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Sustainable funding for hospice services

Health and social impacts of specialist hospice palliative care and an economic case for investment
Final Report

05 September 2024
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Preface

This report has been prepared for a collective of Harbour, Nelson Tasman, Otago, Tōtara, and Waikato hospices by MartinJenkins (Martin, Jenkins & Associates Ltd).

For 30 years MartinJenkins has been a trusted adviser to clients in the government, private, and non-profit sectors in Aotearoa New Zealand and internationally. Our services include organisational performance, employment relations, financial and economic analysis, economic development, research and evaluation, data analytics, engagement, and public policy and regulatory systems.

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Purpose and scope of this report

The vision for New Zealand is that people live well and die well. People need to have confidence that at the end of their life they and their loved ones, if needed, will have access to high-quality palliative care that is consistent across all settings.¹

Purpose of this report

This report has been commissioned by a collective of five hospices: Harbour, Nelson Tasman, Otago, Tōtara, and Waikato. It provides quantitative evidence on the social and health impacts of hospice services, and presents an economic case for investing in sustainable hospice services, across the 28 publicly contracted hospices.

Caveats and limitations

The report is intended to support discussions with Health New Zealand and other agencies. Realising the full value from this work will require active and ongoing engagement with Health New Zealand, the Ministry of Health, and others.

Our financial modelling was based on financial and service datasets from the five commissioning hospices. We extrapolated out the results from these five hospices, to draw conclusions about financial sustainability across the 28 publicly funded hospices as a sector. As such, **our estimates should be regarded as indicative.**

There are considerable data limitations and analytical challenges with quantifying benefits. While there is a significant body of research that demonstrates the clinical benefits of hospice services, the design of studies does not always enable these benefits to be quantified and monetised. We reviewed many research papers and explored different options for quantifying benefits. The estimates presented in this report are based on our conclusions as to the most viable and evidence-based approaches. We have focused on evidence from peer reviewed academic research to inform our modelling assumptions.

Because we have taken a conservative approach, our quantification of benefits excludes several significant benefits. Significant unquantified benefits include:

- reduced ambulance callouts
- more appropriate care, including reduced over-treatment
- improved coordination of the health system, with accompanying resource savings

¹ Ministry of Health, *Palliative Care Action Plan* (Wellington: Ministry of Health, 2017), 2, <https://www.tewhātuora.govt.nz/publications/palliative-care-action-plan/>.



- training, education, and support for healthcare workers and informal caregivers
- reduced burden on caregivers
- support for the bereaved, contributing to improved wellbeing and potentially productivity.

This means that our estimates of the return on government investment in hospice services are under-estimates. Should a less conservative approach be taken, the benefits would increase accordingly. We make several recommendations for further research, that will help to quantify the benefits of hospices more fully in the future.

Report outline

This report is structured as follows.

- An **overview of the palliative care system**, and the role of hospices.
- The **current funding models for publicly contracted hospices**, and the pressures that these hospices are facing to the sustainable delivery of their services.
- Modelling of the **future demand for hospice services**, based on demographic projections, and assumptions about clinical need and receipt of hospice services.
- The estimated **funding shortfall for hospices**, based on projections of their revenue and direct costs.
- The **impacts of hospice services**. This section describes the social, health, and financial benefits of hospice services. It presents quantitative evidence of direct benefits to patients, and the wider community and health system. Where quantification was not possible, it presents a qualitative discussion of the benefits. Taken together with the costing projections in the previous section, this provides estimates of the **financial return on the government's investment** in the 28 publicly funded hospices.
- The **potential impacts on the palliative care system**, and wider health system, if hospices no longer existed. This section explores the implications for the health workforce, primary care caseload, inpatient capacity, and other elements of the health system. It is a qualitative discussion of a theoretical situation, as we lack information on how the health system might respond to this influx of demand, and the direct and indirect costs of providing hospice services in other ways. This lack of data precluded more quantitative methods such as economic impact analysis or cost-benefit analysis.
- **Recommendations** for steps to develop an immediate funding solution, and to expedite work towards a sustainable and equitable funding model for publicly contracted hospices.



Key findings

The palliative care system is facing mounting pressures. New Zealand's population is growing and ageing. The total number of deaths each year is projected to increase from 36,000 to around 53,900 by 2043. If the proportion of deaths receiving hospice services remains the same as now, demand for hospice care will grow by 53%, from 10,880 in 2023 to over 16,000 by 2043. The complexity of care required is also increasing as people are more likely to die at older ages, and with frailties and comorbidities such as dementia. The growing availability of clinical advances is also contributing to increased complexity of care, and resourcing pressure on hospices.

The palliative care system is complex and fragmented. The need for systems change has long been recognised. Work to build a sustainable and equitable palliative care system has been ongoing for more than two decades, but agreed actions have not been completed. The 2022 *Interim health plan* included actions to support a nationally consistent approach to palliative care funding and service delivery. Health NZ's work programme to deliver these actions is still in its early stages.

Hospices are experiencing challenges to the sustainable delivery of their services. The combination of growing demand and rising costs means many hospices are now facing imminent funding shortfalls. Our modelling shows that across the 28 publicly contracted hospices, total expenditure will exceed the total revenues from government and community sources, within the next 12 months.

In the absence of government intervention, hospices will need to take further and more clinically impactful action to manage this funding shortfall. Individually, they are taking actions to manage their costs and improve productivity, including through the use of technology and greater use of partnerships with complementary providers. Over time, they will also take steps to evolve their models of care. Progressive measures may include greater use of telehealth, more outpatient-based systems of care, providing intermittent episodes of care, discharging patients (who would otherwise stay on their service), prioritising which referrals they accept, and closing beds.

This will have impacts on the sustainability of the wider palliative care system, and flow-on impacts to other areas of the health system. The urgency of implementing a nationally agreed and equitable funding model for publicly contracted hospices services is now acute.

Evidence shows that hospice services take pressure off the wider health system. They deliver cost savings such as fewer hospital admissions, ED visits, ambulance callouts, and clinical care events in the community (for example, at home or in aged residential care). They provide benefits to individuals such as improved quality-of-life from better pain and symptom control. Hospices also provide support for informal caregivers and the bereaved, which can translate into social and economic benefits, such as the ability to productively return to work.

Our modelling shows that **for every \$1 the government invests in hospices, it generates at least \$1.59 in benefits**. These benefits include healthcare cost savings, as well as benefits to individual patients in terms of the cost savings from avoided GP visits (patient co-payments), and more significantly, the quality-of-life benefits arising from improved pain and symptom control.



Looking at just the direct cost savings to government, **for every \$1 the government invests, it receives \$1.08 in cost savings across the healthcare system.** On this basis alone, the government is getting a valuable return on its investment.



The palliative care system is fragmented, complex, and at risk of collapse

The palliative care system is facing mounting pressures

The number and complexity of deaths is increasing

New Zealand's population is growing and ageing. The total number of deaths each year is projected to increase from 36,000 to around 53,900 by 2043.² If the proportion of deaths receiving hospice services remains the same as now, demand for hospice care will grow by 53%, from 10,880 in 2023 to over 16,000 by 2043.

In addition to this growth in demand, the complexity of care required is also increasing as people are more likely to die at older ages, and with frailties and comorbidities such as dementia and other non-communicable diseases. These trends are all placing pressure on the palliative care system.

The need for system change has long been recognised...

Work to build a sustainable and equitable palliative care system has been ongoing for over 20 years (see timeline in Appendix 1). Numerous reports, strategies, and plans have been developed. The Ministry of Health's 2017 *Palliative care action plan* stated that:

All sectors recognise the imperative to prepare for these trends. In the health sector, our system needs to change to meet the growing demand for palliative care [...] So it is in everyone's interests to plan now for a refreshed direction for palliative care to meet increasing demands on (and expectations of) palliative care services and service providers.³

... but agreed actions have not yet been completed

The *Action plan* included commitments to define a care or service model for palliative care (including minimum service expectations), define financial and commissioning models, and develop estimates of the costs, benefits, resources, and capability needed. This work has not yet been completed.

² Heather McLeod, 'Palliative Care Projection Model' (Health New Zealand | Te Whatu Ora, June 2023), <https://view.officeapps.live.com/op/view.aspx?src=https%3A%2F%2Fwww.tewhatauora.govt.nz%2Fassets%2Fuploads%2FPalliative-Care-Projection-Model-vF-June-2023-v2.xlsx&wdOrigin=BROWSELINK>.

³ Ministry of Health, *Palliative Care Action Plan*, p. v.



More recently, *Te Pae Tata – Interim health plan 2022* included actions to support a nationally consistent approach to palliative and end-of-life care planning, funding, service delivery, and outcomes.⁴

In mid-2022, the hospice sector, unable to wait further for action, elected eight representative Chief Executives to work with Hospice New Zealand, to form the Equity and Sustainability Pathway Group (ESP). This group has a formal Terms of Reference and is charged with using national data and international best practice to develop a new commissioning model, service network approach, and expected minimum services for each region. The aim is to deliver an equitable and sustainable sector solution to government in line with the objectives of the health reforms. To date, the group has proposed a regional approach to services, developed a set of core hospice service components, and is in the final stage of interrogating a rich dataset of activity, service, and cost.

In 2023, Health New Zealand developed a parallel process across the palliative care system – the Palliative Care Steering Group. With a series of sub-committees, this Steering Group is responsible for developing a palliative care work programme.⁵ This work programme is still in its early stages. Its initial focus included:⁶

- Providing recommendations on achieving equitable access to, and outcomes from, palliative care services for all New Zealanders.
- Identifying and recommending core palliative care services that will be publicly funded.
- Developing a national model for paediatric and adult palliative care.
- Proposing national adult specialist palliative care service specifications and costings.
- Providing recommendations to sustain a clinically, and culturally, competent diverse workforce.

The ESP group is keen to collaborate with the Palliative Care Steering Group to minimise duplication that may unnecessarily extend timeframes for an effective response.

⁴ Health New Zealand | Te Whatu Ora and Te Aka Whai Ora - Māori Health Authority, 'Te Pae Tata Interim New Zealand Health Plan 2022' (Health New Zealand | Te Whatu Ora, 2022), <https://www.tewhatauora.govt.nz/publications/te-pae-tata-interim-new-zealand-health-plan-2022/>.

⁵ Health New Zealand | Te Whatu Ora and Te Aka Whai Ora - Māori Health Authority.

⁶ Health New Zealand, 'National Palliative Care Work Programme', Health New Zealand | Te Whatu Ora, 23 November 2023, <https://www.tewhatauora.govt.nz/for-the-health-sector/specific-life-stage-health-information/palliative/national-palliative-care-work-programme/>.



Palliative care supports people of all ages

Palliative care has its origins in supporting the needs of cancer patients, often in a hospice setting. Over the years, it has expanded well beyond caring for people with cancer. In New Zealand and internationally, it is now recognised as care for people of all ages, including children, with any life-limiting or life-threatening condition, and the care setting can be in a hospice but most care will be provided where the patient lives. Palliative care aims to:

- optimise an individual's quality-of-life until death by addressing the person's physical, psychosocial, spiritual, and cultural needs, and
- support the individual's family, whānau, and other caregivers where needed, through the illness and after death.⁷

The complexity of care required for patients is determined by their individual circumstances, including their age, primary disease, the presence of comorbidities, their physical symptoms, and psychosocial factors. Palliative care may be continuous or episodic, and may be provided for days, weeks, months, or in some cases, even years before death.

Primary palliative care is provided by community and hospital-based staff

Primary palliative care is part of the standard clinical practice of any health care professional. It is provided in the community and in hospitals by individuals and organisations, including general practice teams, Māori health providers, allied health teams, district nurses, aged residential care (ARC) staff, and hospital staff.

Patients with more complex needs may require specialist palliative care

For complex cases, where symptoms are severe and require additional management, where there are comorbidities, or where there are psychosocial issues, **specialist palliative care** may be required.⁸ Specialist palliative care requires a high level of specific training and/or accreditation in palliative care or medicines, and is provided in the context of an expert interdisciplinary team of palliative care professionals. Specialist palliative care may be provided by hospices or hospital-based palliative care services where people have access to, at least, medical and nursing palliative care specialists.⁹ **This report focuses on specialist palliative care provided by hospices.**

⁷ Ministry of Health, 'New Zealand Palliative Care Glossary' (Wellington: Ministry of Health, 2015), 12.

⁸ Hospice Waikato, 'What Does a Tertiary PCU Look like? (Unpublished)' (Hospice Waikato, 2023).

⁹ Ministry of Health, 'New Zealand Palliative Care Glossary', 16.

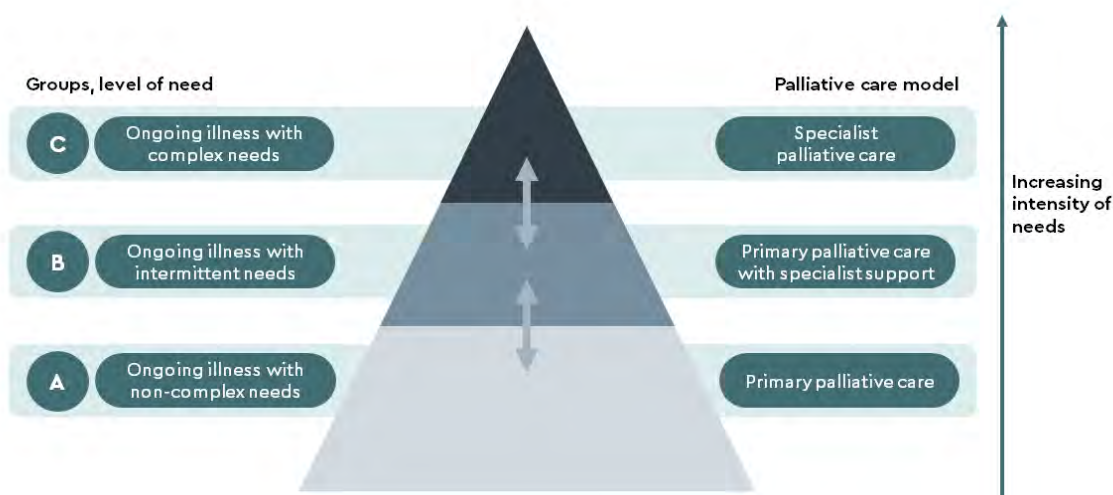


Patients may transition between services and care settings

Figure 1 illustrates the continuum of palliative care based on the needs of types of patients and cases. Patients may move between primary and specialist palliative care through the course of their care journey, and may transition between care settings (such as their home, ARC, hospital, or hospice). These transitions mean that coordination and integration across different services is important for the continuity and quality of patient care.

This "triangle of need" is a traditional model, which is under pressure from the demographic trends outlined above – including the ageing population and growing complexity of need, and by significant workforce pressures in aged care and primary care.

Figure 1: A model of palliative care need within a population of patients who have a life-limiting or life-threatening condition



Source: Adapted from Palliative Care Australia (2005)¹⁰

Notes: Arrows indicate that patients may move between groups

The palliative care system is complex and fragmented

New Zealand's palliative care system involves a complex range of providers and contracting and funding arrangements.

¹⁰ Palliative Care Australia, 'A Guide to Palliative Care Service Development: A Population Based Approach' (Palliative Care Australia, 2005), <https://palliativecare.org.au/wp-content/uploads/2015/05/A-guide-to-palliative-care-service-development-a-population-based-approach.pdf>.



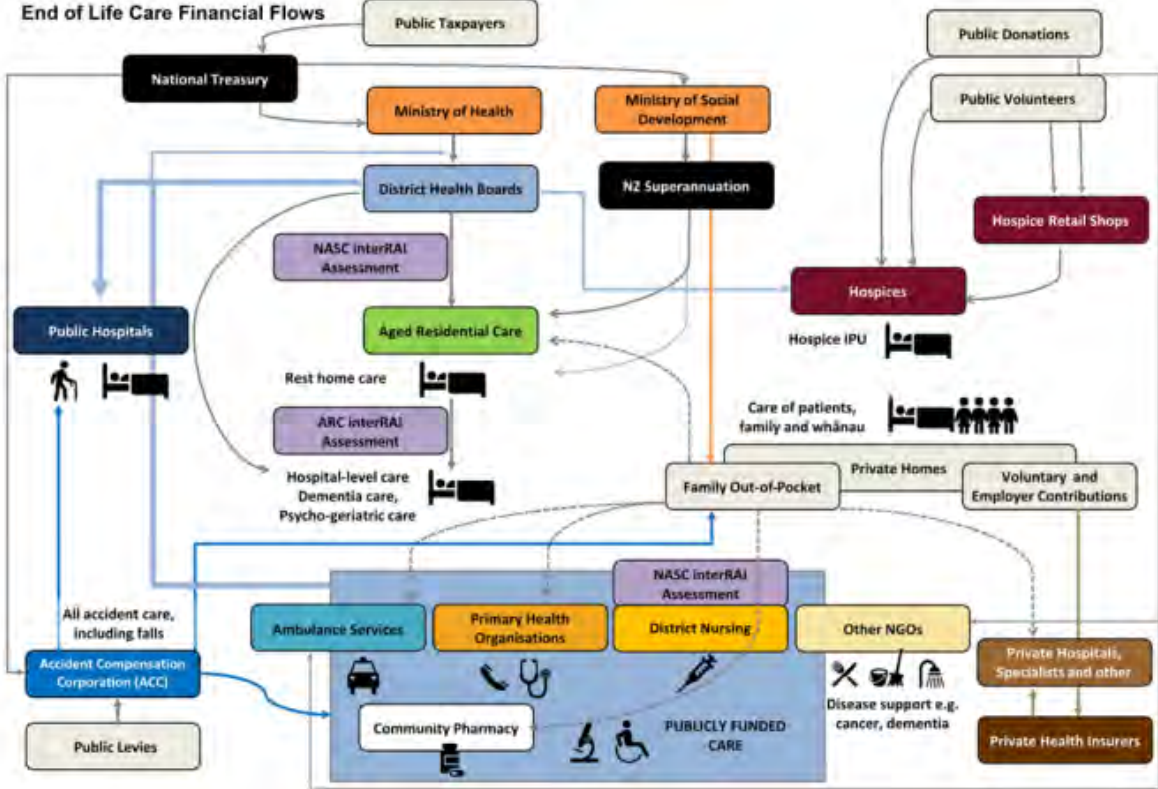
- The **Ministry of Health** is responsible for policy development, strategies that align with national healthcare objectives, ensuring adherence to established standards and best practices. It oversees funding allocation to support palliative care services provided by hospices, hospitals, primary health organisations, and community-based providers.
- **Health New Zealand** is tasked with developing a comprehensive palliative approach to planning, funding, service delivery, and outcomes for palliative and end-of-life (EOL) care across New Zealand. Health New Zealand has contractual arrangements with various entities including hospices, hospitals, primary health organisations (PHOs), and ARC facilities.
- **Hospitals** are managed and funded by Health New Zealand. Palliative care services often integrate within broader service delivery, as many aspects of palliative care intersect with non-palliative care services, especially in managing long-term conditions. Notably, not all hospitals have dedicated specialist palliative care services.
- **Primary health organisations** (PHOs) deliver primary health care services, usually through general practitioners (GPs) practices, and are funded by Health New Zealand. Some PHOs allocate funding for primary palliative care services provided by GPs.
- The **hospice sector** has 28 hospices across New Zealand who receive partial funding from Health New Zealand. These funding contracts vary in terms of purchase units and duration, and in what palliative care services form the basis of the contracts.
- The **aged residential care** (ARC) sector in New Zealand includes retirement villages (which may be privately-owned commercial operations or not-for-profits) and rest homes. Health New Zealand funds ARC services in accordance with the Residential Care and Disability Support Services Act 2018. It has contracts with rest home or hospital owners to provide long-term residential care to residents who are eligible for government funding through the residential care subsidy.¹¹ Hospice teams often collaborate with these facilities to deliver specialised palliative care services to patients in these settings.

The complexity of the funding flows across the palliative care system is illustrated in the following diagram (Figure 2).

¹¹ Health New Zealand, 'Residential Care Questions and Answers', Health New Zealand | Te Whatu Ora, 30 August 2023, <https://www.tewhātuora.govt.nz/for-the-health-sector/specific-life-stage-health-information/health-of-older-people/long-term-residential-care/residential-care-questions-and-answers-2/>.



Figure 2: Financial flows for end-of-life care in New Zealand



Source: McLeod (2019)¹²

¹² Heather McLeod and June Atkinson, 'Policy Brief on Trajectories of Care at the End of Life in New Zealand' (Heather McLeod and Ministry of Health, 2019), 13.



Hospices are facing challenges to the sustainable delivery of their services

Hospices provide specialist palliative care services

Hospices deliver specialist palliative care services, to patients in the community (in their homes, and in ARC), in hospitals, and in their own tertiary palliative care units or inpatient units (IPUs).

Individual hospices have different models of service delivery. For example, around half of the hospices in New Zealand have IPUs.¹³ Inpatient facilities manage patients with complex or refractory symptoms, complex psychosocial/existential distress-related issues, and complex EOL care – that cannot be managed at home, ARC, or other facilities. These facilities provide an environment for multidisciplinary and interdisciplinary care that would be difficult to achieve in other care settings (that is, hospital, ARC, or at home).

Hospice teams comprise specialist medical professionals

Specialist palliative care is an internationally recognised medical specialisation. Hospice teams comprise health professionals who have specialist training or qualifications in palliative care. These include specialist palliative care nurses and nurse practitioners, as well as doctors – usually palliative medicine specialists and medical officers, and GPs – and allied health professionals, such as social workers, physiotherapists, occupational therapists, counsellors, psychologists, pharmacists, complementary practitioners, and cultural and spiritual care workers.¹⁴

Hospices also provide support for families and caregivers, and training and education for healthcare professionals

Hospices also support families and caregivers, providing education, counselling, and respite care. After a patient has died, hospices continue to provide bereavement support for families – this includes non-complex and complex bereavement care for adults, as well as non-complex and complex bereavement care for children.

¹³ Salina Iupati et al., 'Community Specialist Palliative Care Services in New Zealand: A Survey of Aotearoa Hospices', *New Zealand Medical Journal* 135, no. 1566 (2022): 36–48.

¹⁴ Iupati et al.



Some hospices are tertiary clinical teaching sites for undergraduate and postgraduate health professional programmes (nursing, medicine, social work, occupational therapy) and some are also accredited for palliative medicine specialist and nurse practitioner training. Their tertiary education role includes educating universities and other training providers.

Hospices play an important role in building capacity and capability in the palliative care workforce. They offer structured and informal education and training of health and social service providers across the sector – staff in hospitals, GP practices, ARC facilities, and long-term-condition NGOs (for example, Dementia New Zealand and Alzheimer's New Zealand) and social care agencies.

Hospice staff also provide a specialist consultation service that supports medical professionals who are caring for palliative patients, including GPs and ARC staff. This is a 24/7 service, usually run out of a specialist hospice IPU.

Action is urgently needed to maintain hospice services

The urgency of completing a nationally agreed and equitable funding model for hospice services is now acute. The combination of growing demand and rising costs means many hospices are now facing funding shortfalls. For example, based on the data from the five commissioning hospices, we found that the unit costs of inpatient services have increased by 16% a year from 2019 to 2023 (an increase of 78% over four years). The total costs of inpatient services increased 48% over the four-year period.

Over time, hospices will take steps to adjust their models of care in response to funding shortfalls. Progressive measures may include greater use of telehealth, more outpatient-based systems of care, providing intermittent episodes of care, prioritising which referrals they accept, and closing beds. This will have impacts on the sustainability of the wider palliative care system, and flow-on impacts to other areas of the health system. We discuss what these impacts might be in the section "What if hospice services didn't exist?" (see page 40 onwards).

Hospices are funded through a mix of government contracts and fundraising

Hospices rely on a combination of government funding, public donations, and grants. Some hospices have retail businesses that predominantly sell second-hand clothing and goods, to provide additional revenue. Hospices self-fund their buildings and other capital assets. Hospice buildings and retail operations provide important community engagement spaces and meeting venues for the wider community, and in themselves provide an important social good, community, and education role. In aggregate, this is a significant capital investment.



Figure 3 shows the proportion of revenue for the 2023 financial year by source, across the five commissioning hospices. It shows that government contracts are the largest proportion of revenue, at 48%, followed by retail revenue at 30%. The percentage from each funding source varies from year to year, with Health New Zealand contracts ranging from 46% to 53% over the past five years.

Figure 3: 2023 revenue for the five commissioning hospices, by source



Source: MartinJenkins analysis of administrative data from the five commissioning hospices.
Note: "Other revenue" includes grants, donations, bequests and bank interest.

Government funding has not adjusted for rising costs

The amount of government funding varies across hospices, depending on the type and level of services provided, and historic contractual arrangements. The proportion of operating costs covered by the government funding contribution therefore differs across individual hospices.

In 2000/01, government funding equated to around 50% of operating costs, on average.¹⁵ In 2009, the government provided additional funding to, theoretically, increase the average proportion to 70%. The way this funding was apportioned benefitted the better resourced hospices and over time increased the inequity of funding. This, coupled with further one-off funding injections and inconsistent inflation adjusters, means that government funding does not account for significant rises in costs.

Growth in the volume and complexity of demand, together with increases in the cost of inputs to provide services, has eroded the proportion of government funding to less than 50% of operating costs in 2023.

Hospices provide their services free of charge to patients. This means they cannot increase their prices or fees to cover the rising costs of inputs.

¹⁵ Ministry of Health, *The New Zealand Palliative Care Strategy* (Wellington, N.Z.: Ministry of Health, 2001).



This has placed pressure on fundraising from the community

As a result, hospices have had to increase the amount of funding they raise from the community (donations and retail), and from grants. Hospices are finding it difficult to continue growing revenue from these sources.

Hospice services rely on significant inputs from volunteers

In addition to direct funding, hospices rely heavily on a hybrid workforce of paid staff and volunteers to operate their services affordably. Volunteers' contributions allow hospices to offer a broader range of support services to patients and their families. In 2023, volunteers provided hospices with over one million volunteer hours, comprising 36% of total hours worked for hospices.¹⁶

While volunteers play a vital role in providing services and revenue streams for hospices, they do require inputs from hospice staff, such as the time and costs of recruiting, onboarding and training, supervising, administering, and maintaining a large volunteer workforce.

Ensuring pay equity is a significant challenge

Some hospices are faced with a difficult decision when it comes to pay parity for their skilled and experienced staff. They can pay their staff comparably with their counterparts in Health New Zealand and face a deficit; pay their staff less than their counterparts and run the risk of staff attrition; or reduce services to fit staffing levels.

The challenges in providing competitive remuneration for palliative care medical specialists was recognised in 2009 by the Ministry of Health as "one of the biggest – if not the biggest – workforce issue".¹⁷ In recent years, problems with recruiting and retaining staff have been exacerbated by pay relativities with Health New Zealand staff and by overall cost-of-living pressures.¹⁸

In July 2023, the government through the then-Minister of Health, provided \$11.5 million from Vote: Health to hospices to try to close the resulting pay gaps between the public health sector and hospice sector.¹⁹ This was in response to flux within the health labour market that resulted as an outcome of

¹⁶ Based on data from the Charities Register, for the 28 publicly funded hospices.

¹⁷ Ministry of Health and Central Region TAS, 'Gap Analysis of Specialist Palliative Care in New Zealand: Providing a National Overview of Hospice and Hospital-Based Services' (Wellington: Ministry of Health, 2009).

¹⁸ Minister of Health, 'Addressing the Impacts of Pay Disparities in the Health Funded Sector', Cabinet paper (Wellington: New Zealand Government, 25 January 2023), https://www.health.govt.nz/system/files/documents/information-release/cabinet_paper_addressing_the_impacts_of_pay_disparities_in_the_health_funded_sector.pdf.

¹⁹ Hospice New Zealand, 'Hospice Welcomes Funding Boost to Address Pay Parity', *LinkedIn* (blog), 16 June 2023, https://www.linkedin.com/posts/hospice-new-zealand_hospice-welcomes-funding-boost-to-address-activity-7075269352635174912-fYxh/.



public health sector settlement agreements, especially across nursing. This contribution improved terms and conditions but did not achieve pay equity.

Despite this effort to help close the pay gap, hospice staff, including kaiāwhina and allied health, are still being paid less.²⁰ At the same time, hospices are facing ongoing cost pressures from pay equity negotiations. For example:

- Recent collective bargaining agreements for nurses resulted in a total pay increase of 8-10% over two years, along with 6-10% increase on penal rates and allowances.
- Salaries for allied health and social and cultural support staff increased between 9% and 22%, as a result of Health New Zealand's March 2024 agreement.
- Salaries for social workers increased 45-55% following the social work pay equity claim led by Oranga Tamariki. The new pay scale for social workers came into effect in October 2023, requiring year-on-year increases.

Rural patients may face barriers to accessing hospice services

Providing community-based hospice services to patients living rurally requires additional travel time and vehicle costs. The travel time, combined with geographically dispersed populations, means hospices must take on smaller caseloads in rural areas.

Rural patients can also face barriers to accessing IPU hospice services, including travel distance, and the direct and indirect costs to themselves and their families with relocating to receive inpatient services.

Distance is a significant barrier, and rural communities are disadvantaged in terms of access to specialist care. Research using a new protocol for classifying rural and urban areas found a consistent pattern of higher mortality rates for rural populations compared to urban populations.²¹ Access to specialist services and to secondary care is variable across rural New Zealand. A recent study of interhospital transfers from six rural hospitals in New Zealand found that most (73%) were transferred to an urban hospital because that intervention or investigation was not available at the rural hospital.²² While some rural patients have access to a secondary care hospital, few, if any, have access to a hospital palliative care team.

²⁰ Hospice New Zealand, 'Fund Hospice Fairly', Hospice New Zealand, 2023, <https://www.hospice.org.nz/get-involved/fund-us-fairly/>.

²¹ Garry Nixon et al., 'Comparison of Urban and Rural Mortality Rates across the Lifespan in Aotearoa/New Zealand: A Population-Level Study', *Journal of Epidemiology and Community Health* 77, no. 9 (September 2023): 571-77, <https://doi.org/10.1136/jech-2023-220337>.

²² Rory Miller et al., 'A Retrospective Observational Study Examining Interhospital Transfers from Six New Zealand Rural Hospitals in 2019', *Australian Journal of Rural Health* 31, no. 5 (October 2023): 921-31, <https://doi.org/10.1111/ajr.13024>.



As discussed below, we tried to do sensitivity analysis on the differences in services and costs between rural and urban patients. We faced a number of data challenges, and in our recommendations section we identify that further analysis is needed to quantify the inequities for those living in rural areas in need of hospice care. The new research protocol for rural-urban classification for New Zealand health research policy²³ mentioned above could be useful for future research.

Evidence indicates that there will be variation in how different communities access and use palliative care.²⁴ This will need to be accounted for when planning the future care need, as there will be local deviations from national patterns.

COVID-19 affected individual hospices in different ways

COVID-19 had a significant impact on hospices. It resulted in over 24 months of disruption to revenues and service delivery. Its impact was felt differently across individual hospices, due to differences in their revenue structures (the extent to which they are dependent on revenue from retail operations) and geographic location (with those in Auckland experiencing more lockdowns).

During lockdowns, hospices with retail arms were unable to operate their stores, and many fundraising events were cancelled. A one-off funding boost of \$7.35 million was provided from Vote: Health across the 28 hospices. Some hospices with retail staff also received the wage subsidy from the Ministry of Social Development, though this, in itself, did not compensate for revenue losses.

Hospices experienced changes in the nature of demand and in service delivery, that differed across districts. For example, some saw a shift away from IPUs towards more care provided in the community. They also experienced workforce retention, recruitment, and productivity challenges, some of which are ongoing.

²³ Garry Nixon et al., 'Developing the Geographic Classification for Health, a Rural-urban Classification for New Zealand Health Research and Policy: A Research Protocol', *Australian Journal of Rural Health* 29, no. 6 (December 2021): 939–46, <https://doi.org/10.1111/ajr.12778>.

²⁴ McLeod, 'Palliative Care Projection Model'.



The future demand for hospice services

Around a third of people use hospice services as part of their end-of-life trajectory

Using data from actual deaths in 2015, McLeod and Atkinson estimated that 90% of total deaths (around 28,000 people) needed palliative care.²⁵ Considering hospice care alone, approximately 9,500 people used hospice as part of their EOL trajectory. This means that hospices supported around 33% of those needing palliative care, and around 30% of all deaths in New Zealand.

The demand for hospice services is projected to increase by 53% over the next 20 years

We projected the future demand for hospice services, based on demographic projections, and assumptions about clinical need and receipt of hospice services.

Our modelling builds on the Palliative Care Projection model prepared for the Ministry of Health and Hospice NZ by Heather McLeod in 2019, and updated in 2023.²⁶ This model uses Stats NZ's projections of deaths by age group, ethnicity, and districts. It includes projections of broad categories of EOL conditions (including dementia, cancer, chronic disease, and sudden deaths), along with projected hospice use.

Under this assumption, the total number of deaths receiving hospice care grows by 31% over the next 20 years, to over 14,000 by 2043.²⁷

Traditionally, those with cancer are a higher proportion of hospice patients than other causes of death. For example, according to the model's projections for 2023, cancer was 68% of hospice service users, while cancer was 26% of all deaths in New Zealand. Similarly, while dementia-related deaths were a relatively low user of hospice services, they comprised 54% of ARC patients (which includes patients who may access ARC and hospice services).

²⁵ McLeod; Heather McLeod, 'National Model Need for Palliative Care', 2019.

²⁶ McLeod, 'Palliative Care Projection Model'; McLeod, 'National Model Need for Palliative Care'.

²⁷ While the total number of deaths receiving hospice care grows, the proportion of people receiving hospice services declines as a proportion of both deaths needing palliative care, and total deaths. This is because the number of deaths from cancer, and in the cohort aged over 65 years, both decline as a proportion of total deaths over the projection period. Both these cohorts currently comprise a significant proportion of referrals to hospice.



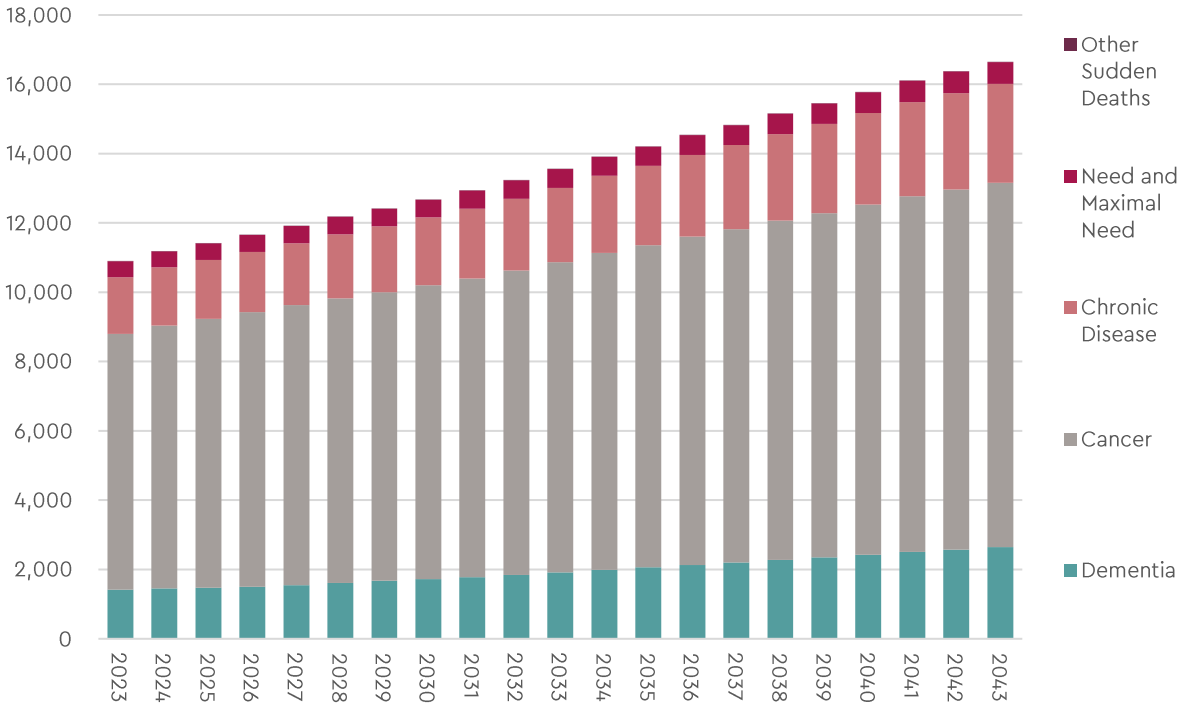
For the purposes of our modelling, we have assumed that the proportion of deaths needing palliative care in a hospice setting remains the same over the projection period (33%). This reflects the hospice sector's strategy of continuing to increase access and move away from the stereotype of being the "cancer facility". It also reflects other factors driving increased uptake of hospice services, including the pressures on ARC beds (the Palliative Care Projection Model assumes ongoing growth and availability of ARC beds, which is not the current reality).

We have also modelled a scenario in which hospice demand increases as a proportion of deaths needing palliative care, from the current 33% to the ESP Group's target of 35%.

Under our base case, the demand for hospice services is projected to increase by 53%, from 10,880 in 2023 to 16,639 by 2043 (Figure 4).

Figure 4: Projected demand for hospice services

Number of patients (deaths) receiving hospice services, total national hospice sector



Source: MartinJenkins modelling, based on McLeod's 2019 model and Stats NZ demographic projections.



Meeting the future demand for hospice services

Key modelling assumptions

We have made several important assumptions in our approach to modelling the future costs and revenues of hospice services.

- Total revenue remains static in real terms, just growing in line with inflation.
- **The current approach to Crown funding continues.** Specifically, we have assumed that Crown revenue accounts for 50% of hospices' operating costs over the long term. This is the average Crown contribution rate for the five commissioning hospices over the last five years.
- All non-Crown revenue goes toward covering costs. This will **over-state the non-Crown revenue available**. This is because hospices have different approaches to the accounting treatment of bequests, and not all hospices can access bequests for operating costs.
- In our base case, we have assumed that **hospices maintain their current share of demand**, that is, the proportion of deaths needing palliative care that receive hospice services (33%). We have also modelled **a scenario where hospices provide services to 35% of deaths needing palliative care**, which is consistent with the ESP target.

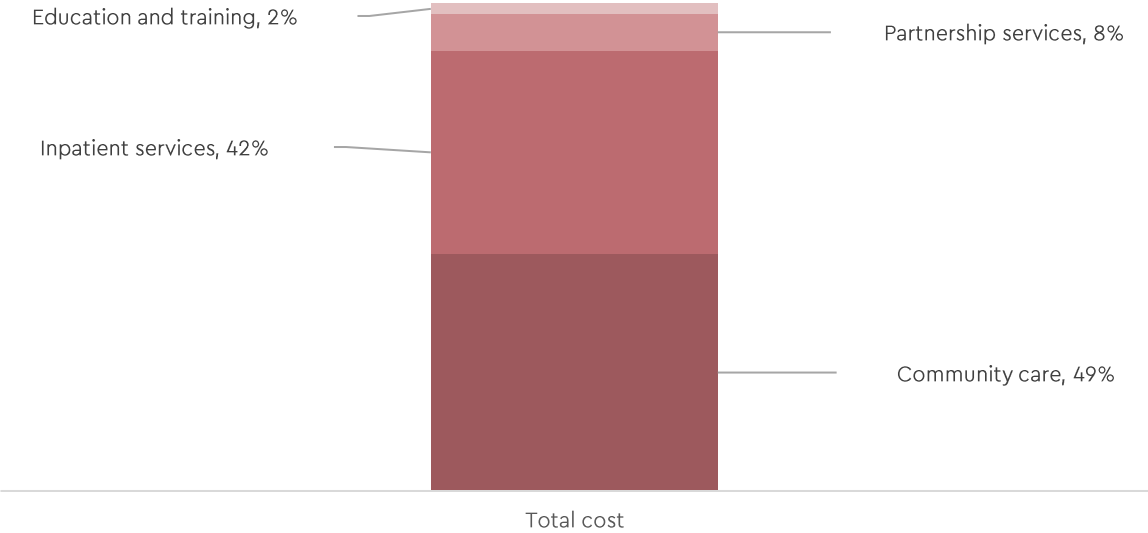
Community care accounts for 49% of costs, and inpatient services for 42%

The following two charts show the composition of costs, across the five commissioning hospices. On the following pages, we describe our approach to analysing and modelling the costs and volumes.

Figure 5 presents the costs of the four major categories of services. It shows that community care events comprise about half of the total costs. Inpatient services account for 42% of costs, with the balance comprising partnership services (8%), and education and training (2%).



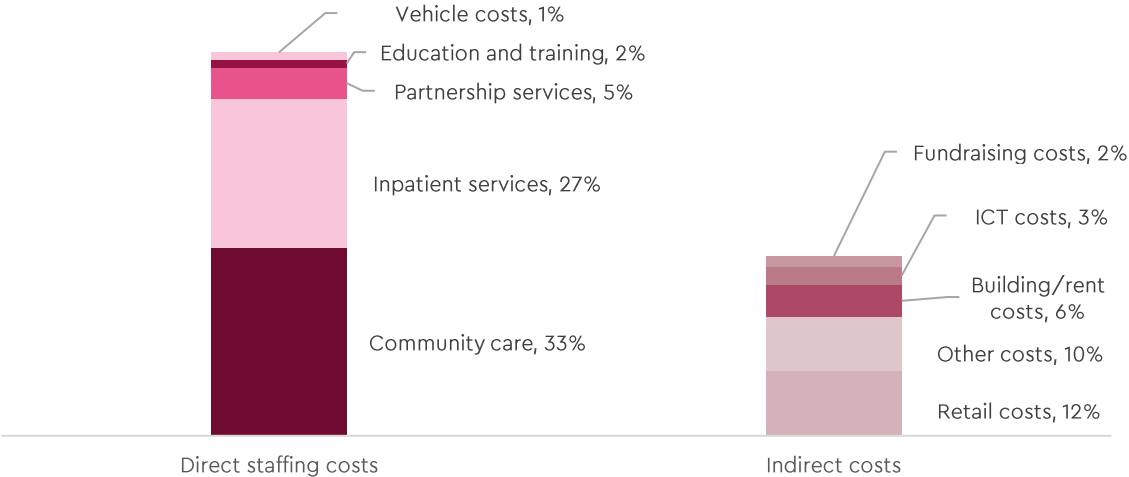
Figure 5: Comparison of total costs for the five commissioning hospices, by category of service



Source: MartinJenkins analysis of data from the five commissioning hospices.

Figure 6 shows a breakdown of cost components, again for the five commissioning hospices. Direct staffing costs account for 68% of costs, and indirect costs (such as retail, ICT, and building costs) for 32%.

Figure 6: Components of costs for the five commissioning hospices



Source: MartinJenkins analysis of data from the five commissioning hospices.



The future costs of service delivery are increasing...

We estimated the direct and indirect financial costs associated with our projections of future demand. There were four steps to this modelling.

1. We created an underlying **dataset on current hospice service delivery**, based on data from the five commissioning hospices. This data included information such as the demographics of patients, referral information, services available, and the volumes of services provided between the 2018 and 2023 financial years, including the number of days those patients spent in the IPU. We consolidated this information into a single dataset with all services classified according to consistent definitions. We also mapped our consolidated dataset against the Hospice Service and Variation Costings Model (HSVC)²⁸ to develop consistent definitions of service lines.
2. We used this base data model and HSVC data to develop a **financial model** that quantifies the unit cost of each service provided by hospice.
3. We then took the expected number of deaths over the next 20 years from our demand projections, and the unit costs per patient who died in 2023, to model the anticipated **costs required to meet future demand**.

For the first three years, all costs (direct and indirect) were increased by 4.0%, 3.5%, and 3.0% a year respectively, to take account of the wage pressures that hospices are facing from recent collective employment agreement bargaining (and reflecting that staffing is the primary cost driver).

For the remaining outyears, direct staffing costs were increased by the historical 10-year annual average Health Care and Social Assistance mean earnings index of 3.4%. Indirect costs (including building, rent, and ICT costs) were increased by the historical 10-year annual average Consumer Price Index of 2.7%.

4. We **extrapolated out the costs for the five hospices, to create an aggregate, national picture** (at the level of all 28 government funded hospices). To do this, we scaled up the data from the five hospices, to maintain hospices' current share of total projected deaths.

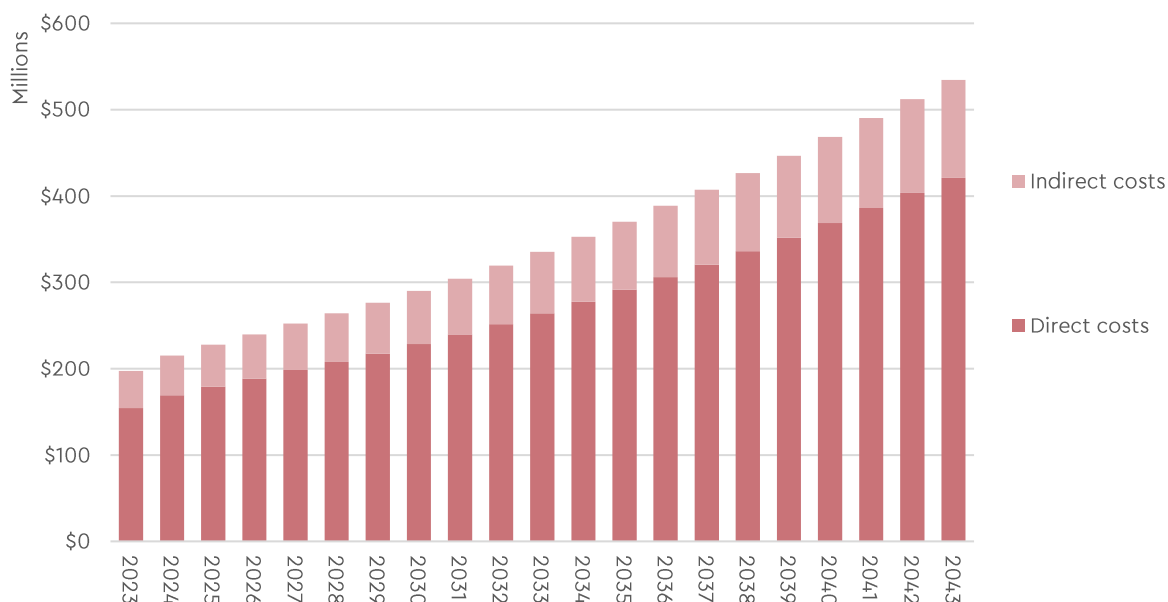
The base case assumptions show that the aggregate costs of hospice service delivery will rise from \$197.5 million a year in 2023 to \$534.4 million a year by 2043, an increase of 171% (Figure 7). These costs are just to keep pace with the expected growth in demand and inflation, and assume no increase in service levels, and no change in the proportion of deaths receiving specialist palliative care from hospice. Most of the cost growth (78%) is due to the impact of inflation, with the remaining 22% due to growth in patient numbers.

²⁸ The HSVC is a project established by the Hospice New Zealand ESP Group which has members across all 28 of New Zealand's government-funded hospices. It takes key datasets from hospices clinical care services and looks to better explain the inconsistencies and challenge of core service provision in specialist palliative care.



Figure 7: Projected financial costs of hospice service delivery

Annual aggregate direct and indirect financial costs for the 28 publicly funded hospices



Source: MartinJenkins modelling, based on data from the five commissioning hospices, HSVC data, McLeod (2019), Stats NZ.

The value of volunteer time

Our costing projections do not include the unpaid volunteer time that goes into delivering hospice services. If this time was valued at the living wage, it would equate to \$27.1 million in 2023. If the activities undertaken by volunteers were met by the paid workforce, the costs would be higher by at least this amount.

We note that volunteering provides benefits to the volunteers themselves, and to wider society. These benefits are discussed further in the next section.

... and projected revenues do not keep up

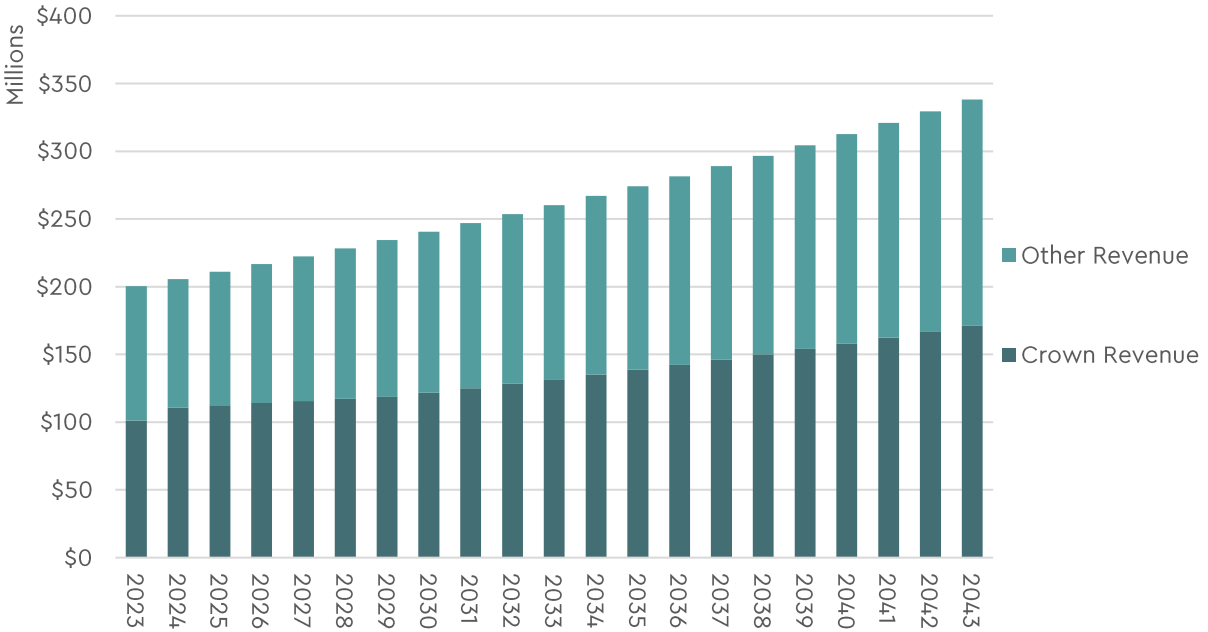
Our revenue modelling focussed on core funding for direct delivery of care to patients. We have excluded government funding provided for innovation initiatives, such as Poi.²⁹ We have also "looked through" the one-off funding boosts provided through COVID-19.

²⁹ Poi is a palliative outcomes initiative delivered by all the specialist hospices in Auckland. It provides education and specialist advice to GPs, GP practices, and ARC facilities, to enable them to provide a palliative approach to care. It was funded by Ministry of Health through a fund ring-fenced for service innovation.



We have assumed that total revenue will grow annually in line with general inflation. We used the 10-year historical annual average Consumer Price Index rate of 2.7% per year to achieve this, with both Crown and other revenue growing annually. The pay equity settlement caused the Crown contribution rate to exceed 50% in 2023/24, so we return the Crown funding contribution to this 50% over a 5-year period (Figure 8). We have not accounted for further pay equity contributions, as we do not know if this will be rolled forward in the future.

Figure 8: Projected hospice revenues
Annual aggregate revenue for the 28 publicly funded hospices



Source: MartinJenkins modelling, based on data from the five commissioning hospices.

There is a funding shortfall from 2024

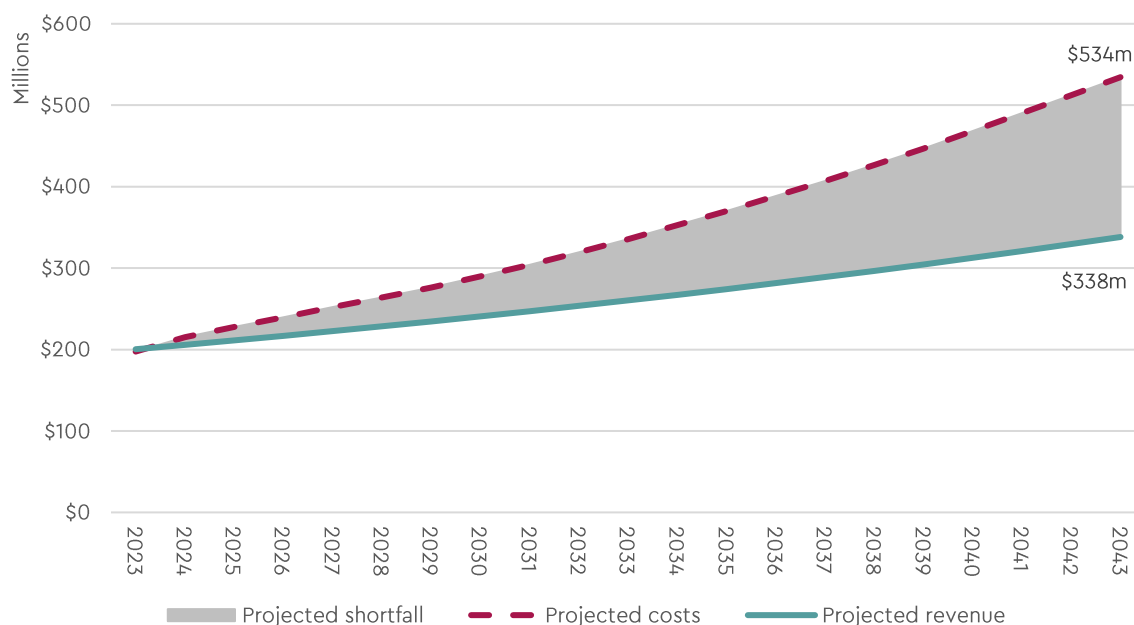
Under the base case, our modelling shows that the hospice sector's costs will exceed revenues within the next 12 months (Figure 9). The annual funding shortfall grows from \$9.4 million in 2024 to \$196 million by 2043.

Our modelling was on an aggregate, annualised basis, so the nature and timing of shortfalls for individual hospices will vary by organisation.



Figure 9: Projected funding shortfall

Annual aggregate funding shortfall, total national hospice sector



Source: MartinJenkins modelling, based on data from the five commissioning hospices.

We explored several ways of testing the assumptions in our projections

Exploring equity of access for rural patients

As noted above, rural patients may face barriers to accessing hospice services that contribute to inequities between rural and urban populations. We tried to explore the differences in access between rural and urban populations, and to investigate any differences in costs for rural patients.

We struck several problems, including:

- Patient identifiable data (such as addresses) at a granular level was not possible to access due to privacy and hence the dataset was not complete.
- At a conceptual level, analysing equity of access also requires assumptions about the model of care for delivering services to rural patients.

To assist further investigation of this issue, it would be useful to have an agreed taxonomy of rural and urban areas that could be applied to such analysis, and a sector-wide conversation about the models of care for rural delivery. As noted above, the research protocol developed for rural-urban



classification for New Zealand for health purposes could be useful for future research.³⁰ We have made recommendations for this future work in the final section.

An increasing burden of chronic disease

Our costing projections assume that the resources and effort required per patient remain static over the projection period, but that the price of these inputs rises in line with inflation.

We also assume that the disease profile of patients remains the same. The five commissioning hospices report that they are seeing stronger growth in patients with chronic disease than is suggested by McLeod's model (which uses 2015 data as its base). This has implications for the unit cost of patients, as different morbidities have different service profiles in terms of episodes of care, duration of engagement with hospice, and IPU bed nights.

We explored data on services and costs from the five hospices, to try and generate alternative assumptions for our demand and cost modelling. We identified some problems with the data:

- not all diagnoses are recorded in the system at the time of referral
- some diagnoses are recorded in a way that does not align to the trajectory groups
- there is a much lower proportion of diagnosis associated with dementia, than is projected in the Palliative Care Projection Model, and
- as with population demographics, disease profiles vary across the five commissioning hospices.

We were therefore unable to model alternative disease profiles. This is an area that could benefit from further work, and is noted later in our recommendations section.

A greater proportion of patients supported by hospice

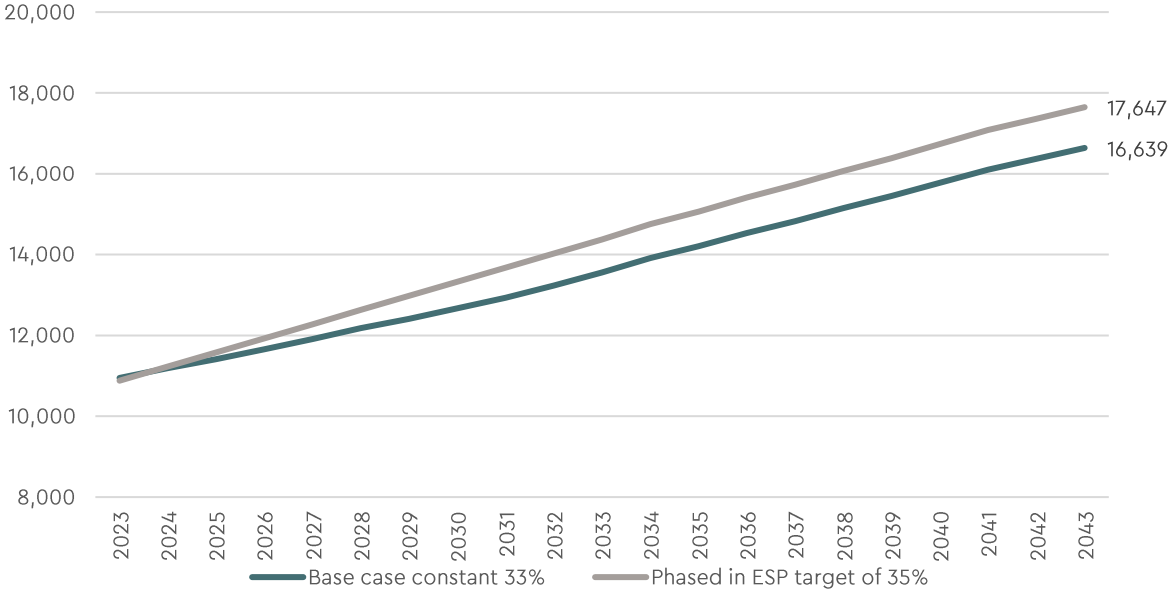
ESP has set a goal for hospices to support 35% of patients who need palliative care, an increase from the current 33%. Achieving this goal would see the number of patients supported increase by an average of about 800 a year over the next 20 years when compared to the base case. By 2043, hospices would be supporting nearly 17,650 patients a year.

For modelling purposes, we assume it takes 10 years from 2023 for the hospices to reach this 35% goal, owing to the need for a larger workforce and other infrastructural needs. This growth is reflected in Figure 10.

³⁰ Nixon et al., 'Developing the Geographic Classification for Health, a Rural-urban Classification for New Zealand Health Research and Policy'.



Figure 10: Comparison of annual patients supported



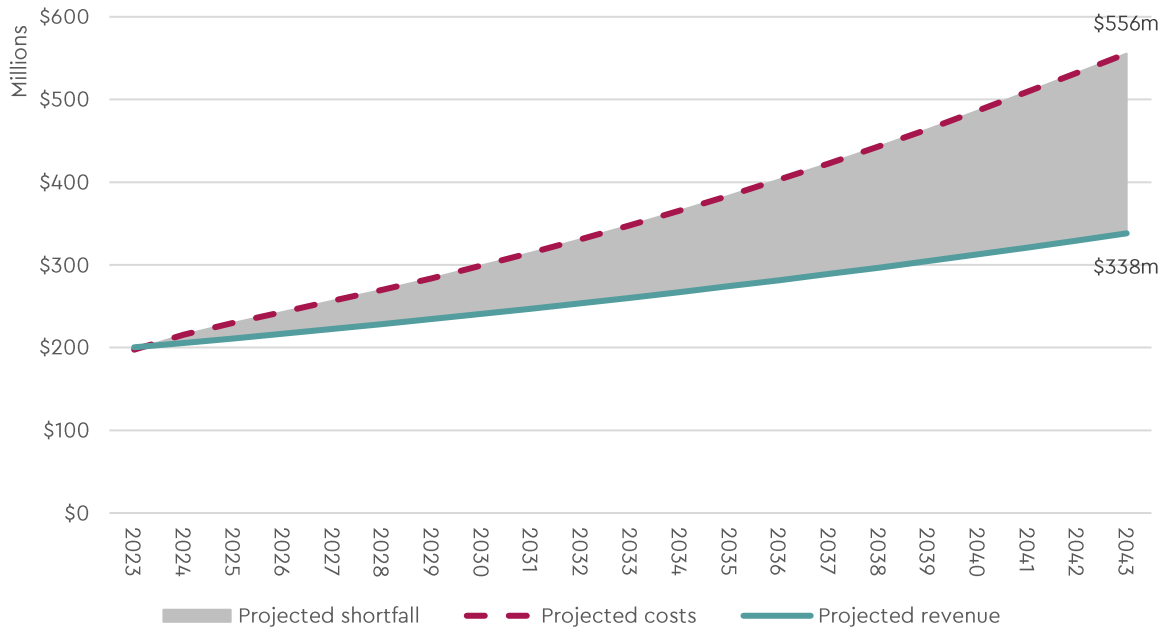
Source: MartinJenkins modelling, based on data from the five commissioning hospices.

Increasing the number of patients supported while holding all other variables constant, including revenue, sees the annual funding shortfall grow from \$9.8 million in 2024 to \$217 million by 2043, as shown in Figure 11. This projected shortfall in 2043 is \$21 million per annum larger than that projected in the base case.



Figure 11: Projected funding shortfall with 35% demand

Annual aggregate funding shortfall, total national hospice sector



Source: MartinJenkins modelling, based on data from the five commissioning hospices.

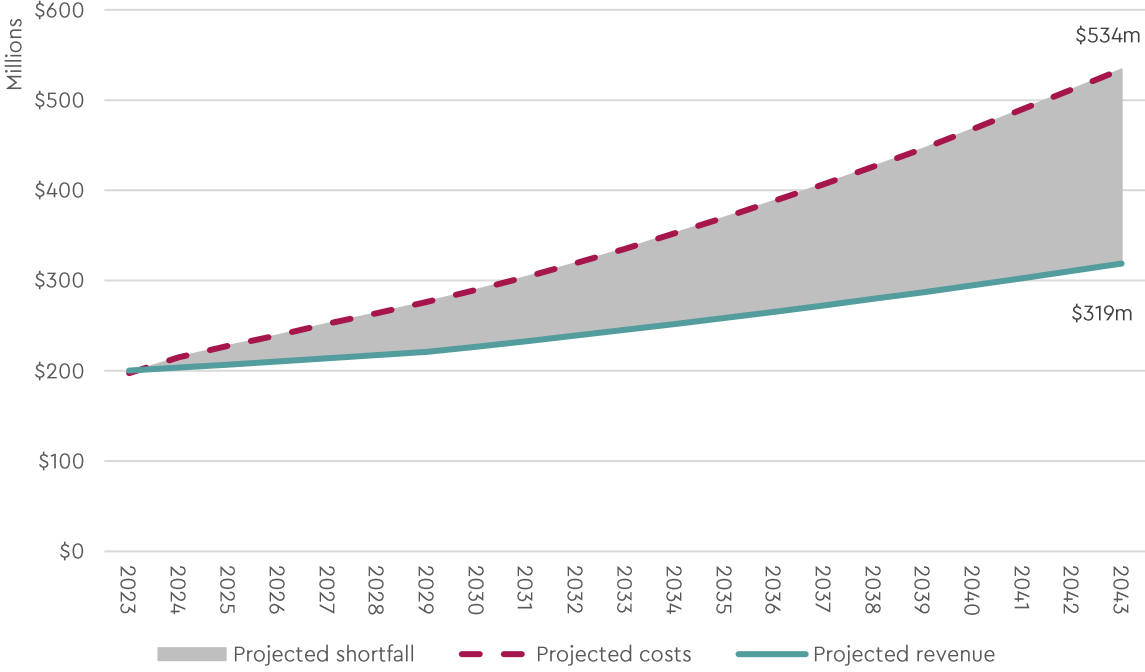
Depressed revenue growth

Hospices receive about 50% of their annual funding from sources other than the Crown. The commissioning hospices are not confident that donations, bequests, and retail revenue can continue to grow at the same rate as inflation in the near term. Further, with many pressures on the government's budgeted operating allowance and no agreed funding model, there is no certainty that Crown funding will keep pace with inflation. We modelled a scenario where total revenue continues to increase, but at a rate 1% less than forecast inflation, until 2030 when it begins growing at the forecast rate of inflation.

Figure 12 shows the impact of this scenario. Every 1% reduction in revenue growth means about \$2 million less in revenue in the early years, increasing the funding shortfall. By 2043, the impact of compounding means the difference in revenue received is \$19 million less a year compared to the base case.



Figure 12: Projected funding shortfall with 1% lower revenue growth in first six years



The case for investing in sustainable hospice services

Our approach to modelling benefits

Estimating the return on the government's investment

In the previous section, we looked at the total costs of providing hospice services. In this section, we focus on the total benefits provided by hospices. We then look at these benefits from the government's perspective, to assess the return generated by its investment.

To do this, we compare the total benefits against the government funding. The reason we use total benefits in this calculation, is that the funding provided by government is essential to the provision of hospice services, and leverages funding from other sources. In terms of the benefits to the wider health system, the government captures these through cost savings in other areas.

We took a conservative approach to quantifying benefits

We have taken a conservative approach to modelling benefits. We focused on evidence from peer reviewed academic research to inform our modelling assumptions.

There are inconsistent definitions and terminology used across studies in the literature. This is partly because studies are across different jurisdictions and health systems, and partly due to the absence of agreed and consistent definitions. This means that in some instances there is no like-for-like cohort match. We have done our best to choose the most appropriate cohort as a basis for our modelling assumptions, depending on the population in the study.

A summary of the literature we reviewed is in Appendix 2. The assumptions used to quantify and monetise benefits are set out in Appendix 3. For cost savings to the health system (such as reduced emergency department (ED) visits and hospital admissions), we applied values from The Treasury's CBAX tool to estimate the monetary value of these benefits.³¹ All estimates use values as at 30 June 2023.

³¹ The Treasury, 'The Treasury's CBAX Tool', 21 December 2023, <https://www.treasury.govt.nz/information-and-services/state-sector-leadership/investment-management/investment-planning/treasurys-cbax-tool>.

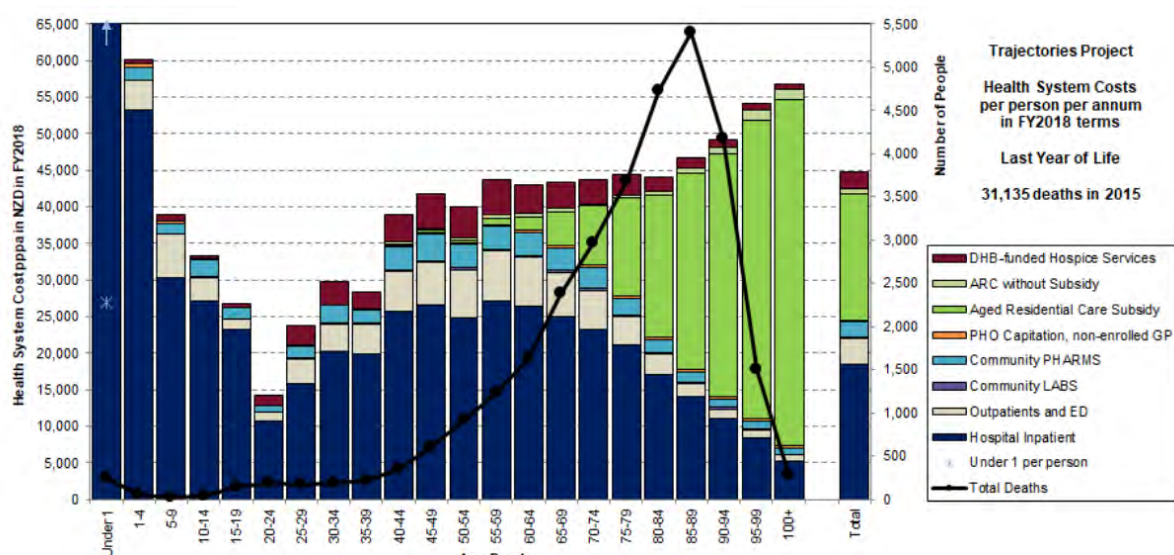


Hospice services take pressure off the health system

In New Zealand, in the final year of life, hospital inpatient costs represent the most significant expense for the healthcare system, accounting for approximately 41% of total healthcare expenditure (Figure 13). That amounts to nearly \$18,500 per person in 2018 dollars.³² Outpatient and ED costs contribute to around 8% of the overall expenses, totalling almost \$3,500 per person.³³

Figure 13: Health system costs in last year of life

Per person, 2018



Source: June Atkinson and Heather McLeod, 'Trajectories of Care at the End of Life: Implications for Health Systems with Ageing Populations' (Economics of Palliative and End of Life Care SIG (EPEC), Wellington, February 2020).

Several studies and systematic reviews consistently demonstrate that home-based interventions and the provision of palliative care at home, ARC, and inpatient settings result in substantial cost savings for a nation's health system. These interventions lead to decreased total healthcare expenses, reduced utilisation of resources, and better outcomes for both patients and caregivers.

³² June Atkinson and Heather McLeod, 'Trajectories of Care at the End of Life: Implications for Health Systems with Ageing Populations' (Economics of Palliative and End of Life Care SIG (EPEC), Wellington, February 2020).

³³ Ibid.



Hospices reduce the likelihood of using hospitals...

A range of studies have consistently shown associations between hospice community care and **reduced ED visits, and hospital admissions and readmissions**.³⁴ Estimates vary by disease cohort. Based on this literature, we applied disease-cohort specific estimates of avoided ED visits and hospital admissions. The figures we used for each are set out in Appendix 3. These result in a total of \$106 million a year in cost savings to the health system.

... and relieve pressure on community clinical care

Data from the five commissioning hospices include figures for **clinical care**, such as syringe drivers, and other “at home” hands-on care. If the hospices were not available to provide these services, this would result in additional costs to the government of \$596,000 a year.

Hospices also undertake other clinical care such as wound management or administering medication. Our estimate for these figures is \$1.8 million a year in cost savings to the government.

As a result, hospices generate significant cost savings to the New Zealand health system

We have estimated the direct cost savings from hospice services at almost \$110 million a year across the health system. This figure is based on financial and service data from the five hospices, and extrapolated out to all 28 government funded hospices.

There are significant unquantified cost savings on top of these estimates

Hospice care also reduces the potential for inappropriate care...

Inappropriate care includes treatment decisions such as over- or under-prescribing or foregoing treatment. Reducing over-prescribing can reduce the costs associated with medication (though this could be offset by reducing under-prescribing).

There is little specific research on the extent to which hospice inpatient and community care reduces over-treatment, but one study of patients and relatives in the Netherlands did find that “appropriate

³⁴ Lorna Rosenwax et al., 'Community-Based Palliative Care Is Associated with Reduced Emergency Department Use by People with Dementia in Their Last Year of Life: A Retrospective Cohort Study', *Palliative Medicine* 29, no. 8 (September 2015): 727–36, <https://doi.org/10.1177/0269216315576309>; Hua-Shui Hsu et al., 'Enhanced Home Palliative Care Could Reduce Emergency Department Visits Due to Non-Organic Dyspnea among Cancer Patients: A Retrospective Cohort Study', *BMC Palliative Care* 20, no. 1 (December 2021): 42, <https://doi.org/10.1186/s12904-021-00713-6>; Katrina Spilsbury et al., 'The Impact of Community-Based Palliative Care on Acute Hospital Use in the Last Year of Life Is Modified by Time to Death, Age and Underlying Cause of Death. A Population-Based Retrospective Cohort Study', ed. Antony Bayer, *PLOS ONE* 12, no. 9 (21 September 2017): e0185275, <https://doi.org/10.1371/journal.pone.0185275>; S. P. M. Iupati and B. R. Ensor, 'Do Community Hospice Programmes Reduce Hospitalisation Rate in Patients with Advanced Chronic Obstructive Pulmonary Disease?', *Internal Medicine Journal* 46, no. 3 (March 2016): 295–300, <https://doi.org/10.1111/imj.12947>.



care" was statistically significantly more likely to occur at home or in a hospice setting than "inappropriate care".³⁵ Inappropriate care was also more likely to occur as an inpatient in hospital, than appropriate care.

Studies in the US have found cost savings associated with discontinuing medications and diagnostic tests that were not consistent with the patient's goals of care. One study found that there was an estimated direct cost reduction of \$100,000 due to treatments being discontinued by the palliative care pharmacist over the study period, while another study found reductions in direct costs per day of \$279 for patients discharged alive, and \$374 for patients who died as inpatients.³⁶ However, we were unable to use these figures in our modelling as the study did not provide sufficient detail on the nature of the marginal cost savings.

Other literature reviews indicate that there is:

*"convincing evidence that the delivery of palliative care concurrent with the disease-directed treatment can improve the quality of life, symptom control, and family satisfaction with care, all while reducing costs associated with aggressive end-of-life care. Palliative care does not shorten life expectancy ..."*³⁷

... and reduce demand for ambulance callouts

A recent evaluation into Poi (palliative outcome initiative) services provided by the Specialist Hospices of Auckland Alliance found that hospice services also reduce demand for ambulance callouts.³⁸ There would be value in further research in this area, to support quantification of this impact in future.

Hospices also provide other direct and indirect benefits for the healthcare system

In addition to cost savings, hospice services provide other benefits to the healthcare system. To be able to quantify these important benefits, we would need good-quality research evidence and New Zealand-specific data. We have made some recommendations for future research in the final section of this report.

³⁵ Eva Elizabeth Bolt et al., 'Appropriate and Inappropriate Care in the Last Phase of Life: An Explorative Study among Patients and Relatives', *BMC Health Services Research* 16, no. 1 (December 2016): 655, <https://doi.org/10.1186/s12913-016-1879-3>.

³⁶ Dharma Naidu et al., 'Palliative Care Pharmacist Interventions in a Community Hospital', *American Journal of Health-System Pharmacy* 75, no. 13 (1 July 2018): 933-36, <https://doi.org/10.2146/ajhp170250>.

³⁷ Daniel Fischberg et al., 'Five Things Physicians and Patients Should Question in Hospice and Palliative Medicine', *Journal of Pain and Symptom Management* 45, no. 3 (March 2013): 595-605, <https://doi.org/10.1016/j.jpainsymman.2012.12.002>.

³⁸ MartinJenkins, 'Evaluation of Poi - Palliative Outcomes Initiative', For the Specialist Hospices of Auckland Alliance, Unpublished (MartinJenkins, 2024).



Training, education, and support for carers and healthcare workers

As discussed above, hospices play an important role in building capacity and capability in the formal and informal palliative care workforce. They are actively involved in teaching programmes to inform both communities and healthcare workers about palliative care.

Education and training for healthcare professionals is designed to prepare them for offering a palliative approach to patient care, particularly care in settings such as ARC, primary care, and general hospital wards. Courses include undergraduate tertiary education, as well as postgraduate courses and clinical teaching. The Fundamentals of Palliative Care programme was developed by, and is offered by, hospices. Hospices also provide ongoing specialist consultation services, typically on a 24/7 basis, to support medical professionals who are caring for palliative patients.

Programmes for carers focus on the essential skills and capabilities to adeptly support and care for their loved ones. They can also include guidance for families throughout the EOL stage.

Improved coordination of the health system

Hospice teams work collaboratively across different parts of the health system, to coordinate and plan the patient's care throughout their EOL journey. Assessments and advanced care plans (ACPs) are developed collaboratively with multidisciplinary teams and are tailored to each individual patient. Some hospices have a dedicated Care Coordinator. Coordination ensures that these plans are implemented effectively, that services are aligned, and that there is ongoing communication among team members.

Hospices also collaborate and establish partnerships with various healthcare entities, including hospitals, GP practices, ARC facilities, ambulance and emergency services, iwi and hapu-based providers, Whānau Ora providers, spiritual and pastoral care organisations, long-term condition NGOs, private hospitals, community pharmacies, and other community-based healthcare providers. These partnerships aim to extend palliative care beyond the hospice facility, ensuring a continuum of care and support across different healthcare settings – building confidence, capacity and capability in all those working with the dying.

Studies show that palliative care services **improve resource use across the health system**.^{39, 40} These studies found that there are significant potential gains from more appropriate treatment, and reductions in aggressive medical treatment. Benefits include cost-efficiency (from using lower-cost interventions), and cost and resource savings from lower healthcare use.

³⁹ Xhylljeta Luta et al., 'Evidence on the Economic Value of End-of-Life and Palliative Care Interventions: A Narrative Review of Reviews', *BMC Palliative Care* 20, no. 1 (December 2021): 89, <https://doi.org/10.1186/s12904-021-00782-7>.

⁴⁰ B Candy et al., 'Hospice Care Delivered at Home, in Nursing Homes and in Dedicated Hospice Facilities: A Systematic Review of Quantitative and Qualitative Evidence', *International Journal of Nursing Studies* 48, no. 1 (2011): 121–33.



Hospice care is also likely to delay patient transitions to aged residential care, allowing them to stay at home longer. This is material for a sector that is facing significant growth in demand, and a shortfall in available beds. There would be value in future research to help quantify the benefit of this, to the system and patients.

Hospice services improve the health and wellbeing of patients, and the wellbeing and productivity of carers

Hospice care improves patients' pain and symptom management

Research shows that hospices provide **more effective pain and symptom management** compared to those receiving palliative care in hospital or ARC, leading to **improvements in quality-of-life**. There is also strong evidence that home-based palliative care is more effective than usual care on relieving the prevalence, frequency, and severity of symptoms for patients.^{41,42} Improved pain and symptom management may consequently support patient choice about place of death, as they feel more confident to stay at home if that is their preference.

The integration of palliative care with disease-directed treatment for patients experiencing physical, psychological, social, or spiritual distress has shown substantial benefits. Research suggests that when palliative care is provided concurrently, not only is the patient's quality-of-life improved, but the family are also more satisfied with the care of their loved one.⁴³

We used estimates from a randomised control trial of palliative home care that showed a 24% increase in patients' quality-of-life (based on the EQ-5D system of subjective wellbeing).⁴⁴ We assumed that hospice patients experience this scale of benefit for four months (based on average length of

⁴¹ Frances Kam Yuet Wong et al., 'Effects of a Transitional Palliative Care Model on Patients with End-Stage Heart Failure: A Randomised Controlled Trial', *Heart* 102, no. 14 (15 July 2016): 1100-1108, <https://doi.org/10.1136/heartjnl-2015-308638>; Amy P. Abernethy et al., 'Delivery Strategies to Optimize Resource Utilization and Performance Status for Patients with Advanced Life-Limiting Illness: Results from the "Palliative Care Trial" [ISRCTN 81117481]', *Journal of Pain and Symptom Management* 45, no. 3 (March 2013): 488-505, <https://doi.org/10.1016/j.jpainsymman.2012.02.024>; Margareta Brännström and Kurt Boman, 'Effects of Person-Centred and Integrated Chronic Heart Failure and Palliative Home Care. PREFER: A Randomized Controlled Study', *European Journal of Heart Failure* 16 (2014): 1142-51.

⁴² Brännström and Boman, 'Effects of Person-Centred and Integrated Chronic Heart Failure and Palliative Home Care. PREFER: A Randomized Controlled Study'.

⁴³ Rosemary Frey et al., 'Factors Associated with Overall Satisfaction with Care at the End-of-life: Caregiver Voices in New Zealand', *Health & Social Care in the Community* 28, no. 6 (November 2020): 2320-30, <https://doi.org/10.1111/hsc.13053>.

⁴⁴ Brännström and Boman, 'Effects of Person-Centred and Integrated Chronic Heart Failure and Palliative Home Care. PREFER: A Randomized Controlled Study'.



engagement with hospice services) and applied the low CBAX values for an increase in life satisfaction (based on the WELLBY scale).⁴⁵ This produced total quality-of-life benefits of \$48.2 million a year.

Patients also save on out-of-pocket medical expenses

As discussed above, hospice generate cost savings for the health system by providing community clinical care services. In addition to the savings to government, hospice patients also save money from avoided GP visits through patient co-payments. Based on our analysis of data from the five commissioning hospices, these savings to patients total around \$468,000 a year.

Hospice services can help reduce the burden on caregivers...

Families that are providing care at home are supported to access hospice care, including respite care. Support includes addressing any concerns caregivers might have regarding their capability to manage a patient's physical and emotional needs which can encourage greater utilisation of hospice services and ensuring better overall care for patients receiving EOL care at home.

Few high-quality studies test the effects of specialist palliative care on the burden experienced by caregivers. A recent systematic review only found one randomised control trial that met the criteria for inclusion.⁴⁶ That study found that specialist palliative care led to fewer informal caregivers perceiving themselves to be highly burdened.⁴⁷

... and provide ongoing support for those left behind

Hospices extend ongoing bereavement support to families and loved ones after a patient's death. Research shows that those who receive bereavement counselling have a **decrease in grief symptoms** compared to those who do not receive counselling.⁴⁸

A recent UK study⁴⁹ estimated that around 24% of those in employment experience a bereavement in a year. Of these, 25% would have experienced intense grief (6.1% of those employed). It assumes that people experiencing intense grief take on average 22 days off work, and their productivity is 70% of normal capacity in the first six months and 95% in the second six months. The total cost to the UK economy from absenteeism, reduced productivity, and lower employment was estimated at £22.9

⁴⁵ WELLBY is wellbeing experienced over one year. It is measured on a life satisfaction scale of 0-10. 1 WELLBY is an increase of 1 on the scale of life satisfaction for one person over one year.

⁴⁶ Salina Iupati et al., 'Systematic Review of Models of Effective Community Specialist Palliative Care Services for Evidence of Improved Patient-Related Outcomes, Equity, Integration, and Health Service Utilization', *Journal of Palliative Medicine* 26, no. 11 (1 November 2023): 1562-77, <https://doi.org/10.1089/jpm.2022.0461>.

⁴⁷ Patrick D. Hoek et al., 'The Effect of Weekly Specialist Palliative Care Teleconsultations in Patients with Advanced Cancer –a Randomized Clinical Trial', *BMC Medicine* 15, no. 1 (December 2017): 119, <https://doi.org/10.1186/s12916-017-0866-9>.

⁴⁸ Catherine Newsom et al., 'Effectiveness of Bereavement Counselling through a Community-based Organization: A Naturalistic, Controlled Trial', *Clinical Psychology & Psychotherapy* 24, no. 6 (November 2017), <https://doi.org/10.1002/cpp.2113>.

⁴⁹ Sue Ryder, 'Grief in the Workplace: How Employers Can Provide Better Bereavement Support' (Sue Ryder, 2020).



billion a year. The impact on public finances from foregone taxes, increased healthcare costs, and increased income support payments was £7.8 billion a year.

To be able to quantify the benefits of bereavement support for the New Zealand context, we would need information on the proportion of people experiencing intense grief who receive bereavement support from hospices, and on the efficacy of this support in reducing the productivity impacts such as absenteeism. This is an area that would benefit from further research; we have included this in our recommendations.

Hospice volunteers also experience wellbeing benefits

Evidence shows that people who volunteer on a weekly basis experience improved subjective wellbeing. The Treasury's CBAX model uses a value of subjective wellbeing, which is based on a Sport NZ study that measured the increase in self-reported life satisfaction of volunteers.⁵⁰

We have taken the CBAX value of \$630 a year, and applied it to a subset of hospice volunteers. While hospices have a total pool of 10,000 volunteers, we have focused on those who are directly involved with patients and whānau. We assume these people are more likely to have a strong connection with hospice, as opposed to other volunteering opportunities. Volunteers in the retail arms may have a looser connection, and be more likely to volunteer elsewhere in the absence of hospices. The commissioning hospices report that 80-100% of their volunteers are regular volunteers, and 43% work in non-retail roles. Based on data from these five hospices, we have assumed that 41% of total hospice volunteers are regular, non-retail volunteers and gain the full wellbeing benefits of volunteering.

Applying these assumptions gives a value of \$2.6 million a year in subjective wellbeing benefits to volunteers.

The direct financial savings to the healthcare system alone make sustainable funding for hospices a worthwhile investment

Our modelling shows a **positive return on investment. For every \$1 the government invests in hospices, it generates at least \$1.59 in benefits.** These benefits include healthcare cost savings, as well as benefits to individual patients in terms of the cost savings from avoided GP visits (patient co-payments), and more significantly, the quality-of-life benefits arising from improved pain and symptom control.

⁵⁰ Simetrica Jacobs, 'Sport NZ – Wellbeing Value Methodology Note' (London, UK: Simetrica Jacobs, 2020), <https://sportnz.org.nz/media/3571/sport-nz-wellbeing-valuation-methods-note-final.pdf>; Simetrica Jacobs, 'Update to Wellbeing Valuation 2022' (London, UK: Simetrica Jacobs, 2022), <https://sportnz.org.nz/media/xmuhfo4f/update-to-wellbeing-valuation-2022.pdf>.



Looking at just the direct cost savings to government, **for every \$1 the government invests in hospices, it receives \$1.08 in cost savings across the healthcare system.** On this basis alone, the government is getting a valuable return on its investment.

There are also significant unquantified benefits. These include:

- reduced ambulance callouts
- more appropriate care, including reduced over-treatment
- improved coordination of the health system, with accompanying resource savings
- training, education, and support for healthcare workers and informal caregivers
- reduced burden on caregivers, and
- support for the bereaved, contributing to improved wellbeing and potentially productivity.

Table 1 summarises the major quantified and unquantified benefits. The values used to monetise benefits are taken from The Treasury's CBAX database and are marginal values. For example, the CBAX value of \$378 for an ED visit is not the total cost of a visit, but the marginal resource cost of an additional visit.



Table 1: Return on investment from government funding for hospice services, 2023

\$ per patient and annual totals

Direct financial costs and benefits	\$ per patient, 2023	Annual total \$, 2023
Costs to government	\$9,261	\$100,758,000
Direct financial benefits (cost savings) to the health system		
<i>Reduced hospital admissions</i>	\$9,377	\$102,018,000
<i>Reduced emergency department visits</i>	\$378	\$4,117,000
<i>Reduced community clinical care</i>	\$220	\$2,390,000
<i>Reduced over-treatment</i>	Not quantified	Not quantified
<i>Reduced ambulance callouts</i>	Not quantified	Not quantified
Cost savings to the health system	\$9,975	\$108,525,000
Additional benefits to the health system		
<i>Training, education, and support for healthcare professionals</i>	Not quantified	Not quantified
<i>Improved coordination of the health system</i>	Not quantified	Not quantified
Net cost savings	\$714	\$7,767,000
Return on investment (cost savings only)	\$1.08	
Other benefits		
<i>Quality-of-life improvements for the patient</i>	\$4,431	\$48,200,000
<i>Reduced GP visits (patient co-payment)</i>	\$43	\$468,000
<i>Subjective wellbeing benefits for volunteers</i>	\$238	\$2,593,000
<i>Reduced caregiver burden</i>	Not quantified	Not quantified
<i>Improved wellbeing and productivity of bereaved</i>	Not quantified	Not quantified
Total quantified benefits	\$4,712	\$51,261,000
Return on investment (all quantified benefits)	\$1.59	



What if hospice services didn't exist?

This section explores the implications for patients and their families, the formal and informal health workforce, and the wider health system, if hospice services didn't exist. It is a qualitative discussion of a theoretical situation, as we lack information on how the health system might respond to this influx of demand, and the direct and indirect costs of providing hospice services in other ways.

We did attempt a quantitative cost comparison, using publicly available data for hospitals and ARC. This exercise showed that further work is needed to be able to develop consistent cost comparisons. This would require engagement with the Ministry of Health, Health New Zealand, and others. We include recommendations for this in the next section.

The lack of comparative cost data precluded more quantitative methods such as economic impact analysis, cost-benefit analysis, or cost-effectiveness analysis. In our final section we set out a high-level timeline of next steps, which include recommending that this work be done.

Reduced access to appropriate palliative care services, and poorer patient outcomes

If hospice services did not exist, patients would have reduced access to appropriate palliative care services.

- With reduced public education, patients and families may have **lower awareness** about the existence of palliative care services and how to access them. A recent survey found that of about 1,300 New Zealanders, the majority (90%) viewed hospice as an essential part of medical services.⁵¹
- Palliative care services that are provided may be less person-centric and less tailored to patients' wishes. This could lead to **poorer quality of care** and hence poorer patient outcomes in terms of distress, and symptom and pain management. In turn, this could **inhibit patient choice**, including about their place of death.
- Services may be less integrated, which could **reduce the continuity of care**. This could make the health system **harder to navigate** and have detrimental impacts on the quality of care received.
- In the absence of 24/7 advice, patients and their families could experience **more distress**. In turn, this could lead to more 111 calls and ED visits.

⁵¹ Perceptive, 'Community Views: Public Perceptions Research 2022-23', For Hospice New Zealand (Perceptive, 2023).



Increased pressure on other parts of the health system

The absence of hospice services would place increased pressure on other parts of the health system, including hospitals, ARC, and primary care. As described in the previous section, these impacts would include greater demand for **hospital inpatient beds, ED visits, and ambulance callouts**. In addition, patients may transition to ARC sooner than they otherwise would if they received hospice care at home. If the beds, workforce, and infrastructure for receiving these patients was not available (or created), then the proportion of **unmet need for palliative care would grow**.

There would also be increased demands on community clinical care which is already stretched, including **primary palliative care caseloads (GPs), district nursing, ARC, and allied health services**. Existing workforce shortages and significant pressures on other areas of the health system would intensify. Without hospices, it is likely that many patients would not be able to access the services they need. Loss of access to specialist knowledge around the clock would place additional pressure on the sector and ultimately impact patients.

Existing workforce gaps would be exacerbated...

There are already forecast shortages in the palliative care workforce, including palliative care nurses, GPs with a special interest in palliative care, and Māori health workers.⁵² This is partly driven by the ageing of the palliative medicine specialist workforce, and the health workforce more generally.

The loss of hospices would **compound the pressures on an already strained health workforce and contribute to greater stress and burnout**. This would lead to gaps in service delivery, lower quality of care, and poorer patient outcomes.

... and the wider health workforce's palliative care literacy would decline

Hospices currently provide specialist education, training, and support for medical, allied health, and nursing staff. If these services were no longer provided, there would be **reduced palliative care literacy in the workforce**, including in primary palliative care and ARC. This could result in lower identification of the need for palliative care services, lower levels and quality of care, and poorer patient outcomes.

⁵² Ministry of Health, *Review of Adult Palliative Care Services in New Zealand* (Wellington: Ministry of Health, 2017), <https://www.tewhaturora.govt.nz/publications/review-of-adult-palliative-care-services-in-new-zealand/>.



A specialist workforce would be lost

The exit of hospice services would result in the **loss of a specialist workforce**, including the skills and relationship capital that have been developed over many years. As noted above, hospice teams have specialist training and qualifications that enable them to provide appropriate and high-quality palliative and EOL care. This expertise is lacking in other areas of the health sector.

Patient care would be less coordinated

The multidisciplinary relationships that are built and maintained by hospice teams enable **coordination of health system resources**, to deliver holistic patient care. This includes connecting in allied health and medical specialists such as social workers, physiotherapists, occupational therapists, and clinical psychologists, according to patient needs. Hospice nurses also have the flexibility to cater to patients with complex and changing clinical needs, including adjusting medication and revisiting in the same day.

Hospices are also one of very few 24/7 services available for advice and acute admissions. In many communities, other than ambulance services and public hospital ED, hospices are the only community-based service that provides round-the-clock care.

In the absence of hospices, the remaining health workforce is unlikely to have the time, flexibility, and relationships to have these cross-disciplinary conversations. For example, appropriate palliative care services can take considerably longer than the allocated times for publicly funded GP and district nursing visits. Left to navigate the health system on their own, patients may struggle to access the necessary care and supports.

The benefits of a large volunteer workforce would also be lost...

A large pool of around 10,000 hospice volunteers contributes to providing a range of services and supports. Their services benefit patients, their families and whānau, and the wider community. In the absence of hospices, **patients and families would lose the direct benefits from these services**.

Communities would also lose the social capital fostered by these volunteers. New Zealand hospices have their origins in community-based advocacy for holistic and specialist care for people at the end of their life. Hospices maintain high levels of community support. Both staff and volunteers build networks and relationships to deliver their services, and help ensure that hospice care remains available as an option for all.



... as would existing infrastructure

Hospices self-fund their **infrastructure and capital assets**, such as buildings, IT, vehicle fleets, and equipment. Buildings include wards and beds, offices, and community hubs that provide a base for community-based staff. Buildings are also being used as community spaces and community meeting rooms – providing important places for social cohesion and social connection. In the absence of hospices, these assets would be repurposed to other uses.

Higher burden on informal caregivers

Many of the **costs of providing palliative care services would be shifted onto informal caregivers**, including patients' family and whānau. This would create a higher burden on these carers. They would face additional costs such as **direct out-of-pocket expenses, as well as the opportunity and productivity costs of time off work, and wellbeing impacts**.⁵³

At the same time, informal caregivers would receive less support for building their capacity and capability to provide these services, and less bereavement support.

⁵³ Iupati et al., 'Systematic Review of Models of Effective Community Specialist Palliative Care Services for Evidence of Improved Patient-Related Outcomes, Equity, Integration, and Health Service Utilization'; Hoek et al., 'The Effect of Weekly Specialist Palliative Care Teleconsultations in Patients with Advanced Cancer –a Randomized Clinical Trial'; Barbara Gomes et al., 'Effectiveness and Cost-Effectiveness of Home Palliative Care Services for Adults with Advanced Illness and Their Caregivers', *Cochrane Database of Systematic Reviews* 2022, no. 7 (6 June 2013), <https://doi.org/10.1002/14651858.CD007760.pub2>; Susan R. Mazanec et al., 'Work Productivity and Health of Informal Caregivers of Persons with Advanced Cancer', *Research in Nursing & Health* 34, no. 6 (December 2011): 483–95, <https://doi.org/10.1002/nur.20461>.



Recommendations for sustainable hospice services

Stabilisation funding is needed now

The five hospices who commissioned this work urge the Ministry of Health and Health New Zealand to work with the hospice sector and agree actions that will stabilise and sustain the sector.

Our modelling shows that with the current government funding contributions, total costs across the 28 publicly funded hospices will exceed revenues within the next 12 months. The annual funding shortfall grows from \$9.3 million in 2024 to \$196 million by 2043.

The immediate priority is for government to provide a funding injection to maintain existing hospice services.

The **minimum financial investment needed to ensure short-term continuity of publicly funded hospice services** is \$39.7 million over the next two fiscal years. This funding would deliver cost savings to the wider health system of at least \$42.9 million. This represents a return on investment of 8%, or \$1.08 for every dollar of funding. If we factor in the quality-of-life benefits to individuals, the benefits rise to \$63.1 million, a return on investment of 59%. These are conservative estimates, as they exclude several significant categories of cost savings and other benefits that could not be quantified.

Hospices are evolving their management and service models

The nature and timing of shortfalls for individual hospices will vary. In the absence of additional government funding, individual hospices will be taking action to manage their own funding shortfalls.

Hospices recognise the need to evolve their approaches to managing costs. Individually, they are taking actions to improve their productivity, including through the increased use of technology and exploring opportunities for more partnerships and economies of scale.

In response to funding shortfalls, they will also take steps to evolve their models of care. Progressive measures may include increased use of telehealth, more outpatient-based systems of care, providing intermittent episodes of care, discharging patients (who would otherwise stay on their service), prioritising which referrals they accept, and closing beds.

Any reductions in caseloads and clinical services will place increased pressure on the wider health system, as patients they would have served seek palliative care from primary care and hospitals. It is likely that some people may miss out altogether on the specialist palliative care they need. In addition,



the benefits that are currently provided to the wider health system (such as avoided hospitalisations and ED visits), will be lost.

In the medium term, work is needed to fill data and research gaps, and develop a new sustainable funding model

In the medium term, a significant programme of work is needed to inform the development of a sustainable funding model for hospice services. Actions include:

- **Filling gaps in administrative data** through agreed definitions and taxonomies, and consistent recording and reporting practices across the hospice sector and the wider palliative care system. This includes:
 - Consistent cost metrics so that the costs of delivery can be compared across different care settings (hospices, ARC, and hospitals), and
 - Consistent data on the cost and delivery of hospice services across rural and urban populations.
- Ongoing **research on benefits and cost savings** from hospice care, to support the case for investing in hospice services. There are opportunities for research to help quantify the impact of hospice services on:
 - reduced ambulance callouts
 - more appropriate care, including reduced over-treatment
 - delayed admission to ARC
 - the resource savings from improved coordination of the health system
 - the training, education, and support for healthcare workers and informal caregivers
 - reduced burden on caregivers, and
 - support for the bereaved, and its contribution to improved wellbeing and potentially productivity.

Research into the impact of the changing profile of disease on the costs of hospice care would also be useful.

- **Defining future models of specialist palliative care**, including for rural populations. This should inform the development of:
 - a **national model of care** for paediatric and adult palliative care, and
 - a set of nationally agreed **minimum service expectations** for palliative care.



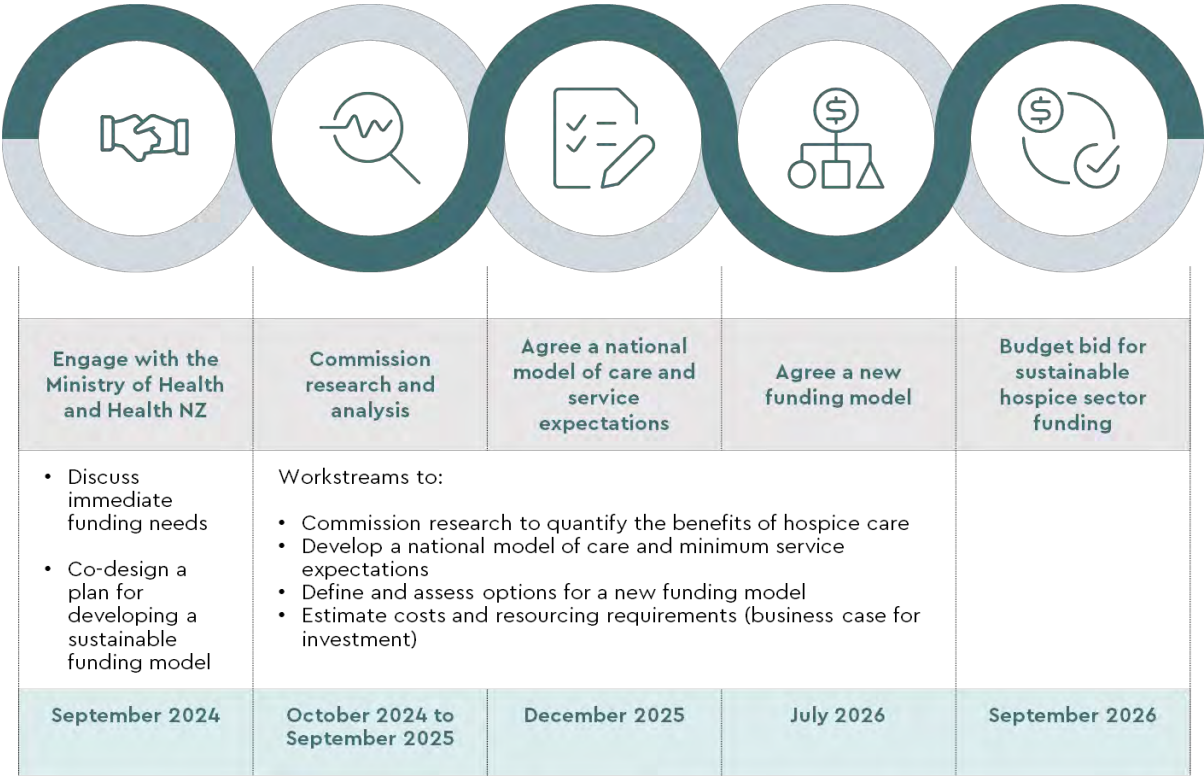
New commissioning and contracting approaches are needed to deliver future funding for hospices, and bring consistency across the sector. Significant work is needed to develop and assess options for sustainable funding models. Options exist for determining funding streams, budget allocation methods, and payment mechanisms. Potential mechanisms include block funding, activity-based payments, and capitation. This work needs to consider the extent to which hospices are government-funded, and funding approaches that enable hospices to continue to deliver a range of services in addition to government-funded services.

Once the commissioning and contracting model has been defined, the next step will be to develop estimates of the costs, benefits, resources, and workforce capability (and capacity) to support sustainable hospice service delivery.

What needs to happen next

The five hospices who commissioned this work encourage government to work with the sector to develop and assess options for a new, sustainable funding model for the 28 publicly funded hospices. Priority actions are illustrated in the following high-level timeline (Figure 14).

Figure 14: Priority actions



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Appendix 1: Timeline of palliative care reviews and reforms

July 2000	Press release: King announces funding injection for Palliative Care and a new, New Zealand Palliative Care Strategy
February 2001	Ministry of Health published "The New Zealand Palliative Care Strategy"
2003	New Zealand Cancer Control Strategy AND Palliative care: report of the palliative care expert working group to the cancer control steering group
2005	New Zealand Cancer Control Strategy Action Plan 2005-2010
2008	Specialist palliative care tier two service specification
November 2008	A National Professional Development Framework for Palliative Care Nursing in Aotearoa New Zealand
December 2009	<p>Ministry of Health report: <i>Gap analysis of specialist palliative care in New Zealand: Providing a national overview of hospice and hospital-based services</i></p> <ul style="list-style-type: none"> • The purpose of the report was to determine how close hospice and hospital providers of specialist palliative care services were to meeting the new draft service specification for specialist palliative care. • The gap analysis (or national stock take) confirmed the anecdotal evidence that there are wide variations in the provision of hospice and other specialist palliative care at both local and regional levels. Hospital services particularly are generally limited to nursing and medical services only. There are opportunities for sharing resources between services, such as between the hospice and the hospital-based palliative care service in the same region, to increase the level of access to specialist palliative care, particularly in terms of support for grief, loss and bereavement, for patients, families and whānau.
2010	Positioning palliative care in NZ: A review of government health policy in relation to the provision of palliative care services in New Zealand
February 2012	Measuring what matters: Palliative care
September 2012	Guidance for Integrated Paediatric Palliative Care Services in New Zealand
January 2013	Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand
May 2013	National Health Needs Assessment for Palliative Care Phase 2 Report: Palliative Care Capacity and Capability
June 2013	National Needs Assessment for Palliative Care
August 2014	Palliative Care and Māori from a Health Literacy Perspective
August 2014	Referral Criteria for Adult Palliative Care Services in New Zealand



<i>November 2015</i>	Press release: New panel to advise on palliative care services (PCAP)
<i>December 2015</i>	New Zealand Palliative Care Glossary
<i>March 2017</i>	Review of Adult Palliative Care Services in New Zealand
<i>March 2017</i>	Palliative Care Action Plan
<i>April 2017</i>	Te Ara Whakapiri: Principles and guidance for the last days of life
<i>1 July 2022</i>	Health sector reforms implemented as well as Pae Ora Healthy Futures for all New Zealanders Te Pae Tata Interim New Zealand Health Plan 2022
<i>August 2023</i>	National Palliative Care Work Programme announced and National Palliative Care Steering Group established. <ul style="list-style-type: none"> • Provides oversight and guidance for the national work programme over a 2-year period. • Working groups: <ul style="list-style-type: none"> - Equity - Models of care – paediatric - Models of care – adult - Contracting and funding - Workforce - Measures and reporting
<i>December 2023</i>	Models of care – paediatric working group established in collaboration with the Paediatric Palliative Care Clinical Network
<i>February 2024</i>	Equity working group established
<i>March 2024</i>	Models of care – adult working group <ul style="list-style-type: none"> • Survey of current services and change priorities open until 31 May 2024 • Seeking nominations and applications



Appendix 2: Summary of literature reviewed

Table 2: Studies on the linkages between specialist palliative care and hospitalisation and emergency service use

Population	Study type and cohort	Findings	Source
English language articles; adult and paediatric studies ⁵⁴	Systematic review of studies between 2012 and 2020. Four randomised controlled trials (RCTs) and eight observational studies met the criteria for inclusion.	Three RCTs found statistically significant reductions in hospitalisation. One RCT found a non-significant increase in hospitalisations. All observational studies found statistically significant and substantial reductions in hospitalisation. For round-the-clock, and episodic care. Statistically significant reduction in ED visits.	Iupati et al (2023) ⁵⁵
Adult; English language studies ⁵⁶	Systematic review of studies between 2002 and 2022. Intervention studies was specialist community palliative care teams involving at least one specialist doctor and one specialist nurse. Eight studies met the criteria. All were retrospective observational studies.	All studies confirmed that specialist palliative care team involvement reduces hospital admissions. All studies reported clinical significance in the reduction of ED usage and in the reduction of hospital death rates due to the impact of care teams. Statistically significant findings for hospital death rates were reported for four studies.	McCarroll et al (2022) ⁵⁷
Greater Wellington, New Zealand	A retrospective study of patient data. Patients with chronic obstructive pulmonary disease (COPD) who were admitted into community hospice programmes in the greater Wellington region between 2007 and 2013.	A mean decrease of 2.375 hospital admissions over a 12-month period, after admission into hospice programme.	Iupati and Ensor (2016) ⁵⁸

⁵⁴ 14 countries: 13 studies from US; 4 studies from Australia; 3 from Seden, 2 from the Netherlands; 2 from Italy; 2 from Canada. One study each from UK, Poland, Spain, Hong Kong, Singapore, Korea, India, and Colombia.

⁵⁵ Iupati et al., 'Systematic Review of Models of Effective Community Specialist Palliative Care Services for Evidence of Improved Patient-Related Outcomes, Equity, Integration, and Health Service Utilization'.

⁵⁶ 2 studies in Australia, 2 in US, 1 in Canada and remaining 3 in Europe.

⁵⁷ Susan McCarroll et al., 'The Impact of Specialist Community Palliative Care Teams on Acute Hospital Admission Rates in Adult Patients Requiring End of Life Care: A Systematic Review', *European Journal of Oncology Nursing* 59 (August 2022): 102168, <https://doi.org/10.1016/j.ejon.2022.102168>.

⁵⁸ Iupati and Ensor, 'Do Community Hospice Programmes Reduce Hospitalisation Rate in Patients with Advanced Chronic Obstructive Pulmonary Disease?'



Population	Study type and cohort	Findings	Source
Taiwan	<p>Retrospective cohort study conducted at China Medical University Hospital, Taichung, Taiwan. Patients who died with a primary diagnosis of cancer were from the linked hospital administrative databases during 2016–17.</p> <p>Two groups:</p> <ul style="list-style-type: none"> • basic home palliative care visits, Monday to Friday • basic home palliative care visits extended to weekend, plus trained home care nurse with formulated standard operating procedures for dyspnea (shortness of breath) care. 	<p>The percentage of ED visits for dyspnea was significantly reduced in extended home care by 31%, in last six months of life.</p>	Hsu et al (2021) ⁵⁹
Australia	<p>Retrospective cohort study of the last year of life of 12,763 Western Australians who died from cancer or one of seven non-cancer conditions.</p>	<p>Hospital admissions decreased by 34% and length of stay decreased by 6% when receiving community-based palliative care.</p> <p>With neoplasms at end of life, patients stayed 1.4 days longer in hospital without community palliative care.</p>	Spilsbury et al (2017) ⁶⁰
Canada	<p>Retrospective cohort study of end-of-life cancer decedents in Ontario, Canada, from 2004 to 2009 by linking administrative databases.</p> <p>Examined the association between home care nursing rate of one week with the ED rate in the subsequent week closer to death. Two groups:</p> <ul style="list-style-type: none"> • Standard short-term nursing care • End of life nursing care. 	<p>Patients receiving end-of-life nursing at any week had a significantly reduced ED rate in the subsequent week of 31% compared with standard nursing.</p> <p>In the last month of life, receiving end-of-life nursing and standard nursing rate of more than five hours/week was associated with a decreased ED rate of 41% and 32%, respectively, compared with standard nursing of one hour/week.</p>	Seow et al (2016) ⁶¹

⁵⁹ Hsu et al., 'Enhanced Home Palliative Care Could Reduce Emergency Department Visits Due to Non-Organic Dyspnea among Cancer Patients'.

⁶⁰ Spilsbury et al., 'The Impact of Community-Based Palliative Care on Acute Hospital Use in the Last Year of Life Is Modified by Time to Death, Age and Underlying Cause of Death. A Population-Based Retrospective Cohort Study'.

⁶¹ Hsien Seow et al., 'Does Increasing Home Care Nursing Reduce Emergency Department Visits at the End of Life? A Population-Based Cohort Study of Cancer Decedents', *Journal of Pain and Symptom Management* 51, no. 2 (February 2016): 204–12, <https://doi.org/10.1016/j.jpainsymman.2015.10.008>.



Table 3: Studies on the linkages between specialist palliative care and caregiver burden

Population	Study type and cohort	Findings	Source
English language articles; adult and paediatric studies ⁶² The Netherlands	Systematic review of studies between 2012 and 2020. One RCT met the criteria for inclusion for this outcome. <ul style="list-style-type: none"> 74 home-based patients with advanced cancer. Randomised to receive weekly teleconsultations, or care as usual, for 12 weeks. 	An RCT on caregiver teleconsultation led to statistically significant and clinically meaningful reduction in caregiver burden in the intervention group – there was a lower proportion of informal caregivers with a high perceived burden in the intervention group. Caregivers also highly satisfied with the intervention.	Iupati et al (2023) ⁶³ Hoek et al (2017) ⁶⁴
Adult home palliative care service	Cochrane review Types of studies <ul style="list-style-type: none"> Patient or cluster randomised controlled trials (RCTs). Patient or cluster controlled clinical trials (CCTs). Controlled before and after studies (CBAs). Interrupted time series analyses (ITSS). Studies up to 2012. 53 reports from 23 studies included.	Conflicting findings about the effect of home palliative care compared with usual care on caregiver burden. There was strong evidence (three RCTs, two of high quality, and one CBA) showing no difference between caregivers who received home palliative care and those who received usual care in terms of the grief intensity they experienced from the moment the patient died to 13 months after. Despite no evidence from trials, a 1986 study found that few caregivers (4%) reported increased absenteeism from work in the first 90 to 120 days after the patient died, with no statistically significant differences among settings.	Gomes et al (2013) ⁶⁵
Informal caregivers who were in a palliative care clinical trial at a Midwestern US National Cancer institute-designated Comprehensive Cancer Center <i>n</i> = 39	Quasi-experimental: Descriptive, correlational design using a cross-sectional approach. No control group.	The impact of caregiving on absenteeism, presenteeism, and non-work activity impairment was measured using the Work Productivity and Activity Impairment Questionnaire (WPAI). It is a 6-item questionnaire. The 39 employed caregivers reported a 9.63% loss in work time (absenteeism) (<i>SD</i> = 23.73). Although 28 caregivers had not missed work in the past 7 days, 11 (28%) reported missing a mean of 17 hours in the last week, which translated into a mean 34.14% loss in work time for that subset of employed caregivers. There was 15.41% (<i>SD</i> = 19.38) impairment while working due to caregiving (presenteeism), indicating	Mazanec et al (2011) ⁶⁶

⁶² 14 countries: 13 studies from US; 4 studies from Australia; 3 from Seden, 2 from the Netherlands; 2 from Italy; 2 from Canada. One study each from UK, Poland, Spain, Hong Kong, Singapore, Korea, India, and Colombia.

⁶³ Iupati et al., 'Systematic Review of Models of Effective Community Specialist Palliative Care Services for Evidence of Improved Patient-Related Outcomes, Equity, Integration, and Health Service Utilization'.

⁶⁴ Hoek et al., 'The Effect of Weekly Specialist Palliative Care Teleconsultations in Patients with Advanced Cancer –a Randomized Clinical Trial'.

⁶⁵ Gomes et al., 'Effectiveness and Cost-Effectiveness of Home Palliative Care Services for Adults with Advanced Illness and Their Caregivers'.

⁶⁶ Mazanec et al., 'Work Productivity and Health of Informal Caregivers of Persons with Advanced Cancer'.



Population	Study type and cohort	Findings	Source
		that caregivers were approximately 85% productive while working. Considering both absenteeism and presenteeism, the mean percentage of overall work productivity loss due to caregiving was 22.88% (SD= 28.47).	

Table 4: Studies on the linkages between hospice care and overtreatment

Population	Study type and cohort	Findings	Source
New Zealand	Literature review`. References Medical Council of New Zealand statements about what good medical practice means in an environment of resource limitation.	Drivers: <ul style="list-style-type: none"> • expanding definition of diseases • advertising • influence of pharmaceutical industry • training of doctors • remuneration of doctors • expectations of patients and families • discomfort of uncertainty • fear of complaints resulting in defensive medicine. Consequences of overtreatment <ul style="list-style-type: none"> • increases cost of care making care less affordable and accessible • increases workload of doctors and other health professionals • wastage • diverts health resources away from other more pressing needs • threatens sustainability of a health system. 	Ooi (2020) ⁶⁷
The Netherlands	Online survey of 592 patients and relatives. They described 429 cases of appropriate care and 309 cases of inappropriate care.	Appropriate care, in terms of supportive care, treatment decisions, following patient's wish, and communication were statistically significantly more likely to occur at home or in a hospice setting. Inappropriate care was statistically significantly more likely to occur as an inpatient in a hospital.	Bolt et al (2016) ⁶⁸
US	Literature review and working group. Decision-making support for clinicians.	Five things physicians and patients should question in hospice and palliative medicine, based on research. One is: don't delay palliative care for a patient with serious illness who has physical, psychological,	Fischberg et al (2013) ⁶⁹

⁶⁷ Kanny Ooi, 'The Pitfalls of Overtreatment: Why More Care Is Not Necessarily Beneficial', *Asian Bioethics Review* 12, no. 4 (December 2020): 399-417, <https://doi.org/10.1007/s41649-020-00145-z>.

⁶⁸ Bolt et al., 'Appropriate and Inappropriate Care in the Last Phase of Life'.

⁶⁹ Fischberg et al., 'Five Things Physicians and Patients Should Question in Hospice and Palliative Medicine'.



Population	Study type and cohort	Findings	Source
		social, or spiritual distress because they are pursuing disease-directed treatment. "There is now convincing evidence that the delivery of palliative care concurrent with the disease-directed treatment can improve the quality of life, symptom control, and family satisfaction with care, all while reducing costs associated with aggressive end-of-life care. Palliative care does not shorten life expectancy and can improve survival in select populations."	
Sweden	Retrospective cohort study of older adults who died with cancer.	Tentatively estimated that about a third of patients received at least one treatment or procedure of potential overtreatment during their last month of life. Researchers were not able to separate out whether location of treatment or death was a factor as transitions to specialised palliative care units were not reliably recorded.	Szilcz et al (2022) ⁷⁰
Community hospital in Monterey, California <i>n</i> = 265	Retrospective medical record review of patient interactions by a palliative pharmacist.	Cost savings associated with pharmacist interventions were calculated on the basis of the direct cost of the discontinued medication, procedure, or test, assuming it would have been continued or administered for an additional 24 hours. Discontinuation of orders was initiated by the pharmacist in consultation with the patient's primary medical team. During the evaluation period, an estimated direct cost reduction of \$100,000 was achieved by treatment discontinuation initiated by the palliative care pharmacist. Cost savings were in line with figures from other studies, for example, another US study where there were reductions in direct costs per day of \$279 for patients discharged alive and \$374 for patients who died as inpatients.	Naidu et al (2018) ⁷¹

Table 5: Studies on the linkages between hospice care and health system costs

Population	Study type and cohort	Findings	Source
New Zealand	Retrospective study of all deaths occurring and registered in 2015.	The total health system cost per person in the last year of life (LYOL) is \$44,785.69 in FY2018 terms.	Atkinson & McLeod (2020) ⁷²

⁷⁰ Máté Szilcz et al., 'Potential Overtreatment in End-of-Life Care in Adults 65 Years or Older Dying from Cancer: Applying Quality Indicators on Nationwide Registries', *Acta Oncologica* 61, no. 12 (2 December 2022): 1437–45, <https://doi.org/10.1080/0284186X.2022.2153621>.

⁷¹ Naidu et al., 'Palliative Care Pharmacist Interventions in a Community Hospital'.

⁷² Atkinson and McLeod, 'Trajectories of Care at the End of Life: Implications for Health Systems with Ageing Populations'.



Population	Study type and cohort	Findings	Source
	Linked data on utilisation of services- RC subsidy, ED admissions, public hospitals, outpatient visits, medicines and laboratory tests, days in public hospital, days in hospice IPU, and place of death.	<ul style="list-style-type: none"> • Total cost for hospital inpatients is, on average, \$18,464.08 per person in the last year of life. <ul style="list-style-type: none"> – Hospital inpatient costs per person per age (pppa) band are highest in the childhood years, lowest at age band 20-24 years, rise in the early adult years and decline from age 55 onwards. • Total cost for the outpatient and ED component is \$3,492.84 per person in the last year of life. Highest outpatient and ED costs are ages 5-9 and then age 40 to 74, with a very strong decline at older ages. • Total cost is \$17,322.97 per person in the LYOL for those in the RC subsidy database and at least \$551.65 per person for those without a subsidy. Together these are \$17,874.62 per person which is 39.9% of total health system costs. The without subsidy component is potentially understated as there is no national database of everyone in RC. • Total cost for the outpatient and ED component is \$3,492.84 per person in the LYOL, which is 7.8% of the total health system cost. • Total cost for the community LABS component is \$227.16 per person in the LYOL, which is 0.5% of the total health system cost. • Total cost for the community PHARMS component is \$2,040.21 per person in the LYOL, which is 4.6% of the total health system cost. • Total cost for PHO capitation and the non-enrolled GP and PHO out of area components is \$298.51 per person in the LYOL, which is only 0.7% of the total health system cost. • Total cost for DHB-funded hospice services is \$2,388.27 per person in the LYOL, which is 5.3% of the total health system cost. Note that the cost is spread over all deaths in the study and is not the per person cost for those using hospice services. The cost pppa is highest from age 40 to 69. 	
New Zealand	Longitudinal study of 213 Māori and 241 non-Māori cohort who had died at time of study.	The average total publicly funded hospital and long-term care home costs in the 12 months prior to death were \$16,211 and \$17,351 for Māori and non-Māori respectively. Non-Māori tended to have long lengths of stay in their last year of life, and non-Māori men had the highest proportion with high costs and long lengths of stay in care homes. Costs in the last year of life were 8.1 times higher in comparison to costs for individuals who did not die in the same period.	Scott et al (2021) ⁷³

⁷³ Oliver W. Scott et al., 'Costs of Inpatient Hospitalisations in the Last Year of Life in Older New Zealanders: A Cohort Study', *BMC Geriatrics* 21, no. 1 (December 2021): 514, <https://doi.org/10.1186/s12877-021-02458-6>.



Population	Study type and cohort	Findings	Source
		Costs are relatively consistent with those in Atkinson and McLeod (2020).	
Australia	Retrospective population-based cohort study of all deaths in Western Australia in 2009 and 2010 from a life-limiting condition considered amenable to palliative care.	Community-based specialist palliative care was associated with a 27% decrease from A\$112 (A\$110-A\$114) per decedent per day to A\$82 (A\$78-A\$85) per decedent per day of cohort averaged hospital costs. Community-based specialist palliative care was also associated a reduction of inpatient averaged hospital costs of 9% (7%-10%) to A\$1030 per hospitalised decedent per day. Hospital cost reductions were observed for decedents with organ failures, chronic obstructive pulmonary disease, Alzheimer's disease, Parkinson's disease and cancer but not for motor neurone disease. Cost reductions associated with community-based specialist palliative care were evident 4 months before death for decedents with cancer and by one to 2 months before death for decedents dying from other conditions.	Spilsbury & Rosenwax, 2017 ⁷⁴
English language studies	Systematic review using PRISMA guidelines. Reviews published between 2000 and 2019. 43 reviews in scope. Written in English.	Overall, most evidence on cost-effectiveness relates to home-based interventions and suggests that they offer substantial savings to the health system, including a decrease in total healthcare costs, resource use and improvement in patient and caregivers' outcomes. The evidence of interventions delivered across other settings was generally inconsistent.	Luta et al (2021) ⁷⁵
English language studies	Systematic review. 18 quantitative studies (including 2 RCTs and 6 cost evaluations), 4 qualitative studies.	Only hospice care at home, nursing homes, and hospice facilities study included in Luta et al (2021). ⁷⁶ Hospice care interventions reduce resource use and costs, improve pain management, and increase death outside the hospital. The strength of this evidence, however, was limited because few of the findings originated from RCTs. ⁷⁷	Candy et al (2011) ⁷⁸

⁷⁴ Katrina Spilsbury and Lorna Rosenwax, 'Community-Based Specialist Palliative Care Is Associated with Reduced Hospital Costs for People with Non-Cancer Conditions during the Last Year of Life', *BMC Palliative Care* 16, no. 1 (December 2017): 68, <https://doi.org/10.1186/s12904-017-0256-2>.

⁷⁵ Luta et al., 'Evidence on the Economic Value of End-of-Life and Palliative Care Interventions'.

⁷⁶ Luta et al.

⁷⁷ Luta et al.

⁷⁸ Candy et al., 'Hospice Care Delivered at Home, in Nursing Homes and in Dedicated Hospice Facilities: A Systematic Review of Quantitative and Qualitative Evidence'.



Table 6: Studies on the linkages between specialist palliative care, pain management, and quality of life

Population	Study type and cohort	Findings	Source
English language articles; adult and paediatric studies ⁷⁹	Systematic review of studies between 2012 and 2020. Five randomised controlled trials (RCTs) and three observations studies met the criteria for inclusion.	All RCTs found statistically significant and clinically meaningful better symptom scores and higher quality of life scores in the intervention groups. The telehealth focused intervention led to significantly worse symptom scores in the intervention group. One of three observations studies found better quality of life and symptom scores for the intervention group. The other two studies found no significant difference.	Iupati et al (2023) ⁸⁰
English language; adult studies	Systematic review and meta-analysis. 10 RCTs, ranging from a few days to 4 months. Mostly advanced cancer.	Small effect for specialist palliative care and improved quality of life scores. Receiving specialist palliative care early was a driver for improved quality of life. Results for secondary outcomes were inconclusive. Secondary outcomes included symptom burden (pain, fatigue, nausea, and dyspnoea), psychosocial variables (distress, depression, anxiety, spiritual wellbeing, social wellbeing, and satisfaction), survival time, place of death, cost of care, and attrition (or completion rate).	Gaertner et al (2017) ⁸¹
New Zealand	Postal questionnaire of bereaved carers for deceased adults in one DHB between 2015 and 2016. Responses were linked to patient DHB data.	The level of satisfaction with care in the last 2 days of life was associated with perceptions of treatment with dignity and respect, adequate privacy, sufficient pain relief and decisions in line with the patient's wishes. Across care settings, pain management was significantly associated with overall care satisfaction. In this study, hospice provision had the highest rated satisfaction – 91% of participants indicated that overall satisfaction with care at hospice was "excellent". The next highest rating for "excellent" were district nurses at 57%.	Frey et al (2020) ⁸²

⁷⁹ 14 countries: 13 studies from US; 4 studies from Australia; 3 from Seden, 2 from the Netherlands; 2 from Italy; 2 from Canada. One study each from UK, Poland, Spain, Hong Kong, Singapore, Korea, India, and Colombia.

⁸⁰ Iupati et al., 'Systematic Review of Models of Effective Community Specialist Palliative Care Services for Evidence of Improved Patient-Related Outcomes, Equity, Integration, and Health Service Utilization'.

⁸¹ Jan Gaertner et al., 'Effect of Specialist Palliative Care Services on Quality of Life in Adults with Advanced Incurable Illness in Hospital, Hospice, or Community Settings: Systematic Review and Meta-Analysis', *BMJ* 357 (4 July 2017): j2925, <https://doi.org/10.1136/bmj.j2925>.

⁸² Frey et al., 'Factors Associated with Overall Satisfaction with Care at the End-of-life'.



Population	Study type and cohort	Findings	Source
Adult home palliative care service	<p>Cochrane review.</p> <p>Types of studies:</p> <ul style="list-style-type: none"> • Patient or cluster randomised controlled trials (RCTs) • Patient or cluster controlled clinical trials (CCTs) • Controlled before and after studies (CBAs) • Interrupted time series analyses (ITs). <p>Studies up to 2012. 53 reports from 23 studies included.</p>	<p>Home palliative care services help reduce the symptom burden people may experience because of advanced illness, without increasing grief for family caregivers after the patient dies.</p> <p>There was conflicting evidence on patients' experience of pain, breathlessness and sleep disturbance.</p> <p>Evidence on cost-effectiveness (six studies) was inconclusive.</p>	Gomes et al (2013) ⁸³
English language	<p>Systematic review of quantitative and qualitative studies between 2003 and 2009.</p> <p>18 comparative evaluations.</p> <p>4 thematic papers.</p>	<p>Main themes in the qualitative literature revealed that home hospice services support families to sustain patient care at home and hospice day care services generate for the patient a renewed sense of meaning and purpose.</p> <p>Methodological limitations in all studies.</p>	Candy et al (2011) ⁸⁴
The following are specific findings from studies included in lupati et al (2023) ⁸⁵			
<p>Patients enrolled with their GPs, newly referred adults, experiencing pain, and were expected to live more than 48 hours.</p> <p>n = 461</p>	<p>RCT in Australian community-based palliative care service.</p> <p>2 x 2 x 2 factorial cluster RCT.</p>	<ul style="list-style-type: none"> • Summary scores for pain, quality of life (QOL), and total symptom burden were calculated in a similar manner to AKPS AUC per day. The patient/ caregiver education significantly reduced total symptom burden (patient/caregiver education 16.2 [SE 1.1] vs. control 19.2 [SE 0.9], p = 0.0325). • Scale of 0-152: 38 possible symptoms each measured on 0-4 scales; total possible score = 152. 	Abernethy et al (2013) ⁸⁶

⁸³ Gomes et al., 'Effectiveness and Cost-Effectiveness of Home Palliative Care Services for Adults with Advanced Illness and Their Caregivers'.

⁸⁴ Candy et al., 'Hospice Care Delivered at Home, in Nursing Homes and in Dedicated Hospice Facilities: A Systematic Review of Quantitative and Qualitative Evidence'.

⁸⁵ 'Systematic Review of Models of Effective Community Specialist Palliative Care Services for Evidence of Improved Patient-Related Outcomes, Equity, Integration, and Health Service Utilization'.

⁸⁶ Abernethy et al., 'Delivery Strategies to Optimize Resource Utilization and Performance Status for Patients With Advanced Life-Limiting Illness'.



Population	Study type and cohort	Findings	Source
Three hospitals in Hong Kong <i>n</i> = 84	RCT. End-stage heart failure patients who had been discharged home from hospitals and referred for palliative service. Interventions consisted of weekly home visits/ telephone calls in the first 4 weeks then monthly follow up, provided by a nurse case manager supported by a MDT.	<ul style="list-style-type: none"> Both measures of QOL, the Chronic heart-failure questionnaire Chinese (CHQC) ($p < 0.01$) and McGill QOL ($p < 0.05$), showed a significant difference in the change over time between groups. McGill Quality of Life Questionnaire (score, SE). McGill is a numerical scale from 0 to 10. Total* Control, group 1 = 6.35 (0.23) group 2 = 6.46 (0.36) Intervention, group 1 = 6.51 (0.22), group 2 = 7.57 (0.21)*** = $p < 0.001$. 	Wong et al (2016) ⁸⁷
County hospital located in northern Sweden. <i>n</i> = 72	RCT. Patients were randomised into either the PREFER intervention or the control group. Patients in the intervention group were offered a multidisciplinary approach involving collaboration between specialists in palliative and heart failure care (that is, specialised nurses, palliative care nurses, cardiologist, palliative care physician, physiotherapist, and occupational therapist). The patients were also offered structured, person-centred care at home.	<ul style="list-style-type: none"> Quality of life improved by 24% ($p = 0.041$) from 49.5 (SE 24.7) to 61.3 (SE 25.5) Euro QoL (EQ-5D): The descriptive system comprises five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has 5 levels: no problems, slight problems, moderate problems, severe problems and extreme problems. Scale 0 - 100 	Brännström and Boman (2014) ⁸⁸

⁸⁷ Wong et al., 'Effects of a Transitional Palliative Care Model on Patients with End-Stage Heart Failure'.

⁸⁸ Brännström and Boman, 'Effects of Person-Centred and Integrated Chronic Heart Failure and Palliative Home Care. PREFER: A Randomized Controlled Study'.



Appendix 3: Assumptions used in estimating benefits

Table 7: CBAX values used

Category	Value per visit (adjusted to 2023 \$)
Hospital admission	\$7,235
ED visit	\$503
GP visit (government contribution)	\$61
GP visit (patient co-payment)	\$48
Home nurse	\$136
Subjective wellbeing benefits of weekly volunteering	\$630 per volunteer

Source: The Treasury⁸⁹

Table 8: Assumptions used in estimating benefits

Cohort	Estimated annual cost 2023	Methodology	Source
Emergency department visits			
Dementia	\$0.387m	1,419 in the dementia cohort utilising hospice care from Palliative Care Projection Model. Study showed 1.4 times more visits to hospital from a dementia facility that didn't have hospice care. There were 1.9 ED visits in the dementia facility without hospice care, so divided by a factor of 1.4, means there were 1.36 visits in a dementia facility with access to hospice care.	Rosenwax et al (2015) ⁹⁰

⁸⁹ The Treasury, 'The Treasury's CBAX Tool'.

⁹⁰ Rosenwax et al., 'Community-Based Palliative Care Is Associated with Reduced Emergency Department Use by People with Dementia in Their Last Year of Life'.



Cohort	Estimated annual cost 2023	Methodology	Source
		That equals 0.54 additional visits. 0.54 additional visits * 1,419 dementia patients = 770 visits. 770 visits * \$503 = \$387,000.	
Cancer	\$2.9m	7,382 in the cancer cohort utilising hospice care from Palliative Care Projection Model. A study found 76,759 patients with cancer, visited the ED 194,017 times over six months, a rate of 2.53 visits per person. There were 31% fewer visits for cancer patients receiving hospice care, a rate of 1.74 visits per person. That equals 0.78 additional visits. 0.78 additional visits * 7,382 cancer patients * \$503 = \$2.9 million.	Hsu et al (2021) ⁹¹
Chronic illness & need and maximal need	\$0.823m	2,091 in the chronic illness & need and maximal need cohorts utilising hospice care from Palliative Care Projection Model. Assumed the illness trajectory of those with chronic illness and need or maximal need was closer to cancer than dementia, so used the same study as above. 0.78 additional visits * 2,091 patients * \$503 = \$823,000.	Hsu et al (2021) ⁹²
Hospital admissions			
Dementia	\$3.8m	1,419 in the dementia cohort utilising hospice care from Palliative Care Projection Model. Study showed there were 9,781 ED visits for dementia patients, 6,631 of which were admitted to hospital after the ED visit, or 68% were admitted. The study on ED visits for dementia patients above found 770 ED visits. 770 visits * 68% rate of admission * \$7,235 = \$3.8 million.	Spilsbury et al (2017) ⁹³

⁹¹ Hsu et al., 'Enhanced Home Palliative Care Could Reduce Emergency Department Visits Due to Non-Organic Dyspnea among Cancer Patients'.

⁹² Hsu et al.

⁹³ Spilsbury et al., 'The Impact of Community-Based Palliative Care on Acute Hospital Use in the Last Year of Life Is Modified by Time to Death, Age and Underlying Cause of Death. A Population-Based Retrospective Cohort Study'.



Cohort	Estimated annual cost 2023	Methodology	Source
Cancer	\$63.0m	7,382 in the cancer cohort utilising hospice care from Palliative Care Projection Model. Study showed cancer patients had 3.48 visits while in not in hospice care, and 2.30 visits while in hospice care, a difference of 1.18. 1.18 additional visits * 7,382 patients = 8,710 visits. 8,710 visits * \$7,235 = \$63 million.	Spilsbury et al (2017) ⁹⁴
Chronic illness & need and maximal need	\$35.0m	2,091 in the chronic illness & need and maximal need cohorts utilising hospice care from Palliative Care Projection Model. Study of 73 patients had 267 hospital visits before hospice intervention, and 97 after hospice intervention. That's 3.66 visits per patients pre hospice intervention, and 1.33 post hospice intervention, a difference of 2.33. 2.33 additional visits * 2,091 patients = 4,869 visits. 4,869 visits * \$7,235 = \$35 million.	Iupati and Ensor (2015) ⁹⁵
Community clinical care			
GP visits (government contribution)	\$0.596m	Clinical care events including syringe driver, catheterisation, blood transfusions etc. Total number of clinical care events for the five commissions hospices = 1,741, or 9,750 projected for all hospices. 9,750 clinical care events * \$61 government contribution = \$595,855.	Modelled numbers based off clinical care services for the five commissioning hospices.
Home nursing	\$1.8m	Clinical care events including wound management etc. Total number of clinical care events for the five commissions hospices = 2,359, or 13,210 projected for all hospices. 13,210 clinical care events * \$136 per visit = \$1.8 million.	Modelled numbers based off clinical care services for the five commissioning hospices. Note that a study indicated that 39% of people who died in Waitemata DHB area had contact

⁹⁴ Spilsbury et al.

⁹⁵ Iupati and Ensor, 'Do Community Hospice Programmes Reduce Hospitalisation Rate in Patients with Advanced Chronic Obstructive Pulmonary Disease?'



Cohort	Estimated annual cost 2023	Methodology	Source
			with a District nurse. ⁹⁶ Community hospice nurses had contact with around 34% of people who died. However, there were no findings available as to those utilising hospice care who were also utilising district nursing.
Quality of life			
Improved quality of life	\$48.2 m	The value ascribed by The Treasury for a one-point increase in life satisfaction (low) is \$5,539 per year or \$462 per month. Patients see a 24% increase (or 2.4 points on a 10-point scale), and experience this for 4 months, equating to \$4,431 per annum per patient. 10,880 patients * \$4,431 = \$48.2 million.	Brännström and Boman (2014) ⁹⁷
GP visit (patient co-payment)			
GP visit	\$0.468 m	Patients contribute financially to clinical care events. Total number of clinical care events for the five commissions hospices = 1,741, or 9,750 projected for all hospices. 9,750 clinical care events * \$48 patient co-payment = \$468,000.	Modelled numbers based off clinical care services for the five commissioning hospices.
Subjective wellbeing benefits of volunteering			
Improved subjective wellbeing	\$2.6 m	The value ascribed by The Treasury for the subjective wellbeing benefits of volunteering on a regular weekly basis. Total number of volunteers = 10,000. 96% of these volunteers are regular. 43% volunteer in	Modelled numbers based on information on volunteers provided by the

⁹⁶ Jackie Robinson and Merryn Gott, 'Community Nursing in an Integrated Model of Palliative Care: An Analysis of Waitemata District Health Board Health Service Utilization Data in the Last Year of Life' (University of Auckland: School of Nursing, 2021); Jackie Robinson et al., 'The Work of Palliative Care from the Perspectives of District Nurses: A Qualitative Study', *Journal of Advanced Nursing* 00 (2023): 1-10.

⁹⁷ Brännström and Boman, 'Effects of Person-Centred and Integrated Chronic Heart Failure and Palliative Home Care. PREFER: A Randomized Controlled Study'.



Cohort	Estimated annual cost 2023	Methodology	Source
		<p>non-retail hospice services, so are assumed to be more likely to have strong ties to hospice (and less likely to volunteer elsewhere in the absence of hospices).</p> <p>$10,000 * 43% * 96% = 4,116.$</p> <p>$4,116 * \\$630 \text{ a year} = \\$2.6 \text{ m.}$</p>	<p>five commissioning hospices and CBAX values for the value of volunteering.</p>



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