

# National Health Needs Assessment for Palliative Care

Phase 2 Report:  
Palliative Care Capacity and Capability  
in New Zealand

June 2013



PALLIATIVE CARE COUNCIL  
OF NEW ZEALAND

# Palliative Care Council of New Zealand

The Palliative Care Council of New Zealand was established in 2008 by Cancer Control New Zealand (formerly the Cancer Control Council of New Zealand) to provide independent and expert advice to the Minister of Health, and to report on New Zealand's performance in providing palliative and end-of-life care.

The research was conducted and this report was prepared by Wayne Naylor, Senior Analyst, Palliative Care Council of New Zealand.

## Acknowledgements

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The following organisations and groups were instrumental in providing data for the Health Needs Assessment:

- hospices and hospital palliative care services throughout New Zealand
- Hospice New Zealand
- Ministry of Health
- Royal New Zealand College of General Practitioners
- National LCP Office
- ElderNet.

Published in May 2013 by:  
Cancer Control New Zealand  
PO Box 5013  
Wellington 6145  
New Zealand

ISBN 978-0-478-40254-4 (print)  
ISBN 978-0-478-40255-1 (online)  
HP 5635

This report is available from the Cancer Control New Zealand website:  
[www.cancercontrolnz.govt.nz](http://www.cancercontrolnz.govt.nz)

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# Foreword

The Palliative Care Council of New Zealand was established in 2008 to provide independent and expert advice to the Minister of Health and to report on New Zealand's performance in providing palliative and end-of-life care.

In a document published in 2010 reflecting on the progress made on the Palliative Care Strategy for New Zealand, we emphasised a number of pressing concerns, including a lack of data on the need for palliative care for New Zealand's population, current service provision and service utilisation. Without evidence and data it is impossible for us to monitor and evaluate progress or to formulate strategic advice to the Minister of Health on initiatives to reduce inequalities in access to palliative care, or to improve the quality of the care provided.

In response to this situation we embarked on two major pieces of research. The first, the *National Health Needs Assessment for Palliative Care: Phase 1 Report* provided the first estimates in New Zealand of the need for palliative care on a national and regional basis. It was released in June 2011. We are now delighted to release the second part of this project, the *National Health Needs Assessment for Palliative Care: Phase 2 Report*, which deals with palliative care capacity and capability in New Zealand. It has been a considerable task, involving hospices and hospital palliative care services throughout the country, as well as organisations that hold data on primary palliative care provision.

The research was conducted by Wayne Naylor, and we are deeply grateful for the energy, commitment and care that he brought to the project. The research involved wide consultation, drawing on the knowledge of a strong Expert Advisory Group and with the close collaboration of the Ministry of Health. The Phase 2 report provides comprehensive new data, so that rather than relying on our individual impressions about the state of palliative care in New Zealand we now have hard evidence. We also understand more about what we don't know, about the difficulties of collecting data when there are no common definitions, and about the problems that arise when we attempt to compare information across different models of care.

The Council believes in encouraging a shared understanding of palliative care so that we can all collaborate and work towards common goals. This report provides a new level of understanding, a common and shared platform for all of us in palliative and end-of-life care. The fact that it raises more questions than it answers is exactly what we need at this time.

We originally planned to compare need and actual services and identify the gaps, but we found that comparisons between services or District Health Board (DHB) regions need to be interpreted with caution. We now know that further work will be required at a regional level to establish the current palliative care service capacity and capability with greater certainty. This report provides a baseline, a starting point for beginning to collect data on a more comparable and comprehensive basis.

Although new data on palliative care in hospices and hospitals was gathered, we have only just begun to develop a full understanding of the palliative services offered by primary palliative care providers. These include general practices, district nursing services, home health care agencies and aged residential care facilities. Our research focus in the next few years will be on addressing the gaps in our knowledge about primary palliative care providers and what their needs are for the future.

This Phase 2 report gives us a shared platform to further our understanding of the palliative care capacity in New Zealand at a specific point in time. We hope that all palliative care providers, as well as funders and researchers, will use this material as a new basis for their conversations and will probe the findings more deeply, asking tough questions and getting more complete answers.

Research is a process, not an event. We are already making plans to redo the first phase of the health needs assessment for palliative care once data and projections from the 2013 Census become available. We anticipate that we will also redo this Phase 2 assessment of capacity and capability in perhaps two years from now.

A handwritten signature in black ink, reading 'Kate Grundy' in a cursive script.

Kate Grundy  
Chair, Palliative Care Council of New Zealand

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# Executive Summary

Phase 1 of the *National Health Needs Assessment for Palliative Care*, completed in 2011, examined the key drivers of palliative care need in New Zealand and used mortality and hospital discharge data to develop estimates of palliative care need on a population basis. These estimates indicate a 24% increase in the number of people who might benefit from palliative care over the next 15 years.

Phase 2 of the *National Health Needs Assessment for Palliative Care* is primarily concerned with access to palliative care. It uses many sources of data from a multitude of organisations to present a comprehensive description of the specialist palliative care services provided by hospices and hospital-based teams. The project has also included an initial exploration of primary palliative care providers, including general practitioners, residential aged care, district nurses, hospitals and home health care providers.

## Primary palliative care providers

Around 80% of people who die from a life-limiting or life-threatening condition will be cared for by a primary palliative care provider. Around half of these will be cared for within the capability of the primary providers and the other half through a collaborative care arrangement with a specialist palliative care service.

At present there is no specific data on palliative care service provision by primary palliative care providers, so a number of proxy measures were used to provide an indication of capacity and capability. These proxy measures included readily available data from published reports and other data collections held by national organisations. Other indicators of the capacity and capability of primary palliative care providers that were investigated included end-of-life care pathway implementation, access to equipment, and education and training.

Overall, primary palliative care providers appear to have a reasonable level of capability. However, it is impossible to draw any firm conclusions because there is limited or no specific data for these services on the number or characteristics of the people who receive palliative care from them, the training and qualifications of staff providing palliative care, the quality of palliative and end-of-life care provided, or the satisfaction of patients and family/whānau with the services received.

## General practice

General practices are the key health service providers in primary care and are involved in the care of people in their own homes, as well as in aged residential care. Other surveys suggest that between 98% and 100% of GPs provide palliative care, yet palliative care is not formally recognised in the *Primary Health Care Strategy* (Ministry of Health 2001b).

In December 2011 there were 1069 general practices in New Zealand, of which 48% were accredited under the Royal New Zealand College of General Practitioners (RNZCGP) Cornerstone programme and thus met the palliative care indicator. Even with Cornerstone accreditation there is still no measure of the quality of the end-of-life care provided by GPs. The change in Cornerstone in the 2011–2014 version, including removing the specific end-of-life care indicator, is a concern for ongoing maintenance of the end-of-life care capability of GPs.

Three evaluation reports on primary care palliative care programmes were reviewed, revealing four common elements that were essential to the success of the programmes: a dedicated funding stream; initial full assessment and ongoing care coordination; specialist palliative care support; and mandatory education. In all three evaluations there was a significant impact of having specific funding available to GPs for the care of palliative patients.

The reduction in hospital admissions should also be seen as an important outcome, because this significantly reduces costs of care. In addition, the improved integration of primary care, secondary care and specialist palliative care providers is in line with current government strategies to enhance the patient experience through integration of services, especially for long-term conditions and care of the elderly (Minister of Health 2012).

### **Aged residential care**

A third of New Zealand deaths occur in aged residential care (ARC) facilities. In 2008, 23% of these deaths were from cancer, 40% from circulatory disease, 10% from respiratory disease, and the rest were from a variety of non-cancer causes. Over half of these deaths were in people aged over 85. Compared to 17 other countries, New Zealand has the highest level of deaths in ARC for people aged over 65 years, at 38%.

Studies show that ARC facilities are experiencing an increase in the number of people being admitted for end-of-life care and increasing use of ARC facilities as a care setting for older people when they are discharged from an acute hospital. The proportion of those judged to have a high level of dependency (based on a resident's mobility, continence and cognitive function) increased from 36% in 1988 to 56% in 2008. Given the increasingly complex needs of ARC residents and the fact that a large number of residents will die while in ARC, it is vitally important that these services be able to provide high-quality end-of-life care.

The Ministry of Health lists Certified Providers of Hospital and Rest Home Services that have achieved certification through HealthCERT, which is responsible for ensuring facilities provide safe and reasonable levels of service, as required under the Health and Disability Services (Safety) Act 2001. At present, all hospitals and rest homes need to meet the Health and Disability Services Standards 2008 (Standards New Zealand 2008). These Standards do not contain any specific requirements related to end-of-life care; rather, they focus on the different components of consumer rights when receiving health services.

Information was combined from the Ministry of Health list, a database maintained by Eldernet and a list of facilities using the Liverpool Care Pathway for the Dying Patient (LCP) for end-of-life care. It was found that there were 686 facilities with 35,010 inpatient beds, of which 13,512 were hospital beds (38.6%) and 21,498 were rest home / dementia beds (61.4%).

It was found that 63% of facilities report some level of palliative care being provided, and that this covers 71% of the residential care beds. Around one-fifth (19%) of facilities report having a palliative care contract, but there is no information on what a 'palliative care contract' means and which organisations contracts are with. Almost half of facilities (45%) were registered with the LCP National Office to use the LCP, although registration alone is not a measure of the impact of LCP implementation on quality of care at end of life. The provision at DHB level was found to be highly variable.

Although this review has provided some information on the preparedness of ARC to provide palliative care, much of the information is self-reported by facilities. Current data is insufficient to draw any firm conclusions about the delivery or quality of end-of-life care in ARC facilities. More specific data is required on residents' demographics, including mortality data, staffing (including numbers with additional training in palliative care), access to specialist palliative care support, and funding/contractual agreements for palliative care.

## Public hospitals

Based on mortality data reviewed in Phase 1 of the Health Needs Assessment, over a third of all deaths in New Zealand occur in hospital. People of Māori, Pacific and Indian ethnic groups are more likely to die in hospital, as are those from more deprived areas.

An important issue for people dying in hospital is that care is provided by staff who are generalists or who are specialised in areas other than palliative care. These staff will require an appropriate level of knowledge and skill in palliative care, as well as the support of a specialist palliative care service for complex patients.

Information on the provision of primary palliative care in public hospitals in New Zealand is very limited. It is possible to say that 14 of the 40 DHB public hospitals have access to a hospital palliative care service, although the availability and professional mix of these teams vary. It was found that 23 DHB hospitals had registered for the LCP, which may be an indication that these hospitals want to improve end-of-life care.

Information on the palliative care workforce in public hospitals is not available directly, but two surveys provide some insight into the numbers of nurses and doctors available.

- The Nursing Council of New Zealand workforce survey in 2012 identified 1423 nurses who reported that palliative care was one of their practice areas (two practice areas can be recorded). It was found that 914 nurses have palliative care as their main practice or employment setting, of whom 816 were registered nurses, 96 were enrolled nurses and two were nurse practitioners.

- In a 2010 survey by the Medical Council of New Zealand there were 84 doctors who indicated they were working in palliative medicine for at least one of their work types (43% specialists, 42% medical officers and 8% registrars). Of these, 54 said palliative medicine was their main work type. Of the 84 doctors who identified palliative medicine as one of their work types, 10 worked in a private hospital and 25 in a public hospital.

## District nursing services

Caring for palliative patients in their own home requires access to support and health care in the community. A core group providing this support and care are district nursing services. A Ministry of Health report in 2010 identified 65 separate district nursing services providing a wide range of home, clinic, and community-based health care services to their communities. While most DHBs employ their own staff, eight DHBs also contracted from a total of 32 non-governmental organisation (NGO) providers.

The qualified district nursing service workforce in 2010 consisted of 1286 registered nurses and 119 enrolled nurses. Most registered nurses and enrolled nurses work part time (on average 0.64 full-time equivalents, or FTE), so there are effectively 826 FTE registered nurses and 79 FTE enrolled nurses. Nine district nursing services also employed health care assistants (50 FTE).

Ninety percent of district nursing services provide palliative care in the community (excluding child health home care services). Some services are sole providers for their area, with remote support from a hospice specialist palliative care service. Where palliative care is not provided by a district nursing service, it is provided in the community by a local hospice palliative care service with a community nursing team.

Every DHB must fund a district nursing service in line with the Ministry of Health's *Specialist Community Nursing Service Specifications (DOM101: Community services – professional nursing services)*. It was found that 10 DHBs have contracts for the M80005 purchase unit: *Palliative Care – Community Services*. Of the district nursing services that provide palliative care, over half said they had established a shared care partnership with their local hospice service. This was the most common example of formal care partnerships, and was reported for 60% of district nursing services (32 out of 53).

Based on service delivery information, 14 DHBs have access to after-hours care by district nursing services, while seven DHBs do not. At the time this report was compiled this included: Bay of Plenty, Hawke's Bay, Northland, Waitemata, Counties Manukau, Auckland and Whanganui. Where after-hours services were available, most district nursing services indicated this was for acute essential palliative care needs only.

An area of concern was access to patient information, which is collected and stored by multiple health care providers (for example, Medtech for general practice, electronic hospital records for secondary care, InterRAI for Needs Assessment and Service Co-ordination, and PalCare for palliative care). These systems are not linked in most areas, or cannot all be accessed by health professionals providing care for a patient in different settings, including district nursing services.



There is no information on the number of palliative patients being cared for by district nursing services, nor is there any data on the quality or outcomes of care.

The 40% of district nursing services providing palliative care with no formal link to a specialist palliative care service is of concern, because these services may not be able to readily access specialist advice and support. The lack of after-hours access to district nursing services in seven DHBs is also concerning, because this is a time when many families encounter problems and there is usually no hospital or GP support available.

### Home health care agencies

Home health care agencies provide services for people who need support to live in their own home. These services can include personal care, household assistance, nursing care, carer relief/respite, and specialist care for people with complex health needs. Access to home health care may be fully funded by the Ministry of Health, the Accident Compensation Corporation (ACC) or a DHB, or it may incur a part or full charge to the patient/client. Access to subsidised services requires an assessment by a contracted assessment agency. A number of privately owned agencies provide home health care services.

It was found that all DHBs have access to one or more home health care agencies that indicated they are able to provide palliative care. This is usually by nursing staff providing direct care or care givers providing carer relief/respite. Some agencies provide their services through DHB, Ministry or ACC contracts, as well as offering private services, which are mainly home help/domestic assistance and personal care. This information is self-reported and there is no information on the number of people receiving palliative care from these agencies.

### End-of-life care pathway implementation

The hospice approach to palliative care has been developed into a variety of end-of-life care pathways designed to transfer the model to other settings. End-of-life care pathways are designed to guide the provision of care and standardise care for the dying person, irrespective of diagnosis or care setting.

The Liverpool Care Pathway for the Dying Patient (LCP) is the most widely recognised and used end-of-life care pathway internationally, having been implemented in different care settings across 21 countries. In New Zealand, national coordination of LCP implementation is managed by the National LCP Office, based in Palmerston North.

Using data from the National LCP Office, it was found that at the end of December 2011 there were 309 individual facilities registered. The majority (83%) of these were aged residential care facilities, followed by hospitals (7%), hospice (6%) and community (4%), which included district nursing services, hospice home care services or health centres.

Implementation of the LCP has not been consistent across DHB regions. Uptake appears to be higher when a large specialist palliative care provider or a large corporate aged residential care provider is the lead organisation. One hospice in Hutt Valley DHB has another end-of-life care pathway in place. A survey by the LCP Office of 99 GPs in 2012 found that 75% of respondents had used the LCP in their practice.

The LCP is an important advance in the care of people at the end of life outside of the hospice setting, and the establishment of the National LCP Office has been a key driver of LCP implementation in New Zealand. The National LCP Office is developing a database to collect information from individual organisations undertaking the LCP Reflective Data Cycle, which should in future provide a much more comprehensive national overview of LCP implementation and impact.

## Access to equipment

For palliative care patients who wish to be cared for at home, either by family members, district nurses, GPs, hospice staff, or a combination of these carers, there is often a need for specialist equipment. This may include a hospital bed, bathing and toileting aids, sliding sheets, walking frames or wheelchair, hoists, syringe drivers and oxygen concentrators.

All DHBs have equipment available for use by palliative care patients in the community, but arrangements for equipment supply vary between DHBs. In many DHB regions the local hospice supplies equipment to patients being cared for at home who are enrolled in the hospice programme. For palliative patients not under the care of a hospice, the DHB will usually provide equipment through their community care services or via a contracted supplier. There may be contractual arrangements with the Ministry of Health, ACC or individual DHBs.

However, the range of equipment available within each DHB is not known, nor is the volume of equipment used by palliative care patients.

## Education and training

There is limited information on the education and training undertaken by primary palliative care provider staff. Therefore, an attempt has been made to identify the education and training available to primary palliative care providers and, where possible, the number of attendees taking part in training or education opportunities.

The *Cancer and Palliative Care Nurses Education Needs Report* looked specifically at undergraduate and postgraduate nursing education. A survey of nursing schools found no specific palliative care modules in the undergraduate curricula, although topics such as pain management, grief and dying are included. Three postgraduate programmes (Certificate and Diploma) in palliative care nursing were identified.

The Royal Australasian College of Physicians (RACP) offers a Clinical Diploma in Palliative Medicine, which allows medical practitioners to spend time in palliative care as part of their vocational training and continuing professional development. The RACP also offers an advanced training programme in palliative care. Doctors who complete this programme are awarded a Fellowship of the Australasian Chapter of Palliative Medicine (FACHPM).

The Ministry of Health has developed and published a professional development framework for palliative care nursing in New Zealand (Ministry of Health 2008). This framework identifies a pathway for registered nurses to develop skills and knowledge in palliative care, and it can be linked to their professional development and recognition programme. While this framework was developed and published by the Ministry of Health, no specific implementation process or funding was allocated to it. However, Palliative Care Nurses New Zealand has taken on the task of implementing the Framework.

Hospice New Zealand currently provides three education programmes aimed at a range of health care staff, with a particular focus on primary palliative care providers. These programmes are provided through hospice educators throughout New Zealand using resources developed and provided by Hospice New Zealand. During 2011, 682 people attended the syringe driver competency programme and 452 attended the care assistant's education. A Fundamentals of Palliative Care programme was introduced in 2011.

Surveys of primary palliative care providers in hospitals and of GPs have consistently found a desire for more education and training in palliative and end-of-life care among these health care professionals.

There appear to be a reasonable number of postgraduate palliative care courses provided in New Zealand, although no data was available on enrolment numbers. Aside from the RACP programme, available postgraduate palliative care courses are multi-profession programmes, which is particularly important for allied health professions who have traditionally not had access to specialist palliative care qualifications.

The level of palliative care training in undergraduate courses for both nursing and medicine is difficult to ascertain but appears to be minimal. Given the need to ensure all health care professionals are able to deliver an appropriate level of palliative care regardless of setting, it would seem vital that palliative care become an integral component of undergraduate nursing, medical and allied health curricula.

## Palliative care services

Data on palliative care services was obtained by surveying all known palliative care services in New Zealand. The survey covered both hospice and hospital-based palliative care services and covered the period 1 July 2010 to 30 June 2011. It was found that there are palliative care services active in every DHB region, comprising 31 hospice services and 6 hospice supportive care services, and 14 hospital palliative care services, including one specialist paediatric palliative care service. There is at least one hospice service in all but two DHB regions (Wairarapa and West Coast). There is a hospital palliative care service located in most major DHB hospitals, run either by a dedicated team or via a hospice consultation service.

Previously there has been no identified core set of palliative care service components in New Zealand. However, during 2011 and 2012 both Hospice New Zealand and Hospital Palliative Care New Zealand undertook projects to describe the capability requirements, in relation to clinical and non-clinical functions and workforce, of their respective services. Comparisons were made between reported service provision and workforce and the service capability recommendations in the *Hospice Capability Recommendations* and the *Hospital Palliative Care Service Capability Framework*.

In both capability documents the functions and workforce roles are separated into three categories:

- **will have** services, which are considered the core functions and roles that a palliative care service will provide
- **will have access to** services, which are also core functions and roles but may not necessarily be provided directly by the palliative care service
- **could offer** services, which are functions and roles that could be provided if resources allow, but are not considered core to the delivery of palliative care.

## Hospice palliative care services

A hospice is not just a building; it is a philosophy of care. Hospices provide care for the whole person: not just their physical needs but also their emotional, spiritual and social needs. They also care for families and friends, both before and after a death. In New Zealand all aspects of hospice care are provided free of charge (Palliative Care Council 2012).

For the purpose of this report, three categories of hospice services were defined, based on the range of services provided and the type of staff employed:

- **comprehensive hospice palliative care services**, which provide community-based care and have a dedicated hospice inpatient unit
- **community hospice palliative care services**, which primarily provide community-based care but may also have access to inpatient beds in a residential care facility or community hospital
- **hospice palliative care support services**, which provide community-based support but do not employ qualified health care staff and so do not provide any clinical care – support is often provided by volunteers, and people receiving support are likely to be receiving clinical care from another hospice service or primary palliative care provider.

It was found that there were 37 hospice palliative care services spread over the 21 DHBs.<sup>1</sup> The majority of DHB regions (17/21) have access to a comprehensive hospice palliative care service, and in two DHBs (Waitemata and Nelson Marlborough) there are two comprehensive services. Those regions without a comprehensive service usually have a community hospice palliative care service, apart from Wairarapa and West Coast, where there is only a supportive care service. In these two regions community palliative care is provided by dedicated district nursing teams, and access to comprehensive hospice services is provided by a neighbouring DHB.

The model of care used by a hospice will have an impact on the number and type of staff they employ, the service components they offer, and how they interact with other health care providers. Models of care have evolved locally and there are variations on the main models of care, as follows.

<sup>1</sup> For the purposes of this report and for comparison to the *Health Needs Assessment Phase 1* report, Southern DHB has been separated into Otago and Southland regions to allow for easier population modelling and analysis of palliative care service data. These regions can be combined for a whole of DHB view.

- **Full service model:** the hospice service undertakes assessment, care planning and care of the patient and family providing all care components – physical care psychological and social support, and spiritual care. The service often also provides inpatient care and bereavement support. The service employs or has access to a range of staff, including medical, nursing, psychological, social and spiritual care and allied health.
- **Care coordination model:** the hospice will be involved in the assessment and care planning stages, but direct patient care is usually provided by a district nursing service and GPs.<sup>2</sup> The hospice may still provide inpatient care and family/whānau support, including bereavement.

Hospice services reported gaps in access to allied health professionals and psychological, social and spiritual care staff. The 'will have' staff roles were present in all comprehensive services, apart from a small number of services without a dedicated social worker or cultural advisor. Most comprehensive services had access to specialist medical roles, but only a few had access to allied health roles, such as occupational therapy, physiotherapy, pharmacist and dietician.

There were gaps in support for paediatric and young person palliative care. Only two-thirds of DHB regions have hospice services that report access to paediatric and young person palliative care. When available, this component of care is usually provided with the support of the National Paediatric Palliative Care Service at Starship Hospital, Auckland, or through working with a local paediatric service.

Most DHB regions have access to hospice outpatient and day care services (86% and 76%, respectively), but again this may be regionally limited and is much more likely to be provided by a comprehensive service.

Community hospice palliative care services also provide many of the 'will have' clinical functions, but there appear to be gaps in the provision of education (50% provide education), but in most cases this would be provided by the comprehensive hospice palliative care service in their region, and less than half reported using an end-of-life care pathway. All of these community hospice palliative care services reported having nursing staff, but availability of other roles varied, with only a third having a medical officer or GP, 25% a social worker and 42% a spiritual carer. Two-thirds of these services had counselling staff, a cultural advisor or a volunteer manager. Provision of the 'will have access to' functions was also variable; in particular, only 7 of the 12 services had access to 24/7 advice.

Across all functions and roles, hospice palliative care support services reported providing far fewer components of the hospice capability recommendations.<sup>3</sup>

<sup>2</sup> Some of the medical services may be provided by hospice GPs.

<sup>3</sup> The survey in this Phase 2 report included all measures thought useful to inform palliative care services planning and future needs. The *Hospice Capability Recommendations* were being developed at the time of the survey and so the Phase 2 report is not reporting directly against the final capability recommendations.

Respite care is available in all but two DHB regions and is commonly provided in an inpatient unit by comprehensive services (95%) or by carer respite at home (58%). Two-thirds of community palliative care services (67%) also have access to inpatient respite beds and 58% have access to carer respite at home.

Two-thirds of hospice services provide 24/7 home visiting and all but one (97%) provide a 24/7 telephone advice service. Telephone advice is predominantly provided by nurses (90% of hospice services), and medical staff are also often available. Several services also indicated they have the ability to provide advice by email. It was found that all DHB regions are able to access telephone advice from a hospice service.

From 1 July 2010 to 30 June 2011 comprehensive and community palliative care services received 11,298 new referrals and accepted 10,878 of these. On average, 4.2% of referrals are declined, with a range of 0–17.2%. Overall there were 13,821 patients receiving care from a hospice service during the survey period, as there were 3083 ongoing care patients at the start of the period.

An attempt was made to link the expected need for palliative care by DHB, as developed in the *Health Needs Assessment Phase 1* report, with the number of patients in each DHB as reported in this survey. Substantial differences were found in some cases. Some of the difference may be due to methodological issues in the estimates at a regional level, but this does not explain the large differences found.

Data on average length of care<sup>4</sup> could be supplied by 29 of the 37 services (78%). It was found that comprehensive hospice palliative care services (n = 17) had an average length of care episode of 127.6 days and a median of 135 days. The minimum length of care episode reported was 1 day and the maximum was 2761 days. Community hospice palliative care services (n = 8) had an average length of care episode of 113.3 days and a median of 103.5 days. The minimum length of care episode reported was 1 day and the maximum was 3554 days. The average length of care episode for hospice palliative care support services (n = 4) was not able to be determined.

All comprehensive services had an end-of-life care pathway in place. Almost exclusively this was the Liverpool Care Pathway for the Dying Patient (LCP), with two services (10%) using an alternative pathway. Five community hospice palliative care services (42%) also had the LCP in place, a further two (17%) were in the process of implementing the LCP, and five (42%) reported having no end-of-life pathway in place.

Providing education is one of the core components of a hospice palliative care service. As well as ensuring that hospice staff remain up to date, hospices also provide education and training for primary palliative care providers working in a variety of settings.

Comprehensive palliative care services deliver the majority of education, with the comprehensive services located in large urban centres tending to provide education to greater numbers. This may be a reflection of population size and the number of other

<sup>4</sup> The definition of average length of care was the average length of time a patient was cared for by the hospice service (in days), from admission date to date of discharge. This should not be confused with average length of stay (ALOS), reported on later, which deals with the length of in-patient stays.



health care providers in large centres, and also the size of the services, which may be able to better afford dedicated education positions.

### Inpatient beds

Data was obtained on the number, location and utilisation of inpatient beds that were designated and funded solely for the care of palliative patients (ie, resourced palliative care beds) during the period 1 July 2010 to 30 June 2011. Across all DHB regions there were 173 hospice inpatient beds and a further 15 palliative care beds used by hospice services located in aged residential care facilities (13) or hospital (2). Most inpatient beds are within DHBs containing a large urban area. DHBs that are predominantly rural (Lakes, Tairāwhiti, Wairarapa and West Coast) have few or no dedicated palliative care beds, and the beds that are available are located in an aged residential care or hospital facility.

An issue identified during the survey and highlighted in consultation feedback is that there are a number of inpatient beds available for palliative care patients that are not dedicated solely for palliative care but are accessed through a variety of funding streams and used on an as-needed basis. The funding is not consistent across DHB regions, and so obtaining detailed data on utilisation of these beds was not possible.

In the period of the study there were 3872 unique inpatient hospice admissions (ie, each patient was counted only once); 3708 of these were in the inpatient facility of a comprehensive hospice service, and 164 were in aged residential care or hospital beds funded by a community palliative care service. The hospice services that provided admission data (n = 22) cared for 12,099 patients during the same time period, meaning that 32% of patients had at least one inpatient admission.

During this same period there were 2735 repeat admissions, most of which were into a hospice inpatient unit bed, with a small number into aged residential care or hospital beds. When added to new admissions, this gives a total of 6612 admission episodes to hospice inpatient beds during the 12-month period.

Twenty-one services were able to provide data on average length of stay (ALOS) for their inpatient beds. The mean ALOS was 8.6 days, with a median ALOS of 8.3 days. The minimum reported ALOS was 1 day or less, and the maximum reported ALOS was 195 days.

The mean bed occupancy rate, which was calculated for all services that also provided ALOS data (n = 21), was 79%. For comprehensive hospice palliative care services only (n = 19), and excluding two outliers, the average bed occupancy rate was 77%.

An attempt was made to determine a national bed:population ratio for palliative care beds needed, and this was estimated to be 6.15 beds per 100,000 of the adult population in 2011. The 2011 bed:population ratio is quite different from 1998/99 data reported in the Palliative Care Strategy (Ministry of Health 2001a), which found a national ratio of 4.03 hospice beds per 100,000.

While the national bed:population ratio appears adequate and within the range suggested by international guidance, the distribution of hospice beds is not uniform across DHB regions, with many DHBs being well below the national ratio. How inpatient hospice beds are distributed across the DHB regions is influenced by a number of factors, such as the model of palliative care delivery in the region, funding and resource availability and community fund raising, ownership and expectations. Further work is required to determine an appropriate palliative care inpatient bed model for New Zealand, and then additional project work is needed at a DHB regional level to establish the best location and funding model for these beds to meet the needs of the local population.

## Community hospice care

All 31 comprehensive and community hospice palliative care services provide community-based palliative care programmes. All these services reported that they provide care in private residences or aged residential care, including some private hospitals. Three-quarters also reported providing palliative care in a hospital, although at a regional level this covered only two-thirds of DHBs.

In the period 1 July 2010 to 30 June 2011 hospice palliative care services reported undertaking 139,343 community visits and 139,926 telephone consultations.<sup>5</sup> This data does not include visits to palliative care patients by district nursing services, who provide a significant proportion of in-home care in some regions.

On average, comprehensive hospice services made 9.7 visits per patient, with a minimum of 1 visit and a maximum of 22. They also had an average of 11.6 phone consults per patient, with a minimum of 2 and a maximum of 25. Community hospice services had slightly higher averages, with 12.2 visits per patient and 14.5 telephone consults. The average varies widely between DHB regions.

The care of patients and families with palliative needs in community settings (home, residential care, etc) requires collaboration between palliative care services and primary and secondary care services to ensure a seamless patient journey. To this end, many hospice services have shared care agreements in place (either formal or informal) with other health care services. Shared agreements with district nursing services were reported by 58%, with general practices by 55%, with aged residential care facilities by 52%, and with hospitals by 45% of comprehensive and community hospice services.

## Day stay programmes

Day stay programmes include a range of day services that are provided at the hospice facility. Services covered in this section include activities-based programmes, outpatient clinics and day procedures. All of these services fall within the 'could offer' functions of the Hospice New Zealand capability recommendations so are not considered essential components of a hospice service. It was found that 22 services reported providing at least one type of day stay service.

<sup>5</sup> This is probably under-reported as some hospices do not capture this data.

Activity programmes were the most commonly offered type of day stay programme, and these were offered by 22 services (81%) that reported having day stay services. The second most common day stay service offered was outpatient clinics, which were provided by all but one (95%) comprehensive service and by 25% of community hospice services. Day procedures were only offered by 53% of comprehensive hospice services.

The number of day stay places could not be determined because data was very incomplete. Further work is required to better understand hospice day programme provision in New Zealand and to develop a national approach to day services for palliative care patients. Volunteers appear to be the backbone of staffing for day stay services.

### **Characteristics of hospice palliative care patients**

An attempt was made to examine the characteristics of hospice patients based on demographic and patient variables included in the Mortality Collection database (age, ethnicity, underlying cause of death and deprivation). Hospice services use a range of patient administration software and collect data in different ways, so not all patient variables in the survey were able to be reported by all services. Deprivation is not reported in hospice databases. In some cases hospice services have included all patients under their care during the period, while others have included only new patients. For these reasons, caution is advised in comparing hospice service and DHB-level data.

Hospices provided data on the age of 12,636 patients. More than three-quarters (78.8%) of hospice patients were over the age of 60 and almost a third (29.2%) were over age 80. Compared to the mid-range estimate in the Health Needs Assessment Phase 1 report, hospices cared for more 60–79-year-olds than the estimate (49.7% versus 41.1%), and fewer people over age 80 (29.2% versus 43.3%).

The 0–19 years age group made up only 1% of hospice patients (127 individuals) and 20–39-year-olds a further 2.5% (313 individuals). This reflects the small number of deaths in this group, as well as the fact that individuals in this age group are less likely to die from a cause where palliative care would be of benefit.

Data was provided on the gender of 11,707 hospice patients, and the proportions of this group were 49% male and 51% female: the same as in the general population.

Hospices provided ethnicity data for 12,064 patients. At a national level hospice services appear to be achieving a close alignment between the ethnicity of patients and the expected ethnic group proportions when compared to all deaths and the mid-range estimate. There were, however, a number of differences at DHB level that cannot be explained by missing data, and further work is needed.

Hospice services were able to provide diagnoses for 11,623 patients: 9163 (79%) of these patients had a cancer diagnosis, while the remaining 21% represented a variety of non-cancer diagnostic groups. Compared to the mid-range estimate of need, there is a much higher proportion of cancer patients receiving hospice care, indicating that a potentially large number of people with a non-cancer diagnosis are missing out on hospice palliative care. There is wide variation in the proportions of cancer and non-cancer patients receiving hospice care in the different DHB regions.

The single largest group of non-cancer patients who do not appear to be accessing hospice care are those people with cardiovascular diagnoses, such as ischaemic heart disease, congestive heart failure and stroke. Of note, HIV/AIDS patients now appear to be uncommon in palliative care, as demonstrated by their almost complete absence from both hospice patient data and the estimate of need.

Hospice services were asked to report the reasons patients ended their care episode (the time from acceptance of referral to discharge from service). For the 10,827 hospice patients reported on in the survey, 75% had their care episode end when they died, 17% were discharged and 4% had another reason for their care episode ending. A further 4% did not have a reason for their episode of care end recorded, but this was mainly in just three DHBs.

Place-of-death data was provided by 27 hospice services for 10,738 patients. Hospice patients most often died in a private residence (33.2%) or a hospice inpatient unit (25.1%). A further 20.7% of hospice patients died in residential care and 15.9% in hospital. Comparing hospice patients to the New Zealand population and the mid-range estimate, hospice patients are much more likely to die in a hospice or in a private residence.

## Hospital palliative care services

The establishment of hospital palliative care services was a key recommendation of the *New Zealand Palliative Care Strategy* in 2001. Hospital palliative care services provide both specialist palliative care when the needs of a patient/family exceed the capability of the patient's principal care team, and support to enhance the capability and capacity of primary palliative care providers.

Survey returns were received from 14 hospital palliative care services covering 12 DHB regions, including one specialist paediatric palliative care team in the Auckland DHB. There are six other hospital palliative care services in other DHB regions, but these are provided by a local hospice service (referred to as hospital in-reach services) and involve hospice staff providing a consultation service within the hospital. At the time of the survey there were three DHB regions that did not have a hospital palliative care service: Whanganui, Wairarapa and West Coast.

Hospital palliative care services provide many of the core, or 'will have', clinical and non-clinical functions described in the *Hospital Palliative Care Service Capability Framework*, and most services also reported having the suggested effective working relationships. All 14 hospital palliative care services reported providing a consultation/liaison service, which in the survey was described as the patient remaining under the clinical care of another service and the hospital palliative care service providing consultation and liaison services. This includes a 'second opinion', advice on a particular problem, case review or patient/carer education.

All hospital palliative care services reported having access to all of the important supportive multidisciplinary team roles ('will have access to' roles) and the key services. Hospital palliative care services reported limited resources to undertake or be involved in research activities. Only 8 of the 14 services had access to clinical supervision for

palliative care service staff, an activity that is considered vital for health care staff involved in end-of-life care.

Two areas where some services reported difficulties were access to bereavement support and discharge coordination. The two areas of difficulty in the 'will have access to' functions were the availability of private/quiet spaces for consultations and family meetings, and single rooms for dying or distressed patients/family.

Only a small number of services were able to provide any of the 'could offer' functions. Five services did not offer any of the functions and most others only two or three of the five functions. No service provided all of the 'could offer' functions; the main restricting factor was reported to be limited resources.

The availability of hospital palliative care services outside of normal working hours is variable and not as common as with hospice services. Almost half of hospital palliative care services reported no ability to provide after-hours telephone cover, which was reported to be related to limited resources. Only one hospital palliative care service provided an after-hours home visiting option. Five hospital palliative care services reported providing a 24/7 telephone advice service and a further service provided telephone advice during the weekend/evening.

During the period 1 July 2010 to 30 June 2011 hospital palliative care services accepted 7049 referrals. The number of referrals generally reflects the size of the DHB population, with larger DHBs having higher numbers of referrals. On average, 2.8% of referrals were declined.

Hospital palliative care services reported 19,861 patient contacts, giving an average of three contacts per patient, with a range of two to nine. Contacts are primarily patient consultations, but also include family consultations/meetings and electronic consultations (ie, by email), as a number of services could not differentiate these contact episodes.

Nine services were able to provide data on the average length of time a patient was cared for by their service (length of care episode), including the paediatric service. The average length of care episode for adult services was 12.6 days on a per service basis, with a range of 3.6 to 58 days. The minimum reported length of care episode was 1 day or less, and the maximum was 253 days.

The paediatric palliative care service's episode of care averaged 62.1 days, with a range of 1 to 260.5 days for children who died during the survey time period. This service noted that many children continue to survive (especially those with non-malignant conditions) and remain under the care of the paediatric palliative care service, and therefore can be under the care of the service for an extended period of time.

All 14 hospital palliative care services provided information on end-of-life care programmes, and six hospital palliative care services had an end-of-life care pathway in place. Five of these (36%) had implemented the Liverpool Care Pathway for the Dying Patient (LCP), and one service reported using an alternative pathway. A further four services (29%) were in the process of implementing the LCP, and four hospital palliative care services (29%) reported having no end-of-life pathway in place.

Ten hospital palliative care services reported providing education as a component of their service, but only four were able to give numbers of attendees (2278 total). The majority of reported education took place in hospital or tertiary education settings.

Only two hospital palliative care services reported having resourced palliative care inpatient beds within their hospital (in Waikato and Canterbury DHBs). There were 927 admissions to these beds during 1 July 2010 to 30 June 2011, almost all in Waikato DHB.

### Characteristics of hospital palliative care patients

Not all hospital palliative care services were able to provide data for all the patients in the survey and so the total number of patients differs for each variable. Hospital palliative care services (excluding the paediatric palliative care service) provided data on the age of 6172 patients. The age of hospital palliative care service patients is almost exactly the same as in hospice services, with over three-quarters of patients aged over 60 (78.3%) and nearly one-third aged over 80. A very small number of patients were aged under 19 (0.35%). The hospital paediatric palliative care service reported on 76 patients, 52 of whom were aged 0–9 (68%). Similarly to hospice services, hospital palliative care services cared for more patients in the 60–69 years age group and fewer in the over 80 age group when compared to the mid-range estimate.

Hospital palliative care services were able to provide data on the gender of 4858 patients, and the gender proportions of this total group were 49.4% male and 50.6% female, again very similar to both the overall hospice patient and mid-range estimate groups. The data on ethnicity needs to be interpreted with some caution as it is unclear which method of assigning ethnicity is used by each service. There appear to be slightly higher proportions of Pacific and Chinese Asian people and consequently a lower proportion of European people in the hospital palliative care service group.

Hospital palliative care services were able to provide diagnoses for 5605 patients, of whom 3626 (65%) had a cancer diagnosis and 1979 (35%) represented a variety of non-cancer diagnostic groups. As with hospice patients, it is notable that HIV/AIDS patients do not feature in hospital palliative care service data. The mid-range estimate had expected more people needing palliative care with a non-cancer diagnosis (57% of adults and 86% of 0–19-year-olds). There is a wide variation in the proportion of cancer patients receiving hospital palliative care services across DHB regions, ranging from 35% to 100%.

For the 6193 hospital palliative care service patients reported on in the survey, just over one-quarter had their care episode end when they died (26.8%); 45.7% were discharged from hospital to a variety of settings, predominantly their home (33.7%), and 19.3% had another reason for their care episode ending (including remaining in hospital but not in palliative care). Hospital palliative care services were unable to provide adequate data for full analysis of the place of death.



## Palliative care workforce

Across hospices and hospital palliative care services there were 1189 individuals employed and a total of 733.2 FTE (including vacancies). Most of these people are employed in hospices (645 FTE), and the largest group was nurses (530 FTE). Currently, staffing varies widely across DHB regions, as indicated by wide variations in staff numbers per 1000 patients and staff-to-patient ratios. There is variable access to many roles in both hospice and hospital palliative care services, especially palliative medicine specialists, allied health and psychological, social and spiritual care. These differences may be partly accounted for by the different models of care, but in most cases this would not be the main reason. These differences need to be explored in more detail and work undertaken to ensure appropriate access is available across all DHB regions.

Palliative care workforce projections have been explored as a potential component of this report, but due to methodological issues the available models were felt to be inappropriate for New Zealand. Instead, examples have been provided of how different models may be applied, while taking into consideration their deficiencies, and it is suggested that each DHB region explore its needs and models of care and develop appropriate and reasonable workforce requirements. The current palliative care project being undertaken by Health Workforce New Zealand should also be monitored, as it will provide important information on the future palliative care workforce and service delivery model.

## Recommendations

Recommendations are made to the Ministry of Health, the National Health Board and IT Board, Health Workforce New Zealand, DHBs, standards and education providers, researchers, and the Palliative Care Council.



# Introduction

## Background

The New Zealand Palliative Care Strategy (Ministry of Health 2001a) had a vision that all people with a life-limiting or life-threatening condition would be able to access essential palliative care services, that services would be delivered in a coordinated way, and that care would recognise the needs of specific population groups. In order to achieve this vision, nine strategies were proposed focusing on access to essential palliative care services, including establishing these services, quality requirements, workforce development, and the education of health care providers and the public.

Since the launch of the Strategy little has been done to evaluate its impact on access to high-quality palliative care. Although this health needs assessment did not specifically look at the impact of the Strategy, the findings do provide a reasonably comprehensive picture of palliative care provision in New Zealand's current health environment. Although, the lack of baseline measures means that any changes since 2001 cannot be clearly identified, the needs assessment does allow us to take stock and begin a process of ensuring palliative care will be available to all those who need it.

## The Phase 1 report

Phase 1 of the National Health Needs Assessment for Palliative Care (referred to hereafter as the HNA) examined some key drivers of palliative care need in New Zealand and used mortality and hospital discharge data to develop estimates of palliative care need on a population basis (Palliative Care Council 2011). The growing population and changing age demographic – towards an increasing elderly population – are likely to be the most important sources of increased palliative care need. Other population demographic factors that will affect how palliative care is delivered include the ethnic and religious diversity of the population, the number of people living alone and in residential care, and the relative deprivation of the population.

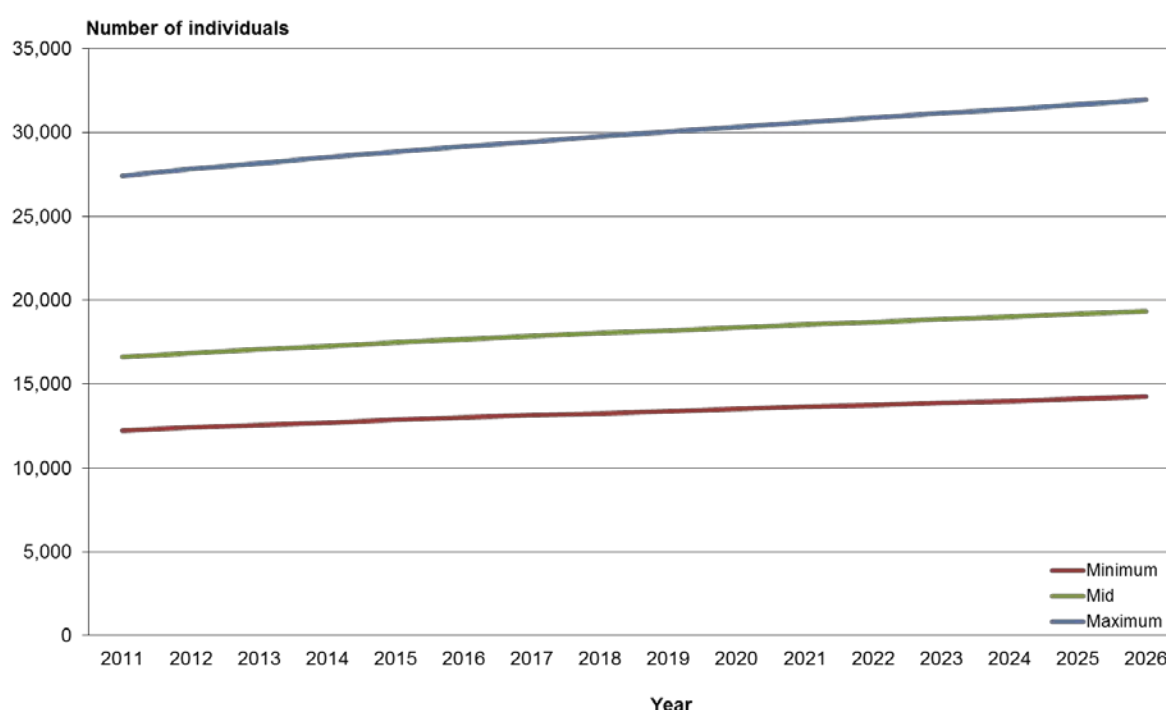
Based on mortality data and hospital discharge data from 2005 to 2007, and using a mid-range estimation model, it can be estimated that 15,452 adults (aged 20 plus) and 272 children and young people per annum would have benefited from palliative care during this time period. This equates to 518 per 100,000 adults and 23 per 100,000 children and young people a year.

Applying this estimate to the projected New Zealand population for 2026 shows that in 15 years' time we can expect the number of adults who would benefit from palliative care to increase by 23.5% to 19,076. The number of children and young people who would benefit from palliative care in 2026 is estimated to be 284, an increase of only 5%.

Projected growth in palliative care need from 2011 to 2026 is illustrated in Figure 1 for the adult group. The figure presents three different estimate models, all based on mortality data (and hospital discharge data for the mid-range) but using different inclusion criteria.

- The minimal estimate is condition specific and includes deaths from specific diseases considered likely to benefit from palliative care.
- The mid-range estimate includes people who had a publicly funded hospital discharge within the last 12 months of life for the same condition as that recorded as the underlying cause of death on the death certificate. This group is intended to represent a needs-based estimate, as the hospital admission indicated the person was suffering from ill health and the disease did not arise in the immediate period before death.
- The maximal estimate is the least restrictive estimate and includes all causes of death except those regarded as not amenable to palliative care. This estimate therefore excludes deaths related to pregnancy, childbirth and the puerperium, those originating during the perinatal period and those resulting from external causes.<sup>6</sup>

**Figure 1:** Projected population need for palliative care in New Zealand, 2011–2026 (adults)



In Phase 1 of the HNA project the Expert Advisory Group agreed that the mid-range estimate was likely to represent the best population estimate for the number of people who would benefit from palliative care in New Zealand. In this group most deaths were in those aged over 65 (78%) and in the European ethnic group, although the group included people of all ages and ethnicities. Both the Māori and Pacific ethnic groups had higher-than-expected numbers of deaths in the 0–19 years age group. In addition, a greater proportion of Māori and Pacific people died between ages 40 and 65 compared to the mid-range estimate group as a whole.

<sup>6</sup> See the HNA Phase 1 report for more detail on these three estimate groups.

Adults in the mid-range estimate group most commonly died from cancer (42.6%), but over 57% died from non-cancer conditions, such as circulatory and respiratory diseases. The children and young people mid-range estimate group contained a large number of children less than a year old who died from conditions arising in the perinatal period and from congenital conditions. If the under-ones are excluded, the main cause of death in this group is also cancer (32.8%), but, again, there was a much greater number of non-cancer diagnoses, in particular external causes of death (23.7%) and diseases of the nervous system (22.3%). The full Phase 1 report can be downloaded from Cancer Control New Zealand.<sup>7</sup>

### Levels of palliative care: some definitions

*Primary palliative care* is provided by all individuals and organisations that deliver palliative care as a component of their service, but whose substantive work is not the care of people who are dying. It is palliative care provided for those affected by a life-limiting or life-threatening condition as an integral part of standard clinical practice by any health care professional who is not part of a specialist palliative care team. Other terms that have been used to describe this level of care include 'generalist palliative care' or 'a palliative approach' (Palliative Care Council 2012).

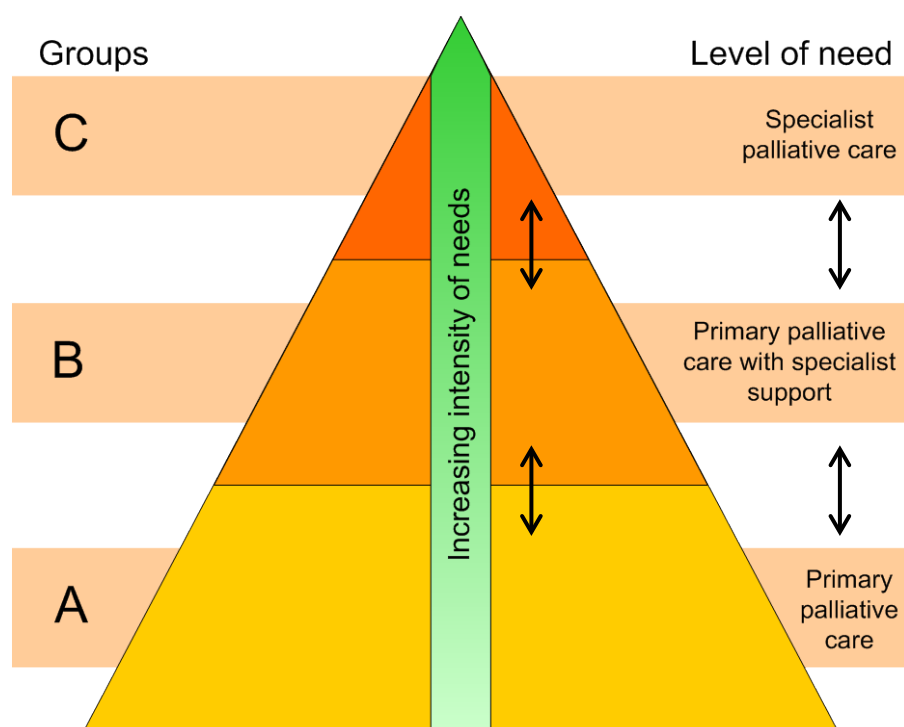
*Specialist palliative care* is palliative care provided by those who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals. Specialist palliative care may be provided by hospice- or hospital-based palliative care services, such that patients have access to at least medical and nursing palliative care specialists (Palliative Care Subcommittee 2007).

Given the already large and increasing number of people who would benefit from palliative care, it is important to remember that not all those with a life-limiting or life-threatening condition will require specialist palliative care. In fact the mid-range palliative care estimate excludes a large number of people whose death can be expected but who fall outside the inclusion criteria for this estimate. This group of people will still require end-of-life care but are unlikely to require specialist palliative care; rather, they can be cared for by a primary palliative care provider.

Palliative Care Australia has suggested that three groups of palliative care patients can be distinguished according to their level of need (see Figure 2). Note that people may move between the groups depending on their level of need.

<sup>7</sup> [www.cancercontrolnz.govt.nz/pub/national-health-needs-assessment-palliative-care](http://www.cancercontrolnz.govt.nz/pub/national-health-needs-assessment-palliative-care)

**Figure 2:** A model of palliative care need within a population of patients who have a life-limiting or life-threatening condition



Adapted from Palliative Care Australia 2005.

Note: Arrows indicate that patients may move between groups.

Group A consists of people who will require care at the end of life but whose level of care can be provided by their primary team, so long as the team is appropriately prepared and resourced to provide palliative care as a part of their standard clinical practice. This level of care falls under primary palliative care.

People in Group B will be cared for through a combination of their primary team and specialist palliative care. They are expected to experience sporadic exacerbations of symptoms and problems that will require access to specialist palliative care services for consultation and advice. Their care is delivered in a partnership model.

The smallest group, Group C, comprises people with complex end-of-life care needs, who will require direct, ongoing care from a specialist palliative care service. This group may still receive some care and support from their primary team as well.

The size of each group is not easily determined, but using figures suggested by Palliative Care Australia (2003), a broad estimate may be:

- group A: 10% of cancer deaths and 60% of non-cancer deaths (equivalent to 41.4% of all deaths)
- group B: 70% of cancer deaths and 30% of non-cancer deaths (equivalent to 39.8% of all deaths)
- group C: 20% of cancer deaths and 10% of non-cancer deaths (equivalent to 12.3% of all deaths).



Note that the total for all deaths included in this example is less than 100% because it excludes the 6.5% of deaths where palliative care is not feasible (eg, deaths that are sudden and/or unexpected).

These proportions should be considered an approximate split across the three groups, but it is worth noting that the number of people identified in the mid-range estimate in Phase 1 of the HNA is very close to the total number of deaths suggested for groups B and C (56.7% and 52.1%, respectively). In addition, the maximal estimate, which represents the ideal situation whereby all those whose death is expected receive palliative care, included all but 7% of deaths, which were the deaths for which palliative care was deemed unfeasible. Again, this is very close to the 6.5% of deaths not included in the Palliative Care Australia model. These similarities lend some credibility to the above group proportions.

Now that we have some understanding of the need for palliative care on a population basis, and how the need may be distributed across the population, the next step is to see how well this need is currently being met, where there are deficiencies and gaps, and what may be required in the future.

## **National Health Needs Assessment for Palliative Care: Phase 2**

Phase 1 of the HNA provided an estimate of the number of people who would benefit from palliative care and their characteristics. Phase 2 focuses on access to palliative care for those in need. It utilises several components that have been adapted from a framework developed by the National Council for Palliative Care in the United Kingdom (Tebbit 2004). These components are:

- mapping the palliative care services currently available
- identifying the core service components required to meet the identified need (from Phase 1)
- comparing the core service requirements to current service provision to identify service deficiencies and gaps
- developing recommendations and priority actions to address service deficiencies and gaps.

The final step of Phase 2 involved consultation with stakeholders to establish whether any further work needed to be undertaken for the needs assessment, and to facilitate discussion and agreement on the priorities for remedying the deficiencies revealed by the assessment and recommendations for service development.

## **Methodology**

Phase 2 is not just about specialist palliative care; it also looks at the provision of primary, or generalist, palliative care. As a result, data collection needed to cover both specialist palliative care services and measures of capacity and capability among primary palliative care providers. Because there is no specific data on primary palliative care provision, a number of proxy measures had to be identified that could provide a good overview of the ability of the wider health sector to deliver palliative care. Areas investigated included:

- general practice
- aged residential care
- public hospitals
- district nursing services
- home care agencies
- end-of-life care pathway implementation
- access to equipment
- education and training.

Where possible, information on the provision of primary palliative care has been extracted from administrative data that was readily available, having been collected by other organisations and in some cases published in reports (eg, accreditation data from the Royal New Zealand College of General Practitioners, and Ministry of Health data on aged residential care facilities and district nursing services). In some instances data was specifically requested from organisations. Each of the data sources for primary palliative care is identified and discussed in the relevant section.

Information on current palliative care service provision was not readily available at the required level of detail, so a survey tool was developed (using Microsoft Excel™) covering the relevant areas of interest for the HNA (see Table 1). The survey was reviewed by the Expert Advisory Group, Hospice New Zealand and several hospice chief executives and hospital palliative care service clinical directors before being sent out. Additional explanatory text and definitions were included in the survey to ensure consistency of responses.

**Table 1: Specialist palliative care service survey question topics**

<b>Service information</b>
1. Name and location of service
2. Functions of the service
3. Availability of team outside normal hours
4. Annual number of new patients
5. Total number of patients cared for ( <i>hospitals – total number of contacts</i> )
6. Average length of care episode
7. End-of-life care programme in use
8. Education programme provided
<b>Inpatient beds</b> ( <i>for hospitals, only if inpatient beds available</i> )
9. Number of palliative care inpatient beds available
10. Annual number of <u>new</u> inpatient admissions
11. Annual number of <u>repeat</u> inpatient admissions
12. Average length of inpatient stay
13. Bed occupancy rate
<b>Community care</b> ( <i>hospice only</i> )
14. Composition of the community care team
15. Total number of community visits
16. Services offered by community care programme
17. Where is community care provided
18. Who are shared-care agreements in place with

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**Day care programmes (*hospice only*)**

19. Composition of the day care team
20. Services offered by day care programme
21. Number of available day care places
22. Total number of day care attendances
23. Percentage of day care places used
24. Total number of different patients attending
25. Total number of new patients attending
26. Average length of a series of attendances

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**Patients**

27. Age of patients
28. Gender of patients
29. Diagnosis of patients
30. Ethnicity of patients
31. Reason for episode of care end
32. Place of death

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**Workforce**

33. Medical workforce
  34. Nursing workforce
  35. Allied health workforce
  36. Psychological/social/spiritual care workforce
  37. Volunteers (*hospice only*)
  38. Number of staff with postgraduate qualifications in palliative care
  39. Professional development programmes
- 

The specialist palliative care survey was sent via email to each palliative care service (hospice chief executives and hospital palliative care service clinical leaders) with a cover letter explaining the purpose of the survey.

In early 2012 two new documents were released outlining the recommended capability requirements for both hospice and hospital palliative care services. Hospice capability recommendations were developed by Hospice New Zealand with the support of all member hospices, and the Hospital Palliative Care Service Capability Framework was developed by Hospital Palliative Care New Zealand and endorsed by its membership. Because the functions and roles described in these capability recommendations had not been fully covered in the Specialist Palliative Care Service Survey, further short surveys were sent out to hospices and hospital services in order to be able to report on current service provision in the light of these new recommendations.

Where possible, data has been summarised by District Health Board (DHB) or as a total of all services combined. Summarising results by DHB also maintains consistency with Health Needs Assessment Phase 1 data reporting. Data has been grouped like this to provide DHBs with an appropriate level of relevant local data for population health planning, and also to provide a suitable level of data breakdown for central government planning. In some instances this may mean that services are identifiable if they are the only palliative care provider in their DHB region. For the purposes of this report, Southern DHB has been separated into Otago and Southland regions to allow for easier population modelling and analysis of palliative care service data. These regions can be combined for a whole of DHB view.

## Limitations of the data

The information presented in this report is considered to be a snapshot of one period in time, and extrapolation of the data may not provide accurate projections. This is because some services were not operating at full capacity during the survey period and others have developed their services since the survey was undertaken.

In addition, there appear to be a number of inconsistencies in how the survey questions were interpreted or how services defined different aspects of their service and staff. This occurred because there are currently no nationally consistent data definitions or dedicated collections for palliative care data. Data consistency was also affected by services using different data management systems, and some services had difficulties reporting the requested survey data because they did not have a specific patient database or were unable to easily extract the requested data.

Together, these issues mean that any comparisons between services or between district health board (DHB) regions must be interpreted with caution, and further work may be required at a regional level to establish current palliative care service capacity and capability. However, this Phase 2 report is the most comprehensive overview of palliative care service availability in New Zealand and should be considered a baseline from which we can develop a better understanding of palliative care need and service provision.

## Consultation process

The consultation period for the Phase 2 report ran from 16 August 2012 to 12 October 2012. Invitation letters were sent to a large number of stakeholder groups, organisations and individuals. The draft report, consultation invitation letter and feedback form were made available via the Cancer Control New Zealand website in the Palliative Care Council section, with a dedicated consultation page.

During the consultation period five meetings were held around the country in collaboration with regional cancer and palliative care networks in Auckland, Hamilton, Palmerston North, Wellington and Invercargill (with videoconference access to all South Island DHBs). The meetings included representatives from palliative care services, DHBs, residential care, and other health providers and consumer groups.

Along with feedback from the consultation meetings, there were 34 submissions received during the consultation period, including six individuals, seven organisations and 21 services (see Appendix 1). The feedback was generally positive and supportive of the report, but a number of concerns were raised about specific sections. Many submissions expressed unease about who would use the report and for what purposes, especially in relation to workforce planning and funding. There were also many additional comments that did not relate directly to the report but to general palliative care services.

The most common concerns revolved around three key areas.

- *Data:* many concerns were raised about data robustness, and a number of services included corrections to the data they had supplied for the survey. The lack of consistency in data collection and reporting by services was highlighted by many submitters. It was suggested that these data issues be made very explicit in the Phase 2 report.

- *Palliative care beds*: concern was raised about the definition of a 'resourced palliative care bed', and the fact that many other beds were accessed for palliative care through a variety of funding streams, and these had not been captured. Submitters also questioned the method for developing the bed projections, example bed numbers and regional allocation of palliative care beds.
- *Workforce projections*: many submitters requested that the workforce projections be removed from the report due to concerns about the methodology and potentially inaccurate data used in the projections. The main issue was the potential to project current inequities into future workforce numbers.

Following the consultation process, the submissions were summarised and presented to the Expert Advisory Group and Palliative Care Council for consideration. Changes to the draft report were agreed and have been incorporated into this final version. Feedback from submissions has also been used to shape the recommendations contained in this report.

## How to use this report

This report should be considered a baseline from which to further explore and develop an understanding of palliative care service delivery in New Zealand. There are a number of differences in how palliative care services are delivered, and this must be considered when interpreting the data presented here.

National-level data can be used for an overview and national strategic planning, but consideration must be given to regional variations in models of care and population characteristics, such as geographical distribution, age, ethnicity and deprivation. The data should be used to explore regional needs and to inform regional planning. Benchmarking can be undertaken, but it will be important to compare like with like if comparisons are to be made, or use national-level data as the benchmark.

Any data, tables or figures taken from this report must be referenced accordingly, including the dates the information was gathered. The report should be used in combination with other data collections, such as the Hospice New Zealand benchmarking project. More in-depth regional studies may be required to fully understand the needs of regional populations. Health care providers must work together to explore regional needs and to develop regional strategies in alignment with national priorities, regional and national strategic directions, and national guidance documents.

# 1 Primary Palliative Care Providers

In the context of end-of-life care, a primary palliative care provider is the principal medical, nursing or allied health professional who undertakes an ongoing role in the care of a patient with a life-limiting or life-threatening condition. They will deliver palliative care as a component of their service, but their substantive work is not in the care of people who are dying. Primary palliative care providers assess and refer patients to specialist palliative care services when the patient's needs exceed the provider's own capability.

Around 80% of people who die from a life-limiting or life-threatening condition will be cared for by a primary palliative care provider, and around half of these people will be cared for in collaboration with a specialist palliative care service. With the expected population changes over the next 20 to 50 years, resulting in a significant rise in the number of people who die from causes where palliative care would be of benefit, primary palliative care providers will be vital in ensuring access to quality end-of-life care for all. In order to meet this challenge, it is important to get an understanding of how and where people are receiving primary palliative care and the capability of primary palliative care providers to deliver high-quality palliative care.

Chapter 1 explores the capability and capacity of the wider health sector to provide primary palliative care. Unfortunately there is no easy way to measure the current level of primary palliative care being delivered, due in part to the diverse settings and providers involved in primary palliative care, but also because of a lack of research into this area of palliative care in New Zealand.

What we do know is that 34% of people die in hospital, 31% in residential aged care and 22% in private residences. In all of these settings care is provided by health care staff whose main work is not care of the dying: they are primary palliative care providers. These settings are the areas of focus for this chapter on primary palliative care, which uses the available data and reports to build a picture of palliative care capability in general practice, residential aged care, at home, and in hospitals.

## 1.1 General practice

### Introduction

General practices are the key health service providers in primary care and are commonly involved in the care of people in their own homes or in aged residential care. Although primary health care has a focus on prevention and health improvement, it also works across the care continuum, including the end of life. Unfortunately, this aspect of care is not formally recognised in the Primary Health Care Strategy (Ministry of Health 2001b), in which the main drive is to improve, maintain and restore people's health – which could be considered inconsistent with a palliative approach. However, it is essential that general practice teams are able to provide appropriate care for people with life-limiting or life-threatening conditions when treatment is no longer effective.



There is no data available on the number of dying people that general practice teams care for, although a survey of rural general practitioners (GPs) in New Zealand (Smyth et al 2010) found that 98% of the 186 respondents provided palliative care, and that over a 12-month period an average of seven palliative patients were cared for. In an unpublished GP survey conducted by the Palliative Care Council (2010), 100% of 61 respondents said they provided palliative care. Two-thirds of these GPs saw five or more palliative patients a year and 13% said they saw more than 20.

### Data source(s)

Because there is a lack of specific data, a number of other sources were investigated to determine the capability of general practice teams to deliver palliative care. The first source is the Royal New Zealand College of General Practitioners (RNZCGP) Cornerstone accreditation programme. This programme evaluates GPs against the *Aiming for Excellence Standard for New Zealand General Practice 2009* (3rd edition). This standard has a specific indicator for palliative care: 'C.8.2 The practice provides services to help patients and families with special care to meet end of life needs'. If a GP has achieved accreditation, then they are considered to meet the three criteria for this indicator, which are:

- C.8.2 – 1 The practice has a system to identify patients that have special end-of-life needs.
- C.8.2 – 2 All patients should be able to access their doctor or an informed deputy at all times.
- C.8.2 – 3 The practice can describe how it follows up patients, families or caregivers after a significant life event or bereavement if appropriate.

Accreditation follows a continuous quality improvement (CQI) process that comprises four separate assessments: a baseline snapshot, self-assessment, external peer review and a final post-CQI assessment. In between assessments, GPs carry out quality improvement activities based on the findings of each assessment.

A second source of data comes from three evaluation reports on primary care palliative care programmes currently in place in New Zealand. The reports have been reviewed to identify where and how the programmes are run and the important components of successful programmes. The three reports are:

- *Evaluation of the MidCentral District Health Board Palliative Care Partnership* (McKinlay & McBain 2006)
- *Evaluation of the ProCare & HealthWEST Palliative Care Programmes* (Adair et al 2011)
- *An Evaluation of the Palliative Care Primary Care Programme (PCPCP) in the Auckland District Health Board Region* (Winstanley 2011).

## Findings

In 2011 there were 1069 general practices in New Zealand; of these, 865 had registered with the Cornerstone programme. At the end of 2011, 111 GPs had withdrawn from the accreditation process and accreditation had expired for 65, leaving 510 (48%) still accredited and therefore meeting the palliative care indicator.

The RNZCGP conducted a review of Cornerstone accreditation data for the period January 2009 to July 2011, looking at changes in achievement of the three criteria indicators over the period of the CQI process. Figure 3 shows the changes during 2009/10. For GPs undergoing accreditation for the first time, the snapshot baseline assessment showed that, on average:

- 40% achieved C.8.2 – 1
- 62.5% achieved C.8.2 – 2
- 30% achieved C.8.2 – 3.

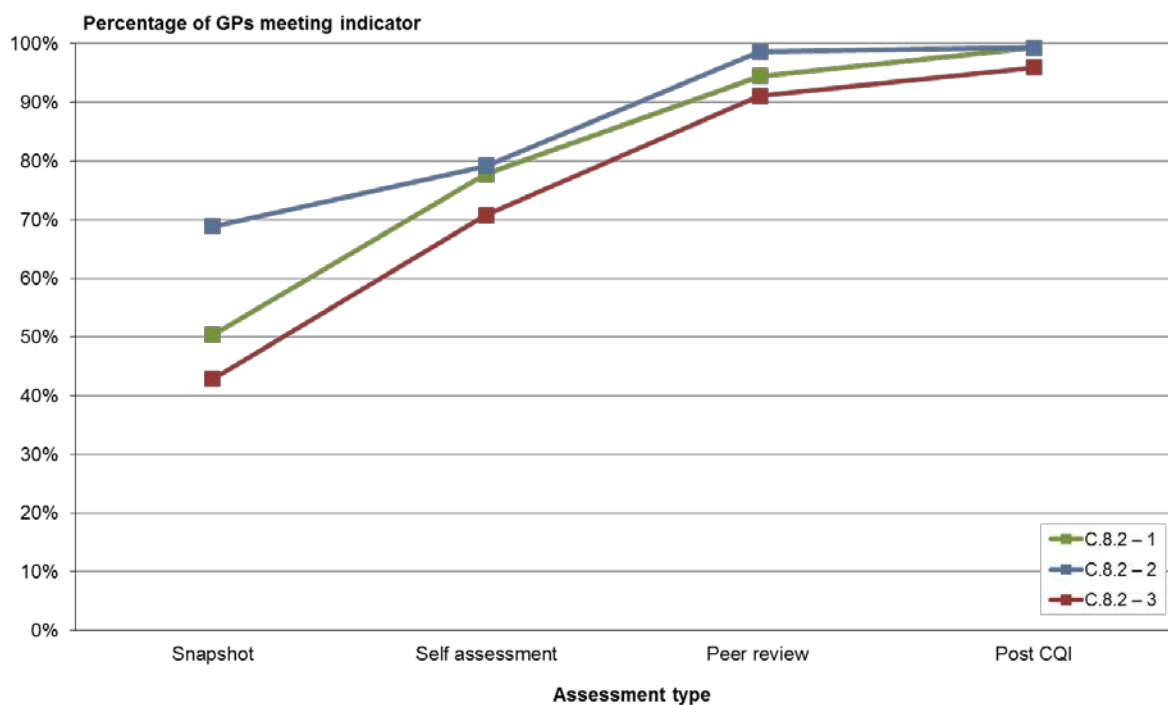
For those GPs being reaccredited, the snapshot baseline assessment found that, on average:

- 71.8% achieved C.8.2 – 1
- 82.1% achieved C.8.2 – 2
- 69.2% achieved C.8.2 – 3.

By the end of the CQI process almost all GPs in the Cornerstone programme had met the requirements for the end-of-life care indicator. Taking both first-time and reaccredited GPs together:

- 99.30% had achieved C.8.2 – 1
- 99.30% had achieved C.8.2 – 2
- 95.90% had achieved C.8.2 – 3.

**Figure 3:** Cornerstone accreditation: all accredited GPs, January 2009–July 2010



In the current version of the *Aiming for Excellence* RNZCGP standard for 2011–2014, the indicators have been revised and the previous one relating to palliative care has been changed. Instead, there is now only one palliative care criterion: ‘32.6 All patients with palliative care needs can access their doctor or an informed deputy at all times’. This sits under indicator 32: ‘The practice has processes to ensure continuity of care’. However, there is also now an opportunity for the development of a separate palliative care module that would allow GPs to specifically develop their palliative care expertise and have it recognised.

Although the Cornerstone data gives some indication of a GP’s preparedness to care for palliative patients, it does not provide any information on the actual delivery of care. However, the three evaluation reports on primary palliative care programmes provide excellent examples of how primary care can deliver high-quality palliative care. The reports cover four programmes in three separate DHBs: Auckland, Waitemata (two programmes) and MidCentral, and all used similar methods, including documentation reviews, surveys and interviews. The MidCentral report was published in 2006, while the Auckland and Waitemata reports were published in 2011.

Across the three reports there were four common elements that were found to be essential to the success of the programmes:

- a dedicated funding stream – this allows GPs to see patients free of charge, including home visits and extended consultations
- an initial full assessment and ongoing care coordination – in two programmes GPs undertake this role, while in the third it is a palliative care coordinator based in a hospice; two programmes also incorporate Advance Care Planning as part of the initial consultation

- specialist palliative care support – in all programmes this is provided by a local specialist palliative care service, either hospice or hospital based
- mandatory education – any GP wishing to register in the primary palliative care programme must undertake a standardised education programme, and education sessions are supported by a resource package in all programmes.

Involvement of practices in the programmes averaged 70% (range 58% to 84%) of general practices in the DHB region enrolled in the programme. Reasons for non-participation in the programme were reported in only one evaluation and included complaints that the remuneration was inadequate and the paper work required was too onerous, although the GPs involved in the programmes who were interviewed for the evaluations did not find these aspects to be barriers.

All GPs interviewed for the programme evaluations stated that they considered palliative care to be an integral part of general practice. All agreed that access to specific funding for palliative patients was extremely important to the success of the programme: it was a relief for patients and families, and it allowed GPs to conduct extended consultations and undertake home visits without concern for loss of income.

In all programmes the average cost per patient was well below the agreed maximum. In addition, the number of hospital admissions was reduced, because GPs were better able to provide after-hours care and home visits. The closer working relationship with the local specialist palliative care service also improved the integration of services by promoting better communication and information sharing, and by encouraging a sense of collegiality.

## Discussion

Fewer than half of GPs in New Zealand have undertaken the Cornerstone accreditation programme, which includes an end-of-life care indicator. Those who do complete accreditation demonstrate a high level of compliance with the end-of-life care indicator, suggesting that the three criteria for this indicator are relevant and achievable. For the 52% of GPs who have not undertaken accreditation, there is no way to determine their preparedness or commitment to delivering end-of-life care. Even with Cornerstone accreditation there is still no measure of the quality of end-of-life care provided by GPs. The change in Cornerstone, including removing the specific end-of-life care indicator, is a concern for ongoing maintenance of the end-of-life care capability of GPs.

The primary palliative care programme evaluations have demonstrated how the programmes positively influenced the delivery of palliative care in the primary care setting and also highlighted the key components that enabled this success. Of significance in all three evaluations was the impact of having specific funding available to GPs for the care of palliative patients. The reduction in hospital admissions should also be seen as an important outcome, as this significantly reduces costs of care. Finally, the improved integration of primary care, secondary care and specialist palliative care providers is in line with current government strategies to enhance the patient experience through integration of services, especially for long-term conditions and care of the elderly (Minister of Health 2012).

## 1.2 Aged residential care

### Introduction

A third of New Zealand deaths occur in aged residential care (ARC) facilities. Of the 8818 deaths in ARC in 2008, 23% were from cancer, 40% from circulatory disease and 10% from respiratory disease; the rest were from a variety of other non-cancer causes. Over half of these deaths were in people aged over 85. Compared internationally to 17 other countries, New Zealand has the highest level of deaths in ARC for people aged over 65 years at 38%,<sup>8</sup> followed closely by Iceland at 37.9%, then Australia and Canada, both at just over 32% (Broad et al 2012).

The palliative care population estimate from Phase 1 of the HNA suggested that just under half of those who die in ARC would benefit from palliative care (approximately 3900 deaths per year). However, the maximal estimate, which represents the ideal situation where all those whose death is expected receive palliative care, includes 97% of all ARC deaths, indicating that almost all ARC residents will require palliative care at the end of their life. It is likely that 50% would benefit from specialist palliative care advice and support, while the other 47% could be managed by the ARC facility, which should be able to provide a generalist level of palliative care.

**Table 2: Place of death for those aged over 65 in New Zealand, 2008**

	Hospital	ARC	Private residence	Hospice	Other	Total
N	7587	8406	4052	1194	958	22,197
%	34%	38%	18%	5%	4%	100%

Source: 2008 Mortality Collection data

A national survey of ARC facilities in 2004 found that there were a number of issues affecting the provision of palliative care by aged-care services (Mitchell 2004); 377 facilities responded to the survey, a 33% response rate. Although ARC facilities reported experiencing an increase in the number of people being admitted for end-of-life care rather than long-term placement, the ability of the facilities to provide good palliative care was being hampered by:

- a lack of qualified health care staff
- a lack of staff with palliative care training or qualifications
- high patient-to-staff ratios
- limited educational opportunities in palliative care, especially for health care assistants
- limited access to syringe drivers
- limited access to specialist palliative care nurses
- inadequate funding available to provide the level of care required
- low uptake of advance directives.

<sup>8</sup> Table 2: Place of death for those aged over 65 in New Zealand, 2008.

Some positive findings were that facilities and equipment were generally available for palliative care patients (apart from syringe drivers), and 70% of respondents said they had access to 24-hour palliative care advice. Respondents also identified priorities to improve palliative care, which included staff education, development of palliative care multidisciplinary team (MDT) (including higher registered nurse ratios), access to specialist equipment, and adequate funding for palliative care patients. However, although ARC staff wanted to care for dying residents and keep them in the facility, the lack of knowledge, resources and funding commonly led to residents being transferred to a different service, often a public hospital, when their symptoms became too complex for staff to manage.

A recent report examined the changes in the characteristics and dependency of ARC facility residents from 1988 to 2008 in the Auckland region (Boyd et al 2009); 153 facilities responded to the survey (a 90% response rate). The proportion of those judged to have a high level of dependency had increased from 36% in 1988 to 56% in 2008. In this study a judgement of dependency was based on a resident's mobility, continence and cognitive function.

In addition to the increasing dependency of residents, data from 2008 shows that 12.4% of residents had an average length of stay of less than three months and 35% a length of stay of less than a year. This shorter length of stay may reflect an increasing use of ARC facilities as a care setting for older people when they are discharged from an acute hospital setting and require end-of-life care. Indeed, the survey found that 46% of residents in ARC palliative care beds had been admitted from a public hospital. Across all ARC facilities 38% of residents were admitted from a public hospital.

Residents in designated ARC palliative care beds had the second highest reported level of urgent hospitalisations at 8% (the average was 4% for all facilities). They were also the most likely to need an unscheduled GP visit: 21% compared to 13% of residents across all facilities.

Given the increasingly complex needs of ARC residents, and the fact that a large number of residents will die while in ARC, it is vitally important that these services be able to provide high-quality end-of-life care. Once again, though, there is very limited information available on care of the dying in ARC, so some alternative measures of capability were sought, including whether ARC providers state that they provide palliative care, whether they have a contract to provide palliative care, and whether they have implemented an end-of-life care programme.

## Data sources

Data on ARC services, including private hospitals and rest homes/dementia units, was accessed from the Certified Providers of Hospital and Rest Home Services (Ministry of Health nd). This source contains information about all those providers that have achieved certification through HealthCERT, which is responsible for ensuring hospitals and rest homes provide safe and reasonable levels of service for consumers, as required under the Health and Disability Service (Safety) Act 2001.

Services seeking certification need to demonstrate that their service complies with all relevant approved standards. At present, all hospitals and rest homes need to meet the Health and Disability Services Standards 2008 (Standards New Zealand 2008). These standards do not contain any specific requirements related to end-of-life care; instead they focus on the different components of consumer rights when receiving health services.

The Eldernet website ([www.eldernet.co.nz](http://www.eldernet.co.nz)) contains a nationwide directory and information about a range of health services for older people, including rest homes, retirement villages, residential care, private hospitals, dementia care and public hospitals. The website is primarily designed as a resource for the general public to find information about residential and community-based care services. The web-based database allows facilities to enter and update their own information. Although Eldernet tries to ensure the information is accurate, it does not guarantee its accuracy. However, surveying all ARC providers was not within the scope of this project, so the Eldernet database was used to obtain information on individual ARC facilities, specifically looking at the provision of palliative care.

The database includes information on the location and type of service, other services provided, personnel, specialities and areas of expertise, and other features available. There are four options for facilities to indicate whether they provide palliative care: two options under the heading 'Specialties or Areas of Expertise – Palliative Care and Specialist Palliative Care', and two under the heading 'Features – Palliative Care Provided and Palliative Care Contract'.

Information on end-of-life care pathway implementation in ARC facilities has been taken from the *LCP Status Report, New Zealand, December 2011* (LCP National Office 2011); see section 1.6, 'End-of-life care pathway implementation' for more detail on this publication.

## Findings

A list of ARC providers was drawn from the Certified Providers of Hospital and Rest Home Services and matched with data from the Eldernet database and the *LCP Status Report*. Because it was unclear how facilities were allocated into each palliative care group, all four response groups were collated into an overall Palliative Care Provided group, as it was assumed that any response to one of the options indicated that palliative care was provided at some level. In addition, any facilities that were registered with the LCP (the Liverpool Care Pathway for the Dying Patient, see section 1.6) but had not indicated on the Eldernet database that they provided palliative care were also included in the Palliative Care Provided group.

A total of 686 facilities were included in the analysis, representing 35,010 inpatient beds, which were divided into 13,512 hospital beds (38.6%) and 21,498 rest home / dementia beds (61.4%). Table 3 summarises data on self-reported palliative care provision by ARC at a national level. Sixty-three percent of facilities reported some level of palliative care being provided, and these facilities contained approximately 71% of the residential care beds. Around one-fifth of facilities reported having a palliative care contract (19%), but there was no information on what a 'palliative care contract' means and which organisations the contracts are with. Almost half of the facilities (45%) were registered with the LCP National Office to use the LCP, although registration alone is not a measure of LCP implementation, so it is unclear how well the LCP is being used by these facilities.



**Table 3: Palliative care in ARC: a national overview**

ARC has:	Palliative care provided	Palliative care contract	LCP registration
No. of premises	432	133	309
% of all premises	63	19	45

Note: N = 684.

Table 4 gives a breakdown of this data into DHB regions, including the number of certified premises within each DHB region. Palliative care provided ranges from 41% to 88%, compared to the national average of 63%. The percentage of premises providing palliative care does not appear to be influenced by the size of the DHB, the number of ARC premises or the presence of a hospice. The percentage of premises that report having a palliative care contract also varies quite widely, from 0 to 58%. Again there does not appear to be any particular factor that determines how many ARC premises have a palliative care contract within a DHB.

There is also a wide range in the percentage of premises that are registered to use the LCP: 4–86%, with no apparent reason for the differences in uptake. The only factor that does seem to increase the likelihood of an ARC being LCP registered is if they are part of a large ARC corporate organisation that is leading LCP implementation within their facilities.

**Table 4: Palliative care service provision in ARC, by DHB**

DHB	No. of ARC premises	Palliative care provided*	Palliative care contract*	LCP registration (December 2011)
Northland	23	65%	17%	4%
Waitemata	59	47%	8%	15%
Auckland	77	60%	22%	42%
Counties Manukau	43	70%	16%	30%
Waikato	52	83%	27%	85%
Lakes	14	86%	50%	71%
Bay of Plenty	31	74%	19%	71%
Tairāwhiti	7	71%	14%	86%
Taranaki	31	74%	58%	23%
Hawke's Bay	27	67%	37%	67%
Whanganui	15	60%	7%	67%
MidCentral	37	76%	24%	78%
Hutt Valley	16	88%	19%	50%
Capital & Coast	34	68%	9%	41%
Wairarapa	13	69%	23%	8%
Nelson Marlborough	27	63%	7%	67%
West Coast	9	44%	0%	22%
Canterbury	90	41%	6%	34%
South Canterbury	13	62%	15%	54%
Southern (Otago)	45	62%	24%	42%
Southern (Southland)	23	52%	22%	35%
<b>National total</b>	<b>686</b>	<b>63%</b>	<b>19%</b>	<b>45%</b>

\* This information was self-reported by ARC facilities, and not all providers will have a separate contract for palliative care.

## Discussion

The fact that one-third of deaths in New Zealand occur in ARC indicates a high level of need for good-quality end-of-life care in these facilities. In addition, most deaths in ARC are from diseases where palliative care is known to be of benefit, such as cancer, circulatory and respiratory diseases, and nervous system diseases. Across New Zealand around two-thirds of ARC facilities say they provide palliative care, although what this actually means in relation to the level of care provided is unclear. Forty-five percent of ARC facilities have registered as sites for LCP implementation, which indicates a willingness to improve end-of-life care, but there is currently no data available on the impact of the LCP on deaths in these facilities and over half of facilities have still not adopted the LCP.

Although this review has provided some information on the preparedness of ARC to provide palliative care, much of the information is self-reported by facilities and is essentially for the purposes of marketing. LCP data currently only reports on facility registration, not implementation or audit of pathway use. Therefore, current data is insufficient to enable any firm conclusions to be drawn about the delivery or quality of end-of-life care in ARC facilities. More specific data is required on residents' demographics, including mortality data, staffing (including numbers with additional training in palliative care), access to specialist palliative care support, and funding/contractual agreements for palliative care.

## 1.3 Public hospitals

### Introduction

Based on mortality data reviewed in Phase 1 of the HNA, over a third of all deaths in New Zealand occur in hospital. When looking just at those people in the mid-range estimate who would benefit from palliative care, the proportion of deaths in hospital is higher: 77.6% of children and young people (predominantly under-one-year-olds) and 47% of adults died in hospital. People of Māori, Pacific and Indian ethnic groups are more likely to die in hospital, as are those from more deprived areas. People in the mid-range estimate group with non-cancer conditions were also significantly more likely to die in hospital. These facts indicate that there are important differences between people who die in hospital and those who die in other settings, and these differences will have an impact on the care required.

In addition to the mortality data estimates from Phase 1, there is additional data that highlights the need for palliative care in hospitals. A survey conducted in 2011 at a large DHB hospital reviewed all inpatient case notes to determine the proportion and characteristics of inpatients with palliative care needs (Gott et al 2011a). Of the 501 patients reviewed, 99 (19.8%) had palliative care needs, based on the Gold Standards Framework Prognostic Indicator Guide. Most of these patients were aged over 83 (mean 70 years old) and had a diagnosis of cancer (47%), a similar demographic to the mid-range estimate of palliative care need. Nearly a third also had cognitive impairment as a secondary condition. Fifty percent had been admitted via the emergency department.

The other important issue for people dying in hospital is that care is provided by staff who are generalists or who are specialised in areas other than palliative care. These staff will require an appropriate level of knowledge and skill in palliative care, as well as the support of a specialist palliative care service for complex patients.

### Data sources

The only data that was available for hospitals came from workforce statistics from the Nursing Council of New Zealand (NCNZ) and Medical Council of New Zealand (MCNZ). Additional information has been taken from the survey of Hospital Palliative Care Services conducted for the HNA.

Data on the nursing workforce is collected annually as part of the annual practising certificate renewal process. Data for the 2011 report is from 1 April 2010 to 31 March 2011 and included 48,563 practising nurses. The response rate to the survey questions component of the practising certificate renewal is between 95 and 100% (Nursing Council of New Zealand 2012). Additional data was requested from NCNZ to identify the main work setting for nurses who identified palliative care as their main or secondary practice area.

The MCNZ workforce survey data was also collected as part of the annual practising certificate renewal process, with survey forms being sent to all registered medical practitioners. In 2010 this included 13,292 doctors, of whom 95% responded. The workforce survey report only includes data from 11,478 doctors who were actively employed for more than four hours a week (Medical Council of New Zealand 2011). Additional data was requested from MCNZ to identify work settings for doctors who indicated they were working in palliative medicine as one of their work sites.

## Findings

The NCNZ workforce survey identified 1423 nurses who reported that palliative care was one of their practice areas (two practice areas can be recorded). Palliative care was recorded as the practice area for three nurse practitioners, all of whom worked in a DHB acute hospital setting, and 1234 registered nurses recorded palliative care as one of their practice areas. Further analysis of workforce data (Table 5) found that 816 registered nurses recorded palliative care as their main practice area (682 reported palliative care as their only work setting), and of these, 52 said they worked in an 'acute' DHB setting, 35 in a DHB 'community' setting and 47 in an 'other' DHB setting. A total of 414 registered nurses recorded palliative care as a secondary practice area, with 67 recording DHB 'acute' as their employment setting, 28 in DHB 'community' and 13 in DHB 'other' (Table 6).

A small number of enrolled nurses also recorded palliative care as a main (n = 96) or secondary (n = 88) employment setting. Seven were in a DHB setting as their main employment and 19 as their secondary employment.

The survey of hospital palliative care services identified 35 registered nurses and two nurse practitioners working as part of a hospital palliative care team in 13 different DHB hospitals. These nurses are likely to be part of the DHB 'acute' employment setting group. It is not known in what capacity the remainder of the nurses working in DHB settings are employed.

**Table 5: Palliative care as the main practice/employment setting**

Employment setting	Nurse practitioner	Registered nurse	Enrolled nurse	Total
DHB (acute)	2	52	2	56
DHB (community)	–	35	2	37
DHB (other)	–	47	3	50
Educational institution	–	1	–	1
Government agency	–	2	–	2
Māori health service provider	–	2	–	2
Nursing agency	–	14	1	15
Other	–	339	45	384
PHO	–	–	1	1
Primary health care	–	121	5	126
Private hospital	–	75	18	93
Rest home/residential care	–	111	17	128
Rural	–	2	1	3
Self-employed	–	9	–	9
(blank)	–	6	1	7
<b>Total</b>	<b>2</b>	<b>816</b>	<b>96</b>	<b>914</b>

Notes:

‘Government agency’ includes the Ministry of Health, the Accident Compensation Corporation (ACC), prisons, Defence Force, etc.

‘Primary health care’ includes primary health organisations (PHOs) and community services (non-DHB).

**Table 6: Palliative care as a secondary practice/employment setting**

Employment setting	Nurse practitioner	Registered nurse	Enrolled nurse	Total
DHB (acute)	–	67	7	74
DHB (community)	–	28	5	33
DHB (other)	–	13	7	20
Educational institution	–	1	–	1
Government agency	–	1	–	1
Māori health service provider	–	1	–	1
Nursing agency	–	18	1	19
Other	–	16	4	20
Pacific health service provider	–	2	–	2
Primary health organisation	–	2	–	2
Primary health care	–	12	1	13
Private hospital	–	71	13	84
Rest home/residential care	–	166	46	212
Rural	–	2	2	4
Self-employed	–	3	2	5
(blank)	–	11	–	11
<b>Total</b>	<b>0</b>	<b>414</b>	<b>88</b>	<b>502</b>

Source: Nursing Council of New Zealand 2012

Notes:

'Government agency' includes the Ministry of Health, ACC, prisons, Defence Force, etc.

'Primary health care' includes PHOs and community services (non-DHB).

In the 2010 workforce survey conducted by MCNZ, 84 doctors indicated they were working in palliative medicine for at least one of their work types (43% specialists, 42% medical officers and 8% registrars). Fifty-four said palliative medicine was their main work type. Of the 84 doctors who identified palliative medicine as one of their work types, 10 said they worked in a private hospital and 25 in a public hospital (see Table 7). Note that some doctors recorded working in multiple settings.

The survey of hospital palliative care services found there were 34 doctors practising palliative medicine in public hospitals in 2011. These doctors identified as 24 specialists and 10 registrars, working a total of 22.80 full-time equivalents (FTE). These doctors are spread across 14 of the 40 DHB public hospitals in New Zealand.

**Table 7: Employer type of doctors who indicated working in palliative medicine in 2010**

Employer type	Number
Commercial company	*
Private hospital	10
Public hospital	25
University	*
Other	51
Not answered	*
<b>Total</b>	<b>90<sup>#</sup></b>

\* Values less than 4 have been removed to prevent the identification of individuals.

# The total is greater than the number of doctors who indicated they were working in palliative medicine, as some doctors indicated multiple worksites for palliative medicine work.

## Discussion

Information on the provision of primary palliative care in public hospitals in New Zealand is very limited. It is possible to say that 14 of the 40 DHB public hospitals have access to a hospital palliative care service, although the availability and professional mix of these teams varies (see chapter 3, 'Hospital Palliative Care Services'). However, having expert palliative care advice available should contribute to better palliative and end-of-life care, although this does rely heavily on appropriate and timely referrals or requests for advice. Hospital palliative care services also provide education to primary palliative care providers within the hospital, but data on this aspect of hospital palliative care services activity is limited.

A number of registered nurses and doctors indicated in workforce statistics that they provide palliative care in a DHB setting outside of a dedicated hospital palliative care service as one of their work types, but it is not possible to establish exactly where they work and in what capacity they are providing palliative care. Many of these health professionals appear to work across more than one health care setting.

Aside from data collected in the survey of hospital palliative care services, no information is available on allied health professionals or psychological, social and spiritual care providers delivering palliative care in the public hospital setting. Even data from the survey shows these health professionals to be a scarce resource in public hospitals.

In addition to this workforce data, it should be noted that 23 DHB hospitals have registered for the Liverpool Care Pathway for the Dying Patient (LCP), which may be considered an indicator of these hospitals wanting to improve end-of-life care (see section 1.6, 'End-of-life care pathway implementation' for more details).



## 1.4 District nursing services

Caring for palliative patients in their own home requires access to support and health care in the community. A core group providing this support and care are district nursing services:

District nurses address health care needs that cannot be met by a generalist medical or nursing service alone. They provide care for people who, without advanced nursing care, are at risk of further health deterioration, and for whom provision of that care in their normal living environment would not further compromise their health status. Collaborating with the wider health care team, district nurses deliver rapidly responsive, intensive, and advanced holistic nursing care that is primarily home based (District Nursing Section of New Zealand Nurses Organisation 2008, p. 5).

Every DHB must fund a district nursing service in line with the Ministry of Health's *Specialist Community Nursing Service Specifications (DOM101: Community services – professional nursing services)*. The purposes of this specification are to:

- prevent avoidable admission to, or enable early discharge from, hospital
- minimise the impact of a personal health problem
- provide support to people with long-term or chronic personal health problems or conditions
- promote self-care and independence
- improve the health of Māori by delivering services to best meet their health needs
- improve the health of Pacific people by delivering services to best meet their health needs
- provide terminal/palliative care in the community where such services are not covered by other service specifications funded by the Ministry of Health.

### Data sources

Information in this section has been taken from the Ministry of Health report *District Nursing Services in New Zealand in 2010*. This report presents findings from phase one of a project funded by the Ministry to profile district nursing services throughout New Zealand. Data was gathered over a four-month period between May and August 2010 from all DHB regions. Sixty-four district nursing services provided data for the survey.

District nursing services were identified as those services that provide *nursing-led health care* based in the community/home *and monitoring activities* for patients at risk of health problems. The *Nationwide Service Framework, Specialist Community Nursing Service Specification* provides a framework for each DHB to fund services that have traditionally been considered 'district nursing' services.

## Findings

Throughout New Zealand, 65 separate district nursing services were identified, providing a wide range of home-, clinic- and community-based health care services to their communities (see Appendix 2). While most DHBs employ their own district nursing service staff, eight DHBs also contracted district nursing services from a total of 32 non-governmental organisation providers, 10 of whose services come under one rural PHO in Canterbury. Eleven DHBs have dedicated child health home care nursing services. There are more district nursing services than DHBs because a number of DHBs provide separate services at different locations across their region.

The qualified district nursing service workforce in 2010 consisted of 1286 registered nurses (826.47 FTE) and 119 enrolled nurses (79.16 FTE). Nine district nursing services (17%) also employed health care assistants (49.99 FTE). Most registered nurses and enrolled nurses work part time, on average 0.64 FTE.

Ninety percent of district nursing services provide palliative care in the community (excluding child health home care services). Some services are sole providers for their area, with remote support from a hospice specialist palliative care service. Where palliative care is not provided by a district nursing service, it is provided in the community by a local hospice palliative care service with a community nursing team.

Ten DHBs have contracts for the M80005 purchase unit *Palliative Care – Community Services*, which is described as a 'programme of community-based care for people assessed as requiring specialist palliative care'. This service specification is for the domiciliary non-medical services component, where this is provided by a DHB community service/specialist palliative care team. District nursing services generally provide palliative care as a component of the DOM101 contract rather than through the M80005 purchase unit for funding palliative care.

Of the district nursing services that provide palliative care, over half said they had established a shared care partnership with their local hospice service. This was the most common example of formal care partnerships and was reported for 60% (32 out of 53) of the services.

Based on service delivery information, 14 DHB regions have access to after-hours care by district nursing services, while seven DHB regions do not. At the time this report was compiled this included: Bay of Plenty, Hawke's Bay, Northland, Waitemata, Counties Manukau, Auckland and Whanganui. Where after-hours services were available, most district nursing services indicated this was for acute essential palliative care needs only.

An area of concern is access to patient information, which is collected and stored by multiple health care providers (eg, Medtech for general practice, electronic hospital records for secondary care, InterRAI for Needs Assessment and Service Co-ordination, and PalCare for palliative care). These systems are not linked in most areas, or cannot all be accessed by health professionals providing care for a patient in different settings, including district nursing services. Nineteen of the fifty-three services used patient-held records, and 18 district nursing services had shared electronic health records within primary health care or hospice teams. All district nursing services indicated they shared patient information through meetings, sharing data, providing patient updates, and discharge summaries.

The report found that district nursing services had adapted to meet local service gaps, and this was often reflected in their entry/exit criteria for the service, which were adapted locally to fit the education and skill set of the service. For example, in areas with few or no palliative care services available, the district nursing service had developed additional skills and knowledge in this area to meet local needs.

## Discussion

District nurses are an integral part of community palliative care service delivery, with many district nursing services working closely with their local specialist palliative care service. In some areas district nursing services are the main provider of home-based palliative care. However, once again there is no information on the number of palliative patients being cared for by these services, nor is there any data on the quality or outcomes of care.

The 40% of district nursing services providing palliative care with no formal link to a specialist palliative care service is of concern, as these services may not be able to readily access specialist advice and support, nor the palliative care education and training required to ensure their practice is evidence-based and up to date. The lack of after-hours access to district nursing services in seven DHBs is also concerning, because this is a time when many families encounter problems and there is usually no hospital or GP support available. Another issue is the difficulties district nursing services encounter with the sharing of patient information, which is vital for safety and continuity of care.

### 1.5 Home health care agencies

Home health care agencies provide a range of services for people who need support to live in their own home. These services can include personal care, household assistance, nursing care, carer relief/respite, and specialist care for people with complex health needs.

Access to home health care may be fully funded by a government health provider, such as the Ministry of Health, ACC or a DHB, or it may incur a part or full charge to the patient/client. Access to subsidised services requires an assessment by a contracted assessment agency.

There are a number of privately owned agencies across New Zealand that provide home health care services. They employ a range of staff, including support workers, caregivers and health care professionals to provide these services.

## Data sources

The Eldernet database and the New Zealand Home Health Association provider database were both used to obtain information on providers of home health services. Data included location of providers and types of services offered. Additional information was sought from provider websites and DHBs.

## Findings

All DHBs have access to one or more home care agencies that indicated they are able to provide palliative care. This is usually by nursing staff providing direct care, or caregivers providing carer relief/respite. Some agencies provide their services through DHB, Ministry or ACC contracts, as well as offering private services, which are mainly home help / domestic assistance and personal care.

## Discussion

The information available on home care agencies is quite basic and again relies on self-report by organisations about the services they provide, principally for the purposes of advertising. With no supporting information on the type or quality of care provided, nor data on the number of people receiving palliative care from these agencies, it is not possible to present a full picture of palliative care provided by home care agencies.

### 1.6 End-of-life care pathway implementation

Clinical or care pathways are used worldwide as a method for reorganising patient care to ensure it is effective and efficient. Clinical pathways are principally concerned with 'designing care processes, implementing clinical governance, streamlining delivered care, improving quality of clinical care, and ensuring that clinical care is based on the latest research' (Vanhaecht et al 2011: 2).

With regard to palliative care, the hospice model of care for the dying patient is regarded as the gold standard. This approach to care has been adapted into a variety of end-of-life care pathways designed to transfer the model into non-palliative care settings. End-of-life care pathways are designed to guide the provision of care for the dying person irrespective of diagnosis or care setting.

According to the Centre for Palliative Care (nd), there is evidence that end-of-life care pathways:

- provide evidence of a shared consensus amongst treating physicians/clinicians that the primary goal of care has changed to palliation
- address inconsistencies in care provisions by providing structured patient management strategies detailing essential steps in caring for patients in the final days and hours of their lives
- facilitate the most appropriate management by the most appropriate providers at the most appropriate time
- represent a formalised multi-disciplinary agreement that is implemented with the aim of achieving the best patient outcomes
- are a quality improvement measure to maximise the care of our most vulnerable population, the dying
- provide the opportunity for benchmarking and auditing to ensure that your service is providing best practice

- are supportive tools for use in services that are not represented by palliative care specialists, in particular in rural and regional settings and for services seeking to provide a standardised tool to aid decision-making by less experienced practitioners
- consequently may lead to an improved quality of life during the last phase of care
- are used extensively nationally and internationally and are widely regarded as the gold standard of palliative care.

The Liverpool Care Pathway for the Dying Patient (LCP) is the most widely recognised and used end-of-life care pathway internationally, having been implemented in different care settings across 21 countries. The LCP was developed by the Royal Liverpool and Broadgreen University Hospital National Health Service Trust and the Marie Curie Palliative Care Institute in Liverpool, to transfer the hospice model of end-of-life care to other non-palliative care settings. It is intended to standardise care of the dying and improve quality of care by providing a standardised template to guide care. In New Zealand, national coordination of LCP implementation is managed by the National LCP Office, based in Palmerston North.

## Data sources

Data has been sourced from the National LCP Office, principally drawn from the December 2011 status report (National LCP Office 2011). This report summarises the LCP registered sites and provides information on registration and review dates, and type of facility.

## Findings

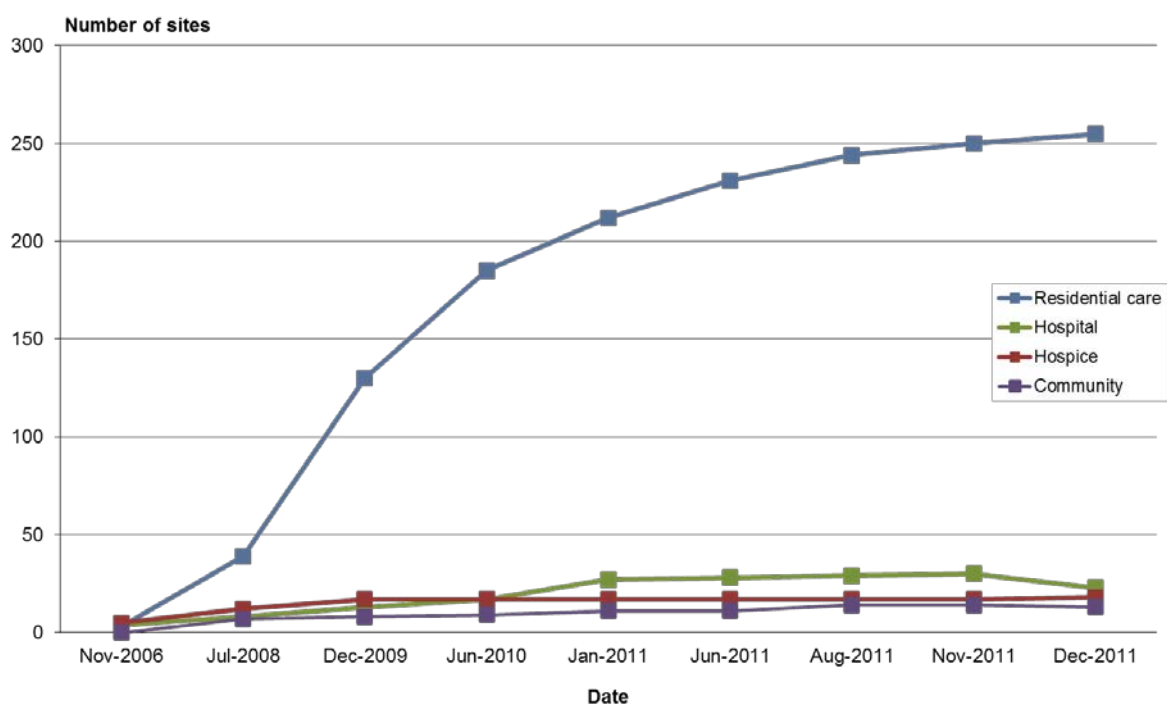
At the end of December 2011 there were 309 individual facilities registered with the National LCP Office. The majority (83%) of these were aged residential care (ARC), followed by hospitals (7%), hospice (6%) and community (4%), which included district nursing services, hospice home care services or health centres. Table 8 and Figure 9 show the increasing uptake of the LCP over time since the establishment of the National LCP Office in 2006.

**Table 8: Liverpool Care Pathway for the Dying Patient: implementation by setting type**

Setting	Nov 2006	Jul 2008	Dec 2009	Jun 2010	Jan 2011	Jun 2011	Dec 2011*
Community	0	7	8	9	11	11	13
Hospice	5	12	17	17	17	17	18
Hospital	4	8	13	17	27	28	23
Aged residential care	3	39	130	185	212	231	255
<b>Total</b>	<b>12</b>	<b>66</b>	<b>168</b>	<b>228</b>	<b>267</b>	<b>287</b>	<b>309</b>

\* Sites were re-categorised for December 2011. This was to align site descriptions with other national directories, such as Eldernet. This change predominantly affected the 'hospital' and 'aged residential care' categories.

**Figure 4:** Implementation of LCP in New Zealand, by care setting



Implementation of the LCP has not been consistent across DHB regions (see Table 9). Uptake appears to be higher when a large specialist palliative care provider is the lead organisation, or where a large corporate ARC provider is the lead organisation. As noted earlier, the number of ARCs with LCP is widely variable across DHB regions. In most DHB regions the hospice service has implemented the LCP, although Wairarapa and West Coast DHBs do not have a hospice service. One hospice in Hutt Valley DHB has another end-of-life care pathway in place.

**Table 9: LCP registered sites, by DHB, as at December 2011**

DHB	Hospice	Hospital	Community	ARC	Total sites
Northland	0	0	0	1	1
Waitemata	2	0	0	7	9
Auckland	1	1	0	30	32
Counties Manukau	1	1	0	11	13
Waikato	1	4	1	38	44
Lakes	0	2	2	6	10
Bay of Plenty	2	2	1	17	22
Tairāwhiti	0	1	0	5	6
Taranaki	1	0	0	6	7
Hawke's Bay	1	2	1	14	18
Whanganui	1	1	1	7	10
MidCentral	1	3	2	23	29
Capital & Coast	0	0	0	8	8
Hutt Valley	1	1	1	11	14
Wairarapa	0	0	0	1	1
Nelson Marlborough	2	2	1	13	18
West Coast	0	0	0	2	2
Canterbury	1	1	0	29	31
South Canterbury	1	0	0	6	7
Southern (Otago)	1	1	3	14	19
Southern (Southland)	1	1	0	6	8
<b>Total</b>	<b>18</b>	<b>23</b>	<b>13</b>	<b>255</b>	<b>309</b>

The National LCP Office, with the support of the Royal New Zealand College of General Practitioners, recently conducted a survey of GPs to understand use of the LCP in this setting (National LCP Office 2012). The survey attracted 99 responses (with an aim of obtaining 100 responses) and found that 75% of respondents had used the LCP in their practice. Of those GPs who had used the LCP, survey responses showed that:

- the majority found the LCP easy to use (72% relatively or very easy)
- GPs used the LCP most frequently in ARC settings, but also in hospices and in patients' homes
- most GPs felt the LCP had positively influenced the quality of care patients and their family/whānau received
- the most helpful aspects of the LCP were the anticipatory prescribing guidelines (93%), prompts to review patient medications (64%), prompts to communicate with patients and their family/whānau (44%), and having to agree the patient was dying before commencing the LCP
- GPs felt a sense of frustration about the nature of the paperwork required and that time and financial remuneration were key challenges for them in providing end-of-life care.



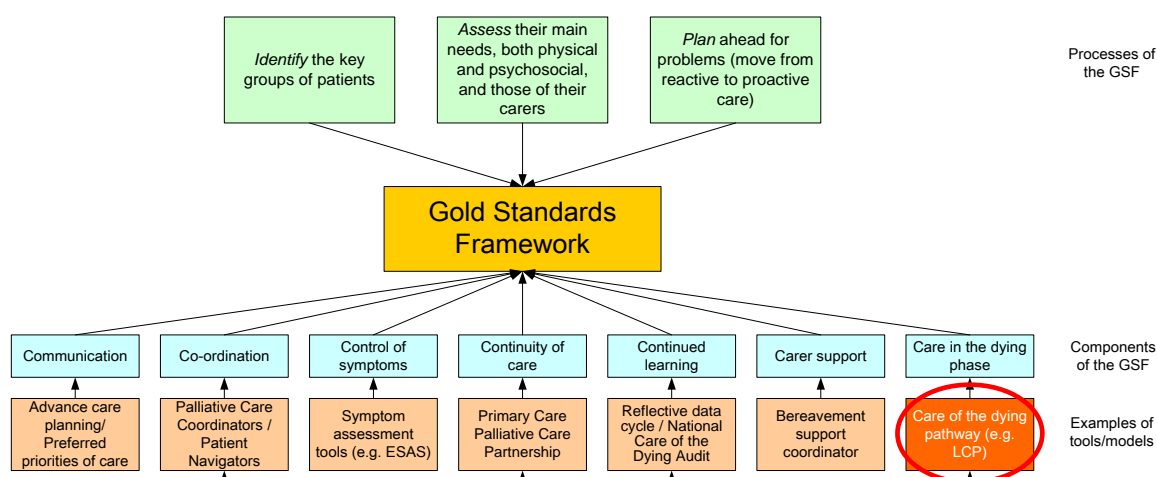
The survey also reinforced that GPs value being involved in end-of-life care. Respondents said the most satisfying aspects were caring for the patient in the context of their family, being able to follow a patient until time of death, and enabling the patient to die at home. They also valued the multidisciplinary team approach to care.

## Discussion

The LCP is an important advance in the care of people at the end of life outside of the hospice setting, and the establishment of the National LCP Office has been a key driver of LCP implementation in New Zealand. At present only data on registration to use the LCP is available, because most organisations have not yet established an audit cycle and data is not yet collected at a national level. While this data shows continuing growth in LCP registration, it is not possible to judge the impact of the LCP on patient care and outcomes. This means that, while LCP registration can be interpreted as a positive sign that an organisation is willing to improve end-of-life care, it does not guarantee that patient care has improved.

It is also worth noting that the LCP is only one aspect of palliative care, and while it should improve the quality and consistency of care in the last days to hours of life, there are many other components of palliative care that also need to be in place to ensure a seamless journey for people with a life-limiting or life-threatening condition. An example that illustrates these other important components required in the months and weeks before the end-of-life phase is the Gold Standards Framework (National Gold Standards Framework Centre 2009) depicted in Figure 5.

**Figure 5:** Diagrammatic representation of the Gold Standards Framework



The National LCP Office is currently in the process of developing a database that will be able to collate and report on data collected by organisations through the LCP Reflective Data Cycle. This data will provide a much more comprehensive national overview of LCP implementation and impact.

## 1.7 Access to equipment

For palliative care patients who wish to be cared for at home, either by family members, district nurses, GPs, hospice staff, or a combination of these carers, there is often a need for specialist equipment to ensure appropriate care can be delivered in the home setting. Equipment may be required to assist with activities of daily living or mobility, to manage symptoms and to ensure carer safety. This may include, for example, a hospital bed, bathing and toileting aids, sliding sheets, walking frames or wheelchair, hoists, syringe drivers and oxygen concentrators.

This equipment is often expensive and requires regular checks and maintenance to ensure its safe operation. Purchasing and maintaining this equipment is therefore not feasible for the majority of patients and their families, and for palliative patients this may not even be desirable because equipment needs can change and equipment may only be needed for a short time. Therefore, it is necessary to make this equipment available, ideally free of charge, when the patient requires it and for as long as they need it from a central supplier in each DHB region.

### Data sources

Data on equipment providers for patients being cared for at home has been provided by the Ministry of Health.

### Findings

All DHBs have equipment available for use by palliative care patients in the community. Equipment is provided by both DHBs and hospices in most regions, as well as by several other providers under contractual arrangements with the Ministry of Health, ACC or individual DHBs. Arrangements for equipment supply varies among DHBs. Table 10 summarises the equipment suppliers in each DHB.

**Table 10: Provision of equipment for palliative care patients in each DHB**

DHB	Equipment provider			
	Hospice	DHB community service	DHB hospital	Other
Northland	Hospice patients only	Most palliative care patients (less than 6 months to live) within the DHB		Palliative care patients within the DHB with longer than 6 months to live have access through 'AccessAble'
Waitemata	Hospice patients only	Non-hospice patients with (less than 6 months to live)		Palliative care patients within the DHB with longer than 6 months to live are assessed for permanent equipment
Auckland	Hospice patients only	Non-hospice patients		
Counties Manukau	Occasionally hospice patients only; small equipment supply	Most palliative care patients within the DHB		
Waikato	Most palliative care patients within the DHB	Palliative care patients within the DHB in regions not serviced by the hospice		
Lakes	Palliative care patients from Taupo via Taupo hospice	If additional equipment is required for Taupo patients	Palliative care patients from Rotorua	
Bay of Plenty	All palliative care patients within the DHB	If additional equipment is required		
Tairāwhiti	Hospice patients only	Non-hospice patients		Palliative care patients on the East Coast through Ngati Porou Hauora equipment service
Taranaki	Hospice patients only	Non-hospice patients		
Hawke's Bay	Hospice patients only	Non-hospice patients		
Whanganui	Most palliative care patients within the DHB		If additional equipment is required	
MidCentral		All palliative care patients within the DHB (via Enable)		
Capital & Coast	Occasionally hospice patients only; small equipment supply	Most palliative care patients (less than 6 months to live) within the DHB		Palliative care patients within the DHB with longer than 6 months to live have access through 'Enable'
Hutt Valley	Hospice patients only	Non-hospice patients		
Wairarapa	Hospice patients only	All palliative care patients within the DHB		

DHB	Equipment provider			
	Hospice	DHB community service	DHB hospital	Other
Nelson Marlborough	Hospice patients only	Non-hospice patients		
West Coast		Most palliative care patients within the DHB		Buller/West Coast home hospice trust additional support for some palliative care patients within the DHB
Canterbury	Occasionally hospice patients only	Most palliative care patients within the DHB	Some palliative care patients within the DHB	Palliative care patients within the DHB with longer than 6 months to live have access through 'Enable'
South Canterbury		All palliative care patients (less than 6 months to live) within the DHB		Palliative care patients within the DHB with longer than 6 months to live have access through 'Enable'
Southern		All palliative care patients within the DHB		

AccessAble is a private provider of equipment, housing alterations and vehicle modifications on behalf of the Ministry of Health and ACC, covering Northland, Waitemata, Auckland and Counties Manukau DHBs.

Ngati Porou Hauora is an integrated health, development and support services provider located in the Gisborne area (Tairāwhiti DHB).

Enable is an operating division of MidCentral DHB and provides an equipment and housing modification service under contract to the Ministry of Health, ACC and for some other DHBs.

## Discussion

In many DHB regions the local hospice supplies equipment to patients being cared for at home who are enrolled in the hospice programme. For palliative patients who are not under the care of a hospice, the DHB will usually provide equipment through their community care services or via a contracted supplier, such as AccessAble or Enable, particularly for those expected to need care for longer than six months.

The type of equipment available includes bathroom, bedroom, kitchen and general living area aids (eg, beds, mattresses, cushions, chairs, commodes, etc), mobility aids (wheelchairs, frames, ramps, etc) and manual handling devices (hoists, slide sheets, etc). However, the range of equipment available within each DHB is not known, nor is the volume of equipment used by palliative care patients.

## 1.8 Education and training

Appropriate education and training in palliative care is a fundamental need of primary palliative care providers to ensure they are well equipped to care for patients with a life-limiting or life-threatening condition and their family/whānau. The provision of education and training must be tailored to each care setting and the particular health care staff.

### Data sources

There is limited information available on the education and training undertaken by primary palliative care provider staff, and so an attempt has been made to identify the education and training available to primary palliative care providers and, where possible, the number of attendees taking part in training or education opportunities. Several different information sources have been reviewed, including:

- *Cancer and Palliative Care Nurses Education Needs Report* (Auckland UniServices/Ministry of Health 2008)
- Hospice New Zealand
- university websites
- the Royal Australasian College of Physicians.

Data has also been drawn from the survey of specialist palliative care services in relation to education provided outside of the specialist setting. In addition, findings from an education needs assessment undertaken in a large DHB hospital have been included.

### Findings

The *Cancer and Palliative Care Nurses Education Needs Report* looked specifically at undergraduate and postgraduate nursing education. A survey of nursing schools found no specific palliative care modules within the undergraduate curricula. There were relevant topics identified within the curricula, such as pain management, grief and dying, but palliative care was considered to be 'integrated' across the undergraduate programme, although the focus appeared to be predominantly on cancer. In some cases there was an opportunity to do 'site visits' or clinical placements with palliative care services. Three postgraduate programmes (certificate and diploma) in palliative care nursing were identified in the report, plus two single papers.

A review of current university programmes shows that there are still three postgraduate courses available, although they are at different institutions to those identified in the above report. All three of these programmes are also described as being open to any health professional with the relevant qualifications and experience. There were no named master's or PhD programmes in palliative care, although these can be undertaken by negotiation with the relevant universities.

The Royal Australasian College of Physicians (RACP) offers a Clinical Diploma in Palliative Medicine, which allows medical practitioners to spend time in palliative care as part of their vocational training and continuing professional development (Royal Australasian College of Physicians nd). The Diploma has a focus on the clinical aspects of palliative care and is completed during a six-month clinical attachment. For doctors wishing to further develop their specialist knowledge and skills in palliative care, the RACP also offers an advanced training programme in palliative care. Doctors who complete this programme are awarded a Fellowship of the Australasian Chapter of Palliative Medicine (FACHPM).

In addition to these academic programmes, the Ministry of Health has developed and published a professional development framework for palliative care nursing in New Zealand (Ministry of Health 2008). This framework identifies a pathway for registered nurses to develop skills and knowledge in palliative care and can be linked to their professional development and recognition programme. Although this framework was developed and published by the Ministry of Health, no specific implementation process or funding was allocated to it. However, Palliative Care Nurses New Zealand has taken on the task of implementing the Framework.

Hospice New Zealand currently provides three education programmes aimed at a range of health care staff with a particular focus on primary palliative care providers. These programmes are provided through hospice educators throughout New Zealand using resources developed and provided by Hospice New Zealand. The programmes are:

- the Subcutaneous Syringe Driver Competency Programme
- palliative care education for care assistants in the aged residential care setting
- Fundamentals of Palliative Care
- Hospice NZ / Genesis Oncology Trust palliative care lecture series.

Hospice New Zealand data shows that during 2011, 682 people attended the syringe driver competency programme and 452 attended care assistants education. The Fundamentals programme was only introduced in 2011.

The survey of palliative care services asked for the number of people that attended education, provided by the service, from different settings. These numbers will include those who attended Hospice New Zealand education programmes, which, as noted above, are run through hospice services. Table 11 summarises the total number of attendees for the 2010/11 year, by work setting, for hospices. Not all services were able to provide accurate data for this question, so the numbers are likely to be an underestimate.

**Table 11: Education provided by hospice palliative care services, 2010/11**

	Primary care	Aged residential care	Hospital	Tertiary institution
No. of attendees	1898	8633	2983	1566

Data was not available for education provided by most hospital palliative care services, although half said they were involved in the education of primary palliative care providers.

A survey undertaken in a large DHB hospital (Gott et al 2011b) asked clinical staff about their training in palliative care, the impact of the training on their clinical care, and the need for further training; 598 staff responded to the survey and 19.7% said they had taken part in training in palliative care. The training was generally one day or less (26.2%). Nearly three-quarters (73.4%) of respondents said they would like additional training in palliative care. When asked about the impact of formal training on the care they delivered, those who had undertaken training reported greater confidence in palliative care tasks and were more likely to access palliative care services. Nurses reported higher levels of training attendance, confidence in palliative care tasks and willingness to undertake further education than doctors.

The Palliative Care Council survey of GPs (Palliative Care Council 2010) found that 77% of 61 respondents reported no formal palliative care training or qualifications. However, most GPs in this survey and that reported by Smyth et al (2010) said they would like more training in palliative care. Respondents suggested that training in the form of online teaching, continuing medical education evenings or lunches, and palliative care specialist visits were their preferred modes of education.

## Discussion

There appear to be a reasonable number of postgraduate palliative care courses provided in New Zealand, although no data was available on enrolment numbers for these programmes or the number of health care professionals with postgraduate qualifications in palliative care. Aside from the RACP programme, available postgraduate palliative care courses are multi-profession programmes, which is particularly important for allied health professions who have traditionally not had access to specialist palliative care qualifications.

The level of palliative care training in undergraduate courses for both nursing and medicine is difficult to ascertain but appears to be minimal. Given the need to ensure all health care professionals are able to deliver an appropriate level of palliative care regardless of setting, it would seem vital that palliative care become an integral component of undergraduate nursing, medical and allied health curricula. In addition, full implementation of the National Professional Development Framework for Palliative Care Nursing would provide nurses with a pathway to achieving appropriate levels of skill, knowledge and qualifications to become competent, expert palliative care nurses.

Surveys of primary palliative care providers in hospitals and of GPs have consistently found a desire for more education and training in palliative and end-of-life care among these health care professionals. Hospices and hospital palliative care teams are providing a considerable amount of education already for these groups, especially in ARC. In particular, the Hospice New Zealand Care Assistant and Fundamentals programmes should be addressing the issues noted by Mitchell (2004) related to the ARC sector lacking staff with palliative care training or qualifications and having limited educational opportunities in palliative care, especially for health care assistants.



## 1.9 Primary palliative care providers: a summary

This chapter has reviewed a number of health care services that provide primary palliative care. These providers are thought to care for around 80% of people who require palliative care, half of them within their own resources and capability and the other half through a collaborative care arrangement with a specialist palliative care service. These providers include:

- general practice
- aged residential care
- public hospitals
- district nursing services
- home health care agencies.

Other indicators of the capacity and capability of primary palliative care providers that were investigated included end-of-life care pathway implementation, access to equipment, and education and training.

Currently there is no specific data on palliative care service provision by primary palliative care providers. Instead, a number of proxy measures were explored in order to provide some indication of capacity and capability. These proxy measures included readily available data from published reports and other data collections held by national organisations.

Overall, primary palliative care providers appear to have a reasonable level of capability. However, it is impossible to draw any firm conclusions because there is limited or no specific data for these services on the number or characteristics of people who receive palliative care from them, the training and qualifications of staff providing palliative care, the quality of palliative and end-of-life care provided, or the satisfaction of patients and family/whānau with the services received.

## 2 Hospice Palliative Care Services

As noted in the Methodology section of the Introduction, data on palliative care services was obtained by surveying all known palliative care services in New Zealand. The service list was built from data obtained from Hospice New Zealand and the Ministry of Health, along with information from the Expert Advisory Group and key informants. The survey covered both hospice and hospital-based palliative care services. A period of one month was allowed for responses. Data was requested for the period 1 July 2010 to 30 June 2011. This chapter covers hospice palliative care services, and chapter 3 discusses the results for hospital palliative care services.

Thirty-nine hospice palliative care services were identified (see Appendix 3) and surveys were sent to 36 of these (three hospices were satellite services of a larger hospice and their data was included in those hospices' returns). There was a 100% response rate from hospice services, although a small number could not provide all of the requested data and one service only provides financial support and equipment.

Survey responses were collated and analysed using Microsoft Excel. Data has been summarised by DHB or as a total of all services combined. Summarising results by DHB also maintains consistency with Phase 1 data reporting. Data has been grouped like this to provide DHBs with an appropriate level of relevant local data for population health planning, and also to provide a suitable level of data breakdown for central government planning. In some instances this may mean that services are identifiable if they are the only palliative care provider in their DHB region.

### 2.1 Hospice palliative care service capability

One of the components of the HNA methodology is to compare core service components with current service provision to identify service deficiencies and gaps. Previously there has been no identified 'core' set of palliative care service components in New Zealand. However, during 2011 and 2012 both Hospice New Zealand and Hospital Palliative Care New Zealand undertook projects to describe the capability requirements, in relation to clinical and non-clinical functions and workforce, of their respective services.

The *Hospice Capability Recommendations* (see Appendix 4) describe and define hospices as providers of specialist palliative care, and show how these services can consistently achieve this level of care. These recommendations are aspirational and will not take effect immediately, but they will inform future Ministry of Health service planning and funding decisions and will evolve over time.

The hospice capability recommendations document is still in development. However, 100% of hospices have agreed to the content, in principle. Hospice New Zealand has stated that the recommendations have been tested and contested to a point where hospice governance and leadership are willing to see them form part of the needs assessment framework. Hospice New Zealand recognises that each hospice and region faces unique opportunities and constraints, and that this will have an impact on how the capability recommendations are positioned and interpreted over the next few years.

In both the hospice and the hospital capability documents the functions and workforce roles are separated into three categories:

- **will have** services are the core functions and roles that a palliative care service will provide
- **will have access to** are also core functions and roles, but they may not be provided directly by the palliative care service
- **could offer** are functions and roles that could be provided if resources allow, but are not considered core to the delivery of palliative care.

Throughout chapters 2 and 3 the two capability documents will be referred to and used as reference points with which to compare current palliative care service provision. Where possible, data from the palliative care service surveys is compared to capability recommendations in an attempt to identify important areas for future service development.

## 2.2 Hospice palliative care services

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

Hospices provide care for the whole person – not just their physical needs but also their emotional, spiritual and social needs. They also care for families and friends, both before and after a death. Irrespective of where a hospice service is, this philosophy of care does not change. In New Zealand all aspects of hospice care are provided free of charge (Palliative Care Council 2012).

A review of survey responses from hospice palliative care services identified that there are three categories of hospice service in New Zealand, based on the range of services provided and the type of staff employed. These categories were used to organise and analyse survey data and are referred to throughout this chapter of the report. Services were assigned to categories based on the following descriptions.

- **Comprehensive hospice palliative care services** – these services provide community-based care as well as having a dedicated hospice inpatient unit. They offer a wide range of clinical services (including all core service components of Hospice New Zealand capability recommendations) and employ a range of qualified health care staff.

- **Community hospice palliative care services** – these services primarily provide community-based care but may also have access to inpatient beds in a residential care facility or community hospital. In some cases the hospice service owns or funds the beds and provides staff support, but the main staff providing inpatient care are not specialised in hospice palliative care. These hospices offer a wide range of clinical services (including all or most of the core service components of the Hospice New Zealand capability recommendations) and employ a range of qualified health care staff.

For the purposes of this project, two DHB hospital-based community palliative care services have been included in the community hospice palliative care service group. These services are located in the Wairarapa and West Coast DHBs. They are the sole providers of community-based clinical palliative care services within their DHB regions and both are supported by a comprehensive hospice palliative care service in a neighbouring DHB.

- **Hospice palliative care support services** – these services provide community-based support but do not employ qualified health care staff and so do not provide any clinical care. They offer a limited range of non-clinical services, which are often provided by volunteers. People under the care of a hospice palliative care support service are likely to be receiving clinical care from another hospice service or primary palliative care provider.

Based on the survey data returned by hospice palliative care services, Table 12 provides a summary of the number of services in each category for each DHB region. The majority of DHB regions (17 out of 21) have access to a comprehensive hospice palliative care service, and in two DHBs there are two comprehensive services. Those regions without a comprehensive service usually have a community hospice palliative care service, apart from Wairarapa and West Coast, where there is only a supportive care service. In these two regions, however, community palliative care is provided by dedicated district nursing teams.

**Table 12: Hospice palliative care services available in each DHB region**

DHB region	Category of service			Total
	Comprehensive hospice palliative care service	Community hospice palliative care service	Palliative care support service	
Northland	1	3	0	4
Waitemata	2	1	0	3
Auckland	1	1	2	4
Counties Manukau	1	1	0	2
Waikato	1	0	2	3
Lakes	0	2	0	2
Bay of Plenty	1	1	0	2
Tairāwhiti	0	1	0	1
Hawke's Bay	1	0	0	1
Taranaki	1	0	0	1
MidCentral	1	0	0	1
Whanganui	1	0	0	1
Capital & Coast	1	0	0	1
Hutt Valley	1	0	0	1
Wairarapa*	0	1	1	2
Nelson Marlborough	2	0	0	2
West Coast*	0	1	1	2
Canterbury	1	0	0	1
South Canterbury	1	0	0	1
Otago	1	0	0	1
Southland	1	0	0	1
<b>Total</b>	<b>19</b>	<b>12</b>	<b>6</b>	<b>37</b>

\* Includes DHB district nursing community palliative care service.

As well as the different types of service described above, there are also several models of care in use across New Zealand that have been developed to meet the needs of each community served by a hospice. The model of care used by a hospice will have an impact on the number and type of staff they employ, the service components they offer, and how they interact with other health care providers. Examples of the main models of care are described here, but there are also variations on these models.

In the *full service model*, the hospice service undertakes full assessment, care planning and care of the patient and family, providing all care components: physical care, psychological and social support, and spiritual care. The service often also provides inpatient care and bereavement support. The service employs or has access to a range of staff who provide medical, nursing, allied health and psychological, social and spiritual care.

In the *care coordination model*, the hospice provides many of the service components noted above, but they do not undertake full patient care. They will be involved in the assessment and care planning stages, but direct patient care is usually provided by a district nursing service and GPs. The hospice may still provide inpatient care and family/whānau support, including bereavement.

There are other permutations of these two models. It is possible that a hospice may provide both of these models at the same time, and each patient is assessed for the level of care they require. In addition, some hospices provide an 'in-reach' service to their local hospital, whereby hospice staff act in a consultation/liaison role to visit patients in hospital and provide specialist assessment and advice and support to the patient's principal care team. Several regional hospice services provide support to a neighbouring DHB that does not have a hospice, and where palliative care is undertaken by the DHB's district nursing service.

## 2.3 Service components

### Staff roles and functions

This section summarises the functions and staff roles reported in the survey of palliative care services and compares them with the components of the *Hospice New Zealand Capability Recommendations* (Hospice New Zealand 2012). A summary of the data is presented in Table 13, which shows the percentage of services within each of the three service categories that reported having the various functions and roles.

**Table 13: Percentage of services providing each Hospice New Zealand hospice capability component, by category of service**

Capability component			Category of service		
			Comprehensive hospice palliative care service	Community hospice palliative care service	Hospice palliative care support service
Will have	Clinical functions	Community care	100%	100%	100%
		Assessment	100%	100%	40%
		Care planning	100%	100%	40%
		Care coordination	95%	100%	40%
		Liaison roles	100%	75%	20%
		Education	100%	50%	80%
		Bereavement care	100%	75%	80%
		End-of-life pathway	100%	42%	20%
		Quality improvement	100%	83%	20%
		Clinical data collection	100%	75%	20%
	Roles	Registered nurses	100%	100%	0%
		Medical officer or GP	100%	33%	0%
		Spiritual care	100%	42%	60%
		Social work	89%	25%	0%
		Counselling	95%	67%	60%
		Cultural advisor	79%	67%	0%

Capability component			Category of service		
			Comprehensive hospice palliative care service	Community hospice palliative care service	Hospice palliative care support service
Will have access to		Volunteer manager/coordinator	100%	67%	20%
		Volunteer workforce	100%	75%	60%
	Functions	Inpatient care	100%	50%	0%
		Equipment (community access)	89%	83%	80%*
		Respite care	100%	75%	20%
		Home help / personal cares	89%	75%	20%
		24/7 medical/nursing advice and care	95%	58%	40%
		Paediatric and young person PC	79%	58%	20%
		Interpreter service	89%	75%	0%
	Roles	Specialist medical	89%	58%	0%
		Occupational therapy	42%	33%	0%
		Physiotherapy	42%	42%	0%
		Pharmacist	32%	0%	0%
		Dietician	11%	25%	0%
		Speech-language therapist	5%	25%	0%
Could offer	Functions	Hospital in-reach	42%	58%	0%
		Day care programme	74%	42%	60%
		Outpatient care	95%	50%	0%
		Group support (patients)	79%	67%	0%
		Family/carer programme	84%	42%	20%
	Role	Complementary therapist	32%	25%	0%
		<b>Number of services</b>	<b>19</b>	<b>12</b>	<b>5</b>

\* Includes Buller West Coast Home Hospice Trust; this is the only component they provide.

Comprehensive hospice palliative care services usually provide all parts of the 'will have' clinical functions, with only one service reporting not having a care coordination component. It should be noted that, based on the information provided for the survey, it is not possible to judge whether the *community care* component fully meets the Hospice New Zealand description of an interdisciplinary team (see section 2.6, 'Community hospice care', for further information).

Five services (25%) do not provide direct clinical patient care in the community; instead they work with the local DHB district nursing service and GPs, with the hospice providing a care coordination role. The 'will have' staff roles were present in all comprehensive services, apart from a small number of services without a dedicated social worker or cultural advisor. Most comprehensive services reported providing all the 'will have access to' functions, although several services did not have access to paediatric and young person palliative care. Most comprehensive services had access to specialist medical roles, but only a few had access to allied health roles, such as occupational therapy, physiotherapy, pharmacist and dietician. Access to these allied health roles was considered a core requirement for specialist palliative care services in the Palliative Care Strategy (Ministry of Health 2001a).



Only a very small number of services reported access to a speech–language therapist. Most comprehensive services ‘could offer’ an outpatient care programme, and many also offered day care programmes, patient group support and a family/carer programme. While a small number offered a hospital in-reach service (42%), comprehensive services were generally less likely to offer hospital in-reach services, probably because most of them are in a DHB region with a large hospital that has its own DHB-employed hospital palliative care service.

Community hospice palliative care services also provide many of the ‘will have’ clinical functions, but there appear to be gaps in the provision of education (50% provide education), although in most cases this would be provided by the comprehensive hospice palliative care service in their region. Fewer than half reported using an end-of-life care pathway. Again, while all services have access to clinical care in the community, not all provide this service component through their own staff. Instead, it is provided by district nursing services and GPs. All of these services reported having nursing staff, but the availability of other roles varied, with only a third having a medical officer or GP, 25% a social worker, and 42% a spiritual carer. Two-thirds of these services had counselling staff, a cultural advisor or a volunteer manager.

Provision of the ‘will have access to’ functions was also variable. In particular, only seven of the twelve services had access to 24/7 advice or paediatric and young person palliative care. Some services did not have access to inpatient beds, respite care, home help or an interpreter service. Over half of the community services had access to specialist medical staff; in most cases this included those services without a medical officer or GP. Only a few of these services reported access to allied health staff, many of which were in one DHB region and accessed through the DHB. A number of services reported providing some of the ‘could offer’ functions, including hospital in-reach (58%), day care and outpatient care (42% and 50%), and patient group support (67%).

Across all functions and roles hospice palliative care support services reported providing far fewer components of the hospice capability recommendations. Although all reported providing community care, this is non-clinical supportive care and in most cases these support services are provided by volunteers. Four of these services also provide bereavement support for families and education for their volunteer workforce. Three of the five support services report having counselling and spiritual care roles and a volunteer workforce. Aside from equipment, and in some cases day programmes (three of five services), supportive care services only provide very limited additional functions that hospices ‘will have access to’ or ‘could offer’, and where they are offered it is by usually by volunteers. Note that the Buller West Coast Home Hospice Trust is not included in the hospice palliative care support services numbers, except for equipment provision.

The data summarised in Table 13 shows that, where a comprehensive or community palliative care service is present, most of the core functions and services described in the Hospice New Zealand capability recommendations will be available. However, there are DHB regions that are not well provided for, as illustrated in Table 14 and Table 15, which identify the number of hospice palliative care services in each DHB region that provide the functions and roles identified in the capability recommendations. This includes Wairarapa and West Coast DHBs, which only have a palliative care support service, with community care being provided by a DHB hospital-based service (district nurses). South Canterbury DHB also has a number of gaps in the ‘will have access to’ functions and roles for

hospice, although a community hospice palliative care service is available in this region and the DHB reports providing most of these components, although not through the hospice. Note that a small number of hospice palliative care services serve only a part of their DHB region, so some hospice service components may not be available across the entire region.

Only two-thirds of DHB regions have hospice services that reported access to paediatric and young person palliative care. Again this varies by service category, with 79% of comprehensive and 50% of community hospice services reporting access to paediatric and young persons' palliative care. When available, this component of care is usually provided with the support of the National Paediatric Palliative Care Service at Starship Hospital, Auckland, or through working with a local paediatric service. There is currently a national project under way through the Ministry of Health to implement a national care coordination service for paediatric palliative care, which should address this variability in support (Ministry of Health 2012).

Most DHB regions have access to hospice outpatient and day care services (86% and 76%, respectively), but again this may be regionally limited and such services are much more likely to be provided by a comprehensive service. While fewer than half the DHB regions have a hospice-provided hospital in-reach service, this is not considered to be a 'core' function, and where not available this service will usually be provided by a dedicated hospital palliative care service employed by the DHB, especially in large tertiary hospitals and many of the larger regional hospitals (see chapter 3, 'Hospital Palliative Care Services').

Across all DHB regions there is generally a high level of access to the 'will have' staffing roles and specialist medical staff (Table 15), although there are some gaps in access to social work and cultural advisor roles. Table 15 again highlights the lack of allied health professional availability within hospice services across all DHBs. Fewer than a quarter of all hospice palliative care services have access to at least one of these allied health professionals. This means that fewer than half of DHB regions had access to a hospice service with a physiotherapist or occupational therapist, and even less access is available to pharmacists (38%) and dieticians (24%). Only one DHB region reported access to a speech-language therapist in hospice. This is further discussed in chapter 4, 'Palliative Care Workforce', which has more detail on the allied health workforce, although it does include those allied health staff accessed via a DHB and not directly employed by a hospice service.

**Table 14: Number of hospice palliative care services providing Hospice New Zealand hospice capability *functions* in each DHB region**

Hospice capability functions		DHB region																				No. of DHBs with service component	
		Northland	Waitemata	Auckland	Counties Manukau	Waikato	Lakes	Bay of Plenty	Tairāwhiti	Hawke's Bay	Taranaki	MidCentral	Whanganui	Capital & Coast	Hutt Valley	Wairarapa*	Nelson Marlborough	West Coast* #	Canterbury	South Canterbury	Otago		
Will have	Community care	4	3	4	2	3	2	2	1	1	1	1	1	1	1	2	2	1	1	1	1	1	21 (100%)
	Assessment	4	3	3	2	1	2	2	1	1	1	1	1	1	1	2	2	1	1	1	1	1	21 (100%)
	Care planning	4	3	3	2	1	2	2	1	1	1	1	1	1	1	2	2	1	1	1	1	1	21 (100%)
	Care coordination	4	3	4	2	1	2	2	1	1	1	1	1	1	1	1	2	1	1	0	1	1	20 (95%)
	Liaison roles	4	3	3	2	1	2	2	0	1	1	1	1	1	1	0	2	0	1	1	1	1	18 (86%)
	Education	2	3	4	1	2	1	2	1	1	1	1	1	1	1	1	2	0	1	1	1	1	20 (95%)
	Bereavement care	3	3	4	2	2	2	2	1	1	1	1	1	1	1	1	2	0	1	1	1	1	20 (95%)
	End-of-life pathway	1	3	2	1	2	2	2	0	1	1	1	1	1	1	0	2	0	1	1	1	1	18 (86%)
	Quality improvement	4	3	3	2	1	2	2	1	1	1	1	1	1	1	0	2	0	1	1	1	1	19 (90%)
	Clinical data collection	4	3	3	2	1	2	2	0	1	1	1	1	1	1	0	2	0	1	1	1	1	18 (86%)
Will have access to	Inpatient care	4	2	2	1	1	0	2	1	1	1	1	1	1	1	0	2	0	1	1	1	1	18 (86%)
	Equipment (community)	4	3	3	2	3	2	2	1	1	1	0	1	1	1	1	2	1	1	0	1	1	19 (90%)
	Respite care	3	3	3	2	1	2	2	1	1	1	1	1	1	1	0	2	0	1	1	1	1	19 (90%)
	Home help/personal care	4	3	3	1	1	2	2	1	1	1	0	1	1	1	0	2	0	1	0	1	1	17 (81%)
	24/7 advice and care	3	3	2	1	1	2	2	1	1	1	1	1	1	1	2	2	0	1	0	1	1	19 (90%)
	Paed. and young person PC	3	3	3	0	1	2	2	0	1	1	0	0	1	1	0	2	0	1	0	1	1	14 (67%)
	Interpreter service	3	3	2	1	1	2	2	1	1	1	1	1	1	1	0	2	0	1	0	1	1	18 (86%)
Could offer	Hospital in-reach	3	0	0	0	0	2	2	1	1	1	0	1	0	1	0	1	0	0	0	1	1	11 (52%)
	Day care programme	1	2	3	1	1	2	2	0	0	1	1	1	1	1	1	1	0	0	1	1	1	17 (81%)
	Outpatient care	2	3	2	1	1	2	1	1	1	1	1	1	1	1	0	2	0	1	0	1	1	18 (86%)
	Group support (patients)	2	3	2	2	1	2	2	1	1	1	0	0	1	1	0	2	0	0	0	1	1	15 (71%)
	Family/carers programme	1	3	3	2	1	1	2	0	1	1	1	1	0	1	0	2	0	1	0	1	0	15 (71%)
	Number of hospice PC services in DHB region	4	3	4	2	3	2	2	1	1	1	1	1	1	1	2	2	2	1	1	1	1	37

\* Includes DHB community palliative care service.

# Missing data.

**Table 15: Number of hospice palliative care services providing Hospice New Zealand hospice capability *roles* in each DHB region**

Hospice capability roles		DHB region																					No. of DHBs with service component	
		Northland	Waitemata	Auckland	Counties Manukau	Waikato	Lakes	Bay of Plenty	Tairarwhiti	Hawke's Bay	Taranaki	MidCentral	Whanganui	Capital & Coast	Hutt Valley	Wairarapa*	Nelson Marlborough	West Coast* #	Canterbury	South Canterbury	Otago	Southland		
Will have	Registered nurse	4	3	2	2	1	2	2	1	1	1	1	1	1	1	1	2	1	1	1	1	1	21 (100%)	
	Medical officer or GP	2	3	2	1	1	0	1	1	1	1	1	1	1	1	0	2	0	1	1	1	1	18 (86%)	
	Spiritual care	2	3	4	1	2	1	2	0	1	1	1	1	1	1	0	2	0	1	1	1	1	18 (86%)	
	Social work	2	3	1	1	1	1	1	0	1	1	1	1	1	1	0	2	0	1	0	1	0	16 (76%)	
	Counselling	2	3	4	2	2	2	2	1	1	1	1	1	1	1	0	2	0	1	1	1	0	18 (86%)	
	Cultural advisor	3	3	1	2	1	2	1	0	1	1	0	0	1	1	0	2	0	1	1	1	1	16 (76%)	
	Volunteer manager / coordinator	3	3	3	2	1	1	2	1	1	1	1	1	1	1	0	2	0	1	1	1	1	19 (90%)	
	Volunteer workforce	4	3	3	2	2	1	2	1	1	1	1	1	1	1	1	2	0	1	1	1	1	20 (95%)	
Will have access to	Specialist medical	4	2	2	1	1	1	1	1	1	1	1	1	1	1	1	2	1	1	0	1	1	20 (95%)	
	Occupational therapy	4	0	0	0	0	1	0	0	1	1	0	0	1	1	0	2	0	1	0	1	0	9 (43%)	
	Physiotherapy	4	2	0	0	0	1	0	0	1	1	0	1	1	0	0	2	0	1	0	0	0	9 (43%)	
	Pharmacist	4	0	1	0	0	0	0	0	1	1	1	0	1	0	0	1	0	1	0	0	0	8 (38%)	
	Dietician	4	0	0	0	0	0	0	0	1	1	0	0	0	0	0	1	0	1	0	0	0	5 (24%)	
	Speech-language therapist	4	0	0	0	0	0	0	0	1	1	0	0	0	0	0	1	0	0	0	0	0	4 (19%)	
Could offer	Complementary therapist	0	2	1	0	0	1	0	0	0	1	0	0	1	1	0	0	0	1	0	0	1	8 (38%)	
	Number of hospice PC services in DHB region	4	3	4	2	3	2	2	1	1	1	1	1	1	1	2	2	2	1	1	1	1	37	

\* Includes DHB community palliative care service.

# Some missing data as the service did not complete the survey.

Although these tables report data on services having a 'liaison role', this actually includes a variety of liaison positions working with different groups or organisations the hospice service maintains relationships with. Table 16 summarises the different liaison roles reported by hospice services. The way in which these liaison roles are provided varies across services, with some being volunteers (in particular cultural liaison), or the liaison aspect may be combined with other roles (eg, community and aged care liaison may be undertaken by community nurses). These approaches mean that in many cases liaison roles are not formally funded.

**Table 16: Number of hospice services providing different liaison roles**

Service category	Liaison role				
	Cultural	Community	Aged care	Hospital	Other
Comprehensive (n = 19)	15 79%	11 58%	16 84%	12 63%	5 26%
Community (n = 12)	7 58%	7 58%	7 58%	5 42%	2 17%

Respite care is available in all but two DHB regions and is commonly provided in an inpatient unit by comprehensive services (95%) or by carer respite at home (58%). Two-thirds of community palliative care services (67%) also have access to inpatient respite beds, and 58% have access to carer respite at home.

### Availability of team outside normal hours

Services were asked about how they provided access to care outside normal working hours. This included when they were available and by what means (home visit, telephone, or other means such as email), and which health professionals were available. Because this question is particularly important for community care, both comprehensive and community care services are grouped together. Palliative care support services are reported separately because they are providing supportive care only.

Table 17 summarises the type of access and times available. Two-thirds of hospice services provide 24/7 home visiting and all but one (97%) provide a 24/7 telephone advice service. A small number of hospice services only provide weekend and evening home visits. In some regions after-hours care is provided by district nurses and GPs, especially where there is no comprehensive or community hospice palliative care service, such as in Wairarapa and the West Coast, or where the hospice service does not have its own community nursing team. In Wairarapa and West Coast DHBs, 24/7 telephone advice is provided by a comprehensive palliative care service in a neighbouring DHB.

**Table 17: Hospice palliative care services providing after-hours service in each DHB region and times available**

DHB region	Home visit			Telephone advice		
	24/7	W/E	None	24/7	W/E	None
Northland	3	0	1	4	0	0
Waitemata	2	1	0	3	0	0
Auckland	0	1	1	2	0	0
Counties Manukau	0	1	1	1	1	0
Waikato	1	0	0	1	0	0
Lakes	1	0	1	2	0	0
Bay of Plenty	2	0	0	2	0	0
Tairāwhiti	1	0	0	1	0	0
Hawke's Bay	1	0	0	1	0	0
Taranaki	1	0	0	1	0	0
MidCentral	1	0	0	1	0	0
Whanganui	0	1	0	1	0	0
Capital & Coast	0	0	1	1	0	0
Hutt Valley	1	0	0	1	0	0
Wairarapa*	1	0	0	1	0	0
Nelson Marlborough	2	0	0	2	0	0
West Coast*	nk	nk	nk	1	0	0
Canterbury	1	0	0	1	0	0
South Canterbury	0	1	0	1	0	0
Otago	1	0	0	1	0	0
Southland	1	0	0	1	0	0
<b>Total</b>	<b>20</b>	<b>5</b>	<b>5</b>	<b>30</b>	<b>1</b>	<b>0</b>
(% of services)	65%	16%	16%	97%	3%	

Notes:

24/7 = 24 hours a day, seven days a week

W/E = weekends and evenings

None = no service provided

nk = not known due to no data provided.

\* Includes DHB community palliative care service.

When home visits are provided, it is usually by nurses (74% of hospice services) or doctors (42% of hospice services), including specialists, Medical Officer Special Scale (MOSS) and GPs (Table 18). Both medical and nursing staff are available for home visits in 10 services. The 'Other' category included allied health, psychosocial support and volunteers.

Telephone advice is predominantly provided by nurses (90% of hospice services), although medical staff are also often available. Several services indicated they have the ability to provide advice by email. Table 18 shows that all DHB regions are able to access telephone advice from a hospice service.

**Table 18: Hospice palliative care services providing after-hours service in each DHB region: health professionals available**

DHB region	Home visit			Telephone advice		
	Nurse	Doctor	Other	Nurse	Doctor	Other
Northland	3	1	1	3	1	
Waitemata	3	2		3	3	
Auckland	1	0	0	1	1	1
Counties Manukau	1	1	0	2	1	0
Waikato	1	0	0	1	0	0
Lakes	1	1	0	1	0	0
Bay of Plenty	2	1	0	2	1	1
Tairāwhiti	1	0	0	1	0	0
Hawke's Bay	1	1	0	1	1	0
Taranaki	1	1	0	1	1	0
MidCentral	1	1	0	1	1	0
Whanganui	1	1	1	1	1	0
Capital & Coast	0	0	0	1	0	0
Hutt Valley	1	1	0	1	1	0
Wairarapa*	1	0	0	0	1	0
Nelson Marlborough	2	0	0	2	0	0
West Coast*	nk	nk	nk	1	0	0
Canterbury	1	0	0	1	0	0
South Canterbury	1	0	0	1	0	0
Otago	0	1	0	1	1	0
Southland	0	1	0	1	0	0
<b>Total</b>	<b>23</b>	<b>13</b>	<b>2</b>	<b>27</b>	<b>14</b>	<b>2</b>
(% of services)	74%	42%	6%	87%	45%	6%

nk = not known due to no data provided.

\* Includes DHB community palliative care service.

Palliative care support services also provide supportive care services after hours. One provides home visits and telephone advice on weekends and evenings, and two provide 24/7 telephone advice. Visits and advice are by volunteers or the volunteer coordinator, except for one service, where 24/7 home visits are available from the local district nursing service.



### **Annual number of new patients**

From 1 July 2010 to 30 June 2011 comprehensive and community palliative care services received 11,298 new referrals and accepted 10,878 of these (see Table 19). On average, 4.2% of referrals are declined (range 0 to 17.2%). The most common decline rate was 0%; in other words, most services accepted all referrals. Hospice palliative care support services accepted an additional 223 referrals: 83 in Auckland DHB, 54 in Waikato DHB and 86 in Wairarapa DHB. These patients may also be included in numbers from comprehensive and community services, who were most likely to be providing their clinical care.

### **Total number of patients cared for**

Most hospice services had ongoing care patients who were already being cared for by the hospice before the start of the time period stipulated for the survey. Along with new referrals, these patients make up the total number of patients under the care of the hospice service during the survey dates. Table 19 summarises this data, showing the number of new referrals, ongoing care patients and total number of patients for each DHB region (excluding hospice supportive care services). Overall there were 13,821 patients receiving care from a hospice service from 1 July 2010 to 30 June 2011; of these, 3083 were ongoing care patients.

**Table 19: Hospice referrals and ongoing care patients**

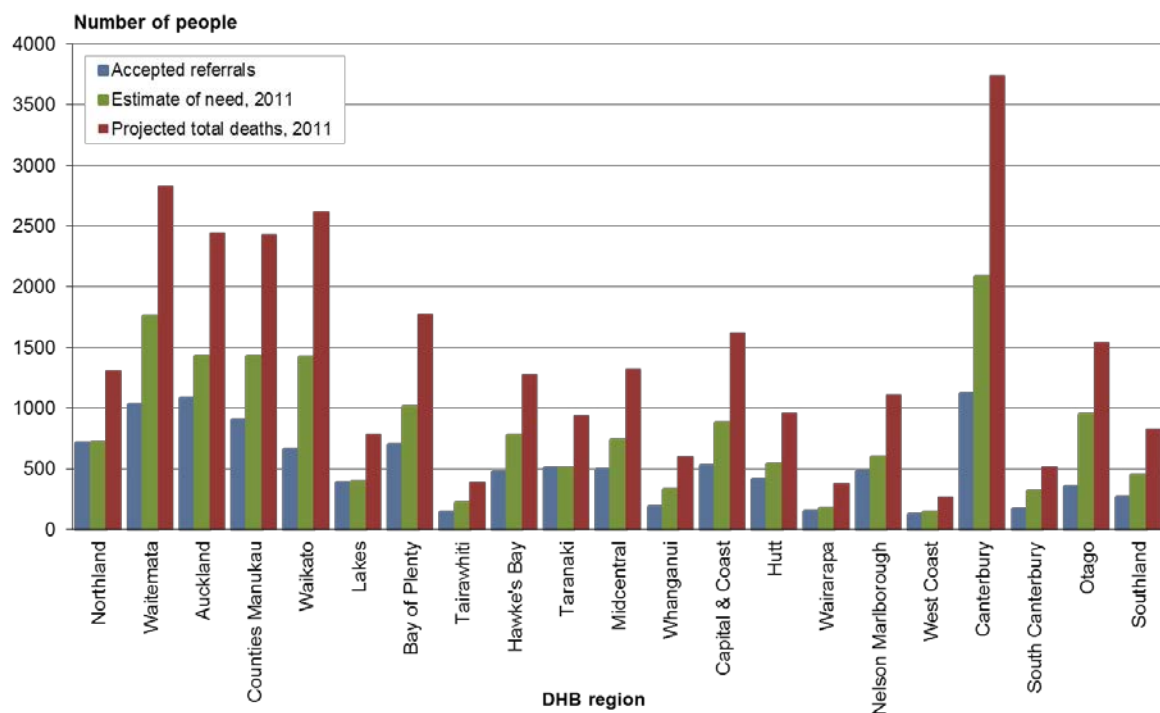
DHB	Accepted new referrals	Ongoing care patients	DHB total
Northland	711	204	915
Waitemata	1030	332	1362
Auckland	1084	462	1546
Counties Manukau	901	362	1263
Waikato	658	275	933
Lakes	384	45	429
Bay of Plenty	699	190	889
Tairāwhiti	145	43	188
Hawke's Bay	474	148	622
Taranaki	509	124	633
MidCentral	494	214	708
Whanganui	187	118	305
Capital & Coast	526	247	773
Hutt Valley	414	161	575
Wairarapa*	148	0	148
Nelson Marlborough	480	150	630
West Coast*	nk	nk	127
Canterbury	1117	157	1274
South Canterbury	168	0	168
Otago	356	130	486
Southland	266	12	278
<b>Total</b>	<b>10,878</b>	<b>3374</b>	<b>14,252</b>

nk = not known due to no data provided.

\* Includes DHB community palliative care service.

One question this part of the needs assessment is attempting to answer is: 'How well is the need for palliative care being met?' One way of answering this question is to compare the estimated number of people who would benefit from palliative care to the number of people actually receiving hospice palliative care over the same time period. Phase 1 of the HNA suggested that all those identified in the mid-range estimate should be referred to a specialist palliative care service for assessment. Therefore, the predicted DHB populations for 2011 (personal correspondence, Ministry of Health from Statistics New Zealand 2010) and the mid-range estimate of need for palliative care from Phase 1 of the HNA have been used to generate an estimate of the number of people who would have benefited from palliative care for each DHB region during 2011. These DHB regional estimates are compared with the number of hospice service referrals accepted, as well as the projected number of total deaths for each DHB region, in Figure 6.

**Figure 6:** Comparison of hospice service referrals accepted to mid-range estimate of need and projected 'all deaths' for 2011, for each DHB region



A total of 16,837 people are estimated to be in the group that would have benefited from palliative care during 2011 – equivalent to 56% of all deaths predicted to occur in 2011 (30,000).

Table 20 shows the number of new referrals accepted by hospice services and estimated need numbers for each DHB region, as well as the difference. A negative number indicates there were more people in the estimate than were referred to, and accepted by, a hospice service. In the ideal situation it would be expected that all those in the mid-range estimate would be referred for palliative care, and the majority of these would be referred to a hospice, so the numbers should be fairly close.

The difference shows that there were 5959 people (35% of the mid-range estimate) who may have benefited from palliative care but who were not referred to a hospice palliative care service. This difference varies widely between DHB regions, from +1% to –63%. All but one hospice service had a negative difference. While this is a relatively crude comparison, it does indicate that there are potentially a large number of people who would benefit from palliative care in their last year of life and who are not being referred to hospice services.

**Table 20: Annual number of hospice patients compared with estimated number of people who would benefit from palliative care for each DHB region**

DHB region	Accepted referrals	Mid-range estimate (2011)	Difference	
Northland	711	720	–9	–1%
Waitemata	1030	1756	–726	–41%
Auckland	1084	1427	–343	–24%
Counties Manukau	901	1429	–528	–37%
Waikato	658	1,418	–760	–54%
Lakes	384	390	–6	–2%
Bay of Plenty	699	1,008	–309	–31%
Tairāwhiti	145	219	–74	–34%
Hawke's Bay	474	774	–300	–39%
Taranaki	509	504	5	1%
MidCentral	494	738	–244	–33%
Whanganui	187	325	–138	–43%
Capital & Coast	526	876	–350	–40%
Hutt Valley	414	537	–123	–23%
Wairarapa*	148	175	–27	–16%
Nelson Marlborough	480	597	–117	–20%
West Coast <sup>#</sup>	127	145	–18	–12%
Canterbury	1117	2,085	–968	–46%
South Canterbury	168	313	–145	–46%
Otago	356	950	–594	–63%
Southland	266	449	–183	–41%
<b>Total</b>	<b>10,878</b>	<b>16,837</b>	<b>–5959</b>	<b>–35%</b>

Note: Total accepted referrals is for 1 July 2010 to 30 June 2011.

\* Wairarapa DHB referrals are for the Masterton Hospital Palliative Care Service, which provides community palliative care.

# West Coast DHB 'accepted referrals' has been taken from M80005 Palliative Care NNPAAC data for the 2011 calendar year.

Some of the difference could be due to the 2011 mid-range estimate being calculated from two figures that are also estimates (size of mid-range group and projected DHB populations), and there is also the likelihood that a number of these people were assessed by a hospital palliative care service and so may not have been referred on to a hospice. However, where there are quite large discrepancies these two factors are unlikely to explain all of the difference. Looking at the diagnosis and age of hospice patients (discussed in detail later in the report), it is likely that the two groups missing out on hospice palliative care are those with a non-cancer diagnosis and people over age 80.

## Average length of care episode

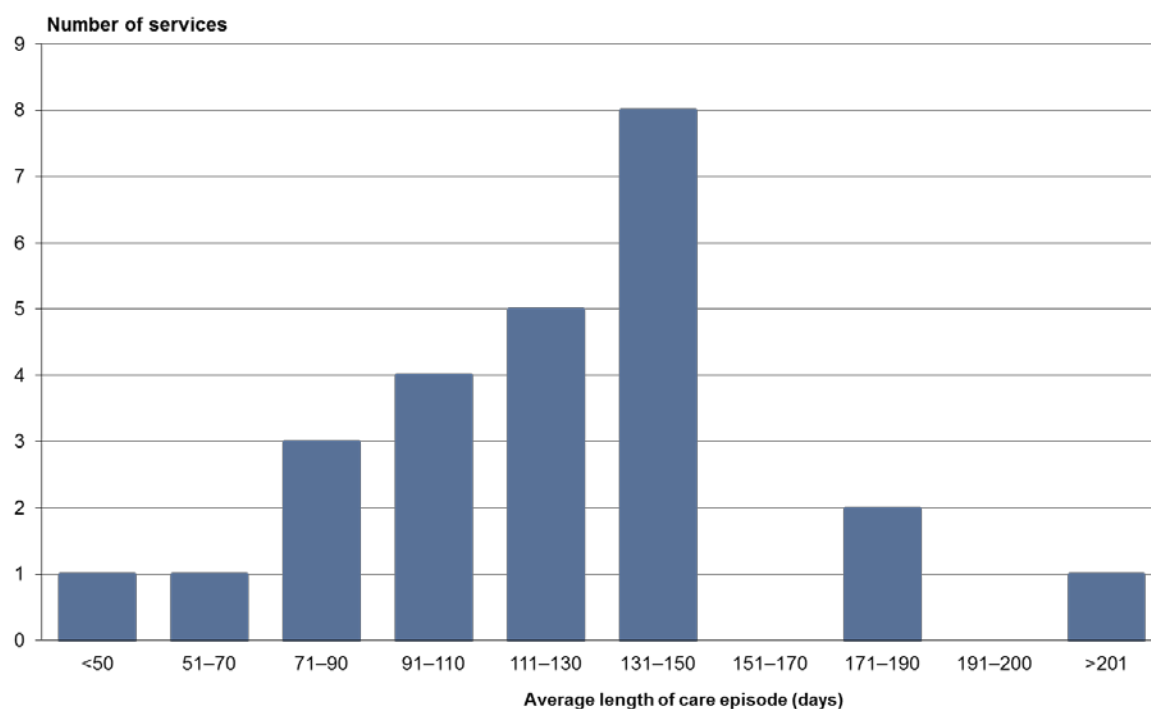
Hospice services were asked to provide data on the average length of time a patient was cared for by their service (in days), from admission date to date of discharge. Twenty-nine services were able to provide data on length of care episode. These were allocated to the three categories of service provider, resulting in a division into 17 comprehensive services, eight community hospice services and four hospice palliative care support services providing data.

The 17 comprehensive hospice palliative care services had an average length of care episode of  $127.6 \pm 13.9$  days (at 95% confidence) and a median of 135 days. The minimum length of care episode reported was one day, and the maximum ranged from 365 to 2761 days.

The eight community hospice palliative care services had an average length of care episode of  $113.3 \pm 32.7$  days (at 95% confidence) and a median of 103.5 days. The minimum length of care episode reported was one day and the maximum ranged from 240 to 3554 days.

Average length of care episodes for the combined comprehensive and community palliative care services have been grouped into 20-day bands and graphed in Figure 7. The average length of care episode for this combined group is  $123 \pm 14$  days (at 95% confidence).

**Figure 7:** Average length of care episode (days) for combined comprehensive and community palliative care services, 1 July 2010 to 30 June 2011



The average length of care episode for the four hospice palliative care support services was unable to be determined due to the very wide range of average length of care episodes reported and the small number of services. The minimum length of care episode reported was one day (with a range of 1 to 14 days) and the maximum ranged from 50 to 2500 days.

### End-of-life care programme in use

Hospice services were asked whether they had implemented an end-of-life care programme and which programme they were using. Thirty-one services provided a response to this question (Table 21). All comprehensive services had an end-of-life care pathway in place, almost exclusively the Liverpool Care Pathway for the Dying Patient (LCP), with two services using an alternative pathway. Five community palliative care services also had the LCP in place, and a further two were in the process of implementing the LCP. Five community services reported having no end-of-life pathway.

Only one of the hospice palliative care support services indicated they had had an end-of-life pathway in place, and in that instance it was in a local hospital rather than being used by the service itself. As these services do not provide direct clinical care, an end-of-life pathway is not likely to be appropriate to their service.

**Table 21: End-of-life care programme in use, by service type**

Type of service	N	End-of-life care programme			
		LCP	Other	In progress	None
Comprehensive	19	17 (90%)	2 (10%)	0 (0%)	0 (0%)
Community	12	5 (42%)	0 (0%)	2 (17%)	5 (42%)

### Education programme provided

Providing education is one of the core components of a hospice palliative care service. As well as ensuring hospice staff remain up to date, hospices also provide education and training for primary palliative care providers working in a variety of settings, including general practice, aged residential care, home health care and hospitals. Hospice staff may also be involved in education programmes run through tertiary institutions.

A summary of the education provided by hospice services in each DHB region is provided in Table 22. Aged residential care staff made up the largest group, with 8807 staff attending hospice education, followed by 7377 hospice staff.

**Table 22: Number of education attendees from each setting, by DHB, 1 July 2010 to 30 June 2011**

DHB region	Hospice	Primary care	Aged residential care	Hospital	Tertiary institution	Other	Total
Northland	132	150	402	243	134	0	1061
Waitemata	1728	20	2,476	19	39	0	4282
Auckland	1098	386	537	240	200	0	2461
Counties Manukau	467	105	239	126	33	0	970
Waikato	617	18	58	876	94	431	2094
Lakes	54	18	20	136	0	0	228
Bay of Plenty	595	28	197	77	75	0	972
Tairāwhiti	217	23	6	29	0	0	275
Hawke's Bay*	0	151	0	0	0	0	151
Taranaki	217	6	201	17	19	0	460
MidCentral	38	162	497	141	126	129	1093
Whanganui	114	35	191	20	4	0	364
Capital & Coast	303	94	1338	33	36	214	2018
Hutt Valley	564	9	75	30	1	0	679
Wairarapa <sup>#</sup>	102	116	174	158	54	0	604
Nelson Marlborough	586	144	689	543	64	0	2026
West Coast	nk	nk	nk	nk	nk	nk	nk
Canterbury	15	119	406	2	0	40	582
South Canterbury	34	5	156	13	2	0	210
Otago	409	184	665	85	602	0	1,945
Southland	87	241	480	331	137	0	1,276
<b>Total</b>	<b>7377</b>	<b>2014</b>	<b>8807</b>	<b>3119</b>	<b>1620</b>	<b>814</b>	<b>23,751</b>

\* The hospice service in Hawke's Bay DHB was closed temporarily during 2011, which affected their ability to provide education.

# Includes DHB community palliative care service.

nk = not known due to no data provided.

Comprehensive palliative care services delivered the majority of the education provided (see Table 23), with those located in large urban centres tending to provide education to greater numbers. This may be a reflection of population size and the number of other health care providers in large centres, and also the size of the services, which may be able to better afford dedicated education positions. Hospice supportive care services appear to be predominantly providing education for their own volunteer staff.



**Table 23: Number of education attendees from each setting, by service type, 1 July 2010 to 30 June 2011**

	Hospice	Primary care	Aged residential care	Hospital	Tertiary institution	Other	Total
Comprehensive (n = 19)	5553	1829	7671	2789	1562	814	<b>20,218</b>
Community (n = 7)	1546	185	1136	308	58	0	<b>3233</b>
Supportive care (n = 4)	278	0	0	22	0	0	<b>300</b>
<b>Total</b>	<b>7377</b>	<b>2014</b>	<b>8807</b>	<b>3119</b>	<b>1620</b>	<b>814</b>	<b>23,751</b>

## 2.4 Inpatient beds

This section looks at the number, location and utilisation of inpatient beds that were designated and funded *solely* for the care of palliative patients (ie, resourced palliative care beds) during the period 1 July 2010 to 30 June 2011. The hospice survey asked each service for the number of inpatient beds available and where the beds were located, with the options of hospice, aged residential care (ARC), hospital, or other. Hospice services were also asked to provide the number of new and repeat admissions, the average length of stay for inpatients and their bed occupancy rate.

An issue identified during the survey and highlighted in consultation feedback is that there are a number of inpatient beds available for palliative care patients that are not dedicated solely for palliative care, but are accessed through a variety of funding streams and used on an as-needed basis. The funding is not consistent across DHB regions and so obtaining detailed data on utilisation of these beds was not possible. Therefore this section only includes inpatient beds that are specifically dedicated to palliative care.

The question of which of these beds might be considered 'specialist palliative care beds' was also raised in feedback. It is likely that only those beds located in a hospice inpatient unit should be considered specialist, as they are staffed by health care professionals who have specialised in palliative care. Beds in hospitals and aged residential care are staffed by primary palliative care providers who deliver a generalist level of palliative care.

### Number of resourced palliative care inpatient beds

Across all DHB regions there were 173 hospice inpatient beds and a further 15 palliative care beds used by hospice services located in ARC facilities (13) or hospitals (2) during the 2010/11 period. The location of these beds by DHB region is summarised in Table 24, and shows that most inpatient beds are in DHBs containing a large urban area. DHBs that are predominantly rural (Lakes, Tairāwhiti, Wairarapa and West Coast) have few or no dedicated palliative care beds, and the beds that are available are located in an ARC or hospital facility.

**Table 24: Number of palliative care beds in each DHB region, by facility type**

DHB region	Facility type			Total
	Hospice inpatient unit	Aged residential care	Hospital	
Northland	6	2	0	8
Waitemata	15	0	0	15
Auckland	13	3	0	16
Counties Manukau	9	0	0	9
Waikato	10	0	0	10
Lakes	0	0	0	0
Bay of Plenty	9	8	0	17
Tairāwhiti	0	0	2	2
Hawke's Bay	8	0	0	8
Taranaki	6	0	0	6
MidCentral	10	0	0	10
Whanganui	5	0	0	5
Capital & Coast	18	0	0	18
Hutt Valley	10	0	0	10
Wairarapa	0	0	0	0
Nelson Marlborough	16	0	0	16
West Coast	0	0	0	0
Canterbury	11	0	0	11
South Canterbury	7	0	0	7
Otago	12	0	0	12
Southland	8	0	0	8
<b>Total</b>	<b>173</b>	<b>13</b>	<b>2</b>	<b>188</b>

Note: There are also 2 respite beds in Waikato DHB for children and young people (located in Rainbow place at Hospice Waikato). These have not been counted.

### Annual number of inpatient admissions

Between 1 July 2010 and 30 June 2011 there were 3872 unique inpatient hospice admissions (ie, each patient counted only once); 3708 of these were in the inpatient facility of a comprehensive hospice service and 164 were in ARC or hospital beds funded by a community palliative care service. Admission data is shown by DHB region in Table 25. Three DHBs have no data because there are no resourced hospice palliative care beds reported in their region.

The 22 hospice services that provided admission data cared for a total of 12,099 patients during the same time period. When compared to the number of unique admissions, this means that 32% of patients had at least one inpatient admission.

**Table 25: New admissions to resourced palliative care beds, by DHB region**

DHB	Service type		
	Comprehensive	Community	Total
Northland	166	11	177
Waitemata	422	n/a	422
Auckland	292	26	318
Counties Manukau	378	n/a	378
Waikato	125	n/a	125
Lakes	No beds	n/a	n/a
Bay of Plenty	209	n/a	209
Tairāwhiti	n/a	127	127
Hawke's Bay	153	n/a	153
Taranaki	226	n/a	226
MidCentral	252	n/a	252
Whanganui	104	n/a	104
Capital & Coast	276	n/a	276
Hutt Valley	216	n/a	216
Wairarapa	No beds	n/a	n/a
Nelson Marlborough	260	n/a	260
West Coast	No beds	n/a	n/a
Canterbury	350	n/a	350
South Canterbury	157	n/a	157
Otago	116	n/a	116
Southland	6	n/a	6
<b>Total</b>	<b>3708</b>	<b>164</b>	<b>3872</b>

Note: n/a means not applicable as the DHB does not have this kind of service.

During this same time period there were 2735 repeat admissions, most of which were into a hospice inpatient unit bed and a small number into ARC or hospital beds (Table 26). When added to new admissions, this gives a total of 6612 admission episodes to hospice inpatient beds during the 12-month period.

Based on the number of new admissions and readmissions, approximately 71% of patients had multiple admissions. However, it is likely that some patients would have had several admission episodes. There is also a wide range of readmission rates between services, which may be due to different models of care but could also be a reflection of data accuracy.

**Table 26: Repeat admissions, new admissions and total admissions, by DHB region**

DHB	Repeat admissions		Total	New admissions	Total admissions
	Comprehensive service	Community service			
Northland	34	5	34	177	211
Waitemata	352	n/a	352	422	774
Auckland	69	5	74	318	392
Counties Manukau	91	n/a	91	378	469
Waikato	9	n/a	21	125	134
Lakes	No beds	n/a	n/a	n/a	n/a
Bay of Plenty	268	n/a	268	209	477
Tairāwhiti	n/a	31	31	127	158
Hawke's Bay	41	n/a	41	153	194
Taranaki	136	n/a	136	226	362
MidCentral	80	n/a	80	252	332
Whanganui	174	n/a	174	104	278
Capital & Coast	399	n/a	399	276	675
Hutt Valley	314	n/a	314	216	530
Wairarapa	No beds	n/a	n/a	n/a	n/a
Nelson Marlborough	419	n/a	419	260	679
West Coast	No beds	n/a	n/a	n/a	n/a
Canterbury	77	n/a	77	350	427
South Canterbury	30	n/a	30	157	187
Otago	80	n/a	80	116	196
Southland	126	n/a	126	6	132
	<b>2699</b>	<b>41</b>	<b>2740</b>	<b>3872</b>	<b>6612</b>

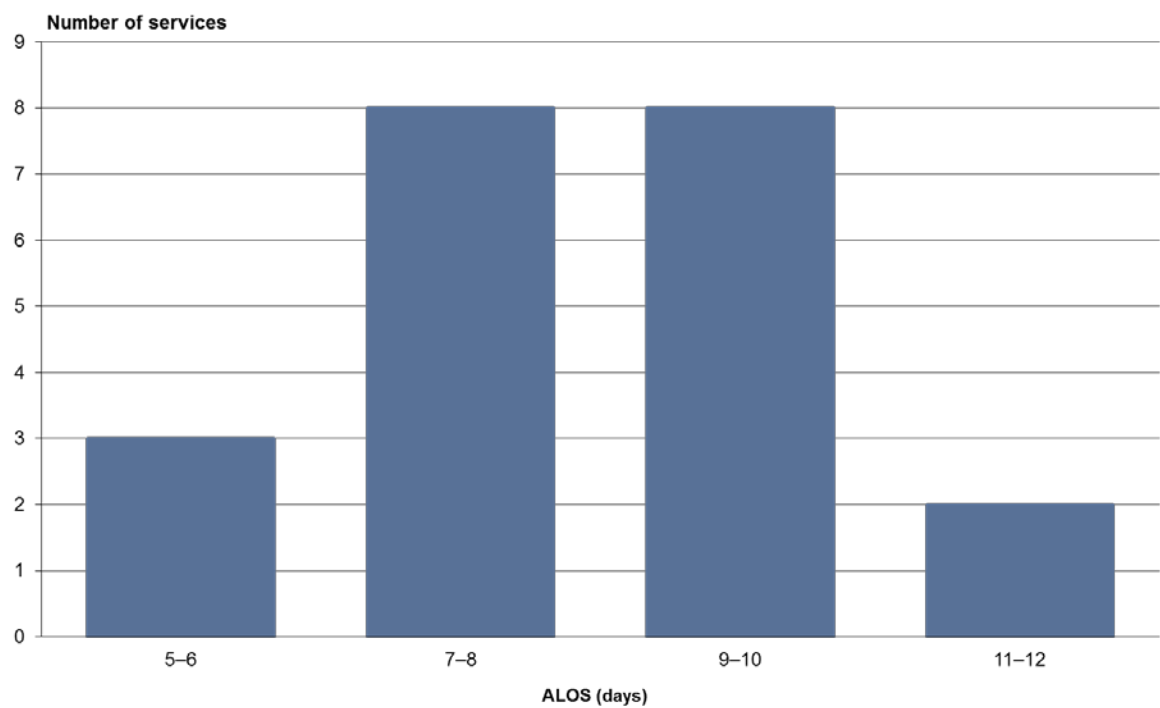
Note: n/a means not applicable as the DHB does not have this kind of service.

### Average length of inpatient stay

Twenty-one services were able to provide data on average length of stay (ALOS) for their inpatient beds. This included all 19 comprehensive services and two community palliative care services. ALOS was calculated as the average length of time, in days, a patient was admitted to the inpatient unit (numbers for 1 July 2010 to 30 June 2011).

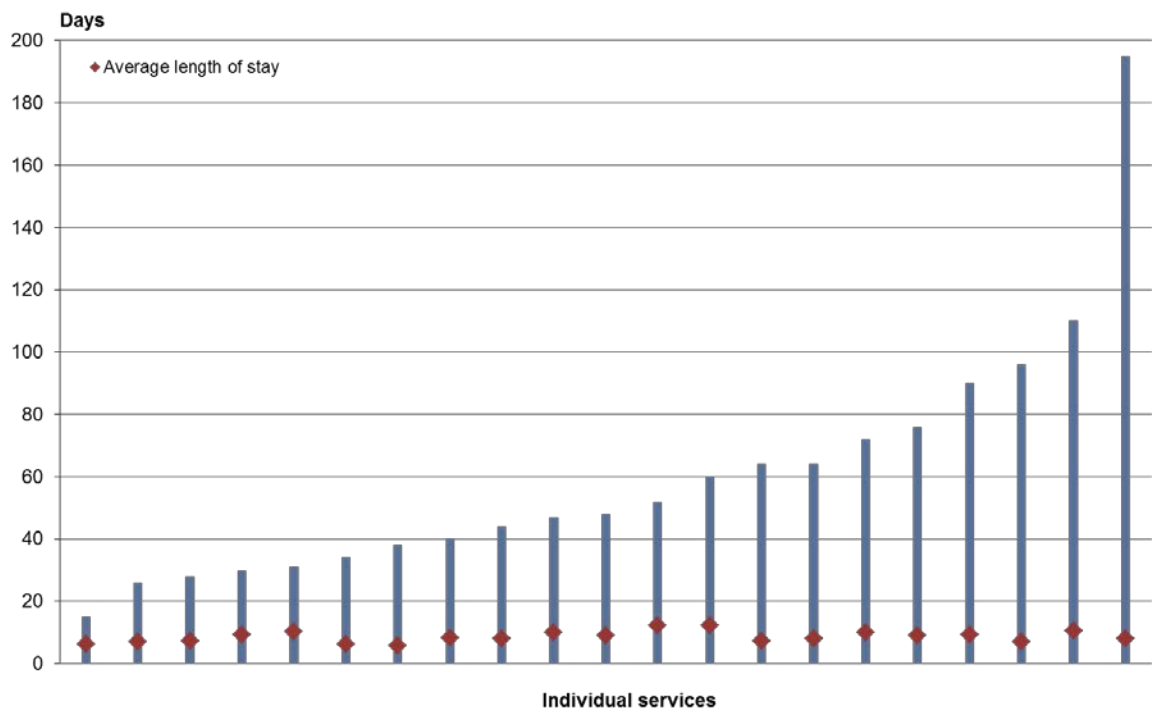
ALOS for the 21 services is summarised in Figure 8. For the 21 services that provided data, the mean ALOS was  $8.6 \pm .08$  days (7.8–9.4 days at 95% confidence), with a median ALOS of 8.3 days. The minimum reported ALOS was one day or less, and the maximum reported ALOS was 195 days. The range of length of stays and the average for each service is illustrated in Figure 9.

**Figure 8:** Average length of stay for resourced hospice palliative care beds



Note: n=21 hospice services

**Figure 9:** Minimum, maximum and average length of stay for 21 hospice services



## Bed occupancy rate

Inpatient bed occupancy rate was calculated for the 12-month survey period by each service using the following equation:

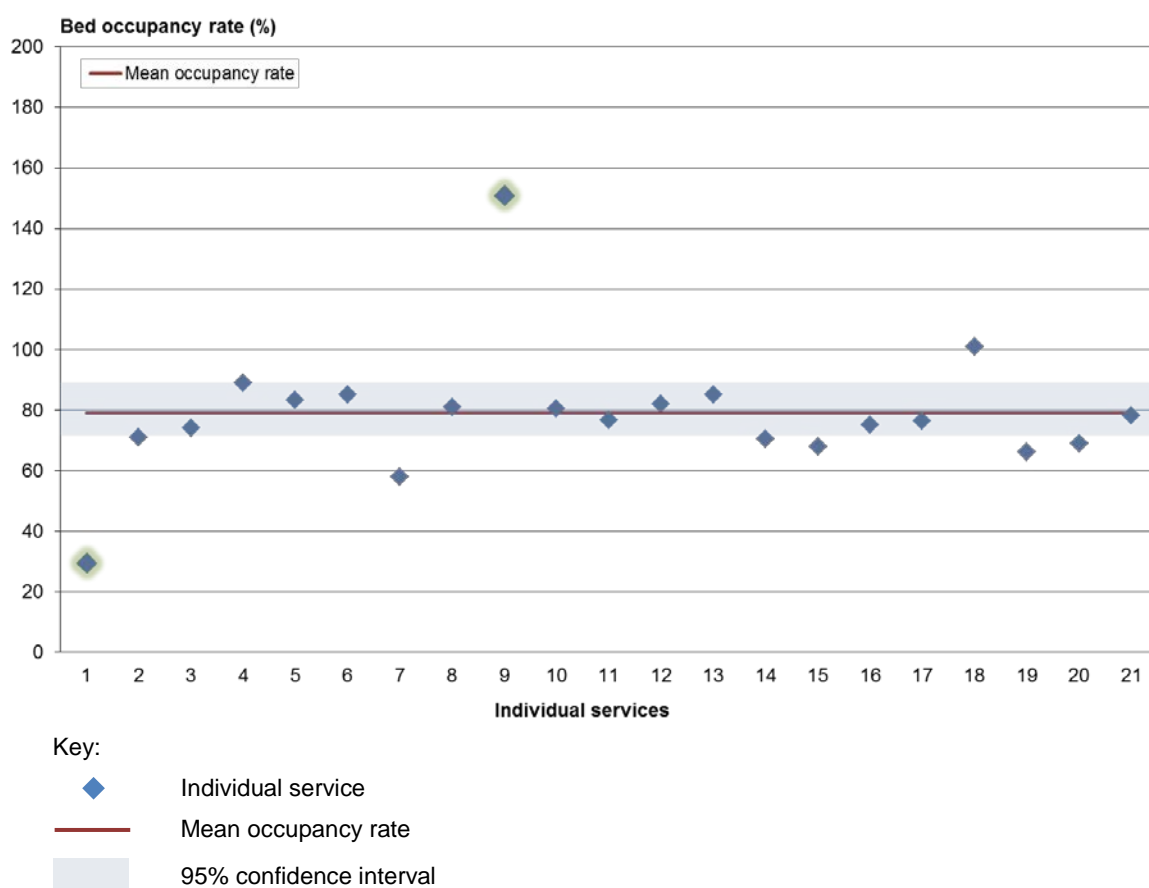
$$\% \text{ occupancy} = \frac{\text{total actual occupied bed days}}{\text{number of bed days available}}$$

where the number of bed days available equals 'available beds x 365 days (or number of days beds were open)'.

The mean bed occupancy rate, which was calculated for all services that also provided ALOS data (n=21), was  $79 \pm 9.2\%$  (69.8–88.2 days at 95% confidence). For comprehensive services only (n = 19), excluding two outliers, the average bed occupancy rate was  $77 \pm 4.3\%$  (72.7–81.3 days at 95% confidence).

Individual service bed occupancy rates are plotted in Figure 10, along with the national average and 95% confidence interval. There are two outliers (highlighted), one with a low occupancy rate of 28.5% and one with a high occupancy rate of 151%. Both of these outliers are community palliative care services. Bed occupancy rates for most comprehensive services fell within or close to the 95% confidence interval for the national mean occupancy rate.

**Figure 10:** Plot of bed occupancy rates for each hospice palliative care service with access to inpatient beds (as a percentage of available bed days)



## 2.5 Estimated need for inpatient palliative care beds

Using data on inpatient bed numbers and admission rates for the 22 services that were able to provide data on bed numbers, admissions and total patients, and the national average ALOS, a national 'bed to population' ratio was calculated for the projected 2011 adult population (see Box 1). Given the reported admission rates and ALOS, there would need to have been 197 inpatient palliative care beds during 2011, giving a ratio of 6.15 beds per 100,000 of the adult population. (With a margin of error of 0.8 days, the true ratio lies between 5.6 and 6.7:100,000). When calculated simply as the ratio of reported beds to the 2011 projected population, the national ratio is 5.9:100,000 (Table 27). The slight difference in ratios can be accounted for in the margin of error inherent in the more complex calculation, missing hospice data, and possible errors in the population projections, which in this case was a medium projection. For the purposes of this report the calculated ratio of 6.15:100,000 will be used as it is based on reported admission data.

The 2011 bed:population ratio is quite different from the 1998/99 data reported in the Palliative Care Strategy, which found a national ratio of 4.03 hospice beds per 100,000. The number of inpatient hospice beds has increased since 2001 from 146 to 188, but the New Zealand population has also increased significantly from that time, as has the number of people requiring palliative care.

### Box 1: Inpatient bed to population ratio calculation (adults)

2011 adult population	3,206,960	(excluding those not in a DHB region)
Total patients cared for	12,099	
New admissions	3872	32% admission rate
Repeat admissions	2740	71% readmission rate
Total admissions	6612	
ALOS (days)	8.6	
Total bed days	56,863	(at 79% occupancy)
At 100% occupancy	71,979	
over 1 year =	197	beds required
<b>Beds per 100,000 =</b>	<b>6.15</b>	

Compared to international recommendations on inpatient palliative care bed ratios, the current New Zealand ratio sits in the middle. The two commonly quoted models for estimating the number of palliative care beds required for a population are from the United Kingdom and Australia.

- The National Council for Palliative Care (UK) originally suggested a rate of 52 beds per million for cancer patients, and 26 beds per million for non-cancer patients, or 7.8 beds per 100,000 of the population for the combined needs of cancer and non-cancer patients (Tebbit 2004). This ratio was subsequently recognised as being unachievable and was revised to 5.3 beds per 100,000 (based on available hospice bed numbers of 51:100,000 plus a 5% increase to accommodate non-cancer patient use), but with an added adjustment for resource need based on the number of deaths and relative deprivation of the local population (Tebbit 2009).



- Palliative Care Australia suggests a minimum of 6.7 beds per 100,000 population (Palliative Care Australia 2003). However, this figure is based on a slightly higher level of occupancy (85%) and an ALOS of 14 days. The shorter ALOS and lower occupancy rate found in New Zealand hospices mean that the current ratio of 6.1:100,000 is probably an appropriate, although conservative, level of resource.

While the national bed:population ratio appears adequate and within the range suggested by international guidance, the distribution of hospice beds is not uniform across DHB regions, with many DHBs being well below the national ratio (see Table 27). The lowest ratio is 0 beds per 100,000 in two DHBs, and the highest is 12.5:100,000 population. Some of the lowest bed ratios are in DHBs with the largest populations (Waitemata, Auckland, Counties Manukau and Canterbury), while many of the highest ratios are in DHBs with smaller populations.

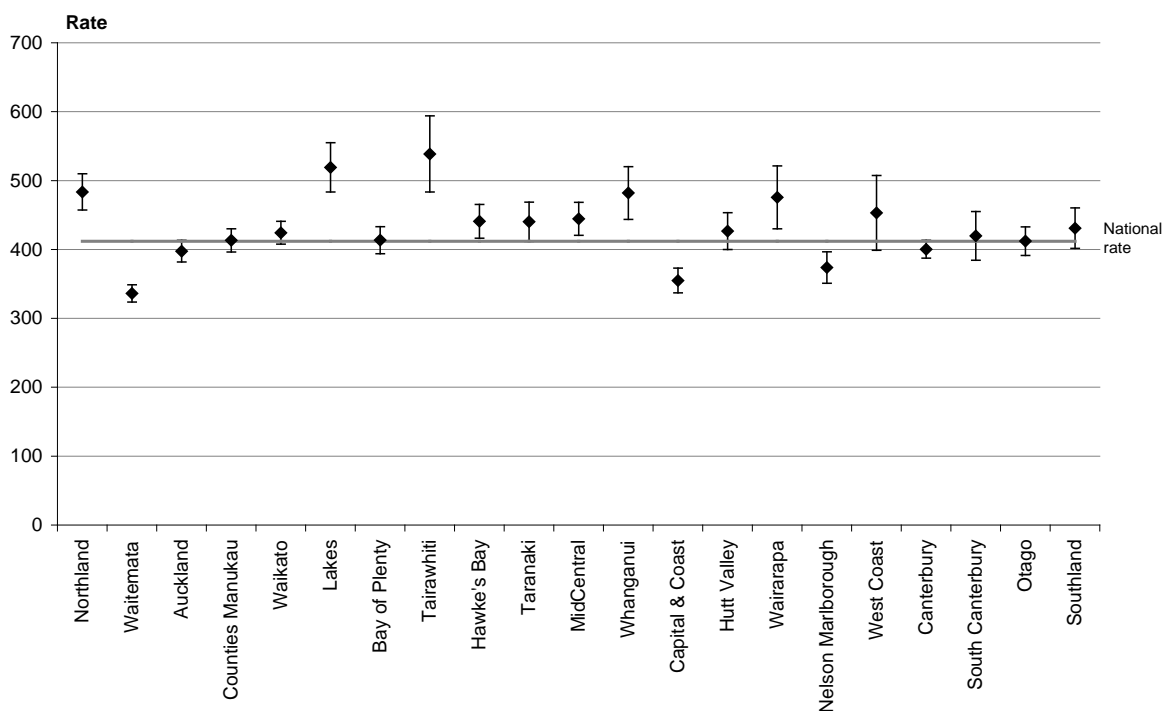
**Table 27: Palliative care bed to adult population ratios**

DHB region	Total projected adult population 2011	Reported palliative care beds in 2011	Ratio of beds to 100,000 population
Northland	113,550	8	7.0
Waitemata	394,620	15	3.8
Auckland	349,080	16	4.6
Counties Manukau	337,420	9	2.7
Waikato	260,910	10	3.8
Lakes	72,510	0	0.0
Bay of Plenty	154,730	17	11.0
Tairāwhiti	31,810	2	6.3
Hawke's Bay	110,710	8	7.2
Taranaki	79,530	6	7.5
MidCentral	122,070	10	8.2
Whanganui	45,890	5	10.9
Capital & Coast	221,400	18	8.1
Hutt Valley	103,230	10	9.7
Wairarapa	29,780	0	0.0
Nelson Marlborough	104,830	16	15.3
West Coast	24,680	0	0.0
Canterbury	380,120	11	2.9
South Canterbury	42,420	7	16.5
Otago	143,870	12	8.3
Southland	83,800	8	9.5
<b>DHB totals</b>	<b>3,206,960</b>	<b>188</b>	<b>5.9</b>

How inpatient hospice beds are distributed across the DHB regions is influenced by a number of factors, such as the model of palliative care delivery in the region, funding and resource availability and community fund raising, ownership and expectations. These and other factors will influence where and how hospice beds are located, but it is important to ensure that equality of access to inpatient hospice care is addressed, and this involves consideration of the required number of inpatient beds if hospice services are to meet the need identified in Phase 1 of the HNA in each DHB region.

A particular driver of palliative care need is the expected increase in access for people with a non-cancer diagnosis. Other factors that need to be taken into account include DHB population size and the number of people who would benefit from palliative care (ie, the proportion of the mid-range estimate). This last factor is likely to be the best option, because it recognises the variation in death rates across the DHB regions (Figure 11) and the associated need for palliative care that was identified in Phase 1.

**Figure 11:** Age-standardised death rates per 100,000 population, by DHB region, 2009



Note: Age-standardised to WHO World Standard Population.

Source: Reproduced from: *Mortality and Demographic Data 2009*, Ministry of Health 2012.

There are a number of ways to allocate hospice beds, but there are drawbacks to each method, not least of which is the current financial restraint within the health system in New Zealand. The three examples presented in Table 28 are based on the following criteria.

- Example 1 uses the current number of hospice beds, based on the national ratio of 6.15:100,000 allocated by DHB population size, to illustrate how current bed numbers might be distributed to ensure equality of access through a more even distribution across DHBs.

- Example 2 uses the national ratio to allocate beds to DHB regions, but with the addition of a population modifier calculated using the mid-range estimate of deaths where palliative care would be of benefit, and a deprivation modifier for each region. The deprivation modifier is based on the relative deprivation of each DHB region calculated from the NZ Deprivation Index 2006 (see Appendix 6 for calculations). This example apportions a share of resources based on population need because there are marked differences in death rates, as illustrated in Figure 11, which affects the size of the mid-range estimate, and in deprivation, which affects the level of resource required by the population to achieve health outcomes comparable to a less deprived region.
- Example 3 uses the mid-range estimate of need, reported admission/readmission rates, ALOS and occupancy rate to determine the number of beds to meet the potential admissions required if the mid-range estimate group were all to receive hospice palliative care. This example would require 9 beds per 100,000 adult population, a substantial increase in the ratio, resulting in 289 beds. For this example the beds have been distributed based on DHB population size.

**Table 28: Examples of hospice palliative care inpatient bed numbers and their distribution**

DHB region	Actual palliative care beds 2011	Example 1: Bed allocation by 2011 population	Example 2: Bed allocation based on population modifier	Example 3: Bed allocation to meet mid-range estimate need
Bed:population ratio	5.9:100,000	6.15:100,000	6.15:100,000	9.0:100,000
Northland	8	7	11	10
Waitemata	15	24	16	36
Auckland	16	21	18	31
Counties Manukau	9	21	21	30
Waikato	10	16	18	23
Lakes	0	4	6	7
Bay of Plenty	17	10	15	14
Tairāwhiti	2	2	4	3
Hawke's Bay	8	7	10	10
Taranaki	6	5	6	7
MidCentral	10	8	9	11
Whanganui	5	3	5	4
Capital & Coast	18	14	8	20
Hutt Valley	10	6	6	9
Wairarapa	0	2	2	3
Nelson Marlborough	16	6	6	9
West Coast	0	2	2	2
Canterbury	11	23	19	34
South Canterbury	7	3	3	4
Otago	12	9	9	13
Southland	8	5	4	8
<b>Total beds</b>	<b>188</b>	<b>197</b>	<b>197</b>	<b>289</b>

As can be seen, these examples result in quite significant differences in the number of hospice beds in each DHB region. If the current hospice beds were to be distributed based on population size (Example 1), the number of beds in many DHB regions would change quite dramatically, but this still may not meet local need. Example 2 is an attempt to distribute hospice beds based on one possible model of DHB population need and results in a different spread of bed allocation. The third example is an attempt to address palliative care need as defined by Phase 1 of the HNA. This example would require either a substantial investment in capital development to increase bed numbers, or a change in funding that could allow palliative care beds to be located in local hospitals or ARC beds.

We also need to consider expected population growth and the related increase in the number of people who would benefit from palliative care in the future. This will have an impact on the number of palliative care beds required (based on current use levels) and how they may be distributed across DHB regions. Using the projected populations for each DHB region for the next 15 years, and the national bed ratio of 6.1:100,000 population, example bed numbers have been calculated for each DHB region (see Table 29). If we take current bed numbers as 197 (based on current utilisation), this means an approximate increase in bed numbers of 1% per annum over the next 15 years. This does not take into account the potential unmet need identified in Phase 1, which is predominantly in non-cancer patients.

**Table 29: Examples of projected inpatient palliative care bed numbers and distribution based on 2011 ratio (6.1:100,000)**

DHB	Example bed allocation 2016	Example bed allocation 2021	Example bed allocation 2026
Northland	7	8	8
Waitemata	26	28	30
Auckland	23	25	26
Counties Manukau	23	25	27
Waikato	17	17	18
Lakes	5	5	5
Bay of Plenty	10	11	11
Tairāwhiti	2	2	2
Hawke's Bay	7	7	7
Taranaki	5	5	5
MidCentral	8	8	8
Whanganui	3	3	3
Capital & Coast	14	15	16
Hutt Valley	6	7	7
Wairarapa	2	2	2
Nelson Marlborough	7	7	7
West Coast	2	2	2
Canterbury	25	26	27
South Canterbury	3	3	3
Otago	9	9	9
Southland	5	5	5
<b>Total PC beds</b>	<b>208</b>	<b>218</b>	<b>228</b>

All of the above are just examples, and further work is required to determine an appropriate palliative care inpatient bed model for New Zealand and then additional project work at a DHB regional level to establish the best location and funding model for these beds to meet the needs of the local population.

## 2.6 Community hospice care

All 31 comprehensive and community hospice palliative care services provide community-based palliative care programmes. This section summarises the community care service components, the setting in which care is provided, patient contacts, and the staff composition of community care teams.

### Service components of hospice community care programmes

As summarised in section 2.1, 'Hospice palliative care service capability', all DHBs have hospice palliative care services in their regions providing all or most of the core clinical functions, which also form part of the community care aspect of hospice service. These include assessment, care planning, care coordination and equipment provision (see Table 30). While the majority of hospice services also provide direct clinical care for community patients, 25% of comprehensive services and 30% of community services rely on other health services for this component of care. For these services, care is usually provided by district nurses and GPs.

Equipment for community patients is not always provided directly by the hospice service, and where this is the case any equipment is provided through the DHB (apart from syringe drivers). Many of the other capability functions are also applicable to community care but were not included in this part of the hospice survey. However, it can be assumed that any service component gaps identified in section 2.1 will also apply to community services, such as access to allied health professionals.

**Table 30: Community care service components**

Service category	Number of services (and %) providing service components				
	Assessment	Care planning	Clinical care	Care coordinators	Equipment provision
Comprehensive hospice service (n=19)	19 (100%)	18 (95%)	14 (74%)	18 (95%)	16 (84%)
Community hospice service (n=12)	12 (100%)	12 (100%)	9 (75%)	12 (100%)	10 (83%)

## Where is community care provided?

All comprehensive services and community hospice services reported that they provided care in private residences or ARC (see Table 31), including some private hospitals. Three-quarters also reported providing palliative care in a hospital, although at a regional level this covered only two-thirds of DHBs. Where a service did not provide care in their local hospital, in most regions the DHB had a dedicated hospital palliative care service. The only exceptions are the Wairarapa and West Coast DHBs, which do not have a DHB hospital palliative care service. One service reported providing hospice palliative care in a prison and one in schools and community centres (for child and young person services). Some said they provided care in whatever setting the patient considered 'home'.

**Table 31: Place of care, by service category**

Service category	Place of care		
	Private residence	Aged residential care	Hospital (public /private)
Comprehensive hospice service (n=19)	19 (100%)	19 (100%)	14 (74%)
Community hospice service (n=12)	12 (100%)	12 (100%)	9 (75%)

## Total number of contacts

In the period 1 July 2010 to 30 June 2011, hospice palliative care services reported undertaking 139,343 community visits and 139,926 telephone consultations. (This data does not include visits to palliative care patients by district nursing services, which provide a significant proportion of in-home care in some regions.) By service category this included:

- 107,356 visits and 110,248 telephone consults by comprehensive hospice services (three services did not have telephone consult data)
- 28,841 visits and 29,098 telephone consults by community hospice services (two services did not have telephone consult data)
- 3146 visits and 580 telephone consults by hospice supportive care services (data was incomplete for this group).

On average, comprehensive hospice services made  $9.7 \pm 2.3$  visits per patient (7.4–12 at 95% confidence), with a minimum of one visit and a maximum of 22. They also had an average of  $11.6 \pm 3.8$  phone consults per patient (7.8–15.4 at 95% confidence), with a minimum of two and a maximum of 25 consults.

Community hospice services had slightly higher averages, with  $12.2 \pm 8.3$  visits per patient (3.9–20.5 at 95% confidence), with a minimum of one visit and a maximum of 44. On average they had  $14.5 \pm 7.6$  phone consults per patient (6.9–22.1 at 95% confidence), a minimum of three and a maximum of 36 consults. Both of these estimates have a very wide confidence interval due to the small number of services and wide variation in number of visits and consults between services. These different averages compared to comprehensive services may reflect the fact that community services have a focus on care provided in community settings, while only a small number have access to inpatient hospice beds, so they are more likely to provide home visits and telephone consults to their patients.

Note that these averages are based only on information from those services able to provide data. As noted above, there were several services in all categories that were unable to provide data, and so averages have been calculated based on the number of patients cared for by services who also provided data on visits and telephone consults. This data also excludes hospice supportive care services because too much data was missing.

Figure 12 illustrates the spread of the ‘average visits per patient’ for each of the services that provided data. This graph only includes comprehensive and community hospice services and excludes three services that did not provide data and one outlier service that had a very high average number of visits (44).

**Figure 12:** Average number of visits for individual hospice services

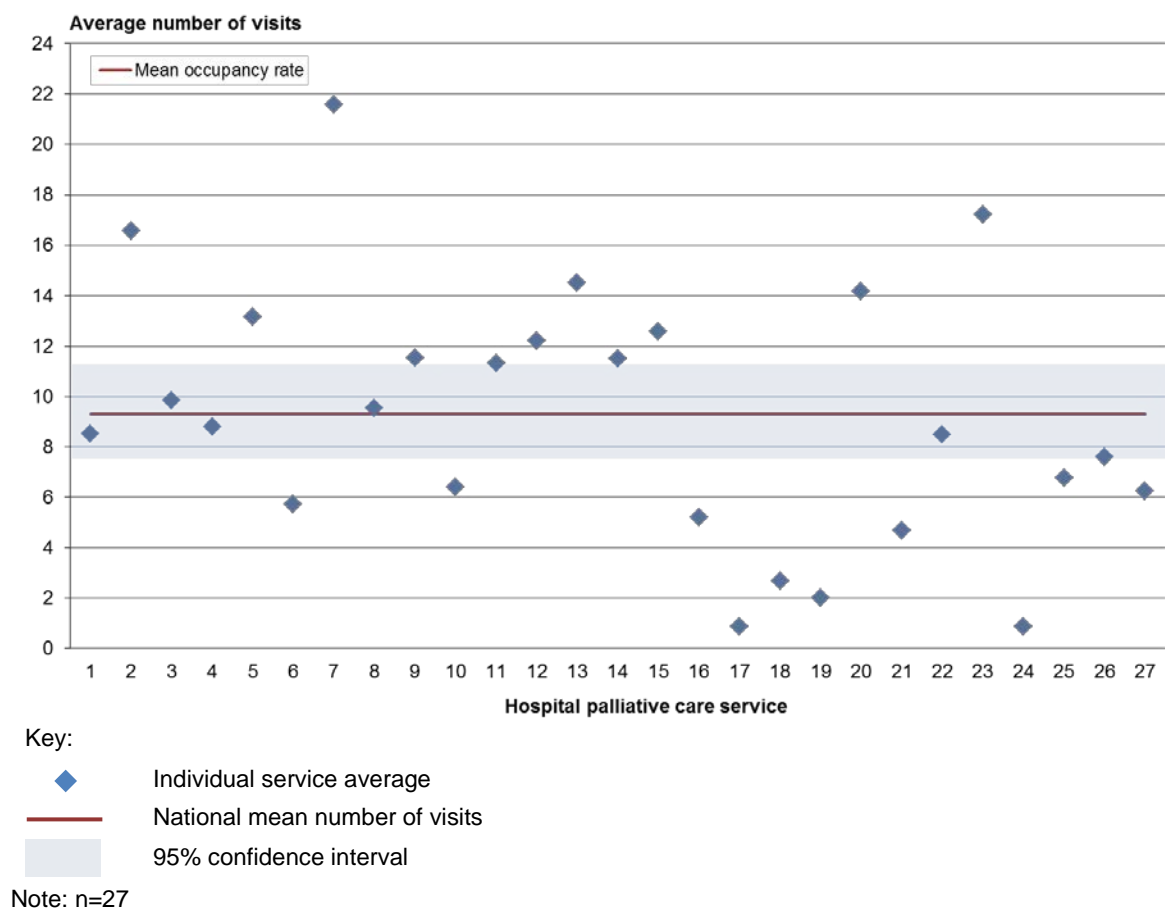
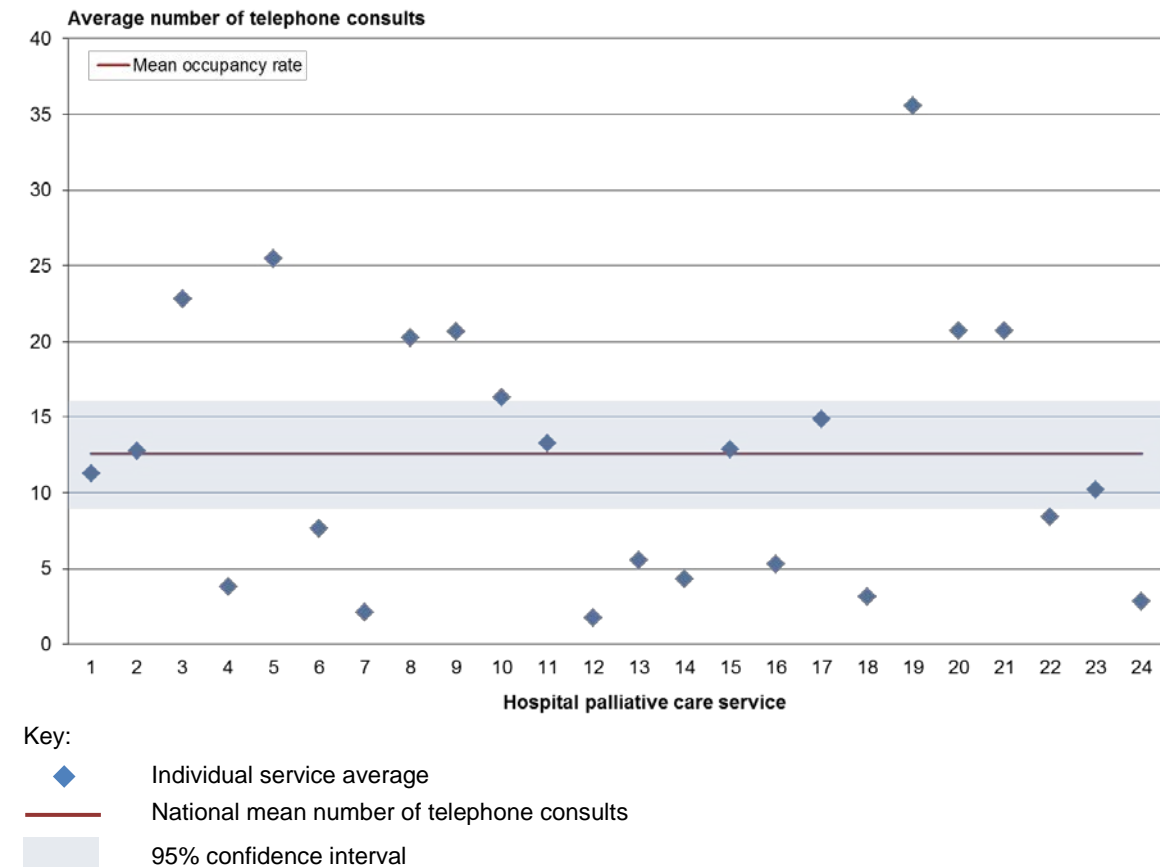


Figure 13 is a plot of individual hospice services' average number of telephone consults, and again demonstrates the wide spread in the averages. Again there is one outlier at 36 telephone consults per patient, but this service has been included in the plot and mean because it is not too much higher than the next nearest service; it is, however, much higher than the national mean.

**Figure 13:** Average number of telephone consults for individual hospice services



Note: n=24

Nationally, the average number of visits per patient was  $9.3 \pm 1.9$  visits per patient (7.4–11.2 at 95% confidence), excluding the outlier with an average of 44 visits per patient. The average number of telephone consults was  $12.6 \pm 3.5$  per patient (9.1–16.1 at 95% confidence). However, the average varies widely between DHB regions (see Table 32).



**Table 32: Number of community palliative care visits and telephone consults, by DHB**

DHB	Community visits	Telephone consults	Total patients cared for 2011	Average visits per patient	Average telephone consults per patient
Northland	8083	8823	915	9	10
Waitemata	18,837	21,216	1362	14	16
Auckland	8840	nk	1546	6	0
Counties Manukau	11,343	21,466	959	12	22
Waikato	5350	3549	933	6	4
Lakes	11,487	2214	429	27	5
Bay of Plenty	15,807	18,955	889	18	21
Tairāwhiti	1171	534	188	6	3
Hawke's Bay	5932	4741	622	10	8
Taranaki	7306	1349	633	12	2
MidCentral	4538	14,328	708	6	20
Whanganui	3450	6292	305	11	21
Capital & Coast	9448	12,582	773	12	16
Hutt Valley	8344	7627	575	15	13
Wairarapa	nk	nk	148	0	0
Nelson Marlborough	7630	2458	630	12	4
West Coast	nk	nk	127	0	0
Canterbury	6638	5476	1274	5	4
South Canterbury	143	nk	168	1	0
Otago	1295	6261	486	3	13
Southland	555	1475	278	2	5
<b>Total</b>	<b>136,197</b>	<b>139,346</b>	<b>13,948</b>	<b>9.3</b>	<b>12.6</b>

Notes:

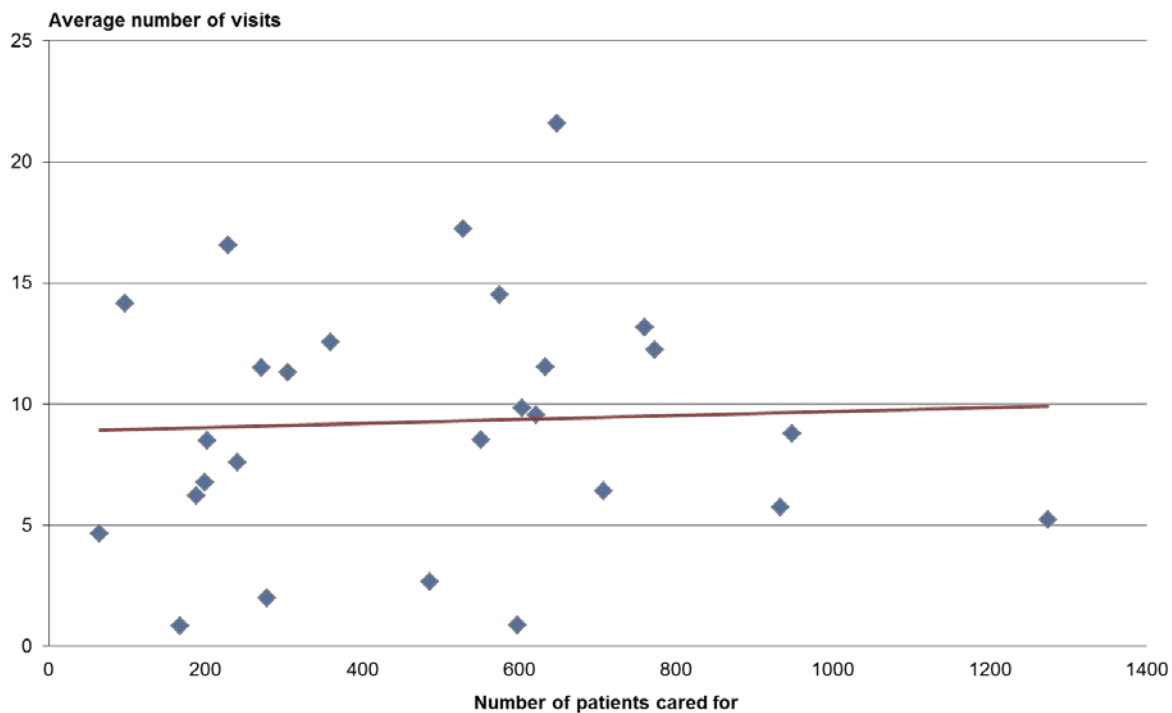
nk = not known due to no data provided.

Total DHB averages are based on service-level data, not DHB figures, and exclude services that did not provide data on visits and/or telephone consults.

Aside from community hospice services having higher average numbers of visits and telephone consults, the number of visits or telephone consults by DHB region does not appear to correlate with the types of service available, whether community palliative care being provided by a hospice service or district nursing service, the number of patients cared for, the number of inpatient hospice beds available or the number of inpatient admissions.

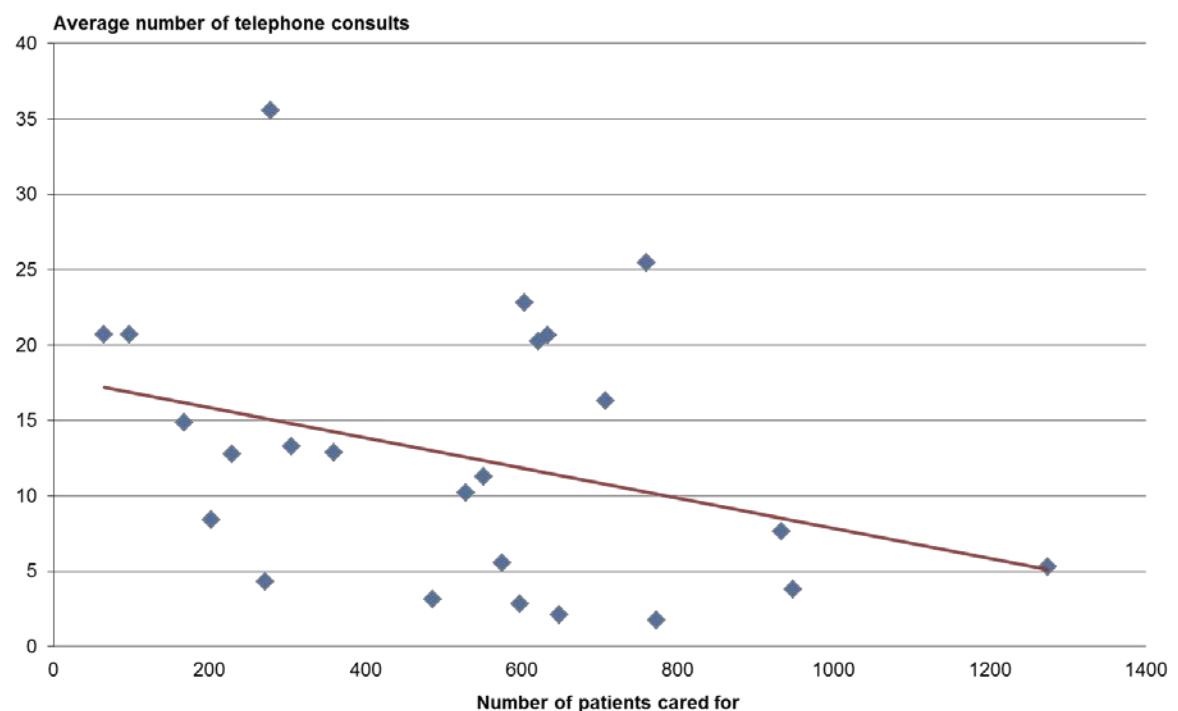
This is illustrated in Figure 14, which plots the average number of visits against the total number of patients for the 27 services that provided data. There is wide scatter of the average visits and the trend line is near horizontal, meaning that the number of patients cared for does not explain the variance in the average number of visits. Interestingly, the average number of telephone consults does appear to be moderately influenced by the total number of patients, but with an inverse relationship. As shown in Figure 15, this suggests that the greater the total number of patients, the lower the average number of telephone consults. This trend remains even if the outlier, with an average of over 35 telephone contacts, is excluded. It is likely that the greater workload allows less time for patient phone calls.

**Figure 14:** Average number of visits versus total patients cared for



Note: n = 27, excludes 1 outlier.

**Figure 15:** Average number of telephone consults versus total patients cared for



Note: n=24.

### Composition of the community care team

There are a number of gaps in the data provided by services, as some did not have readily available or complete data on the staff composition of their community palliative care teams. In all staff groups the full-time equivalent (FTE) number is much lower than the actual head count of staff, due to staff working part time or allocating FTE across different settings, such as a hospice inpatient unit and a community care team. Because of this, and due to the fact that FTE is a more relevant measure of staff availability, only FTE have been reported. The exception is with volunteers, who have been included as a head count because they do not routinely have an FTE recorded.

Table 33 summarises the hospice community care staffing FTE for each DHB region by staff group. Specific roles were not defined for each staff group, but more detailed data on staff composition is presented in chapter 4. The largest group providing clinical care is nursing, at 161.4 FTE, which is one third of the hospice nursing workforce, followed by psychological and social support staff. While the FTE for this group is only 43.3, this is equivalent to half the psychological and social support workforce in hospices.

Around a quarter of medical staff time is allocated to community care (12.5 FTE), although a number of DHBs do not have any allocated community medical staff. One third of allied health staff FTE is dedicated to community care (10.3 FTE); this is a very small FTE allocation and many DHBs do not have any allied health staff allocated to hospice community care. The largest workforce is the volunteers, with 2370 people providing voluntary services to palliative patients and their families in the community across 15 DHB regions.

**Table 33: Summary of hospice community care staff, by DHB**

DHB	FTE involved in community palliative care				Head count
	Medical	Nursing	Allied Health	Psychosocial	Volunteers
Northland	0.0	15.4	0.0	0.8	132
Waitemata	1.4*	15.1*	0.1*	8.3*	482*
Auckland	1.1	10.4	1.4	2.0	137
Counties Manukau	0.5	12.3	0.0	0.6	106
Waikato	0.5	14.9	0.0	7.7	376
Lakes	0.03	9.9	0.0	1.2	15
Bay of Plenty	0.0	18.5	1.8	2.3	274
Tairāwhiti	0.4	1.4	0.0	0.4	0
Hawke's Bay	1.0	7.1	0.0	2.0	0
Taranaki	0.5	5.0	0.3	1.2	10.0
MidCentral	2.9	7.0	0.6	2.9	0
Whanganui	0.0	3.9	0.0	1.0	186
Capital & Coast	0.9	7.8	1.5	3.9	10
Hutt Valley	1.8	9.5	0.5	4.1	31
Wairarapa	0.0	6.7	0.0	0.5	92
Nelson Marlborough	0.0	3.8	0.5	1.2	362
West Coast	0.0	2.5	0.0	0.0	0
Canterbury	1.0	7.1	3.6	2.9	0
South Canterbury	0.0	0.2	0.0	0.5	156
Otago	nk	nk	nk	nk	1
Southland	0.5	3.0	0.0	0.0	0
<b>Total community care staff</b>	<b>12.5</b>	<b>161.4</b>	<b>10.3</b>	<b>43.3</b>	<b>2370</b>
<b>% of total workforce</b>	<b>28%</b>	<b>34%</b>	<b>34%</b>	<b>51%</b>	<b>31%</b>

nk = not known due to no data provided.

## Shared care agreements

The care of palliative patients in community settings (home, residential care, etc) requires collaboration between palliative care services and primary and secondary care services to ensure a seamless patient journey. To this end many hospice services have shared care agreements in place (either formal or informal) with other health care services that may be involved in patient care, including district nursing services, GPs, ARC facilities and hospitals.

Shared care agreements reported by comprehensive and community hospice services are summarised in Table 34. Over half of the hospice services reported shared care agreements with district nursing services, GPs and ARC, and just under half with hospitals. Included in 'Other' services were: home support services, ambulance services, child and adolescent services (children's community resource nursing staff, specialist children's nurses and public health nurses), Māori health providers, other specialist services (such as oncology), and regional specialist palliative care services.

**Table 34: Palliative care services with shared care agreements (comprehensive and community hospice services only)**

Shared care partner	District nursing	General practice	Aged residential care	Hospital	Other
Number of services	18	17	16	14	13
% of all services (n=31)	58%	55%	52%	45%	42%

## 2.7 Day stay programmes

Day stay programmes include a range of day services that are provided at the hospice facility. Services covered in this section include activities-based programmes, outpatient clinics and day procedures. All of these services fall within the 'could offer' functions of the Hospice New Zealand capability recommendations, so they are not considered essential components of a hospice service.

Twenty-two services reported providing at least one type of day stay service: 19 comprehensive services (100%), five community hospice services (50%, excluding the two DHB district nursing services), and three hospice supportive care services (50%). Data is not complete for all aspects of the day stay programme survey questions as a number of services did not routinely collect data on this part of their service.

### Services offered by day stay programmes

Activity programmes were the most commonly offered type of day stay programme, and these were offered by 22 services (81%) that reported having day stay services. Activity programmes included a wide range of options, such as:

- social interaction, friendship, support groups (patients, carers), education, invited speakers
- art, music, crafts
- massage, exercise, Tai Chi, complementary therapies, hair and beauty therapy, lymphoedema therapy
- biography, counselling, grief and loss support.

The second most common day stay service offered was outpatient clinics, which were provided by all but one comprehensive service and a quarter of community hospice services (see Table 35). Day procedures were only offered by 10 (53%) comprehensive hospice services.

**Table 35: Day care programme services**

Category of service	Day stay service		
	Activity programmes	Outpatient clinics	Day procedures
Comprehensive (% of all services in category, n = 19)	14 (74%)	18 (95%)	10 (53%)
Community (% of all services in category, n = 10)	5 (42%)	3 (25%)	
Supportive care (% of all services in category, n = 6)	3 (50%)		

Unfortunately the data reported by hospice services for the day stay section of the survey was very incomplete, with only 10 services able to provide full data on utilisation of their day stay programme, but even that data was questionable due to the wide variability in figures. As a result it is not possible to accurately determine the per annum number of available day stay places, percentage of day stay places used or the number of new or unique attendees.

Eighteen services did report their total day stay attendances for the 12-month survey period. The number of attendees varied widely between services (range 3–1745), but for these 18 services a total of 8780 people attended a day stay programme. Of these hospice services, 13 also provided data on the number of day stay places available during the year, and when compared to attendances this showed that, on average, 66% of available day stay places were used, but with a wide range of 2 to 88%.

In 2004 the National Council for Palliative Care recommended that there should be 20,500 places per year for a population of 1.5 million, distributed by resource level need. However, this number of places was based on a survey in which 95% of use was by cancer patients. More recent data suggests a figure of 10,675 places per million, adjusted for need, plus additional places for increased non-cancer patient numbers (up to 20% of all day care attendees) (Tebbit 2009). Because information on day programmes from the survey was incomplete, it is not possible to say how close hospices are to providing this recommended number of places. Further work is required to better understand hospice day programme provision in New Zealand and develop a national approach to day services for palliative care patients.

### Composition of the day stay team

Seventeen services provided data on the staff composition of their day stay team. Again this data is incomplete and only gives an indication of day stay staffing. Volunteers appear to be the backbone of staffing for day stay services, with 15 services reporting volunteers working in their day stay service. This amounted to 719 volunteers, who are most likely involved in the activity programmes.

Aside from the volunteers, hospice services also reported a small volume of health care professional FTE involved in day stay. This was mainly allied health (18 individuals providing 10.1 FTE across seven services) and psychological/social support staff (15 individuals providing 5.1 FTE across seven services). The involvement of medical and nursing staff was much lower, with nine doctors and 15 nursing staff. In almost all cases staff were working part time in day stay. On average this was around 0.3 FTE, although medical staff usually worked 0.1 FTE.

## 2.8 Characteristics of hospice palliative care patients

Phase 1 of the HNA established an estimate of the number of people who could benefit from palliative care in the different DHB regions. It also examined the characteristics of this group based on demographic and patient variables included in the Mortality Collection database (age, ethnicity, underlying cause of death and deprivation). This information can be used to explore the specific needs of different populations and regions across New Zealand and to inform palliative care service development and strategic direction.

This section reports data on hospice patients, as reported by hospices, across these same patient variables, except for deprivation, which is not reported in hospice databases. Because hospice services use a range of patient administration software and collect data in different ways, not all patient variables in the survey were able to be reported by all services. As a result there are different numbers of patients reported for each of the survey variables. In some cases hospice services have included all patients under their care during the requested data period, while others have included only new patients. For these reasons caution is advised in comparing hospice service and DHB-level data. However, the approach taken here is to include all patient data reported and combine this in the analysis to produce national and DHB-level figures.

Patient data from hospice supportive care services has not been included in this part of the analysis because most could not report data and in most cases their patients will also be under the care of a comprehensive or community hospice service for their clinical care. It should also be noted that hospice services provided collated patient data, not individual patient records, so in-depth analysis was not possible.

As well as reporting on hospice patient characteristics, the principle focus of this section is to compare the group of people who currently receive hospice palliative care with the mid-range estimate group from Phase 1 of the HNA, and in some cases national population figures, to see if there are any obvious differences between the groups that could indicate gaps in access or areas that require further investigation.

## Age of patients

Hospices provided data on the age of 12,636 patients. More than three-quarters (78.8%) of hospice patients were over the age of 60 and almost a third (29.2%) were aged over 80 (see Table 36). Compared to the mid-range estimate group, hospices cared for more 60–79-year-olds than the estimate (49.7% vs 41.1%), and fewer people over age 80 (29.2% vs 43.3%). There are also differences in age group proportions between DHB regions (see Appendix 7). In the mid-range estimate, those over 80 made up the single largest group at 43.3%. This age group also accounts for almost half of all deaths annually.

This difference in proportions suggests there may be an issue with access to hospice care for people aged over 80, although the 0–19 years age group made up only 1% of hospice patients (127 individuals) and 20–39-year-olds a further 2.5% (313 individuals). This reflects the small number of deaths in this group, as well as the fact that this age group is less likely to die from a cause where palliative care would be of benefit, which is verified by the small number of deaths in this age group in the mid-range estimate. Also of note is that 1% of deaths in 0–9-year-olds in the mid-range estimate were in under ones, and almost all of these are neonatal deaths (under 28 days old), which would not be expected to fall under the care of a hospice.

**Table 36: Age of hospice patients compared to the mid-range estimate group**

Age group (years)	% of hospice patients	% of mid-range estimate
0–9	0.3	1.3
10–19	0.7	0.4
20–29	0.8	0.6
30–39	1.7	1.3
40–49	5.9	3.7
50–59	11.8	8.2
60–69	20.6	15.1
70–79	29.1	26.0
80+	29.2	43.3

## Gender of patients

Data was provided on the gender of 11,707 hospice patients, and the proportions of this group were 49% male and 51% female, the same as in the general population. There is a small amount of variability between DHB regions, but generally the gender split is close to 50:50. Regions with smaller patient numbers tend to have the greatest difference, but again it is generally quite small. Auckland DHB region data is affected by one service that has a very high proportion of female patients (83%), which skews their gender proportions.

The slight difference in gender proportions may be explained by the fact that males have a higher rate of death in the younger age groups, especially from accidental or sudden death.



**Table 37: Gender of hospice patients**

DHB	Males (n = 5739)	Females (n = 5968)	Total patients
Northland	51.1%	48.9%	896
Waitemata	47.8%	52.2%	563
Auckland	41.3%	58.7%	1311
Counties Manukau	50.1%	49.9%	947
Waikato	53.0%	47.0%	696
Lakes	46.1%	53.9%	219
Bay of Plenty	53.2%	46.8%	699
Tairāwhiti	43.4%	56.6%	145
Hawke's Bay	51.7%	48.3%	472
Taranaki	47.5%	52.5%	509
Mid Central	51.6%	48.4%	500
Whanganui	42.2%	57.8%	185
Capital & Coast	51.7%	48.3%	547
Hutt Valley	50.7%	49.3%	414
Wairarapa	50.0%	50.0%	6
Nelson Marlborough	50.6%	49.4%	480
West Coast	nk	nk	nk
Canterbury	48.8%	51.2%	2335
South Canterbury	47.8%	52.2%	157
Otago	52.2%	47.8%	356
Southland	48.1%	51.9%	270
<b>Total</b>	<b>49.0%</b>	<b>51.0%</b>	<b>11,707</b>
Mid-range estimate group	50.2%	49.8%	

nk = not known due to no data provided.

### Ethnicity of patients

New Zealand has a diverse ethnic mix, which also varies by DHB region, and so it is important to ensure hospice services are responsive to, and able to meet the needs of, their local population. Ethnic group categories in this section are based on prioritised ethnicity at level 2. However, there is no way to confirm if all hospice services are using this method or how they allocate ethnicity for their patients. Therefore this data from hospices should be interpreted with some caution.

Hospices provided ethnicity data for 12,064 patients, and their ethnicity is summarised in the first column of Table 38. This table also compares hospice patients to the ethnic composition of the total New Zealand population, ethnicity data for all deaths during 2008, and ethnicity of the mid-range estimate group. Note that the higher proportion of 'Other/Not elsewhere included' for hospice patients (7.5%) is due to a small number of hospices being unable to report ethnicity data for all of their patients (see Appendix 8 for DHB region ethnicity data). This will also have an effect on the accuracy of the hospice data.

At a national level hospice services appear to be achieving a close alignment between the ethnicity of patients and the expected ethnic group proportions when compared to all deaths and the mid-range estimate. The only real difference is with the European group, but this may be due to differences in ethnic group allocation and the higher number of patients allocated to the 'Other/Not elsewhere included' group in the hospice data.

**Table 38: Comparison of ethnic group composition of the New Zealand population, all deaths (2008), mid-range estimate group, and hospice patients**

Ethnic group	NZ population (2006)	All deaths 2008	Mid-range estimate	Hospice patients
European <sup>1</sup>	66.9%	84.0%	83.9%	75.5%
Māori	14%	9.9%	9.8%	10.0%
Pacific peoples <sup>2</sup>	5.6%	3.6%	3.6%	3.9%
Chinese Asian	3.4%	0.9%	0.9%	1.5%
Indian Asian	2.5%	0.7%	0.6%	0.6%
Other Asian	2.6%	0.6%	0.6%	0.4%
MELAA <sup>3</sup>	0.8%	0.3%	0.2%	0.5%
Other/Not elsewhere included <sup>4</sup>	4.2%	0.03%	0.3%	7.5%

1. 'European' includes people identified as: New Zealand European, New Zealander, Other European and European not further defined.
2. 'Pacific peoples' includes people identified as Samoan, Cook Island Maori, Tongan, Niuean, Fijian, Tokelauan and any other Pacific groups.
3. 'MELAA' includes people identified as Middle Eastern, Latin American and African.
4. 'Not elsewhere included' includes Response Unidentifiable, Response Outside Scope and Not stated.

Appendix 8 summarises hospice patient ethnicity by DHB region and compares reported ethnic group proportions to the DHB-level mid-range estimate. At this level, the majority of DHBs continue to have a close alignment between hospice patient ethnicity and that expected for people who would benefit from palliative care in their region. There are a few exceptions to this, most commonly with a smaller proportion of European patients, which occurs in Counties Manukau, Waikato, Bay of Plenty, Hawke's Bay, Capital & Coast, Canterbury and Southland. The apparent difference in five of these DHBs can probably be explained by the higher-than-expected number of people allocated to 'Other / Not elsewhere included' (Waikato, Bay of Plenty, Hawke's Bay, Canterbury and Southland). There were, however, a number of differences that cannot be explained by missing data.

Differences in Counties Manukau DHB appear to be a result of higher numbers of Māori, Pacific and Chinese people being cared for by hospice services (17%, 21.5% and 4.7%, respectively). Auckland DHB had slightly lower-than-expected proportions of Māori and Pacific people, but a higher proportion of Chinese Asian patients. Lakes DHB had a lower proportion of Māori hospice patients than would be expected given the relatively high number of Māori who would have benefited from palliative care as identified in the mid-range estimate for this region. Bay of Plenty DHB, on the other hand, had a higher proportion of Māori hospice patients than would be expected. Capital & Coast DHB had higher-than-expected proportions of all the minority ethnic groups; in particular this DHB reported a very high proportion from the MELAA group. Wairarapa DHB only had data for six patients so is incomplete, and the West Coast DHB services did not provide any data.

## Diagnosis of patients

In Phase 1 of the HNA the greater proportion of the mid-range estimate was identified as being people with a non-cancer diagnosis (57% of adults and 86% of 0–19-year-olds). In addition, underlying cause of death was identified as an important factor that influences where people die in New Zealand, with cancer patients being more likely to die in hospice or a private residence, and non-cancer patients more likely to die in hospital or ARC. Given these facts, the diagnosis of patients currently receiving hospice palliative care is of great interest, as it is likely to highlight one of the key growth areas in hospice care, and in particular the level of access for non-cancer patients.

Hospice services provided diagnoses for 11,623 patients; 9163 (79%) of these patients had a cancer diagnosis, while the remaining 21% represented a variety of non-cancer diagnostic groups (see Table 39). There are some significant differences in the proportions of cancer and non-cancer patients receiving hospice care when compared to the mid-range estimate group of people who would benefit from palliative care. Most notably, there is a much higher proportion of cancer patients receiving hospice care, indicating that a potentially large number of people with a non-cancer diagnosis are missing out on hospice palliative care.

**Table 39: Diagnostic groups of hospice patients**

Diagnostic group	Hospice patients	Mid-range estimate
Cancer	78.8%	42.1%
Cardiovascular	5.8%	26.8%
HIV/AIDS	0.1%	0.1%
Renal failure	2.2%	2.5%
Neurological disease	3.7%	5.9%
Respiratory disease	4.3%	9.1%
Other non-cancer	5.0%	13.6%

There is wide variation in the proportions of cancer and non-cancer patients receiving hospice care in the different DHB regions (see Table 40). The proportion of cancer patients ranges from 62 to 88%, and non-cancer patients from 12 to 38%. This data indicates that there is a move towards more non-cancer patients accessing hospice services, but not yet at the level suggested by the mid-range estimate. However, some regions are achieving a much higher proportion of non-cancer patients than others. Appendix 9 compares the reported hospice patient diagnoses to the mid-range estimate for each DHB region.

**Table 40: Diagnosis of hospice patients, by DHB**

DHB	Diagnosis		Total patients
	Cancer	Non-cancer	
Northland	72%	28%	904
Waitemata	85%	15%	1000
Auckland	84%	16%	1254
Counties Manukau	86%	14%	927
Waikato	84%	16%	662
Lakes	81%	19%	219
Bay of Plenty	83%	17%	677
Tairāwhiti	66%	34%	145
Hawke's Bay	70%	30%	474
Taranaki	62%	38%	509
Mid Central	75%	25%	500
Whanganui	74%	26%	187
Capital & Coast	77%	23%	547
Hutt Valley	72%	28%	427
Wairarapa	76%	24%	62
Nelson Marlborough	67%	33%	480
West Coast	nk	nk	nk
Canterbury	81%	19%	1884
South Canterbury	87%	13%	131
Otago	88%	12%	356
Southland	74%	26%	278
<b>Total</b>	<b>79%</b>	<b>21%</b>	<b>11,623</b>

nk = not known due to no data provided.

The single largest group of non-cancer patients who do not appear to be accessing hospice care are those people with cardiovascular diagnoses, such as ischaemic heart disease, congestive heart failure and stroke: 677 hospice patients were reported to be in this group (5.8%), while the mid-range estimate suggested over 4200 people per annum in this diagnostic group could benefit from palliative care (26.8% of the estimate group). This means that potentially fewer than a fifth of people dying from cardiovascular diseases are receiving hospice palliative care. Across the DHB regions only Taranaki DHB and Nelson Marlborough DHB appear to be achieving a significantly higher number of cardiovascular patient referrals, but even these areas are still fewer than half the estimated palliative cardiovascular patients in their regions.

Renal failure and respiratory disease patients appear to be faring a little better, although this may be due to their relatively low numbers, but again only around half appear to be receiving hospice palliative care in most DHB regions. There are some exceptions, with several DHBs achieving or even exceeding expected proportions of these patient groups. Of note, HIV/AIDS patients now appear to be uncommon in palliative care, as demonstrated by their almost complete absence from both hospice patient data and the mid-range estimate.

Finally, there is a large group of 'other non-cancer diagnoses' that do not appear to be receiving hospice care, but again a number of DHB regions (notably Hawke's Bay, Taranaki, MidCentral and Hutt Valley DHBs) seem to be achieving a high proportion of patients in this group.

### Reason for ending episode of care

Hospice services were asked to report the reasons patients ended their care episode. A 'care episode' was described as the time from acceptance of referral to discharge from the service. For the 10,827 hospice patients reported on in the survey, 75% had their care episode end when they died, 17% were discharged and 4% had another reason for their care episode ending. A further 4% did not have a reason for their episode of care end recorded; most of these patients were from three DHBs. The survey did not ask why people were discharged from the hospice service or who their care was transferred to, but presumably this was back to their primary care team/service.

There are some outlier regions in this data, which could indicate differences in model of care or different interpretation of the survey question. For example, in the Counties Manukau DHB, 68% of patients were discharged back to their own home. This is unusually high compared to other regions, where 70 to 90% of patients had death as their reason for episode of care end. The only other exception was Hawke's Bay DHB at 48% discharge to own home, but this was due to the hospice service being temporarily relocated to the hospital for a period of months. Where people are being discharged from the hospice service it will be important that they receive appropriate ongoing care from primary palliative care providers, who in turn need to be well prepared and resourced, and supported by their local palliative care service.

**Table 41: Reason for ending episode of care for hospice patients**

DHB	Death		Discharged		Other	Not recorded	Total
		Own home	ARC	Hospital (acute)			
Northland	75.4%	23.4%	1.0%	0%	0.1%	0%	675
Waitemata	86.7%	8.7%	4.0%	0%	0.6%	0%	978
Auckland	70.5%	8.5%	0%	0%	0%	21.0%	919
Counties Manukau	26.2%	68.3%	4.5%	1.0%	0%	0%	889
Waikato	88.2%	11.8%	0%	0%	0%	0%	642
Lakes	97.2%	2.8%	0%	0%	0%	0%	180
Bay of Plenty	86.0%	10.2%	0.2%	0%	3.6%	0%	637
Tairāwhiti	98.6%	1.4%	0%	0%	0%	0%	141
Hawke's Bay*	34.5%	47.7%	11.2%	6.6%	0%	0%	197
Taranaki	93.3%	5.9%	0.4%	0%	0.4%	0%	490
Mid Central	89.3%	0%	0%	0%	10.7%	0%	524
Whanganui	88.8%	9.1%	0%	0%	0%	2.1%	187
Capital & Coast	85.0%	0%	3.8%	0%	0.5%	10.6%	547
Hutt Valley	84.1%	10.0%	5.9%	0%	0%	0%	422
Wairarapa	38.7%	1.8%	0%	0%	0%	59.5%	163
Nelson Marlborough	83.0%	6.2%	0%	0%	4.6%	6.2%	518
West Coast <sup>#</sup>	nk	nk	nk	nk	nk	nk	nk
Canterbury	69.2%	8.8%	2.9%	1.0%	18.1%	0%	1,814
South Canterbury	66.2%	22.3%	8.9%	2.5%	0%	0%	157
Otago	77.5%	19.4%	2.2%	0.9%	0%	0%	453
Southland	87.3%	10.9%	1.1%	0%	0.7%	0%	275
<b>Total</b>	<b>75%</b>	<b>15%</b>	<b>2%</b>	<b>0%</b>	<b>4%</b>	<b>4%</b>	<b>10,827</b>

\* The hospice service in Hawke's Bay was temporarily relocated to the hospital for a period of months during the survey period, and data for this region may not reflect usual practice.

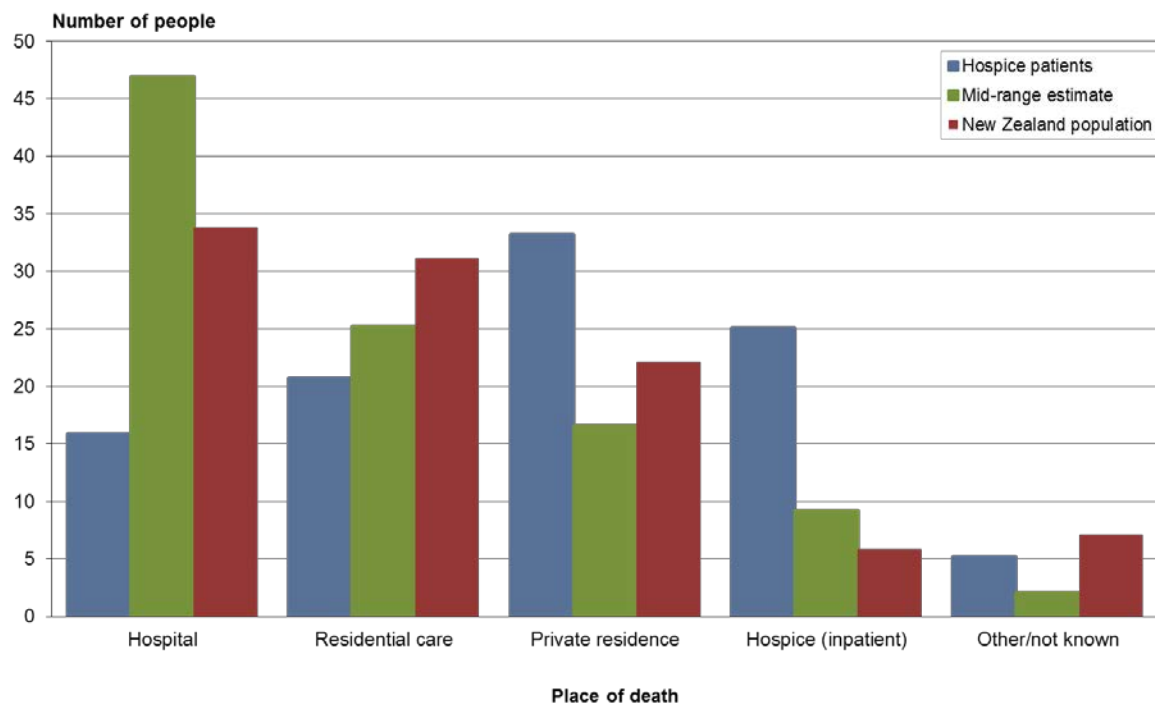
nk = not known due to no data provided.

## Place of death

Twenty-seven hospice services were able to provide data on place of death for 10,738 patients. Hospice patients most often died in a private residence (33.2%) or a hospice inpatient unit (25.1%). A further 20.7% of hospice patients died in residential care and 15.9% in hospital. When compared to overall New Zealand population place of death data and place of death for the mid-range estimate group, this data indicates that being under the care of a hospice service strongly influences place of death. This is illustrated in the graph in Figure 16, which compares place of death for hospice patients to the mid-range estimate and all deaths. Hospice patients are much more likely to die in a private residence or hospice inpatient unit, and less likely to die in hospital or residential care.

Determining the influence of patient demographics on place of death for hospice patients has not been possible in this report because the hospice patient data was not reported at the individual patient level.

**Figure 16:** Place of death comparison: hospice patients, mid-range estimate and total population



### 3 Hospital Palliative Care Services

The establishment of hospital palliative care services was a key recommendation of the New Zealand Palliative Care Strategy. The Strategy suggested these services should initially be established in tertiary hospitals, but that over time all hospitals would have health professionals with training and experience in palliative care (Ministry of Health 2001a).

To further support the need for hospital palliative care services, mortality data shows that around one-third of all deaths in New Zealand currently occur in the hospital setting (Palliative Care Council 2011). Many of these deaths will be the result of an unexpected event (either through illness or accident), but a large proportion of deaths in hospital will be predictable, and in these cases palliative care is likely to be beneficial. Data from Phase 1 of the HNA shows that people who die in hospital from a condition where palliative care would be of benefit are more likely to be of Māori or Pacific ethnicity, come from a more deprived area and have a non-cancer diagnosis.

Hospital Palliative Care New Zealand, an organisation that represents health care staff involved in hospital palliative care services, has provided a description of hospital palliative care as a part of their Service Capability Framework:

One of the key aspects of a Hospital Palliative Care Service (HPCS) is enhancing the capability and capacity of primary palliative care providers to ensure they can deliver high quality palliative care within the limits of their knowledge and ability. The HPCS also provides specialist palliative care when the needs of a patient/family exceed the capability of the patient's principle care team. To achieve this dual role, HPCSs provide advice on symptom management, patient, carer and staff support, technical expertise, and bereavement support. Their involvement with individual patients may range from giving advice and information to the patient's principal care team, conducting patient consultation and assessment, offering short-term interventions, or providing complex ongoing care. The HPCS provides multidisciplinary education, both formal and informal, through one-to-one encounters, ward rounds, study days, courses and formal lectures. A HPCS should also be involved in audit and research within a framework of clinical governance and provide strategic direction to their employing DHB in relation to palliative care. (Hospital Palliative Care New Zealand 2012)

This chapter reports on the survey of hospital palliative care services conducted as part of the HNA Phase 2 data collection process. The survey was sent to 16 hospital palliative care services and 15 responded with data, a 94% response rate. Two services were subsequently moved into the Hospice section of this report, as they only provided a community based nurse led palliative care service and had no service within the hospital. Therefore, survey returns were analysed for 14 HPCS covering 12 DHB regions (see Table 42) including one specialist paediatric palliative care team (Auckland DHB). Six other hospital palliative care services are present in other DHB regions, but these are provided by a local hospice service (hospital in-reach services) and involve hospice staff



providing a consultation service within the hospital. At the time of the survey there were three DHB regions that did not have a hospital palliative care service: Whanganui, Wairarapa and West Coast. A number of the hospital services had difficulty reporting information in the 'patients' section of the survey because they had no specific database recording information about their patients.

**Table 42: Hospital palliative care services, by DHB**

DHB	Hospital palliative care service
Northland	0
Waitemata	1
Auckland	2*
Counties Manukau	1
Waikato	1
Lakes	0
Bay of Plenty	0
Tairāwhiti	0
Hawke's Bay	1
Taranaki	0
MidCentral	1
Whanganui	0
Capital & Coast	1
Hutt Valley	1
Wairarapa	0
Nelson Marlborough	0
West Coast	0
Canterbury	2 <sup>#</sup>
South Canterbury	1
Otago	1
Southland	1
<b>Total</b>	<b>14</b>

\* Includes a specialist paediatric palliative care service.

# Includes Ashburton Hospital with one consultant anaesthetist only.

### 3.1 Hospital palliative care service capability

As we noted in chapter 2, one of the components of the HNA methodology is to compare core service components with current service provision to identify service deficiencies and gaps. Previously there has been no identified 'core' set of palliative care service components in New Zealand. However, during 2011 and 2012 both Hospice New Zealand and Hospital Palliative Care New Zealand undertook projects to describe the capability requirements, in relation to clinical and non-clinical functions and workforce, of their respective services.

The *Hospital Palliative Care Service Capability Framework* (see Appendix 5) was developed to give direction to hospital palliative care services, other palliative care service providers, DHBs, the Ministry of Health and the wider health sector on how hospital palliative care services should be configured. The framework has attempted to address key palliative care outcomes by detailing what is expected of a highly functional hospital palliative care service in terms of workforce, resources and infrastructure, clinical and non-clinical functions, and key working relationships. The Framework is intended to set a minimum standard for hospital palliative care service provision in New Zealand, and to inform the Ministry's Resource and Capability Framework project.

In both capability documents the functions and workforce roles are separated into three categories:

- **will have** services are the core functions and roles that a palliative care service will provide
- **will have access to** are also core functions and roles, but they may not be provided directly by the palliative care service
- **could offer** are functions and roles that could be provided if resources allow, but are not considered core to the delivery of palliative care.

Throughout this chapter the capability document will be referred to and used as a reference point with which to compare current palliative care service provision. Where possible, data from the palliative care service surveys is compared to capability recommendations in an attempt to identify important areas for future service development.

## 3.2 Service components

This section summarises the functions and staff roles reported in the survey of hospital palliative care services and, where possible, compares them with the components recommended in the *Hospital Palliative Care Service Capability Framework* (see Appendix 5). Table 43 provides a summary of the data reported by hospital palliative care services and shows the percentage of services that reported having the various capability functions and roles. Information by DHB is summarised in Appendix 10.

Note that hereafter in this chapter, 'hospital palliative care services' will be abbreviated to 'HPCS', both for ease of use and to emphasise the difference between hospital palliative care services and hospice palliative care services, which were covered in chapter 2.

HPCS provide many of the core, or 'will have', clinical and non-clinical functions described in the HPCS Capability Framework, and most services also have the suggested effective working relationships. Almost half the HPCS reported no ability to provide after-hours telephone cover, which was reported to be related to limited resources. However, this service component was usually provided by the local hospice service. Input into end-of-life care pathway implementation was occurring across most services, and where it was absent this was because the hospital had not implemented a pathway. While many services reported undertaking research/audit activities, this was mostly just audit, as they reported limited resources to undertake or be involved in research activities. Only 8 of the 14 services had access to clinical supervision for palliative care service staff, an activity that is considered vital for health care staff involved in end-of-life care.

Generally, HPCS reported effective working relationships across all key specialties. The two areas where some services reported difficulties were access to bereavement support and discharge coordination. Bereavement support was reported as being an uncommon service in the hospital setting, and most HPCS accessed this service via their local hospice. A similar situation was reported for discharge coordination, where some DHB hospitals did not have this service. Some HPCS provide discharge coordination within their own team. All HPCS reported having a core team of specialist nursing and medical staff, although the size and health professional mix of the teams was highly variable (see chapter 4).

All HPCS reported having access to all of the important supportive multidisciplinary team roles ('will have access to' roles) and the key services. The two areas of difficulty in the 'will have access to' functions were the availability of private/quiet spaces for consultations and family meetings, and single rooms for dying or distressed patients/family. While a number of services reported being able to use such facilities, it was often noted that this was difficult or took significant persuasion, and facilities were often not ideal.

Only a small number of services were able to provide any of the 'could offer' functions. Five services did not offer any of the functions, and most others only two or three of the five functions. No service provided all of these functions. Again the main restricting factor was reported to be limited resources that did not allow for any of these 'added extra' services.

The paediatric palliative care service in Auckland provides a clinical service for the greater Auckland area, as well as being a national consultation service. Like other HPCS this service has limited ability to provide after-hours telephone cover. There is no children's end-of-life pathway available, so the paediatric service is not involved in this aspect of the Capability Framework. However, the service does use and support an advanced care planning document, *Te Wa Aroha*, which supports decisions to allow natural death and which has been adopted by five other DHBs.

Aside from access to residential care beds, which are not appropriate for paediatric patients, this service has access to all of the 'will have access to' functions. It does not offer outpatient clinics, on-site after-hours services or public education. It does offer hypnosis as a complementary therapy provided by a child psychotherapist, but that is the only therapy it provides. It also either employs or has access to all the core health care staff roles.

**Table 43: Percentage of HPCS providing each HPCS Capability Framework component**

Capability functions and roles		% of all HPCS
Will have	the following clinical functions	5-day on-site service
		100
		After-hours telephone cover
		54
		Advanced assessment and care planning
		92
		Liaison with primary care, aged care, hospital teams, hospice, pain services
		100
	the following non-clinical functions	Input into family meetings
		92
		Input into discharge planning
		100
		Input into advance care planning
		92
		Input into end-of-life care pathway implementation
		77
	effective working relationships with	Clinical education
		100
		Supervision/training (other staff)
		85
		Leadership and strategic planning
		100
		Quality improvement
		100
	staff roles	Research/audit
		85
		Clinical data collection
		92
		Access to clinical supervision (HPCS staff)
		62
		Appropriate networks and engagement
		100
	other specialist palliative care services	Other specialist palliative care services
		100
		Bereavement support services
		77
		Hospital medical and nursing staff
		100
		Liaison psychiatry, psych-oncology services
		100
	Pain service – acute and chronic	Pain service – acute and chronic
		92
		Specialist teams
		100
		Discharge coordinator
		77
		Other services as appropriate
		100
	Specialist nursing	Specialist nursing
		100
	Specialist medical	Specialist medical
		100

Capability functions and roles			% of all HPCS
Will have access to	Functions	Private/quiet spaces for consultations and family meetings	46
		Single rooms for dying or distressed patients/family	62
		Interventional pain services/techniques	92
		Paediatric specialist palliative care support/advice	92
		Hospice inpatient care	100
		Residential care beds	92
		Appropriate equipment	92
	Roles	Physiotherapy	100
		Occupational therapy	100
		Speech–language therapy	100
		Dietetics	100
		Pharmacy and clinical pharmacology	100
		Cultural liaison	100
		Interpreter services	100
Could offer	Functions	Outpatient clinics	31
		On-site after-hours services	23
		Family carer education, rehabilitation	23
		Public education	15
		Complementary therapies	23

## Type of service

All 14 HPCS reported providing a consultation/liaison service, which in the survey was described as the patient remaining under the clinical care of another service and the HPCS providing consultation and liaison services. These include a ‘second opinion’, advice on a particular problem, case review or patient/carers education. The other service – not the palliative care service – is the primary provider for this episode. Three services reported providing direct care, where the HPCS is the primary provider and has responsibility for the provision of care.

Five HPCS said they had developed formal shared care arrangements with another service (eg, cancer care, respiratory, GP, motor neuron disease, community health care providers), which included joint care planning and the exchange of relevant clinical information. In shared care, both parties have an ongoing involvement with the patient throughout the episode of care, and both have direct contact with the patient.

## Availability of team outside normal hours

The availability of HPCS outside normal working hours is variable and not as common as with hospice services (see Table 44). In most cases this is because the local hospice service operates the 24/7 advice telephone service. Only one HPCS provides an after-hours home visiting option, and this is by a doctor. Five HPCS reported providing a 24/7 telephone advice service, and a further service provided telephone advice during the weekend/evening. Telephone advice was most commonly provided by a doctor, and in one service also by a nurse practitioner.

**Table 44: HPCS providing after-hours service: times and health professionals available**

DHB	Times available				Health professionals available			
	Home visit		Telephone advice		Home visit		Telephone advice	
	24/7	W/E	24/7	W/E	Nurse	Doctor	Nurse	Doctor
Waitemata	0	0	0	0	0	0	0	0
Auckland	0	0	0	1	0	0	0	1
Counties Manukau	0	0	1	0	0	0	0	1
Waikato	1	0	1	0	0	1	0	1
Hawke's Bay	0	0	0	0	0	0	0	0
MidCentral	0	0	0	0	0	0	0	0
Capital & Coast	0	0	1	0	0	0	0	1
Hutt Valley	0	0	0	0	0	0	0	0
Canterbury	0	0	2	0	0	0	1	2
South Canterbury	0	0	0	0	0	0	0	0
Otago	0	0	0	0	0	0	0	0
Southland	0	0	0	0	0	0	0	0
<b>Total</b>	<b>1</b>	<b>0</b>	<b>5</b>	<b>1</b>	<b>0</b>	<b>1</b>	<b>1</b>	<b>6</b>
% of services	7%	0%	36%	7%	0%	7%	7%	43%

## Annual number of new patients and contacts

There is some missing data from this section of the survey: data on number of referrals was not available from Ashburton Hospital (Canterbury DHB) and Timaru Hospital (South Canterbury DHB). However, patient numbers for Ashburton Hospital have been taken from the patient demographics section of the HPCS survey, which reported on 61 patients, and these have been included in Canterbury DHB numbers. The number of contacts was unavailable from Auckland City Hospital (Auckland DHB), Waikato Hospital (Waikato DHB), Ashburton Hospital and Timaru Hospital. Auckland DHB patient contacts are only for paediatric palliative patients.

During the period 1 July 2010 to 30 June 2011 HPCS accepted 7049 referrals. The number of referrals generally reflects the size of the DHB population, with larger DHBs having higher numbers of referrals (see Table 45). On average, 2.8% of referrals were declined (range 0–14%) by HPCS.

HPCS reported 19,861 patient contacts, giving an average of three contacts per patient, with a range of two to nine. Contacts are primarily patient consultations, but also include family consultations/meetings and electronic consultations (by email) because a number of services could not differentiate these contact episodes.

The paediatric palliative care team in Auckland accepted 76 referrals and had 315 patient contacts, which were usually combined patient and family consultations.

**Table 45: HPCS number of accepted referrals and contacts, by DHB (excluding paediatric service)**

DHB	Total number of accepted referrals	Number of contacts
Waitemata	570	1866
Auckland	1892	nk
Counties Manukau	806	2255
Waikato	740	nk
Hawke's Bay	332	2972
MidCentral	437	1801
Capital & Coast	500	5411
Hutt Valley	305	653
Canterbury	989	3944
South Canterbury	nk	nk
Otago	352	637
Southland	126	322
<b>Total</b>	<b>7049</b>	<b>19,861</b>

nk = not known due to no data provided.

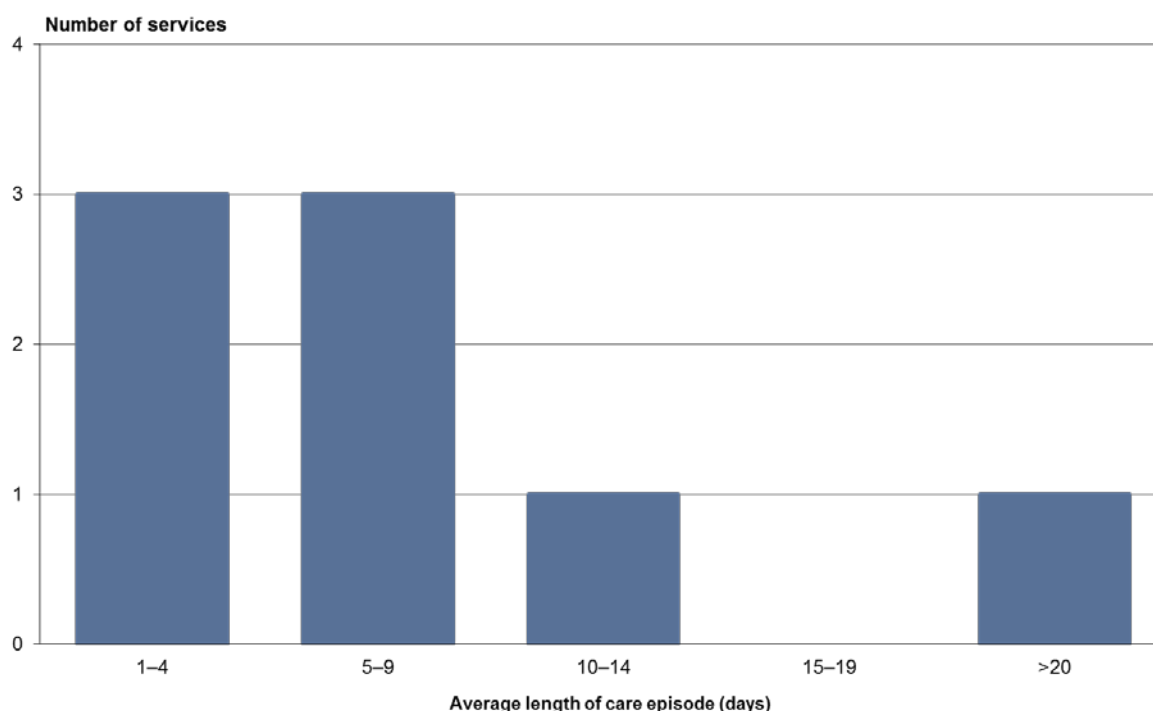
As noted in the section on the annual number of new hospice service patients, there appear to be gaps in some DHBs between the estimated number of people who would benefit from palliative care and the number of new referrals to hospice service. Along with the current number of hospital deaths, the data above on HPCS referrals does lend some credibility to the likelihood that there are a number of patients who receive specialist palliative care from an HPCS and where referral to hospice may not be required or feasible.

### Length of care episode

Nine services were able to provide data on the average length of time a patient was cared for by their service (length of care episode), including the paediatric service. The average length of a care episode was 12.6 days, with a range of 3.6 to 58 days. Data from the eight responding adult services is summarised in Figure 17. The minimum reported length of care episode was one day or less, and the maximum length of a care episode was 253 days.

The paediatric palliative care service's episode of care averaged 62.1 days, with a range of one to 260.5 for children who died during the survey time period. This service noted that many children continue to survive (especially those with non-malignant conditions), and can be under the care of the service for an extended period of time.

**Figure 17:** Average length of care episode (days) for HPCS, 1 July 2010 to 30 June 2011



### End-of-life care programme in use

All 14 HPCS provided information on end-of-life care programmes and which programme they were using, if applicable (see Table 46). Six HPCS had an end-of-life care pathway in place. Five of these had implemented the Liverpool Care Pathway for the Dying Patient (LCP), and one service reported using an alternative pathway. One service noted that the end-of-life care programme had only been implemented in the hospital's bone marrow transplant unit. A further four services were in the process of implementing the LCP, and four HPCS reported having no end-of-life pathway in place.

**Table 46: End-of-life care programme in use by HPCS**

	N	End-of-life care programme			
		LCP	Other	In progress	None
No. services	14	5	1	4	4
% of all services		36%	7%	29%	29%



## Education programme provided

Ten HPCS reported providing education as a component of their service, but only four were able to give numbers of attendees (2278 total); the other HPCS did not have accurately recorded data. The majority of reported education took place in hospital or tertiary education settings.

## 3.3 Inpatient beds

### Resourced palliative care beds

Only two HPCS reported having resourced palliative care inpatient beds in their hospital. These were located in Waikato DHB (approximately 10 beds available in Waikato Hospital, based on admissions, ALOS and occupancy rate), and Canterbury DHB (two beds in Ashburton Hospital). There were 927 admissions to these beds during 1 July 2010 to 30 June 2011, including new and repeat admission episodes (see Table 47).

**Table 47: Hospital inpatient palliative care admissions, 1 July 2010 to 30 June 2011**

DHB	New admissions	Repeat admissions	Total admissions
Waikato	512	266	778
Canterbury (Ashburton Hospital)	61	88	149
<b>Total</b>	<b>573</b>	<b>354</b>	<b>927</b>

Average length of stay was 5.2 days (range 1–92 days) for Waikato and 6.1 days (range 1–27 days) for Canterbury. The bed occupancy rate was only available for Waikato and was reported as 92.5%.

The large number of inpatient admissions to Waikato Hospital is likely to be a result of the local hospice only just opening its inpatient unit in 2010. The number of admissions may also help to explain the large difference in the estimated number who would benefit from palliative care in the Waikato region and total hospice patients (see Table 20), as these patients were probably solely under the care of the hospital team.

## 3.4 Characteristics of hospital palliative care patients

This section explores the characteristics of patients who were referred to, and accepted by, HPCS and compares these characteristics to those of hospice patients and the mid-range estimate group. Not all HPCS were able to provide data for all the patients in the survey, and so the total number of patients may differ for each variable. As with the hospice patient data, the approach to analysis has been to include all patients reported on in order to produce data from as large a group as possible. The total number of patients reported on is included in each section. Caution is again advised when interpreting or comparing data on HPCS patients due to differences in data reporting methods, interpretation or survey questions and missing data in this section of the survey.

## Age of patients

HPCS provided data on the age of 6172 patients (excluding the one hospital paediatric palliative care service). The age of HPCS patients is almost exactly the same as for those in hospice services, with over three-quarters of patients aged over 60 (78.3%) and nearly one-third over 80 (Table 48). A very small number of patients were under age 19 (0.35%). The hospital paediatric palliative care service reported on 76 patients, 52 of whom were aged 0–9, 20 aged 10–29, and two aged 20–29. The two additional patients were two pregnant women referred to the service with pregnancy complications.

As in hospice services, HPCS cared for more patients in the 60–69 years age group and fewer in the over 80 age group when compared to the mid-range estimate. There are also differences in age group proportions between the DHB regions; this data is presented in more detail in Appendix 11.

**Table 48: Age of HPCS patients, compared to hospice patients and mid-range estimate group**

Age group (years)	% of HPCS patients	% of hospice patients	% of mid-range estimate
0–9	0.05	0.3	1.3
10–19	0.3	0.7	0.4
20–29	1.6	0.8	0.6
30–39	2.2	1.7	1.3
40–49	6.3	5.9	3.7
50–59	11.3	11.8	8.2
60–69	21.7	20.6	15.1
70–79	25.3	29.1	26.0
80+	31.3	29.2	43.3
<b>Total patients</b>	<b>6172</b>	<b>12,636</b>	

## Gender of patients

HPCS were able to provide data on the gender of 4858 patients, and the gender proportions of this total group were 49.4% male and 50.6% female, again very similar to both the overall hospice patient and mid-range estimate groups. There is a small amount of variability between DHB regions (see Table 49), with the greatest variability in those regions reporting on smaller patient numbers.

**Table 49: Gender of HPCS patients, by DHB region**

DHB	Males (n = 2400)	Females (n = 2458)	Total patients
Waitemata	47.7%	52.3%	665
Auckland	nk	nk	nk
Counties Manukau	47.9%	52.1%	560
Waikato	53.9%	46.1%	512
Hawke's Bay	50.4%	49.6%	615
MidCentral	51.0%	49.0%	459
Capital & Coast	48.8%	51.2%	500
Hutt Valley	42.4%	57.6%	66
Canterbury	51.5%	48.5%	712
South Canterbury	nk	nk	nk
Otago	47.2%	52.8%	652
Southland	41.0%	59.0%	117
<b>Total</b>	<b>49.4%</b>	<b>50.6%</b>	<b>4858</b>
Hospice patients	49.0%	51.0%	
Mid-range estimate group	50.2%	49.8%	

nk = not known due to no data provided.

### Ethnicity of patients

Ethnic group categories in this section are based on prioritised ethnicity at level 2 for both the mid-range estimate and all-deaths groups. However, as with hospice services, there is no way to confirm if all HPCS are using this method, and if not, how they allocate ethnicity for their patients. Therefore, this data from hospitals should be interpreted with some caution.

HPCS provided ethnicity data for 6140 patients (Table 50). This table also compares HPCS patients to the ethnic composition of hospice patients, the mid-range estimate group and all deaths during 2008. For the total HPCS patient group, hospital services appear to be achieving a relatively close alignment between the ethnicity of patients and the expected ethnic group proportions when compared to all deaths and the mid-range estimate, although there are slightly higher proportions of Pacific and Chinese Asian people, and consequently a lower proportion of European people in the HPCS group.

**Table 50: Comparison of ethnic group composition of HPCS patients, hospice patients, mid-range estimate group and all deaths, 2008**

Ethnic group	All deaths 2008	Mid-range estimate	Hospice patients	HPCS patients
European <sup>1</sup>	84.0%	83.9%	75.5%	76.5%
Māori	9.9%	9.8%	10.0%	9.4%
Pacific peoples <sup>2</sup>	3.6%	3.6%	3.9%	6.1%
Chinese Asian	0.9%	0.9%	1.5%	2.5%
Indian Asian	0.7%	0.6%	0.6%	1.3%
Other Asian	0.6%	0.6%	0.4%	0.9%
MELAA <sup>3</sup>	0.3%	0.2%	0.5%	0.5%
Other/Not elsewhere included <sup>4</sup>	0.03%	0.3%	7.5%	2.9%

1 'European' includes people identified as: New Zealand European, New Zealander, Other European and European not further defined.

2 'Pacific peoples' includes people identified as Sāmoan, Cook Island Māori, Tongan, Niuean, Fijian, Tokelauan and any other Pacific groups.

3 'MELAA' includes people identified as Middle Eastern, Latin American and African.

4 'Not elsewhere Included' includes Response Unidentifiable, Response Outside Scope and Not Stated.

Appendix 12 summarises HPCS patient ethnicity by DHB region and compares reported ethnic group proportions to the DHB mid-range estimates. The majority of DHBs continue to have quite a close alignment between HPCS patient ethnicity and that expected for people who would benefit from palliative care in the DHB region, except for the consistently lower proportion of European patients in all DHB regions (apart from Southland). Some of the larger differences in the European groups may again be a result of higher numbers of Other/Not elsewhere included patients, a group that includes those whose ethnicity was 'Not known' (Waitemata, Counties Manukau, Waikato and Canterbury).

There are a few other exceptions, most notably in Auckland DHB, which has higher proportions of Māori, Chinese Asian, Indian Asian and Other Asian than the mid-range estimate group, which may reflect population changes since the 2006 Census. Counties Manukau DHB also has a higher proportion of Pacific people in the HPCS patient group.

## Diagnosis of patients

As noted earlier, the greater proportion of the mid-range palliative care estimate were people with a non-cancer diagnosis (57% of adults and 86% of 0–19-year-olds), but this was not reflected in hospice patient diagnoses, which were mostly cancer. The diagnoses of HPCS patients, on the other hand, fall much closer to the mid-range estimate, although the majority are still cancer patients. Although not a direct correlation, this does also align with place of death data that shows people with a non-cancer diagnosis are more likely to die in hospital.

HPCS were able to provide diagnoses for 5605 patients, of whom 3626 (65%) had a cancer diagnosis and 1979 (35%) represented a variety of non-cancer diagnostic groups (see Table 51). As with hospice patients, it is notable that HIV/AIDS patients do not feature in HPCS data.

**Table 51: Diagnostic groups of HPCS patients**

Diagnosis	HPCS	Hospice	Mid-range estimate
Cancer	64.7%	78.8%	42.1%
Cardiovascular	7.8%	5.8%	26.8%
HIV/AIDS	0.0%	0.1%	0.1%
Renal failure	3.2%	2.2%	2.5%
Neurological disease	4.4%	3.7%	5.9%
Respiratory disease	6.0%	4.3%	9.1%
Other non-cancer	14.0%	5.0%	13.6%
<b>Total patients</b>	<b>5605</b>	<b>11,623</b>	

There is quite a wide variation in the proportions of cancer and non-cancer patients receiving HPCS care across DHB regions (see Table 52). The proportion of cancer patients ranges from 35 to 100%, and of non-cancer patients from 0 to 65%. Appendix 13 compares the reported HPCS patient diagnoses to the mid-range estimate for each DHB region, which illustrates the wide variation in diagnostic groups between DHB regions. These variations may be explained by some DHBs having a cancer treatment centre and therefore tending to have higher numbers of cancer patients compared to those without a cancer centre. The variations could also indicate that some HPCS may be actively promoting their service outside of cancer and/or differences in referral practices.

Note that the mid-range estimate diagnoses are based specifically on ICD-10-AM coding and this may not be the case for HPCS patients, which may also account for some of the variation. Also of note is the higher-than-expected proportion of 'Other non-cancer' diagnoses in Counties Manukau and Waikato DHBs. This may be a result of either differences in diagnostic classification, missing data or possibly higher rates of other non-cancer conditions in these DHBs, although that seems unlikely.

Again, as with hospices, it is people with a cardiovascular diagnosis that appear to be missing out on referral to an HPCS at the end of life, with this group only making up 7.8% of HPCS patients compared to the 26.8% in the mid-range estimate group.

**Table 52: Diagnosis of HPCS patients, by DHB region**

DHB	Cancer	Non-cancer	Total patients
Waitemata	74%	26%	644
Auckland	65%	35%	1562
Counties Manukau	35%	65%	806
Waikato	48%	52%	168
Hawke's Bay	75%	25%	650
Mid Central	76%	24%	446
Capital & Coast	72%	28%	500
Hutt Valley	nk	nk	nk
Canterbury	65%	35%	712
South Canterbury	nk	nk	nk
Otago	nk	nk	nk
Southland	100%	0%	117
<b>Total HPCS patients</b>	<b>65%</b>	<b>35%</b>	<b>5605</b>
Hospice patients	79%	21%	
Mid-range estimate group	42%	58%	

nk = not known due to no data provided.

### Reason for ending episode of care

Hospice services were asked to report the reason for ending each patient care episode. A 'care episode' was described as the time from acceptance of referral to discharge from service. For the 6193 HPCS patients reported on in the survey, just over one-quarter had their care episode end when they died (26.8%); 45.7% were discharged from hospital to a variety of settings, predominantly their home (33.7%); and 19.3% had another reason for their care episode ending (see Table 53). This group of 'Other' includes patients discharged from service but remaining in hospital. A further 8.2% did not have a reason for their episode of care end recorded; most of these patients were from one DHB.

There is significant variability in reason for ending the care episode between DHB regions (Appendix 14), which could indicate differences in model of care or different interpretations of the survey question. For example, in Waikato DHB 100% of patients had death as the reason for ending their care episode, while MidCentral DHB reported that 19.9% of patients were discharged to hospice, and Canterbury DHB reported 19.2% being discharged to residential care.

**Table 53: Reason for ending episode of care, HPCS patients compared to hospice patients**

Reason for ending episode of care	HPCS patients	Hospice patients
Death	26.8%	75%
Discharge – own home	33.7%	15%
Discharge – residential care	6.1%	2%
Discharge – hospital (acute)	3.0%	0%
Discharge – hospice	2.9%	not applicable
Other	19.3%	4%
Not recorded	8.2%	4%
<b>Total patients</b>	<b>6193</b>	<b>10,827</b>

### Place of death

HPCS were unable to provide adequate data for full analysis. Most deaths appear to be in hospital, although place of death for the larger proportion was not known.

## 4 Palliative Care Workforce

This chapter focuses on the workforce employed specifically to deliver palliative care and that was reported as part of the palliative care services survey. It does not attempt to describe the workforce providing primary palliative care, because that would include almost the entire health workforce in New Zealand. The survey also only collected data on health care staff and volunteers and did not include non-clinical management staff or domestic staff. Another group it does not include, but who deserve a particular mention, are the often unrecognised family members and friends who provide essential care and support to palliative patients. There was no possibility, within the confines of this project, of ascertaining the volume of care provided by these informal carers.

In this section, full-time equivalent (FTE) refers to the proportion of a standard 40-hour working week an employee works. 'FTE employed' is the number of FTE currently employed in a role, and 'FTE vacant' is the number of FTE currently vacant for the role. Where the workforce is described as 'total FTE', the number includes both employed and vacant FTE, because it is assumed that the total FTE allocated per role is that required to meet the service's current workload. Vacant FTE is indicated in brackets beside total FTE numbers. 'Head count' is the number of actual people employed in a specific role. Head count and FTE figures for roles are usually different because many staff employed in palliative care services appear to work part time (ie, less than 1.0 FTE).

Workforce numbers are for the period 1 July 2010 to 30 June 2011, with most services providing workforce data based on FTE as at 30 June 2011. During this time period hospices employed 1098 health care staff with a total FTE of 644.9 (17.7 vacant), and HPCS employed 91 health care staff with a total FTE of 64 (6.2 vacant), giving a total workforce of 1189 individuals and 733.2 FTE (including vacancies).



**Table 54: Total palliative care workforce, by occupation, 2011**

Occupation	Hospice			Hospital			Total		
	FTE	(FTE vacant)	Head count	FTE	(FTE vacant)	Head count	FTE	(FTE vacant)	Head count
<b>Medical</b>									
Specialist	24.3	(5.3)	40.0	15.8	(2.0)	24.0	40.1	(7.3)	64.0
MOSS	18.4	(1.6)	44.0	0.0	(0.0)	0.0	18.4	(1.6)	44.0
Registrar	4.8	(0.0)	5.0	10.0	(1.0)	10.0	14.8	(1.0)	15.0
House surgeon	0.0	(0.0)	0.0	0.5	(0.0)	1.0	0.5	(0.0)	1.0
GP	5.9	(0.0)	33.0	0.0	(0.0)	0.0	5.9	(0.0)	33.0
Other medical	0.3	(0.0)	4.0	0.0	(0.0)	0.0	0.3	(0.0)	4.0
<b>Total medical</b>	<b>53.7</b>	<b>(6.9)</b>	<b>126.0</b>	<b>26.3</b>	<b>(3.0)</b>	<b>35.0</b>	<b>80.0</b>	<b>(9.9)</b>	<b>161.0</b>
<b>Nursing</b>									
Nurse practitioner	0.0	(0.0)	0.0	3.0	(1.0)	2.0	3.0	(1.0)	2.0
Senior nurse	93.7	(3.0)	122.0	26.5	(0.7)	35.0	120.2	(3.7)	157.0
Registered nurse	292.3	(4.5)	488.0	0.0	(0.0)	0.0	292.3	(4.5)	488.0
Enrolled nurse	39.4	(0.0)	59.0	0.0	(0.0)	0.0	39.4	(0.0)	59.0
Care assistant	47.7	(0.6)	94.0	0.0	(0.0)	0.0	47.7	(0.6)	94.0
Educator	13.6	(0.5)	22.0	0.0	(0.0)	0.0	13.6	(0.5)	22.0
End-of-life care Facilitator	8.3	(0.0)	14.0	5.3	(1.0)	6.0	13.6	(1.0)	20.0
<b>Total nursing</b>	<b>495.0</b>	<b>(8.6)</b>	<b>799.0</b>	<b>34.8</b>	<b>(2.7)</b>	<b>43.0</b>	<b>529.8</b>	<b>(11.3)</b>	<b>842.0</b>
<b>Allied health</b>									
Physiotherapist	2.0	(0.0)	4.0	0.0	(0.0)	0.0	2.0	(0.0)	4.0
Occupational therapist	6.1	(0.0)	10.0	1.0	(0.0)	1.0	7.1	(0.0)	11.0
Speech therapist	0.0	(0.0)	0.0	0.0	(0.0)	1.0	0.0	(0.0)	1.0
Dietician	0.4	(0.0)	1.0	0.0	(0.0)	2.0	0.4	(0.0)	3.0
Pharmacist	2.3	(0.0)	6.0	0.0	(0.0)	2.0	2.3	(0.0)	8.0
Podiatrist	0.0	(0.0)	0.0	0.0	(0.0)	0.0	0.0	(0.0)	0.0
Allied health assistant	0.7	(0.0)	1.0	0.0	(0.0)	0.0	0.7	(0.0)	1.0
Other allied health	5.6	(0.0)	7.0	0.0	(0.0)	0.0	5.6	(0.0)	7.0
<b>Total allied health</b>	<b>16.9</b>	<b>(0.0)</b>	<b>29.0</b>	<b>1.0</b>	<b>(0.0)</b>	<b>6.0</b>	<b>17.9</b>	<b>(0.0)</b>	<b>35.0</b>

Occupation	Hospice			Hospital			Total		
	FTE	(FTE vacant)	Head count	FTE	(FTE vacant)	Head count	FTE	(FTE vacant)	Head count
<b>Psychosocial care</b>									
Psychologist	0.0	(0.0)	1.0	0.5	(0.5)	0.0	0.5	(0.5)	1.0
Social worker	22.0	(0.0)	32.0	1.0	(0.0)	4.0	23.0	(0.0)	36.0
Spiritual care	9.2	(0.0)	22.0	0.0	(0.0)	1.0	9.2	(0.0)	23.0
Music therapist	0.2	(0.0)	1.0	0.0	(0.0)	0.0	0.2	(0.0)	1.0
Complementary therapist	8.2	(1.2)	22.0	0.0	(0.0)	0.0	8.2	(1.2)	22.0
Grief and bereavement	32.3	(1.0)	51.0	0.0	(0.0)	0.0	32.3	(1.0)	51.0
Case manager	0.8	(0.0)	1.0	0.0	(0.0)	0.0	0.8	(0.0)	1.0
Other psychosocial care	6.6	(0.0)	14.0	0.4	(0.0)	2.0	7.0	(0.0)	16.0
<b>Total psychosocial care</b>	<b>79.3</b>	<b>(2.2)</b>	<b>144.0</b>	<b>1.9</b>	<b>(0.5)</b>	<b>7.0</b>	<b>81.2</b>	<b>(2.7)</b>	<b>151.0</b>
<b>Total PC workforce</b>	<b>645</b>	<b>(17.7)</b>	<b>1,098</b>	<b>64</b>	<b>(6.2)</b>	<b>91</b>	<b>709</b>	<b>(23.9)</b>	<b>1,189</b>

## 4.1 Hospice workforce

The 645 FTE hospice staff are summarised by DHB region in Table 55, which gives the total FTE for each professional group. A further breakdown by individual role is provided in Appendix 15, also by DHB region.

**Table 55: Total hospice workforce (FTE), by DHB, 2011**

DHB	Medical	Nursing	Psychosocial, spiritual care	Allied health
Northland	2.4	31.0	3.4	3.0
Waitemata	7.9	57.1	12.7	0.6
Auckland	5.8	40.3	12.7	1.1
Counties Manukau	3.2	32.9	5.0	0.0
Waikato	1.0	29.0	9.6	0.0
Lakes	0.0	11.9	1.4	0.0
Bay of Plenty	2.8	34.3	4.0	0.0
Tairāwhiti	0.5	1.9	0.7	0.5
Hawke's Bay	2.8	21.0	2.5	1.0
Taranaki	2.5	23.6	2.0	0.2
MidCentral	3.6	23.1	2.9	1.4
Whanganui	1.0	15.7	1.0	0.0
Capital & Coast	3.5	38.6	6.4	4.9
Hutt Valley	5.0	27.8	4.1	0.5
Wairarapa	0.2	6.7	0.5	0.0
Nelson Marlborough	3.2	35.4	2.7	0.0
West Coast	0.0	2.5	0.0	0.0
Canterbury	3.1	20.4	3.3	2.6
South Canterbury	1.2	10.6	0.7	0.0
Otago	2.1	19.0	2.2	1.2
Southland	2.0	12.3	1.6	0.0
<b>Total</b>	<b>53.7</b>	<b>495.0</b>	<b>79.3</b>	<b>16.9</b>
% of workforce	8.3%	76.8%	12.3%	2.6%

## Medical staff

Medical staff made up 8.3% of the total hospice workforce (53.7 FTE), with the largest number being specialists/consultants (45%; 24.3 FTE), followed by medical officer special scale (MOSS) at 35% (18.4 FTE) (see Figure 18). There were only a small number of registrars (four) reported, and these are likely to be training positions. No house officers were working in the hospice setting. A number of services reported employing GPs with an interest in palliative care. This included 28 individual GPs providing a total of 5.9 FTE (11% of medical FTE). All of these positions were part time, and they often provided evening and/or weekend cover.

**Figure 18:** Hospice medical workforce composition, June 2011

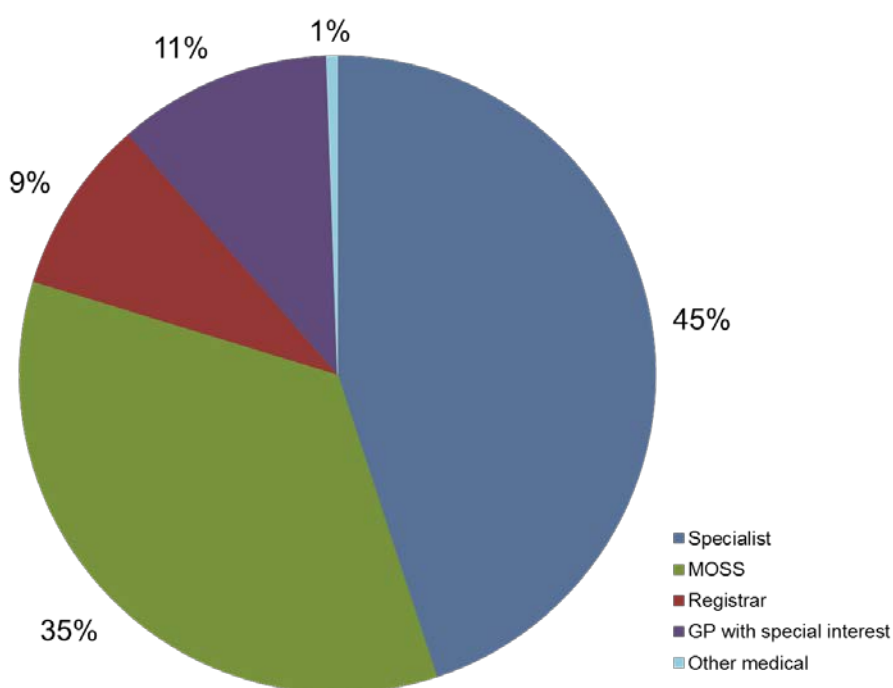


Table 56 summarises the national-level hospice medical workforce as FTE per 1000 patients and staff:patient ratios. The FTE per 1000 patients includes all medical staff employed in hospice roles and the national total number of patients reported by hospices. Staff-to-patient ratios have been calculated for each medical role using reported FTE and total number of patients. Only data from services that reported having the staff roles and their corresponding patient volumes have been used in the ratio calculations.

The following national ratios have been calculated as described above, and the number of DHBs included is noted, along with the range of ratios. Where the ratio is high, this means there is a very low staff FTE. For example, Lakes DHB has a specialist staff:patient ratio of 1:17,160 because they only have 0.025 FTE specialists for their 429 patients. A full breakdown of the different hospice medical roles per 1000 patients and staff:patient ratios by DHB region can be found in Appendices 16 and 17.

**Table 56: Hospice medical staff FTE per 1000 patients and staff:patient ratios, by role, June 2011**

Position	FTE per 1000 patients	Staff:patient ratio
Specialist	1.7	1:568 (n=20, range 1:168–1:17,160)
MOSS	1.3	1:611 (n=15, range 1:270–1:3185)
Registrar	0.3	1:1574 (n=4, range 1:733–1:1274)
GP	0.4	1:1485 (n=10, range 1:525–1:7080)
Other medical	0.02	1:7737 (n=2, range 1:6810–1:9580)
<b>Total medical staff</b>	<b>3.8</b>	<b>1:260 (n=20, range 1:116–1:17,160)</b>

## Nursing staff

The largest single group of staff in hospice care is nurses, who account for just over 75% of the total hospice workforce (497.7 FTE). Most of these staff are registered nurses (59%) or in designated senior nurse roles (19%) (see Figure 19). A smaller proportion are enrolled nurses (8%; 40.2 FTE) or care assistants (10%; 49.7 FTE). Also included in the nursing group are educators (3%) and end-of-life care facilitators (2%), as these roles were reported as being positions held by nurses. No nurse practitioners were employed in the hospice setting.

**Figure 19: Hospice nursing workforce composition, June 2011**

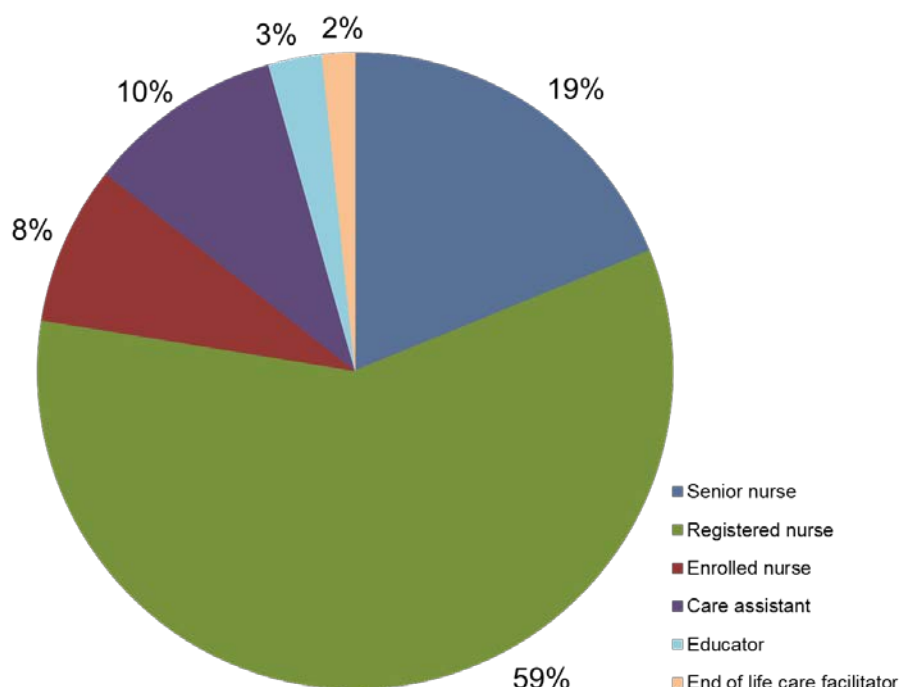


Table 57 summarises the national-level hospice nursing workforce as FTE per 1000 patients and staff:patient ratios. The FTE per 1000 patients includes all nursing staff employed in hospice roles and the national total number of patients reported by hospices. Nursing staff to patient ratios have been calculated for each nursing role using reported FTE and total number of patients. Only data from services that reported having the staff roles and their corresponding patient volumes have been used in these calculations. The following ratios have been calculated as previously described. A full breakdown of the different hospice nursing roles per 1000 patients and staff:patient ratios by DHB region can be found in Appendices 16 and 17.

**Table 57: Hospice nursing staff FTE per 1000 patients and staff:patient ratios, by role, June 2011**

Position	FTE per 1000 patients	Staff:patient ratio
Senior nurse	6.7	1:140 (n=19, range 1:37–1:1199)
Registered nurse	21.0	1:47 (n=21, range 1:24–1:168)
Enrolled nurse	2.9	1:295 (n=15, range 1:37–1:1166)
Care assistant	3.6	1:222 (n=15, range 1:95–1:3050)
Educator	1.0	1:694 (n=13, range 1:305–1:2061)
End-of-life care facilitator	0.6	1:1077 (n=12, range 1:420–1:2333)
<b>Total nursing staff</b>	<b>35.7</b>	<b>1:28 (n=21, range 1:16–1:99)</b>

### Hospice psychological, social and spiritual care workforce

Hospice services do not employ many staff in the psychological, social and spiritual care category, with a total of only 87.6 FTE across all DHB regions. As noted earlier, they also reported limited access to these staff roles from other services (see Table 13). The largest groups employed in this workforce group are grief and bereavement counsellors (41%; 32.3 FTE), social workers (28%; 22 FTE) and spiritual carers (chaplaincy and pastoral care staff, 12%; 9.2 FTE) (see Figure 20). It is possible that a number of these roles are provided by volunteers and so were not reported as employed staff.

**Figure 20:** Composition of hospice psychological, social and spiritual care workforce, June 2011

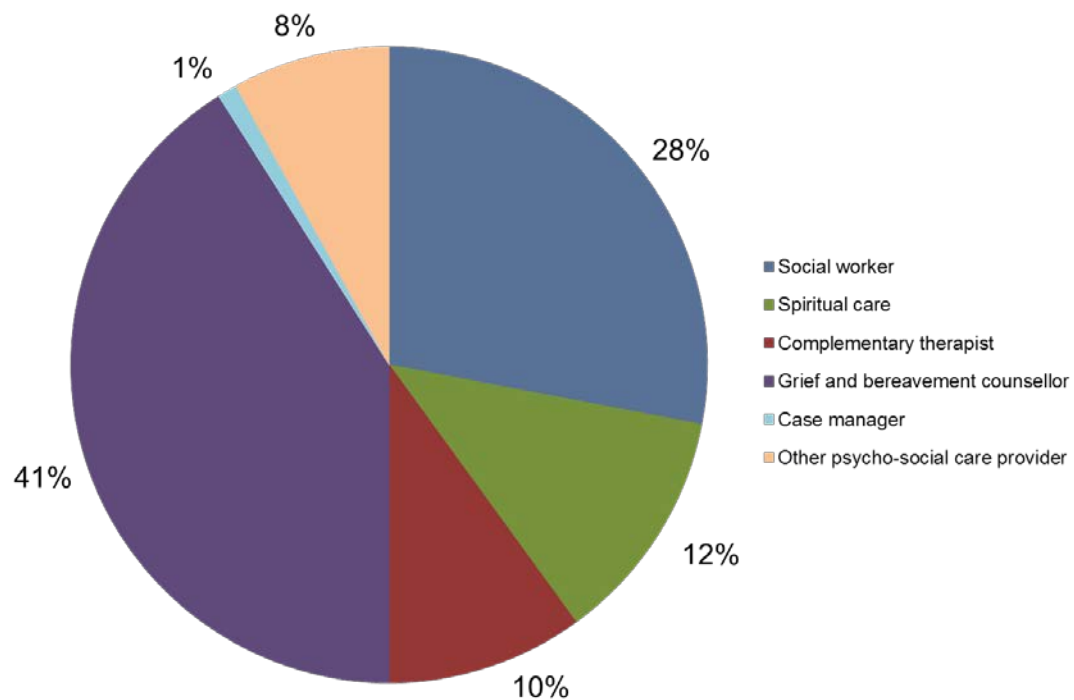


Table 58 summarises the national-level hospice psychological, social and spiritual care staff as FTE per 1000 patients and staff:patient ratios. The FTE per 1000 patients includes all psychological, social and spiritual care staff employed in hospice roles and the national total number of patients reported by hospices. Staff-to-patient ratios have been calculated for each psychological, social and spiritual care role using reported FTE and total number of patients. Only data from services that reported having the staff roles and their corresponding patient volumes have been used in these calculations. The following ratios have been calculated as previously described. A full breakdown of the different staff roles per 1000 patients and staff:patient ratios by DHB region can be found in Appendices 16 and 17.

**Table 58: Hospice psychological, social and spiritual care staff FTE per 1000 patients and staff:patient ratios, by role, June 2011**

Position	FTE per 1000 patients	Staff:patient ratio
Social worker	1.58	1:580 (n=13, range 1:324–1:1583)
Spiritual care	0.66	1:1217 (n=15, range 1:429–1:6330)
Music therapist	0.01	1:5153 (n=1)
Complementary therapist	0.59	1:744 (n=7, range 1:319–1:6370)
Grief and bereavement counsellor	2.32	1:423 (n=19, range 1:133–1:3540)
Case manager	0.06	1:1703 (n=1)
<b>Total</b>	<b>0.48</b>	<b>1:174 (n=20, range 1:97–1:386)</b>

## Allied health staff

Allied health staff roles included in the workforce survey were physiotherapist, occupational therapist, speech therapist, dietician, pharmacist, podiatrist and allied health assistant. There were only 16.9 FTE allied health staff (29 individuals) employed across all DHB regions. These were predominantly occupational therapists (6.1 FTE), physiotherapists (2 FTE) and pharmacists (2.3 FTE). There were no dietitians or podiatrists employed in hospices.

Overall, the total allied health staff numbers are too low for any meaningful analysis of staff:patient ratios. All of these allied health roles are designated as 'will have access to' in the Hospice New Zealand capability recommendations, so it may not be surprising that hospices do not directly employ many of these staff. In addition, very few hospices reported having access to these professions through other services.

## 4.2 HPCS workforce summary

The main roles reported in the survey of HPCS were medical and nursing, with only a very small number of FTE reported for other roles. Medical and nursing staff totalled 59.6 FTE and are summarised by DHB region in Table 59. A further breakdown by individual role is provided in Appendix 18, also by DHB region. Note that a number of DHBs do not currently have a DHB-employed HPCS, hence the number of zeroes spaces in Table 59.

While allied health staff were reported in the head count of HPCS, they did not have any FTE recorded, suggesting they provide a service to the HPCS but are not directly employed by them.

There were only 1.9 FTE psychological, social and spiritual care staff reported to be employed in HPCS (2% of the total workforce). Of this total, 1.4 FTE were employed in the paediatric palliative care service in Auckland DHB, comprising a social worker, child psychotherapist and child psychiatrist. The remaining 0.5 FTE was a vacant psychologist position.



**Table 59: Total HPCS workforce (FTE), by DHB, June 2011**

DHB	Medical	Nursing
Northland	0	0
Waitemata	1.8	2.4
Auckland	6.9	7.5
Counties Manukau	2.7	5.4
Waikato	6.6	6.0
Lakes	0	0
Bay of Plenty	0	0
Tairāwhiti	0	0
Hawke's Bay	0.5	1.5
Taranaki	0	0
MidCentral	0.9	1.8
Whanganui	0	0
Capital & Coast	3.0	4.0
Hutt Valley	0.3	1.0
Wairarapa	0	0
Nelson Marlborough	0	0
West Coast	0	0
Canterbury	1.8	2.7
South Canterbury	0.1	0
Otago	0.5	1.0
Southland	0.2	1.0
<b>Total</b>	<b>25.3</b>	<b>34.3</b>
	41%	56%

### Medical staff

Medical staff made up 41% of the HPCS workforce (25.3 FTE), with the largest number being specialists (62%), followed by registrars (36%) and one house officer (see Figure 21). No HPCS reported employing MOSS, GPs or other medical staff.

**Figure 21:** HPCS medical workforce composition, June 2011

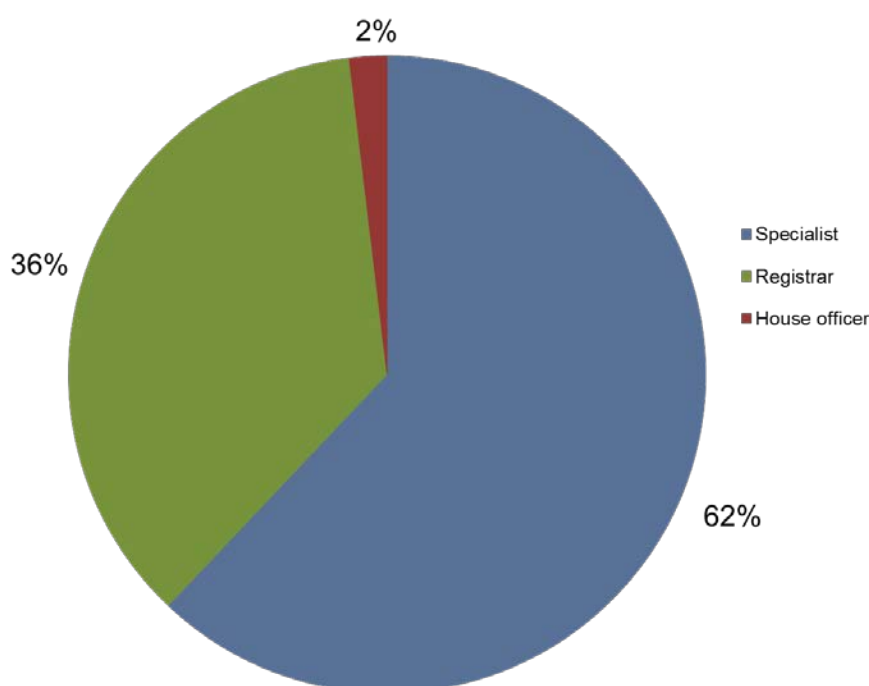


Table 60 summarises the national-level HPCS medical workforce as FTE per 1000 patients and staff:patient ratios. The FTE per 1000 patients includes all medical staff employed in HPCS roles and the national total number of patients reported by HPCS. Staff-to-patient ratios have been calculated for each medical role using reported FTE and total number of patients. Only data from services that reported having the staff roles and their corresponding patient volumes has been used in the ratio calculations.

The following national ratios have been calculated as described above, and the number of DHBs included is noted, along with the range of ratios. A full breakdown of the different HPCS medical roles per 1000 patients and staff:patient ratios by DHB region can be found in Appendices 19 and 20.

**Table 60: HPCS medical staff FTE per 1000 patients and staff:patient ratios, by role, June 2011**

Position	FTE per 1000 patients	Staff:patient ratio
Specialist	2.24	1:451 (n=11, range 1:239–1:1236)
Registrar	1.28	1: 1:619 (n=6, range 1:247–1:989)
House officer	0.07	1:1480 (n=1)
<b>Total</b>	<b>3.59</b>	<b>1:282 (n=11, range 1:112–1:1017)</b>

## Nursing staff

Nursing staff accounted for 56% of the total HPCS workforce (34.3 FTE). Most of these staff were in designated senior nurse roles (77%) and three (9%) were nurse practitioners (see Figure 22). The only other workforce group in nursing were end-of-life care pathway facilitators, employed in five HPCS and accounting for 15% of nursing roles. There were no staff nurses (registered nurses), enrolled nurses or care assistants employed in HPCS.

**Figure 22:** HPCS nursing workforce composition, June 2011

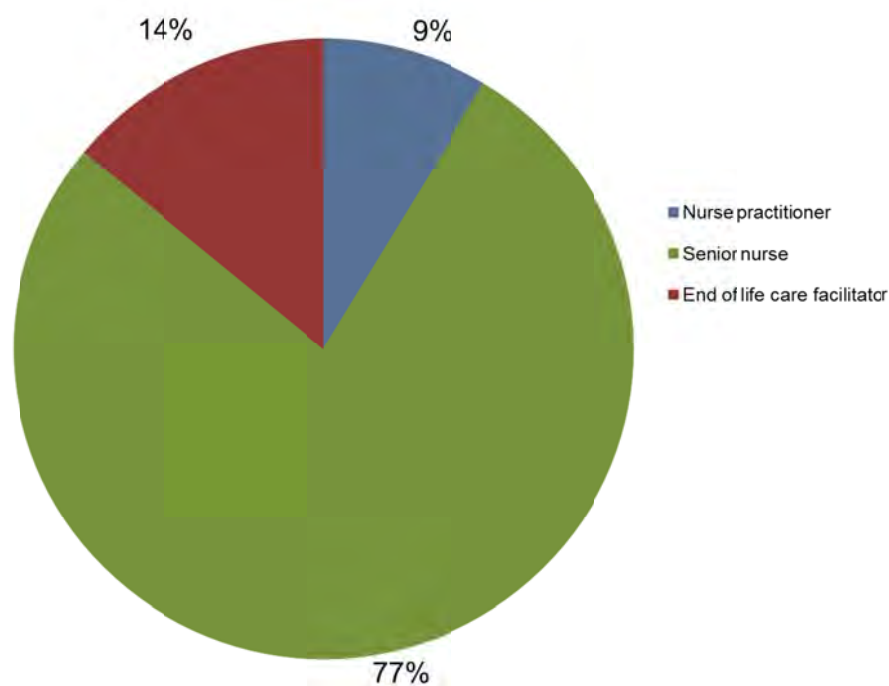


Table 61 summarises the national-level HPCS nursing workforce as FTE per 1000 patients and staff:patient ratios. The FTE per 1000 patients includes all medical staff employed in HPCS roles and the national total number of patients reported by HPCS. Staff-to-patient ratios have been calculated for each nursing role using reported FTE and total number of patients. Only data from services that reported having the staff roles and their corresponding patient volumes have been used in the ratio calculations.

The following national ratios have been calculated as described above, and the number of DHBs included is noted in the table, along with the range of ratios. A full breakdown of the different HPCS nursing roles per 1000 patients and staff:patient ratios by DHB region can be found in Appendices 19 and 20.

**Table 61: HPCS nursing staff FTE per 1000 patients and staff:patient ratios, by role, June 2011**

Position	FTE per 1000 patients	Staff:patient ratio
Nurse practitioner	0.43	1:1152 (n=3, range 1:500–1:1968)
Senior nurse	3.76	1:1:269 (n=11, range 1:126–1:582)
End-of-life care facilitator	0.68	1:905 (n=5, range 1:403–1:1968)
Total	4.87	1:208 (n=11, range 1:125–1:366)

## 4.3 Volunteers

This data on volunteers is from hospice palliative care services only, and a few of these services were unable to provide data on their volunteer workforce. For the period 1 July 2010 to 30 June 2011, 7501 people volunteered for hospice across the 30 services that provided data. These volunteers provided 584,081 hours of work; an average of 77 hours per annum per volunteer (see Table 62).

To put this into an economic context, an approximate monetary value can be calculated based on the current minimum wage of \$13.50 an hour to show that these hospice volunteers contributed at least \$7,885,093 worth of labour during the 12-month survey period, although in reality the skill required for many volunteer roles would be valued above this minimum wage value.

**Table 62: Hospice volunteer numbers and hours worked, by hospice service type, July 2010–June 2011**

Hospice service type	N	Head count	Annual hours worked	Average hours worked
Comprehensive	19	6780	528,351	78
Community	8	541	41,925	77
Supportive care	3	180	13,805	77
<b>Total</b>	<b>30</b>	<b>7501</b>	<b>584,081</b>	<b>78</b>

This volunteer workforce is distributed across all DHB regions (see Table 63), providing each hospice service with a substantial amount of work hours. Although data was not available from the West Coast DHB region, there is a Home Hospice Trust service on the West Coast providing volunteer services.

**Table 63: Hospice volunteers hours worked, by DHB region, July 2010–June 2011**

DHB	Head count	Annual hours worked
Northland	326	15,028
Waitemata	1148	102,008
Auckland	581	48,582
Counties Manukau	703	40,102
Waikato	378	39,863
Lakes	38	7454
Bay of Plenty	530	50,467
Tairāwhiti	18	445
Hawke's Bay	350	36,000
Taranaki	115	5637
MidCentral	463	50,802
Whanganui	186	35,988

Capital & Coast	752	41,688
Hutt Valley	500	32,000
Wairarapa	92	5400
Nelson Marlborough	501	24,556
West Coast	nk	nk
Canterbury	59	3698
South Canterbury	156	4441
Otago	355	27,922
Southland	250	12,000
<b>Total</b>	<b>7501</b>	<b>584,081</b>

Note: nk = not known due to no data provided.

## 4.4 The future of the palliative care workforce

Projecting palliative care workforce requirements into the future is not easy, for several reasons. First, there are no national or internationally agreed guidelines that clearly identify the workforce requirements for the different palliative care services. In addition, there are a number of variables that can influence population need for palliative care, such as incidence and cure rates for conditions that would benefit from palliative care, population growth and movement, and health care service structural changes. The model of care in use also has an influence on the size and mix of the palliative care workforce required within a region.

The two main approaches that were identified and evaluated as potentially informing this report are from Australia and represent two different methods of determining workforce requirements.

Palliative Care Australia (PCA) have recommended specialist palliative care FTE levels per 100,000 population, or, for some roles, per acute hospital beds or per palliative care designated beds, depending on the setting in which they are located (Palliative Care Australia 2003). Some examples of the PCA modelling are presented below to show how these figures might be applied in New Zealand (see Table 64).

PCA recommends 1.5 FTE palliative care specialists and 1.0 FTE registrar positions per 100,000 population and suggests that these roles should have both community and inpatient responsibilities. Table 64 gives an example of what these recommendations could mean if applied to the projected 2011 DHB adult populations. This approach would result in 80.2 FTE specialist and registrar medical staff across all DHBs and palliative care services.

**Table 64: Example of PCA recommended numbers: medical roles**

DHB	Adult population 2011	Palliative medicine specialists	Registrars
Northland	113,550	1.7	1.1
Waitemata	394,620	5.9	3.9
Auckland	349,080	5.2	3.5
Counties Manukau	337,420	5.1	3.4
Waikato	260,910	3.9	2.6
Lakes	72,510	1.1	0.7
Bay of Plenty	154,730	2.3	1.5
Tairāwhiti	31,810	0.5	0.3
Hawke's Bay	110,710	1.7	1.1
Taranaki	79,530	1.2	0.8
MidCentral	122,070	1.8	1.2
Whanganui	45,890	0.7	0.5
Capital & Coast	221,400	3.3	2.2
Hutt Valley	103,230	1.5	1.0
Wairarapa	29,780	0.4	0.3
Nelson Marlborough	104,830	1.6	1.0
West Coast	24,680	0.4	0.2
Canterbury	380,120	5.7	3.8
South Canterbury	42,420	0.6	0.4
Otago	143,870	2.2	1.4
Southland	83,800	1.3	0.8
<b>Total</b>	<b>3,206,960</b>	<b>48.1</b>	<b>32.1</b>

The nursing recommendations from PCA cover a number of roles, but for this example only nursing staff FTE for designated palliative care beds have been explored. PCA recommends sufficient nurses to provide 6.5 hours of direct nursing care per day (over a 24-hour period). This is a similar level of nurse cover as would be found in a high dependency ward in an acute hospital. In order to determine the number of nurses required for a given inpatient setting, a nurse hours per patient day (NHpPD) calculation must be undertaken using the number of designated beds, occupancy rate (expressed as an average daily occupied bed day (OBD) and normal working hours per fortnight (usually 80). Table 65 shows examples of how this calculation can be applied for different bed numbers and occupancy rates.

**Table 65: NHpPD for different in-patient unit bed numbers**

Beds	% occupancy	OBD	Total NHpPD	Nursing hours per 14 days	FTE
10	50	5	33	455	5.7
10	70	7	46	637	8.0
10	90	9	59	819	10.2
5	85	4	28	387	4.8
15	85%	13	83	1160	14.5
Explanation	Average number of beds occupied	Number of beds x occupancy rate	OBD to 6.5 NHpPD	Total daily NHpPD x 14	Nursing hours per 14 days ÷ 80 hours (normal working hours per 14 days)

Allied health roles are more complicated, as PCA recommends different FTE for different care settings. An example of the FTE by setting is provided in Table 66.

**Table 66: PCA recommended FTE for different allied health roles**

Position	Community-based service*	Acute hospital consultative service**	Palliative care designated beds***
Psychology	0.25	0.1	0.1
Social work	0.5	0.25	0.25
Bereavement support	0.25	0.1	0.1
Pastoral care	0.25	0.25	0.25
Speech pathology	0.2	0.2	0.2
Dietician	←	0.2	→
Physiotherapy	0.4	0.2	0.2
Occupational therapy	0.4	0.2	0.2
Pharmacist	0	0.25	0.1
Complementary therapy	0.5	0	0.25

\* EFT per 100,000 population

\*\* EFT per 125 beds

\*\*\* EFT per 6.7 designated palliative care beds

The Victorian Government Department of Human Services used a supply and demand study method to assess future workforce requirements of the palliative care workforce (Department of Human Services 2006). This involves quite a complex methodology that requires information on the size, composition and distribution of the workforce over time, the use of palliative care services and population trends. Workforce capacity is determined based on workforce supply (number of FTE available) and the service provided (number of patients cared for). This produces workforce ratios that can be applied to projected service demand to determine future workforce requirements.

Here is an example of how the Victorian modelling might be applied in New Zealand for registered nurse roles:

- 292 FTE
- 13,821 patients
- staff:patient ratio = 1:47
- assume all hospice services require the same FTE
- project mid-range estimate of palliative care need (based on projected DHB populations)
- apply ratio to projected estimate of need.

Year	Service demand (ie, estimate of need)	Registered nurse FTE
2011	16,837	358
2016	17,947	382
2021	18,838	400
2026	19,639	418

The final step is to determine where these FTE should be located to best meet patient need and service delivery requirements.

Unfortunately, both of these Australian approaches have drawbacks that make the resultant workforce projections unreliable. The PCA guideline provides no rationale for the recommended staffing FTEs, and the model of palliative care in Australia is different to New Zealand so the recommendations may not result in an appropriate size and mix of workforce to meet the need for palliative care in this country. The Victorian model assumes that current workforce supply and demand are appropriate, but the overwhelming response from palliative care services in the consultation for this report was that the current palliative care workforce is inadequate. In addition, Phase 1 of the HNA suggested that palliative care need is not currently being met and so current service utilisation levels are not a reflection of the true palliative care service demand if all those who could benefit from palliative care were being referred. Therefore this approach is likely to simply project inadequacies and inequalities into future workforce projections. There is also a concern that using population projections and estimates of need may introduce too much error into the results of this approach.

Health Workforce New Zealand (HWNZ) has undertaken a review of the palliative care workforce using the Victorian method (Health Workforce New Zealand 2011). This review used 2008 workforce data, projected deaths and projected palliative care patients. Although the workforce data used was incomplete and from 2008, it did show an increasing requirement for both palliative care medical and nursing staff in the next 15 years (see Table 67). It did not attempt to forecast the need for allied health professionals or the psychological, social and spiritual care workforce. The FTE recorded for 2008 is actually substantially less than that reported for 2011, which found 80 FTE medical staff and 530 FTE nursing staff.



**Table 67: Health workforce New Zealand projected palliative care workforce, 2008–2026**

Workforce	2008 FTE	Projected 2026 FTE	Projected increase
Medical	59.9	73.9	23%
Nursing	376.2	466.2	24%

The HWNZ palliative care workforce service review group identified several important palliative care workforce issues, including the following.

- There is a large variation in workforce numbers across regions. The number of FTE (medical and nursing) per 1000 patients varies between 20.7 per 1000 patients (upper South Island) to 42.2 per 1000 (Central region), with the average being 27.9 per 1000 patients.
- There are a number of palliative care workforce issues that need to be addressed, including an ageing workforce; recruitment and retention of palliative care medicine specialists; a shortage of GPs with an interest in palliative care; a shortage of nurses with specialist palliative care skills; confusion over advanced nursing practice in specialist palliative care across clinical settings; and a need to define and develop the role of allied health professionals within the multidisciplinary team.
- There is a need to develop and rationalise training for both palliative care specialists and non-specialist health professionals.

HWNZ currently has a second phase of their workforce review project under way to evaluate a new approach to palliative care service delivery using a managed clinical network across several DHB regions.

Given that work is already under way to develop the palliative care workforce through HWNZ, as well as the issues identified with currently available workforce modelling methods, this report does not attempt to project workforce requirements into the future. Instead it has provided an in-depth overview of the 2011 palliative care workforce that could be used for further workforce analysis and planning.

## 5 Summary and Main Findings

Phase 2 of the Health Needs Assessment (HNA) was primarily concerned with access to palliative care for those in need. It used many sources of data from a multitude of organisations, including published reports, existing databases and an in-depth survey of palliative care services. The project has included an exploration of primary palliative care providers, including GPs, residential aged care, district nurses, hospitals and home health care providers, as well as a survey of palliative care services. The following is a summary of the important findings of the report, followed by recommendations for service development.

### 5.1 Primary palliative care providers

Currently there is no specific data on palliative care service provision by primary palliative care providers, so a number of proxy measures were explored in order to provide some indication of capacity and capability. These proxy measures included readily available data from published reports and other data collections held by national organisations.

Overall, primary palliative care providers appear to have a reasonable level of capability, based on the data and reports reviewed. However, it is impossible to draw any firm conclusions because there is limited or no specific data on the number or characteristics of the people who receive palliative care from them, the training and qualifications of staff providing palliative care, the quality of palliative and end-of-life care provided, or the satisfaction of patients and family/whānau with the services received.

It is well recognised that primary palliative care providers play a very important role in the care of people with life-limiting and life-threatening illnesses, and that their capability in palliative care needs to be enhanced because they can expect a greater number of people requiring palliative care in the future. It will be important that these health professionals have ready access to education and training in palliative care, advice and support from specialist palliative care, and the ability to refer patients to a specialist palliative care service when their needs exceed the provider's knowledge and abilities.

### 5.2 Specialist palliative care services: hospices and hospitals

There are palliative care services active in every DHB region, including 31 hospice services (plus six hospice supportive care services) and 14 hospital palliative care services (HPCS), including one specialist paediatric palliative care service. There is at least one hospice service in all but two regions, and HPCS are present in many DHB hospitals, either in the form of a dedicated team or via a hospice consultation service. However, these hospice and hospital services do not all provide the same type and level of palliative care.

One of the most significant issues with the survey of palliative care services was the availability and consistency of data. There is no nationally agreed minimum data set in use, leading to problems with access to and reporting of data, the range of data being recorded, and definitions of terms, including 'ethnicity', 'diagnosis' and 'age group'. Collecting this type of service data on a national level would allow hospices to clearly show the impact they have on the New Zealand population. Because many HPCS rely on a DHB hospital system to record patient information, data extraction was difficult for some services.

Comparing the reported service components and health professional roles to the capability recommendations from Hospice New Zealand and Hospital Palliative Care New Zealand identified a wide variability in access to core service components, as well as some significant gaps across all services.

For hospices, the main gaps were in access to allied health professionals and psychological, social and spiritual care staff. These gaps were particularly prominent in community hospice palliative care services, although access to allied health staff was almost universal. Community hospice palliative care services also had gaps in the provision of education, end-of-life care pathway use, 24/7 advice and care, and support for paediatric and young person palliative care. Hospice palliative care support services in general offered only a few capability components.

The gaps identified in HPCS capability also included a limited ability to provide after-hours telephone cover, which is reported to be related to limited resources, and which is also the case for undertaking or being involved in research activities. There was also a lack of clinical supervision available for palliative care service staff. Other areas where some HPCS reported difficulties were access to bereavement support and discharge coordination, availability of private/quiet spaces for consultations and family meetings, and single rooms for dying or distressed patients/family.

Hospices provided care for 14,252 people during the 12-month survey period, and the average length of care episode for hospice patients was approximately four months. When comparing the number of new patients cared for by hospices in the different DHB regions and the estimated number of people who would benefit from palliative care, there are some significant differences. Overall, 5959 people who may have benefited from palliative care were not referred to a hospice, but the proportion potentially not referred varies widely by DHB region from about the same as to 63% less than the estimate. The reason for non-referral and the variation require further investigation to determine why these differences exist.

HPCS accepted 7049 referrals during the survey period and made 19,861 patient contacts, usually through face-to-face consultations. For services able to report length-of-care data, the average length of a care episode was 12.6 days.

Hospice services provided a considerable amount of education over the 12-month survey period, with 23,751 individuals attending education, over a third of whom were from aged residential care settings. HPCS also provide education as a core component of their service, but they had difficulty reporting attendee numbers because this is not routinely recorded.

All hospice services provide community care, including caring for people in their own home, residential care facility or hospital. All services offered assessment and care planning as part of this service, and then either care coordination, direct clinical care or a combination of both. Most hospices also provided equipment into people's homes. Contact with patients was by telephone or visit, and there was a wide range in the number of phone calls or visits patients received across the DHB regions, indicating that there is no specific model of care. It also raises concern about equity of access to palliative care support between DHB regions. It could be that the differences are related to data collection, as most of the differences were quite random except that services with greater numbers of patients tended to make fewer telephone calls, on average, to their patients.

Hospices tended to admit fewer older patients than would be expected when compared to the mid-range estimate of need, and also slightly fewer European patients, although there was wide variation across the DHB regions, which may be related to differences in regional ethnic group populations. Many more people with a cancer diagnosis were accepted into hospice care (78.8%) than were in the mid-range estimate (42.1%), indicating there are still barriers to people with a non-cancer diagnosis accessing hospice services. There were wide variations in the cancer/non-cancer split across DHB regions, indicating potentially different referral criteria or varying relationships with non-cancer services.

Looking at the diagnosis and age of hospice patients, there is a high likelihood that the two groups missing out on hospice palliative care are those with a non-cancer diagnosis and people over age 80. The single biggest group of non-cancer patients who do not appear to be referred to hospice are those with a cardiovascular diagnosis.

Those people who are under hospice care are much more likely to die in a private residence (usually their home) or an inpatient hospice unit, less likely to die in aged residential care, and significantly less likely to die in hospital.

HPCS were unable to provide data on all of their patients due to their data access issues, as previously noted. However, the data that was submitted shows that HPCS are seeing a similar age group to hospices (ie, fewer over 80s, as well as a similar ethnic mix, although slightly more Pacific and Asian people). HPCS reported more non-cancer patients being accepted into their services at 35.5%, but this is still below the estimated level of 57.9% non-cancer, and again there were variable rates between services. Again, like hospices, it is people with a cardiovascular diagnosis that appear to be missing out on referral to an HPCS at the end of life.

### **5.3 Palliative care beds**

The survey found there were 188 designated palliative care beds in New Zealand (173 in hospices, 13 in aged residential care facilities and two in hospitals) during the 2010/11 period. With an overall occupancy rate of 79%, 148 of these beds were occupied by palliative care patients on any given day. There were 6612 admissions reported during the survey period, with an average length of stay of 8.6 days. While the national ratio of palliative care beds to adult population (6.1:100,000) is consistent with international recommendations, the palliative care beds are not evenly distributed across the DHB

regions in relation to population size, resulting in wide variation in access to inpatient palliative care.

Two HPCS also reported having designated palliative care beds available: 10 in one hospital and two in another. The HPCS with access to 10 beds had been operating as the main inpatient palliative care facility in the DHB region and had recorded 778 admissions for the survey period, with an average length of stay of 5.2 days.

Only those beds located in a hospice inpatient unit should be considered specialist, as they are staffed by health care professionals who have specialised in palliative care. Beds in hospitals and aged residential care are staffed by primary palliative care providers who deliver a generalist level of palliative care. There are also a number of inpatient beds available for palliative care patients that are not dedicated solely for palliative care but are accessed through a variety of funding streams and used on an as-needed basis, although fund allocation and use is not consistent across DHB regions.

Further work is required to determine the appropriate number and location of palliative care beds in each DHB region. This will be influenced by the size of the population, funding and resource availability, level of palliative care need, and model of hospice care delivery.

## 5.4 Workforce

Across hospices and HPCS there were 1189 individuals employed and a total of 733.2 FTE (including vacancies). Most of these people are employed in hospices (645 FTE), and the largest group was nurses (530 FTE). Currently, staffing varies widely across DHB regions, as indicated by wide variations in staff numbers per 1000 patients and staff-to-patient ratios.

There is variable access to many roles in both hospices and HPCS, especially palliative medicine specialists, allied health, and psychological, social and spiritual care. These differences may be partly accounted for by the different models of care, but in most cases this would not be the main reason. The differences need to be explored in more detail and work undertaken to ensure appropriate access is available across all DHB regions.

Palliative care workforce projections were explored as a potential component of this report, but due to methodological issues the currently available models were felt to be inappropriate for New Zealand. Instead, examples have been provided of how different models may be applied, while taking into consideration their deficiencies, and it is suggested that each DHB region explore its needs and models of care and develop appropriate and reasonable workforce requirements. The current palliative care project being undertaken by Health Workforce New Zealand will provide important information on the future palliative care workforce and service delivery model.

# Recommendations

The following recommendations have been grouped according to where the main responsibility for their implementation lies. Although they are numbered consecutively, this is not intended to indicate any specific priority.

## Recommendations for the Ministry of Health

The Ministry of Health includes Health Workforce New Zealand, the National Health Board and the IT Health Board.

1. The release of the Hospice Capability Recommendations and the Hospital Palliative Care Service Capability Framework was timely and important because they have informed the Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand, published by the Ministry in January 2013. The Resource and Capability Framework should now be used to inform the funding framework and service specifications for palliative care.
2. The Health and Disability Services Standards 2008 apply to hospitals, hospices, rest homes and those providers of residential disability care that have five or more residents. The Ministry should ensure that these standards include specific requirements related to end-of-life care. The standards need to be aligned with the Resource and Capability Framework.
3. The funding streams for primary care should include specific funding for palliative care needs so that continuity of care can be maintained in the community. The primary care palliative care partnership models could serve as an example.
4. The project in the National Joint Work Programme 2012 entitled 'National Specialist Palliative Care Data Definitions Standard and Data Business Process Standard' needs to be brought to completion, following thorough piloting. The standards should be implemented following the IT Health Board processes.
5. National approaches need to be developed on a model of care for the delivery of palliative and end-of-life care in order to reduce regional variation that may have an impact on access to, and the quality of, palliative care services.
6. The IT Health Board, a subsidiary of the National Health Board, should give consideration to national standards for the collection of palliative care data and to a minimum palliative care data set for both primary palliative care providers and palliative care services. This will need to include clear data definitions that are based on nationally accepted definitions and codes so that comparisons can be made with other national collections.

7. An area of concern that needs further IT Health Board consideration is access to patient information that is collected and stored by multiple health care providers. The National Health IT Plan needs to commit to improving palliative care information across different settings, including general practice records, hospital records, aged care records and hospice records. These systems are not linked in most areas, or cannot all be accessed by health professionals providing care for a patient in different settings, including district nursing services.
8. The palliative care workforce project initiated by Health Workforce New Zealand should be informed by the findings of this Phase 2 report. Palliative care delivery is critically dependent on people as well as buildings and technology, and the planning for future workforce requirements is of vital importance to the sector.
9. Variations in access to palliative care workforce roles need to be addressed to ensure equitable service delivery, regardless of DHB region or geographic location. The Resource and Capability Framework needs to be used to revise the Health Workforce New Zealand plans, particularly with regard to backup, support and coverage in all regions.

## Recommendations for district health boards

10. DHBs should ensure that each primary palliative care provider has 24/7 access to specialist palliative care support and advice, as well as the ability to refer patients to a specialist palliative care service.
11. DHBs should ensure that all district nursing services providing palliative care have formal links to a specialist palliative care service for specialist advice and support.
12. DHBs should ensure that families and patients have after-hours access to district nursing services where these are providing palliative care support.
13. DHBs should measure and monitor their own capacity against the recently published *Resource and Capability Framework*.
14. DHBs should work with hospice services to address the following issues, which are considered core capability requirements to ensure consistency across services and regions:
  - a. access to a palliative medicine specialist
  - b. access to specialist palliative care nurses
  - c. access to allied health professionals, in addition to the full range of psychosocial and spiritual support
  - d. consistency in end-of-life care pathway implementation
  - e. the ability to provide, or have access to, 24/7 advice and care
  - f. ensuring each palliative care service has support for paediatric and adolescent and young adult palliative care
  - g. access to a cultural advisor.



15. DHBs should ensure that hospital palliative care services can achieve their core capability requirements, in particular:
  - a. resources to provide, or have access to, after-hours telephone cover
  - b. access to clinical supervision for palliative care service staff
  - c. bereavement support services
  - d. a discharge coordinator
  - e. the availability of private/quiet spaces for consultations and family meetings
  - f. single rooms for dying or distressed patients/family.
16. Services within each DHB region should collaborate on workforce planning that meets the requirements of their local model of palliative care service delivery and the needs of their population. Specific areas to address include:
  - a. access to palliative medicine specialists
  - b. access to specialist palliative care nurses
  - c. access to the full range of allied health professionals
  - d. ensuring the availability of staff to provide psychological, social and spiritual care.

## **Recommendations on standards and for education providers**

17. The Royal New Zealand College of General Practitioners (RNZCGP) Cornerstone programme should contain explicit end-of-life care indicators.
18. Education providers should develop primary palliative care provider capability through targeted education and training. This should include undergraduate training in palliative care for all health professional groups and multidisciplinary postgraduate training in palliative care.

## **Recommendations for researchers**

19. Further work is required to investigate why there are regional differences in patient referral numbers compared to the estimate of need. Further work to develop a national approach to patient referral criteria for both hospice and hospital palliative care services is needed. This work should focus on referrals of non-cancer patients and older age groups.
20. Further work needs to be undertaken to determine an appropriate palliative care inpatient bed model for New Zealand. Once established, further work at a DHB regional level will be needed to establish the best location and funding model for these beds to meet the needs of the local population.



## Recommendations for the Palliative Care Council

21. With substantial progress having been made on monitoring palliative care capability in the specialised palliative care services, the focus of research and monitoring by the Palliative Care Council needs to shift to primary palliative care providers. There is a need to understand more about the major primary palliative care providers and any obstacles they encounter in providing palliative care equitably across the country.
22. Because 38% of deaths over age 65 in New Zealand occur in aged residential care facilities, it is important that the ability of these facilities to incorporate palliative care be investigated more thoroughly. The project identified in the *National Joint Work Programme 2012* entitled 'Palliative Care Provision in Aged Residential Care' should receive priority in 2013. More specific data is required on residents' demographics, including mortality data, staffing (including numbers with additional training in palliative care), access to specialist palliative care support, and funding/contractual agreements for palliative care.
23. The project in the National Joint Work Programme 2012 entitled 'Palliative Care Provision in Primary Care' should be undertaken as soon as resources allow.
24. The Palliative Care Council needs to work closely and constructively with Health Workforce New Zealand to ensure the future need for palliative care is anticipated in the planning and development of the palliative care workforce.
25. The palliative care capacity and capability component of the Phase 2 report should be repeated in two years' time to evaluate the impact of service development initiatives and other project work being undertaken at national and local levels. Because it is unlikely that work on a national minimum palliative care data set will have progressed before repeating the survey component, the Council needs to work towards greater consistency of data within the sector to ensure comparability between regions.

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## Appendix 1: List of consultation submitters

Title	First name	Last name	Organisation	Type
	Andrea	Bunn	Whanganui DHB	Organisation
Dr	Anne	O'Callaghan	Auckland City Hospital PCT	Individual
	Beth	Tester	Manager Hospice Marlborough	Service
	Biddy	Harford	Te Omanga Hospice	Service
	Bridget	Marshall	National LCP Office	Organisation
Dr	Carol	McAllum	Hawke's Bay DHB	Service
Dr	Cathy	Miller	Palliative Care Service North Shore and Waitakere Hospitals	Service
	Clare	Randall	Chief Executive, Arohanui Hospice	Service
	Helen	Blaxland	Cranford Hospice Hawke's Bay	Service
	Jackie	Hantz	Cranford Hospice	Service
	Janet	Copeland	Physiotherapy New Zealand	Organisation
	Jason	Power	South Canterbury DHB	Organisation
	Jean	Clark	Hospital Palliative Care Service, Palmerston North Hospital	Service
	Joanne	Edwards	Wairarapa DHB	Organisation
Dr	Jonathan	Adler	Wellington Hospital	Individual
	Jude	Boxall	Palliative Care Nurses New Zealand Society Inc	Organisation
	Judy	Hindrup	Atawhai Assisi Home & Hospital	Service
	Karen	Anderson	Hospice Wanganui	Service
	Karyn	Bycroft	Paediatric Palliative Care, Starship Children's Hospital	Individual
Dr	Kate	Grundy	Clinical Director, Christchurch Hospital Palliative Care Service	Service
	Kevin	Nielson	Hospice Taranaki	Service
	Lynda	Smith	Mercy Hospice Auckland	Service
	Marianne	Mackenzie	Hospice Waikato	Individual
	Ngaire	Lewis	Hospice Eastern Bay of Plenty	Service
	Peter	Bassett	North Haven Hospice	Service
	Raewyn	Jenkins	Nurse Maude Hospice Palliative Care Service	Service
	Raewyn	Calvert	National Cancer Consumer Representative Advisory Group	Organisation
	Ria	Earp	Mary Potter Hospice	Service
	Ricarda	Vandervorst	Ministry of Health	Organisation
	Richard	Thurlow	Waipuna Hospice	Service
Dr	Sara	Rishworth	Mercy Hospice Auckland	Individual
	Shona	Lowson	Hospice South Canterbury	Service
Dr	Sinead	Donnelly	Wellington Regional Hospital PCT	Individual
	Stephanie	Fletcher	Midcentral DHB	
	William	Landman	Middlemore Hospital	Service

## Appendix 2: District nursing services, by DHB, 2010

DHB	DHB provider	Palliative care	After-hours service
Northland	Northland DHB District Nursing Service		
Waitemata	Community Services for Older Adults and Home Health	✓	
Auckland	A+ Links Home Health	✓	
	Waiheke Health Trust (NGO)	✓	✓
Counties Manukau	Adult Rehabilitation & Health of Older People Service	✓	
Waikato	Waikato DHB District Nursing Service	✓	✓
Lakes	Lakes DHB District Nursing Service	✓	✓
	Reporoa Health Trust (NGO)	✓	✓
Bay of Plenty	Bay of Plenty DHB District Nursing Service	✓	
Tairāwhiti	Western Rural Area District Nursing Service	✓	✓
	Gisborne District Nursing Service	✓	
	Ngāti Porou Hauora PHO (NGO)	✓	✓
Hawke's Bay	Hawke's Bay DHB Rural and Community Services	✓	
Taranaki	Taranaki DHB District Nursing Service	✓	✓
	Urenui and Districts Health Group (NGO)	✓	✓
	Inglewood Community Trust (NGO)	✓	✓
	Mokau Community Nursing Services (NGO)	✓	
MidCentral Health	MidCentral Health District Nursing Service	✓	✓
Whanganui	Whanganui DHB District Nursing Service	✓	
	Otaihape Health Community Trust (NGO)	✓	
Capital & Coast	DHB Community Health Services	✓	✓
Hutt Valley	Hutt Valley DHB Community Health Services	✓	✓
Wairarapa	Wairarapa DHB Community Nursing and Health Service	✓	✓
Nelson Marlborough	Nelson Marlborough DHB District Nursing Service		✓
West Coast	West Coast DHB Community Nursing Services	✓	✓
Canterbury region	Ashburton and Rural Health Services, a division of Canterbury DHB	✓	✓
	Ali's Home Healthcare (NGO)	✓	✓
	Access Homehealth (NGO)	✓	✓
	Health Care New Zealand (NGO)	✓	✓
	Nurse Maude (NGO)	✓	✓
	Rural Canterbury PHO (NGO) (10 providers)	✓	✓
South Canterbury	South Canterbury DHB Primary and Community Services	✓	✓

DHB	DHB provider	Palliative care	After-hours service
Southern (Otago)	Otago DHB District Nursing Service	✓	
	Waitaki District Health Services Ltd (NGO)	✓	
	West Otago Health Services Ltd (NGO)	✓	✓
	Central Otago Health Services Ltd (NGO)	✓	
	Tuapeka Community Health Co Ltd (NGO)	✓	✓
	Roxburgh District Medical Service Trust (NGO)	✓	✓
	Maniototo Health Services Ltd (NGO)	✓	✓
	Milton Community Trust (NGO)	✓	✓
	Clutha Community Health Company (NGO)	✓	
Southern (Southland)	Southland DHB Community Nursing Service	✓	
	Waiau Health Trust (NGO)	✓	✓
	Nightcaps Community Medical Trust (NGO)	✓	
	Gore Health Trust (NGO)	✓	✓
Number of DNSs providing service component		43	29
Percentage of DNSs providing service component		96%	64%

Notes:

Excludes child health home care services (<16 years old).

\* The Canterbury region has 14 non-DHB services providing district nursing services, comprising six private businesses and eight community trust district nursing services. Ten of these come under the Rural Canterbury PHO, so it has been counted only as one NGO provider.

Summarised from: Appendix 4: Profiles of Current District Nursing Services in New Zealand by DHB Region (Ministry of Health 2011: 46–105).

## Appendix 3: Palliative care services in New Zealand, by DHB, 2011

DHB	Service name
<b>Hospice palliative care services</b>	
Northland	Far North Community Hospice
	Hospice Kaipara
	Hospice Mid Northland
	North Haven Hospice
Waitemata	Hibiscus Hospice
	Hospice West Auckland
	North Shore Hospice
	Warkworth Wellsford Hospice
Auckland	Amitabha Hospice
	Eastern Bays Hospice (Dove House)
	Hospice Waiheke Homecare
	Mercy Hospice Auckland
Counties Manukau	Franklin Hospice
	Totara Hospice South Auckland
Waikato	Hospice Waikato (Gallagher Family Hospice)
	Rainbow Place
	Tokoroa Hospice
	Whangamata Hospice & Cancer Support Trust
Lakes	Lake Taupo Hospice
	Rotorua Community Hospice
Bay of Plenty	Hospice Eastern Bay of Plenty
	Waipuna Hospice
Tairāwhiti	Hospice Tairāwhiti (Gisborne Palliative Care)
Hawke's Bay	Cranford Hospice
Taranaki	Hospice Taranaki
MidCentral	Arohanui Hospice
Whanganui	Hospice Wanganui
Capital & Coast	Mary Potter Hospice
Hutt Valley	Te Omanga Hospice
Wairarapa	Hospice Wairarapa
Nelson Marlborough	Hospice Marlborough
	Nelson Region Hospice
West Coast	Buller West Coast Home Hospice Trust Inc
Canterbury	Nurse Maude Hospice



DHB	Service name
South Canterbury	Hospice South Canterbury
Southern (Otago)	Otago Community Hospice
	Dunstan Hospital Hospice Service
	Waitaki Hospice Care Trust
Southern (Southland)	Hospice Southland
<b>Hospital palliative care services</b>	
Waitemata	WDHB Hospital Palliative Care Service (covering North Shore and Waitakere Hospitals)
Auckland	Auckland City Hospital Palliative Care Service
	Starship Children's Hospital Palliative Care Service
Counties Manukau	Middlemore Hospital Palliative Care Service
Waikato	Waikato Hospital Palliative Care Service
Hawke's Bay	Hawke's Bay Regional Hospital Palliative Care Service
Mid-Central	Palmerston North Hospital Palliative Care Service
Capital & Coast	Wellington Hospital Palliative Care Service
Hutt Valley	Hutt Hospital Palliative Care Service
Wairarapa	Wairarapa Hospital Palliative Care Service
West Coast	Grey Base Hospital Palliative Care Service
Canterbury	Christchurch Hospital Palliative Care Service
	Ashburton Hospital Palliative Care Service
South Canterbury	Timaru Hospital Palliative Care Service
Southern (Otago)	Dunedin Public Hospital Palliative Care Service
Southern (Southland)	Southland Hospital Palliative Care Service

## Appendix 4: Hospice New Zealand Hospice Capability Recommendations



### Hospice capability – what should our community expect of us?

The underlying intentions to this piece of work are equity of access, quality of care, and fairness of hospice care for the people of New Zealand.

Alongside this is the certainty that each hospice is very important to their local community, but what we also know is that patients and families are not necessarily concerned if the care they receive is delivered by generalist or specialist providers. What is important is that the right services are delivered by the right people, at the right time, in the place that is right for the patient and their family.

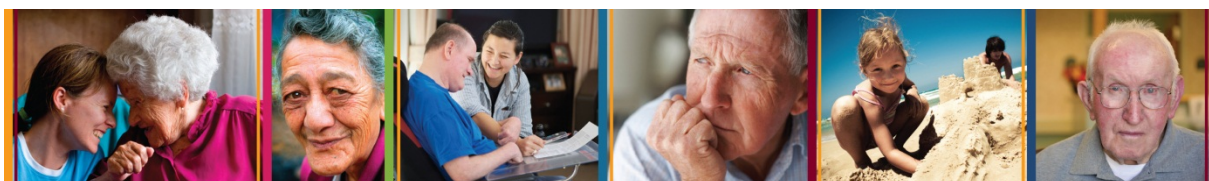
We acknowledge and honour the range of services, the diversity of models, and the locally driven adaptations to meet communities' needs. We have taken the best of this, agreed the core of local community hospice care, and developed a way to strengthen and position hospices to lead palliative care in the future.

By working together to define hospice care as it stands now, we can ensure that the founding values of hospice continue to underpin the care delivered by hospices throughout New Zealand in the future.

It is acknowledged that we are facing demographic changes in communities, an aging population, an increase in chronic conditions, which will contribute to an increase in demand for hospice services – which will be challenged by workforce shortages, and funding constraints.

As an organisation, we felt it was timely to actively lead and participate in sector developments that will change the face of health care and palliative care delivery in New Zealand. By leading the future shape of hospice we will positively influence the development of policy, service and funding models, and service planning.

We strongly believe, as do our communities, that hospices have an important and valid role to play both now and in the future.



## Hospice capability key questions

- What is it that people in our communities need?
- What needs to be in place to meet the expectations of people?

## Hospice capability key assumptions

- That the majority of New Zealanders want to choose where they live during their illness and where they die
- That people and their families and whānau will need access to skilled people who take responsibility for ensuring their care is coordinated and appropriately linked to other health providers and social agencies
- That people have appropriate access to clinicians who can provide expert symptom management, assistance with practical matters, psychosocial and spiritual support (or a team who sees them as a whole person – social, spiritual, member of a family and community), carer respite, education of carers, night care, equipment, etc
- That criteria for entrance to a service be based on patient need, not on diagnosis or what services offer
- That families want the problem sorted, not so concerned by whom, but they do expect a quality service, delivered by professionals who are able to effectively solve their problem
- That the unit of care is the person and their family and whānau
- That care should be delivered in a culturally appropriate manner
- Hospices review their services against the Hospice NZ Standards for Palliative Care and use the quality review programme tools to guide quality improvement.

## What should all hospices be capable of providing?

To ensure consistent and quality care is delivered within all communities, each hospice will have:

### Clinical functions

- Community palliative care services delivered by the interdisciplinary team to meet the needs of the patient and family (hands on community nursing care will be offered or accessible, when needed)
- Advanced assessment and care planning – medical, nursing, psychosocial and spiritual
- Care coordination/case management in place
- Liaison – cultural, community, aged care, hospital and social services, where necessary
- Education – both of the public and health workforce
- Counselling and support programmes during illness and into the bereavement phase
- End of life pathway and or alternate model of sector wide training
- Quality improvement and management
- Clinical data collection; accurate and timely.

See also, clinical functions that are to be accessed, as a minimum standard of care.

### Non-clinical functions

- Effective governance and leadership
- Volunteer management and systems
- Responsible and ethical fundraising.

## All hospices will employ or contract people for each of these roles, with subsequent required competencies depending on profession

### Nurses

The majority of specialist palliative care is delivered through the nursing workforce, most of whom will have post graduate qualifications in palliative care. Inpatient units will have a mix of experienced and specialist qualified staff. The following outlines the minimum requirements.

Consistent with current PDRP (see appendix for abbreviations)	Graduate	Competent	Proficient	Expert (EN at this level called accomplished)	Senior TL CNS CNE	Nurse Practitioner
IPU RNs	Yes	Yes	Yes	Yes	Yes	Optional
IPU ENs	Yes	Yes	N/A	Yes	N/A	N/A
IPU HCAs	N/A	Yes	N/A	N/A	N/A	N/A
Community care coordinator	No	No	No	Minimum	Yes	Optional
Community nursing	No	No	Minimum	Yes	Yes	Optional
RNs – at least 60% with relevant qualifications (PG cert in PC) and proficient/expert ENs – at least 60% proficient/expert within scope of practice Senior nurses – competencies plus qualification, minimum PG Diploma (PC endorsement), preferably Masters						

### Doctor

Hospices will need General Practitioners and/or Medical Officers on staff, who are vocationally registered, and preferably have a post graduate diploma or clinical diploma in palliative care. These staff will also need access to, and supervision from, a palliative medicine specialist.

### Cultural liaison/advisor

Each hospice team will include cultural support staff, competent in palliative care. These competencies are yet to be developed, but this will be done in partnership with hospice cultural advisors currently delivering this care and drawing on international best practice.

### Social work

#### Counselling

#### Spiritual care

The psychosocial team is pivotal to the delivery of comprehensive and holistic patient, family and whānau care. The following outlines the registration, qualifications and competencies of these staff that all hospices will be working towards.

	Membership required	Registration required	Qualification required	Competency required To be developed
Social work	ANZASW	SWRB	PG cert in PC	Yes
Counselling	NZAC	Application with HPCA	PG cert in PC	Yes
Spiritual care	Does not currently exist	Does not currently exist	PG cert in PC	Yes

## **Educators**

Educators are from a wide range of professions, although the lead is often taken by nurses. The qualifications and competencies are as laid out for the CNE role; educators will demonstrate competencies to an expert level, plus have or be working towards a minimum qualification of PG Diploma (PC endorsement) and preferably a Masters degree in an area relevant to palliative care provision.

## **Volunteer services**

All hospices will have a volunteer workforce, undertaking roles that enhance services. This workforce will be managed by trained managers who will demonstrate competencies in palliative care. These competencies are yet to be developed, but this will be done in partnership with experienced hospice managers of volunteer services.

### **All hospice services will either provide or have access to:**

- Inpatient care – e.g. hospice inpatient unit, aged residential care, hospital (dedicated palliative care beds)
- Equipment for patients and families at home
- Respite – night and day nursing and carer relief
- Home help for personal care
- 24/7 medical and nursing advice and care, in the home
- Paediatric and young person palliative care services
- Specialist teams – such as renal, respiratory, cardiac, and mental health services, health of older people services, children and young people services, disability services, etc
- Interpreter services, including deaf interpreter.

### **Specific expertise/roles and their competencies**

#### **Specialist medical**

Some hospices will employ Specialist Medical staff who will then support, advise, and supervise medical officers. They will also provide support and advice to local general practitioners and in some cases provide services to other hospices. These staff will be vocationally registered in Palliative Medicine with MCNZ (and Fellows of the RACP or Chapter of Palliative Medicine).

A smaller group of hospices will provide advanced training opportunities for registrars in Palliative Medicine and other specialities. These hospices must meet RACP criteria to become a training site.

#### **Occupational therapy**

#### **Physiotherapy**

#### **Clinical pharmacist**

#### **Dietician**

#### **Speech-language therapist**

Role	Registration required	Qualification	Competency
Occupational therapy	Occupational Therapy Board	PG cert in PC	Yes
Physiotherapy	Physiotherapy Board	PG cert in PC	Yes
Clinical pharmacist	Pharmacy Council	PG cert in PC	Yes
Speech-language therapy	New Zealand Speech-Language Therapists' Association (not covered by HPCA)	PG cert in PC	Yes
Dietician	Dieticians Board	PG cert in PC	Yes

### Hospice services could offer, depending on local community needs:

It is widely acknowledged that the provision of day programme, group support, supportive therapies and a range of other services greatly contributes to the care provided to a patient and their family and whānau. However, due to financial and human resource limitations there are often challenges involved in providing these therapies. Therefore where possible, a hospice could choose to offer:

- Hospital in-reach services, multidisciplinary with psychosocial and spiritual care components
- Day programme and therapies
- Group support for patients, carers, families, etc
- Family carer information and bereavement services, etc
- Complementary therapies.

### Specific expertise/roles and their competencies may include:

**Music therapy**

**Art therapy**

**Massage therapy**

**Aroma therapy**

Hospices who offer complementary therapies will ensure these services are delivered by qualified and registered staff, with competencies in palliative care. Hospices may encourage staff to undertake palliative care specific qualifications and these staff would then be specialist in their respective role.

### Regional collaboration for service provision

Looking to the future, with increased demand on services and funding constraints, it is not realistic or necessary for each hospice to provide all services to their communities.

The sharing of services through a regional collaborative approach/network will ensure all patients and families receive care and support through effective partnerships amongst hospice providers.

Within this model, hospices may collaborate on:

- standardised policies and audit processes
- shared medical specialists
- shared quality systems, clinical leadership support
- centralised administration, technology, and other backroom functions.

The cornerstones of regional collaboration:

- The configuration of services will require strong governance
- A strong caution against another layer of bureaucracy
- Flexible services to meet community needs
- Cannot impact on community funding or support
- Community relationships remain vital to the local hospice.

The model could be described as follows: (Note: Hospices x, a, z, b and y are situated within one region.)

An example of a regional collaborative network			
	Services:	Services:	Services:
	<ul style="list-style-type: none"> <li>• Community palliative care services</li> <li>• Advanced assessment and care planning</li> <li>• Care coordination/case management</li> <li>• Liaison</li> <li>• Education</li> <li>• Bereavement support</li> <li>• End of life care pathway</li> <li>• Quality improvement</li> <li>• Clinical data collection</li> <li>• Effective governance and leadership</li> <li>• Volunteer management and systems</li> <li>• Responsible fundraising</li> </ul>	<ul style="list-style-type: none"> <li>• Inpatient care</li> <li>• Equipment</li> <li>• Respite</li> <li>• Home help, personal cares</li> <li>• 24/7 medical and nursing advice and care</li> <li>• Paediatric and young person palliative care</li> <li>• Specialist teams</li> <li>• Interpreter services, including deaf interpreter</li> </ul>	<ul style="list-style-type: none"> <li>• Hospital in-reach (or there will be a Hospital Palliative Care Team in place)</li> <li>• Day programme</li> <li>• Group support</li> <li>• Family carer education, rehabilitation, etc</li> </ul>
Local hospice x	Will have	Will have access to	May offer
Local hospice a	Will have	Will have access to	Do offer
Regional hospice z	Will have	Will have	Will have
Local hospice b	Will have	Will have access to	Do offer
Local hospice y	Will have	Have	May offer

## Where to from here – for Hospice New Zealand and members?

There is a need for local and regional impacts to be identified prior to any new models, agreements or partnerships being established. Hospice NZ and members will participate in Ministry of Health service planning and funding model development. Additionally, stemming from the hospice capability development and consultation process, we have multiple areas for future discussion and development. These can be broadly grouped into five areas:

### Core services definition

1. Defining what is meant by each of the core clinical and non-clinical functions as listed in the hospice capability recommendations above, so that there is a shared understanding and standard across all hospice services

## **Competency definition**

2. Describing the levels of psychosocial competency required for all staff, those carrying out advanced assessment and lead psychosocial professionals
3. Clearly identifying where one role of expertise finishes and where access and referral to another expert is required
4. Development of allied health and psychosocial palliative care competencies
5. Development of spiritual care competencies
6. Development of 'all staff' and 'expert staff' guidelines for cultural competencies
7. Development of agreed quality capability and competencies

## **Volunteer support**

8. Development of an agreed description of volunteer functions and roles, defining how these hospice services work alongside all palliative care
9. Development of competencies for managers of volunteer services

## **Qualifications development**

10. Partner with HWNZ and universities to develop training options for all hospice professions
11. Defining 'equivalent' post graduate qualifications

## **Palliative care as part of the wider health sector**

12. Defining how hospice services work alongside all palliative care providers and describing how hospice services are integrated into the whole population health sector.

## **Abbreviations used in this document**

ANZASW: Australia New Zealand Association of Social Workers

CNE: clinical nurse educator

CNS: clinical nurse specialist

EN: enrolled nurse

FTE: full time equivalent

GP: general practitioner

HCA: health care assistant

HPCA: Health Practitioner Competency Act

HWNZ: Health Workforce New Zealand

IPU: inpatient unit

MCNZ: Medical Council New Zealand

MOSS: Medical Officer Special Scale

NZAC: New Zealand Association of Counsellors

PC: palliative care

PDRP: professional development and recognition programme

PG: post graduate

PM: palliative medicine

RACP: Royal Australian College of Physicians

RN: registered nurse

SWRB: Social Worker Registration Board

TL: team leader



## The background to this project

Hospice NZ identified the need for a framework that clearly defined all services that should be offered by hospices, and the staffing skills and experience required to deliver these services.

This was endorsed at a membership and governance level of the organisation.

The project was overseen by a specifically convened governance group, with a separate working group contributing their time and expertise.

### Hospice Capability Governance Group

Mary Schumacher (Chair)	Hospice NZ CEO
Rod MacLeod	Honorary Clinical Professor, University of Auckland, and Palliative Care Development Manager, Hospice North Shore
Kevin Nielsen	Hospice Taranaki CEO
Peter McIntyre	Hospice NZ board member, Otago Community Hospice board member
Jan Nichols	Mercy Hospice CEO

### Hospice Capability Working Group

Suzie Kuper	Lake Taupo Hospice	Nursing representative
Karen Talbot	Hospice West Auckland	Nursing representative
Paul Ranby	Arohanui Hospice	Psychosocial representative
Clare Greensmith	Otago Community Hospice	Allied health representative
Diane Greenwood-Havea	Te Omanga Hospice	Psychosocial representative
Marion Taylor	Hospice Wanganui	GPwSI representative
Brian Ensor	Mary Potter Hospice	Medical specialist representative
Deb Peters	PCAG	Consumer representative
Wayne Naylor	Cancer Control Council	Senior analyst
Richard Thurlow	Waipuna Hospice	CEO representative

The first work of the governance group was to clarify the scope of this project. Additionally, they assisted the project team to further identify risks, assumptions and interdependencies that might impact on the project. The working group developed the core service description, identified the professional qualification and recommended palliative care competency specific to their specialist role.

## Appendix 5: Hospital Palliative Care Service Capability Framework

### Introduction

The strategic vision for palliative care in New Zealand is that ‘all people who have a life limiting illness, and their family/whānau, who could benefit from palliative care have timely access to quality palliative care that is culturally appropriate and provided in a co-ordinated way’.<sup>9</sup> In order to achieve this vision, there are three key long term outcomes that the palliative care sector and wider health sector must work towards. These are:

1. Access to palliative care regardless of setting.
2. All palliative care providers are configured to ensure a seamless care pathway.
3. Palliative care provision is high quality.

These outcomes are important because together they constitute the things that are necessary to achieve the palliative care strategic vision. Achieving these longer term outcomes will require a number of system level approaches that result in changes to important short-term outcomes.

The system level areas that need to be addressed include: sufficient capacity (workforce, services and infrastructure), appropriate referrals (awareness of palliative care referral processes, palliative care principles are understood), *continuity and coordination of care* (palliative care is integrated throughout the health sector, palliative care services/providers are coordinated with each other), *best practice is followed* (standards for palliative care service provision are met, inter-disciplinary team approach to palliative care), and *palliative care meets the needs of the patient, their family and whānau* (needs of specific population groups are met, culturally appropriate care, effective treatments and support).<sup>9</sup>

This document, the *Hospital Palliative Care Service Capability Framework*, has been developed to give direction to hospital palliative care services (HPCS), other palliative care service providers, District Health Boards, the Ministry of Health and the wider health sector, on how hospital palliative care services should be configured to achieve the vision for palliative care. The framework has attempted to address each of the system level outcomes by detailing what is expected of a highly functional HPCS in terms of workforce, resources and infrastructure, clinical and non-clinical functions and key working relationships.

### Background

In 2001, the New Zealand Palliative Care Strategy identified the need for hospital palliative care services and recommended the establishment of Hospital Palliative Care Services in all hospitals.<sup>10</sup> It was recognised then that many people were dying in hospitals without ready access to palliative care. Current mortality data shows that this continues to be the case with approximately one-third of all deaths in New Zealand occurring in hospital.<sup>11</sup> Many of these deaths are sudden and unexpected, but there are a large number where death can be expected and where palliative care would be of benefit. An analysis of mortality data from 2005-2007 estimated that around 57% of all deaths in New Zealand (15,724 individuals) could have benefited from palliative care. Of this estimate group, 47% of adult deaths and 78% of deaths in 0–19 year olds occurred in hospital. These figures suggest that the need for palliative care is present to a high level in the hospital

<sup>9</sup> Palliative Care Council of New Zealand. 2012. *Measuring What Matters: Palliative care*. Wellington: Cancer Control New Zealand.

<sup>10</sup> Ministry of Health. 2001. *The New Zealand Palliative Care Strategy*. Wellington: Ministry of Health.

<sup>11</sup> Palliative Care Council. 2011. *National Health Needs Assessment for Palliative Care: Phase 1 report: Assessment of palliative care need*. Wellington: Cancer Control New Zealand.

setting. In addition, people who would benefit from palliative care and who die in hospital are more likely to be Māori or Pacific people (or other ethnic minority), come from a more deprived area, and have a non-cancer diagnosis.

One of the key aspects of a HPCS is enhancing the capability and capacity of primary palliative care providers (ie, those health care providers that deliver palliative care as a component of their service, but their substantive work is not in the care of people who are dying) to ensure they can deliver high quality palliative care within the limits of their knowledge and ability. The HPCS also provides specialist palliative care when the needs of a patient/family exceed the capability of the patient's principle care team. To achieve this dual role, HPCS provide advice on symptom management, patient, carer and staff support, technical expertise, and bereavement support. Their involvement with individual patients may range from giving advice and information to the patient's principal care team, conducting patient consultation and assessment, offering short-term interventions, or providing complex ongoing care.<sup>12</sup> The HPCS provides multidisciplinary education, both formal and informal, through one-to-one encounters, ward rounds, study days, courses and formal lectures. A HPCS should also be involved in audit and research within a framework of clinical governance and provide strategic direction to their employing DHB in relation to palliative care.<sup>13</sup>

## Framework development

The Ministry of Health is developing a national Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand. The purpose of the Framework is to 'provide guidance to health service providers, funders and policy makers to inform planning and strategic development of palliative care services'.<sup>14</sup> This includes the resources and capability required to support service delivery. As a result of this work, Hospital Palliative Care New Zealand identified the need to clearly articulate what a Hospital Palliative Care Service is in New Zealand from the perspective of the services themselves. This Framework is intended to set a minimum standard for hospital palliative care service provision in New Zealand, and also to inform the Ministry's Resource and Capability Framework project.

The Palliative Care Council (PCC) offered to support HPCNZ with this piece of work by providing secretariat support, and invited HPCNZ to a meeting to begin developing a hospital palliative care capability framework. A call for members of HPCNZ to form a working party and participate in this meeting was made to the HPCNZ membership. Four representatives from HPCNZ agreed to sit on the working group along with Dr Kate Grundy, Chair of PCC, and staff from the Palliative Care Council and Ministry of Health.

<sup>12</sup> National Council for Palliative Care. 1996. *Palliative Care in the Hospital Setting (Occasional Paper 10)*. London: National Council for Palliative Care.

<sup>13</sup> NHS Scotland. 2002. *Clinical Standards: Specialist palliative care*. Edinburgh: Clinical Standards Board for Scotland.

<sup>14</sup> Ministry of Health. 2012. *Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand: Consultation document*. Wellington: Ministry of Health.

## Hospital Palliative Care Service Capability Framework Project Working Group

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The working group identified the core workforce, functions (clinical and non-clinical) and essential working relationships required for a HPCS, including staff qualifications. These are referred to as the '**will have**' components of the framework.

There are a number of staff members and functions and facility requirements that are not always a part of the core HPCS, but which the service regularly requires access to and support from; these are referred to as the '**will have access to**' components of the framework.

Given the diversity of HPCS configurations, service delivery models and funding streams, the Working Group also identified a number of service components that a HPCS '**could offer**', including other specialist staff positions.

An underlying principle of the framework is that Hospital Palliative Care Services are delivered by a specialist interdisciplinary team to meet the needs of all patients who are referred and their family/whānau. Education and staff support are also essential functions.

The draft Framework was sent to the Hospital Palliative Care New Zealand (HPCNZ) membership for consultation and was then discussed at a national meeting of HPCNZ on 25 May 2012. This meeting resulted in further refinement of the Framework.

## Hospital Palliative Care Service Capability Framework

While the Framework describes a minimum standard for a HPCS, it is recognised that many services are not currently configured or resourced in line with the Framework and so a realistic time-frame will need to be set for these services to develop to an appropriate level. This will need to be accompanied by a commitment from DHBs to invest in service development and ongoing resourcing.

In addition, HPCS need to be configured and resourced at an appropriate level to meet local need, and they may not need to provide all components of the Capability Framework. For example, a HPCS in a smaller provincial hospital may have some components provided by a regional HPCS; for example, 24/7 telephone advice, and may not require full time staff.

**It is recommended that hospital palliative care services should be configured as follows:**

Hospital Palliative Care Services **will have**:

### Staff

- Specialist nursing
- Specialist medical
- Administration/data management.

## **Clinical functions**

- Five-day on-site service (with after-hours telephone cover)
- Consultation, advice, and liaison with referring team (MDT)
- Advanced assessment (initial and ongoing) and care planning – medical, nursing, psychosocial, spiritual
- Liaison – community (primary care), aged care, hospital teams, hospice (inpatient and community services), pain services
- Input into family meetings
- Input into discharge planning
- Input into advance care planning
- Input into end-of-life care pathway implementation.

## **Non-clinical functions**

These functions are considered critical to enhancing the knowledge and skills of primary palliative care providers and ensuring leadership and strategic direction for palliative care.

- Clinical education – both formal/structured and informal
- Supervision/training (medical and nursing)
- Leadership and strategic planning
- Quality improvement
- Research/audit
- Clinical data collection
- Access to clinical supervision
- Appropriate networks and engagement (local, regional and national).

## **Effective working relationships with:**

- Other specialist palliative care services (within DHB and beyond as required)
- Bereavement support services
- Hospital medical and nursing staff
- Allied health staff (eg, social workers, physiotherapists, occupational therapists, chaplaincy and spiritual support services)
- Liaison psychiatry, psych-oncology services
- Pain Service – acute and chronic
- Specialist teams – oncology, children and young people services, mental health services, renal, cardiac and respiratory services, health of older people services, wound, disability services, etc.
- Discharge coordinator
- Other services as appropriate to ensure good patient/family/whānau outcomes.

Hospital Palliative Care Services will not always offer directly but **will have access to:**

- Private/quiet spaces for consultations and family meetings
- Single rooms for dying or distressed patients/family
- Interventional pain services/techniques
- Paediatric specialist palliative care support/advice
- Hospice inpatient care
- Residential care beds
- Equipment.

### **Staff**

- Physiotherapy
- Occupational therapy
- Speech-language therapy
- Dietetics
- Pharmacy and clinical pharmacology
- Cultural liaison
- Interpreter services.

Hospital Palliative Care Services **could offer:**

- Inpatient care (ie, dedicated inpatient palliative care beds)
- Outpatient clinics
- On-site after-hours services
- Family carer education, rehabilitation
- Public education
- Complementary therapists – including art, music, massage, aromatherapy, etc.

### **Hospital Palliative Care Services could also include the following staff:**

These roles are particularly important in HPCSs with a high level of need, such as a tertiary level hospital with a cancer centre. These 'high need' services would be expected to at least include the roles marked '\*'.

- Registrar/Palliative Medicine Advanced Trainee\*
- Nurse Practitioner/Nurse Practitioner candidate\*
- Clinical Psychologist\*
- Specialist Palliative Care Social Worker\*
- End-of-life care pathway facilitator\*
- Bereavement support worker
- Palliative Care Nurse Specialist Trainee
- Advance Care Planning facilitator.

## Staff qualifications and competencies required in a Hospital Palliative Care Service

### Nursing

Position	Registration required	Relevant qualification(s)	PDRP level
Nurse Practitioner™	NCNZ	Masters	n/a
Senior Nurse / CNS	NCNZ	PG Diploma	Expert
RNs	NCNZ	PG cert in PC	Proficient – expert

Senior nurse/CNS – competencies plus qualification, minimum PG Diploma (PC endorsement), preferably Masters

RNs – all will have relevant qualifications (PG cert in PC) and be proficient/expert

Nurse Educator and LCP/End of Life care pathway facilitator will be at least RN with PG Cert in PC

RN PDRP levels – graduate, competent, proficient, expert

(Levels of competence should be based on the National Professional Development Framework for Palliative Care Nursing in Aotearoa New Zealand)

### Medical

Position	Registration required	Relevant qualification(s)
Palliative Medical Specialist	MCNZ Vocational Registration in Palliative Medicine	FRACP, FACHPM (or equivalent)
Registrar / Palliative Medicine Advance Trainee	MCNZ	MBChB
MOSS / General Practitioner	MCNZ	Clinical Diploma in Palliative Medicine

Some services may employ a House Surgeon as well as a Registrar.

### Allied Health

Position	Registration required	Relevant qualification(s)
Occupational Therapy	Occupational Therapy Board	Not applicable as allied health are employed by other services. If employed specifically by a HPCS then they require a PG Cert in PC.
Physiotherapy	Physiotherapy Board	
Clinical Pharmacist	Pharmacy Council	
Speech-Language Therapy	New Zealand Speech-Language Therapists' Association (not covered by HPCA)	
Dietician	Dieticians Board	
Cultural liaison	None exist	

## Psychosocial

Position	Registration required	Relevant qualification(s)
Social work	Social Workers Registration Board (SWRB)	Not applicable as allied health are employed by other services. If employed specifically by a HPCS then they require a PG Cert in Palliative Care.
Counselling	New Zealand Association of Counsellors (NZAC – application with HPCA)	
Spiritual care	None exist	

Notes:

PG cert in PC = Postgraduate Certificate in Palliative Care

HPCA = Health Practitioners Competence Assurance Act 2003



## Appendix 6: Deprivation modifier calculations

DHB region	All deaths per 100,000 (mid-range 2006)	Index value	Deprivation modifier	Modified index value	DHB need index value	Effect on resource need	2011 projected population	2011 weighted population	Ideal share of resources based on weighted population
Northland	650	85.6	1.68	144	261	+161%	113,550	296,254	5.6%
Waitemata	455	59.9	1.00	60	109	+9%	394,620	429,389	8.2%
Auckland	426	56.1	1.32	74	134	+34%	349,080	469,190	8.9%
Counties Manukau	437	57.6	1.57	90	164	+64%	337,420	552,161	10.5%
Waikato	559	73.6	1.38	102	185	+85%	260,910	482,042	9.2%
Lakes	552	72.7	1.58	115	208	+108%	72,510	150,649	2.9%
Bay of Plenty	668	88.0	1.61	142	257	+157%	154,730	396,892	7.5%
Tairāwhiti	704	92.8	2.00	185	335	+235%	31,810	106,696	2.0%
Hawke's Bay	715	94.2	1.39	131	237	+137%	110,710	262,910	5.0%
Taranaki	647	85.2	1.28	109	197	+97%	79,530	156,755	3.0%
Midcentral	620	81.7	1.29	105	191	+91%	122,070	232,890	4.4%
Whanganui	720	94.9	1.66	157	285	+185%	45,890	130,642	2.5%
Capital & Coast	411	54.2	1.02	55	100	+0%	221,400	221,400	4.2%
Hutt	530	69.8	1.23	86	155	+55%	103,230	160,155	3.0%
Wairarapa	598	78.8	1.21	96	173	+73%	29,780	51,533	1.0%
Nelson Marlborough	586	77.2	1.08	83	151	+51%	104,830	158,321	3.0%
West Coast	601	79.2	1.33	105	191	+91%	24,680	47,139	0.9%
Canterbury	559	73.6	1.02	75	136	+36%	380,120	516,275	9.8%
South Canterbury	759	100.0	1.07	107	194	+94%	42,420	82,353	1.6%
Otago	673	88.7	1.05	93	169	+69%	143,870	243,617	4.6%
Southland	552	72.7	1.08	79	142	+42%	83,800	119,224	2.3%
							<b>3,206,960</b>	<b>5,266,488</b>	<b>100%</b>

Based on 2006 Census data (NZDep2006)

## Appendix 7: Age of hospice patients compared to mid-range estimate age groups, by DHB

DHB	Age (years)								
	0–9	10–19	20–29	30–39	40–49	50–59	60–69	70–79	80+
<b>Proportion of all hospice patients (n = 12,636)</b>	<b>0.3%</b>	<b>0.7%</b>	<b>0.8%</b>	<b>1.7%</b>	<b>5.9%</b>	<b>11.8%</b>	<b>20.6%</b>	<b>29.1%</b>	<b>29.2%</b>
<b>Proportion of mid-range estimate group</b>	<b>1.3%</b>	<b>0.4%</b>	<b>0.6%</b>	<b>1.3%</b>	<b>3.7%</b>	<b>8.2%</b>	<b>15.1%</b>	<b>26.0%</b>	<b>43.3%</b>
Northland	0.6%	0.2%	0.8%	1.7%	6.6%	15.4%	22.1%	28.0%	24.7%
	1.3%	0.5%	0.8%	1.4%	4.3%	9.8%	16.7%	28.0%	37.2%
Waitemata	0.3%	0.1%	0.7%	1.5%	5.5%	11.4%	23.1%	25.0%	32.3%
	1.1%	0.4%	0.6%	1.5%	4.0%	8.1%	14.7%	23.9%	45.7%
Auckland	0.0%	0.1%	0.5%	2.4%	7.2%	11.6%	16.0%	44.1%	18.1%
	1.6%	0.4%	0.6%	1.5%	4.0%	8.2%	13.5%	21.6%	48.5%
Counties Manukau	0.0%	0.1%	1.1%	2.0%	6.4%	13.0%	23.9%	28.4%	25.1%
	2.7%	0.5%	1.0%	2.4%	5.4%	10.3%	18.0%	24.9%	34.9%
Waikato	2.4%	1.7%	0.9%	1.7%	5.3%	10.4%	21.0%	28.2%	28.4%
	1.7%	0.5%	0.8%	1.3%	4.3%	8.6%	16.3%	25.1%	41.4%
Lakes	0.0%	0.0%	0.0%	0.9%	5.5%	10.0%	22.4%	25.6%	35.6%
	1.7%	0.4%	0.9%	2.0%	5.0%	9.4%	18.7%	26.6%	35.4%
Bay of Plenty	0.3%	0.7%	0.9%	1.1%	3.7%	11.0%	20.9%	28.0%	33.3%
	1.3%	0.3%	0.5%	1.0%	3.5%	7.8%	15.4%	27.2%	43.0%
Tairāwhiti	0.0%	0.0%	0.7%	2.1%	6.2%	12.4%	19.3%	31.0%	28.3%
	1.4%	0.8%	0.6%	1.6%	4.3%	8.9%	19.1%	28.9%	34.3%
Hawke's Bay	0.0%	0.2%	0.2%	0.8%	3.8%	7.6%	22.9%	24.8%	39.6%
	1.2%	0.4%	0.4%	1.4%	4.1%	8.5%	14.7%	26.9%	42.3%
Taranaki	0.2%	0.0%	0.4%	1.0%	2.9%	5.6%	15.3%	24.2%	50.4%
	0.8%	0.6%	0.5%	1.2%	4.2%	8.3%	14.7%	27.9%	41.8%

DHB	Age (years)								
	0–9	10–19	20–29	30–39	40–49	50–59	60–69	70–79	80+
MidCentral	0.0%	0.0%	1.0%	1.0%	4.2%	10.9%	17.0%	26.5%	39.5%
	1.0%	0.7%	0.4%	1.0%	2.8%	6.9%	14.0%	27.0%	46.2%
Whanganui	0.0%	0.5%	0.5%	0.5%	2.8%	7.4%	19.0%	36.1%	33.3%
	0.5%	0.5%	0.9%	1.4%	2.8%	8.1%	14.9%	27.5%	43.3%
Capital & Coast	0.0%	0.5%	0.5%	0.9%	3.7%	10.1%	19.4%	28.5%	36.4%
	1.7%	0.4%	0.7%	1.4%	3.2%	7.9%	15.1%	26.1%	43.6%
Hutt Valley	0.7%	0.0%	0.2%	1.5%	5.4%	12.3%	19.3%	27.4%	33.1%
	1.0%	0.3%	1.0%	1.7%	3.5%	9.6%	13.6%	26.0%	43.3%
Wairarapa	0.0%	0.0%	12.5%	6.3%	12.5%	6.3%	62.5%	0.0%	0.0%
	0.6%	0.6%	0.6%	0.4%	4.0%	6.1%	12.9%	31.9%	43.0%
Nelson Marlborough	0.4%	0.4%	0.4%	0.6%	6.0%	10.2%	20.2%	24.8%	36.9%
	1.0%	0.5%	0.5%	0.7%	3.9%	8.3%	14.5%	26.4%	44.2%
West Coast	nk	nk	nk	nk	nk	nk	nk	nk	nk
	1.0%	0.7%	0.5%	0.7%	2.7%	6.7%	18.6%	28.4%	40.7%
Canterbury	0.4%	2.3%	1.5%	2.6%	8.1%	14.9%	22.1%	24.1%	24.0%
	0.7%	0.3%	0.6%	1.0%	3.1%	7.2%	13.7%	26.2%	47.2%
South Canterbury	0.0%	0.0%	0.0%	0.6%	4.5%	11.5%	18.5%	23.6%	41.4%
	0.8%	0.8%	0.2%	0.6%	2.0%	5.9%	13.9%	28.0%	48.0%
Otago	0.6%	0.0%	0.0%	0.3%	5.1%	11.0%	20.2%	33.7%	29.2%
	0.9%	0.2%	0.4%	0.7%	2.6%	6.5%	14.6%	26.8%	47.4%
Southland	0.0%	0.7%	0.7%	1.1%	3.5%	11.9%	25.6%	28.4%	28.1%
	1.2%	0.5%	0.8%	1.5%	3.2%	8.1%	15.1%	30.3%	39.3%

## Appendix 8: Ethnic group proportions for hospice patients compared to mid-range estimate group, by DHB

DHB	European <sup>(1)</sup>	Māori	Pacific peoples <sup>(2)</sup>	Chinese Asian	Indian Asian	Other Asian	MELAA <sup>(3)</sup>	Other / not elsewhere included <sup>(4)</sup>	Total patients
<b>Proportion of all hospice patients</b>	<b>75.5%</b>	<b>10.0%</b>	<b>3.9%</b>	<b>1.5%</b>	<b>0.6%</b>	<b>0.4%</b>	<b>0.5%</b>	<b>7.5%</b>	<b>12,064</b>
<b>Proportion of mid-range estimate group</b>	<b>83.9%</b>	<b>9.8%</b>	<b>3.6%</b>	<b>0.9%</b>	<b>0.6%</b>	<b>0.6%</b>	<b>0.2%</b>	<b>0.3%</b>	
Northland	72.4%	25.2%	0.8%	0.2%	0%	0.6%	0.4%	0.4%	<b>890</b>
	73.3%	25.3%	0.9%	0.1%	0.1%	0.1%	0.1%	0.1%	
Waitemata	84.7%	4.2%	5.4%	1.4%	0.8%	1.4%	0.6%	1.5%	<b>1037</b>
	85.5%	5.7%	4.6%	1.3%	0.7%	1.4%	0.5%	0.3%	
Auckland	74.1%	4.7%	9.8%	5.9%	2.9%	1.3%	0.8%	0.7%	<b>1311</b>
	75.3%	6.0%	11.6%	3.2%	1.9%	1.1%	0.7%	0.1%	
Counties Manukau	55.9%	17.0%	21.5%	4.7%	0.1%	0%	0%	0.8%	<b>771</b>
	64.1%	13.8%	15.7%	2.2%	2.3%	1.4%	0.4%	0%	
Waikato	69.9%	16.8%	2.3%	0.1%	0.4%	0.5%	0.4%	9.6%	<b>752</b>
	82.1%	15.0%	1.3%	0.3%	0.5%	0.5%	0.2%	0.2%	
Lakes	77.2%	19.6%	2.3%	0%	0.9%	0%	0%	0%	<b>219</b>
	71.6%	25.8%	1.6%	0.1%	0.3%	0.4%	0.1%	0.3%	
Bay of Plenty	71.6%	21.7%	0.7%	0.1%	0.3%	0.1%	0%	5.4%	<b>700</b>
	82.5%	16.0%	0.5%	0.1%	0.4%	0.2%	0%	0.3%	
Tairāwhiti	66.9%	33.1%	0%	0%	0%	0%	0%	0%	<b>145</b>
	61.3%	37.1%	0.6%	0.3%	0.2%	0%	0.5%	0%	
Hawke's Bay	72.9%	14.0%	1.3%	0.4%	0%	0%	0.4%	11.0%	<b>472</b>
	82.3%	14.8%	1.3%	0.4%	0.3%	0.3%	0.2%	0.4%	
Taranaki	88.8%	10.6%	0.2%	0%	0%	0.4%	0%	0%	<b>509</b>
	90.4%	8.9%	0.3%	0.2%	0.1%	0%	0%	0%	

DHB	European <sup>(1)</sup>	Māori	Pacific peoples <sup>(2)</sup>	Chinese Asian	Indian Asian	Other Asian	MELAA <sup>(3)</sup>	Other / not elsewhere included <sup>(4)</sup>	Total patients
MidCentral	86.6%	9.8%	1.4%	0.2%	0%	0%	0%	2.0%	<b>500</b>
	90.2%	7.8%	0.5%	0.8%	0.2%	0.2%	0%	0.2%	
Whanganui	82.9%	15.0%	1.1%	0.5%	0%	0%	0%	0.5%	<b>187</b>
	82.6%	16.8%	0.3%	0.1%	0.1%	0%	0%	0.1%	
Capital & Coast	72.4%	7.7%	6.8%	4.2%	1.8%	0%	7.1%	0%	<b>547</b>
	82.0%	5.5%	5.7%	1.5%	1.0%	0.9%	0.5%	2.9%	
Hutt Valley	83.3%	10.9%	3.1%	1.4%	1.0%	0.2%	0%	0%	<b>414</b>
	83.5%	8.9%	4.3%	1.1%	0.7%	0.7%	0.1%	0.8%	
Wairarapa	100.0%	0%	0%	0%	0%	0%	0%	0%	<b>6</b>
	90.1%	8.1%	0.8%	0.8%	0%	0%	0%	0.2%	
Nelson Marlborough	91.0%	5.0%	0.4%	0.2%	0%	0%	0%	3.3%	<b>480</b>
	95.8%	3.4%	0.4%	0.1%	0.1%	0.2%	0%	0%	
West Coast	nk	nk	nk	nk	nk	nk	nk	nk	<b>nk</b>
	94.5%	5.0%	0.2%	0%	0%	0.2%	0%	0%	
Canterbury	68.4%	1.8%	0.9%	0.6%	0.2%	0.3%	0.04%	27.7%	<b>2,335</b>
	94.8%	3.1%	0.8%	0.4%	0.1%	0.5%	0.2%	0.1%	
South Canterbury	98.1%	1.3%	0%	0.6%	0%	0%	0%	0%	<b>157</b>
	98.1%	1.6%	0.1%	0.1%	0%	0.1%	0%	0%	
Otago	96.1%	1.4%	0.3%	0.3%	0.3%	0.3%	0%	1.4%	<b>356</b>
	96.6%	2.1%	0.4%	0.5%	0.1%	0.2%	0.1%	0%	
Southland	82.6%	6.5%	0%	0%	0%	0%	0%	10.9%	<b>276</b>
	92.9%	5.9%	0.9%	0.1%	0.1%	0%	0.2%	0.1%	

nk = not known due to no data provided.

## Appendix 9: Diagnostic group of hospice patients compared to mid-range estimate group, by DHB

DHB	Cancer	Cardio-vascular	HIV/AIDS	Renal failure	Neurological disease	Respiratory disease	Other non-cancer	Total patients
<b>Proportion of all hospice patients</b>	<b>78.8%</b>	<b>5.8%</b>	<b>0.1%</b>	<b>2.2%</b>	<b>3.7%</b>	<b>4.3%</b>	<b>5.0%</b>	<b>11,623</b>
<b>Proportion of mid-range estimate group</b>	<b>42.1%</b>	<b>26.8%</b>	<b>0.1%</b>	<b>2.5%</b>	<b>5.9%</b>	<b>9.1%</b>	<b>13.6%</b>	
Northland	72.5%	8.8%	0.0%	3.8%	3.7%	5.9%	5.4%	<b>904</b>
	41.6%	25.7%	0.0%	3.9%	4.9%	9.1%	14.7%	
Waitemata	84.6%	3.7%	0.0%	2.7%	3.0%	4.0%	2.0%	<b>1000</b>
	42.7%	26.8%	0.0%	2.8%	6.8%	7.8%	13.0%	
Auckland	84.0%	4.1%	0.4%	2.2%	2.5%	3.3%	3.6%	<b>1254</b>
	38.1%	28.4%	0.2%	2.8%	7.4%	8.9%	14.2%	
Counties Manukau	86.1%	4.3%	0.0%	3.8%	1.9%	3.5%	0.4%	<b>927</b>
	43.7%	24.1%	0.0%	3.1%	5.3%	8.4%	15.4%	
Waikato	84.3%	4.5%	0.0%	2.1%	2.1%	2.7%	4.2%	<b>662</b>
	44.0%	25.1%	0.0%	2.3%	5.4%	8.8%	14.3%	
Lakes	81.3%	7.8%	0.0%	2.7%	2.7%	0.0%	5.5%	<b>219</b>
	44.4%	24.7%	0.2%	2.7%	3.8%	9.9%	14.4%	
Bay of Plenty	83.2%	5.6%	0.0%	3.1%	2.5%	3.8%	1.8%	<b>677</b>
	44.2%	25.5%	0.0%	2.8%	5.8%	9.1%	12.6%	
Tairāwhiti	66.2%	3.4%	0.0%	3.4%	10.3%	8.3%	8.3%	<b>145</b>
	38.8%	28.5%	0.2%	2.7%	4.3%	8.7%	16.9%	
Hawke's Bay	69.8%	5.5%	0.0%	2.3%	5.7%	3.2%	13.5%	<b>474</b>
	40.4%	29.1%	0.0%	3.1%	4.7%	8.1%	14.5%	
Taranaki	61.7%	13.6%	0.0%	0.0%	2.4%	6.1%	16.3%	<b>509</b>
	43.2%	29.1%	0.1%	3.0%	3.4%	9.2%	12.1%	

DHB	Cancer	Cardio-vascular	HIV/AIDS	Renal failure	Neurological disease	Respiratory disease	Other non-cancer	Total patients
MidCentral	74.6%	8.2%	0.0%	2.8%	0.8%	2.0%	11.6%	<b>500</b>
	41.3%	28.5%	0.0%	1.7%	5.7%	9.6%	13.1%	
Whanganui	73.8%	7.0%	0.0%	4.8%	1.6%	10.2%	2.7%	<b>187</b>
	40.4%	31.6%	0.1%	2.0%	4.6%	10.2%	11.2%	
Capital & Coast	76.8%	6.4%	0.0%	1.6%	4.8%	5.3%	5.1%	<b>547</b>
	40.0%	26.4%	0.1%	2.8%	7.4%	9.2%	14.1%	
Hutt Valley	71.7%	4.0%	0.2%	2.3%	4.9%	3.7%	13.1%	<b>427</b>
	39.6%	25.6%	0.1%	3.1%	6.7%	9.7%	15.1%	
Wairarapa	75.8%	4.8%	0.0%	3.2%	0.0%	11.3%	4.8%	<b>62</b>
	40.0%	26.3%	0.0%	2.2%	4.8%	11.1%	15.6%	
Nelson Marlborough	66.9%	11.7%	0.0%	2.3%	4.4%	9.0%	5.8%	<b>480</b>
	43.9%	25.5%	0.1%	1.7%	6.9%	9.2%	12.6%	
West Coast*	nk	nk	nk	nk	nk	nk	nk	<b>nk</b>
	41.4%	24.8%	0.2%	1.9%	7.0%	10.1%	14.5%	
Canterbury	81.3%	5.1%	0.1%	1.3%	7.1%	2.8%	2.4%	<b>1884</b>
	42.9%	27.6%	0.0%	1.4%	6.1%	9.6%	12.4%	
South Canterbury	87.0%	4.6%	0.8%	0.0%	3.1%	3.1%	1.5%	<b>131</b>
	40.2%	28.3%	0.1%	2.0%	6.9%	8.6%	13.9%	
Otago	88.5%	1.1%	0.0%	0.3%	2.0%	6.2%	2.0%	<b>356</b>
	42.0%	26.5%	0.0%	2.4%	5.8%	9.9%	13.3%	
Southland	74.1%	4.7%	0.4%	0.0%	3.6%	10.1%	7.2%	<b>278</b>
	44.5%	26.7%	0.0%	2.6%	4.8%	9.3%	12.1%	

nk = not known due to no data provided.

## Appendix 10: HPCS Capability Framework components available in each DHB with an HPCS

HPCNZ capability functions and roles			DHB												
			Waitemata	Auckland*	Counties Manukau	Waikato	Hawke's Bay	MidCentral	Capital & Coast	Hutt Valley	Canterbury	Otago	South Canterbury	Southland	
Will have	clinical functions	5 day on-site service	1	1	1	1	1	1	1	1	1	1	1	1	
		After-hours telephone cover	0	1	1	1	1	1	1	1	1	0	1	0	1
		Advanced assessment and care planning	1	1	1	1	1	1	1	1	1	1	1	0	1
		Liaison with primary care, aged care, hospital teams, hospice, pain services	1	1	1	1	1	1	1	1	1	1	1	1	1
		Input into family meetings	1	1	1	1	1	1	1	1	1	1	0	1	1
		Input into discharge planning	1	1	1	1	1	1	1	1	1	1	1	1	1
		Input into advance care planning	1	1	1	1	1	1	1	1	1	1	0	1	1
		Input into end-of-life care pathway implementation	0	1	1	1	1	1	1	1	0	1	1	1	1
	non-clinical functions	Clinical education	1	1	1	1	1	1	1	1	1	1	1	1	1
		Supervision/training (other staff)	1	1	1	1	1	1	1	1	0	1	1	1	0
		Leadership and strategic planning	1	1	1	1	1	1	1	1	1	1	1	1	1
		Quality improvement	1	1	1	1	1	1	1	1	1	1	1	1	1
		Research/audit	1	1	1	1	1	1	1	1	1	1	0	1	0
		Clinical data collection	1	1	1	1	1	1	1	1	1	1	0	1	1
		Access to clinical supervision (HPCS staff)	1	1	1	0	0	0	1	1	1	1	0	0	1
		Appropriate networks and engagement	1	1	1	1	1	1	1	1	1	1	1	1	1



HPCNZ capability functions and roles		DHB											
		Waitemata	Auckland*	Counties Manukau	Waikato	Hawke's Bay	MidCentral	Capital & Coast	Hutt Valley	Canterbury	Otago	South Canterbury	Southland
effective working relationships with	Other specialist palliative care services (within DHB and beyond as required)	1	1	1	1	1	1	1	1	1	1	1	1
	Bereavement support services	0	1	1	1	1	0	0	1	1	1	1	1
	Hospital medical and nursing staff	1	1	1	1	1	1	1	1	1	1	1	1
	Liaison psychiatry, psych-oncology services	1	1	1	1	1	1	1	1	1	1	1	1
	Pain service – acute and chronic	1	0	1	1	1	1	1	1	1	1	1	1
	Specialist teams	1	1	1	1	1	1	1	1	1	1	1	1
	Discharge coordinator	1	0	0	1	0	1	1	1	1	1	1	1
	Other services as appropriate to ensure good patient/family/whānau outcomes	1	1	1	1	1	1	1	1	1	1	1	1
	% of HPCS 'will have' components	88%	92%	96%	96%	92%	92%	96%	92%	96%	79%	88%	92%
Will have access to	Private/quiet spaces for consultations and family meetings	0	0	1	1	0	0	1	0	0	1	0	1
	Single rooms for dying or distressed patients/family	0	0	1	1	1	1	1	0	0	1	0	1
	Interventional pain services/techniques	0	1	1	1	1	1	1	1	1	1	1	1
	Paediatric specialist palliative care support/advice	1	1	1	1	1	1	1	1	1	0	1	1
	Hospice inpatient care	1	1	1	1	1	1	1	1	1	1	1	1
	Residential care beds	1	1	1	1	1	1	1	1	1	1	1	1
	Appropriate equipment	1		1	1	1	1	1	1	1	1	1	1
	% of HPCS 'will have access to' components	57%	57%	100%	100%	86%	86%	100%	71%	71%	86%	71%	100%
Could offer	Outpatient clinics	0	1	1	1	0	0	0	0	1	0	0	0
	On-site after-hours services	0	0	0	1	0	0	0	0	0	1	0	1
	Family carer education, rehabilitation	0	0	0	0	0	0	0	1	0	1	0	0
	Public education	0	0	0	1	0	0	0	0	1	0	0	0
	Complementary therapies	0	0	0	0	0	0	0	0	0	1	0	1
	% of HPCS 'could offer' components	0%	20%	20%	60%	0%	0%	0%	20%	40%	60%	0%	40%

\* Auckland DHB excludes the Paediatric Palliative Care Service.

## Appendix 11: Age of hospital palliative care service patients compared to mid-range estimate age groups, by DHB

DHB	Age (years)								
	0–9	10–19	20–29	30–39	40–49	50–59	60–69	70–79	80+
<b>Proportion of all HPCS patients (n = 6172)</b>	<b>0.05%</b>	<b>0.3%</b>	<b>1.6%</b>	<b>2.2%</b>	<b>6.3%</b>	<b>11.3%</b>	<b>21.7%</b>	<b>25.3%</b>	<b>31.3%</b>
<b>Proportion of mid-range estimate group</b>	<b>1.3%</b>	<b>0.4%</b>	<b>0.6%</b>	<b>1.3%</b>	<b>3.7%</b>	<b>8.2%</b>	<b>15.1%</b>	<b>26.0%</b>	<b>43.3%</b>
Waitemata	0.0%	0.0%	0.2%	0.8%	3.5%	7.6%	23.1%	25.1%	39.8%
	1.1%	0.4%	0.6%	1.5%	4.0%	8.1%	14.7%	23.9%	45.7%
Auckland	0.0%	0.1%	2.5%	4.2%	8.9%	15.9%	21.3%	20.5%	26.6%
	1.6%	0.4%	0.6%	1.5%	4.0%	8.2%	13.5%	21.6%	48.5%
Counties Manukau	0.0%	0.2%	0.5%	1.1%	6.1%	12.9%	23.8%	25.5%	30.0%
	2.7%	0.5%	1.0%	2.4%	5.4%	10.3%	18.0%	24.9%	34.9%
Waikato	0.0%	0.0%	1.4%	2.3%	6.3%	11.7%	24.8%	29.1%	24.4%
	1.7%	0.5%	0.8%	1.3%	4.3%	8.6%	16.3%	25.1%	41.4%
Hawke's Bay	0.2%	0.8%	2.9%	1.0%	10.9%	8.3%	28.8%	25.2%	22.0%
	1.2%	0.4%	0.4%	1.4%	4.1%	8.5%	14.7%	26.9%	42.3%
MidCentral	0.0%	0.0%	0.4%	2.0%	4.8%	9.8%	22.4%	25.1%	35.5%
	1.0%	0.7%	0.4%	1.0%	2.8%	6.9%	14.0%	27.0%	46.2%
Capital & Coast	0.4%	0.8%	1.4%	3.2%	6.4%	11.8%	23.8%	26.0%	26.2%
	1.7%	0.4%	0.7%	1.4%	3.2%	7.9%	15.1%	26.1%	43.6%
Hutt Valley	nk	nk	nk	nk	nk	nk	nk	nk	nk
	1.0%	0.3%	1.0%	1.7%	3.5%	9.6%	13.6%	26.0%	43.3%
Canterbury	0.0%	0.3%	0.8%	1.4%	3.5%	11.7%	16.4%	28.1%	37.8%
	0.7%	0.3%	0.6%	1.0%	3.1%	7.2%	13.7%	26.2%	47.2%
South Canterbury	nk	nk	nk	nk	nk	nk	nk	nk	nk
	0.8%	0.8%	0.2%	0.6%	2.0%	5.9%	13.9%	28.0%	48.0%

DHB	Age (years)								
	0–9	10–19	20–29	30–39	40–49	50–59	60–69	70–79	80+
Otago	0.0%	0.6%	3.2%	1.7%	4.4%	6.3%	14.7%	27.8%	41.3%
	0.9%	0.2%	0.4%	0.7%	2.6%	6.5%	14.6%	26.8%	47.4%
Southland	0.0%	0.0%	0.0%	0.9%	3.5%	12.4%	15.0%	31.0%	37.2%
	1.2%	0.5%	0.8%	1.5%	3.2%	8.1%	15.1%	30.3%	39.3%

nk = not known due to no data provided.

## Appendix 12: Ethnic group proportions for hospital palliative care service patients compared to mid-range estimate group, by DHB

DHB	European <sup>(1)</sup>	Māori	Pacific peoples <sup>(2)</sup>	Chinese Asian	Indian Asian	Other Asian	MELAA <sup>(3)</sup>	Other/not elsewhere included <sup>(4)</sup>	Total patients
<b>Proportion of all HPCS patients</b>	<b>76.5%</b>	<b>9.4%</b>	<b>6.1%</b>	<b>2.5%</b>	<b>1.3%</b>	<b>0.9%</b>	<b>0.5%</b>	<b>2.9%</b>	<b>6140</b>
<b>Proportion of mid-range estimate group</b>	<b>83.9%</b>	<b>9.8%</b>	<b>3.6%</b>	<b>0.9%</b>	<b>0.6%</b>	<b>0.6%</b>	<b>0.2%</b>	<b>0.3%</b>	
Waitemata	73.6%	5.6%	2.6%	3.2%	1.8%	1.6%	0.0%	11.6%	<b>500</b>
	85.5%	5.7%	4.6%	1.3%	0.7%	1.4%	0.5%	0.3%	
Auckland	67.2%	8.9%	12.0%	5.5%	2.7%	2.5%	0.8%	0.4%	<b>1463</b>
	75.3%	6.0%	11.6%	3.2%	1.9%	1.1%	0.7%	0.1%	
Counties Manukau	54.1%	15.0%	21.1%	3.9%	2.3%	0.5%	0.5%	2.5%	<b>560</b>
	64.1%	13.8%	15.7%	2.2%	2.3%	1.4%	0.4%	0.0%	
Waikato	77.0%	16.6%	1.4%	0.8%	0.4%	0.0%	0.4%	3.5%	<b>512</b>
	82.1%	15.0%	1.3%	0.3%	0.5%	0.5%	0.2%	0.2%	
Hawke's Bay	79.5%	18.2%	1.3%	0.2%	0.0%	0.0%	0.0%	0.8%	<b>615</b>
	82.3%	14.8%	1.3%	0.4%	0.3%	0.3%	0.2%	0.4%	
MidCentral	86.8%	10.4%	0.6%	0.6%	0.2%	0.2%	0.8%	0.4%	<b>509</b>
	90.2%	7.8%	0.5%	0.8%	0.2%	0.2%	0.0%	0.2%	
Capital & Coast	77.4%	7.0%	7.0%	4.2%	1.2%	0.4%	1.4%	1.4%	<b>500</b>
	82.0%	5.5%	5.7%	1.5%	1.0%	0.9%	0.5%	2.9%	
Hutt Valley	nk	nk	nk	nk	nk	nk	nk	nk	<b>nk</b>
	83.5%	8.9%	4.3%	1.1%	0.7%	0.7%	0.1%	0.8%	
Canterbury	85.1%	3.5%	1.1%	0.6%	0.3%	0.3%	0.6%	8.6%	<b>712</b>
	94.8%	3.1%	0.8%	0.4%	0.1%	0.5%	0.2%	0.1%	

DHB	European <sup>(1)</sup>	Māori	Pacific peoples <sup>(2)</sup>	Chinese Asian	Indian Asian	Other Asian	MELAA <sup>(3)</sup>	Other/not elsewhere included <sup>(4)</sup>	Total patients
South Canterbury	nk	nk	nk	nk	nk	nk	nk	nk	<b>nk</b>
	98.1%	1.6%	0.1%	0.1%	0.0%	0.1%	0.0%	0.0%	
Otago	94.3%	2.5%	0.9%	0.3%	0.8%	0.3%	0.0%	0.9%	<b>652</b>
	96.6%	2.1%	0.4%	0.5%	0.1%	0.2%	0.1%	0.0%	
Southland	93.2%	6.0%	0.9%	0.0%	0.0%	0.0%	0.0%	0.0%	<b>117</b>
	92.9%	5.9%	0.9%	0.1%	0.1%	0.0%	0.2%	0.1%	

nk = not known due to no data provided.

## Appendix 13: Diagnostic group of hospital palliative care service patients compared to mid-range estimate group, by DHB

DHB	Cancer	Cardiovascular	HIV/AIDS	Renal failure	Neurological disease	Respiratory disease	Other non-cancer	Total patients
Waitemata	73.8%	7.3%	0.0%	2.6%	2.6%	4.3%	9.3%	644
	42.7%	26.8%	0.0%	2.8%	6.8%	7.8%	13.0%	
Auckland	65.5%	7.0%	0.0%	5.1%	7.0%	3.8%	11.7%	1562
	38.1%	28.4%	0.2%	2.8%	7.4%	8.9%	14.2%	
Counties Manukau	35.4%	11.2%	0.0%	0.7%	1.6%	13.2%	38.0%	806
	43.7%	24.1%	0.0%	3.1%	5.3%	8.4%	15.4%	
Waikato	47.6%	7.1%	0.0%	3.0%	0.6%	4.2%	37.5%	168
	44.0%	25.1%	0.0%	2.3%	5.4%	8.8%	14.3%	
Hawke's Bay	75.1%	10.2%	0.0%	2.9%	1.8%	10.0%	0.0%	650
	40.4%	29.1%	0.0%	3.1%	4.7%	8.1%	14.5%	
MidCentral	75.6%	6.1%	0.0%	2.5%	0.0%	3.6%	12.3%	446
	41.3%	28.5%	0.0%	1.7%	5.7%	9.6%	13.1%	
Capital & Coast	72.0%	7.0%	0.0%	3.0%	5.8%	4.4%	7.8%	500
	40.0%	26.4%	0.1%	2.8%	7.4%	9.2%	14.1%	
Hutt Valley	nk	nk	nk	nk	nk	nk	nk	nk
	39.6%	25.6%	0.1%	3.1%	6.7%	9.7%	15.1%	
Canterbury	64.7%	7.3%	0.0%	3.4%	9.4%	4.4%	10.8%	712
	42.9%	27.6%	0.0%	1.4%	6.1%	9.6%	12.4%	
South Canterbury	nk	nk	nk	nk	nk	nk	nk	nk
	40.2%	28.3%	0.1%	2.0%	6.9%	8.6%	13.9%	
Otago	nk	nk	nk	nk	nk	nk	nk	nk
	42.0%	26.5%	0.0%	2.4%	5.8%	9.9%	13.3%	

DHB	Cancer	Cardiovascular	HIV/AIDS	Renal failure	Neurological disease	Respiratory disease	Other non-cancer	Total patients
Southland	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	117
	44.5%	26.7%	0.0%	2.6%	4.8%	9.3%	12.1%	
<b>Total</b>	<b>64.7%</b>	<b>7.8%</b>	<b>0.0%</b>	<b>3.2%</b>	<b>4.4%</b>	<b>6.0%</b>	<b>14.0%</b>	<b>5605</b>
Mid-range estimate	42.1%	26.8%	0.1%	2.5%	5.9%	9.1%	13.6%	

nk = not known due to no data provided.

## Appendix 14: Reason for episode of care end for hospital palliative care service patients, by DHB

DHB	Death	Discharge				Other	Not recorded	Total patients
		Own home	ARC	Hospital (acute)	Hospice			
Waitemata	25.2%	20.9%	0.0%	0.0%	0.0%	44.1%	9.8%	674
Auckland	19.1%	18.8%	3.8%	1.1%	4.0%	53.2%	0.0%	1,312
Counties Manukau	14.3%	65.5%	4.7%	13.9%	0.0%	1.6%	0.0%	806
Waikato	100.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	320
Hawke's Bay	16.3%	61.1%	7.0%	2.6%	6.2%	0.0%	6.8%	615
MidCentral	14.9%	47.1%	8.9%	5.7%	19.9%	0.0%	3.4%	437
Capital & Coast	23.6%	40.8%	8.0%	0.0%	0.0%	27.6%	0.0%	500
Hutt Valley	nk	nk	nk	nk	nk	nk	nk	nk
Canterbury	29.1%	44.2%	19.2%	1.9%	0.0%	5.6%	0.0%	877
South Canterbury	nk	nk	nk	nk	nk	nk	nk	nk
Otago	41.1%	0.0%	0.0%	0.0%	0.0%	0.0%	58.9%	652
Southland	nk	nk	nk	nk	nk	nk	nk	nk
Total	26.8%	33.7%	6.1%	3.0%	19.3%	8.2%	2.9%	6,193

nk = not known due to no data provided.



## Appendix 15: Hospice workforce (total FTE), 2011

### Medical and nursing

DHB	Medical practitioners					Nurses							Total nursing
	Specialist	MOSS	Registrar	GP with special interest	Other medical	Total medical	Senior nurse	Registered nurse	Enrolled nurse	Care assistant	Educator	End-of-life care facilitator	
Northland	0.98	0.0	0.0	1.40	0.0	<b>2.38</b>	5.4	22.4	1.90	0.30	1.01	0.0	<b>30.98</b>
Waitemata	4.30	3.00	0.0	0.40	0.20	<b>7.90</b>	15.2	35.2	1.60	3.30	1.80	0.0	<b>57.05</b>
Auckland	2.60	0.60	2.00	0.60	0.0	<b>5.80</b>	11.6	18.9	1.90	6.10	0.75	1.0	<b>40.25</b>
Counties Manukau	1.50	0.60	1.00	0.0	0.10	<b>3.20</b>	0.8	26.4	2.60	1.50	1.60	0.0	<b>32.90</b>
Waikato	0.50	0.0	0.0	0.50	0.0	<b>1.00</b>	1.9	19.5	0.80	9.20	0.0	0.4	<b>31.80</b>
Lakes	0.03	0.0	0.0	0.0	0.0	<b>0.03</b>	4.8	4.1	0.0	3.00	0.0	0.0	<b>11.85</b>
Bay of Plenty	1.00	1.80	0.0	0.0	0.0	<b>2.80</b>	5.2	22.3	2.20	3.67	0.0	1.0	<b>34.32</b>
Tairāwhiti	0.20	0.0	0.0	0.25	0.0	<b>0.45</b>	0.0	1.4	0.0	0.0	0.50	0.0	<b>1.90</b>
Hawke's Bay	0.50	2.30	0.0	0.0	0.0	<b>2.80</b>	0.0	16.6	2.20	0.70	0.50	1.0	<b>21.00</b>
Taranaki	1.10	0.60	0.0	0.80	0.0	<b>2.50</b>	5.0	12.0	3.20	2.20	0.70	0.5	<b>23.60</b>
MidCentral	0.80	1.90	0.80	0.10	0.0	<b>3.60</b>	2.0	15.7	1.80	2.00	1.00	0.6	<b>23.10</b>
Whanganui	0.48	0.50	0.0	0.0	0.0	<b>0.98</b>	1.0	8.6	1.90	3.20	1.00	0.0	<b>15.70</b>
Capital & Coast	2.50	1.00	0.0	0.0	0.0	<b>3.50</b>	11.2	14.4	3.60	7.20	1.70	0.5	<b>38.60</b>
Hutt	2.75	1.75	0.0	0.45	0.0	<b>4.95</b>	4.0	23.8	0.0	0.0	0.0	0.0	<b>27.80</b>
Wairarapa	0.20	0.0	0.0	0.0	0.0	<b>0.20</b>	1.8	3.6	0.0	1.30	0.0	0.0	<b>6.70</b>
Nelson Marlborough	0.50	1.53	0.0	1.20	0.0	<b>3.23</b>	1.8	25.6	0.0	5.80	1.80	0.4	<b>35.35</b>
West Coast	0.0	0.0	0.0	0.0	0.0	<b>0.00</b>	2.5	0.0	0.0	0.0	0.0	0.0	<b>2.50</b>
Canterbury	1.50	0.40	1.00	0.20	0.0	<b>3.10</b>	8.3	8.1	3.00	0.0	0.0	1.0	<b>20.40</b>
South Canterbury	1.00	0.20	0.0	0.0	0.0	<b>1.20</b>	4.5	1.0	4.50	0.20	0.0	0.4	<b>10.60</b>
Otago	0.90	1.18	0.0	0.0	0.0	<b>2.08</b>	5.7	6.8	4.80	0.0	0.70	1.0	<b>19.00</b>
Southland	1.00	1.00	0.0	0.0	0.0	<b>2.00</b>	1.0	6.1	4.20	0.0	0.50	0.5	<b>12.30</b>
<b>Total FTE</b>	<b>24.3</b>	<b>18.4</b>	<b>4.8</b>	<b>5.9</b>	<b>0.3</b>	<b>53.7</b>	<b>93.7</b>	<b>292.3</b>	<b>40.2</b>	<b>49.7</b>	<b>13.6</b>	<b>8.3</b>	<b>497.7</b>

## Psychological, social and spiritual care

DHB	Psychological, social and spiritual care workforce							Total
	Social worker	Spiritual care	Music therapist	Complementary therapist	Grief and bereavement counsellor	Case manager	Other psycho-social care provider	
Northland	0.80	0.40	0.0	0.00	1.35	0.0	0.80	<b>3.35</b>
Waitemata	4.20	1.70	0.0	0.70	3.45	0.80	1.80	<b>12.65</b>
Auckland	1.60	0.80	0.0	5.00	3.60	0.0	1.68	<b>12.68</b>
Counties Manukau	1.55	0.0	0.0	0.0	3.40	0.0	0.0	<b>4.95</b>
Waikato	2.60	0.0	0.0	0.0	7.00	0.0	0.0	<b>9.60</b>
Lakes	0.0	0.0	0.0	0.20	1.10	0.0	0.10	<b>1.40</b>
Bay of Plenty	1.26	0.50	0.0	0.0	2.26	0.0	0.0	<b>4.02</b>
Tairāwhiti	0.0	0.0	0.0	0.0	0.70	0.0	0.0	<b>0.70</b>
Hawke's Bay	0.80	0.40	0.0	0.0	0.80	0.0	0.50	<b>2.50</b>
Taranaki	0.40	0.10	0.0	0.10	1.40	0.0	0.0	<b>2.00</b>
MidCentral	1.80	0.90	0.0	0.0	0.20	0.0	0.0	<b>2.90</b>
Whanganui	0.55	0.37	0.0	0.0	0.10	0.0	0.0	<b>1.02</b>
Capital & Coast	1.98	1.80	0.15	0.0	2.05	0.0	0.40	<b>6.38</b>
Hutt	0.80	0.30	0.0	1.80	0.70	0.0	0.50	<b>4.10</b>
Wairarapa	0.50	0.0	0.0	0.0	0.0	0.0	0.0	<b>0.50</b>
Nelson Marlborough	0.95	0.50	0.0	0.0	0.40	0.0	0.85	<b>2.70</b>
West Coast	0.0	0.0	0.0	0.0	0.0	0.0	0.0	<b>0.0</b>
Canterbury	1.00	0.60	0.0	0.20	1.50	0.0	0.0	<b>3.30</b>
South Canterbury	0.0	0.20	0.0	0.0	0.50	0.0	0.0	<b>0.70</b>
Otago	1.20	0.30	0.0	0.0	0.73	0.0	0.0	<b>2.23</b>
Southland	0.0	0.30	0.0	0.20	1.10	0.0	0.0	<b>1.60</b>
<b>Total FTE</b>	<b>21.99</b>	<b>9.17</b>	<b>0.15</b>	<b>8.20</b>	<b>32.34</b>	<b>0.80</b>	<b>6.63</b>	<b>79.28</b>

## Appendix 16: Hospice workforce staff FTE per 1000 patients, by DHB, 2011

### Medical and nursing

DHB	Medical practitioners						Nurses						
	Specialist	MOSS	Registrar	GP with special interest	Other medical	Total medical	Senior nurse	Registered nurse	Enrolled nurse	Care assistant	Educator	End-of-life care facilitator	Total nurse
Northland	1.1	0.0	0.0	1.5	0.0	2.6	5.9	24.5	2.1	0.3	1.1	0.0	33.9
Waitemata	3.2	2.2	0.0	0.3	0.1	5.8	11.2	25.8	1.2	2.4	1.3	0.0	41.9
Auckland	1.7	0.4	1.3	0.4	0.0	3.8	7.5	12.2	1.2	3.9	0.5	0.6	26.0
Counties Manukau	1.6	0.6	1.0	0.0	0.1	3.3	0.8	27.5	2.7	1.6	1.7	0.0	34.3
Waikato	0.5	0.0	0.0	0.5	0.0	1.1	2.0	20.9	0.9	9.9	0.0	0.4	34.1
Lakes	0.1	0.0	0.0	0.0	0.0	0.1	11.2	9.4	0.0	7.0	0.0	0.0	27.6
Bay of Plenty	1.1	2.0	0.0	0.0	0.0	3.1	5.8	25.0	2.5	4.1	0.0	1.1	38.6
Tairāwhiti	1.1	0.0	0.0	1.3	0.0	2.4	0.0	7.4	0.0	0.0	2.7	0.0	10.1
Hawke's Bay	0.8	3.7	0.0	0.0	0.0	4.5	0.0	26.7	3.5	1.1	0.8	1.6	33.8
Taranaki	1.7	0.9	0.0	1.3	0.0	3.9	7.9	19.0	5.1	3.5	1.1	0.8	37.3
MidCentral	1.1	2.7	1.1	0.1	0.0	5.1	2.8	22.2	2.5	2.8	1.4	0.8	32.6
Whanganui	1.6	1.6	0.0	0.0	0.0	3.2	3.3	28.2	6.2	10.5	3.3	0.0	51.5
Capital & Coast	3.2	1.3	0.0	0.0	0.0	4.5	14.5	18.6	4.7	9.3	2.2	0.6	49.9
Hutt	4.8	3.0	0.0	0.8	0.0	8.6	7.0	41.4	0.0	0.0	0.0	0.0	48.3
Wairarapa	1.4	0.0	0.0	0.0	0.0	1.4	12.2	24.3	0.0	8.8	0.0	0.0	45.3
Nelson Marlborough	0.8	2.4	0.0	1.9	0.0	5.1	2.9	40.6	0.0	9.2	2.9	0.6	56.1
West Coast	0.0	0.0	0.0	0.0	0.0	0.0	19.7	0.0	0.0	0.0	0.0	0.0	19.7
Canterbury	1.2	0.3	0.8	0.2	0.0	2.4	6.5	6.4	2.4	0.0	0.0	0.8	16.0
South Canterbury	6.0	1.2	0.0	0.0	0.0	7.1	26.8	6.0	26.8	1.2	0.0	2.4	63.1
Otago	1.9	2.4	0.0	0.0	0.0	4.3	11.7	14.0	9.9	0.0	1.4	2.1	39.1
Southland	3.6	3.6	0.0	0.0	0.0	7.2	3.6	21.9	15.1	0.0	1.8	1.8	44.2
All DHBs	1.7	1.3	0.3	0.4	0.02	3.8	6.7	21.0	2.9	3.6	1.0	0.6	35.7

## Psychological, social and spiritual care

DHB	Psychological, social and spiritual care workforce								
	Psychologist	Social worker	Spiritual care	Music therapist	Complementary therapist	Grief and bereavement counsellor	Case manager	Other psycho-social care provider	Total
Northland	0.0	0.87	0.44	0.0	0.0	1.48	0.0	0.87	<b>3.7</b>
Waitemata	0.0	3.08	1.25	0.0	0.51	2.53	0.59	1.32	<b>9.3</b>
Auckland	0.0	1.03	0.52	0.0	3.23	2.33	0.0	1.09	<b>8.2</b>
Counties Manukau	0.0	1.62	0.0	0.0	0.0	3.55	0.0	0.0	<b>5.2</b>
Waikato	0.0	2.79	0.0	0.0	0.0	7.50	0.0	0.0	<b>10.3</b>
Lakes	0.0	0.0	0.0	0.0	0.47	2.56	0.0	0.23	<b>3.3</b>
Bay of Plenty	0.0	1.42	0.56	0.0	0.0	2.54	0.0	0.0	<b>4.5</b>
Tairāwhiti	0.0	0.0	0.0	0.0	0.0	3.72	0.0	0.0	<b>3.7</b>
Hawke's Bay	0.0	1.29	0.64	0.0	0.0	1.29	0.0	0.80	<b>4.0</b>
Taranaki	0.0	0.63	0.16	0.0	0.16	2.21	0.0	0.0	<b>3.2</b>
MidCentral	0.0	2.54	1.27	0.0	0.0	0.28	0.0	0.0	<b>4.1</b>
Whanganui	0.0	1.80	1.21	0.0	0.0	0.33	0.0	0.0	<b>3.3</b>
Capital & Coast	0.0	2.56	2.33	0.19	0.0	2.65	0.0	0.52	<b>8.3</b>
Hutt	0.0	1.39	0.52	0.0	3.13	1.22	0.0	0.87	<b>7.1</b>
Wairarapa	0.0	3.38	0.0	0.0	0.0	0.0	0.0	0.0	<b>3.4</b>
Nelson Marlborough	0.0	1.51	0.79	0.0	0.0	0.63	0.0	1.35	<b>4.3</b>
West Coast	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	<b>0.0</b>
Canterbury	0.0	0.78	0.47	0.0	0.16	1.18	0.0	0.0	<b>2.6</b>
South Canterbury	0.0	0.0	1.19	0.0	0.0	2.98	0.0	0.0	<b>4.2</b>
Otago	0.0	2.47	0.62	0.0	0.0	1.50	0.0	0.0	<b>4.6</b>
Southland	0.0	0.0	1.08	0.0	0.72	3.96	0.0	0.0	<b>5.8</b>
<b>Total DHBs</b>	<b>0.00</b>	<b>1.58</b>	<b>0.66</b>	<b>0.01</b>	<b>0.59</b>	<b>2.32</b>	<b>0.06</b>	<b>0.48</b>	<b>5.68</b>

## Appendix 17: Hospice staff:patient ratios, by DHB, 2011

### Medical and nursing

DHB	Medical practitioners					Nurses							
	Specialist	MOSS	Registrar	GP with special interest	Other medical	Total medical	Senior nurse	Registered nurse	Enrolled nurse	Care assistant	Educator	End-of-life care facilitator	Total nursing
Northland	1:938			1:654		1:385	1:170	1:41	1:482	1:3050	1:909		1:30
Waitemata	1:317	1:454		1:3405	1:6810	1:172	1:90	1:39	1:851	1:413	1:757		1:24
Auckland	1:595	1:2577	1:773	1:2577		1:267	1:133	1:82	1:814	1:253	1:2061	1:1546	1:38
Counties Manukau	1:639	1:1598	1:959		1:9590	1:300	1:1199	1:36	1:369	1:639	1:599		1:29
Waikato	1:1866			1:1866		1:933	1:491	1:48	1:1166	1:101		1:2333	1:29
Lakes	1:17,160					1:17,160	1:89	1:106		1:143			1:36
Bay of Plenty	1:889	1:494				1:318	1:171	1:40	1:404	1:242		1:889	1:26
Tairāwhiti	1:940			1:752		1:418		1:134			1:376		1:99
Hawke's Bay	1:1244	1:270				1:222		1:37	1:283	1:889	1:1244	1:622	1:30
Taranaki	1:575	1:1055		1:791		1:253	1:127	1:53	1:198	1:288	1:904	1:1266	1:27
MidCentral	1:885	1:373	1:885	1:7080		1:197	1:354	1:45	1:393	1:354	1:708	1:1180	1:31
Whanganui	1:642	1:610				1:313	1:305	1:35	1:161	1:95	1:305		1:19
Capital & Coast	1:309	1:773				1:221	1:69	1:54	1:215	1:107	1:455	1:1546	1:20
Hutt	1:209	1:329		1:1,278		1:116	1:144	1:24					1:21
Wairarapa	1:740	1:00				1:740	1:82	1:41		1:114			1:22
Nelson Marlborough	1:1260	1:413		1:525		1:195	1:350	1:25		1:109	1:350	1:1575	1:18
West Coast							1:51						1:51
Canterbury	1:849	1:3185	1:1274	1:6370		1:411	1:153	1:157	1:425			1:1274	1:62
South Canterbury	1:168	1:840				1:140	1:37	1:168	1:37	1:840		1:420	1:16
Otago	1:540	1:412				1:234	1:85	1:71	1:101		1:694	1:486	1:26
Southland	1:278	1:278				1:139	1:278	1:46	1:66		1:556	1:556	1:23
Total DHBs	1:568	1:611	1:1574	1:1485	1:7737	1:260	1:140	1:47	1:295	1:222	1:694	1:1077	1:28

Note: Total hospice FTE:patient ratios are based on the actual patients seen by services that have the staff roles, not the total patient group.

## Psychological, social and spiritual care

DHB region	Psychological, social and spiritual care workforce							Total
	Social worker	Spiritual care	Music therapist	Complementary therapist	Grief and bereavement counsellor	Case manager	Other psycho-social care provider	
Northland	1:1144	1:2288			1:678		1:1144	1:273
Waitemata	1:324	1:801		1:1,946	1:395	1:1,703	1:757	1:108
Auckland	1:966	1:1933		1:309	1:429		1:920	1:122
Counties Manukau	1:619				1:282			1:194
Waikato	1:359				1:133			1:97
Lakes				1:2,145	1:390		1:4290	1:306
Bay of Plenty	1:706	1:1778			1:393			1:221
Tairāwhiti					1:269			1:269
Hawke's Bay	1:778	1:1555			1:778		1:1244	1:249
Taranaki	1:1583	1:6330		1:6,330	1:452			1:317
MidCentral	1:393	1:787			1:3540			1:244
Whanganui	1:555	1:824			1:3050			1:299
Capital & Coast	1:390	1:429	1:5,153		1:377		1:1933	1:121
Hutt	1:719	1:1917		1:319	1:821		1:1150	1:140
Wairarapa	1:296							1:296
Nelson Marlborough	1:663	1:1260			1:1575		1:741	1:233
West Coast								
Canterbury	1:1274	1:2123		1:6,370	1:849			1:386
South Canterbury		1:840			1:336			1:240
Otago	1:405	1:1620			1:666			1:218
Southland		1:927		1:1,390	1:253			1:174
<b>Total DHBs</b>	<b>1:580</b>	<b>1:1217</b>	<b>1:5153</b>	<b>1:744</b>	<b>1:423</b>	<b>1:1,703</b>	<b>1:1033</b>	<b>1:174</b>

Note: Total hospice FTE:patient ratios are based on only the actual patients seen by services that have the staff roles, not the total patient group.

## Appendix 18: Hospital palliative care service workforce (total FTE), medical and nursing, 2011

DHB	Medical practitioners				Nurses			Total nursing
	Specialist	Registrar	House officer	Total medical	Nurse practitioner	Senior nurse	End-of-life care facilitator	
Northland	0.0	0.0	0.0	<b>0.0</b>	0.0	0.0	0.0	<b>0.0</b>
Waitemata	0.80	1.00	0.0	<b>1.80</b>	0.0	2.40	0.0	<b>2.40</b>
Auckland	4.90	2.00	0.0	<b>6.90</b>	1.00	5.50	1.00	<b>7.50</b>
Counties Manukau	1.70	1.00	0.0	<b>2.70</b>	0.0	3.40	2.00	<b>5.40</b>
Waikato	3.10	3.00	0.50	<b>6.60</b>	0.0	5.00	1.00	<b>6.00</b>
Lakes	0.0	0.0	0.0	<b>0.0</b>	0.0	0.0	0.0	<b>0.0</b>
Bay of Plenty	0.0	0.0	0.0	<b>0.0</b>	0.0	0.0	0.0	<b>0.0</b>
Tairāwhiti	0.0	0.0	0.0	<b>0.0</b>	0.0	0.0	0.0	<b>0.0</b>
Hawke's Bay	0.50	0.0	0.0	<b>0.50</b>	0.0	1.50	0.0	<b>1.50</b>
Taranaki	0.0	0.0	0.0	<b>0.0</b>	0.0	0.0	0.0	<b>0.0</b>
MidCentral	0.90	0.0	0.0	<b>0.90</b>	0.0	1.80	0.0	<b>1.80</b>
Whanganui	0.0	0.0	0.0	<b>0.0</b>	0.0	0.0	0.0	<b>0.0</b>
Capital & Coast	2.00	1.00	0.0	<b>3.00</b>	1.00	2.20	0.80	<b>4.00</b>
Hutt	0.30	0.0	0.0	<b>0.30</b>	0.0	1.00	0.0	<b>1.00</b>
Wairarapa	0.0	0.0	0.0	<b>0.0</b>	0.0	0.0	0.0	<b>0.0</b>
Nelson Marlborough	0.0	0.0	0.0	<b>0.0</b>	0.0	0.0	0.0	<b>0.0</b>
West Coast	0.0	0.0	0.0	<b>0.0</b>	0.0	0.0	0.0	<b>0.0</b>
Canterbury	0.80	1.00	0.0	<b>1.80</b>	1.00	1.70	0.0	<b>2.70</b>
South Canterbury	0.10	0.0	0.0	<b>0.10</b>	0.0	0.0	0.0	<b>0.0</b>
Otago	0.50	0.0	0.0	<b>0.50</b>	0.0	1.00	0.0	<b>1.00</b>
Southland	0.20	0.0	0.0	<b>0.20</b>	0.0	1.00	0.0	<b>1.00</b>
<b>Total FTE</b>	<b>15.8</b>	<b>9.0</b>	<b>0.5</b>	<b>25.3</b>	<b>3.0</b>	<b>26.5</b>	<b>4.8</b>	<b>34.3</b>

## Appendix 19: Hospital palliative care service workforce staff, medical and nursing, FTE per 1000 patients, by DHB, 2011

DHB	Medical practitioners				Nursing				
	Specialist	MOSS	Registrar	House officer	Total medical	Nurse practitioner	Senior nurse	End-of-life care facilitator	Total nursing
Waitemata	1.40	0.0	1.75	0.0	3.16	0.0	4.21	0.0	4.21
Auckland	2.59	0.0	1.06	0.0	3.65	0.53	2.91	0.53	3.96
Counties Manukau	2.11	0.0	1.24	0.0	3.35	0.0	4.22	2.48	6.70
Waikato	4.19	0.0	4.05	0.68	8.92	0.0	6.76	1.35	8.11
Hawke's Bay	1.51	0.0	0.0	0.0	1.51	0.0	4.52	0.0	4.52
MidCentral	2.06	0.0	0.0	0.0	2.06	0.0	4.12	0.0	4.12
Capital & Coast	4.00	0.0	2.00	0.0	6.00	2.00	4.40	1.60	8.00
Hutt	0.98	0.0	0.0	0.0	0.98	0.0	3.28	0.0	3.28
Canterbury	0.81	0.0	1.01	0.0	1.82	1.01	1.72	0.0	2.73
South Canterbury	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Otago	1.42	0.0	0.0	0.0	1.42	0.0	2.84	0.0	2.84
Southland	1.59	0.0	0.0	0.0	1.59	0.0	7.94	0.0	7.94
Total DHBs	2.24	0.0	1.28	0.07	3.59	0.43	3.76	0.68	4.87



## Appendix 20: Hospital palliative care service staff:patient ratios, medical and nursing, by DHB, 2011

DHB region	Medical practitioners			Nurses				
	Specialist	Registrar	House officer	Total medical	Nurse practitioner	Senior nurse	End-of-life care facilitator	Total nursing
Northland								
Waitemata	1:713	1:570		1:317		1:238		1:238
Auckland	1:402	1:984		1:285	1:1968	1:358	1:1968	1:262
Counties Manukau	1:474	1:806		1:299		1:237	1:403	1:149
Waikato	1:239	1:247	1:1480	1:112		1:148	1:740	1:123
Lakes								
Bay of Plenty								
Tairāwhiti								
Hawke's Bay	1:664			1:664		1:221		1:221
Taranaki								
MidCentral	1:486			1:486		1:243		1:243
Whanganui								
Capital & Coast	1:250	1:500		1:167	1:500	1:227	1:625	1:125
Hutt	1:1017			1:1017		1:305		1:305
Wairarapa								
Nelson Marlborough								
West Coast								
Canterbury	1:1236	1:989		1:549	1:989	1:582		1:366
South Canterbury	–			–				
Otago	1:704			1:704		1:352		1:352
Southland	1:630			1:630		1:126		1:126
Total DHBs	1:451	1:619	1:1,480	1:282	1:1152	1:269	1:905	1:208