

Waikato Palliative Care Strategic Plan 2016-2021

An integrated population based approach for improving the quality of living and dying in our community



Mihi

Ngā Peehitanga Tāngata o te ao Hurihuri, ngā whakaritenga mo te tika me te ora morimori atawhai.

The trials people face in a challenging world, can be overcome by caring for and loving one another.

– Reverend Buddy Te Whare for the support and citation on the cover page.

Foreword from the Waikato DHB chief executive

Welcome to the second Palliative Care Strategy Plan for the Waikato District Health Board. At some stage in our lives, each of us will know a person who is suffering from cancer or another life-limiting chronic illness. We know that they and their whānau /family may need a range of support in their last days of life. These diseases create a burden for patients, their whānau/ families and our community, and also place strain on our health care system. During what is always a difficult time, we need to feel confident that our local health care system is working to take good care of us.

As our population ages, the demand for palliative care services will only continue to increase. While the majority of people would choose to die in their own home, this ageing means that it is likely more people will live their last days in residential care and we need to support this workforce to manage these patients effectively.

Waikato DHB has a large Māori population, which is disproportionately represented in the incidence of cancer and other chronic illnesses. They often also live in rural locations and in lower socio-economic areas and which increases the difficulties they have in accessing care. This plan reflects a strong commitment to ensure that equity issues with respect to palliative care are addressed.

Waikato DHB is committed to improving the performance of the health care system with respect to palliative care by driving clinical leadership, quality, accountability, innovation and value.

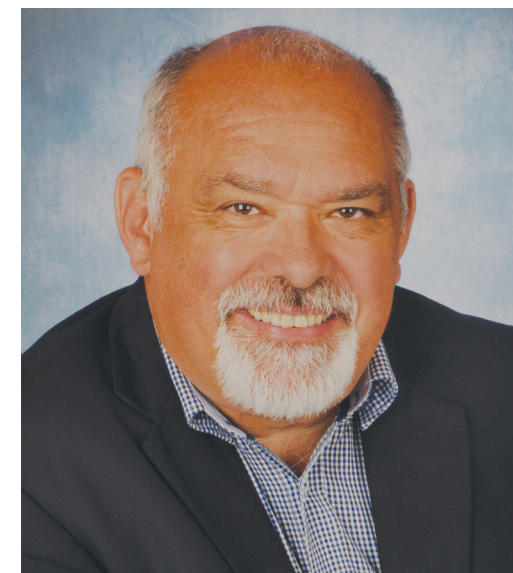
The Waikato DHB Palliative Care Strategic Plan 2016-2021 provides a clear vision and framework for the development of future services. It will also guide the way for health professionals and organisations to work together to deliver high quality palliative care services over the next five years. The key priorities are:

- Improving access to palliative care services for Māori and those in rural areas;
- Educating and supporting the extensive primary based workforce who will deliver the majority of care into the future;
- Increasing the availability of nursing and allied health professionals to support patients and their families/whānau;
- Ensuring the specialist workforce is adequately resourced and trained to support both the increasing patient load and the non-specialist workforce delivering palliative care;
- Developing the infrastructure (IT, equipment) and processes to provide seamless care;
- Strengthening the continuous quality improvement philosophy and related research capabilities.

Waikato has dedicated health professionals and a strong foundation on which to further develop our services. The involvement of voluntary groups working with a committed workforce will deliver positive outcomes and help ease the stress for both patients and their whānau/ families. Engagement with consumers and other stakeholders and their involvement in co-design of innovative service delivery options is critical.

Implementation of the plan will be phased to reflect national, regional and local priorities and will require the collaborative action of all stakeholders. We must respond to the challenge created by our changing demographics and ensure we are able to deliver the palliative care services our patients require.

Dr. Nigel Murray, Chief Executive, Waikato DHB



Dr. Nigel Murray

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1 Executive summary

Palliative care has extended its reach beyond its traditional involvement with those near the end of life. It now walks hand in hand with curative treatments (following a terminal diagnosis) and interacts with patients over an ever increasing length of time.

The demands on clinical staff delivering palliative care will continue to grow as the **population ages and the location and causes of death change**. The percentage of **deaths at home or in aged residential facilities** will increase. Thus the majority of palliative care will be delivered by staff operating in the primary and community sectors. They will need to be well trained and well supported by specialists who are accessible at any time, using a range of modalities. The balance of tasks undertaken by specialists will shift to more training, mentoring and advice. However, it is likely that the group requiring 'hands on' palliative care from specialists will also increase, as patients with complex needs live longer and require highly specialised intervention. Medical advances have also increased life expectancy for children with complex high health needs, leading to an increased demand in **skilled care and resources for these children** who are predominantly cared for in the community.

Our strategy for the next five years is based on an enhanced model of care, where **primary, community and generalist health professionals deliver high quality palliative care**, supported by specialists who provide both **clinical support and education and mentoring for the wider workforce**. Wherever patients interact with services across the continuum of care – be it episodic or end of life care, they will have providers who are highly skilled in palliative care and have fast and simple access to advice and support.

Palliative care will **work in parallel with curative treatments** throughout a patient's illness and will promote Advanced Care Planning to guide future decision making around patient care. Our model will respond to the unique challenges of our district, in terms of rurality, ethnicity and demographic changes.

The model aims to achieve three key objectives:

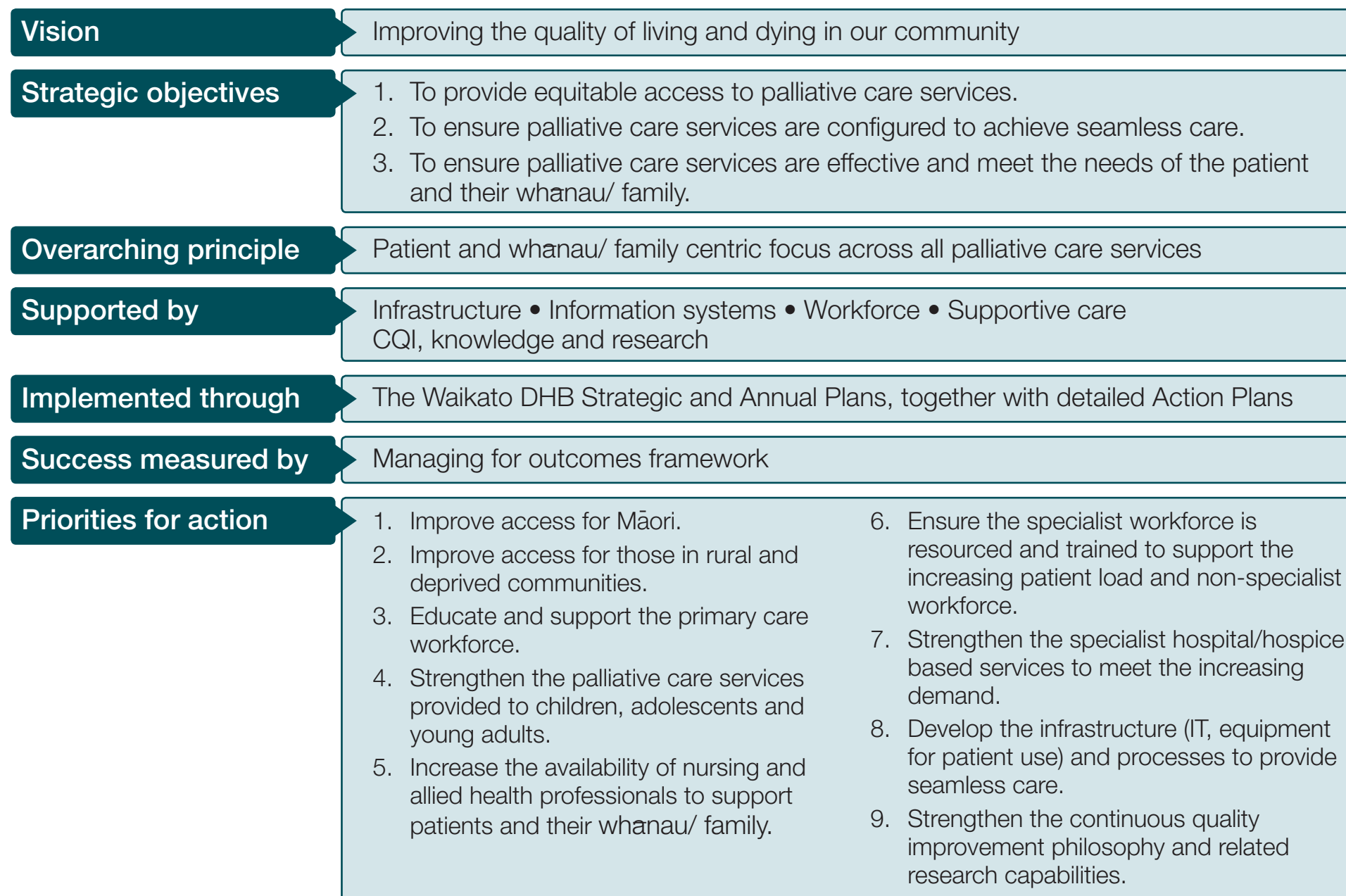
- **To provide equitable access to palliative care services.**
- **To ensure palliative care services are configured to achieve seamless care.**
- **To ensure palliative care services are effective and meet the needs of the patient and their whānau/ family.**

Listening to our patients and their carers helps us identify specific areas for improvement and we will continue to engage with them to ensure our services meet their changing needs.

The organisation is committed to meeting the needs of Māori and their whānau through targeted initiatives. Our planning will also consider the specific services that may be required for the following groups: those living in rural areas, children and adolescents and young adults (especially as they transition to adult services); elderly patients with dementia; prisoners; people with disabilities or mental health issues; and, younger patients (under 65 years) requiring residential care.

We will continue to build on the progress that has been made over a number of years by the dedicated and committed staff we have working in palliative care within the DHB area.

Our strategic framework is depicted diagrammatically below



2 Introduction

This strategy provides an integrated and population based approach with an emphasis on improving care for Māori, those living in rural communities and a focus on equity for all. The document provides guidance and direction for Waikato DHB in its objective of delivering high quality, equitable and effective palliative care services. Building on work previously undertaken, it identifies the key challenges the DHB faces and the priorities for action over the next five years. Other planning documents (including the operational plans) will provide the detail of the activities required to deliver on the organisation's vision of *"Improving the quality of living and dying in our community"*.

Definition of palliative care

Palliative care is defined as "care for people of all ages with a life-limiting or life-threatening illness 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."

The World Health Organisation (2010) expands this definition:

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

The period during which palliative care is delivered may include, but is not restricted to the last days of life. The 'last days of life' defines "the period of time in which a person is dying. It is the period in which death is imminent, and may be measured in hours or days."

Palliative care is commonly provided by "primary palliative care providers" – usually general practice teams. They work together with secondary care services, specialist palliative care services and other providers of care, such as aged-care facilities, and home-based support services.

Supporting an integrated palliative care model

Traditionally, referrals to palliative care services occur when all options for active treatment have been exhausted. Referrals are therefore often made late in the course of a terminal illness, and when patients are in the active phase of dying. In many instances the palliative needs of these patients may not be adequately addressed, and late referrals may also reduce the potential benefits to be gained from palliative intervention.

Causes of death have changed over recent years and other illnesses such as circulatory disease now outnumber cancer deaths. This is also the case for children, where chronic conditions such as cystic fibrosis are the leading contributors.

Carers and families of people with chronic terminal illness also have capacity to benefit from timely access to palliative care. Studies show that caregivers often have impaired physical and psychological health. It has also been shown that family are more likely to experience an extended grief period when the person they care for has unresolved spiritual or psychological symptoms at the end of their lives.

The traditional model of palliative care is shown in the first diagram in Figure 1. The second diagram illustrates how an integrated disease modifying (including curative) and palliative approach differs. Current research suggests that a combined approach is the most beneficial approach for people with a chronic terminal illness, including cancer, as many patients may still receive benefits from life prolonging or disease modifying treatments while having their palliative care needs addressed simultaneously. This approach is already in place for children and young adults suffering from chronic conditions.

In reality, an increasing number of New Zealanders dying from a disease process will be offered some form of palliative care, be it a specialist consult, symptom control or psychosocial support. And it will be offered at a difficult time, both for the patient or their whānau. Thus it is important that this care is explained clearly and is well co-ordinated, so to relieve stress and not compound it.

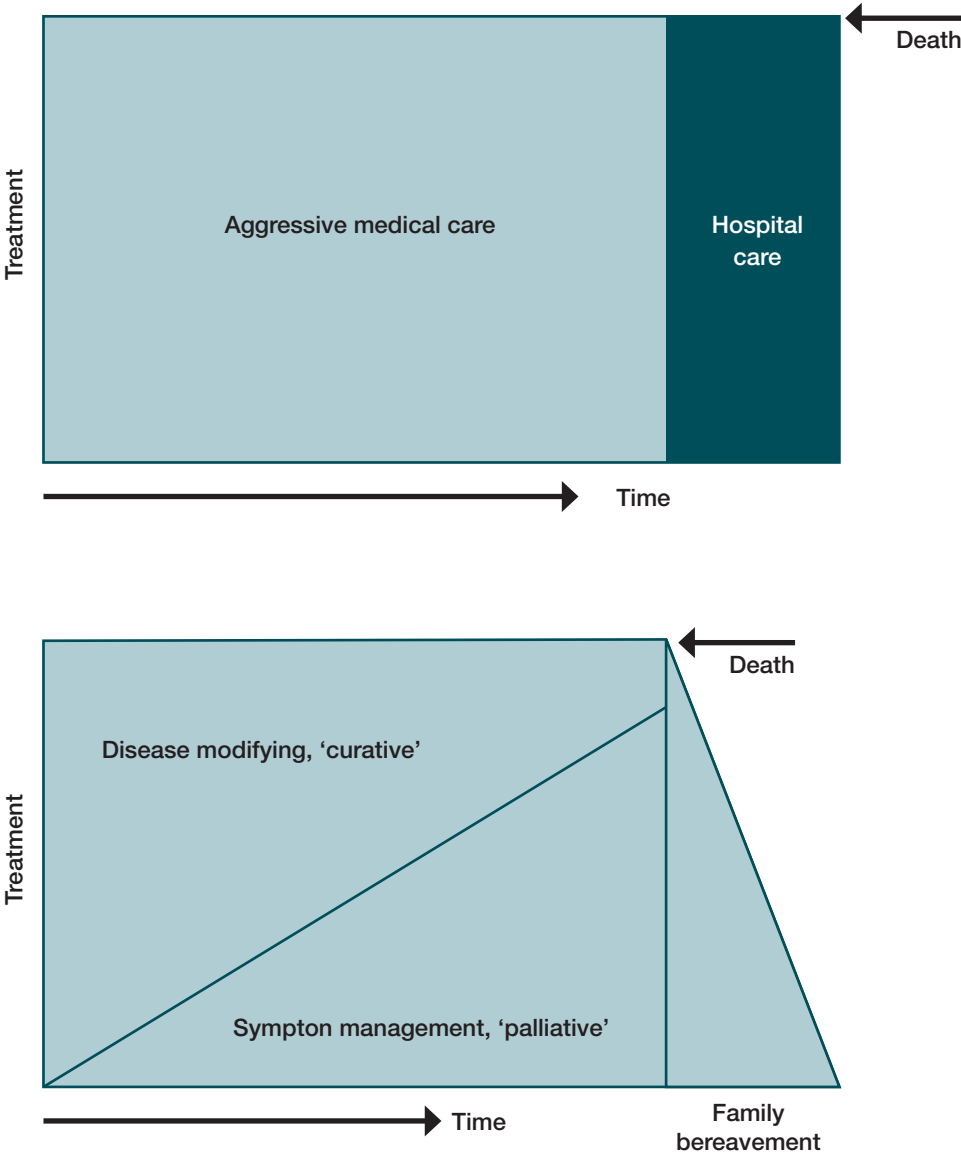


Figure 1: Traditional and Integrated Palliative Care Models
From Lynn J., Adamson D.M., White Paper; Living Well at the End of Life – Adapting Health Care to Serious Chronic Illness in Old Age. Rand, 2003.

Patients' interaction with palliative care services do not follow a traditional 'pathway', but are dependent on the illness that they will die from.

Palliative care has historically been linked to cancer services and this area still constitutes a large contributor for adults (cancer is a major cause of death in New Zealand at 30%). In New Zealand, the majority of hospice patients are diagnosed with cancer. Figure 2 illustrates that generally cancer patients progress rapidly from diagnosis and treatment to dying (in line with the first diagram in Figure 1).

However, it is now recognised that, as New Zealanders live longer with chronic diseases, patients dying from other conditions (e.g. renal failure, respiratory issues, motor neurone disease) will all benefit from high quality palliative care services. In addition, the length of time palliative care services may maintain input into a patient's journey will continue to increase. This applies to both adults and children, as children continue to live longer with congenital conditions such as cystic fibrosis.

Interaction with palliative care services may begin during a 'serious episode' (see diagram 2 in Figure 2) and may continue throughout the remainder of the illness. Difficulty in making accurate prognoses of chronic terminal illnesses can result in inability and/or reluctance of clinicians to predict time frames associated with disease progression.

Diagram 3 in Figure 2 illustrates the 'prolonged dwindling', where timeframes may differ significantly between patients. This can result in people not receiving the information about their disease necessary to make advance decisions about prioritising their resources, including time, psychological energy and financial resources. It also causes issues for those funding palliative care services, as for many patients it is very difficult to define when a patient becomes 'palliative'.

Finally, palliative symptoms of people with chronic terminal illness are often unrecognised and/or under treated. For example, there is evidence to show the recognition of pain for people with dementia is poor.

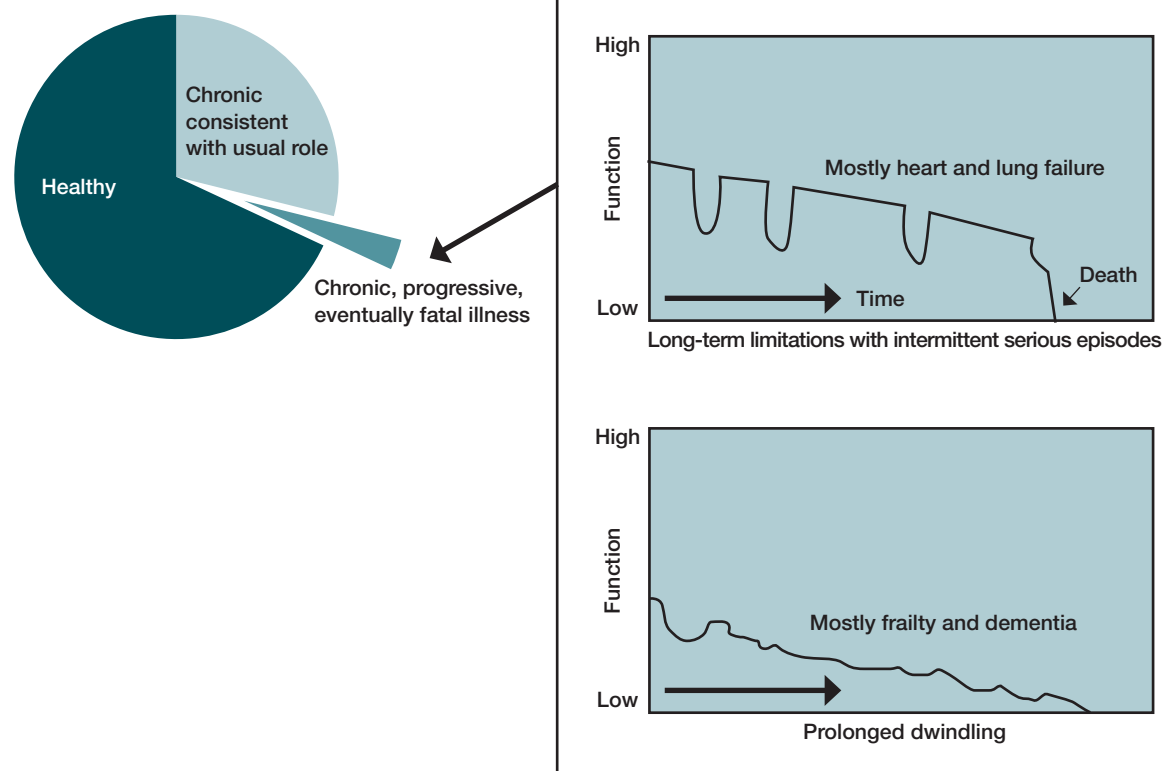


Figure 2: Trajectories of Chronic Illness in the Elderly.

From Lynn J., Adamson D.M., White Paper; Living Well at the End of Life – Adapting Health Care to Serious Chronic Illness in Old Age. Rand, 2003

3 Waikato context

It is acknowledged that Waikato DHB has made significant local gains in the delivery of palliative care services and has played a positive role in the development of services across the Midland region. Some of these 'successes' are detailed in our record so far. (Information on the national and regional context are included in Appendix A and B respectively).

Our record so far

Together we will build on the accomplishments of our earlier plan. Waikato has actively contributed to regional palliative care initiatives as well as making significant local investment into palliative care services including the:

- Establishment of the Waikato Palliative Care Operations Group;
- Development of a Waikato palliative care services and provider directory;
- Extension of Hospice Waikato services (in 2006) to include Coromandel, Whitianga, Whangamata and Tairua;
- Review of the collaborative nursing service and Disability Support Services (DSL) related to palliative care in 2006;
- Establishment of a CNS (link nurse) to work with aged residential care organisation;
- Establishment of a lead CNS for implementing a last days of life programme across all settings (previously known as LCP);
- Appointment of (jointly between Hospice and hospital) a third palliative care physician in 2007, and a palliative care clinical director alongside a 24/7 telephone consultancy service;
- Review of Waikato palliative care rural hospitals and community based services 2008;
- Establishment of a specialist medical palliative care outreach service for Lakes DHB at both Taupo and Rotorua;
- Support of generalist education including working with Maori health providers;
- Appointment of Waikato's first palliative care nurse practitioner;
- The purchase and installation of the PalCare information system by all Midland Hospices (Tairāwhiti due to implement 1/7/16);
- Placement of Midland Last Days of Life care plans (x4) on web-based repository; development of the Midland Last Days of Life Care Plan (LDL) goal definitions/data dictionary;
- Establishment of Palliative Care Grand Round Waikato tele-linked with Waikato rural community, Lakes and Tairāwhiti. Bay of Plenty will come online 2016;
- Delivery of study days for nurses twice a year, which includes attendees from across Midland and elsewhere. This complements the Hospice Waikato education packages;
- Community funded Hospice Waikato new campus with an administration building, Rainbow Place for children and its first dedicated 10 bed inpatient unit (previously outsourced 4 beds) and the recently built Wellness Centre;
- Formal consultation process (October 2012), resulting in a proposal to change the model of service for adult specialist palliative care in Waikato. The proposed model of service sought to:
 - place emphasis on the development of specialist palliative care services and support in community settings, including the inpatient unit at Hospice Waikato, residential care facilities and care for people in their own homes;
 - re-focus specialist services within Waikato Hospital toward providing support for patients and family/whānau with the most complex needs, and supporting other specialities in their care of patients and family/whānau with palliative needs or who are at end of life;
 - use the skills of the palliative care specialists (medical, nursing and support services) across the range of settings where palliative care is delivered.
- Implementation of the following changes over the period December 2012 through to July 2013:
 - Improved specialist support for Hospice Waikato inpatient unit, both in hours and out of hours.
 - Strengthened Hospice Waikato as the base for community specialist palliative care services.
 - Development of a hospital consult-liaison service in Waikato Hospital, with associated exit of a fully direct inpatient care model of hospital specialist palliative care.
- Development of the Midland Medical Advanced Palliative Care Trainee Model of Service Development Plan 2015-2018 with appointment of a Medical Training Lead, confirmation of provisional accreditation for Hospice Waikato, and establishment of an additional advanced trainee post with new HWNZ funding;
- Development of standardised Referral Criteria for Adult Palliative Care Services in Midland.

4 Current service provision

This section summarises the Waikato palliative care providers and services and demonstrates the reliance on integration and collaboration with multiple organisations and services.

Primary palliative care

The majority of palliative care support for patients and whānau/ family is provided by general practice with partnership support from specialist palliative care, district nursing and/or NGOs as required.

Primary care has a programme to enable the general practice team to provide home support visit to people who are in end stage of a disease and are unable to attend the GP surgery.

General practice can access GP beds in aged residential care facilities for short term respite care or long term residential placement via Disability Support Link (DSL). DSL palliative care support services include funding for those patients in the last six weeks of life:

- carer support night/day relief – two days a week or the funding equivalent of \$150
- respite/last days of life rest home (respite care) for a maximum of six weeks where the patient is deemed to be in the terminal phase.

Child and young person's palliative care services

The Paediatric Palliative Care Clinical Network leads and provides clinical oversight of the implementation of the Guidance for Integrated Paediatric Palliative Care Services in New Zealand. It provides advice on service and treatment issues to the Paediatric Society of New Zealand and Ministry of Health through the Palliative Care Advisory Group.

Starship is the national lead for specialist palliative care and has strong links to support district paediatric palliative care services.

Waikato paediatric and neonate services have an integrated approach with multiple providers such as general practice, paediatric home care nursing teams, district nursing, adolescent and young adult key workers, child development centre, and other NGOs such as the Child Cancer Foundation, Canteen.

Hospice Waikato's Rainbow Place offers care and support to children and young people aged from 0 to 18 years, and their families, when a child or young person has a life-limiting or life-threatening condition and is either not expected to live far into adulthood, or their condition may result in premature death. Care and support will be provided for as long as the child or young person needs it; this may be for many years in some cases. Rainbow Place provides children and young people with holistic care addressing their physical, emotional, social, cultural and spiritual needs, and their families/whānau with support throughout the child or young person's life, death and bereavement. Rainbow Place staff include paediatric nurses, counsellors, social worker and spiritual care coordinator, who provide hospital, in-house and community based care and support, including respite and symptom management admissions to the Hospice Waikato Inpatient Unit. Rainbow Place also provides grief and loss support to children and young people affected by the death of someone close to them. Rainbow Place is part of the comprehensive Hospice Waikato palliative care service and so has access to a broad range of hospice support services.

True Colours Children's Health Trust provides access to counselling, nursing advice and education. In addition, they provide opportunities for creative therapy through music, art and play. There are also workshops, presentations and support groups facilitated by True Colours staff.

Specialist adult palliative care model of service

Waikato has a one service, two provider specialist palliative of care model of service. A major change in the delivery of specialist palliative services in the Waikato DHB area occurred in 2013. The aim of the service change was to place emphasis on the development of specialist palliative care services and support in community settings, including the inpatient unit at Hospice Waikato, residential care facilities and care for people in their own homes; a re-focus specialist services within Waikato Hospital toward providing support for patients and family/whānau with the most complex needs, and supporting other specialties in their care of patients and whānau/ family with palliative needs or who are at end of life; and the use the skills of the palliative care specialists (medical, nursing and support services) across the range of settings where palliative care is delivered.

Hospice Waikato specialist palliative care services

- Single point of entry for referrals, triage process and multidisciplinary review for community referrals
- Hamilton based outpatients clinics from the Wellness Centre
- Coordination and support for home visits and rural hospital outpatient clinics
- Hospice@Home for all palliative care home based support and care for Hamilton City, Ngāruawāhia and Cambridge
- Rural outreach service to outer Waikato areas working in partnership with district nurses
- 11 bed inpatient unit for symptom management, last days of life care and arranged respite care, including a dedicated Rainbow Place inpatient room
- District and regional clinical nurse leadership for the last days of life programme
- 24/7 access to specialist palliative care nursing telephone advice through the Hospice inpatient unit
- Specialist palliative care support for residential care facilities, including a CNS Resthome Liaison
- Primary and the community palliative care education - plan, coordinate and deliver in partnership with the hospital palliative care team. This includes facilitating Hospice NZ education programmes for health professionals
- Family services – counsellors, social workers and a spiritual care coordinator provides patients, whānau/ families with an opportunity to identify and deal with all aspects relating to the emotional, mental and spiritual impact of terminal illness. Run therapeutic programmes
- Other services: support groups for whānau /family, family support volunteers, life review for patients, equipment resources and library books for loan.

Waikato Hospital specialist palliative care services

- Waikato hospital consult liaison service
- 24/7 specialist medical telephone advice
- Hospital nurse CNS for last days of life for secondary hospital services
- Plan, coordinate and deliver palliative care education for hospital based education and growth of palliative care skill in generalist workforce in the hospitals (also in partnership with Hospice team)
- Plan, coordinate and deliver the Midland advanced medical training programme
- Support medical training and research activities with the Clinical School
- Specialist outreach service to Lakes DHB including specialist palliative care medical visiting outreach services.

What our patients and whānau/family have told us is important in their care

Patients and their whānau/ family are at the centre of this plan and patients' experiences have helped inform it.

Thank you to the palliative care team for their beautiful manner and attention to our father's needs. We felt helpless.

To be able to die at home, pain free, surrounded by family.

Our experience with a fragmented and uncaring palliative care service was the most devastating and demoralising aspect of our life.

No help, no advice, no contact. My father suffered terribly as a result of ... discharge package never happening!

(Needed) some more insight about those last few days and what to expect...

Symptoms and pain treated promptly and everything explained so we understood.

Apologising for the lack of practical palliative care. Rural service did little to make up for the shock of being left alone to manage.

Thanks to the member of the palliative care team who was frank and sensitive to issues facing our family. Mum appreciated his time and concern.

The key aspects that whānau/ family want in regard to care of people in their last days of life are:

1. A responsive workforce available any time of the day or night, any day of the week that treats the person who is dying and their family/whānau with compassion and empathy within appropriate cultural and spiritual aspects
2. Clear and simple communication with the person and family/whānau occurs at all levels, including when the person may be dying; the proposed approach to treatment and care of the person; including use of a care plan; and what opportunities may exist for the family/whānau to contribute to the care of the person
3. All services and facilities that deal with people who are dying should have fully trained staff in all respects of care who are accessible and available for advice and the delivery of care and treatment of the person
4. In hospital settings, people who are dying should be managed by the palliative care team
5. Most importantly: "Listen to the person, and if the person is unable to communicate then listen to the family/whānau of the person."

(Palliative Care Council of New Zealand, 2015. Draft results of a survey of family/whānau caring for people in their last days of life).

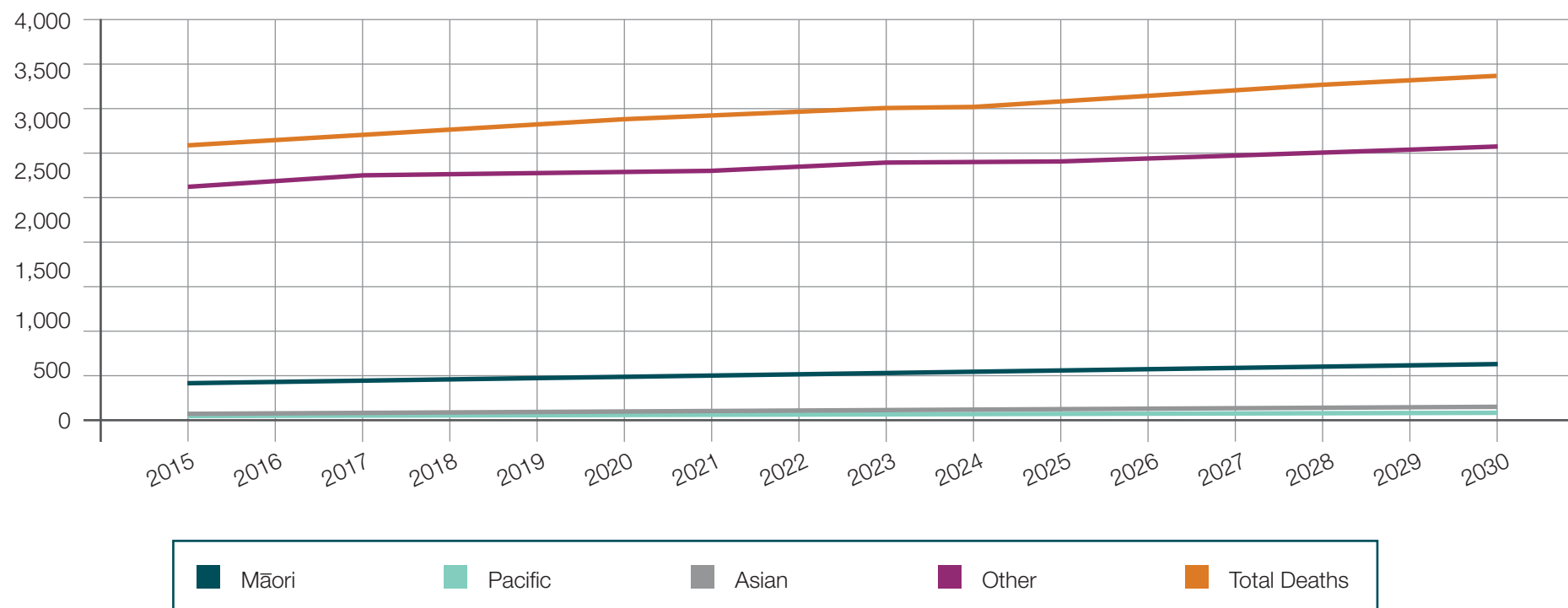
5 Challenges for Waikato DHB

A stocktake of services using the national resource and capability framework and a number of consultation surveys and/or workshops were held to identify what stakeholders thought was working well as well as identifying opportunities for the future. This section aims to capture the key challenges and opportunities for improving Waikato palliative care services.

Ageing population and changes in causes of death

In line with the rest of New Zealand, the Waikato DHB population is ageing and this brings with it the increased need for palliative care. Deaths are estimated to increase by 27% (from 2,620 in 2015 to 3,340 by 2030). As well as an increase in the number of deaths, the age at which death occurs is also set to change, with a significant increase in the number of deaths in those 75 years and over.

Table 1: Waikato DHB projected total deaths and deaths by ethnic group 2015 – 2030



Research for the WHO in 2004 suggested that approximately 60% of worldwide deaths could have benefitted from palliative care¹. This is in line with NZ indications that estimated 56.7% of deaths would benefit, with approximately 75% of these requiring generalist palliative care and 25% requiring specialist palliative care services.

¹ Davies and Higginson 2004 Better Palliative Care for Older People (WHO Europe)

Estimates from the Department of Human Services in Australia project that over the next ten years or more, demand for palliative care will grow at a faster rate than that indicated by the ageing population (and therefore death rate). This is due to the traditional link between palliative care and cancer. Hospice Waikato figures show that 79% of referrals are for a cancer diagnosis. However, the greatest (and increasing) cause of death is circulatory disease at approx. 40% of all deaths compared to cancer at approx. 30%. This under-representation of non-cancer diagnoses will cause a 'blip' in the demand for palliative care services.

Further information on the Waikato DHB demographics and growing need for palliative care is included at Appendix C.

Place of death

Both research and common sense suggest that wherever possible, a person will choose to die in their home. Facilitating this preference is a key challenge for the DHB, especially given the geographic dispersion of the population. As well as equipment and medication, support for the family and the primary medical carer (usually the GP) is vital. However, given the increasing age of death, for many people 'home' will be an Aged Residential Care facility (ARC). Compared to 17 other countries, New Zealand has the highest level of deaths in ARC for people aged over 65 years, at 38%³. Support and education for this workforce will be an increasing demand on specialist palliative care services.

In this context, it should be noted that around 80% of people who die from a life-limiting or life-threatening condition will be cared for by a primary palliative care provider⁴.

Where a patient requires care that goes beyond the home or ARC, appropriately resourced palliative care beds need to be available as close to home or family as possible. The current location of beds available for palliative care patients are detailed in Appendix D.

Who will be the carers?

In many instances the primary carer for a dying person is a whanau/ family member. During what is already a difficult time, they may be expected to absorb complicated information, learn how to use unfamiliar equipment and liaise with a range of healthcare providers. To allow them to focus on their loved one means that health providers must provide clear and concise information together with psychosocial support.

In terms of palliative care health providers, there are three main groups:

- Those that have occasional involvement with people at the end of their lives (e.g. hospital staff during intermittent admissions);
- Those that have regular involvement with people at the end of their lives (e.g. GPs, ARC staff);
- Those that focus their clinical practice solely or substantially on caring for people with life-threatening illnesses (e.g. palliative care specialists).

As noted above, the key healthcare providers are the primary care providers. Specialist palliative care services should not be required to provide care for everyone, but in fact their most valuable role can be in supporting other healthcare teams to provide the best possible palliative and end of life care.

² National Health Needs Assessment for Palliative Care Phase 1 Report: Assessment of Palliative Care Need – Palliative Care Council June 2011

³ National Health Needs Assessment for Palliative Care Phase 2 Report: Palliative Care Capacity and Capability – Palliative Care Council June 2013.

⁴ *ibid*

6 Equity

We are committed to improving palliative care services for our population. In the Waikato district, this means that people, irrespective of their ethnicity, age, gender, locality or socio-economic status, must have every opportunity to access services. We are particularly aware of the high proportion of Māori in our district and the need to provide appropriate services to Māori patients and their whānau.

Ethnicity

As noted above, Waikato has a larger proportion of Māori than in the overall NZ population and a range of factors impact on their ability to access palliative care services – one of these being health literacy and the availability of culturally appropriate services offered⁵. Regional research into prostate cancer also confirms these findings. The table below indicates that there are higher populations of Māori living in more rural areas of the DHB district and this potentially increases their lack of access.

District	Māori	Percentage	Non Māori	Percentage	Grand Total
Thames-Coromandel District	4145	16%	21949	84%	26094
Hauraki District	3426	20%	13574	80%	17000
Waikato District	10967	23%	37278	77%	48245
Matamata-Piako District	4471	14%	27010	86%	31481
Hamilton City	28424	20%	112947	80%	141371
Waipa District	6113	13%	40302	87%	46415
Otorohanga District	2325	26%	6760	74%	9085
South Waikato District	6675	31%	15183	69%	21858
Waitomo District	3493	40%	5291	60%	8784
Ruapehu District	3073	40%	4561	60%	7634
Grand Total	73112		284855		357967

Table 2: Māori versus non-Māori by district. Census 2013

To improve services for Māori, this Strategic Plan is guided by the overarching framework and aspirations in the Māori Health Strategy He Korowai Oranga (Ministry of Health 2014) and assessment against the Equity of Health Care for Māori: A framework that guides health practitioners, health organisations and the health system to achieve equitable health care for Māori. An equity framework has been developed that can be applied to all existing and new approaches that aim to improve palliative care services for Māori, with the intent to reduce the disparity of care for Māori and vulnerable population groups (Appendix E). In essence this means we are committed to:

- Leadership – championing the provision of high-quality healthcare that delivers equity of access for Māori.
- Knowledge – developing knowledge about the ways to effectively deliver and monitor high-quality care for Māori.
- Commitment – being committed to providing high-quality palliative care that meets the health care needs and aspirations for Māori.

⁵ Ministry of Health. 2014. Palliative Care and Māori from a Health Literacy Perspective. Wellington: Ministry of Health.

We are also committed to continue to actively engage with the Hei Pa Harakeke for ongoing Māori leadership guidance and advice and engage with our consumers via the Midland Cancer Consumer and Carer Work Group. There is a need to improve health literacy which is the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.

The picture on the right shows the ethnic mix of the child palliative care population in the Waikato. In 2015 the Waikato birth cohort was 6,234 with 40% of this cohort identified as Māori. Currently, there are 82,000 children in Waikato in the 0-14 age group, and approximately 35% of this population identify as Māori. At 29,090 Waikato DHB has the largest population of Māori children of any DHB.

Deprivation

In terms of deprivation, the table below shows the different districts by deprivation decile. The districts with high deprivation (over 50% in deciles 8-10) show a high degree of correlation with those with high Māori populations. This heightens the need to concentrate efforts on these rural populations.

Palliative children by ethnicity



■ Māori (35%)	■ Pacific Islander 5%	■ European (50%)
■ Asian (8%)	■ Other/unknown (2%)	

Waikato DHB District	NZ Dep Decile										Total
	1	2	3	4	5	6	7	8	9	10	
Thames-Coromandel District	0%	3%	0%	0%	0%	17%	16%	50%	15%	0%	100%
Hauraki District	0%	0%	0%	0%	0%	23%	26%	0%	2%	50%	100%
Waikato District	19%	10%	0%	12%	6%	18%	3%	6%	9%	17%	100%
Matamata-Piako District	0%	0%	3%	0%	25%	27%	13%	22%	9%	1%	100%
Hamilton City	4%	12%	3%	4%	5%	10%	13%	21%	17%	11%	100%
Waipa District	8%	12%	23%	5%	22%	0%	2%	26%	0%	1%	100%
Otorohanga District	0%	0%	0%	0%	44%	25%	0%	0%	28%	3%	100%
South Waikato District	0%	0%	0%	1%	23%	0%	0%	11%	34%	31%	100%
Waitomo District	0%	0%	0%	0%	0%	16%	20%	16%	0%	48%	100%
Ruapehu District	0%	0%	0%	0%	7%	2%	0%	32%	7%	53%	100%

Table 3: Deprivation by decile by district

Rurality

The third element of equity relates to rurality, which affects people's ability to access due to distance and limited availability of local services. Like the other Midland DHBs, Waikato is more rural than New Zealand as a whole, with almost 50% of the population living outside the main urban areas. The more rural nature of the Waikato population creates particular challenges in getting services to patients and families and the extensive low population density areas may also result in people having fewer informal carers (family, friends) able to care for them in time of illness. However it is noted that for Māori there is little reported difference in health outcomes for those who live in rural areas and those who live in urban areas.

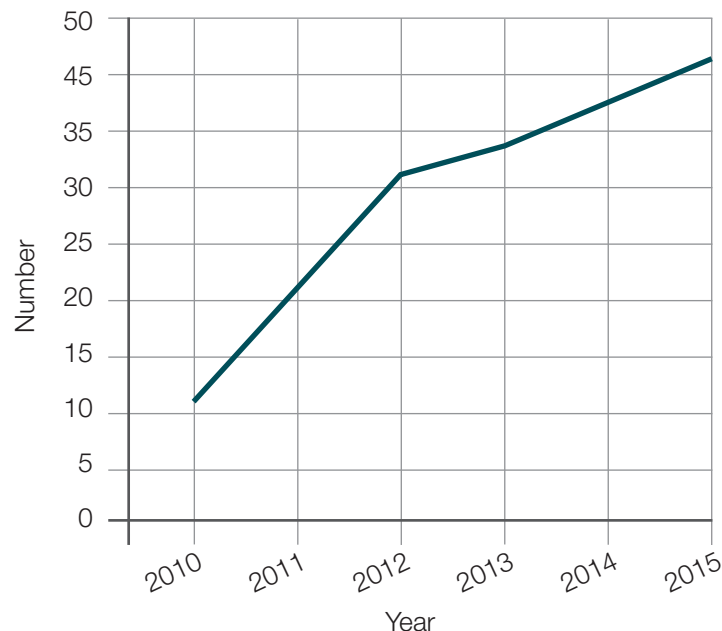
7 Children (including neonates and adolescents and young adults)

Palliative care for children is different from adult palliative care in a number of significant ways (ACT/RCPCH 1997):

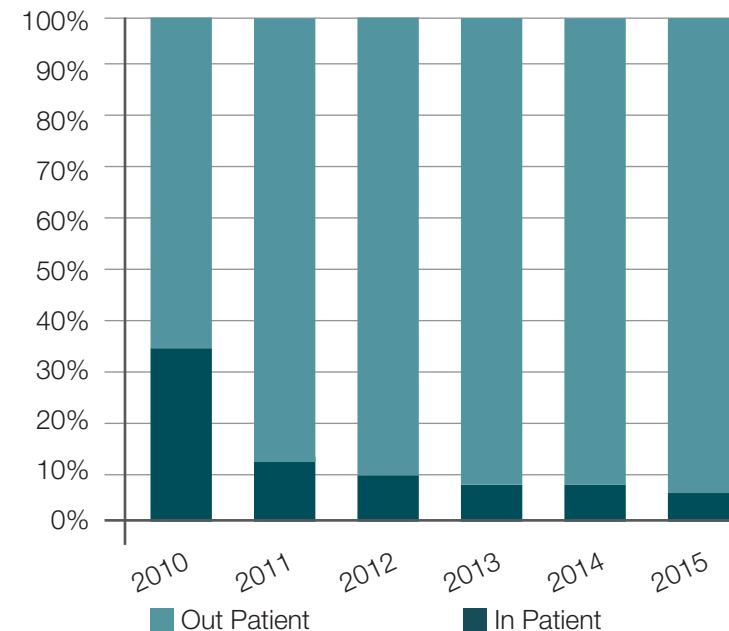
- The number of children who die is small compared with the number of adults.
- Many of the conditions are extremely rare with diagnoses specific to childhood, although the child may survive into early adulthood.
- The timescale of childhood illness is generally different from adults; palliative care may last only a few days, weeks or months, or may be delivered on and off for a number of years.
- Many of the conditions are genetic, and therefore more than one child in the family may be affected.
- Children's palliative care embraces the whole family. Family members, especially parents and siblings, will be vulnerable as they face the changes in life that the child's diagnosis creates, and as they anticipate bereavement.
- Children's palliative care providers need to be aware of the continuing physical, emotional and cognitive development throughout childhood and respond to each child's changing levels of communication and their ability to understand.
- Provision of education and play when a child is seriously ill is essential. This introduces an additional dimension which adds to the complexity of care provision.

The paediatric setting is further characterised by complicating factors such as a high prognostic uncertainty and the diminished decision making capacity in many patients. As shown below, the paediatric palliative care population is increasing, with a growing proportion of care being delivered in an outpatient setting.

Paediatric palliative care population (per 10,000)



Care delivery for paediatric palliative care patients



Further information on this group is included at Appendix C.

There is a lack of a local cohesive model of paediatric palliative care and a lack of co-ordination of service provision. We will therefore need to plan our services to deliver to the changing requirements of this increasing population. This will require strengthening both the hospital and community based services, with appropriately trained staff to deliver to the specific needs of these patients and their whānau.

Adolescents and young adults have not seen the same gains in outcomes as younger children have achieved. Strong linkages to AYA Cancer Network Aotearoa should lead to more coordinated and consistent treatment for this group. Hand in hand with the treatment improvements, we need to develop age appropriate support services. We also need to better transfer their care from child to adult services, by developing a transition pathway.

8 Other groups

During the development of this plan, a number of other groups were identified as needing services tailored to meet their specific circumstances. These were:

- Elderly patients with dementia - symptom control and pain management is a particular area of need for those who can't communicate easily.
- Prisoners - we need to consider how to improve access to services for patients in their unique location;
- Mental Health patients - improving the link with health professionals in this area, so patients are referred as necessary;
- People with disabilities - we need to ensure our services provide for their specific needs;
- Younger patients (under 65 years) requiring residential care - we need to consider alternatives to aged residential care facilities for this group.

9 Specialist palliative care

The specialist palliative care service change in 2013 led to enhanced working relationships. However a 'split' in service provision without adequate systems to ensure continued coordination, a view has developed that the services have become fragmented. The governance structure was never implemented to ensure all recommendations were implemented with a sustainable approach. The opening of inpatient hospice beds in Hamilton has also left some rural areas feeling disenfranchised. As well as access to beds, there is variable availability of other support services, such as pharmacy, patient equipment and psychosocial support. Other issues identified through surveys and forums include:

- timely and consistent access to specialist advice for primary and community providers;
- confusion around funding – for both episodic care (where patient is not yet in their last days of life, but requires symptom control or other interventions) and for the end of life phase;
- information systems that don't link up, so information is not shared between providers;
- the need for a large range of staff (both hospital and community) to be trained in high quality palliative care as a standard part of care delivery;
- some primary providers was left unsure who was providing what services.

In addition, the national lack of progressing implementation of the national specialist palliative care service specifications and associated reporting requirements continue to cause frustration amongst stakeholders.

10 Workforce and training

As noted previously, the palliative care workforce has been defined as vulnerable at a national and regional level. The size of many staff groups (medical staff, nurses, allied health staff, counsellors) will need to increase over time to meet the increasing demand for both adult and paediatric services. In addition, support and training for larger groups (GPs, ARC staff, general hospital clinical staff) is necessary to ensure that specialist palliative care providers only see the patients requiring their unique skills. Waikato DHB also need to allocate dedicated paediatric medical and nursing expertise as the Waikato population is now too large and too distant from Starship Hospital. The perceived assumption that Starship Hospital can provide the required level of clinical expertise for service delivery on a day to day basis is no longer sufficient. In addition we acknowledge the challenges facing the adolescent and young adult workforce. This strategy acknowledges the challenges facing the primary care workforce.

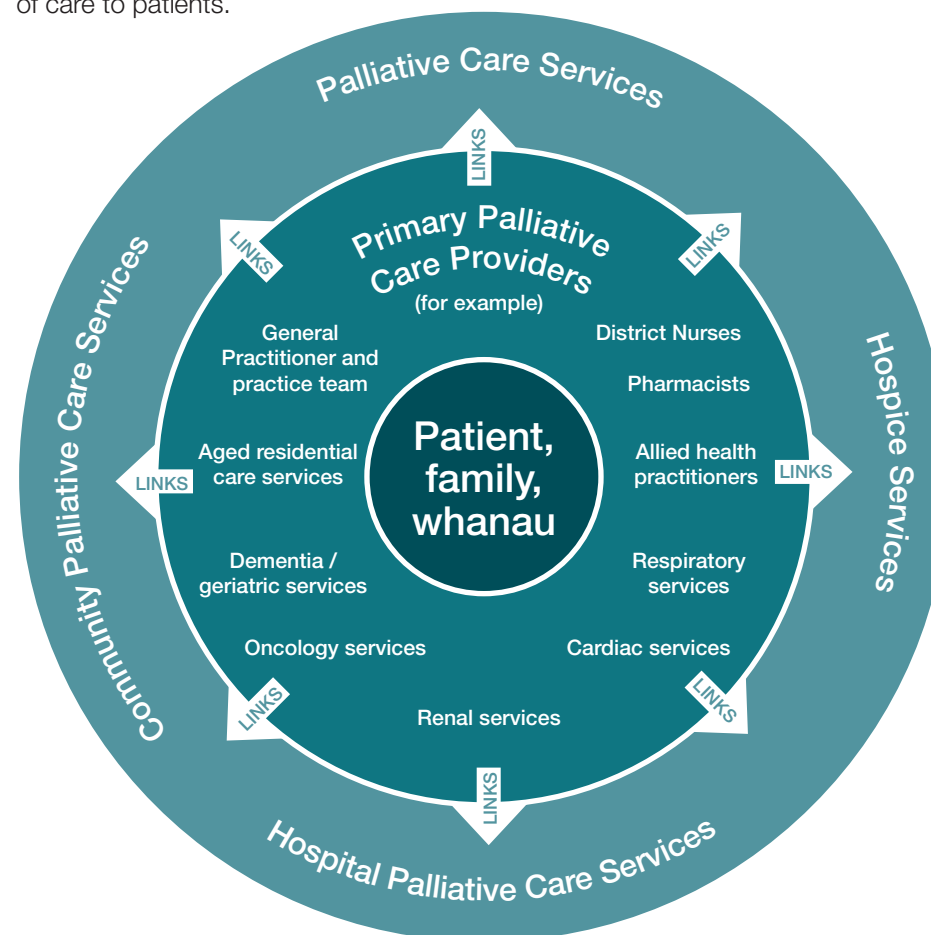
11 Information systems and telehealth virtual care

Telehealth is defined as the use of electronic information and telecommunications technologies to support long-distance clinical health care, patient and professional health-related education, public health and health administration. The Waikato DHB have invested in an application which extends telehealth into a more mobile platform than has traditionally been possible. This application is encompassed under the umbrella of Virtual Healthcare and allows for the provision of not only traditional telehealth but also storage of patient consultations, reminder and task lists, as well as resources and patient feeds which can be customised. Waikato DHB has entered into a strategic partnership with Hospice Waikato to bring these services to both patients and providers – the Hospice Anywhere Project which is part of Hospice Waikato's new service innovation funding investment.

12 The palliative care system and continuum of care

As can be seen from the diagram, there are a large number of health providers who are involved in providing palliative care. In addition, there are many voluntary organisations that interact with palliative patients e.g. Cancer Society, Motor Neurone Disease Association, Multiple Sclerosis Society, Cystic Fibrosis NZ. Ensuring there is communication and co-ordination between all these providers is and will continue to be a key challenge.

Transfer of care between providers has been identified as an area for improvement and the continuing development of clinical pathways, administrative processes and information systems is required to support the seamless delivery of care to patients.



13 Our Strategy 2016- 2021



Model of Care

Our strategy is based on an enhanced model of care, where primary, community and generalist health professionals deliver high quality palliative care, supported by specialists who provide both clinical support and education and mentoring for the wider workforce. Wherever patients interact with services across the continuum of care – be it episodic or end of life care, they will have providers who are highly skilled in palliative care and have fast and simple access to advice and support.

Palliative care will walk ‘hand in hand’ with disease modifying (including curative) treatments throughout a patient’s illness and will promote Advanced Care Planning to guide future decision making around patient care.

Our model will respond to the unique challenges of our district, in terms of rurality, ethnicity and demographic changes.

The model aims to achieve three key objectives:

- 1. To provide equitable access to palliative care services.**
This means that everyone can access the same level of care, irrespective of their location, ethnicity, etc. It also requires the services to support individuals to die in the place they choose (wherever possible). Achieving this requires a range of resources and capabilities.
- 2. To ensure palliative care services are configured to achieve seamless care.**
At present, there are a number of perceived gaps in the co-ordination of services and as a result patients are not receiving optimal care. Communication between care providers is key in ensuring all components of care ‘line up’. Palliative care needs to be integrated across the health sector.
- 3. To ensure palliative care services are effective and meet the needs of the patient and their whānau/family.**
Effective palliative care means that best practice is followed and that there is an interdisciplinary team approach to the delivery of care. Services need to meet the physical, psychosocial and spiritual needs of the patient and support the family/whānau before and after the death of the individual.

More detailed information on the proposed adult model of care is provided in Appendix F.

14 Priorities for action

Our overarching principle is to have a “patient and whānau/family centric focus across all palliative care services”. Using this as a basis, we have identified the following priorities for action.

To address the population profile challenges we recognise that multiple strategies and/or approaches maybe required. All providers of care will share the responsibility for achieving the key performance indicators that monitor and evaluate the population profile challenges.

The detailed actions, timeframes and responsibilities supporting these have been developed in a Framework for Action document. It is evident that additional investment into palliative care resources is required as a result of implementing these priorities.

1. **Improve access for Māori.**

We will include Māori participation at governance level and will partner with Māori consumers to develop resources specific to the Māori population. The aim of this key priority area is to increase health literacy and to ensure services are appropriate to meet the needs of Māori. We also need to develop support mechanisms for whānau who provide care to patients. To ensure a continual focus on equity, we will implement equity focussed reporting for all palliative care performance indicators.

2. **Improve access for those in rural and deprived communities.**

This will include an assessment of the need for inpatient beds at rural facilities; developing technological solutions to allow care to be co-ordinated and delivered remotely; and, ensuring the specialist workforce is able to provide 24/7 support to primary carers. These initiatives will assist in facilitating access for those in remote and isolated areas.

3. **Educate and support the primary care workforce.**

This means we need strong training programmes delivered by highly qualified specialist staff, who can connect both face to face and through other technologies with the carers in residential facilities and other primary service providers.

4. **Strengthen the palliative care services provided to children and adolescents and young adults.**

A number of areas identified for improvement echoed the adult services – increased access for rural areas, increased access to after-hours specialist advice, 24/7 community support for patients and families (including community nurses, social workers, psychology services and counsellors) and increased training opportunities. A Ministry of Health review in 2012 recommended clinical leadership, meaning DHBs appoint nurse co-ordinators and lead paediatricians to facilitate paediatric palliative care service provision within their district. We also need to improve the transition from child to adult services for this group.

5. **Increase the availability of nursing and allied health professionals to support patients and their whānau/ families.**

We need to strengthen our capability in the areas of nurse practitioners, clinical nurse specialists, physiotherapists, occupational therapists, psychologists, social workers, counsellors and pharmacists. A multidisciplinary approach to care is required.

6. **Ensure the specialist workforce is resourced and trained to support the increasing patient load and the non-specialist workforce.**

As previously noted, specialists will not deliver care to all patients, but those requiring their specialist knowledge and expertise will increase. In addition, they will need adequate resourcing to provide clinical support to those caring for palliative patients: staff in other hospital specialties and in rural hospitals, GPs and other community based staff.

7. **Strengthen the specialist hospital/hospice based services to meet the increasing demand.**

This will involve joint clinics with other specialties, having an adult crisis team working in the emergency department to assess patients and establishing adult transition beds under the care of palliative care specialists. It will also involve the development of clinical leadership to support paediatrics, adolescent and young person's care and transitioning to adult services.

8. **Develop the infrastructure and processes to provide seamless care.**

Telehealth Virtualising Healthcare is a priority for the DHB and investment in this technology will assist in both carers and whānau/ patients having timely access to specialist care. The supply of equipment used to support patients remaining in their homes will need to be increased. Clinical guidelines, referral pathways and consistent discharge planning will facilitate the progress of a patient through the health care system. The plan supports the Waikato DHB principle and initiatives to work towards a common patient record.

9. **Strengthen the continuous quality improvement philosophy and related research capabilities.**

Our services need to be built on a continuous quality improvement methodology. We need to be able to share our learnings intra-regionally and we will seek to develop practical means for doing this, such as a central information repository. Our involvement in clinical trials ensures our patients receive the most up to date treatments and is one part of our strategy to ensure patients achieve the optimum outcomes. Our aim is to become a national leader in palliative care research and to build the proportion of our patients who are able to participate in clinical trials.

In setting these priorities for action, we have ensured they reflect the following core principles:

Care must be:

- patient and whānau/family centred
- culturally appropriate
- evidence based best practice
- multidisciplinary
- coordinated
- delivered safely as close to home as possible
- inclusive of strong multidisciplinary team engagement

Strategies must be:

- equitable
- clinically led
- integrated
- sustainable
- collaborative with a partnership approach
- innovative and responsive to change
- research and knowledge driven

15 Enablers

Services cannot be developed or enhanced without a range of support mechanisms. We have identified five of these required to 'back-up' the service provision.

1. **Infrastructure.**

Having the necessary infrastructure such as governance, facilities, equipment and technologies is essential to the support delivery of excellent palliative care services.

2. **Information systems.**

Waikato DHB needs to improve information technology systems to support excellent palliative care service delivery as well as having the necessary data to inform service planning, modelling and service improvement.

3. **Workforce.**

We need to ensure that we have the necessary trained and credentialed workforce to deliver the growing demand for palliative care services. We need to build on and develop the palliative care workforce capacity and capability so that they are working at the top of their scope. Key focus areas include medical and nursing staff, allied health staff and spiritual and cultural advisors.

4. **Supportive care.**

As our palliative care services are used increasingly for those with long term chronic illnesses, we need to continue to provide support services throughout this extended journey. Advanced care planning (ACP) needs to be encouraged as part of a broad approach.

5. **Continuous Quality Improvement (CQI), knowledge and research.**

Waikato DHB covers a largely rural population, which includes a high proportion of Māori. For a number of years the DHB has been involved in research, which has predominantly been carried out in conjunction with researchers from the Waikato Clinical Campus, University of Auckland and from Waikato Hospital where there is an active clinical trials group. The Waikato Clinical Campus cancer research group are particularly focused on health services research and research aimed at reducing the inequities for Māori. This has included studies into palliative care, including a study of health literacy for Māori with palliative care needs funded by the HRC. This research helps inform us of the health needs of patients in the Waikato district, helps identify the causes of inequalities and guides the development of new initiatives. By being research active we build capacity and improve our ability to attract and retain staff.

16 Managing for outcomes framework

Progress towards the Waikato palliative care strategic vision and direction needs to be monitored and evaluated. The following has been based on Measuring What Matters: Palliative Care (PCCNZ. 2012). Managing for outcomes ensures that the Waikato strategic view identifies the intermediate and long term outcomes and high level impact for the whole of palliative care (Figure 4. The Logic Chain). The strategic view links the outcomes to the actions and activities of all Waikato palliative care health providers. Essentially managing for outcomes is about planning, implementing and evaluating programmes in a cycle of continuous improvement. There are five important steps: direction setting, governance, planning, implementation and evaluation.

The Waikato palliative care network needs to be re-established with a clinical lead to lead, coordinate and implement this Strategy Plan. An annual work plan should be incorporated into the Waikato DHB Annual Plan with regular reports against progress. The Waikato palliative care managing for outcomes framework will guide monitoring and evaluation of the Strategy Plan as we further develop palliative care indicators.

Palliative care indicators

As previously noted:

- The voice of individuals and their whānau/ family.
- Hospice Waikato has Palcare system – while this may not be perfect it is the gold standard compared to all others
- There are national service specifications for specialist palliative care and specialist community nursing and allied health services, however the national reporting requirements have not yet been defined. Midland has drafted Palliative Care 2015 Report Requirements – reporting service specification 12.0 and a draft report.
- There are no national palliative care indicators developed, except for faster cancer treatment where palliative care is first treatment for new cancer patients
- Waikato specialist palliative care contractual information is not easily available or retrievable
- There is no primary and/or generalist palliative care reporting
- There are HISO national specialist palliative care business process and data definitions, however these have not been implemented for the district as a whole, nor is the data captured in a central repository.

Hei Pa Harakeke have requested that the Midland Equity Indicator Matrix and Equity Focused Reporting Template (2016) is applied when monitoring and reporting on progress against this Strategic Plan.

We do capture data and information; however this is fragmented and incomplete. Waikato data and clinical information systems for palliative care need to improve to support planning, monitoring and evaluation. If you cannot measure, you cannot demonstrate improvement.

There is value in developing a standardised structure for information capture (an example of such a model is the Australian Palliative Care Outcomes Collaboration) where three levels of information describe the patient clinical outcomes whilst receiving palliative care:

- level 1 patient level describes demographics
- level 2 episode level describes the setting of care
- level 3 describes patient needs and clinical condition.

The Logic Chain

Figure 4

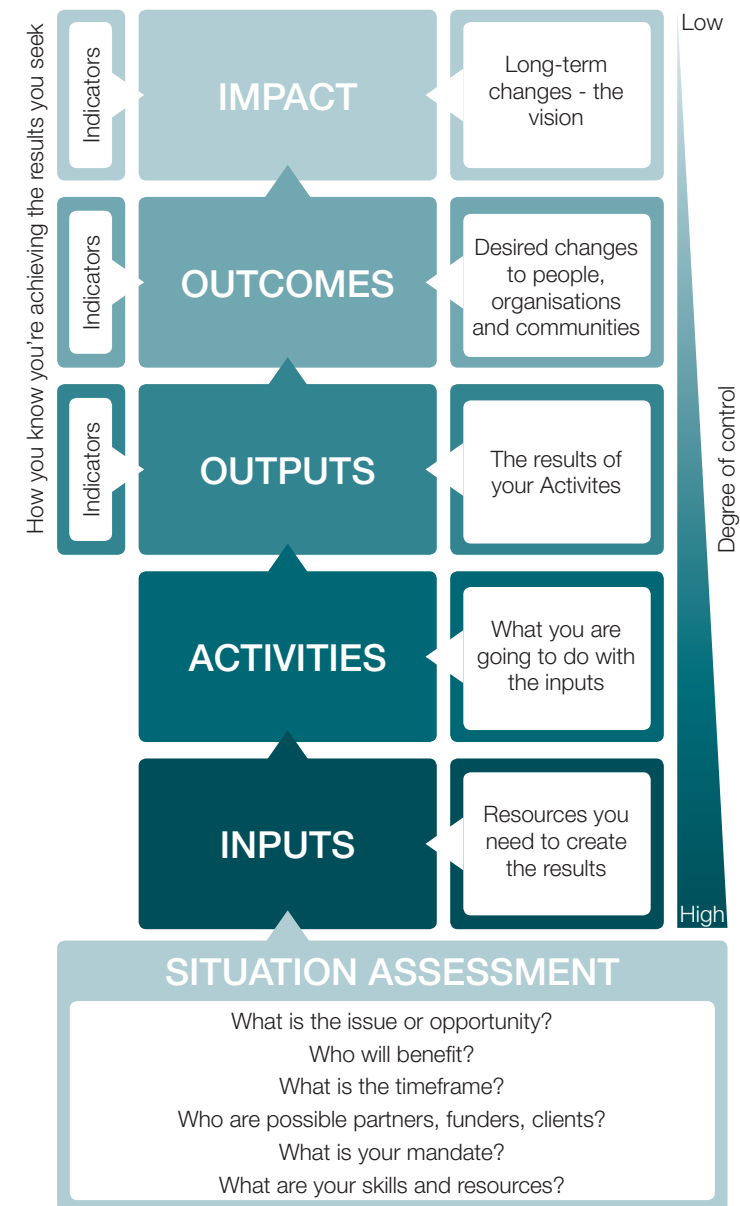


Figure sourced from Ministry of Health 2016

17 Next steps

The next steps beyond this strategy plan will focus on ensuring strong governance and leadership are in place to support implementation. The immediate focus for action will be on the identified priority areas. Given the five year span of the plan attention must also be given to tracking progress to ensure we are continually working towards our goal of better quality integrated, population based palliative care in the Waikato.

Appendix A – National context

Until 2015, the Palliative Care Council of New Zealand was the primary driver of national work. Nationally there are a number of documents published, these include:

- Service Provision for Adolescent and Young Adult Cancer Patients in New Zealand including Standards of Care (provisional March 2016)
- Te Ara Whakapiri: principles and guidance for the last days of life (21 December 2015)
- Referral Criteria for Adult Palliative Care Services in New Zealand (31 August 2014)
- Palliative Care and Maori from a Health Literacy Perspective (1 August 2014)
- Eleven Standards of Service Provision for Cancer Patients in New Zealand (Ten tumour standards are provisional; December 2013; NZ Lung May 2016)
- National Health Needs Assessment for Palliative Care Phase 2 Report: Palliative Care Capacity and Capability (14 May 2013)
- Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand (22 January 2013)
- National Specialist Palliative Care Data Definitions Standard (HISO 10039.2) and Data Business Process Standard (HISO 10039.1) (updated 2013)
- Guidance for Integrated Paediatric Palliative Care Services in New Zealand (25 September 2012)
- Measuring What Matters: Palliative Care (1 February 2012)
- National Health Needs Assessment for Palliative Care Phase 1 Report: Assessment of Palliative Care Need (30 June 2011)

All of these documents have been useful in the preparation of this plan.

While many New Zealanders receive excellent palliative care, the Government wants to ensure high quality care is consistently provided to all who need it. The Minister of Health has requested a review of adult palliative care services (Review) overseen by a cross-Ministry Steering Group. The Review team sits within the Policy Business Unit of the Ministry of Health. An expert Palliative Care Advisory Panel (PCAP) has been established to provide guidance and advice on the Review. The PCAP replaces the disbanded Palliative Care Council of New Zealand and will provide advice to the Ministry of national priorities.

National key priorities include:

- review of palliative care services for adults (discussed below)
- finalisation of the National Health Needs Assessment for Palliative Care
- Last days of Life – Te Ara Wharapiki implementation
- finalisation of the Palliative Care Glossary
- palliative care workforce
- update on the end-of-life component of the Health of Older People Strategy
- implementation of budget 2015 palliative care funding (including services in the aged care and primary care sectors) (discussed below).

Review of adult palliative care services

The Review will look at how best to ensure equitable, high quality care and improved service integration over the next 3 to 5 years. It will also consider projected needs for palliative care services over the next 10 to 20 years. The review is expected to have an interim report 30 April and final report by 30 September 2016.

The Review objectives include:

- current service capability and capacity across all care settings and providers
- projected need for palliative care services over the next 10 to 20 years
- gaps and barriers to achieving high quality and equitable provision of care, including workforce issues, funding settings, and standards of care
- actions to improve integrated services across all providers and care settings over the next 3 to 5 years
- actions to improve access to, and quality and standards of care, and ensure equitable provision of care over the next 3 to 5 years, including within existing funding levels.

The Review has several workstreams:

1. projected demand for palliative care services
2. quality and standards of care, including service users' perspectives
3. workforce issues
4. integration of, and equitable access to, services
5. funding and sustainability.

Workforce

Specialist palliative care medicine has been identified as a vulnerable medical speciality by Health Workforce New Zealand (HWNZ) and the Cancer Programme Steering Group. In New Zealand there continues to be unfilled trainee positions and ongoing Senior Medical Officer (SMO) vacancies.

In 2015 HWNZ funded a contribution towards an additional medical registrar position for Midland palliative care, this position has been implemented.

A National Professional Development Framework for Palliative Care Nursing in Aotearoa New Zealand (Palliative Care Nurse NZ, updated 2014) describes the competencies required for all nurses to provide palliative care across a range of clinical settings.

Service specifications

The new tier 2 Specialist Palliative Care Service Specification was endorsed at the end of 2014 with a 'recommended' status allowing time to implement the 2013 Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand as reflected in the service specification. These specifications have been in development since 2007.

New purchase units for the specialist community nursing and allied health services have been included in the new tier 2 Community health, transitional and support services – specialist community nursing specification and Allied health services service specification.

The Ministry of Health notified DHBs (January 2016) that no further changes will be made to the specialist palliative care service specifications or palliative care purchase units until after the Ministry's review of adult palliative care is completed. As a temporary solution DHBs can continue to block purchase/bulk fund using the COPL series of purchase units for 2016/17, and the use of the service specifications will remain optional.

The national reporting requirements for the service specifications have not been defined.

Budget 2015 palliative care new service innovations funding

In the Budget 2015, the Government allocated new funding of \$76.1 million over four years to hospice community palliative care services across New Zealand. Of this, \$13 million per annum was for sustainable funding to ensure service sustainability and to address hospice funding shortfalls. An additional \$3.1 million in 2015/16, rising to \$7 million from 2016/17 has been allocated for new services and innovations that improve the quality of palliative care in aged residential care, primary care and community settings. The extra \$20 million of funding each year will commence from July 2015. This funding is in addition to the extra \$15 million a year from the Boost Hospice Care funding initiative announced in 2009.

National tumour standards of service provision

National tumour standards have been developed for lung, breast, bowel, head and neck, lymphoma, myeloma, gynaecological, sarcoma, thyroid, melanoma and upper gastrointestinal cancers. These standards describe the level of service that an adult person with cancer should have access to and each contains a section on access to palliative care. In this section, the link between ongoing treatment for the particular cancer type and palliative care is described and 'good practice points' are offered. The national tumour standards are available on the Ministry of Health website.

Palliative care for children

The Guidance for Integrated Paediatric Palliative Care Services in New Zealand (Ministry of Health 2012) is a guide to improve the integration of palliative care service delivery to children and young people in New Zealand. The Guidance was commissioned by the Ministry of Health. It was developed in response to the national review of paediatric sub-specialty programmes (Ministry of Health 2010), which found that paediatric palliative care services in New Zealand, other than in Auckland, are not fully coordinated or sufficiently specialised, and generally provide no access to specialist care. The review found that many families of children with palliative care needs rely on local primary health care, community services and non-governmental organisations (NGOs) to provide palliative care.

The Guidance examines existing paediatric palliative care services, both in New Zealand and internationally, and uses the results in the proposed framework.

The proposed framework provides structure for developing a coherent, integrated and coordinated system of paediatric palliative care service delivery. The proposed framework includes:

- extending the role of the Starship Children's Health Paediatric Palliative Care Team to include national support services; specifically facilitating 24/7 support to DHB nurse coordinators
- confirmation of DHB nurse coordinators and lead paediatricians
- developing and implementing an education and training process for nurse coordinators and lead paediatricians
- establishing a National Paediatric Palliative Care Network.

The Paediatric Palliative Care Clinical Network has been established to lead and provide clinical oversight of the implementation of the Guidance. It also provides advice on service and treatment issues to the Paediatric Society of New Zealand and Ministry of Health through the Palliative Care Advisory Group. The Paediatric Palliative Care Clinical Network key activities include the:

- establishment of a key contact list
- development of a Memorandum of Understanding with Hospice NZ on collaborative care between hospices and paediatric services
- development of clinical guidelines for end-of-life care and pain management
- development of paediatric palliative care clinical network model of care
- establishment of monthly clinical education programme.

The purpose of the Guidance for Integrated Paediatric Palliative Care Services was to support local DHBs in their development of paediatric palliative care services with Starship specialist service providing input as needed. The guidance was written with the understanding of a cost-neutral approach to service development across the country. However in developing this plan it is deemed by Waikato stakeholders and Starship that this approach is no longer feasible given the growth in demand as well as the growing inequity of resourcing between adult and paediatric palliative care.

The national End of Life Care Clinical Guideline for Paediatric Palliative Care is a resource via Starship and Kids Health websites to support clinicians providing end of life care to children and AYA.

The national paediatric palliative care education forum, via a videoconferencing format, provides regular teaching on a range of topics to support clinicians and provides the most up-to-date knowledge and ultimately, improves care delivery. In addition Starship specialist palliative care service supported by the national paediatric palliative care clinical reference group ran a successful train the trainer course early 2016 and is working to build capacity to provide further educational opportunities.

Adolescent and young adult (AYA) cancer patients in New Zealand

The AYA Cancer Network Aotearoa has been established connecting professionals, patients, carers and other stakeholders with an interest in improving AYA cancer outcomes across the continuum of care for AYA. A key focus for the AYA Cancer Network Aotearoa is to develop a five year national strategy for AYA cancer care. To ensure the strategy is well informed and based on strong evidence and best practice, the development of the “Service Provision for Adolescent and Young Adult Cancer Patients in New Zealand” including Standards of Care (provisional 2016) has been a priority. The AYA standards will sit alongside the eleven existing adult tumour standards (as above).

The AYA service provision and standards document includes palliative care - Standard 6.2 AYA cancer patients will have access to palliative care services. Where appropriate, access will start at diagnosis.

National specialist palliative care business processes and data definitions

The national specialist palliative care business process and its associate data definitions document was first developed in 2011 as interim and in 2013 the status moved to full. The intention is to ensure that the minimum agreed palliative care data is collected and stored in a consistent manner wherever it is collected and stored. The national specialist palliative care business process and its associate data definitions have not been implemented within Waikato specialist palliative care providers.

There are no national primary palliative care data definitions developed.

Hospice Waikato has implemented PalCare alongside their hospice colleagues within Midland. PalCare is compliant with the national specialist palliative care data definitions. Waikato DHB specialist palliative care service does not utilise PalCare. Hospice Waikato contributes to the faster cancer treatment health target and indicator when palliative care is first treatment. Monthly reporting for Waikato from PalCare is provided regionally via Waipuna Hospice.

Appendix B – Regional context

The Midland Palliative Care Work Group has been active for many years and has recently developed the Midland Specialist Adult Palliative Care Service Development Plan 2015-2018, which details the key areas of focus over that period. It includes:

- workforce recruitment and retention of specialist palliative care staff (Midland Medical Advanced Palliative Care Trainee Model of Service Development Plan 2015-2018 – implementation is work in progress). A clinical director of training appointed and an additional registrar position was implemented 2016
- last days of life care
- national palliative care service specifications (note: developed draft Palliative Care 2015 Report Requirements – reporting service specification v12.0 (T. Novess. BOP). PalCare have developed and released reports to Waipuna Hospice, these reports have tested successfully. Implementation continues.
- clinical guidelines
- education and training of specialist and generalist providers
- equity of access – implemented Referral Criteria for Adult Palliative Care Services in Midland Region (September 2014)
- quality data to inform service planning and faster cancer treatment data collection where palliative care is the first treatment – completed
- quality improvement initiatives
- telehealth innovations.

The Midland Palliative Care Work Group is clinically led with a supporting hospice executive. The Group assists with the regional and local palliative care service improvement planning and implementation.

Regionally there has been little focus on paediatric palliative care as this has been led by the national Paediatric Palliative Care Clinical Network. Regionally the Midland Cancer Network is supporting Lakes Paediatric Palliative Service Improvement Project.

Regionally the Midland Cancer Network facilitated the establishment of the AYA Cancer Service, including access to local palliative care services.

Midland regional service plan

The Midland Regional Service Plan (RSP) 2015-2018 describes the joint planning priorities, direction and collective investment of the Midland DHBs. Regional governance is via the Midland Regional Governance Group (MRGG, DHB Chairs and CEs) and DHB Chief Executives (CEs). Included in this plan are the following references to palliative care:

Regional Initiatives: Faster Cancer Treatment: Improve palliative care services

- facilitate DHBs/hospices to implement the Midland Adult Specialist Palliative Care Service Development Plan recommendations 2015-2018; (page 56) and Faster Cancer Treatment: Primary-secondary pathway tools
- continue to develop the Midland palliative care Map of Medicine pathway (page 65)

And included under “Future trends affecting Midland region populations”

Demography - greater focus on refining care for those ‘in last year of life’ will identify a need for more comprehensive palliative care services (page 134)

Technology - technological advances together with reduced cardiac and accident mortality mean that people with incurable diseases are likely to survive for longer, resulting in increased demand for palliative care. (page 135)

Appendix C – Waikato demographics and assessment of palliative care burden

Demographics

Waikato DHB is one of the largest DHBs and covers approx. 21,220km². Over a quarter of the population live in Hamilton, with the rest spread over smaller towns and rural areas. The population is approx. 9.5% of the total NZ population.

The population is expected to increase by 9% to over 430,000 in the next ten years and by 15% to nearly 455,000 in 20 years. Most significantly, in the next 20 years the population over 65 years will increase from 15% to 24% of the total population (and those 75 years and over will increase from 7% to 13%).

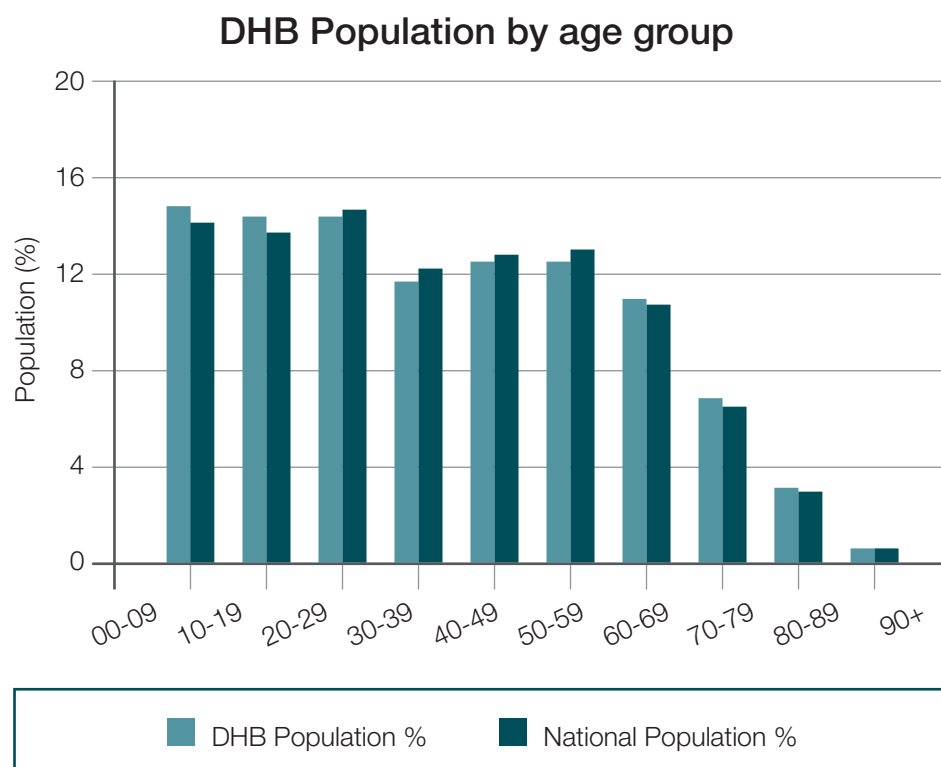


Figure 5: Waikato DHB population by age compared to NZ population

Waikato DHB (2015/16 projection)

394,340 people

88,295 Māori

8 iwi – Waikato, Hauraki

Ngāti Maniapoto, Ngāti Raukawa

Ngāti Haua, Tuwharetoa,

Whanganui, Maata Waka

Population projections for Waikato domicile patients

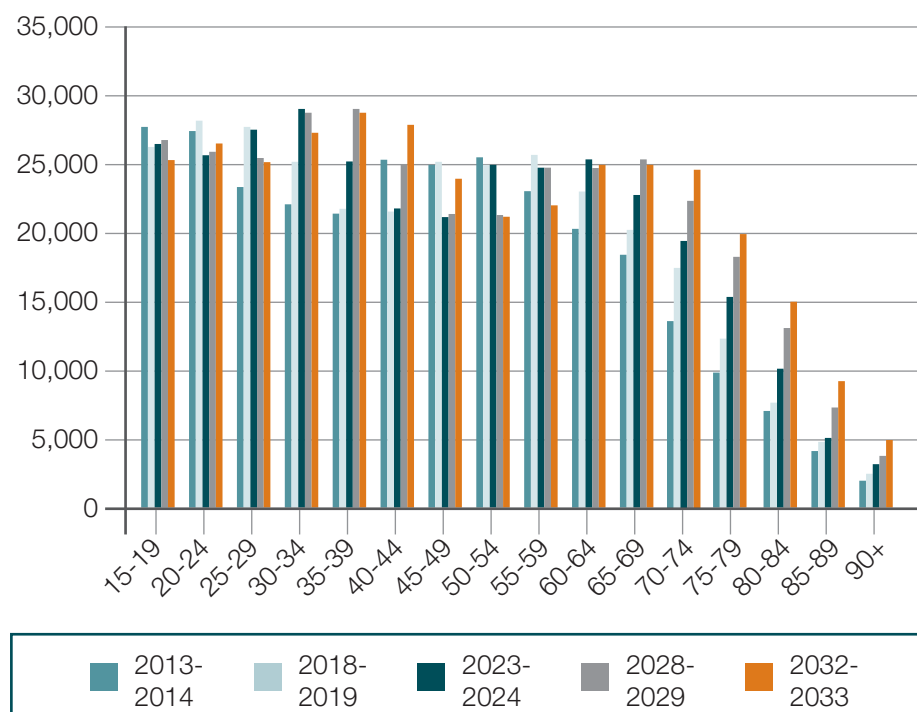


Figure 6: Waikato DHB population age group projections

Ethnicity

Waikato has a higher than average Māori population and fewer Pacific people than NZ as a whole (Table 1). Approximately 14% of the New Zealand Māori population live in the Waikato. As can be seen, the percentage of Māori in the Waikato population is expected to increase over the next twenty years.

Year / Ethnicity	2015/16		2026 / 27		2036 / 37	
	Number	%	Number	%	Number	%
Māori	89810	23%	108960	25%	128560	28%
Other	293110	74%	306580	71%	306290	67%
Pacific	11420	3%	15620	4%	19490	4%
Total	394340	100%	431160	100%	454340	100%

Table 4: Waikato DHB population projections for main ethnic groups

Māori are disproportionately represented in the most deprived areas and therefore at higher risk of death from a range of diseases compared to non-Māori. Waikato Māori have nearly twice the age-standardised mortality rate than non-Māori.

Deprivation

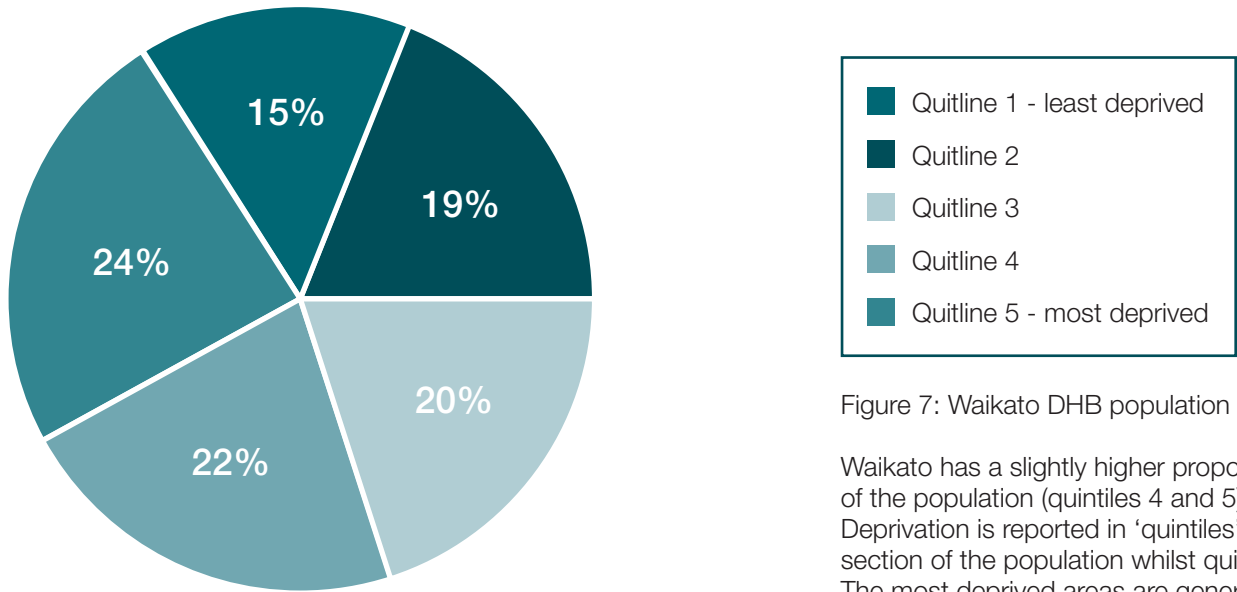


Figure 7: Waikato DHB population deprivation, by quintile

Waikato has a slightly higher proportion of people in the more deprived sections of the population (quintiles 4 and 5) than the national average (Figure 6). Deprivation is reported in ‘quintiles’. Quintile 1 represents the least deprived section of the population whilst quintile 5 represents the most deprived section. The most deprived areas are generally located in the rural Waikato and in areas with a high Māori population. See also Table 3 on Page 15.

The Palliative Care Burden

Deaths

The palliative care burden is generally linked to the expected number of deaths in the district. However, as noted earlier, there is an expectation that as the number of patients with life-limiting, non-malignant diseases make greater use of palliative care services, a 'blip' in demand may occur over the next few years. In terms of deaths, new projections have been provided by Hospice. These show that by 2026 the number of deaths in the Waikato DHB district will have risen from 2720 (in 2016) to 3170 (16.5% in ten years). Based on 60% of these deaths requiring palliative care, this indicates a palliative care population of 1872 by 2025.

Children's services

Quantifying the paediatric palliative care population group in the Waikato DHB is a difficult task. There is a lack of data available for assessing the prevalence of life-limiting conditions in children in New Zealand. Many estimates are based on mortality data which doesn't fully consider the significance of healthcare needs for children with life limiting or life threatening conditions during their lives. As children live longer with their condition these figures are likely to be underestimates; anecdotally clinicians working in paediatric palliative care consider the data to under represent the burden of disease. However, research undertaken in the last ten to fifteen years is providing some information on the numbers of children who would benefit from a paediatric palliative care approach.

International Estimates

The key findings from a UK study (Fraser, Miller, Aldridge, McKinney, & Parslow, 2011n 2011) confirmed the prevalence of life-limiting conditions in children and young people aged 0 – 19 years was more than double previous prevalence estimates in England, with steadily increasing annual numbers. Figures taken from 2000 - 2010 for Scotland, Wales and Northern Ireland also confirmed higher prevalence.

- Northern Ireland: from 23.5/10,000 in 2000 to 27.8/10,000 in 2010
- England: from 25/10,000 in 2000 to 32/10,000 in 2010
- Scotland: from 32/10,000 in 2000 to 38.6/10,000 in 2010
- Wales: from 34.9/10,000 in 2000 to 44.6/10,000 in 2010

The prevalence of life-limiting conditions in children and young people was highest in the under 1 age group and this prevalence decreased with age. Congenital anomalies constituted the largest diagnostic subgroup within the life-limiting conditions in children and young people.

The prevalence of life-limiting conditions in children and young people was significantly higher in the male population compared to the female population. The report clearly identifies an escalating need for paediatric palliative care services and recommends the use of ICD-10 coding framework to identify other national datasets.

National Estimates

The Palliative Care Council of New Zealand undertook a national needs assessment in 2011 in order to determine the need for palliative care on a population basis (Naylor, 2011). This report analyses mortality data for children and young people aged 0 – 19 years over a three year period (2005 – 2007). This data is likely to significantly underestimate the prevalence of children and young people with life limiting conditions. Mortality data is unable to quantify the burden of care for children living with these conditions.

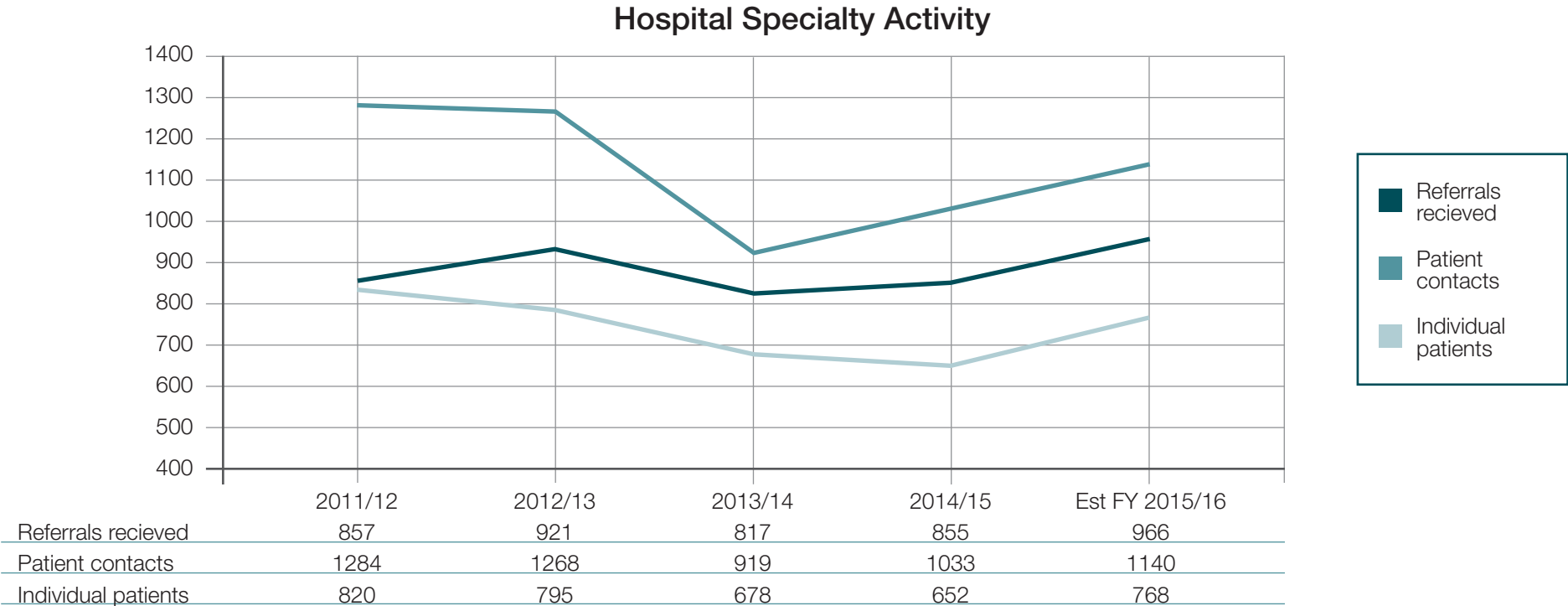
- Estimate of 273 deaths per year where palliative care would be of benefit
- This represents 41.9% of total deaths or 2.3 deaths/10,000 New Zealand children and young people.

The report goes on to estimate annual paediatric palliative care population numbers for each DHB region. In 2006, this varied from a low of 25.6% of total deaths in Whanganui DHB to a high of 54% in Auckland and South Canterbury DHBs. The Waikato DHB paediatric palliative care population is estimated to be 38.7% of total deaths (n=29). This equates to 2.7 deaths per 10,000 children and young people in the district. This positions Waikato DHB as having the second largest paediatric palliative care population in New Zealand. These numbers are projected to rise no more than 5% nationally until 2026 as the total population size of children and young people is expected to remain fairly static.

Adult specialist services

Information on the need for palliative care has been sourced from historic ‘activity’ data and current patient numbers.

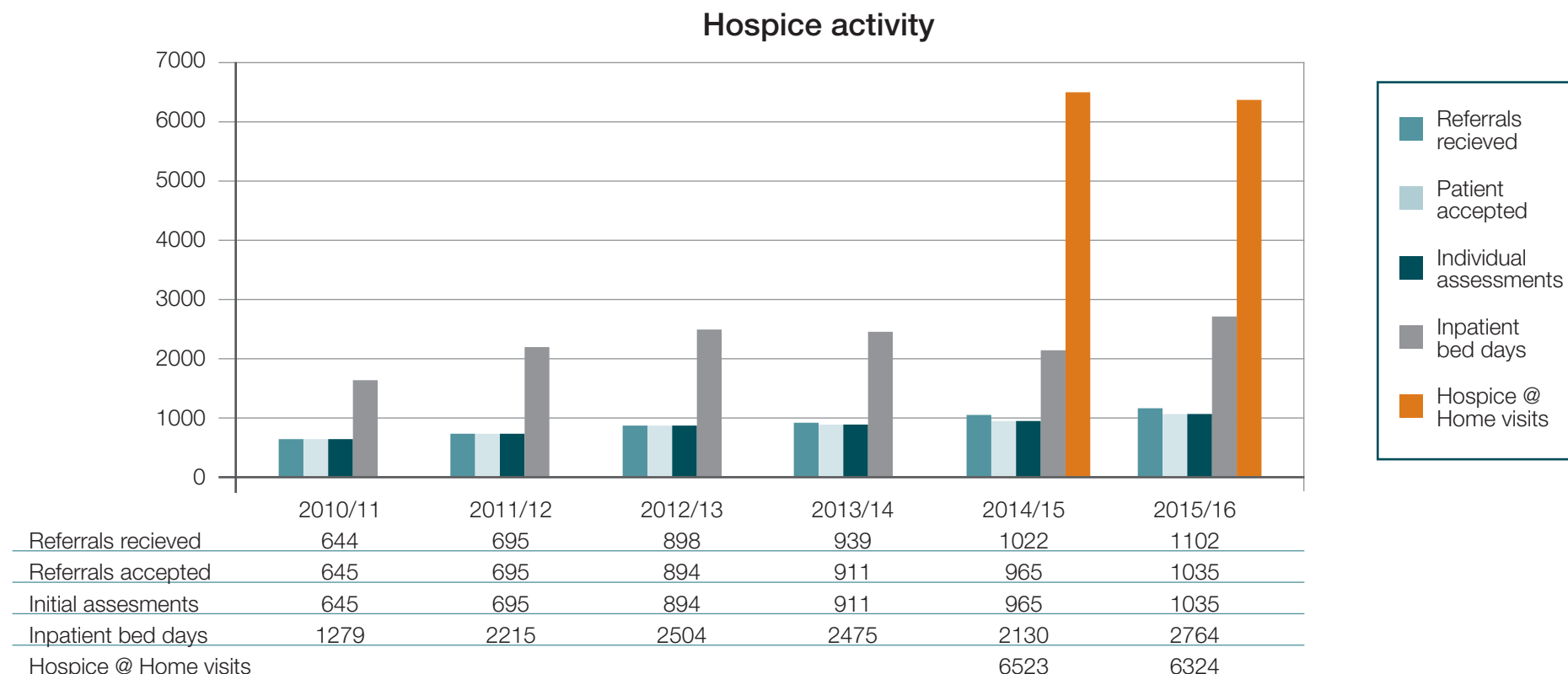
- 1. A match was done of adult patients currently on the databases held by both the hospital service and Hospice. This data showed over 440 patients ‘active’ across the district. Anecdotally, this is up from around 300 a few years ago.
- 2. Hospital activity is shown in terms of referral numbers and contacts.



The activity for the 2015/16 year was estimated by doubling the actual activity for the six months to 31 December 2015.

This data also showed an increase in referrals from specialties other than oncology (notably general medicine, respiratory medicine, orthopaedics and vascular surgery), reflecting the non-malignant diseases.

3. The data for a number of Hospice activities over the past five years is shown below. The Hospice@Home began in 2014.

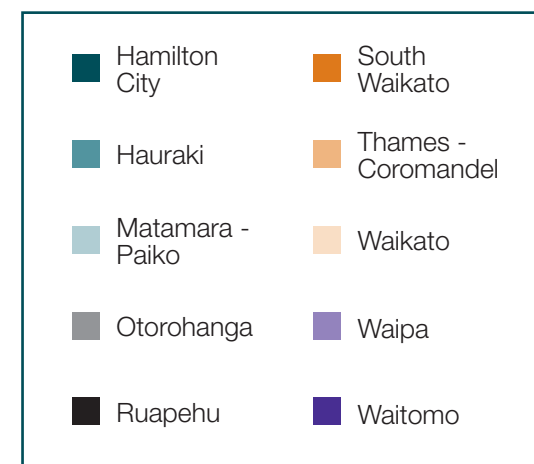
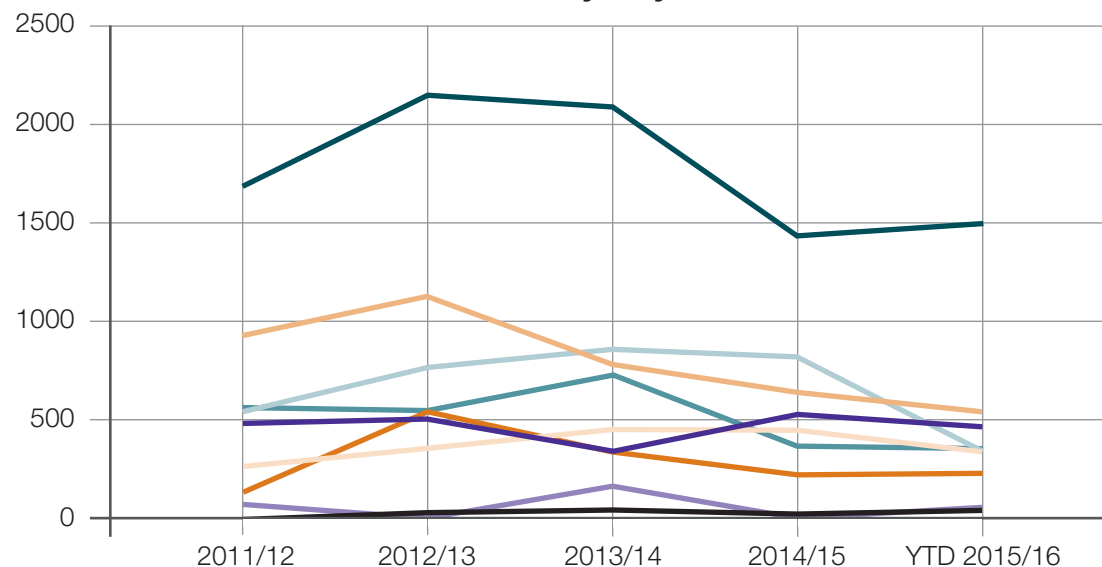


Note: The activity for the 2015/16 year has been estimated by extrapolating the results to 31 March 2016.

Activity in Aged Residential Care facilities

The table shows bed days by facility funded under the 'End of Life' funding. This is shown by Territorial Land Authority (TLA) within the Waikato DHB. Palliative patients may also be receiving funding through several other mechanisms, including carer support and other home based support services (also allocated via Disability Support Link) and short term access to primary access beds for symptom control etc.

Bed Days by TLA



Hamilton City	1698	2143	2091	1439	1499
Hauraki	565	544	720	374	359
Matamara - Paiko	535	779.5	867	811	343
Otorohanga	0	0	0	0	0
Ruapehu	0	26	48	4	36
South Waikato	125	528	333	211	223
Thames - Coromandel	923	1123	796	638	531
Waikato	265	349	453	446	335
Waipa	487	502	339	524	470
Waitomo	73	0	163	0	58

As can be seen there is no real pattern over the period shown. However it is likely that the full year 2015/16 will show an increase in total days.

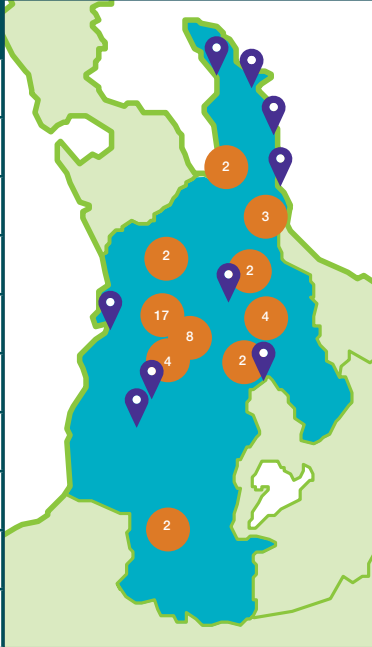
Other data available gives the average number of days in each facility per TLA (over the four and a half years to 31 December 2015). This shows the highest usage is in Hamilton City, Hauraki and Thames-Coromandel.

Aged Residential Care Facilities by TLA	No of Facilities	Average Days per facility
Hamilton City	14	634.00
Hauraki	3	854.00
Matamara - Paiko	7	476.50
Otorohanga	1	-
Ruapehu	2	57.00
South Waikato	3	473.33
Thames - Coromandel	6	668.50
Waikato	6	308.00
Waipa	12	193.50
Waitomo	1	294.00

Appendix D – Beds available for palliative care patients in the Waikato district

There are five DHB hospitals (Waikato, Thames, Te Kuiti, Taumarunui, Tokoroa) in the area, together with a Hospice inpatient unit in Hamilton, resulting in increased demand for palliative care. (page 135)

Territorial Authority	ARC Facilities
Thames-Coromandel District	6
Hauraki District	3
Waikato District	6
Matamata-Piako District	7
Hamilton City	14
Waipa District	12
South Waikato District	3
Otorohanga District	1
Waitomo District	1
Ruapehu District	2



In addition, there are 55 accredited aged care facilities in the area providing 2,997 beds for a range of service types including rest home care, dementia care, medical and geriatric care. Approximately 40 of these have “Hospital level” beds, which are those generally accessed by palliative care patients. These are paid at a bed day rate. Non hospital level beds are also used for respite care. Access to palliative care funding is dependent on a clinician confirming that the patient has less than six weeks to live.

Facility size is widely variable from 15 to 170 beds. 25 facilities are located in or close to Hamilton, including Ohaupo, Cambridge and Ngaruawahia, the remainder are distributed widely across the Waikato). The predominant workforce within ARCs is Health Care Assistants/Caregivers, with a small number of Registered Nurses and fewer Enrolled Nurses. (Source: Hospice Waikato survey).

Appendix E – Equity framework for palliative care

Health System	Leadership <i>Leadership is about setting an expectation that good Palliative Care provision will contribute to better health equity for all New Zealanders</i>	Knowledge <i>Quality service delivery requires knowledge to adapt to the specific needs of the Palliative Care patients and community</i>	Commitment <i>Palliative Care is committed to reconfiguring services to deliver high-quality services that meet the need of all New Zealanders</i>
	<p>Health system leadership by Waikato DHB is expressed through ensuring:</p> <ul style="list-style-type: none"> • There is a raised awareness and strategic direction for palliative care provision. • There is a raised awareness and set direction for palliative care health literacy at governance and senior leadership levels. • Excellent palliative care provision is embedded in all levels of the health system, including planning, work programmes and reporting. • The organisation establishes linkages to regional and national palliative and supportive care workgroups/leads. • That equity is a central focus for all palliative care planning and reviews, using a frame incorporating ages/rurality/disability/ethnicity/gender/location and elderly. • There is sufficient representation of Māori, Pacific and other high risk groups on governance and operational workgroups. • Palliative care services provide an effective leadership forum in consultation with patients, to deliver a coordinated service appropriate to needs. • The palliative care system acknowledges the importance of leading an equity health care service, which prioritises services to those most in need and promotes accessible, acceptable, affordable and timely services. • Services are coordinated in such a way that all those requiring palliative care have equal access to appropriate levels of care where and when they need it. 	<p>The system will:</p> <ul style="list-style-type: none"> • Develop ways to effectively deliver and monitor high-quality palliative care for Māori. • Collaborate and share information between services, programmes and initiatives. • Develop methods to ensure that services, programmes and initiatives share knowledge and contribute to developing excellent and equitable palliative care services. • Ensure that high quality ethnicity data is available for planning and monitoring services. • Ensure that evidenced based methods are used to achieve equity access, and quality of care. • Deliver palliative care information in an integrated fashion with “seamless” transition across care settings so that patients and their families can easily gain access to the care and information they need through any entry point. • Allow individuals and families to make informed decisions about their care choices with support from a system which focuses on the needs of the individual and works in partnership with individuals, families and carers. 	<p>The system will commit to:</p> <ul style="list-style-type: none"> • The availability of high quality data/information to measure and ensure high quality equitable access to palliative services. • Having a health system that is organised and improved in a way that makes it easier for individuals and whānau to navigate, understand, and make decisions regarding palliative care support. • Ensuring that equity quality targets are developed. • Ensuring high quality palliative care that is equitable for Māori, Pacific and other groups that are striving to achieve improved outcomes etc. • Building and maintaining a health workforce responsive to the palliative care needs and aspirations of those groups seeking to achieve positive gains in health indicators • Building a workforce that is skilled in cultural competency and appropriateness supported by specialist tertiary level services, community support and volunteers. • Ensuring the workforce reflects that of the patient population including in terms of ethnicity and age. • Acknowledging the need to balance the tensions of receiving and providing support during the last days of life journey for patients. • Examining and checking that the number of referrals by age, rurality, disability, ethnicity, gender and location reflect equitable access. • Identifying and removing barriers experienced by patients and whānau navigating the palliative care system, especially their understanding of hospice and related services. • Ensuring treatment and support options availability reflect the differences in ethnicity, geography, disability, age and gender.

Health organisations	Leadership <i>Leadership is about setting an expectation that good Palliative Care provision will contribute to better health equity for all New Zealanders</i>	Knowledge <i>Quality service delivery requires knowledge to adapt to the specific needs of the Palliative Care patients and community</i>	Commitment <i>Palliative Care is committed to reconfiguring services to deliver high-quality services that meet the need of all New Zealanders</i>
	Leaders will ensure that: <ul style="list-style-type: none"> • Linkages with primary and secondary health services are developed, fostered and established to enable whānau to have their palliative support needs met. • Palliative care improvement is embedded across all levels of health organisations including policy, planning, procedures, patient safety and service quality improvement. • Service providers address the needs of their populations that have varying degrees of palliative care requirements. • There is a linkage with local service providers including Māori, aged care, disability and prison services, etc. • Palliative care services develop working relationships with Midland Māori cancer work group (Hei Pa Harakeke) who actively supports and provides leadership and advice for services. • Regional palliative care leadership builds linkages to ensure services meet the needs of patient and whānau. • Better improved palliative care services are developed through leadership facilitation in collaboration with whānau and the wishes of the dying • The infrastructure is planned to support services particularly where there are geographical inequalities in the location of services e.g. rural vs urban, and provision of services/providers in low socio-economic areas. 	The organisation will: <ul style="list-style-type: none"> • Review supportive care practices in their services and health care environment. • Deliver palliative care in a way that is appropriate to the culture. • Collaborate across the health and social services to achieve positive working relationships to build knowledge on supportive care needs. • Acknowledged and support Mātauranga Māori (Māori Knowledge) to improve palliative care referral pathways for Māori whānau and individuals. • Utilise patient focus groups and consumers in the development and testing of strategies to improve palliative care services. • Improve palliative care by innovative strategies and information relevant to the local context. • Ensure the five dimensions of health literacy (functional, technical, interactive, political and cultural) are key factors in palliative care health literacy documentation. 	The organisation will commit to: <ul style="list-style-type: none"> • Reviewing the status of supportive care practices to improve standards, pathways and action plans. • Workforce development in the areas of psychosocial and supportive care needs. • Providing adequate investment and resourcing to sustain supportive care services. • Including consumers are involved in the development and improvement of service models (where appropriate). • Growing champions to support sustained effort to improving psychological support. • Ensuring Midland Cancer Supportive Care workgroup actively supports and provides advice in the development of new initiatives and supportive care programmes. • Ensuring services are structured to ensure effective and efficient use of available resources that meet the needs of patients and families.

Health Practitioners	Leadership	Knowledge	Commitment
	<p><i>Leadership is about setting an expectation that good Palliative Care provision will contribute to better health equity for all New Zealanders</i></p>	<p><i>Quality service delivery requires knowledge to adapt to the specific needs of the Palliative Care patients and community</i></p>	<p><i>Palliative Care is committed to reconfiguring services to deliver high-quality services that meet the need of all New Zealanders</i></p>
	<p>Leaders will ensure:</p> <ul style="list-style-type: none"> • Palliative care practitioners develop meaningful relationships with Māori and Pacific individuals, whānau, and communities. • Provision of high quality palliative care that delivers equitable health outcomes. • Palliative care health practitioners recognise the link between palliative care support and cultural competencies with both being expressed as good practice standards. 	<p>Knowledge will be utilised by:</p> <ul style="list-style-type: none"> • Encouraging palliative care practitioners to build their knowledge base on how they can effectively communicate, and provide supportive care information to support whānau and individuals, using all five dimensions of health literacy across their communication tools. • Realising individuals and whānau may have reduced ability to process supportive care information when they are sick and vulnerable during a diagnosis. 	<p>Service commitment will be demonstrated by:</p> <ul style="list-style-type: none"> • Palliative care professionals and other staff able to readily describe the pathway in relation to psychological and supportive care requirements. • Ensuring training pathways are available for all workforce including support workforce (e.g. allied health).

Appendix F – Proposed model of care for adult specialist palliative care services

The 2021 Waikato model of palliative care: one programme, two sites

Waikato Specialist Palliative Care will be a fully integrated service ensuring optimum care for Waikato palliative patients and their families.

In addition to the existing service this will be achieved by:

Telementoring of primary practitioners in medical and nursing disciplines

- Weekly educational sessions will be held in the rural hospitals by means of the current videoconferencing facilities and will include case presentations, didactic sessions and resources for evidence-based information. (ECHO model- see Innovative Telementoring for Pain Management: Project ECHO Pain, Journal of Continuing Medical Education in the Health Professions, Volume 34, Issue 1, pp 68-75. Winter 2014).

This would be site specific telementoring and would not replace the more formal Grand Rounds.

Consultations by palliative care specialists at a distance

- In the initial phase these would occur in the rural hospitals where there are existing video-conferencing facilities. Ultimately they will be extended to in home consults.

Hospital

- Joint Clinics will be established with oncology, renal, respiratory and cardiovascular medicine for all patients transitioning to palliative care.

Palliative care patients in emergency department

- Palliative patients presenting to ED would be seen by a palliative care crisis team consisting of a Nurse Practitioner and/or an Advanced Trainee Palliative Registrar as well as a Social worker in order to determine whether admission is indicated, either to hospital or hospice, or whether they can be cared for in the home, and followed up in the community.

Transitional palliative care beds

- These are needed in the hospital for patients who are actively dying, for complex patients and for patients requiring admission under palliative care when no hospital level of care rest home or hospice beds are available.

Long Term palliative care beds in the community

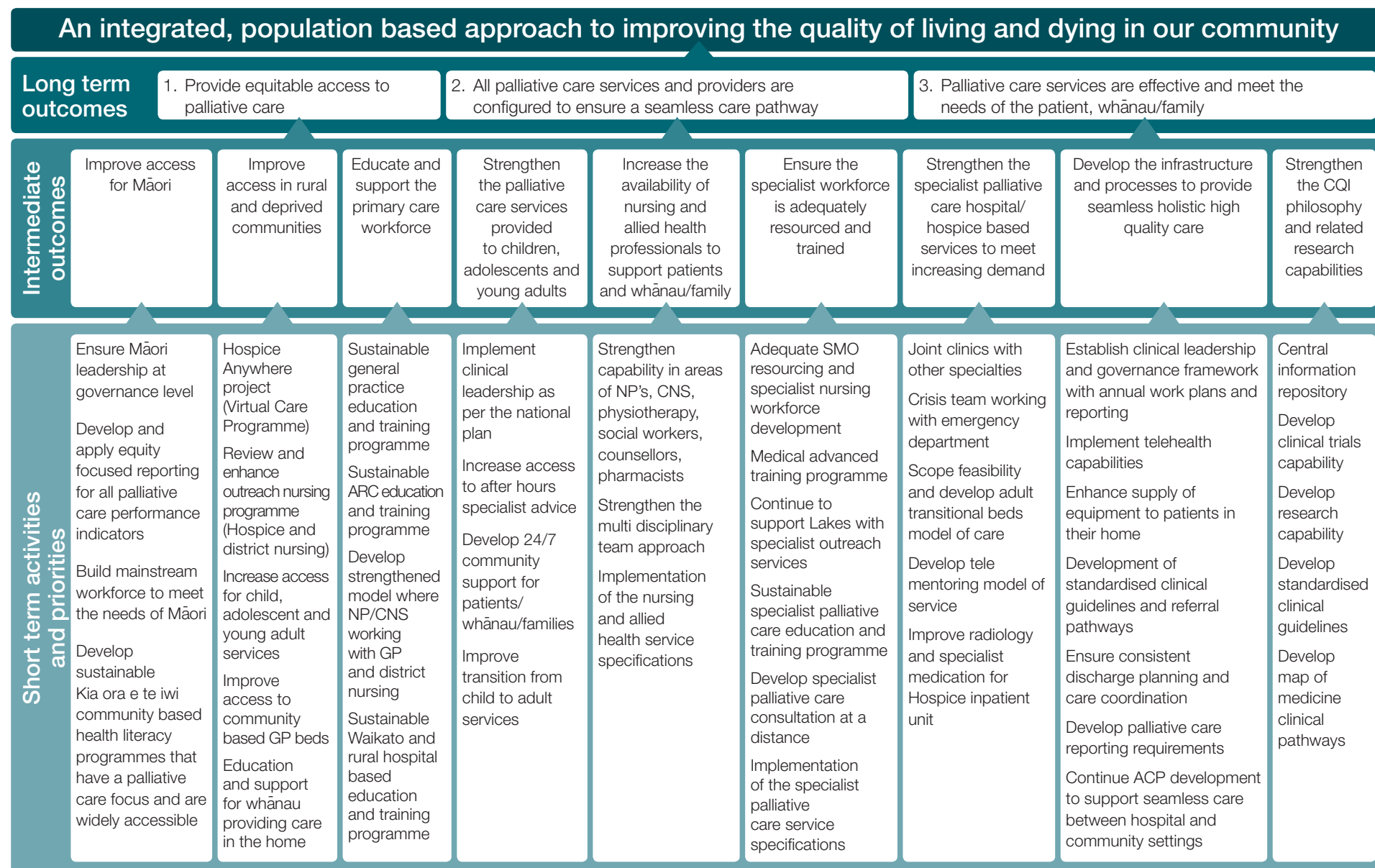
- There is a need for these beds for palliative patients not actively dying but who are not suitable for hospital level of rest home care either because of age or complexity of their condition.

Palliative care in General Practice

- Support offered by nurse practitioners or palliative care clinical nurse specialists working in concert with the GP and district nursing service needs to be significantly expanded to ensure continued GP involvement in palliative care.

Primary health care professionals should have access to the telementoring described earlier.

Appendix G – Waikato Palliative Care Outcomes Framework



NOTE: Many of the short term priorities relate to more than one intermediate outcome

