

National Health Needs Assessment for Palliative Care: **Summary**

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

June 2013



PALLIATIVE CARE COUNCIL
OF NEW ZEALAND

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". The signature is written in a cursive, flowing style.

Kate Grundy

Chair, Palliative Care Council of New Zealand

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.¹ 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.

¹ 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.² 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.

² Some of the medical services may be provided by hospice GPs.

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

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 care⁴ 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.

³ 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.

⁴ 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.

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 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.⁵ 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

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

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.

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.

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.