The Need for Palliative Care in New Zealand

Technical Report

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June 2016
Funding and Disclaimer

This work on a revised model of need for palliative care in New Zealand was initially performed for the Palliative Care Council. The completion of the model of need and this technical report were funded by the Ministry of Health.

Any views expressed in this technical report are those of the author in her professional capacity as a health actuary and are not the views of the Ministry of Health.

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Acknowledgements

The author would like to thank the following people who provided useful insights and shared their expertise and experience on the need for palliative care in various settings:

Palliative Care in Residential Care
- Kate Gibb, Nursing Director, Older People - Population Health, Canterbury District Health Board
- Dr Michal Boyd, Senior Lecturer and Nurse Practitioner, School of Nursing, University of Auckland

Paediatric and Adolescent Palliative Care, Perinatal and Congenital Conditions
- Dr Ross Drake, Paediatric Palliative Care and Pain Medicine Specialist, Clinical Lead, Paediatric Palliative Care Service, Starship Child Health
- Karyn Bycroft, Nurse Practitioner, Paediatric Palliative Care Service, Starship Child Health

Clinical Panel and Palliative Care in Public Hospitals
- Dr Jonathan Adler, Palliative Medicine Consultant and Clinical Leader, Palliative Care Service, Wellington Regional Hospital
- Dr Simon Allan, Director of Palliative Care, Arohanui Hospice, and Consultant Medical Oncologist and Palliative Care Physician, Palmerston North Hospital
- Dr Kate Grundy, Palliative Medicine Physician and Clinical Director, Canterbury Integrated Palliative Care Services
- Professor Rod MacLeod, Senior Staff Specialist, HammondCare, and Conjoint Professor in Palliative Care, University of Sydney
- Dr Carol McAllum, Palliative Medicine Specialist and Associate Dean Undergraduate Studies Hawke’s Bay, Hawke’s Bay District Health Board
- Wayne Naylor, Director of Nursing, Hospice Waikato
Executive Summary

The first estimate of the need for palliative care in New Zealand was produced by the Palliative Care Council in 2011. Three estimates were produced, a minimal estimate based on a list of conditions recorded on the death certificate, a mid-range estimate that included hospital admission data, and a maximal estimate based on a longer list of conditions. The report established, for the first time, the number of people who might benefit from palliative care in New Zealand. Overall, combining adults and children, the mid-range estimate in 2006 was that 56.3% of all deaths were amenable to palliative care.

Subsequent to the publication of the HNA1 report in 2011, there have been a number of new papers and revised thinking on the conditions to include in estimates of the need for palliative care. A paper by Murtagh and colleagues has been particularly influential as it compared the results obtained from the earlier Rosenwax approach (the basis for the first New Zealand estimate) to two other methodologies and proposed a revised approach. The proportion of deaths needing palliative care increased substantially in England, from a minimal estimate of need of 37% of all deaths using the Rosenwax methodology to 63% of all deaths using Murtagh’s revised approach. This alone is sufficient reason to revise the New Zealand estimates of need.

Further reasons to revise the New Zealand estimates of need include providing results over a longer period of projection, using more recent projections, using projected deaths (rather than the projected population) and removing anomalies between the adult and child lists of conditions. The key concern when projecting with a rapidly ageing population is that the patterns at the older ages seem plausible. The methodology used in the first estimate in New Zealand produces a shape by age and gender which declines rapidly at older ages. Thus as the population ages, this approach produces a lower need for palliative care. This result is counter-intuitive and is a key reason for reconsidering and revising the methodology.

The historic patterns of deaths in New Zealand were examined using data from the Ministry of Health Mortality Collection (MORT). The data for this analysis was extracted in December 2015 and covers all deaths registered in the calendar years 2000 to 2013. Patterns by age, gender, ethnicity and deprivation were examined. Strong patterns were found for cause of death and place of death by age and gender. An important part of the investigation was the examination of the persistence of historic patterns by region and over time, with the results leading to a decision to use the historic patterns over the period 2009-2013 in the model of need for palliative care.

Methodologies for determining the need for palliative care typically use cause of death lists to determine need but this ignores the context in which the end of life is reached and the likelihood of palliative care being provided. The revised New Zealand estimates of need use an approach which combines cause of death lists with place of death. The cause of death lists were revised by a clinical panel convened from people experienced in providing palliative care in public hospitals, aged residential care and in hospices. Examples of conditions now included in the definition of need in New Zealand are deaths from chronic rheumatic fever, tuberculosis (in the light of the rise of antibiotic-resistance) and gangrene. As children and young adults now live much longer with congenital conditions, the palliative care team at Starship Child Health was also consulted.

The need for palliative care is an estimate of need at a population level for the whole palliative care system. Conceptually, the aim is to include all deaths that typically benefit from a palliative care approach. In no way do these lists of conditions determine who gets palliative care in practice, as that must always be based on the individual patient and judgement of need at the time.
The revised NZ Need for Palliative Care, when tested on historic MORT data from 2000 to 2013, produces a need for palliative care of 79.4% of all deaths. Note that this is the historic proportion and not the proportion of need that should be applied in future.

A second estimate, the NZ Maximal Need for Palliative Care is also produced which includes all deaths other than those in pregnancy and childbirth, and sudden deaths from external causes (like accidents and self-harm). All three estimates are useful to planners: the need for palliative care, the maximal need for palliative care and all deaths.

The historic patterns of need for palliative care by age, gender, ethnicity, deprivation, cause of death and place of death were examined. Importantly, the shape of the need for palliative care by age and gender is more intuitive and appropriate than the previous estimate, with the need for palliative care increasing at older ages.

As the population ages, so the need for palliative care as a proportion of all deaths will increase slightly. The proportion of need will also differ depending on the age structure of a particular District Health Board (DHB) and how this evolves over time. A spreadsheet model has been developed which provides projections and graphs of the need for palliative care at national, regional and local DHB level. Results are given to enable planning for public hospitals, residential care and hospice care.

Projections of future deaths from Statistics New Zealand are used in the model. National population projections from 2016 to 2068 are used to produce long-term projections of need which are useful for policy purposes and for workforce planning. Shorter projections are produced annually by Statistics New Zealand, according to assumptions specified by the Ministry of Health. The projections from 2016 to 2038 are used in the model and these are the same projections used for DHB funding and planning.

The final technical report on the methodology used includes commentary on the national results and a summary of the results by DHB. More detailed information by region and DHB is available in the spreadsheet model. Recommendations are made in the report on the frequency of updates for the model and the events which might trigger a revision of the methodology used.

From a planning perspective, palliative care is certainly not only about care at death. Palliative care and curative care co-exist from the diagnosis of a life-limiting condition, with palliative care becoming more important as the condition progresses. There is insufficient evidence as yet to build a model of need that takes into account the care provided during the course of a life-limiting disease.

Suggestions for further research on the need for palliative care prior to death are made. In particular, suggestions are made as to how linked data might be used to provide greater understanding of the place of care and different trajectories at the end of life. With greater numbers of deaths and the projected ageing of deaths, the implications of longer and slower trajectories of dying are of critical importance for planning future palliative care.
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1. Introduction and Background

The Palliative Care Council produced the first estimate of the need for palliative care in New Zealand (Palliative Care Council, 2011). This was followed by a report on the capability to deliver palliative care in New Zealand, in order to monitor capacity against need (Palliative Care Council, 2013b). This formed a critical part of a framework for “Measuring what Matters” (Palliative Care Council & Cancer Control New Zealand, 2012).

It was recognised at the time that the estimate of the need for palliative care would need to be updated and this was reflected in the work programme of the Palliative Care Council (Palliative Care Council, Hospice New Zealand et al., 2012). The work on an updated estimate of need began in 2013 and this technical report is the culmination of a number of working papers that explored aspects of deaths in New Zealand and the need for palliative care in more detail (Palliative Care Council, 2013a, 2014b, 2014c, 2014a, 2015b, 2015a).

The revised estimate of need for palliative care in New Zealand is described and quantified in this technical report, produced for the Ministry of Health1. The primary aim of the technical report is to document the study and the decisions reached so as to enable the Ministry of Health or other researchers to produce updated estimates in the future.

1.1. First Estimate of Need in New Zealand

The first estimate of the need for palliative care in New Zealand (Palliative Care Council, 2011) was based on cause-specific mortality data and hospital admission data. The underlying cause of death was obtained from the Ministry of Health Mortality Collection (MORT data) for three calendar years, from 2005 to 2007. The first estimate also used hospital admission data from the National Minimum Dataset (NMDS) for hospital events for the same period. Both collections use ICD-10-AM2 coding.

Three estimates were produced, for adults and children (under age 20) separately:

- **Minimal estimate:** condition-specific and included deaths from defined disease groups (using ICD-10-AM codes) considered likely to benefit from palliative care.
- **Mid-range estimate:** included 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.
- **Maximal estimate:** least restrictive estimate and included all causes of death, except those regarded as not amenable to palliative care. Excludes deaths for pregnancy and childbirth, deaths originating during the perinatal period, and deaths resulting from external causes.

Two papers from Australia by Rosenwax and McNamara (Rosenwax, McNamara et al., 2005; McNamara, Rosenwax et al., 2006) were the basis for the choice of conditions amenable to palliative care for adults. The list of conditions for children (those under age 20) was taken from work in the UK by Cochrane (Cochrane, Liyanage et al., 2007). In this technical report, this methodology from the Health Needs Assessment Phase 1 report is described as HNA1.

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1 The Palliative Care Council and Cancer Control New Zealand were disestablished by the Minister of Health in July 2015. [https://www.beehive.govt.nz/release/cancer-control-nz-thanked-their-work](https://www.beehive.govt.nz/release/cancer-control-nz-thanked-their-work)

The report established, for the first time, the number of people who might benefit from palliative care in New Zealand. For adults, this was found to be 41.8% of all adult deaths for the minimal estimate, 56.7% for the mid-range estimate and 93.6% of all adult deaths for the maximal estimate. Overall, combining adults and children, the mid-range estimate in 2006 was that 56.3% of all deaths were amenable to palliative care.

The proportion of the population needing palliative care was determined at a national level for the minimal, mid-range and maximal estimates. The rate per 100,000 of population for each DHB for the mid-range estimate was also given. The projections of the population used were the District Health Board Population Projections, 2007–26 (2006-Base), prepared by Statistics New Zealand for the Ministry of Health. Estimates of need were published nationally and by DHB for three dates: 2006, 2016 and 2026.

The final HNA1 report (Palliative Care Council, 2011) considered patterns by age, gender, ethnicity, deprivation (using NZDep2006\(^3\)), place of death and cause of death for the mid-range estimate. An analysis of the population using data from Census 2006 was also provided.

The model and report were prepared for the Palliative Care Council by Wayne Naylor. The data and results have subsequently been included in a number of international papers, which he has co-authored (Cohen, Pivodic et al., 2015; Moens, Houttekier et al., 2015; Reyniers, Deliens et al., 2015; Pivodic, Pardon et al., 2016).

1.2. Rationale for Revising the Estimate of Need

Subsequent to the publication of the HNA1 report in 2011, there have been a number of new papers and revised thinking on the conditions to include in estimates of the need for palliative care. These include estimates of need in Spain (Gómez-Batiste, Martinez-Munoz et al., 2012; Gómez-Batiste, Martinez-Munoz et al., 2014), England (Murtagh, Bausewein et al., 2014), Ireland (Kane, Daveson et al., 2015), Germany (Scholten, Gunther et al., 2016) and the first world-wide estimates (Worldwide Palliative Care Alliance & World Health Organization, 2014).

There have also been several new papers on the palliative care needs of children (Fraser, Miller et al., 2011; Hain, Devins et al., 2013; Noyes, Edwards et al., 2013; United Nations Children’s Fund & International Children’s Palliative Care Network, 2013).

The paper by Murtagh and colleagues (Murtagh, Bausewein et al., 2014) has been particularly influential as it compared the results obtained from the earlier Rosenwax approach (Rosenwax, McNamara et al., 2005; McNamara, Rosenwax et al., 2006) to methodology by Higginson and by Gómez-Batiste. The paper showed that results could be obtained by using only death certificate data and that it was not necessary to use hospital admission data as well. This considerably simplifies the estimates of need and the same methodology has been applied to Ireland and Germany (Kane, Daveson et al., 2015; Scholten, Gunther et al., 2016).

The proportion of deaths needing palliative care increased substantially in England, from a minimal estimate of need of 37% of all deaths using the Rosenwax methodology to 63% of all deaths using Murtagh’s revised approach. This alone is sufficient reason to revise the New Zealand estimates of need. The impact of this advance in methodology is covered in more detail in section 3.4.

\(^3\) New Zealand Deprivation Index 2006, [http://www.otago.ac.nz/wellington/departments/publichealth/research/hirp/otago020194.html](http://www.otago.ac.nz/wellington/departments/publichealth/research/hirp/otago020194.html)
There are five further reasons for revising the methodology used for the first estimate of the need for palliative care:

a) **Period of Projection**: the HNA1 projection provided estimates of need for the years 2016 and 2026. With the passage of time, this period is now too short for planning purposes. There are also longer-term impacts of the effects of longevity and the “Baby Boomers” reaching the end of life, which are not captured with projections over a short period. This is examined in more detail in section 5.1.

b) **Projected using Population and not Deaths**: the HNA1 projection used the proportion of the population needing palliative care, expressed as a rate per 100,000 of population. This is an explicit assumption that the proportion of deaths to population will remain constant in the future, which is not the case in the Statistics NZ projections, as shown in Figure 1. After a long period of decline in the death rate per 100,000 lives we are entering a period where the rate is expected to increase to levels last seen in the early 1950s. It is thus critical to project the need for palliative care using projected deaths and not the projected population.

![Figure 1: Deaths relative to Population in New Zealand](source)

Source: (Palliative Care Council, 2013a), using National Population Projections: 2011(base)–2061

c) **Results from Census 2013**: the HNA1 report used projections with base 2006 and these have been superseded with national and DHB projections using base 2013. The information from a census is used to calibrate the projections and provides important information about the extent of immigration and internal migration. It will be essential to amend the model when new projections are available after the next census, which is planned for 2018 (Statistics New Zealand, 2016).

d) **Separate Adult and Child Lists of Conditions**: the approach used by Rosenwax and McNamara, (the basis for the New Zealand HNA1 report) uses separate lists of conditions for adults and children (under age 20). The adult list consisted of ten disease groups while the child list, based on work in the UK, covered many more conditions. This leads to anomalies between the child and adult lists, with nearly half of congenital deaths excluded if they occur from age 20 onwards. An example is cystic fibrosis, which is included in the need for palliative care under age 20 but not over that age.
e) **Pattern at Older Ages**: the key concern when projecting with a rapidly ageing population is that the patterns at the older ages seem plausible. The Rosenwax and McNamara methodology for the adult estimate was based on ten disease groups with frailty and dementia not fully represented. The HNA1 Minimal and Maximal estimates, when applied to the MORT data 2000-2013, are shown in Figure 2. The HNA1 Minimal estimate gives a need for palliative care of 40.2% of total deaths, while the HNA1 Maximal estimate gives 93.6% of total deaths.

![Figure 2: Pattern of Need for Palliative Care using HNA1 Methodology on MORT Data 2000-2013](image)

The HNA1 Minimal shape declines rapidly at lower ages, thus as the population ages, there would be a lower need for palliative care. This result is counter-intuitive and is a key reason for reconsidering and revising the methodology.

### 1.3. Structure of the Model for Estimating Need

The essence of the model of need for palliative care is a set of patterns of need (by age and gender) which are applied to future projections of deaths (also by age and gender). The patterns of need are derived from extensive evaluation of historic deaths in New Zealand, using all deaths over the period 2000 to 2013. A more recent subset of those deaths, from 2009 to 2013, is used for the patterns in the model, as argued in section 2.7.

Two sets of projections of deaths will be used, as described in section 0. The longer set projects at a national level from 2016 to 2068, with more detailed projections at regional and DHB level for the period 2016 to 2038.

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4 Neoplasms, Heart failure, Renal failure, Liver failure, Chronic obstructive pulmonary disease, Motor Neuron Disease, Parkinson’s disease, Huntington’s disease, Alzheimer’s disease, HIV/AIDS.
The results from the model are tables and graphs at DHB, regional and national level. These have been produced in the form of a spreadsheet tool available to policy-makers, planners and funders, researchers and stakeholders.

1.4. Outline of the Technical Report

The structure of the report follows from the outline of the model of the need for palliative care in Figure 3 by considering the historic patterns and future projections separately.

Section 2 deals with the key results from the examination of the historic patterns of deaths in New Zealand. An important part of that investigation was the examination of the persistence of historic patterns by region and over time, with a decision on the period to use for the historic patterns in the final model.

Section 3 considers the papers published on the methodology used for estimating the need for palliative care, concentrating on developments since the first New Zealand estimate. The conceptual approach adopted for the pattern of need in New Zealand is argued, the work of the Clinical Panel is outlined and the revised methodology is described. Section 4 provides results of the historic need for palliative care in New Zealand, using the revised methodology.

Section 5 turns to the future projections used in the model, outlining key features of the projections of future deaths to 2068 and 2038. Section 6 then brings together the historic patterns and future projections of deaths to provide projections of the future need for palliative care.

Section 7 considers some limitations of the methodology, makes recommendations for updating the model of need and makes recommendations for further research.
2. Historic Patterns of Deaths in New Zealand

This section highlights key results from the examination of the historic patterns of deaths in New Zealand, over the period 2000 to 2013. An important part of that investigation was the examination of the persistence of historic patterns by region and over time, with the results leading to a decision on the historic patterns to use in the model of need for palliative care.

This analysis uses data from the Ministry of Health Mortality Collection (MORT data). This collection classifies the underlying cause of death for all deaths registered in New Zealand and is typically available 18 months to two years after the completion of a calendar year. The data for this analysis was extracted in December 2015 and covers all deaths registered in the calendar years 2000 to 2013. The data supplied includes place of death (Palliative Care Council, 2014b) and the New Zealand Index of Deprivation (NZDep) for 2001, 2006 and 2013.

2.1. Age, Gender and Ethnicity

New Zealand has relatively few deaths at younger ages, with only 5.5% of all deaths occurring before age 40 in the study period. Deaths under age 65 accounted for 22.2% of the total while those for age 85 and over were 31.3% for the study period. Over the 14-year period, there has been a sustained increase in the age at which deaths occur, as shown in Figure 4. Deaths at age 85 and over were 25.9% of total deaths in the year 2000, reaching 35.3% of total deaths in 2013.

![Figure 4: Age of Deaths in New Zealand, 2000-2013](image)

There is a very strong gender pattern by age, as shown in Figure 5. There are more male deaths in the childhood years, late teens and early adulthood. Women have longer life expectancy and deaths at the oldest ages are predominantly of women.
Women typically die at older ages than men. Over the study period, 17.9% of women but 26.4% of men who died were under age 65. Conversely, 40.4% of women but only 22.2% of men who died were age 85 and over. The difference in pattern by age and gender is a core reason for doing all the modelling by both age and gender.

The MORT data is supplied with prioritised ethnicity in the order Māori, Pacific, Asian and Other (which includes pakeha).
For all deaths over the study period, the proportion of Māori was 9.9%, with 3.7% Pacific and 2.2% Asian. The proportion of Māori and Pacific deaths has remained relatively similar throughout the period, with Asian deaths increasing substantially but off a very low base.

There is a very strong pattern of ethnicity by age, as shown in Figure 7. There is a distinct wedge-shape with proportionately many more Māori, Pacific and Asian deaths at younger ages. The total number of deaths in each band is shown in the same figure, with very high numbers of deaths occurring in older age bands where the Other ethnicity predominates.

![Figure 7: Ethnicity of Deaths by Age Band in New Zealand, 2000-2013](image)

The difficulty of modelling by ethnicity is that there is very little data on deaths at older ages for Māori, Pacific and Asian people, so that reliable historic patterns by age cannot be produced. The projections of future deaths, discussed in section 5.1, show that there is expected to be a substantial increase in the age at which Māori and Pacific deaths occur. Projections of need by age, gender and ethnicity are not considered viable given the very little historic data available at the older ages.

As will be discussed in section 5.1, the proportion of Māori and Pacific deaths is expected to remain constant from 2016 to 2038, which supports not producing projections by age, gender and ethnicity over this period.
2.2. Cause of Death

Over the study period, there has been a proportional decline in deaths from circulatory system conditions and an increase in deaths from other conditions (which include frailty and dementia).

Figure 8: Cause of Death in New Zealand, 2000-2013

Figure 9: Cause of Death by Age and Gender in New Zealand, 2000-2013
The very strong pattern by age and gender in Figure 9 is significant for the development of a model of need for palliative care. Deaths from external causes (including vehicle accidents, violence and suicides) are the predominant cause of death in the late teenage and early adult years and are proportionately larger for men than for women. The peak for deaths from neoplasms occurs at about age 50 for women and age 65 for men.

At older ages, the proportion of deaths from neoplasms falls sharply for both men and women, to be replaced by circulatory system deaths and deaths from other conditions. The proportion of deaths from other conditions increases strongly with age in the older age bands. Other conditions include deaths from respiratory conditions, dementia and frailty.

Over the study period, the increase in deaths from other conditions in Figure 8 is consistent with the strong pattern for cause of death by age and gender in Figure 9, and an ageing population as shown in Figure 4.

### 2.3. Place of Death

There is a similarly strong pattern of place of death by age and gender, as illustrated in Figure 11. Thus, with an ageing population, there has been a proportional decline in deaths in public hospital and other settings, and a substantial increase in the proportion of deaths in residential care.

![Figure 10: Place of Death in New Zealand, 2000-2013](image)

For the most recent year, 2013, close to one third of deaths occurred in public hospital (32.7%), one third in residential care (33.1 %), 23.0% in private residences and 6.9% in hospice inpatient units (IPU).
Note that this analysis substantially undercounts the involvement of hospice with deaths in New Zealand, as the MORT data only provides for place of death in the hospice IPU. Studies on hospice data (Hospice New Zealand, 2016) show that in the year to June 2015, 74% of hospice patients had no admission to any hospice inpatient unit. Hospice New Zealand finds that only 23% of hospice patients died in a hospice IPU, while 69% of deaths were in the community, either at home or in residential aged care.

The reach of hospice care can thus not be obtained directly from the mortality data. In the model of the need for palliative care, hospice care will be represented by deaths in hospice IPU, together with a proportion of deaths in residential care and private residences, with smaller proportions of deaths in public hospitals and other settings.

The strong pattern of place of death by age and gender is shown in Figure 11.

![Figure 11: Place of Death by Age and Gender in New Zealand, 2000-2013](image)

Deaths in public hospital are highest for those under 1 year and decline rapidly at the oldest ages. Deaths in other settings (including roads, rivers, mountains and public places) mirrors to some extent the deaths from external causes shown in Figure 9.

The most significant feature in Figure 11 is the expanding “funnel” of deaths in residential care at older ages. Note that the mortality data does not separate aged residential care from all residential care. However, an earlier study (Palliative Care Council, 2015a) found that deaths under age 65 years accounted for 5.1% and deaths under age 50 years accounted for only 1.3% of total deaths in residential care. While the majority of recipients of subsidies for aged residential care are aged 65 years and older, this subsidy is also available to those aged 50 to 64 years who are single with no dependent children.

The OPAL study (Boyd, Michal, Connolly et al., 2009; Boyd, M., Broad et al., 2011) found that over a 20-year period there has seen substantial ageing of the residents in residential aged care in Auckland. Over the same period, there has also been a substantial increase in the levels of dependency of residents.
Researchers have described residential aged care as becoming a “de facto hospice” for older people in New Zealand (Connolly, Broad et al., 2013). The three figures below show the substantial increase in the numbers of deaths in residential care in recent years for men (Figure 12), women (Figure 13) and for all deaths from neoplasms (Figure 14).

![Figure 12: Place of Death in New Zealand: Male Deaths, 2000-2013](image1)

![Figure 13: Place of Death in New Zealand: Female Deaths, 2000-2013](image2)
There are strong differences by gender that are apparent in the actual numbers of historic deaths. The most common place of death for men is public hospitals, as shown in Figure 12. Between 2011 and 2013, residential care surpassed private residence as the next most likely place of death for men.

For women, since 2001 residential care has been the most likely place of death, as shown in Figure 13. Over the period 2000 – 2013 the gap between residential care and public hospital widened.

In the early part of the study period, deaths from neoplasms in public hospitals were at about the same levels as deaths in private residences, as shown in Figure 14. Throughout the study period deaths from neoplasms have increased in residential care so that by the end of the period, residential care is the next most likely place of death after private residence.

While all of the patterns are consistent with an ageing population, there appears to have been some change in more recent years in the use of residential care for end of life care. This issue is taken up again in section 0 in considering the persistence of the age-gender patterns over time.

2.4. Deaths by NZ Deprivation Index

New Zealand has a consistent set of socioeconomic deprivation indices, NZDep and NZiDep, produced by the Department of Public Health at the University of Otago, Wellington. The NZ Deprivation Index (NZDep) has been produced following the Statistics New Zealand census for every census since 1991, resulting in the following sets of tables: NZDep91, NZDep96, NZDep2001, NZDep2006 and NZDep2013.
NZDep describes the deprivation experienced by groups of people in small areas and is based on geocoding of the address. It is important to interpret the NZDep results carefully, as the authors warn (White, Gunston et al., 2008):

“Users of NZDep indexes should refer to ‘areas that have the most deprived NZDep scores’ rather than ‘the most deprived areas’.” “It is important to remember that NZDep describes general socioeconomic deprivation in an area. It does not describe the deprivation of an individual.” [emphasis added]

The MORT data received from the Ministry of Health contained NZDep 2001, NZDep 2006 and NZDep2013. Although it is usual practice to use the NZDep index available at the time the data is recorded, the MORT data team advised that, due to anomalies and missing recent linkages, NZDep2006 should be used for the analysis of deaths over the period from 2000 to 2013.

NZDep uses a scale of 1-10, with 1 being the areas with the least deprived NZDep score and 10 the areas with the most deprived NZDep scores. By population, there are approximately equal numbers of people in each NZDep category, not exactly equal numbers. Total deaths over the study period are shown by NZDep2006 category in Figure 15.

![Figure 15: Deaths in New Zealand 2000-2013 by NZDep2006](image)

The highest number of deaths was not in people from areas with the highest deprivation score, but in people from categories 7 and 8. Dep 7, 8, 9 and 10 together make up just under half (48.9%) of total deaths. While the results are shown above for the whole period, the high numbers of deaths in areas with NZDep scores of 7 and 8 persist over time. Over the period deaths from Dep 1 and 2 have been the lowest but are the fastest growing.

Substantial analysis has been done from a number of angles but the graphs of deaths by NZDep are not at all simple to interpret. It is important to remember that it is not the person but the area in which they live which is assigned an NZDep score. The siting of residential care facilities and how these are treated for assigning an NZDep score may be a reason why deaths appear to be clustered in NZDep categories 7 and 8.
2.5. Persistence of Patterns Regionally

An important issue in building the projection model is whether the strong patterns by age and gender, for cause of death and place of death, persist regionally and over time. The persistence regionally is considered in this section and the persistence over time in the section that follows.

The patterns by age\(^5\) for each of the four planning regions (Northern, Midland, Central and South Island) are shown for cause of death in Figure 16 and place of death in Figure 17.

\(^5\) The patterns were analysed by age and gender but are shown only by age in this technical report.
The patterns for cause of death by age and gender in Figure 9 remain persistent across the four regions. The smaller regions (Midland and Central) have patterns that become less stable at younger ages, given the small numbers of deaths at those ages. There are some differences in the proportion of deaths from external causes, and the proportion of deaths from cancer are very slightly higher in the South Island region in the age bands around 50 to 60 years.

![Figure 17: Comparison by Region of Place of Death by Age Bands, 2000-2013](image)

For place of death, all four regions show broadly similar patterns to Figure 11. Deaths in public hospitals are highest at under one year, declining at the oldest ages, accompanied by an expanding proportion of deaths in residential care at older ages.

The most noticeable differences are in the proportion of deaths in hospice IPU between the Midland and Central regions. The Midland region operates with a more community-based model and very few hospice IPU beds. The beds that are in use were added in the latter part of the period and so reduce the average over the whole period. The Central region has a much higher supply of hospice IPU beds and has had these over a longer period of time. The first hospice in New Zealand was Mary Potter hospice, opened in the Central region in 1979.
2.6. Persistence of Patterns over Time

In order to use historic patterns for future projections, it is necessary to understand the extent of changes in the patterns by age and gender over time. Four periods were compared in the analysis:

- the period of the initial studies for the Palliative Care Council – 2000 to 2010
- the new data received i.e. the most recent three-year period – 2011 to 2013
- the full period of the study for this technical report – 2000 to 2013
- the most recent five-year period – 2009 to 2013.

The historic patterns for cause of death and place of death by age and gender are shown to be consistent over all periods with very minor changes in the later years. This is illustrated visually in pairs of graphs showing the pattern for the full period (2000 to 2013) on the left and the five-year period (2009 to 2013) on the right.

Figure 18

In Figure 18, the cause of death pattern for the full period on the left is remarkably similar to the five-year period on the right. In the detail, the proportion of deaths due to circulatory system causes seems to be declining at the oldest ages, to be replaced by proportionally more deaths from other conditions.

In Figure 19, the place of death pattern for the full period on the left is again remarkably similar to the five-year period on the right. There has been a small decrease in the proportion of deaths in public hospitals at the oldest ages, with a small increase in the proportion of deaths in residential care in the more recent period. Deaths in hospice IPU are also proportionately a little higher in some age bands but this is not many cases and is consistent with the development of hospice IPU beds in later years in the Midland region.
It is reassuring to see how the main features of the patterns by age and gender have persisted over the 14-year period of the study (2000 to 2013) with relatively minor differences in the more recent data.

2.7. Choice of Historic Patterns for Projection Model

The conclusion from the analysis by region is that the main projection table, for most purposes, should be the New Zealand table. The spreadsheet model also includes four regional tables to enable the results to be compared. This is particularly important for estimates of deaths in hospice IPU and enables the practice of a region to be compared to the national practice.

DHBs are too small an area to use for historic patterns as, even over the 14 years of the study period, there is insufficient data to produce stable patterns by age and gender. However, projections of deaths by DHB are available and are used in the model. The projections of deaths by DHB are then combined with either the relevant regional table or the national table.

With the relatively small numbers of deaths in New Zealand (some 30,000 a year), there is a tension between using the most recent data and having sufficient data to generate smooth stable patterns.

There are very few deaths at the youngest ages in New Zealand and this creates instability in patterns over shorter periods of time. Using the full period from 2000 to 2013 certainly produces very stable patterns but has the disadvantage that newer features of the patterns are averaged out over a long 14-year period. A time period that is more responsive to recent developments in models of care and causes of death is thus preferable.
The choice of period is informed by the need to produce patterns for New Zealand as a whole, as well as the four regions. If there was a need to produce a pattern only for New Zealand as a whole, then using the most recent three years of data (2011 to 2013) would have been sufficient. However, at a regional level the patterns become unstable with the small numbers of deaths.

The periods under consideration are illustrated in Figure 20, with the dark blue bars representing the study for this technical report (2000 to 2013). While Statistics NZ has already published total deaths for the calendar years 2014 and 2015, the MORT data for these years is not yet available.

![Figure 20: Deaths in New Zealand, 2000 to 2015, with Illustrated Historic Periods](image)

The period chosen for the initial study of need in New Zealand is shown as HNA1 and the initial study for the Palliative Care Council (over the period 2000 to 2010) is shown as PCC. In hindsight, the period used for the HNA1 study was a period of relatively fewer deaths compared to the years on either side. This also illustrates the problems with relatively small numbers and that there can be significant changes in the total number of deaths in New Zealand from year to year.

On balance, it was decided to use patterns from the most recent five years of data, from 2009 to 2013. This uses the features of the more recent patterns yet gives sufficient data for extracting regional historic patterns.
3. Methodology for Estimating Need

In section 1.1, the methodology that was used for the first estimate of need in New Zealand (Palliative Care Council, 2011) was described and, in section 1.2, the rationale for revising the methodology is given. This section considers the growing body of international papers published on the methodology for estimating the need for palliative care. The conceptual approach for the historic patterns of need in New Zealand is then argued and the work of the Clinical Panel described. Finally, the methodology adopted for this technical report is described and compared to the initial methodology used in the first estimate in New Zealand.

3.1. Defining the Need for Palliative Care

Palliative care as a philosophy of care has developed rapidly since the 1960s, moving from an initial focus on end-of-life care needs of patients with advanced malignant disease to earlier stages in the disease progression, as well as to those with non-malignant life-limiting disease. (Clark, 2007). Palliative care became a medical speciality in the UK in the late 1980s and subsequently in many other countries. Revisions to definitions of palliative care internationally continue, with the World Health Organization (WHO) definition of 2002 being clarified by statements by the Worldwide Palliative Care Alliance (WPCA), including the following key points (WPCA & WHO, 2014, pp. 7-9):

- “Palliative care is needed in chronic as well as life-threatening or life-limiting conditions. Early intervention, well before the terminal stage, is recognised as optimal.
- There is no time or prognostic limit on the delivery of palliative care. Palliative care should be delivered on the basis of need, not diagnosis or prognosis.
- There is a need for palliative care at all levels of care. Palliative care is not limited to specialist palliative care services but includes primary and secondary level care.
- Palliative care is not limited to any one care setting and is provided wherever a person’s care takes place.”

A systematic review of the definition of “need” for palliative care (Higginson, Hart et al., 2007) found underpinning definitions of need from the fields of psychology and sociology. For needs assessment work, the definition of need from the UK National Health Service Executive is “the ability to benefit from health care”. The authors found that “need” is equated with “capacity to benefit”, where benefit is not restricted to clinical benefit, but includes reassurance, supportive care, and relief of carers. The authors found that need can be assessed by adopting an epidemiological approach (using disease-specific mortality and related to the duration of symptoms prior to death) or by examining health service usage (although the latter does not measure unmet need).

The “ability to benefit” from healthcare is the core concept behind the “need for palliative care” in the New Zealand estimates. The first estimate of need in New Zealand consisted of two reports, the Phase 1 report (Palliative Care Council, 2011) covering the epidemiological need, and the Phase 2 report (Palliative Care Council, 2013b) covering usage and the capability of the health system. This revised estimate of need will adopt an epidemiological approach and the projections should be measured against the provision of palliative care to determine gaps in service provision.

In general, the “need for palliative care” methodologies do not distinguish between the need for specialist palliative care and primary palliative care, but provide estimates of need for the whole palliative care system. Palliative care is both a philosophy of care and a medical speciality, a combination that causes some confusion. Further clarification on this point, as it applies to the definition of “need”, is included in section 3.7.
Definitions used in this technical report are those in the New Zealand Palliative Care Glossary, first published in 2012 (Palliative Care Council, 2012) and revised in 2015 (Ministry of Health, 2015b). The current definitions for palliative care, the palliative care system, specialist palliative care, primary palliative care and the palliative care approach are provided in Appendix 1.

3.2. Advances in Methodology Internationally

An early paper on the need for palliative care (Franks, Salisbury et al., 2000) focussed on the need for symptom control, particularly for pain, respiratory problems and nausea/vomiting. These symptoms were initially considered in cancer populations and then contrasted with their prevalence in those dying from non-malignant disease. Other symptoms such as fatigue, poor sleep, weakness, confusion, appetite, incontinence, constipation, depression and anxiety were also considered but not available in all studies.

Papers on the extension of palliative care from cancer to non-malignant disease by Higginson (Higginson, 1998; Higginson & Addington-Hall, 1999) had taken a similar line of reasoning, focussing on the importance of palliative care for symptom control. Higginson produced one of the first known quantitative estimates of need (Higginson, 1997), using the number of people with selected causes of death (grouped as cancer and six non-cancer groups) multiplied by the prevalence of symptoms. The symptom prevalence was estimated from systematic reviews, separately for cancer and non-cancer patients.

Higginson’s approach of using the number of deaths multiplied by a score for the prevalence of symptoms formed the basis of the approach for the first international estimate of the need for palliative care (WPCA & WHO, 2014). The conditions to be included were assessed separately for adults and children by Delphi studies conducted by the WHO. The numbers of deaths by ICD-10 code were obtained from the WHO Global Health Estimates for 2011. The prevalence of pain was used to modify the total number of deaths from each cause. The pain prevalence was updated from the original work by Higginson by using results from a 2006 review of symptom prevalence of non-cancer conditions. For example, the pain prevalence was 84% for cancer in adults and 67% for COPD, meaning that 84% of cancer deaths and 67% of COPD deaths were used in the calculation of need.

This approach of using a percentage applied to number of deaths was also used in a study in Catalonia in Spain (Gómez-Batiste, Martinez-Munoz et al., 2012). Gómez-Batiste used a flat percentage of 75% across deaths from all conditions in the initial estimate of need.

The approaches using a percentage modification of deaths do not fully take into account differing needs as the population ages. In Gómez-Batiste’s approach, the need for palliative care will remain a constant percentage of deaths despite the ageing of the population. In Higginson’s approach and that of the WHO, the pain score for cancer is higher than for most other conditions6 hence, as cancer deaths are replaced by deaths from other conditions in an ageing population, the need for palliative care would reduce. The WHO approach can, however, be used with readily available burden of disease data and so lends itself to large international comparisons of need at a point in time.

6 In the WHO methodology, only Rheumatoid arthritis (89%) and Drug-resistant tuberculosis (90%) have higher pain scores than for cancer (84%).
More recent work in Spain (Gomez-Batiste, Martinez-Munoz et al., 2014) used direct measurement of the prevalence of people in need of palliative care and was done for advanced chronically ill patients in Catalonia. This approach used the NECPAL CCOMS-ICO© tool, based on similar instruments used in the UK, validated for the Spanish cultural and clinical context. The tool includes the “surprise question” (Gold Standards Framework, 2011) by asking whether the clinician would be surprised if this person were to die in the next twelve months. As with the Gold Standards Framework, general clinical indicators of severity and progression are used, together with specific clinical indicators for particular diseases. While this approach is directly useful to identify palliative care need for specific patients in a health service, it requires a great deal of time to administer and does not lend itself to being used for national planning over time.

The predominant method used for planning for a national population has been identifying those deaths amenable to palliative care by using lists of conditions defined by ICD-10 code on mortality data, supplemented by additional data. Rosenwax and McNamara produced estimates in Western Australia using 100% of the deaths for a list of defined conditions (Rosenwax, McNamara et al., 2005; McNamara, Rosenwax et al., 2006). The ten groups of conditions used for adults were neoplasms, heart failure, renal failure, liver failure, chronic obstructive pulmonary disease, motor neuron disease, Parkinson’s disease, Huntington’s disease, Alzheimer’s disease and HIV/AIDS.

As described in section 1.1, this Rosenwax methodology was the basis of the first estimate for adults in New Zealand. The Rosenwax approach produces three estimates of need: minimal, mid-range and maximal. The minimal and maximal estimates use number of deaths from mortality data, while the mid-range estimate also requires hospital admission data. Patients are included if they have had an admission in the last year of life for one of the ten groups of conditions used in the minimal estimate. The availability of detailed hospital admission data can be problematic and the approach of combining mortality and hospital data adds complexity to the estimates, with the potential for duplication if data linkage is not achieved for all records. The reasons for admission may also not be the conditions coded for after investigations during the period in hospital.

A comparison of the methodologies of Higginson, Gómez-Batiste and Rosenwax was made in a significant paper by Murtagh and colleagues (including Higginson) in the UK (Murtagh, Bausewein et al., 2014). The three approaches and a revised approach recommended by Murtagh were applied to all deaths in England for 2006 to 2008, producing the results shown below.

<table>
<thead>
<tr>
<th>Methodology</th>
<th>Estimate</th>
<th>Percent of total deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Higginson</td>
<td>Pain</td>
<td>60.3%</td>
</tr>
<tr>
<td></td>
<td>Breathlessness</td>
<td>39.1%</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td>30.5%</td>
</tr>
<tr>
<td>Rosenwax</td>
<td>Minimal estimate</td>
<td>37.0%</td>
</tr>
<tr>
<td></td>
<td>Maximal estimate</td>
<td>96.6%</td>
</tr>
<tr>
<td>Gómez-Batiste</td>
<td></td>
<td>75.0%</td>
</tr>
<tr>
<td>Murtagh</td>
<td>Minimal estimate</td>
<td>63.0%</td>
</tr>
<tr>
<td></td>
<td>Intermediate estimate – lower limit</td>
<td>69.0%</td>
</tr>
<tr>
<td></td>
<td>Intermediate estimate – upper limit</td>
<td>81.9%</td>
</tr>
<tr>
<td></td>
<td>Maximal estimate</td>
<td>96.6%</td>
</tr>
</tbody>
</table>
Of particular interest is that Murtagh found that results could be obtained by using only death certificate data and that it was not necessary to use hospital admission data as well. This considerably simplifies the estimates of need as only one source of data is needed.

Murtagh still differentiates between a minimal estimate (with more conditions than Rosenwax) and two mid-range or intermediate estimates. The minimal estimate uses the underlying cause of death in the mortality data, while the mid-range estimates use both underlying cause of death and contributory cause of death. The methodology pays particular attention to deaths from dementia, frailty and renal disease as these tend to be under-recorded on death certificates.

The publication of the paper by Murtagh has led to the application of the simplified methodology in other settings and has been applied to Ireland (Kane, Daveson et al., 2015) and to Germany (Scholten, Gunther et al., 2016). The application of the Murtagh methodology for adults to the New Zealand data is considered in section 3.4.

The Rosenwax methodology, with 10 disease conditions considered as being amenable to receiving palliative care, was examined again in Western Australia, nearly a decade after the first study. The paper (Rosenwax, Spilsbury et al., 2016) found that 53.7% of all deaths were amenable to palliative care and that 46.3% of deaths received specialist palliative care (defined as community-based or hospital-based palliative care). This was a 3.5% increase on access to specialist palliative care in the last year of life from the initial study conducted a decade earlier. This is the only paper that clearly specifies the estimate of need as being for specialist palliative care. This estimate, using ten conditions, is very particular to the models of care in Western Australia and may not be applicable in other countries.

There is increasing interest in comparative measurements of end of life care across countries, encouraged by the work of Joachim Cohen and the International Place of Death (IPoD) study. New Zealand has participated in this work as a result of the earlier estimates by Wayne Naylor, together with Rod MacLeod. A forthcoming paper compares place of death and cause of death for estimates of need in 14 countries. The paper uses the Rosenwax and Murtagh methodologies, together with a methodology from the French National Observatory on End-of-Life Care (Observatoire National de la Fin de Vie, 2011), which is based on lists derived in Quebec, Canada (Institut national de santé publique du Québec, 2006). This French Observatory list has been added to the methods tested against the longer New Zealand data in this technical report, covering the period 2000 to 2013.

3.3. Advances in Paediatric Methodology

The methodologies discussed in the section above for Rosenwax, Murtagh and the first New Zealand estimate are for adult deaths. In all these estimates, adults are taken to be those aged 20 and over and a separate approach is taken for children, defined as under age 20. All three use a list for paediatric palliative care developed by Cochrane in the UK (Cochrane, Liyanage et al., 2007). Separate lists were also developed for children in the work of the French Observatory.

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7 The lower intermediate estimate includes all those in the minimal estimate together with deaths for where Alzheimer’s, dementia or senility, or renal disease is recorded as a contributory cause. The upper intermediate estimate includes all deaths with any mention of any of the specified chronic conditions for the minimal estimate, either as underlying or contributory cause of death in the death certificate.


9 Belgium, Canada, Czech Republic, England, France, Hungary, Italy, Mexico, the Netherlands, New Zealand, Spain, South Korea, USA and Wales.
The study by Cochrane and colleagues (2007) was part of a consideration of the way children’s hospices were funded in England. It included an analysis of mortality data and hospital admission data for children and young adults, and identified conditions likely to require palliative care.

Cochrane reflected on the different needs in paediatric palliative care, saying (p12):

“Children’s palliative care is different from that of adults and by comparison the number of children dying is small. However, a child’s need for palliative care involves much longer term provision and increasing complexity of care needs, beginning immediately after diagnosis of a life threatening or life-limiting illness, with the potential for death to occur before adulthood but timing is often uncertain. It is for this reason that the paper includes information on young adults aged 20-39 [emphasis added].”

An important consideration is that clinical care has improved substantially in recent decades and the life expectancy of children and young adults from congenital conditions, such as cerebral palsy, muscular dystrophy and cystic fibrosis, has increased substantially. Cochrane (2007) therefore points out that the prevalence of these conditions is increasing due to improved survival. For example, a study showed that the median estimated life expectancy of children with cystic fibrosis born in 1990 had become 40 years, a doubling over the previous 20 years. A subsequent study showed continuing improvement in survival in successive cohorts, confirming a prediction of median survival exceeding 50 years for those born in the year 2000.

A major concern with using the Cochrane list only for those under age 20 is the discontinuity of inclusion of congenital conditions like cystic fibrosis. In the Rosenwax, Murtagh and first New Zealand estimates, deaths from cystic fibrosis are included under the age of 20 but not when death occurs at older ages. The impact on all congenital deaths was tested on mortality data in New Zealand over the period 2000-2010, as shown in Figure 21.

![Figure 21: Age of Deaths from Congenital Conditions in New Zealand, 2000 to 2010](image)

It was found in New Zealand that 45.4% (almost half) of all deaths from congenital conditions occur over age 20. In the previous estimate of need, only congenital deaths under age 20 were included.
The findings were discussed with Dr Ross Drake and Karyn Bycroft of the palliative care team at Starship Hospital and there was consensus that the revised methodology should include all congenital deaths in the Cochrane list, regardless of age at death. As the cut-off at age 20 affects only 0.4% of deaths from perinatal conditions, the extension to all ages has almost no effect.

Further work on the need for paediatric palliative care was done by Hain and colleagues, using data from Wales (Hain, Devins et al., 2013). As a result of the work, a Paediatric Directory of Life-Limiting Conditions was published (Hain & Devins, 2014). Permission to use the directory was obtained from Hain and tested against the New Zealand mortality data for the period 2000 to 2010, then discussed with the palliative care team at Starship. The results for all perinatal and congenital deaths (regardless of age at death) are illustrated below and were rather surprising.

![Comparison of Cochrane and Hain Methodologies on Perinatal and Congenital Deaths in New Zealand, 2000 to 2010](image)

The area of overlap between the Cochrane list and the Hain list was found to be only 21.2% of all perinatal and congenital deaths. This was a surprising finding, given the extensive lists developed by Hain. It was found that the Hain list added 0.2% of deaths not included by Cochrane, but that Cochrane added 70.9% of deaths not included by Hain.

Hain & Devins (2014) had commented on the applicability of the list, saying it was important to remember that:

- **the Directory is not exhaustive** – some conditions are too rare to be captured by the method used of surveying those receiving specialist palliative care in a defined study period.
- **the Directory is not determinative** – it includes conditions that can limit life and is not a list of children who should be referred to specialist palliative care.
- **the Directory is not definitive** – the list involves a degree of subjective judgement, influenced by current understandings and the availability of technology.
Hain & Devins also raise the issue that acute trauma from external causes (as in vehicle accidents) is not currently considered to be a "life-limiting condition" for estimating the need for palliative care, but that there are cogent reasons to consider that this should be included in future. This point is taken up again, for adults and children, in the discussion on external causes of death in section 3.7.

Discussions were held with the Starship palliative care team on the list of perinatal and congenital conditions to adopt in New Zealand. An important consideration was that the Hain list was built up from observations of children receiving palliative care in Wales, rather than from consideration of all ICD-10 codes. The use of detailed three-digit ICD-10 codes rather than two-digit groups of codes, meant that many conditions in the mortality data in New Zealand were not represented on the list. Although this may be due partly to coding practice and partly to epidemiology, the Paediatric Directory of Life-Limiting Conditions, as developed in Wales, is not suitable to use to estimate the need for palliative care for perinatal and congenital conditions in New Zealand. Accordingly, there was consensus in continuing to use the Cochrane list, but to include deaths across all age bands, not only those occurring under age 20.

### 3.4. Murtagh-Cochrane Methodology applied to New Zealand

In section 1.2, the application of the HNA1 methodology (Rosenwax-Cochrane as used for the first estimate in New Zealand) gives a minimal estimate of need for palliative care of 40.2% of total deaths over the period 2000 to 2013. The application of the Murtagh-Cochrane methodology gives a substantially higher minimal estimate of 79.8% of total deaths. All of these approaches use the same maximal estimate, which gives 93.6% of total deaths. The Murtagh-Cochrane approach has a very different shape to the HNA1 methodology (see Figure 2) and is illustrated below.

![Figure 23: Pattern of Need for Palliative Care using Murtagh-Cochrane Methodology on MORT Data 2000-2013](image-url)
A notable feature of the shape for the Murtagh-Cochrane minimal estimate is the levelling-off of the proportion of total deaths from around age 55 onwards. This is due partly to a welcome attention on dementia and frailty in the Murtagh list, compared to the Rosenwax list. As most deaths in New Zealand happen at older ages, the Murtagh list gives virtually a doubling in the estimate of need for palliative care.

In early trials of the Murtagh methodology, concerns were raised about the extent of inclusion of some ICD-10 codes and the consequent effect on the ICD-10 chapters. The change from HNA1 to the Murtagh methodology for adults is illustrated below by gender and cause of death.

![Comparison of HNA1 and Murtagh-Cochrane Methodologies by Gender and Cause of Death, 2000-2010](image)

The most striking change is in the circulatory system conditions, where the HNA1 approach gave an inclusion of 4.5% of deaths for women and 2.5% of deaths for men. The Murtagh-Cochrane approach increases the need for palliative care for circulatory conditions to 90.8% of deaths for women and 91.8% for men.

Following initial tests on data for 2010, concerns were expressed to the Palliative Care Council about the inclusion of deaths from a number of acute conditions, such as deaths from pneumonia, influenza, asthma, acute kidney failure and a very large number of deaths from acute myocardial infarction. Attempts to discuss the consequences of the inclusion directly with Murtagh were not successful and it was resolved that there should be consultation with a New Zealand clinical panel on the list of conditions to be included.
### 3.5. Using Place of Death with Cause of Death

A concern with simply using cause of death lists to determine the need for palliative care is that this ignores the context in which the end of life is reached and the likelihood of palliative care being provided. An example is that the Murtagh-Cochrane cause of death lists, when applied to New Zealand, would exclude 3.9% of deaths in hospice IPU. These patients, by definition, have received specialist palliative care.

The table below shows the numbers of deaths over the study period, 2000 to 2013, by both cause of death and place of death.

**Table 2: Place of Death and Cause of Death in New Zealand, 2000-2013**

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>Public Hospital</th>
<th>Residential Care</th>
<th>Hospice Inpatient Unit</th>
<th>Private Residence</th>
<th>Other</th>
<th>Total Deaths 2000 to 2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neoplasms</td>
<td>30,401</td>
<td>29,121</td>
<td>22,135</td>
<td>33,298</td>
<td>2,709</td>
<td>117,664</td>
</tr>
<tr>
<td>Circulatory System</td>
<td>54,165</td>
<td>51,816</td>
<td>1,216</td>
<td>33,303</td>
<td>9,218</td>
<td>149,718</td>
</tr>
<tr>
<td>Other Conditions</td>
<td>41,915</td>
<td>42,679</td>
<td>1,522</td>
<td>14,948</td>
<td>2,645</td>
<td>104,110</td>
</tr>
<tr>
<td>Maternity</td>
<td>75</td>
<td>3</td>
<td>1</td>
<td>16</td>
<td>7</td>
<td>102</td>
</tr>
<tr>
<td>Perinatal and Congenital</td>
<td>3,462</td>
<td>267</td>
<td>37</td>
<td>639</td>
<td>117</td>
<td>4,522</td>
</tr>
<tr>
<td>External Causes</td>
<td>6,701</td>
<td>2,090</td>
<td>74</td>
<td>7,291</td>
<td>9,142</td>
<td>25,298</td>
</tr>
<tr>
<td>Total Deaths 2000 to 2013</td>
<td>136,119</td>
<td>125,976</td>
<td>24,986</td>
<td>89,495</td>
<td>24,838</td>
<td>401,414</td>
</tr>
</tbody>
</table>

Key learnings in studies of deaths in New Zealand have included greater understanding of place of death and the increasing importance of residential care as a place of death for the frail elderly in New Zealand, as discussed in section 2.3. A number of deaths in residential care are from infectious diseases (such as pneumonia) or external causes (such as falls), which are traditionally excluded from the cause of death lists.

Extensive discussion on deaths in residential care (Palliative Care Council, 2015a) led to the conclusion that, with increasing age at admission and increasing levels of frailty on admission, there was a strong case for including all deaths in residential care in the revised definition of need for palliative care in New Zealand.

The conceptual need for palliative care in New Zealand is shown in Table 3. All deaths from neoplasms are included in the definition, regardless of place of death. All deaths in residential care and in hospice IPU are also included in the definition, except for deaths due to pregnancy and childbirth. The deaths from neoplasms and deaths in residential care and hospice IPU are shown in light green, reflecting that all deaths in these cells of the table are included.
Table 3: Conceptual Need for Palliative Care in New Zealand

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>Place of Death</th>
<th>Proportion by Cause of Death</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Public Hospital</td>
<td>Residential Care</td>
</tr>
<tr>
<td>Neoplasms</td>
<td>All deaths</td>
<td>All deaths</td>
</tr>
<tr>
<td>Circulatory System</td>
<td>Clinical panel</td>
<td>All deaths</td>
</tr>
<tr>
<td>Other Conditions</td>
<td>Clinical panel</td>
<td>All deaths</td>
</tr>
<tr>
<td>Maternity</td>
<td>none</td>
<td>none</td>
</tr>
<tr>
<td>Perinatal and Congenital</td>
<td>As agreed with Starship</td>
<td>All deaths</td>
</tr>
<tr>
<td>External Causes</td>
<td>none</td>
<td>All deaths</td>
</tr>
<tr>
<td>Proportion by Place of Death</td>
<td>x%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Only some of the deaths in the light blue and purple cells are included, based on the advice of clinical teams. The advice on paediatric and young adult palliative care, together with advice on all perinatal and congenital conditions was provided by the palliative care team at Starship Children’s Hospital. The cells where they provided advice are shown in light purple in the table above.

A Clinical Panel, with extensive experience across hospices, community palliative care and hospital-based palliative care, was convened. A number of the panel members, including the lead researcher at the time, had experience of the previous estimate of need in New Zealand. The advice and decisions of the Clinical Panel affect the proportions in the six blocks in pale blue. The outer proportions of the table are then calculated and the result is shown later in Table 4.

3.6. Operation of the Clinical Panel

The Clinical Panel was presented with spreadsheets of underlying cause of death by ICD-10-AM code. Causes of death were supplied at the three-digit code level and summarised in sub-chapters and chapters. The historic number of deaths and the place of death from each cause were provided in the same spreadsheets.

Alongside each cause of death, the lists used in other methodologies were given in the form of 0 for exclusion and 1 for inclusion, colour-coded to highlight the inclusions. The decisions for the original HNA1 methodology, Rosenwax, Murtagh, Gómez-Batiste, the WHO, Cochrane and Hain were included. During the process, the list used by the French Observatory was added.

A modified Delphi approach was used for the operation of the Clinical Panel. Note that the work on the perinatal and congenital conditions had already been carried out separately with the palliative care team at Starship Child Health, using similar spreadsheets and approach.

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10 For example, in the chapter “C00-D48 II Neoplasms”, the sub-chapter “C15-C26 Malignant neoplasms of digestive organs”, the three-digit ICD code and description “C18 Malignant neoplasm of colon”. The complete list of ICD-10 codes and descriptions is available on: [http://apps.who.int/classifications/icd10/browse/2016/en](http://apps.who.int/classifications/icd10/browse/2016/en)
An introductory PowerPoint presentation was provided to the Clinical Panel, setting out what was known about the need for palliative care definition and where concerns had been raised in early testing. The scope of the work was outlined and the role of the Clinical Panel explained. The panel was asked to review the findings of the Palliative Care Council on deaths from neoplasms and deaths from external causes, and to concentrate efforts on circulatory system conditions and deaths from other conditions (a particularly long and difficult section).

Round one of the process began with the lead researcher highlighting anomalies across all methodologies, identifying areas that needed discussion and suggesting a proposed NZ Minimal and NZ Maximal list in the spreadsheets. Each member of the Clinical Panel then independently recorded their decisions about inclusion or exclusion for each three-digit ICD-10-AM code, with the spreadsheets automatically colour-coding the decisions.

The returned spreadsheets were collated and combined by the lead researcher, with the anomalies between the members of the Clinical Panel identified. The degree of consensus was shown and comments made by the lead researcher on the anomalies. The second set of spreadsheets was circulated for round two.

At this point, the Clinical Panel decided to call for a teleconference to discuss the anomalies and understand the principles being applied by each person. Although this took some time to convene, the discussions proved particularly helpful and consensus in the approach was rapidly gained. In the course of discussion, the sections on neoplasm and deaths from external causes were finalised. Those who had decided to amend their responses to the circulatory systems and other conditions sections were then given the opportunity to do so and the results were combined.

There was much greater consensus at this stage, but still some conditions where there were differences of opinion. A change of approach was used and the lead researcher developed lists of the remaining anomalies and questions which were circulated by email. Suggestions were made as to a possible resolution in each case.

This approach worked well for the Clinical Panel and a week of lively discussion ensued, with people responding to the questions and proposals using colour-coded text. This approach emerged spontaneously from the dynamic of the group. Consensus emerged as people added examples and experiences of delivering palliative care for the particular conditions.

A particular point to emerge from the discussions was the difference in treatment for some conditions when these deaths occurred in a public hospital. The experience of the Clinical Panel across different settings of care was particularly useful in this regard. The discussions were supplemented by recent academic papers on palliative care provision in hospitals and in the emergency department, supplied by a member of the Clinical Panel.

The lead researcher collated the decisions and suggestions and produced the final NZ Cause of Death Minimal (NZ COD Minimal) and NZ COD Maximal lists. A summary of the major decisions is provided in the section which follows. The impact of the decisions was tested in STATA and graphed in Excel, with the first results shared with the Clinical Panel.

The spreadsheets containing the final collated results and comments from the Clinical Panel are available to other researchers from the author or the Ministry of Health. The STATA “Do-files” contain the scripts written to include or exclude specific ICD-10 codes and these are also freely available to other researchers.
3.7. Principles of the Need for Palliative Care

This section summarises the findings of the Palliative Care Council and the Clinical Panel and documents the principles used and decisions made in defining the need for palliative care.

a) **Concept of “need”:** The Clinical Panel came to the consensus that the need for palliative care was an estimate of need for the whole palliative care system and thus was all deaths that typically benefit from a palliative care approach. No attempt would be made to distinguish between the need for specialist palliative care and primary palliative care (see definitions in Appendix A).

b) **The lists are for population planning and not individual patients:** It is important for this work to take a population-based approach and focus on the planning needs for the whole population. In no way do these lists of conditions determine who gets palliative care in practice. That is always based on the individual patient and judgement of need at the time. A related issue is that the lists are compiled retrospectively, after death has occurred and the condition is considered to be the underlying cause of death. Many people may have a diagnosis of the same condition but not require palliative care. The lists provided in Appendix 2 should not be used to trigger the provision of palliative care.

c) **Use of three-digit ICD-10 codes:** In some cases, a four-digit code condition has been specified by other researchers, rather than the over-arching three-digit group code. In other cases, some four-digit codes are included but not all under the three-digit group. This can occur when the methodology includes only those conditions found during a particular study and where the study may have been over a short period or on a small population. Rare conditions may not have appeared in the study and thus are not included in the lists of need for palliative care. This can cause confusion and much extra work when the methodology is applied to another country or at another point in time. It has not been found necessary to use four-digit codes and all decisions about inclusion or exclusion have been made at the three-digit code level. Generally, the modifications to ICD-10, like ICD-10-AM which is used in Australia and New Zealand, follow the same structure as ICD-10 at three-digit code level.

d) **Inclusion of entire neoplasm chapter:** There is no difference of opinion amongst researchers on the need to include all deaths from malignant neoplasms (codes C00-C99 in the chapter “C00-D48 II Neoplasms”). Most researchers have included all deaths from in situ neoplasms, benign neoplasms and neoplasms of uncertain or unknown behaviour (codes D00-D48), for both children and adults. Murtagh, however, excluded all of the section and the French Observatory excluded some codes. The Clinical Panel concurred with earlier work by the palliative Care Council that all in the neoplasm chapter (codes C00-D48) be included.

e) **Inclusion of sequelae from external causes:** Deaths from external causes are largely from self-harm and accidents and these generally need to be excluded from estimates of the need for palliative care. This is modified by place of death later for deaths in hospice IPU and residential

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11 A good example is “I20 Angina pectoris” which is listed as the cause of death for only 68 people over the 14 years of the historic study.

12 For example, the four-digit codes G300, G301, G308 and G309 are included in one methodology. These are all the elements of the three-digit code “G30 Alzheimer disease”.

13 For example, N180, N188 and N189 are included in one methodology. These are some of the parts of the three-digit code “N18 Chronic Kidney Disease”. A key omission at four-digit code level is “N185 Chronic kidney disease, stage 5 - End stage kidney disease”.

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care. There are deaths from external causes that may occur some time after the incident where palliative care plays a key role, for example when a person does not recover consciousness and life support is discontinued. There is a precedent for inclusion of some deaths from external causes, with Cochrane including the sequela of external causes of death. It was decided to include “Y85–Y89 Sequelae of external causes of morbidity and mortality” across all settings.

f) **Exclusion of all deaths in the pregnancy and childbirth chapter:** these are usually acute and unexpected conditions. Deaths from conditions in the chapter “O00-O99 XV Pregnancy, childbirth and the puerperium” are to be excluded completely across all setting of care\(^\text{14}\).

g) **Inclusion of all deaths from perinatal and congenital causes, regardless of age:** With young people living longer than before with congenital conditions, cutting out all congenital deaths from age 20 onwards was shown to result in excluding nearly half of all deaths from congenital conditions (see section 3.3). The revised methodology will include all congenital deaths, regardless of age. There is consistent treatment of conditions included in the need for palliative care across all age groups and hence no need for separate lists at different ages.

h) **Inclusions in the circulatory system chapter:** The chapter “I00–I99 IX Diseases of the circulatory system” is where the greatest discrepancies between methodologies were found. Splitting in the inclusion between what might occur in a hospital setting from the same condition occurring in a private residence (or other setting) was a mechanism used extensively in this chapter and discussed in more detail below. A specific inclusion in New Zealand is the sub-chapter “I05–I09 Chronic rheumatic heart diseases” as the high rate of rheumatic fever is receiving particular public health attention.

i) **Separate treatment of deaths in public hospitals:** This is best illustrated by the sub-chapter “I20–I25 Ischaemic heart diseases” and code “I21 Acute myocardial infarction”\(^\text{15}\). Murtagh included this group completely but this inclusion of an acute condition that can result in sudden death has been a concern for the New Zealand estimates. The issue was resolved by excluding the condition when death occurred in a private residence or other setting, including it fully when death occurred in a hospice IPU or residential care, and including 50% of the deaths when death occurred in a public hospital. The Clinical Panel made recommendations that included 50% of some conditions and 100% of certain other conditions when deaths occurred in a public hospital. The conditions and proportions used are provided in Appendix 2.

j) **Inclusions of other conditions:** This is a very long list of conditions that ranges from skin conditions to respiratory failure and end stage renal failure. The Clinical Panel expressed some surprise as to deaths being from some of the named conditions, but this goes to the question of what is recoded on death certificates and is taken up in section 7.3. The experience of the Clinical Panel was essential in determining whether to include or exclude conditions, and many examples were provided in the course of the discussions. Some notable conditions added to the New Zealand estimates include tuberculosis (“A15-A19 Tuberculosis”\(^\text{16}\)), multiple sclerosis and related conditions (“G35-G37 Demyelinating diseases of the central nervous system”), and

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\(^{14}\) In the 14-year period of the historic MORT data study, there were only three deaths in residential care and one in hospice IPU from these causes. To maintain consistency, these were excluded in the NZ COD Minimal definition and not replaced when all other deaths in residential care and hospice IPU were added back.

\(^{15}\) This is a very large code with 39,567 deaths over the 14-year study period. Of these, 14,824 (37.5%) were in a public hospital and 11,888 (30.0%) in a private residence. There were 9,848 deaths (24.9%) in residential care, 120 (0.3%) in a hospice IPU and 2,887 (7.3%) in other settings.

\(^{16}\) This is of increasing importance in an era of antibiotic resistance and drug-resistant tuberculosis is included in the WHO estimates of need.
deaths from gangrene “L88 Pyoderma gangrenosum” and “R02 Gangrene, not elsewhere classified”). A number of conditions have been included from the chapter “M00-M99 XIII Diseases of the musculoskeletal system and connective tissue” as experience of the Clinical Panel has been that these are very painful and disabling conditions where palliative care is needed. The full list of conditions included is given in Appendix 2.

k) **Inclusion of all deaths in hospice IPU**: By definition, all those who die in a hospice IPU have had specialist palliative care. All deaths in hospice IPU are therefore included, regardless of cause of death. The only exception is deaths from “O00-O99 XV Pregnancy, childbirth and the puerperium” which are not included in any setting.

l) **Inclusion of all deaths in residential care**: All deaths occurring in residential care are to be included in the national estimate, but separately identified for planning purposes. The only exception is deaths from “O00-O99 XV Pregnancy, childbirth and the puerperium” which are not included in any setting.

The full list of ICD-10-AM codes included in the NZ COD Minimal list, with the modifications for deaths in public hospitals, is given in Appendix 2. The modifications for deaths in residential care and hospice IPU are also shown, although that adjustment is made at a later stage in the STATA coding.

### 3.8. Revised Estimate of Need for New Zealand

The NZ COD Minimal List described in the section above is adapted by the inclusion of the remaining deaths in residential care and hospice IPU (except those in pregnancy and childbirth\(^{17}\)) to give the NZ Need for Palliative Care. The steps in that process are illustrated in Figure 25, using age bands to age 100+.

Until the NZ COD Minimal list had been tested in STATA it was not certain whether a maximal estimate would be needed as well. On analysis it was decided to include three projections in the final model: the need for palliative care, the maximal need for palliative care, and all deaths. The NZ COD Maximal list is all deaths other than:

- The chapter “O00-O99 XV Pregnancy, childbirth and the puerperium”
- Codes V00-Y84 from the chapter “V00-Y89 XX External causes of morbidity and mortality”\(^{18}\).

The NZ COD Maximal List is then adapted by the inclusion of the remaining deaths in residential care and hospice IPU (except those in pregnancy and childbirth\(^{17}\)), to give the NZ Maximal Need for Palliative Care. The steps in that process are illustrated in Figure 26 using age bands to age 100+.

As the projections of the population from Statistics New Zealand are available only to age 95+, the final tables for both the NZ Need for Palliative Care and the NZ Maximal Need for Palliative Care are produced only to age 95+. In time it may be necessary to extend the table to higher age bands as the numbers dying at the oldest ages increases. The shape of both the NZ Need for Palliative Care and the NZ Maximal Need for Palliative Care are illustrated in Figure 27.

\(^{17}\) The whole of chapter “O00-O99 XV Pregnancy, childbirth and the puerperium”.

\(^{18}\) In other words, all external causes of death, other than “Y85-Y89 Sequelae of external causes of morbidity and mortality”, are excluded from the NZ COD Maximal List.
Figure 25: Construction of the Need for Palliative Care in New Zealand by Age and Gender

Figure 26: Construction of the Maximal Need for Palliative Care in New Zealand by Age and Gender
Figure 27: Historic Pattern of Need and Maximal Need for Palliative Care in New Zealand by Age and Gender, 2000 to 2013

The patterns for the NZ Need for Palliative Care and the NZ Maximal Need for Palliative Care are shown using the full historic data, 2000 to 2013. In the projection model, deaths from 2009 to 2013 only are used for the final patterns.

Technically, the projection model is an actuarial model, a part of a widely used class of models called component-based models (Astolfi, Lorenzoni et al., 2013). The authors describe an important subclass of these models, cohort-based models:

“An important subclass of component-based models is represented by cohort-based models. In cohort-based models, individuals are grouped into cells according to several key attributes. Typically, age is the principal criteria used to stratify the population of interest (generally into five-year age cohorts).”

“Further refinements are obtained by sub-dividing the cohorts according to other commonly-used attributes, such as gender, health status, and proximity to death. These models are often referred to as actuarial models or cell-based models, where the term cell identifies the sub-categories into which each cohort is divided.”

In the New Zealand model of need for palliative care, the cohorts are grouped by five-year age bands (with Under 1 and 0-4 years separated), gender, cause of death and place of death. As some of those cells become very small, we tend to focus on the results either by age and gender, as in Figure 27, or by cause of death and place of death, as in the tables which follow.

The first table below, Table 4, shows the proportions of all deaths in the revised estimate of the need for palliative care, for each cause of death and place of death cell. In total, 79.4% of all deaths met the definition of need for palliative care over the period 2000-2013. Note that this is the historic proportion and not the proportion of need to be applied in future. This is why the final model tables are produced by age and gender – to be able to model the impact of an ageing population.

Table 5 gives the actual numbers of deaths that met the need for palliative care over the same historic period, 2000 to 2013. All deaths in New Zealand were shown in the same format in Table 2.
Table 4: Proportion of Need for Palliative Care in Revised New Zealand Estimate

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>Place of Death</th>
<th>Proportion by Cause of Death</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Public Hospital</td>
<td>Residential Care</td>
</tr>
<tr>
<td>Neoplasms</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Circulatory System</td>
<td>80.5%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Other Conditions</td>
<td>55.0%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Maternity</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Perinatal and Congenital</td>
<td>91.2%</td>
<td>100.0%</td>
</tr>
<tr>
<td>External Causes</td>
<td>3.5%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Proportion by Place of Death</td>
<td>73.5%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Table 5: The Need for Palliative Care in New Zealand, 2009 to 2013

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>Place of Death</th>
<th>Total Need 2000 to 2013</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Public Hospital</td>
<td>Residential Care</td>
</tr>
<tr>
<td>Neoplasms</td>
<td>30,401</td>
<td>29,121</td>
</tr>
<tr>
<td>Circulatory System</td>
<td>43,595</td>
<td>51,816</td>
</tr>
<tr>
<td>Other Conditions</td>
<td>22,704</td>
<td>42,679</td>
</tr>
<tr>
<td>Maternity</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Perinatal and Congenital</td>
<td>3,159</td>
<td>267</td>
</tr>
<tr>
<td>External Causes</td>
<td>235</td>
<td>2,090</td>
</tr>
<tr>
<td>Total Need 2000 to 2013</td>
<td>100,094</td>
<td>125,973</td>
</tr>
</tbody>
</table>
3.9. Comparison to Other Methodologies

This final methodology section compares the first estimate of need in New Zealand (Palliative Care Council, 2011) to the revised estimate of need, noting key differences in the models. Comparisons of the final shape and proportions are also made to the Murtagh methodology (Murtagh, Bausewein et al., 2014), which has been used in a number of other countries (Kane, Daveson et al., 2015; Scholten, Gunther et al., 2016).

Table 6: Comparison of Methodologies used for New Zealand Estimates of Need

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Period of study for historic patterns</td>
<td>2005 to 2007</td>
<td>2000 to 2013, with final patterns using the more recent period 2009 to 2013</td>
</tr>
<tr>
<td>Data used</td>
<td>Mortality data, with hospital admission data for mid-range estimate</td>
<td>Mortality data</td>
</tr>
<tr>
<td>Patterns for projection of need</td>
<td>Proportion of population (expressed as a rate per 100,000 population)</td>
<td>Historic patterns of cause of death and place of death, by age and gender.</td>
</tr>
<tr>
<td>Projections of Deaths</td>
<td>Not used</td>
<td>Deaths by age and gender, as for population projections.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Deaths by ethnicity, as for population projections.</td>
</tr>
<tr>
<td>Dates for future projections</td>
<td>Estimates of need for three years: 2006, 2016 and 2026</td>
<td>Estimates of national need annually from 2016 to 2068;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>National, regional and DHB needs annually from 2016 to 2038</td>
</tr>
<tr>
<td>Projections produced</td>
<td>Minimal, mid-range and maximal estimates at national level.</td>
<td>NZ Minimal Need for Palliative Care, NZ Maximal Need for Palliative Care, All Deaths.</td>
</tr>
<tr>
<td></td>
<td>Mid-range estimate produced by DHB.</td>
<td>Spreadsheet model at national, local and DHB level.</td>
</tr>
<tr>
<td></td>
<td>Projections as tables in final report.</td>
<td>Material for planning for public hospitals, residential care and hospice care.</td>
</tr>
</tbody>
</table>
In the graph below, the pattern for the NZ Need for Palliative Care by age and gender is compared to the previous HNA1 methodology (based on Rosenwax), the Murtagh methodology and the French Observatory methodology.

Figure 28: Comparison of NZ Need for Palliative Care to Other Methodologies, by Age and Gender, 2000 to 2013

While the Murtagh methodology and the revised NZ Need for Palliative Care have a fairly similar shape by age and gender and produce similar overall results, there are differences by cause of death and place of death, as shown in Table 7.

Table 7: Comparison of NZ Need for Palliative Care with Other Methodologies, by Cause of Death and Place of Death, 2000 to 2013
The previous estimate in New Zealand, the HNA1 Minimal shape in Figure 28, produces a historic need for palliative care of 40.2%, using data from 2000 to 2013. It was not possible to reproduce the mid-range estimate using only mortality data (see section 1.1). The revised shape, the NZ Need for Palliative Care, produces a need for palliative care of 79.4% of all deaths.

The shape of the revised NZ Need for Palliative Care seems more intuitive and appropriate than the HNA1 shape, particularly the feature that palliative care need increases with age at death.

The NZ Need for Palliative Care, at 79.4% of all deaths, is almost identical to the Murtagh methodology at 79.8% of deaths. There are, however, significant differences in the cells of the results in Table 7. Murtagh has a higher proportion for circulatory system conditions and much lower proportion for other conditions. Murtagh has higher proportions in private residence and other settings, with lower proportions in residential care and hospice IPU.

Overall, the NZ Need for Palliative Care better reflects the practice of palliative care in New Zealand.

A final test of the revised methodology is shown below, comparing the historic pattern from the whole period of the study with the period intended to be used for the model of need.

![Figure 29: Comparison of NZ Need and Maximal Need for Palliative Care, by Age and Gender, 2000-2013 and 2009-2013](image)

The patterns for the NZ Need for Palliative Care and the NZ Maximal Need for Palliative Care are shown, comparing the full period (2000 to 2013) on the left with the period used for the projection model (2009 to 2013) on the right. There are some differences in the childhood years where data is sparse but the pattern remains stable over the shorter period. The patterns over the period 2009-2013 are the ones used in the final projection model.
4. Historic Patterns of Need for Palliative Care

This section provides results of the historic need for palliative care, with comparisons over time, region, age, gender, ethnicity, deprivation index, cause of death and place of death. The investigation of the historic need for palliative care in New Zealand uses the MORT data from 2000 to 2013, as used for the historic patterns of deaths in section 2.

The methodology for determining “need” is described in section 3.8 and the key graph, of need by age and gender, is reproduced below. This graph is key to understanding the historic patterns that emerge.

![Historic Pattern of Need for Palliative Care by Age and Gender, 2000 to 2013](image)

The strongest feature of the pattern of need is the high proportion of deaths in the teenage years that are not included in the definition of need. This is a reflection of the role of external causes of death such as accidents and suicides in those age bands. Greater proportions of male deaths are excluded in the teenage and early adult years as external causes of death are significantly higher for men than for women.

At the oldest ages, the need for palliative care increases slightly with age. This is an important determinant of the results seen across time, by region and DHB.

4.1. Need by Year of Registration

For the full period 2000 to 2013, the need for palliative care was 79.4% of all deaths. The maximal need for palliative care added a further 14.8%, for a total of 94.2% of all deaths, leaving 5.8% of all deaths excluded from the definition of need. As the population ages, so the need for palliative care increases. In Figure 31, the proportion of need is shown to have increased from 78.1% of all deaths in the year 2000 to 80.7% of all deaths in 2013.

The Need for Palliative Care in New Zealand
Over the shorter period used in the projection model, 2009 to 2013, the proportion of need is 79.9% of all deaths. The fluctuations in the “not included” category over time are due largely to fluctuations in the numbers of deaths from external causes.

4.2. Need by Region and DHB

In Figure 32 the proportion of need is shown by DHB and grouped by region.
The area with the lowest proportion of historic need was Tairawhiti DHB at 75.1% of all deaths, followed by Northland DHB at 75.7%, and West Coast DHB at 75.9% of all deaths. The areas where the proportion of need was highest relative to all deaths were Southern DHB at 82.0% and Auckland DHB and Nelson Marlborough DHB, both at 81.5% of all deaths. The South Island region had the highest historic need at 80.8% of all deaths.

The summary proportions are a direct consequence of the different age structures and causes of death in each area. Note also that these are the historic values, not the proportions to be used in future planning.

4.3. Need by Gender, Ethnicity and Deprivation

Summary measures of the need for palliative care need to be interpreted with great caution, as illustrated by considering need by ethnicity and gender in Figure 33.

![Figure 33: Historic Need for Palliative Care by Ethnicity and Gender, 2000 to 2013](chart)

Overall, the historic need for palliative care for women was 82.3% of all deaths, while that for men was 76.4% of all deaths. Men have greater proportions of deaths from external causes which has a large impact on the deaths excluded from the definition of need.

This is seen in the figures by ethnicity, with the need for Māori women being 71.9% of all deaths and the need for Māori men being 62.5% of all deaths.

This does not mean that women have an intrinsically higher need or that Māori have an intrinsically lower need for palliative care. The summary proportions are a consequence of the different age structures and historic causes of death in each group. Palliative care for the same conditions always needs to be available, regardless of ethnicity and gender.
A similar caution in interpretation is needed with regard to the New Zealand Index of Deprivation, using NZDep2006 in the two figures below.

Figure 34: Historic Need for Palliative Care by NZ Index of Deprivation, 2000 to 2013 - Proportion

Figure 35: Historic Need for Palliative Care by NZ Index of Deprivation, 2000 to 2013 – Numbers
The patterns in Figure 34 for are similar for women and men, with proportionately lower need for palliative care at higher levels of NZDep. This is a function of the ages and causes of death, which are not identical across the categories. Note the caution in section 2.4 that NZDep relates to the general socioeconomic deprivation in an area and not to the deprivation of individual people.

By total numbers, it is important to remember that there are more deaths needing palliative care in Dep 7&8 than in any other quintile. The total numbers needing palliative care in areas with Dep 7&8 are roughly double those in areas with Dep 1&2. See section 2.4 for further discussion on the difficulty of interpreting results by NZDep.

### 4.4. Need by Cause and Place of Death

As described in section 3.8, the methodology for determining “need” is based on lists by cause of death, overlaid by considerations of place of death. The summary of need by cause of death is shown in Figure 36, by place of death in Figure 37 and by both cause of death and place of death together in Figure 38.

![Figure 36: Historic Need for Palliative Care by Cause of Death, 2000 to 2013](image)

In the New Zealand methodology, 100% of deaths from neoplasms are included. The greater inclusion of deaths from circulatory system conditions and from other conditions are important features of the revised estimate of need in New Zealand. The methodology results in 78.4% of circulatory system deaths and 73.9% of deaths from other conditions being included. A summary of the proportions of deaths included by other methodologies is included in Table 6 in section 3.9.

Only 10.0% of deaths from external causes are included, largely where these are from the sequelae of external causes or where the death occurred in a hospice IPU or residential care.
Figure 37: Historic Need for Palliative Care by Place of Death, 2000 to 2013

Figure 38: Historic Need for Palliative Care by Cause of Death and Place of Death, 2000 to 2013
In Figure 37, the result of overlaying cause of death with place of death is illustrated, showing that all deaths in hospice IPU and residential care are included. The need for palliative care is 73.5% of deaths in public hospital and 64.9% of deaths in private residence.

In Figure 38, the relationship between cause of death and place of death is shown in more detail. External causes of death are included only to the extent of deaths from sequelae when the place of death is public hospital, private residence or other settings. However, all deaths in hospice IPU and in residential care from external causes are included. In residential care, 63.9% of the deaths from external causes are the result of falls.

The Clinical Panel gave direction on the inclusion of deaths from circulatory system conditions in public hospitals (see section 3.7). All deaths in hospice IPU and residential care are included, as with all causes of death. For deaths in private residence and other settings, only the cause of death lists are used, giving a need for palliative care of 48.5% in private residences and 50.3% in other settings. However, when deaths from circulatory system conditions occur in a public hospital, more are included, giving a need for palliative care of 80.5% of deaths.

4.5. Palliative Care: Community and Hospice Care

Deaths in public hospital and residential care are mutually exclusive. The balance of deaths under the NZ Need for Palliative Care is shown below as being in the community, excluding residential care.

Figure 39: Historic Need for Palliative Care by Age and Gender: Hospitals, Residential Care and the Community, 2000 to 2013

Note that this analysis is using place of death and not place of care. The definition of “community” in this graph is also not equivalent to the care provided in the community by hospices, and further ways to estimate the pattern of need for hospice care have been developed.
Hospice New Zealand has reported on an analysis of hospice patient data (Hospice New Zealand, 2016), finding that only 26% of people using hospice services had any admission to an inpatient facility. Place of death for hospice patients includes hospice IPU, public hospitals, residential care and private residences. Hospice NZ finds that 69% of people who died supported by hospice, did so in the hospice definition of community, which is either private residence or residential aged care facility.

Work done on a model of need for palliative care for hospices, the Hospice NZ Demand Model\(^\text{19}\), has been used in this national model of need. The approach builds on the relationship between cause of death and place of death, as described in section 3.5, but includes only those causes and places of death that are likely to be part of hospice care, as shown below.

Table 8: Need for Hospice Care in New Zealand, 2009 to 2013

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>Place of Death</th>
<th>Public Hospital</th>
<th>Residential Care</th>
<th>Hospice Inpatient Unit</th>
<th>Private Residence</th>
<th>Other</th>
<th>Proportion by Cause of Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neoplasms</td>
<td>All deaths</td>
<td>All deaths</td>
<td>All deaths</td>
<td>All deaths</td>
<td>All deaths</td>
<td>100.0%</td>
<td></td>
</tr>
<tr>
<td>Circulatory System</td>
<td>None</td>
<td>All deaths</td>
<td>All deaths</td>
<td>48.5%</td>
<td>None</td>
<td>46.2%</td>
<td></td>
</tr>
<tr>
<td>Other Conditions</td>
<td>None</td>
<td>All deaths</td>
<td>All deaths</td>
<td>52.2%</td>
<td>None</td>
<td>50.1%</td>
<td></td>
</tr>
<tr>
<td>Maternity</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>0.0%</td>
<td></td>
</tr>
<tr>
<td>Perinatal and Congenital</td>
<td>Congenital only</td>
<td>All deaths</td>
<td>All deaths</td>
<td>Congenital only</td>
<td>Congenital only</td>
<td>53.0%</td>
<td></td>
</tr>
<tr>
<td>External Causes</td>
<td>None</td>
<td>All deaths</td>
<td>All deaths</td>
<td>Sequelea only</td>
<td>None</td>
<td>9.0%</td>
<td></td>
</tr>
<tr>
<td>Proportion by Place of Death</td>
<td>24.7%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>64.9%</td>
<td>11.3%</td>
<td>60.7%</td>
<td></td>
</tr>
</tbody>
</table>

Two versions of the hospice need are determined, one with only neoplasms and congenital deaths in residential care (similar to historic practice for hospices) and the second with all deaths in residential care. Hospice care might be in a supportive role to residential care or, in some cases, might be direct care of patients. Models of collaboration are evolving throughout the country and there is increased focus on the role of hospices alongside residential care facilities.

Using the historic data from 2000 to 2013, the lower estimate of need for hospice care is 36.6% of all deaths and the upper estimate (including all deaths in residential care) is 60.7% of all deaths in New Zealand.

The historic patterns by age and gender for the two estimates of hospice care are illustrated in Figure 40.

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\(^\text{19}\) This work was carried out for Hospice NZ, with funding from the Ministry of Health. An early version of the Hospice NZ Demand Model was released on 2 November 2016. An updated version, with the same projection tables as used in this national model of need, was released in January 2016. The estimates in the Hospice NZ model were based on preliminary cause of death lists and users were cautioned that these would be revised by the Clinical Panel as part of the work on the national model of need. This technical report therefore includes the revised need for palliative care estimates for hospices.
The need for hospice care is shown relative to the overall NZ Need for Palliative Care. Two versions are shown, the lower line with only cancer deaths and congenital deaths in all settings (similar to historical practice) and the upper line adding support to all deaths in residential care.

### 4.6. Summary Comparison of All Deaths and Need for Palliative Care

This final historical section provides pairs of pie charts, comparing all deaths to the deaths that fall within the definition of need for palliative care. These are provided for broad age bands, ethnicity, cause of death and place of death.

While none of the results should be a surprise, given the analysis in previous sections, these pairs of pie charts are provided as a high-level benchmark for policy-makers and researchers.

The point is illustrated with reference to the ethnicity graph in Figure 42. It is often observed that people compare delivery of palliative care by ethnicity to the ethnicity of the population, not the ethnicity of deaths. This can lead to erroneous conclusions that certain groups are not receiving palliative care. Likewise, comparing delivery of palliative care to all deaths rather than to the need for palliative care can lead to erroneous conclusions. As shown in Figure 42, Māori account for 9.9% of all deaths but 8.3% of the need for palliative care.

In general, the deaths included in the need for palliative care are older, predominantly of Other ethnicity[^20], and show a higher proportion with cancer and a greater proportion in residential care than for all deaths.

[^20]: This analysis is done using the Ministry of Health approach of prioritised ethnicity, where the order of priority is Māori, Pacific, Asian and then Other.
Figure 41: All Deaths and Need for Palliative Care by Age Bands, 2000 to 2013

Figure 42: All Deaths and Need for Palliative Care by Ethnicity, 2000 to 2013
Note that deaths from neoplasms are 29.3% of all deaths but 36.9% of the need for palliative care.

Deaths in residential care are 39.5% of the need for palliative care. While a larger proportion of all deaths are in public hospital than in residential care, this reverses in the need for palliative care with residential care being the place of death for 39.5% compared to 31.4% in public hospital. Deaths in private residences account for 18.2% of the need for palliative care.
5. Projections of Deaths in New Zealand

Section 5 turns to the future projections used in the model. The key projections used are of future deaths, with projections of the population used only as a denominator for reporting on deaths relative to population.

Two sets of projections from Statistics New Zealand are used in the model, and the period over which deaths are projected is illustrated in Figure 45:

- National Population Projections: 2014 (base)–2068

The national population projections are made publicly available by Statistics New Zealand on NZ.Stat. The publicly available tables of deaths are by age bands only, but Statistics NZ were able, on request, to provide tables of deaths by age and gender. The national projections are produced for a range of results and scenarios around a median (50th percentile) projection.

The median projection from Statistics New Zealand is that deaths will rise from around 30,000 a year to 45,000 a year by 2038 and 55,500 a year by 2068.

Not only is there projected to be a large increase in the number of deaths each year, but the deaths are projected to be at much older ages, as illustrated using the median projection in Figure 46. Note particularly the very large proportionate increases in deaths age 85-94 and age 95+.

21 NZ.Stat is available on http://nzdotstat.stats.govt.nz
Statistics NZ provides a set of projections annually to the Ministry of Health, based on assumptions chosen by the Ministry (Statistics New Zealand, 2015). This median projection of the population, births and deaths is currently available to end June 2038.

In Figure 45 and Figure 46, the period over which the shorter DHB and regional projections are available is shown. It is critical for planning purposes to realise that the figures projected to 2038 are part of a longer period of increase in the number of deaths and the ageing of those deaths. Aiming only at the results in the projections to 2038 will see the palliative care sector being only roughly half-way in the huge demographic shift expected.

5.1. Statistics NZ Projections 2016 to 2068

Population projections use the latest population estimates as a base and make assumptions about future fertility, mortality, and migration. As Statistics New Zealand points out, projections are not predictions (Statistics New Zealand, 2014). Projections need to be used as an indication of the overall trend and direction, not as exact forecasts.

Projections by Statistics New Zealand up to those made with base 2006 were on the basis of sets of chosen assumptions about fertility, mortality and (the most uncertain) migration. Since 2011, the national projections have been made using a method that gives a single stochastic (probabilistic) projection based on an assessment of past trends and assumptions about future changes in fertility, mortality and migration. Thus instead of producing a single estimate at each point in time for each scenario, a range and associated probability are produced. The median estimate (the 50th percentile) is used for most work, which is the point about which half the estimates are higher and half the estimates are lower. Further scenarios are also tested to explore the impact of changes to particular assumptions.
The national projections of deaths, 2014 (base)–2068, are illustrated below. Figure 47 shows the range for the stochastic projections, giving seven projections from the 5th percentile to the 95th percentile around the median (50th percentile) projection. Figure 48 shows the additional five scenarios produced, making 12 projections in total. The scenarios produced are for Very high fertility, Very low mortality, No migration, Cyclic migration and Very high migration.

Figure 47: Range for Stochastically Projected Deaths in New Zealand, 2016 to 2068

Figure 48: Additional Scenarios for Projected Deaths in New Zealand, 2016 to 2068

Seven projections are made publicly available. The 10th and 90th percentile projections are not included on the graph in order to make for greater clarity.
The range of projected deaths in 2068 is from 51,700 (5th percentile) to 59,900 (95th percentile) with a median projection of 55,500 deaths. The Very high fertility scenario affects the numbers being born more than the numbers dying and thus produces a projection fairly close to the median (55,800 deaths). The three scenarios for migration (None, Cyclic and Very high) produce results within the 5th to 95th percentile range (52,400, 55,200 and 58,700 deaths respectively).

The Low mortality scenario is the only one to produce total deaths outside the 5th to 95th percentile range, with projected deaths of 47,500 in 2068. This is a scenario where life expectancy is higher than expected. The lower annual deaths in this scenario are a function of the delaying of deaths beyond the period of the projections, and this scenario therefore has greater ageing of the deaths that do occur.

5.2. Projections of Deaths 2016 to 2038

The shorter projections for the Ministry of Health (Statistics New Zealand, 2015) are produced by age, gender and ethnicity at national level, by ethnicity at DHB level, and by age and gender (but not ethnicity) at DHB level. The projections are used for planning purposes and for the allocation of funds to the DHBs using the Population-Based Funding Formula. It is for this reason that the shorter projections to 2038 are given particular attention in the need for palliative care estimates.

![Figure 49: Historic Deaths and Projections of Deaths in New Zealand to 2068](image)

For New Zealand as a whole, deaths are projected to increase from 30,500 a year in 2016 to 45,000 a year in 2038, an increase over the 22-year period of 47.5%.

---

23 Quoting Statistics New Zealand (2014): The median projection assumes recent reductions in age-specific death rates continue over the projection period. If recent increases in period life expectancy at birth continue, people might live even longer, with life expectancy reaching 96.0 years for males and females in 2068.
The projections produced for the Ministry of Health do not include regions, but these are derived using the allocation used for planning purposes. Over the 22-year period, the total number of deaths by DHB and by region is projected to grow as shown in the table below.

Table 9: Projected Deaths in New Zealand by Region and DHB, 2016 and 2038

<table>
<thead>
<tr>
<th>Region</th>
<th>Year to end June</th>
<th>2016</th>
<th>2038</th>
<th>Increase 2016 to 2038</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern Region</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northland DHB</td>
<td>1,420</td>
<td>2,110</td>
<td></td>
<td>48.6%</td>
</tr>
<tr>
<td>Waitemata DHB</td>
<td>2,920</td>
<td>4,870</td>
<td></td>
<td>66.8%</td>
</tr>
<tr>
<td>Auckland DHB</td>
<td>2,430</td>
<td>3,710</td>
<td></td>
<td>52.7%</td>
</tr>
<tr>
<td>Counties Manukau DHB</td>
<td>2,560</td>
<td>4,200</td>
<td></td>
<td>64.1%</td>
</tr>
<tr>
<td>Midland Region</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Waikato DHB</td>
<td>2,720</td>
<td>4,000</td>
<td></td>
<td>47.1%</td>
</tr>
<tr>
<td>Lakes DHB</td>
<td>800</td>
<td>1,110</td>
<td></td>
<td>38.8%</td>
</tr>
<tr>
<td>Bay of Plenty DHB</td>
<td>1,840</td>
<td>2,670</td>
<td></td>
<td>45.1%</td>
</tr>
<tr>
<td>Tairawhiti DHB</td>
<td>380</td>
<td>490</td>
<td></td>
<td>28.9%</td>
</tr>
<tr>
<td>Taranaki DHB</td>
<td>950</td>
<td>1,260</td>
<td></td>
<td>32.6%</td>
</tr>
<tr>
<td>Central Region</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hawke's Bay DHB</td>
<td>1,330</td>
<td>1,860</td>
<td></td>
<td>39.8%</td>
</tr>
<tr>
<td>Whanganui DHB</td>
<td>620</td>
<td>740</td>
<td></td>
<td>19.4%</td>
</tr>
<tr>
<td>MidCentral DHB</td>
<td>1,370</td>
<td>1,840</td>
<td></td>
<td>34.3%</td>
</tr>
<tr>
<td>Capital and Coast DHB</td>
<td>1,670</td>
<td>2,450</td>
<td></td>
<td>46.7%</td>
</tr>
<tr>
<td>Hutt Valley DHB</td>
<td>960</td>
<td>1,340</td>
<td></td>
<td>39.6%</td>
</tr>
<tr>
<td>Wairarapa DHB</td>
<td>420</td>
<td>580</td>
<td></td>
<td>38.1%</td>
</tr>
<tr>
<td>Three Wellington DHBs</td>
<td>3,050</td>
<td>4,370</td>
<td></td>
<td>43.3%</td>
</tr>
<tr>
<td>South Island Region</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nelson Marlborough DHB</td>
<td>1,170</td>
<td>1,870</td>
<td></td>
<td>59.8%</td>
</tr>
<tr>
<td>West Coast DHB</td>
<td>270</td>
<td>370</td>
<td></td>
<td>37.0%</td>
</tr>
<tr>
<td>Canterbury DHB</td>
<td>3,730</td>
<td>5,480</td>
<td></td>
<td>46.9%</td>
</tr>
<tr>
<td>South Canterbury DHB</td>
<td>580</td>
<td>760</td>
<td></td>
<td>31.0%</td>
</tr>
<tr>
<td>Southern DHB</td>
<td>2,390</td>
<td>3,250</td>
<td></td>
<td>36.0%</td>
</tr>
<tr>
<td>New Zealand</td>
<td>30,500</td>
<td>45,000</td>
<td></td>
<td>47.5%</td>
</tr>
</tbody>
</table>

24 The sum of the four regional projections is not always equal to the New Zealand projection due to rounding by Statistics NZ. The regions are the sum of the rounded projections by DHB.
5.3. Projections of Increasing Age at Death

Not only are the total numbers of deaths projected to increase substantially, but the age at which those deaths occur is also projected to increase substantially, as illustrated to 2068 and 2038 below.

Figure 50: Age Bands of Projected Deaths in New Zealand, 2016 to 2068

Figure 51: Projected Age of Deaths in New Zealand, 2016-2038
While the point has already been made in Figure 46 that deaths will be at older ages, the actual numbers projected in each age band through to 2068 for the median projection are shown in Figure 50. Of critical importance for planning are the very large increases in deaths age 85-94 and age 95+. The increase in deaths age 95+ is most noticeable in the period from 2038 to 2068. This ageing of the population and of deaths is historically unprecedented in developed countries.

Although the major effects of the ageing of deaths are projected to occur from the 2030s onwards, the shorter median projection period to 2038 still shows a substantial ageing of deaths, as illustrated in Figure 51. The proportion of deaths occurring at age 85+ is expected to increase from 37.0% in 2016 to 55.6% in 2038.

Providers of palliative care in New Zealand will need to cope with a much greater number of deaths of older people, more people with co-morbidities and, potentially, a higher prevalence of dementia (Palliative Care Council, 2015b). This is likely to challenge models of care and models of reimbursement for palliative care.

### 5.4. Projections of Ethnicity of Deaths

Over the 22-year period from 2016 to 2038, the number of deaths each year is projected to increase by 47.5% from current levels. This differentially affects ethnicity groups, with the number of Māori deaths increasing by 48.5%, Pacific deaths by 50.0%, Asian deaths by 270.0% and deaths of Other ethnicity by 38.4%. The very high projected increase in Asian deaths is the result of large increases in Asian immigration and an older age structure for the Asian population.

Over the period to 2038, the proportion of Māori deaths relative to total deaths is projected to remain largely unchanged, from 10.8% in 2016 to 11.1% during the period and 10.9% by 2038. A significant feature of the Statistics New Zealand projections for the Ministry of Health is the ageing of both Māori and Pacific deaths. This is illustrated for Māori deaths below.

![Figure 52: Age Structure of Projected Māori Deaths in 2016 and 2038](image)
In Figure 52, there is projected to be a large reduction in the numbers of Māori deaths in the 40-64 age bands and a very large increase in deaths in all the age bands above 75. The change is particularly noticeable at the oldest age bands.

5.5. Projections of Cause of Death and Place of Death

The sections above have simply interpreted the projections produced by Statistics New Zealand. The projections of deaths are made in total and not by specific cause of death. If the historic patterns of cause of death by age and gender, as described in section 2.2 and illustrated in Figure 9, persist, then the projected cause of death may evolve as shown below.

Over long periods of time the causes of death have evolved as treatment has evolved. Deaths from infectious diseases were more common before the introduction of antibiotics in the 1940s. Historical mortality data from 1948 onwards (Ministry of Health, 2014) shows that the absolute numbers of deaths from cerebrovascular disease peaked in the early 1970s while those from ischaemic heart disease peaked in the early 1980s. Over time the cause of death has been replaced by more deaths from cancer and from other causes. This reduction in deaths from cardiovascular conditions has been one of the major successes of the healthcare system in the last fifty years.

The analysis in section 2.6 showed that the historic patterns of cause of death (and place of death) have remained relatively stable over the 14-year period from 2000 to 2013. Over long periods of projection, it would be expected that the causes of death would change, however, over the 22 years of the current projection period, the changes may only be gradual. A distinct possibility is a reduction in the number of circulatory system deaths with more deaths from other conditions in the graph above. Other conditions include deaths from frailty and dementia, but also those due to the obesity epidemic. More deaths from infectious diseases are a possibility in an era of antibiotic resistance and these are also currently grouped under other conditions.
In Figure 54 the historic patterns for place of death by age and gender are applied to the projections of deaths to 2038. The same methodology is then applied to the longer projection period to 2068 in Figure 55.

**Figure 54: Projected Place of Death, 2016-2038**

**Figure 55: Projected Place of Death, 2016-2068, without Longevity Adjustment**
Over the period of 22 years to 2038, deaths in residential care are projected to increase from 10,400 in 2016 to some 19,000 in 2038, an increase of more than 80%. Over the longer period to 2068, the projection is that deaths in residential care reach some 29,000, an increase of more than 180%. Critically, this is a demand model and does not take into account capacity constraints in residential care facilities.

It is over the longer time period that the projections feel the least comfortable. Capacity constraints and changes in the models of care are very likely over this time period. The refreshed health strategy for New Zealand (Ministry of Health, 2016a, 2016b) has as one of five themes that people receive the care and support they need closer to home (Ka aro mai ki te kāinga).

It is not at all clear that it will be feasible to move deaths of very old, frail people out of residential care to private residences. Residential care becomes the new place of residence for many at the older ages. Evidence from the waves of the OPAL study in Auckland over a 20-year period (Boyd, Michal, Connolly et al., 2009) shows that people are entering residential aged care more frail and needing more assistance than in earlier years. The trade-off seems more likely to be between deaths in residential care and deaths in public hospital, particularly if there are capacity constraints in residential care facilities.

The sensitivity of the projections to the continuation of the historic patterns of place of death thus needs to be tested.

## 5.6. Longevity and Healthy Life Expectancy

A critical assumption in the model of the projections of need for palliative care is the extent to which the historic patterns can be applied to the future.

The issue has been considered in modelling future health expenditure, and the issues and techniques are summarised in a useful OECD working paper. While modelling of future deaths is not the same as future health expenditure, some of the techniques can be adapted to test the effects of increased longevity on the patterns by cause of death and place of death.

As the authors of the OECD paper (Astolfi, Lorenzoni et al., 2013) point out, using an ageing population with a historic set of costs by age and gender is essentially a very negative and unlikely assumption about the health status of the future elderly as it implies that all gains in life expectancy result in increased years lived in ill health.

The question about whether increased longevity means more years of ill health or more years of good health has generated much heated academic debate in recent decades. This is not the place to revisit all the arguments, but it is useful to conceptualise the possibilities as shown in Figure 56. Astolfi et al describe three possibilities as follows:

- **Dynamic equilibrium (or healthy ageing):** assumes that the period of ill health (morbidity) prior to death remains unchanged as life expectancy increases, so that each year gained in life expectancy corresponds to an equal increase in years of healthy life.

- **Extension (or expansion) of morbidity:** is a pessimistic view which assumes that increases in life expectancy result in a longer period of morbidity and reduced quality of life. It is based on a view that, by living longer, more people would be exposed to the disabling diseases of old age (Parkinson’s disease, dementia, vision hearing and mobility loss).
• **Compression of morbidity**: is an optimistic view which assumes increases in longevity result in increases in the healthy life period.

![Figure 56: Possible Relationships between Life Expectancy and Morbidity](source)

The evidence for the possibilities outlined above in particular countries is mixed and often contradictory. Other authors, notably Michel & Robine, (2004) have explained conditions under which each of these possibilities can be observed. New theories of ageing are based on a cyclical movement where disability first rises, then reduces, and then rises again when the age of death increases so much that many people spend their last years with multiple chronic diseases and frailty.

In New Zealand, the impact of longevity on superannuation has been considered (O’Connell, 2014) and there was some early work done on the impact of ageing populations on healthcare expenditure (Bryant, J., Teasdale et al., 2004; Cornwall & Davey, 2004). The New Zealand National Treasury produced a number of useful background reports to the 2013 report on the long-term fiscal position (New Zealand Treasury, 2013a). These include the fiscal sustainability of health care (New Zealand Treasury, 2013c), the fiscal sustainability of long-term care (New Zealand Treasury, 2013d), an assessment of the impact of an ageing population (New Zealand Treasury, 2013b) and a consideration of the key assumptions used in projections (New Zealand Treasury, 2013e).

The approach used for the need for palliative care is similar conceptually to that used in the New Zealand Treasury long-term-fiscal position model for healthcare and long-term care. Effectively, it is assumed that the increase in longevity means that the patterns previously experienced at age (say) 85 will be experienced only by those who are much older. The patterns by cause of death and place of death are thus effectively “stretched” to the right. The extent of the improvement is linked to the assumptions about longevity in the population projections.
In the median projections to 2068, Statistics NZ has assumed the following:

- Women will have period life expectancy\(^{25}\) at birth of 91.5 years, up from 83.9 years now, an increase of 7.6 years.
- Men will have period life expectancy at birth of 89.0 years, up from 80.2 years now, an increase of 8.8 years.

The approach of stretching the patterns effectively says “91 is the new 84” (for women) with respect to the historic patterns. The results for stretching the pattern to one that might apply in 2038 and one which might apply in 2068 are presented with commentary in Appendix 3.

The main feature of the historic pattern of place of death in Figure 11 is the expanding funnel of deaths in residential care at older ages. Stretching the age at which that pattern applies to higher age bands reduces the numbers in residential care somewhat, but does not change the trend of a large increase in numbers of deaths in residential care.

At the oldest ages, very few deaths proportionally occur in private residences and most of the reductions in deaths in residential care are replaced by deaths in hospital. The issue is not the scenarios, of which many could be modelled, but the shape of the pattern of place of death at older ages. It would take a significant commitment by DHBs, the residential aged care sector, hospices, district nursing and general practice to change the place of death at the very oldest ages.

The usefulness of a very long-term model is not so much in the numbers it produces but in the trends shown and the options created for discussions about different futures. The paragraph below from the OECD working paper (Astolfi, Lorenzoni et al., 2013, p. 39) is a useful reminder of the role of long-term models:

“While very short-term forecasts should be valued for their predictive accuracy, similar to a weather forecast, medium-to-longer term forecasts should be valued for their ability to demonstrate the likely future course of events, if past trends continue. In so doing, they are like a map, an abstraction of reality that shows the way to several potential destinations and the various choices of routes that may be taken.”

The projection of the future population in New Zealand continues to assume that longevity will improve, although at a slower pace than historically. A detailed discussion about the historic assumptions used and the likelihood of future gains in life expectancy is argued in a paper by Bryant (2013). He contrasts the arguments about plausible ceilings for human life expectancy with those who argue for a continuation of historical improvements in life expectancy. In this model of need, the longevity assumptions chosen by Statistics New Zealand and the Ministry of Health have not been questioned.

The question of whether New Zealand is experiencing dynamic equilibrium, extension or compression of morbidity with increased longevity was studied using data from 1981 and 1996 (Graham, Blakely et al., 2004). The authors found that dynamic equilibrium was the best fit to the available evidence at that time. However, more recent work has come to different conclusions.

Of particular importance for planning for palliative care has been the report produced on independent life expectancy in New Zealand (Ministry of Health, 2015a).

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\(^{25}\) Period life expectancy is a rather artificial construct but is used extensively in demography. It works out the life expectancy based on the current experience across all age groups. The more correct measurement is cohort life expectancy at birth which is the actual life lived by people, based on their year of birth. This can be fully determined only once all or nearly all people born in the same year have died and so can be produced only up to the mid-1940s at present.
The authors found that, although people are living longer, they are also living with more years of disability. Over the period of the study, from 1996 to 2013, independent life expectancy at birth did increase. However, the proportion of years lived independently (relative to life expectancy) was lower in 2013 than it had been in 1996.

Effectively this study presents a fourth alternative to the three possibilities (dynamic equilibrium, extension and compression) described above. In New Zealand we are living longer, we are living more years of healthy life, and we are living more years with disability at the end of life.

At the age of 65 years, people can expect to live roughly half of their remaining lives independently, as described in two examples below (Ministry of Health, 2015a, p. 11):

A female New Zealander at 65 years of age in 2013 can expect to live:
- another 10.6 years independently, on average, which is 49.5% of her remaining life
- a further 10.7 years with functional limitations requiring assistance
  - non-daily assistance for 5.9 years
  - daily assistance for the final 4.8 years;

A male New Zealander at 65 years of age in 2013 can expect to live:
- another 10.2 years independently, on average, which is 54.1% of his remaining life
- a further 8.7 years with functional limitations requiring assistance
  - non-daily assistance for 5.6 years
  - daily assistance for the final 3.1 years.

It has not been possible as yet to build this work into the model of need for palliative care, as the model works only on deaths, not the period of care needed. The period over which care is provided is an important consideration which is taken up in the final recommendations for further research.
6. Projected National Need for Palliative Care

Section 6 brings together the projections of future deaths with the historic patterns of the need for palliative care, in order to provide projections of the future need for palliative care. The results in this section are a small selection of the results available in the Excel spreadsheet model, the National Model of Need for Palliative Care. The results available at national level are discussed in this technical report and the results available at regional and local level (DHBs) are described.

6.1. Projections of Need 2016 to 2068

In Figure 57 the need for palliative care and the maximal need for palliative care are shown to 2068, with deaths not included in the definition of need also shown.

Figure 57: Projected Need for Palliative Care in New Zealand, 2016-2068

Total deaths rise from 30,300 a year in 2016 to 55,500 in 2068, an increase of 83%\(^{26}\). The need for palliative care rises from 24,400 in 2016 to 46,700, an increase of 92%. This greater increase for need compared to total deaths is a function of the ageing of the population.

The maximal need for palliative care is 28,700 in 2016, rising to 53,800 in 2068, an increase of 88%. Planners at regional and DHB-level should consider all three figures: total deaths, the need for palliative care and the maximal need for palliative care. The maximal need is essentially all deaths, excluding maternity deaths and excluding sudden deaths from external causes, unless these occur in residential care or a hospice IPU.

While sudden deaths may not have been amenable to palliative care for the patient, the grief for the family and whānau may be more severe and more bereavement support may be necessary than for deaths that are expected after a long period of decline at older ages.

\(^{26}\) Figures have been rounded. For practical planning purposes the shorter projections to 2038 are preferable.
The proportion of total deaths included in the need for palliative care and the maximal need is shown in Figure 58. Over the period from 2016 to 2068, the proportion of deaths in the NZ Need for Palliative Care increases slightly as the population ages. This is shown in greater detail on a different scale and with a range of values in Figure 58.

Figure 58: Proportion of Need and Maximal Need for Palliative Care, 2016-2068

Figure 59: Range of Projected Proportion of Need for Palliative Care, 2016-2068

Note: x-axis does not start at zero.
The truncated scale makes it possible to see the change in the range of results over time. The most important feature, for all projections, is that the proportion of need, as a percentage of total deaths, increases as the population ages. For the median projection the proportion increases from 80.4% in 2016\(^{27}\) to 84.1% of total deaths in 2068.

This same feature will be apparent at the regional and local levels as well. It is thus critical to plan using the proportions in the model spreadsheet, rather than use a fixed proportion of total deaths into the future.

### 6.2. Projections of National and Regional Need 2016 to 2038

The results to 2068 above should be used to get a general sense of the trends and are most useful for long-term planning of the workforce. The underlying population projections for the shorter period to 2038 are performed at a different time and using slightly different assumptions, as specified by the Ministry of Health. The shorter set of projections to 2038 are used for the Population Based Funding Formula and thus should be used for DHB, regional and facility planning purposes. The projection of need and maximal need is illustrated below.

![Projected Need and Maximal Need](image)

**Figure 60: Projected Need and Maximal Need for Palliative Care in New Zealand, 2016 to 2038**

The number of deaths needing palliative care is projected to increase from 24,680 in 2016 to 37,286 by 2038, an increase of 51.0%. This compares to an increase in the total number of deaths of 47.5% over the 22-year period.

---

\(^{27}\) Note that the figures in the 2016-2068 projections are slightly different to those in the 2016-2038 projections. For practical planning purposes the shorter set of projections, 2016 to 2038, should be used.
With an ageing population, the proportion of deaths needing palliative care increases from 80.9% in 2016 to 82.8% in 2038. It is critically important to use the spreadsheet model and not simply apply a constant percentage of need over time. The proportion of deaths needing palliative care is a function of the age and gender of the area and how this changes over time. The projected need for palliative care in 2016 and 2038 is shown for each region and DHB in the table below.

Table 10: Projected Need for Palliative Care in New Zealand by Region and DHB, 2016 and 2038

<table>
<thead>
<tr>
<th>Region</th>
<th>2016</th>
<th>2038</th>
<th>Increase 2016 to 2038</th>
<th>2016</th>
<th>2038</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Projected Need for Palliative Care</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Year to end June</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Northern Region</strong></td>
<td>7,446</td>
<td>12,246</td>
<td>64.5%</td>
<td>79.8%</td>
<td>82.2%</td>
</tr>
<tr>
<td>Northland DHB</td>
<td>1,163</td>
<td>1,761</td>
<td>51.3%</td>
<td>81.9%</td>
<td>83.4%</td>
</tr>
<tr>
<td>Waitemata DHR</td>
<td>2,843</td>
<td>4,019</td>
<td>71.6%</td>
<td>80.2%</td>
<td>87.5%</td>
</tr>
<tr>
<td>Auckland DHB</td>
<td>1,922</td>
<td>3,023</td>
<td>57.3%</td>
<td>79.1%</td>
<td>81.5%</td>
</tr>
<tr>
<td>Counties Manukau DHB</td>
<td>2,019</td>
<td>3,443</td>
<td>70.5%</td>
<td>78.9%</td>
<td>82.0%</td>
</tr>
<tr>
<td><strong>Midland Region</strong></td>
<td>5,457</td>
<td>7,918</td>
<td>45.1%</td>
<td>81.6%</td>
<td>83.1%</td>
</tr>
<tr>
<td>Waikato DHB</td>
<td>2,195</td>
<td>3,303</td>
<td>50.5%</td>
<td>80.7%</td>
<td>82.6%</td>
</tr>
<tr>
<td>Lakes DHB</td>
<td>656</td>
<td>928</td>
<td>41.5%</td>
<td>81.9%</td>
<td>83.6%</td>
</tr>
<tr>
<td>Bay of Plenty DHB</td>
<td>1,512</td>
<td>2,226</td>
<td>47.3%</td>
<td>82.2%</td>
<td>83.4%</td>
</tr>
<tr>
<td>Tairawhiti DHB</td>
<td>314</td>
<td>410</td>
<td>30.9%</td>
<td>82.5%</td>
<td>83.8%</td>
</tr>
<tr>
<td>Taranaki DHB</td>
<td>782</td>
<td>1,051</td>
<td>34.4%</td>
<td>82.3%</td>
<td>83.4%</td>
</tr>
<tr>
<td><strong>Central Region</strong></td>
<td>5,193</td>
<td>7,337</td>
<td>41.3%</td>
<td>81.5%</td>
<td>83.3%</td>
</tr>
<tr>
<td>Hawke's Bay DHB</td>
<td>1,092</td>
<td>1,556</td>
<td>42.5%</td>
<td>82.1%</td>
<td>83.7%</td>
</tr>
<tr>
<td>Whanganui DHB</td>
<td>514</td>
<td>621</td>
<td>20.8%</td>
<td>82.9%</td>
<td>83.9%</td>
</tr>
<tr>
<td>MidCentral DHB</td>
<td>1,119</td>
<td>1,335</td>
<td>37.2%</td>
<td>81.7%</td>
<td>83.4%</td>
</tr>
<tr>
<td>Capital and Coast DHB</td>
<td>1,337</td>
<td>2,023</td>
<td>51.2%</td>
<td>80.1%</td>
<td>82.6%</td>
</tr>
<tr>
<td>Hutt Valley DHB</td>
<td>785</td>
<td>1,115</td>
<td>42.1%</td>
<td>81.7%</td>
<td>83.2%</td>
</tr>
<tr>
<td>Wairarapa DHB</td>
<td>347</td>
<td>487</td>
<td>40.2%</td>
<td>82.7%</td>
<td>83.9%</td>
</tr>
<tr>
<td>Three Wellington DHB</td>
<td>2,468</td>
<td>3,624</td>
<td>46.8%</td>
<td>80.9%</td>
<td>82.9%</td>
</tr>
<tr>
<td><strong>South Island Region</strong></td>
<td>6,609</td>
<td>9,733</td>
<td>47.3%</td>
<td>81.2%</td>
<td>83.0%</td>
</tr>
<tr>
<td>Nelson Marlborough DHB</td>
<td>963</td>
<td>1,566</td>
<td>62.5%</td>
<td>82.3%</td>
<td>83.7%</td>
</tr>
<tr>
<td>West Coast DHB</td>
<td>224</td>
<td>310</td>
<td>38.6%</td>
<td>82.9%</td>
<td>83.9%</td>
</tr>
<tr>
<td>Canterbury DHB</td>
<td>3,005</td>
<td>4,528</td>
<td>50.7%</td>
<td>80.6%</td>
<td>82.6%</td>
</tr>
<tr>
<td>South Canterbury DHB</td>
<td>481</td>
<td>639</td>
<td>32.7%</td>
<td>83.0%</td>
<td>84.0%</td>
</tr>
<tr>
<td>Southern DHB</td>
<td>1,936</td>
<td>2,691</td>
<td>39.0%</td>
<td>81.0%</td>
<td>82.8%</td>
</tr>
<tr>
<td><strong>New Zealand</strong></td>
<td>24,680</td>
<td>37,266</td>
<td>51.0%</td>
<td>80.9%</td>
<td>82.8%</td>
</tr>
</tbody>
</table>
The total number of deaths and the evolution of the percentage need for palliative care are shown for the four regions in the graphs below.

![Figure 61: Projected Need for Palliative Care by Region, 2016 to 2038](image)

![Figure 62: Proportion of Need for Palliative Care, Regions compared to New Zealand, 2016 to 2038](image)

Note the x-axis does not start at zero.
Over the period to 2038, the projected need for palliative care increases by 51.0% for New Zealand, 64.5% for Northern, 45.1% for Midland, 41.3% for Central and 47.3% for the South Island region. However, throughout the period, the total number of deaths is greater in the Northern region, followed by the South Island region.

In the spreadsheet model, more detail is provided on age bands, the cause of death and place of death, both for total deaths and for the need for palliative care.

### 6.3. Planning for Public Hospitals

The spreadsheet model contains results for planning for public hospitals, residential care and hospice care. The graph below shows one of the graphs for hospital palliative care.

![Graph: Projected Need for Palliative Care in Hospitals, 2016 to 2038](image)

The number of deaths needing palliative care in public hospitals is projected to increase from 7,307 in 2016 to 10,045 by 2038, an increase of 37.5%.

The proportion of deaths in hospital that need palliative care is projected to decline slightly from 72.0% in 2016 to 69.6% in 2038. This is a function of more deaths at older ages which in the historic pattern have a slightly lower need for deaths in hospital. It seems likely that older patients in need of palliative care are transferred to residential care which is then reflected as the place of death. The maximal need for palliative care is projected to remain at about the same levels relative to total hospital deaths: 94.6% in 2016 and 94.3% in 2038.

It is important to understand what the total need for palliative care for all patients is in hospitals, not only need based on deaths. A prospective survey of the need for palliative care at one New Zealand hospital (Gott, Frey et al., 2013) found that one-fifth of all hospital inpatients met the criteria for palliative care need and that the majority of these were over age 70.
Practice with respect to identifying those in need of palliative care in hospitals is evolving rapidly (Weissman & Meier, 2011; Clark, Armstrong et al., 2014), particularly in the emergency department (Barnett, Williams et al., 2016; Moretti, Quadri et al., 2016). The Clinical Panel commented that hospital palliative care specialists have found that the more they discuss palliative care with colleagues from other specialities, the more referrals are received by the palliative care team.

As the relationship between need in public hospitals and residential care is inter-linked, the figures for need in public hospitals by region and DHB are shown with those for residential care in Table 11.

### 6.4. Planning for Residential Care

If there is insufficient capacity for end of life care in aged residential care facilities, then the likelihood is that public hospitals will bear the consequences through higher numbers of admissions. The graph below therefore shows the projected number of deaths needing palliative care in public hospitals and residential care together.

![Graph showing projected need for palliative care in hospitals and residential care](Figure 64)

Figure 64: Projected Need for Palliative Care in Hospitals and Residential Care, 2016 to 2038

Note that the model of need for palliative care does not take any capacity constraints into account. Based on the historic patterns of place of death, it is projected that the number of deaths needing palliative care will increase from 10,420 in 2016 to 19,190 in 2038. The need for palliative care is projected to increase by 37.5% in public hospitals and 84.2% in residential care by 2038. The projected need by region and DHB is shown in the table below.
In a study of the percentage of deaths occurring in hospital and residential aged care settings in 45 countries (Broad, Gott et al., 2013), New Zealand was found to have amongst the highest proportion of deaths in residential aged care (RAC). The authors suggested that the relatively small percentage of deaths in hospital and high percentage in RAC (compared to other countries) may be due to discharges of older people from acute hospital care into RAC near the end-of-life.

The OPAL Study in 2008 (Boyd, Michal, Connolly et al., 2009) found that 38% of all aged residential care residents in the Auckland region had been admitted from a public hospital.

### Table 11: Projected Need for Palliative Care in Hospitals and Residential Care, by Region and DHB, 2016 and 2038

<table>
<thead>
<tr>
<th>Projected Need for Palliative Care</th>
<th>Public Hospitals</th>
<th>Residential Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year to end June</td>
<td>2016</td>
<td>2038</td>
</tr>
<tr>
<td>Northern Region</td>
<td>2,237</td>
<td>3,327</td>
</tr>
<tr>
<td>Northland DHB</td>
<td>352</td>
<td>476</td>
</tr>
<tr>
<td>Waitemata DHB</td>
<td>695</td>
<td>1,066</td>
</tr>
<tr>
<td>Auckland DHB</td>
<td>568</td>
<td>832</td>
</tr>
<tr>
<td>Counties Manukau DHB</td>
<td>621</td>
<td>953</td>
</tr>
<tr>
<td>Midland Region</td>
<td>1,615</td>
<td>2,137</td>
</tr>
<tr>
<td>Waikato DHB</td>
<td>656</td>
<td>897</td>
</tr>
<tr>
<td>Lakes DHB</td>
<td>194</td>
<td>253</td>
</tr>
<tr>
<td>Bay of Plenty DHB</td>
<td>447</td>
<td>589</td>
</tr>
<tr>
<td>Taumarumaru DHB</td>
<td>93</td>
<td>114</td>
</tr>
<tr>
<td>Taranaki DHB</td>
<td>226</td>
<td>284</td>
</tr>
<tr>
<td>Central Region</td>
<td>1,527</td>
<td>1,960</td>
</tr>
<tr>
<td>Hawke's Bay DHB</td>
<td>321</td>
<td>415</td>
</tr>
<tr>
<td>Whanganui DHB</td>
<td>149</td>
<td>168</td>
</tr>
<tr>
<td>MidCentral DHB</td>
<td>329</td>
<td>408</td>
</tr>
<tr>
<td>Capital and Coast DHB</td>
<td>396</td>
<td>539</td>
</tr>
<tr>
<td>Hutt Valley DHB</td>
<td>232</td>
<td>301</td>
</tr>
<tr>
<td>Wairarapa DHB</td>
<td>101</td>
<td>130</td>
</tr>
<tr>
<td>Three Wellington DHBs</td>
<td>728</td>
<td>969</td>
</tr>
<tr>
<td>South Island Region</td>
<td>1,936</td>
<td>2,612</td>
</tr>
<tr>
<td>Nelson Marlborough DHB</td>
<td>280</td>
<td>410</td>
</tr>
<tr>
<td>West Coast DHB</td>
<td>66</td>
<td>85</td>
</tr>
<tr>
<td>Canterbury DHB</td>
<td>883</td>
<td>1,224</td>
</tr>
<tr>
<td>South Canterbury DHB</td>
<td>137</td>
<td>169</td>
</tr>
<tr>
<td>Southern DHB</td>
<td>570</td>
<td>723</td>
</tr>
<tr>
<td>New Zealand</td>
<td>7,307</td>
<td>10,045</td>
</tr>
</tbody>
</table>
The ARC Services Review (Grant Thornton, 2010) found that for aged residential care there is substantially (more than 25%) higher utilisation of secondary services, emergency department and pharmacy services in New Zealand than in comparative international programmes.

It is therefore critical that DHBs develop models of care, referral criteria and reimbursement that support people to receive palliative and end of life care in the most appropriate place.

### 6.5. Planning for Hospice Care

As described in section 4.5, two estimates are produced for the need for hospice care as it overlaps with residential care: one with only neoplasms and congenital deaths in residential care (similar to historic practice for hospices) and the second with all deaths in residential care. This is partly to reflect the changing practice in New Zealand, with hospices increasingly supporting aged residential care facilities.

![Figure 65: Projected Need for Hospice Care, including Support to Residential Care, 2016 to 2038](image)

The number of deaths needing hospice care is projected to increase from 11,329 in 2016 to 13,867 by 2038, an increase of 22.4%. When support to residential care is included, the increase is from 19,295 deaths in 2016 to 29,296 in 2038, an increase of 51.8%. Some of these deaths may move into the community rather than be in residential care. Local models of care are evolving and the way in which each DHBs organises services will affect the local mix of hospice care and residential care at the end of life.

The estimates of hospice need, including support for residential care, are shown at regional and DHB levels in Table 12.
Table 12: Projected Need for Hospice Care, including support to Residential Care, by Region and DHB, 2016 and 2038

<table>
<thead>
<tr>
<th>Region</th>
<th>Year to end June 2016</th>
<th>Year to end June 2038</th>
<th>Increase 2016 to 2038</th>
<th>Hospice Care as Percentage of Total Deaths 2016</th>
<th>Hospice Care as Percentage of Total Deaths 2038</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern Region</td>
<td>5,817</td>
<td>9,627</td>
<td>65.5%</td>
<td>62.3%</td>
<td>64.7%</td>
</tr>
<tr>
<td>Northland DHB</td>
<td>906</td>
<td>1,383</td>
<td>52.6%</td>
<td>63.8%</td>
<td>65.5%</td>
</tr>
<tr>
<td>Waitemata DHB</td>
<td>1,833</td>
<td>3,169</td>
<td>72.8%</td>
<td>62.8%</td>
<td>65.1%</td>
</tr>
<tr>
<td>Auckland DHB</td>
<td>1,506</td>
<td>2,374</td>
<td>57.7%</td>
<td>62.0%</td>
<td>64.0%</td>
</tr>
<tr>
<td>Counties Manukau DHB</td>
<td>1,573</td>
<td>2,701</td>
<td>71.7%</td>
<td>61.4%</td>
<td>64.3%</td>
</tr>
<tr>
<td>Midland Region</td>
<td>4,263</td>
<td>6,221</td>
<td>45.9%</td>
<td>63.7%</td>
<td>65.3%</td>
</tr>
<tr>
<td>Waikato DHB</td>
<td>1,712</td>
<td>2,592</td>
<td>51.4%</td>
<td>62.9%</td>
<td>64.8%</td>
</tr>
<tr>
<td>Lakes DHB</td>
<td>513</td>
<td>728</td>
<td>41.8%</td>
<td>64.2%</td>
<td>65.6%</td>
</tr>
<tr>
<td>Bay of Plenty DHB</td>
<td>1,180</td>
<td>1,754</td>
<td>48.7%</td>
<td>64.1%</td>
<td>65.7%</td>
</tr>
<tr>
<td>Tairawhiti DHB</td>
<td>245</td>
<td>321</td>
<td>30.9%</td>
<td>64.6%</td>
<td>65.5%</td>
</tr>
<tr>
<td>Taranaki DHB</td>
<td>613</td>
<td>826</td>
<td>34.7%</td>
<td>64.6%</td>
<td>65.5%</td>
</tr>
<tr>
<td>Central Region</td>
<td>4,063</td>
<td>5,772</td>
<td>42.1%</td>
<td>63.8%</td>
<td>65.5%</td>
</tr>
<tr>
<td>Hawke's Bay DHB</td>
<td>854</td>
<td>1,224</td>
<td>43.3%</td>
<td>64.2%</td>
<td>65.8%</td>
</tr>
<tr>
<td>Whanganui DHB</td>
<td>403</td>
<td>487</td>
<td>20.8%</td>
<td>65.0%</td>
<td>65.8%</td>
</tr>
<tr>
<td>MidCentral DHB</td>
<td>874</td>
<td>1,208</td>
<td>38.2%</td>
<td>63.8%</td>
<td>65.7%</td>
</tr>
<tr>
<td>Capital and Coast DHB</td>
<td>1,046</td>
<td>1,594</td>
<td>52.4%</td>
<td>62.6%</td>
<td>65.0%</td>
</tr>
<tr>
<td>Hutt Valley DHB</td>
<td>614</td>
<td>877</td>
<td>42.8%</td>
<td>63.9%</td>
<td>65.4%</td>
</tr>
<tr>
<td>Wairarapa DHB</td>
<td>272</td>
<td>382</td>
<td>40.3%</td>
<td>64.8%</td>
<td>65.8%</td>
</tr>
<tr>
<td>Three Wellington DHBs</td>
<td>1,931</td>
<td>2,852</td>
<td>47.7%</td>
<td>63.3%</td>
<td>65.3%</td>
</tr>
<tr>
<td>South Island Region</td>
<td>5,173</td>
<td>7,651</td>
<td>47.9%</td>
<td>63.5%</td>
<td>65.2%</td>
</tr>
<tr>
<td>Nelson Marlborough DHB</td>
<td>756</td>
<td>1,234</td>
<td>63.3%</td>
<td>64.6%</td>
<td>66.0%</td>
</tr>
<tr>
<td>West Coast DHB</td>
<td>175</td>
<td>243</td>
<td>38.4%</td>
<td>64.9%</td>
<td>65.6%</td>
</tr>
<tr>
<td>Canterbury DHB</td>
<td>2,351</td>
<td>3,557</td>
<td>51.3%</td>
<td>63.0%</td>
<td>64.9%</td>
</tr>
<tr>
<td>South Canterbury DHB</td>
<td>378</td>
<td>502</td>
<td>33.0%</td>
<td>65.1%</td>
<td>66.1%</td>
</tr>
<tr>
<td>Southern DHB</td>
<td>1,514</td>
<td>2,115</td>
<td>39.7%</td>
<td>63.3%</td>
<td>65.1%</td>
</tr>
<tr>
<td>New Zealand</td>
<td>19,295</td>
<td>29,296</td>
<td>51.8%</td>
<td>63.3%</td>
<td>65.1%</td>
</tr>
</tbody>
</table>
6.6. Model for National, Regional and Local Planning

This section outlines the reports and graphs available in the Excel spreadsheet model, the National Model of Need for Palliative Care. The sections in the spreadsheet model are as follows:

- **Assumptions chosen**: All assumptions used in the model are grouped on a single page. This sheet has choices for the historic patterns and future projections to be used, with choices typically made from drop-down boxes. This sheet also has information about the version of the model, the underlying assumptions, and contact information if there are queries.

- **Projections at a National Level to 2068**: This section will be of most use for policy purposes and for long-term workforce planning. The main feature of these projections is that a range of results is produced for the twelve projections of deaths supplied by Statistics NZ. One projection is chosen in the assumptions for more detailed results. Reports and graphs are provided for All Deaths, followed by the Need for Palliative Care.

- **Projections at a National Level to 2038**: This section is the detailed national projection of all deaths and the need for palliative care. It should be used for all planning purposes. There are three colour-coded sections to the report and graphs: All Deaths, Need for Palliative Care, and Planning for Facilities. The facilities section has information for planning for hospitals, residential care and hospice care.

- **Projections at a Regional Level to 2038**: This has identical reports and graphs to the National level above, but produced for a chosen region. It is possible to use historic patterns for the region chosen or for New Zealand as a whole. This section is most useful for regional network planning. In the model, DHBs are allocated to regions as follows:
  - **Northern Region**: Northland DHB, Waitemata DHB, Auckland DHB and Counties Manukau DHB
  - **Midland Region**: Waikato DHB, Lakes DHB, Bay of Plenty DHB, Tairawhiti DHB and Taranaki DHB
  - **Central Region**: Hawke’s Bay DHB, Whanganui DHB, MidCentral DHB, Capital and Coast DHB, Hutt Valley DHB and Wairarapa DHB.
  - **South Island Region**: Nelson Marlborough DHB, West Coast DHB, Canterbury DHB, South Canterbury DHB and Southern DHB.

- **Projections at a Local Level to 2038**: This has identical reports and graphs to the National level above, but produced for the chosen DHB, combination of DHBs or portion of a DHB. It is possible to use historic patterns for the region chosen or for New Zealand as a whole. This section is most useful for planning at DHB level and for planning by hospitals, residential care and hospice facilities within DHBs. The purpose of having all three levels (National, Regional and Local) is that it is often useful to simultaneously compare the DHB results to those of the region and the country.

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28 Note that the long-term projections are produced with some differences in the assumptions (and hence the results) to those produced annually for the Ministry of Health. For all practical planning by regional networks, DHBs and facilities, the shorter projections to 2038 should be used.

29 The last three DHBs in this region (Capital and Coast DHB, Hutt Valley DHB and Wairarapa DHB) are also grouped for planning purposes as Three Wellington DHBs.
Summary Projections All Regions and DHBs: This section has a high-level summary of total deaths, the need for palliative care and the facility planning information across all DHBs, using the same assumptions as used at a national level. This section is likely to be most useful for national planning but is also helpful as an overview across all DHBs to enable regions and DHBs to see how they compare.

Own report and highlights: The spreadsheet has space for the user to develop their own report by collating results from any of the other sections.

Tables and Workings: The underlying calculations and structure are likely to be of interest only to researchers and to people updating the model in future. These sheets are hidden from view but can be accessed by “unhiding” the subsequent sheets. Password protection is used to prevent inadvertent alterations of the tables and formulae, not to prevent access and the password is thus freely available on the first assumptions sheet. The tables and working sheets are organised in two groups: the projections available and chosen; and the historic patterns available and chosen. The derivation of the tables used is in a separate spreadsheet which is available from the author or the Ministry of Health.

The need for palliative care as a proportion of total deaths is different across DHBs, regions and over time. This is a function of the ageing of deaths and the different age structures projected for each DHB. It is thus critical to plan using the proportions from the model spreadsheet, rather than use a fixed proportion of total deaths into the future.

It is therefore strongly recommended that the spreadsheet model be made freely available within the health sector to enable the evidence to be widely used in planning and discussions about future models of care.
7. Recommendations for Updates and Further Research

This final section considers some limitations of the methodology and makes recommendations for further research and for updating the model of need for palliative care.

7.1. Limitations and Caveats to the Model

Firstly, projections are NOT predictions. Statistics New Zealand issue the following warning with population projections (Statistics New Zealand, 2014):

“National population projections give an indication of the future population usually living in New Zealand. They indicate probable outcomes based on different combinations of fertility, mortality, and migration assumptions. … These projections are not predictions. They should be used as an indication of the overall trend, rather than as exact forecasts.”

Projections change as new information becomes available and historic patterns may evolve over time. These points are discussed in section 7.2 with recommendations for updating the model.

The OECD reminds us of the role of models, saying (Astolfi, Lorenzoni et al., 2013, p. 13) that “medium to long-term forecasting models are useful but certainly imperfect abstractions of reality that point the way to a set of possible alternative future outcomes. The value of forecasting models does not lie in their ability to “predict” the future – a task that no medium-to-long term model could realistically accomplish.” The authors quote the Swedish Ministry of Health and Social Affairs that “Effective forecasts change the future, which means that they prove – and have to prove – wrong”.

The main purpose of models such as this one is to provide hard evidence to facilitate discussions between planners, funders, the providers of healthcare, industry bodies, professional bodies and those involved in training professionals for the future.

Palliative care will be successful in reaching all those who need care at the end of life only if a palliative care approach is fully embedded throughout the health system. (Stjernward, Foley et al., 2007; World Health Organization, 2014). To this end, leadership is needed and this model can contribute to developing a common understanding of the future.

The most serious limitation of the model is that it is based on deaths and not the whole period of care needed. The international methodologies, however, also take the approach of using mortality data to determine the need for palliative care. Concerns with the quality of mortality data are taken up in section 0 and the issue of place of care is considered in section 7.4.

With the ageing of the population in future, there is a strong possibility that the periods over which palliative care is needed will be longer than at present. The importance of further research on trajectories at the end of life is discussed in section 7.5.

Finally, the use of lists by cause of death should in no way be seen as a limitation on who needs access to palliative care. The cause of death lists are simply a means for identifying, at a population level, the general level of need. The need at an individual level should always be based on the needs of that patient (Higginson & Addington-Hall, 1999). Palliative care needs to be provided on the basis of patient and family / whānau need and not diagnosis.
7.2. Updating Historic Patterns and Population Projections

The analysis in section 2.6 showed that the patterns of cause of death and place of death by age and gender have been reasonably stable over the 14-year period of the historic study. This has given confidence for using these patterns for the projections through to 2038. Some concerns were expressed about using the patterns throughout the longer projection period to 2068.

There is value in monitoring how cause of death and place of death evolve and it is recommended that the historic study of mortality data be repeated every five years. The next study should thus be initiated only when MORT data for the years 2014 to 2018 becomes available. This is likely to be in the year 2020 if the historic time delays for releasing MORT data continue.

The need for palliative care, as a function of both cause of death and place of death, may stand for a longer period and it might be possible to use the cause of death lists prepared by the Clinical Panel for perhaps two cycles of historic data, or ten years. This would also be useful to see how the need evolves over time. However, if there are substantial developments in the methodology used internationally or commitments to use one methodology across all countries, then this may need to be revisited.

As palliative care practice evolves in New Zealand, so the need for palliative care definition may need revision, but again a ten-year period seems like a reasonable time for models of care to have evolved and to be evident in the mortality data. Changing models of care might mean that additional figures are needed for planning but these could be added to the existing model by someone with good Excel skills.

The cause of death lists currently use ICD-10-AM. A major revision of the ICD codes is underway to create ICD-11. This is not a simple update or addition of a few codes, but a complete rework of the architecture of the coding system to better fit with electronic systems and multiple needs. Once released and in use, there is no doubt that the cause of death lists will need to be amended. The World Health Organization expects to finalize ICD-11 during 2018 but as yet there is no timetable for the adoption in New Zealand.

The most important time frame with regard to population projections is tied to the date of the census. While there are attempts to consider continuous census-like information based on administrative data (like births, deaths and immigration), the results of a census provide important information about the movement of people within the country. The next census is due in 2018 and the national population projections are typically complexly revised about 18 months after the census. It will be essential to modify the projection of need model when the new national population projections, with a new base date, are published.

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30 International Classification of Diseases, version 10, Australian modification.
31 For example, under ICD-10 all cancers and benign tumours are included in one chapter, “C00-D48 II Neoplasms”. However, under ICD-11 these will be distributed among different chapters. ICD-11 will have a single underlying structure but different “linearizations” of the codes for different purposes, such as cause of death reporting, disease reporting at primary care level or on admission, and for research. More information, the beta version and timetable for implementation are at: http://www.who.int/classifications/icd/revision/en/
Between census dates, Statistics New Zealand update long-term national projections every two to three years. Release dates are available well in advance and the following have been scheduled:

- **National population projections** (next release late 2016). Information release for New Zealand population projections by age and sex.
- **Subnational population projections** (next release early 2017). Information release for regional council, territorial authority and Auckland local board area population projections by age and sex.
- **National ethnic population projections** (next release 2017). Information release for New Zealand Māori, Pacific, Asian, and ‘European or Other’ ethnic population projections by age and sex.

It will be useful to look at the updated population projections released in late 2016 and see how different they are to the existing projections. A decision can then be taken whether to update the model.

There may be calls for projection of need by ethnicity, and with new national ethnic population projections due in 2017 this may become an issue. In the historic study of patterns of deaths there are very few deaths for Māori, Pacific and Asian lives at the older ages. This means that the crucial patterns at older ages would not be strong enough to use with an ageing population. Until there is stronger evidence at older ages, as well as evidence that there are significant differences between the ethnicity groups (after age, gender, cause and place of death), projection of need by ethnicity is not recommended. Note that the model does have projections of total deaths by ethnicity.

The shorter projections required by the Ministry of Health are produced annually by Statistics New Zealand and are available from November or December each year. As these are used for planning by DHBs, it is recommended that the new projections each year be considered and compared to the existing ones in the model, in order to determine whether to replace the tables used in the model.

In summary, the following investigations and updates are recommended for the model, in order of timing:

- Evaluation of revised long-term national population projections and decision about whether to amend model – when released in late 2016. Repeat whenever projections are released.
- Evaluation of revised medium-term population projections (DHB-level) and decision about whether to amend model – released annually in November/December. Repeat annually.
- Essential update of model on release of revised long-term national population projections following census 2018 – when released, possibly late 2020. Repeat at census intervals.
- Evaluation of historical patterns of death, when MORT data is available for period 2014 to 2018 - preparation of revised patterns for the model, possibly late 2020. Repeat at five-yearly intervals.
- Revision of methodology – based on international developments and evolution in practice in New Zealand. Consider at time of five-yearly MORT data investigation.
- Complete revision of cause of death lists once ICD-11 has been fully implemented in New Zealand – date unknown.

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32 Statistics NZ Projections
7.3. Limitations of Planning using Mortality Data

The Murtagh paper (Murtagh, Bausewein et al., 2014) raises some of the issues with using death certificate data for estimating the need for palliative care. The authors argue that death certification is not always accurate in ascertaining the actual cause of death and that this is particularly true for some of the conditions to which palliative care has more recently been extended. This was partly addressed by considering both underlying causes of death and contributory causes of death. Although periods of hospitalisation prior to death were also considered, the authors found that death registration data was reliable enough without needing symptom or hospital activity data.

Dementia is typically poorly recorded on death certificates. In Australia, it was found (Australian Institute of Health and Welfare, 2007) that there were 4,413 deaths with dementia as the underlying cause of death in 2003. However, when the contributory cause of death was also included, a further 9,820 deaths from dementia were counted.

In New Zealand, the issues faced by GPs in completing death certificates have been studied (McAllum, St George et al., 2005). The authors found that uncertainty in clinical medicine means that the certificates cannot always be completed with certainty. Other factors that influenced what was recorded included the family of the deceased and cultural needs and/or practices. The Palliative Care Advisory Panel advised that new training modules for doctors on death certification have been developed in Canterbury DHB and are available to other DHBs.

Even if the death certificates are fully completed, the information contained has not always been fully captured in the past. An attempt to replicate the Murtagh approach of considering both underlying and contributory causes of death had to be abandoned when it was found that only a few key contributory causes had been captured in the early mortality data. It is understood that capturing of the information has improved in more recent years.

However, no matter the quality of the death certificate data, the usefulness of mortality data is that we know with certainty that the person has died. There are a few cases where a coroner needs to issue a finding of death months or years later, but this is a small number of cases and typically affects deaths from external causes. While there are standards for specialist palliative care data (Health Information Standards Organisation, 2013a, 2013b), these are not mandatory and have not been fully implemented. There are no standards for capturing palliative care data in primary care or in aged residential care.

From a planning perspective, palliative care is certainly not only about care at death. Figure 66 illustrates how palliative care and curative care co-exist from the diagnosis of a life-limiting condition and that palliative care tends to become more important towards the end of life.

The definition of palliative care in New Zealand (Ministry of Health, 2015b) includes the sentence: “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.” The workload for palliative care is thus not only in the immediate period around death.

There is insufficient evidence as yet to build a model of need that takes into account the care provided during the course of a life-limiting disease. This is, however, a potentially fruitful area for further research and should be considered along with the research into trajectories at the end of life in section 7.5.
From a planning perspective the question often arises of whether care is provided by specialist palliative care providers or is provided by primary palliative care (see Appendix 1 for definitions).

An update of the original study of need in Western Australia uses the more limited Rosenwax list of conditions to determine the need for specialist palliative care (Rosenwax, Spilsbury et al., 2016). The authors found that 46.3% of all deaths received community and/or hospital based specialist palliative care.

The Clinical Panel did not feel this methodology would be a good estimate of the need for specialist palliative care in New Zealand. Models of care are different and models are evolving differently across DHBs so that it is not feasible to separate out, at a national level, the need for specialist palliative care. The issue needs to be addressed at DHB and regional planning levels, based on the levels to which palliative care has been embedded in the health system for that area.

### 7.4. Place of Care rather than Place of Death

In using place of death as a central part of the planning model, it is acknowledged that this is an over-simplification of a complex web of movements. Ideally, we should be considering a model based on place of care, not place of death.

For hospice patients, deaths occur in hospice IPU, in private residences, in public hospitals and in residential care, with a few deaths recorded in other settings. There are complex movements between settings, for example:

- People moving between residential care and hospital.
- People moving between private residence and hospice IPU.
- People moving between private residence and hospital.
- Other more complex combinations of all three.
There have been some studies of the movements between aged residential care and public hospital in the Auckland area (Boyd, Michal, Connolly et al., 2009; Boyd, M., Broad et al., 2011; Broad, Gott et al., 2013). However, there has been no study as yet linking movements between private residences, public hospital, residential care, hospice community-based care and admission to hospice IPU.

Palliative care provided by primary care, district nursing, hospice teams and public hospital palliative care teams is not recorded in a consistent way or in one place. It is thus very difficult for a DHB to determine whether the need is being met and, more importantly, what groups did not have needs met at the end of life.

It is feasible to begin to study some of these movements at the end of life and whether people were cared for by hospice teams, by linking data from hospices, residential care and hospitals using NHI numbers. The infrastructure and security to link data are being provided by Statistics New Zealand under the Integrated Data Infrastructure (IDI) initiative. While the IDI currently has mortality data, ACC claims data, public hospital admissions, out-patient visits, primary care enrolments, laboratory tests and pharmaceutical data, it has gaps in data crucial to studies at the end of life. Residential care data, residential care subsidies, interRAI data and hospice data would need to be integrated, preferably through the same IDI infrastructure.

7.5. Changing Trajectories at the End of Life

The concept of different trajectories at the end of life that require different resourcing for palliative care has been described by a number of researchers, including Higginson (1997) and Franks et al (2000), and adopted by the World Health Organization (WPCA & WHO, 2014).

In adult palliative care, three main trajectories using functional ability have been identified at the end of life, based on the work of Lynn & Adamson (2003). Figure 67 illustrates these three trajectories.

Palliative Care Australia (2010) describes the three trajectories and makes the assertion that the trajectories are roughly sequential in age, describing the palliative care needs as follows:

- **Trajectory 1** is characterised by a short period of evident decline over a period of weeks or months. Good function may be maintained for some time, with a few weeks or months of rapid decline as the illness becomes overwhelming and leads to death. Generally, there is time to anticipate needs and plan for end of life care. While many diseases follow this course, it is typical of the major cancers. This trajectory meshes well with traditional palliative care services that concentrate on providing comprehensive care over the last weeks or months of a person’s life. About 20% of people will follow this trajectory.

- **Trajectory 2** is characterised by long-term limitation of function with intermittent severe, acute episodes. Patients with heart failure or chronic obstructive pulmonary disease (COPD) are usually ill for many years. They frequently experience acute and often severe exacerbation of their physical symptoms. These exacerbations are frequently associated with admission to hospital and intensive treatment. If patients survive an episode, they may well return home without much progression of their everyday disabilities. Patients usually

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survive many such episodes but, at some point, rescue attempts fail. The timing of death is often a surprise in this group, despite their long-term chronic illness. Although many illnesses can follow this course, chronic heart failure and emphysema are the most common. About 25% of people will follow this trajectory.

- **Trajectory 3**: Those who escape cancer and organ failure as they age will be likely to die of either dementia or generalised frailty. This trajectory is characterised by progressive disability from a baseline of already low cognitive or physical function. Gradual decline in functional capacity combined with the impact of often minor physical events—for example a fall or a respiratory or urinary infection—can prove fatal. Approximately 40% of people will follow this trajectory.

The three characteristic trajectories described above are roughly sequential in relation to the ages afflicted, with illness trajectory 1 (cancer) peaking around age 65, fatal chronic organ system failure (trajectory 2) about a decade later and frailty and dementia (trajectory 3) afflicting those who live past their mid-eighties.”

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**Figure 67: Trajectories at the End of Life**  
Source: (Palliative Care Australia, 2010), based on (Lynn & Adamson, 2003)
The evidence in New Zealand for cause of death patterns by age and gender, as shown in section 2.2, supports the Palliative Care Australia assertion of the trajectories being sequential. In particular, proportional deaths from cancer in New Zealand are shown to peak at around age 50-54 for women and age 60-64 for men. There is evidence that more people are dying of other conditions, which include dementia and frailty, when considering the population as a whole.

Given the ageing of deaths, the implications of a change in trajectories, to more people dying of longer and slower trajectories, are of critical importance for planning future palliative care.

There are other disease trajectories which would be useful to explore at the same time. The characterisations of childhood palliative care (Hain, Devins et al., 2013) are useful in that they allow for the provision of palliative care when there is a possibility of reasonable functioning for a time. The groups are based on the four ACT/RCPCH35 paediatric archetypes and illustrated in Figure 68:

- **Group I: Potential for cure - life is threatened, not necessarily limited.** Conditions for which treatment may be feasible but can fail, e.g. cancer, some cardiac anomalies.
- **Group II: Period of normality despite having fatal diagnosis.** Conditions where premature death is inevitable but where there may be long periods of participation in normal activities, e.g. Duchenne muscular dystrophy.
- **Group III: Relentless deterioration from, or before, time of diagnosis.** Progressive conditions without curative treatment options, where treatment is exclusively palliative and commonly extends over many years, e.g. metabolic or neurodegenerative conditions.
- **Group IV: Unpredictable course whose progression is not easily judged from natural history.** Irreversible but non-progressive conditions causing likelihood of premature death through complications, e.g. severe cerebral palsy, traumatic brain injury, septic brain injury.

![Paediatric Trajectories of Palliative Care](image)

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35 The Royal College of Paediatrics and Child Health (RCPCH) worked with the Association for Children’s Palliative Care (ACT) in 1997 to define the concept of life-limiting conditions through a series of archetype descriptions.
A possible set of trajectories for older people from the World Report on Ageing and Health is shown below. This may be particularly useful for characterising care in aged residential care and for deaths at the oldest ages.

![Figure 69: Hypothetical Trajectories of Physical Capacity](image)

Source: (World Health Organization, 2015, p. 31)

The research needed to characterise trajectories at the end of life in New Zealand would be feasible using linked NHI data through the IDI infrastructure, as described at the end of section 7.4. Once the trajectories are characterised, it would be feasible, in my opinion, to investigate the utilisation of healthcare and perform costings in the public health system. This should be complemented by work on out-of-pocket expenditure and the burden placed on carers.

Research on the characteristic trajectories at the end of life will enable more detail to be added to future models of the need for palliative care in New Zealand.
References


Moens, K., Houttekier, D., Van den Block, L., Harding, R., Morin, L., Marchetti, S. , ... Cohen, J. (2015). Place of death of people living with Parkinson's disease: a population-level study in


Appendix 1: Palliative Care Definitions

The definitions below are reproduced from the New Zealand Palliative Care Glossary (Ministry of Health, 2015b).

**Palliative Care:** is care for people of all ages with a life-limiting or life-threatening condition which aims to:
- optimise an individual’s quality of life until death by addressing the person’s physical, psychosocial, spiritual and cultural needs
- support the individual’s family, whānau, and other caregivers where needed, through the illness and after death.

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 located.

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. This includes but is not limited to; Māori, children and young people, immigrants, those with intellectual disability, refugees, prisoners, the homeless and those in isolated communities.

**Palliative Care System:** comprises specialist palliative care services, primary palliative care providers and the other factors that enable them to deliver palliative care, such as communication and coordination between providers. It is not simply the existence of primary palliative care providers and palliative care services that comprises the palliative care system; it is the links between that tie together ‘a system’. An interdisciplinary team approach to palliative care is one example of how such links can be developed and maintained.

**Specialist Palliative Care:** is palliative care provided by those who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals.

Specialist palliative care may be provided by hospice or hospital-based palliative care services where people have access to at least medical and nursing palliative care specialists.

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36 This is the New Zealand definition of palliative care, based on the World Health Organization definition. The Glossary also has a definition for paediatric palliative care.
Specialist palliative care is delivered in two key ways:

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

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

**Primary Palliative Care**: is provided by all individuals and organisations that deliver palliative care as a component of their service, and who are not part of a specialist palliative care team.

Primary palliative care is provided for those affected by a life-limiting or life-threatening condition as an integral part of standard clinical practice by any healthcare professional.

In the context of end of life care, a primary palliative care provider is the principal medical, nursing or allied health professional who undertakes an ongoing role in the care of people with a life-limiting or life-threatening condition. A primary palliative care provider may have a broad health focus or be specialised in a particular field of medicine. It is provided in the community by general practice teams, Māori health providers, allied health teams, district nurses, and residential care staff etc. It is provided in hospitals by general ward staff, as well as disease specific teams – for instance oncology, respiratory, renal and cardiac teams.

Primary palliative care providers assess and refer people to specialist palliative care services when the needs of the person exceed the capability of the service.

**Palliative Care Approach**: an approach to care which embraces the definition of palliative care. It incorporates a positive and open attitude toward death and dying by all service providers working with the person and their family, and respects the wishes of the person in relation to their treatment and care.

Quality care at the end of life is realised when strong networks exist between specialist palliative care providers, primary palliative care providers, support care providers and the community – working together to meet the needs of the person and family/whānau.
## Appendix 2: ICD-10-AM Codes in Definition of Need for Palliative Care

<table>
<thead>
<tr>
<th>Cause of Death – included in all settings</th>
<th>Place of Death</th>
<th>Included when in Public Hospital</th>
<th>Included when in Residential Care</th>
<th>Included when in Hospice Inpatient Unit</th>
</tr>
</thead>
<tbody>
<tr>
<td>ICD-10-AM Chapter</td>
<td>ICD-10-AM Codes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A00-B99 I Certain infectious and parasitic diseases</td>
<td>A15-A19, B20-B24, B25, B44, B90–B94</td>
<td>All codes</td>
<td>All codes</td>
<td></td>
</tr>
<tr>
<td>C00-D48 II Neoplasms</td>
<td>C00-D48</td>
<td>All codes</td>
<td>All codes</td>
<td></td>
</tr>
<tr>
<td>D50-D89 III Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism</td>
<td>D55–D59, D60-D61, D64, D66-D69, D70–D77, D81-D89</td>
<td>All codes</td>
<td>All codes</td>
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</tr>
<tr>
<td>E00-E90 IV Endocrine, nutritional and metabolic diseases</td>
<td>E22-E24, E34, E70-E85, E88</td>
<td>All codes</td>
<td>All codes</td>
<td></td>
</tr>
<tr>
<td>F00-F99 V Mental and behavioural disorders</td>
<td>F01-F04, F72-F79</td>
<td>All codes</td>
<td>All codes</td>
<td></td>
</tr>
<tr>
<td>G00-G99 VI Diseases of the nervous system</td>
<td>G00–G09, G10-G14, G20-26, G30-G32, G35-G37, G41, G60-G64, G70-G73, G80-G83, G90-G99</td>
<td>50% of G40</td>
<td>All codes</td>
<td>All codes</td>
</tr>
<tr>
<td>H00-H59 VII Diseases of the eye and adnexa</td>
<td>none</td>
<td>All codes</td>
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</tr>
<tr>
<td>H60-H95 VIII Diseases of the ear and mastoid process</td>
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<td>I00-I99 IX Diseases of the circulatory system</td>
<td>I05-I09, I11-I15, I25, I27-I28, I31, I34-I37, I42, I50-I51, I69, I85, I89</td>
<td>50% of I20-I24, I26 100% of I60-I67 100% of I71-I78</td>
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<td>J00-J99 X Diseases of the respiratory system</td>
<td>J41-J44, J47, J60-J70, J82, J84, J85-J86, J96</td>
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<td>Cause of Death – included in all settings</td>
<td>Place of Death</td>
<td>Included when in Public Hospital</td>
<td>Included when in Residential Care</td>
<td>Included when in Hospice Inpatient Unit</td>
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<td>K00-K93 XI Diseases of the digestive system</td>
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<td>M00-M99 XIII Diseases of the musculoskeletal system and connective tissue</td>
<td>M00, M05, M06, M08, M30-M36, M40-M43, M45-M49, M50-M54, M60-M63, M65-M68, M70-M79, M80-M85, M86-M90, M91-M94, M95-M99</td>
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<td>N01-N08, N11-N16, N18-N19, N25-N29, N31-N32</td>
<td>100% of N00, N10, N17</td>
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<td>P00-P96 XVI Certain conditions originating in the perinatal period</td>
<td>P07, P10-P11, P20-P29, P35-P37, P39, P52-P54, P77, P91</td>
<td>All codes</td>
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<td>Q00-Q99 XVII Congenital malformations, deformations and chromosomal abnormalities</td>
<td>Q00-Q07, Q20-Q28, Q30-Q34, Q38-Q45, Q60-Q62, Q64, Q77-Q79, Q80-Q81, Q85-Q89, Q90-Q93</td>
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<td>R00-R99 XVIII Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified</td>
<td>R02, R54</td>
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<td>V00-Y98 XX External causes of morbidity and mortality</td>
<td>Y85-Y89</td>
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Appendix 3: Impact of Longevity on Place of Death

Figure 3A: Projected Place of Death, 2016-2068, without adjustment for longevity

Figure 3B: Projected Place of Death, 2016-2068, with historic pattern adjusted for longevity in 2038, applied to full period
Commentary:

If the historic patterns persist, then deaths in residential care are projected to increase from around 10,000 a year to nearly 30,000 a year by 2068. This is shown in Figure 3A.

Figure 3B uses the pattern that might apply in 2038, based on assumed longevity in 2038. That 2038 pattern has been applied to the whole period to test the sensitivity. It is more likely that pattern would evolve only over the middle of the period from 2016 to 2038.

Figure 3C uses the pattern that might apply in 2068, based on assumed longevity in 2068. That 2068 pattern has been applied to the whole period to test the sensitivity. It is more likely that pattern would evolve from that in 3A, to that in 3B, and finally to that in 3C over the later part of the period.

It is feasible to model other scenarios, but the shape of the place of death has an increasing funnel for deaths in residential care at older ages and this is the main driver of the results.

Technical note: This “stretching” of the historic patterns has been done as a best estimate with the data available. The historic patterns are available to age 100+ but the projections of the population are only to age 95+. Ideally, projections are needed to much higher age bands in order to properly test the “stretched” patterns. The derivation of the “stretched” patterns is available in spreadsheet from the author or the Ministry of Health.