

# **Gap Analysis of Specialist Palliative Care in New Zealand**

Providing a national overview of  
hospice and hospital-based services

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## Definitions

The following definitions are drawn from the draft service specification for specialist palliative care.

### Specialist palliative care

Specialist palliative care is palliative care provided by those who have undergone specific training and/or accreditation in palliative care or medicine, and who are working in the context of an expert interdisciplinary team of palliative care health professionals. Specialist palliative care may be provided by hospices (community), hospital-based palliative care services, or paediatric specialist palliative care teams.

Specialist palliative care will increasingly be provided through services that meet standards developed nationally and that work exclusively in palliative care. Specialist palliative care practice builds on the palliative care provided by generalist providers and reflects a higher level of expertise in complex symptom management, spiritual support, psychosocial support, cultural support, and grief and loss support. Specialist palliative care provision works in two ways.

1. It works directly by providing direct management and support to people, their families and whānau where complex palliative care need exceeds the resources of the generalist provider. The involvement of specialist palliative care with any person and their family and whānau can be continuous or episodic depending on their assessed changing need. Complex need in this context is defined as a level of need that exceeds the resources of the generalist team: this may apply in any of the domains of care – physical, psychosocial, spiritual or cultural, for example.
2. It works indirectly by providing advice, support, education and training to other health professionals and volunteers to support their generalist provision of palliative care.

### Generalist palliative care

Generalist palliative care is palliative care provided for those affected by life-limiting illness as an integral part of standard clinical practice by any health care professional who is not part of a specialist palliative care team. It is provided in the community by general practice teams, Māori and Pacific health providers, allied health teams, district nurses, residential care staff, community support services, and community paediatric teams. It is provided in hospitals by general adult and paediatric medical and surgical teams, as well as disease specific teams – for instance, oncology, respiratory, renal, intensive care and cardiac teams.

Some of these generalist providers, such as general practice teams, will have ongoing contact with a family throughout and following illness. Others, such as district nurses and hospital teams, will have episodic contact, depending on the needs of the person and their family and whānau.

Providers of generalist palliative care will have defined links with specialist palliative care team(s) for the purposes of support and advice, or in order to refer people with complex needs. They will also have access to palliative care education and learning to support their practice.

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# Executive Summary

Between January and June 2009 the Ministry of Health undertook a national stocktake or gap analysis to determine how close hospice and hospital providers of specialist palliative care services were to meeting the new draft service specification for specialist palliative care.

This Phase 1 report provides an overview of the current provision of specialist palliative care in New Zealand and highlights gaps against the draft service specification. The second phase of the project is to develop a costing model for specialist palliative care. This costing analysis is not presented in this report.

To obtain the data for this report, questionnaire templates for hospices and hospital providers of palliative care were developed in consultation with several palliative care personnel. The questionnaires were piloted before being rolled out nationally.

## Main findings

The main findings with identified gaps are summarised below. This gap analysis confirmed the anecdotal evidence that there are wide variations in the provision of hospice and other specialist palliative care at both local and regional levels. Hospital services particularly are generally limited to nursing and medical services only. There are opportunities for sharing resources between services, such as between the hospice and the hospital-based palliative care service in the same region, to increase the level of access to specialist palliative care, particularly in terms of support for grief, loss and bereavement, for patients, families and whānau.

## Workforce

Many of the gaps identified in this report are linked to workforce shortages. Some of these shortages relate to a national shortage of suitability trained staff (eg, medical specialists and nurses) and others to a lack of funding for a particular role (eg, end of life care co-ordinators).

Recruitment and retention of palliative care medical specialists is one of the biggest – if not the biggest – workforce issue for both hospices and hospitals. It is influenced by a shortage of suitability trained personnel and difficulties with providing competitive remuneration. For similar reasons a shortage of nurses with palliative care training is another key issue. Poor pay parity with multi-employer collective agreement (MECA) rates also makes it more difficult for hospices to recruit medical and nursing staff.

Other factors adding to the demand for palliative care medical specialists and nurses are: the opening of several new inpatient units; the requirements of the new tier two service specification regarding education and 24-hour, seven days a week (24/7) support; the growing and ageing population; increasing life expectancy; longer palliative survival; and patients with higher acuity and multiple co-morbidities leading to more complex symptom management. A shortage of palliative care medical specialists and nurses will affect the capacity of services to deliver key components of the new specialist service specification.

In addition, there is a lack of administrative support available to hospital-based palliative care teams. Amongst other consequences, such a shortfall exacerbates gaps around auditable response times and reporting requirements.

Palliative care teams within hospices are more multidisciplinary in their approach to care than hospital-based palliative care teams. The lack of a multidisciplinary approach in hospitals is a recognised gap that in turn results in gaps in delivery of components of the service specification, for example grief and loss support. There is an opportunity to work across the local area or region to ensure these services are provided to patients and their family and whānau.

Education and training, particularly programmes to upskill the available workforce, are key enablers to address workforce issues.

### **End of life care programmes**

Across New Zealand, hospices and hospitals are at different stages with regard to the implementation of end of life care programmes. The Liverpool Care of the Dying Pathway (LCP) is the end of life programme that is most commonly applied, with national LCP's support functions funded by the Ministry of Health. Some providers have rolled out LCP within their own organisation and into the community, others are at the pilot phase, and still more are waiting for funding; some are yet to determine their approach. No other end of life programmes have been introduced in New Zealand. Therefore the size of the gap in relation to end of life care programmes is variable.

### **Grief and loss support**

All but one hospice appear to be equipped to meet the grief and loss support requirements of the draft service specification. Most (62%) employ or have access to trained staff, or both. Of these, 93% offer one-to-one follow-up grief and loss counselling and support to bereaved families and whānau.

Provision of grief and loss support represents a much greater gap for hospital-based palliative care services: only three of the eleven services provide such support after death to family and whānau of a patient. Fewer hospital-based palliative care services have dedicated bereavement resources. There may be an opportunity for hospital-based palliative care services to consider formalising links with a local hospice, and referring bereaved families and whānau to the hospice for follow-up grief and loss support. This approach is utilised on an ad hoc basis by one hospital-based palliative care service.

### **Education**

Hospices appear well placed to deliver the education component of the draft service specification. Most (60%) have dedicated education staff, with one introducing the role during 2009. Many are looking at expanding the scope of education available to generalists.

Hospital-based palliative care teams currently do not have dedicated education staff and education is predominantly provided by the clinical staff. Often there are not enough resources to both attend to clinical demands and address the ongoing education needs of generalists.

There is an opportunity for greater collaboration between hospices and hospital-based palliative care services in providing education. Given that many hospices already deliver this component well, it seems feasible to share resources locally and establish a local education lead in palliative care. Further, there is an opportunity to share information nationally. The Hospice New Zealand education courses are those most commonly used in the sector, such that if Hospice New Zealand develops nationally consistent education courses for a wider audience, it will bring significant benefits to all specialist palliative care providers.

The transitioning nature of the generalist workforce poses challenges for both types of palliative care providers.

### **24-hour support**

Provision of 24-hour, seven days a week specialist telephone advice to generalists is of a greater concern for hospital-based palliative care teams than hospices. All but one hospice currently have a mechanism in place to provide 24/7 advice to generalists and provide urgent telephone advice to them within one hour. Where the one hospice does not currently provide this service, its District Health Board (DHB) is investigating a 24/7 arrangement with another hospice. A similar arrangement involving three hospices is already in place in other parts of the country.

Provision of telephone advice outside normal working hours, particularly for new referrals, presents a gap for hospital-based palliative care teams. Telephone advice outside of normal working hours is currently not funded for seven out of the ten hospital-based palliative care teams answered.

Two hospitals have a link with their local hospices for telephone advice. Given that some hospices also have arrangements with other hospices, integrated collaboration within and between hospices and hospitals may be a way to address this gap.

Face-to-face consultation outside of normal working hours presents an even greater resource challenge. For all but one hospice, home visits by nurses are currently provided through a combination of hospice staff and district nursing services. Home visits by medical personnel are currently provided by either general practitioners or medical specialists for all but three hospices. However these arrangements are not always ideal for either patient or staff.

Only two hospitals currently provide on-site consultation outside of normal working hours. (Two more do so occasionally.)

## **Paediatric palliative care**

In some instances, the small number of paediatric patients seen by some services has meant that these services have not developed clear referral guidelines for children or formal links with paediatric services. At the same time, because these services see very few children, they will be less experienced in addressing the specific needs of children as specialist providers of paediatric care and it is therefore imperative that appropriate referral guidelines and linkages are in place to enable equitable delivery of paediatric palliative care across New Zealand.

The draft service specification states:

In meeting the palliative care needs of children and adolescents the paediatric specialist palliative care team at Starship Hospital Auckland is the national resource service. It is available to collaborate with the patient's primary paediatric team, any local paediatric palliative care services/support and, if necessary, the local adult specialist palliative care services.

Other palliative paediatric services include Rainbow Place and True Colours in Waikato; and Skylight, a national service that provides specialised support to children, young people and their families and whānau through change, loss, trauma and grief.

## **IT systems**

Providers of palliative care require appropriate information technology (IT) tools to both manage the day-to-day running of the service and meet reporting requirements.

The Palcare patient management system has been developed specifically for palliative care and many hospices are currently implementing it (10 hospices) or plan to implement it (six hospices) or are investigating it (two hospices). Hospices using electronic Palcare should be reasonably well placed to address their operational needs. Further, these hospices are likely to meet the future service specification reporting requirements. Although these requirements have not been finalised, they are unlikely to involve more reporting than is required under the version released in February 2008. Whether sufficient staff resources are available to gather and enter the relevant data is another issue.

There are likely to be IT-related gaps between now and the implementation of Palcare (where applicable) and in those hospices without Palcare or an alternative patient management system.

The requirement of adequate IT systems poses a gap for several hospital-based palliative care teams, despite some having links to their hospital IT systems. Improvements to these systems or extension of the data collected are dependent on organisational resources and prioritisation against other organisational projects.

Ineffective IT tools in both hospice and hospital-based palliative care environments will impact on staff time which might be better utilised in other ways.

## **Auditable response times**

Auditable response times represent a gap for some service providers. Only 15 of the hospices (56%) and three of the hospital services (30%) are currently able to provide auditable response times for all four situations set out in the questionnaire.

In particular, many providers cannot audit the response time for urgent telephone advice to generalists. The capacity to audit response times is linked to two issues already identified – IT and administrative support. Also contributing to this gap are issues around policies, staff training and compliance.

## **Opportunities for action**

As identified above, there are key opportunities for action by palliative care providers at both local and regional levels to ensure each DHB district delivers specialist palliative care services to its population that meet the requirements of the draft service specification. These opportunities for action are founded on collaboration between providers, with a focus on an integrated service model for the patient, which is centred on the patient and their family and whānau. Some districts and regions already provide this kind of model in some aspects, such as in the provision of 24/7 telephone advice, shared palliative care medical resources, and referrals to a hospice for grief and loss support to bereaved families and whānau. In an economically constrained environment, the challenge is for funders and providers to continue to collaborate and develop sensible and appropriate local and regional solutions.

# Introduction

Over the last three years the Ministry of Health ('the Ministry') has been working with the palliative care sector (both hospice and hospital-based palliative care services) to develop a revised draft service specification for specialist palliative care in New Zealand.

Once the service specification is ratified, the level of service described will become the minimum level of service required in the sector. The draft service specification was released to palliative care providers in February 2008 along with \$2 million in funding. While several hospices and hospital-based palliative care teams were working towards incorporating all or some of the components of the draft service specification, the Ministry undertook a national stocktake or gap analysis to determine how close services in their current form were to meeting this new service specification.

The objectives of the gap analysis were to source:

1. qualitative-based assessment of services against the draft service specifications
2. quantitative financial and patient-level data.

The data were collected to:

1. present an overview of the current state of service provision in hospice/specialist palliative care on a consistent basis regionally using data from the 2007/08 financial year
2. identify specific gaps in service provision relative to the draft service specifications
3. determine the resources required to implement the draft service specification
4. develop the costing models to inform the development of the purchase unit codes for the draft service specification
5. inform the joint Ministry of Health and District Health Board Service Specification Programme Executive and assist with the ratification of the draft service specification.

This report presents Phase 1 of the results of the largely qualitative service analysis and provides a national overview of where specialist palliative care delivery is at using data from the 2007/08 financial year. Phase 2 of the gap analysis will address the resources required, and develop funding models for the draft service specification.

This report has not attempted to address the quality of specialist palliative care providers, nor does it make any recommendation as to the appropriateness of the level of service provided. It concentrates instead on the aspects of services as articulated in the draft specialist palliative care service specification.

It should be noted that the ability to collect data (patient activity level) was significantly limited by a number of factors including information technology (IT) infrastructure and the time lag between the first release of the draft service specification to the sector and the requested timeframe for data. Thus there was large variability in service providers' ability to submit the data requested. In view of these limitations, this report is intended as a general guide rather than as a source of definitive data on the palliative care sector. The information it presents, like that to be used in Phase 2 of the gap analysis, was previously not available and will contribute to the development of more accurate work nationally.

## **Methodology**

The project's scope was established and objectives were defined. The project team consisting of Ministry of Health staff and staff resource from Central Region's Technical Advisory Services agreed the methodology and timeframe. Expertise was drawn from across the specialist palliative care sector to support the process.

### **Data collection and analysis**

The project team was responsible for identifying the data required for collection. Its decisions were based on the aims and objectives of the gap analysis (see introduction), and the draft service specification for specialist palliative care. It was agreed that the data would be collected over the financial year 1 July 2007 to 30 June 2008, as it was the most recent complete financial year at the time of the data collection. It was agreed that in some instances where provider data were unavailable from that period, more recent data or data related to a more limited timeframe (eg, six months) would be permissible, on the grounds that the priority was to gain data at a basic level for each provider.

### **Development of the templates**

Separate templates were developed for hospices and hospital-based palliative care services. For each service, three templates were developed: a qualitative questionnaire in Microsoft Word, a quantitative questionnaire in Microsoft Word, and a quantitative patient-level data request in Microsoft Excel. This development phase took place over a month, from late January to late February 2009.

The first (Word) template was developed by the project team in consultation with experts from across the specialist palliative care sector. In developing the qualitative questionnaire, key requirements of the draft service specification were rephrased as questions. Answer options involved tick boxes along with an 'other' answer option. Some topics not specifically from the service specification were also included in the questionnaire. Open-ended questions were limited. Providers were asked to supply information on the current state of their service (during the financial year of data collection). The questionnaire was initially developed using tick and text box functions in Microsoft Word which required macros to be enabled. A non-macro version was later developed.

The second (Word) and third (Excel) templates were both quantitative in nature. The project team developed the second template; Ministry of Health staff developed the third template and will complete the costing work. Both templates were developed in consultation with the specialist palliative care sector and were largely based on data required to inform the costing model.

It is noted that the financial year chosen, 2007/08, includes months prior to the release of the draft specification in February 2008. In addition the patient-level data requested differed to the data currently required to be reported to the Ministry of Health. If services were unable to provide the data for the requested financial year, they were asked to provide data for an alternative (clearly stated) time period. These factors will be taken into account in the modelling methodology.

Although the themes were similar, the specific questions asked in the hospice and hospital questionnaires differed from each other to reflect the different nature of their respective service models. Furthermore the development of the hospital questionnaire was slightly behind that of the hospice questionnaire and some minor changes to the hospital questionnaire were made after the hospice questionnaire had rolled out nationally. More detail on these differences is given in the relevant sections in this report.

The gap analysis templates for hospices were sent to 28 hospices throughout New Zealand; the quantitative templates were received back from all 28, and the qualitative template from 27. All the qualitative and quantitative templates were received back from the 10 hospital-based palliative care services to which they were sent, and a partially complete template from one other hospital.

Note that an additional template for District Health Board (DHB) Planning and Funding teams was later developed to support the above data collection. Detailed results from this template will not be reported on but will be used to inform the gap analysis process.

## **Pilot and national roll-out**

Before they were piloted, the first two hospice templates were reviewed by Hospice New Zealand. The hospice templates were then piloted in four hospices over two weeks in late February and early March 2009 and rolled out nationally in mid-March 2009. The hospital templates were piloted by two hospital-based palliative care teams over three weeks in late February and early March, and then rolled out nationally in late March 2009.

Documentation accompanying the pilot and national roll-out of the gap analysis included a general information sheet, a data dictionary, a 'How to complete the Excel template' document, a document explaining how to enable macros, and a copy of the February 2008 draft tier two service specification.

Hospices and hospitals that were to receive the gap analysis templates were identified by the Ministry of Health. Prior to national roll-out, the Ministry informed hospices and hospital-based palliative care teams of the upcoming gap analysis, and Hospice New Zealand also communicated with hospices regarding the analysis. Hospices and hospitals were both given five weeks to complete the templates. Follow-up continued until June 2008. The Ministry was available throughout the process to answer any questions from providers.

## Analysis of data

On receipt of the first two (Word) templates from the respondents, the responses were checked for any inconsistencies, missing data and incorrectly interpreted questions and any issues were communicated back to the hospital or hospice for their response. More follow-up was required for hospices than hospitals due to the more complex nature of their questionnaire. The most common reasons for follow-up with hospices were to match up the education courses identified in the qualitative with those identified in the quantitative templates; to clarify an unclear nursing-related question; and to check totals against individually reported figures for workforce salaries, income and expenses. Occasionally a respondent did not answer a certain question, which is noted in the results where applicable.

The project team entered the data from the first two templates into Excel for analysis and identified common themes from the qualitative responses. In this Phase 1 gap analysis report, only some of the quantitative data are reported.

Data checking and analysis associated with the patient-level data request and other costing data form Phase 2 of the gap analysis.

## Limitations

The limitations of this gap analysis include the following.

1. Terms were not uniformly defined (eg, what constitutes a 'care co-ordination' event or 'community care') although definitions were provided. Providers differed in the way they used some terms. Further, the way in which activities were measured in different services limits the comparisons that can be made between services. The Ministry of Health is currently developing proposed minimum data sets for specialist palliative care, which will allow activities and services to be defined consistently, and provide national standardisation.
2. Providers varied in their responses regarding the level of postgraduate education in the palliative care workforce. Levels of training and expertise (eg, certificate, diploma, master's degree) vary across the disciplines, mainly nursing, and across providers. Promisingly, however, a significant number of the workforce has undertaken postgraduate training of some sort.
3. Since the 2007/08 financial year for which the data are reported, in some instances new services have been developed and staffing levels have changed. The qualitative template included an opportunity for providers to identify proposed changes to their service or staffing.
4. Although the project team experienced an extremely high level of co-operation and was able to garner data sets from all providers, the lack of IT infrastructure and previous data collection made it necessary to extrapolate some of the data from other services. This information is required for Phase 2 of the gap analysis.
5. The report provides information on the structure of services and in Phase 2 on the activity levels. This information does not in itself provide a measure of quality.

## The Need for Specialist Palliative Care

This section provides a range of data on cause of mortality, the ageing population and place of death that indicate the extent to which specialist palliative care may be needed in New Zealand.

### Mortality and cancer

Cancer mortality data for the 2007 calendar year were sourced on 16 September 2009 from the mortality collection (part of the National Collections). In 2007 there were 8487 deaths from cancer. Table 1 outlines the distribution of cancer deaths by region and District Health Board.

**Table 1:** Distribution of cancer deaths by Regional Cancer Network and District Health Board, 2007

Regional Cancer Network	Deaths of those aged 15 and over with cancer as an underlying cause for the region	District Health Board	Deaths of those aged 15 and over with cancer as an underlying cause
Northern	2,585	Auckland	704
		Counties Manukau	661
		Northland	389
		Waitemata	831
Midland	1,493	Bay of Plenty	511
		Lakes	228
		Waikato	754
Central	2,151	Tairāwhiti	97
		Taranaki	298
		Capital and Coast	468
		Hawke's Bay	365
		Hutt Valley	289
		MidCentral	379
		Wairarapa	95
		Whanganui	160
Southern	2,258	Canterbury	1,044
		Nelson Marlborough	306
		Otago	453
		South Canterbury	163
		Southland	225
		West Coast	67

## Mortality and conditions other than cancer

Specialist palliative care services also need to be made available to those dying of conditions not related to cancer. From the data within the mortality collection, it was not possible to gauge with any certainty the percentage of non-cancer deaths that would have benefited from specialist palliative care.

## Population aged over 65 years

The ageing population will increase the prevalence of both cancer and non-cancer conditions that result in death. Correspondingly there is likely to be a need for incremental growth of specialist palliative care. Table 2 shows the spread of the ageing population across District Health Boards, breaking down this information by ethnicity.

**Table 2:** Population aged 65+ years by District Health Board and ethnicity, 2008

Regional Cancer Network	District Health Board	Population aged 65 years and over	Population aged 65 years and over (Māori)	Population aged 65 years and over (Pacific)	Population aged 65 years and over (European /Other)
Northern	Auckland	42,000	1,500	2,980	37,520
	Counties Manukau	42,960	2,490	4,440	36,030
	Northland	23,400	3,140	110	20,150
	Waitemata	58,750	1,640	1,530	55,580
Midland	Bay of Plenty	33,680	2,840	110	30,730
	Lakes	12,690	1,740	110	10,840
	Waikato	46,230	3,370	450	42,410
Central	Tairāwhiti	5,595	1,340	45	4,210
	Taranaki	16,435	880	35	15,520
	Capital and Coast	30,290	1,030	1,160	28,100
	Hawke's Bay	21,930	1,780	180	19,970
	Hutt Valley	16,650	710	500	15,440
	MidCentral	23,960	1,240	120	22,600
	Wairarapa	6,860	320	30	6,510
	Whanganui	10,255	840	35	9,380
Southern	Canterbury	67,360	1,390	360	65,610
	Nelson Marlborough	20,945	580	55	20,310
	Otago	27,460	450	100	26,910
	South Canterbury	10,295	160	5	10,130
	Southland	14,675	600	55	14,020
	West Coast	4,730	150	–	4,580

Source: Data accessed from population projection for 30 June 2008 and sourced from Statistics New Zealand standard populations which are derived from the 2006 Census results.

## Place of death

There is a relative lack of good quality data on the place of death of those who die in New Zealand, making it difficult to directly match cause of death with place of death. Table 3 below shows the percentage of the population who died of cancer in each of the categories for which place of death is recorded: public hospital, private hospital (including hospices with inpatient beds but excluding rest homes where the rest home is the individual's usual place of residence) and other.

**Table 3:** Place of death of those who died of cancer, 2007

Facility type	Deaths of those aged 15 and over with cancer as an underlying cause
Public hospital	26.3%
Private hospital	36.8%
Other	36.9%

Source: Data accessed for the 2007 calendar year on 16 September 2009 from the mortality collection (part of the National Collections).

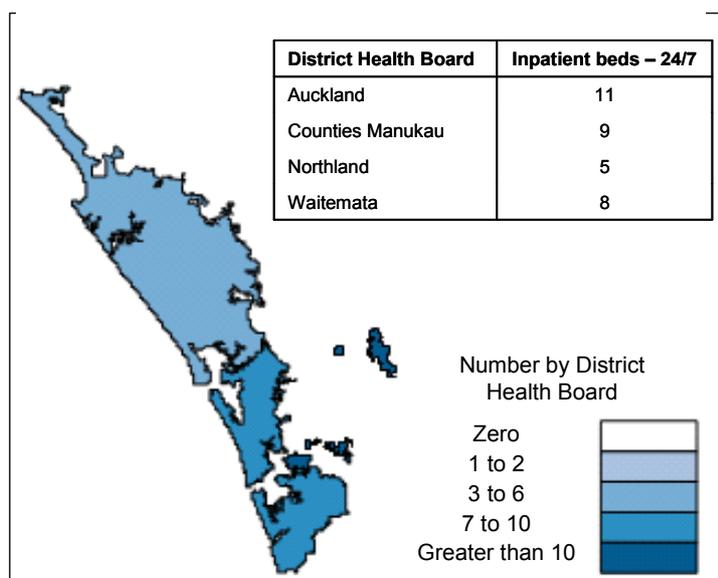
## Service Overview 2007/08

This section presents a national overview of palliative care services in New Zealand. It sets out the location of hospices and hospital-based palliative care services in each region, with more detailed analysis by District Health Board, along with the population served by each hospice. Regional Cancer Networks are used as the regional boundaries because many services connect via the Palliative Care and Cancer networks of the regional cancer networks. Specific hospices and hospitals are named only in this section to provide context. For the remaining sections of this report they are not identified by name except in a few cases to again set out the context of current and future services.

### Northern Region

The Northern Region is comprised of Northland, Waitemata, Auckland and Counties Manukau DHBs.

**Figure 1:** Number of inpatient beds for hospice-based palliative care services in Northern Region DHBs



### Hospices

The Northern Region, with 10 hospices, has the largest number of any region. Northland DHB has one tertiary regional hospice and three smaller hospices operating in a hub and spoke model. Within the Waitemata DHB there are three hospices; within Auckland DHB there is one hospice; and within Counties Manukau DHB there are two hospices. Table 4 below shows the population range that each hospice serves.

**Table 4:** Approximate population size served by each Northern Region hospice

Population range	Number of hospices	Hospice name(s)
< 50,000	3	MidNorthland (Northland DHB), Far North (Northland DHB), Kaipara (Northland DHB)
50,000–99,999	2	Franklin (Counties Manukau DHB), Hibiscus Coast (Waitemata DHB)
100,000–199,999	1	North Haven* (Northland DHB)
200,000–399,999	2	North Shore (Waitemata DHB), West Auckland (Waitemata DHB)
400,000+	2	Mercy (Auckland DHB), South Auckland (Counties Manukau DHB)

Note: \* The local population served by North Haven hospice is 76,000 but its regional population is 150,000.

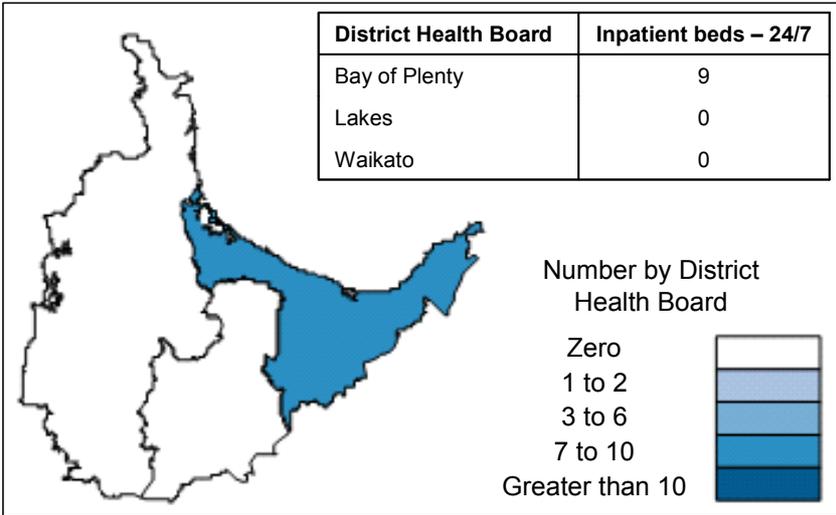
**Hospitals**

The Northern Region has three hospital-based palliative care teams, located at North Shore Hospital, Auckland City Hospital, and Middlemore Hospital. North Haven hospice are contracted to provide a hospital-based palliative care service in Whangarei Hospital.

**Midland Region**

The Midland Region is comprised of Waikato, Bay of Plenty, and Lakes DHBs.

**Figure 2:** Number of inpatient beds for hospice-based palliative care services in Midland Region DHBs



## Hospices

The Midland Region has five hospices. Within the Waikato DHB there is one hospice (excludes Rainbow Place and True Colours both providing paediatric services; and Tokoroa Hospice which is not a specialist service); Bay of Plenty and Lakes DHBs have two hospices each. At the time of data collection, Waikato Hospice had no inpatient beds but this situation is due to change shortly. Table 5 below shows the population range that each hospice serves.

**Table 5:** Approximate population size served by each Midland Region hospice

Population range	Number of hospices	Hospice name(s)
<50,000	1	Taupo (Lakes DHB)
50,000–99,999	2	Rotorua (Lakes DHB), Eastern Bay of Plenty (Bay of Plenty DHB)
100,000–199,999	1	Waipuna (Bay of Plenty DHB)
200,000–399,999	1	Waikato (Waikato DHB)

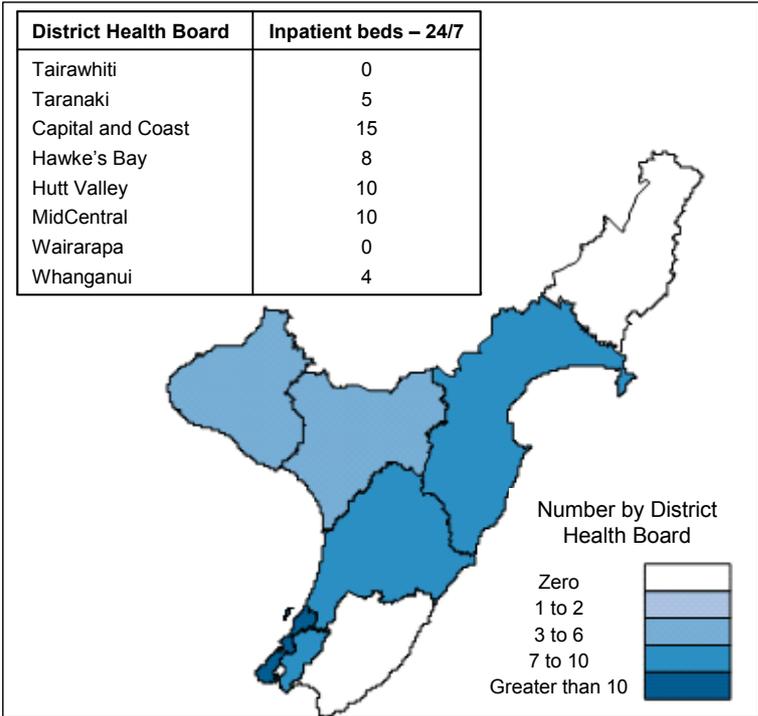
## Hospitals

The Midland Region has one hospital-based palliative care team in New Zealand, based at Waikato hospital. This is the only hospital service with inpatient beds for palliative care. Waikato provides services to six other community hospitals.

## Central Region

The Central Region is comprised of Taranaki, Tairāwhiti, Whanganui, MidCentral, Capital & Coast, Hutt Valley, Wairarapa and Hawke's Bay DHBs.

**Figure 3:** Number of inpatient beds for hospice-based palliative care services in Central Region DHBs



**Hospices**

The Central Region has seven hospices. Taranaki, Tairawhiti, Whanganui, MidCentral, Capital & Coast, Hutt, and Hawke’s Bay DHB each have one hospice. Wairarapa DHB has a palliative care service. Table 6 below shows the population range that each hospice serves.

**Table 6:** Approximate population size served by each Central Region hospice

Population range	Number of hospices	Hospice name(s)
<50,000	1	Gisborne (Tairawhiti DHB)
50,000–99,999	1	Wanganui (Whanganui DHB)
100,000–199,999	3	Te Omanga (Hutt Valley DHB), Cranford (Hawke’s Bay DHB), Taranaki (Taranaki DHB)
200,000–399,999	2	Mary Potter (Capital & Coast DHB), Arohanui (MidCentral DHB)

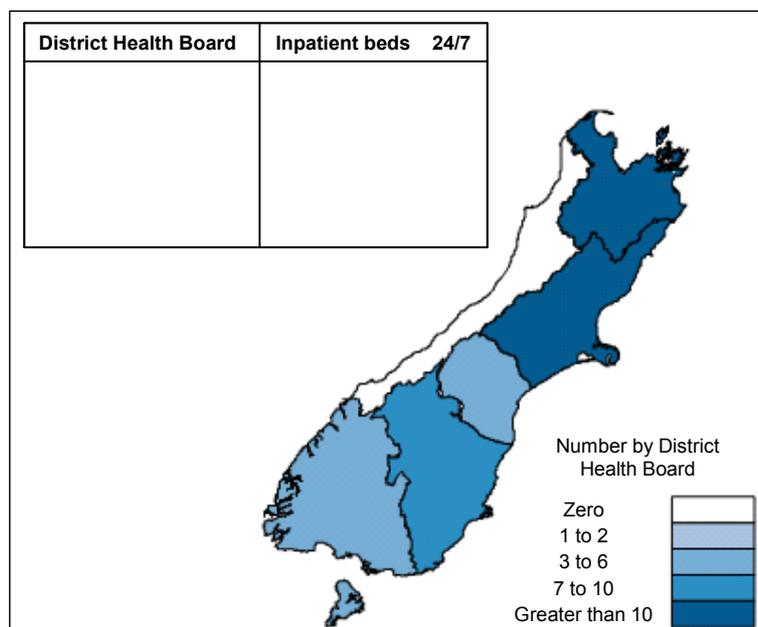
**Hospitals**

The Central Region has three hospital-based palliative care teams at Palmerston North, Hawke’s Bay and Wellington Regional Hospitals. The hospice is contracted to provide palliative care services in Hutt Hospital.

## Southern Region

The Southern Region is comprised of Nelson Marlborough, West Coast, Southland, Otago, South Canterbury, and Canterbury DHBs.

**Figure 4:** Number of inpatient beds for hospice-based palliative care services in Southern Region DHBs



## Hospices

The Southern Region has six hospices. Nelson Marlborough DHB has two, and Southland, Otago, South Canterbury and Canterbury DHBs have one hospice each. There are no dedicated hospice services located in the West Coast DHB, rather the DHB operates a nursing based palliative care service. Table 7 below shows the population range that each hospice serves.

**Table 7:** Approximate population size served by each Southern Region hospice

Population range	Number of hospices	Hospice names
<50,000	1	Marlborough (Nelson Marlborough DHB)
50,000–99,999	2	Nelson (Nelson Marlborough DHB), South Canterbury (South Canterbury DHB)
100,000–199,999	2	Otago (Otago DHB), Southland (Southland DHB)
400,000+	1	Nurse Maude (Canterbury DHB)

## Hospitals

The Southern Region has two recognised hospital-based palliative care services: one at Christchurch Hospital and the other at Dunedin Hospital. Christchurch Hospital also

provides services to four community hospitals. Some palliative care is provided part-time in non-clinical time by a persistent pain specialist in Timaru Hospital.

## **Paediatric palliative care**

The paediatric palliative care service at Starship Children's Hospital is a national service and also provides direct care to children in the three DHBs in the greater Auckland region. This service commented that although it is a consultative service, it provides direct clinical input especially for children at home. This focus means that care of children in hospital is a small part of its service provision and approximately 80% of care is delivered in the community.

Two other hospital-based palliative care services indicated that their service caters for paediatric patients. Another hospital commented that it sees paediatric patients on an ad hoc basis.

The questionnaire did not ask how many paediatric patients were seen by each service, nor about the scope of the paediatric service provided. Starship Children's Hospital expressed the following opinion on the template:

... an adult service that sees five children or less per year can answer yes (to catering for paediatric patients) but may not have the necessary specific paediatric focus or training. In an environment of quality assurance and credentialing of services and specific roles, such as medical specialists, it is questionable that adult services should be caring for children and adolescents and their families. However the question could also highlight the use of adult services because of gaps in paediatric service provision. Even if children are cared for in adult settings they should always remain under the care of primary paediatric services.

The other hospitals in the survey indicated that they refer paediatric patients to the paediatric service within their own hospital or Starship as appropriate.

## Workforce Overview 2007/08

Specialist palliative care demands specialist skills from trained professionals. This section presents a national overview of the medical specialists and nurses in the specialist palliative care workforce in New Zealand, based on the information submitted by hospices and hospitals.

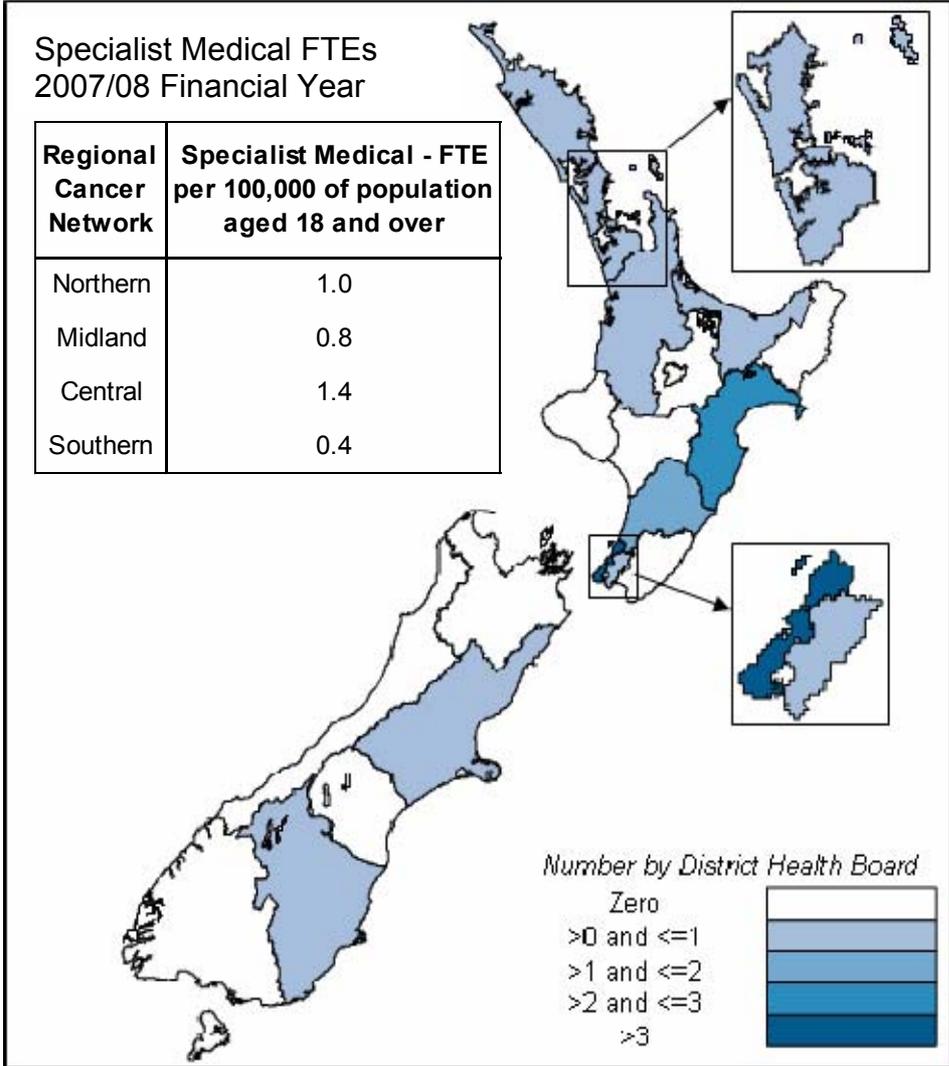
### Palliative care medical specialists

Figure 5 shows the total number of full-time equivalent (FTE) palliative care medical specialists employed in each region and DHB in 2007/08. Since the survey, a number of services have employed additional FTE medical specialists. The figures below clearly illustrate the need for services to collaborate regionally to ensure people throughout the country have access to palliative care medical specialists when required.

**Table 8:** Total FTE palliative care medical specialists by region, 2007/08

<b>Regional Cancer Network</b>	<b>Specialist Medical – Number of FTE</b>
Northern	11.0
Midland	3.8
Central	10.0
Southern	3.2

**Figure 5:** Total FTE palliative care medical specialists per 100,000 by region and DHB, 2007/08



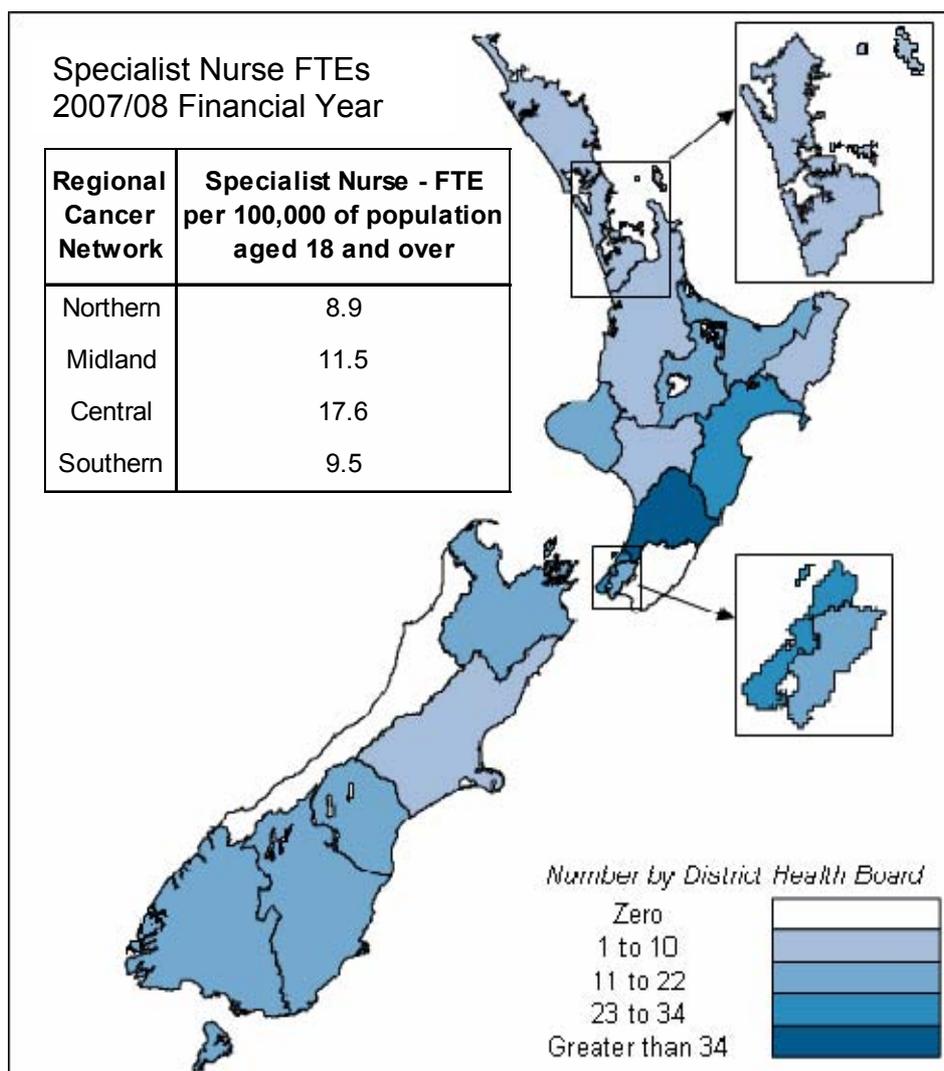
**Palliative care specialist nurses**

Figure 6 shows the total number of FTE palliative care nurses with postgraduate qualifications employed in each DHB and region in 2007/08. West Coast DHB (which has no palliative care nurses, as indicated in the figure) was not included in the gap analysis as it had no specialist palliative care service at the time of the survey. However, since the survey the DHB has employed specialist palliative care nurses with a total of 2.5 FTE.

**Table 9:** Total FTE palliative care nurses with postgraduate qualifications by region, 2007/08

Regional Cancer Network	Specialist Nurse – Number of FTE
Northern	102
Midland	55
Central	129
Southern	73

**Figure 6:** Total FTE palliative care nurses with postgraduate qualifications per 100,000 by region and DHB, 2007/08



# Requirements of the Service Specification

This final section presents a national overview of palliative care services in New Zealand. At this stage the aim is to describe the state of those services rather than to offer solutions to any issues identified. A review of the specific gaps for individual providers is to be presented in a separate report.

The order in which the results are presented largely follows the format of the qualitative questionnaire which itself was based on the draft tier two service specification. Where appropriate, text from this specification has been presented to set the context.

## Referrals

Each specialist service should have a clear and specific mechanism for processing referrals which is appropriate and understood by all potential referrers in their locality.

Draft tier two service specification

## Hospices

All 27 hospices have clear and specific mechanisms in place for processing referrals for adults from generalists. Such mechanisms are also in place in all but two hospices for self referrals and in 16 out of 27 (59%) for referrals for children (0–14 years).

### Referrals for adults from generalists

Urgency of referral is addressed by all hospices, although one hospice states that this is only done for electronic referrals (not paper). All but one hospice addresses the timeframe from referral to first contact and identifies whether patients' needs are appropriate for specialist care (as opposed to that which could be provided by a generalist). The hospice that does not address these two aspects is currently assessing its referral processes.

For all but three hospices, referral processes address arrangements for first assessment. Measurement of acuity is addressed in the referral process for less than half (12 out of 27, or 44%) of hospices.

Other aspects assessed by some hospices include the patient's medical history, rurality, social support and/or isolation, family or whānau support, other agencies involved and specific patient needs.

### Self referrals

One of the two hospices that do not have a mechanism for self referrals is the hospice that is currently assessing its referral processes. Hospices were asked if their process involves obtaining the patient's permission for the hospice to contact the patient's general practitioner (GP) or advising the patient to contact their GP themselves. The two processes are not mutually exclusive, and 11 hospices address both. In total 19 of

the 25 (76%) hospices that have a self referral mechanism obtain the patient's permission for the hospice to contact the patient's GP and 17 (68%) advise the patient to contact their GP themselves.

### **Referrals for children**

Of the 16 hospices with clear referral mechanisms for children, all but one responded that they contact a paediatric service. Although the questionnaire did not ask them to identify the particular paediatric service, several hospices named Starship Children's Hospital as that service. For others, referral to a paediatric service is likely to include their hospital provider arm paediatric service. Waikato Hospice governs a specialised palliative care service for children, young people and their families (Rainbow Place) focusing on enhancing the quality of life for the child and support for the family and whānau. It will have two beds for children in late 2009.

### **Declined referrals**

Although the questionnaire did not ask hospices to supply the number of referrals they received, it did ask about the number of declined referrals. Quantifiable results in this regard were received from 22 hospices (79%). Among those hospices that did not supply this information, most were unable to do so because they did not record these data.

The number of declined referrals ranged from 0 (three hospices) to 125 or 8% of all patients who were referred to this particular hospice. On average across the hospices that provided these data, 3% of referrals were declined. The questionnaire did not specifically ask about reasons for declining referrals.

### **Hospitals**

The gap analysis questionnaire for hospitals focused on a generic referral process rather than on specific types of referrals (eg, adults, self referrals and children). All 11 hospitals in the survey indicated that they have referral guidelines, although for one hospital these are informal.

In their referral guidelines, all hospitals address patient referral criteria, urgency of referral and how to refer (eg, pager or fax). All but two address which hospital staff can refer and eight include the timeframe from referral to first contact. The referral guidelines for five hospitals address arrangements for first assessment while four include measurement of acuity or triaging.

The data provided by the 11 hospitals on the number of referrals seen annually and the annual number of declined referrals cover different time periods and vary in their level of accuracy so are not reported here. The data will be modelled and used to inform the costing project.

## Timeframe from referral to first contact

### Hospices

In asking hospices about the timeframe from referral to first contact, the questionnaire did not separate out urgent and non-urgent patients as it did for hospitals.

The timeframe from referral to first contact for 16 of the 27 hospices (59%) is within 24 hours, and within 48 hours for another eight hospices (30%). Another hospice has a timeframe of within 24 hours for urgent patients and 72 hours for non-urgent patients; for a further hospice, the timeframe is whatever is indicated on the referral form. Two of the hospices with a timeframe of within 48 hours specify that they see urgent cases more quickly if the need is indicated by the referrer. One hospice has a timeframe of seven days for all referrals.

### Hospitals

In all 11 hospitals the timeframe from referral to first contact for urgent patients is within 24 hours (with the caveat added by two hospitals that this timeframe applies during week days).

In six of the ten hospitals, the timeframe for non-urgent patients is within 48 hours. Two of the hospitals with a timeframe of 48 hours for non-urgent patients, however, commented that the majority of patients are seen within 24 hours. Two hospitals has a timeframe for non-urgent patients of within 24 hours; at the other end of the spectrum is a hospital with a timeframe of within one week. The remaining hospital sees patients within a timeframe as discussed with the referrer.

## Inpatient units

Inpatient care includes all admissions to a specialist palliative care unit which include an overnight stay.

Draft tier two service specification

### Hospices

Eighteen (67%) hospices currently have an inpatient unit (IPU), in which the total number of inpatient beds ranges from two to 18, with an average of nine. However, it should be noted that the IPU of the hospice with two beds is not recognised nor funded by its DHB (which the hospice is seeking to change). Three other hospices are anticipating the opening of an IPU either towards the end of 2009 or within the next 12 months and six of the hospices that already have an IPU anticipate acquiring extra beds (between one and nine) within the next three years. Some of the hospices currently without an IPU access residential beds, hospital beds or other hospice beds.

When the data are analysed in terms of the number of beds per 100,000 population, the number of inpatient beds ranges from two to nearly 12 among the 18 hospices that have an IPU.

All hospice IPUs have a process for prioritising admissions. For all but two, this process involves multidisciplinary team (MDT) discussion. No hospice indicated that they use a formal acuity tool and only four use a triage tool. Other comments include assessment against criteria on referral form/contract, social and familial support, rurality, and bed availability.

On a scale of one (not at all effective) to five (extremely effective) to rate the effectiveness of the processes for prioritising admissions, four hospices (22%) gave themselves a rating of five, 11 (61%) gave a rating of four and three (17%) gave a rating of three.

Nine (50%) of the hospices with an IPU rotate their nurses between their IPU and the community. One other rotates nurses for locum cover; one hospice with an IPU did not answer this question.

## Interdisciplinary teams

The person's ongoing care will be reviewed regularly in a specialist interdisciplinary setting.

Draft tier two service specification

The questions asked about interdisciplinary teams were similar for both hospices and hospitals and key results are summarised in Table 10. Note that the template questions for interdisciplinary teams for hospices dealt with inpatients and community patients separately.

## Hospices

### Inpatients

Of the 18 hospices with an IPU, all but one regularly reviews ongoing inpatient care in an interdisciplinary setting. The exception is also the only hospice to not regularly review ongoing care for community patients in an interdisciplinary setting.

Of the 17 hospices holding interdisciplinary meetings for inpatients, four meet both daily and weekly (noting that daily meetings may be less formal), 12 meet daily, and four more meet weekly. The other hospice holds meetings twice a week.

For all 17 hospices that hold interdisciplinary meetings for inpatients, medical and nursing staff are regularly involved in these meetings and for all but one, so are grief and loss staff. Fifteen of the 17 (88%) also regularly involve allied health staff and 13 (76%) regularly involve care co-ordinators (noting that this figure is probably an underestimate as care co-ordinators may be included in the nursing category).

Additional staff may be included in these meetings as well (see the possible roles involved under community patients below).

Interdisciplinary meetings of inpatient teams address the following aspects of care: medical, nursing and family/whānau support (17 hospices); care co-ordination and personal care (15); and allied health and home help (13). Other aspects reported include day stay attendance, review of family requirements following death, chaplaincy/ pastoral support, discharge planning, care planning review, and liaison with other services.

## **Community patients**

Twenty-six of the 27 hospices regularly review ongoing care for community patients in an interdisciplinary setting. Three hospices reported that they meet both daily and weekly, and another two who meet weekly commented that they have either morning clinical meetings each day or daily debrief and handover meetings. It may be that other hospices also undertake this practice but have not reported it. In total, 18 hospices (69%) meet weekly, four (in addition to the three mentioned above) meet regularly on a daily basis, and one other meets three times a week.

For all hospices that undertake regular interdisciplinary meetings regarding community patients, these meetings involve employed nursing staff, and for 16 hospices these meetings also regularly involving external nursing staff such as district nurses. In some cases district nurses are not actually present but provide input for their patients. Another hospice meets with its district nursing team fortnightly and a further one involves them as appropriate, such as for more difficult cases.

Employed medical staff are less likely to be involved in interdisciplinary meetings for community patients (79%) than for inpatients (100%). Three hospices also reported regular involvement of external medical personnel such as GPs.

Twenty-three (88%), 21 (84%) and 20 (77%) hospices regularly involve care co-ordinators, grief and loss staff and allied health staff respectively in their interdisciplinary meetings for community patients. Other staff involved include support services co-ordinators, volunteer co-ordinators, day stay co-ordinators, pharmacists, chaplains, complementary therapists, Māori liaison staff, hospital-based palliative care teams, patient advocates, medical and nursing students, and cancer society personnel.

The seven identified aspects of care (see Table 10) were each addressed by between 21 and all 26 hospices that undertake interdisciplinary meetings for community patients. Other aspects of care discussed at these meetings include all of those topics listed above for inpatients plus equipment, meals, transport, volunteer services, complementary therapies, remembrance, peer support, quality of life, bereavement risks, rural location of teams, and individual safety and security.

## **Hospitals**

All but one hospital regularly review patient ongoing care in an interdisciplinary setting. Of these 10 hospitals, one hospital undertakes such reviews informally on a per patient basis which can be daily and three others do so both daily (working days) and weekly

(eg, daily informal reviews or daily for patients within own team and weekly for formal review or with site-specific MDTs). For the other six hospitals, interdisciplinary meetings occur daily (four or five days per week).

All 10 hospitals that hold regular interdisciplinary review meetings regularly involve both medical and nursing staff in these meetings. Five hospitals also involve additional staff; those mentioned were care co-ordinators, and allied health, pharmacy and grief and loss staff.

The following aspects of care are regularly reviewed by all 10 hospitals undertaking interdisciplinary meetings: medical, nursing, and care co-ordination. Family support (psychosocial) is regularly reviewed by nine of the ten hospitals. Seven hospitals review allied health. Other aspects of care discussed include communication, staff support and ethics.

The hospital-based palliative care team that does not regularly review patient ongoing care in an interdisciplinary setting does have a weekly interdisciplinary meeting with the hospice at which there is representation of medical, nursing, family support and care co-ordination teams. However, only hospice patients are reviewed, not hospital inpatients (unless they are also known to the hospice).

**Table 10:** Summary of the staff involved and the aspects of care addressed at interdisciplinary meetings of hospice and hospital-based palliative care teams, 2007/08

	Hospice inpatients (17 hospices)		Hospice community patients (26 hospices)		Hospital patients (10 hospitals)	
	No.	%	No.	%	No.	%
<b>Staff involved</b>						
Employed medical	17	100	19	79	10	100
Employed nursing	17	100	26	100	10	100
Care co-ordinators	13	76	23	88	2	20
Allied health	15	88	20	77	3	30
Grief and loss	16	94	21	84	1	10
External nursing eg, district nurses	5	29	16	62	0	0
<b>Aspects of care</b>						
Medical	17	100	25	96	10	100
Nursing	17	100	26	100	10	100
Allied health	13	76	22	85	7	70
Care co-ordination	15	88	25	96	10	100
Family support (psychosocial)	17	100	26	100	9	90
Home help	13	76	21	81	Not asked	
Personal care	15	88	22	85	Not asked	

## Communication with generalists

The general practice team and other relevant generalist providers will be included in decision making and care planning through regular written and verbal communication.

Draft tier two service specification

### Hospices

The template questions for hospices regarding communication with generalists dealt with inpatients and community patients separately. For a definition of generalist providers of palliative care, please refer to the appendix.

### Inpatients

All 18 of the hospices with an IPU communicate with generalists regarding the care of admitted patients, and the majority (16 out of 18, or 89%) do so after a significant change in episode of care. The extent of additional communication is variable between hospices. Eleven (61%) regularly communicate with generalists regarding discharge/discharge planning and 10 (56%) communicate after first assessment. Other times at which hospices communicate with generalists are on admission, on deterioration, on death, on transfer, on commencement on the Liverpool Care of the Dying Pathway (LCP), before or after family meetings, and 'as needed'.

The number of different types of communication used by hospices to communicate with generalists regarding inpatient care ranges from one to five, with 14 out of 18 hospices (78%) regularly using between three and five methods. Phone is the most common method (17 out of 18, or 94%), closely followed by fax (16 out of 18, or 89%) and letter (15 out of 18, or 83%). Other methods used by between one and five hospices are visits, email and the patient management system Palcare.

### Community patients

Although all hospices communicate with generalists regarding care for community patients, they differ in the extent to which they do so, as with inpatient communication. All but two of the hospices communicate with generalists after first assessment and after a significant change in episode of care. Communication after each MDT meeting is less common: six hospices do so regularly. Other times at which hospices communicate with generalists include (but are not limited to) on initial referral, on death, on transfer, on commencement of LCP, after specialist visits/medical review, following medical outpatient visits, on routine discharge, on hospice admission and discharge, on referral to other community service providers, after any change in medication, if there are bereavement risk concerns, and at the request of the generalist.

The majority of hospices most regularly communicate with generalists regarding community care via more than one mode of communication. Only two hospices reported using only one mode of communication (email and phone respectively); 11 hospices reported between two and three modes; and 13 hospices reported between four and five modes of communication.

Among the specific modes of communication used with generalists regarding community patients, the most common mode is phone (25 out of 27, or 93%), followed by fax (23 out of 27, or 85%), letter (20 out of 27, or 74%) and visits (16 out of 27, or 59%). Email is used by six hospices. Palcare was reported as a method of communication by three hospices, and another plans to use this method once staff are more familiar with the system. One hospice has recently completed a survey with all GPs in its area to see if it might use teleconferencing or Skype to involve them in MDT meetings and the majority of GPs have requested this kind of arrangement. The hospice will look at trialling this approach towards the middle of 2009.

### **Communication regarding the service specification**

Once the draft service specification rolls out more formally, there will need to be extensive communication with generalists regarding the changes and how those changes will affect the care provided by both specialist and generalist providers of palliative care. This point was highlighted by one hospice which has been working with a version of the new specification since 2007; this hospice feels that, even with extensive communication, there is still some confusion in the sector.

### **Hospitals**

Much of the consultative work undertaken by hospital-based palliative care teams involves working with generalists based within the hospital setting. The questionnaire did not delve into this kind of communication, focusing instead on communication with GPs, as generalists outside the hospital setting.

Hospitals were specifically asked, 'for approximately what percentage of patients does your service send communication, eg, a letter, to a patient's GP following patient discharge or death?' In response, one service reported that it does not communicate with GPs for any patients. Among the other hospitals, four send communication for 51–90% of patients, four do so for 91–100% of patients and two do so for only 1–10% of patients.

One hospital writes that service and workload issues preclude routine letter writing.

## Community care

Ongoing follow-up care follows an initial assessment and will monitor and address the person's changing situation, and their family's, whānau's and carer's circumstances in order to:

- address unmet and/or changing clinical need
- plan and provide psychosocial and procedure based care in the most appropriate place
- develop and adapt advanced care planning to changing circumstance and help pre-empt emergency situations
- maintain continuity of care and effective communication.

Draft tier two service specification

## Hospices

### Model of care

Hospices were asked which of the following models they currently use to provide palliative care in the community:

1. care co-ordination and nursing visits usually provided by the same person, and that person is employed by the hospice
2. care co-ordination provided by the hospice and nursing visits provided via links with another service (eg, district nursing)
3. care co-ordination provided by designated individuals within the hospice and nursing visits provided by other staff within the same hospice.

Noting that 13 hospices (48%) have more than one model of care, the results show that 18 use the first model above, 18 use the second model and 10 use the third. Six hospices plan to change their model of care for community patients.

### Home visits outside of normal working hours

Home visits outside of normal working hours are provided by nurses employed by a hospice in 21 instances (78%) and by nurses employed by another service such as district nursing in 13 instances (48%), again noting that some hospices use more than one model. One hospice reported that it does not provide this service.

Among medical personnel, it is more common for GPs to make home visits outside of normal working hours than medical specialists employed by hospices (18 versus 10 instances respectively). Although a medical specialist is generally available for advice, they are only likely to make home visits under extenuating circumstances. Some hospices note that using GPs for after hours visits can give rise to issues of unfamiliarity with the patient, access and expense (one hospice noting that a GP charges cash upfront before visiting).

## Home help and personal care

Home help and personal care services may be provided via more than one means. Eighteen hospices reported using disability support services (eg, Needs Assessment and Service Co-ordination services – NASCs) to provide home help services and 16 reported that they use the same service to provide personal care services. Provider arm community-based support services provided home help for 11 hospices and personal care for 12 hospices. Non-provider arm community-based support services (eg, Presbyterian Support) were used by six hospices for home help services and by five hospices for personal care services. In eight hospices, their own staff provide personal care services. Hospice staff are less likely to provide home help – only two hospices have this arrangement.

For at least one hospice, there is a gap in the provision of home help and personal care services for those surviving their illness for longer than six months and those aged under 65 years.

## Day stay procedures

This may occur in a hospice, hospital or sometimes in a person's home. It includes routine scheduled medical procedures including transfusions, infusions, and paracenteses. It does not include procedures where overnight stay is necessary: these would be classified as inpatient events.

Draft tier two service specification

## Hospices

Two thirds of the hospices (18 out of 27, or 67%) perform infusions, 13 (48%) perform paracentesis and nine perform transfusions. Another hospice performs all three procedures on inpatients only, and admits specifically for these procedures if required. A further hospice can provide transfusions but has only done so once or twice a year. In most cases where a hospice does not perform the procedures, a nearby hospital undertakes them. A hospital in the home service is provided by at least one district nursing service.

## Day stay programmes

This includes day care with planned psychosocial and spiritual support, specialist activity based programmes, and respite programmes. Ongoing assessment of needs, defined entry and exit criteria, and targeted programmes/activities will be key components of psychosocial ongoing care.

Draft tier two service specification

## Hospices

Three-quarters of the hospices (20 out of 27, or 74%) currently provide a day stay programme. Programmes are forthcoming in a further three hospices: one has a programme currently under development; one has plans for a programme once its hospice extension is completed later in the year; and a third plans to re-establish a programme which was stopped in 2007/08 due to funding deficits and decreasing patient numbers.

The day stay programmes vary in the activities they offer. For example, one hospice stated that it provides activities based on each patient's needs while others listed up to 10 different activities. Each of the hospices with a day stay programme undertakes one or more of the following activities: guest speakers (18 out of 20, or 90%), art (17 out of 20, or 85%), crafts (16 out of 20, or 80%), massage (15 out of 20, or 75%) and external visits (12 out of 20, or 60%). Other activities provided include (but are not limited to) companionship (eg, morning teas), complementary therapies (eg, acupuncture, breathing and relaxation, reiki, shiatsu, aromatherapy), music, beauty therapy, pet therapy, recreational group activities (eg, puzzles, crosswords), theme days and patient biography service.

Fifteen hospices provided information on the number of unique individuals attending one or more day stay programmes in 2007/08: this number ranged from 1 to 155, with an average of 47.

## End of life care programmes

This relates to people in whom death is expected within days rather than weeks regardless of setting. This recognises that dedicated systematic approaches such as clinical pathways have a key role in improving end of life care (eg, Liverpool Care Pathway for the Dying Patient).

It is acknowledged that many dying people will never require direct specialist palliative care involvement. Therefore these programmes should be implemented across all settings.

The role of the specialist palliative care service with end of life programmes should be to:

1. provide leadership and collaborate in the development of a District approach to end of life care
2. implement specific end of life care pathways within specialist palliative care inpatient units
3. work collaboratively with generalist providers in order to implement these programmes in people's homes, residential care facilities and public hospitals
4. support ongoing sustainability of last days of life programmes.

Draft tier two service specification

## Hospices

Currently 16 hospices (59%) have or have begun to implement an end of life care programme based on the Liverpool Care Pathway for the Dying Patient (LCP). Another has a different programme and a further hospice has a dying checklist which it uses in the community (but plans to implement LCP in its new IPU).

Of the 16 hospices with an LCP programme, three began implementing it in 2005, one in 2006, five in 2007 and seven in 2008. Eleven of these 16 hospices (69%) have a dedicated end of life care co-ordinator (note that actual FTE was not consistently reported). Although only a few hospices implement LCP in their IPU, others have implemented it in residential care facilities (13 hospices), in public hospitals (seven hospices) and within the home (four hospices).

Seven hospices without an end of life care programme plan to implement LCP. Three others are yet to make the decision although at least two of these are likely to choose LCP. Four hospices without an end of life care programme plan to implement one before the end of 2009, two others within the first six months of 2010, and one within the next three years. Timeframes are unknown for the remainder.

## Hospitals

Half (45%) of the hospital-based palliative care teams have implemented or have begun to implement an end of life care programme in the hospital setting. In five of these cases this programme is LCP; the other hospital is working with a modified version of LCP. Implementation for two hospitals commenced in 2005, for another in 2007 (still in the pilot phase), and for the fourth in 2008, and the fifth in early 2009. The fifth hospital had just begun a trial at the time of the gap analysis.

Four of the six programmes have dedicated end of life care co-ordinator(s) who generally work across hospital and hospice settings. The number of FTEs ranges between 1.0 and 2.0. Where this funding is held or sourced also varies – for example, it may come from the hospital, a hospice or a private charitable trust. Three hospitals have ongoing funding for end of life care; the other has funding for one year; and another is trying to secure funding for 1.0 FTE for a three-year term.

The extent to which LCP is being implemented varies among the four hospitals in which it is being used or introduced. In the hospital that began implementation around the time of the gap analysis, the programme is being trialled in a medical and oncology ward. In the hospital that began implementation in early 2009, the programme is being implemented in the first medical and surgical ward. In another hospital LCP is implemented in 30% of the medical wards. The two other hospitals are further along with their implementation. One has implemented the programme in all medical, surgical and elder health wards plus its oncology ward and coronary care unit (CCU). The other has also implemented the programme in its oncology ward and CCU, in 75% of its medical wards and in 33% of its surgical wards; it is also involved in implementing the programme in its community hospitals, local hospice, district nursing service and private facilities (23 out of 63 services, or 37%).

Situations for the five hospitals without an end of life care programme differ. The paediatric service has no programme because there are no programmes suitable for children at this time. The remaining four hospitals all have issues around funding for an end of life care co-ordinator. Two of them have not requested this funding, in one case due to a shortfall in other FTEs but implementation of an end of life care programme is in its strategy. For another hospital service, an end of life care programme is not seen as a priority for the DHB so the focus is on one-to-one education with ward staff using the principles behind LCP. This form of education is greatly improving staff confidence in dealing with death and dying and helping staff to manage aggressive treatment and supportive terminal management. For the remaining hospital, a business case is being developed.

One hospital highlighted the question of the sustainability of LCP, especially in the current economic climate and in sites with high turnover and lower skill mix. Another hospital highlighted issues with support for the ongoing audit of LCP data to inform practice.

## Grief and loss support

As part of the specialist palliative care interdisciplinary team, grief and loss support services will be available for the person and/or for the family/whānau and carers. These will in particular acknowledge and address specific cultural needs, as well as the needs of children and adolescents.

Grief and loss support will be increasingly provided by an appropriately qualified counsellor, a registered social worker with specific training in grief and loss support, a spiritual support person with specific training in grief and loss support, or a trained and supervised volunteer within an appropriate cultural context.

Grief and loss follow-up for caregivers and family/whānau will be through a managed programme to ensure systematic follow-up with specific entry and discharge criteria provided at a level that is determined by assessed need.

Draft tier two service specification

## Hospices

### Grief and loss support to patients, family and whānau

Currently 93% of hospices offer one-to-one grief and loss support to patients or family and whānau of patients in their service. Seventeen hospices provide grief and loss support to individuals and their families and whānau in cases where the individual does not receive any other support from the hospice (ie, they are in the care of a generalist provider). Two of these 17 hospices clarified that they provide such a service only occasionally.

The questionnaire contained no direct questions about links between hospices and hospital-based palliative care teams for grief and loss services. However, one hospital reported that, although the procedure is not routine, it can refer a patient's family or whānau to the local hospice bereavement service.

The questionnaire also did not specifically ask if the grief and loss support was provided by appropriately qualified or trained personnel. However, information on the number of social workers, counsellors and chaplains available to hospices is provided under 'Grief and loss staff' below.

### Needs of children

All hospices address and acknowledge the need for grief and loss support among children (0–14 years) and their families and whānau. Two-thirds of hospices provide such support via links with a specialist child counselling service, and approximately two-thirds do so via a trained member of staff such as a counsellor or social worker; some hospices therefore use both means of support.

Specific child-focused services that hospices mentioned are Rainbow Place and Skylight. Two hospices mentioned the Growing through Grief programme offered by Anglican Support Services. A further two hospices mentioned that they provide art therapy for children.

### **Grief and loss follow-up support**

All 27 hospices provide grief and loss follow-up support to bereaved families and whānau. All provide remembrance services, all but two provide one-to-one counselling and support, and 23 provide support groups. Thirteen hospices mentioned that they provide other follow-up support as well, which includes (but is not limited to) bereavement packs, bereavement visits, bereavement courses, follow-up phone contact, sympathy and anniversary cards, creative therapy, complementary therapies, acupuncture, aromatherapy, drop-in mornings, informal afternoon teas, website linkages and access to the library.

### **Grief and loss staff**

In 2007/08, 15 hospices indicated that they employed one or more social workers and another hospice contracted one social worker. The average social worker FTE for the 15 hospices was 1.1, ranging from 0.5 to 2.8 FTE.

For the same financial year, 16 hospices employed one or more counsellors, and two more had a fee for service arrangement. The average counsellor FTE was 1.2, ranging from 0.2 to 3.4 FTE.

Again for 2007/08, 13 hospices employed one or more chaplains. Several others either contracted this service or had it provided by volunteers. Employed FTE ranged from 0.01 to 0.9, averaging 0.5 FTE.

Five hospices mentioned that, following 2007/08, they have increased or will increase their social worker/counsellor hours. Another two anticipated such an increase with the opening of their IPU. One hospice has since disestablished its counsellor position.

### **Hospitals**

Three hospitals provide grief and loss support after death to family and whānau of patients who were in their service. None provide it to family and whānau of patients who were not in their service.

One hospital service contracts a social worker and part-funds a grief and bereavement counsellor. Four other hospitals have access to a social worker although their time allocated to palliative care is not specified. It is expected that other hospital-based palliative care teams also have access to hospital social workers although they did not report this access in the gap analysis questionnaire. A further hospital has funding for a psychologist (0.5 FTE) – the position is to be advertised at the time of writing this report.

## Education programmes for generalist and support services

An education and advice service for generalist providers of palliative care and support services will be provided by specialist palliative care services.

Draft tier two service specification

### Hospices

Hospices were asked to provide details for each course delivered to generalists in 2007/08 and then for any additional courses delivered since then or in the planning stages. Hospices differed in their interpretation of this question, so the summarised results here represent an estimation of what education is provided and are likely to under-report the actual provision.

Hospices were not asked about education strategies, in contrast to hospital-based palliative care services (see results on hospitals below).

### Unique education courses

In 2007/08 the number of unique education courses (as opposed to the actual number of courses held) provided by hospices ranged from 0 to 19 with an average of seven and a total of 188. Only one hospice provided no education courses, another eight provided between one and four unique courses and 14 hospices provided between five and nine unique courses. A further five hospices provided between 10 and 19 unique courses for the 2007/08 year.

### Common topics

Table 11 provides a breakdown of courses by topic. The most common courses to be offered were the Hospice New Zealand education packages for syringe drivers and for care assistants. In 2007/08, 23 hospices (82%) provided approximately 251 syringe driver courses, educating approximately 59,000 generalists. Note that these calculations are an estimate as data provided were averages, and not all hospices provided these data for all courses. Twenty hospices (71%) provided the care assistants courses, totalling approximately 56 courses and educating approximately 12,000 generalists.

The most common topic for unique courses was 'general palliative care' (approximately 212 courses, educating approximately 159,000 generalists). This course category of 'general palliative care' has been assigned when a course covered several aspects of palliative care. Some hospices provided courses that were more focused on a given aspect of palliative care and these have been identified separately, for example as pain and symptom management, or as grief and loss.

Other course topics addressed in detail but not presented in Table 11 were volunteer training, link nurse programmes, spiritual and emotional needs, case studies/review, placements and visits, non-malignant palliative care, dignity/sexuality, communication, ethics, cancer control workshops, nutrition at end of life, family/carers, and complementary therapies.

### **Target audience**

For the individual course types identified, nurses were by far the most common target audience, followed by allied health staff, care assistants, GPs and medical trainees. Other target audiences included but were not limited to volunteers, residential care staff, student nurses, and chaplains/ministers/clergy. Often courses were targeted at more than one health profession.

### **Course type**

Hospice New Zealand education packages and courses designed in-house were the two most common types of course.

### **Academic links**

Approximately 27 unique courses had links to academic institutions, including Auckland University, Auckland Institute of Technology, Auckland University of Technology, Massey University, Otago University, Royal New Zealand College of General Practitioners, Southern Institute of Technology, Victoria University, and Whitireia Community Polytechnic.

### **Sustainability issues**

Sustainability issues included: the availability of personnel (clinical nurse specialist or medical specialist) to run the courses; staff release to attend courses and associated backfill (particularly for aged care staff, as well as for GPs, who need funding to attend); time and travel constraints; rurality; cost of air fares and accommodation; competing priorities in acute care education plans; and funding in general.

### **New courses**

At least 22 hospices have implemented new courses since 2007/08 or plan to do so within the next three years. Topics for these new courses are general palliative care (15 hospices), LCP (eight hospices), spiritual and emotional needs (eight hospices), syringe drivers associated with the new syringe driver pumps (six hospices), care assistants (six hospices), grief and loss (five hospices) and non-malignant palliative care (five hospices).

Three of the hospices with no plans for future education courses are the smaller Northland hospices. They have no such plans because Northland DHB has developed and contracted to its tertiary hospice a regional Palliative Care Specialist Nurse Educator and Advisory Service (commenced April 2008).

## Educators

In 2007/08, 16 hospices had some FTE for an educator role, ranging from 0.2 to 3.8 and averaging 1.1 FTE. Some hospices have since established such a role and others are looking to extend their education FTEs. Note that these data are likely to be an underestimation of education FTEs as these responsibilities will often be assumed by a clinical nurse specialist or medical specialist and not identified separately.

**Table 11:** Summary of education provided by hospices and number of participants, 2007/08

Topic	Number of hospices providing one or more courses for this topic	% of hospices providing this course topic	Approximate number of courses held for this topic this year	Approximate number of participants receiving education on this topic this year
Syringe drivers	23	82%	251	58,985
Care assistants	20	71%	56	12,040
General palliative care	19	68%	212	158,576
Introduction/orientation to palliative care	11	39%	42	7,686
Pain/symptom management	10	36%	52	13,260
Grief and loss	8	29%	18	3,132
Genesis oncology breakfast lectures	8	29%	70	5,040
Older people	5	18%	12	1,092
LCP	5	18%	26	1,092

## Hospitals

Unlike hospices, hospital-based palliative care teams were not asked to provide details of each course delivered to generalists in 2007/08 or of any additional courses delivered since then or in the planning stages. Instead, the questionnaire asked hospitals about their education service in more general terms and about education strategies.

### Education strategies for palliative care

Seven hospital-based palliative care teams currently have an education strategy, of which two are part of a district-wide education strategy for palliative care. One other hospital with its own education strategy was involved in a strategic planning session for a district-wide strategy in late May 2009. A further hospital has an education strategy for nursing and is involved in the local DHB strategy for education due to be completed in June 2009. Furthermore, one hospital without an education strategy plans to have a district-wide education strategy completed in July 2009. The other three hospitals without an education strategy plan to develop one.

## **Education of generalist hospital staff**

All hospitals provide education to hospital staff. All teams educate junior doctors and nurses, and 10 educate allied health staff. Nine hospitals provide education for senior doctors and medical students and eight provide it for pharmacists, care assistants. All six hospitals with a radiation therapy facility provide education for radiation therapists. Several hospitals also provide education to other staff including student nurses, NGO support workers, dieticians, play specialists, counsellors/therapists and food service workers.

All hospitals provide informal one-to-one teaching, 10 offer group teaching sessions, six provide workshops and four provide sequential services. Some provide study days. Also mentioned were video conferencing, e-learning opportunities, newsletters and online journals.

All hospitals address the following in their education activities: assessment of palliative care needs; symptom control; end of life care; psychosocial support; communication skills; and syringe drivers. Eight hospitals address spiritual support, grief and loss, and ethics.

## **Education resources**

Five hospitals indicated that they have dedicated time allocated to education activities, although one mentioned that in practice this time is often sacrificed. Another hospital replied that while it did not have dedicated time, priority was given to making this time during the working week. Four hospitals answered 'no' to this question and a further hospital provided an ambiguous answer.

In response to the question about the estimated time medical staff spend each week on preparation and delivery of formal education, answers ranged from 10 hours per year to approximately eight hours per week. For eight of the hospitals, nursing staff spent more time per week on such preparation and delivery; for the other two hospitals nursing staff spent about the same time as medical staff. Times given for nursing staff ranged from one hour to 12 hours plus per week. One answered that their service would be able to expand teaching as an additional medical specialist FTE was employed.

## **Education issues**

Several hospitals commented on the education component of the new service specification. Their comments include:

Clinical demand can adversely affect our ability to deliver formal education across all disciplines and all forums.

The education component of funding has resulted in an additional \$... for our service enabling us to develop an education plan and put some medical and nursing resource into education resource development. The funding is not adequate however to meet the ongoing education needs of ... clinical staff in the hospital.

Funding and support for education of generalist staff is critical to meet core palliative care needs in hospital settings.

Lack of provision of formal education on a planned sequential curriculum basis, due to time constraints and lack of recognition of current service.

Keeping up with training for a constantly high generalist turnover.

## Telephone advice and support to generalist providers

All generalist providers within each DHB will have access to telephone advice 24 hours a day from a specialist palliative care service covering:

1. referred patients (patients currently under the care of specialist palliative care)
2. un-referred patients (patients not currently under the care of specialist palliative care).

Draft tier two service specification

## Hospices

Currently there is one hospice that does not have a mechanism in place to provide advice 24 hours a day, seven days a week (24/7) to generalists and to provide urgent telephone advice to generalists within one hour.

Some of the hospices with a mechanism in place do not actually provide the service themselves. The DHB for two hospices has a contract with another DHB to provide this service and a further hospice refers generalists to the hospital-based palliative care service.

The hospice that does not provide this service at present writes:

Our nurses are available from 8 am to 8 pm, seven days a week and generalists are able to contact them regarding patients who are under our service. Nurses will contact our specialist if necessary. Nurses are available 24/7 to patients and their generalists if identified as high need. At this point we do not offer advice for patients not under our service. DHB currently looking into 24/7 telephone advice to generalists.

It is understood that this may involve an arrangement with a hospice in a neighbouring DHB.

## **Hospitals**

### **Service provision**

Provision of 24/7 service is of concern for many hospitals, with six of the ten hospitals commenting on it separately to the specific questions dealing with it in the questionnaire. Their concerns relate to funding, clinical and administrative resource, impacts on Monday to Friday service, diminishing accessibility of generalist care provision in the community after hours, and the geographical spread required to be covered. An additional concern is that low frequency of out of hours calls (in a small unit), as might be expected with a reasonable degree of planning and education provision, might be too expensive and out of proportion to the need.

All hospitals provide telephone advice during normal working hours for both patients known to their service and new referrals. Six hospitals provide telephone advice outside of normal working hours to patients known to their service; of these, all but one also provide it for new referrals. A further two hospitals provide telephone advice outside of normal working hours 'informally' or 'sometimes' (for both known and new patients) and one other hospital provides it on occasion depending on the situation for known patients only. Two hospitals do not provide this service as it is provided by their local hospice.

Two hospitals provide on-site consultation outside of normal working hours for patients known to their service; a further two may do so very occasionally.

### **Funding**

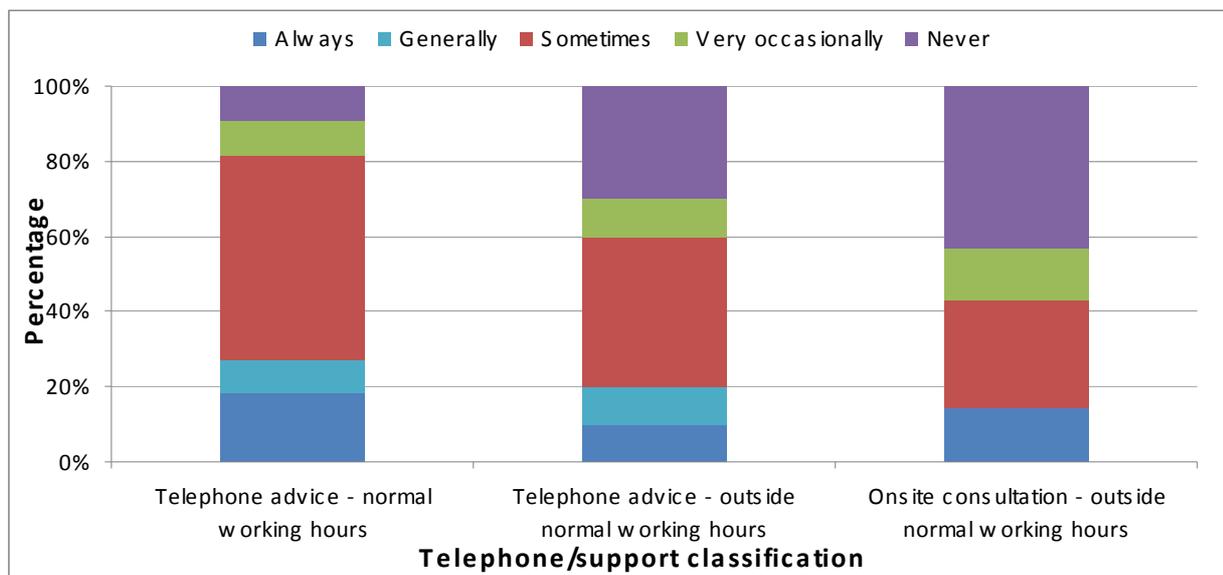
Telephone advice during normal working hours is funded for all but two hospitals; telephone advice outside of normal working hours is funded for only three hospitals. On-site consultation outside of normal working hours is funded for only one hospital-based palliative care team.

### **Recording of contacts**

Hospitals were asked if they recorded: (a) the number of contacts they had; and (b) the time involved with each contact. These results are presented in Figures 7 and 8 below, as a percentage of applicable responses.

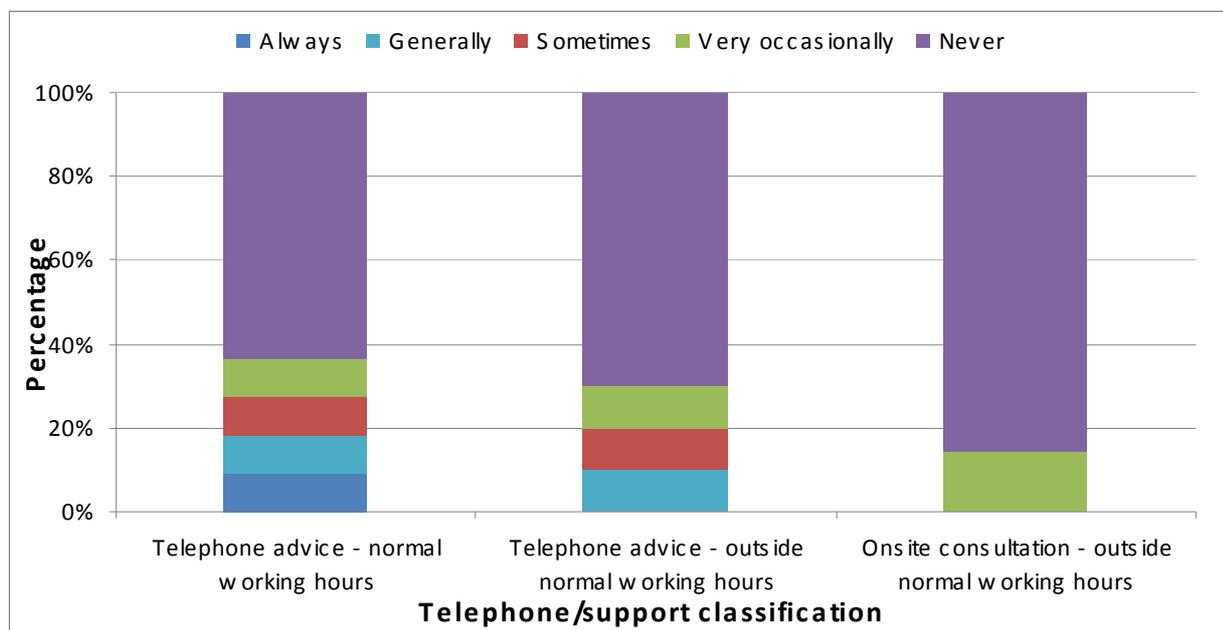
Only two hospitals always record the number of telephone contacts during normal working hours with another six doing so generally or sometimes. Two may do so occasionally and one hospital never records this information. Eight hospitals never record the time involved with each contact during normal working hours and the percentage is even higher for telephone advice and onsite consultation outside of normal working hours.

**Figure 7:** Percentage of hospital-based palliative care services recording number of telephone and support services, 2007/08



Note: Number of applicable responses to each question is as follows: telephone advice during normal working hours (11); telephone advice outside of normal working hours (10); and on-site consultation outside of normal working hours (6).

**Figure 8:** Percentage of hospital-based palliative care services recording time spent on telephone and support services, 2007/08



Note: Number of applicable responses to each question is as follows: telephone advice during normal working hours (11); telephone advice outside of normal working hours (10); and on-site consultation outside of normal working hours (6).

## Linkages

Generalists and specialist palliative care providers within each District will demonstrate formal links to one another for readily accessible advice, support, consultation, referral and education, and integrated and collaborative service planning, eg, via the District Palliative Care network.

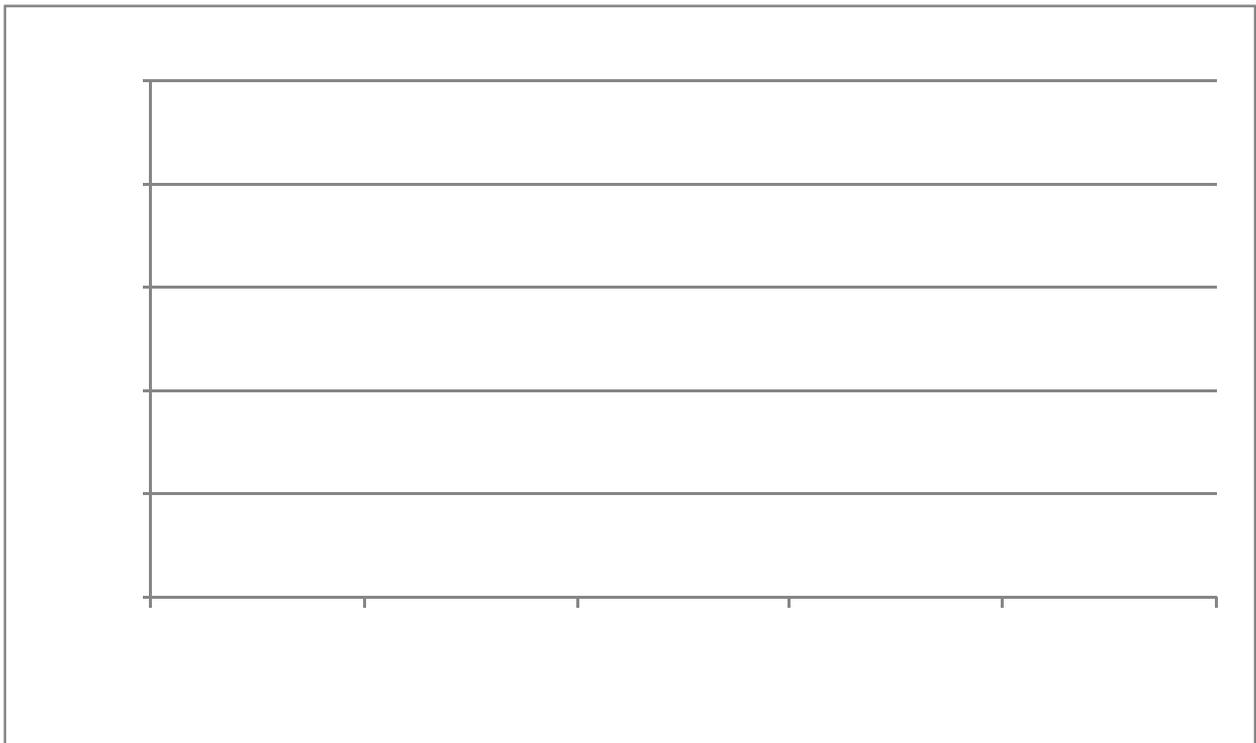
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## Hospices

### District/regional palliative care or cancer networks and other meetings/forums

Hospices were asked if they had links with either district or regional palliative care or cancer networks and other regular meetings and forums. The results are shown in Figure 9 below. Linkages with district palliative care networks and regional cancer networks (both reported by 18 out of 27 hospices, or 67%) were the most common.

**Figure 9:** Percentage of hospices with links to either district or regional palliative care/cancer networks and other regular meetings/forums, 2007/08



Other regular meetings include (but are not limited to) those with hospital-based palliative care teams, district nursing services, link nurses, regional children’s grief and loss network, national association for grief and loss, local iwi, Asian health services, regional rural palliative care network, primary care advisory network, chief executive officers and educators of Auckland hospices, Māori advocate organisations, paediatric working party, motor neurone disease network, Alzheimers Society, Pacific services and locality meetings to link generalist nursing and home care providers.

Specific forums identified include GP forum, primary nurse forum, palliative care nurse interest forum, aged care managers forum, and clinical governance forum.

In addition a couple of hospices have memoranda of understandings or have entered partnerships with primary health organisations (PHOs) and trusts.

However it should be noted that one hospice responded that ‘this area is still quite confused and fragmented’ and another commented that it has ‘representatives on both these groups [district palliative care network and local cancer network] but would not say we link for “integrated and collaborative service planning”’.

### Linkages with specified bodies/organisations/services

Hospices were also asked if they had effective and appropriate links with 11 specified bodies, organisations and services. The results are presented in Table 12. All hospices had effective and appropriate links with adult oncology services and disability support services. Only 16 hospices (59%) had effective and appropriate links with paediatric oncology services and tertiary-level education centres.

**Table 12:** Hospice linkages with identified bodies, organisations and services, 2007/08

Body/organisation/service	Number			% 'Yes'
	'Yes'	'No'	Unknown	
Adult oncology services	27	0	0	100
Disability support services	27	0	0	100
Older people/rehabilitation services	24	2	1	89
Provider arm community-based support services	24	3	0	89
Non-provider arm community-based support services	22	4	1	81
Laboratory diagnostic services	22	5	0	81
Transport services including district/regional ambulance providers	20	5	2	74
Pharmacy for out of hours access to medication	20	7	0	74
Diagnostic imaging services	19	7	1	70
Paediatric oncology services	16	7	4	59
Medical schools and other tertiary-level clinical education centres	16	9	2	59

## Linkages outside own DHB

Where all specialist palliative care service components are not provided within the district, linkages will be made to services within other districts as appropriate.

Draft tier two service specification

## Hospices

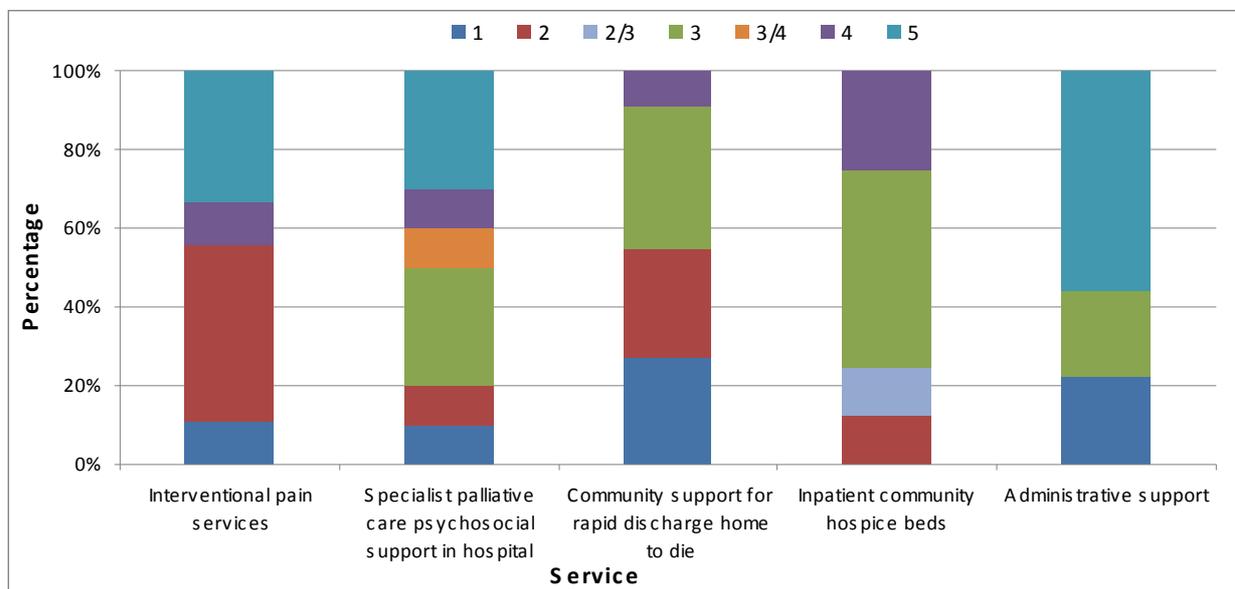
Just over half (14 out of 27, or 52%) of the hospices reported that they have links with DHBs for services not available within their own DHB. These services were predominantly related to oncology, radiotherapy and chemotherapy.

## Hospitals

Linkage questions for hospitals related to: (a) the availability of selected services for patients; and (b) the adequacy of selected support services for hospital-based palliative care staff.

Figures 10 and 11 below show the results. Administrative support is lacking for both patients and for staff (60% of hospitals in both cases). See the data on the workforce later in this section for more detail.

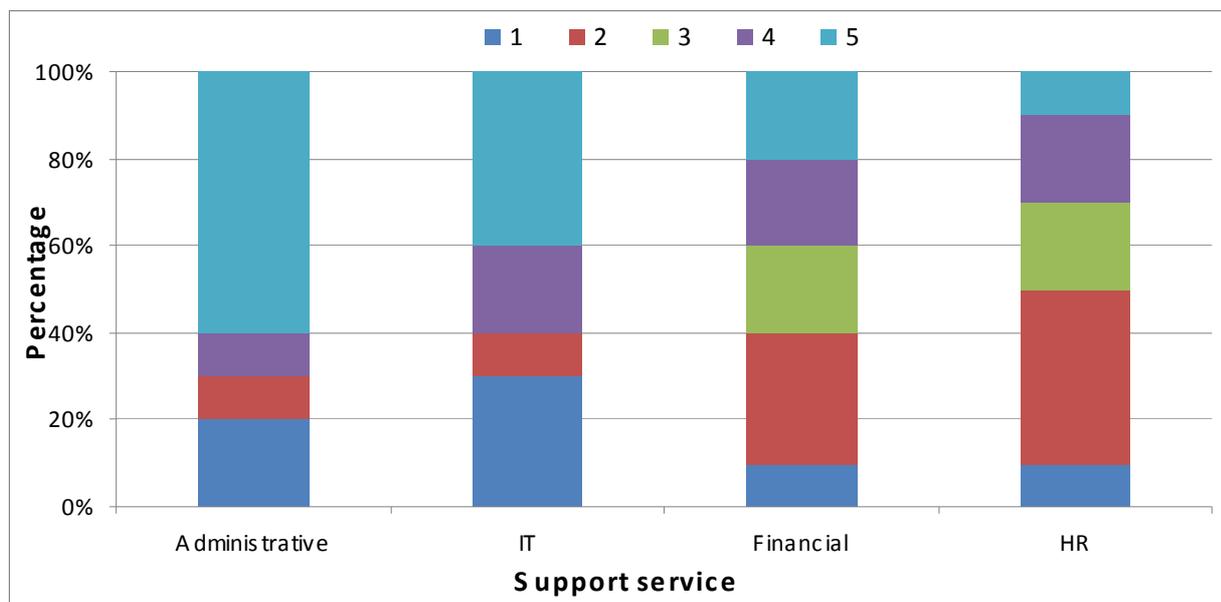
**Figure 10:** Availability of support services for hospital-based palliative care patients (rating expressed as a percentage), 2007/08



### Notes:

1. Ratings range from 1 = readily available to 5 = significant delays in availability.
2. The number of hospitals responding to each question is as follows: 11 on community support for rapid discharge home to die; 10 on specialist palliative care psychosocial support in hospital, 8 on inpatient community hospice beds; and 3 on the other three questions.

**Figure 11:** Adequacy of support services for hospital-based palliative care teams (rating expressed as a percentage), 2007/08



Notes:

1. Ratings ranged from 1 = adequate support, little clinical time taken up with this activity, to 5 = inadequate support, significant clinical time taken up with this activity.
2. 10 hospitals responded to all of these questions.

## Staff education

### Hospices

All 27 hospices support continuous professional development (CPD) and provide staff with release time. All but one hospice provide funding for study. All hospices provide ongoing support and education for volunteers.

### Hospitals

With hospital-based palliative care teams it is assumed that CPD for doctors is addressed under the national contract. Therefore staff education questions were directed to: (a) nursing staff; and (b) non-doctor, non-nursing staff. However, for most hospital-based palliative care teams, the latter category of staff is not applicable so responses about it are not reported here.

All hospital-based palliative care teams support CPD for their nursing staff. Ten hospital-based palliative care teams provide regular release time for CPD and the tenth does so sometimes. Eight hospital-based palliative care teams reported that they provided funding for study. Two do not provide it and the other reported that such funding is limited for nursing team members.

## **Registrar training**

### **Hospices**

Only hospitals were asked if they provided registrar training. However, from the workforce data it is evident that at least four hospices employed a registrar in 2007/08 as well.

### **Hospitals**

Seven hospitals provide registrar rotation for advanced training in palliative medicine. Of these, six provide rotation for general training and five advanced training in another specialty.

One hospital reported that providing positions for registrar training is one of its three workforce issues.

## **Management of patient data**

### **Hospices**

Ten hospices (37%) currently use or are transitioning to the Palcare patient management system. A further six hospices are planning to implement Palcare and two more are investigating this system. Potentially therefore up to two-thirds (18, 67%) of hospices could be using the same system. The timeframe for implementation of Palcare is not known for all hospices planning to implement it. Of the five hospices that did provide this information, one is planning to do so by the end of 2009, two within the first six months of 2010, and the other two have indicated between July 2010 and June 2011 as their timeframe for implementation.

Six hospices presently utilise MedTech. However, four of these hospices are either changing to Palcare or investigating the suitability of Palcare.

Six other hospices have no current plans to change their patient management system. Two of these have in place their own patient management system (two hospices); others are using a Filemaker program, Houston VIP patient management system, or Excel spreadsheets/Access database and paper-based system. A further hospice currently using an Access database and paper-based system is planning on implementing a new patient management system but has not yet decided which one.

Many of the hospices with electronic patient management systems also use Excel spreadsheets (11 hospices), Access databases (six hospices) or paper-based systems (15 hospices).

## **Hospitals**

One hospital did not respond to the question about the management of patient data. Of the nine that did respond, seven have palliative care services with links or an interface to their hospital's patient management system. The three hospitals without such links instead use a combination of Excel spreadsheets and paper-based systems (two hospitals) or an Access database (one hospital). These three hospitals plan to develop links to their patient management system but the timeframes are unknown as they are linked to organisational IT projects.

Of the hospitals with links to their hospital patient management systems, one is trying to develop its database to provide more reliable and accurate reports, another is to expand on the clinical information available, and a third has a system under continual development, and a fourth is developing an electronic discharge summary.

The hospital that did not complete the management of patient data component of the questionnaire commented that a service issue is 'lack of adequate IT systems available to palliative care for recording patient contacts outside of inpatient interactions directly under palliative care management'.

Data sharing among hospitals, community teams and hospices is an issue highlighted by one hospital. The questionnaire did not delve into data links among different providers of palliative care. However, it is known that in at least one DHB Palcare provides for data sharing among the hospice, GPs and hospital.

## **Reporting requirements**

### **Hospices**

Although the questionnaire did not ask directly about the proposed reporting requirements associated with the draft service specification, three hospices expressed concern about meeting these requirements. These requirements do not appear to be such an issue for those hospices with Palcare.

### **Hospitals**

Meeting the proposed reporting requirements is of concern to hospitals. One hospital wrote, 'our existing data base could be modified to collect much of the information sought. However, the gathering and entry of additional data adds to a currently high workload and additional support to meet data requirements would be needed'.

Hospitals also expressed concern about the data accurately reflecting the complexity and time involved in the provision of palliative care by hospital teams.

## Response times

Response time should be auditable in each locality.

Draft tier two service specification

As the questions relating to response times for hospices and hospitals were the same, the results for both groups are reported here together.

Table 13 below shows the number and percentage of hospices and hospitals that can audit their response times, breaking down this information by type of response. Note that one hospital did not answer this section of the questionnaire. Response times for referral to first assessment are most likely to be auditable in both providers. Response time for urgent telephone advice to generalist is least likely to be auditable in both hospices and hospitals.

**Table 13:** Hospices and hospital-based palliative care services with auditable response times by type, 2007/08

Response time	Hospice		Hospital	
	Number auditable	Percentage auditable	Number auditable	Percentage auditable
Referral to first assessment	24	89	9	90
Urgent telephone advice to generalist	16	59	3	30
Urgent face to face	18	67	7	70
Non-urgent face to face	19	70	7	70

Table 14 below shows that 15 hospices (56%) and three hospitals (33%) have auditable response times in all four response categories. In three hospices (11%) and one hospital, none of the four response times is auditable.

**Table 14:** Number of auditable response times for hospices and hospital-based palliative care services, 2007/08

Number of auditable response times	Hospice		Hospital	
	Number	Percentage	Number	Percentage
0	3	11	2	18
1	5	19	2	18
2	0	0	0	0
3	4	15	3	27
4	15	56	4	36

In providing reasons why they do not have auditable response times, eight hospices and three hospitals cite lack of an electronic patient management system or lack of capacity in the existing patient management system. Lack of a formal policy to record times or information simply being not collected is an issue for eight hospices and three hospitals. Another reason given by four hospices is a lack of staff training in policy to record times, including through lack of staff compliance and lack of computer skills. One hospice also cites lack of broadband coverage to access Palcare when out of the office. Three responses from hospitals identify impracticality and lack of support staff and clinical time.

## Equipment

Specialist palliative care providers will have explicit and agreed processes for obtaining equipment in a timely manner dependent on the situation of the district they serve in order to enable, where possible and realistic, a person to stay in their own home.

These explicit and agreed processes will ensure those with specialist palliative care needs will have access to include the following equipment:

- Home oxygen
- Stomal supplies
- Continence, iv, enteral and parenteral supplies
- Subcutaneous pumps and supplies
- Intraspinal analgesia pumps and supplies
- Lymphoedema bandages and hosiery
- General aids and equipment.

Purchasing, supply, and maintenance of equipment is outside the scope of this service specification.

Draft tier two service specification

## Hospices

Hospices were asked if they had explicit and agreed processes to ensure that those with specialist palliative care needs have access to the items of equipment listed above (with the exception of intraspinal analgesia pumps and supplies). Seventeen hospices have processes for all six equipment types, four hospices have processes for five, three hospices have processes for four, and three hospices have processes for three sets of equipment. One hospice did not have a process for any of the six sets of equipment queried. The equipment for which fewest hospices have a process in place is lymphoedema bandages and hosiery.

Only one hospice is funded to provide an equipment service.

## Quality

Each specialist palliative care service will have a continuous quality improvement programme which will include the following domains of quality:

- Effectiveness of service
- Consumer participation and feedback
- Cultural appropriateness
- Systems performance
- Safety of service.

It is recognised and encouraged that that more appropriate quality reporting requirements may be adopted in agreement with providers and purchasers as national standards are agreed, and new ways of service provision are addressed,.

Draft tier two service specification

Note that the exact text on quality in the service specification may be amended to be less prescriptive around the specific domains of quality identified.

## Hospices

### Formal quality programmes

Just over half of the hospices (14 out of 27, or 52%) are accredited to Quality Health New Zealand. A further six have one of the following:

- BVQ certification
- Q safe
- membership of the hospice network for quality and a contractor who provides quality advice and support
- a quality programme without subscribing to a formal accreditation programme although a quality consultant participates in a national quality group and processes are comparable with accredited hospices
- an international certification process under way
- an in-house/internally managed programme.

Irrespective of whether they have a formal quality programme, all hospices address the following domains of quality: consumer participation and feedback; systems performance; and safety of service. All but two hospices address effectiveness of service and cultural appropriateness.

## **Consumer participation**

In addressing consumer participation and feedback, all hospices have family, whānau and patient satisfaction surveys, and all but one address complaints management. Twenty-three involve family, whānau and patients in care planning. Six hospices have a consumer advisory group and a seventh plans to reactivate its group. Four have a consumer representative on their board (noting that in some other instances board members may have been consumers but they do not hold a formal consumer position).

## **Systems performance**

In addressing systems performance, all hospices have both annual and audited accounts. Twenty-one have continuous improvement systems and 16 perform system evaluations; a further hospice is working on addressing both these aspects.

## **Safety of service**

Safety of service is addressed by incidents and accidents reporting in all hospices, by staff training in all but one, by risk management in 25, and by health and safety plans in 24 hospices. Furthermore 16 hospices have exception reporting.

## **Effectiveness of service**

Effectiveness of service is addressed by GP feedback (17 hospices), feedback from residential care facilities (14 hospices), feedback from DHBs (13 hospices) and other external surveys (14 hospices). Other means of addressing effectiveness of service include self audit, other audits, focus groups and, in one instance, a research project.

## **Cultural appropriateness**

Among the 25 hospices that address cultural appropriateness, all have links with Māori health providers, 21 have kaumatua guidance, 21 hold cultural workshops, 11 have links with Pacific service providers and 10 have Māori service plans. Other ways of addressing cultural appropriateness as identified in the survey include having a Māori representative on the board (two hospices), Pacific service plans (two hospices), links with Asian health providers, a Māori liaison officer, cultural training (eg, certificate in Māori), Chinese guidance, hui, bicultural signage through building, a kaitakawaenga role in partnership with a local Māori health provider, a memorandum of understanding with a Māori charitable trust, and a Māori Health Plan Group.

## **Hospitals**

### **Quality improvement plans**

Again the scope of the questions for hospitals differed slightly to that for hospices. Hospitals were asked if they had an annual quality improvement plan. Six of the ten have such a plan. Of the other five, three plan to develop one.

Only one hospital has a quality improvement plan that is part of a district-wide quality plan for palliative care. Another hospital states that although it does not have a district-wide plan as such, it does liaise with its local hospice regarding quality.

## **Cultural appropriateness**

Cultural appropriateness was the only domain of quality about which hospitals were specifically questioned. All hospital-based palliative care services have links with Māori health providers, eight have kaumatua guidance, seven hold cultural workshops, six have Māori service plans and five have links with Pacific service providers (informal in one instance). Other means of addressing cultural appropriateness that hospitals reported include having the Whare Tapu Whā holistic model of care as the basis for strategy, working closely with staff from the Māori Health Unit, linking in with a hui organised by a local hospice, having Pacific service plans, and seeking consultation prior to meeting families from different cultural groups.

## **Prescriptions**

### **Hospices**

Just over half of the hospices (14 out of 27, or 52%) indicated that they have issues accessing certain medications and slightly more (17 out of 27, or 63%) indicated that they fund unfunded medications. Some specific issues they identified include:

- weekend and after hours access to medications including no after hours pharmacist or GP
- some GPs not agreeing to pre-emptive scripts
- out of stock issues
- downtime of the Electronic Special Authority system
- hospital patients not realising they may not be able to get their prescriptions filled straight away
- hospital discharging patients with a prescription that is free in the hospital but costs a lot in the community (eg, Tramadol)
- changes in availability of medications that meet patient need alongside of finding replacement drugs
- identification (by medical staff recruited from overseas) that some highly effective medications are not available in New Zealand.

Issues accessing medication, and funding of unfunded medications, were most commonly cited for the following medications; ketamine (14 instances), octreotide (13 instances) and fentanyl patches/injections (12 instances).

## Hospitals

It may be easier for hospitals to access certain medications; particularly those that are not on the community schedule as these are generally available to prescribers in the hospital. However, some District Health Boards run restrictive formularies that stop access to some medicines.

## Income and expenses

### Hospices

All 27 hospices provided information on their income and expenses. Some hospices reported caveats with their data which are noted; for example, one hospice reported data for the 2008 calendar year and another clarified that a large sum of included money was from the one-off sale of an asset.

This breakdown of income and expenditure reported via the gap analysis template will be used to inform the costing model. Of note is that costs have most likely risen since 2007/08 due to general increases in running costs, increases in wages and salaries, and changes in employer contributions to Kiwi Saver and the Accident Compensation Corporation (ACC).

### Hospitals

Hospitals provided information on income and expenses for four of the 11 hospital-based palliative care services, and another was able to provide information on costs relating to salaries and wages. The costs of several of the other hospital-based palliative care services are tied up with the other services in which they are based. Due to the small number of hospitals involved and because these data were collected largely to inform the costing of specialist palliative care, no figures are reported here.

## Volunteers

### Hospices

Volunteers provide a myriad of invaluable services to all hospices in New Zealand. These services include duties associated with the running of inpatient units (eg, administration, food services, cleaning, gardening), patient-related services (eg, complementary therapies, assistance with day stay programmes, biography service), transport in the community (patients, equipment), and grief and loss support (eg, chaplains, bereavement support). In many hospices, volunteers also provide a significant input to the hospice fundraising campaign, including through shop staffing.

The specific data collected in the gap analysis are not presented here. Instead, as well as informing the costing model, these data will provide a baseline against which to assess any future trends in volunteer services to hospices.

## Hospitals

No hospital-based palliative care services currently have positions filled by volunteers. It was considered relevant to ask about this input as a means of establishing a benchmark for future reference, as having volunteers in some hospital-based positions is a trend beginning to develop overseas.

## Workforce

The teams/services involved in providing comprehensive and interdisciplinary specialist palliative care may vary in the type and complexity of need that they are able to address, depending on the populations they serve and the funding available.

The precise workforce needs for specialist teams will usually be worked out on a specialist palliative care population based needs assessment. Their minimum requirements are:

1. For a hospital specialist service:
  - a. an accredited and registered palliative medicine specialist
  - b. a specialist palliative care nurse with specific training in palliative care
  - c. formal and specific access to allied health services
  - d. administration support
2. For a hospice:
  - a. access to an accredited and registered palliative medicine specialist
  - b. specialist palliative care nurses with specific training in palliative care
  - c. specialist psychosocial and allied health professionals (with palliative care training where available)
  - d. administration support
3. Paediatrics:
  - a. an accredited and registered paediatric palliative medical specialist
  - b. a specialist paediatric nurse with specific training in paediatric palliative care
  - c. paediatric psychological and allied health professionals (with paediatric palliative care training where available)
  - d. remit to work across the hospital/community continuum
  - e. administration support

In a hospital that does not have a specialist palliative care service, there should be formal linkages to external specialist palliative care services.

The specialist interdisciplinary team may also include additional medical and nursing staff as well as staff from the following disciplines: physiotherapy, occupational therapy, social work, spiritual care, dietetics, counselling, psychology, pharmacy, speech language therapy, art and music therapy, play therapy and complementary therapies.

Draft tier two service specification

## Hospices

### Specialists

Under the draft service specification, specialist level hospices require 'access to an accredited and registered palliative medicine specialist'. Throughout New Zealand this role is generally filled by palliative care specialists, medical officers special scale (MOSS) or GPs with special interest. However, recruitment and retention of such professionals is one of the major workforce issues for hospices. In this gap analysis, 15 hospices specifically identified this issue, highlighting that recruitment of such professionals is an issue not just in provincial centres but also in major urban centres; recruitment of a specialist in one major centre took over a year to fill.

The demand for palliative care specialists is set to grow with: the opening of several new inpatient units; the education and 24/7 support requirements of the new tier two service specification; the growing and ageing population; increasing life expectancy; longer palliative survival; and patients with higher acuity and multiple co-morbidities leading to more complex symptom management. A general shortage of GPs precedes a shortage of those with the time and commitment to train as GPs with a special interest in palliative care.

Several hospices reported that a related issue concerns pay parity with DHBs and multi-employer collective agreement (MECA) rates.

Some hospices are working together in an attempt to address the shortage in specialists. In Northland, where there are four hospices, the tertiary provider employs a specialist who is available to the other three hospices. Three other DHBs are also looking to appoint a (sub-) regional medical specialist.

In 2007/08, 12 hospices reported that they employed a palliative care specialist, between 0.35 to 2.7 FTE, averaging 1.35 FTE. Several other hospices also had access to a contracted or on-call specialist. In the same financial year, nine hospices reported that they employed a MOSS, ranging in FTE from 0.25 to 1.55 with an average of 0.9 FTE. Twelve hospices either employed or contracted a GP with special interest, with FTEs ranging from 0.1 to 3.9 and an average of 0.9 FTE. Four hospices had access to a registrar and several others had access to other medical staff.

### Nursing

Recruitment and retention of nursing staff with training in palliative care is another workforce issue for many hospices; several specifically highlighted it. In the majority of instances the nursing workforce is made up of part-time appointments which are often supplemented by casual staff. This arrangement can fragment service planning and delivery as one hospice highlighted in identifying this workforce issue.

In some instances a nurse may have more than one role; for example they may be part FTE as an IPU nurse and part FTE as a LCP facilitator.

Hospices were asked how many nurses they had with postgraduate qualifications. Of the 25 out of total 28 hospices that answered this question, all but one employed at least one nurse with postgraduate training, and three hospices employed between 20 and 24 nurses with such training. In total the 25 hospices employed at least 255 nurses with postgraduate training. Translating this number into a percentage of all nurses employed in the hospices is fraught with caveats as hospices did not report the data consistently. However, it is estimated that at least 45% of nursing staff employed by hospices within New Zealand have postgraduate training. Data for at least seven hospices indicate that 75% or more of the nursing staff in these hospices have postgraduate training.

The actual number of nurses by nursing type is not reported here but will inform the costing model.

As with specialists, achieving pay parity for nurses against the DHB MECA is a workforce issue for hospices.

Other workforce issues involving nurses include the workload for community nurses and professional development. Other more systemic comments that relate to nurses are reported under 'Systemic workforce issues' below.

### **Other members of the workforce**

The number of end of life care co-ordinators, social workers/counsellors/chaplains and educators for hospices have been discussed above (see 'End of life care programmes', 'Grief and loss support', and 'Education programmes for generalist and support services').

Thirteen hospices reported that they employed care assistants in 2007/08. At least one other hospice accesses such staff casually.

Not all hospices actually employ allied health staff (eg, physiotherapists, occupational therapists). Sometimes their services may be provided on a fee for service basis, contracted from a DHB or provided by a volunteer. A similar situation applies for human resource staff.

The majority of hospices employ staff in the roles of fundraising, administration and management. Lack of administrative support is not highlighted as an issue for hospices to the same extent as it is for hospitals. Note that in many hospices volunteers undertake some administrative tasks.

Other staff employed by some hospices include (but are not limited to) volunteer co-ordinators, quality managers, Māori liaison officers, pharmacists, complementary support therapists and family support co-ordinators.

Most hospices have experienced changes in their workforce since 2007/08. They provided details of such changes, which will be considered in the costing model.

## **Systemic workforce issues**

Hospices also raised the following systemic workforce issues:

- funding the cost of the workforce
- lack of funding leading to high workload requirements and poor staff morale
- need for a number of volunteers due to inability to pay full workforce
- recruitment of volunteers
- increasing demand on services
- succession planning
- reliance on ageing workforce (paid and volunteer)
- availability of trained palliative care staff in rural areas
- training staff new to palliative care in the community
- lack of cultural diversity within palliative care workforce
- maintenance of clinical competence/currency
- skilled aged care staff
- professional isolation
- acuity models to contribute to safe and effective staffing levels
- staff IT compliance and competency.

## **Hospitals**

Specialist and senior nurses make up the majority of the current workforce in hospital-based palliative care teams. As with hospices, recruitment and retention of specialists is an issue due to the lack of a competitive market and comparable remunerations.

## **Specialists**

With full employment, specialist FTE for the palliative care hospital services would range from 0.5 to 3.8 FTE. However the service with highest FTE requirements had a vacancy for a 1.0 FTE senior medical officer (SMO) at the time of reporting. Locums and MOSS have been employed to help address the shortage of specialists.

Four hospitals reported changes or anticipated changes to their specialist FTEs between 2007/08 and the end of 2009. Another hospital commented that these FTEs would need to increase to address after hours cover. Five hospitals commented on workforce issues in relation to general recruitment and retention of specialists, and another two commented on the need to address this in relation to 24-hour support.

## **Nursing**

The number of senior nurses (nurse practitioners or clinical nurse specialists) employed by hospital-based palliative care services ranges from 1.0 to 4.83 FTE. Three hospitals commented on workforce issues in relation to general recruitment and retention of qualified palliative care nurses. Another hospital commented on the lack of recognition of community palliative care nurses as specialists rather than as generalist district nurses.

## **Administration**

Three services reported that they employ an administrative resource, and another shares this resource with other services. As reported in 'Linkages' above, administrative support is a workforce issue for several hospital-based palliative care services. Six hospitals commented on administration-related issues, which concern: lack of dedicated administrative support; clinicians spending time on administrative activities; lack of administration support which reduces the ability to respond to clinical workload; and difficulties with attracting suitably qualified administrative staff.

## **Other members of the workforce**

The number of end of life care co-ordinators, social workers and counsellors for hospital-based palliative care teams have been discussed elsewhere in this report (see 'End of life care programmes', 'Grief and loss support', and 'Education programmes for generalist and support services') as has registrar rotation (see 'Registrar training').

The need to establish or extend other positions and disciplines within hospital-based palliative care teams was also mentioned. Positions identified include psychosocial support (three hospitals), grief and bereavement support (two hospitals), and occupational therapy, physiotherapy and play therapy/adolescent therapy. One hospital commented that although allied health staff are provided, they work on a rotational basis and the staff have no specific palliative care training. Providing positions for registrar training is an issue for one hospital.

## **Systemic workforce issues**

Hospitals also identified the following systemic workforce issues:

- succession planning
- availability of staff with the appropriate level of expertise for 'backfilling/cover' within the service
- funding and backfill to support professional development
- competing demands and time constraints presented by, for example, clinical work, service development, interfaces with other stakeholders and education on limited resource
- difficulties in covering distinct geographically separate hospitals
- inequitable delivery of paediatric palliative care across New Zealand.

## **Service issues**

The hospital gap analysis specifically asked for the top three service issues each service is facing and the responses are summarised below. As hospices were not asked this question directly, the issues for hospices reported below are sourced from other parts of the questionnaire.

## **Hospices**

The service issues that hospices highlighted include:

- current funding inadequate to provide the desired level of service
- desire for long-term sustainable funding
- lack of development to ensure sustainability
- managing and maintaining growth in service provision
- late referral practices increasing acuity
- meeting response times as community patient needs become more complex
- difficulty in providing urgent and non-urgent face-to-face support in rural areas
- inappropriate use of specialist palliative care because of lack of district nursing and general practice capacity to respond to palliative care needs, especially after hours
- acuity models to facilitate patient prioritisation and service provision
- working collaboratively with the hospitals to provide a seamless level of care and to be able to support the staff at the hospital with their palliative patients and families and whānau
- separation of the specialist and generalist roles will require a transitional phase and upskilling of the generalist provider through education and specialist support which is resource intensive and requires planned implementation
- transient nature of GPs
- absence of non-governmental organisations (NGOs) when some DHBs undertake service assessment and evaluation
- separation of governance and management
- improving quality systems and lack of policy and procedures development
- development and standardisation of clinical guidelines and medication guidelines in palliative care, with regular consistent reviews
- standardisation of administering medication via syringe drivers.

## **Hospitals**

Hospitals highlighted the following service issues:

- inadequate resource and funding for several areas already covered in this report
- resource issues in providing palliative care support to other DHBs who have no specialist palliative care service
- access to ancillary resources
- impact of under-resourced generalist community services – that is, lack of affordable 24-hour GP and district nursing support and 24-hour community specialist palliative care support – which results in unnecessary admissions and delays in discharge
- increasing referrals and increasing demand re service interfaces, education, networking and governance with no corresponding increases in staff

- ensuring team sustainability with demanding work and retention issues
- entry into the service can be limited due to the shortage of clinical resource – triaging of referrals becomes tighter and, although the response times are appropriate, the depth of service availability is limited
- changing culture within acute hospital environment towards earlier involvement of palliative care approach and services
- providing hospital-based palliative care for patients from DHBs with very variable community services
- the lack of availability of and access to in-home and out of home respite care for children and their families and whānau, which also highlights the need for more appropriate financial assistance
- tension between time allocated for clinical consultation and development of resources to support generalists (particularly out of hours)
- unable to protect non-clinical time
- obtaining a cohesive district-wide palliative care strategy including service development
- overall co-ordination throughout primary and secondary care and community
- difficulty in responding in a timely manner to national and local workstreams (despite desire to be involved) due to time constraints
- care co-ordination, in particular around appropriate discharge planning which is a significant part of the service and, if urgent, can be very labour intensive
- referrals not reflecting need
- recognition of requirement for local specialist palliative care service
- difficulty in establishing requirements within the new service specification for an intermediate-sized hospital and population.

## **Where to Next?**

This report represents Phase 1 of the broader project to determine the gaps in specialist palliative care provision in New Zealand. From here this report and the data from which it is derived will be integrated with the costing model, the individual gap analyses for each service provider and information reported via the DHB Planning and Funding templates.

Once all aspects are integrated, the Ministry of Health will work with the sector to determine how services can be assisted to collaborate both locally and regionally to address the gaps.