whilst its adoption has not been extensive, there is evidence to support the use of ACPs improve patient care and outcomes at the end of their life.

Children with life-limiting conditions have additional unique needs to those of the adult population. These needs include the potential for longer term palliation and respite for parents, transitioning children through paediatric care to an adult service and the complexity of grief which come with a death of a child. With limited specialist paediatric palliative care services in Australia, meeting the demands of these children is generally based on statewide models of service supporting generalist physicians.

There is comparatively poor engagement of Aboriginal and Torres Strait Islander people in end-of-life care compared with non-Indigenous Australians. A limited trained health workforce as well as cultural and spiritual rituals is recognised as likely to impact on end-of-life care services for this population.³⁷

Queensland population

At 30 June 2013, the preliminary estimated resident population of Queensland was 4,658,557 people—an increase of 2.0 per cent (93,028 persons) on the previous year (2012). Though in the 10 years to June 2012, Queensland's average annual population growth rate was 2.3 per cent, this rate is slowing and expected to average 1.9 per cent per annum in the years to 2021. By 2031, the Queensland population is projected to be 6.6 million people, an increase of approximately 1 million people per decade.

The influences which are resulting in the lower population growth rate are also impacting on its ageing. In 2012,

- children aged 0–15 years accounted for 19.2 per cent of the Queensland population compared to 22.5 per cent in 1992
- persons aged 65 years and over accounted for 13.3 per cent of the Queensland population compared to 10.9 per cent in 1992.²³

By 2026, those aged 65 years and over are expected to increase to 18.1 per cent of the population.²⁴ In the 20 years to 2012, the median age of the Queensland population had increased by 4.7 years to 36.1 years. By 2026, the median age is expected to increase by a further 3.2 years to 39.3 years.²⁴

Based on the 2011 Census, Aboriginal and Torres Strait Islander people were estimated to account for 4.2 per cent (188,954 persons) of the total (2011) Queensland population.²⁵ The median age of the Aboriginal and Torres Strait Islander population in 2011 was 21 years—this is relatively unchanged from the previous 20 years. The Aboriginal and Torres Strait Islander population is projected to increase by 30.4 per cent in the 10 years to 2021.

Based on the 2011 Census, of those born overseas (almost 900,000 people), 5.2 per cent (46,800 people) did not speak English well, if at all.²⁶ Additionally, almost 18 per cent of the Queensland population lived in areas classified as outer regional, remote or very remote. The majority (49 per cent) lived in major cities or inner regional areas of the state. These trends are expected to remain unchanged with the majority of population growth projected to occur in the south east of the state.³⁹

Health status and estimating the end-of-life care population

Overall, the life expectancy of the Queensland population is among the highest in the world and people self-assess their health status as 'good'.²⁷ Since 2000, life expectancy for non-Indigenous people in Queensland has increased by approximately three years and in 2011 were 79.5 years for males and 84.1 years for females. Life expectancy for Indigenous people in Queensland is however lower, in 2005–07, the life expectancy for Indigenous males was 10.4 years lower (68.3 years) than the non-Indigenous population and for women, was 8.9 years lower (73.6 years).

In 2006, the health adjusted life expectancy (HALE) at birth in Queensland was 73.6 years for non-Indigenous people and 59.9 years for Aboriginal and Torres Strait Islander people.²⁷ Based on life expectancy for this year (2006), this equates to approximately 7.6 years for non-Indigenous people and 8.4 years for Indigenous people where health status would not be optimum.

Though burden of disease and hospitalisation rates for many conditions are decreasing, the actual numbers are increasing due to ageing and growth of the population.²⁷ In 2007 chronic diseases, including cancer, accounted for 88 per cent of the burden of disease in Queensland with differences in the burden occurring across population groups based on Indigenous status, sex, socioeconomic disadvantage and remoteness. In the period 2007–09, an average of 25,864

people died each year in Queensland—an all-cause death rate of 607.8 deaths per 100,000 population with a higher rate for Aboriginal and Torres Strait Islander people.^b

Recent research has estimated that anywhere between half—and almost all—of those who die require some level of palliative care. Exploring the health status and deaths of Queenslanders can assist in understanding the subset of the population, who may be in, or approaching, the last stages of their life and therefore inform the potential need for health services.

Borrowing from the methodology developed by Rosenwax, McNamara and colleagues¹³ preliminary estimates of the population in Queensland who died in the period 2007–09 who may have benefitted from palliative care were estimated. Whilst Table 1 provides only the (preliminary) estimates, determining the population who may benefit from end-of-life care may be broader than palliative care.

Table 1 Preliminary estimates of the Queensland population who may have benefitted from palliative care, 2007–09

Estimated palliative care population	Population that may benefit from end-of-life care per annum	Proportion—total deaths per annum
Minimum estimate (top 10 leading causes of death*)	13,686	53%
Mid-range estimate (top 20 leading causes of death*)	17,200	67%
Maximum estimate (all causes of death*)	24,067	93%

Source: Policy and Planning Branch. Estimates calculated based on death rate data sourced from Australian Bureau of Statistics. Causes of death, Australia, 2010. Cat. no. 3303.0. ABS: Canberra; 2012.

*Excludes those not amenable to end-of-life care.

Palliative care activity in hospitals

Although Palliative Care Australia estimated approximately 73 per cent of Australians who died in 2011 would have benefitted from access to palliative care services,²⁸ comprehensive data for those receiving palliative and/or end-of-life care is not readily available in Queensland. The information in this section is based on inpatient care in acute hospitals coded as palliative and recognises this is only one component of end-of-life care.^c

Of those who died in 2009–10, about 24.5 per cent (approximately 4900 people) had at least one stay in a Queensland hospital in the last 12 months of their life where the care was coded as palliative. However, 75 per cent (20,200 people) of those who died had at least one admission to a hospital during this last year of life. Of all those admitted, 32.1 per cent had only one stay and 24.7 per cent had five or more stays. The average total length of stay for those hospitalised in the last 12 months of life was approximately 32 days. (The stay/s in hospital may not necessarily have been for the condition of which they died).²⁹

The public health sector has consistently provided the majority of inpatient palliative care health services over the 5 years to 2011–12, this care equated to 77.5 per cent of the total inpatient bed days (coded as palliative). Public inpatient palliative care separations are increasing—in the five years to 2011–12; the number of separations increased by 41.9 per cent and total occupied bed

^b In 2010, the death rate for Aboriginal and Torres Strait Islander people was 2.8 times that of non-Indigenous people (Australian Bureau of Statistics. Causes of death, Australia, 2010. Cat. no. 3303.0. ABS: Canberra; 2012.)

^c Data on palliative and/or end of life care provided outside of hospital settings is not available nor is acute hospital inpatient palliative care which is concurrent with other inpatient care.

days has increased by 20.5 per cent. Consistent with provision of care close to home, 80 per cent of these separations were for people who received care at a hospital within their HHS of residence.

Adult patients with medical oncology conditions have consistently accounted for the highest proportion of inpatient palliative care in the five years to 2011–12, followed by respiratory, and then neurology conditions (with each accounting for less than 10 per cent of the total care). The significant difference between medical oncology and the other service-related groups (or conditions) is consistent with Australian trends but may also highlight a higher need for access to specialist palliative care services for those with diagnoses other than cancer.¹⁵

Aboriginal and Torres Strait Islander people accounted for 1.9 per cent of all inpatient palliative care (compared to 4.7 per cent for all inpatient activity) in 2011–12. The proportion for palliative care has remained virtually unchanged in the five financial years since 2007–08 and is higher than the 2008–09 Australian average of 1.5 per cent of all palliative care separations.^{d,15}

Public and private hospital inpatient care coded as palliative care for children (aged 0–19 years) has accounted for an average of just under 50 separations in each of the five financial years to 2011–12 with the majority being from the Royal Children's or Mater Children's Hospitals. The average length of stay in 2011–12 for children was 9 days which has remained virtually unchanged since 2007–08.

^d Data for Tasmania, Australian Capital Territory and private hospitals in Northern Territory was not included in Australian average.

Appendix 1 Policy themes

The profile of end-of-life and palliative care has been increasing in recent years. In addition to international, national and state (Queensland) policy and frameworks developed by government and non-government organisations to guide service delivery and practice for palliative and end-of-life care. There have also been government inquiries at these levels.

The following national and state documents have informed this strategy.

National strategy

- Australian Government—*Supporting Australians to live well at the end-of-life : National palliative care strategy 2010*

National inquiry

- *The Senate Community Affairs References Committee Palliative care in Australia, Report October 2012* (Response to recommendations not available at as at February 2013)

National guideline

- *Health system reform and care at the end-of-life: a guidance document. 2010*

Queensland (state) inquiry

- *Parliamentary Committees, Palliative and community care in Queensland: toward person-centred care. Report No 22, Health and Community Services Committee May 2013.*
- *Government response to recommendations Health and Community Services Committee, Palliative and community care in Queensland: toward person-centred care. (Report No 22) (August 2013)*

Queensland service frameworks

- *Clinical Services Capability Framework version 3.1*—specifically Palliative Care Services module but also support service requirements outlined in other modules.

A number of key recent guiding documents which identify system issues, barriers (to the provision of care) and potential service delivery solutions have also informed the development of this strategy.

Appendix 2 Hospital and Health Service mapping

The following geographic areas have been used for differentiation of HHS in sections of this paper. The geographic areas are for this paper only and are not based on an endorsed remoteness structure or classification system.

Hospital and Health Services (as at 1 July 2013) by geographic area

Geographic area	Hospital and Health Service
South East Queensland	Sunshine Coast Hospital and Health Service Metro North Hospital and Health Service Metro South Hospital and Health Service Gold Coast Hospital and Health Service Mater Health Service (Public Hospitals)
Regional Queensland	Cairns and Hinterland Hospital and Health Service Townsville Hospital and Health Service Mackay Hospital and Health Service Central Queensland Hospital and Health Service Wide Bay Hospital and Health Service Darling Downs Hospital and Health Service West Moreton Hospital and Health Service
Rural/Remote Queensland	Torres Strait-Northern Peninsula Hospital and Health Service Cape York Hospital and Health Service North West Hospital and Health Service Central West Hospital and Health Service South West Hospital and Health Service

Note: excludes Children's Health Queensland which provides services throughout the State.

Glossary

A

Access/Accessible

Ability to utilise a service or the skills of a suitably qualified person—without difficulty or delay—via a variety of communication mediums. Access may be provided via documented processes with an off-site provider on an inpatient or ambulatory basis.

Source: Fundamentals of Framework. Clinical Services Capability Framework for Public and Licenced Private Health Facilities v3.1, Queensland Health.)

Acute resuscitation plan

An acute resuscitation plan is a medical order which prescribes what treatment will be provided where it can be reasonably expected that a patient might suffer an acute event in hospital in the foreseeable future necessitating the process of resuscitation planning.

Advance care plan

An advance care plan is often the result of an advance care planning discussion. Advance care plans state preferences about health and personal care and preferred health outcomes. There are many ways of recording an advance care plan including oral and written versions.

Source: A National Framework for Advance Care Directives 2011, The Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers Advisory Council

Advance care planning

Advance care planning is a process of planning for future health and personal care whereby the person considers their values, beliefs and preferences and makes them known to surrogate decision makers so that can guide decision-making at a future time when that person cannot make or communicate his or her decisions. Advance care planning encompasses a broader approach to health and personal care planning than advance health directives.

Source: A National Framework for Advance Care Directives 2011, The Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers Advisory Council

Advance care planning discussions involve health professionals and patients and, if possible, their family or carers.

Advance health directive (Queensland)

An advance health directive is a legal document that states a person's wishes or directions regarding future healthcare for various medical conditions. It comes into effect only if the person is unable to make their own decisions and must be followed unless it would be good medical practice not to do so. Advance health directives must be written—there is a standard though not mandatory form—and can be undertaken at any time or within advance care planning processes.

Sources: Department of Justice and Attorney-General, Form 4 Advance Health Directive; Powers of Attorney Act 1998 S44(2)

B

Burden of disease

Disease burden: measured as disability adjusted life years (DALY). A measure of overall burden of disease and injury, where the DALY for a disease or condition is the sum of the years lost due to premature death (YLL) and years of healthy life lost due to disability (YLD).

Source: Burden of Disease: A Snapshot in 2013, Queensland Health. Preventative Health Unit

E

End-of-life care

End-of-life care helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

Source: National Council for Palliative Care, 2006

The care phase associated with end-of-life is inherently linked from the point at which the need is identified (by the clinician or patient) to the point of death (which may be days, months or years).

H

Health adjusted life expectancy (HALE)

Health-adjusted life expectancy (HALE) provides an estimate of the average years of equivalent 'healthy' life that a person can expect to live at various ages, given current risks of mortality.

Source: Burden of disease and health adjusted life expectancy, Population Health Queensland, Queensland Health, 2009

I

Inpatient

A patient who undergoes a hospital's formal admission process to receive treatment and/or care. Care may occur in hospital or in the home.

Source: Queensland Health. Queensland Health Admitted Patient Data Collection (QHADPC) 2013-2014 v 1.3)

Inter-professional team

A team of providers working together to develop and implement a plan of patient care. An inter-professional team may include allied health workers, doctors, nurses and support staff.

P

Palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Source: World Health Organisation.

Palliative care for children

Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when the illness is diagnosed and continues regardless of whether or not the child receives treatment directed at the disease.

Source: World Health Organisation, 1998

S

Surprise question

The use of a 'surprise' question can improve end-of-life care by identifying individuals or populations with a likely poor prognosis ('would I be surprised if this patient dies in the next year?' or 'how many of my current patients would I not be surprised if they were to die in the next year?').

T

Terminal phase of life

In this document, the terminal phase of life is the last weeks or days of life.

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