

Strengthening palliative care policy

Conceptual framework for evaluation

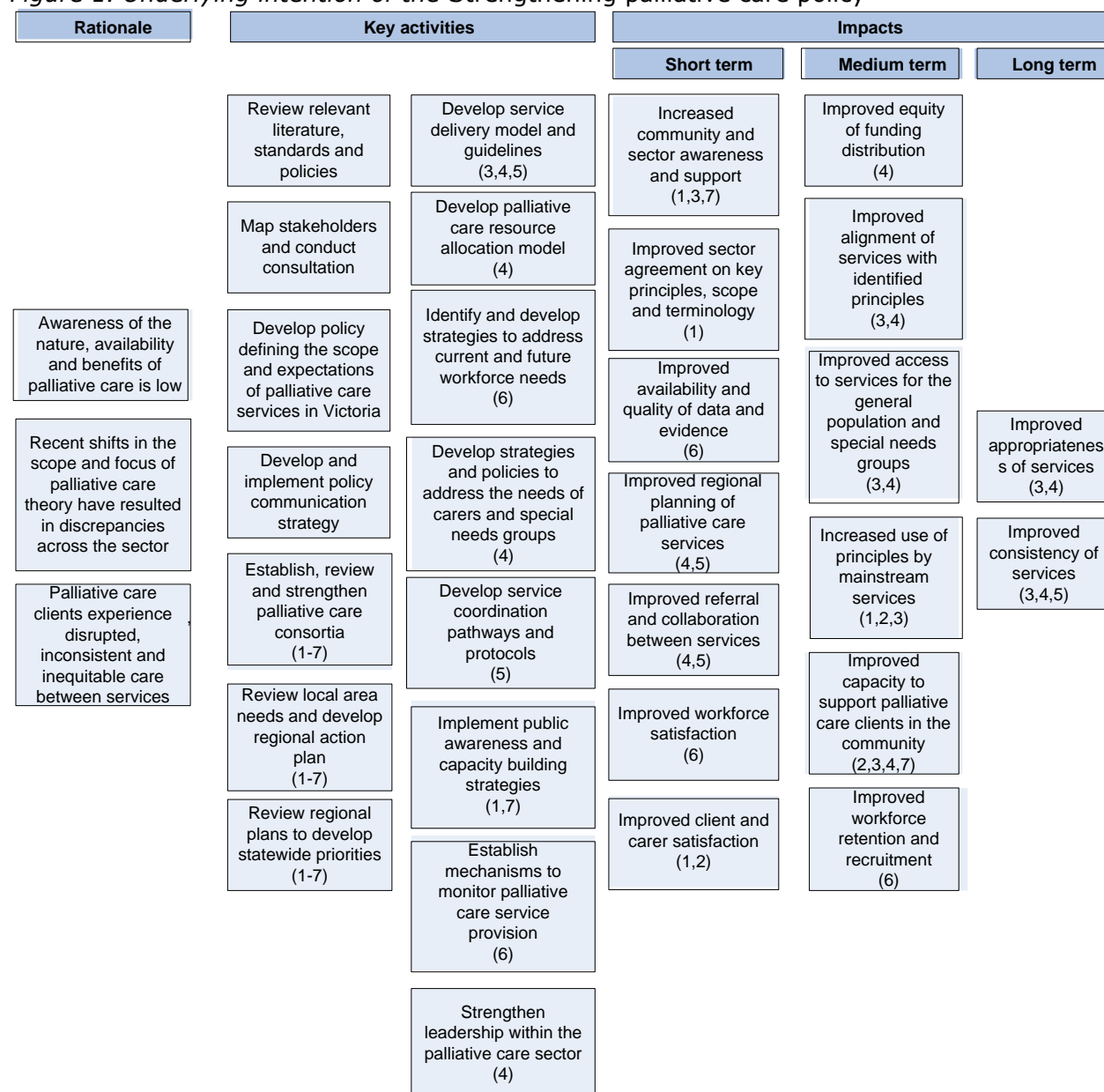
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This document outlines a framework for evaluating the *Strengthening palliative care policy*.

Project structure

An outline of 'what is supposed to happen' through implementing the *Strengthening palliative care policy* is presented in Figure 1. The numbers in parentheses refer to the corresponding policy principles.

Figure 1. Underlying intention of the Strengthening palliative care policy



Aims of the evaluation

The Department of Human Services will conduct a formal evaluation of the *Strengthening palliative care policy 2004–2009*, including:

- assessing the strengths and weaknesses of the current policy format and content
- identifying the impact of the policy implementation on the delivery of palliative care in Victoria
- identifying ongoing barriers and enablers regarding the development and delivery of best practice palliative care in Victoria
- identifying and assessing options for refreshing the *Strengthening palliative care policy* for 2010 to 2015.

Key evaluation questions

In order to address the objectives of the evaluation, a number of key evaluation questions will be formulated. These specific questions will focus on four overarching questions as outlined in Table 1.

Table 1. Key evaluation questions

Overarching question	Specific questions
How relevant was the policy given the environment in which it was established and developed?	<ul style="list-style-type: none"> ▪ What was the rationale for establishing the <i>Strengthening palliative care policy</i>? ▪ What were the environmental and satisfaction factors that influenced the development of the policy? ▪ How well do the principles and content of the <i>Strengthening palliative care policy</i> align with best practice and relevant state and Commonwealth policies?
Has the policy been written and implemented in a useful way?	<ul style="list-style-type: none"> ▪ Is the <i>Strengthening palliative care policy</i> acceptable to patients, staff and other health services? ▪ What were the key processes involved in implementing the <i>Strengthening palliative care policy</i>? ▪ How consistent are these processes with established guidelines, policies and procedures?
What outcomes have been achieved as a result of implementing the policy?	<ul style="list-style-type: none"> ▪ What outcomes have been achieved by the <i>Strengthening palliative care policy</i> for patients, carers, health services, the system and the community? ▪ Which elements of localised models/projects of implementation (clinical and administrative) have resulted in successful outcomes? ▪ What positive and negative outcomes (planned and unplanned) have arisen from implementing the <i>Strengthening palliative care policy</i>?
What are the ongoing implications for implementing the policy?	<ul style="list-style-type: none"> ▪ What barriers and facilitators exist to influence ongoing and statewide implementation of the palliative care principles? ▪ What is the overall level of sustainability of palliative care services/initiatives in their current configuration/s? ▪ What gaps in policy, planning and service provision need to be addressed in the next version of the policy?

Sources of data

The department defined a range of key activities for implementing the *Strengthening palliative care policy*. The extent of implementation of any initiative usually affects the level of impact(s) achieved by an initiative. As such, it is important to measure the extent to which the activities have occurred during implementation. Output indicators can be used to assess the delivery of activities associated with implementing the *Strengthening palliative care policy*.

Table 2. Key activities and outputs of implementing Strengthening palliative care policy

Activities	Outputs of interest to the evaluation
Review relevant literature, standards and policies	<ul style="list-style-type: none"> ▪ Key documents identified ▪ Literature review completed
Map stakeholders and conduct consultation	<ul style="list-style-type: none"> ▪ Stakeholders identified and documented ▪ Number and range of consultation activities completed ▪ Percentage of identified stakeholder groups included in consultation
Develop policy defining the scope and expectations of palliative care services in Victoria	<ul style="list-style-type: none"> ▪ Reported stakeholder satisfaction with policy format ▪ Reported stakeholder satisfaction with policy content ▪ Reported stakeholder satisfaction with policy usability
Develop and implement policy communication strategy	<ul style="list-style-type: none"> ▪ Communication strategy documented ▪ Dissemination of policy by location/service type ▪ Number and range of communication activities completed ▪ Awareness of palliative care policy principles among palliative care service providers and consortia
Establish, review and strengthen palliative care consortia	<ul style="list-style-type: none"> ▪ Consortia terms of reference and memorandum of understanding documented and endorsed ▪ Number and type of consortia members ▪ Compliance with attendance requirements ▪ Functionality of consortia
Review local area needs and develop regional action plans	<ul style="list-style-type: none"> ▪ Sources of need evidence identified (qualitative) ▪ Number and range of local needs identified ▪ Percentage of regions with a documented action plan based on local objectives ▪ Implementation of initiatives in regional plans ▪ Evaluation and review of regional plans
Review regional plans to develop statewide priorities	<ul style="list-style-type: none"> ▪ Priorities identified, documented and endorsed ▪ Priorities implemented
Develop service delivery model and guidelines	<ul style="list-style-type: none"> ▪ Principles identified and endorsed ▪ Service delivery framework developed ▪ Stakeholder satisfaction with service delivery model
Develop palliative care resource allocation model	<ul style="list-style-type: none"> ▪ Funding model developed and documented ▪ Funding allocated by service/LGA ▪ Stakeholder satisfaction with funding model
Identify and develop strategies to address current and future workforce needs	<ul style="list-style-type: none"> ▪ Current and future workforce requirements estimates documented ▪ Gap analysis against requirements documented ▪ Strategies developed to address gaps
Develop strategies and policies to address the needs of carers and special needs groups	<ul style="list-style-type: none"> ▪ Special needs groups identified ▪ Needs analysis conducted against each special need group ▪ Number and range of strategies undertaken by all services ▪ Number and range of strategies undertaken by statewide services to address the needs of special needs groups

Activities	Outputs of interest to the evaluation
Develop service coordination pathways and protocols	<ul style="list-style-type: none"> Percentage of palliative care services/consortia that have documented key partners and referral protocols Number and type of service coordination strategies developed and implemented by each consortium Number and type of service coordination initiatives developed and implemented statewide
Implement public awareness and capacity-building strategies	<ul style="list-style-type: none"> Number and range of activities conducted Number and range of populations targeted Number and type of services that initiated and implemented public awareness and capacity-building strategies Effectiveness of capacity-building partnerships and initiatives
Establish mechanisms to monitor palliative care service provision	<ul style="list-style-type: none"> Minimum dataset identified Data collection system implemented Service provision reports reviewed regularly
Strengthen leadership within the palliative care sector	<ul style="list-style-type: none"> Number and type of leadership initiatives undertaken Effectiveness of leadership initiatives undertaken

Impact measures can be used to assess the impact of the *Strengthening palliative care policy*. Key impacts are outlined in Table 3.

Table 3. Impacts and measures

Impacts	Measures (areas of interest to the evaluation)
Increased community and sector awareness and support	<ul style="list-style-type: none"> Service delivery staff awareness of palliative care principles by profession and service type (self-reported) Increased referral to palliative care services Increased appropriateness and timeliness of referral to palliative care services Self-reported understanding of palliative care services by clients and carers at time of referral to specialist palliative care services
Improved palliative care sector agreement on key principles, scope and terminology	<ul style="list-style-type: none"> Consistency of palliative care terminology used by key stakeholders Reported agreement with scope and principles as specified in policy (within and across stakeholder groups)
Improved availability and quality of data and evidence	<ul style="list-style-type: none"> Percentage of palliative care services collecting mandated data in relation to client/carer satisfaction, outputs and outcomes Percentage of palliative care services reporting in compliance with specified format and frequency Number and type of data reports provided back to services
Improved regional planning of palliative care services	<ul style="list-style-type: none"> Regional EFT (located within palliative care consortia) devoted to palliative care planning and monitoring Percentage of regions with a palliative care regional plan Number of initiatives in regional plan implemented and evaluated Sector satisfaction with regional planning
Improved referral and collaboration between services	<ul style="list-style-type: none"> Reported compliance with protocols (according to the <i>Victorian service coordination practice manual</i>) Average number of referrals generated per service by destination

Impacts	Measures (areas of interest to the evaluation)
	<ul style="list-style-type: none"> ▪ Average number of referrals received per service by source ▪ Number and frequency of meetings between partnership service staff ▪ Reported satisfaction with relationship with partner services
Improved workforce satisfaction	<ul style="list-style-type: none"> ▪ Self-reported satisfaction by profession and service type
Improved client and carer satisfaction in relation to care from specialist palliative care services and generalist services	<ul style="list-style-type: none"> ▪ Reported satisfaction of clients by population segment ▪ Reported satisfaction of carers ▪ Reported satisfaction of clients and carers across all domains of care – physical, social, emotional and spiritual ▪ Reported satisfaction of clients and carers in relation to use of multidisciplinary approach by specialist palliative care services
Improved equity of funding distribution	<ul style="list-style-type: none"> ▪ Comparison of existing funding distribution to PCRAM and other relevant guidelines
Improved alignment of services with identified principles	<ul style="list-style-type: none"> ▪ Number of new initiatives based on identified principles ▪ Percentage of service policies that align with principles
Improved access to palliative care services for the general population and special needs groups	<ul style="list-style-type: none"> ▪ Increased number of clients admitted to existing services ▪ Increased number and location of services available ▪ Increased number of special needs clients accessing services by service type ▪ Increases in funding to palliative care
Increased use of principles by mainstream services (including aged care facilities and acute health services) as part of implementing the palliative approach	<ul style="list-style-type: none"> ▪ More appropriate and timely referral to palliative care (internal and external) ▪ Improved integration and coordination of care between services such as partnerships established, mechanisms for coordination developed) ▪ Effective use of palliative care consultation models ▪ Number and type of education and training initiatives undertaken by specialist palliative care services for mainstream services
Improved capacity to support palliative care clients in the community	<ul style="list-style-type: none"> ▪ Increase in resourcing for community palliative care ▪ Increase in equitable funding distribution to community palliative care services
Improved workforce retention and recruitment	<ul style="list-style-type: none"> ▪ Number and type of education and training initiatives delivered for specialist palliative care workers (including volunteers) ▪ Number of unfilled positions by profession/service type ▪ Workforce turnover (between palliative care services and to/from palliative care sector) ▪ Volunteer satisfaction, numbers and turnover
Improved appropriateness of services	<ul style="list-style-type: none"> ▪ Assessment of current practice against PCA guideline regarding how palliative care should be provided (see glossary)
Improved consistency of services	<ul style="list-style-type: none"> ▪ Consistent implementation of service delivery framework model ▪ Development of regional/service level service delivery type models
Other	

Methods for determining the success of the program

In order to maximise the value of information collected for evaluation it is important to identify reliable information sources and data collection methods and tools, and select realistic study design that provides the strongest and most consistent evidence. The department has undertaken preliminary work to define a data collection strategy and set the minimum requirements for an methodology. The data collection strategy is described in Table 4.

Table 4. Data collection strategy

Information sources	Data collection
Project information	Document review
Service delivery statistics	Service data (document review)
Client, carer, service provider and staff information	Surveys, interviews, focus groups

Compliance with the department's information management principles

The department requires that evaluation data be collected and reported in accordance with established principles for best practice information management. Accordingly approval of this document is taken to signify compliance with the criteria outlined in Table 5. Noncompliance with any specific criteria must be explained below.

Table 5. Compliance with best practice information management

Statement of compliance with department information management principles			
The need to collect specific information has been demonstrated	Yes No	Relevant stakeholders consulted in development of evaluation methods	Yes No
All existing sources of potential departmental data have been reviewed	Yes No	Requirements for ethics committee approval have been considered	Yes No
Data collection has been designed to minimise burden	Yes No	Roles and responsibilities for data collection have been specified	Yes No
Frequency and duration of data collection has been specified	Yes No	Scope of data collection activities is congruent with available funding*	Yes No
Method of reviewing evaluation information has been identified	Yes No	Appropriate standards of measurement have been adopted	Yes No
Method of validating evaluation information has been specified	Yes No	Guidelines to assist data collection and reporting have been provided	Yes No
* Conduct of the supplementary comparison data is subject to available funds.			

Glossary

Appropriate and timely palliative care

'Specialist palliative care is provided in two main ways. Firstly, specialist services can provide consultation-based advice and support to primary care providers. In this situation specialist providers undertake a direct assessment of the patient and establish a plan of care with the patient, primary carer and family, and the primary care provider.

The primary care provider, using criteria established by the specialist service, would undertake ongoing care and reassessment of the patient. Secondly, and much less commonly, specialist services may be involved for a longer period of ongoing care. In general all care provided by a specialist palliative care services will be provided in partnership with a primary care provider. Patients requiring a specialist palliative care consultancy would typically experience:

- An exacerbation of a previously stable symptom, and/or
- Identified needs (physical, social, emotional or spiritual) that exceed the capacity (knowledge, resources, facilities) of the primary care providers.

It would be expected that the patient would remain in the care of the primary care provider, and that ongoing care, monitoring and assessment would be undertaken by them.

Patients receiving care from a specialist palliative care services on an ongoing basis will generally have one or more of the following:

- Complex pain or symptoms not responsive to established management protocols that has not stabilised following consultation
- Complex psychological and/or social needs
- Increased risk of complicated bereavement for the primary carer and family.'

(Quoted from: Palliative Care Australia, *A guide to palliative care service development: a population based approach*, p 33. Expanded version of reference on p 37 of the policy.)

Palliative care

'Palliative care improves the quality of life of patients and their families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement.

Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor to postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life and may also positively influence the course of the illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.'

(Quoted from: World Health Organization (WHO) website, 16 July 2004. Available: www.who.org)