

Partners in Palliative Care Reference Group

Response to Green Paper and Role Delineation Framework

The response provided to both the Green Paper and Role Delineation Framework from the Partners in Palliative Care (PIPC) Reference Group has a strong focus on the provision of palliative and end of life care within the context of the public health approach to healthcare. Some comments focus on the provision of palliative care at a regional and Specialty Service level, however the PIPC Reference Group have sought to represent the palliative care sector in Tasmania as a whole.

Background

The Partners in Palliative Care Reference Group (PIPC) is a state and sector wide committee that meets every 8 weeks. This group has been convened to inform the ongoing and sustainable development of palliative care in Tasmania. The purpose of the group is to promote and strengthen capacity across the palliative care service system and to inform service system planning, enhancements and linkages.

Membership of the group is representative of stakeholder organisations from across the Tasmanian health, aged and community service sectors, and other entities with a role in palliative care advocacy and capacity building.

The PIPC is pleased to provide this response to the Government's Green Paper and draft Role Delineation Framework.

Response to the Green Paper Questions

Is the Tasmanian health system all it should be, or should we be open to change in order to improve outcomes for all Tasmanians regardless of where they live?

- PIPC believes that the Tasmanian health system should be open to change and improvement to ensure that is safe and responsive to patient and community needs.
- There is a need for greater recognition of the role and value of palliative care in the community.
- There is a need to improve access to community based palliative care so that people can choose to die at home if that is their wish
- From a palliative care perspective we need to be supporting and encouraging service providers to meet the treatment/care, palliative care, and/or end-of-life wishes of patients. This will involve assisting them to find information and resources on palliative care.
- There is a need to improve how the community accesses information about palliative care in Tasmania. The DHHS website is poorly structured and the DHHS internet search function is not effective and it is difficult to find information.

- There also needs to be a greater focus on further education and development for palliative care, and to better define services, this includes health and community services.
- It is also important to identify the differences that exist between services delivered by a clinician in an acute setting, and services that are delivered in the community. In addition, an improvement in continuity and coordination of care across these services is required.

How would you find out about what travel support, information and services are available to you to get the right care, by the right person, the first time?

- There needs to be more effort made to communicate to patients and their carers that palliative care is available in the home/community setting to minimise travel. For example, patients need to know what specialist support (if any) is available in rural areas.
- There also needs to be a coordinated patient centred plan in place to assist in transition from specialist palliative care services to primary care palliative care. To date funding models have prevented this from occurring.
- Further thought is needed around what support is required to help people when they need to travel. It is important that the travel burden is minimised as much as possible for this group of patients. While many patients receive palliative care in the home, there will still be a need to travel to specialist services from time to time, and this undertaking presents risks for the patient and for others. There will be an increased need for transport services between facilities. The focus should be on enabling the patient to stay at home and access palliative care as close to their home as possible.
- The public health/transport services need to be reviewed to allow care and services to continue in the community.
- Consideration also needs to be given to the scheduling of appointments and more emphasis should be placed on whether tele-health facilities can be used to reduce the need to travel.
- Volunteer funding needs to be reviewed, as a number of volunteer organisations assist with travel.
- The focus on travel needs to be broader. If there is to be an improvement in the way people access safe, specialist services it is important to think beyond the constraints of 'access to transport'.
- For many patients and their families/carers (especially those from rural and remote areas) there will be a need for accommodation near the specialist service and access to childcare support. Workplace commitments and the considerable financial impost that travel can impose also need to be considered. These are significant issues that can prevent access to services and engagement and participation in treatment.

If you are already a user of these services, are they sufficient?

- The website needs to be reviewed and updated. The information currently available online around how to access services is not clear. This needs to be constantly monitored and updated as appropriate.
- There is a need for hospital avoidance strategies to be discussed, resourced and integrated into care management processes, as well as improved education around what palliative care is and what assistance is available to patients, carers and their families.
- Further education and development of all health and community services is required to increase their capacity to provide palliative care, in line with National Standards for the provision of quality palliative care for all Australians

If it improves the quality and safety of care, do you agree we should limit the number of sites at which some services are provided?

- Concerns have been raised that services are being provided differently across the three regions. This may lead to varying standards of care being provided in Tasmania and inequitable access to services. Duplication should be reduced where possible, without compromising the quality of service delivery.
- The ability of a dying person to choose to receive the palliative approach to care is a fundamental right and should never be rationed. Future sustainability of Tasmania's small regional Specialist Palliative Care Services is reliant on all providers (health and social services) having access to training and capacity to deliver a palliative approach to care.

If yes, what should we consider in deciding where a service is located and what support needs to be considered to ensure patients have equitable access?

- All health professionals need to be aware of what can be accessed and delivered in the community. This information could be provided via an updated and maintained website that is compliant with health literacy principles.
- The work of TML on Health Pathways is a good example of increasing access to information and knowledge about pathways to access care.
- TML's work in the area of care co-ordination of services, and in particular transfers of care, needs to be fully embraced to ensure better planning and access to community services/care.
- Co-ordinating and consistently communicating the transfer of care will be important to avoid duplication, releasing information and managing relationships and perceptions of other stakeholders and the community.
- Recognition of the high level of socio-economic disadvantage in Tasmania needs to be a priority consideration in the redesign of service delivery models.

What services do you currently receive in a hospital setting that you think could be

safely delivered in your community?

- We need to build the understanding of what palliative care is: what it already provides in the community.
- Further education and awareness around medication and symptom management for patients, carers and their families.
- Symptom management for palliative care can be improved and this could be better planned and managed in the community with support from specialists and primary careproviders. Appropriately trained health professionals must be available to visit clients at home.
- IT support and resources to enable the community sector to access up to date information about patients will assist in better coordination and symptom management in the community.

How can we better help you understand the standard of care you are entitled to, and support your involvement in your healthcare decisions?

- Need to ensure all Tasmanians have equitable access to services and there is a need to be committed to supporting this.
- There is a need for clear pathways and requirements to support advance care planning. This requires a whole of system response.
- Health literacy and community understanding is an important focus and has to be a priority if members of the community are to become active participants in their care. This will also require health professional and community service providers to have skills in engagement and to support active self-management for the consumer.
- There will also need to be a strong focus on community capacity building around health care self-agency as well as building capacity of providers. Supporting consumer involvement in healthcare and end of life decisions requires different architecture than we have currently – the Canterbury District Health Board *Connecting Care Communities* demonstrates what can be achieved through an integrated health and social service system that is built for person centred care.

What public-private partnerships should we explore for the delivery of health service in Tasmania?

- Private sector collaboration and the level of cover available from insurers - this needs to be better integrated for a more responsive private-public health care response.
- Making the most of public and private sectors – there is scope for sharing governance between private and public providers.
- Private Insurance rates – there is a high rate of private insurance in Tasmania but people don't know how/when private insurance can support them with palliative care. In addition there is a need for better access to home support and allied health services for people with private health insurance, e.g. access to OT assessments to facilitate discharge home.

- Service availability and coordination – there needs to be better understanding of what public and private services are available and how these services can be coordinated – both could be improved.

General Comments

- There is no acknowledgement in the Green Paper / Tasmanian Role Delineation Framework of the non-clinical support provided to clients, particularly by volunteers in the community setting.
- A stronger focus is required to raise awareness as to what alternatives to hospital are available for people with palliative care needs. This will require the provision of regular education training for new/existing health professionals and community service providers.
- Role of education – for new staff it is important to provide access to bereavement training and pastoral care support.
- After the Better Access to Palliative Care funding runs out, how will the development of the palliative care sector be sustained?

Feedback on the Role Delineation Framework

How well does the proposed framework for palliative care (Tasmanian Role Delineation Framework) align with practice in palliative care?

- The term 'palliative care service' is used interchangeably within the document. In some cases it is used to refer specifically to Tasmania's three dedicated Specialist Palliative Care Services (SPCS) (e.g. dot points in beginning text under header Palliative Care Services). The term is also used generically to refer to all providers, i.e. generalist and specialist providers of palliative care. This causes confusion with interpretation of the Role Delineation Framework (RDF).
- The RDF should be linked to reflect national palliative care policy and frameworks, and national definitions.
- There is no acknowledgement of the skills of the aged and community sector staff or volunteers in delivery of the palliative care. Aged care services are involved in providing palliative care as are disability support workers. The palliative care service profile in the RDF needs to acknowledge the work of all who provide care and support within this sector.
- The role of the multidisciplinary team needs to be better articulated. Allied health and social work are very important in palliative care – not just in specialist palliative care services but across the health care sector. Better articulation is required around the role of allied health (allied health teams) in providing care to clients.

Where are the gaps?

- There are gaps in terms of cohesive advance care planning, coordination of care, bereavement services and education of primary providers of palliative care symptom management.
- There are also gaps in access to palliative care in community settings.
- GP availability to visit clients at home (without commitment from GPs to undertake home visits, the expectation of health delivery moving from the acute sector to the community setting will not eventuate).
- The North West does not have an inpatient facility for palliative care clients
- Current staff resources will not meet future demand

Are there any services being inappropriately provided, or planned, for palliative care?

- There is considerable work being delivered by primary, specialist and community services. The challenge is to ensure effective coordination and engagement of all key services providers, in particular GPs.

Palliative Care service description

- In general the DHHS Specialist Palliative Care Services described in the paper commence at Level 3.
- Of note, the North West service is consistent with the Level 3 definition, but it currently does not provide an After-hours service.
- PIPC believes it is difficult to accommodate the proposed palliative care role delineation framework and there is a concern that transferring the current 4 levels of service provision to a service profile framework delineated across 6 levels has the potential to create confusion among service providers.

Palliative Care service requirements

- Palliative care service development and delivery in Australia is guided by well-established and regarded national policy approaches and resources. These are available at the Palliative Care Australia website <http://www.palliativecare.org.au/Policy/ReferenceDocuments.aspx>. These are national resources and provide advice and guidance in terms of standards, service planning, and population based approaches and workforce requirements. The DHHS role delineation documentation does not clearly present or suggest synergy with these national palliative care strategic planning and policy resources.
- Palliative care services in Australia are delivered in accordance with a nationally developed and accepted 4-tier model (<http://www.palliativecare.org.au/Policy/ReferenceDocuments.aspx>). It is quite challenging to connect this with the Level 1-6 framework set out in the RDF.
- The information presented in Level 2 and Level 4 is in general not representative of specialist palliative care services and amendment to these levels has been provided (see Attachment 1).
- Community development awareness, education and training are critical elements of palliative care. These are not represented in the levels presented in this role delineation document. Community and public health initiatives and participation are embedded in the national palliative care service planning framework.
- The role of primary health, residential aged care and community care providers and rural hospitals in the delivery of the palliative approach is not well articulated using this 1-6 level approach, which although presented as a whole of health service approach, has a strong metropolitan hospital/acute care focus.
- There is some confusion as to whether the palliative care role delineation descriptors in the draft framework are future looking and based on evidence and palliative care practice standards or whether they are intended to describe current service configuration and delivery.
- Given that palliative care is embedded in a primary health care approach it is difficult to apply the service delivery model to the role delineation descriptors in the paper.
- The document's wording is not clear as to what is required of those participating in this consultation process.

- In examining how other jurisdictions have addressed or applied the role delineation approach the PIPC group notes that South Australia has been able to integrate this approach with the national palliative care tiered approach (see page 8 Attachment 2).
- The SA service delineation matrix could help us to refine our existing 4 level approach, by filling in possible levels 3 and 5 based on our actual Tasmanian resources/emergent services.
- To improve the palliative care service requirements there is a need to align with national palliative care standards and strategy.
- Based on local and national projections demand for palliative care services is likely to continue to increase.

Palliative Care workforce requirements

- Allied health across regions may vary between levels. There are nationally accepted palliative care workforce and service planning resources that could inform this process with more consistency and rigour.
- Allied health requirement is inconsistent in the document in particular the level of specialist knowledge and skills is inconsistent when compared to the level of knowledge and skills describe for the medical and nursing disciplines.
- Levels 3 and 4 need to be strengthened. (Confusion about levels of services provided makes it difficult to provide adequate feedback to assist this process)
- Volunteers are also not included in the framework they are a critical component of the palliative care system
- Oncology services are closely supported by palliative care services in the North West.
- Post graduate positions in Specialist palliative care are limited and funding issues impact on numbers progressing. A pathway/model for palliative care is needed together with more education and training.
- Workforce development is vital to ongoing sustainability of palliative care services
- Access to professional development and education is very important to maintaining high standards both within specialist palliative care and amongst primary health, residential aged care and community care providers. Skilled practitioners of whatever discipline are important to maintaining and facilitating strong linkages across services to ensure appropriate and timely care in the place of the clients choosing whenever possible.

Palliative care support service requirements

- The group did not specifically discuss these issues; however, it is notable that these support services are significant for palliative care service delivery in particular pharmacy, radiology and pathology services, volunteer services and allied health services.

- Given the palliative care primary health approach these services are important in the three regional population areas.

Additional information

- PIPC believes the TCSP needs to more clearly articulated so that acceptability and applicability can be more fully explored by key stakeholders.
- Broader consideration of the setting and context of the primary health care system beyond the hospital is required. Ideally this should be occurring at the same time as the consideration of acute care services as the two are interrelated. Discharge planning starts at admission with a designated discharge planner in-situ.
- Broader engagement and recognition of other external organisations involved in health care delivery is required to best ensure the proper integration of services across regions/hospitals, particularly given the strong interface and complementary way in which health and community services work.
- A willingness to explore alternative approaches to delivering services is needed to ensure patient access to services.
- Health and community service professionals require access to eHealth alternatives and solutions that are easy to use and time efficient to help ensure access to services.
- Professional development and support is also required to shift existing organisational cultural and established practice that are not conducive to using these alternative modes of health care delivery.

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Attachment I

PALLIATIVE CARE SERVICES

Palliative care services refer to a group of services that cover the continuum of care required for all people who are experiencing a life limiting illness with little or no prospect of a cure. Services also extend to the patient's family, friends and their carers and are provided in acute hospital, sub-acute and community settings.

The scope of this Framework recognises that:

- Patients with life-limiting illnesses require different levels of involvement from the Department of Health and Human Services Palliative Care Service (Palliative Care Service) based on their needs and the primary care provider's capability and capacity to meet those needs;
- Many patients receive primary palliative care without having any contact with the Palliative Care Service (Level 1) and makes a clear distinction between the consultation-liaison (Level 2), shared care (Level 3) and services provided directly by the Palliative Care Service (Level 4; and
- The Palliative Care Service supports palliative care service provision across all four levels.

Level 1 Palliative Care Services

Service description

A Level 1 service provides culturally appropriate palliative care for the patient, carer and family in accordance with the National Standards for Palliative Care by a primary care provider. This includes patients, carer and family being informed and involved in decision making. The primary care provider is the designated Coordinator of Care.

A Level 1 service can consult with a higher level service if information is needed or refer the patient for assessment if the patient needs exceed the primary care provider's capability and/or capacity.

Service requirements

- Assess patient needs
- Pain and symptom control
- Provides social, spiritual and emotional support to patients and their carers and family
- Patient risk assessments
- Agreed care plans
- Provides after-hours support
- Co-ordination of patient, carer and family needs
- Offers bereavement support.

Level 2 Palliative Care Services

~~A Level 2 service coordinates and manages all the patient's needs using a palliative care approach by a primary care provider (designated Coordinator of Care) but with consultation and liaison from a higher level service (Palliative Care Service).~~

~~Level 2 palliative care patients have been referred to Palliative Care Service due to an identified unmet need. However, upon assessment the Palliative Care Service has determined in consultation with the primary care provider and the patients that the patient's needs can continue to be met by the primary care provider with the provision of advice, resources and/or the development of a plan for care. The patient is not admitted to a higher level.~~

~~Following the development of a plan of care and/or provision of advice from the Palliative Care Service, the primary care provider is to provide culturally appropriate palliative care for the patient, carer and family in accordance with the National Standards for Palliative Care. This includes patients, carer and family being informed and involved in decision making.~~

~~A Level 2 service can consult with a higher level service if information is needed or re-refer the patient for further assessment if the patient needs exceed the primary care provider's capability and/or resources.~~

A Level 2 service coordinates and manages all the patient's needs using a palliative care approach by a primary care provider but with consultation and liaison from a higher level service.

A Level 2 service can consult with a higher level service if information is needed or re-refer the patient for further assessment if the patient needs exceed the primary care provider's capability and/or resources.

Service requirements

As for level 1. Care provided in accordance with the National Standards for Palliative Care.

Level 3 Palliative Care Services

Service description

A Level 3 service provides multidisciplinary services to patients with complex and unstable conditions to receive ongoing high level care. Level 3 patients have been admitted to the Palliative Care Service. Care of patients is shared between the primary care provider and the Palliative Care Service.

A Level 3 service negotiates and formalises arrangements to meet the patient's needs with the primary care provider, patient, carer and family. The designated co-coordinator of care (lead agency) may be a palliative care physician.

Service requirements

- Patient assessment and care coordination and management shared between the Palliative Care Service and the primary care provider

- 24 hours, seven days a week support and advice to the patient, carer and primary care provider
- Provide episodic assessment, care planning and/or advice to lower level services (primary care providers)
- Provide after-hours services
- Regular reviews of the plan of care with the primary care provider, patient, carer and family as required
- Access to bereavement support
- Provide training and professional development for lower level services (primary care providers) through the provision of resources and information
- Access to some allied health services and social worker for psycho-emotional, social and spiritual problems

Workforce requirements

- Access to a palliative medicine specialist
- 24 hour cover from a clinical nurse with experience in palliative care services
- 24 hour cover from specialist palliative care nurses
- Social worker with palliative care expertise.

Level 4 Palliative Care Services

Service description

A Level 4 service is provided directly by the multidisciplinary Palliative Care Service to patients with complex and unstable conditions to receive ongoing high level care.

A Level 4 service negotiates and formalises arrangements to meet the patient's needs with the primary care provider, patient, carer and family and assumes primary responsibility for patient management, usually in its dedicated inpatient specialist palliative care unit..

Service requirements

As for Level 3 plus:

- 24 hour clinical management by the specialist palliative care team.
- Team consists of allied health members with specialised palliative care experience and knowledge
- Formal undergraduate and postgraduate education programs in place
- Research and development

Workforce requirements

As for level 3.

Attachment 2

South Australian – Palliative Care Services Plan 2009-2016 (May 2009)

Extract from Page 8

Table 3
South Australian service delineation, resource and capability matrix^a

Level	Capability	Typical resource profile
Acute, chronic, aged and community providers of end of life care.	Quality end of life care including assessment, triage, care coordination and clinical management, bereavement risk assessment and bereavement care for patients with uncomplicated needs associated with end of life care. Has formal links with a palliative care services for purposes of referral, consultation and access to specialist care as necessary.	General medical practitioner, nurse practitioner, practice nurse, generalist community nurse, Aboriginal health worker, allied health staff. Health care providers from a range of community and acute specialties and disciplines would be included at this level.
Level 2 palliative care service (PCA Level I)	Provide palliative care for patients, primary caregivers and families whose needs exceed the capability of primary care providers. Provides assessment, & community & clinical education. Care consistent with needs and provides consultative support, information and advice to primary care providers. Has formal links with primary care providers and a formal partnering relationship with a Level 6 service as well as with a local Level 4 service (through clustering arrangements if present) to meet the needs of patients, caregivers and families with complex problems. Has quality and audit programs.	A rural palliative care nurse coordinator with local support from general medical practitioner, allied health staff, pastoral care and volunteers. A designated staff member if available coordinates a volunteer service.
Level 4 palliative care service (PCA Level II)	As for Level 2, able to support higher resource level (due to population base or the presence of a Country General Hospital that brings with it additional responsibility to a cluster of smaller services), or the presence of a hospice associated with an adjacent Level 6 service. Provides inpatient care; within satellite hospice unit beds (in periurban centres) or a small cluster of (non-dedicated) palliative care beds within each Country General Hospital. Has formal links to primary care providers and a formal partnering relationship with a Level 6 service as well as with Level 2 services (within a cluster if present) to meet the needs of patients, caregivers and families with complex problems.	A rural palliative care nurse coordinator with addition of dedicated GP with a special interest, NP position and or advanced practice nurse with relevant specialist qualifications. Includes designated allied health and pastoral care staff.
Level 6 palliative care service (PCA Level III)	Provides comprehensive care for the needs of patients with complex need, and support for their caregivers and families. Provides inpatient care: Mostly in hospice units with some capacity within acute care beds of metropolitan hospitals based on need. Has formal links with primary care providers and formal partnering agreements with a number of Level 4 and Level 2 services across the state to meet the needs of patients, caregivers and families with complex problems. Contributes to high quality specialist research, advanced clinical training and graduate education programs and has integrated links to relevant academic units including professorial chairs where available.	Interdisciplinary team including a service director, palliative medicine specialists, a clinical nurse leader, advanced practice nurses, nurse practitioners and an expanded range of clinical and allied health staff with specialist qualifications and dedicated consultant roles in palliative care.

^a Adapted for the South Australian context from the Palliative Care Australia service delineation matrix (2005)