

National Health Needs Assessment for Palliative Care

Phase 1 Report:
Assessment of Palliative Care Need

June 2011



PALLIATIVE CARE COUNCIL
OF NEW ZEALAND

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The Palliative Care Council of New Zealand

The Palliative Care Council (PCC) 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.

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Contents

List of Tables	4
List of Figures	5
Executive Summary	7
National Palliative Care Health Needs Assessment	11
Introduction	11
A National Health Needs Assessment	13
Methodology	13
Data Sources	17
Defining the Populations to be Assessed	19
Age Structure of the New Zealand Population	20
Numbers of Males and Females in the New Zealand Population	21
Age-Related Mortality	22
Ethnic Composition and Religion of the New Zealand Population	25
Living in Households	28
Relative Deprivation	29
Palliative Care Population Estimates	31
Adult Estimates (age 20+)	33
Children and Young People Estimates (ages 0–19)	37
Characteristics of the Whole Mid-Range Estimate Group	40
Prevalence of Problems/Symptoms (Adults)	45
Place of Death	46
Overall Assessment of Palliative Care Need	51
References	53
Appendices	55

List of Tables

Table 1: District Health Board populations 2006	19
Table 2: Percentage of people in each main ethnic group (prioritised to level 2) by DHB	26
Table 3: Single person and retired households and aged residential care residents by DHB region: Number of individuals (% of total population)	28
Table 4: Percentage of CAUs in each deprivation quintile by DHB	30
Table 5: Total number of individuals in each estimate group over a three-year period (2005–2007)	33
Table 6: Adult group national palliative care population estimates (age 20+), average annual deaths from 2005 to 2007	33
Table 7: Mid-range estimate of the number of adults who would benefit from palliative care per year, and projected numbers for 2016 and 2026, by DHB	34
Table 8: Children and young people group national palliative care population estimates (age 0–19), average annual deaths from 2005 to 2007	37
Table 9: Mid-range estimate of the number of children and young people who would benefit from palliative care per year, and projected numbers for 2016 and 2026, by DHB	38
Table 10: Mid-range estimate by deprivation quintile (three-year average)	42
Table 11: Place of death for all deaths over a five-year period (2003–2007)	47

List of Figures

Figure 1: Variables included in the NZDep2006	18
Figure 2: Projected changes in DHB populations (indexed to 2006)	20
Figure 3: Estimated changes in age group proportions in the New Zealand population 2006, 2016 and 2026	21
Figure 4: Percentage of males and females, by age group, for total New Zealand population (2007)	22
Figure 5: Proportion of deaths by age group for four main ethnic groups in New Zealand	23
Figure 6: Proportion of all deaths in 2007 for each gender, by age group	23
Figure 7: Proportion of all deaths in 2007 for Māori and Pacific ethnic groups (by gender and age group)	24
Figure 7(continued): Proportion of all deaths in 2007 for Māori and Pacific ethnic groups (by gender and age group)	25
Figure 8: DHB region populations by deprivation quintile	31
Figure 9: Mid-range estimate: deaths by age group	40
Figure 10: Ethnic group composition of New Zealand population (based on Census 2006) compared with mid-range estimate groups for adults and CYP	41
Figure 11: Ethnic group composition of different age groups in the mid-range estimate	41
Figure 12: Underlying cause of death — adults (entire mid-range estimate; n = 46,481)	43
Figure 13: Underlying cause of death — CYP (entire mid-range estimate: n = 826)	44
Figure 14: Underlying cause of death — CYP excluding perinatal deaths and deaths from congenital conditions (n = 363)	45
Figure 15: Place of death — New Zealand population versus mid-range estimate populations 2005–2007	47
Figure 16: Place of death for the different age groups in the mid-range estimate	48
Figure 17: Place of death by ethnic group (adult mid-range estimate)	49
Figure 18: Place of death by deprivation quintile (NZDep2006) 2005–2007 mid-range estimate (adult group)	49
Figure 19: Place of death by deprivation quintile (NZDep2006) 2005–2007 mid-range estimate (CYP group)	50

Executive Summary

Palliative care aims to optimise the quality of life until death for people of all ages who suffer from a life-limiting illness, by addressing the person's physical, psychosocial, spiritual and cultural needs. It also provides support for the person's family, whānau and other caregivers where needed, through the illness and after death. Palliative care is provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away. It may also be suitable when treatments aimed at improving quantity of life are being given (Palliative Care Subcommittee 2007).

The vision of *The New Zealand Palliative Care Strategy* (Ministry of Health 2001) is that "All people who are dying and their family/whānau who could benefit from palliative care services have timely access to quality palliative care". However, the number and characteristics of people that constitute the "all" has not yet been clearly defined for New Zealand.

Introduction

This report presents findings from Phase 1 of The Palliative Care Council's National Health Needs Assessment for Palliative Care ("Needs Assessment"). It establishes, for the first time, the number of people who might benefit from palliative care in New Zealand, on both a national and regional basis. Further work on the Needs Assessment will make an assessment of the services required to meet the identified need, and determine how this compares with current service provision.

Methodology

The Health Needs Assessment for Palliative Care is based on a framework developed for The National Council for Palliative Care in the United Kingdom. A modification has been made to this methodology with the addition of an Australian model for estimating the palliative care population. This approach establishes minimal, mid-range and maximal estimates of potential users of palliative care services. Estimates have been developed for adults (those over 20 years old) and children and young people (CYP) (0–19 years old).

Phase 1 of the Needs Assessment uses mortality data and hospital admission data to estimate the level of need for palliative care. It also provides an analysis of New Zealand population demographic data relevant to palliative care. Sources of data for Phase 1 included the Mortality Collection, National Minimum Dataset (hospital admissions), the 2006 Census of Population and Dwellings (Statistics New Zealand 2006), and the *Atlas of Socioeconomic Deprivation in New Zealand* (NZDep2006) (White et al 2008).

Population demographics relevant to palliative care

In the next 15 years the New Zealand population is expected to increase by just over 19%, but some District Health Boards (DHBs) can expect greater population growth of between 20% and 40%. Critically, this will not be a general increase across all age groups, instead there is going to be a significant increase in the older age groups. In 2006, the estimated percentage of people aged 65 and over in New Zealand was 12.2%, and 1.4% were over 85 years old. This is projected to increase to 18.9% and 2.3% respectively by 2026.

Overlying this increasing age of the population is the fact that the majority of deaths occur in the over 65 age group, accounting for 77% of all deaths in 2007. However, in the Māori, Pacific and Asian ethnic groups, people tended to die at a younger age, including significantly more deaths than expected for Māori in the under 1 age group. As a consequence of this higher mortality in younger age groups, Māori had significantly fewer deaths in the over 80 age group.

These changing population demographics are not unique to New Zealand; they are occurring in all developed countries. For this reason, the World Health Organization believes that palliative care should be given priority status within public health and disease-control programmes.

The majority of the New Zealand population identify as New Zealander, New Zealand European or European (67%), followed by Māori (14%) and Pacific (5.6%). However, these proportions are not consistent across DHBs, with some being predominately European, especially in the South Island, and some, like Auckland, having a very diverse ethnic mix. This will need to be taken into consideration when evaluating and developing the cultural responsiveness of palliative care services.

Around half the New Zealand population identified with the collective group of Christian denominations, but there is also an important array of other religions within the population. Nearly one third (31.45%) of people, the largest single group, reported having no religion. This is a much larger group than is reported in other countries. This diverse range of religious affiliations, and the high number of people with no stated religion, has important implications for the provision of spiritual care at the end of life.

Approximately 1 in 20 people over 65 years old live in aged residential care and are likely to die there. Research has shown the physical dependence of these people has significantly increased over the past 20 years. Therefore, residential care facilities will require adequate resources and appropriately trained staff, as well as access to specialist support, to deliver high-quality palliative care.

Although research is limited to date, there is some evidence showing that providing palliative care for people in deprived areas requires greater resources than in more affluent areas. Some DHBs have relatively high levels of deprivation and this must be taken into account when developing service delivery models and allocating resources.

Palliative care estimates

Mortality Collection and hospital admission data covering the years 2005, 2006 and 2007 was analysed to establish how many people might have benefited from palliative care. This analysis included 84,131 individual death records. Based on the estimate criteria, the following national level estimates were developed:

	Estimates (No. of individuals and % of all deaths)		
	Minimal	Mid-range	Maximal
Estimated palliative care population — children and young people	287 (44.0%)	273 (41.9%)	388 (59.5%)
Estimated palliative care population — adults	11,390 (41.8%)	15,452 (56.7%)	25,515 (93.6%)

Based on population growth over the next 15 years, the number of adult deaths in 2026 where palliative care may be of benefit is estimated to be 19,076. This is an increase of 23.5% from the baseline estimate (which could be considered a 2006 figure), or around 180 additional deaths every year. This reflects the increasing proportion of the population in the older adult groups. For children and young people the estimated increase is only around 5% from the 2006 baseline figure of 272 (i.e. up to 284 by 2026).

Characteristics of the palliative care population

The Expert Advisory Group for the Needs Assessment project agreed the mid-range estimate was likely to represent the best population estimate of the number of people who would benefit from palliative care. This estimate is needs focused and includes people already in contact with health services and who had a known, potentially life-threatening health condition. Therefore, this estimate was used to explore specific characteristics of the palliative care population.

Most individuals in the mid-range estimate (84%) were over 60 years old. The proportion of European people in the adult group was higher than in the national population. In fact, 70% of the mid-range estimate were Europeans and over 60 years old. In contrast, both the Māori and Pacific ethnic groups contributed more deaths to the 0–19 age group than would be expected given their national population size.

Over half of all deaths in the mid-range estimate occurred in the most deprived quintile 4 and 5 groups: 55% in the CYP group and 49% in the adult group. The reason for this is not clear, but it may be because this estimate included many more non-cancer deaths where environmental or lifestyle factors, such as obesity and tobacco use, contributed to a higher incidence in populations with high deprivation.

For adults, cancer was the single biggest cause of death in the mid-range estimate (43%). However, non-cancer related deaths made up over 57% of deaths in this group, with circulatory and respiratory diseases the greatest contributors. In the CYP group the greatest numbers of deaths were due to perinatal conditions and congenital abnormalities, accounting for almost 70% of all deaths. These deaths occurred almost entirely in the under 1 age group. Cancer and external causes were the next leading causes of death.

Among the adults who died from cancer, the four most prevalent symptoms/problems were likely to be pain, loss of appetite, vomiting or feeling sick and sleeplessness. For those who died of non-cancer causes, the four most common symptoms/ problems were likely to be pain, trouble with breathing, mental confusion and loss of appetite.

On a national basis, most deaths occurred in a hospital setting (34%), followed by residential care (31%) and private residence (22%). A smaller number of deaths were in a hospice inpatient unit. In the mid-range estimate group more deaths occurred in hospital, especially in the CYP group with 77.6% of deaths in a hospital setting. For adults in this estimate, 47% of deaths were in hospital, 25% in residential aged care and 17% in private residence.

Where a person dies appears to be influenced by several factors. In the mid-range estimate, statistically significant differences in place of death were found based on age, ethnicity, deprivation and the underlying cause of death.

Conclusion

In New Zealand, palliative care should be available to people of all ages with a life-limiting illness, and to their family and whānau. There is agreement at a national level that palliative care is provided according to need, and that it may be provided over a period from a few days to months or even years. It should also be available wherever the person may be and in such a way as to meet the unique needs of individuals from particular communities or groups. This Needs Assessment project is the first attempt to identify the level of need for palliative care on a national basis in New Zealand. While the methodology is still somewhat embryonic, it nevertheless provides some very useful information on the size of the potential palliative care population and some of the key features of this group of people.

While the data from this phase of the Needs Assessment is informative in its own right, it will also be used in the next phases of the Needs Assessment, which will look at the core palliative care services required to meet the identified need and how that compares with currently available services. The final step of the Needs Assessment will be undertaken in collaboration with palliative care service providers, other stakeholders and health funders to identify gaps in service provision, how these gaps may be remedied within current financial and resource constraints, and priorities for action.

National Palliative Care Health Needs Assessment

Introduction

“Good health and wellbeing for all New Zealanders throughout their lives” is a statement made within *The New Zealand Health Strategy* (Ministry of Health 2010, p. 8). This statement must also encompass those New Zealanders whose health is failing and the need to ensure wellbeing at the end of their lives. This is achievable with the vast majority of people whose death is foreseeable and is one of the main objectives of palliative care. The World Health Organization (WHO) defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” (World Health Organization 2002, p. 84).

Palliative care for children is considered a similar but separate area of practice, as children and young people with life-limiting or life-threatening illnesses present different challenges, and their families may have different needs. WHO has developed a specific definition of palliative care appropriate for children and their families (World Health Organization 1998):

- Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child’s physical, psychological and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children’s homes.

In New Zealand, a working definition of palliative care has been developed that takes into consideration the fundamental place of the Treaty of Waitangi, the evolving practice of palliative care, the diversity of cultures, the importance of primary care, and the need to integrate specialist and generalist palliative care (*Box 1*) (*Palliative Care Subcommittee 2007*).

Box 1: The New Zealand definition of palliative care

Care for people of all ages with a life-limiting illness which aims to:

1. Optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs.
2. Support the individual's family, whānau, and other caregivers where needed, through the illness and after death.

Palliative care is provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away. It may be suitable sometimes when treatments are being given aimed at improving quantity of life.

It should be available wherever the person may be.

It should be provided by all health care professionals, supported where necessary, by specialist palliative care services.

Palliative care should be provided in such a way as to meet the unique needs of individuals from particular communities or groups. These include Māori, children and young people, immigrants, refugees, and those in isolated communities.

(Palliative Care Subcommittee 2007)

The New Zealand definition goes on to define generalist and specialist palliative care as follows:

Generalist palliative care is palliative care provided for those affected by life-limiting illness as an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team.

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.

The vision of *The New Zealand Palliative Care Strategy*, that "All people who are dying and their family/whānau who could benefit from palliative care services have timely access to quality palliative care service ..." (Ministry of Health 2001, p. 7), clearly identifies the ideal situation hoped for as an outcome of the strategy.

'Need' in the context of health care, has been defined as the ability or capacity to benefit from health care (Stevens and Gillam 1998; Stevens and Raftery 1997), and therefore the strategy's vision implies a requirement to understand the palliative care needs of New Zealand's population. However, the starting point to understanding the level of this need is an appreciation of the size of the number of people who could benefit from palliative care. At present, this has not yet been clearly defined for New Zealand as a whole. At the time the Strategy was written an attempt was made to establish current levels of need based on demographic trends. This really only provided a broad estimate for people with cancer and some rather imprecise indications of need for those with a non-cancer diagnosis and for children.

The Strategy did identify the increasing need for palliative care services, based on changing population demographics, in particular the growing number of older people and rising cancer incidence. It also highlighted the potential for people with non-cancer diagnoses to benefit from palliative care, which could also drive up the need for palliative care services. In an attempt to address issues of inequality of access to palliative care services, the strategy drew attention to the needs of specific population groups, including Māori, Pacific peoples, people with disabilities, people under 65 years of age and children. The strategy also noted that the newly established

District Health Boards (DHBs) were tasked with ensuring services were meeting the needs of their local population. In recent years a small number of studies have attempted to understand the palliative care needs of some DHB populations, notably these have been undertaken by the Auckland DHB, Nelson Marlborough DHB and the Central Cancer Network.

Internationally, work has been undertaken to describe the palliative care population, identify the level of need within subgroups of that population, and how well the need is being met. In particular, needs assessment projects that are translatable to New Zealand have been undertaken in the United Kingdom (UK) and Australia using different methods.

A National Health Needs Assessment

A key recommendation from the Palliative Care Council of New Zealand (2009) report *Positioning Palliative Care in New Zealand: A review of government health policy in relation to the provision of palliative care services in New Zealand*, was to undertake a national needs assessment to determine the need for palliative care on a population basis for all people who would benefit from palliative care in New Zealand.

The Needs Assessment project aims to achieve this recommendation by using recognised methodologies to develop estimates of palliative care need on both a national and regional basis, provide an assessment of the services required to meet the identified need and how these compare with current service provision. The final step of the Needs Assessment will be undertaken in collaboration with palliative care service providers and funders to identify gaps in service provision, how these gaps may be remedied within current financial and resource constraints, and priorities for action.

This project has required collaboration between different health agencies to ensure accurate and comprehensive data could be obtained and analysed to inform the project. In particular the key organisations involved in the Phase 1 work have included the Palliative Care Council of New Zealand (leading the project), the Ministry of Health (“the Ministry”) and Hospice New Zealand. Data for Phase 1 has been provided by the Ministry, National Health Board Analytical Services and Statistics New Zealand.

Methodology

Health needs assessments for palliative care is an emerging area and it is therefore important to recognise that this means it is not an exact science. The techniques currently available provide only estimates of need based on the principal factors that influence need, such as the number and causes of deaths and levels of deprivation. It is particularly challenging to identify what constitutes the group of people who would benefit from palliative care given there is no clear consensus on the characteristics of this group. While the most accurate and up-to-date data has been used for this Needs Assessment, it must be remembered that, although established national data has been used, such as census and mortality data, the findings of this project on the need for palliative care are estimates. These estimates will allow for service planning and modelling, and provide data that will enable the needs of one population to be compared with another, i.e. measurements of comparative need.

The Health Needs Assessment for Palliative Care is based on a needs assessment framework developed for The National Council for Palliative Care (NCPC) in the UK (previously called National Council for Hospice and Specialist Palliative Care Services) (Tebbit 2004). The framework is presented in a step-by-step manual and is founded on five principle stages of needs assessment:

1. An assessment of the palliative care needs of the population.
2. An assessment of the core service components required to meet those needs.

3. A mapping of the services currently available to meet those needs.
4. A comparison of what services are needed with what is already available in order to identify service gaps.
5. An assessment of the priorities for filling the service gaps.

Following a model previously developed by Stevens and Raftery (1997) and adapted for palliative and terminal care by Higginson (1997), this framework uses a 25-step process for undertaking a population-based needs assessment. It focuses on three main areas: assessment of palliative care need, assessment of the need for core service components and mapping of available services. The final step compares currently available services with the assessment of core services required to identify gaps and establish priorities for addressing any deficiencies exposed by the needs assessment.

A modification has been made to the NCPC approach to modelling the estimates of need for palliative care in the population. The modified approach uses a model developed in Western Australia for estimating the palliative care population (McNamara et al 2006). This model aims to establish minimal, mid-range and maximal estimates of potential users of palliative care services, rather than a single estimate. This approach allows for different resource modelling to be undertaken based on the three estimates.

The estimation model is based on cause-specific mortality data and hospital admission data. The different estimates are constructed as follows:

- **Minimal estimate** — this estimate is condition specific and includes deaths from specific diseases considered likely to benefit from palliative care.
- **Mid-range estimate** — this estimate group 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.
- **Maximal estimate** — this 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, originating during the perinatal period, and resulting from external causes.

A further adaptation of this approach to estimating the size of the palliative care population is the development of separate estimates for children and young people (CYP). There is widespread recognition that paediatric palliative care is different from that offered to adults, and as such there is a requirement to give specific attention to the needs of this population. Therefore, an alternative estimation model has been developed for CYP (age 0–19 years old). A key reason for undertaking this separate analysis is that the range of conditions seen in paediatric palliative care is very broad and differs considerably from adults, and this must be captured in order to provide accurate estimation figures for this group. The CYP model has also been developed as minimal, mid-range and maximal estimates in a similar way to the McNamara et al (2006) model.

Adult estimates

The adult estimates are for the 20 years and over age group.

Minimal estimate: This estimate includes 10 key disease groups considered likely to benefit from palliative care. The 10 disease groups were established through focus groups and key informant interviews, and then further refined by a literature review. Specific ICD-10-AM codes for these diseases were used as the criteria for this estimate. Adult minimal estimate disease groups included:

- neoplasm
- HIV/AIDS

- motor neuron disease
- Parkinson's disease
- Huntington's disease
- Alzheimer's disease
- heart failure
- renal failure
- diabetes mellitus with end stage renal failure
- chronic obstructive pulmonary disease
- bronchiectasis
- liver failure.

Mid-range estimate: all mortality registrations for people with age at death of 20 years and over who within the last 12 months of life had a publicly funded hospital discharge with any diagnosis or external cause code matching the underlying cause of death code.

Maximal estimate: all mortality registrations from 2005 to 2007 for people with age at death of 20 years and over and the underlying cause of death is **not** listed below:

- pregnancy, childbirth and the puerperium
- originating during the perinatal period
- resulting from external causes of morbidity and mortality.

Children and young people estimates

The children and young people estimates are for the 0–19 years age group.

Minimal estimate: This estimate includes categories of diseases taken from the 2007 UK Department of Health report *Palliative Care Statistics for Children and Young Adults* (Department of Health 2007). This report provides an analysis of mortality and hospital admission data for children and young people with conditions likely to require palliative care. Using this report as a guide will also allowed for international comparisons with UK data. Again, specific ICD-10-AM codes for the key diseases were used as the criteria for this estimate. Minimal estimate diseases for children and young people include:

- certain infectious and parasitic diseases
- neoplasms
- diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism
- endocrine, nutritional and metabolic diseases
- mental and behavioural disorders
- diseases of the nervous system
- diseases of the circulatory system
- diseases of the respiratory system
- diseases of the digestive system
- diseases of the musculoskeletal system and connective tissue
- diseases of the genitourinary system
- certain conditions originating in the perinatal period
- congenital malformations, deformations and chromosomal abnormalities
- sequelae of external causes of morbidity and mortality.

Mid-range estimate: all mortality registrations for people with age at death of 0–19 years who within the last 12 months of life had a publicly funded hospital discharge with any diagnosis or external cause code matching the underlying cause of death code.

Maximal estimate: all mortality registrations for people with age at death of 0–19 years and the underlying cause of death is **not** listed below:

- pregnancy, childbirth and the puerperium
- originating during the perinatal period
- resulting from external causes of morbidity and mortality.

Specific ICD-10-AM codes used in the estimates are listed in Appendix 1.

Ethics

Advice was sought from the Multi-Region Ethics Committee regarding the release of unit level data from the mortality collection for use in this study. It had been previously agreed that the unit level data would use encrypted National Health Index (NHI) numbers as the unique identifier for each record and any identifiable data would not be included. The Committee felt because anonymised data was being used, and only grouped data would be published, ethics approval was not necessary for this project.

Modelling estimate

While three different estimates are produced using the methodology described above, there are certain limitations that may influence the applicability of the estimates to the reality of today's health care environment. The maximal estimate represents the ideal situation, where every person who is dying, apart from those whose death is sudden and unexpected, is able to access palliative care. However, due to current constraints, such as service availability, funding, attitudes to death and dying, and patterns of referral, this estimate is not considered feasible. The minimal estimate, while specifically focused on diseases where palliative care is known to benefit, is solely condition specific and likely to be somewhat conservative. This estimate is likely to be too narrow in its definition and does not consider patient need (Rosenwax et al 2005).

In a published study on the application of the estimation model, Rosenwax et al (2005) suggest the mid-range estimate is most likely to represent a feasible population estimate. This is because the mid-range estimate includes people already in contact with health services and who have a known, potentially life-threatening health condition. This group should therefore have easier access to palliative care than those identified in the maximal estimate, and the minimal and mid-range estimates are already very close (5.5% difference in the reported study).

The Expert Advisory Group for the Needs Assessment project agreed the mid-range estimate was likely to represent the best population estimate of the number of people who would benefit from palliative care. Therefore, this estimate has been used to explore specific details of the palliative care population, and will be used as the basis for further work on assessing the required core services to meet the needs of people who would benefit from palliative care in New Zealand.

Data analysis

Data was analysed using Microsoft® Excel (Microsoft Corporation) and Stata® (StataCorp LP) version 11, to generate descriptive statistics and to undertake statistical tests of significance.

Data Sources

In order to reduce the burden on palliative care and other health care services, the health needs assessment has been based primarily on available sources of administrative data. This includes national data collections and survey data held by the Ministry of Health, and the results of national population surveys conducted by Statistics New Zealand. Each key data source is described here to provide some clarity about where the data is from, what it represents and how it was collected. The time period for each data collection is also included.

Mortality Collection

The Mortality Collection is maintained by the National Collections and Reporting services and is derived from information provided by Births, Deaths and Marriages, which includes electronic death registration information (for the previous month's registrations), Medical Certificates of Causes of Death, and Coroners' reports (Ministry of Health 2009a).

Additional information on underlying cause of death is obtained from electronic hospital discharge data from the National Minimum Dataset and private hospital discharge returns, the New Zealand Cancer Registry, the Department for Courts (Ministry of Justice), the Police, the New Zealand Transport Agency, Water Safety New Zealand, Media Search, and from correspondence with certifying doctors, coroners and medical records officers in public hospitals.

The Mortality Collection classifies the underlying cause of death for all deaths registered in New Zealand using the ICD-10-AM 2nd Edition and the WHO Rules and Guidelines for Mortality Coding.

National Minimum Dataset (Hospital Events)

The National Minimum Dataset (Hospital Events) collects unit record data on public and private hospital discharges, including clinical information, for inpatients and day patients. Data is submitted electronically in an agreed format by public hospitals (since 1993) and by private hospitals for publicly funded events (since 1997) (Ministry of Health 2009b).

2006 Census of Population and Dwellings (Census 2006)

The census is the official count of population and dwellings in New Zealand, providing a 'snapshot' of New Zealand society. The census is taken every five years. The 2006 Census of Population and Dwellings was undertaken on Tuesday 7 March 2006 (Statistics New Zealand 2006).

The census provides a unique source of detailed demographic, social and economic data relating to the entire population at a single point in time. It covers all dwellings in New Zealand on 7 March 2006 and every man, woman, child and baby alive in New Zealand on that date.

Overseas residents and people in diplomatic residences in New Zealand, including housekeeping staff, uniformed military personnel or members of diplomats' families are included in the census, as are foreign military personnel and their families located in New Zealand on census night (including foreign warships in New Zealand territorial waters on census night).

New Zealand military, naval and diplomatic personnel and their families located outside New Zealand on census night are not included in the census.

The geographic coverage of the census includes the North Island, South Island, Stewart Island and the Chatham Islands, plus offshore islands including the Kermadec Islands, Three Kings Islands, Mayor Island, Motiti Island, White Island, Moutohora Island, Bounty Islands, Snares Islands, Antipodes Islands, Auckland Islands and Campbell Island. The Ross Dependency is excluded from the population count.

Atlas of Socioeconomic Deprivation in New Zealand (NZDep2006)

The New Zealand Index of Deprivation 2006 (NZDep2006) is included in the above publication and provides a measure of *relative* socioeconomic deprivation experienced by groups of people in small areas (each with a usually resident population of at least 100 people). The index is created from nine variables taken from the Census 2006 (Figure 1) using principal components analysis (Salmond et al 2007). It provides a summary deprivation score from 1 to 10 for each small area. This scale of deprivation divides New Zealand into tenths of the distribution of the first principal component scores so that a score of 1 is allocated to the 10 percent of areas that have the least deprived NZDep scores, and a score of 10 is allocated to the 10 percent of areas that have the most deprived NZDep scores (White et al 2008).

The NZDep2006 ordinal scale ranges from 1 to 10, where 1 represents the areas with the least deprived scores and 10 the areas with the most deprived scores. NZDep2006 deprivation scores apply to *areas* rather than individual people.

Figure 1: Variables included in the NZDep2006
(in order of decreasing weight in the index) (White et al 2008, p. 9)

• People aged 18–64 receiving a means-tested benefit
• People living in equivalised* households with income below an income threshold
• People not living in own home
• People aged < 65 living in a single parent family
• People aged 18–64 unemployed
• People aged 18–64 without any qualifications
• People living in equivalised* households below a bedroom occupancy threshold
• People with no access to a telephone
• People with no access to a car

**Equivalisation is a method to control for household composition.*

Defining the Populations to be Assessed

The first step of a health needs assessment is to determine the populations to be assessed, and which will be subject to comparative assessment. For the purposes of this project, and to provide a fit with the current health care system in New Zealand, the analysis of data has been undertaken from a national perspective and at DHB level. This level of analysis should provide DHBs with an appropriate level of relevant local data for population health planning, and also provide a suitable level of data breakdown for central government planning. Table 1 shows DHB region populations from 2006, as well as the size of the two key age groups 0–19 and 20+ years of age, which are the two main groups being investigated in this project. Just over 400 people live in an area outside of a DHB. This refers to areas that do not fall within a DHB boundary and are usually associated with an island, inlet or oceanic area.

Table 1: District Health Board populations 2006

District Health Board	Total Population	Age group 0–19	20+
Northland	152,650	46,610	106,040
Waitemata	504,700	145,550	359,150
Auckland	428,310	108,580	319,730
Counties Manukau	454,800	153,640	301,160
Waikato	350,220	106,040	244,180
Lakes	101,520	31,880	69,640
Bay of Plenty	200,790	58,550	142,240
Tairāwhiti	45,930	15,530	30,400
Taranaki	107,440	31,140	76,300
Hawke's Bay	152,600	46,140	106,460
Whanganui	63,980	18,940	45,040
MidCentral	163,990	47,860	116,130
Hutt Valley	140,930	42,380	98,550
Capital and Coast	277,940	73,370	204,570
Wairarapa	39,580	11,060	28,520
Nelson Marlborough	133,630	35,210	98,420
West Coast	32,100	8,570	23,530
Canterbury	483,360	128,580	354,780
South Canterbury	55,110	14,380	40,730
Otago	184,610	48,200	136,410
Southland	109,980	29,590	80,390
Area outside of DHB	420	35	385
Total population	4,184,590	1,201,835	2,982,755

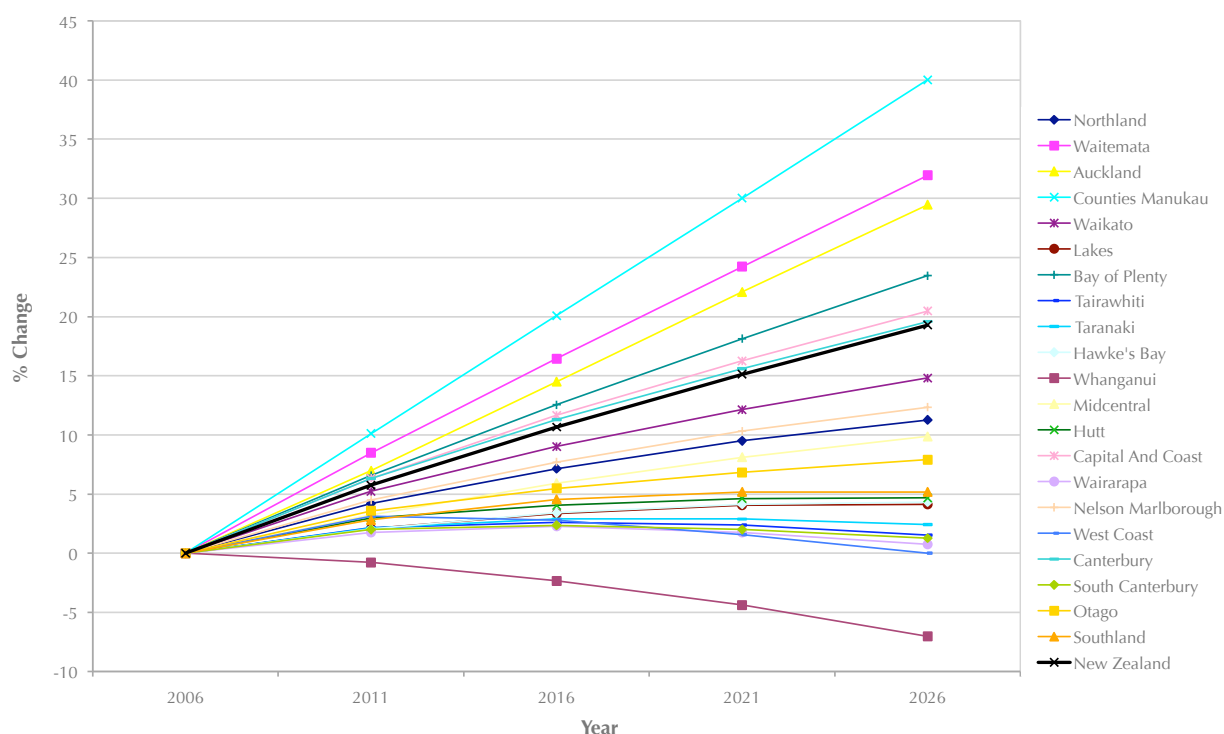
Notes on Table 1

Owing to rounding, individual figures may not always sum to the totals shown.

Based on District Health Board Population Projections, 2007–26 (2006-Base) produced by Statistics New Zealand in September 2010.

In the next 15 years almost every DHB can expect a growth in the size of their population. Using 2006 as the base year, Figure 2 illustrates the projected percentage change in the size of each DHB population between 2006 and 2026. As a whole, New Zealand's population is expected to increase by just over 19% during this period. However, Counties Manukau, Waitemata, Auckland, Bay of Plenty, Capital and Coast and Canterbury DHBs can expect greater population growth of between 20% and 40%. Whanganui is the only DHB where a decrease in population is expected.

Figure 2: Projected changes in DHB populations (indexed to 2006)



Both *The New Zealand Palliative Care Strategy* (Ministry of Health 2007) and the current New Zealand definition of palliative care (Palliative Care Subcommittee 2007) emphasise that palliative care must be provided in a way that meets the unique needs of different communities or groups. From this point of view, it is important to have some understanding of the key population groups that may influence palliative care need. The following section explores different population attributes and groups that are relevant to palliative and end-of-life care, including age, gender, ethnicity, religion, living situation and deprivation.

Age Structure of the New Zealand Population

For palliative and end-of-life care, an important factor is likely to be the number of people aged 65 and over, as this age group makes up the largest proportion of deaths and people in this group also tend to die from chronic diseases (rather than external causes) where palliative care could be of benefit. Variability in the size of this group within each DHB may impact on the number of deaths and therefore the level of resource required for palliative and end-of-life care. In 2006, the estimated proportion of people aged 65 and over in New Zealand was 12.2%, and 1.4% were over 85. This is projected to increase to 19% and 2.3% respectively by 2026 with a corresponding reduction in the proportion of the younger age groups (Figure 3). Appendix 2 provides a further breakdown of the 2006 DHB populations by age group, and Appendix 3 shows projected populations by age group for 2026.

Figure 3: Estimated changes in age group proportions in the New Zealand population 2006, 2016 and 2026



Source: District Health Board Population Projections, 2007–26, Statistics New Zealand 2010. The red line indicates the same population group as it moves across the projected populations over time.

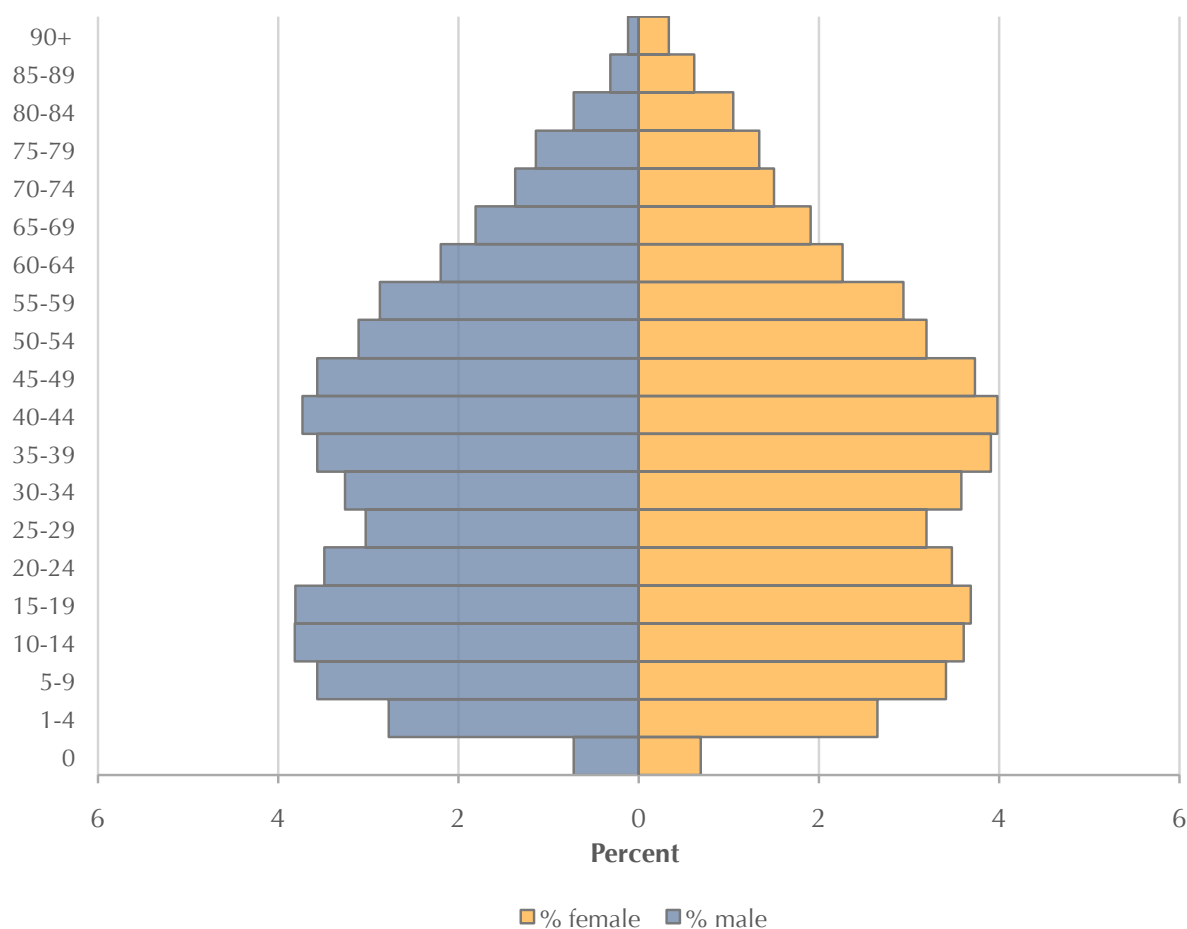
The changing age demographic of the New Zealand population is of significant concern to health services. As more people live longer there is likely to be a rise in chronic diseases, such as heart disease, cerebrovascular disease, respiratory disease and cancer, leading to an increased need for health care and a corresponding increase in need for palliative and end-of-life care. This rather bleak picture is tempered somewhat by the fact that some evidence suggests successive generations are actually remaining in better health as they age (WHO 2004). Another concern is the changing ratio of older people to those of working age in relation to the health care workforce, informal carers and financial burden. A crude estimate of this change can be calculated by comparing the number of working age people in the population (aged 15–64) to the number of people aged 65 and over. For 2006 the ratio of working age people to those over 65 was approximately 5:1, but by 2026 the estimated ratio will be approximately 3:1.

These changing age demographics are not unique to New Zealand; they are occurring in all developed countries. For this reason the WHO believes palliative care should be given priority status within public health and disease-control programmes (WHO 2002).

Numbers of Males and Females in the New Zealand Population

The proportion of males and females in the New Zealand population is 49% and 51% respectively. Across the DHB regions these proportions stay very close to this national split, apart from on the West Coast, where the difference is reversed with 50.8% males and 49.2% females. However, these proportions change with age and it is important to consider the implications this has for older people. The population pyramid in Figure 4 shows how the gender structure of the population changes with age. For the most part, the split remains fairly constant until age 65, where the proportion of females begins to steadily increase. The difference becomes more marked as age increases until in the age 90+ group there are over 70% females. This is set to change by 2026 with more males living to be older than 80, and in the 90+ age group there will be 37.5% males.

Figure 4: Percentage of males and females, by age group, for total New Zealand population (2007)

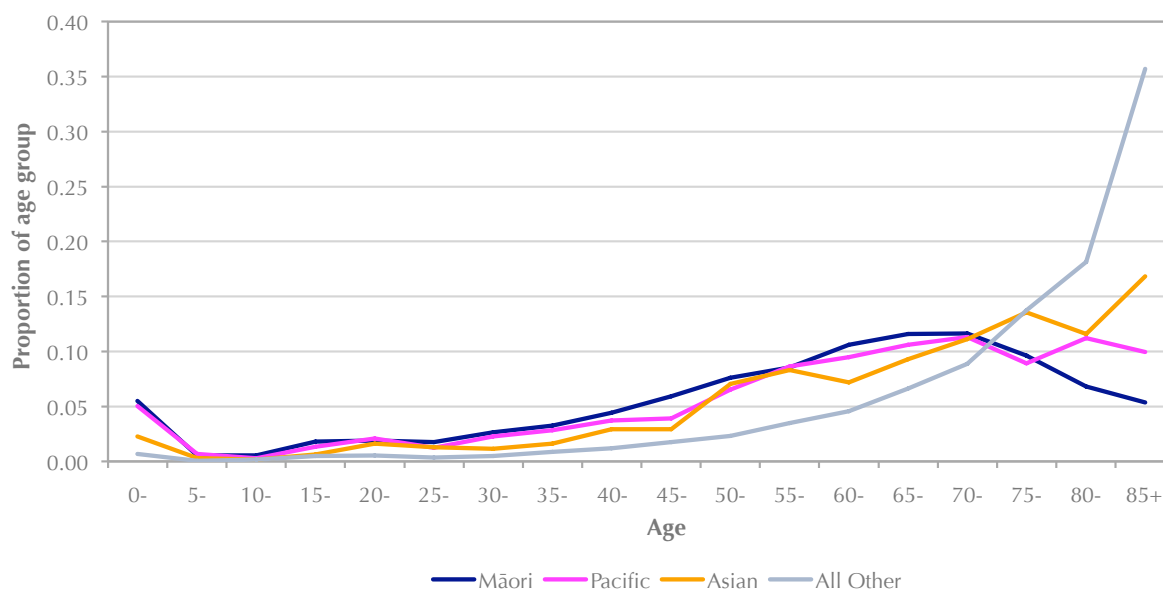


Source: District Health Board Population Projections, 2007–26, Statistics New Zealand 2010.

Age-Related Mortality

Alongside and linked to these population trends is the number of deaths in the older age groups. With the increasing size of this older age group comes a similar proportional increase in the number of deaths. Mortality data from 2007 shows 77.6% of all deaths (22,193) were of those aged 65 and over. The proportion of deaths by age group for the main ethnic groups in New Zealand is illustrated in Figure 5 using data from 2007. A notable feature of this graph is the difference in mortality by age group for Māori, Pacific and Asian ethnic groups compared with the All Other group. In these three ethnic groups more people died at a younger age, which led to fewer deaths in the over 65 age group. The All Other group includes people who identified as New Zealand European, New Zealander, Other European and European not further defined; Middle Eastern, Latin American and African (MELAA), Other Ethnicity and Not Elsewhere Included. Deaths in the All Other group closely reflects the overall national age-related mortality trend.

Figure 5: Proportion of deaths by age group for four main ethnic groups in New Zealand

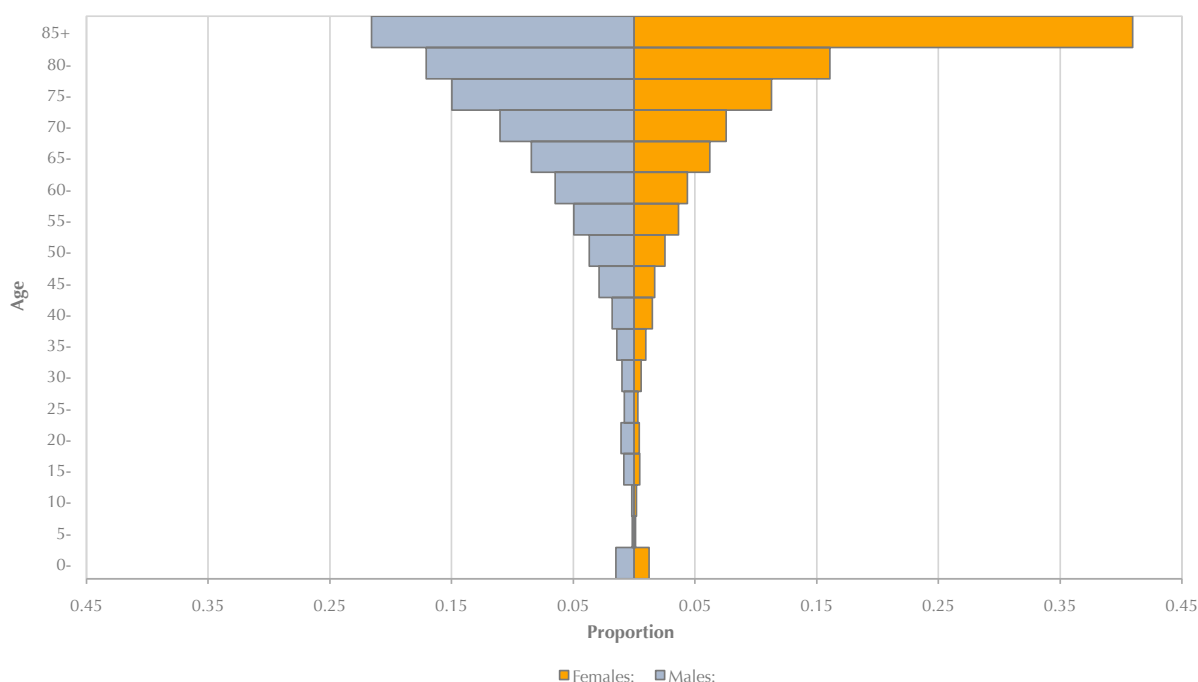


Source: Mortality and Demographic Data 2007 (Ministry of Health 2010).

The differences in age-related mortality based on ethnicity are statistically significant for the Māori and Pacific groups ($\chi^2(51) = 3821$ Pr = 0.000). There are significantly more deaths in the under 1 age group, and significantly fewer deaths in the over 85 age group for both ethnic groups. For Māori there are also significantly more deaths in the middle age groups (30–60 years old).

The trend in gender proportions of the population is also reflected in the number of deaths for each gender across the different age groups (Figure 6). In 2007, 73.1% of male deaths (10,480) were of men aged 65 or older, while 82.1% of female deaths, nearly 10% more, were of women aged 65 or older. As can be seen in Figure 6, the proportion of deaths of females was even higher in the over 80 age group accounting for 57% of all female deaths (8138 deaths) and 66% of deaths in this age group.

Figure 6: Proportion of all deaths in 2007 for each gender, by age group



Source: Mortality and Demographic Data 2007 (Ministry of Health 2010).

The implication of the gender differences is that many women will survive their male spouse or partner to live alone and probably require care. This is reflected in a study of Auckland residential aged care in 2008 that found females made up 70% of residents (Broad et al 2011).

Figure 7 illustrates the age-related mortality for males and females in the Māori and Pacific ethnic groups and clearly illustrates the different patterns of mortality for these groups compared with the population as a whole. While this paints a disquieting picture of health for these people, it also raises the importance of not only having culturally appropriate palliative and end-of-life care services, but also ensuring services take account of the younger age at death of these ethnic groups. It should be noted, however, that the actual number of deaths in these ethnic groups is considerably smaller than for the rest of the population, except in the under 10 age group. Nonetheless, certain DHBs with larger population groups of Māori, Pacific and Asian people can expect a proportionally higher number of these people needing palliative and end-of-life care.

Figure 7: Proportion of all deaths in 2007 for Māori and Pacific ethnic groups (by gender and age group)

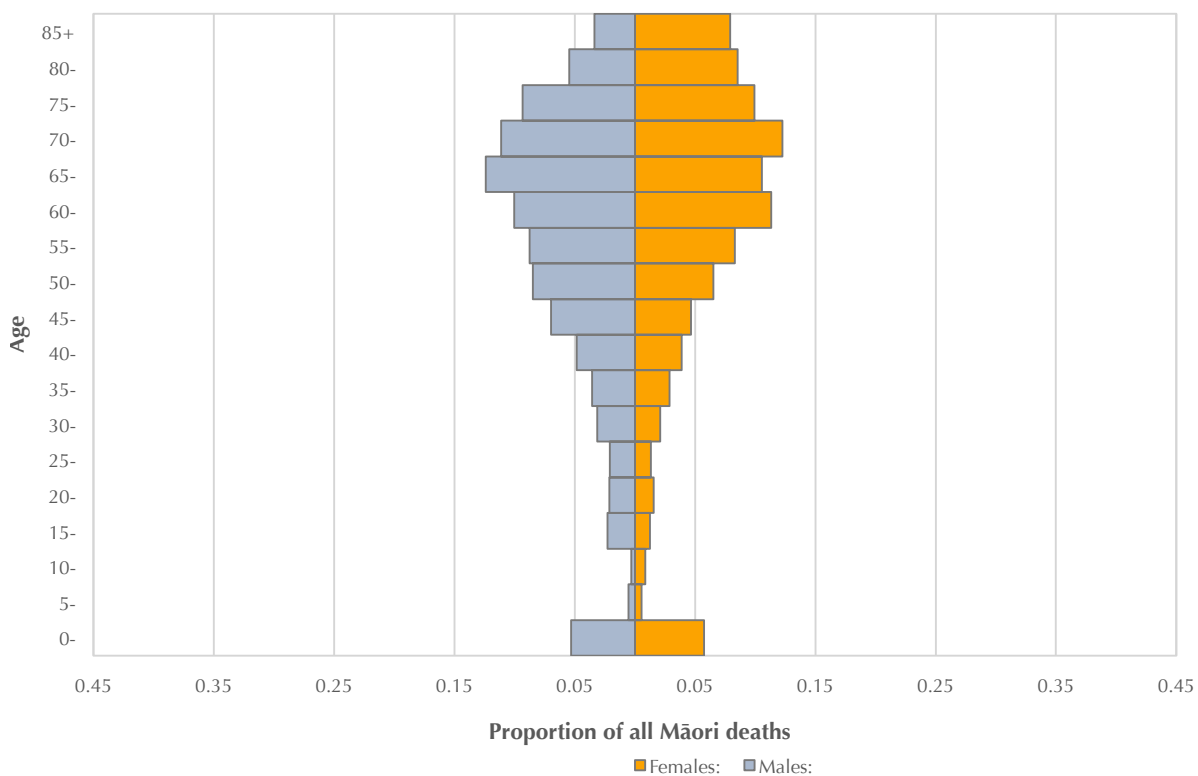
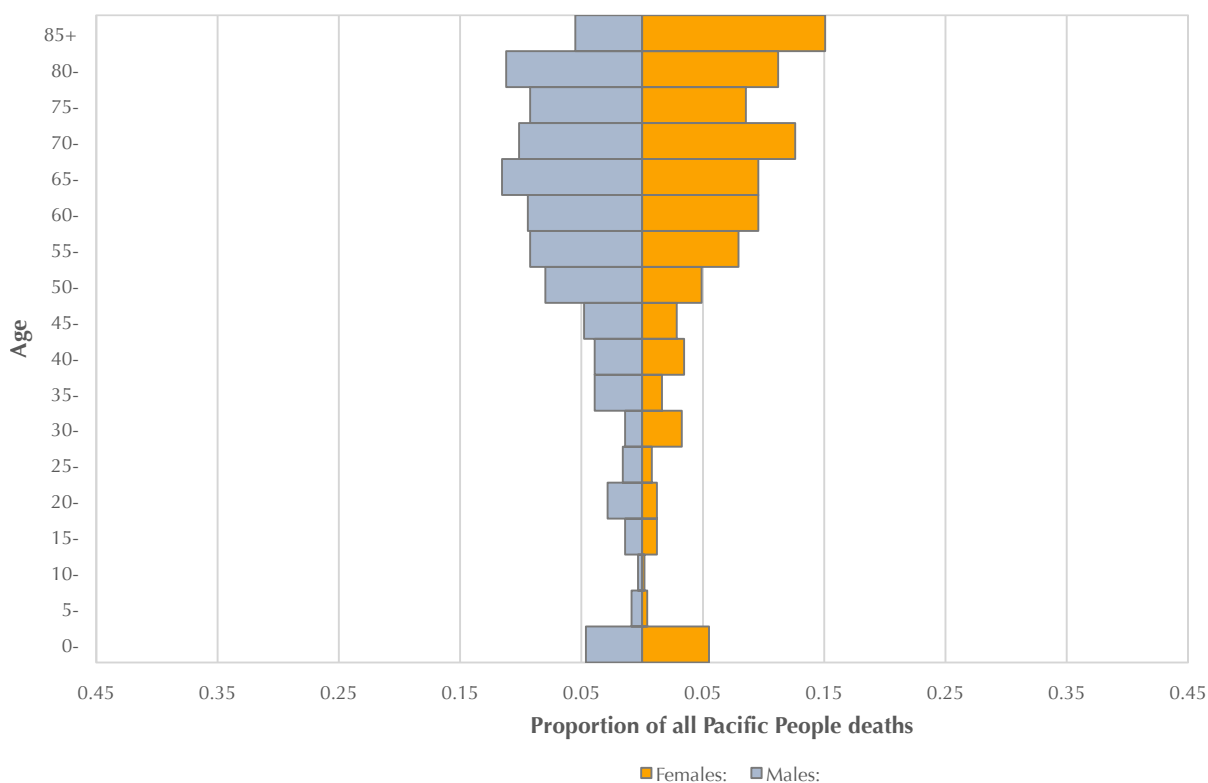


Figure 7 (continued): Proportion of all deaths in 2007 for Māori and Pacific ethnic groups (by gender and age group)



Source: *Mortality and Demographic Data 2007* (Ministry of Health 2010).

Ethnic Composition and Religion of the New Zealand Population

The New Zealand health system has a focus on providing culturally appropriate care, and this view is clearly stated in *The New Zealand Palliative Care Strategy* (Ministry of Health 2007) and New Zealand definition of palliative care (Palliative Care Subcommittee 2007). Ethnicity and religion are two important defining components of culture and so are explored here as a way of incorporating this element into palliative care need.

New Zealand has a very diverse ethnic makeup. Alongside the major ethnic groups, European, Māori and Pacific, there are several other growing ethnic groups, including Chinese, Indian and other Asian ethnicities, plus a range of people from Middle Eastern, Latin American and African countries. However, these ethnic groups are not evenly dispersed around New Zealand. It is therefore important to establish the ethnic composition of DHB regions, as this may have implications for the level and type of resources needed. For example there may be a requirement for additional interpreting services for people with English as a second language, or cultural competency training for the palliative care workforce. Any differences across regions will also allow services to take into account the different disease burden and noted differences in age-related mortality between ethnic groups.

Similarly, there is a wide range of religious groups in New Zealand, and again it will be very useful to understand the distribution of these groups within the DHB regions. This will allow services to ensure they are adequately resourced to meet the spiritual needs of their population.

Data on ethnicity and religious affiliation have been collected from the Census 2006. Specific data requests were made to Statistics New Zealand for this data to make sure it was of sufficient detail

to allow for meaningful regional analysis. Ethnicity was reported as prioritised to level 2 in the following order: Māori, Pacific Peoples, Asian, MELAA, Other, New Zealander and European and Not Elsewhere Included, e.g. if a person is both Pacific Peoples and Asian, then they are counted in the Pacific Peoples category.

The majority of the New Zealand population identify as New Zealander, New Zealand European or European (67%), followed by Māori (14%) and Pacific (5.6%). The Pacific group includes people who identify as Samoan, Cook Island Māori, Tongan, Niuean, Fijian, Tokelauan and any other Pacific Peoples groups. The other major ethnic groups include Chinese (3.4%), Indian (2.5% and Other Asian (2.6%). However, these groups do not necessarily follow the national averages across all DHB regions, with some notable differences in ethnic mix (Table 2). Notably, all DHBs in the South Island have a higher than average number of Europeans, with a corresponding lower number of all other ethnic groups. There are around half as many Māori as would be expected in all South Island DHBs when compared with the national average of 14%, except for Southland DHB where Māori make up 10% of the population. Canterbury also has a slightly higher number of Chinese and Other Asian people; however, this is still lower than the national average.

In contrast, the North Island DHBs generally have a Māori population that is at or above the national average. The exceptions are Auckland and Waitemata as the only DHBs with a lower than average Māori population. Northland and Lakes DHBs both have approximately 30% Māori in their populations, and Tairāwhiti DHB has the highest proportion of Māori at just over 44% — almost half the DHB population. Auckland DHB has probably the greatest ethnic diversity, with a lower number of European and Māori than the New Zealand average, but higher numbers of all the other main ethnic groups; in particular the proportions are significantly higher for Pacific, Chinese, Indian and Other Asian. Counties Manukau DHB has the highest proportion of Pacific Peoples at 19%, as well as higher numbers of Chinese and Indian people.

Further details, including estimated numbers of people in each ethnic group from the Census 2006, are provided in a table in Appendix 4.

Table 2: Percentage of people in each main ethnic group (prioritised to level 2) by DHB

DHB ⁽¹⁾	European ⁽²⁾	Māori	Pacific Peoples ⁽³⁾	Chinese Asian	Indian Asian	Other Asian	MELAA ⁽⁴⁾	Other	Not Elsewhere Included ⁽⁵⁾
Northland	60.27%	29.32%	1.25%	0.30%	0.41%	0.73%	0.19%	0.01%	7.52%
Waitemata	65.45%	8.90%	6.32%	5.32%	3.01%	5.43%	1.31%	0.04%	4.23%
Auckland	51.63%	7.38%	11.26%	10.26%	7.23%	5.14%	1.61%	0.03%	5.47%
Counties Manukau	42.45%	15.53%	19.15%	5.91%	6.61%	3.57%	1.13%	0.04%	5.63%
Waikato	67.98%	19.89%	2.13%	1.86%	1.48%	1.50%	0.66%	0.03%	4.48%
Lakes	57.42%	31.91%	2.18%	0.73%	0.81%	1.45%	0.26%	0.04%	5.20%
Bay of Plenty	68.53%	23.42%	1.13%	0.46%	1.14%	0.78%	0.24%	0.01%	4.29%
Tairāwhiti	46.39%	44.44%	1.66%	0.51%	0.44%	0.34%	0.14%	—	6.06%
Taranaki	78.20%	15.17%	0.83%	0.67%	0.55%	0.68%	0.18%	0.01%	3.71%

Hawke's Bay	68.60%	22.87%	2.63%	0.72%	0.74%	0.66%	0.36%	0.01%	3.42%
Whanganui	69.81%	23.19%	1.46%	0.65%	0.60%	0.45%	0.18%	0.02%	3.64%
MidCentral	73.68%	16.82%	2.13%	2.07%	0.80%	1.25%	0.55%	0.02%	2.69%
Hutt Valley	66.81%	15.78%	7.24%	2.36%	2.37%	2.11%	0.91%	0.02%	2.40%
Capital and Coast	68.41%	9.94%	7.13%	3.75%	2.70%	2.83%	1.40%	0.03%	3.81%
Wairarapa	79.57%	14.23%	1.61%	0.49%	0.35%	0.44%	0.21%	0.04%	3.05%
Nelson Marlborough	85.24%	8.42%	1.01%	0.37%	0.31%	0.95%	0.33%	0.02%	3.35%
West Coast	85.18%	9.31%	0.61%	0.19%	0.26%	0.51%	0.20%	–	3.73%
Canterbury	81.63%	7.16%	1.93%	2.69%	0.66%	2.57%	0.66%	0.02%	2.67%
South Canterbury	89.76%	5.86%	0.68%	0.43%	0.21%	0.76%	0.18%	–	2.12%
Otago	84.96%	6.39%	1.46%	1.83%	0.55%	1.31%	0.51%	0.03%	2.97%
Southland	82.48%	10.60%	1.13%	0.43%	0.36%	1.03%	0.43%	0.02%	3.54%
New Zealand	66.88%	14.04%	5.62%	3.41%	2.48%	2.57%	0.81%	0.03%	4.17%

Notes on Table 2

1. Confidentiality rules have been applied to all cells in this table. Individual figures may not add up to totals, and values for the same data may vary in different tables. A '–' indicates there were no residents who identified with this ethnicity.
2. 'European (including New Zealand European)' includes people who identified as: New Zealand European, New Zealander, Other European and European not further defined.
3. 'Pacific Peoples' includes people who identified as Samoan, Cook Island Māori, Tongan, Niuean, Fijian, Tokelauan and any other Pacific Peoples groups.
4. 'MELAA' includes people who identified as Middle Eastern, Latin American and African.
5. 'Not Elsewhere Included' includes Response Unidentifiable, Response Outside Scope and Not Stated.

Seventeen religious groups were identified in the Census 2006, not including 'Other Religions' and 'Not Elsewhere Included' responses. Half the New Zealand population identified with the collective group of Christian denominations, most commonly Anglican and Catholic. A very small number of people (1.4%) identified with Māori Christian religions (including Ratana and Ringatū). There is also an important array of other religions within the population, the appearance of many of these is likely to be a result of the increasing ethnic diversity in New Zealand. Not surprisingly, there are clusters of these religions in DHB regions that have higher than average numbers of these ethnic groups. For example Auckland and Counties Manukau have higher levels of people identifying with Buddhist, Hindu and Islam/Muslim religions, which reflects the higher number of Asian, Indian and Middle Eastern groups in these DHBs. The main implication of these differences is that health care staff may require additional education and resources in order to meet the spiritual care needs of their local population. Appendix 5 provides a summary of DHB and national level information on population proportions identifying with each religious group based on Census 2006 data.

In the Census 2006 nearly one third (31.45%) of people reported having 'No Religion', which is by far the largest single group and much larger than in other countries. In Australia the group reporting No Religion comprised 19% of the population in their 2006 Census, and in the 2001 Census of the United Kingdom population this group was 15%. Across the DHB regions this group remains fairly constant, with a range of 24.4% to 37.4%. Such a high proportion of people with no stated religious affiliation may also have important implications for the provision of spiritual care at the end of life.

Living in Households

For people to be cared for at home during the last year of life, it is important that alongside good professional care they have support from informal carers. If an individual is living alone then informal support may be more difficult to access, and if this person is also retired there may be additional personal and financial strain. This may also be the case for retired couples. Given the analysis of males and females in the population (discussed earlier), there is a high likelihood older people living alone will be female. The number of people, and percentage of the population each group makes up, is presented in Table 3 for each DHB and for New Zealand as a whole.

Table 3: Single person and retired households and aged residential care residents by DHB region: Number of individuals (% of total population)

DHB (% of population)	Single person households ⁽¹⁾	Single person retired ⁽²⁾ households	All other retired households ⁽³⁾	Resident of ARC facility or private hospital (>65 y.o.) ⁽⁴⁾
Northland	12,660 (8.3%)	4,650 (3.0%)	7,713 (5.1%)	738 (0.5%)
Waitemata	31,176 (6.2%)	11,328 (2.2%)	18,627 (3.7%)	2,358 (0.5%)
Auckland	33,129 (7.7%)	9,033 (2.1%)	9,672 (2.3%)	2,904 (0.7%)
Counties Manukau	19,326 (4.2%)	6,942 (1.5%)	11,457 (2.5%)	1,488 (0.3%)
Waikato	27,456 (7.8%)	9,957 (2.8%)	15,618 (4.5%)	1,890 (0.5%)
Lakes	7,848 (7.7%)	2,658 (2.6%)	4,041 (4.0%)	570 (0.6%)
Bay of Plenty	16,257 (8.1%)	6,852 (3.4%)	13,062 (6.5%)	1,227 (0.6%)
Tairāwhiti	3,627 (7.9%)	1,332 (2.9%)	1,563 (3.4%)	231 (0.5%)
Taranaki	10,119 (9.4%)	4,023 (3.7%)	5,757 (5.4%)	870 (0.8%)
Hawke's Bay	13,416 (8.8%)	5,337 (3.5%)	7,158 (4.7%)	1,020 (0.7%)
Whanganui	6,690 (10.5%)	2,706 (4.2%)	3,426 (5.4%)	531 (0.8%)
MidCentral	14,964 (9.1%)	5,724 (3.5%)	7,851 (4.8%)	1,020 (0.6%)
Hutt Valley	11,856 (8.4%)	4,113 (2.9%)	5,295 (3.8%)	894 (0.6%)
Capital and Coast	23,766 (8.6%)	6,957 (2.5%)	9,708 (3.5%)	1,320 (0.5%)
Wairarapa	4,110 (10.4%)	1,698 (4.3%)	2,289 (5.8%)	378 (1.0%)
Nelson Marlborough	12,066 (9.0%)	4,680 (3.5%)	7,548 (5.6%)	978 (0.7%)
West Coast	3,600 (11.2%)	1,116 (3.5%)	1,527 (4.8%)	219 (0.7%)
Canterbury	42,174 (8.7%)	15,900 (3.3%)	23,499 (4.9%)	4,308 (0.9%)
South Canterbury	5,901 (10.7%)	2,628 (4.8%)	4,125 (7.5%)	516 (0.9%)
Otago	17,817 (9.7%)	7,005 (3.8%)	9,870 (5.3%)	1,593 (0.9%)
Southland	10,206 (9.3%)	3,666 (3.3%)	4,851 (4.4%)	768 (0.7%)
New Zealand	328,164 (8.1%)	118,305 (2.9%)	174,657 (4.3%)	25,821 (0.6%)

Notes on Table 3

The figures in this table refer to individual people and are based on Census2006 data.

1. Includes people aged over 15 only.
2. 'Retired' has been defined as 'over 65 and not in the labour force'.
3. 'All other retired households' includes people who identified as being in a couple only household and who were over 65 and not in the labour force (i.e. retired). It is possible that the other person in the household may not meet the 'retired' criteria described in Note 2.
4. Only those residents identified as not in the labour force are included.

Most DHB regions follow the national average figures for household composition, but with a few notable exceptions. Counties Manukau has around half the number of people living in single and retired households than the general population. Auckland also has fewer retired households. This may be due to the DHBs having a younger population (62% under age 40 compared with 56% of the New Zealand population) and/or possibly that single and retired people tend to live in large family homes rather than in their own home. There is a similar, although not as dramatic, pattern in other DHBs within a major city where populations are generally younger. Whanganui, West Coast and South Canterbury DHBs on the other hand, have a higher than average number of single person households, with South Canterbury also having a higher number of retired households.

The number of aged residential care (ARC) residents is of great importance to palliative care, as many of these people will die within these facilities from chronic diseases or age-related disorders. Based on the Census 2006 data, there were 511,200 people over the age of 65 in New Zealand. Approximately 1 in 20 of these people were living in ARC.

An analysis of four cross-sectional functional census surveys of aged care residents, completed from 1988 to 2008 in Auckland, has found that physical dependence of the residential aged care population increased significantly over this 20-year period (Boyd et al 2011). It is therefore vital that these services are adequately resourced and have appropriately trained staff to provide high-quality palliative and end-of-life care. As part of resourcing, ARC facilities should be able to access specialist palliative care support when required.

Relative Deprivation

Deprivation is a state of observable and demonstrable disadvantage relative to the local community or the wider society or nation to which an individual, family or group belongs (Townsend 1987). In New Zealand deprivation is measured through the Index of Deprivation, which provides a measure of *relative* socioeconomic deprivation experienced by groups of people in small areas (each with a usually resident population of at least 100 people). The index is created from nine variables taken from the Statistics New Zealand Census of Population and Dwellings and reported in the *Atlas of Socioeconomic Deprivation in New Zealand* (White et al 2008). Therefore the most recent deprivation data is from 2006, referred to as NZDep2006. Areas are ranked by total deprivation score and then divided into tenths and allocated an NZDep2006 scale score from 1 to 10, each representing 10% of the population. The lowest 10% of scores are the least deprived group (decile 1), and the highest 10% of scores are the most deprived (decile 10). Therefore, a value of 10 indicates that an area is in the most deprived 10% of areas in New Zealand. This method produces a measure of relative deprivation; it is not a measure of wealthiest versus poorest.

Although research is limited to date, there is some evidence showing that providing palliative care for people in more deprived areas requires more resources than in the most affluent areas. A study undertaken by St Christopher's Hospice in London found that people in the most deprived district of their catchment required, on average, twice as many home visits as people from more affluent districts (Clark 1997). After the annual incidence of deaths, deprivation is therefore considered the second most important factor affecting palliative care resource needs in a population (Tebbit 2004).

Data analysis on deprivation has been conducted using census area units (CAU) as the smallest area of measure. There are 1792 CAUs, spread across the DHB regions, although the number of CAUs within a DHB varies ranging from 23 to 189. The CAUs are constructed from 41,376 meshblocks, which are small areas created by Statistics New Zealand for the census. This means there may be considerable variation in deprivation among the small areas (meshblocks) that is hidden when using an average deprivation statistic for a CAU, and even more so when taking a DHB average. Therefore, the approach taken in this analysis was to create an overview of the number of CAUs within each DHB region that fall within specific deprivation quintiles (Table 4).

This approach provides an indication of the spread of deprivation within a DHB, but it does not give detailed information on deprivation within different areas or population groups of each DHB, nor can it be applied to individuals within the DHB.

While this data and associated analysis provides an indication of the relative deprivation of each DHB population, it may not accurately represent deprivation experienced by those over the age of 65 in New Zealand. This is because several of the variables used to create the deprivation index exclude people over the age of 65, in particular income, employment status and qualifications. The rationale for this is that a guaranteed retirement income is available to all those over the age of 65. However, this does not necessarily mean that these people are relatively well off compared with those under the age of 65.

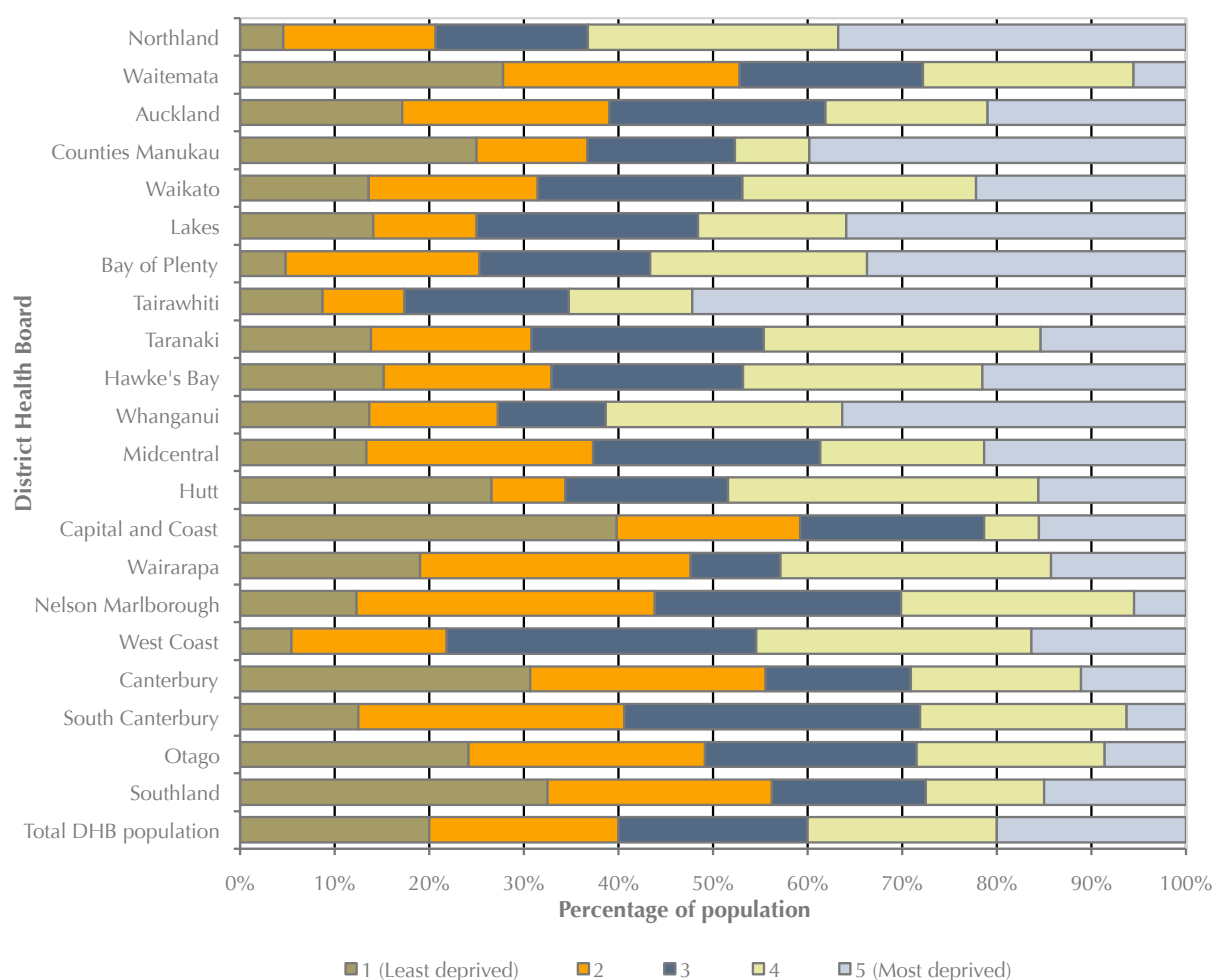
Table 4: Percentage of CAUs in each deprivation quintile by DHB

DHB name	Deprivation quintile					No. of CAUs
	1 Least deprived	2	3	4	5 Most deprived	
Northland	5%	16%	16%	26%	37%	87
Waitemata	28%	25%	19%	22%	6%	144
Auckland	17%	22%	23%	17%	21%	105
Counties Manukau	25%	12%	16%	8%	40%	128
Waikato	14%	18%	22%	25%	22%	162
Lakes	14%	11%	23%	16%	36%	64
Bay of Plenty	5%	20%	18%	23%	34%	83
Tairāwhiti	9%	9%	17%	13%	52%	23
Taranaki	14%	17%	25%	29%	15%	65
Hawke's Bay	15%	18%	20%	25%	22%	79
Whanganui	14%	14%	11%	25%	36%	44
MidCentral	13%	24%	24%	17%	21%	75
Hutt Valley	27%	8%	17%	33%	16%	64
Capital and Coast	40%	19%	19%	6%	16%	103
Wairarapa	19%	29%	10%	29%	14%	21
Nelson Marlborough	12%	32%	26%	25%	5%	73
West Coast	5%	16%	33%	29%	16%	55
Canterbury	31%	25%	15%	18%	11%	189
South Canterbury	13%	28%	31%	22%	6%	32
Otago	24%	25%	22%	20%	9%	116
Southland	33%	24%	16%	13%	15%	80
Total DHB population	20%	20%	20%	20%	20%	1792

Figure 8 graphically depicts the distribution of deprivation for each DHB region, and shows some substantial differences in DHB populations. Northland, Bay of Plenty, Tairāwhiti and West Coast DHBs have a much smaller number of CAUs in the least deprived quintile (5%–9%) and in a number of other DHBs just over 10% of CAUs fall into this quintile. In some cases these DHBs also have a much larger proportion of CAUs in the most deprived group (quintile 5), most notably Northland, Bay of Plenty and Tairāwhiti, but there are also several other DHBs with a high proportion of CAUs in the most deprived group. This includes Counties Manukau, Lakes and Whanganui. A number of DHBs also have a higher than average number of CAUs in the

least deprived quintile 1, including Waitemata, Hutt Valley, Capital and Coast, Canterbury and Southland. Counties Manukau is quite interesting, as it has large groups in both the most deprived quintile 5 (40%) and the least deprived quintile 1 (25%) suggesting this region has pockets of both low and high deprivation. The Nelson Marlborough, West Coast and South Canterbury DHB populations sit predominantly in the middle quintiles.

Figure 8: DHB region populations by deprivation quintile



Source: *Atlas of Socioeconomic Deprivation in New Zealand (NZDep2006)*.

What this analysis illustrates is that even though overall deprivation across the DHBs fits neatly into 20% quintiles, deprivation is not consistent across DHB regions, and within DHB populations there can be a wide range of deprivation. DHBs need to take this into account when developing service delivery models and allocating resources. Taking into consideration the increased resource needs of more deprived population groups, any national planning approach will need to consider not only the population size and number of deaths in each DHB, but also the relative deprivation of the population as well.

Palliative Care Population Estimates

Apart from the general agreement that access to palliative care should be based on need, there is no clear guidance available on how to define the group of people who should receive palliative care. This creates some difficulty in forming a functional definition for use in palliative care planning and research. Various attempts have been made to describe this group, most commonly based on certain diagnoses where palliative care is known to be of benefit (Higginson 1997;

McNamara et al 2006). But this approach does not take need into account; instead it has a condition-specific focus, and is not in line with the philosophical definition of palliative care being provided based on need rather than diagnosis. Therefore, the model chosen for this Needs Assessment attempts to address these issues by producing three different estimates of the number of people who would benefit from palliative care. The estimates incorporate both condition-specific and needs-based criteria, as well as an 'ideal' situation. (See the Methodology section for more detail on how these estimates were generated, including the inclusion and exclusion criteria for each estimate.)

The estimates produced from the model used in this project do not differentiate between those patients who would benefit from specialist versus generalist palliative care, as the criteria are not that specific. Without detailed clinical information it is not possible to assess which individuals might have been suitable for these different levels of palliative care. In addition, there is limited evidence available on the number of cancer and non-cancer patients who should receive either specialist or generalist level palliative care. Palliative Care Australia's service planning guide does offer some advice on this, however, and this has been incorporated into the estimate modelling (Palliative Care Australia 2003).

Data was obtained from the Mortality Collection held by National Collections and Reporting, Information Delivery and Operations, National Health Board, Ministry of Health. Data was extracted using the defined criteria for each estimate for the two age groups and provided as individual SAS® files by age group and estimate. This resulted in six data sets, one for each of the three estimates for CYP and adults.

The datasets contained individual records for each person who met the inclusion criteria. Individual records did not include any personally identifiable information and were uniquely identified by an encrypted NHI number. Encryption was undertaken by National Health Board Analytical Services prior to the datasets being released. The following data fields were provided for each individual death record:

- encrypted NHI
- age at death
- age group
- sex
- prioritised ethnicity (level 2)
- ethnicity 1 (level 2)
- ethnicity 2 (level 2)
- ethnicity 3 (level 2)
- domicile code
- New Zealand deprivation index quintile 2006 (based on domicile code)
- Territorial Local Authority (TLA) of domicile
- District Health Board of domicile
- facility
- place of death*
- underlying cause of death (diagnosis type 'D')
- other relevant diseases present (B1) (diagnosis type 'F')†
- other contributing causes (B2) (e.g., medical misadventure) (diagnosis type 'G')†
- date of death
- year of death.

* Place of death category was derived using a combination of facility type and the free text 'location of death field'.

† All recorded diagnoses of type 'F' and 'G' were provided.

All datasets were reviewed and cleaned to ensure all records met the inclusion criteria. As most variables were coded by a number, some recoding was undertaken to allow for meaningful data extractions, for example, ethnicity codes were allocated ethnic group names and ICD-10-AM codes were allocated a disease group name based on standard ICD-10-AM groupings.

All estimates are based on data averaged over a three-year period to allow for any unusually high or low counts. The most recently available Mortality Collection data has been used covering the years 2005, 2006 and 2007. Over these three years there were a total of 84,131 deaths. Table 5 shows the total number of individual records in each estimate group (based on the specified inclusion and exclusion criteria) for this three-year period.

Table 5: Total number of individuals in each estimate group over a three-year period (2005–2007)

Estimate	Children and young people (0–19)	Adults	
		20+	65+
Minimal	862	34,257	26,434
Mid-range	826	46,481	36,812
Maximal	1164	76,824	62,936

Adult Estimates (age 20+)

During the period 2005 to 2007 there were 82,156 deaths from all causes in the over 20 age group; an average of 27,385 deaths per year. Note the category ‘areas outside of a DHB’ has been excluded from the data analysis, which reduces the number of average deaths per year to 27,257. Table 6 shows the number of deaths where palliative care may have been of benefit based on the three different estimation criteria. These figures also exclude deaths in ‘areas outside of a DHB’. Taking the condition-specific approach (minimal estimate) this would mean, on average, 11,390, or 41.8% of deaths may have benefited from palliative care. The mid-range, or needs-based, estimate produces a slightly higher number of 15,452 (56.7%), while the maximal estimate includes most adult deaths (93.6%).

Table 6: Adult group national palliative care population estimates (age 20+), average annual deaths from 2005 to 2007

	Estimates (No. of individuals and % of all adult deaths)		
	Minimal	Mid-range	Maximal
All adult deaths ⁽¹⁾	27,257	27,257	27,257
Cancer deaths (% of all adult deaths)	8116 (29.8%)	6579 (24.1%)	8116 (29.8%)
Non-cancer deaths (% of all adult deaths)	3274 (12.0%)	8873 (32.6%)	17,399 (63.8%)
Estimated palliative care population (% of all adult deaths)	11,390 (41.8%)	15,452 (56.7%)	25,515 (93.6%)

Notes on Table 6

1. 'All deaths' is taken from the Mortality and Demographic Data Annual Statistical Publication Series and figures are averaged over three years (2005, 2006 and 2007).
2. Excludes deaths in areas outside of a DHB.

Further analysis of the mid-range estimate has been undertaken to provide DHB regional data on the estimated number of people who would benefit from palliative care per year. This has been compared with the average number of deaths per annum from all causes over the same period (2005–2007) (Table 7). Overall, the mid-range estimate includes around 57% of all deaths, with a range of 49.8% in the Wairarapa DHB, to 63.1% in the Otago DHB. In addition, the estimate has been converted into a number per 100,000 of the population for each DHB. This figure has then been used to calculate projected figures for 2016 and 2026.

Table 7: Mid-range estimate of the number of adults who would benefit from palliative care per year, and projected numbers for 2016 and 2026, by DHB

DHB	2006 population ⁽¹⁾	All deaths (12 month average) ⁽²⁾	Mid-range estimate deaths per 100,000 population	Mid-range estimate (% of all deaths)	Projected mid-range estimate of numbers likely to benefit from palliative care	
					2016	2026
Northland	106,040	1157	624	662 (57.2%)	746	789
Waitemata	359,150	2549	439	1576 (61.8%)	1886	2174
Auckland	319,730	2310	401	1282 (55.5%)	1521	1740
Counties Manukau	301,160	2129	410	1236 (58.1%)	1538	1832
Waikato	244,180	2384	532	1300 (54.5%)	1463	1568
Lakes	69,640	699	527	367 (52.6%)	396	409
Bay of Plenty	142,240	1597	642	913 (57.1%)	1069	1195
Tairāwhiti	30,400	382	674	205 (53.7%)	221	223
Taranaki	76,300	885	626	478 (54.0%)	510	513
Hawke's Bay	106,460	1245	688	732 (58.8%)	786	811
Whanganui	45,040	570	702	316 (55.5%)	325	315

MidCentral	116,130	1244	595	691 (55.5%)	758	798
Hutt Valley	98,550	869	514	506 (58.3%)	546	560
Capital and Coast	204,570	1501	388	794 (52.9%)	913	997
Wairarapa	28,520	334	583	166 (49.8%)	178	179
Nelson Marlborough	98,420	1043	562	553 (53.0%)	618	656
West Coast	23,530	243	578	136 (56.0%)	146	143
Canterbury	354,780	3406	543	1926 (56.5%)	2187	2391
South Canterbury	40,730	508	729	297 (58.5%)	316	315
Otago	136,410	1415	654	892 (63.1%)	973	1006
Southland	80,390	787	527	424 (53.9%)	455	462
Total	2,982,370	27,257	518	15,452 (56.7%)	17,550	19,076

Notes on Table 7

1. Populations are based on District Health Board Population Projections, 2007–26 (2006-Base) produced by Statistics New Zealand in September 2010.
2. 'All deaths' is for a 12-month period and is averaged over three years (2005, 2006 and 2007). Figures are taken from the Mortality and Demographic Data Annual Statistical Publication Series.

Based on population growth over the next 15 years, the number of adult deaths in 2026 where palliative care may be of benefit is estimated to be 19,076. This is an increase of 23.5% from the baseline estimate (which could be considered a 2006 figure), or around 180 additional deaths every year.

The actual number of deaths varies quite widely between DHBs and is largely a reflection of their population size, although this may also be affected by the age structure of the populations. This will need to be taken into account when planning services from a national perspective, so that resources are appropriately allocated and located to meet population need. However, the added component of deprivation, which as noted earlier is a vital driver of health resource need, must also be taken into account.

How many adults might need specialist palliative care?

There is limited evidence available on how the number of people who could benefit from palliative care can be allocated into the groups of those requiring specialist palliative care and those who could be cared for adequately by generalist palliative care providers. Palliative Care Australia (PCA) has developed recommended rates of referral and ongoing care for specialist palliative care, "based on best available empirical evidence" (Palliative Care Australia 2003, p. 21).

PCA recommends 90% of people who ultimately die of cancer should be referred to a specialist palliative care (SPC) service for assessment. Seventy percent should receive ongoing consultancy from a SPC service and 20% should receive direct care by a SPC service. Those who need 'ongoing consultancy' are likely to require short-term or intermittent support from SPC, but would predominantly be cared for by a generalist palliative care provider. One could therefore surmise that 70% of people who die from cancer would receive the majority of their care from a generalist palliative care provider with SPC support. The 20% who need 'direct care' are likely to be complex and require ongoing SPC input.

If we assume that the mid-range estimate captures all those cancer patients in need of palliative care (the estimate includes 81% of all people who died from cancer) then this is likely to be a good estimate of the number of individuals who should be referred for specialist assessment. This would be 6579 adults per annum. Applying the relative proportions suggested by PCA (approximately a 70/20 split assuming the estimate is equivalent to their suggested 90% needing assessment), this would equate to 5117 adults per annum receiving generalist palliative care with SPC support, and 1462 adults per annum requiring ongoing care from a SPC service.

For people with a non-cancer diagnosis, the PCA recommendations are that 50% of people expected to die from non-cancer diseases should be referred for SPC assessment. Of these, 30% should receive ongoing consultancy from a SPC service, and 10% will need direct care from a SPC service.

The mid-range estimate includes 46% of all non-cancer deaths, which again is quite close to the PCA recommended referral rate of 50%. Applying the PCA recommendations to this group would mean all individuals in the estimate should be referred for assessment by SPC. This would amount to 8873 individuals per annum. Once again, by applying the relative proportions suggested by PCA, 5324 adults per annum should receive care from generalist palliative care providers with SPC support, and 1775 adults per annum should receive ongoing care from a SPC service. It must be presumed that the remaining 10% of those referred for assessment are deemed not to have palliative care needs.

Children and Young People Estimates (ages 0–19)

During the period 2005 to 2007 there were 1975 deaths in the 0–19 age group; an average of 652 deaths per year (excluding areas outside of a DHB). Table 8 shows the number of deaths where palliative care may have been of benefit based on the three different estimation criteria. Taking the condition-specific approach this would mean that, on average, 287, or 44% of these deaths might have benefited from palliative care. The mid-range, or needs-based, estimate produces a slightly lower number of 273 (41.9%), while the maximal estimate suggests a little over half (59.5%) of all deaths in this age group may have benefited from palliative care.

Table 8: Children and young people group national palliative care population estimates (age 0–19), average annual deaths from 2005 to 2007

	Estimates (No. of individuals and % of all CYP deaths)		
	Minimal	Mid-range	Maximal
All CYP deaths ⁽¹⁾	652	652	652
Cancer deaths	46 (7.1%)	38 (6.0%)	46 (7.1%)
Non-cancer deaths	241 (37.0%)	234 (35.9%)	342 (52.5%)
Estimated palliative care population	287 (44.0%)	272 (41.8%)	388 (59.5%)

Notes on Table 8

1. 'All deaths' is taken from the Mortality and Demographic Data Annual Statistical Publication Series and figures are averaged over three years (2005, 2006 and 2007).
2. Excludes deaths in areas outside of a DHB.

The difference in the maximal estimate for this group and that of the adult group may be due to the high number of perinatal deaths and deaths from external causes that occur in the CYP group, the majority of which were excluded from the CYP maximal estimate. There are also notable differences in the number of cancer versus non-cancer deaths between the two age groups, with adults having a much higher proportion of cancer deaths across all estimates. This probably reflects the much higher incidence of cancer in adults, as well as the higher likelihood of non-cancer deaths in this age group.

Further analysis of the mid-range estimate has been undertaken to provide DHB regional data on the estimated number of children and young people who would benefit from palliative care per year, and how this compares with the average annual number of deaths from all causes over the same time period (i.e. 2005–2007) (Table 9). On average this is about 43% of all deaths, with a range of 25.6% in Whanganui DHB to 54% in Auckland and South Canterbury DHBs. In addition, the estimate has been converted into a number per 100,000 of the population for each DHB. This figure has then been used to calculate projected figures for 2016 and 2026.

Table 9: Mid-range estimate of the number of children and young people who would benefit from palliative care per year, and projected numbers for 2016 and 2026, by DHB

DHB	2006 population ⁽¹⁾	All deaths (12 month average) ⁽²⁾	Mid-range estimate deaths per 100,000 population	Mid-range estimate (% of all deaths)	Projected mid-range estimate of numbers likely to benefit from palliative care	
					2016	2026
Northland	46,610	31	26	12 (39.8%)	12	12
Waitemata	145,550	51	16	24 (47.1%)	26	28
Auckland	108,580	50	25	27 (54.0%)	28	30
Counties Manukau	153,640	98	27	41 (42.2%)	46	51
Waikato	106,040	74	27	29 (38.7%)	29	29
Lakes	31,880	22	25	8 (36.4%)	7	7
Bay of Plenty	58,550	34	26	15 (44.1%)	15	16
Tairāwhiti	15,530	12	30	5 (38.9%)	4	4
Taranaki	31,140	17	21	7 (39.2%)	6	6
Hawke's Bay	46,140	31	27	12 (39.8%)	12	11
Whanganui	18,940	13	18	3 (25.6%)	3	3
MidCentral	47,860	31	25	12 (38.7%)	12	12
Hutt Valley	42,380	20	16	7 (33.3%)	6	6
Capital and Coast	73,370	33	23	17 (51.5%)	17	18
Wairarapa	11,060	6	15	2 (27.8%)	1	1
Nelson Marlborough	35,210	17	24	8 (49.0%)	8	8

West Coast	8,570	6	23	2 (33.3%)	2	2
Canterbury	128,580	54	16	20 (37.7%)	21	22
South Canterbury	14,380	8	30	4 (54.2%)	4	4
Otago	48,200	25	19	9 (37.3%)	9	9
Southland	29,590	19	25	7 (38.6%)	7	7
Total	1,201,800	652	23	272 (41.8%)	276	284

Notes on Table 9

1. Populations are based on District Health Board Population Projections, 2007–26 (2006-Base) produced by Statistics New Zealand in September 2010.
2. 'All deaths' is for a 12-month period and is averaged over three years (2005, 2006 and 2007). Figures are taken from the Mortality and Demographic Data Annual Statistical Publication Series and figures are averaged over three years (2005, 2006 and 2007).

For children and young people the estimated increase is only around 5% from the 2006 baseline figure of 272 (i.e. up to 284 by 2026). This relatively small increase is due to the population size of this group remaining fairly static over the next 15 years, although the proportion of this age group in the general population is expected to decrease as the adult group increases in size.

The actual number of deaths does not vary so widely between DHBs in this group, mainly due to the low number of deaths overall and the smaller size of this population group. However, some DHBs do experience more deaths in the CYP group, again usually related to population size, and in these regions consideration should be given to the availability of specific palliative and end-of-life care services for this age group. It should also be noted again that no account for levels of deprivation has been made in this analysis.

How many children and young people might need specialist palliative care?

A method for estimating how many of the CYP group may require specialist palliative care versus generalist palliative care is not available. However, given the relatively small number of individuals in this group, especially when perinatal and congenital condition deaths are excluded, it might be deemed reasonable that **all** of these children and young people be assessed by a specialist palliative care service to develop a plan of care in collaboration with other health service providers.

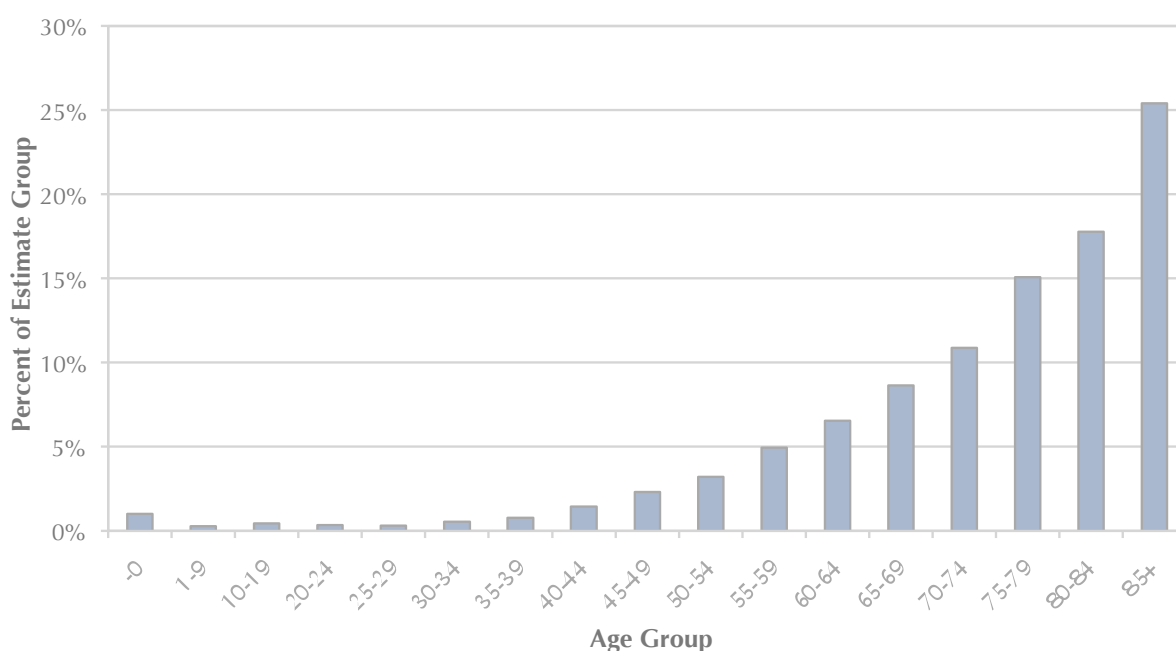
Characteristics of the Whole Mid-Range Estimate Group

Aside from the actual number of deaths, there is also a need to understand the demographics of the group of people who would benefit from palliative care. This information will be vital when planning services to ensure they are appropriate to meet the needs of people dying in New Zealand. For the purposes of this report only national level data is presented due to the volume of data, and once again it focuses on the mid-range estimate group.

Age

Figure 9 represents the entire mid-range estimate group, including both CYP and adults, divided into age groups. The trend of this graph corresponds to the rising incidence of death as age increases, with 78% of deaths in the over 65 age group. There were, however, a slightly higher number of deaths in the under 1 age group (approximately 1%). Most of these were accounted for by two key diagnostic groups: 'certain conditions originating in the perinatal period' and 'congenital malformations, deformations and chromosomal abnormalities'.

Figure 9: Mid-range estimate: deaths by age group



Ethnicity

While the mid-range estimate includes a range of ethnic groups, it does not follow the same pattern as the population as a whole. Figure 10 illustrates the distribution of ethnic groups in the New Zealand population compared with the adult and CYP mid-range estimate groups. The proportion of European people in the adult group was higher than in the national population and the proportions for all other ethnic groups were less than would be expected. In contrast, both the Māori and Pacific ethnic groups contributed more deaths to the 0–19 year age group than would be expected given their national population size.

Figure 10: Ethnic group composition of New Zealand population (based on Census 2006) compared with mid-range estimate groups for adults and CYP

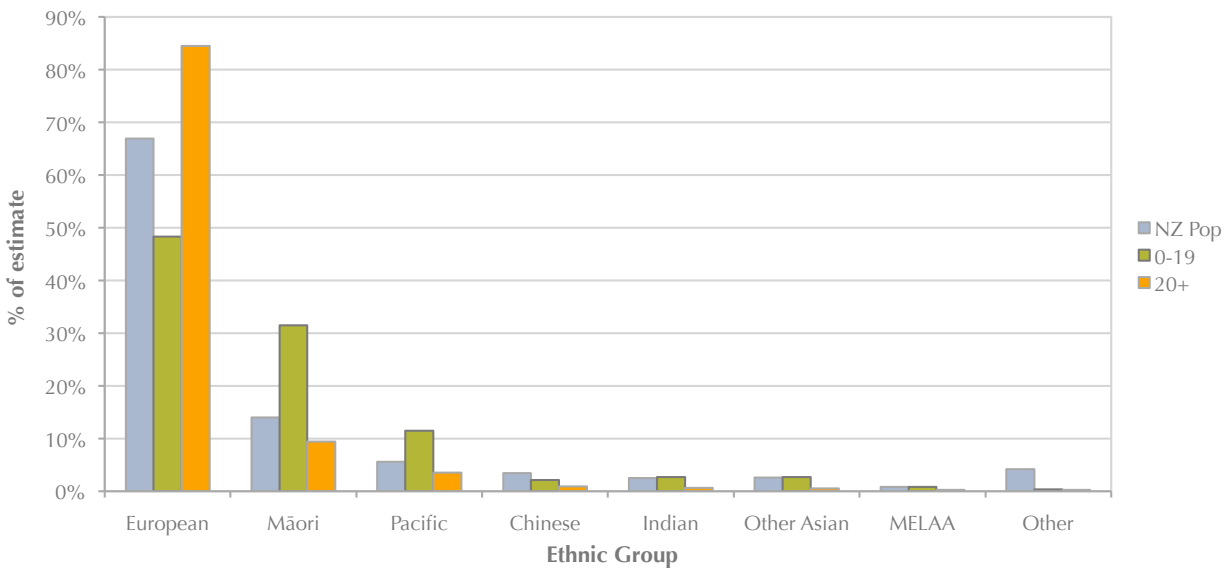
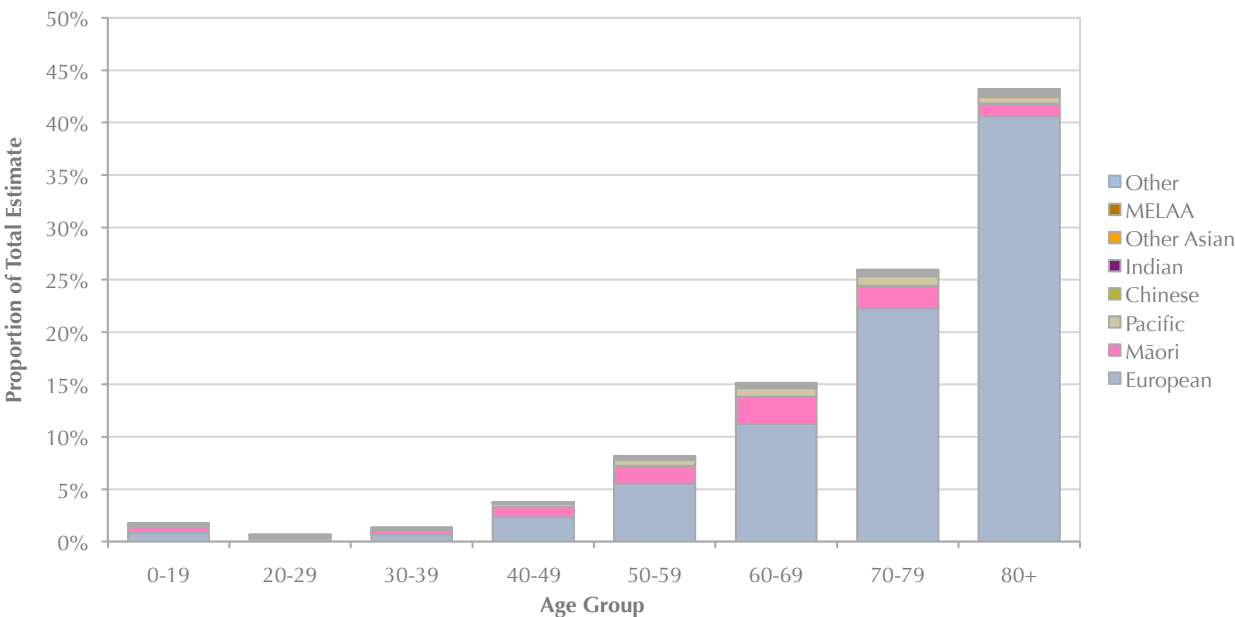


Figure 11 takes this analysis a step further by combining both age and ethnic group to show the proportionate contribution each group makes to the entire mid-range estimate. This graph demonstrates quite clearly two key aspects of the mid-range estimate. The first is the majority of people were over 60 years of age (almost 84%). Second, the European ethnic group contributed the greatest number of people in this estimate, particularly in the 40 and over age groups, but substantially so in the over 60 age groups, where it accounted for over 70% of the total mid-range estimate group.

Figure 11: Ethnic group composition of different age groups in the mid-range estimate



Deprivation

There are some important differences in the number of deaths in this estimate based on deprivation (Table 10), particularly so in the 0–19 age group. In this group over 55% of deaths occurred in the most deprived quintile 4 and 5 groups. Substantially more deaths in these quintile groups occurred in two disease groups: ‘certain conditions originating in the perinatal period’ (62%), and ‘congenital malformations, deformations and chromosomal abnormalities’ (55%). For perinatal deaths the rate was over four times higher in the quintile 5 group compared with quintile 1 (least deprived) and for congenital malformations it was three times higher.

For the adult group there were more deaths in the quintiles 3, 4 and 5 groups, with 49% of deaths in the two most deprived groups (quintiles 4 and 5). This may be due to the inclusion of a wider range of diseases where deprivation could be a contributing factor, such as diseases of the circulatory and respiratory systems related to poor diet and tobacco use. However, these patterns occurred in the same way across all three estimates, with the greatest number of deaths always occurring in the more deprived quintiles. Looking at the older age groups, the distribution of deprivation did not vary a great deal. This is probably because these age groups, particularly the over 65 year olds, contributed the majority of deaths in this estimate group.

Table 10: Mid-range estimate by deprivation quintile (three-year average)

Deprivation quintile	Age group			
	0-19	20+	65+	85+
1	11.3%	13.7%	13.7%	15.0%
2	14.5%	16.5%	16.9%	18.0%
3	18.0%	20.8%	21.5%	22.3%
4	21.7%	27.2%	27.9%	28.0%
5	34.5%	21.8%	20.1%	16.6%

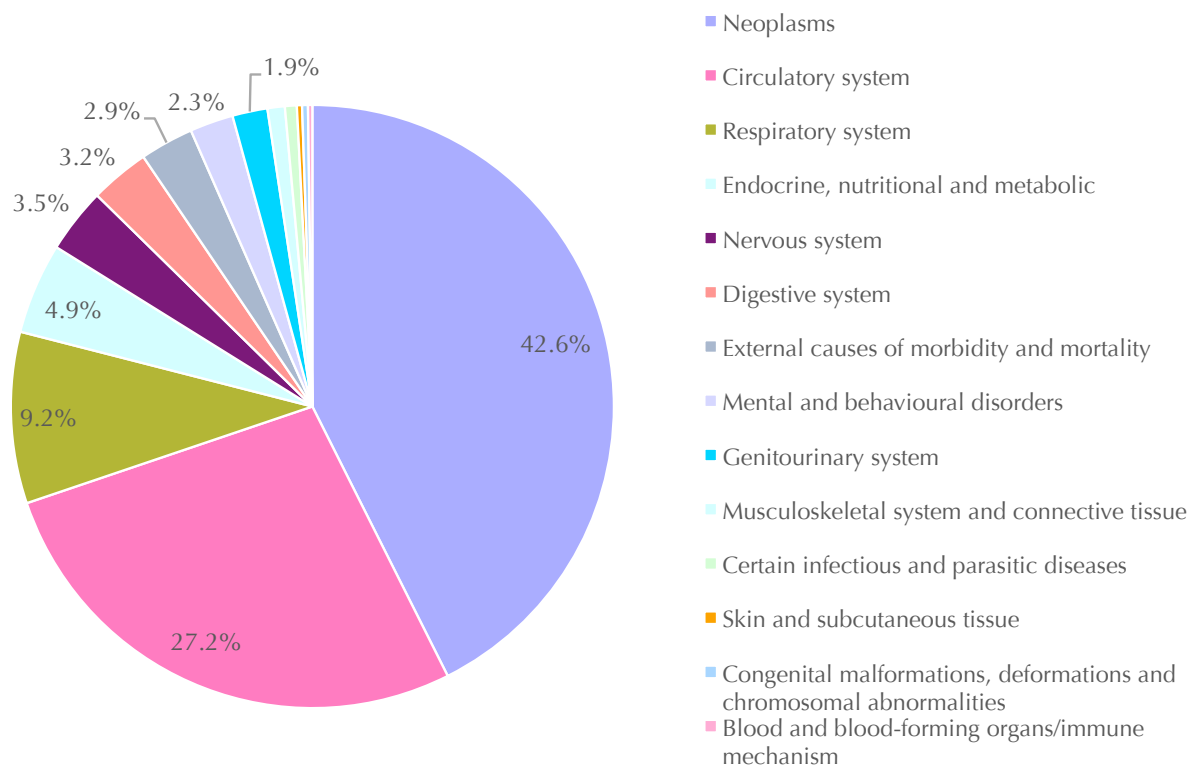
Cause of death — adults

Another important aspect of this group is the distribution of diseases, especially as the mid-range estimate does not specify particular diagnoses in its inclusion criteria. This means the range of underlying causes of death in this estimate is broader than those identified as ‘benefiting from palliative care’ in the minimal estimate. This diversity of diseases is important because it highlights the potential range of diseases where palliative care could be useful, which will be vital for service planning, especially given the current drive to extend services to the non-cancer population. In addition to service planning, it will also be important that this information is taken into account in staff education and resource development, including for non-specialist staff.

For the purposes of this analysis, underlying cause of death was provided as an ICD-10-AM code for each individual. Because there are a large number of separate codes, they have been grouped into disease categories. While this makes analysis somewhat easier, it does not provide a great amount of detail on the actual diseases that resulted in death. In addition, this analysis has not attempted to incorporate ‘other relevant diseases present’ or ‘other contributing causes’ fields that were included in the individual records, apart from a sub-analysis of dementia and related illnesses. This is an important caveat, as many people with a chronic disease are likely to have multiple medical problems, especially older adults, creating greater care needs than a single disease would (WHO 2004).

Figure 12 shows the underlying cause of death for the adult sample in the mid-range estimate. Neoplasms were still the single biggest cause of death, but non-cancer causes made up over 57% of deaths in this group with circulatory and respiratory diseases the greatest contributors.

Figure 12: Underlying cause of death — adults (entire mid-range estimate; n = 46,481)



Note: Segments with no % figure are all <1%.

Dementia sub-analysis

Dementia is an internationally growing concern, with an estimated 24.3 million people worldwide suffering from dementia in 2005, and 4.5 million new cases every year (Ferri et al 2005). Dementia prevalence rates are highest in developed countries and are expected to double every 20 years. In Australia it is estimated that 50%–55% of ARC residents have dementia, with greater proportions in high-level care (Brodaty and Cumming 2010). Studies in the UK have estimated the dementia prevalence rate as over 60% among residential and nursing care home residents (Albanese et al 2007; Matthews and Denning 2002). Given New Zealand's growing and aging population, the prospect of rising rates of dementia is of particular concern for New Zealand's government and the ARC sector. Additionally, there is growing recognition that palliative care can play an important role for people with dementia. Therefore, a sub-analysis has been undertaken to explore the contribution of relevant nervous system diseases and dementia to the palliative care population estimate.

In the adult mid-range estimate there were 1617 people who had a disease of the nervous system as the underlying cause of death (6% of all non-cancer deaths in the estimate group). Of these deaths, over 80% were due to five diseases: Alzheimer's disease (512), Parkinson's disease (430), motor neuron disease (244), multiple sclerosis (97) and Huntington's disease (32). In addition, there were 987 individuals whose underlying cause of death was dementia (4% of non-cancer deaths in this estimate group). Most commonly this was classified as 'unspecified dementia' or as one of a group of vascular-related dementias. Dementia-related deaths are included in the 'mental and behavioural disorders' group. A further 662 individuals in the mid-range estimate group had a dementia diagnosis recorded in the category 'other relevant diseases present', meaning that, as well as their underlying cause of death they also had a dementia diagnosis. Almost all of these individuals had one of the nervous system diseases noted above as their underlying cause of death (not including motor neuron disease or multiple sclerosis).

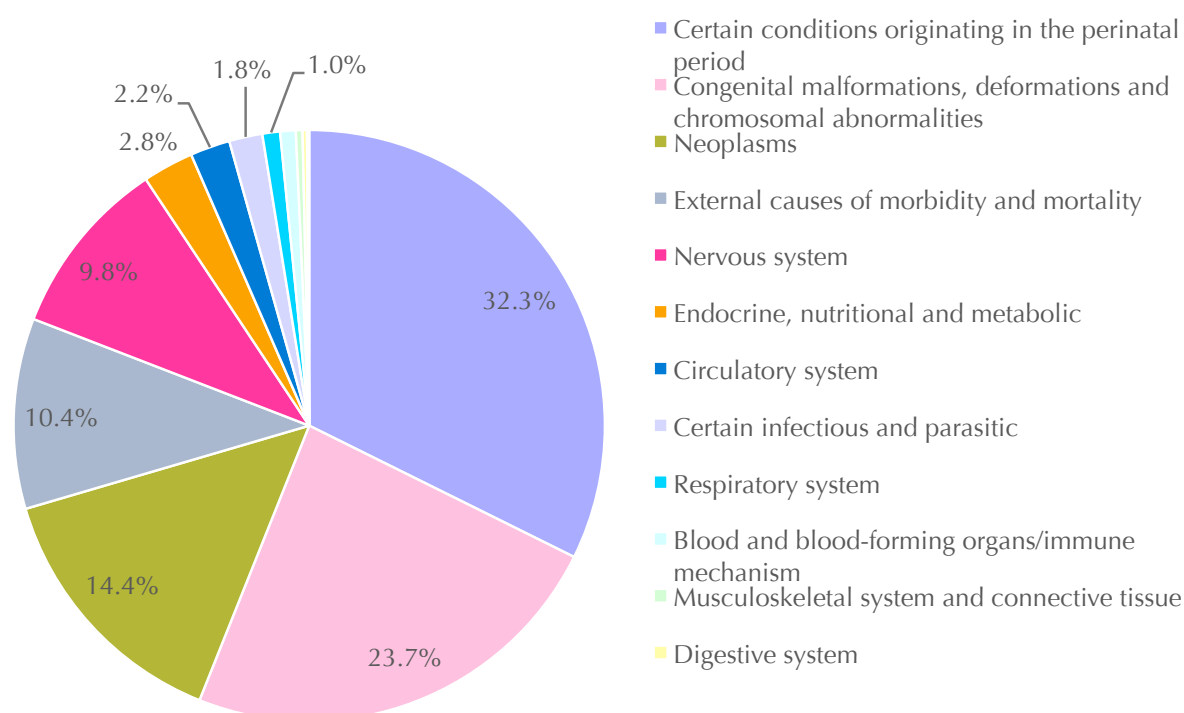
Of those who died from nervous system diseases, 79% were aged over 65 and 47% aged over 80. Fifty-five percent of these deaths were in ARC and 31% in a public hospital. For deaths where dementia was recorded as the underlying cause, all individuals were aged over 50 and 94% were aged over 75. Most of these people (70%) died in ARC and 25% died in hospital.

Analysis of all ARC deaths in the maximal estimate group was also undertaken, as this estimate included a much larger number of ARC deaths ($n = 25,452$). This analysis found 7.5% of deaths in ARC had one of the nervous system diseases as the underlying cause of death, and around 7% of deaths had dementia as the underlying cause. Most deaths in ARC had circulatory disease (42%) or neoplasm (24%) as the underlying cause. Given the estimated prevalence of dementia in aged care institutions, these figures are highly likely to under-represent the burden of dementia in ARC. In fact, if 60% of ARC residents have dementia and approximately 30% of deaths occur in ARC, then it could be estimated that dementia may be a factor in almost 20% of all deaths.

Cause of death — CYP

The picture of the cause of death for the CYP group is quite different from that of adults (Figure 13), which lends support to the opinion that this is a very different group from adults and therefore requires specific attention in relation to palliative care needs. Within the whole group, the largest numbers of deaths were from certain conditions originating in the perinatal period and congenital malformations, deformations and chromosomal abnormalities. These two causes combined accounted for almost 70% of all deaths in this age group. As noted earlier these deaths occurred almost entirely in the under 1 age group. A similar incidence of deaths in these disease groups has been found in both Ireland and the UK during studies of palliative care need based on mortality data (Department of Health 2007; Department of Health and Children 2005).

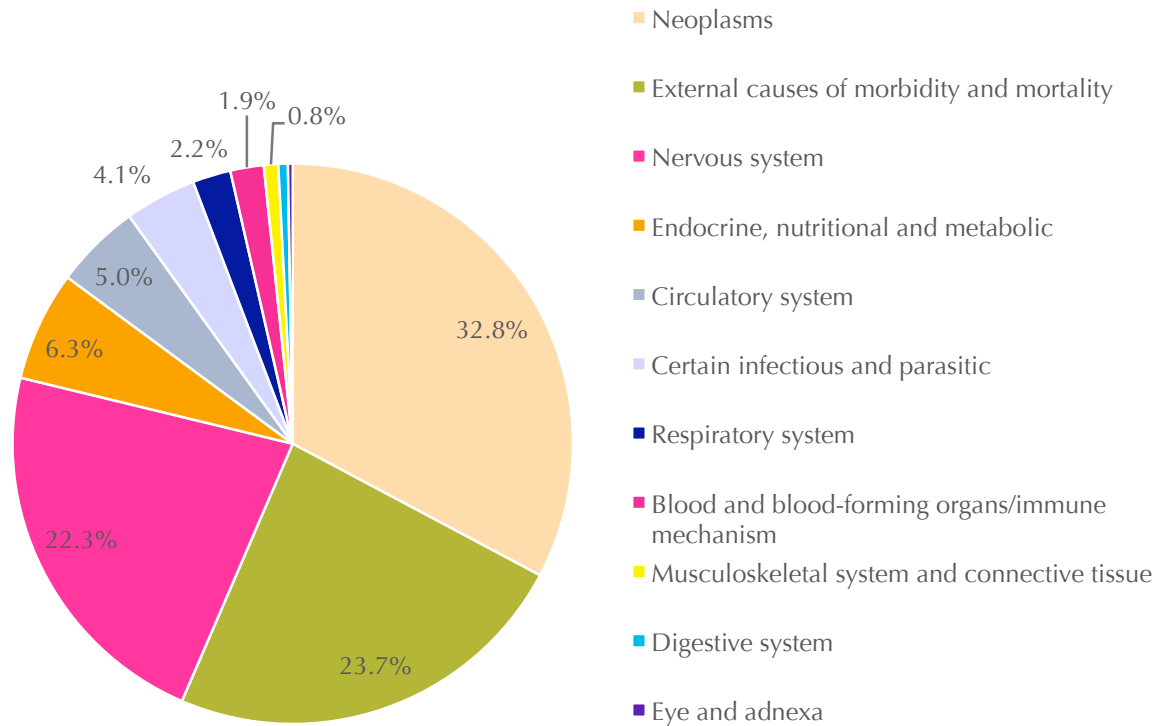
Figure 13: Underlying cause of death — CYP (entire mid-range estimate: $n = 826$)



Note: Segments with no % figure are all <1%.

When the 'certain conditions originating in the perinatal period' and 'congenital malformations, deformations and chromosomal abnormalities' diagnostic groups are removed from the sample, effectively removing most of the under 1 year olds, the pattern of cause of death changes (Figure 14). Now the leading cause of death is neoplasm, followed by external causes and diseases of the nervous system. Sixty-one percent of deaths from neoplasm occurred in the 10–19 age group, and 61% of external cause deaths occurred in the 15–19 age group. Deaths from diseases of the nervous system were spread evenly across all age groups, apart from in the under 1 age group, where the incidence was double.

Figure 14: Underlying cause of death — CYP excluding perinatal deaths and deaths from congenital conditions (n = 363)



Note: Segments with no % figure are all <1%.

The mid-range estimate of people who are likely to benefit from palliative care presents a widely varying demographic picture. The differences in mortality due to age are expected, but the variations across ethnic groups based on age are noteworthy, in that for the main minority ethnic groups, there are a greater number of younger people in this estimate. There is also an imbalance in the contribution of each ethnic group to the total estimate, with Māori and Pacific people having a disproportionate number of deaths in the CYP group. This estimate group also has an interesting deprivation profile, with a larger number of deaths occurring in the more deprived groups. This has implications for resources, as it has been noted that people in deprived areas have greater resource needs. Because the mid-range estimate is designed to be needs based there is a wider range of diagnoses included in this group, and this may mean a much wider group of people could be benefiting from access to palliative care. It would also indicate a need for broader disease focused education for palliative care staff.

Prevalence of Problems/Symptoms (Adults)

The prevalence of symptoms and problems may be a useful indicator of needs, as well as identifying the core services that may be required to provide appropriate care to people in need of palliative care. Unfortunately, there is no New Zealand-based research on which to calculate symptom and problem burden in palliative care patients. There is work previously conducted in the UK that attempted to establish symptom and problem prevalence in a random sample of deaths using the views of bereaved carers (Higginson 1997). A study using case note review to determine symptom burden in 400 palliative care patients found the presence of similar symptoms, but not at the same levels as that reported by Higginson (Potter et al 2003). A recent systematic review of symptom burden in chronic organ failure (congestive heart failure, chronic obstructive pulmonary disease, chronic renal failure) also reported many of the same symptoms but again at different prevalence rates (Janssen et al 2008). While this is not an ideal situation, the approach taken for

this project uses the prevalence levels reported by Higginson, as this is the method applied in the needs assessment framework. This analysis has only been undertaken for adult data, as no comparative information on symptom/problem prevalence could be found for children.

The symptom/problem prevalence data has been applied to the mid-range adult estimate in Appendix 6 for people with a cancer diagnosis. The table shows the estimated prevalence of each symptom or problem among the mid-range estimate individuals who died from cancer, by DHB region. Across this group, the four most prevalent symptoms/problems were pain, loss of appetite, vomiting or feeling sick, and sleeplessness.

Appendix 7 presents the same symptom/problem prevalence estimates for non-cancer deaths in the mid-range estimate. Based on these values, the four most common symptoms/problems in the non-cancer group were pain, trouble with breathing, mental confusion and loss of appetite.

Place of Death

Although there is some debate about the interpretation of place of death data, it has been proposed as an indicator of the effectiveness of palliative care services, which may be judged by the number of people who die at home. The rationale for this is that when asked, most people state a preference for dying at home (McNamara and Rosenwax 2007). A more precise indicator, although not easily measurable, would be the number of people who die in the place of their choosing, as it is widely recognised that this can change as the time of death approaches (WHO 2004). Possibly a more important use of this information, for the present at least, is as a guide to where services should be focused, based on where people actually do die so that palliative and end-of-life care services are more easily accessible and appropriately tailored to local needs.

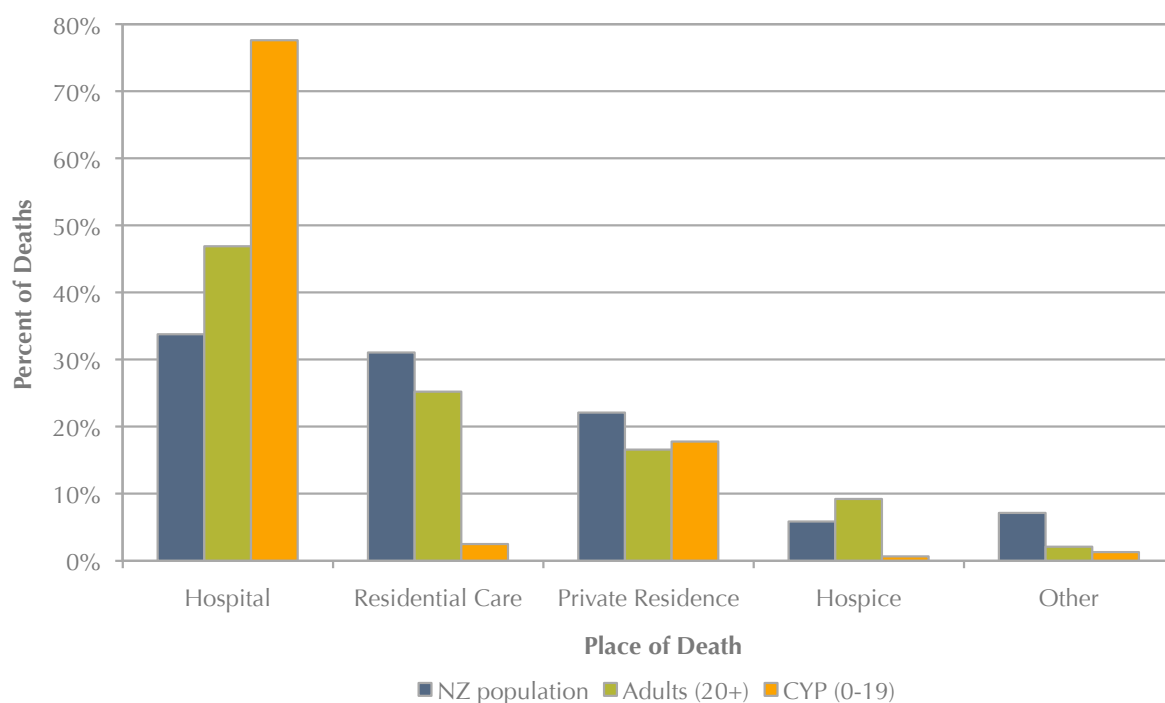
The current New Zealand Mortality Collection does not have a dedicated 'place of death' field; rather it has several data fields that pertain to the location of death without ascribing an overarching 'place' category, such as a hospital, hospice or residential care. In order to group death locations into 'place of death' categories an algorithm was developed by National Collections and Reporting services analyst staff. The algorithm allocated a 'place of death' category to each individual record based on the available location of death details. The algorithm used a 'facility code' if present, and/or an analysis of specific words in free text entries, such as 'hospice' or 'rest home' in the institution name field. While this system of allocating a place of death is not perfect, a manual data check revealed good alignment of facility codes with the allocated place of death category.

This code was also applied to all mortality data from 2003 to 2007 to produce an overview of national place of death figures for all causes of mortality (Table 11). On a national basis, most deaths occurred in a hospital setting, followed by residential care and private residence. A smaller number of deaths were in a hospice inpatient unit. Over the five-year period the proportion of deaths in each location stayed relatively static.

Table 11: Place of death for all deaths over a five-year period (2003–2007)

Place of death	Percent of all deaths (03-07)	Average annual count
Hospital	34%	9535
Residential care	31%	8694
Private residence	22%	6170
Hospice (inpatient)	6%	1683
Other	7%	1963

This national level data is compared with the place of death for both the adult and CYP mid-range estimates in Figure 15. In these groups the likelihood of dying in hospital is higher, especially so for the CYP group where 77.6% of deaths occurred in a hospital setting. It is unclear where the small number of CYP deaths in residential care occurred, but these will have been allocated based on free text information and may include residential care services for young people. Slightly more people in the adult group died in a hospice inpatient setting, and this may be due to the large number of people with cancer in the estimate group, as cancer patients are traditionally more likely to receive hospice care. Less than 1% of CYP deaths were in a hospice. Unfortunately, it is not possible to tell how many deaths in a hospital, residential care or private residence had specialist palliative care support or were receiving general palliative care (for example by a general practitioner or district nurse).

Figure 15: Place of death — New Zealand population versus mid-range estimate populations 2005–2007

Note: Adults $n = 46,841$; CYP $n = 826$.

A number of studies have found demographic factors can influence where people die (McNamara and Rosenwax 2007). Therefore the place of death for the mid-range estimate group has been evaluated by several important demographic variables to determine any statistically significant differences in where individuals died.

Figure 16 depicts place of death by age group in more detail. There are statistically significant differences in where individuals died depending on their age (Pearson $\chi^2(65) = 5900$ $Pr < 0.001$). Across most adult age groups hospital deaths remained fairly stable at just under 50%, and there were no significant differences by age group for adults. However, there were more hospital deaths than would be expected for the CYP group. As would be expected, significantly more people over the age of 80 died in ARC and significantly less people under the age of 74 died in ARC. Over 40% of those over the age of 85 died in residential care. People aged 45–69 were significantly more likely to die in a private residence, accounting for 42% of deaths in that age group. In contrast, significantly less people over the age of 80 than expected died in private residence. Significantly more people aged 50–69, and significantly less people over the age of 80, died in a hospice inpatient unit.

Figure 16: Place of death for the different age groups in the mid-range estimate

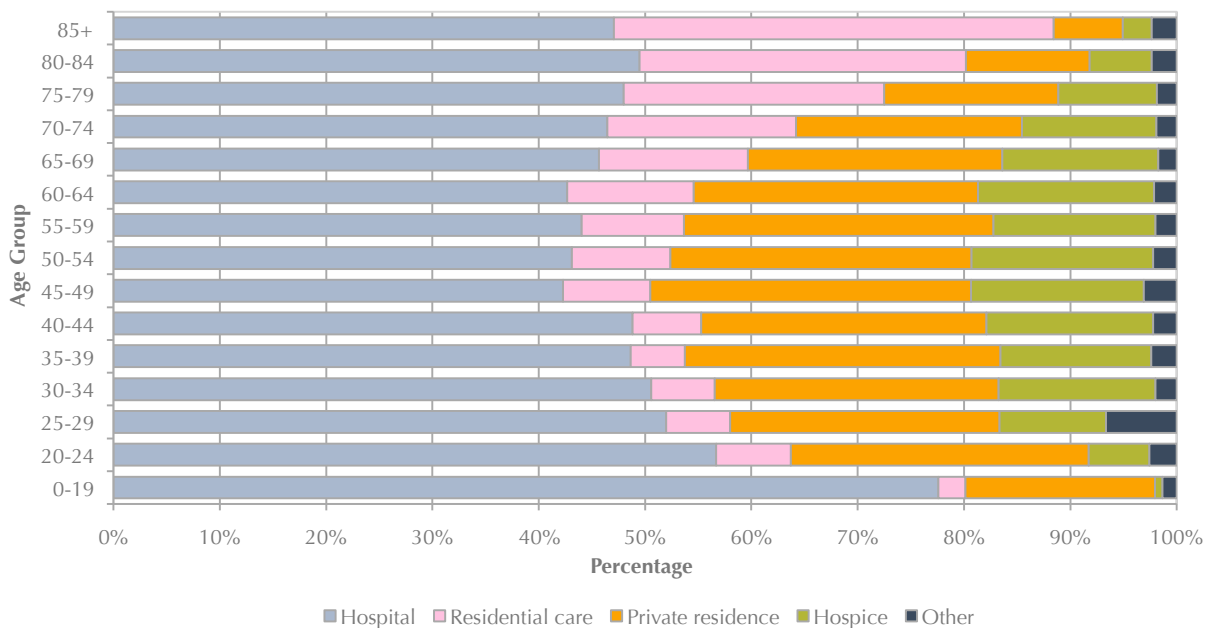
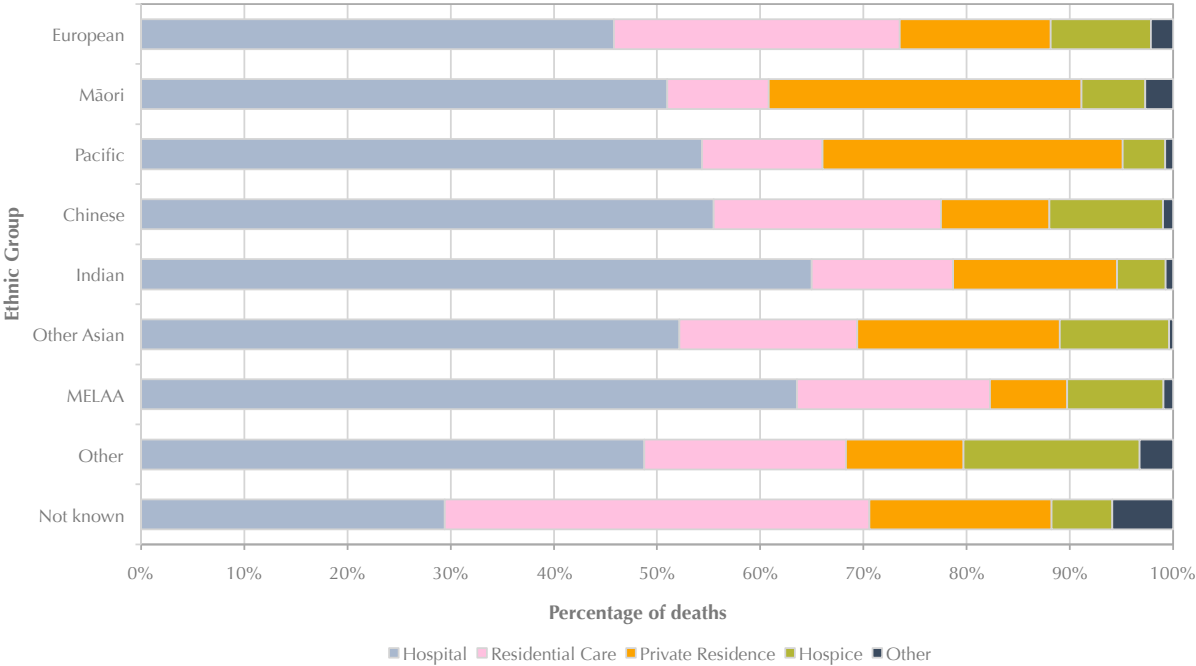


Figure 17 illustrates the distribution of place of death for each of the ethnic groups in the adult mid-range estimate and shows some important differences based on ethnicity. A Chi-square analysis of this data revealed there were statistically significant differences in where people died based on their ethnic group ($\chi^2(40, N = 46481) = 1640.3$; $p < 0.001$). The most important contributors to these differences were: European were more likely to die in residential care or in a hospice, and less likely to die in a private residence. Māori were more likely to die in a private residence or hospital, and less likely to die in residential care or a hospice. Pacific people were also more likely to die in a private residence or hospital, and less likely to die in residential care or a hospice. Indian people were more likely to die in a hospital and less likely to die in residential care (note there is a very small sample size for this group).

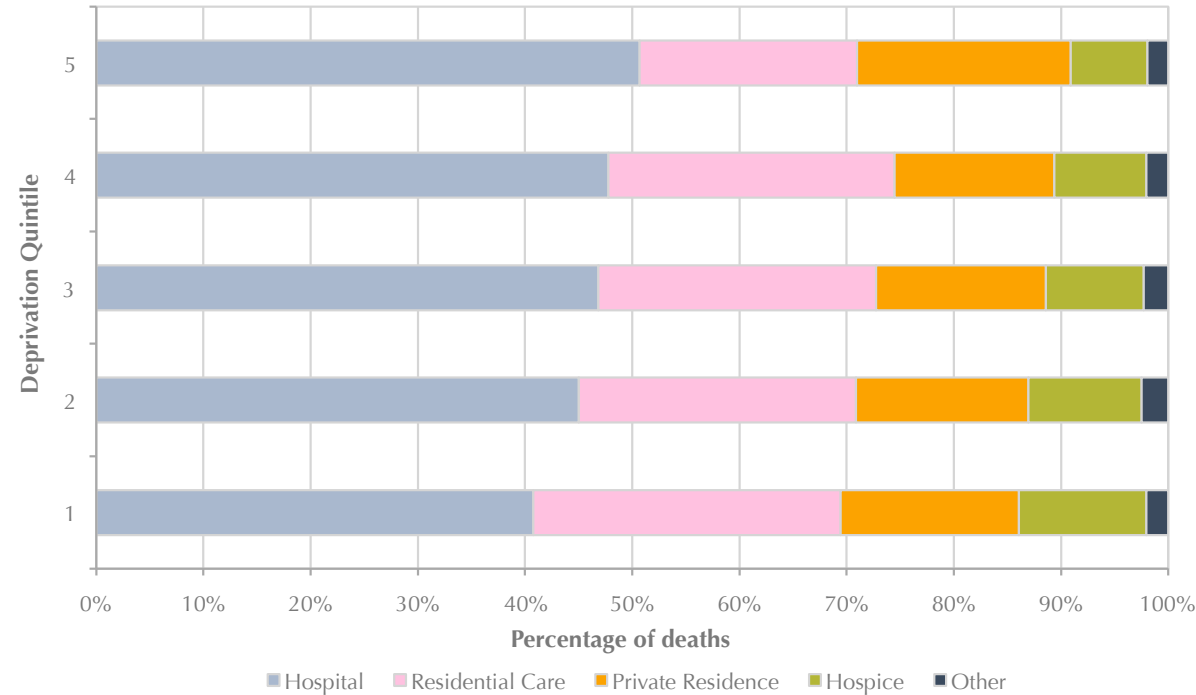
There were no significant differences in where children and young people died based on ethnic group. However, comparison between CYP ethnic groups was not very reliable due to the very low numbers in the minority ethnic groups.

Figure 17: Place of death by ethnic group (adult mid-range estimate)



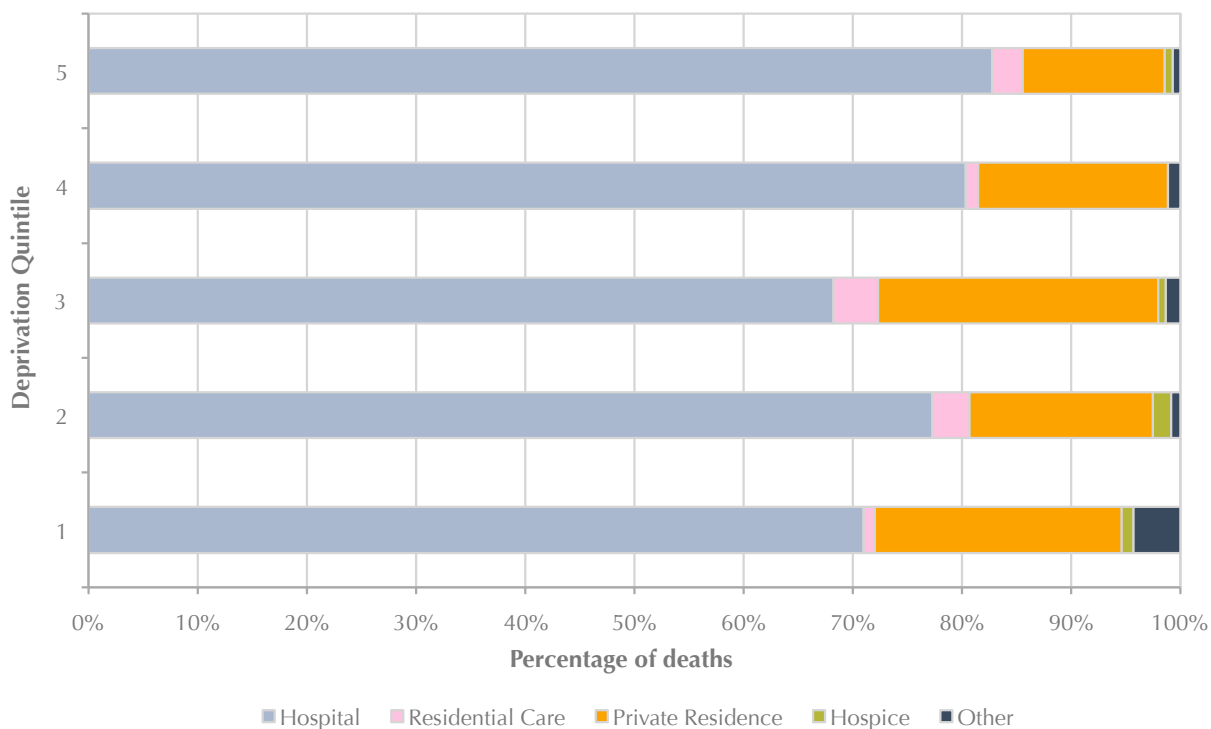
Place of death also appeared to be influenced by deprivation status (Figure 18), especially for the most deprived group, with analysis showing significant differences based on deprivation quintile ($\chi^2(20) = 463.3$ Pr = 0.000). Significantly more adults in quintile 5 died in hospital than any other group. In fact there was a 10% difference when compared with the least deprived group in quintile 1 (40% versus 50% of deaths). Adults in quintile 5 were also significantly more likely to die in a private residence and significantly less likely to die in residential care. In contrast, more people from quintile 1 died in residential care than any other group. There were also significant differences in hospice inpatient deaths, with more people from the two least deprived groups 1 and 2 dying in a hospice, although this was only statistically significant for the quintile 1 group. Significantly less people from the most deprived (quintile 5) group died in a hospice.

Figure 18: Place of death by deprivation quintile (NZDep2006) 2005–2007 mid-range estimate (adult group)



In the CYP mid-range estimate group there were no statistically significant differences, although there was a trend towards more hospital deaths and fewer private residence deaths as deprivation increased (Figure 19).

Figure 19: Place of death by deprivation quintile (NZDep2006) 2005–2007 mid-range estimate (CYP group)



The last part of this analysis evaluated the impact of the underlying cause of death on the place of death, and this also revealed statistically significant differences (Pearson $\chi^2(85) = 11293.4$ $P = 0.000$). In the adult group, those with neoplasms were more likely to die in a hospice or private residence, and less likely to die in a hospital. Individuals who died from mental and behavioural disorders or diseases of the nervous system were more likely to die in residential care. When circulatory disease was the cause of death, the individual was more likely to die in a hospital, and less likely to die in a hospice or private residence. A similar pattern was seen with respiratory diseases, where a hospital was a more likely place of death and dying in a hospice was less likely. Finally, deaths from external causes were more likely to occur in a hospital and less likely to occur in a private residence.

For the CYP group the only significant finding was that those with a neoplasm were more likely to die in a private residence. Even when all individuals under 1 year old or all perinatal deaths were removed from the sample, there were no significant differences except for the group with neoplasm as the underlying cause of death.

Overall Assessment of Palliative Care Need

In New Zealand, palliative care should be available to people of all ages with a life-limiting illness, and to their family and whānau. There is agreement at a national level that palliative care is provided according to need, and that it may be provided over a period from a few days to months or even years. It should also be available wherever the person may be, and in such a way as to meet the unique needs of individuals from particular communities or groups. While these aims are most certainly admirable, and hopefully achievable, there is a paucity of information available on the number of people who would benefit from palliative care in New Zealand, and the characteristics of this group. This lack of data means it is very difficult, if not impossible, to ensure palliative care is being made available to all the people in need, let alone plan for future requirements.

The changing age demographics of the New Zealand population are of significant concern to health services. As more people live longer there is likely to be a rise in chronic diseases, such as heart disease, cerebrovascular disease, respiratory disease, dementia and cancer, leading to an increased need for health care and a corresponding increase in the need for palliative and end-of-life care. This rather bleak picture is tempered somewhat by the fact that some evidence suggests successive generations remaining in better health as they age.

This Needs Assessment project is the first attempt to identify the level of need for palliative care on a national basis in New Zealand. While the methodology is still somewhat embryonic, it nevertheless provides some very useful information on the size of the potential palliative care population and some of the key features of this group of people.

Using mortality data from 2005, 2006 and 2007 and based on a mid-range estimate of need (i.e. people who were admitted to hospital in the 12 months before they died for the same diagnosis from which they ultimately died), there were 15,452 adults (people over age 20) per year, or 56.7% of all adult deaths, where palliative care might have been of benefit. This equates to 518 deaths per 100,000 of the adult population. The age range of this group closely mirrors age-related mortality in the New Zealand population, with most deaths occurring in people over 65 years of age. An interesting finding in the adult group was a higher level of deprivation among those people who died from diseases where palliative care might have been of benefit.

The same analysis of mortality data for children and young people (aged 0 to 19) estimated there were, on average, 273 deaths a year (41.9% of all CYP deaths) where palliative care might have been of benefit. This equates to 23 deaths per 100,000 of this population group. Many of the deaths in this group were of children under 1 year old. There was also a greater proportion of Māori and Pacific deaths in the CYP group than would be expected given the proportion of these ethnic groups in the total population, especially for the under 1 age group.

It is important to note the estimates produced using this methodology do not differentiate between people who would benefit from specialist versus generalist palliative care. This is partly due to the estimate criteria not being that specific, but also because we have little understanding of the current level of palliative care being provided and what patient characteristics might indicate differing levels of need. However, an attempt has been made to classify the adult group into those who require specialist palliative care assessment, those who would benefit from short-term or intermittent input from a specialist palliative care service, and those who should receive ongoing care from a specialist palliative care service.

In the entire mid-range estimate (adults and CYP), 78% of deaths were in the over 65 age group, and approximately 1% were under 1 year old. The majority of people in the estimate group were European, but both the Māori and Pacific ethnic groups contributed more deaths to the 0–19 year group than would be expected based on their national population size. Overall, 70% of the total mid-range estimate group were Europeans aged over 60. Over 55% of deaths in the 0–19 year group occurred in the most deprived quintile 4 and 5 groups. In the adult group, 49% of deaths were also in the two most deprived groups.

Neoplasms were the single biggest cause of death (42.6%) in the adult mid-range estimate group, but non-cancer causes made up over 57% of deaths in this group. Circulatory and respiratory diseases were the greatest contributors to non-cancer deaths. For the CYP group perinatal conditions and congenital abnormalities were the main causes of death, accounting for almost 70% of all deaths. These deaths occurred almost entirely in the under 1 age group. The next main causes of death in the CYP group were cancer (14.4%) and external causes (10.4%).

The data presented in this report on place of death is new for New Zealand and there are some potential issues with the method used to allocate a 'place of death' category to mortality records. However, it does provide some very useful insights into where people die in New Zealand, and when evaluating the potential palliative care population it raises important questions about the influence of social demographics and diagnosis on where people die. On a national basis, most deaths occurred in a hospital setting (34%), followed by residential care (31%) and private residence (22%). A smaller number of deaths were in a hospice inpatient unit. These figures were different in the mid-range estimate group where the likelihood of dying in hospital was higher, especially for the CYP group where 77.6% of deaths occurred in a hospital setting. This information must be incorporated into service planning and models of care to ensure palliative care is available to all those who would benefit. Analysis of where people die could also provide useful information on where services should be situated, and may also assist in identifying the level of care required.

While the data from this phase of the Needs Assessment is informative in its own right, it will also be used in next phases of the project, which will look at the core palliative care services required to meet the identified need and how that compares with currently available services.

Next Steps

The next phase of the National Health Needs Assessment will focus on an assessment of the core service components required to meet the need for palliative care identified in Phase 1. It will also include the mapping of currently available services, with an emphasis on specialist palliative care, but also an attempt to elucidate where and how generalist level palliative care is being provided.

The final step in the Needs Assessment is to compare the core service components identified as being required to meet population need, with the services that are currently available. This analysis will identify where services are already meeting identified population needs, where there are gaps or deficiencies, and what may be required in the future.

Following this, a consultation period will be undertaken with the palliative care sector and other stakeholders to establish interventions that will address any gaps and deficiencies exposed by the Needs Assessment. Decisions will also need to be made on priorities for action, and who will be responsible for implementing and evaluating these actions.

References

- Albanese E, Banerjee S, Dhanasiri S, Fernandez J, Ferri C, Knapp M, McCrone P, Prince M, Snell T, Stewart R. (2007) *Dementia UK: a report into the prevalence and cost of dementia prepared by the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at King's College London, for the Alzheimer's Society. Summary of key findings*. London: Alzheimer's Society.
- Boyd M, Broad J, Kerse N, Foster S, von Randow M, Lay-Yee R, et al (2011) Twenty year trends in dependency in residential aged care in Auckland, New Zealand: a descriptive study. *Journal of the American Medical Directors Association* (In press).
- Broad J, Kerse N, Whitehead N, Chelimo C, Lay-Yee R, von Randow M, Foster S, Connolly MJ. (2011) Residential aged care in Auckland, New Zealand 1988–2008: do real trends over time match predictions? *Age and Ageing* (In press).
- Brodaty H, Cumming A. (2010) Dementia services in Australia. *International Journal of Geriatric Psychiatry*, 25, 887–895.
- Clark, CR (1997) Social deprivation increases workload in palliative care of terminally ill patients. *British Medical Journal*, 341, 1202.
- Department of Health and Children (2005) *A palliative care needs assessment for children*. Dublin: Department of Health and Children Stationary Office.
- Department of Health. (2007) *Palliative care statistics for children and young adults*. London: Department of Health. Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_074701.
- Ferri CP, Prince M, Brayne C, Brodaty H, Fratiglioni L, Ganguli M, Hall K, Hasegawa K, Hendrie H, Huang Y, Jorm A, Mathers C, Menezes PR, Rimmer E, Scazufca M. (2005) Global prevalence of dementia: a Delphi study. *The Lancet*, **366**(9503), 2112–2117.
- Higginson I. (1997) Palliative and terminal care. In A Stevens and J Raftery (Eds). *Health care needs assessment: the epidemiologically based needs assessment reviews* (pp. 183–260). Oxford: Radcliffe Medical Press.
- Janssen DJA, Spruit MA, Wouters EFM, Schols JMGA. (2008) Daily symptom burden in end-stage chronic organ failure: a systematic review. *Palliative Medicine*, **22**, 938–948.
- Matthews FE, Denning T. (2002) Prevalence of dementia in institutional care. *The Lancet*, **360**(9328), 225–226.
- McNamara B, Rosenwax LK. (2007) Factors affecting place of death in Western Australia. *Health & Place*, 13, 356–367.
- McNamara B, Rosenwax LK, Holman CD. (2006) A method for defining and estimating the palliative care population. *Journal of Pain and Symptom Management*, **32**(1), 5–12.
- Ministry of Health. (2001) *The New Zealand palliative care strategy*. Wellington: Ministry of Health.
- Ministry of Health. (2009a) *Data and statistics: mortality collection (MORT)*. Wellington: Ministry of Health. Accessed 9 August 2010, from URL: <http://www.moh.govt.nz/moh.nsf/indexmh/dataandstatistics-collections-mortality>.

- Ministry of Health. (2009b) *Data and statistics: national minimum dataset (hospital events) (NMDS)*. Wellington: Ministry of Health. Accessed 9 August 2010, from URL: <http://www.moh.govt.nz/moh.nsf/indexmh/dataandstatistics-collections-nmds>.
- Ministry of Health (2010). *The New Zealand health strategy*. Wellington: Ministry of Health.
- Ministry of Health. (2010) *Mortality and demographic data 2007*. Wellington: Ministry of Health. Available from: <http://www.moh.govt.nz/moh.nsf/indexmh/mortality-demographic-data-2007>.
- Palliative Care Australia. (2003) *Palliative care service provision in Australia: a planning guide*. Deakin West ACT: Palliative Care Australia.
- Palliative Care Council of New Zealand. (2009). *Positioning palliative care in New Zealand: a review of government health policy in relation to the provision of palliative care services in New Zealand*. Wellington: Cancer Control New Zealand. Available from: <http://cancercontrolnz.govt.nz/files/Positioning%20Palliative%20care%20in%20NZ.pdf>.
- Palliative Care Subcommittee. (2007) *New Zealand palliative care: a working definition*. Wellington: Ministry of Health. Available from: [http://www.moh.govt.nz/moh.nsf/pagesmh/2951/\\$File/nz-palliative-care-definition-oct07.pdf](http://www.moh.govt.nz/moh.nsf/pagesmh/2951/$File/nz-palliative-care-definition-oct07.pdf).
- Potter J, Hami F, Bryan T, Quigley C. (2003) Symptoms in 400 patients referred to palliative care services: prevalence and patterns. *Palliative Medicine*, **17**, 310–314.
- Rosenwax LK, McNamara B, Blackmore AM, Holman CDJ. (2005) Estimating the size of a potential palliative care population. *Palliative Medicine*, **19**, 556–562.
- Salmond C, Crampton P, Atkinson J. (2007) *NZDep2006 index of deprivation*. Wellington: Department of Public Health, University of Otago.
- Statistics New Zealand. (2006) *Introduction to the census: 2006 census of population and dwellings*. Wellington: Statistics New Zealand. Available from: <http://www.stats.govt.nz/census/about-2006-census/introduction-to-the-census.aspx>.
- Stevens A, Gillam S. (1998) Needs assessment: from theory to practice. *British Medical Journal*. **316**, 1148–52.
- Stevens A, Raftery J. (1997) *Health care needs assessment: the epidemiologically based needs assessment reviews*. Oxford: Radcliffe Medical Press.
- Tebbit P. (2004) *Population-based needs assessment for palliative care. a manual for cancer networks*. London: National Council for Hospice and Specialist Palliative Care Services.
- Townsend P. (1987) Deprivation. *Journal of Social Policy*, **16** (1), pp. 125–146.
- White P, Gunston J, Salmond C, Atkinson J, Crampton P. (2008) *Atlas of socioeconomic deprivation in New Zealand NZDep2006*. Wellington: Ministry of Health.
- World Health Organization. (1998) *Cancer pain relief and palliative care in children*. Geneva: World Health Organization,
- World Health Organization. (2002) *National cancer control programmes, policies and managerial guidelines* (2nd ed.). Geneva: World Health Organization.
- World Health Organization. (2004) *Better palliative care for older people*. Copenhagen: World Health Organization.

Appendices

Appendix 1: ICD-10-AM codes used in estimates

Appendix 2: 2006 DHB populations by age group

Appendix 3: Projected 2026 DHB populations by age group

Appendix 4: Ethnic groups in the New Zealand population, by District Health Board

Appendix 5: Religious affiliation by DHB and New Zealand

Appendix 6: Estimated prevalence of symptoms and problems in the adult mid-range estimate for cancer deaths

Appendix 7: Estimated prevalence of symptoms and problems in the adult mid-range estimate for non-cancer deaths

Appendix 8: Advisory Group

Appendix 1: ICD-10-AM codes used in estimates

Adult estimates

Minimal estimate: underlying cause of death is one of 10 key disease groups:

- Neoplasm (C00-D48)
- Heart failure (I111, I130, I132, I500, I501, I509)
- Renal failure (N102, N112, N120, N131, N132, N180, N188, N189)
- Liver failure (K704, K711, K721, K729)
- Chronic obstructive pulmonary disease (J40, J410, J411, J418, J42, J430, J431, J432, J438, J439, J440, J441, J448, J449)
- Motor Neuron Disease (G122)
- Parkinson's disease (G20)
- Huntington's disease (G10)
- Alzheimer's disease (G300, G301, G308, G309)
- HIV/AIDS (B20--B24)

Maximal estimate: underlying cause of death is **not** listed below:

- During pregnancy, childbirth, or puerperium (O00-O99)
- Originating during the perinatal period (P00-P96)
- Resulting from injury, poisoning, and certain other external causes (S00-T98); or
- Resulting from external causes of morbidity and mortality (V01-Y98)

Children and young people estimates

Minimal estimate: underlying cause of death is one of the key disease groups from the 2007 UK Department of Health report *Palliative Care Statistics for Children and Young Adults*:

- Neoplasms (C00-C26, C30-C34, C37-C41, C43-C58, C60-C85, C88, C90-C97, D17-D48)
- Certain infectious and parasitic diseases (B20-B25, B44, B90-B92, B94)
- Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism (D55-D61, D63, D64, D66-D77, D81-D84, D86, D89)
- Endocrine, nutritional and metabolic diseases (E22-E25 (excluding E24.4), E31, E32, E34, E35, E70-E72, E74-E80, E83-E85, E88, E90)
- Mental and behavioral disorders (F01-F04, F72, F73, F78, F79)
- Diseases of the nervous system (G10-G13, G20-G26, G31, G32, G35-G37, G41, G45, G46, G60-G64, G70-G73, G80-G83, G90, G91, G93-G96, G98, G99)
- Diseases of the circulatory system (I11-I13, I15, I20-I25, I27, I28, I31, I34-I37, I42, I50, I51, I69, I70, I77, I85, I89)
- Diseases of the respiratory system (J43, J44, J47, J82, J84, J961)
- Diseases of the digestive system (K72-K77)
- Diseases of the musculoskeletal system and connective tissue
- M07, M08, M30-M32, M35, M40, M41, M43, M85, M95
- Diseases of the genitourinary system (N07, N11-N13, N15, N16, N18, N19, N25-N29, N31-N33)
- Certain conditions originating in the perinatal period (P00-P03, P07, P08, P10, P11, P20-P29, P35-P37, P39, P52-P54, P57, P77, P90, P91)
- Congenital malformations, deformations and chromosomal abnormalities (Q00-Q07, Q20-Q28, Q30-Q34, Q38-Q45, Q60-Q62, Q64, Q77-Q81, Q85-Q87, Q89-Q93)

- Injury, poisoning and certain other consequences of external causes (T86, T90, T91, T94-T98)
- External causes of morbidity and mortality (Y85-Y89)

Maximal estimate: underlying cause of death is **not** listed below:

- During pregnancy, childbirth, or puerperium (O00-O99)
- Originating during the perinatal period (P00-P96, except P00-P03, P07, P08, P10, P11, P20-P29, P35-P37, P39, P52-P54, P57, P77, P90, P91)
- Resulting from injury, poisoning, and certain other external causes (S00-T93, except T86, T90, T91, T94-T98); or
- Resulting from external causes of morbidity and mortality (V01-Y98, except Y85-Y89)

Appendix 2: 2006 DHB populations by age group

DHB	Age group										Total
	0-9	10-19	20-29	30-39	40-49	50-59	60-69	70-79	80-89	90+	
Northland	22,320	24,290	13,610	18,580	22,810	20,610	15,700	9760	4270	700	152,650
Waitemata	69,970	75,580	65,530	77,180	79,990	59,640	38,830	23,840	12,110	2030	504,700
Auckland	52,920	55,660	81,380	72,320	63,740	46,450	27,680	16,350	9,680	2130	428,310
Counties Manukau	76,080	77,560	60,930	66,510	66,850	49,270	31,480	17,230	7700	1190	454,800
Waikato	51,120	54,920	45,280	46,760	50,180	42,040	29,470	19,610	9340	1500	350,220
Lakes	15,870	16,010	11,470	14,100	15,060	12,240	8550	5440	2440	340	101,520
Bay of Plenty	28,470	30,080	19,670	25,510	29,460	25,520	19,820	14,180	7030	1050	200,790
Tairāwhiti	7670	7860	4900	5850	6640	5610	3600	2460	1130	210	45,930
Taranaki	14,700	16,440	11,480	14,170	16,010	13,610	9630	7080	3690	630	107,440
Hawke's Bay	22,350	23,790	15,660	19,780	22,680	19,840	13,630	9300	4780	790	152,600
Whanganui	8840	10,100	6460	7,820	9460	8200	5950	4500	2230	420	63,980
MidCentral	22,300	25,560	21,600	20,930	23,470	19,540	14,430	10,220	5090	850	163,990
Hutt Valley	20,720	21,660	16,930	21,010	21,860	16,800	10,840	6990	3520	600	140,930
Capital and Coast	35,710	37,660	46,270	45,420	41,550	31,300	19,880	12,530	6500	1120	277,940
Wairarapa	5280	5780	3370	4730	5890	5740	4240	2890	1440	220	39,580
Nelson Marlborough	16,600	18,610	12,890	17,780	21,350	19,260	13,250	8600	4570	720	133,630
West Coast	4020	4550	3090	4240	5380	4620	3170	1930	950	150	32,100
Canterbury	61,140	67,440	64,660	70,010	72,770	60,770	40,440	28,290	15,320	2520	483,360
South Canterbury	6550	7830	4660	6710	8410	7930	5870	4520	2260	370	55,110
Otago	20,790	27,410	27,420	23,090	26,800	23,820	16,360	11,740	6190	990	184,610
Southland	14,400	15,190	14,250	16,000	17,190	13,780	9310	6290	3030	540	109,980
Total	577,820	623,980	551,510	598,500	627,550	506,590	342,130	223,750	113,270	19,070	4,184,170

Based on District Health Board Population Projections, 2007–26 (2006-Base) produced by Statistics New Zealand in September 2010.

Appendix 3: Projected 2026 DHB populations by age group

DHB	Age group										Total	% Change
	0–9	10–19	20–29	30–39	40–49	50–59	60–69	70–79	80–89	90+		
Northland	21,820	21,670	14,080	19,510	17,370	21,440	24,630	18,960	8710	1670	169,860	11%
Waitemata	82,430	87,850	84,570	93,190	83,780	80,270	72,780	49,890	25,600	5510	665,870	32%
Auckland	62,160	58,560	87,510	97,230	85,520	63,070	51,640	32,560	13,490	2720	554,460	29%
Counties Manukau	95,120	95,220	86,070	89,510	74,470	71,030	63,360	40,930	17,770	3300	636,780	40%
Waikato	52,150	55,420	48,690	50,890	45,320	46,030	47,310	35,890	17,020	3390	402,110	15%
Lakes	14,220	13,930	11,380	13,560	11,430	12,790	13,470	9880	4,280	790	105,730	4%
Bay of Plenty	30,860	30,830	24,590	30,600	27,400	29,900	32,220	25,500	13,150	2810	247,860	23%
Tairāwhiti	6880	6630	4600	5850	5050	5530	5840	4300	1640	290	46,610	2%
Taranaki	13,720	14,350	10,070	13,530	11,870	13,140	14,710	11,700	5720	1170	109,980	2%
Hawke's Bay	20,190	21,120	15,630	18,990	16,810	19,380	21,020	16,710	7830	1560	159,240	4%
Whanganui	7270	7370	5600	7430	5550	6740	8560	6970	3340	700	59,530	-7%
MidCentral	22,040	23,980	23,260	22,710	18,470	19,580	22,090	17,390	8810	1820	180,150	10%
Hutt Valley	18,870	19,600	17,300	19,920	16,710	17,810	17,510	12,500	6070	1230	147,520	5%
Capital and Coast	38,930	39,090	50,140	52,230	44,860	38,770	33,420	23,470	11,540	2460	334,910	20%
Wairarapa	4620	4640	2880	4370	4000	4980	5960	5300	2640	530	39,920	1%
Nelson Marlborough	15,860	17,320	13,190	17,170	16,750	20,030	21,860	17,540	8610	1730	150,060	12%
West Coast	3690	3650	2590	3950	3380	4010	4950	3830	1710	320	32,080	0%
Canterbury	64,070	73,550	73,450	71,860	68,200	73,070	70,040	52,880	25,550	5370	578,040	20%
South Canterbury	6,150	6,480	4,440	6380	5370	6830	8220	7180	3910	890	55,850	1%
Otago	20,660	24,790	28,120	26,230	22,590	21,560	24,290	19,720	9310	1920	199,190	8%
Southland	13,930	14,140	12,140	15,550	14,710	13,900	14,550	10,770	5000	1020	115,710	5%
Total	615,640	640,190	620,300	680,660	599,610	589,860	578,430	423,870	201,700	41,200	4,991,460	19%

Based on District Health Board Population Projections, 2007–26 (2006-Base) produced by Statistics New Zealand in September 2010.

Appendix 4: Ethnic groups in the New Zealand population, by District Health Board ^{(1) (2)}

DHB	European ⁽³⁾	Māori	Pacific Peoples ⁽⁴⁾	Chinese Asian	Indian Asian	Other Asian	MELAA ⁽⁵⁾	Other	Not Elsewhere Included ⁽⁶⁾
Northland	89,466 (60.27%)	43,530 (29.32%)	1,854 (1.25%)	438 (0.30%)	606 (0.41%)	1,077 (0.73%)	288 (0.19%)	21 (0.01%)	11,163 (7.52%)
Waitemata	315,198 (65.45%)	42,876 (8.90%)	30,420 (6.32%)	25,617 (5.32%)	14,475 (3.01%)	26,160 (5.43%)	6,291 (1.31%)	207 (0.04%)	20,376 (4.23%)
Auckland	208,890 (51.63%)	29,847 (7.38%)	45,555 (11.26%)	41,526 (10.26%)	29,235 (7.23%)	20,805 (5.14%)	6,504 (1.61%)	135 (0.03%)	22,119 (5.47%)
Counties Manukau	183,825 (42.45%)	67,248 (15.53%)	82,917 (19.15%)	25,590 (5.91%)	28,608 (6.61%)	15,474 (3.57%)	4,881 (1.13%)	180 (0.04%)	24,363 (5.63%)
Waikato	230,580 (67.98%)	67,476 (19.89%)	7,227 (2.13%)	6,297 (1.86%)	5,007 (1.48%)	5,079 (1.50%)	2,226 (0.66%)	102 (0.03%)	15,189 (4.48%)
Lakes	56,451 (57.42%)	31,377 (31.91%)	2,142 (2.18%)	720 (0.73%)	798 (0.81%)	1,422 (1.45%)	255 (0.26%)	36 (0.04%)	5,115 (5.20%)
Bay of Plenty	133,593 (68.53%)	45,645 (23.42%)	2,196 (1.13%)	897 (0.46%)	2,229 (1.14%)	1,518 (0.78%)	462 (0.24%)	24 (0.01%)	8,361 (4.29%)
Tairāwhiti	20,625 (46.39%)	19,758 (44.44%)	738 (1.66%)	225 (0.51%)	195 (0.44%)	150 (0.34%)	63 (0.14%)		2,694 (6.06%)
Taranaki	81,543 (78.20%)	15,816 (15.17%)	867 (0.83%)	702 (0.67%)	576 (0.55%)	705 (0.68%)	192 (0.18%)	9 (0.01%)	3,867 (3.71%)
Hawke's Bay	101,691 (68.60%)	33,906 (22.87%)	3,900 (2.63%)	1,074 (0.72%)	1,095 (0.74%)	975 (0.66%)	528 (0.36%)	15 (0.01%)	5,073 (3.42%)
Whanganui	43,425 (69.81%)	14,424 (23.19%)	909 (1.46%)	405 (0.65%)	372 (0.60%)	279 (0.45%)	111 (0.18%)	15 (0.02%)	2,265 (3.64%)
Midcentral	117,036 (73.68%)	26,712 (16.82%)	3,378 (2.13%)	3,282 (2.07%)	1,266 (0.80%)	1,980 (1.25%)	870 (0.55%)	36 (0.02%)	4,272 (2.69%)
Hutt	90,930 (66.81%)	21,483 (15.78%)	9852 (7.24%)	3,207 (2.36%)	3,228 (2.37%)	2,874 (2.11%)	1,245 (0.91%)	24 (0.02%)	3,270 (2.40%)
Capital and Coast	182,415 (68.41%)	26,493 (9.94%)	19,017 (7.13%)	10,002 (3.75%)	7,197 (2.70%)	7,551 (2.83%)	3,738 (1.40%)	81 (0.03%)	10,173 (3.81%)
Wairarapa	30,726 (79.57%)	5,496 (14.23%)	621 (1.61%)	189 (0.49%)	135 (0.35%)	171 (0.44%)	81 (0.21%)	15 (0.04%)	1,179 (3.05%)
Nelson Marlborough	110,859 (85.24%)	10,953 (8.42%)	1,308 (1.01%)	480 (0.37%)	405 (0.31%)	1,242 (0.95%)	435 (0.33%)	30 (0.02%)	4,353 (3.35%)
West Coast	26,682 (85.18%)	2,916 (9.31%)	192 (0.61%)	60 (0.19%)	81 (0.26%)	159 (0.51%)	63 (0.20%)		1,167 (3.73%)
Canterbury	380,709 (81.63%)	33,417 (7.16%)	8,991 (1.93%)	12,567 (2.69%)	3,063 (0.66%)	12,006 (2.57%)	3,093 (0.66%)	99 (0.02%)	12,465 (2.67%)
South Canterbury	48,360 (89.76%)	3,159 (5.86%)	369 (0.68%)	231 (0.43%)	111 (0.21%)	408 (0.76%)	96 (0.18%)		1,140 (2.12%)
Otago	152,412 (84.96%)	11,466 (6.39%)	2,625 (1.46%)	3,285 (1.83%)	981 (0.55%)	2,352 (1.31%)	909 (0.51%)	48 (0.03%)	5,322 (2.97%)
Southland	88,110 (82.48%)	11,319 (10.60%)	1,203 (1.13%)	456 (0.43%)	384 (0.36%)	1,095 (1.03%)	459 (0.43%)	21 (0.02%)	3,780 (3.54%)
Area outside DHB	318 (71.62%)	15 (3.38%)	6 (1.35%)			12 (2.70%)			84 (18.92%)
National Total	2,693,817 (66.88%)	565,326 (14.04%)	226,293 (5.62%)	137,256 (3.41%)	100,050 (2.48%)	103,506 (2.57%)	32,796 (0.81%)	1,113 (0.03%)	167,784 (4.17%)

Notes

- (1) Data presented here is based on prioritised ethnicity (level 2) from the 2006 New Zealand Census of Population and Dwellings. Ethnic groups have been prioritised to level two in the following order: Māori, Pacific Peoples, Asian, MELAA, Other, New Zealander and European and Not Elsewhere Included, e.g. if a person is both Pacific Peoples and Asian, then they are counted in the Pacific Peoples category. Within these broad level groups there are sub-groups which also have a prioritisation order.
- (2) Confidentiality rules have been applied to all cells in this table, including randomly rounding to base 3. Individual figures may not add up to totals, and values for the same data may vary in different tables. A blank space indicates there were no residents who identified with this ethnicity.
- (3) 'European (including New Zealand European)' includes people identified as: New Zealand European, New Zealander, Other European and European not further defined.
- (4) 'Pacific Peoples' includes people identified as Samoan, Cook Island Māori, Tongan, Niuean, Fijian, Tokelauan and any other Pacific Peoples groups.
- (5) 'MELAA' includes people identified as Middle Eastern, Latin American and African.
- (6) 'Not Elsewhere Included' includes Response Unidentifiable, Response Outside Scope and Not Stated.

Appendix 5: Religious affiliation by DHB and New Zealand⁽¹⁾

DHB of usual residence	Christian denominations (2)	Māori Christian religions(3)	Buddhist	Hindu	Islam / Muslim	Judaism / Jewish	Spiritualism and New Age religions	Other religions	No religion	Object to answering	Not Elsewhere Included(4)
Northland	48%	3.6%	0.4%	0.3%	0.1%	0.1%	0.5%	0.4%	30.0%	0.03%	16.6%
Waitemata	49%	0.7%	1.6%	1.9%	1.2%	0.2%	0.5%	0.4%	33.4%	0.02%	11.6%
Auckland	46%	0.7%	2.7%	4.7%	2.5%	0.4%	0.4%	0.6%	29.8%	0.01%	11.9%
Counties Manukau	51%	1.7%	2.1%	3.8%	1.6%	0.1%	0.3%	1.5%	24.4%	0.01%	13.3%
Waikato	49%	1.4%	0.9%	0.8%	0.6%	0.1%	0.5%	0.7%	32.7%	0.02%	13.4%
Lakes	48%	3.9%	0.5%	0.5%	0.2%	0.0%	0.4%	0.4%	31.5%	0.03%	14.1%
Bay of Plenty	49%	4.0%	0.4%	0.4%	0.2%	0.1%	0.4%	0.8%	31.4%	0.02%	13.3%
Tairāwhiti	56%	5.0%	0.2%	0.2%	0.1%	0.0%	0.3%	0.4%	23.6%	0.03%	13.9%
Taranaki	53%	0.7%	0.4%	0.3%	0.2%	0.1%	0.4%	0.3%	31.1%	0.03%	13.9%
Hawke's Bay	54%	3.3%	0.5%	0.3%	0.3%	0.1%	0.5%	0.5%	28.5%	0.02%	12.4%
Whanganui	52%	3.8%	0.4%	0.3%	0.2%	0.1%	0.5%	0.3%	28.7%	0.03%	13.4%
MidCentral	53%	1.4%	0.6%	0.5%	0.5%	0.1%	0.5%	0.3%	32.0%	0.02%	11.3%
Hutt Valley	53%	1.3%	1.1%	1.9%	0.6%	0.2%	0.5%	0.3%	31.5%	0.02%	10.3%
Capital and Coast	49%	0.6%	1.6%	1.9%	0.9%	0.3%	0.5%	0.3%	34.5%	0.02%	10.6%
Wairarapa	54%	1.3%	0.3%	0.2%	0.1%	0.1%	0.4%	0.4%	31.1%	0.02%	11.8%
Nelson Marlborough	48%	0.4%	0.8%	0.2%	0.1%	0.1%	0.6%	0.3%	37.4%	0.02%	12.3%
West Coast	51%	0.3%	0.3%	0.2%	0.1%	0.1%	0.5%	0.2%	34.2%	0.03%	13.5%
Canterbury	53%	0.4%	0.9%	0.5%	0.5%	0.1%	0.5%	0.3%	34.1%	0.02%	10.3%
South Canterbury	59%	0.3%	0.3%	0.1%	0.1%	0.03%	0.4%	0.2%	29.0%	0.03%	10.2%
Otago	51%	0.3%	0.7%	0.3%	0.4%	0.1%	0.5%	0.2%	35.5%	0.02%	10.6%
Southland	55%	0.6%	0.4%	0.2%	0.2%	0.1%	0.3%	0.2%	31.3%	0.02%	11.3%
New Zealand	50%	1.4%	1.2%	1.5%	0.8%	0.1%	0.5%	0.5%	31.5%	0.02%	12.1%

Notes

1. Data is based on prioritised religious output, i.e. each respondent is allocated to a single religious group using the priority recording system. Therefore, each respondent appears only once in the data.
2. Christian Denominations includes: Anglican, Baptist, Catholic, Christian not further defined, Latter-day Saints, Methodist, Pentecostal, and Presbyterian, Congregational and Reformed.
3. Māori Christian Religions includes: Ratana, Ringatū and Other Māori Christian Religions.
4. Includes the remaining religious affiliations not elsewhere specified.

Appendix 6: Estimated prevalence of symptoms and problems in the adult mid-range estimate for cancer deaths

Cancer deaths	Symptom/Problem											
	Pain	Loss of appetite	Vomiting or feeling sick	Sleepless-ness	Trouble with breathing	Constipation	Depression	Loss of bladder control	Mental confusion	Pressure ulcers	Loss of bowel control	Unpleasant smell
% with symptom	84%	71%	51%	51%	47%	47%	38%	37%	33%	28%	25%	19%
Northland	235	199	143	143	131	131	106	103	92	78	70	53
Waitemata	571	483	347	347	319	319	258	251	224	190	170	129
Auckland	416	351	252	252	232	232	188	183	163	139	124	94
Counties Manukau	464	392	282	282	260	260	210	204	182	155	138	105
Waikato	488	413	296	296	273	273	221	215	192	163	145	110
Lakes	139	117	84	84	78	78	63	61	55	46	41	31
Bay of Plenty	343	290	208	208	192	192	155	151	135	114	102	78
Tairāwhiti	67	57	41	41	38	38	30	30	26	22	20	15
Taranaki	174	147	105	105	97	97	79	76	68	58	52	39
Hawke's Bay	252	213	153	153	141	141	114	111	99	84	75	57
Whanganui	108	91	65	65	60	60	49	47	42	36	32	24
MidCentral	242	204	147	147	135	135	109	107	95	81	72	55
Hutt Valley	170	144	103	103	95	95	77	75	67	57	51	39
Capital and Coast	270	229	164	164	151	151	122	119	106	90	81	61
Wairarapa	56	48	34	34	31	31	25	25	22	19	17	13
Nelson Marlborough	207	175	126	126	116	116	94	91	81	69	62	47
West Coast	48	40	29	29	27	27	22	21	19	16	14	11
Canterbury	697	589	423	423	390	390	315	307	274	232	208	158
South Canterbury	102	86	62	62	57	57	46	45	40	34	30	23
Otago	317	268	193	193	178	178	144	140	125	106	94	72
Southland	160	135	97	97	90	90	72	71	63	53	48	36
DHB Total	5,526	4,671	3,355	3,355	3,092	3,092	2,500	2,434	2,171	1,842	1,645	1,250

Appendix 7: Estimated prevalence of symptoms and problems in the adult mid-range estimate for non-cancer deaths.

	Non-cancer deaths	Symptom/Problem											
		Pain	Trouble with breathing	Mental confusion	Loss of appetite	Sleepless-ness	Depression	Loss of bladder control	Constipation	Vomiting or feeling sick	Loss of bowel control	Pressure ulcers	Unpleasant smell
% with symptom		67%	49%	38%	38%	36%	36%	33%	32%	27%	22%	14%	13%
Northland	382	256	187	145	145	138	138	126	122	103	84	53	50
Waitemata	896	600	439	340	340	323	323	296	287	242	197	125	116
Auckland	788	528	386	299	299	284	284	260	252	213	173	110	102
Counties Manukau	683	458	335	260	260	246	246	226	219	185	150	96	89
Waikato	719	482	352	273	273	259	259	237	230	194	158	101	93
Lakes	202	135	99	77	77	73	73	67	65	55	44	28	26
Bay of Plenty	504	338	247	192	192	182	182	166	161	136	111	71	66
Tairāwhiti	125	84	61	48	48	45	45	41	40	34	28	18	16
Taranaki	271	182	133	103	103	98	98	89	87	73	60	38	35
Hawke's Bay	432	290	212	164	164	156	156	143	138	117	95	61	56
Whanganui	188	126	92	71	71	68	68	62	60	51	41	26	24
MidCentral	403	270	197	153	153	145	145	133	129	109	89	56	52
Hutt Valley	304	203	149	115	115	109	109	100	97	82	67	43	39
Capital and Coast	472	316	231	179	179	170	170	156	151	127	104	66	61
Wairarapa	99	67	49	38	38	36	36	33	32	27	22	14	13
Nelson Marlborough	306	205	150	116	116	110	110	101	98	83	67	43	40
West Coast	79	53	39	30	30	28	28	26	25	21	17	11	10
Canterbury	1,096	734	537	416	416	395	395	362	351	296	241	153	142
South Canterbury	176	118	86	67	67	63	63	58	56	48	39	25	23
Otago	515	345	252	196	196	185	185	170	165	139	113	72	67
Southland	233	156	114	89	89	84	84	77	75	63	51	33	30
DHB Total	8,873	5,945	4,348	3,372	3,372	3,194	3,194	2,928	2,839	2,396	1,952	1,242	1,154

Appendix 8: Health Needs Assessment Expert Advisory Group

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Professor Rod MacLeod

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