Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand
Consultation document
Acknowledgements

Many thanks to the individuals and organisations who willingly contributed their time and shared their thoughts, opinions and experiences, their contributions have been immensely valuable to the project and are greatly appreciated.
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Executive Summary

Purpose
The purpose of the Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand (the Framework) is to provide guidance to health service providers, funders and policy makers to inform planning and strategic development of palliative care services that are accessible and of equitable high quality for all New Zealanders with palliative care need.

The Framework describes a structured approach to integrated palliative care services that differentiates levels of service to support more consistent access to and purchasing of palliative care services across the country. The document describes the levels of care and staffing resources appropriate for the New Zealand context, and is also a necessary step in finalising the Specialist Palliative Care Service Specifications.

Context
A lack of common understanding regarding the composition of specialist and primary palliative care services has created confusion amongst health service providers, funders and policy makers. This has impacted on the strategic development of palliative care services both locally and regionally.

The health sector is currently facing the challenge of an ageing population, increasing demand for many services including palliative care, and constrained funding. These challenges necessitate robust planning and strategic development of palliative services in order to meet future population need.

It should be noted that the recommendations contained in the Framework are to be considered in the context of current funding and available resources.

Sector views
The development of the Framework is strongly informed by the sector’s views. Input into this work was provided through a consultation questionnaire and a representative workshop. At the workshop, attendees supported a single level of specialist palliative care, delivered by integrated providers working collaboratively, as the model of service delivery most appropriate for New Zealand. This collaborative working is formalised through a partnership model referred to as a hub and spoke.

Recommendations
It is recommended that:
- the palliative care sector:
  - adopt the Framework
  - adopt a national standards and accreditation programme for palliative care across settings and providers
– adopt national guidelines for evidence-based symptom management to reduce duplication and resources required for review

• the District Health Boards:
  – take into account population palliative care need during regional clinical service planning
  – use the Framework to inform planning and strategic development of palliative care services
  – implement care pathways (eg, Liverpool Care of the Dying Pathway)

• the Ministry of Health:
  – defines the core palliative care services to be funded by Vote Health
  – establish an expert clinical short-term working group to develop and adopt national eligibility criteria for access to specialist palliative care services
  – establish an expert clinical short-term working group to develop a common national assessment tool to be used for referrals for specialist palliative care services

• Health Workforce New Zealand:
  – develop a consistent understanding and definition of non-regulated advanced nursing roles (eg, clinical nurse specialist)

• the universities and education providers:
  – develop qualifications appropriate for the allied health workforce to maximise the potential for the discipline-specific skills they bring to the provision of palliative care services
  – develop e-learning opportunities that will enable staff who live outside of main centres to access training and qualifications
  – establish a national palliative care education and research hub to lead and support education and research in New Zealand.
1 Introduction

1.1 Purpose
The purpose of the Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand (the Framework) is to provide guidance to health service providers, funders and policy makers to inform planning and strategic development of palliative care services. The Framework supports the delivery of accessible, equitable and high quality palliative care services for all New Zealanders.

The Framework describes a structured approach to palliative care services that differentiates services to support more consistent access to and purchasing of palliative care services across the country. The document describes the levels of care and staffing resources appropriate for the New Zealand context, and the formalised links between all providers of palliative care to meet the needs of the patient, family and whānau.

This document is based on the concept that for many people, the need for palliative care can be appropriately met by their existing primary palliative care provider and any identified need for specialist services is likely to be episodic rather than required on an ongoing basis. It also promotes an integrated approach to service delivery.

For information on the project methodology see Appendices section 8.1.

1.2 Commissioning the Framework
The Ministry of Health commissioned the development of a framework appropriate to the New Zealand context in May 2011. The Framework was developed in close collaboration with the sector and under guidance from the Ministry of Health’s Palliative Care Advisory Group (PCAG).

The development of the Framework was commissioned in response to the PCAG’s concerns with the disparities in access to palliative care, and the lack of a common understanding or agreement as to what constituted primary palliative care or specialist palliative care services.

Linkages to the development of Specialist Palliative Care Service Specifications
The Framework is one of three service development projects required before final approval is sought for the specialist palliative care service specifications through the formal service specification approval process. The PCAG recommended that this work be undertaken first as sector feedback on the final draft specialist palliative care service specifications, completed in September 2010, identified significant concern regarding the policy context and financial implications associated with the service specifications.
Linkages to other palliative care projects

The Framework is informed by other palliative care projects including the *Gap Analysis of Specialist Palliative Care Services in New Zealand* and the *National Health Needs Assessment for Palliative Care Phase 1 Report*. See Appendices section 8.2 for more information on these and other palliative care projects linked to this document.

1.3 Definition of palliative care

The Palliative Care Subcommittee of the New Zealand Cancer Treatment Working Party (2007) developed a working definition of palliative care for New Zealand as the care for people of all ages with a life-limiting illness which aims to:

- optimise an individual’s quality of life until death by addressing the person’s physical, psychosocial, spiritual and cultural needs
- support the individual’s family, whānau, and other caregivers where needed, through the illness and after death.

The principles of palliative care service provision are that it should be:

- provided according to an individual’s need, and may be suitable whether death is days, weeks, months or occasionally even years away
- available wherever the person may be
- provided by all health care professionals, supported where necessary, by specialist palliative care services
- provided in such a way as to meet the unique needs of individuals from particular communities or groups. These include Māori, children and young people, immigrants, refugees, and those in isolated communities.

The Framework adopts this definition. For the full definition and definitions of other selected terms used in this document see the Glossary section 6.
2 Need for Palliative Care

2.1 Introduction

New Zealand, as in many other countries, faces the challenge of an ageing population with people living longer as the result of more effective health interventions.

Increasing number of people with chronic conditions can benefit from palliative care

Health Workforce New Zealand (2011) predicts that the number of people requiring palliative care will increase by nearly 25 percent over the next 15 years, and will be just over double the current level by 2061. This includes the increasing recognition of the number of people who can benefit from palliative care to improve their quality of life, a shift from when patients with cancer were the predominant service users. Changes in clinical practices have influenced the trajectories of illness, and an increasing number of people are living with chronic conditions, with a longer period of decline than cancer, could also benefit from palliative care.

Access to palliative care services is variable

Access to services across the country varies significantly and is influenced by the availability of existing services, geographical location and diagnosis rather than by the need for palliative care. Further, access to palliative care services for some population groups; including Māori, Pacific and rural populations, residents of aged residential care facilities and those with chronic illness; is more limited.

Aged care facilities have an increasing role in providing palliative care

Aged residential care facilities are becoming increasingly important in the delivery of palliative care. The estimated proportion of people aged over 65 years was 12.2 percent in 2006, and is predicted to increase to 19 percent by 2026 (Palliative Care Council 2011). This is important because people in this age group make up the largest proportion of deaths in the population and have a tendency to die from chronic diseases where palliative care could be of benefit (Palliative Care Council, 2011). The profile of aged care residents has changed over time with residents demonstrating increasing levels of dependency over the last 20 years (Boyd et al 2011). In its report Caring for Older Australians, the Australian Productivity Commission (2011) suggests palliative and end of life care should be core business for aged care services yet in practice the quality of care is variable and residents are transferred to hospital when the needs are beyond the resources of residential care staff. Specialist palliative care services have an important role to play in supporting aged care facility staff, who are predominantly caregivers rather than registered or enrolled nurses, to deliver effective palliative care.
No common understanding of palliative care services impacts service planning

There is no common understanding or agreement on the components of a specialist palliative care service or a primary palliative care service. This has implications for both funders and providers of palliative care services in the planning and strategic development of palliative care services to meet the predicted population need.

Further, it is not clear what the workforce for specialist and primary palliative care providers should comprise in terms of staff numbers and qualifications. There is already a shortage of staff with qualifications in palliative care (Health Workforce New Zealand 2011) and this is likely to worsen as palliative care staff, a comparatively older workforce, are ageing themselves.

Funding of palliative care services is mixed, disadvantaging some populations

The current funding of palliative care services is a mixed model combining charitable funds for some services, and Vote Health funding. This funding model combined with the lack of agreed definitions disadvantages some populations particularly those populations in geographical areas where palliative care services have been more recently developed.

2.2 Levels of need

The Framework supports an episodic need for specialist palliative care, based on the concept that for many people, the need for palliative care can be appropriately met by their existing primary palliative care provider. Research on levels of patient need identifies three groups of patients, as illustrated in Figure 1 (Palliative Care Australia, 2005). Group A, the largest group, comprises patients whose needs are met through the support of primary palliative care providers and who do not need access to specialist care. Patients in group B may require episodic access to specialist services, but will continue to have their care managed by their primary palliative care provider. The smallest group is group C. The needs of these patients are complex and do not respond to standard palliative clinical practice guidelines. Group C patients are likely to require ongoing care by specialist services.
Randall and Downie (2006) challenge the current growing demand for specialist palliative care services. They argue that specialist palliative care resources must be directed only to those patients whose symptoms cannot be managed by conventional end of life care with the support of specialist advice where necessary.

This supports an episodic need for specialist palliative care, based on the concept that for many people, the need for palliative care can be appropriately met by their existing primary palliative care provider. The Framework uses this levels of patient need approach.

2.3 Integrated care to best meet patient need

There are many situations where people do not receive available services that best meet their needs at the best time in a way that maximises the outcome, including because:

- care is not handed over appropriately between different service providers – accidents occur and there is no overview of the user’s full needs and services
- care information is not transferred in a timely, secure, easily used way, and is gathered many times, often inaccurately. This is inefficient and reduces the quality of service
- people are unaware of the services available to them – important benefits, both stand-alone and synergistic, are foregone
- the locations of services are scattered and difficult to access – beneficial services are omitted which is a loss in itself and undermines the effectiveness of the services received
• services attract different user charges – providing incentives that may direct people away from the service that is most cost-effective for their needs
• service providers operate in isolation from one another – no-one, other than the service-user, is considering the full set of the user’s needs and services.

Integration is considered critical to address these situations with integration being the process of bringing organisations and professionals together, with the aim of improving outcomes for patients and services users through the delivery of integrated care (Fulop et al, 2005).

Integration is a heterogeneous concept, having a number of dimensions and the potential to be advanced in many ways. A useful typology, see figure 2, highlights the different types of integration which can occur: organisational, functional, service and clinical all with the ultimate aim of providing integrated care to patients (Fulop et al, 2005).

**Figure 2: Typology of integration**

![Typology of integration diagram](image)

- Organisational integration, where organisations are brought together formally by mergers or through ‘collectives’ and/or virtually through coordinated provider networks or via contracts between separate organisations brokered by a purchaser.
- Functional integration, where non-clinical support and back-office functions are integrated, such as electronic patient records.
- Service integration, where different clinical services provided are integrated at an organisational level, such as through teams of multidisciplinary professionals.
- Clinical integration, where care by professionals and providers to patients is integrated into a single or coherent process within and/or across professions, such as through use of shared guidelines and protocols.
- Normative integration, where an ethos of shared values and commitment to coordinating work enables trust and collaboration in delivering health care.
- Systemic integration, where there is coherence of rules and policies at all organisational levels. This is sometimes termed an ‘integrated delivery system’.

In addition to the above, integration can occur horizontally at different levels of the system, or vertically, and in real or virtual ways. Horizontal integration is when two or more organisations or services delivering care at a similar level come together. Vertical integration occurs where two or more organisations delivering care at different levels come together such as primary, community and hospital services. Integration is termed real when organisations merge, and virtual when achieved through the establishment of partnerships, networks and alliances. Neither the types nor the dimensions are mutually exclusive and a mix and match approach is often taken.
In palliative care the care remains variable according to location. The suggested barriers to implementation of integrated care include organisational complexity, divisions between general practitioners (GPs) and (specialists), perverse financial incentives and the absence of a single electronic medical record (Ham et al, 2011).
3 The Framework

3.1 Understanding the Framework

The Framework has been agreed through stakeholder consultation and is represented by Figure 3.

Figure 3: Framework for integrated adult palliative care services

The patient and family/whānau are at the centre of the framework, with the primary carer providing the first level of care. In many cases a family member takes this primary role in coordinating and delivering care and support to the patient. The primary carer as a family/whānau member is both a provider and a recipient of care.

Primary palliative care services are the main providers of formal care. They work with an ‘integrated approach’ with secondary care services, specialist palliative care services and other providers of care such as local community hospices, aged residential care facilities and home-based support services. The context of all care is that the patient and family/whānau are members of a community.
Enablers of integrated care include:

- a shared electronic record across formal care providers (with patient consent)
- formalised shared care arrangements, including between specialist palliative care services and general practice teams
- use of care pathways (eg, Liverpool Care of the Dying Pathway) and shared clinical management guidelines
- clarity around roles and responsibilities, underpinned by formal agreements (eg, Memoranda of Understanding)
- education and training for primary palliative care providers, including practice-based education to support a palliative approach.

3.2 Principles underpinning the Framework

The following principles underpin the Framework:

- Patient and family/whānau are the unit of care.
- An integrated system approach is applied to the entire pathway of care.
- Most palliative care services are provided by primary palliative care providers supported by specialist services.
- There is one level of specialist palliative care. This may be provided using a hub and spoke model see the Framework in practice section 4.
- Palliative care services will be provided according to need in a seamless manner, regardless of setting, diagnosis or location.
- A regional planning approach will be implemented, allowing for local flexibility.
- Specialist palliative care services will target their direct care service provision to those patients and families/whānau with the most complex needs that cannot be met, or cannot be met alone by primary palliative care providers.
- Patients will access specialist services through nationally agreed eligibility criteria.
- Specialist palliative care support will be accessible 24 hours a day, 7 days a week (24/7).
- A national standards and accreditation programme is adopted for palliative care across settings and providers.
- Enablers, including a shared electronic record for patients, are supported and formalised partnership agreements detailing roles and responsibilities are in place.
3.3 The Framework and integrated care

The best practice model for integrated palliative care has been identified as including universality, care coordination, assured access to a broad range of basic and advanced end of life services and end of life care regardless of setting (Canadian Hospice Palliative Care Association 2010). The Canadian Hospice Palliative Care Association proposes an integrated systems approach to improve access to high-quality hospice, palliative and end of life care regardless of setting. It argues that best practice, which includes common assessment tools, collaborative care plans, interdisciplinary teams, consistent care across settings and support for family caregivers, has been proven to improve patient and family satisfaction and reduce health care costs.

Figure 4 – Hub and Spoke model for integrated care

3.4 The Framework capability matrix

Specialist palliative care services

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<tr>
<td>Specialist palliative care – hub</td>
<td>Capability</td>
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| Services provided               | • Provides services, including physical, psychological, social and spiritual care for patients, including patients in aged residential care facilities, and family/whānau where assessed needs exceed the capability of the primary palliative care providers (specialist care may be episodic, shared or ongoing for a small group of patients)  
• Provides specialist assessment of patient and family/whānau  
• Provides consultation services and support to primary palliative care providers – on an ‘in-reach’ basis to hospital-based staff and an ‘outreach’ basis to community-based services  
• Provides or has access to dedicated inpatient palliative care beds  
• Provides symptom management of complex unstable medical conditions  
• Provides management for complex grief, social and spiritual problems  
• Provides 24/7 telephone advice and support  
• Supports the implementation of an end of life care pathway  
• Provides consultation for services outside the district through formalised network arrangements  
• Participates in advance care planning |
| Geographical coverage           | • District and regional |
| Indicative staffing profile     | • Comprehensive interdisciplinary team which may be ‘virtual’ rather than employed by a single agency  
• Medical specialist(s) with specialist qualifications in palliative medicine (Fellow of Chapter of Palliative Medicine)  
• Medical practitioners with specialist qualifications in palliative medicine  
• Specialist nursing (may include nurse practitioner, clinical nurse specialist) with a postgraduate certificate in palliative care as the minimum qualification  
• Specialist allied health staff (eg, occupational therapist, social worker, physiotherapist, pharmacist, speech language therapist) with specific training (or perhaps postgraduate qualifications) in palliative care  
• Psychosocial staff (eg, psychologist, psychotherapist, counsellor) with specific training (or perhaps postgraduate qualifications) in palliative care  
• Cultural advisors with specific training and experience in palliative care  
• Spiritual advisors with specific training and experience in palliative care. |
| Service linkages                | • Formal linkages with primary palliative care providers (eg, primary health organisations, aged care facilities)  
• Formal linkages with “spoke” specialist palliative care services  
• Formal linkages with other tertiary/secondary services or specialties (eg, pain service)  
• Formal linkages with regional clinical networks |
| Education/training             | • Participates in undergraduate and postgraduate teaching  
• Provides education about a palliative approach and formal training programmes for health professionals across a range of settings  
• Has capability for registrar or general practitioner with special interest (GPSI) training  
• May have formal links with academic units |
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<th>Specialist palliative care – hub</th>
<th>Capability</th>
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| Infrastructure                  | • Access to telehealth facilities  
• Access to equipment loan  
• Shared electronic record |
| Performance improvement         | • Leads research and quality activities at regional level  
• Assesses against national standards  
• Participates in benchmarking and continuous quality improvement |

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<th>Specialist palliative care – spoke</th>
<th>Capability</th>
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| Services provided                 | • Manages palliative care patients in the community and local community hospices with non-complex needs  
• Provides access to support and services where assessed needs exceed the resources of the primary palliative care provider  
• Provides 24/7 on-call coverage through a regional service (hub)  
• Participates in advance care planning |
| Geographical coverage             | • Local |
| Staffing profile                  | • Medical practitioners with specialist qualifications in palliative medicine (eg, GP with a special interest in palliative care)  
• Nursing staff with a postgraduate certificate in palliative care  
• Facilitates access to other palliative care services including allied health, psychological, social, cultural and spiritual care |
| Service linkages                  | • Formal agreements, linkages and referral arrangements with primary palliative care providers of hub specialist palliative care services |
| Education/training                | • Provides formal training and clinical practice teaching sessions for local primary palliative care providers |
| Performance improvement           | • Assesses against national standards  
• Participates in benchmarking and data collection |
| Infrastructure                    | • Shared electronic record  
• Access to inpatient beds  
• Access to telehealth facilities  
• Access to equipment loan |
Primary palliative care providers

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<th>Primary palliative care providers delivering a palliative approach to all end of life patients</th>
<th>Capability</th>
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| Services provided                                                                         | • Delivers a palliative approach to patients at end of life, supported by specialist palliative care services as required  
  • Participates in advance care planning  
  • Performs a care coordination/key worker function                                           |
| Geographical coverage                                                                    | • Local    |
| Staffing profile                                                                         | • Health care professionals or health care providers who are not part of a specialist palliative care team (see the glossary for a definition of primary palliative care provider) |
| Service linkages                                                                         | • Formal linkages with specialist palliative care services  
  • Consultation with specialist palliative care services when standard guidelines do not meet patient and family/whânau needs  
  • Awareness of services available                                                        |
| Education/training                                                                       | • Participates in palliative care education programmes provided by specialist palliative care services |
| Performance improvement                                                                  | • Self assesses against national standards  
  • Runs accreditation programmes as applicable                                                 |
| Infrastructure                                                                           | • Shared electronic record  
  • Access to telehealth facilities  
  • Access to equipment loan                                                                |
4 The Framework in Practice

4.1 Introduction

Given New Zealand’s small population and the limited size of its specialist palliative care workforce, the Framework recommends one level of specialist palliative care service. The notion of partnership and integration underpins the Framework to enable the use of existing resources within a region where expertise is not available from a single provider. The partnership also includes the primary palliative care providers, as they provide palliative care for most of the population. This partnership approach is referred to in the framework as hub and spoke.

A hub and spoke approach is generally understood to describe an arrangement where one site (the hub) acts as a base that provides services to support satellite sites (the spokes). Arrangements can vary to suit the configuration of the organisations involved and the types of services being provided. In rural areas, this model provides an identifiable local presence and facilitates access to services that would otherwise be difficult to achieve. The Framework requires specialist palliative care services to collaborate with virtual teams comprised of professionals from a variety of providers to maximise access to specialist resource on the basis of need. For example, hospital palliative care teams do not currently have ready access to grief and loss services but could access these through hospice services, and on-call palliative medicine specialist rosters could be shared between the hospice and the hospital specialist providers. Spoke services are not specialist services in their own right, but gain the specialist level of service through accessing hub services.

The following case studies demonstrate the hub and spoke approach in practice but there are a range of ways to configure and resource specialist palliative care services to meet local population need sustainably.

Local refers to the community in which the patient lives. District refers to a District Health Board (DHB) catchment and region indicates responsibility beyond the DHB to a regional grouping which may be defined by regional DHB groupings, regional cancer network groupings or regional palliative care managed clinical networks as recommended in the Palliative Care Workforce Service Review (Health Workforce New Zealand 2011).
4.2 A regional service supporting a district service: West Coast

This case study describes how a regional service (hub) supports a district service (spoke) in a neighbouring, smaller DHB see figure 4. The local service does not meet the capability requirements to be a stand-alone specialist service, however with the support from the regional hub the smaller spoke can provide their population with access to the full range of specialist services. The regional service may be delivered by a specialist hospice team or a hospital specialist team, or by a partnership between the two providers.

Figure 5: Regional service supporting a district service

The West Coast district covered by the West Coast DHB is provided with palliative care services via a palliative care team comprised of 2.0 full-time equivalent (FTE) palliative care clinical nurse specialists (backed up by a clinical nurse specialist – oncology) who works in partnership with general practice teams, district nurses, allied health staff and aged residential care providers. Access to specialist medical palliative care is provided through a formalised arrangement with Nurse Maude Hospice, Canterbury DHB. A palliative medicine specialist visits every two months depending on demand, and a fortnightly audio-conference is scheduled to provide support. After-hours specialist advice and support are accessed via the on-call service covering Canterbury DHB which is shared between Nurse Maude Hospice and the Canterbury DHB Hospital Palliative Care Service.

The palliative care clinical nurse specialist is a registered nurse working at an advanced level, who has undertaken relevant postgraduate study. The palliative care clinical nurse specialist also leads the implementation of the Liverpool Care of the Dying Pathway. A second role is the coordination of local palliative care education and support, which includes arranging for the palliative medicine specialist to deliver education sessions to staff as required.
There is no hospice facility on the West Coast. Care outside the West Coast DHB’s hospital facilities is available with aged residential care providers where clinically appropriate and, less often, individual packages of ‘hospice-in-the-home’ care. In addition, the Buller West Coast Home Hospice Trust raises charitable funds to support people with palliative care need through equipment loans, sponsoring health professional training, and by making charitable contributions to ‘hospice-in-the-home’ and family support.

The integrated palliative care service is governed by the West Coast DHB’s local cancer network.

4.3 A local service providing local community and local hospital palliative care services: Southland

Figure 6: Local service providing local community and local hospital palliative care services

In this case study, a local service provides community and hospital palliative care services for the population of Southland and Wakatipu in partnership with a local hospital palliative care service of limited capacity see Figure 5.

Hospice Southland (hub) provides the specialist palliative care service for the population of Southland and Wakatipu. Hospice Southland uses formalised criteria to ensure specialist services are targeted to those patients and family/whānau with more complex needs rather than those whose needs can be met by primary palliative care providers. Hospice Southland strives to ensure equity of access to palliative care regardless of the bed a patient is in.
Hospice Southland employs two palliative medicine specialists who have responsibilities across the local hospice inpatient unit, local outpatient services, and local community outreach services, Southland hospital and the provision of education locally. Medical staff are supported by other dedicated medical officers working in the hospice inpatient unit and outpatient services. The hospice community team includes nurses who have a coordination role, working in collaboration with general practice teams and district nurses who provide hands-on care. The hospice also employs spiritual and bereavement support workers, and has access to allied health services from Southland hospital. One nurse works with the rest homes, and is also the Liverpool Care of the Dying Pathway facilitator/educator.

Hospice Southland has a formal palliative care education team led by the medical director, with other members including the nursing director, spiritual support worker, Liverpool Care Pathway facilitator and in-service education coordinator. Lunchtime education sessions are provided once a month and targeted to doctors and other health professionals at the local hospital. There is also a broader approach to education for general practice teams, focused on topics that general practices identify they would like covered. Monthly sessions are delivered around the Southland and Wakatipu communities.

The local hospital palliative care service located at Southland hospital (spoke) works in partnership with Hospice Southland. The local hospital palliative care service employs a clinical nurse specialist who has postgraduate qualifications in palliative care and is based at the hospice. A Memorandum of Understanding between the hospice and the hospital outlines roles, responsibilities and linkages. The clinical nurse specialist works closely with the hospice team, attending the daily hospice clinical meeting, and also works with a variety of teams at the hospital, including the intensive care unit and the emergency department. The clinical nurse specialist sees patients on a consultancy basis assessing need; not all patients require referral to the hospice service.

Linkages are also maintained across Southern DHB, including Otago. Southern DHB’s palliative care contract manager manages contracts for Hospice Southland and Otago Community Hospice. The two hospices are also in the process of developing a project to identify how they will collaborate to use resources most effectively. A number of Hospice Southland personnel were also involved in the establishment of the Southland palliative care network and continue to be members, co-chairing the network meetings.
4.4 A district service providing local community and district hospital palliative care services and support to other local community palliative care services: Northland

Figure 7: District service providing local community and district hospital palliative care services, and support to other local community palliative care services

This case study illustrates a district service providing local community and district hospital palliative care services, and providing support to other local community palliative care services district-wide, including the relationships with primary palliative care providers.

Northland DHB has pioneered the hub and spoke approach to improve access to specialist palliative care services, and support primary palliative care providers. There are four hospices in the Northland DHB area, each with individual contracts, independent governance boards and different service delivery models based on historical classification of hospice services. North Haven Hospice (hub), located in Whangarei, provides district-wide services alongside services to the local population. The district services include district-wide specialist multidisciplinary clinical resource, service development, specialist inpatient beds, palliative medicine specialist role, education and advisory service and the hospital liaison team (initially at Whangarei hospital, and now also at Kaitaia and Bay of Islands hospitals). The spokes (Hospice Kaipara, Hospice Mid North and the Far North Community Hospice) are led by nurses with postgraduate palliative care qualifications who work with the wider multidisciplinary team including district nurses, aged residential care facilities, general practitioners, iwi providers and other community-based health and support services.
North Haven Hospice also works in partnership with three other hospices in the district. This partnership is based on shared principles rather than contracts or formal agreements. The principles include a commitment to deliver specialist palliative care locally to a consistent standard, an emphasis on partnership, integration and support, and the consistent involvement of a multidisciplinary team. A general practitioner with a special interest role is supported in the Far North and continues to be the future workforce development focus area. A shared patient management system to support integrated care has also been implemented. This is used by specialist palliative care services, general practitioners and secondary services.

The district-wide approach is focused on increasing the capacity and capability across palliative care services, particularly in the primary palliative care provider sector. To facilitate access to specialist services, there is a ‘wide gate’ for referrals, along with a regular review of service users to check that the service continues to be appropriate as needs change over time. An end of life pathway such as the Liverpool Care of the Dying Pathway has not yet been implemented but has been prioritised in the prospective Northland Health Services Plan.

Northland DHB has initiated discussions to further develop the hub and spoke model of specialist palliative care services to ensure the model meets the future population needs. Topics for discussion include how these services might be delivered using different workforce inputs, how resourcing and contracting mechanisms could change, and how to network with the greater Auckland region.

4.5 A unified regional service delivered by combining district community and hospital palliative care services

This case study involves a unified regional service delivered through a specialist hospital–specialist hospice hub integrating services in two DHBs.

Two DHBs, each with a large metropolitan centre, are investigating sharing specialist palliative medicine resource across the specialist hospital and the specialist hospice palliative care services in their districts. As part of this proposal, the palliative medicine specialists would be employed by a single employer.

This arrangement would involve a single clinical director working across both districts. The intention is to enable more effective and coordinated use of scarce resources across both organisations, and a combined approach to planning that considers the resources required to meet the needs of the combined population. The anticipated governance structure will include representation from both DHBs.

An integrated hub would be responsible for delivering care to those requiring a range of specialist palliative care services, and providing regional education and support to primary palliative care providers across the two districts. With an integrated hub, patients and families/whānau would have access to a wider interdisciplinary team, including allied health services and bereavement support services, which is not always possible at present.
4.6 A dedicated primary palliative care service for poor access areas: Thames and Coromandel

In this case study a dedicated primary palliative care service for poor access areas, the Oranga Wairua Care Coordination Service, provides a kaupapa Māori approach to the provision of primary palliative care. The service is supported by a district specialist service and is integrated with local primary care services.

Iwi health care organisation Te Korowai Hauora o Hauraki is in the middle of a three-year pilot funded by the Ministry of Health’s Māori Health Innovation Fund to provide local community-based mobile palliative care support services for Hauraki family/whānau in Thames and Coromandel. The service provides a whānau-centred approach focused on whānau decision-making and empowerment to improve service coordination and communication among family/whānau and service providers.

Health professionals or family/whānau members can refer a family/whānau member facing a life-limiting illness to the service. The Oranga Wairua Care Coordination Service is a primary palliative care provider, and linkages are in place with other local primary palliative care providers (eg, general practice teams, district nurses and home-based support workers) and with the district hospital specialist palliative care service at Waikato DHB to provide access to specialist services.

The service complements existing local services by addressing issues such as late diagnosis, communication gaps, rural isolation, financial hardship and transportation difficulties. The Oranga Wairua team is comprised of two nurses, a social worker and a kaiāwhina. The team assess and plan care with the whānau, provide information and support in decision-making and provide liaison with other services as required. Additional services offered are rongoā (Māori natural medicine), mirimiri (Māori massage) and tohunga (Māori spiritual healer). Clients may also request karakia (prayer) from a kaumātua. These additional services make the service unique and predominantly for Māori, although 20 percent of clients are Pākehā.

The service also provides clinical equipment, such as hospital beds, commodes, walking frames and bath rails, when clients cannot access these from other services. There is a limited budget allocated per client, which can be used for pillows, sheets and household provisions as individual circumstances require. Post bereavement counselling and ongoing support is provided when needed.

The Oranga Wairua Care Coordination Service has successfully assisted the dying person to remain at home with their whānau, when this may not otherwise have been possible through existing mechanisms. The pilot will be formally evaluated in 2012.
5 Recommendations

The Framework’s key recommendations are that:

- **the palliative care sector:**
  - adopt the Framework
  - take into account regional palliative care need during service planning
  - adopt a national standards and accreditation programme for palliative care across settings and providers
  - adopt national guidelines for evidence-based symptom management to reduce duplication and resources required for review
  - implement established, evidence based care pathways (eg, Liverpool Care of the Dying Pathway)

- **District Health Boards:**
  - adopt the Framework
  - move to funding that incentivises effective palliative care outcomes rather than a historical basis
  - take into account population palliative care need during regional clinical service planning
  - use the Framework to inform planning and strategic development of palliative care services
  - implement care pathways (eg, Liverpool Care of the Dying Pathway)

- **the Ministry of Health:**
  - defines the core palliative care services to be funded by Vote Health
  - change funding models to incentivise effective palliative care outcomes
  - establish an expert clinical short-term working group to develop and adopt national eligibility criteria for access to specialist palliative care services
  - establish an expert clinical short-term working group to develop a common national assessment tool to be used for referrals for specialist palliative care services

- **Health Workforce New Zealand:**
  - develop a consistent understanding and definition of non-regulated advanced nursing roles (eg, clinical nurse specialist)

- **the universities and education providers:**
  - develop qualifications appropriate for the allied health workforce to maximise the potential for the discipline-specific skills they bring to the provision of palliative care services
  - develop e-learning opportunities that will enable staff who live outside of main centres to access training and qualifications
  - establish a national palliative care education and research hub to lead and support education and research in New Zealand.

These recommendations are to be considered in light of current available resources and funding.
5.1 Suggested approach to implementation

Implementation of the Framework has implications for existing service configuration and service development planning, including:

- review and influence the way both primary palliative care and specialist providers complete strategic development to include an integrated model
- promote the development of collaborative linkages between primary palliative care providers and specialist providers
- develop agreed referral and assessment protocols to meet populations palliative care need
- determine workforce configuration
- consider service development for local, district, regional and national levels.

The Framework emphasises the role of primary care providers and specialist palliative care services to ensure sustainable and comprehensive health care that meets population need. The Framework recommends that patient access to primary palliative care and specialist services is based on assessed need rather than on diagnosis or locality. This means there will be a likely increase in the acuity of patients seen by specialist palliative care services, with primary palliative care providers caring for less complex patients.

Comprehensive resource material, such as palliative care guidelines, will need to be developed to support primary care providers including general nursing services, general practitioners, aged residential care facilities and acute hospitals. Many resources have already been developed, and could be shared nationally.

Development of the Framework is not intended to be a cost-shifting exercise. It is anticipated that when this Framework is implemented in full, all those with palliative care needs will have access to an appropriate level of care.

Involving users in the development of health services is one way of ensuring that the needs of the patient and family/whānau are understood, and that services are developed to include their perspective. Involving users is also an opportunity to treat patients and carers as stakeholders in the service. They can make an important contribution to service planning and decision-making and help keep the service patient-and family/whānau-centred. A toolkit to involve users in the design of health services sponsored by the Ministry of Health, is available at www.healthcodesign.org.nz
6 Glossary

Sourced from the New Zealand Palliative Care Glossary, unpublished.

**Advance Care Planning (ACP)**

Advance Care Planning (ACP) is a process of discussion and shared planning for future health care. It is focused on the individual and involves both the person and the health care professionals responsible for their care. It may also involve the person’s family/whānau and/or carers if that is the person’s wish. ACP provides individuals with the opportunity to develop and express their preferences for care informed not only by their personal beliefs and values but also by an understanding of their current and anticipated future health status and the treatment and care options available.

**Chronic condition**

A biological or physical condition where the natural evolution of the condition can significantly impact on a person’s overall quality of life, including an irreversible inability to perform basic physical and social functions. Serious and persistent chronic conditions are multidimensional, interdependent, complex and ongoing. Chronic conditions are characterised by persistent and recurring health consequences lasting for three months or more.

**End-of-life care**

End-of-life care is the provision of supportive and palliative care in response to the assessed needs of the patient and family/whanau during the end of life phase. It focuses on preparing for an anticipated death and managing the end stage of a life-limiting or life-threatening condition. This includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both the person and the family/whanau 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 and support for the family.

**Family**

A family is defined as those who are closest to the patient in knowledge, care and affection. The family may include the biological family, the family of acquisition (related by marriage/contract), and the family of choice and friends (including pets). See also Whanau.

**Primary palliative care (generalist)**

Primary palliative care is provided by all individuals and organisations that deliver palliative care as a component of their service, but their substantive work is not in the care of people who are dying. It is palliative care provided for those affected by a life-limiting or life-threatening condition as an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team.
In the context of end of life care, a primary palliative care provider is the principal medical, nursing or allied health professional who undertakes an ongoing role in the care of patients with a life-limiting or life-threatening condition. A primary palliative care provider may have a broad health focus or be specialised in a particular field of medicine. It is provided in the community by general practice teams, Māori health providers, allied health teams, district nurses, and residential care staff etc. It is provided in hospitals by general ward staff, as well as disease specific teams – for instance oncology, respiratory, renal and cardiac teams.

Primary palliative care providers assess and refer patients to specialist palliative care services when the patient’s needs exceed their services capability.

Quality care at the end of life is realised when strong networks exist between specialist palliative care providers, primary palliative care providers, support care providers and the community – working together to meet the needs of all people.

Note: this terminology is in a transitional phase, moving from the term ‘Generalist Palliative Care’ to ‘Primary Palliative Care’. Only the term primary palliative care is used in the Framework.

Hospice

Hospice is not only a building; it is a philosophy of care. The goal of hospice care is to help people with life-limiting and life-threatening conditions make the most of their lives by providing high quality palliative and supportive care.

Hospices provide care for the whole person, not just their physical needs but also their emotional, spiritual, and social needs. They also care for families and friends, both before and after a death. Irrespective of where a hospice service is, this philosophy of care does not change. In New Zealand all aspects of hospice care are provided free of charge.

Interdisciplinary team

A group of individuals with diverse training and backgrounds who work together as an identified unit or system. Team members consistently collaborate to solve problems that are too complex to be solved by one discipline or many disciplines in sequence.

Membership varies depending on the services required to identify and address the expectations and needs of the patient, caregiver and family. A palliative care interdisciplinary team typically includes one or more doctors, nurse, social workers, spiritual advisers, pharmacists and personal care workers. Other disciplines will be part of the team as resources permit.

Primary carer

The primary carer is generally in the close kin network of the patient and is usually self identified. The primary carer can be the patient’s spouse, child, another relative, family member or friend. They may be supported by other careers, but generally will take a primary role in the co-ordination and delivery of care and support to the patient. This person provides for the practical needs of the patient and takes on additional tasks that may be of a technical nature, to provide ongoing care for the patient, eg, the administration of medications. They provide the primary support role for the patient at all levels of need.
Specialist palliative care

Is palliative care provided by those who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals. Specialist palliative care may be provided by hospice or hospital based palliative care services where patients have access to at least medical and nursing palliative care specialists.

Specialist palliative care will be provided through accredited services (or organisations) that work exclusively in palliative care and meet specific palliative care standards as they are developed nationally. Specialist palliative care practice builds on the palliative care provided by generalist providers and reflects a higher level of expertise in complex symptom management, psychosocial support, grief and bereavement. Specialist palliative care provision works in two ways:

1. Directly – to provide direct management and support of patients and families/whānau where more complex palliative care need exceeds the resources of the generalist provider. Specialist palliative care involvement with any patient and the family/whānau can be continuous or episodic depending on the changing need. Complex need in this context is defined as a level of need that exceeds the resources of the generalist team – this may be in any of the domains of care – physical, psychological, spiritual, etc.

2. Indirectly – to provide advice, support, education and training of other health professionals and volunteers to support the generalist provision of palliative care provision.

Standards

A standard is something established as a measure or model to which other similar things should conform. For example: the Hospice New Zealand Standards set out best practice in relation to the provision of end of life care in hospice. They identify the essential elements that need to be in place to ensure consistent quality end of life care in hospices. They identify the essential elements that need to be in place to ensure consistent quality end of life care across the hospice sector.

Whānau

Whānau means the extended family, family group, a familiar term of address to a number of people – in the modern context the term is sometimes used to include friends who may not have any kinship ties to other members.
7 References


8 Appendices

8.1 Project methodology

A working draft of the Framework was developed using the role delineation model published by Palliative Care Australia (2005) and the differentiation of services published in the Independent Palliative Care Funding Review (Hughes-Hallet et al 2011).

The draft Framework was presented to three key stakeholder groups (DHB General Managers Planning and Funding; DHB Chief Operating Officers; and a joint meeting of the Palliative Care Advisory Group and the Palliative Care Council) and sent to Hospice New Zealand seeking initial thoughts and feedback prior to wider consultation. The consultation process was endorsed through these discussions.

The Framework was then presented, by invitation, at a number of forums around the country including cancer and palliative care network meetings, individual hospice meetings and DHB meetings. Feedback was also sought from health professional groups with an interest in palliative care and from consumer groups.

A questionnaire was widely distributed in August 2011 to capture feedback on the draft Framework and understand the sectors views on issues including qualifications, eligibility criteria for specialist services and team composition. A response rate was not calculated as the distribution process encouraged the questionnaire to be circulated to all interested groups and individuals.

In November 2011 the Ministry of Health hosted a workshop to consult with representatives from key organisations / groups the palliative care sector on selected findings from the questionnaire. The purpose was to agree an approach to issues where the questionnaire responses demonstrated a lack of consensus. The outcome of the workshop was a framework that reflects the New Zealand context. This Framework is presented in this document for final consultation and feedback.

8.2 Linkages with other national palliative care projects

The following projects have been recently undertaken:

- **Development of Specialist Palliative Care Service Specifications (2005–2010).**
  Draft specialist palliative care service specifications were developed, with significant sector input into the drafts presented for consultation in 2008 and 2010. The consultation feedback in 2012 identified the need to complete further service development work (including the development and finalisation of this framework) before the specialist palliative care service specifications are submitted for final approval.
• **Gap Analysis of Specialist Palliative Care Services in New Zealand (Ministry of Health 2009).**
  The purpose of the national gap analysis was to determine how close self-identified specialist palliative care hospice and hospital providers were to meeting the service components identified in the 2008 draft service specification for specialist palliative care. The national gap analysis confirmed the anecdotal evidence that the structure, resourcing and provision of hospice and other self-identified specialist palliative care providers varies considerably at both local and regional levels. The variability is understandable given that historically in New Zealand many services were developed in response to local need and available resources in an effort to provide local access to palliative care services. The gap analysis identified opportunities at both local and regional levels for sharing resources between services, such as between the hospice and the hospital-based palliative care service in the same region. Such initiatives would increase the level of access to specialist palliative care for patients, families and whānau, particularly access to grief, loss and bereavement support services.

• **Positioning Palliative Care in New Zealand (Palliative Care Council 2010).**
  The purpose of positioning palliative care document was to review of strategic health documents across the New Zealand health system to establish the presence of palliative care in these documents, and to compare this with government health policy from the United Kingdom, Australia and Canada. It identified a relatively poor presence of, or articulation of the need for, palliative care in the selected government health strategies. In response to this finding, the document recommended the need to undertake following actions: address service gaps, review the New Zealand Palliative Care Strategy, raise awareness of palliative care and incorporate it fully into overarching health policy and chronic disease strategies.

• **National Palliative Care Health Needs Assessment Phase 1 Report: Assessment of Palliative Care Need (2011).**
  The purpose of the health needs assessment was to establish the number of people who might benefit from palliative care in New Zealand on both a national and regional basis, and to project likely future need. The assessment uses New Zealand population demographic data, including DHB populations and projections by age and ethnicity. Further work is underway to assess what services are required to meet the identified need and determine how the level required compares with current service provision.

• **Palliative Care Workforce Service Review (Health Workforce New Zealand 2011).**
  The purpose of the workforce service review was to develop a vision and model of palliative care service and workforce for 2020 in a context of increasing demand and limited funding. The workforce service review proposed the development of eight managed clinical networks that are linked nationally to manage palliative care in New Zealand. It also recommended the development of a funding model for primary care services to provide community palliative care. Further recommendations focused on the use of advanced nursing roles and development of the roles of allied health professionals.
8.3 Stakeholders consulted

District health boards – Planning and Funding  
District health boards – provider arm  
Hospice New Zealand  
Palliative Care Council  
Hospital Palliative Care New Zealand  
Primary health organisations  
College of General Practitioners  
Regional cancer networks  
Australian and New Zealand Society of Palliative Medicine Inc  
Palliative Care Nurses New Zealand  
New Zealand Nurses Organisation  
College of Nurses Aotearoa  
Allied health directors of district health board  
New Zealand Aged Care Association  
Bupa Care Services  
Metlifecare  
Oceania Group  
Presbyterian Support National Office  
Ryman Healthcare  
Summerset  
National Council of Women  
Māori Women’s Welfare League  
Grey Power  
Age Concern  
Cancer Voices

8.4 Selected literature review

A limited literature review was undertaken focusing on differentiating levels of care.

Australia

In 2005 Palliative Care Australia published *A Guide to Palliative Care Service Development: A population approach* which set out a service planning framework based on role delineation to outline the relationship between specialist and primary care services. Role delineation provides a consistent and common language to describe and differentiate health care services in terms of their complexity. The guide described three levels of specialist palliative care services in terms of their resources, capability and linkages. It defined primary care services as services whose substantive work was not in palliative care, matching the New Zealand definition of generalist palliative care. The Australian guide identified which of the three levels of specialist palliative care would work together with primary care providers to deliver services, based on the need across designated populations as established by population size (eg, small towns, metropolitan centres).
Each state has subsequently developed its own role delineation model or resource and capability framework as a component of planning for the delivery of palliative care services. The following are some examples of these initiatives.

- New South Wales (Department of Health, NSW 2007) has adopted three levels of specialist palliative care. Three identified components of its model are: the relationships and roles of primary care services and specialist care providers; the classification of specialist palliative care services into three levels in terms of resources and capability; and access to community support services required by both primary and specialist services.

- Western Australia (Department of Health, WA 2005) has mapped the levels described in the Palliative Care Australia framework against the six levels of the Western Australian Health Clinical Services Framework and is in the process of implementing a new model of palliative care.

- Tasmania (Department of Health and Human Services, TAS 2008) has adopted a service delivery model with four levels of care – two primary and two specialist. The roles and responsibilities for primary and specialist providers are defined at each level.

- Most recently the state of Victoria (Department of Health, VIC 2011) has adopted a palliative care service capability framework which includes three types of services (inpatient, community and consultancy) and three levels of inpatient categories – two levels of community-based services and one level of consultancy. Each of the inpatient categories is mapped against seven dimensions that measure and describe capability.

**United Kingdom**

The National Institute for Clinical Excellence manual *Improving Supportive and Palliative Care for Cancer* (2004) differentiates general and specialist palliative care services. It notes many services specialise in providing palliative care services but are not full specialist palliative care services because the focus of their care is not on complex problems. The recent palliative care funding review (Hughes-Hallet et al 2011) differentiated the elements of dedicated palliative care as specialist palliative care services (delivered by specialist providers), core palliative care services (delivered by people whose primary focus is palliative care) and universal palliative care services delivered by generalists.