Blood Cancer NZ

EVERY BLOOD CANCER . EVERY PERSON . EVERY JOURNEY

State of Blood Cancer in New Zealand

April 2026

bloodcancer.org.nz

Deloitte.

My blood cancer diagnosis came as a shock, as it does for many. I was told I had a 40 to 50% chance of survival. Immediately, my life was in free-fall; nothing made sense.

At first, I thought the falling would go on for the rest of whatever time I had left.

But then it didn't. Support wrapped around me.

My wife, equally in shock, stepped up front and centre. My sister. My then 12-year-old son. The other blood cancer patients in the ward, sharing perspective, knowledge and kind words. Blood Cancer NZ, offering considered advice and a kind ear. The nurses, nurse specialists, and doctors; they leaned in, empathetic and understanding, and let me know that there was a way through. Together, we got the cancer under some control. Some trust, and hope, built.

But then I couldn't recover from the treatment, and so it couldn't continue.

There was still some hope, but only one option remained: a stem cell transplant. And that is when the mess started. I was put on a waitlist and told to expect to be waiting months. I waited for approval for unfunded medicines to keep the cancer controlled, and there were further delays with the delivery of that medicine.

And when my place on the waitlist came up 7 months later, we found the cancer was back in force. I couldn't go ahead as planned.

Through all of these failings, I felt back in free-fall. I felt for the medical team who had to break the news to me, to tell me of the consequences they knew didn't have to exist. I could see the clear conflict in their eyes. They then did everything they could with what they had and 42 days later they got me back to transplant readiness. I felt relief, but I was so sick and I felt survival was unlikely.

Stem Cell Transplant is brutal. I cannot even describe how brutal it was on me, on my wife bearing the load beside me, and it was almost more than my son could bear.

That was a year and a half ago.

I lived. I am writing this today because I lived. I am grateful. I can live with the legacy of fatigue and weakness. And despite all the trauma, I like to tell myself I've grown, so this is a good news story for me.

When I talk to my transplant doctor about how long recovery is taking; about how deep a hole I am still in all this time later; or about my frustration on not being able to get back to work; he says that I went into transplant with much more "baggage in my back-pack" than most. And he looks serious. He knows I'm happy the team got me through, but he also knows the gaps hurt me, and hurt my wife and son. The whole team feels that pain.

Some patients I met during my time on the cancer ward have had their kind voices silenced. Some fell right through the cracks in our system, and they simply can't tell their stories now.

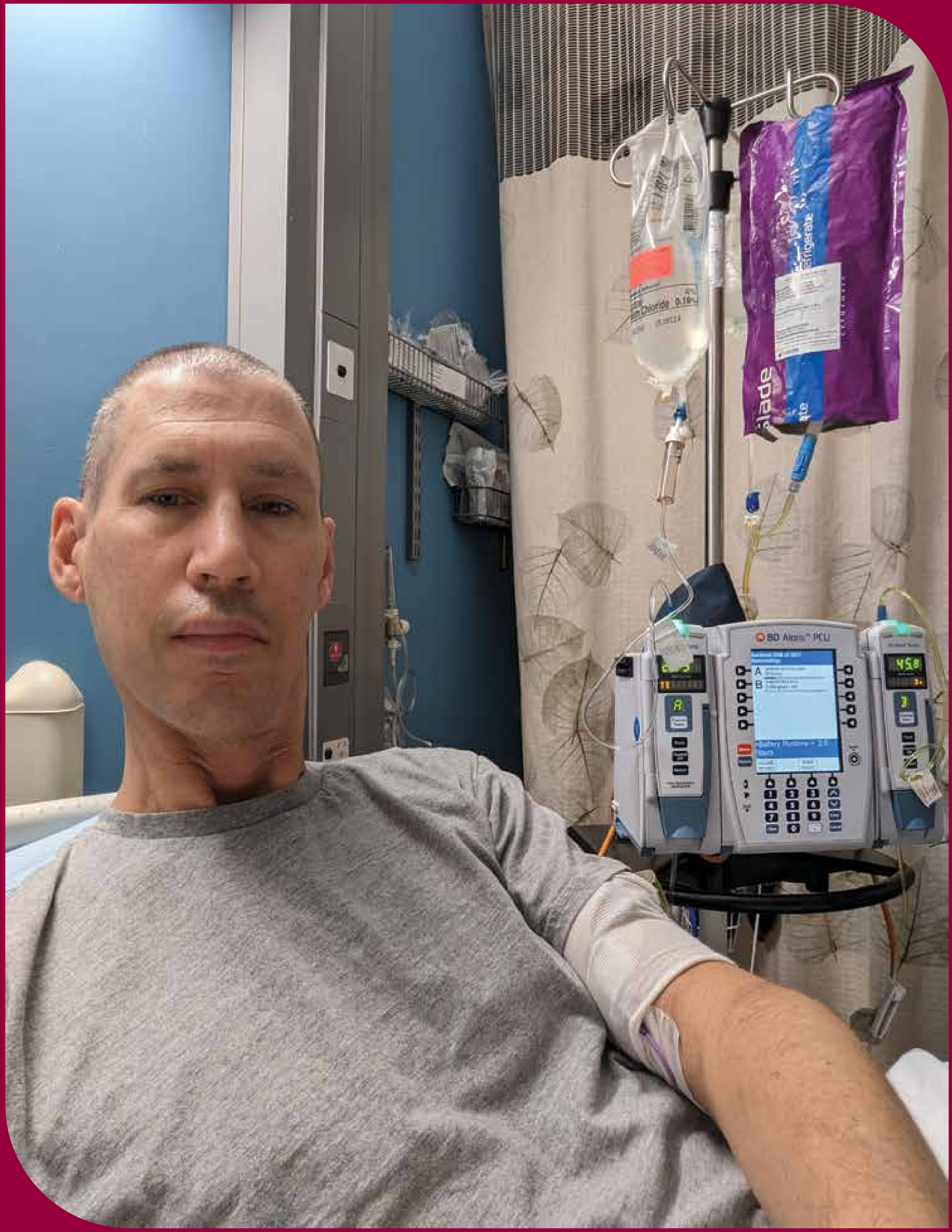
Shortly after my transplant, my father was also diagnosed with leukaemia, and as I write this, the news is still fresh that he has moved to palliative only care. I had feared for how the system would treat him, and now I worry about how his final days will play out.

But, I fear more for my son. I feel for the trauma he felt coming so close to losing a parent and the strain of living in a cancer household. And, much more than that, I worry about what the genes he might share with my father and me might mean for his future. I need to know that if he ever finds himself in that free-fall after a blood cancer diagnosis, he will get the best shot at the best outcome.

I applaud Blood Cancer NZ's efforts. They help those living with (or having survived) blood cancer to speak with one voice. They also give a voice to those who haven't made it.

And, they advocate for all New Zealanders, and their families, who may have a blood cancer diagnosis in their future.

Andrew Mackintosh
a New Zealand blood cancer survivor



> **I am hopeful that actions taken in response to this report will get New Zealand ready to support those families affected by blood cancer, and give them the best outcome that we know is possible.**

Andrew Mackintosh
a New Zealand blood cancer survivor

Executive Summary

This report provides the first comprehensive assessment of blood cancer in New Zealand, bringing together epidemiology, patient experience, system performance, and treatment access. Drawing on national data as well as insights from 744 patients and carers, and 85 healthcare professionals, it identifies a widening gap between what is clinically possible and what the health system currently delivers. At a time when innovation is transforming outcomes internationally, New Zealand is not keeping pace.

Blood cancer outcomes are highly dependent on health system performance. With prevention and screening pathways not viable for blood cancers, survival relies on timely diagnosis, access to specialist haematology services, and the availability of effective treatments. In New Zealand, these elements are constrained by siloed investment models, fragmented health system planning, and limited access to modern therapies, leaving patients with fewer treatment options, a reduced likelihood of remission, and poorer outcomes than those seen in comparable countries.

This gap reflects a system that has not adapted to the realities of modern blood cancer care. Advances in treatment are redefining what is possible, with increasingly targeted therapies capable of delivering durable or curative outcomes. However, delays in adopting innovation, barriers to accessing medicines and clinical trials, and capacity constraints across the workforce and service infrastructure continue to limit the system's ability to respond.

The opportunity is clear. Aligning policy, funding, and delivery with international best practice would enable rapid and measurable improvements in care. A future in which no lives are needlessly lost to blood cancer is within reach, and this report sets out the roadmap and priority actions needed to achieve that change for patients by 2035.

1. **Establish a national blood cancer taskforce** to provide system leadership, coordination, and accountability

2. **Enable access to treatment aligned with international best practice** ensuring timely and predictable access to standard-of-care therapies

3. **Support consistent diagnostic and treatment pathways** by aligning system capability with existing national guidance

4. **Strengthen access to research and clinical trials** so patients can benefit from emerging therapies

5. **Build workforce and service capacity** to meet current and future demand

Disclaimer: This report was commissioned by Blood Cancer New Zealand and co-authored by Deloitte as an independent, paid professional engagement. Deloitte's role was to research, analyse and author an evidence-based assessment of the blood cancer sector in New Zealand, drawing on publicly available data and stakeholder insights. The report focuses on the sector as a whole and does not assess or evaluate the performance, effectiveness, or financial position of Blood Cancer New Zealand as an organisation. The results of the Integrated Data Infrastructure (IDI) analysis are not official statistics. They have been created for research purposes from the IDI which is carefully managed by Stats NZ. For more information about the IDI please visit https://www.stats.govt.nz/integrated-data/ . The results are based in part on tax data supplied by Inland Revenue to Stats NZ under the Tax Administration Act 1994 for statistical purposes. Any discussion of data limitations or weakness is in the context of using the IDI for statistical purposes and is not related to the data's ability to support Inland Revenue's core operational requirements. AI has been used to support the development of this report. AI-generated content has been checked by the report authors.

Blood cancer is a growing and uniquely system-dependent health challenge

Blood cancer is one of New Zealand's most significant and fastest growing cancer burdens. Around 3,000 people are diagnosed each year, and approximately 27,000 people are currently living with the disease.[1] This number has increased steadily over time, reflecting an ageing and growing population, as well as improvements in survival that mean more people are living longer with blood cancer.

While New Zealand does not publish long-term projections, trends in comparable countries suggest the burden will continue to grow. In Australia, blood cancer is projected to become the most diagnosed cancer by 2035 (Leukaemia Foundation Australia, 2025).

It is currently the third leading cause of cancer death in New Zealand and the fastest growing contributor to cancer mortality over the past decade (Health NZ, 2025). It is the most common and fatal ***unpreventable*** cancer.

More New Zealanders are diagnosed with blood cancer than with melanoma or lung cancer, and more die from it than from prostate or breast cancer (Health NZ, 2025).

Blood cancer is fundamentally different from most other cancers in ways that directly shape how care must be delivered. It cannot be prevented or detected through screening, and often there is no surgical pathway to remove disease. As a result, outcomes are exceptionally dependent on the health system's ability to deliver timely diagnosis, specialist care, and effective treatment.

For many patients, this means unexpectedly becoming reliant on the public health system for both immediate and ongoing care. Unlike many other cancers, where prevention, screening, or surgery can alter the course of disease, blood cancer outcomes are disproportionately shaped by whether the system can provide the right care at the right time.

Key facts about blood cancer in New Zealand

3,000 people diagnosed each year

27,000 people living with blood cancer

1 in 18 people will develop blood cancer

Third leading cause of cancer death

Most common cancer that cannot be prevented or screened

One of the fastest growing contributors to cancer mortality in New Zealand

Sources: Health NZ (2025), Stats NZ (2024), Sun et al (2025)

Why blood cancer is different

Most cancers	Blood cancers
Prevention	No prevention
Screening	No screening
Surgery	No surgery
Medicines	Treatment is the main option

Blood cancer survival has been transformed by advances in treatment

Over the past two decades, advances in diagnostics and treatment have fundamentally changed outcomes for blood cancer. Many blood cancers are now treated with curative intent, and many people are living full, active lives as a result of effective treatment.

Blood cancer has often led the way in medical innovation, from the early use of chemotherapy and targeted therapies to newer approaches such as immunotherapies and cellular therapies that harness a patient's own immune system to destroy cancer cells. These advances are delivering deeper, more durable remissions with reduced toxicity and are driving a broader shift toward more personalised, precision-based interventions across healthcare.

Despite this progress, New Zealand's policy, planning, and funding settings are not keeping pace with comparable countries. Therapies that are now standard of care for blood cancer internationally remain unavailable in New Zealand.

For clinicians, this means being unable to provide the standard of treatment their patients should receive, and carrying the moral burden of seeing the consequences reflected in poorer outcomes. For patients, it can mean attempting to self-fund care, facing significant personal cost, leaving the country during a time of acute vulnerability, or accepting treatment that is less effective, with poorer quality of life and reduced survival.

A clear and measurable gap in access to modern treatment

New Zealand has a consistent and well-documented gap in access to modern blood cancer therapies compared with similar countries. These are not marginal or experimental therapies. Many are now standard of care internationally and form the backbone of modern treatment.

This gap extends beyond medicines alone. Stem cell transplantation is a highly specialised intervention that can offer curative intent or long-term remission for many blood cancers, but access in New Zealand is constrained. Patients face delays beyond clinically recommended timeframes due to current waitlists, which can result in disease progression and in some cases, missing the opportunity for cure.

For patients, this gap narrows the treatment pathways available to them:

- Fewer options at the point of diagnosis, reducing the likelihood of achieving optimal outcomes from the outset
- Treatment options are exhausted more quickly, across relapsing and refractory disease
- Reduced access to therapies with curative potential, limiting the opportunity for long-term survival or cure

As international standards continue to advance, New Zealand is not keeping pace in incorporating new therapies and scaling access to complex treatments.
The result is a widening gap over time between the standard of care internationally and what patients can access in New Zealand.

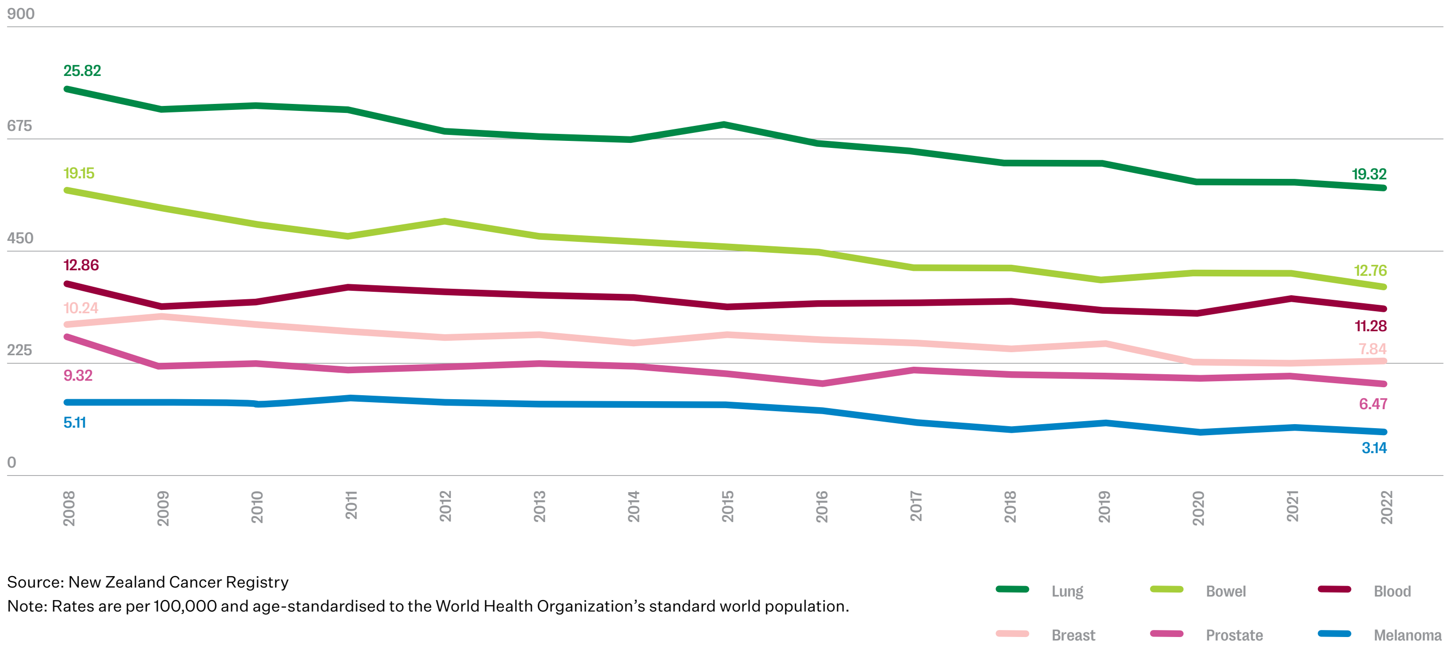
Select blood cancer medicines funded in Australia but not New Zealand

Disease type	Medicines funded in Australia but not New Zealand
Acute myeloid leukaemia	· Gilteritinib · Oral azacitidine (maintenance therapy) · CPX-351 (liposomal daunorubicin + cytarabine) · Decitabine + cedazuridine (INQOVI)
Acute lymphoblastic leukaemia	· Blinatumomab · Tisagenlecleucel (CAR T-cell therapy)
Chronic myeloid leukaemia	· Asciminib · Ponatinib · Nilotinib (first-line) · Dasatinib (first-line)
Chronic lymphocytic leukaemia	· Acalabrutinib · Idelalisib
Non-Hodgkin lymphoma	· Acalabrutinib · Zanubrutinib · Polatuzumab vedotin · Axicabtagene ciloleucel (CAR T-cell therapy) · Tisagenlecleucel (CAR T-cell therapy)
Multiple myeloma	· Daratumumab · Carfilzomib · Selinexor · Elranatamab
Myeloproliferative neoplasms	· Momelotinib · Ruxolitinib (polycythaemia vera)
Myelodysplastic syndromes	· Decitabine + cedazuridine (INQOVI)
Graft-versus-host disease	· Ruxolitinib

Note: Table summarises selected medicines funded through Australia's Pharmaceutical Benefits Scheme that are not publicly funded in New Zealand at the time of analysis. It does not represent a complete formulary comparison.

[1] Stats NZ (2024). ***Integrated Data Infrastructure***. Statistics New Zealand. https://www.stats.govt.nz/integrated-data/integrated-data-infrastructure/

Age standardised rate of annual cancer deaths for major cancer types in New Zealand, 2008-2022



Source: New Zealand Cancer Registry
Note: Rates are per 100,000 and age-standardised to the World Health Organization's standard world population.

Outcomes in New Zealand are not keeping pace with what is possible

Over the past 15 years, outcomes for people with blood cancer in New Zealand have not kept pace with improvements seen in other major cancers. At the same time, advances in treatment overseas have led to better survival, longer remissions, and new pathways to cure.

When blood cancers are combined, New Zealand does not show an improvement in age-standardised mortality over the past 15 years, unlike all other major cancers and unlike progress seen overseas (Health NZ, 2025). Annual deaths from blood cancer have also increased by almost 40% since 2008.

Australia is often used as a benchmark due to its similar population demographics and comparable health system. It is also where many New Zealand patients travel for care. Across several blood cancers, survival rates are higher in Australia, highlighting what is possible when people can access modern treatment sooner.

Because treatment is the primary driver of survival in blood cancer, delays in access to modern therapies lead to poorer outcomes, and this is now reflected in New Zealand's comparatively worse survival rates.

Five-year survival for selected blood cancers in New Zealand and Australia, latest available estimates (up to 2021)

Cancer type	New Zealand	Australia
Leukaemia	57.7%	66.4%
Hodgkin lymphoma	80.2%	88.6%
Non-Hodgkin lymphoma	68.4%	77.4%
Myeloma	58.9%	60.7%

Sources: New Zealand: Net survival at 5-years (2020-2021 period estimate) from State of Cancer dashboard, available at: https://minhealthnz.shinyapps.io/state_of_cancer/
Australia: Relative survival (2017-2021 diagnoses) from Australian Institute of Health and Welfare (AIHW), available at https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/survival
Note: New Zealand estimates use net survival calculated, while Australian estimates use relative survival. These measures are conceptually similar but not directly equivalent and are best interpreted as directional rather than exact comparisons.

The system is not designed for the realities of blood cancer care

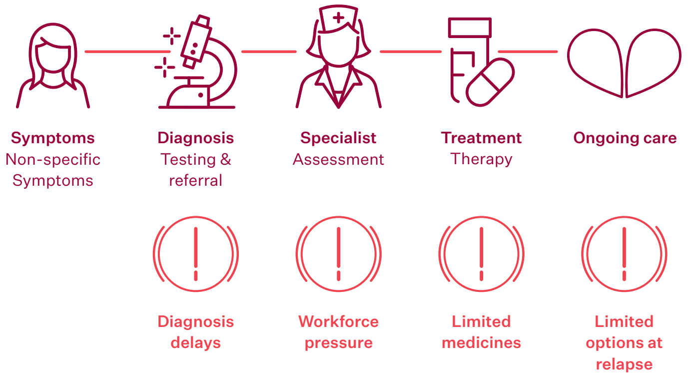
While access to modern therapies is a major driver of outcomes, it is not the only gap in the system. Blood cancer care is becoming increasingly complex, and the health system has not kept pace with this change.

Key constraints include:

- Workforce shortages across haematology and specialist roles
- Limited diagnostic capability, including genomics and molecular testing
- Infrastructure gaps for delivering advanced therapies
- Barriers to accessing medicines and clinical trials

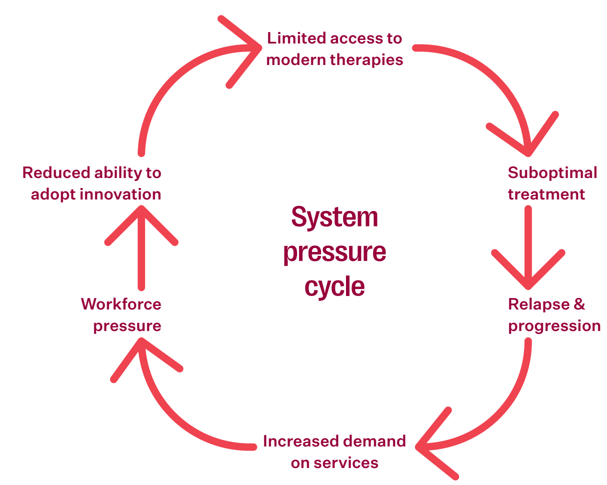
These constraints are interconnected and affect the patient pathway from diagnosis through to treatment and ongoing care.

Blood cancer patient journey and key system pressure points in New Zealand



As demand grows, these pressures reinforce one another. Limited access to effective treatment increases the need for more intensive care, while service pressure and workforce shortages make it harder to deliver timely diagnosis, treatment, and follow-up care. This creates a self-reinforcing cycle that both drives and sustains poorer outcomes.

System pressure cycle in blood cancer care



Workforce and system sustainability are at risk

Blood cancer care relies on a highly specialised workforce.

Current pressures include:

- Difficulty recruiting and retaining haematology specialists
- Increasing workload and complexity of care
- Limited ability to deliver internationally standard treatments

When clinicians are unable to provide optimal care, it contributes to professional frustration and impacts workforce sustainability. In a clinician survey, 70% of haematologists reported being dissatisfied with blood cancer care in New Zealand.

This also affects New Zealand's position internationally, reducing attractiveness as a place to train and work.

The consequences are experienced directly by patients and whānau

The impact of these system constraints is felt in the day-to-day reality of people living with blood cancer.

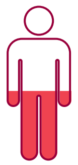
The significant health burden faced by patients is accompanied by a substantial emotional burden. Patients and their whānau must navigate uncertainty, repeated treatment, and the ongoing stress of knowing that more effective options may exist but are not accessible.

Blood cancer severely impacts physical health, mental wellbeing and overall quality of life, with anxiety and depression 2–3 times more common than with other cancers. Carers face emotional and practical strain, with 74% reporting negative mental health impacts and many reduce or leave employment.[2]

The financial impact adds a further layer of pressure. A blood cancer diagnosis often brings:

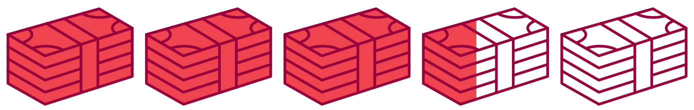
- A loss of income following diagnosis
- Ongoing out-of-pocket costs for care
- Increased reliance on social support

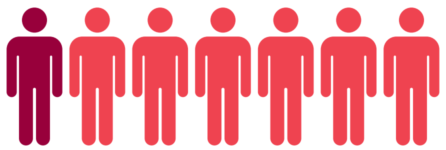
Financial toxicity is widespread in blood cancer.



Nearly half of patients (45%) report significant out-of-pocket costs

69% draw on life savings to fund their care





One in seven patients spends more than $100,000 on unfunded medicines, with myeloma patients disproportionately affected

Source: Patient and Caregiver survey

For many, access to treatment becomes dependent on their financial means or their ability to leave the country. Patients may attempt to self-fund or rely on fundraising, or proceed with publicly available treatments that fall short of international standards of care.

This creates variation in access to optimal treatment, influenced by a patient's ability to navigate alternative pathways such as travel, private care, or fundraising, reinforcing inequities in access and outcomes.

The health, social and economic impact of blood cancer is significant and growing

Blood cancer places significant financial pressure on New Zealand's health system. In 2023, hospital-based care cost nearly $209 million, with most of this driven by inpatient care.[1] At the same time, outpatient care and associated costs are increasing as more treatment is delivered through day-stay settings and more people live longer with blood cancer. As incidence rises and survivorship improves, pressure on hospital services will continue to grow.

The burden also extends beyond the health system. In 2024, people with blood cancer accessed more than $56.3 million in social benefits, and in 2023 half of people living with blood cancer accessed some form of benefit support.[1] Integrated Data Infrastructure (IDI) income data also shows a marked impact on workforce participation, with the proportion of income earners significantly dropping post diagnosis.

These findings show that blood cancer has substantial wider social and economic impacts, including lost income, reduced workforce participation and increased reliance on public support.

A fragmented system and a clear opportunity for change

There is no coordinated, national plan for blood cancer care in New Zealand. Responsibility is distributed across multiple agencies, with no single mechanism to align action or drive system-wide improvement.

This fragmentation results in:

- Inconsistent investment across the continuum of care
- Constraints on medicine access disproportionately affecting people with blood cancer
- Variable diagnostic capability
- Limited participation in clinical trials
- Misalignment between planning, funding, and delivery

As a result, progress is slow and uneven.

The current trajectory is not sustainable. As the number of people diagnosed increases and treatment becomes more complex, pressure on the system will continue to grow, and the gap between what is possible and what is delivered will widen.

However, this is not an intractable problem. Blood cancer outcomes can improve rapidly when systems are aligned with modern care, and many of the required policies, procedures, and interventions are already known and achievable.

[1] Stats NZ (2024). ***Integrated Data Infrastructure***. Statistics New Zealand. https://www.stats.govt.nz/integrated-data/integrated-data-infrastructure/

[2] Blood Cancer NZ. (2025). Patient and Caregiver Survey [unpublished survey data].

Delivering on the goal: no lives needlessly lost to blood cancer

New Zealand has the opportunity to deliver blood cancer care that aligns with international best practice and ensures that lives are not lost due to avoidable delays, constrained service capacity, or lack of access to effective treatments.

The goal over the next decade is that no lives are needlessly lost to blood cancer. Achieving this goal is possible but requires a coordinated national response aligned with how modern blood cancer care is delivered.

The following five priority areas focus on the points in the system where targeted action will have the greatest impact on outcomes:

Priority 1: Establish a National Blood Cancer Taskforce

Sustained improvement in blood cancer outcomes will require coordinated action across medicines access, service planning, workforce, research, and policy settings. Many of the barriers identified cut across agencies and cannot be resolved through existing governance structures or isolated initiatives.

Priority 2: Enable Access to Treatment Aligned with International Best Practice

Access to modern blood cancer treatments is one of the strongest drivers of survival and quality of life. International standards increasingly rely on targeted immune-based, and cellular therapies delivered within coordinated models of care. In New Zealand, delays and gaps in access to these therapies significantly constrain clinical options and contribute directly to poorer outcomes.

Priority 3: Support Consistent Diagnostic and Treatment Pathways

Variation in access to specialised pathology, molecular testing, and advanced imaging can delay diagnosis and treatment initiation, contributing to regional differences in care. National mechanisms such as multidisciplinary meetings and shared clinical information systems offer opportunities to reduce unwarranted variation and support consistent, high-quality decision-making across the country.

Priority 4: Strengthen Access to Research and Clinical Trials

Clinical trials are integral to best practice blood cancer care, offering patients access to emerging therapies and enabling clinicians to engage with advances that shape international standards of treatment. In New Zealand, trial participation is constrained by system factors including limited delivery capability, restricted access to standard-of-care therapies required for eligibility, geographic barriers, and the absence of clear pathways from trial participation to funded access for proven treatments.

Priority 5: Build Workforce and Service Capacity

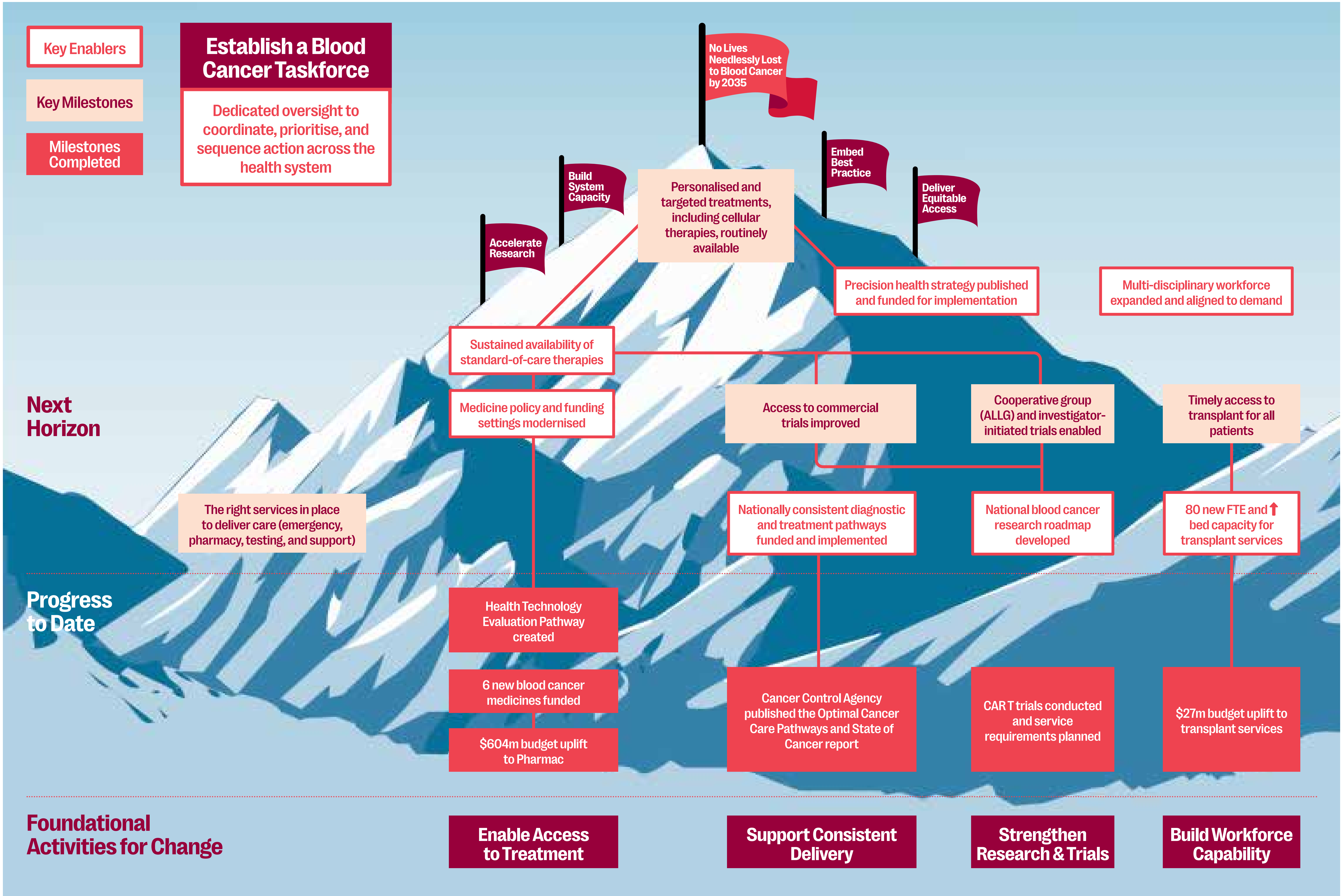
Rising incidence, growing prevalence, and increasing treatment complexity are placing sustained pressure on the workforce and services that deliver blood cancer care. Workforce shortages contribute directly to treatment delays and increased clinical and patient burden. Building workforce and service capacity is therefore foundational to all other priorities.

These priorities are interdependent and must be delivered as a coordinated programme of work. Progress in one area will not be sustained without alignment across funding, policy, planning, and service delivery.

Delivering on these priority actions requires acknowledging the current gap between what is possible and what is delivered, and committing to a system that enables equitable access to modern blood cancer care.

The roadmap for change

Through these changes, New Zealand can build a stronger and more responsive blood cancer care system, supporting people at every stage of their journey and helping ensure that no lives are needlessly lost to blood cancer.



Key Enablers
Key Milestones
Milestones Completed
Establish a Blood Cancer Taskforce
Dedicated oversight to coordinate, prioritise, and sequence action across the health system
No Lives Needlessly Lost to Blood Cancer by 2035
Build System Capacity
Accelerate Research
Embed Best Practice
Deliver Equitable Access
Personalised and targeted treatments, including cellular therapies, routinely available
Precision health strategy published and funded for implementation
Multi-disciplinary workforce expanded and aligned to demand
Sustained availability of standard-of-care therapies
Next Horizon
Medicine policy and funding settings modernised
Access to commercial trials improved
Cooperative group (ALLG) and investigator-initiated trials enabled
Timely access to transplant for all patients
The right services in place to deliver care (emergency, pharmacy, testing, and support)
Nationally consistent diagnostic and treatment pathways funded and implemented
National blood cancer research roadmap developed
80 new FTE and ↑ bed capacity for transplant services
Progress to Date
Health Technology Evaluation Pathway created
6 new blood cancer medicines funded
$604m budget uplift to Pharmac
Cancer Control Agency published the Optimal Cancer Care Pathways and State of Cancer report
CAR T trials conducted and service requirements planned
$27m budget uplift to transplant services
Foundational Activities for Change
Enable Access to Treatment
Support Consistent Delivery
Strengthen Research & Trials
Build Workforce Capability

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Blood Cancer NZ

Introduction

Blood cancers – including leukaemia, lymphoma, myeloma, myeloproliferative neoplasms, and myelodysplastic syndromes – have a profound impact on the lives of up to approximately 27,000 New Zealanders living with these conditions, and their families.

Blood cancers disrupt the normal production and function of blood cells, leading to severe health complications, impact on quality of life, and for many, premature death. Approximately 27,000 New Zealanders are living with blood cancer, collectively the fourth most common cancer in the country.

Over 3,000 people are diagnosed with blood cancer each year in New Zealand and with blood cancer being the third leading cause of cancer death, many lives are lost to these diseases.

Blood Cancer NZ is a charity that, since 1977, has been committed to improving the quality of life for patients and their families living with blood cancers and other related blood conditions. This State of Blood Cancer report illustrates current challenges, and seeks to drive change in patient outcomes for how New Zealanders experience blood cancer. It is inspired by equivalent reports commissioned by the Leukaemia Foundation Australia which have helped position blood cancer as a national health priority.

This report defines the burden of blood cancer in New Zealand by drawing on survey responses from 744 patients and carers, and 85 clinicians and allied health workers. These voices build a clear picture of what is required for New Zealand to deliver the global standard of care. This is supported by evidence from New Zealand's Integrated Data Infrastructure (IDI), a resource that links interrelated data across health, social, and economic domains. For the first time, the IDI has been used to capture a holistic view of the impact of blood cancer on New Zealanders.

The report also incorporates epidemiological analyses undertaken by researchers at the University of Auckland's School of Population Health, which provide insights into epidemiological patterns across the major blood cancer groups. Detailed research methodology can be found in the appendices.

It is only by having an accurate understanding of the existing landscape that we can map the road towards the goal of no lives needlessly lost to blood cancer by 2035.

This goal mirrors that of Australia, which recognises that with sustained system improvement and equitable access to best practice care, a meaningful proportion of current mortality is preventable over the next decade.

A blood cancer diagnosis is life-changing for many and often comes as a profound shock to patients and their families, who suddenly find their lives in the hands of the health system. There are few known risk factors or preventative strategies for blood cancers. Blood cancers can severely affect a person's physical and emotional wellbeing, as well as their ability to participate socially and be productive, such as go to work and/or run a household. Yet, with the right interventions and health system resources, many blood cancers are highly treatable or manageable and people can continue to lead productive and meaningful lives.

Innovations in blood cancer treatment have significantly improved survival outcomes in recent decades. Yet, haematologists in New Zealand often bear a moral burden of having to explain to their patients that there is nothing further they are able to do for them, not because treatments do not exist or advancements have not been made, but because the health system is unable to offer them. This report provides a roadmap and recommendations to urgently close these critical gaps in best practice care.

A historic lack of data and understanding around the true incidence, prevalence, survival rates, and mortality of blood cancer has contributed to inadequate health system planning. Disjointed and variable reporting of blood cancers by subtypes has contributed to a distorted understanding of the burden of blood cancers nationally. For the first time, this report quantifies the impact of blood cancer and provides a true and compelling picture of the challenges and inequities faced by patients.

The actionable roadmap in this report illustrates what needs to change to ensure New Zealanders receive the best global standard of care, and that no lives are needlessly lost to blood cancer.

1. Understanding the current landscape

1. Understanding the current landscape

Blood cancer is the fourth most diagnosed cancer in New Zealand, with up to 29,000 people affected by the disease every year. A blood cancer diagnosis is associated with considerable health, social, and economic impacts. Over 1,000 Kiwis die of blood cancer each year, making it the third leading cause of cancer death in New Zealand.[1]

1.1 Defining blood cancer

Blood cancer refers to a group of malignancies that affect the blood, bone marrow, and lymphatic system. These cancers typically originate in the bone marrow, where blood cells are produced, and result in the uncontrolled growth of abnormal blood cells. This disrupts the normal balance and function of blood components, impacting immunity, oxygen transport, and clotting.

There are over 100 different types of blood cancer, each with distinct features. There are many ways to categorise blood cancer. For this report, we consider blood cancer collectively in the first instance, followed by reference to the five major subtypes of blood cancer:

1. **Leukaemia:** A cancer of white blood cells, usually originating in the bone marrow, that leads to the rapid production of abnormal cells that crowd out normal blood cells. Leukaemia is classified as acute (fast-progressing) or chronic (slower-progressing), depending on the disease course. Common types include acute lymphocytic leukaemia (ALL), acute myeloid leukaemia (AML), chronic myeloid leukaemia (CML), and chronic lymphocytic leukaemia (CLL).
2. **Lymphoma:** A cancer of the lymphatic system, which helps the body fight infection. Lymphoma involves malignant lymphocytes (a type of white blood cell) that accumulate in lymph nodes and organs. Lymphoma can be divided into two main categories, Hodgkin lymphoma and non-Hodgkin lymphoma.
3. **Myeloma:** A cancer of plasma cells (the white blood cells responsible for producing antibodies). Myeloma causes impaired immune function and damage to bones and kidneys. It most commonly presents as multiple myeloma, affecting several sites in the body.
4. **Myelodysplastic Syndromes (MDS):** A group of disorders caused by ineffective or abnormal blood cell production in the bone marrow. MDS often results in anaemia, infection, and bleeding due to low blood counts. MDS can progress to acute leukaemia in some patients.
5. **Myeloproliferative Neoplasms (MPN):** A group of diseases where the bone marrow produces too many mature blood cells. MPN increases the risk of blood clots, bleeding, and, in some cases, progression to acute leukaemia. MPN includes conditions such as polycythaemia vera, essential thrombocythemia, and myelofibrosis.

To describe the current landscape, this report draws on publicly reported data from Health New Zealand's Cancer Data Web Tool, analysis using Statistics New Zealand's Integrated Data Infrastructure (IDI), and epidemiological analyses led by researchers at the University of Auckland's School of Population Health. It also draws on a national survey of patients, carers and clinicians. Together, these sources provide both an official reporting perspective and a comprehensive view of blood cancer in New Zealand.

[1] Health New Zealand. (2025). ***Cancer Web Tool*** [Data set, extract]. https://tewhatuora.shinyapps.io/cancer-web-tool/

1.2 Blood cancer: an under-represented cancer burden

Key findings

- **Blood cancer represents a substantial but under-recognised share of New Zealand's cancer burden, limiting its visibility in national cancer control planning.**
- **It ranks as the fourth most diagnosed cancer overall, the second most common in adolescents and young adults, the most common cancer in children, and the third leading cause of cancer death.**
- **Mortality from blood cancer exceeds that of prostate and breast cancer and has seen an increase in annual deaths of almost 40% since 2008.**
- **With no options for prevention or screening, blood cancers are New Zealand's most common unavoidable cancer. As a result, patient outcomes are closely tied to system performance.**
- **When blood cancers are combined, New Zealand does not show an improvement in age-standardised mortality over the past 15 years, unlike all other major cancers and unlike progress seen overseas.**

Health system planning for blood cancer in New Zealand remains fragmented, in part due to how blood cancers are classified and reported. When major blood cancer types are considered individually, their collective burden is diluted in comparisons with other major cancers such as breast, prostate, bowel, and lung.

When considered collectively, however, blood cancer represents a substantial share of New Zealand's cancer burden: it is the fourth most diagnosed cancer overall, the second most common in adolescents and young adults, the most common cancer in children, and the third leading cause of cancer death (Health NZ, 2025).

The 2025 State of Cancer in New Zealand report published by the Cancer Control Agency has improved visibility by grouping four major blood cancers (leukaemia, myeloma, non-Hodgkin lymphoma, and Hodgkin lymphoma). However, several recognised blood cancer types that are reported through the cancer web tool remain excluded, including myelodysplastic syndromes, polycythaemia vera, and cancers recorded under the 'immunoproliferative' coding category.

When these are included, the overall burden shifts materially. More New Zealanders are diagnosed with blood cancer than with melanoma or lung cancer as shown in Figure 1, and more die from blood cancer than from prostate or breast cancer as depicted in Figure 2. Because blood cancers cannot be prevented or detected through screening, they are New Zealand's most common cancer type that cannot be avoided. As a result, patient outcomes are closely tied to system performance.

Trends over time further underscore the significance of this burden. Figure 3 shows that annual deaths from blood cancer has increased by almost 40% since 2008, and Figure 4 reveals that when blood cancers are combined, New Zealand does not show an improvement in age-standardised mortality rate over the past 15 years, unlike all other major cancers and unlike progress seen overseas.

New Zealand does not currently publish long-range projections for blood cancer incidence. However, given similar demographic trends and ageing patterns, it is reasonable to expect that New Zealand will follow trajectories observed in comparable countries such as Australia, where blood cancer is projected to become the most commonly diagnosed cancer by 2035 (Leukaemia Foundation Australia, 2025).

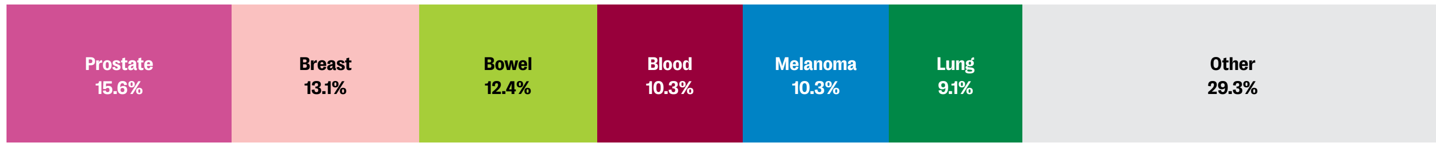


Figure 1
New cancers diagnosed in New Zealand, 2018-2022
Source: New Zealand Cancer Registry

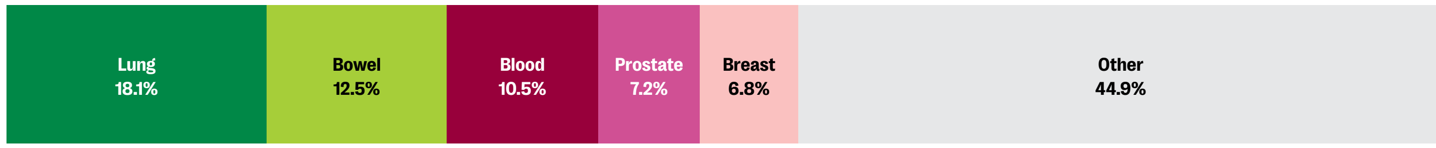


Figure 2
Deaths from cancer in New Zealand, 2017-2021
Source: New Zealand Cancer Registry

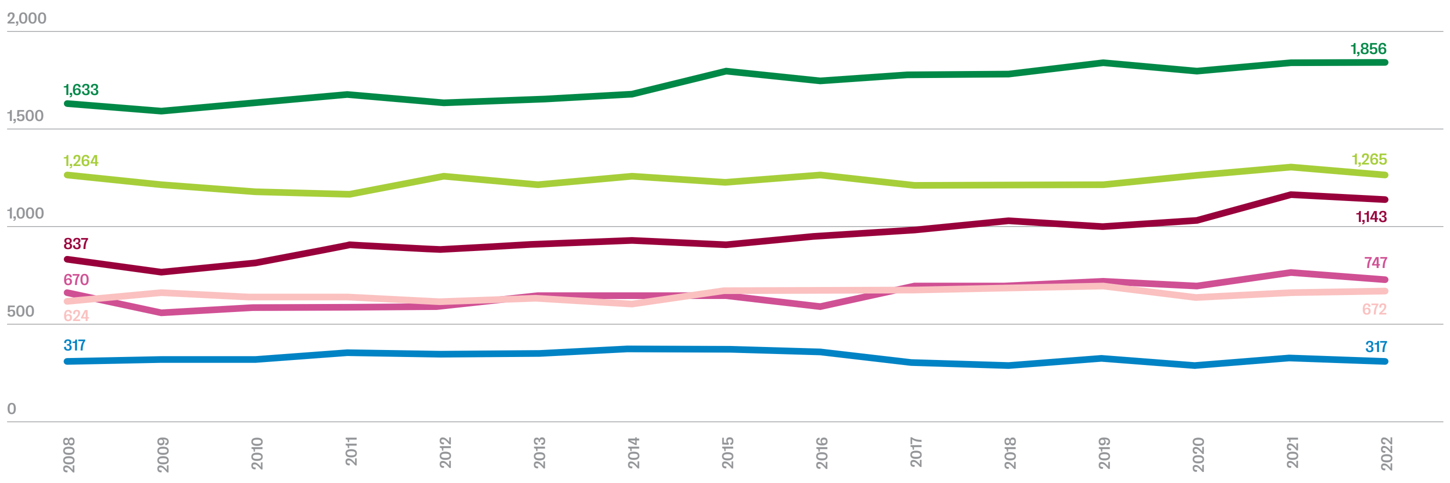


Figure 3
Number of annual cancer deaths for major cancer types in New Zealand, 2008-2022
Source: New Zealand Cancer Registry

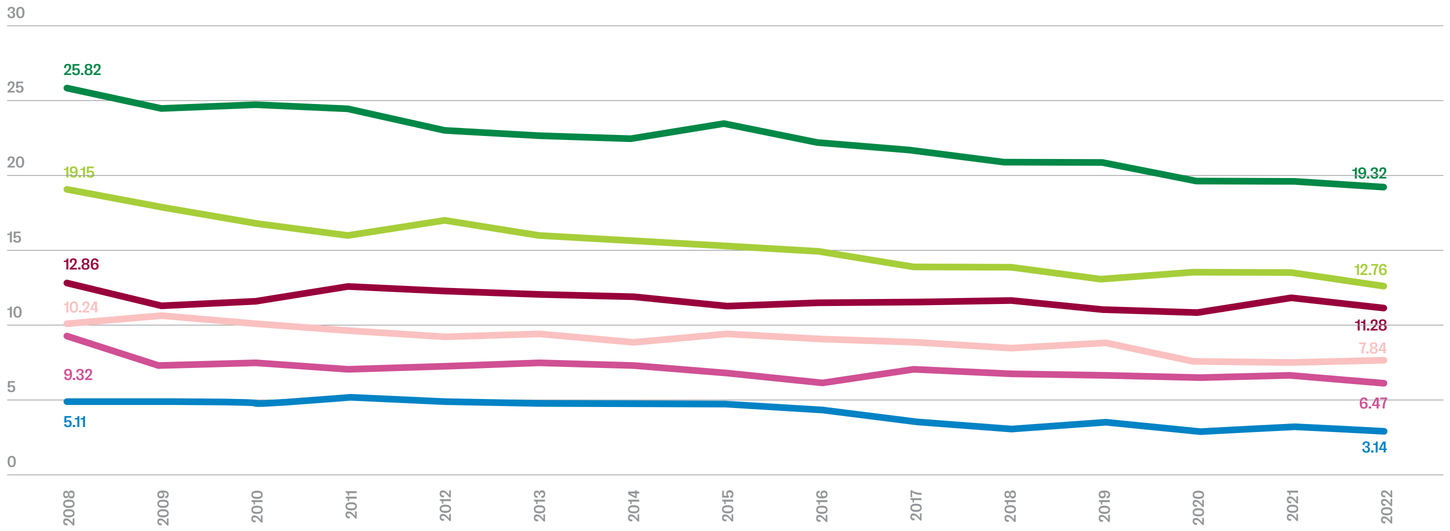


Figure 4
Age standardised rate of annual cancer deaths for major cancer types in New Zealand, 2008-2022
Source: New Zealand Cancer Registry

Although much of this information is publicly available, it is not widely recognised due to current reporting conventions. As framed, high-level cancer reporting can give the impression that screening and prevention programmes address most of the national cancer burden. This risks obscuring a major group of cancers that cannot be screened for or prevented, and for which survival outcomes are highly dependent on timely diagnosis, service capacity, and access to modern therapies.

This issue has been addressed elsewhere. In Australia, Leukaemia Foundation's State of the Nation report prompted a shift toward more consistent collective reporting of blood cancers alongside subtype-level analysis. This change materially improved visibility of the overall burden of blood cancer and enabled clearer alignment between epidemiology, service planning, and investment decisions.

While the Cancer Control Agency has made progress toward clearer blood cancer reporting, the continued underrepresentation of blood cancer in high-level comparisons limits its visibility in policy prioritisation and system planning. Addressing this gap is a prerequisite for informed decision-making and for aligning cancer control efforts with the true distribution of cancer burden in New Zealand.

1.3 Advances in diagnosis and treatment

Key findings

- **Global innovations, such as cellular therapies, bispecific antibodies and genomic-guided care, have transformed survival internationally.**
- **Many standard-of-care medicines remain unfunded in New Zealand, despite proven survival benefits and long-standing availability overseas.**
- **Precision diagnostics are not consistently accessible, delaying risk-adapted treatment.**
- **Urgent investment in infrastructure, workforce and funding pathways is needed to translate innovation into improved patient outcomes.**

The past two decades have seen extraordinary progress in the treatment of blood cancers, driven by advances in molecular diagnostics, targeted therapies, and immunotherapy. Haematology has repeatedly acted as a testbed for innovation, from stem cell transplantation in the 1950s to kinase inhibitors in the 1990s and CAR T in the 2010s. Many types of leukaemia, lymphoma, and myeloma that were once fatal can now be treated with precision-based approaches that have transformed survival outcomes. Many of these modern therapies provide long-lasting remissions and cures.

In acute lymphoblastic leukaemia (ALL) advances in treatment have lifted five-year survival rates in children to over 90% in many high-income countries, up from about 10% in the 1960s (Hunger & Mullighan, 2015). For chronic myeloid leukaemia (CML), the introduction of tyrosine kinase inhibitors has converted a previously fatal disease into one with near-normal life expectancy for most patients (Hochhaus, 2020). In multiple myeloma, combinations of proteasome inhibitors and immunomodulatory drugs have doubled median survival since the early 2000s (Rajkumar, 2022).

Since 2010, chimeric antigen receptor (CAR) T-cell therapies have transformed treatment for certain relapsed or refractory blood cancers, including B-cell acute lymphoblastic leukaemia, several types of aggressive B-cell lymphomas, mantle cell lymphoma, follicular lymphoma, and multiple myeloma. This one-time, personalised treatment involves collecting a patient's T cells, genetically reprogramming them to recognise cancer, and reinfusing them into the patient to seek out and destroy malignant cells, with the potential for long-term remission or even cure in some patients.

A next generation of cellular immunotherapy, known as in vivo CAR T, is now emerging. Unlike current CAR T therapies, which require a patient's T cells to be removed, genetically modified in a specialised laboratory and reinfused, in vivo CAR T aims to engineer immune cells directly within the patient's body using targeted gene delivery technologies such as viral vectors or lipid nanoparticles. This approach could dramatically simplify manufacturing, reduce costs and expand access to cell therapy. Early clinical research suggests it may deliver CAR-like immune responses without the complex supply chains required for current personalised products. While still at an early stage of development, in vivo approaches are widely viewed as a key future direction in cellular immunotherapy.

Alongside advances in cellular therapy, targeted and immune-based therapies are transforming blood cancer care. Targeted small-molecule medicines, such as BTK and BCL2 inhibitors, are now widely used and have significantly improved outcomes across several blood cancers. Bispecific T-cell engagers (BiTEs) have long been established in acute lymphoblastic leukaemia, but their use in lymphoma and myeloma represents an emerging wave of immunotherapy. These newer agents, along with multi-specific antibodies and antibody-drug conjugates, are achieving high response rates in selected lymphomas and myelomas, with some suitable for outpatient administration. Together, these therapies are contributing to deeper and more durable remissions across multiple disease types.

Modern blood cancer treatment is closely aligned with precision medicine. Genomic profiling is used to identify actionable mutations, guide therapy choices, and predict treatment response. As such, routine testing for mutations is now standard of care in many types of blood cancer (NCCN, 2023). Similarly, liquid biopsies and minimal residual disease testing offer more sensitive ways to monitor treatment response and allow for earlier adjustments when needed.

New Zealand has also contributed to global innovation, with our haematology services having actively contributed to commercial registration trials, and to practice-changing co-operative group trials.

BioOra is a local biotech start-up that has established onshore, automated CAR T-cell manufacturing for use in controlled clinical trial settings. In partnership with the Malaghan Institute, which has developed a CAR T construct for treating aggressive non-Hodgkin lymphoma, New Zealand patients can now access CAR T-cell therapy through the ENABLE trial programme. This collaboration strengthens national capability in cell therapy and provides an early foundation for wider availability in the future. Local production represents an important step in improving access and reducing treatment delays. Achieving broader, sustainable availability will require modernised regulatory pathways, specialist workforce, and coordinated national service planning.

Despite these global and local advances, many of the most effective therapies are still not publicly funded or routinely available in New Zealand. As global standards continue to evolve, there is an urgent need to ensure the health system can deliver the full benefits of modern blood cancer care. Realising this will require well-defined health technology assessment and funding pathways, sufficient diagnostic and data infrastructure, and workforce capacity that enables specialist centres to meet growing demand. This will be essential to turning the next wave of innovation into measurable gains in survival and quality of life for New Zealanders.

1.4 Epidemiology of blood cancer in New Zealand.

Key findings

- **New Zealand and Australia have the highest global lifetime risk of blood cancer (1 in 18 people) - more than three times the global average.**
- **The prevalence of blood cancer is rising, with approximately 27,000 people living with blood cancer. Annual diagnoses have exceeded 3,000 since 2018.**
- **Mortality remains high and stable despite treatment advances. An ageing population is expected to increase the number of people diagnosed with and dying from blood cancer over the next two decades.**
- **Māori and Pacific peoples experience higher incidence and mortality, while Asian populations show the fastest growth in incidence.**

People living in New Zealand and Australia have the highest lifetime risk of developing blood cancer, that being 5.68% or approximately 1 in 18 people - more than three times the global average (Sun, 2025). The lifetime risk of dying from blood cancer in New Zealand and Australia is also higher, sitting at almost 3.0% as compared to the global average of 0.98%% (Sun, 2025).

According to the IDI analysis, an estimated 28,860 people were living with a blood cancer diagnosis in New Zealand as at June 2024. This figure represents a point-in-time count of people living with a blood cancer diagnosis and does not capture deaths occurring in the remainder of 2024. Based on recent patterns, deaths over July–December 2024 are expected to reduce this point-in-time count by approximately 1,800 people.

For public reporting, this figure is conservatively rounded to approximately 27,000 people currently living with blood cancer. This is a conservative estimate as the total number is likely to be higher today due to ongoing increases in diagnoses and survivorship.

By contrast, Figure 5 reports full calendar-year totals of people ever diagnosed with blood cancer, including both those still alive and those who have died. On this basis, the total number of individuals ever diagnosed increased from 13,875 in 2007 to 29,970 in 2023, showing a consistent upward trend.

1.4.1 Incidence

Blood cancer incidence in New Zealand has already increased over the past ten years, and projections indicate that this growth will continue. As the population grows and ages, the number of people diagnosed with blood cancer is expected to rise substantially over the coming two decades (Teng, 2024).

New Zealand does not currently publish long-range projections for blood cancer incidence. However, comparable countries such as Australia project blood cancers to become the most commonly diagnosed cancer grouping by 2035 (Leukaemia Foundation Australia, 2025). Given similar demographic and epidemiological trends, New Zealand is likely to follow a comparable trajectory, with case numbers expected to rise substantially.

Blood cancer incidence in New Zealand is publicly reported by Health New Zealand's Cancer Data Web Tool and has additionally been assessed through analyses led by researchers at the University of Auckland's School of Population Health. Both utilise data from the New Zealand Cancer Registry (NZCR), available through to 2022.

The following sections describe the changes in incidence and mortality over time for the major blood cancer subtypes.

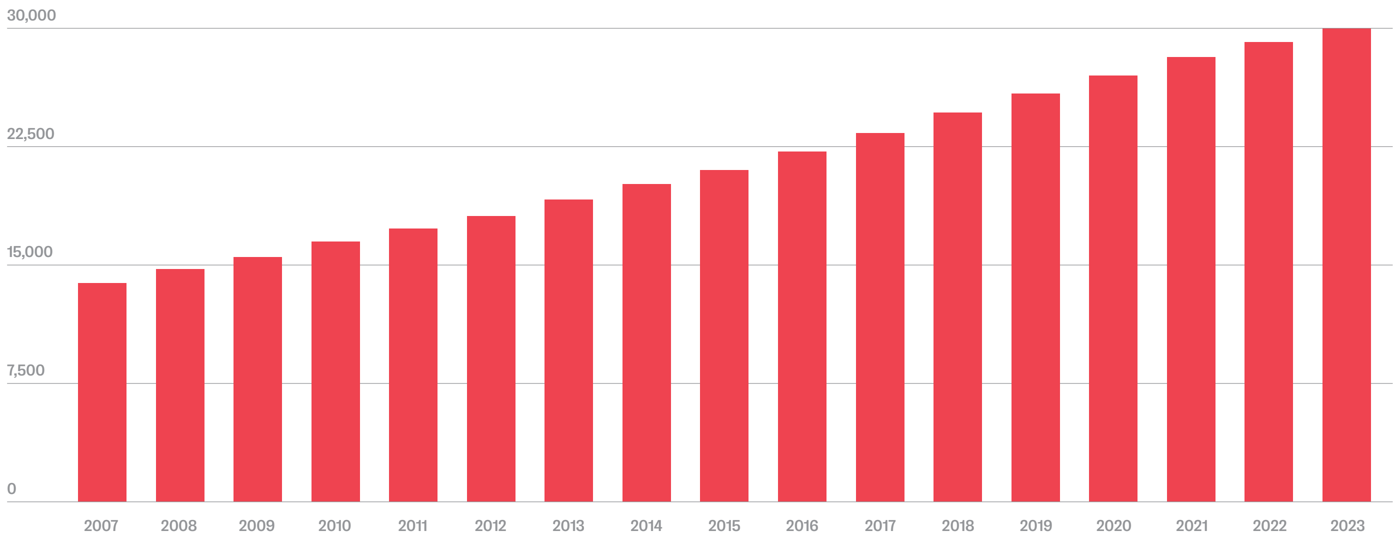


Figure 5
Trends in the number of people living with a blood cancer diagnosis in New Zealand, 2007–2023
Source: Integrated Data Infrastructure

1.4.1.1 Leukaemia

Leukaemia comprises several biologically distinct diseases with markedly different incidence patterns, treatments, and outcomes. However, these subtypes are grouped together in public reporting via the Cancer Data Web Tool. As a result, subtype-specific patterns for acute and chronic leukaemias cannot be reported from publicly available datasets. Greater differentiation of leukaemia subtypes within the NZCR would improve visibility of disease-specific trends and support more accurate monitoring of outcomes across the health system.

This aggregation likely obscures important differences between acute leukaemias, such as acute myeloid leukaemia (AML), which are typically aggressive and associated with higher short-term mortality, and chronic leukaemias such as chronic lymphocytic leukaemia (CLL), which often follow a more indolent, relapsing course and contribute substantially to overall prevalence. Because CLL is the most common form of leukaemia in New Zealand, combined reporting may disproportionately reflect its epidemiology and mask trends relevant to more aggressive acute subtypes.

According to the NZCR, the age standardised incidence of leukaemia in 2022 was 10.26 per 100,000, equivalent to 806 people that year. In the 15 years between 2008-2022 this rate has remained relatively stable, as depicted in Figure 7.

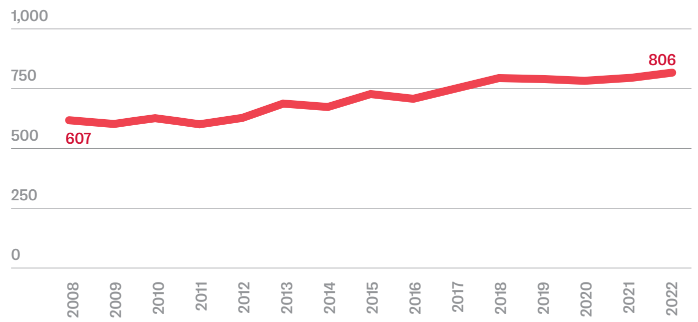


Figure 6
Annual leukaemia cases in New Zealand, 2008-2022
Source: New Zealand Cancer Registry

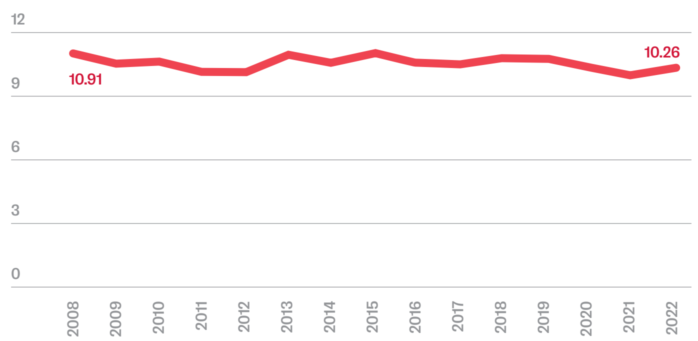


Figure 7
Annual leukaemia incidence rates in New Zealand (per 100,000), 2008-2022
Source: New Zealand Cancer Registry
Rates are per 100,000 and age-standardised to the World Health Organization's standard world population.

1.4.1.2 Lymphoma

Non-Hodgkin lymphoma is the most common blood cancer type in New Zealand, with an incidence rate of 12.15 per 100,000 in 2022, equivalent to 1,048 people that year. Hodgkin lymphoma is comparatively rare, with an incidence rate of 2.29 per 100,000 in 2022, equivalent to 130 people that year. This is depicted in Figure 8 and Figure 9.

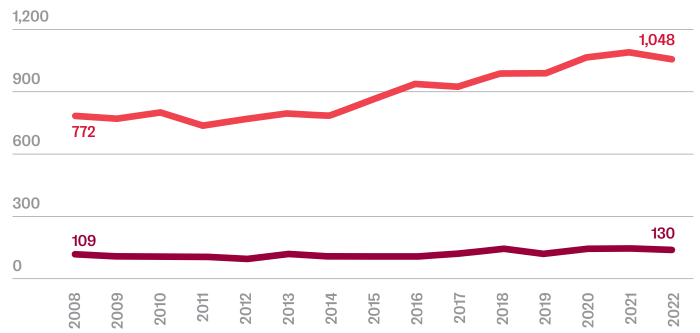


Figure 8
Annual lymphoma cases in New Zealand, 2008-2022
Source: New Zealand Cancer Registry

Non-Hodgkin lymphoma
Hodgkin lymphoma

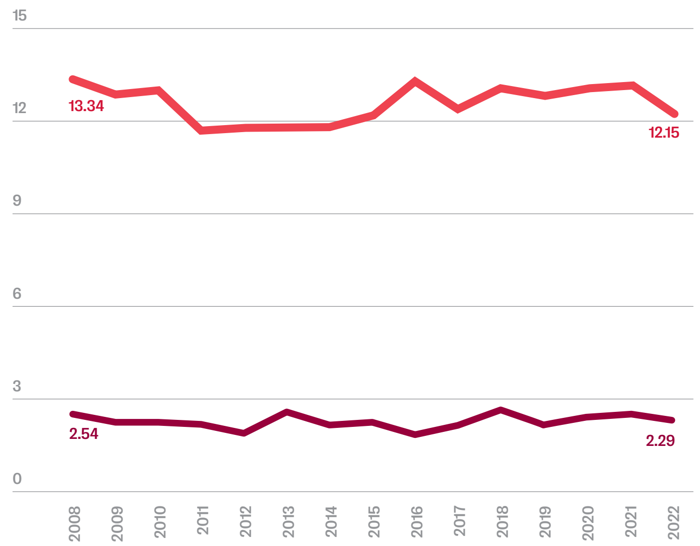


Figure 9
Annual lymphoma incidence rates in New Zealand (per 100,000), 2008-2022
Source: New Zealand Cancer Registry
Rates are per 100,000 and age-standardised to the World Health Organization's standard world population.

Non-Hodgkin lymphoma
Hodgkin lymphoma

1.4.1.3 Myeloma

While incidence rates for the other major blood cancers were relatively stable, or declined slightly, over the period 2008 to 2022, the incidence of myeloma has been increasing. As of 2022, the incidence rate was 5.1 per 100,000 people, translating to 468 individuals that year, as depicted in Figure 10 and Figure 11.

Because myeloma is a chronic, relapsing condition, even modest increases in incidence translate into substantial prevalence growth and rising demand for long term management, monitoring, and supportive care.

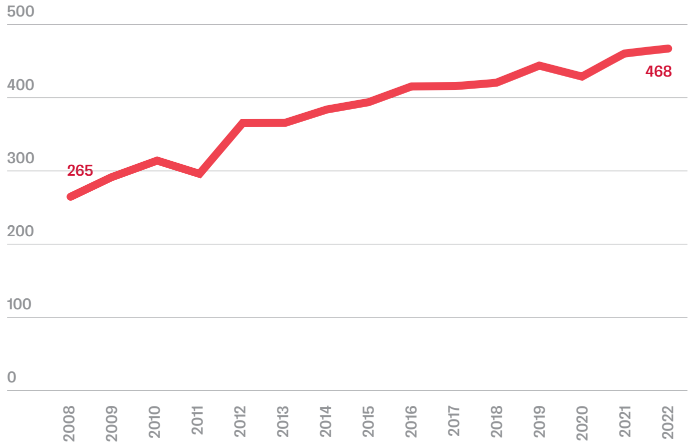


Figure 10
Annual myeloma cases in New Zealand, 2008-2022
Source: New Zealand Cancer Registry

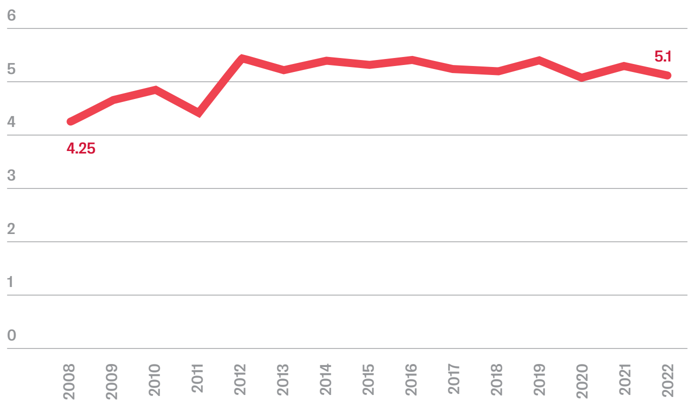


Figure 11
Annual myeloma incidence rates in New Zealand (per 100,000), 2008-2022
Source: New Zealand Cancer Registry
Rates are per 100,000 and age-standardised to the World Health Organization's standard world population.

1.4.1.4 Myelodysplastic syndromes

NZCR data show that the number of recorded MDS cases has fluctuated over time but generally increased between 2008 and 2022, as illustrated in Figure 12. Despite this increase, the incidence rates have slightly declined over time to 2.53 per 100,000, as depicted in Figure 13

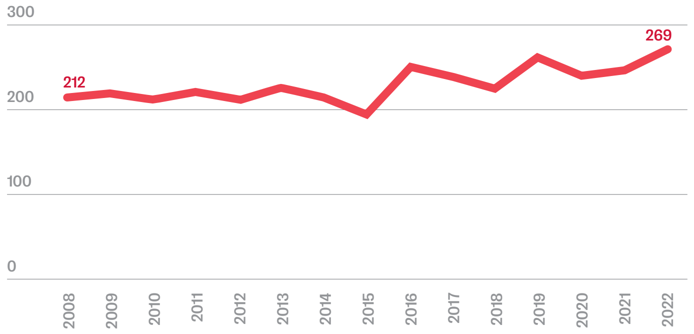


Figure 12
Annual MDS cases in New Zealand, 2008-2022
Source: New Zealand Cancer Registry

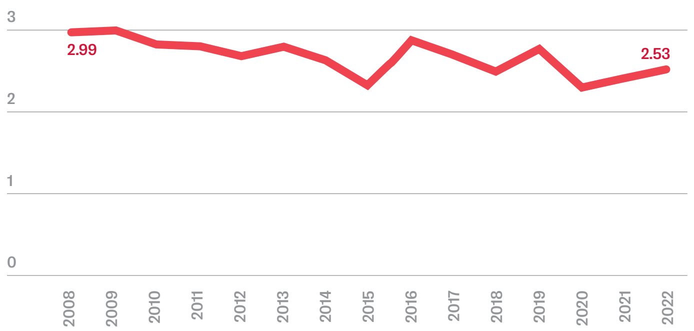


Figure 13
Annual MDS incidence rates in New Zealand (per 100,000), 2008-2022
Source: New Zealand Cancer Registry
Rates are per 100,000 and age-standardised to the World Health Organization's standard world population.

1.4.1.5 Myeloproliferative neoplasms

MPNs are not reported separately in publicly available NZCR tools due to small case numbers, variable historical registration and confidentiality requirements. These conditions are therefore analysed only through controlled-access datasets and research extracts.

A published analysis of NZCR data provides the clearest national picture of MPN epidemiology (Varghese, 2021). Across 2010 to 2017, 787 cases of polycythaemia vera, essential thrombocythemia and primary myelofibrosis were recorded. In 2017, age-standardised incidence rates were 0.90 per 100,000 for polycythaemia vera, 1.56 for essential thrombocythemia and 0.92 for primary myelofibrosis, illustrating that MPNs are rare but clinically significant chronic blood cancers.

1.4.2 Mortality and survival

Blood cancer mortality in New Zealand is publicly reported by Health New Zealand's Cancer Data Web Tool and has additionally been assessed through analyses led by researchers at the University of Auckland's School of Population Health. Both utilise data from the NZCR, available through to 2022.

1.4.2.1 Leukaemia

Leukaemia accounts for the highest number of deaths among the major blood cancers in New Zealand. Between 2008 and 2022, annual deaths ranged from approximately 230 to more than 300 per year. Over this period, age-standardised mortality rates fluctuated but remained relatively stable overall, generally sitting between 3 and 5 deaths per 100,000 people.

However, current mortality reporting presents leukaemia as a single combined category, which masks important differences between individual subtypes.

Acute and chronic leukaemias have distinct disease trajectories, treatment pathways, and survival outcomes, yet mortality data are not published at this level of detail. Clinicians have noted that this limits the system's ability to monitor progress, identify inequities, and evaluate the impact of new therapies.

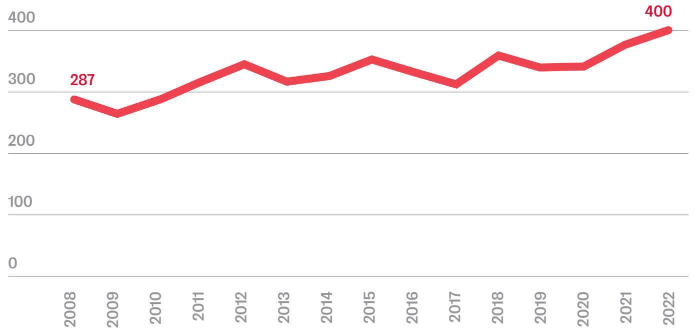


Figure 14
Annual leukaemia deaths in New Zealand, 2008-2022
Source: New Zealand Cancer Registry

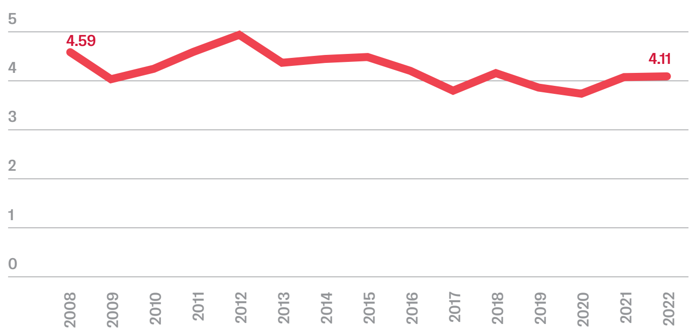


Figure 15
Annual leukaemia death rates in New Zealand (per 100,000), 2008-2022
Source: New Zealand Cancer Registry
Rates are per 100,000 and age-standardised to the World Health Organization's standard world population.

1.4.2.2 Lymphoma

Mortality from lymphoma, particularly non-Hodgkin lymphoma, contributes substantially to the overall burden of blood cancer deaths in New Zealand. Between 2008 and 2022, non-Hodgkin lymphoma deaths typically ranged between 260 and 380 per year, with age-standardised mortality rates generally falling between 3.5 and 4.5 deaths per 100,000 people.

Hodgkin lymphoma, by contrast, remained a very rare cause of death, with annual deaths usually between 15 and 30 and corresponding mortality rates well below 1 death per 100,000 throughout the period. These trends reflect the markedly different survival profiles of these two diseases.

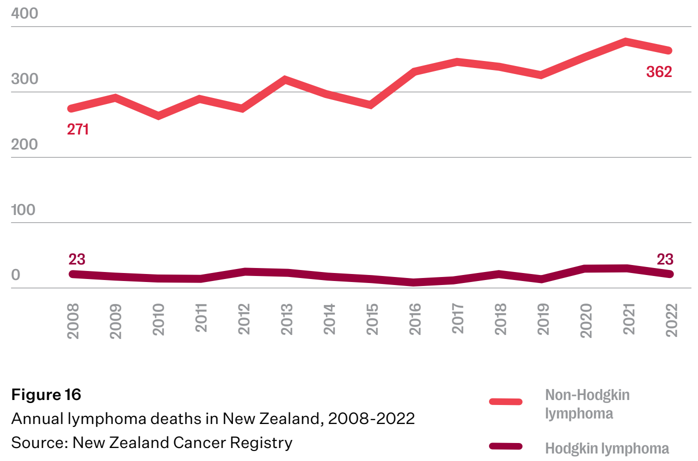


Figure 16
Annual lymphoma deaths in New Zealand, 2008-2022
Source: New Zealand Cancer Registry

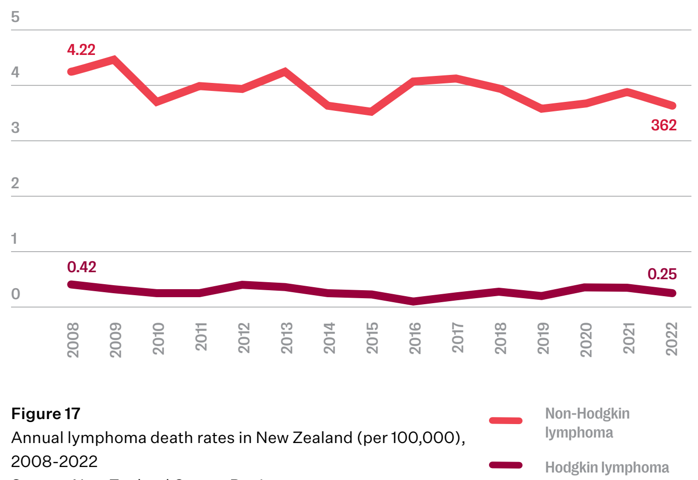


Figure 17
Annual lymphoma death rates in New Zealand (per 100,000), 2008-2022
Source: New Zealand Cancer Registry
Rates are per 100,000 and age-standardised to the World Health Organization's standard world population.

1.4.2.3 Myeloma

Myeloma mortality increased gradually over the 2008 to 2022 period. Annual deaths rose from around 120 in the late 2000s to more than 200 deaths per year in the early 2020s. Age-standardised mortality rates generally sat between 2 and 3.5 deaths per 100,000 people, with a gradual upward trend over time.

This rise in mortality is consistent with increasing incidence and the chronic, relapsing nature of myeloma, which continues to contribute to long-term mortality even as survival improves with newer therapies.

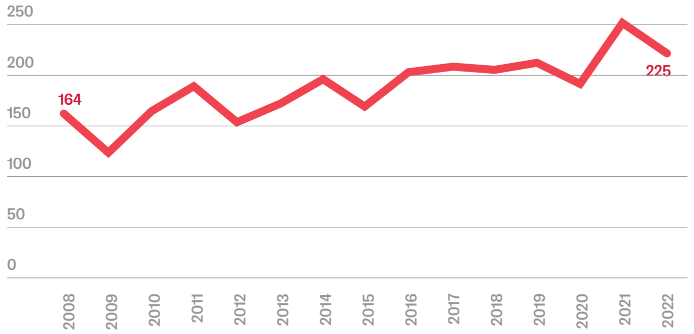


Figure 18
Annual myeloma deaths in New Zealand, 2008-2022
Source: New Zealand Cancer Registry

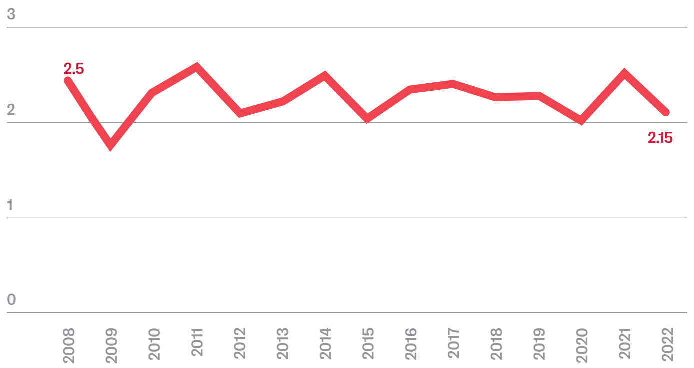


Figure 19
Annual myeloma death rates in New Zealand (per 100,000), 2008-2022
Source: New Zealand Cancer Registry
Rates are per 100,000 and age-standardised to the World Health Organization's standard world population.

1.4.2.4 Myelodysplastic syndromes

Mortality attributed to MDS has remained relatively steady over time, with annual deaths usually ranging between 120 and 170 deaths per year between 2008 and 2022. Age-standardised mortality rates were generally low, commonly falling between 2 and 3 deaths per 100,000 people.

Although recorded case numbers have increased, mortality rates have remained stable overall, reflecting both the heterogeneity of MDS and improvements in supportive care.

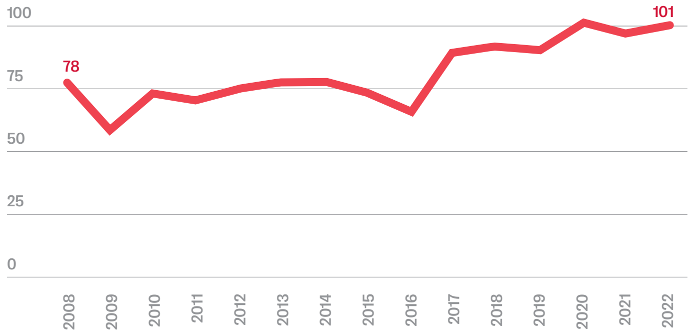


Figure 20
Annual MDS deaths in New Zealand, 2008-2022
Source: New Zealand Cancer Registry

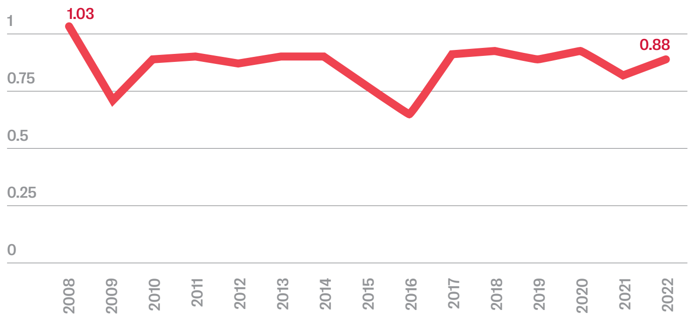


Figure 21
Annual MDS death rates in New Zealand (per 100,000), 2008-2022
Source: New Zealand Cancer Registry
Rates are per 100,000 and age-standardised to the World Health Organization's standard world population.

1.4.2.5 Myeloproliferative neoplasms

MPNs are not reported separately in publicly available NZCR tools due to small case numbers, variable historical registration and confidentiality requirements. This reflects standard suppression protocols applied to registry data to protect patient privacy.

1.4.3 Demographic trends

1.4.3.1 Age and cancer type

In 2023, almost two-thirds (64.9%) of people diagnosed with blood cancer were aged 65 years or older, while almost a third (30.1%) were working-age adults (25–64 years). Adolescents (15–24 years) represented 2.1% of blood cancer diagnoses, and children under 15 accounted for 2.9% of cases.

Of the 3,054 people diagnosed with blood cancer in 2023, lymphoma was the most common, accounting for 38.4% of total blood cancer diagnoses. Non-Hodgkin lymphoma was the most common lymphoma sub-type, with 1,008 individuals diagnosed (85.8% of lymphomas).

Leukaemia was the second most common blood cancer in 2023, accounting for a quarter (25.4%) of diagnoses. This was followed by myeloma (16.5%), myelodysplastic syndromes (8.3%), and Hodgkin lymphoma (3.7%).

	The proportion of diagnoses that occurred in each age group							
	0-4	5-14	15-24	25-44	45-54	55-64	65-74	75+
Leukaemia	72.2%	62.8%	35.1%	26.2%	27.5%	27.9%	28.1%	26.8%
Hodgkin Lymphoma	0.6%	11.0%	33.6%	17.9%	4.9%	2.7%	1.7%	1.2%
Non-Hodgkin Lymphoma	10.5%	20.2%	21.6%	36.6%	41.2%	38.9%	35.1%	28.2%
Myelodysplastic Syndrome	1.9%	2.3%	2.3%	2.3%	2.5%	3.9%	7.4%	16.7%
Myeloma	0.0%	S	S	5.3%	13.4%	16.2%	16.4%	14.7%
Uncertain behaviour of lymphoid, haematopoietic and related tissue	14.7%	3.8%	7.4%	10.9%	9.3%	8.7%	9.2%	10.4%

Table 1
Distribution of blood cancer diagnoses by age group (1995 to June 2024)
Source: Integrated Data Infrastructure
Note: Data for myeloma in people aged 5–24 years has been suppressed due to low numbers

An additional 11.4% (348) of cases were classified as 'other', comprising blood cancers with uncertain or ambiguous behaviour of lymphoid and related tissues.

Table 1 shows the distribution of blood cancer diagnoses by age group from 1995 to June 2024.

For individuals aged 25 and over, leukaemia and non-Hodgkin Lymphoma are the most commonly observed types overall.

Among children aged 0–4 years, leukaemia accounts for the majority of cases (72.2%), followed by cancers of uncertain behaviour (14.7%) and non-Hodgkin Lymphoma (10.5%). In the 5–14 age group, leukaemia remains the most common diagnosis (62.8%), with non-Hodgkin Lymphoma at 20.2% and Hodgkin Lymphoma at 11.0%. In young adults aged 15–24, the distribution begins to shift: leukaemia accounts for 35.1% of diagnoses, Hodgkin Lymphoma for 33.6%, and Non-Hodgkin Lymphoma for 21.6%.

1.4.3.2 Gender distribution

In 2023, 1,230 females (40.4%) and 1,820 males (59.6%) were diagnosed with blood cancer. Figure 22 shows an increasing trend of a higher proportion of New Zealand males being diagnosed with a blood cancer since 1995.

This pattern of blood cancer more frequently occurring in males is well documented internationally. Evidence points to several contributors, such as sex-based differences in immune function and inflammation, hormonal influences on haematopoiesis, and genetic factors including X-linked tumour suppressor variation (Klein, 2016).

Greater exposure to risk in males, such as smoking and specific occupational hazards, also contributes to elevated incidence.

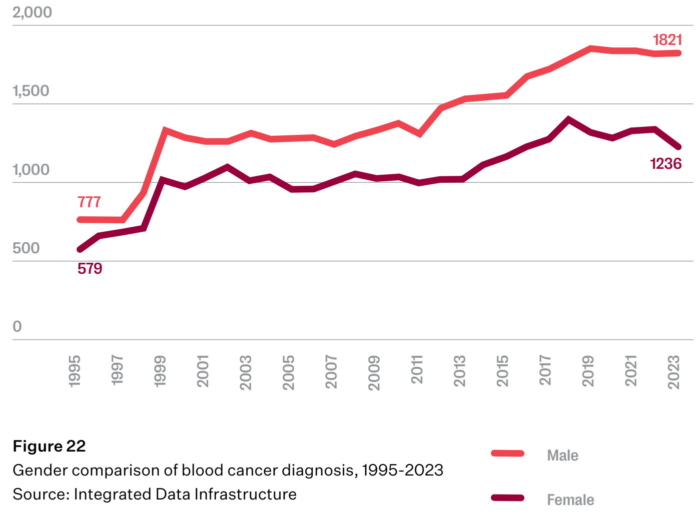


Figure 22
Gender comparison of blood cancer diagnosis, 1995-2023
Source: Integrated Data Infrastructure

1.4.3.3 Ethnicity distribution

Epidemiological analysis of ethnicity distribution was undertaken by the School of Population Health at the University of Auckland. These are preliminary research findings that are yet to be peer-reviewed.

Age standardised incidence rates were calculated using the World Health Organization standard population. This allows for meaningful comparison across ethnic groups by adjusting for differences in population age structure, which is particularly important for Māori and Pacific populations who are younger on average than European and Asian populations.

Only the four major blood cancer groups, Hodgkin lymphoma, non-Hodgkin lymphoma, leukaemia and myeloma, were included in the ethnicity specific incidence analysis. These conditions have sufficient annual case numbers to allow reporting without breaching confidentiality requirements.

Ethnicity reporting in the NZCR has some limitations, including variation in how ethnicity is recorded across health services, incomplete capture of multiple ethnicities and historical inconsistencies in coding. These factors can affect the accuracy of ethnicity specific rates and should be considered when interpreting differences between groups.

Figure 23 shows the variation in average incidence rates across blood cancer types and ethnic groups for the period 2007 to 2022. For all cancers, rates were lowest among people of Asian ethnicity and highest among Māori, Pacific and Other ethnic groups, with Europeans generally sitting between these ranges depending on the subtype.

Leukaemia and non-Hodgkin lymphoma displayed the greatest variation, with Māori and Pacific peoples experiencing rates that were noticeably higher than those observed for Asian and European populations. Myeloma also showed marked differences, with Māori and Pacific incidence almost double that of Europeans. Hodgkin lymphoma rates were low overall, but the same relative pattern was observed.

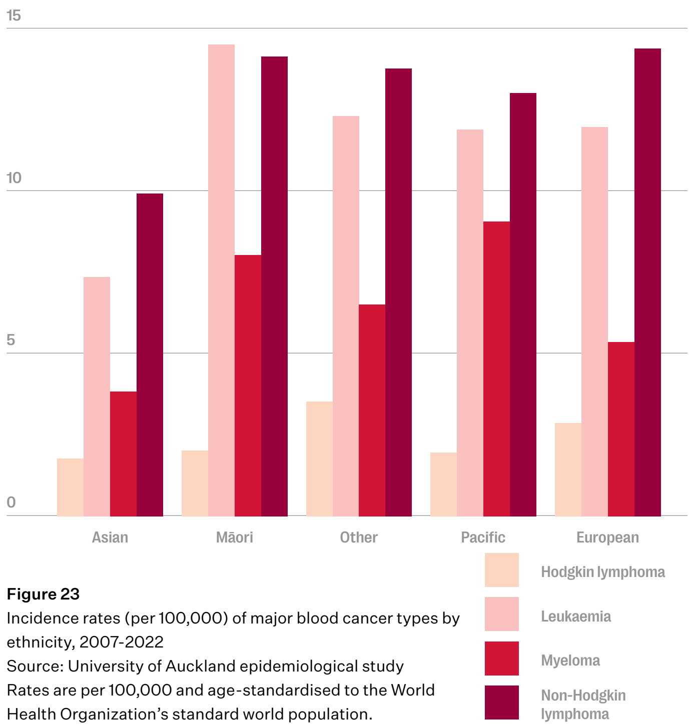


Figure 23
Incidence rates (per 100,000) of major blood cancer types by ethnicity, 2007-2022
Source: University of Auckland epidemiological study
Rates are per 100,000 and age-standardised to the World Health Organization's standard world population.

Māori face significantly higher age-adjusted incidence and mortality rates for several blood cancers (Clough, 2024). When adjusted for age, Māori are both more likely to be diagnosed and more likely to die from blood cancers.

These patterns are also reflected in the University of Auckland mortality data, which reports average annual mortality rates for the period 2007 to 2020, as shown in Figure 24. Mortality rates were consistently lowest among Asian peoples and highest among Māori, Pacific and Other groups, with Europeans generally sitting between these ranges. The largest gaps appeared in leukaemia and non-Hodgkin lymphoma, where Māori and Pacific mortality rates were noticeably higher than those of Asian and European populations. Myeloma showed a similar pattern, with elevated mortality for Māori and Pacific peoples in line with their higher incidence. Hodgkin lymphoma mortality was low across all groups but followed the same relative distribution.

Hodgkin lymphoma was not included in ethnicity specific mortality analyses because annual death counts were too small to produce stable age standardised rates, and reporting at this level would breach confidentiality suppression requirements.

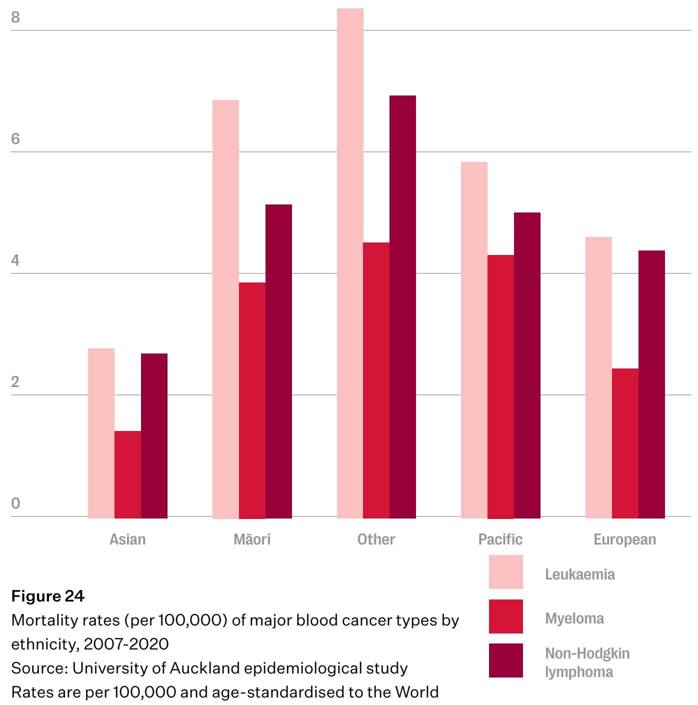


Figure 24
Mortality rates (per 100,000) of major blood cancer types by ethnicity, 2007-2020
Source: University of Auckland epidemiological study
Rates are per 100,000 and age-standardised to the World Health Organization's standard world population.

1.4.3.4 Geographic trends

Geographically, 33.3% of those in New Zealand with blood cancer reside in the Northern region, followed by 26.3% in the South Island, 20.4% in Midland, and 19.2% in the Central regions (Figure 25, Table 2).

Region	Total	%
Northern | Te Tai Tokerau	8,919	33.3
Midland | Te Manawa Taki	5,460	20.4
Central | Te Ikaroa	5,145	19.2
South Island | Te Waipounamu	7,059	26.3
Unknown	213	0.8
Total	26,796	100

Table 2
Number of people living with a blood cancer diagnosis by Health NZ region as at June 2024
Source: Integrated Data Infrastructure

Figure 25 maps the blood cancer population based on the former District Health Board (DHB) districts. It illustrates the Cancer DHB domicile of the population as of June 2024 on or before the date they were diagnosed with blood cancer, based on registered cancer start date.

Figure 25 highlights that there is a high proportion of blood cancer patients who lived in Canterbury at the time of diagnosis, 11.5%, while 10.8% lived in Waitematā, 8.5% in Auckland and 8.2% in Counties Manukau.

When comparing people's region when their cancer was first diagnosed to their current place of residence, there is a major increase in the percentage of people now living in main cities like Auckland, Christchurch, and Wellington. This shift could be attributed to factors such as relocation for treatment, as major cities typically have better healthcare infrastructure, specialised cancer centres, and access to more advanced treatments. It could also be due to general urbanisation trends seen nationally for reasons like employment, education or lifestyle.

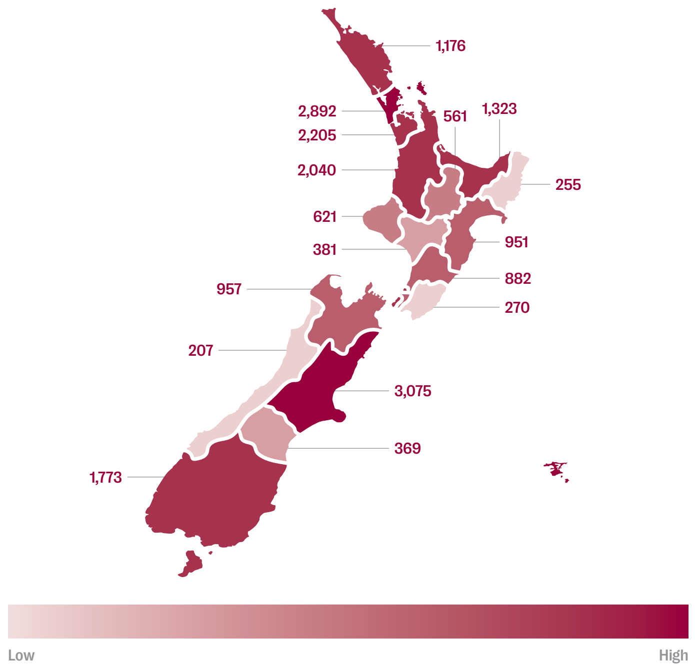


Figure 25
Geographic distribution of people living with blood cancer, 2024
Source: Integrated Data Infrastructure

1.4.3.5 Socioeconomic distribution

The New Zealand deprivation index is a tool that assesses socioeconomic deprivation using census data. Decile 1 represents the least deprived areas, whereas decile 10 indicates the most deprived regions.

A higher proportion of people living with blood cancer live in the least deprived areas, with 21.5% living in deciles 1 and 2, compared to 17.2% in deciles 9 and 10.

1.4.3.6 Overall observation

Blood cancer in New Zealand is a growing health issue, with incidence and prevalence steadily increasing. Approximately 27,000 people are living with the disease, and annual diagnoses have exceeded 3,000 since 2018. Mortality remains substantial, and the number of annual deaths has increased over time. While age-standardised mortality rates have been relatively stable, New Zealand's ageing population means the total number of deaths from blood cancer is expected to continue rising.

Significant inequities remain across ethnicity and geography. Māori and Pacific peoples experience higher incidence and worse mortality, while Asian populations show the fastest growth in incidence. Rural communities face persistent access challenges and unmet needs persist across all groups.

Key considerations for the system are as follows:

- The increasing disease burden will lead to greater demand for cancer services and ongoing support.
- It is essential to address systemic inequities in mortality rates and access to treatment for Māori, Pacific, and Asian populations.
- Delivery of care should be planned to ensure equity of access across all regions.

1.5 Impact of blood cancer on people's lives

Key findings

- **Blood cancer severely impacts physical health, mental wellbeing and overall quality of life, with anxiety and depression 2-3 times more common than with other cancers.**
- **Patients experience 'time toxicity' from frequent hospital visits and prolonged treatments disrupt work, education and family life.**
- **Carers face emotional and practical strain, with 74% reporting negative mental health impacts and many reduce or leave employment.**

1.5.1 Impact on patients

New Zealanders with blood cancer experience multifaceted impacts on their health and quality of life. Physical health and wellbeing, and overall quality of life are significantly negatively impacted by a diagnosis (Figure 26). This includes a negative impact on mental health and emotional wellbeing, and material impacts on the ability to work and participate in family life. This is consistent with published evidence demonstrating that chronic pain, sleep disturbances, reduced cognitive and physical functioning and fatigue substantially a ffect daily activities and overall quality of life for blood cancer patients (Immanuel, 2019).

The disease trajectory in many haematological cancers is unpredictable, and treatments are often intensive and prolonged. This drives heavier symptom loads than are typically seen in many solid tumours, alongside immune vulnerability, frequent hospital visits, and uncertainty about relapse.

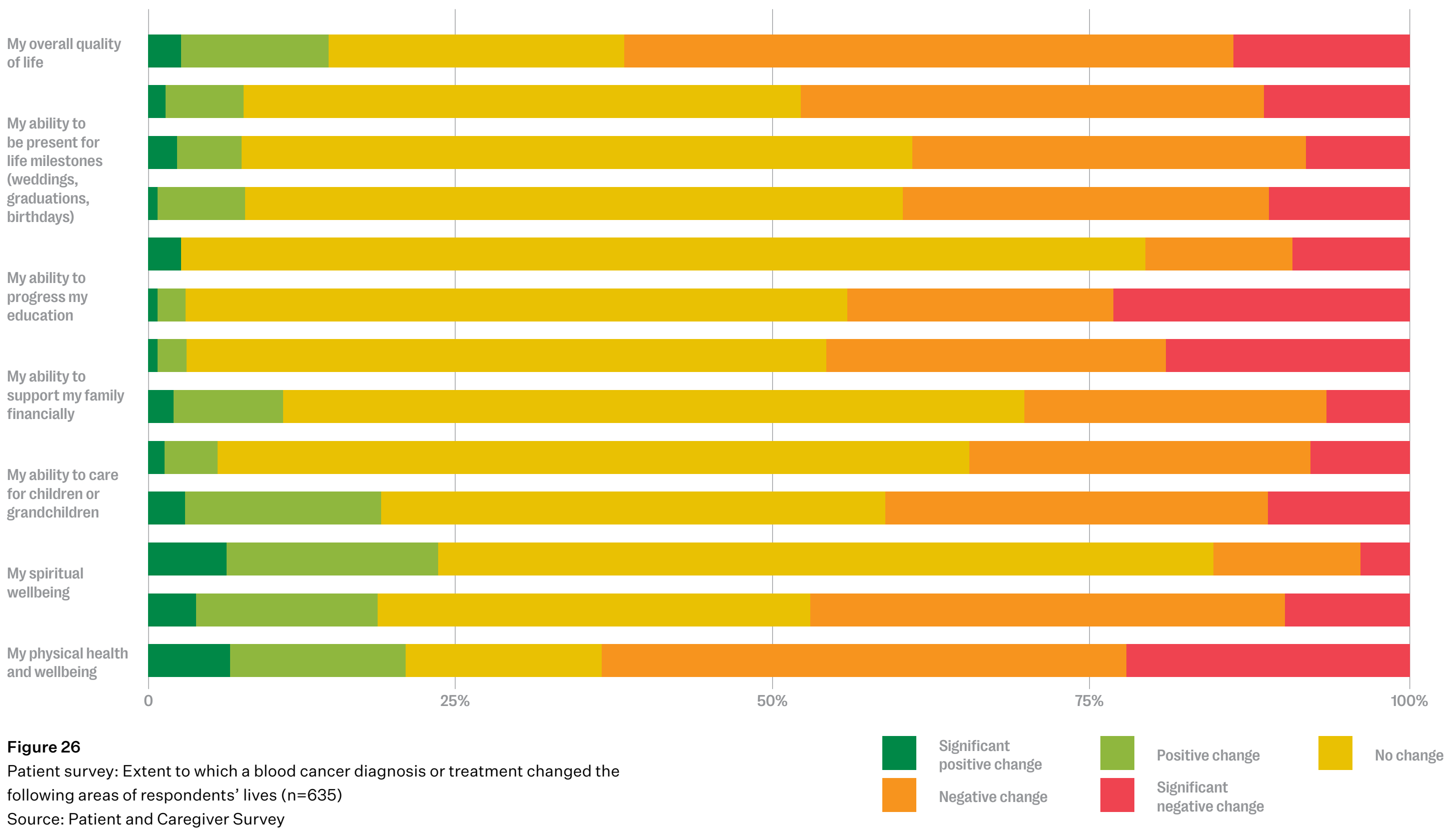


Figure 26
Patient survey: Extent to which a blood cancer diagnosis or treatment changed the following areas of respondents' lives (n=635)
Source: Patient and Caregiver Survey

While a number of people reported a negative or significant negative change in life domains, it is important to note that some patients reported no change, while others reported a positive or significant positive change. Positive changes may result from 'benefit finding' or 'post-traumatic growth' - whereby patients are able to identify shifts in meaning-making, personal connections, and perceptions on quality of life following a diagnosis. Type of blood cancer may also influence reporting with some blood cancers being well managed with long-term medication and others benefiting from curative treatment (Almeida et al., 2022; Michel et al., 2010).

Treatments for many blood cancers also pose significant risks to fertility. Chemotherapy, radiotherapy, and stem cell transplantation can lead to temporary or permanent infertility, creating additional emotional distress and complex decision-making for patients of reproductive age.

Anxiety and depression affect around one in four cancer patients, but are 2-3 times more common in blood cancers. This is attributed to their unpredictable and aggressive illness trajectory and protracted and isolating treatment courses (Waddington, 2024). Patients also experience significant 'time toxicity' in the form of repeated appointments, long infusions, and regular monitoring – all of which disrupts work, education, and family life.

Social support networks, such as friends and family, play a vital role in alleviating the psychosocial impacts of blood cancer (Raphael, 2019). Patients however carry additional stress, worrying about the impact their diagnosis is having on their loved ones, and not wanting to be a 'burden'.

"Having a blood cancer has changed my life. I am not able to do the physical activities I used to. Pain and fatigue have been considerable and are hard to manage. People find it hard to understand the change you experience because they can't see it."

- Patient

The impact of childhood blood cancer is lifelong. Survivors of paediatric blood cancer have lower marriage rates, employment status, and educational attainment compared to their siblings or the general population (Cho, 2023). The intensity of treatment and long-term nature for some blood cancers has consequences on social development, education and career progression (Cho, 2023; Stefanski, 2021) especially for teenage children studying for formal qualifications.

Families face profound emotional strain, balancing grief and disruption with the need to maintain normalcy. Parents report significant psychological stress when managing their child's treatment, often exacerbated by time spent away from home (Long, 2018). Recent studies also show that siblings of children with cancer are at elevated risk of anxiety, depression, post-traumatic stress symptoms, and behavioural changes, yet psychosocial support for siblings remains inconsistent and limited (Batchelor, 2025).

1.5.2 Impact on caregivers

Survey results show that blood cancer has a significant impact on carers, with three quarters (74%) of carers reporting a negative impact on their mental health and emotional wellbeing (Figure 27).

"[It] has completely changed my life – feeling isolated from society, I can't plan anything in regards to looking after myself and the younger siblings living uncertainly, being neglected and our own quality of life has all suffered. There is an element of resentment and burden with looking after a sick child."

- Carer of child

Three-quarters (74%) of carers feel that caregiving negatively impacts their ability to participate in society, and 70% feel like caregiving has a negative impact on their overall quality of life. They lack sufficient resources to manage stresses associated with providing care, and therefore experience negative psychological and behavioural outcomes such as post-traumatic stress disorder, significant sleep disturbances, negative impact on family relationships, and overall reduced quality of life (Yucel, 2021).

International evidence aligns with these findings. A recent multinational qualitative study of carers supporting adults with acute leukaemia found that caregiving imposes a severe multidimensional burden across emotional, social, financial, and physical domains (Nier, 2025). The study identified three interconnected drivers of burden: strain on relationships, challenges balancing multiple roles including employment, and the tendency for carers to prioritise the patient at the expense of their own wellbeing. Carers frequently described constant vigilance, limited freedom to plan ahead, and persistent anxiety relating to relapse or treatment complications. These findings mirror the experiences of carers in New Zealand and highlight the breadth of support required by families affected by blood cancer.

Figure 27 shows the extent to which caring for a person with blood cancer changes key areas of carers' lives in New Zealand.

As observed in patients, some carers also reported positive changes following their loved one's blood cancer diagnosis. This may reflect post-traumatic growth, whereby new perspectives promote gains in personal strength, relationships with others, new possibilities, appreciation of life, and spiritual change (Cormio et al., 2014).

1.5.3 Impact on education

Blood cancer affects educational participation for children and young people in New Zealand. At this stage, only participation data is available. Educational outcomes such as achievement or attainment were not part of the dataset and therefore are not reported here. However, treatment, recovery periods and health related disruption is highly likely to influence the ability of children and young people with blood cancer to engage regularly with schooling.

Analysis of Integrated Data Infrastructure (IDI) cohort data (Table 3) shows that students with blood cancer have lower school presence rates and higher justified absences than their peers. For ages 5 to 14, presence is 78% for students with blood cancer compared with 88.2% for peers, while justified absences are nearly three times higher (18.4% vs 6.5%). These patterns indicate that treatment schedules and recovery needs have a substantial effect on day-to-day attendance and participation in learning.

	Age 5–14	Age 15–24
No. of blood cancer students	318	153
No. of schools / providers	255	93
Presence (blood cancer students)	78%	76.5%
Presence (peer)	88.2%	84%
Justified absence (blood cancer students)	18.4%	17.1%
Justified absence (peer)	6.5%	8.1%
Unjustified absence (blood cancer students)	3.6%	6.4%
Unjustified absence (Peer)	5.3%	7.9%

Table 3
Overall impact of blood cancer on educational participation for youth in New Zealand
Source: Integrated Data Infrastructure

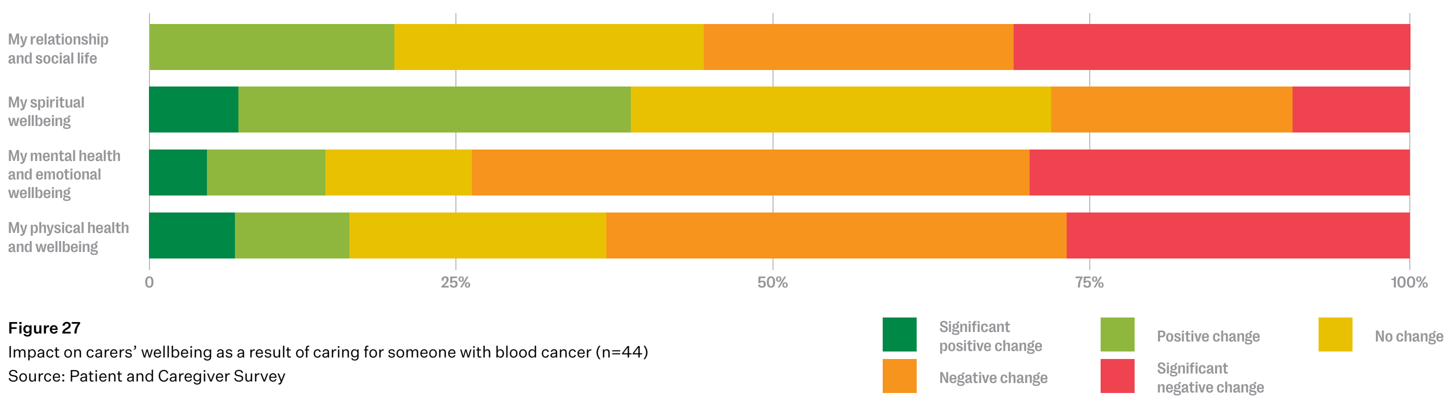


Figure 27
Impact on carers' wellbeing as a result of caring for someone with blood cancer (n=44)
Source: Patient and Caregiver Survey

	Hodgkin Lymphoma	Leukaemia	Non-Hodgkin Lymphoma	Uncertain behaviour of lymphoid, haematopoietic and related tissue
No. of sample blood cancer students	93	225	123	30
No. of schools / providers	72	180	99	30
Presence (blood cancer students)	76.1%	77.8%	77.3%	77.4%
Presence (peer)	85.6%	86.9%	81.3%	82.2%
Justified absence (blood cancer students)	19.6%	17.8%	17.6%	18.1%
Justified absence (peer)	7.6%	7.3%	7.6%	8.2%
Unjustified absence (blood cancer students)	4.3%	4.3%	5.1%	4.5%
Unjustified absence (peer)	6.8%	5.8%	11.1%	9.6%

Table 4
Impact of blood cancer on educational participation for youth in New Zealand, by cancer sub-type
Source: Integrated Data Infrastructure
Note: myelodysplastic syndrome and myeloma data has been suppressed due to low numbers

Sub-type analysis (Table 4) shows consistent trends. Hodgkin lymphoma students have the highest justified absence rate (19.6%), reflecting intensive treatment schedules. Leukaemia students show slightly higher presence (77.8%), but still experience substantial interruption compared with peers. Non-Hodgkin lymphoma students also demonstrate lower presence and elevated justified absences.

Together, these findings highlight participation based educational impacts, where prolonged absence and disrupted attendance may place students at risk of disengagement and wider psychosocial stress. There is documented evidence that survivors of childhood cancer are at greater risk of low educational attainment and unemployment (Devine et al., 2022). Although educational outcomes cannot be assessed from the available data, the significant disruption to participation suggests potential long-term implications for learning that warrant further investigation.

1.6 Financial burden of a blood cancer diagnosis

Key findings

- **Financial toxicity is widespread, with 45% of patients incurring significant out-of-pocket costs and 69% using life savings to fund care.**
- **One in seven patients surveyed spends over $100,000 on unfunded medicines, with myeloma patients most affected.**
- **Half of all blood cancer patients rely on social benefits, costing the system $56M annually.**
- **Financial hardship is most severe for Māori, Pacific, rural and high-deprivation communities, deepening existing inequities.**

Financial toxicity – defined as the negative impact of the cost of medical care on a patient's financial well-being – is well-documented in blood cancers and is associated with poorer clinical and psychological outcomes (Dee, 2023).

Contributing factors include loss of income, travel costs, co-payments, and expenses for prolonged or novel therapies (Edward, 2023).

Almost half of respondents to the patient survey (288, 45%) felt that they had experienced significant out-of-pocket costs during their diagnosis or treatment, especially from travelling to and from treatment (336, 72%) and having to reduce or change their working hours or role (218, 47%).

Productivity loss across blood cancer patients was significant – only 8.5% of the 632 patient survey respondents were able to continue working through their treatment. A third (32%) had to reduce their hours or take some time off work, while 17% needed to leave their jobs altogether. One in three respondents (32%) were retired, reflecting the higher prevalence of blood cancer in older age groups.

> **"The financial impact is huge. I can't imagine how a single parent does this financially."**
> **- Parent.**

363 (69%) of survey respondents had to utilise their life savings to pay for their care, as shown in Figure 28. Savings, alongside insurance or financial backing from employers, family and friends prove crucial in managing costs of blood cancer care in New Zealand.

High out-of-pocket costs for medicines and treatment can reduce adherence, as patients may delay, skip, or stop therapies to manage expenses. Studies report that to afford care, patients often cut spending on essentials such as food, clothing, and utilities. These are decisions that can compromise nutritional status, increase stress, and ultimately undermine treatment effectiveness, wellbeing, and both the length and quality of life (Knight, 2020).

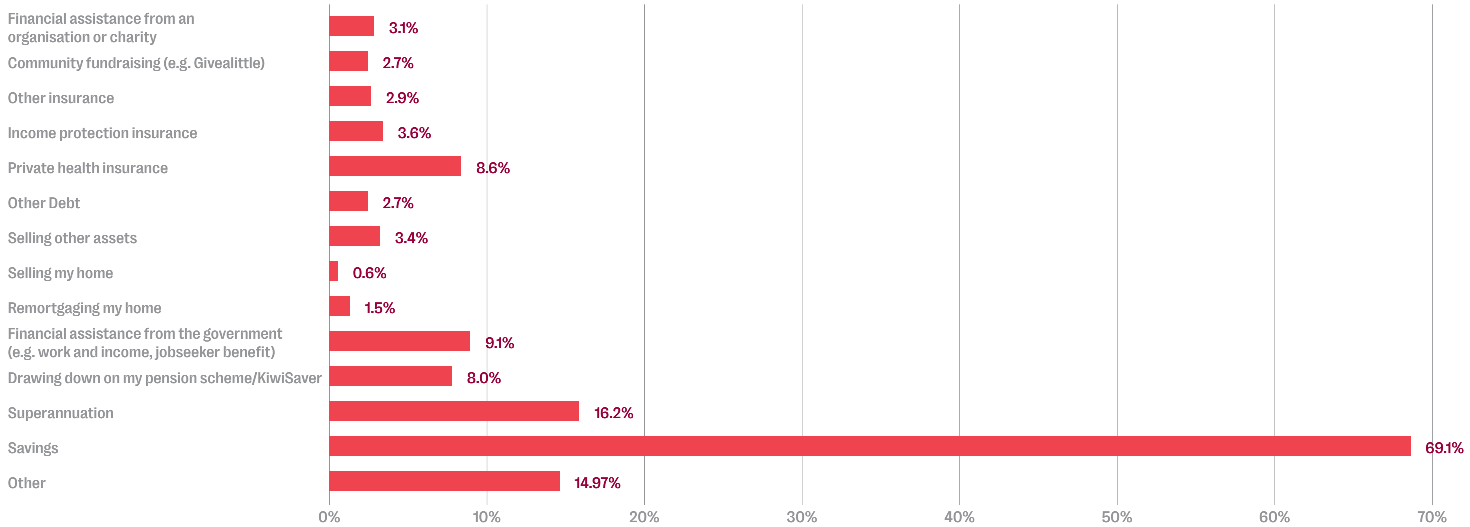


Figure 28
How New Zealand blood cancer patients cover out-of-pocket costs (n=525)
Source: Patient and Caregiver Survey

Not only are the out-of-pocket costs high, but a blood cancer diagnosis also results in a drastic loss of income. Transitioning from stable salaries to relying on government support and/or a single income places immense strain on families.

In 2023, approximately 50.6% of the people living with a blood cancer diagnosis that year accessed social benefits.'

Long-term financial security is a significant concern for patients, particularly in relation to their homes, retirement savings, and the ability to leave an inheritance for their children. Many are forced to choose between preserving this security for their loved ones or extending their lives with modern medicines that can rapidly deplete the nest egg they had intended to pass on.

Overall, the financial impact of blood cancer is debilitating, affecting patients and their families deeply, highlighting the urgent need for comprehensive support systems, and greater access to funding to alleviate the economic impact on those battling blood cancer.

1.6.1 Income analysis

An analysis using Inland Revenue Department (IRD) Income Data available within the IDI was undertaken to examine the financial circumstances of blood cancer patients at different time points relative to their diagnosis.

Between 2013 and 2022, there were 28,803 individuals aged 15 years and over diagnosed with cancer. Of these, 36.0% (10,362 people) were active in the workforce at the time of diagnosis. Two years after diagnosis, only 23.0% (6,627 people) from the same cohort remained income earners, reflecting income loss or death.

Income data also shows a clear financial loss at the time of diagnosis. Average earnings drop noticeably in the year of diagnosis, reflecting treatment disruptions, reduced capacity to work, or time off employment.

For those diagnosed in 2022, the impact is stark. By 2024 the number of people earning an income fell 44.4%, from 1,122 to just 624.

This analysis likely understates the true effect, as it excludes individuals who passed away within two years or permanently left the workforce, creating what is known as survivorship bias.

Among patients who do return to work following successful treatment, average income begins to recover in the two years after diagnosis. This highlights the wider economic benefits of timely access to effective treatment, particularly for people of working age.

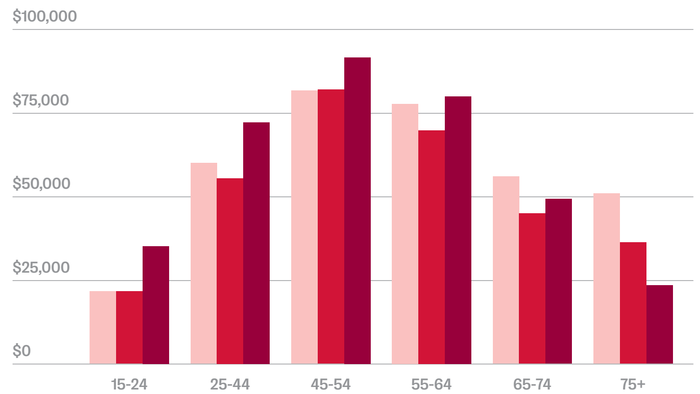


Figure 29
Average income of blood cancer patients pre & post diagnosis
Source: Patient and Caregiver Survey

As illustrated in Figure 29, changes in income around the time of diagnosis vary by age group rather than showing a uniform pattern. For some age groups, income remains stable at the year of diagnosis, while for others it declines.

- **Younger and mid working age adults (25–54):** income at the cancer year appears broadly similar to, or only slightly lower than, income two years prior.
- **Older working age adults (55–64):** income decreases noticeably at the year of diagnosis before partially recovering two years later.
- **Older adults (65+):** experience substantial decrease in income at the time of diagnosis, with limited recovery thereafter. In particular, those aged 75 and over show sustained income decline beyond diagnosis.

These patterns suggest income disruption in the diagnosis year increases with age, with small absolute changes under 55 and markedly larger declines from 55 onwards, especially among people aged 65 and over. While Figure 29 presents average income in dollar terms, the proportional impact of income loss is likely greater at older ages due to lower baseline incomes.

Considering the larger drop in older adults, there are a number of factors outside of blood cancer that could be impacting this:

- **Acceleration towards Retirement:** The onset of a serious illness like blood cancer may accelerate retirement plans, influencing financial dynamics.
- **Disability Impact:** Possible impacts of disability related to the illness might contribute to reduced income, as individuals may reduce work hours or stop working entirely.
- **Savings Reduction:** Expenses related to healthcare and the reduced ability to work could lead to decreased savings and financial stability, affecting overall income figures.

1.6.1.1 Impact on carers' incomes

Carers' incomes are negatively impacted by a family member's blood cancer diagnosis. Only 5 carers surveyed (11%) were able to continue working with no impact. A further 13 (30%) were able to continue working but had to reduce their hours. One in six carers (7, 16%) needed to leave their job altogether.

1.6.1.2 Indirect and direct costs of treatment

International estimates show that 20-50% of blood cancer patients experience financial toxicity (Ouchveridze, 2022) and up to 85% for caregivers of patients with blood cancer (Edward, 2023).

Differences in financial toxicity between blood cancers are linked to more acute and aggressive diseases, necessitating intensive and prolonged treatment. Factors such as frequent hospitalisations, high-cost medications, and longer recovery periods contribute to these disparities. Chronic blood cancers might involve ongoing, but less intense, financial demands (Sears-Smith, 2023).

In New Zealand, travelling for treatment incurs an incredibly high cost that blood cancer patients must bear. Indirect costs such as travelling or relocating for treatment is driven by the large geographical distances between specialist treatment centres and where people live. This is compounded by home and personal care expenses, as individuals often require in-home assistance and domestic help due to their inability to perform daily tasks, and increased childcare costs when caregivers are unavailable.

Some patients and families make major decisions to move, either permanently or long term, uprooting them from their homes and support networks.

"It is literally stop [and] drop your whole life – everything – and just pack and you don't know how long you're ... going to be gone for. The first time we didn't know"
- Parent

Direct costs of paying for unfunded medicines brought significant expense to many patients. One in seven patients surveyed had spent more than $100,000 on unfunded medicines. This is even higher in some groups, with almost 1 in 4 myeloma patients having spent more than $100,000 on unfunded medicines (16, 24%).

"It's disgusting that all blood cancer patients must fully fund drugs that are not funded by Pharmac"
- Patient

1.6.2 Demographic trends

The financial impact of blood cancers differs across various demographic groups. Individuals who are younger, have lower incomes, are unemployed, or reside in rural areas are more likely to experience financial hardship (Ouchveridze, 2022). While blood cancer reduces income levels across all groups, patients living in areas of higher deprivation (NZ Deprivation quintile 5, based on 2023 scores) are most severely affected. Data from the Integrated Data Infrastructure (IDI), presented in Table 5, demonstrates a clear relationship between deprivation and income continuity following a blood cancer diagnosis.

Across all NZ Deprivation quintiles, the proportion of patients earning an income (typically aged 15 years and over) declines markedly two years after diagnosis. This decline is most pronounced in Quintile 5 (highest deprivation), where the number of income earners decreases by 40.4%, compared to a 31.6% decrease in Quintile 1 (lowest deprivation).

The counts of unique individuals are shown to provide context for income estimates and to highlight how many people remain represented in the data over time. Fewer people appear two years after diagnosis due to factors such as mortality, illness related exit from work, or loss of recorded income. This is important to understand the impact of blood cancer, as it shows not only income loss among those still earning, but also that a growing number of people may no longer have income at all.

The pattern of attrition differs by deprivation level, indicating that people with blood cancer living in more deprived areas may be more likely to experience sustained economic disruption. These results suggest that patients in more deprived areas are disproportionately affected by income loss after diagnosis, likely due to greater challenges in returning to work or maintaining employment during treatment and recovery. This evidence underscores the economic vulnerability of communities experiencing high deprivation and highlights the importance of targeted financial and employment support to help reduce long-term hardship.

NZDep23 Quintile	No. of unique persons in year of diagnosis	No. of unique persons two years after diagnosis	% difference in income (two years after year of diagnosis)
0	2,016	1,254	-37.8%
1	3,756	2,568	-31.6%
2	3,831	2,523	-34.1%
3	3,753	2,394	-36.2%
4	3,675	2,292	-37.6%
5	3,195	1,905	-40.4%

Table 5
Economic impact of blood cancer: Income loss and deprivation inequities in New Zealand
Source: Integrated Data Infrastructure
Note: NZDep23 Quintile 0 means the area does not have a valid deprivation score and therefore cannot be assigned to a deprivation quintile. Counts show the number of distinct individuals with valid income data at each time point. Differences reflect attrition over time rather than changes in sample design.

1.6.2.1 Impact on income for different types of blood cancer

Income loss following a diagnosis is common across all blood cancer types, with more pronounced effects observed in aggressive forms. In New Zealand, individuals diagnosed with Hodgkin lymphoma tend to experience the highest levels of income volatility after diagnosis. In comparison, those with non-Hodgkin lymphoma or leukaemia generally face more stable income levels, though their post-cancer income growth is slower. Other blood cancer types typically show a stronger recovery in income over time.

Table 6 shows that a diagnosis of blood cancer is associated with a marked and immediate decline in income across all cancer types examined. In the year of diagnosis, average incomes fell between 12% and 17% compared with earnings two years earlier, indicating a substantial disruption to work capacity and employment stability. The largest immediate declines were seen among people diagnosed with myeloma (-17.7%), myelodysplastic syndrome (-17.0%), and cancers of uncertain behaviour (-17.1%), suggesting that these conditions may lead more abruptly to reduced ability to work or increased time away from employment. While other cancer types such as leukaemia (-15.2%) showed slightly smaller decreases, the overall pattern reflects a consistently significant economic shock at the time of diagnosis.

	% change of average income (cancer diagnosed year compared to 2 years before)	% change of average income 2 years after compared to cancer diagnosed year
Hodgkin Lymphoma	-12.4%	29.6%
Leukaemia	-15.2%	19.7%
Myelodysplastic Syndrome	-17.0%	8.7%
Myeloma	-17.7%	16.8%
Non-Hodgkin lymphoma	-13.8%	21.2%
Uncertain behaviour of lymphoid, haematopoietic and related tissue	-17.1%	22.1%

Table 6
Economic impact of blood cancer: Income changes by cancer type in New Zealand
Source: Integrated Data Infrastructure
Note: Figures above cover cancer diagnosed year before 2018 to 2022. Negative figures represent reduction in income, with positive figures representing an increase in income.

Recovery patterns in the two years following diagnosis vary across cancer types but are uniformly positive. Conditions that see positive rebounds suggest that for many patients, income recovers at least partially as treatment stabilises and individuals re-engage with work.

In contrast, conditions associated with more intensive or prolonged treatment, such as myelodysplastic syndrome (+8.7%) and myeloma (+16.8%), show more modest post-diagnosis improvement. This possibly reflects the longer-term impacts of these diseases and their ongoing effects on labour market participation.

1.6.2.2 Ethnic disparities in income and financial recovery

Māori and Pacific Peoples face significant challenges, including lower baseline incomes and a more pronounced decline in income following diagnosis. Their financial recovery after diagnosis is also slower when compared to Asian and Other groups, who tend to have higher incomes prior to diagnosis and experience a stronger financial recovery, as illustrated in Figure 30.

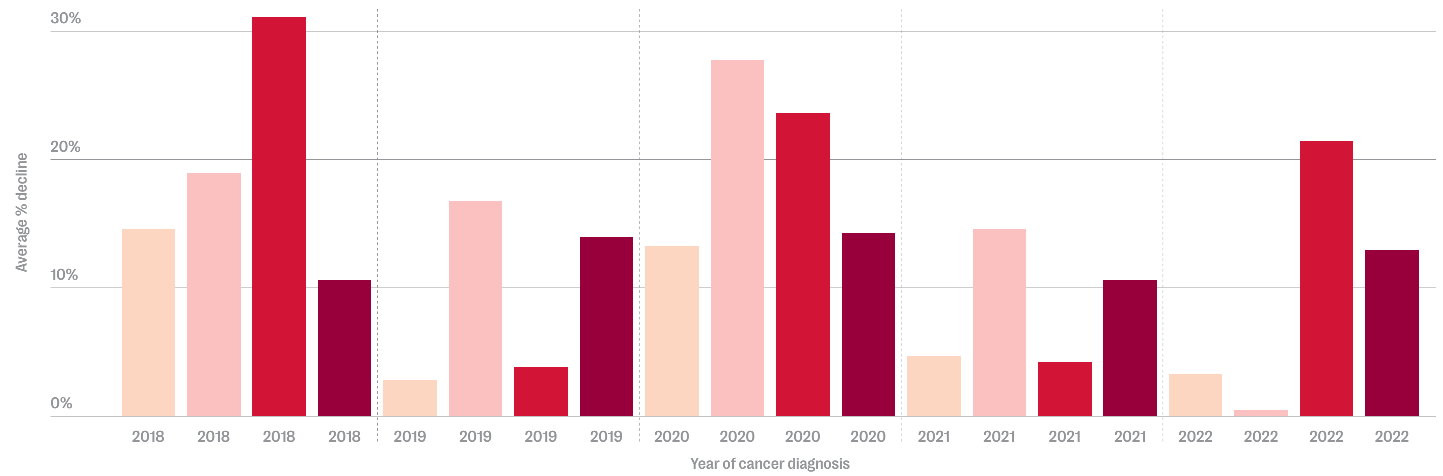


Figure 30
Average decline in income during cancer versus two years before, by ethnic group and year, 2018-2022
Source: Integrated Data Infrastructure.
Note: All percentage changes are negative declines in income. Ethnicity "Other" includes NZ European, and all other non-Māori, non-Pacific, and non-Asian people

1.6.2.3 Gender disparities in income

In 2022, there was a significant income gap between males and females diagnosed with cancer. On average, females earned $45,695 during their year of diagnosis, while males earned $67,790 – a difference of more than $22,000. This disparity remained consistent over the five-year period from 2018 to 2022, with males earning between $16,000 and $25,000 more than females each year.

Both males and females experienced a decline in income during the year of diagnosis, with females' income decreasing by 11% to 13% and males' by 11% to 17%. Income levels recovered in subsequent years; two years after diagnosis, females' income had increased by 17-24%, while males saw an increase of 20-31%.

1.7 Economic impact on the public system

Key findings

- **Blood cancer cost the health system $209 million in 2023, with inpatient services making up 72% of total costs. Inpatient costs have increased substantially since 2009.**
- **There is a shift to day-stay treatments and longer survivorship, with outpatient costs rising sharply.**
- **Emergency department use was high, with over 9,300 patients accounting for 19,270 visits in 2023. indicating repeat presentations.**

Blood cancer places significant financial pressure on New Zealand's health and social support systems. This section provides an overview of the direct and indirect costs associated with diagnosis, treatment, ongoing care and support services. Drawing on national datasets and international evidence, it highlights patterns in service utilisation, rising cost burdens, pharmaceutical expenditure and the level of financial assistance accessed by individuals and whānau affected by blood cancer.

1.7.1 Health system use

Access to hospital services for blood cancer patients involves a mix of inpatient, outpatient, and emergency department (ED) services. Blood cancer patients often require inpatient care for intensive treatments such as chemotherapy, stem cell transplants, or management of severe complications. Outpatient care is a channel for early interventions, day treatment, side effect management, and to triage demand for hospital beds.

All hospital care for blood cancer patients represented a significant investment, with costs nearing $209 million in 2023. The majority of this, 71.6%, was driven by inpatient care, reflecting the intensive nature of treatment and hospital stays. Outpatient services accounted for 27.2%, while emergency department visits made up just 1.1% of the total.

While ED care represented a small share of total hospital costs, the high volume of presentations reflects the acute and complex nature of blood cancer and the pressure placed on emergency services

Stem cell transplantation also represents a substantial component of hospital resource use. Allogeneic transplants, in particular, require prolonged inpatient stays, intensive supportive care, and significant multidisciplinary input. As demand for transplantation grows in line with rising incidence and improved survivorship, this will contribute further to the overall hospital burden.

Looking ahead, newer therapies offer the potential to shift more care into outpatient settings. Targeted small-molecule medicines, CAR T, and bispecific antibodies are increasingly delivered outside of inpatient wards, which may reduce the need for prolonged hospital stays in the future and support more efficient use of hospital resources.

1.7.1.1 Inpatient services

Between 2009 and 2023, New Zealand spent an estimated $1.52 billion on inpatient care for people with blood cancers, covering approximately 260,000 hospital events.

Costs are shown in nominal dollars and reflect changes in service use and rising health-sector costs over time.

In 2023 alone, over 5,000 individuals with blood cancer utilised hospital inpatient services, resulting in approximately 18,700 admissions and a total of 76,000 overnight stays. These services are estimated to have cost the health system around $149.6 million. This included around $135.1 million for inpatient activities and about $14.5 million for other relevant inpatient services, such as intravenous chemotherapy and oncology radiotherapy.

Inpatient care for blood cancers encompasses both urgent and scheduled treatments. Acute admissions arise from sudden and sometimes life-threatening complications – such as infections, bleeding, or severe treatment side effects – and typically require emergency or oncology ward admission. Nonacute admissions are planned and generally relate to chemotherapy, transfusions, or ongoing symptom management.

Over time, the costs associated with inpatient care have increased steadily, as shown in Figure 31. Between 2009 and 2023, the estimated average annual cost per patient rose from $19,423 to $31,033, representing an increase of approximately 60%. Over the same period, the average cost per hospital event increased from $5,749 to $11,881, an increase of approximately 107%. These trends likely reflect a combination of increasing treatment complexity, evolving models of service delivery, broader health sector cost pressures, and inflation over the 14-year period rather than abrupt changes in demand. Adjusted for inflation using the Consumer Price Index, the 2009 cost per patient is equivalent to approximately $24,400 in 2023 dollars, and the 2009 cost per hospital event is equivalent to approximately $7,200 in 2023 dollars. Because costs are shown in nominal dollars, changes over time reflect a combination of service use, treatment intensity, and health sector price growth. The figures therefore provide insight into the extent and nature of hospital care required for blood cancer, rather than whether costs are increasing or decreasing in real terms.

In 2023, 72.3% of hospitalisations for blood cancer were nonacute, with the remaining 27.7% classified as acute. Acute admissions were significantly more costly, averaging $18,730 per event, compared with $11,230 for nonacute admissions. This cost differential underscores the higher level of resources and specialist care required for emergency and complex interventions, and the need for effective planning to support both urgent and ongoing hospital services in the management of blood cancer.

Different types of blood cancer place very different demands on New Zealand's hospitals. In 2023, leukaemia was the most resource-intensive, with 1,335 patients accounting for over 25,000 hospital days and the highest per-patient 12-month cost at $45,610.

Myelodysplastic syndrome had fewer patients but the most frequent admissions per patient, while non-Hodgkin lymphoma involved the largest number of patients overall.

Inpatient costs associated with blood cancers represent a substantial component of hospital expenditure. In 2023, inpatient expenditure reached $17.9 million for leukaemia, $23.9 million for non-Hodgkin lymphoma, and $11.6 million for myeloma, as illustrated in Figure 32. Although the distribution of costs between blood cancer types has remained relatively stable over time, total inpatient expenditure has increased since 2009.

Between 2009 and 2023, the average inpatient cost per blood cancer patient increased by around 60% in nominal terms. Over the same period, consumer price inflation increased by approximately 25%.

As an illustration, inflating 2009 costs to 2023 price levels would account for a substantial portion of the observed increase. On this basis, the remaining growth is equivalent to an increase in real costs of approximately 30% relative to 2009 levels.

These figures should be interpreted as indicative rather than exact. The true real increase would need to account for additional factors such as changes in case mix, treatment complexity, clinical practice, workforce costs, and health sector specific price pressures, which are not captured through general CPI adjustment alone.

Per patient inpatient costs vary across blood cancer types. In 2023, the average inpatient cost per patient was $45,613 for leukaemia, $24,385 for non-Hodgkin lymphoma, and $21,874 for myeloma, as illustrated in Figure 33.

Average inpatient costs per hospital event vary across blood cancer types. In 2023, the average inpatient cost per event was $17,014 for leukaemia, $12,324 for non-Hodgkin lymphoma, and $11,489 for myeloma, as illustrated in Figure 34. Other blood cancers recorded similar costs, including Hodgkin lymphoma at $11,672 per event and myelodysplastic syndrome at $11,616 per event.

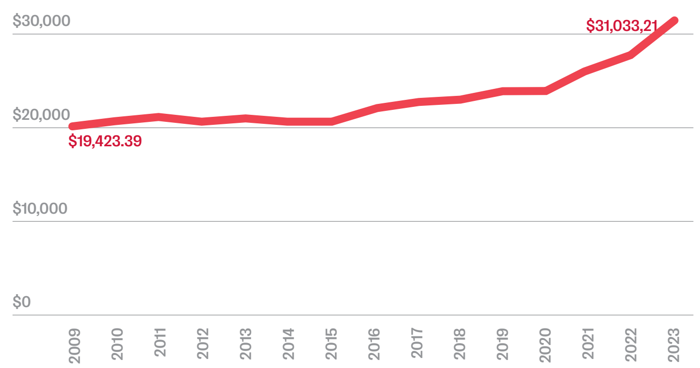


Figure 31
Estimated average cost per patient per year for inpatient hospital care over time, 2009-2023
Source: Integrated Data Infrastructure
Note that the figures are for casemix funded events only. Cost weights and price per cost weight have been used to estimate costs.
Figures are presented in nominal dollars. Between 2009 and 2023, consumer price inflation increased by approximately 25% according to the Stats NZ Consumer Price Index (all groups). Cost changes over this period therefore reflect both underlying price inflation and changes in patterns of service delivery.

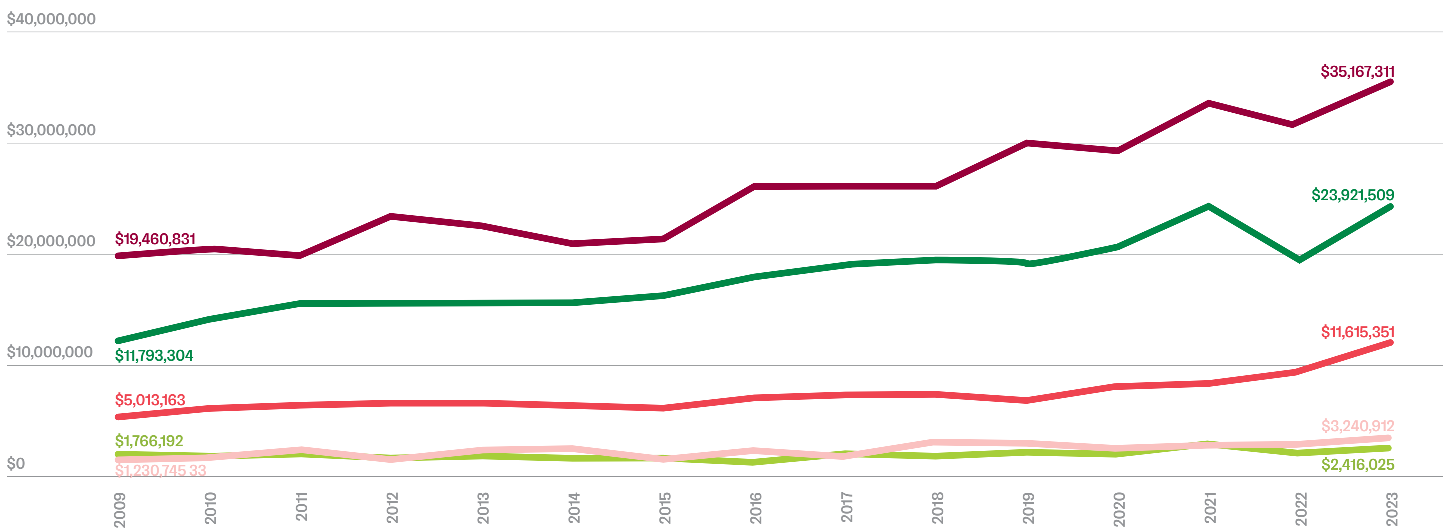


Figure 32
Total inpatient hospital costs for blood cancers by primary diagnosis, 2009-2023
Source: Integrated Data Infrastructure
Note that the figures are for casemix funded events only. Cost weights and price per cost weight have been used to estimate costs. Figures are presented in nominal dollars. Between 2009 and 2023, consumer price inflation increased by approximately 25% according to the Stats NZ Consumer Price Index (all groups). Cost changes over this period therefore reflect both underlying price inflation and changes in patterns of service delivery.

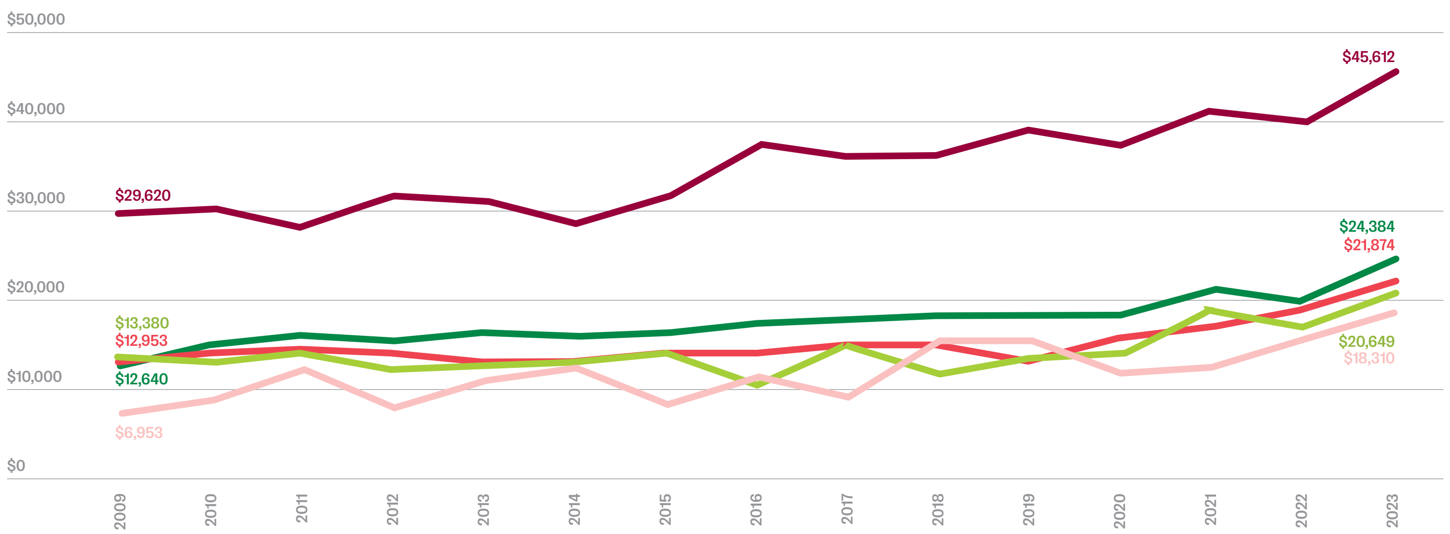


Figure 33
Average inpatient cost per patient for blood cancers by primary diagnosis
Source: Integrated Data Infrastructure
Note that the figures are for casemix funded events only
Cost weights and price per cost weight have been used to estimate costs.
Figures are presented in nominal dollars. Between 2009 and 2023, consumer price inflation increased by approximately 25% according to the Stats NZ Consumer Price Index (all groups). Cost changes over this period therefore reflect both underlying price inflation and changes in patterns of service delivery.

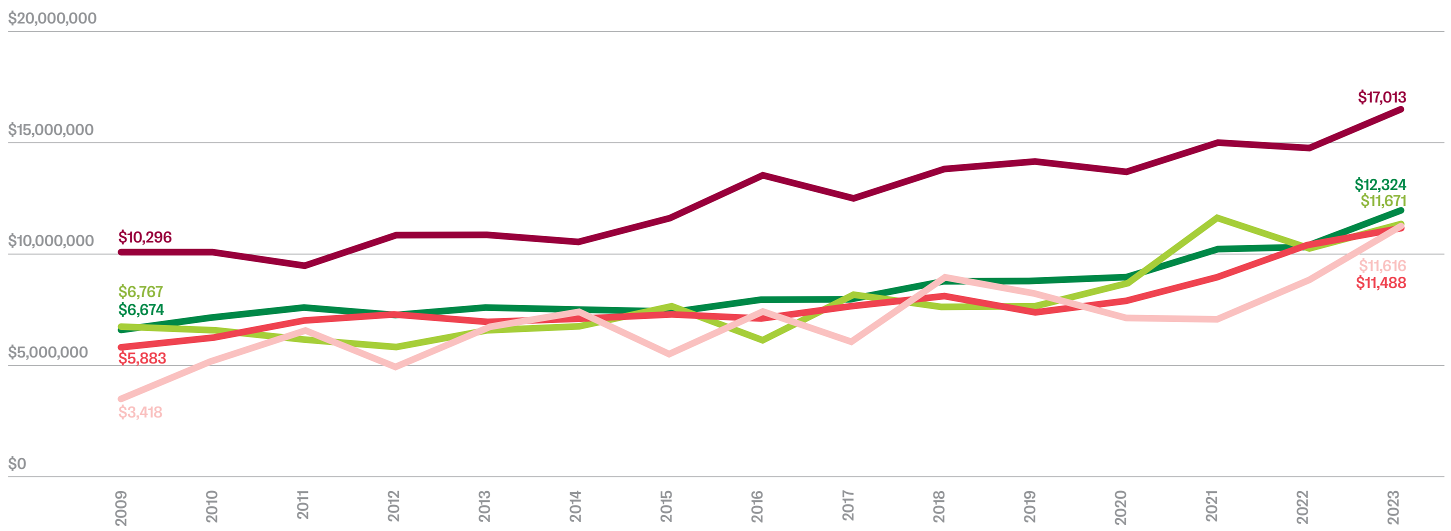


Figure 34
Average inpatient cost per event for blood cancers by primary diagnosis, 2009-2023
Source: Integrated Data Infrastructure
Note that the figures are for casemix funded events only. Cost weights and price per cost weight have been used to estimate costs. Figures are presented in nominal dollars. Between 2009 and 2023, consumer price inflation increased by approximately 25% according to the Stats NZ Consumer Price Index (all groups). Cost changes over this period therefore reflect both underlying price inflation and changes in patterns of service delivery.

1.7.1.1.1 Demographic trends

Please refer to Appendix 5.4 for a comprehensive summary of demographic trends related to blood cancer-specific inpatient services.

In 2023, younger patients – especially those in the 0–4 and 15–24 age groups – used significantly more hospital resources for blood cancer care than other age groups. These patients had more hospital events per person, stayed longer in hospital (both overall and per admission), and had higher costweighted discharge values, indicating more complex clinical needs. As a result, their average costs were notably higher than those of other age groups.

The 15–24 age group recorded the highest level of resource use, with the highest average cost per patient at $77,900 and the highest average cost per event at $20,670.

By contrast, patients aged 75 and over had the lowest use of hospital services for blood cancer. They experienced fewer admissions, shorter stays, lower clinical complexity, and the lowest associated costs. For this group, the average cost per patient was $15,590, and the average cost per event was $10,080 for cases where blood cancer was the principal diagnosis (Table 7).

Available data does not allow conclusions to be drawn about the underlying drivers of this pattern, such as treatment intent, eligibility for intensive therapies, or preferences for care, which are not captured within available administrative datasets.

		Average events per patient	Average length of stay per patient	Average cost per patient	Average cost per event
Age group	00-04	3.9	23.8	$71,584	$18,473
	05-14	3.7	14.2	$48,771	$13,301
	15-24	3.8	30.3	$77,898	$20,667
	25-44	2.8	20.2	$50,756	$17,880
	45-54	2.6	13.6	$34,675	$13,389
	55-64	2.5	13.1	$32,168	$12,955
	65-74	2.0	10.6	$25,497	$12,593
	75+	1.5	6.6	$15,592	$10,078
Ethnicity	Asian	2.1	16.3	$39,864	$18,793
	Māori	2.5	16.6	$41,439	$16,352
	Other	2.2	10.6	$26,989	$12,391
	Pacific	2.3	14.0	$33,358	$14,344

Table 7
Summary of average inpatient events, length of stay and cost by major demographic group, 2023
Source: Integrated Data Infrastructure
Note that the figures are for casemix funded events only. Cost weights and price per cost weight have been used to estimate costs. Ethnicity "Other" includes NZ European and all other non-Māori, non-Pacific, and non-Asian people.

1.7.1.2 Outpatient services

Outpatient services for blood cancer patients in New Zealand have expanded significantly over the past 15 years, reflecting a shift toward delivering treatments, such as many chemotherapy regimens, in outpatient or daystay settings rather than through hospital admission.

As treatment regimens have become more complex, outpatient utilisation and associated costs have grown. In 2023, more than 14,000 people received outpatient care for blood cancer, generating nearly 89,000 visits nationwide.

Patient numbers increased steadily until 2021 before slightly declining. However, the intensity of care per patient has continued to rise, when considering the availability of more advanced treatments and a growing population living longer with complex needs.

In 2023, outpatient services cost the health system nearly $57 million, with 93% of spending related to follow-up care. On average, each patient cost $3,973, and each visit cost $684.

Across blood cancer types, non-Hodgkin lymphoma was the most common condition treated in outpatient settings, accounting for roughly one third of patients. Leukaemia and myeloma followed. Myeloma patients required the most frequent visits, underscoring the particularly intensive nature of their outpatient care.

Outpatient care represents a significant component of blood cancer service delivery. In 2023, total outpatient expenditure reached $15.89 million for myeloma and $14.58 million for non-Hodgkin lymphoma, as illustrated in Figure 35. Other blood cancers, including Hodgkin lymphoma and leukaemia, also generated notable outpatient costs, reflecting the important role of outpatient services in the ongoing management of blood cancer.

Average outpatient costs per patient also vary across blood cancer types. In 2023, the average outpatient cost per patient was $5,994 for myeloma, $4,090 for leukaemia, and $3,118 for non-Hodgkin lymphoma, as shown in Figure 36. Hodgkin lymphoma recorded lower but still meaningful outpatient costs per patient.

The average cost per outpatient event was more consistent across blood cancer types. In 2023, the average outpatient cost per event was $693 for myeloma, $686 for leukaemia, $647 for non-Hodgkin lymphoma, and $824 for myelodysplastic syndrome, as illustrated in Figure 37. Hodgkin lymphoma recorded similar costs per event.

In 2023, the average outpatient cost per event was $686 for leukaemia, $824 for myelodysplastic syndrome, $693 for myeloma, and $647 for non-Hodgkin lymphoma. Other blood cancers, including Hodgkin lymphoma, recorded similar costs per outpatient event.

1.7.1.2.1 Demographic trends

See Appendix 5.4 for a full summary of demographic trends for blood cancer-specific outpatient services.

Clear age-related differences are evident. Younger patients, especially those aged 0–4, required the most intensive outpatient care, recording 17.5 events per patient, as shown in Table 8. Children aged 5–14 also had higher-than-average utilisation. In contrast, individuals aged 75 and over required the fewest visits, averaging 5.2 events per patient.

Cost patterns follow similar trends. The 0–4 age group recorded the highest average cost per patient at $10,674, substantially above all other age groups. While utilisation declines with age, the cost per event increases gradually – from $610 in the youngest group to $701 in those aged 75+ – indicating that older adults attend fewer appointments, but each tends to involve more resource-intensive care.

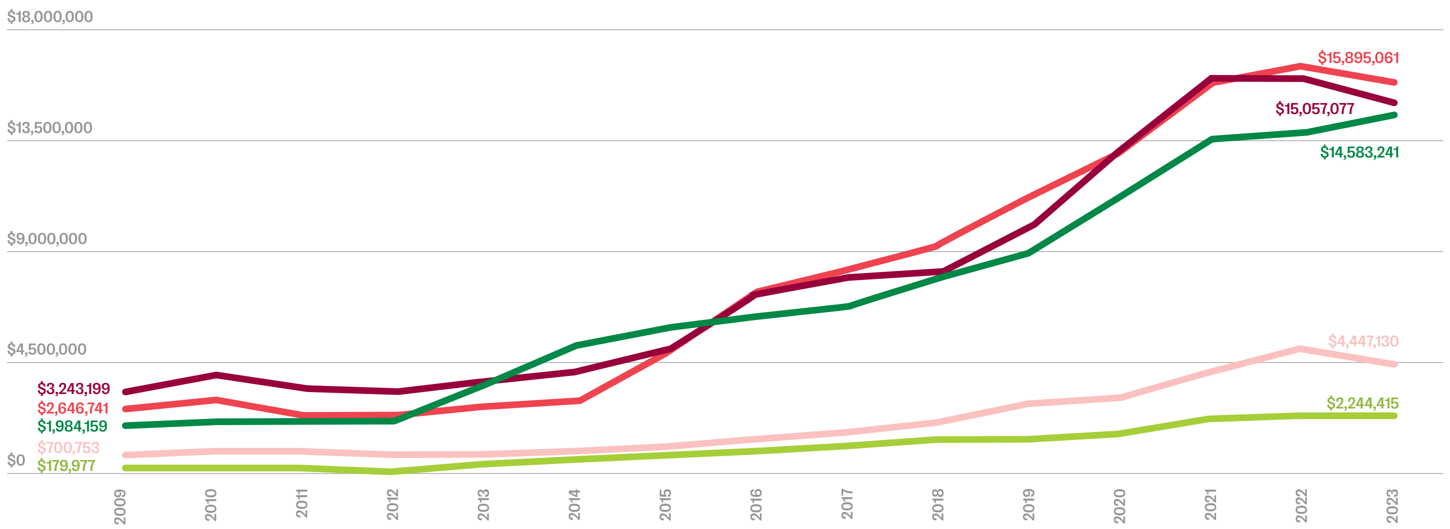


Figure 35
Total outpatient hospital costs for blood cancers by primary diagnosis, 2009-2023
Source: Integrated Data Infrastructure
Figures are presented in nominal dollars. Between 2009 and 2023, consumer price inflation increased by approximately 25% according to the Stats NZ Consumer Price Index (all groups). Cost changes over this period therefore reflect both underlying price inflation and changes in patterns of service delivery.

Despite lower per-patient intensity, patients aged 65 and over accounted for 61.6% of total outpatient expenditure, reflecting the overall volume of care delivered to this group.

Outpatient resource use also varies by ethnicity. Asian patients had the highest average cost per patient ($4,700) and among the highest costs per event, suggesting comparatively intensive outpatient episodes. Pacific Peoples recorded the highest cost per event ($718). Māori and Other ethnic groups had slightly lower average costs, despite similar visit volumes overall.

Marked regional variation was also evident. Rural areas such as Nelson Marlborough and the West Coast recorded the lowest per-patient costs (around $2,000) and fewer visits per-patient (3.6 on average).

These patterns may reflect differences in service accessibility, lower utilisation, or referral pathways that direct more complex cases to larger urban centres.

Urban centres, particularly Counties Manukau and Auckland District Health Boards, recorded higher utilisation and perpatient costs. This is likely attributable to their roles as specialist referral centres, managing a greater proportion of complex blood cancer cases.

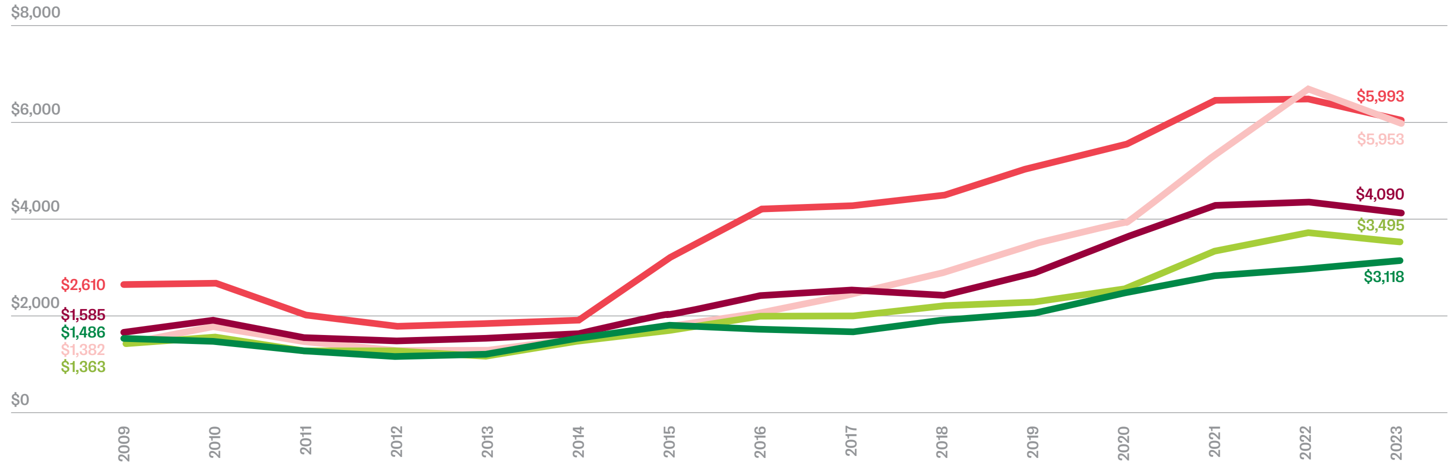


Figure 36
Average outpatient cost per patient for blood cancers by primary diagnosis, 2009-2023
Source: Integrated Data Infrastructure
Figures are presented in nominal dollars. Between 2009 and 2023, consumer price inflation increased by approximately 25% according to the Stats NZ Consumer Price Index (all groups). Cost changes over this period therefore reflect both underlying price inflation and changes in patterns of service delivery.

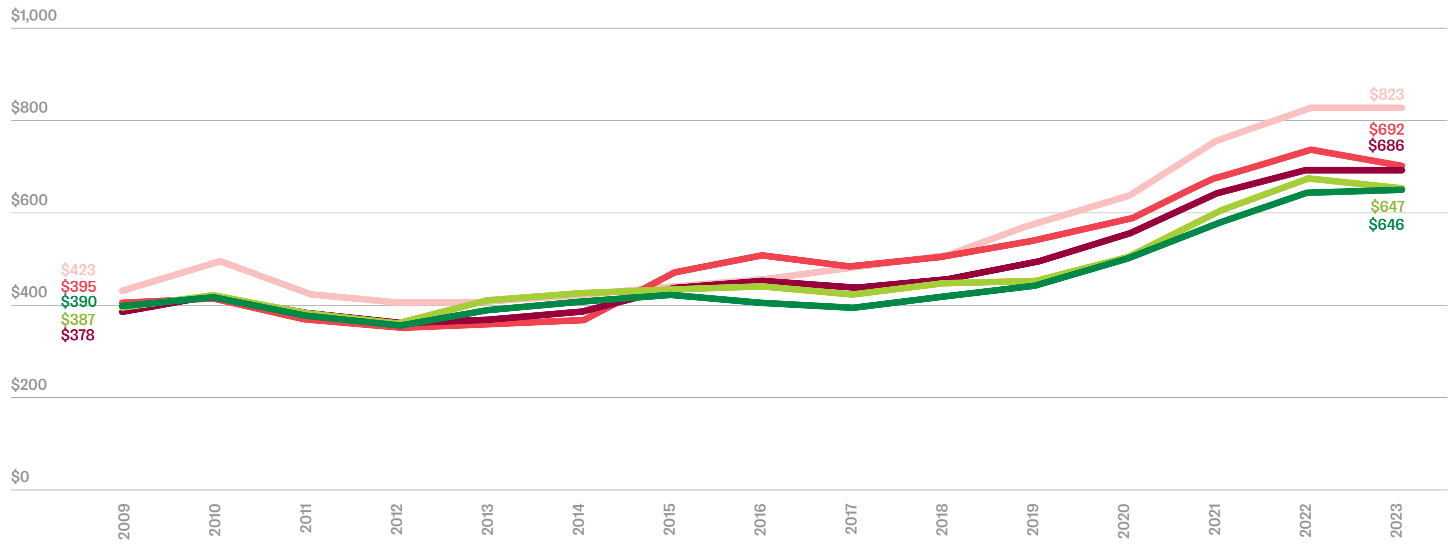


Figure 37
Average outpatient cost per event for blood cancers by primary diagnosis, 2009-2023
Source: Integrated Data Infrastructure
Figures are presented in nominal dollars. Between 2009 and 2023, consumer price inflation increased by approximately 25% according to the Stats NZ Consumer Price Index (all groups). Cost changes over this period therefore reflect both underlying price inflation and changes in patterns of service delivery.

		Average events per patient	Average cost per patient	Average cost per event
Age group	00-04	17.5	$10,674	$610
	05-14	8.1	$4,806	$595
	15-24	6.4	$4,135	$645
	25-44	5.4	$3,511	$653
	45-54	5.8	$3,919	$671
	55-64	6.3	$4,260	$681
	65-74	6.0	$4,128	$692
	75+	5.2	$3,668	$701
Ethnicity	Asian	6.7	$4,700	$697
	Māori	6.2	$4,296	$695
	Other	5.7	$3,876	$680
	Pacific	6.1	$4,381	$718

Table 8
Summary of average outpatient events and cost by major demographic group, 2023
Source: Integrated Data Infrastructure
Note: Ethnicity "Other" includes NZ European and all other non-Māori, non-Pacific, and non-Asian people.

1.7.1.3 Emergency department use

In 2023, 9,315 unique blood cancer patients presented to emergency departments (EDs) across New Zealand, generating 19,278 visits, as outlined in Table 9. Around 75% of these visits involved patients who stayed longer than three hours or were admitted to hospital, highlighting the high clinical acuity associated with blood cancers.

Across all blood cancer types, patients averaged more than two ED visits each (Table 9). Those with myelodysplastic syndrome required the most frequent emergency care at 2.5 visits per person, indicating more regular acute episodes. Non-Hodgkin lymphoma and leukaemia patients accounted for 60% of all ED activity, reflecting the recurring and urgent symptoms that commonly drive ED presentations.

In 2023, 3,026 blood cancer patients were discharged home following ED treatment, representing 4,458 events and costing the health system nearly $2.4 million (Table 10). Over the five-year period from 2019 to 2023, these ED discharge events totalled approximately 24,000, with cumulative costs exceeding $10.3 million.

Although cost data for ED visits resulting in hospital admission is not available, discharge-related ED costs reached $2.4 million in 2023. While this remains lower than outpatient expenditure, it highlights the role of emergency departments in managing acute episodes and complications for people with blood cancer.

In 2023, non-Hodgkin lymphoma accounted for 33.7% of ED discharge costs, followed by leukaemia at 25.3%, and myeloma at 14.6%. Average costs per event were similar across cancer types (approximately $530–$540), but patients with myelodysplastic syndrome had the highest average cost per unique person at $832, due to more frequent or complex visits.

Around 75% of these visits involved extended emergency department stays or resulted in admission, suggesting that many encounters required more than brief assessment or treatment. However, these measures reflect patterns of service use rather than clinical acuity alone, as emergency department length of stay is shaped by both patient needs and system level factors such as capacity and bed availability

These findings illustrate that, while ED discharges are less costly than inpatient care, they still represent a meaningful and varied burden across blood cancer types (Table 10).

In 2023, ED discharge patterns varied significantly across ethnic groups. The Other ethnic category accounted for 81.2% of total ED discharge costs due to its larger population base, but Pacific Peoples had the highest average cost per event at $718, indicating more resource-intensive visits on average.

Asian and Māori patients had similar average costs per event (around $695–$697), though Asian patients had the highest average number of events per person at 6.7, compared with 6.2 for Māori, 6.1 for Pacific Peoples, and 5.7 for the Other group. Despite making up a smaller share of overall costs, Asian patients experienced more frequent ED discharge events.

Average costs per person were also consistently higher among Māori, Pacific Peoples, and Asian patients-between $4,296 and $4,700 – suggesting more complex or repeated care needs relative to the wider population. Māori patients, in particular, relied more heavily on ED services compared with outpatient care, which may indicate challenges in accessing early intervention, follow-up support, or primary care services.

Overall, the data shows that EDs play a significant and sustained role in the care of people with blood cancer, with utilisation driven primarily by repeat presentations and the volume of patients rather than large differences in cost per visit.

Although ED discharge events are less costly than inpatient admissions, they represent a meaningful and ongoing burden on emergency services, with notable variation across cancer types and population groups. These patterns highlight the importance of emergency departments in managing acute episodes and complications related to blood cancer, contributing to system pressure alongside inpatient and outpatient care.

Cancer Type	Total unique person	Total ED events	Avg event per person	% of unique person
Leukaemia	2,388	4,899	2.1	25.6%
Hodgkin Lymphoma	399	810	2.0	4.3%
Non-Hodgkin lymphoma	3,111	6,255	2.0	33.4%
Myelodysplastic Syndrome	648	1,623	2.5	7.0%
Myeloma	1,458	3,042	2.1	15.7%
Uncertain behaviour of lymphoid, haematopoietic and related tissue	1,116	2,265	2.0	12.0%
Total	9,315	19,278		100%

Table 9
Total ED visits by blood cancer type (total events, average per person, and share of patients), 2023
Source: Integrated Data Infrastructure
Note that the figures are for ED discharged and ED admitted events recorded in National Non-Admitted Patient Collection (NNPAC).

Cancer Type	No. of unique patients	No. of events	Average events per person	Total cost	Average cost per person	Average cost per event	% of total ED discharged cost
Hodgkin Lymphoma	17	258	1.5	$137,646	$778	$534	5.8%
Leukaemia	804	1,128	1.4	$602,571	$749	$534	25.3%
Myelodysplastic Syndrome	174	276	1.6	$144,773	$832	$525	6.1%
Myeloma	471	642	1.4	$348,048	$739	$542	14.6%
Non-Hodgkin lymphoma	1,080	1,500	1.4	$804,498	$745	$536	33.7%
Uncertain behaviour of lymphoid, haematopoietic and related tissue	399	546	1.4	$290,944	$729	$533	12.2%
Total	3,026	4,458		$2,386,098			100%

Table 10
ED discharge events by blood cancer type, 2023
Source: Integrated Data Infrastructure
Note that the figures are for ED discharged events (based on purchase unit's definition) recorded in National Non-Admitted Patient Collection (NNPAC) only. It does not include ED admitted (EDa) records subsequently discharged through ED.

1.7.1.4 Pharmaceutical expenditure

Key findings

- **Access to modern medicines is the cornerstone of blood cancer care, yet New Zealand lags behind OECD peers in medicine availability.**
- **New Zealand matches the OECD in health spending but falls well behind in medicines investment, exposing a structural funding gap that directly impacts treatment access.**
- **The funding model for the health system is siloed and operates within Pharmac's constrained and capped budget.**
- **Funding constraints distort the profile of medicines that are available to patients when higher total cost medicines cannot be funded within limited budget allocations. This results in delays in access to innovative therapies.**
- **Public spending on blood cancer medicines has not kept pace with global innovation, leaving patients reliant on private funding or migration.**
- **Closing the medicine gap is critical to improving survival and aligning New Zealand with international standards.**

Access to modern medicines is fundamental to the care and survival of people with blood cancer. Unlike solid tumours, many blood cancers cannot be treated with surgery or localised radiation. This makes access to pharmaceutical therapies the cornerstone of care. However, New Zealand has consistently underperformed in providing timely access to these treatments.

Despite significant global progress in blood cancer therapies, New Zealand's limited investment has resulted in slow and inconsistent adoption of these treatments locally. Over the past decade, public expenditure on blood cancer medicines has failed to keep pace with clinical innovation or with the increasing incidence of these diseases. Compared to other OECD countries, New Zealand lags significantly in both the number and speed of funded treatments for blood cancers (NZIER, 2025).

New Zealand's blood cancer treatment landscape is characterised by gaps in access to foundational standard-of-care therapies, alongside more pronounced deficits in funding for next-generation targeted agents, immunotherapies, and cellular therapies. In health system with comparable GDP per capita, these treatments are routinely available and deliver measurable improvements in overall survival and disease control.

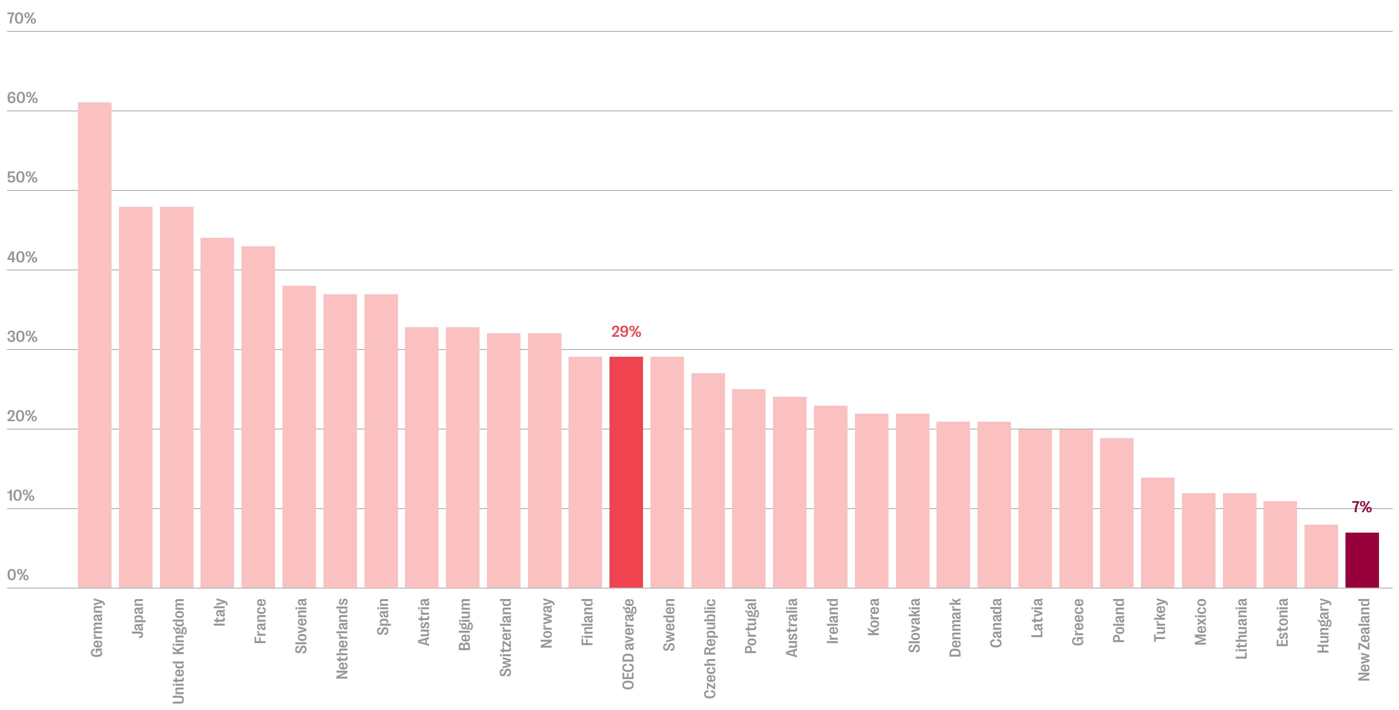


Figure 38
Percentage of new medicines reimbursed by public insurance plans by OECD country (of all 460 new medicines launched from 2012 to end of 2021)
Source: NZIER, based on PhRMA (2023)

The analysis shows that several treatments regarded internationally as standard of care across multiple haematological malignancies remain unfunded in New Zealand. These include advanced therapies used in the treatment of acute and chronic leukaemias, aggressive and indolent lymphomas, and multiple myeloma, which are routinely incorporated into care pathways in comparable health systems.

The absence of these treatments in New Zealand limits the range of clinically appropriate options available to patients and clinicians, constrains alignment with international standards of care, and widens divergence from peer health systems, underscoring the need for strategic investment in high-impact blood cancer therapies.

New Zealand spends a similar proportion of its GDP on health compared to other OECD countries, but allocates a markedly smaller share of that investment to medicines. Publicly funded pharmaceutical expenditure accounts for around 0.4% of GDP in New Zealand, compared with an OECD average of approximately 1.4%, and just 4.9% of government health expenditure, versus an OECD average of 13.3% (NZIER, 2025). This indicates a structural imbalance in how health funding is distributed and highlights opportunities to improve both the efficiency and equity of health system investment.

A core issue lies in the way medicines funding is structured. Pharmac operates under a fixed and constrained budget, separate from other parts of the health system. This structural separation limits allocative efficiency and often distorts investment decisions. While other health services can direct funding toward surgical or radiological infrastructure, typically benefitting patients with solid tumours, the need for sophisticated and often costly pharmaceutical treatments in blood cancer care is frequently overlooked. As a result, patients with blood cancers face systemic delays and reduced access to therapies that are standard elsewhere.

These limitations not only create inequities in health outcomes but also place added pressure on clinicians and families navigating a system that is not equipped to meet the needs of this patient population.

Understanding this landscape is essential to shaping a more responsive and effective roadmap for the future of blood cancer care in New Zealand.

1.7.1.4.1 Pharmac expenditure on blood cancer medicines

Recent changes in public spending on blood cancer medicines illustrate how current funding settings shape treatment access in practice. While system constraints influence which medicines enter the schedule, dispensing data provides a view of how funded treatments are being used and how costs are shifting over time.

Table 11 presents recent expenditure data from Pharmac and illustrates how public spending on blood cancer medicines has shifted over the past two financial years. The figures reflect gross expenditure before confidential rebates (which can range from ~30-70%), so actual spend will be less than shown.

Between 2023/24 and 2024/25, spending fell for several established therapies, including azacitidine, bendamustine, bortezomib, ciclosporin, dasatinib, imatinib and thalidomide. Some of this reduction is likely due to the availability of lower cost generics and biosimilars, such as the transition from branded lenalidomide to Viatris products. Decreases across several tyrosine kinase inhibitors may also reflect changing prescribing patterns or shifts in the number of patients eligible for treatment.

In contrast, expenditure increased for a number of newer, high-cost targeted therapies. Brentuximab vedotin more than doubled in cost, rising from around $865,000 to more than $2 million. Venetoclax, obinutuzumab, pegaspargase and ruxolitinib also maintained high levels of spend, reflecting their growing role in treating acute leukaemias, lymphomas and myeloproliferative neoplasms.

Overall, expenditure fell significantly between the two years. This suggests that even when medicines come off patent and generate savings within Pharmac's budget (e.g., lenalidomide), the existing approval system does not prioritise new medicines for the same diagnosis - rather returning to the general pool of funding for all medicines.

For further description on the medicine gap for blood cancer, see Section 2.2.2.

Chemical name	Gross cost ex GST	
	2023/24	2024/25
Azacitidine	$830,595	$467,726
Bendamustine hydrochloride	$1,385,804	$992,270
Bortezomib	$829,249	$684,550
Brentuximab Vedotin	$865,383	$2,084,224
Chlorambucil	$22,380	$16,853
Ciclosporin	$4,207,825	$3,435,388
Dasatinib	$9,783,972	$4,353,400
Fludarabine phosphate	$171,462	$153,275
Fluorouracil	$338,184	$408,526
Gemtuzumab ozogamicin	$1,158,489	$940,802
Ibrutinib	$1,351,253	$1,908,898
Imatinib mesilate	$1,542,855	$378,437
Lenalidomide (Revlimid)	$46,718,988	$12,073,903
Lenalidomide (Viatris)		$449,726
Midostaurin		$619,838
Nilotinib	$4,934,288	$3,781,789
Obinutuzumab	$2,205,297	$2,381,739
Pegaspargase	$906,592	$1,126,866
Pomalidomide		$284,994
Rituximab (Mabthera)	$10,190,658	$8,959,132
Rituximab (Riximyo)	$7,832,655	$6,629,928
Ruxolitinib	$11,705,312	$9,828,036
Thalidomide	$854,402	$307,557
Tocilizumab	$5,326,970	$5,025,086
Venetoclax	$12,613,504	$11,428,401
Pegylated interferon alfa-2a	$973,617	$1,092,249
Pembrolizumab (for R/R HL only)		$315,084
Total	$126,749,734	$80,128,677

Table 11
Pharmac expenditure on blood cancer medicines
Source: Pharmac
Note that these costs are gross expenditure before rebates and are significantly higher than the actual costs paid by Pharmac after confidential rebates are factored in.

1.7.2 Social system use

Key findings

- **Over 14,000 people with blood cancer accessed social benefits in 2024, costing $56 million.**
- **Main benefits (e.g., Jobseeker, Supported Living Payment) account for 60% of total benefit spend.**
- **Supplementary benefits (e.g., Disability Allowance, Accommodation Supplement) are widely used but provide limited financial relief.**
- **Benefit use has grown sharply over the past decade, reflecting the long-term economic impact of blood cancer.**

Living with blood cancer affects more than just health. It impacts income, independence, and the ability to participate fully in work and daily life. For many, the social welfare system is a critical safety net during treatment, recovery, or long-term management. Yet the scale and nature of this support has remained largely invisible in broader health policy discussions.

As of June 2024, over 14,000 individuals with blood cancer in New Zealand were receiving some form of social benefit. This section explores how those benefits are distributed, how trends have shifted over time, and what these patterns reveal about the wider economic impact of blood cancer.

1.7.2.1 Overview of benefit use

In 2024, the total value of social benefits accessed by people with blood cancer exceeded $56.3 million. Each beneficiary received an average of approximately $4,000 annually. Benefits were categorised as work-related, health-related, or other. The highest value came from health-related benefits, with 5,256 people receiving a combined $29.1 million.

- Health-related benefits: 5,256 recipients, totalling $29.1 million
- Work-related benefits: 471 recipients, totalling $3.3 million
- Other benefits: 13,611 recipients, totalling $23.9 million

Blood cancer patients who were Māori received the highest average benefit in the work-related and health-related categories. Individuals classified under 'Other' ethnicities represented the majority of recipients, aligning with their larger share of the blood cancer population.

There were two main types of support accessed:

- Main benefits such as Job Seeker Benefits and Supported Living Payments were received by over 2,600 individuals. These made up 60% of total benefits, with an average of $12,900 per person per year. In total, $33.8 million was allocated to main benefits.
- Supplementary benefits such as the Disability Allowance and Accommodation Supplement were received by over 14,100 individuals. These benefits averaged $1,600 per person per year and totalled $22.6 million in 2024.

A total of 2,480 people received both types of benefits, comprising 17.3% of the blood cancer beneficiary population.

1.7.2.2 Trends over time

Benefit access has grown significantly over the past decade. Figure 39 shows a marked increase in both the number of beneficiaries and the total amount of benefits distributed.

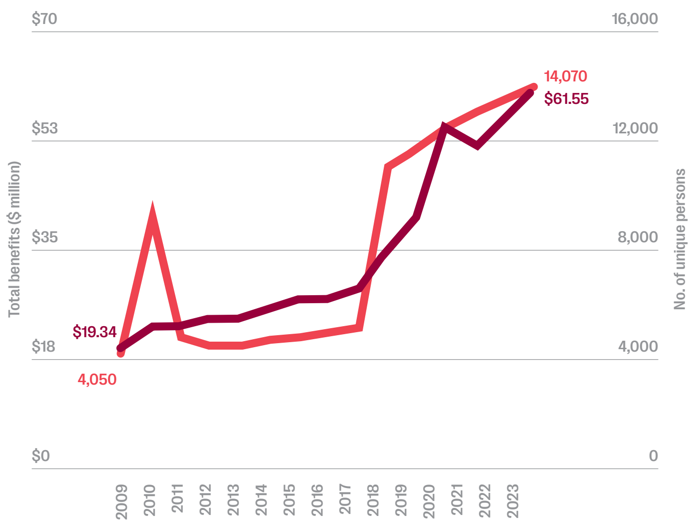


Figure 39
Number of beneficiaries and associated benefits distributed, 2009-2023
Source: Integrated Data Infrastructure

A sharp increase occurred in 2018, likely due to changes in the Benefit Product Suite 1 policy, which expanded intensive case management services for jobseekers with health conditions or disabilities from 8,000 to 20,000 individuals.

Although the proportion of blood cancer patients receiving main benefits (as per MSD definitions) has decreased from 70.8% in 1995 to 60% in 2024, the number of main benefit recipients increased by 43.3% between 2014 and 2024. Over the same period, average benefit amounts rose by 44.2%, resulting in a doubling of overall main benefit expenditure.

Supplementary benefits grew even more sharply. From 2014 to 2024, the number of recipients increased by 221.4%. Although the average payment decreased by 23.4%, total supplementary benefit payments increased by 146.1%.

Despite more people receiving some form of support, the proportion receiving both main and supplementary benefits dropped from 31.4% in 2014 to 17.3% in 2024. This points to a shift in benefit distribution patterns and could be due to changes in benefit eligibility criteria.

Although more people with blood cancer are receiving some form of financial support, fewer are now receiving both core income support and additional top-up payments at the same time. In practice, this means that while support is reaching more people, it is increasingly being provided through a single payment rather than a combination of benefits that help cover the full range of costs associated with serious illness.

The available data do not show whether people are better or worse off as a result of these changes. However, receiving only one form of support may increase the risk that some costs, such as disability related expenses, housing pressures, or ongoing care needs, may not be fully accessed.

It is also important to note that benefit amounts are reported in nominal dollars and are not adjusted for inflation. As a result, increases in total benefit spending over time reflect growth in the number of people receiving support and general price inflation, rather than a clear increase in the real value of financial assistance. Taken together, these trends suggest that while access to benefits has expanded, the level and structure of support may or may not be keeping pace with the real cost pressures faced by people living with blood cancer and their families.

1.7.2.3 Most commonly accessed benefits

The most accessed forms of support included:

- Job Seeker Benefits: Around 1,200 recipients (4.5% of the blood cancer population), totalling $9.9 million in 2024 with an average of $8,200 per person.
- Job Seeker Health Condition and Disability: Represented 15% of total benefits paid.
- Supported Living Payment for Health Conditions: Made up 32.4% of total benefits.
- Accommodation Supplement: Accounted for 15% of total benefits.

Additional forms of support such as the Disability Allowance and Winter Energy Payment were also widely accessed. In 2024, approximately 4,250 individuals received the Disability Allowance and 1,330 received the Supported Living Payment related to health conditions. Over the last decade, Supported Living Payments increased by 73.4%. The Disability Allowance rose more modestly, with a 6.8% increase between 2014 and 2024.

Social benefit use among people living with blood cancer has increased substantially in both scale and complexity. Shifting patterns reflect not only changes in policy and eligibility but also the growing need for financial support linked to the long-term impacts of cancer. These trends suggest an urgent need to align health, social, and income support systems more closely with the lived realities of people with blood cancer.

1.8 Current government level strategies and plans

Key findings

- **New Zealand lacks a dedicated blood cancer strategy, leaving haematology under-prioritised in national cancer planning.**
- **Optimal Cancer Care Pathways exist, but are not funded for implementation, limiting their impact.**
- **The Pharmac Reset Programme improves transparency but does not address funding constraints.**
- **Precision medicine and genomic infrastructure remain underdeveloped, hindering adoption of global best practice.**

There has never been a dedicated national strategy for haematology in New Zealand. Although government cancer frameworks have evolved over the past decade, they have done so primarily through a solid tumour lens. The absence of a blood cancer specific plan has meant that the distinctive needs of haematology patients have not been adequately reflected in national policy, workforce planning, service configuration, or investment decisions.

This gap provides the rationale for the State of Blood Cancer report, which examines where blood cancers sit within the current health system landscape and identifies the policy shifts required to achieve best practice care.

1.8.1 National direction for health and cancer

The Pae Ora (Healthy Futures) Act 2022 sets the architecture for national direction, including six Pae Ora strategies: the New Zealand Health Strategy, Pae Tū (Hauora Māori Strategy), Te Mana Ola (Pacific Health Strategy), the Health of Disabled People Strategy, the Rural Health Strategy, and the Women's Health Strategy. These strategies provide the statutory framework for how the health system should evolve.

The Government Policy Statement on Health 2024 to 2027 (GPS) then sets the Government's priorities, objectives, and expectations for a three-year period. It also determines the parameters for the New Zealand Health Plan, which is the costed operational plan that Health New Zealand uses to deliver publicly funded services in line with the GPS.

Cancer is identified as one of five priority conditions within the GPS. This includes a faster cancer treatment target: 90% of patients to receive cancer management within 31 days of the decision to treat.

To support delivery on these priorities, the Ministry of Health has developed the Health Implementation Plan. It sets out actions to operationalise the GPS and includes a specific action intended to reduce unwanted variation in access to cancer care. This includes increasing capacity for allogeneic stem cell transplantation at Auckland, Wellington, and Christchurch, recognising the importance of this service for patients requiring complex haematology treatment.

Outside of this single commitment relating to stem cell transplantation, blood cancers are not referenced explicitly in any of the foundational strategies or health plans. Given the complexity of haematological care and its reliance on coordinated, multi specialist pathways, blood cancers risk being underserved when embedded within broader oncology plans that do not account for their unique requirements.

The consequences of this policy gap are increasingly visible internationally. In March 2026, 35 expatriate New Zealand haematologists, researchers and clinicians working in leading cancer centres around the world wrote to the Government expressing deep concern about the widening divergence between blood cancer care in New Zealand and that available in comparable countries (Haematology Society of Australia and New Zealand, 2026).

The clinicians described a system that has fallen materially behind global standards, particularly in access to modern medicines and participation in international clinical trials. Many noted that the inability to practise with contemporary therapies and research infrastructure is discouraging expatriate specialists from returning to New Zealand, with those overseas deeply concerned about the care available to patients in their home country.

1.8.2 The role of the Cancer Control Agency

The Cancer Control Agency provides national leadership and oversight of cancer control in New Zealand.

National cancer policy in New Zealand has historically been structured around the cancer care continuum and the system-wide enablers that support it. These include prevention, screening, diagnosis, treatment, survivorship, palliative care, data and workforce, rather than planning by tumour stream.

This functional approach directs most planned activity toward prevention, screening and early detection. While these interventions are essential for improving outcomes in many solid tumours, they do not benefit blood cancer patients whose diseases are seldom preventable, screenable or identifiable earlier through symptom awareness. As a result, much of the emphasis of the Cancer Control Agency does not shift survival outcomes for people with blood cancers.

The key driver of improved survival for people with blood cancer is timely access to modern systemic therapies delivered by a specialised workforce. The Cancer Control Agency has developed a Systemic Anti-Cancer Therapy (SACT) Model of Care to support the safe and consistent delivery of systemic treatments across New Zealand. While this framework provides important guidance on service design, workforce capability and treatment delivery, it will not substantially improve outcomes for blood cancer patients unless clinicians have access to the medicines required to deliver contemporary care.

Similarly, the Cancer Control Agency has developed a Transplant and Cellular Therapies Model of Care to guide the delivery of complex treatments such as stem cell transplantation and emerging cellular therapies. These treatments require specialised clinical services, workforce capability and hospital infrastructure, meaning that effective implementation depends on coordinated health service planning and investment.

Taken together, these initiatives demonstrate a strong commitment to improving the structure and delivery of cancer services in New Zealand. However, the current policy architecture limits the Cancer Control Agency's ability to influence the factors that most directly determine outcomes for people with blood cancer. As a result, despite the scale of need among the approximately 27,000 New Zealanders living with blood cancer, many of the levers required to improve survival and quality of care remain beyond the scope of the Agency's current functions.

1.8.3 Optimal Cancer Care Pathways

The Cancer Control Agency has developed a suite of Optimal Cancer Care Pathways to define nationally consistent expectations for how cancer care should be delivered across New Zealand. They translate clinical best practice into guidance for providers, with a focus on improving coordination, timeliness and equity for people affected by cancer.

The OCCP model originated in Australia to establish national benchmarks for quality of care and reduce unwarranted variation across jurisdictions. In New Zealand, the pathways have been adapted to reflect local clinical context and the cultural dynamics of Aotearoa.

Sixteen OCCPs have now been published, including eight covering major blood cancers. For the first time, standard expectations exist for how timely diagnosis, staging, treatment, follow-up and supportive care should be delivered across the country for people with haematological malignancies.

While publication of the pathways is an important milestone, implementation remains variable. There are currently no dedicated resources, performance measures or accountability mechanisms to ensure that OCCP standards translate into consistent access to diagnostics, specialist services or modern systemic therapies. As a result, OCCPs risk functioning as guidance documents rather than operational levers for change, particularly where expectations exceed current system capacity.

1.8.4 Pharmac Reset Programme

Pharmac describes the Reset Programme as a five-year improvement initiative designed to reshape how the organisation interacts with the health sector and public. Its stated aims include enhancing clinician and consumer engagement, building stronger relationships with patient and community groups, improving transparency of decision making and strengthening trust. The programme also includes the establishment of a Consumer and Patient Working Group and new mechanisms to support stakeholder participation.

While these improvements may support better communication and process transparency, they do not address the primary barrier to timely access to modern cancer medicines in New Zealand. The greatest determinant of access is the level of funding available to Pharmac.

The Reset Programme is not designed to increase investment in medicines. As a result, it is unlikely to deliver the change required to improve outcomes for blood cancer patients who continue to face long delays for treatments that are already standard of care in comparable health systems.

1.8.5 Precision health, AI and genomics

The Ministry of Health describes precision health as an approach that tailors treatment and prevention strategies to the specific characteristics of individuals, incorporating factors such as genes, environment and lifestyle. The Ministry is developing a multi-year operational strategy in partnership with Health New Zealand that focuses on three key pillars. These are workforce and leadership, coordination of data and digital systems, and laboratory infrastructure. A future steering group is expected to guide implementation, supported by short term regional initiatives that can begin to build toward longer-term goals.

Progress has been limited. There is not yet a cohesive national genomics strategy for the health system, nor a funded plan for sequencing and infrastructure. Genomic data are also not systematically integrated into treatment-planning or Pharmac's evidence pipeline.

For blood cancer, this gap is particularly impactful. Precision medicine underpins the diagnosis, risk stratification and treatment selection of haematological malignancies. It also enables patients to be matched to appropriate clinical trials that provide access to novel targeted therapies and immunotherapies. Without an integrated genomics and data framework, New Zealand cannot fully adopt international best practice in targeted therapies, immunotherapies, cellular treatments or trial-based innovation for blood cancer.

In parallel, precision medicine depends on timely access to the therapies it identifies. Without a rapid and fit-for-purpose funding pathway for novel targeted and immune-based treatments, genomic insights cannot be translated into improved outcomes for patients. Precision medicine requires precision medicines.

1.8.6 Policy gaps and implications for blood cancer

Despite a maturing national policy framework for cancer, the mechanisms required to deliver improved outcomes for blood cancer remain absent.

Haematologists surveyed for this report unanimously disagreed or strongly disagreed that the government has clear policies, plans or direction for blood cancer. This reflects a sector-wide view that accountability, prioritisation and coordinated delivery are lacking for haematology.

Key gaps include:

- No dedicated haematology or blood cancer plan within national cancer strategies
- No funded implementation framework to ensure delivery against OCCP standards
- Limited investment in precision medicine, genomic capability and digital infrastructure
- Disconnect between the Cancer Control Agency, Health New Zealand and Pharmac regarding systemic therapy access and service commissioning

These gaps prevent New Zealand from achieving the improvements in survival that have been realised in comparable countries. They also leave patients reliant on individual advocacy, private funding or geographic luck to access modern blood cancer treatment and specialist care.

1.8.7 Summary

New Zealand has developed several national frameworks intended to improve cancer care. Pae Ora provides structure for system planning. The OCCPs set clinical expectations for care delivery. The Pharmac Reset Programme seeks to improve transparency and engagement. A precision health and genomics programme is being developed.

However, these frameworks do not guarantee that New Zealanders with blood cancer will receive care that reflects the best global standard. The most impactful drivers of improved survival for blood cancers including modern diagnostics, specialised expertise and access to contemporary systemic therapies are not consistently delivered or funded.

Closing this gap requires:

- Recognition of blood cancer as a defined priority area within national cancer planning and investment decisions
- Funded delivery of the haematology OCCPs
- Alignment of Pharmac's decision making with contemporary standards of care for blood cancers
- A coordinated plan for genomics, workforce and infrastructure that enables precision haematology
- Clear accountability for improving clinical outcomes for blood cancer patients

Until these elements are adopted, New Zealand will continue to fall behind comparable countries in achieving improvements in blood cancer survival.

2.

Assessing the effectiveness of New Zealand's blood cancer care system

2. Assessing the effectiveness of New Zealand's blood cancer care system

New Zealand's haematology services are designed to address the complex needs of individuals affected by blood cancer. Assessing the system's effectiveness involves a thorough examination of its performance against international best practice and its existing strengths and barriers to delivering best practice care. This is crucial for informing future healthcare policy, planning, and investment.

New Zealand's approach to blood cancer care falls materially behind international best practice. Limited access to modern medicines through Pharmac has left the system reliant on treatment options that do not meet contemporary clinical standards.

These constraints create significant challenges for both clinicians and patients. Clinicians can face moral distress and moral injury when required to deliver care that does not align with contemporary clinical standards (Dean et al., 2019), while patients and their families are often left to self-fund essential treatment. Where resources allow, patients may seek treatment offshore, highlighting both the financial burden imposed and the system's failure to retain care domestically.

These pressures are compounded by limited health insurance coverage for modern but unfunded medicines. As seen across all disease types, when the public system does not fund clinically appropriate treatment, there are no credible alternative pathways for access, leaving patients to bear the full cost themselves or go without care. This exposes a growing disconnect between lifelong tax contributions and the expectation that the health system will provide appropriate care when it is needed.

There are areas where New Zealand's health system demonstrates strong performance. In particular, children benefit from robust legislative protections under section 8(1)(b) of the Pae Ora (Healthy Futures) Act 2022 that support access to necessary medicines. However, these protections do not extend to adults or adolescents who face greater barriers to treatment access than children, resulting in age-based inequities in care.

Finally, the absence of access to standard-of-care treatments and the lack of a clear reimbursement pathway for clinically effective therapies limit New Zealand's ability to participate in international clinical trials. This reduces opportunities for patients to access innovative treatments and contributes to New Zealand's growing lag in research activity and clinical development.

The chapter is structured in four parts:

1. A review of global best practices, mapped to the patient journey.
2. A comparison of New Zealand's performance against global practice
3. A summary of areas where New Zealand excels, in spite of systemic constraints.
4. A review of barriers that currently prevent New Zealand from delivering the best global standard of care

2.1 Global best practice in blood cancer care

Key findings

- **International best practice prioritises timely diagnosis, risk-adapted treatment, and coordinated multidisciplinary care, supported by rapid access to genomic testing, molecular profiling, and radiology.**
- **Access to medicines is foundational. In high-performing health systems, funding decisions are aligned with established clinical guidelines, including NCCN, ESMO, and ASCO.**
- **Clinical trials are embedded within routine care, with the infrastructure and workforce required to support consistent patient participation.**
- **Survivorship and palliative care are integrated into standard care models, ensuring patients receive appropriate psychosocial, functional, and supportive care throughout the disease trajectory.**

New Zealand's blood cancer care system is central to the outcomes and quality of life experienced by people diagnosed with blood cancers. Yet across the patient journey, evidence suggests that the current system is fragmented, under-resourced, and falling behind global peers.

Determination of global best practice draws on expert clinician feedback and benchmarks from leading international frameworks including the National Comprehensive Cancer Network (NCCN), the European Society for Medical Oncology (ESMO), and the American Society of Clinical Oncology (ASCO). These frameworks define what constitutes high-quality, evidence-based cancer care across diagnosis, treatment, and survivorship.

2.1.1 Diagnosis and referral

The NCCN, ESMO, and ASCO promote an integrated diagnostic model that includes:

- Morphological examination
- Flow cytometry
- Cytogenetic testing (e.g., karyotyping, FISH)
- Molecular or genomic profiling

Radiology is also a core component of the diagnostic pathway for many blood cancers. Imaging modalities such as CT, MRI, and PET or PET-CT are essential for accurate staging, assessment of disease burden, and evaluation of treatment response. PET scanning is particularly important for lymphoma and myeloma, where metabolic imaging can be more informative than genomic or measurable residual disease testing.

This approach helps define the specific disease subtype, assign risk status, and guide personalised treatment decisions. Risk stratification incorporates clinical, pathological, cytogenetic, and molecular factors to determine prognosis, treatment intensity, clinical trial eligibility, transplant suitability, and monitoring through measurable residual disease (MRD) testing (European Society for Medical Oncology, 2023; National Comprehensive Cancer Network, 2024)

The WHO's 5th Edition Classification serves as the global diagnostic taxonomy. It integrates histopathology, immunophenotyping, cytogenetics, and molecular findings to standardise blood cancer diagnoses internationally (World Health Organization, 2024; Li W., 2022).

For plasma cell neoplasms, clinicians typically rely on criteria developed by the International Myeloma Working Group for diagnosis, staging, and risk assessment. The IMWG framework incorporates clinical features, biomarkers, imaging findings, and laboratory measures to determine disease stage, progression risk, and treatment urgency. WHO classification provides the overarching disease categorisation, while IMWG criteria guide how these conditions are diagnosed and managed in practice.

Reflex genomic testing is increasingly performed at the time of diagnosis, particularly for high-risk or ambiguous cases. In many settings, turnaround times for essential molecular testing are expected within 7–10 days. While not yet standard across all regions, this approach is gaining traction in high-performing systems.

Accurate and reproducible diagnosis is enabled through centralised or networked haematopathology services, access to subspecialist haematopathologists, standardised diagnostic reporting, and robust external quality assurance processes (WHO, 2024).

Guidelines from NCCN, ASCO, and ESMO emphasise the importance of multidisciplinary team input at the point of diagnosis. MDTs often include haematologists, oncologists, pathologists, nurse specialists, psychologists, palliative care experts, and social workers. Multidisciplinary review is considered essential to ensure that each case benefits from collective clinical judgment before initiating therapy (American Society of Clinical Oncology, 2024; National Comprehensive Cancer Network, 2024).

Many national systems have established defined timelines for diagnostic testing and treatment initiation to promote equity of care. Care coordinators or patient navigators help manage complex transitions, assist with appointments and referrals, and ensure that patients and families remain supported throughout the process.

2.1.2 Treatment access

International guidelines highlight that timely access to risk-adapted therapy, delivered through multidisciplinary teams and specialist centres, is critical to achieving optimal outcomes for people with blood cancer.

NCCN (2024), ESMO (2023), and ASCO (2024) emphasise that access to novel and potentially curative therapies is a marker of health system performance. Delays in treatment directly impact both survival and quality of life (American Society of Clinical Oncology, 2024; European Society for Medical Oncology, 2023; National Comprehensive Cancer Network, 2024).

2.1.2.1 Specialist procedures

Stem cell transplantation (SCT) and advanced cellular therapies are among the most complex and potentially curative treatments for blood cancers. Their effectiveness depends on delivering treatment within defined timeframes, supported by data reporting systems that track referral-to-treatment intervals, early mortality, and long-term outcomes.

Stem cell transplant

SCT replaces diseased bone marrow with healthy stem cells to restore normal blood and immune function.

- Autologous SCT reinfuses a patient's own stem cells after high-dose chemotherapy, most commonly in myeloma and some lymphomas to prolong remission.
- Allogeneic SCT uses donor cells and is potentially curative in conditions like acute leukaemia and myelodysplastic syndromes through an immune-mediated graft-versus-leukaemia effect.

Both are highly time-sensitive and require coordinated planning between haematology, transplant, and donor registry teams.

- Autologous SCT: High-performing systems complete transplantation within 6–8 weeks of the treatment decision (American Society of Clinical Oncology, 2024; National Comprehensive Cancer Network, 2024).
- Allogeneic SCT: For high-risk acute leukaemia, the goal is 6–8 weeks from eligibility confirmation to transplant, and within 12 weeks for other curative indications (National Comprehensive Cancer Network, 2024). Centres should maintain capacity to deliver transplants within three months to avoid increased relapse and mortality risk (European Society for Medical Oncology, 2023).

Post-transplant care is an equally critical part of the pathway. Management of complications such as graft-versus-host disease often requires specialised therapies, including ruxolitinib and extracorporeal photopheresis, alongside intensive multidisciplinary follow-up.

Cellular therapies

Cellular therapies, such as CAR T-cell therapy, have transformed treatment for patients with relapsed or refractory lymphoma, leukaemia, and myeloma. These therapies engineer a patient's own immune cells to attack malignant cells.

CAR T-cell therapy is now standard care in many high-income countries. Guidelines recommend immediate referral once relapse is confirmed, with apheresis ideally within 2–3 weeks and infusion within 4–6 weeks (American Society of Clinical Oncology, 2024; European Society for Medical Oncology, 2023; National Comprehensive Cancer Network, 2024). Delays reduce treatment eligibility and survival.

Optimal systems coordinate logistics, manufacturing, and post-infusion monitoring. Accredited centres manage both clinical delivery and cellular manufacturing and include multidisciplinary teams for toxicity management and data reporting to international registries.

2.1.2.2 Medicines access

For most people with blood cancer, access to the right medicine at the right time determines whether remission is durable or relapse occurs. The ability of a health system to deliver these treatments quickly and consistently is a key marker of best practice.

NCCN, ESMO, and ASCO publish evidence-based clinical practice guidelines that define the standard of care for each major blood cancer subtype. These guidelines outline the recommended therapeutic options based on efficacy, safety, and quality of evidence, and serve as international reference points for evaluating national treatment practices.

Many countries use these clinical practice guidelines as a benchmark for defining evidence-based standards of care. Funding and reimbursement decisions are then informed by national Health Technology Assessment (HTA) processes, which often evaluate the clinical benefit, cost-effectiveness, and budget impact of new medicines in the context of those standards.

Medicines are widely recognised as a cornerstone of efficient and equitable healthcare, and many countries set investment levels to reflect their central role in improving outcomes. An effective HTA system defines the value that an intervention offers a population and guides timely funding decisions. Divergence from international guidelines in national formularies may signal weaknesses in HTA or funding mechanisms.

Efficient systems align evidence-based guidelines with HTA decisions and public funding. Continuous review and horizon-scanning mechanisms help minimise delays between regulatory approval and clinical use, supported by early-access and compassionate-use programmes that bridge interim gaps.

2.1.2.3 Clinical trials and research

Globally, best practice considers clinical trials as a standard component of optimal care rather than an optional adjunct. All eligible patients are assessed for trial enrolment at the time of treatment planning, with clear referral pathways between centres.

In optimal settings, dedicated infrastructure supports both industry-sponsored and investigator-initiated studies, including research nurses, data managers, and ethics coordination. National registries or coordinating offices maintain visibility of open trials and facilitate equitable participation across regions. Health services also require infrastructure to support patient enrolment into clinical outcome registries that capture real-world data on diagnosis, treatment patterns and outcomes. These registries are an essential complement to clinical trials, enabling continuous evaluation of care and supporting evidence generation for emerging therapies.

Participation in international cooperative groups is encouraged to expand access to novel therapies and ensure national data contribute to global evidence generation.

Clinical trial activity also plays a critical role in developing and retaining skilled staff, embedding research capability across clinical teams, and strengthening readiness to deliver new treatments once approved.

2.1.3 Survivorship, supportive, and palliative care

International guidelines view survivorship and palliative care as interconnected elements of a continuous care pathway, with supportive interventions starting at diagnosis and extending across treatment, remission, or end of life.

High-performing systems offer structured survivorship planning for all individuals diagnosed with blood cancer. ASCO guidelines highlight the need for individualised care plans that address late effects, coordinate follow-up between oncology and primary care, and support both psychosocial and functional recovery (American Society of Clinical Oncology, 2024). Dedicated survivorship or late-effects clinics coordinate multidisciplinary input and provide continuity between hospital and community settings, involving allied health professionals such as psychologists, physiotherapists, dietitians, and social workers to manage the long-term consequences of cancer and its treatment.

Palliative care is integrated early and consistently throughout the treatment course. Palliative care teams are embedded within haematology and oncology services, contributing to multidisciplinary reviews and therapeutic planning. Advance care planning is initiated early and updated over time to ensure care remains consistent with the patient's evolving values, goals, and clinical needs.

At the system level, international best practice includes national models of care that link survivorship and palliative services, as well as standardised referral pathways and outcome tracking. This includes data collection on quality of life and symptom burden.

Together, these elements help ensure that patients and families receive coordinated, comprehensive support across the continuum – from diagnosis through survivorship or, when needed, palliative and end-of-life care.

2.2 Understanding New Zealand's Performance Against Global Standards

Key findings

- **New Zealand has a highly skilled haematology workforce that delivers strong clinical care within existing resource constraints.**
- **Despite this capability, there is no dedicated, system-level plan for haematology, nor the sustained investment required to implement one, resulting in performance that falls short of international standards.**
- **Diagnostic pathways are fragmented, with uneven access to advanced testing and prolonged turnaround times.**
- **Access to medicines lags behind comparable countries, constraining improvements in outcomes and limiting eligibility for international clinical trials.**
- **Survivorship and palliative care services are underdeveloped and inconsistently available, with the greatest gaps evident outside major centres.**

New Zealand delivers high-quality clinical care and benefits from a skilled haematology workforce, strong professional networks, and growing collaboration across the cancer sector. Many services are aligned with international guidelines in intent and philosophy.

However, variation in access, fragmentation between regions, and slower adoption of new therapies and technologies limit full alignment with best practice.

In a clinician survey that included 21 haematologists, none of the haematologists indicated that New Zealand was fully aligned with international best practices in blood cancer care.

> **"One of the fundamental problems is that it is very hard to be a haematologist in NZ at the moment – we are constantly telling patients we cannot provide them with funded treatment considered standard of care anywhere else in the developed world."**
>
> **- Haematologist**

This section outlines areas where performance diverges from global standards. Subsequent sections outline the areas where New Zealand already demonstrates strengths and the barriers that must be addressed to achieve best practice consistently nationwide.

2.2.1 Diagnosis and referral

Accurate and timely diagnosis relies on well-coordinated pathways that connect primary care, hospital-based services, specialist review, and laboratory diagnostics. In New Zealand, these components operate with variable integration, leading to regional differences in timeliness, quality, and access to advanced testing.

2.2.1.1 Governance and consistency

Diagnostic governance in New Zealand currently shows significant variation. Coordination between primary care, hospitals and laboratory services differs by region, and access to advanced testing remains inconsistent due to a lack of uniformly applied national standards and oversight.

Around three-quarters of pathology testing capacity is provided by commercial laboratories under regional contracts, with limited national oversight or alignment of quality standards. This structure has contributed to duplication, siloed data systems, and variation in turnaround times.

Advanced haematopathology, cytogenetic and molecular testing are principally provided in tertiary centres, with many smaller hospitals relying on external referrals. A formal national quality-assurance framework and unified clinical governance structure across the diagnostic pathway remains incomplete in New Zealand, contributing to variation in access and standardisation.

The New Zealand Institute of Medical Laboratory Science (NZIMLS) and sector leaders have long advocated for a national governance structure to oversee diagnostic services, set turnaround-time expectations, and promote equitable access. Health New Zealand has since confirmed plans to establish a National Pathology Clinical Network and Governance Group, acknowledging workforce and capacity challenges within the sector.

2.2.1.2 Workforce and turnaround times

The pathology workforce remains under significant strain. Persistent shortages of scientists, technicians, and haematopathologists contribute to service delays, with many laboratories operating below safe staffing levels. Heavy reliance on overseas recruitment, limited training placements, and lack of structured career progression compound these pressures.

Turnaround times for pathology and genomic testing are frequently measured in weeks rather than days. These delays stem from under-resourced laboratories, aging equipment, and the transport of samples between facilities because of fragmented contracting arrangements.

2.2.1.3 Reform momentum

The proposed National Pathology Governance Group and emerging Clinical Network provide the structural foundation for standardising diagnostic processes, turnaround-time expectations, and referral protocols.

At the same time, Health New Zealand is leading work on a national precision health agenda that focuses on genomics, artificial intelligence, and personalised diagnostic pathways. This work aims to develop a precision health strategy that better integrates molecular diagnostics into clinical decision-making and ensures equitable access across regions.

Embedding this leadership, alongside investment in workforce training, technology, and equitable access to molecular diagnostics, will be essential to aligning New Zealand's diagnostic capacity with global best practice.

> **"We need a national strategy on diagnostic genetics and more funding for gold standard genetic testing and improved imaging technologies."**
>
> **- Haematologist**

2.2.2 Treatment access

Access to treatment for New Zealanders with blood cancer remains significantly out of step with global best practice. Despite international advances in precision medicine, immunotherapy, and cellular therapy, underinvestment and fragmented policy attention across the health system have left haematology largely overlooked.

Several oncology initiatives have prioritised solid tumours, resulting in funding, infrastructure, and workforce decisions that fail to meet the complexity and pace of change in blood cancer treatment.

The result is a system in which standard-of-care therapies are available only to a limited number of patients through private funding or medical migration, while many evidence-based options recommended by NCCN, ESMO, and ASCO remain unfunded or delayed by years.

Insufficient national planning, underinvestment, and workforce pressures, together with limited system-level coordination, limit access to specialist procedures such as stem cell transplantation and advanced cellular therapies.

Blood cancer clinicians consistently describe the gap between what is clinically possible and what is publicly available as widening. Addressing this imbalance requires a nationally coordinated approach to treatment planning, distinct prioritisation of haematology within oncology policy, and investment that aligns with global standards of care.

> **"[We need to] Improve access to and availability of effective specialist clinical and supportive care. Develop National paediatric oncology Standards of care. Allocated practitioners for national guideline development, maintenance, and practitioner education support and delivery"**
>
> **- Clinical Nurse Specialist**

2.2.2.1 Specialist procedures

Stem cell transplant

New Zealand's capacity for stem cell transplant continues to fall short of global standards. Long waitlists result in delays that can reduce survival, increase relapse risk and cause avoidable harm by forcing patients to undergo additional cycles of toxic chemotherapy while awaiting transplant. Avoidable death is the most serious consequence of these delays.

Transplant services are delivered through three allogeneic centres (Auckland, Wellington and Christchurch) and two additional autologous centres (Waikato and Palmerston North). Starship Children's Hospital delivers timely transplant care for paediatric patients, but adult waitlists have grown steadily, and many patients wait beyond clinically safe timeframes.

For more than a decade, reviews have identified chronic underinvestment, limited workforce capacity and inadequate national planning. The national Model of Care for Transplant and Cellular Therapy Services in Aotearoa New Zealand (2023) acknowledged the harm caused by prolonged waitlists and described the attributes of an optimal and equitable service.

In response, in November 2025 the government announced significant investment to expand stem cell transplant capacity across all three adult centres, including new inpatient transplant beds in Auckland, Wellington and Christchurch over the next three years (New Zealand Government, 2025).'. This $27 million expansion is intended to increase throughput, reduce wait times and improve national consistency of access.

Clinicians report that extended waits now require many patients to receive additional chemotherapy cycles, which carry cumulative toxicity and increased risk of death. The new investment will lift capacity, but the current backlog means delays and associated harm will persist until national capacity is able to meet demand.

Demand for transplant is projected to rise by up to 50% by 2030. Meeting this need will require a fully funded and nationally coordinated service. Clinical service planning, workforce development and transparent reporting of wait time and harm metrics are essential to deliver timely treatment for all New Zealanders who require stem cell transplant.

Cellular therapies

In New Zealand, CAR T-cell therapy remains largely unavailable outside limited clinical access arrangements. The Malaghan Institute and BioOra partnership has established the country's first domestic CAR T manufacturing capability and is leading the ENABLE clinical trial programme for relapsed and refractory blood cancers. The initiative demonstrates that New Zealand sites can safely deliver CAR T-cell therapies.

Patients outside the trial must still travel overseas at personal cost or go without, reinforcing inequities in access to curative therapies.

2.2.2.2 Medicines access

New Zealand's overall expenditure on medicines remains among the lowest in the OECD. Pharmac operates within a fixed and tightly constrained budget, which limits both the number of medicines that can be funded and the speed at which funding decisions can be made. This structure can create incentives to prioritise medicines with lower upfront costs even when more effective treatments are available internationally.

Blood cancer patients are particularly affected by this dynamic because many modern therapies are targeted treatments developed through recent scientific advances. These therapies often involve higher upfront costs but can deliver substantial gains in survival, quality of life, and reduced healthcare utilisation over time

The Cancer Control Agency's 2024 report Understanding blood cancer medicine availability in Aotearoa New Zealand provided the first systematic comparison of publicly funded blood cancer medicines between New Zealand and Australia (Te Aho, 2024). The analysis identified 24 blood cancer medicines funded in Australia but not in New Zealand, representing 42 medicine–indication pairs and 37 regimen–indication pairs. Of these, 12 medicine–indication pairs were assessed as providing substantial clinical benefit using the European Society for Medical Oncology Magnitude of Clinical Benefit Scale for Haematological Malignancies (ESMO-MCBS:H).

The use of the ESMO framework has an important limitation in this context. The scale was developed to assess the magnitude of clinical benefit at the time of medicine registration based on registrational clinical trial data. In New Zealand, however, medicines are typically assessed for funding several years after regulatory approval. By the time funding decisions are considered, the evidence base has often evolved substantially through longer follow-up data, additional clinical trials, and real-world evidence. Applying a framework designed for use at the time of registration therefore risks underestimating the clinical benefit of medicines that have subsequently demonstrated improved survival outcomes in clinical practice. As a result, the number of medicines offering meaningful benefit to New Zealand patients is likely to exceed the subset identified in the Cancer Control Agency analysis.

In response to growing concern about access to medicines, the Government provided Pharmac with a $604M funding uplift over four years in Budget 2024. This enabled the funding of 33 cancer medicines, including six medicines relevant to blood cancers. Although presented as a major investment in cancer treatment, the direct impact for blood cancer patients has been relatively modest. Several of the funded medicines were generic therapies or indicated for small patient populations, meaning that the most significant areas of unmet need remain unresolved.

Disease type	Medicines funded in Australia but not New Zealand	Implications for NZ patients and the health system
Acute myeloid leukaemia	· Gilteritinib · Oral azacitidine (maintenance therapy) · CPX-351 (liposomal daunorubicin + cytarabine) · Decitabine + cedazuridine (INQOVI)	Patients lack access to targeted therapies, maintenance treatments and specialised regimens used internationally. This limits treatment personalisation, increases reliance on intensive chemotherapy and reduces opportunities to prolong remission or bridge to stem cell transplantation.
Acute lymphoblastic leukaemia	· Blinatumomab · Tisagenlecleucel (CAR T-cell therapy)	Limited access to immune-based therapies reduces the likelihood of achieving deep remissions in relapsed disease. Patients are more likely to receive intensive salvage chemotherapy with greater toxicity and lower response rates.
Chronic myeloid leukaemia	· Asciminib · Ponatinib · Nilotinib (first-line) · Dasatinib (first-line)	Restricted access to newer and first-line tyrosine kinase inhibitors limits treatment optimisation from diagnosis and reduces options for managing resistance or intolerance.
Chronic lymphocytic leukaemia	· Acalabrutinib · Idelalisib	Patients with relapsed disease have fewer targeted treatment options, limiting therapy sequencing and personalised treatment pathways that extend remission duration.
Non-Hodgkin lymphoma	· Acalabrutinib · Zanubrutinib · Polatuzumab vedotin · Axicabtagene ciloleucel (CAR T-cell therapy) · Tisagenlecleucel (CAR T-cell therapy)	Absence of modern targeted and cellular therapies limits effective treatment for relapsed disease and restricts access to potentially curative options such as CAR T-cell therapy.
Multiple myeloma	· Daratumumab · Carfilzomib · Selinexor · Elranatamab	Patients exhaust funded treatment options earlier than international peers, limiting depth and durability of response and reducing survival gains seen in countries with broader access to novel therapies.
Myeloproliferative neoplasms	· Momelotinib · Ruxolitinib (polycythaemia vera)	Patients have fewer targeted treatment options when existing therapies fail, limiting symptom control and management of disease complications.
Myelodysplastic syndromes	· Decitabine + cedazuridine (INQOVI)	Lack of oral therapy increases reliance on intravenous treatment and hospital visits, adding to treatment burden for patients and the health system.
Graft-versus-host disease	· Ruxolitinib	Patients with steroid-refractory graft-versus-host disease have limited treatment options, increasing the risk of ongoing complications following stem cell transplantation.

Table 12
Selected blood cancer medicines funded in Australia but not New Zealand and implications for patients
Note: Table summarises selected medicines funded through Australia's Pharmaceutical Benefits Scheme that are not publicly funded in New Zealand at the time of analysis. It does not represent a complete formulary comparison.

Since the publication of the Cancer Control Agency report, the international treatment landscape has continued to evolve. New medicines and expanded indications have been funded overseas, including through Australia's Pharmaceutical Benefits Scheme. While New Zealand has funded a small number of additional therapies, the overall difference in medicine availability between New Zealand and Australia has not narrowed in a sustained way and in some areas has widened.

Comparison of the Australian and New Zealand formularies[1] as at March 2026 shows that Australia funds a broader range of targeted therapies across most major blood cancer types, particularly for relapsed or treatment-resistant disease (Table 12).

Australia itself represents a relatively conservative benchmark for international comparison. Many other high-income countries provide access to a broader range of blood cancer medicines through national health systems, including newer targeted therapies, bispecific antibodies and cellular therapies. Patients in countries such as the United States, Germany, France and the United Kingdom therefore have access to additional treatment options that can extend survival or provide further opportunities for remission.

Limited access to modern therapies also has wider system implications. It reduces opportunities for participation in international clinical trials and contributes to clinician and patient migration overseas in search of treatment options.

Closing the blood cancer medicine gap will require structural reform of the current assessment and funding system and a commitment to align medicine investment more closely with international peers.

The implications of these treatment differences become clearer when examining survival outcomes, as described in Section 2.2.4.

2.2.2.3 Clinical trials and research

Clinical trial activity in New Zealand has declined over the past decade, reflecting both commercial and structural barriers. While regulatory and ethics requirements are relatively streamlined compared with other countries, the absence of a clear pathway from trial participation to reimbursement makes New Zealand a less attractive destination for industry-led studies. Limited exposure to standard-of-care therapies also means that many New Zealand patients no longer meet eligibility criteria for global clinical trials, further reducing opportunities for participation and collaboration.

Investigator-initiated research faces additional structural barriers. Underinvestment in research infrastructure, limited availability of trial coordinators and data managers, and the absence of protected research time within many clinician job plans restrict the ability of haematologists to lead or sustain academic studies. Clinical trial units within public hospitals also face increasing pressure to operate on a cost-recovery basis, limiting their ability to support investigator-led research and reducing flexibility to open complex early-phase or cooperative group studies.

In many centres, clinicians carry full clinical workloads with no dedicated research FTE, limiting participation in trials and contributing to the loss of research-active clinicians overseas. Research is not consistently treated as core business within Health New Zealand hospitals, and despite ongoing work to establish a national Research and Innovation Network, coordinated oversight and infrastructure remain limited. Without a centralised registry of open studies, visibility of available trials is low and patient access varies considerably across the country.

Participation in trans-Tasman cooperative groups is also constrained. The Australasian Leukaemia and Lymphoma Group (ALLG) remains the primary investigator-initiated trials network for blood cancers across Australia and New Zealand. Most haematologists treating blood cancer in New Zealand are members of the ALLG and express strong interest in providing clinical trial opportunities for their patients. However, the lack of access to internationally recognised standard-of-care therapies, combined with limited research infrastructure within clinical trial units, means that many New Zealand sites are unable to open trials even when investigators are willing to participate.

Historically, New Zealand participation has relied heavily on trial coordination and infrastructure funded through Australian programmes such as the National Health and Medical Research Council and the Medical Research Future Fund. New Zealand receives proportionally less support from the Health Research Council of New Zealand, limiting local capacity to open, deliver, and sustain ALLG trials. This reduces access to emerging therapies and narrows opportunities for clinicians to contribute to the academic research ecosystem.

Recent data from ALLG further illustrate the volatility of clinical trial activity across New Zealand hospital sites. Aggregated across twelve participating centres, the number of blood cancer trials registered has fluctuated markedly in recent years, as shown in Table 13.

Year	Clinical trial registrations
2021	15
2022	41
2023	37
2024	33
2025	3

Table 13
New Zealand sites participating in ALLG trials
Source: ALLG

The sharp decline observed in 2025 highlights the fragility of the current system and the dependence of trial activity on infrastructure capacity, funding availability, and alignment with international trial requirements.

"[We need] more investment in blood cancer research for better treatments ... [and] include diverse groups in clinical trials to ensure treatments work for all"

- Clinical Nurse Specialist

Historically, clinical research has been an important pathway for early access to new therapies and for building clinical capability in advanced treatments. Health New Zealand's planned Research and Innovation Network presents an opportunity to strengthen national coordination, expand trial capacity, and integrate research into routine clinical care. Realising that potential will require parallel investment in workforce, infrastructure, and policy settings that connect research participation with timely access to funded therapies.

2.2.3 Survivorship, supportive and palliative care

Survivorship and supportive-care services remain variable and under-developed across New Zealand. Access to post-treatment support, rehabilitation, and palliative care differs by cancer type and region, with many patients lacking structured survivorship planning or coordinated follow-up. Integration between specialist haematology and palliative-care teams is inconsistent, and demand for community-based palliative services continues to outstrip capacity, particularly outside major centres.

Palliative care in New Zealand is undergoing reform to address long-recognised fragmentation, workforce shortages, and inequities in access. The Proposed National Model for Integrated Adult Palliative Care (Health New Zealand, 2025) notes that around two-thirds of people currently receive palliative care through generalist services such as general practice, aged residential care, or hospitals, while only one-third receive specialist input. Demand for both types of care is projected to almost double by 2053, as annual deaths increase from 36,000 to 63,000.

The model emphasises early intervention, coordinated multidisciplinary support, and seamless transitions between primary and specialist services, yet acknowledges that capacity remains uneven and workforce shortages continue to undermine equity.

For people with blood cancers, these challenges are particularly pronounced. Specialist haematology and palliative-care services are concentrated in tertiary centres, leaving those in regional and rural areas with limited access to timely, coordinated care.

The proposed national model marks an important step toward consistent, person-centred palliative care across New Zealand. It seeks to achieve timely, coordinated, and compassionate support wherever people live. The model prioritises early integration of palliative care, stronger collaboration between generalist and specialist providers, and smoother transitions across care settings. Its success will depend on sustained investment so that palliative care is resourced as a core function of the health system, not a peripheral service.

[1] Formularies are authoritative lists of medicines that guide which medicines are recommended, subsidised, and how they should be used.

2.2.4 International survival benchmarking

Five-year survival, defined as the proportion of patients alive five years after diagnosis, is one of the most widely used indicators of health system performance in cancer care. For blood cancers, survival outcomes reflect a combination of factors including timely diagnosis, access to effective therapies, and the availability of coordinated specialist services.

The CONCORD programme is the world's largest international comparison of population-based cancer survival. The most recent published analysis, CONCORD-3, includes five-year survival data for a subset of haematological malignancies across many countries (Allemani, 2018). These estimates are derived from cancer registry data covering diagnoses between 2000 and 2014. As a result, the findings largely reflect treatment patterns and health system performance more than a decade ago.

This lag is unavoidable in international survival studies. Reliable five-year survival estimates require long follow-up periods and extensive validation of registry data across multiple jurisdictions. The coordination required to harmonise classification systems, validate datasets, and standardise analytical methods across hundreds of registries means that global survival comparisons inevitably reflect historical treatment environments rather than contemporary clinical practice.

CONCORD-3 reported that survival outcomes for blood cancers in New Zealand were broadly similar to those in other developed countries during the period examined. However, these findings do not capture major changes in treatment paradigms that have occurred over the past decade. Advances such as targeted therapies, CAR T-cell therapy, and novel immunotherapies have substantially improved outcomes for many blood cancers in health systems where these treatments are widely available.

Given the limitations in the timeliness of global survival datasets, this report uses Australia as the primary international comparator for New Zealand.

Australia provides a particularly appropriate benchmark because the two countries share many structural similarities, including:

- comparable population demographics
- similar health system structures and coverage models
- closely aligned clinical training pathways and professional networks
- similar cancer registry methodologies

Australian cancer data is comprehensive, consistently reported and publicly accessible. Importantly, survival analyses from the Australian Institute of Health and Welfare extend closer to the present day than global datasets such as CONCORD, enabling a more meaningful assessment of relative system performance while maintaining a high degree of methodological comparability.

Both New Zealand and Australia publish five-year survival estimates for major blood cancer types, although the statistical methods used differ slightly. New Zealand reports net survival using a period-based approach, which estimates current survival based on mortality patterns observed in the most recent calendar period. Australia reports relative survival for cohorts of patients diagnosed within specific years.

Although these methods are not identical, both aim to estimate the proportion of patients who survive at least five years after a cancer diagnosis while adjusting for deaths from other causes. The resulting figures can therefore be interpreted as broadly reflecting contemporary survival outcomes in each country. They are best used to illustrate the overall direction and relative position of survival outcomes rather than precise point-to-point differences.

Across all major blood cancers, Australia currently reports higher five-year survival rates than New Zealand, as shown in Figure 40.

Cancer type	New Zealand	Australia
Leukaemia	57.7%	66.4%
Hodgkin lymphoma	80.2%	88.6%
Non-Hodgkin lymphoma	68.4%	77.4%
Myeloma	58.9%	60.7%

Table 14
Five-year survival for selected blood cancers in New Zealand and Australia, latest available estimates (up to 2021)
Sources: New Zealand: Net survival at 5-years (2020-2021 period estimate) from State of Cancer dashboard, available at: https://minhealthnz.shinyapps.io/state_of_cancer/
Australia: Relative survival (2017-2021 diagnoses) from Australian Institute of Health and Welfare (AIHW), available at https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/survival
Note: New Zealand estimates use net survival calculated, while Australian estimates use relative survival. These measures are conceptually similar but not directly equivalent and are best interpreted as directional rather than exact comparisons.

When examining survival trends over time, a consistent pattern emerges. Survival outcomes in Australia (Figure 40) have improved more rapidly and reached higher levels than in New Zealand (Figure 41) across all major blood cancers. While New Zealand has made progress over the past two decades, improvements have been slower and more variable.

Key observations include:

- Australia reports higher five-year survival across all major blood cancers in every time period
- New Zealand has achieved gradual improvements, but progress has been slower and less consistent
- The survival gap between the two countries has widened over time, suggesting divergent system performance
- Hodgkin lymphoma survival remains consistently high in Australia, while New Zealand shows greater variability
- Myeloma survival has improved in both countries, although gains occurred earlier and more rapidly in Australia
- Leukaemia survival has improved more slowly in New Zealand, with Australia achieving substantially higher outcomes in recent periods.

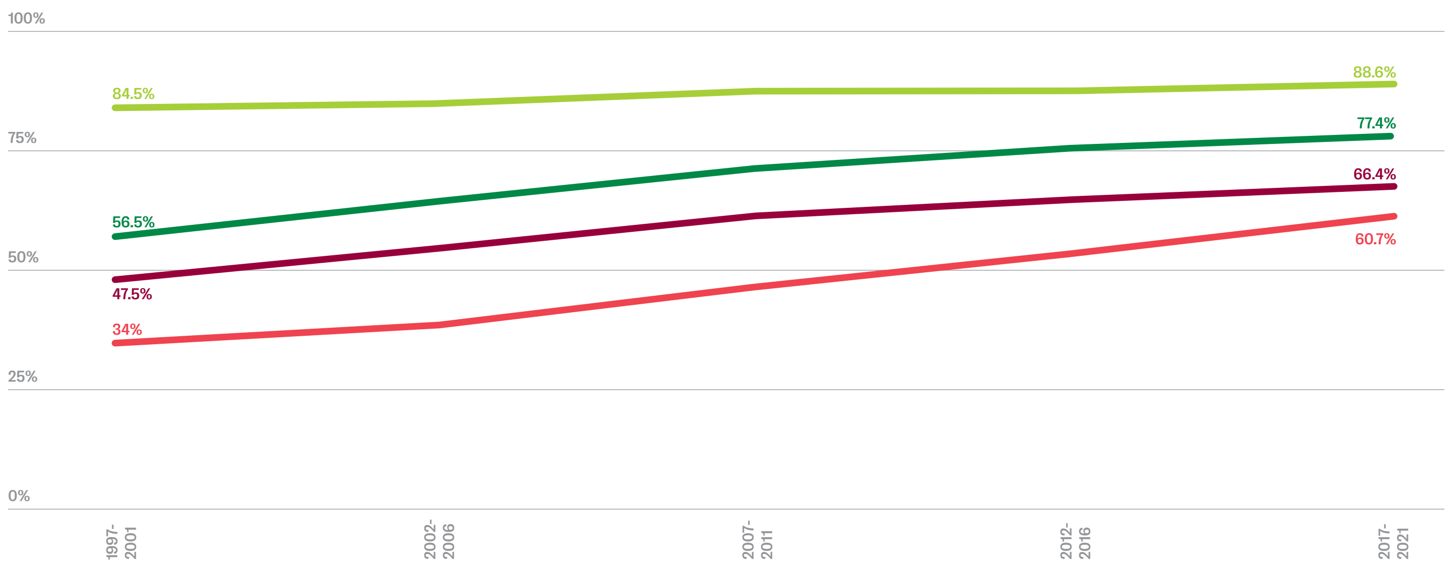


Figure 40
Australian five-year survival estimates for select blood cancers, 1997 through to 2021
Source: Relative survival from Australian Institute of Health and Welfare (AIHW), available at https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/survival

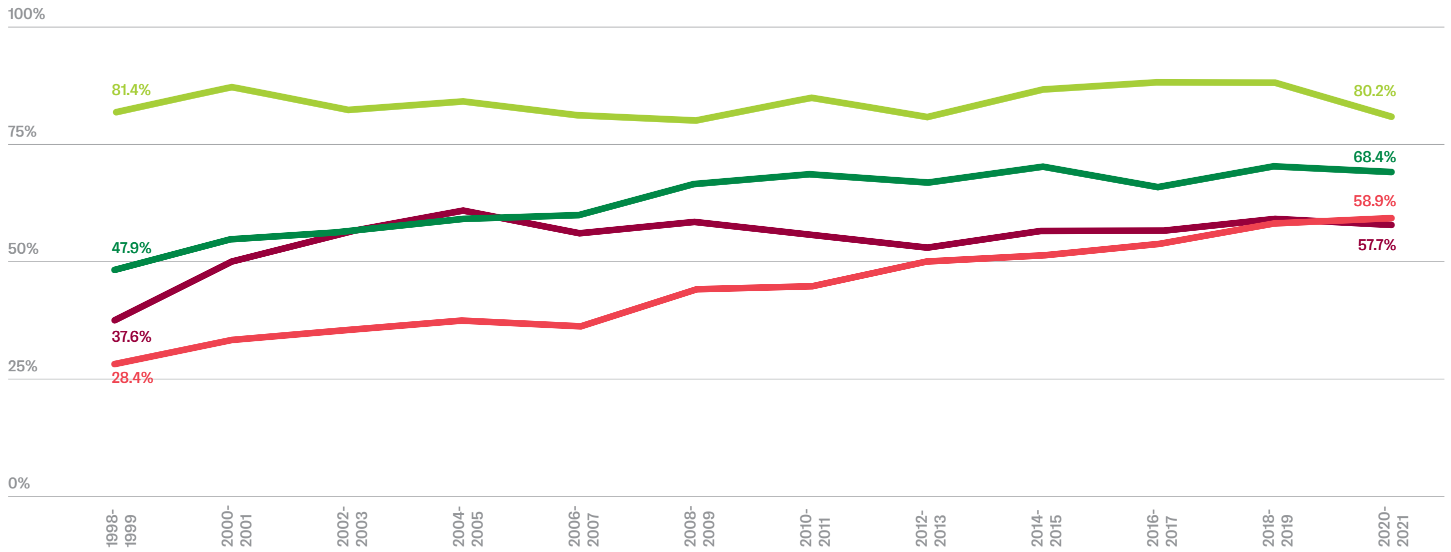


Figure 41
New Zealand five-year survival estimates for select blood cancers, 1998 through to 2021
Source: Net survival at 5-years from State of Cancer dashboard, available at: https://minhealthnz.shinyapps.io/state_of_cancer/

While the most recent survival estimates extend to around 2021, they do not fully capture improvements associated with therapies introduced in recent years. For example, findings from the Myeloma and Related Diseases Registry, which includes patients from both Australia and New Zealand diagnosed between 2012 and 2023, reported a 14.5-month difference in median overall survival between the two countries (Li J. M., 2025). Median survival was 65.3 months in New Zealand compared with 79.8 months in Australia, with New Zealand patients experiencing a 12% higher risk of death after adjusting for age, comorbidities, and disease stage.

The study attributed these differences to lower rates of autologous stem cell transplantation, restricted access to modern therapies such as lenalidomide and anti-CD38 monoclonal antibodies, and continued reliance on older induction regimens.

Together, these findings reinforce the relationship between treatment availability and outcomes. As modern therapies become the standard of care internationally, delays in access to these medicines risk widening survival differences between New Zealand and comparable health systems.

2.3 Areas where we are already succeeding

Key findings

- **New Zealand demonstrates strong clinical expertise and levels of collaboration, supported by robust professional networks.**
- **Coordination of stem cell transplantation is supported by effective integration with international donor registries and well-established donor identification and matching processes.**
- **Paediatric blood cancer care is a standout strength, with timely diagnosis and world-class treatment pathways. The flexible medicine access for children (Rule 8.1b) enables rapid adoption of best practice therapies.**
- **These successes show the value of national coordination and flexible funding models for improving outcomes.**

New Zealand has several strengths in blood cancer care that provide a strong foundation for future improvement. Despite resource constraints, clinicians and patients consistently described high quality interpersonal care, strong professional networks and effective coordination in key parts of the system. These strengths show that with the right investment and national leadership, New Zealand is well positioned to align more closely with global standards.

2.3.1 Optimising resources

Clinicians noted that, relative to available resources, the quality of care delivered is strong. Many centres have well established multidisciplinary approaches that support coordinated, patient centred decision making. Even under pressure, team-based care is viewed as a core strength that helps maintain quality and responsiveness. Early recognition of symptoms in higher risk groups and proactive follow up in known haematological conditions were also highlighted as areas where services are performing well.

Bone marrow donor coordination was frequently mentioned as an example of good practice. The increased focus on recruiting more Māori and Pacific donors has strengthened equity of access for patients requiring transplantation, and clinicians described donor matching processes as reliable and well supported.

2.3.2 Harnessing expertise and collaboration

A significant feature of the New Zealand haematology landscape is the depth of clinical expertise and the strong collegial culture across services. Clinicians described robust communication and collaboration between centres, supported by long standing professional networks that enable rapid discussion of complex cases. This contributes to timely decision making and helps reduce variation in diagnostic interpretation, particularly where dedicated haematopathology expertise is available.

Respondents of the clinician survey also highlighted the value of patient support and advocacy organisations. Many clinicians viewed these services as essential to good patient experiences, providing practical and emotional support that complements clinical care.

2.3.3 Excelling in paediatric blood cancer care

Paediatric blood cancer care was consistently described by parents and clinicians as an area where New Zealand performs strongly. Survey responses highlighted timely diagnosis, coordinated pathways and highly responsive clinical teams across the national paediatric oncology network. Parents reported that their children were assessed quickly, treatment discussions were clear and compassionate, and care was delivered with confidence and expertise.

A key enabler of this high-quality experience is the medicines access pathway described in Section 8.1b of the Pharmaceutical Schedule. Rule 8.1b allows paediatric cancer services to access any pharmaceutical needed for treatment, even when that medicine is not listed on the standard funding schedule. This exemption exists because paediatric cancers are rare, diverse and often require rapid access to specialist or novel therapies. Without this mechanism, children would face delays or limited access to essential treatments that are standard in comparable countries. Clinicians noted that the flexibility provided by Rule 8.1b helps enable the level of care that many families described as world class.

> **"As far as I'm aware, [I've] got the best ... world class care"**
> **- Parent**

> **"There are no barriers to accessing medicine ... but that's not the case for adults"**
> **- Parent**

Clinicians also observed that paediatric services benefit from stronger national coordination, more consistent access to diagnostics and clearer treatment pathways than those available in adult care. These strengths demonstrate the value of nationally defined systems, clear pathways and flexible medicines access, and offer important lessons for improving adult blood cancer services.

2.4 Barriers to achieving best practice care in New Zealand

Key findings

- **Workforce shortages and service pressure create delays and clinician burnout, undermining care quality.**
- **Diagnostic delays and inconsistent access to genomic testing hinder timely treatment decisions.**
- **Medicines access remains the largest barrier, with New Zealand 20 years behind in funding new therapies.**
- **Clinical trial participation is low due to eligibility gaps and underinvestment in research infrastructure.**
- **Geographic inequities, travel burden and limited psychosocial support exacerbate patient and whānau distress.**

While New Zealand has many strengths in blood cancer care, patients and clinicians consistently identified barriers that limit the system's ability to deliver timely, equitable and internationally aligned care. These barriers arise from workforce shortages, resource constraints, inconsistent pathways and structural limitations that affect diagnosis, treatment and follow up. The themes below reflect the most common issues reported in the surveys and provide insight into the systemic challenges that shape people's experiences.

2.4.1 Workforce shortages and service pressure

In New Zealand's healthcare landscape, haematologists and other clinicians face significant dissatisfaction and burnout, primarily due to a lack of national planning, coordination, and access to essential diagnostic and treatment options. This specialist workforce is demoralised by the necessity to provide care that falls short of international standards.

Figure 42 illustrates the workplace environment's impact on clinician wellbeing, with mental health and emotional wellbeing most adversely affected, particularly among haematologists and nurses.

Haematologists are by far the most dissatisfied group, with over 70% (17) of those surveyed stating that they are dissatisfied or very dissatisfied with blood cancer care in New Zealand. Generally, levels of satisfaction with the current system are not particularly high, with only just above one third of all staff reporting being very satisfied or satisfied with blood cancer care in New Zealand (22, 39%).

Clinicians describe that they feel like they are being to set up to fail by being made to work in a system that does not enable them to provide the best possible care to patients.

Staff suggestions for enhancing workplace wellbeing emphasise increased support and staffing to alleviate workloads and prevent burnout. Calls for better work-life balance, flexible scheduling, and time-off options were common. Mental health resources are critical, with staff advocating for stress management and emotional wellbeing support, including counselling services.

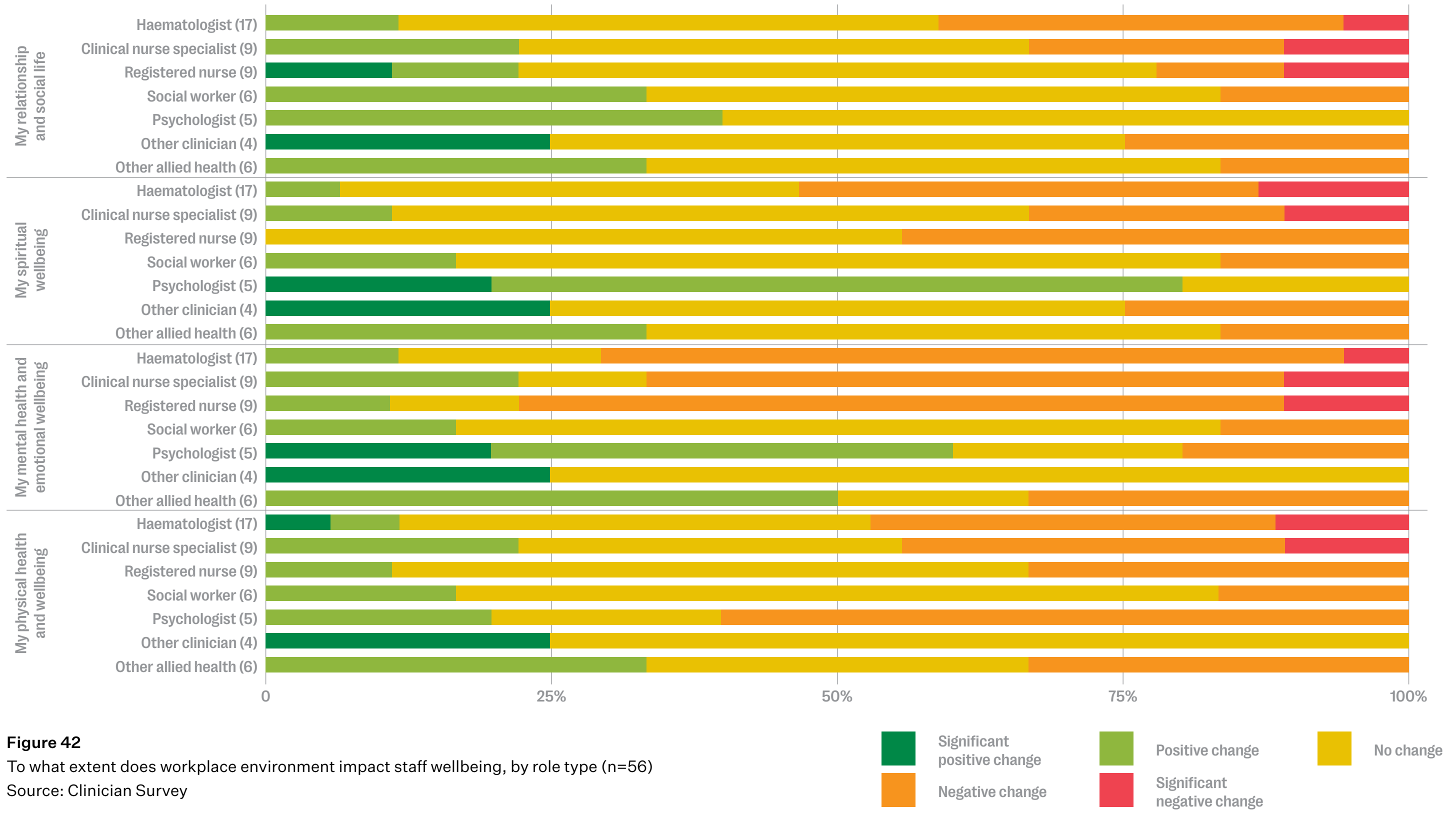


Figure 42
To what extent does workplace environment impact staff wellbeing, by role type (n=56)
Source: Clinician Survey

2.4.2 Delays and variation in diagnosis

There is a consistent call for regular, case-based training for primary care teams and frontline clinicians on early blood cancer signs and symptoms, reinforcing knowledge of red flags and atypical presentations to improve early diagnosis.

Updated guidelines and referral pathways are crucial for streamlining decision-making and improving care access, alongside increasing access to critical diagnostic tests like genomic testing.

> **“[There is a need for] national review and standardisation of community health pathways. National guidelines are only useful if updated regularly, and even the UK (BCSH) and Australia struggle to keep their guidelines up-to-date … current NZ guidelines are too long and too infrequently updated to be useful in practice”**
>
> **- Haematologist**

Access to appropriate diagnostic tests is another critical barrier in New Zealand’s blood cancer care landscape. Nearly half of surveyed haematologists (9, 47%) report limited or no access to advanced diagnostic tools, hampering timely and accurate diagnoses. Delays in diagnosis can severely impact treatment efficacy.

When asked, a high proportion of patient survey respondents did not know whether or not they had a genomic test (327, 46%). Of those that did know that they had a test (206, 29%), only one in five knew that it had changed their diagnosis or treatment plan.

Clinicians surveyed described how there is a lack of access to gold standard genetic testing and enhanced imaging technologies in New Zealand which creates these delays. Expanding the repertoire of available tests, such as molecular, cytogenetic tests, and laser capture mass spectrometry for conditions like amyloidosis, will significantly bolster diagnostic capabilities.

Additionally, more haematologists and laboratory personnel are needed to reduce diagnostic wait times and enhance patient care, alongside infrastructure expansion, including additional surgical theatre slots, hospital beds, and diagnostic centres.

2.4.3 Delays to first specialist appointments (FSA)

National health targets set by Health New Zealand state that 95% of patients must be seen for their FSA within four months, and that 90% of patients receive cancer management within 31 days (1 month) of the decision to treat. These targets are not being met for blood cancers, with only 86% of patients surveyed attending their FSA in less than four months, and 80% receiving cancer management within target timelines (Figure 43). This highlights that there is still a need for improvement, even within our own best practice care goals. These targets drive better coordinated, faster quality care for patients.

There were disparities in these times to treatments across cancer and ethnic groups. Patients with ALL, AML, and CML appear to benefit from faster time to diagnosis and treatment to other cancers. Rural patients had slightly longer average wait times, likely due to living further away, and/or due to limited access to specialists in rural areas.

2.4.4 Barriers to accessing medicines

In New Zealand, the absence of publicly funded medicines for blood cancer patients highlights a significant healthcare challenge. This deficiency compromises patient outcomes and obstructs clinicians from delivering optimal care due to limited treatment options. The emotional impact on both patients and clinicians is significant, with many experiencing fear, frustration, and disappointment over New Zealand’s lag in providing effective treatments compared to other countries.

> **“I think that there should be more options for treatment. More medicines like overseas available”**
>
> **- Parent**

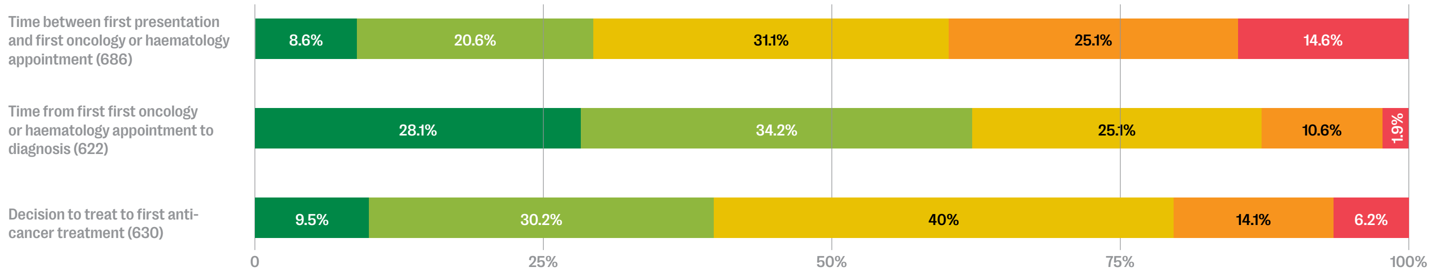


Figure 43
Tracking time across the patient journey to diagnosis
Source: Clinician Survey
Note: results exclude non-time answers such as “Not applicable”, “I don’t know”, and blanks, meaning not all totals consolidate to 100%

Patient survey results reveal that nearly half of the patients (46%) are aware of more effective treatments available overseas, with Myeloma (153, 74%) and MDS patients (25, 63%) particularly affected (Figure 44). Feelings of being undervalued by the healthcare system are widespread, as one patient expressed:

> **“[I feel] hopeless. Absolutely deflated. So disappointed in the government, Health NZ and Pharmac.”**
>
> **- Patient**

The lack of accessible treatments not only threatens life expectancy but also compels some patients to consider self-funding costly treatments or relocating abroad for better options. This situation adds financial strain and emotional distress, as highlighted by another patient. Limited access also affects the clinical workforce, with some clinicians leaving New Zealand or delaying return because contemporary treatment options are not available here.

> **“I will be looking potentially at moving abroad away from loved ones … The thought of moving abroad is extremely distressing.”**
>
> **- Patient**

These narratives reflect patient concerns about fairness and equity in access to care. They also suggest a belief that government support has been insufficient for individuals facing the need for life-changing treatment.

> **“I mean, I’ve paid tax all my life … been a good citizen … and yeah, if no other country funded it, that would, that would probably make it easier … but to know all the others do … ”**
>
> **- Patient**

Healthcare professionals confirm these concerns, citing New Zealand’s significant lag in funding blood cancer treatments compared to other western countries.

> **“New Zealand is at least 20 years behind in funding new medicines”**
>
> **- Haematologist**

These concerns are reinforced by calls from clinicians for improved funding processes and more timely assessment of new medicines.

> **“Fund the medicines blood cancer patients deserve! Develop a model for rapid assessment of new drugs and recommendation that they be funded if appropriate – maybe just agreeing to do this jointly with Australia would be a good idea”**
>
> **- Haematologist**

Pharmaceutical stakeholders provide insight into systemic barriers. They recognised the current system’s emphasis on cost-saving measures, but caution that this long-term underinvestment limits access to clinical trials and exacerbates therapeutic inequities.

> **“Pharmac will generally not fund things within a year or two of its patent life .. they prefer to fund it when it’s gone generic [waiting until the medication is much cheaper]”**
>
> **- Pharmaceutical representative**

Pharmac’s requirement to work within a capped budget has contributed to delays in the availability of new medicines and may have led to haematology applications being deprioritised in favour of lower cost treatments.’

These challenges highlight the need to reconsider Pharmac’s statutory objective so that decision making reflects more than a cost-benefit model alone. A broader and more balanced approach is required to support timely access to effective blood cancer treatments.

Ultimately, New Zealand needs a clear national policy on medicine access and funding prioritisation. This includes aligning with international standards and ensuring that resources are allocated in a way that delivers the best possible outcomes for patients.

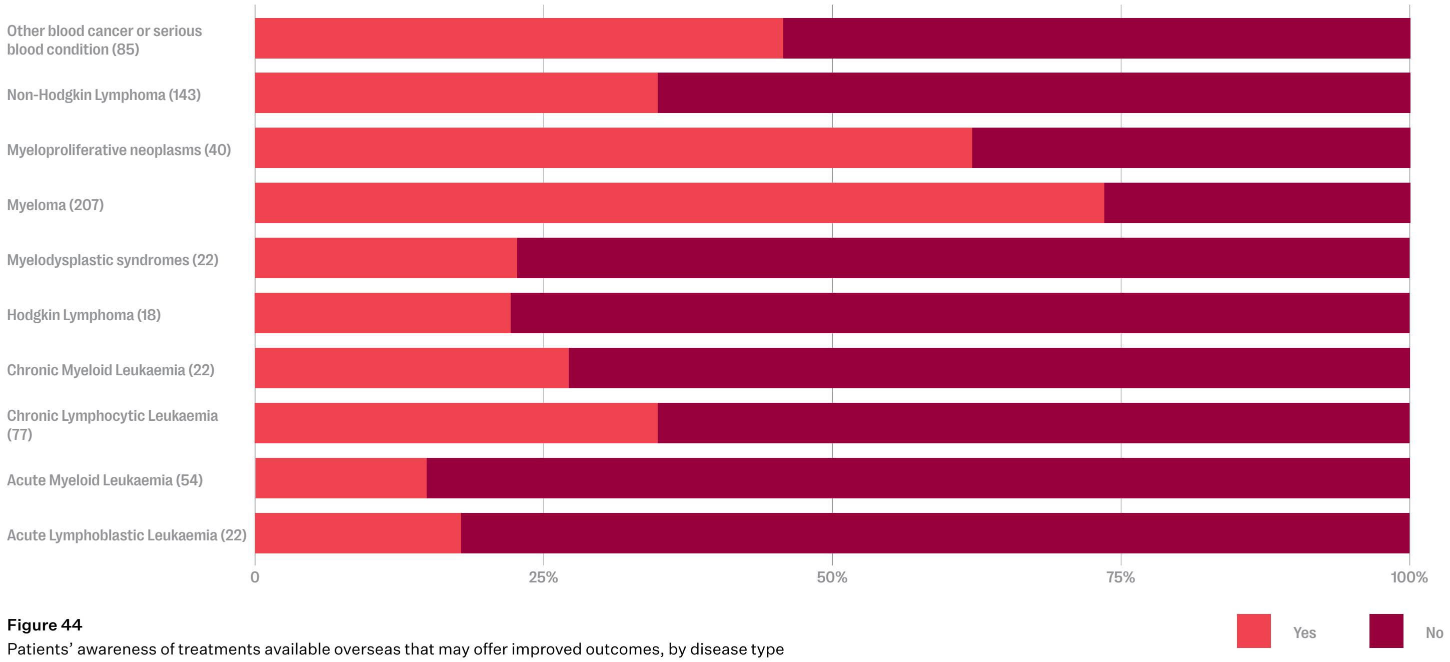


Figure 44
Patients' awareness of treatments available overseas that may offer improved outcomes, by disease type
Source: Patient and Caregiver Survey

2.4.5 Barriers to accessing clinical trials

In spite of the systematic inadequacies around medication funding, New Zealand has historically coped by getting patients access to new and effective treatments through local and international clinical trials. However, New Zealand now struggles to sustain this pathway for advanced treatments because our patients no longer meet baseline trial requirements.

"We can't bring our clinical trials to New Zealand .. because they're not treated with standard of care"
- Pharmaceutical representative

However, structural barriers within the health system also limit New Zealand's ability to host and run clinical trials. Research is not consistently treated as core business within Health New Zealand hospitals, and many clinicians carry full clinical workloads without dedicated research time or research-related FTE within their job plans. Limited availability of trial coordinators and data managers further constrains the ability of clinical teams to initiate or sustain investigator-led studies and participate in international trials.

Administrative processes can also create barriers to trial participation. In some cases, clinicians must apply for Special Authority Waivers from Pharmac to allow medicines to be used within a clinical trial where existing funding criteria do not align with the trial protocol. While the waiver mechanism is intended to facilitate access in exceptional circumstances, the application process can be complex and time-consuming for already time-constrained clinicians and research staff. Trial recruitment timelines may be shorter than the time required to complete the waiver process, meaning New Zealand sites can miss opportunities to participate in international studies.

Clinical trial units also face infrastructure limitations, including insufficient research facilities, limited clinic space, and competition for infusion chairs within haematology day-stay units. In many centres, existing infusion facilities are already operating at capacity for routine patient care, leaving little room to accommodate clinical trial participants. Dedicated funding to expand research infrastructure is largely absent.

Diagnostic and laboratory capacity can also affect trial participation. Some specialised molecular and genomic tests required for eligibility screening or treatment monitoring are not routinely available in New Zealand, requiring blood or tissue samples to be sent overseas. This creates logistical challenges related to specimen collection, transport timelines, and laboratory turnaround times, which can delay or prevent patient enrolment in time-sensitive trials.

Limited access to internationally recognised standard-of-care medicines also restricts participation in global studies. Many clinical trials require prior exposure to specific therapies that are not routinely funded in New Zealand, meaning otherwise suitable patients do not meet eligibility criteria for enrolment.

Across patient survey respondents, only 14% (97) respondents had ever taken part in a clinical trial. Of these 89 (92%) had only taken part in trials in New Zealand, 6 both in New Zealand and overseas, and only two respondents had only taken part in overseas clinical trials. Respondents in a city were more likely to have taken part in a clinical trial (36, 16%) than those living rurally (10, 10%). Geographic barriers also influence access to trials, as many studies are concentrated in larger metropolitan centres. Travel requirements, accommodation costs, and time away from work or family can limit the ability of patients from regional or rural areas to participate.

Awareness and visibility of clinical trials can also be limited. Without centralised tools or systems that enable clinicians and patients to easily identify open studies, opportunities for participation may be missed. Time pressures on clinicians and high turnover among research staff further constrain the ability of teams to actively screen and recruit patients.

There is a clear call from clinicians for greater investment in research and development to support better treatments, increase access to clinical trials, and improve outcomes. Evidence shows that centres active in clinical research achieve better outcomes even for patients who are not enrolled in trials, as research participation strengthens service quality, clinical capability, and overall engagement with best-practice care.

"More investment in blood cancer research for better treatments ... [and] include diverse groups in clinical trials to ensure treatments work for all"
- Clinical Nurse Specialist

2.4.6 Limited integration of palliative care

Clinicians consistently highlighted the need for earlier and better integration of palliative care within blood cancer pathways. Many patients and families are referred late, which means they miss opportunities for advance care planning, symptom management and emotional support.

"Late referrals are a critical barrier. We often meet people only days before the end of life, which makes meaningful planning almost impossible."
- Palliative care specialist

Late referral limits the ability of palliative care teams to demonstrate the benefits of early, holistic involvement, and results in poorer outcomes for patients and whānau. Misunderstandings about the role of palliative care also contribute to delays, with some clinicians perceiving it as relevant only once active treatment has ceased.

Sustained underinvestment exacerbates these issues. Clinicians with international experience described New Zealand's palliative care services as comparatively under resourced. Hospices rely heavily on fundraising to maintain core operations, and fundraising capacity varies across regions, resulting in inequities in service availability and quality.

Clinicians also expressed concern that current reforms, including changes to paediatric palliative care, may reduce capacity further at a time when demand continues to rise.

Another clinician described the emotional impact of these system limitations:

"It can be hard to watch a patient go through multiple rounds of treatment and not have the time or space to prepare for the end of their life."
- Clinician

Overall, the findings indicate that palliative care remains insufficiently integrated into blood cancer care. Ensuring earlier referral, strengthening services and addressing long standing funding gaps are essential to providing person centred support for patients and families.

2.4.7 Travel burden and inequities in access

Geographic location critically influences access to quality cancer care in New Zealand, with rural patients facing significant transport challenges to reach essential services. Systemic resource limitations and funding issues exacerbate these inequalities, particularly in rural areas where shortages of staff and equipment create geographic gaps in service delivery, delaying diagnosis and treatment.

These resource and funding constraints often lead to geographic gaps in service delivery. Clinical survey respondents described how there are inconsistent practices across regions, with variations in adherence to treatment guidelines leading to disparities in patient care. The regional variation is exacerbated by the limited access to essential drugs and treatment.

Unsurprisingly, patient survey respondents living in cities travelled a shorter distance to their treatment centre when compared to patients living rurally. 44 people (6%) reported that they moved to be closer to their treatment centre.

The patient survey explored what proportion of respondents were able to access the National Travel Assistance (NTA) scheme, and reasons they did not utilise the NTA. Overall, 44% of survey respondents identified they needed travel support, and importantly, one in three people who identified they needed travel support were not able to access it (Figure 45). Many individuals confirmed that they were unaware of the NTA and its services, with numerous comments indicating that respondents did not know it existed or how to apply for assistance.

Many users expressed that the reimbursement provided by the NTA did not fully cover their travel and accommodation expenses. Several respondents mentioned difficulties with the paperwork and the application process, which they found to be cumbersome and time-consuming, especially during a challenging time of illness.

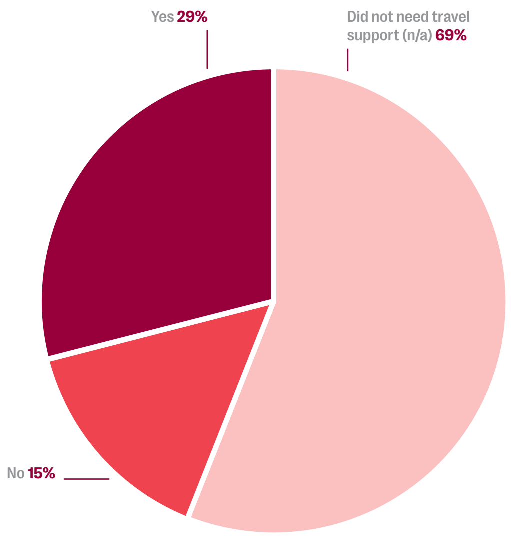


Figure 45
Ability to access NTA travel support if needed
Source: Patient and Caregiver Survey

2.4.8 Limited access to information, navigation and psychosocial support

Patients navigating blood cancer often face significant challenges due to limited information, fragmented support pathways and inconsistent access to psychosocial services. The intensity and duration of treatment create substantial emotional, financial and practical strain, yet many patients reported that they did not receive the guidance they needed to manage treatment impacts or understand the supports available to them.

Patient survey responses highlighted ongoing gaps in survivorship support, including delays accessing counselling, nutritional advice and physical rehabilitation. Awareness of available services was uneven, with some patients only discovering options after actively seeking them. As one patient noted,

"I asked for it versus it being offered."
- Patient

Geography added further pressure. Patients travelling from rural and remote areas described higher levels of fatigue, cost burden and isolation, and local hospitals often lacked the specialist expertise required for blood cancer care. Parents of paediatric patients frequently found themselves coordinating between local and national providers, describing the process as feeling like "project managing" their child's care.

Caregivers also experienced unmet needs. Almost half of patient respondents wished they had access to more support, particularly psychological and emotional support, nutritional guidance and practical assistance during treatment. Many relied heavily on family, friends or online peer networks to fill gaps. As one patient shared,

"Facebook groups have been more helpful than medical professionals at times."
- Patient

Health literacy challenges were common. Patients described difficulty understanding clinical terminology and sought clearer explanations tailored to their specific cancer type. Allied health staff also noted that cultural needs, particularly for Māori whānau, were not always met, citing environments and communication that felt overly clinical and unfamiliar.

One in six patients had no support services discussed with them at all, underscoring the inconsistency of support pathways. Allied health clinicians identified inconsistent referral processes, limited clinician awareness of available services and constrained staff capacity as key contributors to delays.

One social worker commented that:

"Referrals are often delayed because clinicians do not know what our service provides."
- Social worker

Overall, the findings point to a need for clearer information pathways, timely and consistent referrals, culturally responsive communication and stronger navigation and survivorship support. Addressing these gaps would significantly improve the experience and wellbeing of patients and whānau throughout the blood cancer journey.

3.
Roadmap to the future – no lives needlessly lost to blood cancer

3. Roadmap to the future – no lives needlessly lost to blood cancer by 2035

In pursuit of a future where lives are not lost to blood cancer due to avoidable system constraints, New Zealand must take a deliberate and coordinated approach to how blood cancer care is planned, funded, and delivered. This roadmap sets out five priority areas for action where change is most likely to reduce avoidable harm and loss, informed by the evidence presented in this report and the realities of clinical practice.

The priorities focus on establishing a national mechanism to drive delivery, enabling access to treatments aligned with international best practice, ensuring consistent diagnostic and treatment pathways, strengthening access to research and clinical trials, and building the workforce and service capacity required to meet current and future need. Together, they provide a clear direction for government and health system leaders to act, in partnership with clinicians, to improve blood cancer outcomes in New Zealand.

3.1 The vision

New Zealand has the opportunity to deliver blood cancer care that aligns with international best practice and ensures that lives are not lost due to avoidable delays, constrained service capacity, or lack of access to effective treatments.

This vision recognises that blood cancers differ fundamentally from many solid tumours. They cannot be screened for or prevented, often require rapid and complex clinical decisions, and increasingly depend on advanced diagnostics and therapies. Outcomes are therefore highly sensitive to how the system performs.

Blood cancers also require distinct clinical infrastructure and expertise. Care is delivered by haematologists rather than medical oncologists and frequently involves intensive therapies such as induction chemotherapy, stem cell transplantation, and emerging cellular therapies such as CAR T-cell therapy. These treatments rely on specialised diagnostics, multidisciplinary teams, and coordinated inpatient and outpatient services. As a result, system design and service capability play an especially important role in determining outcomes.

Achieving this vision requires a coordinated national approach that enables clinicians to deliver optimal care.

3.2 What 'no lives needlessly lost' means in practice

The goal of no lives needlessly lost to blood cancer does not imply that all deaths are preventable. Blood cancers are a diverse group of diseases, many of which remain life limiting despite best efforts. However, the evidence presented in this report shows that a meaningful proportion of current mortality and morbidity in New Zealand is not an unavoidable consequence of disease biology.

Blood cancers are particularly sensitive to how well the health system functions. Many require prompt diagnosis, early access to effective therapies, rapid access to timely supportive care, and sustained treatment over long periods. Delays in diagnosis, limited treatment options, constrained service capacity, or inconsistent access to specialised expertise can materially change outcomes.

In New Zealand, avoidable loss most often arises not from a lack of clinical knowledge or capability, but from system constraints that limit clinicians' ability to deliver care aligned with international best practice. These constraints include restricted access to medicines, variation in diagnostic and treatment pathways, workforce and infrastructure pressures, limited participation in research and clinical trials, and delays in urgent or emergency care.

Importantly, New Zealand already has a highly skilled haematology workforce and strong pockets of excellence in blood cancer care. Where the system enables clinicians to act, outcomes can approach those seen internationally. Where it does not, patients experience delayed treatment, reduced options, and greater physical, psychological, and financial burden.

'No lives needlessly lost' therefore refers to outcomes that could be improved if the system were better aligned to the clinical realities of blood cancer. It frames an achievable ambition that focuses on removing avoidable barriers, supporting clinicians to deliver optimal care, and ensuring that inequities in outcomes between socio-economic and ethnic groups are addressed and that patients are not disadvantaged by where they live or by system design.

This framing underpins the priority areas set out in the following section.

3.3 Five priority areas for action

The following five priority areas define where focused action is most likely to reduce avoidable harm and loss for people with blood cancer in New Zealand. They reflect points in the system where current constraints limit clinical action and where targeted change would most directly improve outcomes.

These priorities have been identified through synthesis of the evidence presented in this report, including epidemiological analysis, health system utilisation data, clinician insights, and the experiences of patients and whānau navigating blood cancer care in New Zealand. Together, these perspectives highlight where system constraints most directly affect outcomes and where targeted action is most likely to deliver meaningful improvement. The priorities are intended to guide policymaking, health system planning, and investment decisions toward areas with the greatest potential impact.

Together, they provide a practical framework for directing action and investment toward the areas most critical to delivering progress toward the goal of no lives needlessly lost to blood cancer.

Priority 1: Establish a National Blood Cancer Taskforce

Delivering sustained improvement in blood cancer outcomes will require coordinated action across multiple parts of the health system. Many of the constraints identified in this report sit across medicines funding, service planning, workforce, research, and policy settings, and cannot be resolved through isolated initiatives or existing governance structures.

A national blood cancer taskforce would provide a focused mechanism to drive delivery against the priorities set out in this roadmap. Its purpose would be to translate evidence into action, align decision-making across agencies, and maintain momentum on issues that directly contribute to avoidable harm and loss.

For this mechanism to be effective, the taskforce must have a clearly defined mandate, authority, and access to implementation capability across the health system. Without this authority, there is a risk that recommendations could remain advisory in nature and fail to achieve the system change required.

The taskforce should be time-limited, clinically informed, and accountable for progress. Its role is not to duplicate existing structures, but to address cross-cutting barriers that prevent timely and effective delivery of best practice blood cancer care.

What will be different?	A single, accountable mechanism exists to drive progress across blood cancer priorities. Decision-making is coordinated across funding, planning, and service delivery. Barriers that cut across agencies are actively addressed rather than deferred.
Key dependencies	• Clear mandate and scope • Clinical leadership and credibility • Authority to coordinate implementation across agencies • Access to policy and implementation capability • Defined reporting and accountability arrangements
Key partners for implementation	• Ministry of Health policy leadership • Haematology clinical leaders • Health system planners and service leaders • Medicines funding and procurement bodies • Research and clinical trials stakeholders
Timeline for implementation	• Establishment within 6 to 12 months • Time-limited mandate with defined review points
How will we measure our success?	• Taskforce established with agreed terms of reference • Clear work programme aligned to the priority areas for action • Demonstrable progress against identified system barriers • Transparent reporting of actions and outcomes

Priority 2: Enable Access Aligned to International Best Practice

Access to modern blood cancer medicines is one of the most important drivers of survival and quality of life. International guidelines increasingly recommend targeted and immune-based therapies as standard care across many blood cancer subtypes.

In New Zealand, restricted or delayed access to these treatments limits clinical options, contributes to avoidable morbidity, and places patients and families under significant emotional and financial strain.

However, access to treatment is not determined solely by medicines funding. Modern blood cancer care relies on a broader system of care delivery, including specialist diagnostics, pharmacy services, infusion capacity, emergency care for treatment complications such as neutropenic sepsis, and multidisciplinary supportive care. Ensuring access aligned with international best practice therefore requires coordination across funding, service delivery, and clinical infrastructure.

Access to internationally recognised standard-of-care treatments also affects New Zealand's ability to participate in international clinical trials. Where foundational therapies are not available, patients and clinicians are often unable to participate in trials that could otherwise provide early access to emerging treatments.

This priority focuses on establishing a medicines access approach that is timely, predictable, and aligned with comparable health systems.

What will be different?	Clinicians can deliver treatments consistent with contemporary international standards, supported by the service infrastructure required to deliver modern therapies. Patients experience timely access to medicines, diagnostics, supportive care and multidisciplinary treatment services.
Key dependencies	• Medicines assessment and funding settings that support timely access • Alignment between regulatory, funding, and service delivery processes • Adequate infusion, pharmacy and emergency care capacity to support modern therapies • Access to internationally recognised standard-of-care therapies that enable participation in clinical trials • Data to support prioritisation and sequencing
Key partners for implementation	• Medicines funding and assessment bodies • Haematology clinicians • Health system planners • Pharmaceutical sponsors • Emergency medicine and pharmacy services • Allied health and supportive care services
Timeline for implementation	• Short-term actions within 1 to 2 years • Medium-term alignment over 3 to 5 years
How will we measure our success?	• Reduction in time between international regulatory approval to funded availability in New Zealand • Increased proportion of patients receiving standard-of-care therapies • Reduced reliance on self-funded treatment or Australia's health system • Reduction in regional variation in access to recommended therapies • Improvements in equity of access and outcomes across New Zealanders

Priority 3: Support Consistent Diagnostic and Treatment Pathways in Practice

National guidance for blood cancer care already exists, including the Optimal Cancer Care Pathways, and provides a foundation for consistent practice.

However, evidence in this report indicates that whether these pathways can be followed in practice depends on local service capability, particularly access to specialised diagnostics and procedures.

Variation in diagnostic capability, including access to advanced molecular testing and imaging technologies, can lead to differences in how quickly patients are diagnosed and treated across regions.

This priority focuses on supporting consistent use of existing pathways by aligning system capability with pathway expectations. It is not about redesigning guidance, but about ensuring that published pathways can be delivered in practice without reliance on workarounds.

National multidisciplinary meetings and shared clinical information systems may provide important mechanisms to support consistent decision-making and reduce regional variation.

The aim is to ensure that existing pathways can be followed in practice, supported by service capability that aligns with pathway expectations.

What will be different?	Patients experience care that more consistently reflects existing national guidance. Diagnostic and treatment decisions are less influenced by local service constraints, and clinicians are better supported to apply pathways in practice without relying on workarounds. Readily available supportive care ensures that patients presenting to acute care settings receive timely assessment and treatment, particularly for complications that require urgent intervention.
Key dependencies	• Access to subspecialist diagnostics and pathology • Alignment between pathway expectations and local service capability • National coordination mechanisms such as multidisciplinary meetings and shared clinical information systems • Implementation support to enable consistent application of existing guidance
Key partners for implementation	• Haematopathology services • Haematology clinicians • Health service providers • Universities and research institutions • National and regional service planners • Digital health and clinical information system providers
Timeline for implementation	• Short-term focus on implementation support within 12 to 24 months • Ongoing alignment of service capability with pathway expectations over subsequent years
How will we measure our success?	• Reduced variation in diagnostic timelines • Increased consistency in treatment initiation • Clinician and patient confidence in care pathways • Reduced regional variation in access to advanced diagnostics

Priority 4: Strengthen Access to Research and Clinical Trials

Clinical trials and research are integral to best practice blood cancer care, providing patients with access to emerging therapies and enabling clinicians to engage with advances shaping standard treatment internationally.

In New Zealand, trial availability is constrained by delivery capability and by the absence of a clear pathway from trial participation to reimbursement of proven therapies, reducing both research investment and patient access.

Participation in clinical trials is influenced by a range of system factors beyond research capability alone. These include access to modern diagnostic technologies, availability of standard-of-care therapies required for trial eligibility, geographic barriers faced by patients living far from major centres, and limited access to clear information about available trials. Addressing these barriers will require coordinated action across technology, medicines policy, service delivery, and workforce capability.

Access aligned with international best practice also depends on fit-for-purpose regulatory pathways for advanced therapies, particularly where products are personalised, rapidly evolving, or manufactured locally.

New Zealand's trial landscape must encompass a balanced mix of commercial studies, cooperative group trials, and investigator-initiated research. Cooperative group trials, such as those led by the Australasian Leukaemia and Lymphoma Group, require stable national infrastructure, data coordination, and protected clinician time to participate. Investigator-initiated studies, including programmes such as ENABLE, rely on different forms of support, including flexible funding, research nursing capacity, and streamlined ethics processes. These needs differ from those of wholly commercial trials, which often require rapid activation pathways, strong site performance metrics, and clear reimbursement signals for successful products.

Strengthening access requires clarity about where New Zealand can contribute uniquely to new knowledge and where the focus should be on timely adoption of international evidence, ensuring that research activity delivers direct and timely benefit to patients.

What will be different?	More patients are offered trial participation where appropriate. Clinicians are better supported to recruit and deliver trials. Research activity is better aligned with areas of greatest clinical need.
Key dependencies	• Availability of internationally recognised standard-of-care treatments required for trial eligibility • Access to modern diagnostic and monitoring technologies required for trial participation • A pathway from trial participation to reimbursement of proven therapies • Alignment between research participation, regulatory processes, and funding settings • Targeted investment in trial delivery capability • Regulatory settings that keep pace with scientific and clinical advances
Key partners for implementation	• Clinical researchers • Research institutions • Trial sponsors • Health service providers • Diagnostic laboratories and pathology services • National research coordination bodies and clinical trial networks
Timeline for implementation	• Near-term actions to improve research settings and investment signals within 1 to 2 years • Medium-term growth in trial availability and participation over 3 to 5 years
How will we measure our success?	• Increased availability of blood cancer clinical trials in New Zealand • Increased proportion of patients enrolled in blood cancer clinical trials • Access to funded therapies aligned with positive trial results • Increased geographic participation in trials through mechanisms such as teletrials or distributed trial delivery models

Priority 5: Build Workforce and Service Capacity

Rising incidence and prevalence of blood cancer are placing sustained pressure on the workforce and services required to deliver care. Workforce shortages, limited infusion capacity, and service constraints contribute directly to delays in treatment and increased burden on patients and clinicians.

Building workforce and service capacity is essential to ensure the system can meet current demand and prepare for future growth. This includes capacity across medical, nursing, allied health, and support roles required to deliver comprehensive blood cancer care.

Delivery of modern therapies, including CAR T, also requires specialised multidisciplinary expertise across haematology, apheresis, cell processing, quality systems, pharmacy, and intensive care. These capabilities cannot be rapidly expanded without deliberate long-term investment in training, retention, and service planning.

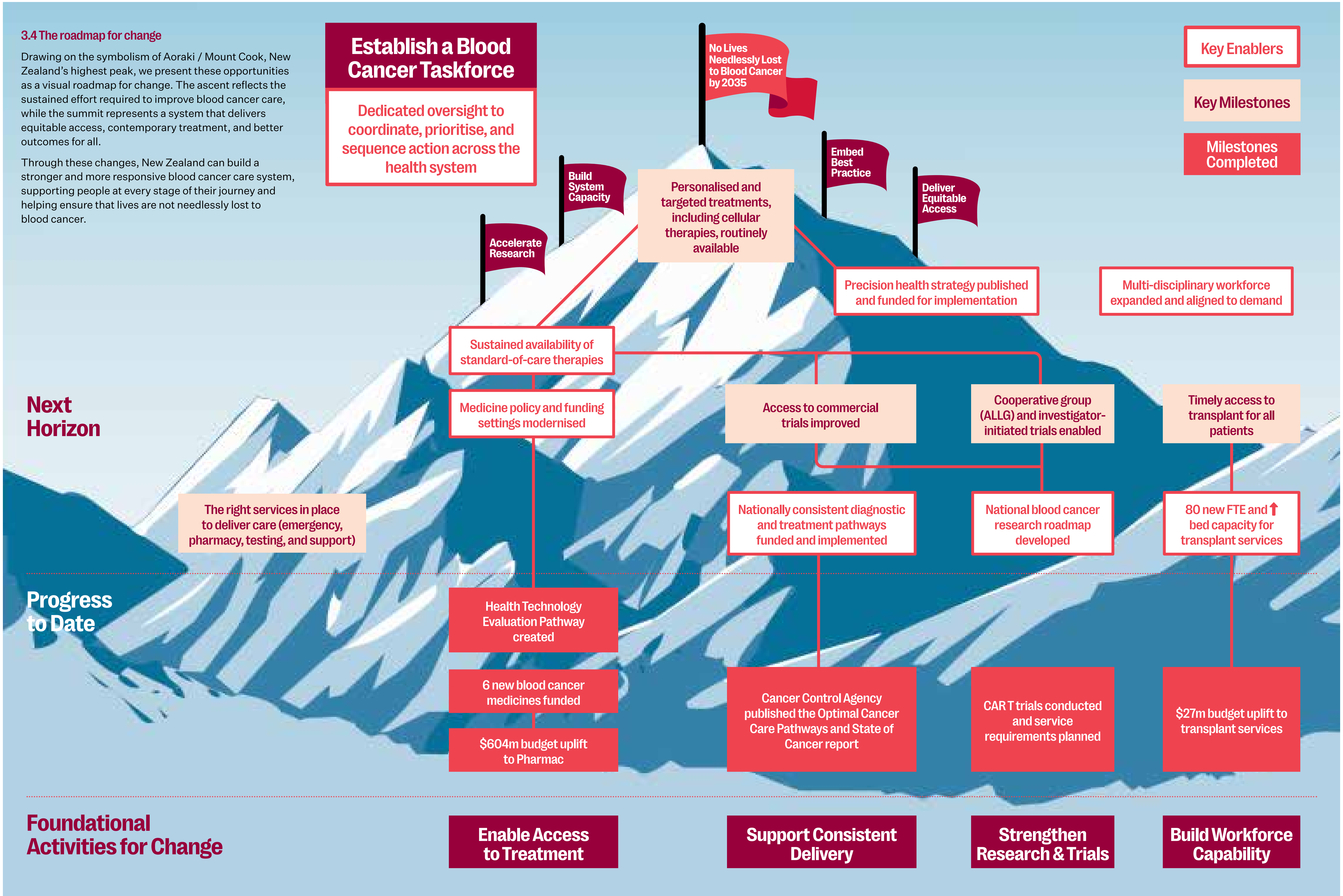
This priority underpins the successful delivery of all other priorities.

What will be different?	Services are better able to meet demand. Treatment delays related to capacity are reduced. Clinician workload and burnout pressures are better managed.
Key dependencies	• Workforce planning aligned to projected demand • Investment in treatment and infusion capacity • Training and retention strategies • Workforce capability to support advanced cellular and immunotherapies
Key partners for implementation	• Health workforce planners • Service providers • Professional bodies • Education and training institutions
Timeline for implementation	• Short-term capacity relief within 1 to 2 years • Long-term workforce development over 5 to 10 years
How will we measure our success?	• Reduced wait times for treatment • Improved workforce retention • Sustained capacity aligned to demand

3.4 The roadmap for change

Drawing on the symbolism of Aoraki / Mount Cook, New Zealand's highest peak, we present these opportunities as a visual roadmap for change. The ascent reflects the sustained effort required to improve blood cancer care, while the summit represents a system that delivers equitable access, contemporary treatment, and better outcomes for all.

Through these changes, New Zealand can build a stronger and more responsive blood cancer care system, supporting people at every stage of their journey and helping ensure that lives are not needlessly lost to blood cancer.



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5. Appendices

5. Appendices

5.1 Detailed Methodology

The data collection for this report utilised a mixed-method approach, integrating quantitative and qualitative data sources.

This included analysis of existing health and social sector data available in Stats New Zealand's Integrated Data infrastructure (IDI) database, findings from patient and clinician surveys, desktop research, and insights from targeted interviews and focus groups.

5.1.1 Quantitative Methodology

Integrated Data Infrastructure (IDI)
Information provided is based on IDI March 2025 release[2]

Cancer Registration data was available from 1995 – Dec 2023

Publicly funded hospital discharges (NMDS) data was available from pre1990 – Jun 2024

Population cohort demographics and address data was available from 2003 – Jan 2025

National non-admitted patient collection (NNPAC) data was available from 2007 – Jun 2024

Blood Cancer Population Cohort
The blood cancer population is defined based on specific International Classification of Disease (ICD) codes, the full list of codes are captured in ICD codes draft Mar25 v5 and can be provided upon request.

A Person is uniquely selected from both the Cancer registrations and Publicly funded hospital discharges table where there is a match in blood cancer ICD code.

Cancer start date and ICD code
The earliest occurrence of having a blood cancer ICD code comparing the cancer diagnosis date from Cancer Registrations and discharge date from Publicly funded hospital discharges are selected as person cancer start date.

The latest ICD code is selected by comparing the dates across both tables.

Selection of ICD, DRG codes and categorisation of cancer type and subtype
The list of ICD and DRG code are refined with the support from Angela Pidd and Tracey Thompson from The Ministry of Health (MoH).

The cancer type is defined to align with the overall report and cancer sub type is based on the HNZ Cancer Web Tool.

Demographic sources
Administrative Population Census (APC) and MoH Population Demographics are used predominantly on retrieving a person's demographic information such as Birth year which is used to derive age, Gender and Ethnicity*

Death information is sourced from the Department of Internal Affairs (DIA) data as per suggested by Stats NZ and MoH

**The reason for not identifying European out is due to the small number count for non-Māori non-Pacific non-Asian non-European ethnicity groups. Given that there are some trends to tell for Māori, Pacific and Asian, European, MELAA and Other has been grouped as Other for the purpose of this analysis*

Region and Deprivation
Cancer DHB of domicile are taken from NMDS and NNPAC on or before diagnosed with blood cancer based on cancer start date.

Cancer DHB are then grouped into the following four regions:

- Northern | Te Tai Tokerau
  – Northland
  – Waitemata
  – Auckland
  – Counties Manukau
- Midland | Te Manawa Taki
  – Waikato
  – Lakes
  – Bay of Plenty
  – Tairawhiti
  – Taranaki
- Central | Te Ikaroa
  – MidCentral
  – Whanganui
  – Capital and Coast
  – Hutt Valley
  – Wairapapa
  – Hawkes Bay
- South Island | Te Waipounamu
  – Canterbury
  – West Coast
  – Nelson Marlborough
  – Southern
  – South Canterbury

DHB referenced in Outpatient and ED cost refers to the DHB domicile which according to Stats NZ NNPAC Data Dictionary it is calculated as follow:

- If sent domicile rating = 'Current' then the DHB domicile is the one that relates to the sent domicile code
- If sent domicile rating is not 'Current' and NHI domicile code is present and not overseas or undefined, then the DHB domicile code is the one that relates to the NHI domicile code
- If neither of the above, the DHB code is the DHB that submitted the file

Information on latest Region recorded where the person resides is based on Address Notification[3] which is a collation of all address updates from the Ministry of Health (PHO and NHI registers), Ministry of Social Development, Ministry of Education, ACC, and Inland Revenue. Cases where the latest region is not found in Address Notification, HSU data as at October 2024 is used and latest region will be the same as cancer DHB if no information could be found.

Latest region has also been grouped into four regions stated above.

For simplicity, deprivation is all mapped using NZDep2023 which was the latest version available during the analysis.

Deprivation* score is derived using meshblock. Cancer deprivation score derived using meshblock on or before cancer start date and latest deprivation score using latest meshblock available. Both meshblocks are sourced from Address Notification otherwise the MoH Address.

**Deprivation are grouped into quintiles from 0-5 and where deprivation score is not known it has been defaulted to 0*

[2] Data in the IDI March-2025-Data-in-the-IDI.pdf
[3] Geographic information in IDI

Inpatient Cost
The following filters have been shared by Michael Chang from MoH when looking at inpatient data, and this has been incorporated into our analysis. Filtering records from Publicly funded hospital discharges to only include:

- blood cancer ICD codes
- domicile not equal to 9999
- DHB of domicile that is not 'Overseas'
- facility type in ('01', '02', '03', '10', '25', '99')[4]
- event type in ('IP', 'BT', 'ID', 'IM')[5]
- purchaser code not in ('06', '19', 'A1', 'A2', 'A3', 'A4', 'A5', 'A6', 'A7')[6]
- discharge year from 2007 onwards to align with University of Auckland analysis

In order to calculate cost more accurately, casemix and non-casemix funded events are separated based on Purchase Unit (PUs) Allocation. PU is allocated by mapping the Health Specialty Code to a PU from the National Service Framework. This process uses the Purchase Unit Data Dictionary (PUDD)[7], which provides a comprehensive mapping between health specialty codes and purchase units. The PUDD is updated annually and includes the relevant codes and definitions necessary for counting, funding, and contracting health services.

Events that have a purchase unit of EXCLU (i.e., Not eligible) are excluded from using the NZ Casemix Framework Weighted Inlier Equivalent Separations (WIES)[8].

Therefore, events where PU is not EXCLU, the costweight of that event is multiplied by respective WIES price during that period.

Cost of Casemix funded events = costweight x WIES prices for that period

Prices are only available up until 2021/22 Financial Year which covers from 1st July 2021 to 30th June 2022. Prices for 2022/23 and 2023/24 are extrapolated from data available.

Events where PU is EXCLU (non-casemix events), there is another field that captures the events underlying PU.

There will be a unit of measure (UoM) specified for each PU. The UoM defines how the service is counted and, therefore, how costs or volumes are calculated for reporting and funding purposes.

A request has been sent to MoH for historical set of Inter-District Flow (IDF)/ National prices. The file provided includes the PU, UoM and reference price from 2008/09 to 2024/25.

Prices are not available consistently for every PU across different periods because of several reasons related to the way health service pricing is developed, reviewed, and implemented. Prices are typically reviewed and updated on an annual basis, accurate pricing relies on comprehensive cost and activity data from providers where there can be delays in collecting, validating and analysing the data. Over time, new services may be introduced or existing services may be redefined, merged or discontinued. When this happens, prices may not be available for the affected PU.

The information provided is based on data collected three years prior (i.e., 2020/21 informs 2023/24 reference prices) and projected using point-in-time inflationary assumptions to estimate reference values for the year. Therefore, this does not account for specific cost variances and real time factors that may impact current costs. There may also be policy and funding, retrospective adjustments which can delay the publication of prices or gaps in price availability.

The non-casemix PU are matched against the IDF pricing list and calculated based on its UoM and period.

Analysis has been done to categorise the UoM to calculation method e.g. if the UoM are like Attendance, Procedure, Discharge etc then the cost will be multiplying the number of events to the IDF price for that period.

Cost of nonCasemix funded events = number of events x IDF Price for that period

If the UoM are Bed Day, Relative Value Unit etc, the cost will then be calculated by multiplying the length of stay to the IDF price for that period.

Cost of nonCasemix funded events = lenght of stay x IDF Price for that period

Calculation where the cost is 0 has been taken out of the analysis as often it indicates data entry error, missing information, or non-billable events. By focusing on positive costs, it ensures the analysis is based on valid, meaningful cost data, as such, inpatient cost is calculated as follows:

Inpatient Cost = Σ Cost of casemix funded events + cost of non casemix funded events

5.1.1.1 Subtypes listed under each grouping

Hodgkin Lymphoma includes several subtypes of classical and nodular lymphocyte-predominant Hodgkin lymphoma (C810–C819). These cancers are characterised by the presence of Reed-Sternberg cells and typically affect lymph nodes. Subtypes include:

- Nodular sclerosis
- Mixed cellularity
- Lymphocyte-rich and lymphocyte-depleted forms
- Other and unspecified classical types

These are generally treated with chemotherapy and/or radiotherapy and have high cure rates, especially in younger patients.

Immunoproliferative Cancers (C880–C889) includes rare malignancies involving abnormal proliferation of immune cells, particularly plasma cells and lymphocytes. Conditions include:

- Waldenström macroglobulinaemia
- Heavy chain diseases (alpha and other types)
- Immunoproliferative small intestinal disease
- MALT lymphoma (mucosa-associated lymphoid tissue)
- Other and unspecified malignant immunoproliferative diseases

Leukaemia is the most extensive group (C910–C959), encompassing a wide range of acute and chronic blood cancers affecting both lymphoid and myeloid cell lines. It includes:

- Acute and chronic lymphoblastic leukaemia (ALL, CLL)
- Acute and chronic myeloid leukaemia (AML, CML)
- Hairy cell, prolymphocytic, monocytic, and erythroid leukaemias
- Myeloid sarcoma and myeloproliferative disorders
- Leukaemia of unspecified or mixed cell types

Non-Hodgkin Lymphoma (C82–C86, C96) encompasses a wide and diverse range of lymphoid malignancies that do not exhibit the Reed-Sternberg cells characteristic of Hodgkin lymphoma. It includes:

- Follicular lymphomas (grades 1–3b)
- Diffuse large B-cell lymphoma, mantle cell lymphoma, and Burkitt lymphoma
- T-cell and NK-cell lymphomas, such as mycosis fungoides, Sezary disease, and anaplastic large cell lymphoma
- Rare histiocytic and dendritic cell neoplasms, including Langerhans-cell histiocytosis and histiocytic sarcoma

[4] Facility type code table Common code tables – Health New Zealand | Te Whatu Ora
[5] Event type code table Common code tables – Health New Zealand | Te Whatu Ora
[6] Principle health service purchaser code table Common code tables – Health New Zealand | Te Whatu Ora
[7] Te Whatu Ora Purchase unit codes – Health New Zealand | Te Whatu Ora
[8] Te Whatu Ora CFD-WIESNZ25-v1.1-March-2025_Clean-Copy.docx

Myeloma (C90–C90.3) includes:

- Multiple myeloma, the most common plasma cell malignancy
- Plasma cell leukaemia, a rare and aggressive variant
- Solitary plasmacytoma and extramedullary plasmacytoma, which are localised forms of plasma cell tumours

Myelodysplastic Syndrome (D46) includes various subtypes of MDS, such as:

- Refractory anaemia
- MDS with excess blasts
- MDS with single or multilineage dysplasia
- MDS with isolated del(5q)

Uncertain Behaviour of Lymphoid, Haematopoietic and Related Tissue (D47) includes neoplasms with uncertain or borderline malignant potential, such as:

- Monoclonal gammopathy of undetermined significance (MGUS)
- Chronic myeloproliferative diseases
- Essential thrombocythaemia
- Osteomyelofibrosis
- Chronic eosinophilic leukaemia

These conditions may not require immediate treatment but are clinically significant due to their potential to progress to more aggressive diseases.

5.1.1.2 Outpatient Cost

The National non-admitted patient collection (NNPAC) records data on non-admitted patient events, including both outpatient and emergency department (ED) visits.

For the purpose of this analysis, an arbitrary field has been created to categorise the types of activities. Where PU code:

- starts with ‘ED’ it will be considered as an ED event
- starts with ‘ED’ and ends with ‘A’ it will be considered as an ED admitted event that would have an associated record in NMDS
- in the following list M54001, M50031, M30002, M50021, M3003, M50PRE, M30001, M50023, M50028, M50009, M50020, M50029, M50001, M34001, M50022, M54002, M30PRE, M54003, M54004, M50027, MS02001, M30020, M50030 it will be considered as a Blood Cancer Related activity
- is none of the above scenarios, it will have a tag of ‘not ED or BC’ for analysis, reason being these are still blood cancer patients identified in the population cohort but may not have a visit for blood cancer related services

Similar filters had been applied to exclude overseas patients, limiting purchaser code and only looking at records from National non-admitted patient collection (NNPAC) from the year 2007 onwards.

IDF Price is also used here. Note data provided by MoH starts from 2008/09 therefore the earliest cost calculation would be from service received date of 1st July 2008.

Volume of PU corresponding to UoM has been recorded for NNPAC, therefore, the calculation would be straightforward multiplying volume with the IDF Price for the period.

Cost = Σ colume amount x IDF Price for that period

The arbitrary field created earlier would be used to separate and look at Outpatient and ED cost specifically.

5.1.1.3 ED Cost

Calculating the cost of ED is not straightforward due to the overlapping nature of ED and inpatient activities, particularly for patients who are admitted after spending time in the ED. The challenges includes:

- **Non-mutually exclusive event:** ED visits are not always separate from inpatient admissions. Patients who are admitted may have significant time and care delivered in the ED, which can be counted as both ED and inpatient activity, leading to potential double-counting or misallocation of costs
- **Administrative Classification:** the point at which an ED visit becomes an inpatient admission is often determined administratively, not clinically. This can result in costs incurred during the ED stay being attributed to the inpatient episode, especially if the patient remains in the ED due to bed shortages or other delays.

5.1.1.4 Benefit

Income support payment code module[9] created using Ministry of Social Development (MSD) benefits data was used to analyse if people receive any income support due to blood cancer.

The main benefit and supplementary benefit table are being selected for analysis. The main benefit code module captures primary income support like Jobseeker Support, Supported Living Payment, Sole Parent Support etc, while supplementary benefit captures additional targeted assistance like Disability Allowance and such.

Main and supplementary benefits are the most directly relevant to understanding the economic impact of blood cancer on individuals. These codes reflect situations where blood cancer has led to a loss of income or increased living costs significant enough to require government support. Ad hoc, tax credits or retirement benefit codes may not be specific to health-related needs or may be unrelated to the impact of blood cancer, see full description, limitations and scope from Stats publication.

On top of the supplementary benefit, effort has also been put in to exclude any obvious benefits that are non-blood cancer such as any special or war-related benefit.

Some calculation steps are made to get the total net payment. As the payment is captured in days in the code module, the following steps are required:

1. Finding the difference in days between payment start and payment end to get the number of days receiving benefit
2. Minus the tax from payment to find nett payment
3. Then multiplying the nett payment with number of days receiving benefit to get the total net payment

Any benefit received prior to blood cancer start date will not be considered as part of blood cancer associated cost. i.e. if patient does not receive a benefit after cancer diagnosis but received before cancer diagnosis, this person is not counted.

5.1.1.5 Income

Total Income code module[10] created from Inland Revenue (IRD) data is used to analyse income loss impacted by blood cancer, see full description and limitation from Stats publication.

As total income code module includes all income sources such as: investment returns; government benefits; pensions etc; wages; salary; and self employment, income is selected as it represents the primary source of earned income for most working-age adults. These categories directly reflect a person’s ability to work and generate income through employment or self-employment.

Negative income is observed which commonly arises in self-employment when business expenses exceed business revenue, resulting in a net loss for the year. For this analysis, where the primary interest in loss of income due to blood cancer is the reduction in earned income, i.e. how much less people are making compared to before diagnosis. Including negative incomes can lead to overestimating the economic impact, as business losses may not equate to reduction in personal disposable income and does not reflect real economic hardship. Therefore, restricting the analysis to positive income allows for more meaningful comparisons across individuals or groups as it measures the actual drop in income available rather than fluctuations in business profitability or accounting loss.

There is no restriction applied on age, every individual with a recorded income stream will be included. This can be valuable for understanding the total societal impact across the entire blood cancer population but may introduce variability as income sources and levels can differ widely by age (e.g. retirees, students, or adolescents with part-time work)

A 2 year before-after cancer start year income analysis has been made.

The earliest income data available is from 1999 onwards, therefore, the analysis period of income loss is only from 2001-2022. E.g. if cancer start at before 2000, income 2 years before which is 1998 is not available; similarly, if cancer start 2023, 2 years after would be 2025 which is also not available.

5.1.1.6 Education

To analyse education attendance for the blood cancer population and its cohort group. The following approach is used.

Datasets used

- [IDI_Community].[cm_read_MOE_SCH_ATT_YEAR].[moe_sch_att_year_202503]
- [IDI_Sandpit].[DL-MAA2025-07].[MASTER_BLOOD_CANCER_POPULATION]

Data outputs

- For release: 12 aggregated tables by population groups
- Not for release: 12 raw tables for reference only

Variables and confidentiality rules

Each table includes common variables such as gender, age at cancer start, ethnicity (Māori, Pacific, Asian, Other), and cancer subtype. Attendance measures include:

- LBC_count – count of individuals in the LBC population (suppressed if <6)
- LBC_provider_count – count of education providers (suppressed if <3)
- Attendance proportions (p_proportion_lbc, u_proportion_lbc, j_proportion_lbc) – derived from annual attendance codes, suppressed if thresholds not met

Peer group measures follow the same derivation method, excluding the blood cancer population.

Confidentiality rules applied

- Suppress cell totals and means for counts <20
- RR3 applied; no zero counts removed.

5.1.2 Qualitative Methodology

5.1.2.1 Patient Survey

The online patient survey was implemented via the Survey Monkey platform, leveraging the Leukaemia Foundation Australia (LFA) survey as a template. The survey design process involved adapting and expanding upon the LFA’s questions to suit the specific objectives of this study. Initial piloting was conducted with members of the Blood Cancer NZ consumer advisory group to refine question clarity and relevance.

Distribution occurred through emails sent to existing Blood Cancer NZ contacts, ensuring wide reach among potential respondents. Consent was inferred through the completion of a tick-box on the survey form.

Data analysis comprised using descriptive statistics to delineate patterns in the responses and content analysis for open-ended questions to extract underlying themes. Microsoft Excel facilitated quantitative data handling, while artificial intelligence software aided the researcher in the thematic analysis.

5.1.2.2 Clinician Survey

This survey was also executed on Survey Monkey, with its content undergoing rigorous review by internal Blood Cancer NZ clinicians to ensure relevance and clarity.

Distribution mirrored the patient survey, targeting clinicians and allied health professionals within Blood Cancer NZ’s network. Implied consent was obtained through the survey’s introductory statement, which participants acknowledged by proceeding.

Analytical procedures mirrored those of the patient survey, employing descriptive statistics through Microsoft Excel and content analysis by the lead researcher. Theme derivation from qualitative data was supported by artificial intelligence software.

5.1.2.3 Survey Limitations

Non-response bias or self-selection bias may have impacted our survey results. While the survey achieved a response rate consistent with overall ethnicity distribution for blood cancer, it is noted that statistical significance is compromised in smaller populations which may affect the extent to which a population’s perspectives are accurately captured.

Across qualitative components, thematic analysis is inherently subject to researcher bias as interpretations may vary based on researchers’ perspectives.

While the desktop research offers valuable context, it was not a systematic review, so some relevant articles or recent developments may not have been captured.

5.1.2.4 Patient Interviews

Four patient interviews, each lasting approximately 60 minutes, were conducted via online video platforms, ensuring accessibility and convenience. A semi-structured interview format was utilised, with questions derived from engagement gaps in the survey results.

Recruitment leveraged existing Blood Cancer NZ networks and key contacts to identify suitable participants. Audio recordings were transcribed with the support of AI software. Thematic analysis of the interview transcripts was conducted by a researcher supported by AI software, allowing for effective theme identification and interpretation.

5.1.2.5 Focus Groups

Two focus groups were organised online; the first was a 60-minute session with three palliative care clinicians, and the second was a 90-minute session with five parents or caregivers of children with blood cancer. Semi-structured questions were crafted based on insights from the clinician and patient surveys. Participants were recruited through Blood Cancer NZ networks and contacts, ensuring diverse perspectives.

Thematic analysis of the focus group discussions was conducted by a researcher supported by AI software. Two additional palliative care clinicians who were unable to attend provided written feedback over email.

5.1.2.6 Pharmaceutical Stakeholder Feedback

Feedback was collected through two online discussions with pharmaceutical representatives from two organisations and two written feedback submissions from other organisations. Transcripts and written responses underwent content review, with thematic analysis performed with the support of AI tools.

[9] Stats NZ MSD Income Support Payments - Stats NZ Integrated Data Commons
[10] Stats NZ Total income module collection landing page - Stats NZ Integrated Data Commons

5.1.2.7 Desktop Research

This involved an examination of publicly available academic literature and white papers that addressed the project's primary research questions. Initial desktop research was conducted at the project's outset to establish a foundational understanding, while supplemental literature was reviewed post-primary data collection to contextualise findings and address any emergent gaps. Content analysis was enhanced by the use of AI software, enabling efficient processing and synthesis of large volumes of text.

5.2 Patient Survey Demographics

The patient survey was sent to 3,008 people via email utilising existing Leukaemia & Blood Cancer (Blood Cancer NZ) New Zealand lists and contacts. A total of 744 responses that met eligibility requirements were received, giving a response rate of 25%. Of the 744 responses, 675 completed the entire survey. Among these, 44 were carers (7 carers for children under 15), and 631 were individuals living with blood cancer.

In this report, the number of responses to each question may vary depending on how many participants reached the question, whether multiple responses were allowed, who was eligible to answer, and whether individuals chose to respond (e.g., total responses are higher than 744 as respondents could select more than one ethnicity).

Of the 774 respondents, 99.6% (771) currently live in New Zealand, and 0.4% (3) used to live in New Zealand but moved overseas to obtain access to blood cancer treatment (one each to Australia, the United Kingdom, and 'Other').

Respondents were primarily New Zealand European (624, 77%), with the next largest ethnic group being Māori (66, 8%). Prioritised ethnicity produced little change in overall ethnicity proportions (except for other). Prioritised ethnicity will be used for any sub-analyses by ethnicity.

It is important to note that there were small numbers of Pacific (16) and Asian (15) respondents. Respondents were located across the country, with Auckland and Canterbury having the highest proportion of respondents.

Slightly more females (408, 55%) than males (336, 45%) responded to the survey. Only 1 respondent identified as non-binary and 1 preferred not to specify their gender.

Over three-quarters of respondents were over the age of 55 (616, 84%), and over half over the age of 65 (432, 59%). Only 7 respondents (1%) were caregivers responding on behalf of a person aged under 15. In alignment with the age distribution, the majority of respondents reported living either alone (139, 19%) or with a spouse or partner (532, 71%). Some respondents also reported living with their children (133, 18%), and only a small number of respondents had other living situations, such as multi-generational homes or flatmates.

There was a relatively good spread of respondents across self-reported rurality markers, with approximately one third of respondents living in a city (244, 33%), one-third, in a suburb or town near a city (255, 34%), and one third in either a small town (127, 17%), or rurally (115, 16%).

The most represented blood cancer amongst respondents was Myeloma (215, 29%), followed by Non-Hodgkin Lymphoma (154, 21%), and Chronic Lymphocytic Leukaemia (83, 11%). Many respondents reported having another blood cancer or serious blood condition (91, 12%) outside of those listed. The most mentioned 'other' conditions were Waldenström macroglobulinemia (7), Multiple Myeloma (7), Amyloidosis (7), and Mantel Cell Lymphoma (6). All except six respondents knew their blood cancer diagnosis. It is important to note that not all ethnic groups were represented in each cancer type.

Just under two thirds of respondents reported having received a diagnosis since 2020 (446, 60%). Of these, 11 have had their blood cancer transform, 25 had a relapse, and 3 have had both. One third of respondents were diagnosed before 2020 (245, 33%), and of these 4 have had their blood cancer transform since 2020, 29 have experienced a relapse since 2020, and 1 has experienced both. Some people did not select a diagnosis category, and reported only either having a relapse (13), or have had their blood cancer transform since 2020 (19), and 18 participants chose not to say. There was a variety of number of lines or treatments across participants with either 10 treatments or 1 treatment being most common. Whether or not respondents had had treatment in the last 18 months did not appear to affect the number of lines of treatment they had received.

Overall, three-fifths of respondents (453, 61%) have had anti-cancer treatment in the last 18 months, and two-fifths (39%, 285) have not. A smaller proportion of people who were diagnosed before 2020 have received treatment in the last 18 months (26%).

Given the limited diversity in age across respondents is unlikely to yield reliable differences in responses by age group, any sub analyses will focus on exploring any differences between ethnic groups, cancer types, and self-reported rurality across respondents.

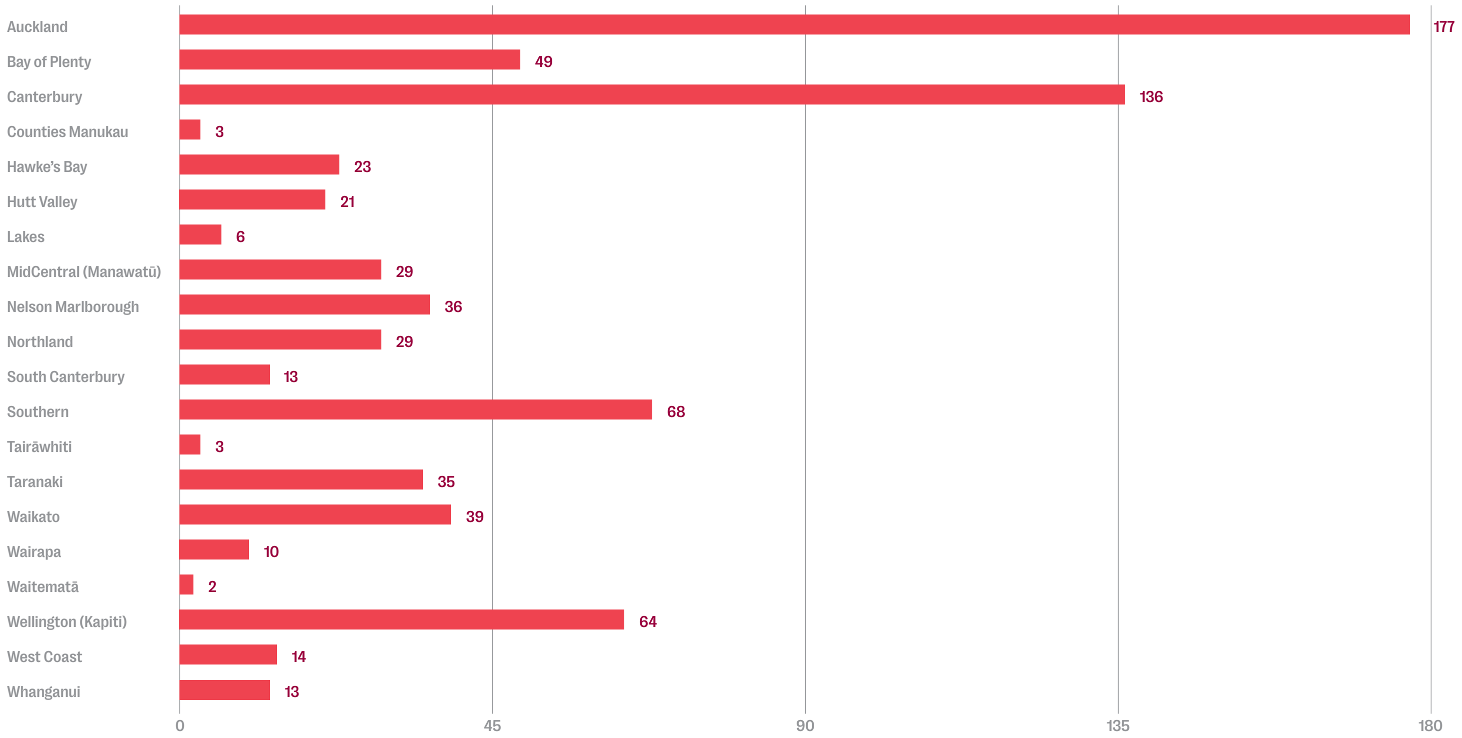

Figure 46
Respondent location (n=770)
Source: Patient and Caregiver Survey

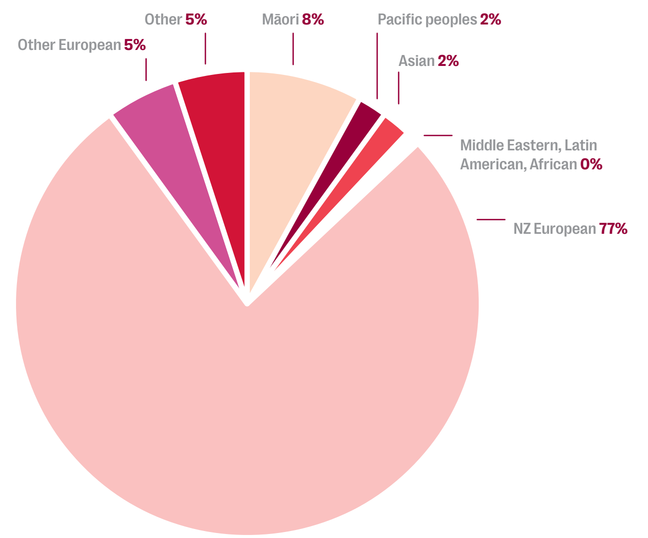

Figure 47
Total respondent ethnicity (n=809)
Source: Patient and Caregiver Survey

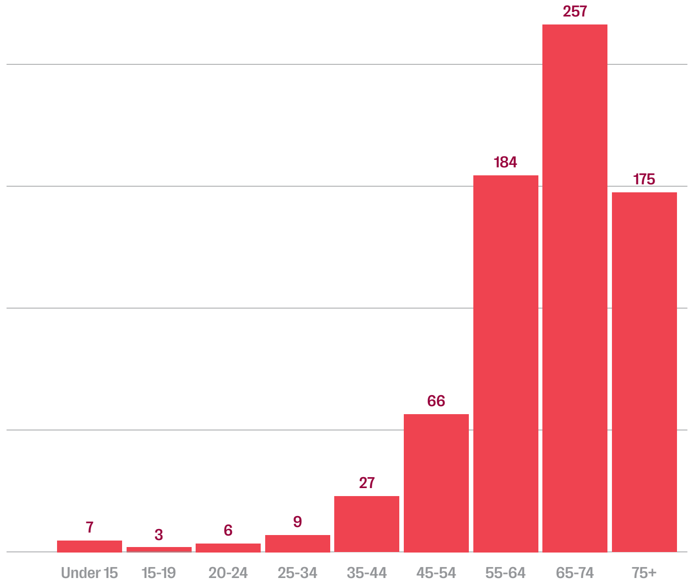

Figure 48
Respondent age (n=734)
Source: Patient and Caregiver Survey

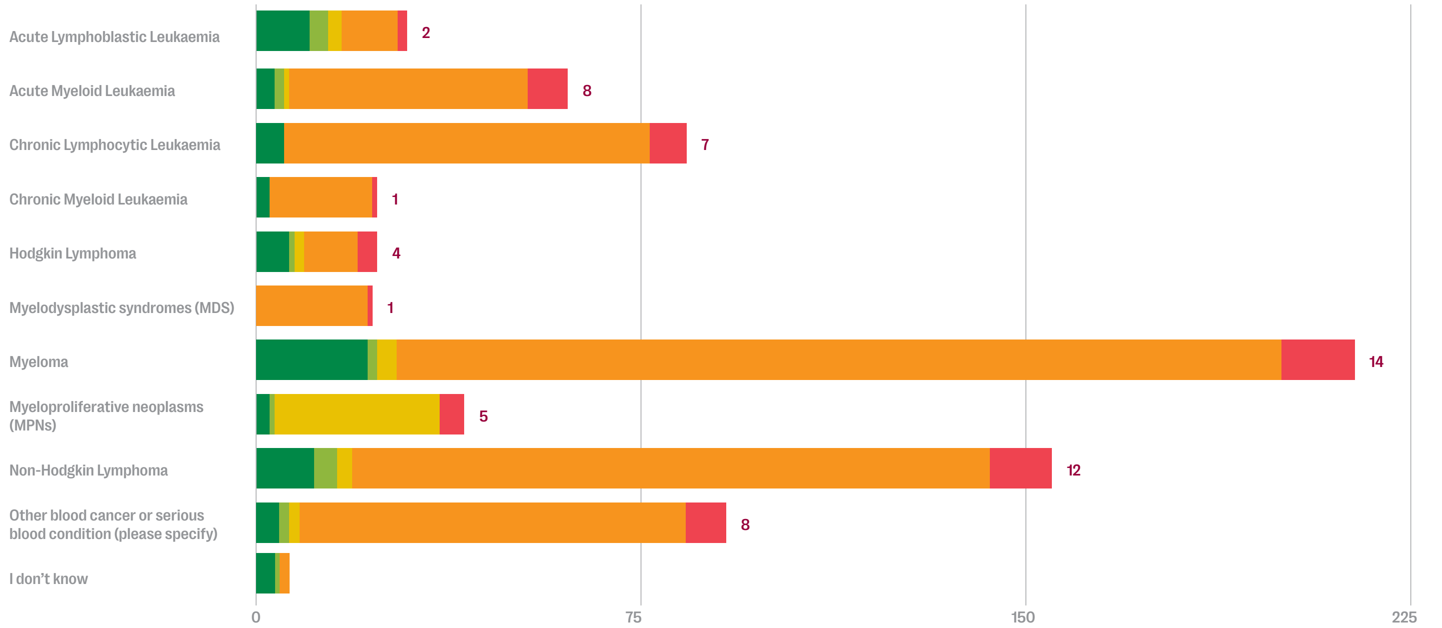

Figure 49
Blood cancer type across ethnicity of respondents
Source: Patient and Caregiver Survey

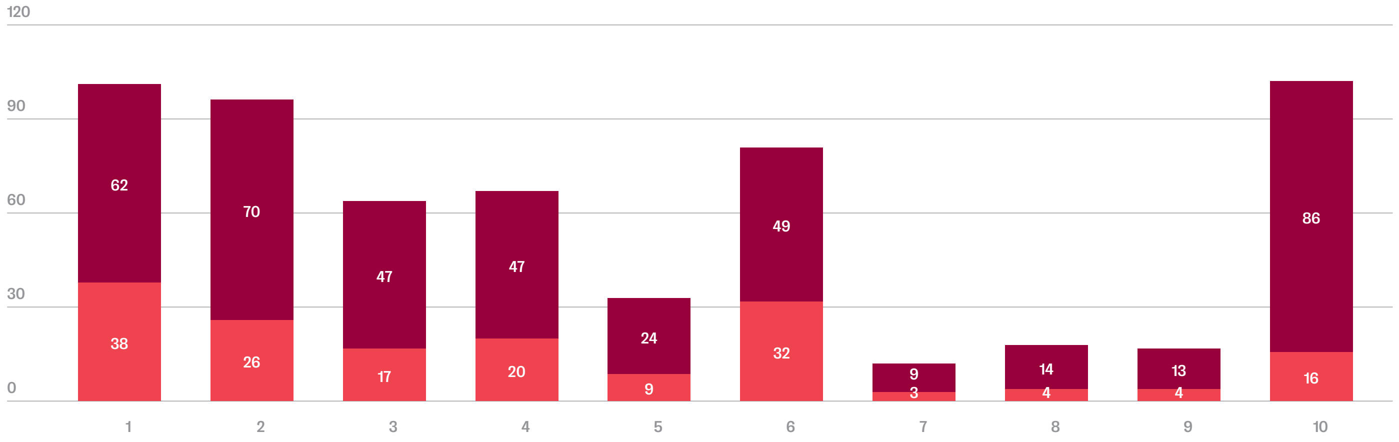

Figure 50
Number of lines/rounds of treatment (n=591)
Source: Patient and Caregiver Survey

5.3 Clinical Survey Demographics

There were 66 clinical staff and 19 allied health staff who responded to the survey. Among the 7 clinical staff who selected "other", six were different types of nurses and one was a non- training registrar.

The lack of general practitioners is a significant gap in the survey responses. The majority of respondents were from Auckland (31, 37%) or Wellington (17, 20%). Seven regions had less than two staff respond. Location is congruent with self-reported rurality, with 91% of staff respondents residing in a city or a suburb or town near a city.

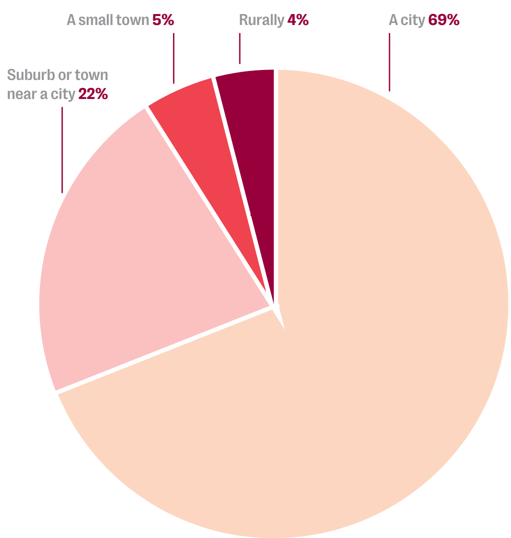

Figure 52
Self reported rurality
Source: Patient and Caregiver Survey

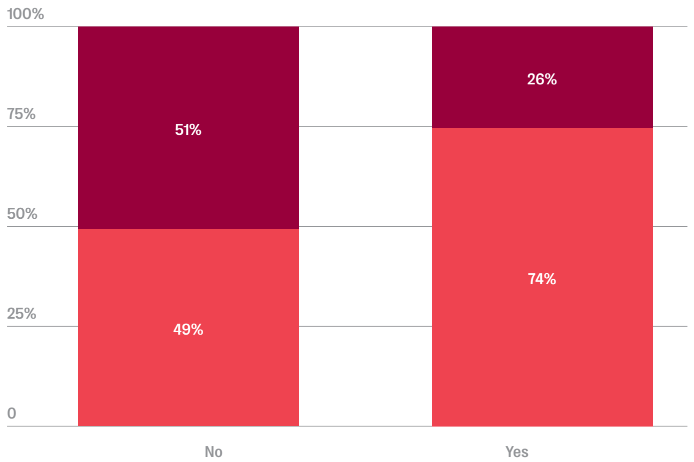

Figure 51
Proportion of those diagnosed with blood cancer who have received treatment in the last 18 months.
Source: Patient and Caregiver Survey

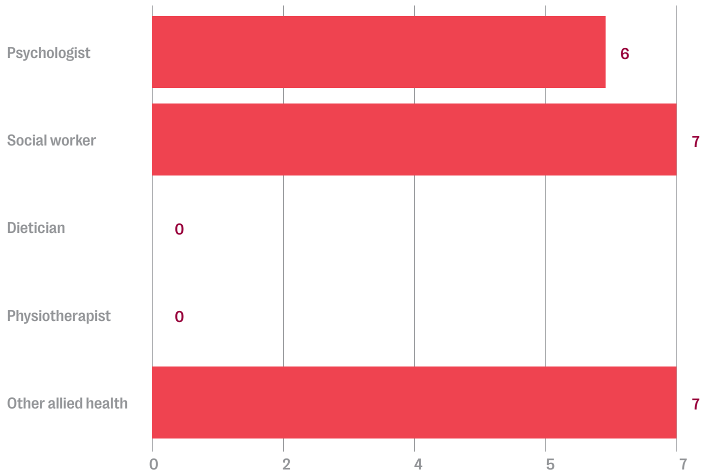

Figure 53
Clinical staff roles (n=66)
Source: Clinician Survey

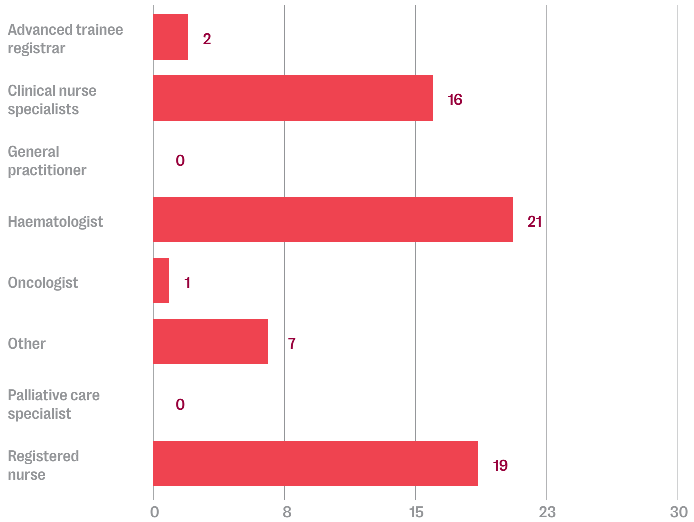

Figure 54
Allied Health staff roles (n=19)
Source: Clinician Survey

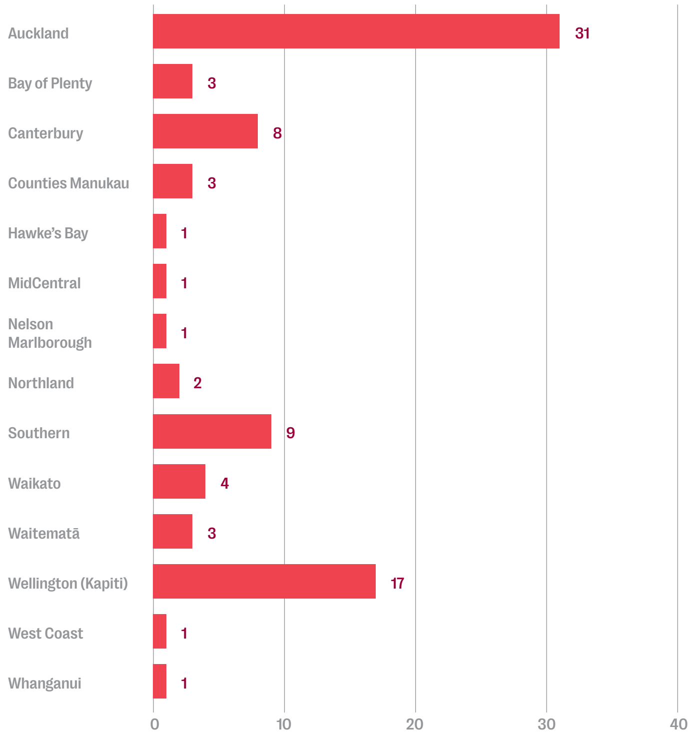

Figure 55
Location of staff (n=85)
Source: Clinician Survey

5.4 Supplementary Evidence

5.4.1 Hospital utilisation and costs

Within funded inpatient services, each hospital event is assigned a principal diagnosis i.e., the condition identified, after clinical assessment and investigation, as being primarily responsible for the patient's admission.

Casemix concerns the mix of patients treated, as described by a system which aggregates information about patients and treatments into groups based on the health condition or type of procedure (Ministry of Health, 2015). Casemix systems are used for a variety of purposes including hospital planning, clinical reviews, funding, monitoring, benchmarking and management.

Note that casemix funding applies to inpatient hospital admissions. Including only these events ensures there is a price for estimating costs. Costweights and price per costweight have been used to estimate costs. A costweight is a relative costs of the different inpatient events.

For events where a blood cancer condition (such as leukaemia, lymphoma, or myeloma) is recorded as the principal diagnosis, this indicates that the admission was directly related to the management or treatment

of the blood cancer itself. These events form the core of analysis for understanding the direct impact of blood cancers on hospital resource use, clinical workload, and funding.

In some casemix-funded inpatient events, blood cancer is not recorded as the principal diagnosis, but instead appears as a secondary or additional diagnosis. This means that while the patient has a blood cancer condition, the primary reason for admission was another health issue such as an infection, organ complication, or treatment side effect.

These events are still clinically significant because blood cancer may influence the complexity of care, even if it is not the main reason for admission. The presence of blood cancer can increase the risk of complications, prolong recovery, or require specialised management. These cases contribute to the overall

burden of disease and resource use, even if not directly attributed to cancer treatment. Table shows the proportion of total estimated costs between events that have blood cancer as the principal diagnosis and events with blood cancer as the secondary diagnosis.

The estimated cost of $135.1 million is based on the national price, which reflects the standard cost weight for a secondary service event. Additional costs not captured in the national price, such as tertiary services, are excluded in the estimated cost.

Year	No. of patients	No. of events	Total length of stays	Average length of stays per patient
2009	4,155	18,930	78,524	18.9
2010	4,329	19,962	88,225	20.4
2011	4,338	19,803	84,044	19.4
2012	4,548	19,998	84,149	18.5
2013	4,641	20,262	88,267	19.0
2014	4,632	19,146	72,979	15.8
2015	4,659	18,969	80,322	17.2
2016	4,845	19,740	85,815	17.7
2017	4,869	19,065	75,316	15.5
2018	5,028	18,822	77,452	15.4
2019	4,893	18,666	83,774	17.1
2020	4,944	18,969	72,432	14.7
2021	5,103	19,239	80,771	15.8
2022	5,061	18,711	69,495	13.7
2023	5,010	18,666	75,998	15.2

Table 15
Hospital discharges
Source: Integrated Data Infrastructure

5.4.1.1 Hospital utilisation and costs by blood cancer type

For the purposes of this analysis, blood cancers have been broadly categorised into seven diagnostic groups based on the NZ ICD-10-AM codes and the Health NZ web tool grouping. These groupings reflect the major types of haematological malignancies commonly encountered in hospital settings across New Zealand:

- Hodgkin Lymphoma
- Immunoproliferative Cancers
- Leukaemia
- Myelodysplastic Syndrome
- Myeloma
- Non-Hodgkin Lymphoma
- Uncertain Behaviour of Lymphoid, Haematopoietic and Related Tissue

Within the total volume of publicly funded inpatient activity in 2023, approximately 62.6% of events were casemix-funded, accounting for around 91.4% of the total inpatient costs.

In 2023, within all casemix-funded inpatient activities, events where a blood cancer ICD code was recorded as the principal diagnosis accounted for a slightly greater share of hospital resource use compared to those where the condition was recorded as secondary diagnosis.

Principal diagnosis events made up 53.2% of all casemix-funded events, contributing to 53.0% of the total length of stay, 59.5% of total cost-weighted discharges, and 59.5% of total inpatient costs. In contrast, events with blood cancer as secondary diagnosis represented 46.8% of events, 47.0% of the total length of stay, and accounted for 40.5% of both total cost-weighted discharges and costs.

This distribution highlights that while secondary diagnosis events are nearly as frequent as principal ones, they tend to be associated with lower clinical complexity and cost per event, as reflected in their smaller share of cost-weighted discharges and cost.

In 2023, casemix-funded inpatient events in New Zealand with blood cancer ICD codes as the principal diagnosis were most commonly associated with three major cancer types. Leukaemia accounted for 34.2% of events, followed by non-Hodgkin lymphoma at 32.1%, and myeloma at 16.7%. These three categories represented the majority of blood cancer-related hospitalisations where the condition was the primary reason for admission.

When blood cancer was recorded as a secondary diagnosis, the distribution shifted slightly. Leukaemia remained the most prevalent, associated with 41.1% of events, while non-Hodgkin lymphoma and myeloma accounted for 23.3% and 17.4% of events, respectively.

Leukaemia-related inpatient activity also demonstrated the highest resource intensity among secondary diagnosis events. Patients with leukaemia had an average length of stay of 16.7 days per person, and 6.2 days per event. These events also carried the highest average cost-weighted discharges, with 6.5 per unique patient and 2.4 per event, indicating a high level of clinical complexity and resource use. Non-Hodgkin lymphoma followed, with an average length of stay of 10.9 days per patient and 5.5 days per event.

In 2023, a total of 2,844 patients were hospitalised with blood cancer recorded as a secondary diagnosis, accounting for 5,325 inpatient events and a combined length of stay of 28,353 days. These events generated 7,806.6 cost-weighted discharges and an estimated total cost of $54.7m.

Among the cancer types as secondary diagnosis in 2023, Leukaemia had the highest impact, with 828 patients and 2,187 events, resulting in 8,215 hospital days, 2,556.8 cost-weighted discharges, and an estimated cost of $17.9m.

Non-Hodgkin lymphoma followed, with 714 patients and 1,239 events, contributing to 6,985 hospital days and $12.7m in estimated costs.

Myeloma also represented a significant burden, with 597 patients, 924 events, and $10.4m in costs. While other cancer types such as myelodysplastic syndrome, uncertain behaviour of lymphoid/haematopoietic tissue, Hodgkin lymphoma, and immunoproliferative cancers contributed smaller but still notable shares of inpatient activity and cost.

Over the 15-year period from 2009 to 2023, the distribution of costs across different blood cancer types for casemix-funded inpatient events with a principal diagnosis of blood cancer has remained relatively stable with a slight upward trend. There has been minimal change in the proportional cost share between cancer types, indicating consistent patterns in how inpatient resources are allocated across the spectrum of blood cancers.

However, during the same period, there has been a gradual increase in average costs per unique patient per year across all blood cancer types.

Over the 15-year period from 2009 to 2023 blood cancers recorded as secondary diagnoses in casemix-funded inpatient events have also contributed significantly to hospital resource use and costs.

Year	No. of patients	No. of events (including day case and non-day case)	Estimated cost	Average no of events per patient	Average length of stays per patient	Average cost per patient
2009	3,483	9,597	$67,651,702	2.8	15.3	$19,423
2010	3,606	9,930	$72,224,058	2.8	14.7	$20,029
2011	3,591	9,828	$73,543,097	2.7	14.8	$20,480
2012	3,774	9,807	$75,637,874	2.6	14.3	$20,042
2013	3,819	9,876	$77,795,629	2.6	14.0	$20,371
2014	3,888	9,861	$77,298,948	2.5	14.1	$19,881
2015	3,894	9,720	$77,712,872	2.5	13.8	$19,957
2016	4,104	10,122	$87,948,037	2.5	14.1	$21,430
2017	4,164	10,632	$91,915,679	2.6	13.6	$22,074
2018	4,389	10,590	$98,224,118	2.4	13.4	$22,380
2019	4,188	10,437	$97,489,221	2.5	13.6	$23,278
2020	4,293	10,599	$100,468,471	2.5	13.3	$23,403
2021	4,458	11,235	$114,148,597	2.5	13.3	$25,605
2022	4,380	11,217	$119,815,126	2.6	13.4	$27,355
2023	4,353	11,370	$135,087,586	2.6	13.8	$31,033

Table 16
Hospital discharges (Casemix-funded only)
Source: Integrated Data Infrastructure

Diagnosis type	No. of patients	No. of events	Estimated cost	% of cost
Principal diagnosis	2,733	6,042	$80,376,913	59.5%
Secondary diagnosis	2,736	5,328	$54,710,673	40.5%
Total	5,469	11,370	$135,087,586	100.0%

Table 17
Hospital discharges – diagnosis types in 2023
Source: Integrated Data Infrastructure

Blood cancer type	No. of patients	No. of events	Length of stays (total)	No of events per patient
Hodgkin Lymphoma	159	537	1,839	3.4
Immunoproliferative cancers	102	324	707	3.2
Leukaemia	1,335	6,021	25,350	4.5
Myelodysplastic Syndrome	552	2,550	7,671	4.6
Myeloma	1,107	3,186	14,091	2.9
Non-Hodgkin lymphoma	1,506	4,539	20,945	3.0
Uncertain behaviour of lymphoid, haematopoietic and related tissue	534	1,509	5,395	2.8

Table 18
Inpatient activities by blood cancer type (All publicly funded events) in 2023
Source: Integrated Data Infrastructure

Blood cancer type	No. of patients	No. of events	Length of stays	Total cwd	Estimated cost
Hodgkin Lymphoma	117	207	802	339.2	$2,416,026
Immunoproliferative cancers	51	147	204	113.8	$794,402
Leukaemia	771	2,067	12,859	5,025.4	$35,167,311
Myelodysplastic Syndrome	177	279	1,214	466.1	$3,240,912
Myeloma	531	1,011	5,372	1,642.0	$11,615,352
Non-Hodgkin lymphoma	981	1,941	10,649	3,420.1	$23,921,510
Uncertain behaviour of lymphoid, haematopoietic and related tissue	171	390	831	451.6	$3,221,401
Total	2,799	6,042	31,931	11,458.3	$80,376,913

Table 19
Casemix-funded inpatient activities by blood cancer type (Principal diagnosis) – total in 2023
Source: Integrated Data Infrastructure

Blood cancer type	Average events per patient	Average los per patient	Average cwd per patient	Average cwd per event	Average cost per patient	Average cost per event
Hodgkin Lymphoma	1.8	6.9	2.9	1.6	$20,650	$11,672
Immunoproliferative cancers	2.9	4.0	2.2	0.8	$15,577	$5,404
Leukaemia	2.7	16.7	6.5	2.4	$45,613	$17,014
Myelodysplastic Syndrome	1.6	6.9	2.6	1.7	$18,310	$11,616
Myeloma	1.9	10.1	3.1	1.6	$21,874	$11,489
Non-Hodgkin lymphoma	2.0	10.9	3.5	1.8	$24,385	$12,324
Uncertain behaviour of lymphoid, haematopoietic and related tissue	2.3	4.9	2.6	1.2	$18,839	$8,260

Table 20
Casemix-funded inpatient activities by blood cancer type (Principal diagnosis) – averages in 2023
Source: Integrated Data Infrastructure

Blood cancer type	No. of patients	No. of events	Length of stays	Total cwd	Estimated cost
Hodgkin Lymphoma	69	132	706	198.0	$1,400,148
Immunoproliferative cancers	39	66	380	102.2	$720,335
Leukaemia	828	2,187	8,215	2,556.8	$17,935,735
Myelodysplastic Syndrome	306	435	3,261	772.5	$5,410,657
Myeloma	597	924	5,605	1,465.1	$10,356,762
Non-Hodgkin lymphoma	714	1,239	6,985	1,820.7	$12,670,364
Uncertain behaviour of lymphoid, haematopoietic and related tissue	291	342	3,201	891.3	$6,216,671
Total	2,844	5,325	28,353	7,806.6	$54,710,673

Table 21
Casemix-funded inpatient activities by blood cancer type (Secondary diagnosis) – total in 2023
Source: Integrated Data Infrastructure

Blood cancer type	Average events per patient	Average los per patient	Average cwd per patient	Average cwd per event	Average cost per patient	Average cost per event
Hodgkin Lymphoma	1.9	10.2	2.9	1.5	$20,292	$11,672
Immunoproliferative cancers	1.7	9.7	2.6	1.5	$18,470	$5,404
Leukaemia	2.6	9.9	3.1	1.2	$21,662	$17,014
Myelodysplastic Syndrome	1.4	10.7	2.5	1.8	$17,682	$11,616
Myeloma	1.5	9.4	2.5	1.6	$17,348	$11,489
Non-Hodgkin lymphoma	1.7	9.8	2.5	1.5	$17,746	$12,324
Uncertain behaviour of lymphoid, haematopoietic and related tissue	1.2	11.0	3.1	2.6	$21,363	$8,260

Table 22
Casemix-funded inpatient activities by blood cancer type (Secondary diagnosis) – averages in 2023
Source: Integrated Data Infrastructure

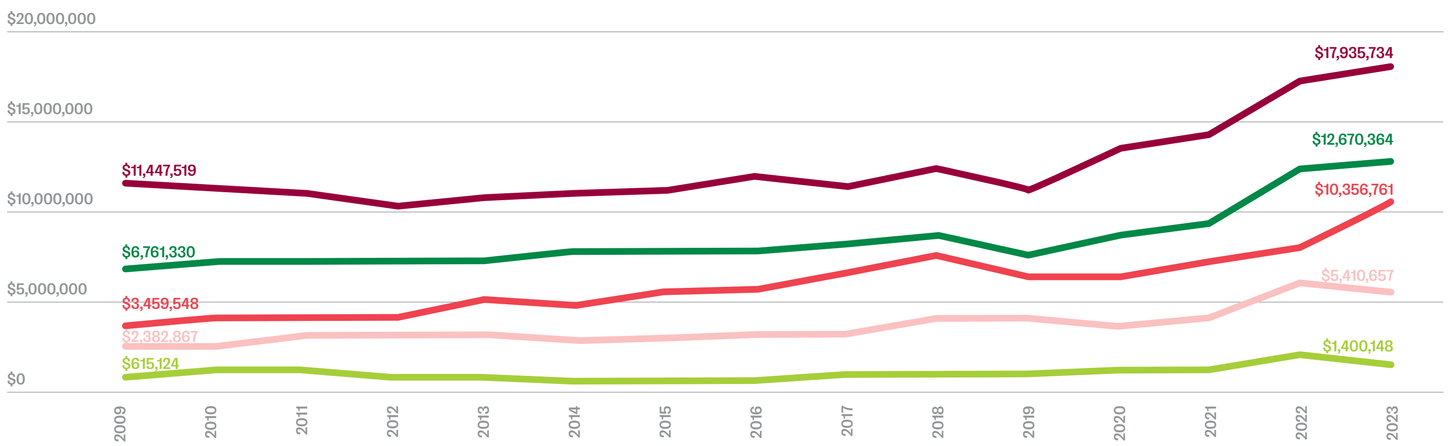

Figure 56
Estimated cost for casemix-funded inpatient events with blood cancer as secondary diagnosis (2009-2023)
Source: Integrated Data Infrastructure

Blood cancer type	Total unique person	Total outpatient events	Avg event per person	% of unique person
Leukaemia	3714	22923	6.2	25.7%
Hodgkin Lymphoma	651	3726	5.7	4.5%
Immunoproliferative cancers	387	1686	4.4	2.7%
Non-Hodgkin lymphoma	4707	25083	5.3	32.6%
Myelodysplastic Syndrome	756	5703	7.5	5.2%
Myeloma	2673	24078	9.0	18.5%
Uncertain behavior of lymphoid, haematopoietic and related tissue	1548	5727	3.7	10.7%
Total	14436	88926	41.8	100%

Table 23
Outpatient activity in 2023 by blood cancer type
Source: Integrated Data Infrastructure

5.4.1.2 Demographic trends for hospital and casemix funding

In 2023, casemix-funded inpatient events with a blood cancer ICD code as the principal diagnosis showed notable variation across age groups.

In 2023, casemix-funded inpatient events with a blood cancer ICD code as the principal diagnosis showed notable variation across districts. Canterbury and several smaller districts – Tairāwhiti, Wairarapa, West Coast, and South Canterbury – recorded higher event rates per patient, ranging from 2.7 to 2.9 events per person.

Lakes, Tairāwhiti, and Wairarapa had the highest total length of stay per patient, between 20.7 and 22.0 days annually. When looking at length of stay per event, Lakes, Capital & Coast, Counties Manukau, and Wairarapa reported the longest durations, ranging from 7.7 to 8.5 days.

Cost data also varied significantly. The highest average cost per patient was observed in the Lakes district at $51,830, while Hawke's Bay recorded the lowest at $16,380. Similarly, the highest average cost per event was $21,340 in Lakes and $19,180 in Capital & Coast. The lowest average event costs, ranging from $8,450 to $9,880, were seen in Canterbury, Hawke's Bay, Northland, South Canterbury, and West Coast.

These differences likely reflect a combination of factors, including patient complexity, local service delivery models, and inter-district transfers to larger centres with specialist cancer services.

In 2023, casemix-funded inpatient events with a blood cancer ICD code as the principal diagnosis showed notable variation across ethnic groups in New Zealand.

Māori patients had the highest number of events per patient, the longest total length of stay per patient, and the highest average cost-weighted discharges per patient – indicating more complex care needs and greater resource use. Asian patients recorded the longest average length of stay per event and the highest average cost-weighted discharges per event. They also had the second-highest total length of stay and cost-weighted discharges per patient.

Cost patterns reflected these differences. Māori patients had the highest average cost per patient at $41,440, while the lowest was $26,990 among non-Māori, non-Pacific, non-Asian patients. Asian patients had the highest average cost per event at $18,793, compared to the lowest of $12,390 for the same non-Māori, non-Pacific, non-Asian group.

Age	No. of patients	No. of events	Length of stays	Total cwd	Estimated cost
00-04	48	186	1,140	496.8	$3,436,025
05-14	99	363	1,410	686.1	$4,828,285
15-24	78	294	2,367	862.6	$6,076,015
25-44	186	528	3,756	1,352.2	$9,440,572
45-54	234	606	3,186	1,151.4	$8,113,870
55-64	528	1,311	6,928	2,420.2	$16,984,629
65-74	729	1,476	7,696	2,650.2	$18,587,528
75+	828	1,281	5,448	1,838.8	$12,909,987
Total	2,730	6,045	31,931	11,458.3	$80,376,913

Table 24
Total hospital resource use for blood cancer by age group, 2023
Source: Integrated Data Infrastructure

Ethnicity	No. of patients	No. of events	Length of stays	Total cwd	Estimated cost
Asian	198	420	3,219	1,144.0	$7,893,022
Māori	219	555	3,646	1,292.5	$9,075,170
Other	2,190	4,770	23,262	8,408.5	$59,105,576
Pacific Peoples	129	300	1,804	613.4	$4,303,145
Total	2,736	6,045	31,931	11,458.3	$80,376,913

Table 25
Casemix-funded events with blood cancer as principal diagnosis by ethnicity – total in 2023
Source: Integrated Data Infrastructure

Ethnicity	Average events per patient	Average los per patient	Average cwd per patient	Average cwd per event	Average cost per patient	Average cost per event
Asian	2.1	16.3	5.8	2.7	$39,864	$18,793
Māori	2.5	16.6	5.9	2.3	$41,439	$16,352
Other	2.2	10.6	3.8	1.8	$26,989	$12,391
Pacific	2.3	14.0	4.8	2.0	$33,358	$14,344

Table 26
Casemix-funded events with blood cancer as principal diagnosis by ethnicity – averages in 2023
Source: Integrated Data Infrastructure

Day case and non-day case inpatient activities

In the context of blood cancer treatment, inpatient activity can also be observed and categorised into day case and non-day case. Day cases involve procedures or treatments where patients are admitted and discharged on the same day, while non-day cases require an overnight stay or longer due to the complexity or intensity of the treatment or the patient's condition.

In 2023, casemix-funded inpatient events with a blood cancer ICD code recorded as the principal diagnosis showed distinct differences between day case and non-day case activity.

Non-day case events accounted for 53.6% of all events, while 26.4% were day cases. The average length of stay per patient for non-day cases was 16.9 days.

In terms of clinical complexity, the average cost-weighted discharges per event was 3.1 for non-day cases, compared to 0.5 for day cases. Patients had an average of 1.7 non-day case events and 2.1 day case events per year.

Cost data further highlights the difference in resource use. The average cost per patient was $37,740 for non-day cases and $6,910 for day cases. On a per-event basis, the average cost was $21,940 for non-day cases and $3,310 for day cases.

These figures reflect the higher intensity and complexity of care associated with non-day case admissions, which typically involve longer stays and more resource-intensive treatment.

Acute and non-acute inpatient events

People diagnosed with blood cancers often require hospital care that varies in urgency and clinical complexity. It is useful to distinguish these hospital events as either acute or non-acute to better understand and plan for their care needs.

Acute events typically involve sudden or severe complications such as infections, bleeding, or treatment-related side effects which require immediate medical attention, often in a hospital's emergency department or oncology ward. These situations are common during intensive treatment phases or when the disease progresses rapidly.

On the other hand, non-acute events are usually planned admissions for ongoing care, such as chemotherapy, blood transfusions, or symptom management. These are important for maintaining quality of life and supporting long-term treatment goals, and may occur in both hospital and community-based settings.

In 2023, among casemix-funded inpatient events in New Zealand where blood cancer ICD codes were recorded as the principal diagnosis, 27.7% were classified as acute, while 72.3% were non-acute. This distribution highlights that the majority of hospitalisations for blood cancer involved planned or lower-urgency care.

The average cost per event also varied significantly between the two categories. Acute events incurred an average cost of $18,730 per admission, compared to $11,230 for non-acute events. This cost difference reflects the higher resource demands typically associated with acute care episodes.

Similarly, the average cost-weighted discharges were higher for acute events at 2.7, compared to 1.6 for non-acute events. These figures reinforce the greater intensity and complexity of acute inpatient care for blood cancer patients.

5.4.1.3 Outpatient services

The outpatient cohort comprises blood cancer patients with events recorded in the National non-admitted patient collection (NNPAC) containing blood cancer-related Purchase Unit (PU) codes, explicitly excluding Accident Compensation Corporative (ACC)-funded events, as these are considered non-medical activities.

Outpatient utilisation shows significant growth, with 14,436 unique patients accounting for 88,923 events in 2023. While unique patient numbers increased steadily from 2007 to 2021, a slight decline (-1.2%) occurred from 2021 to 2023.

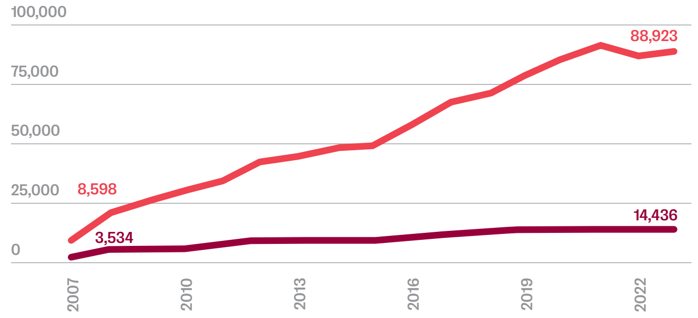

Figure 57
Outpatient count and events from 2007-2023
Source: Integrated Data Infrastructure

Non-Hodgkin Lymphoma patients constituted the largest cohort (32.6%, 4707 patients), followed by Leukaemia patients (25.7%, 3714 patients). Patients with Myeloma required the most frequent visits (9.0 events/patient), reflecting intensive treatment protocols, followed by Myelodysplastic Syndrome (7.5 events/patient) and Leukaemia (6.2 events/patient).

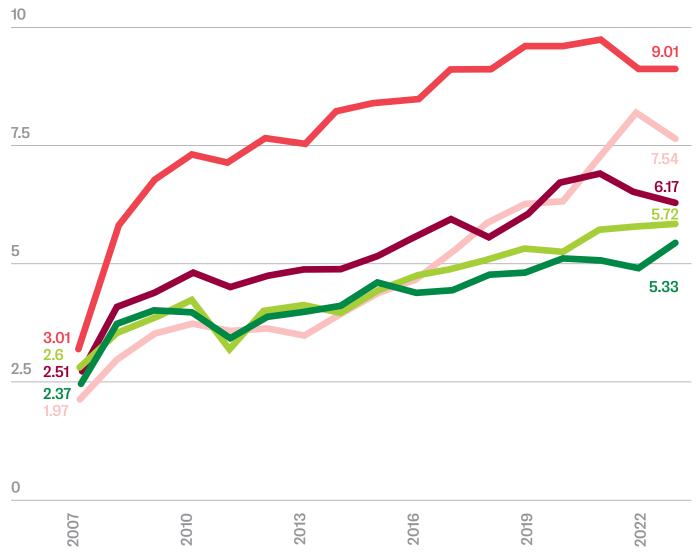

Figure 58
Average outpatient event per patient by cancer type from 2007-2023
Source: Integrated Data Infrastructure

The average number of outpatient events per patient has generally been increasing across all cancer type from 2007 – 2023.

- Hodgkin Lymphoma: 2.6 in 2007 to 5.7 in 2023
- Immunoproliferative cancers: 2.2 in 2007 to 4.4 in 2023
- Leukaemia: 2.5 in 2007 to 6.2 in 2023
- Myelodysplastic Syndrome: 2.0 in 2007 to 7.5 in 2023
- Myeloma: 3.0 in 2007 to 9.0 in 2023
- Non-Hodgkin Lymphoma: 2.4 in 2007 to 5.3 in 2023
- Uncertain behaviour of lymphoid, haematopoietic and related tissue: 2.0 in 2007 to 3.7 in 2023

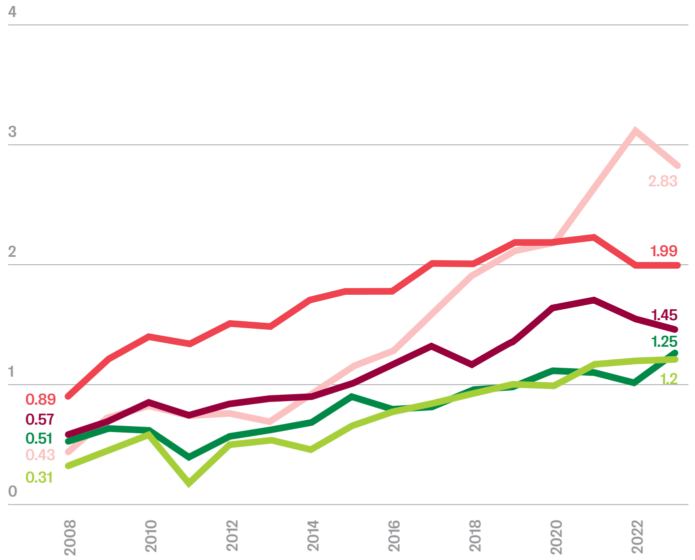

Figure 59
Rate of average outpatient event per patient increase by cancer type from 2007-2023
Source: Integrated Data Infrastructure

Myelodysplastic Syndrome has shown the fastest rate of increase followed by Myeloma and Hodgkin Lymphoma.

Total outpatient expenditure reaches $56.9 million in 2023 – a 5.8-fold increase from 2009 with an average of $3,973 per patient and $684 per event. In general, 93% of the costs were associated with follow up appointments with only 2.2% of events were recorded as "Did Not Attend"

Cost Analysis

Over the past 15 years, the total outpatient cost has increased with respect to the total outpatient events. From $9.8m in 2009 to $56.9m in 2023 – a 5.8 times increase. When looking in terms of average, the magnitude is smaller:

- Average outpatient cost per patient at 2.4x ($1,632 in 2009 to $3,973 in 2023)
- Average outpatient cost per event at 1.8x ($387 in 2009 to $684 in 2023)

Patients (00-04 years) demonstrated exceptionally high utilisation (17.5 visits/patient), nearly double the rate of 05-14 years old (8.1 visits/patient).

Older Adults (65+) accounted for 61.6% of costs ($35.1 million), while children (00-04) incurred the highest per-patient costs ($10,700).

Other ethnicity make up 81.2% of total outpatient cost incurring $46.2m reflecting population distribution, followed by Māori at 7.6% $4.3m, Asian 7.2% $4.1m and Pacific People 3.9% at $2.2m. Asian have the highest average per patient cost at $4,700. Pacific People have the highest average cost per event at $718.

Year	Total unique person	Total outpatient events	Avg event per person	Total outpatient cost	Avg cost per unique person	Avg cost per event
2009	5976	25197	4.2	$9,753,228	$1,632	$387
2010	6513	27564	4.2	$11,519,386	$1,769	$418
2011	7026	26685	3.8	$10,060,561	$1,432	$377
2012	7398	27429	3.7	$9,739,530	$1,317	$355
2013	9552	34356	3.6	$12,660,312	$1,325	$369
2014	9912	39075	3.9	$15,031,157	$1,516	$385
2015	9696	44583	4.6	$19,193,260	$1,980	$431
2016	11184	56883	5.1	$25,234,898	$2,256	$444
2017	12135	64755	5.3	$27,869,952	$2,297	$430
2018	12855	69252	5.4	$31,273,540	$2,433	$452
2019	13434	76515	5.7	$37,313,771	$2,778	$488
2020	13872	83997	6.1	$45,736,132	$3,297	$544
2021	14502	89769	6.2	$56,472,592	$3,894	$629
2022	14313	84717	5.9	$58,749,539	$4,105	$693
2023	14313	83172	5.8	$56,869,709	$3,973	$684

Table 27
Outpatient cost from 2009-2023
Source: Integrated Data Infrastructure

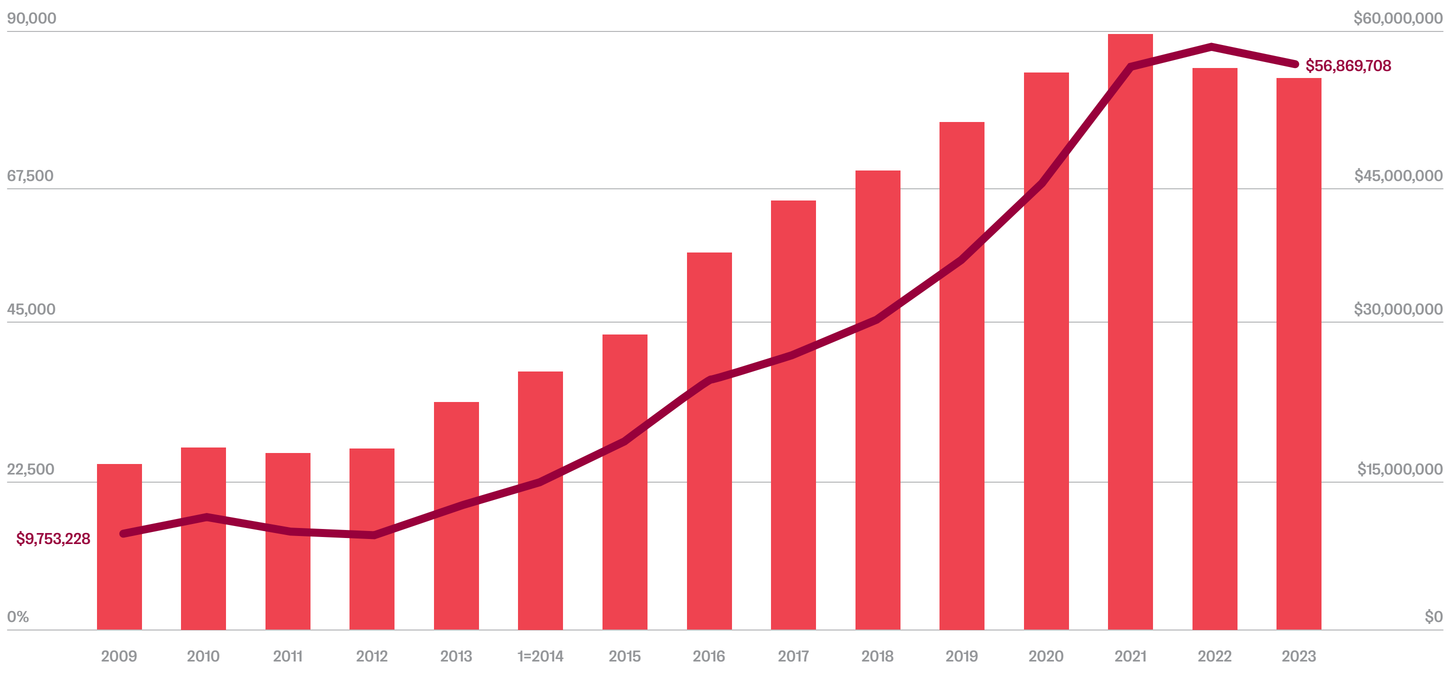

Figure 60
Total outpatient events and costs from 2009 to 2023
Source: Integrated Data Infrastructure

Urban centres dominated utilisation with Waitemata, Counties Manukau and Auckland DHB collectively accounting for 32.2% of national outpatient costs ($18.3m) (Table 29). Counties Manukau recorded the highest per-patient cost at $5,220 -31% above the national average paired with the second-highest visit frequency of 7.1 events/patient (Table 29). This likely reflects its role as a tertiary referral hub for complex cases. Rural DHBs showed markedly lower intensity

- Nelson Marlborough and West Coast had the lowest-per-patient costs (~$2,000) and visit rates of 3.6 events per patient
- Tairawhiti and South Canterbury followed similar patterns.

The 2.6x cost differential between urban/rural DHBs suggest either there is an under-utilisation in rural areas due to access barriers or appropriate risk-stratification redirecting complex cases to urban centres.

Emergency department (ED) services

Blood cancer patients frequently visit EDs due to complications such as infections, pain, or treatment side effects. ED events were identified by PU codes beginning with "ED" and exclude accident-related cases.

ED services recorded 9,318 unique patients and 19,278 events in 2023. This includes both admitted and discharged services and only discharged ED events would be included in the cost calculation below.

The number of ED events and person have stayed fairly stable over the years.

In 2023, almost 70% of visits resulted in hospitalisation (admitted into inpatient), indicating high clinical acuity and only 30% have been discharged.

Non-Hodgkin Lymphoma patients constituted the largest cohort (33.4%, 3111 patients), followed by Leukaemia patients (25.6%, 2388 patients). The average visit per cancer type is more than 2 across all cancer type with Myelodysplastic Syndrome patients showing the highest ED reliance (2.5 visits/patient).

The average number of ED events per patient increased at a slower rate compared to outpatient across all cancer types from 2007 – 2023.

- Hodgkin Lymphoma: 1.51 in 2007 to 2.03 in 2023
- Immunoproliferative cancers: 1.58 in 2007 to 1.97 in 2023
- Leukaemia: 1.50 in 2007 to 2.05 in 2023
- Myelodysplastic Syndrome: 1.61 in 2007 to 2.50 in 2023
- Myeloma: 1.51 in 2007 to 2.09 in 2023
- Non-Hodgkin Lymphoma: 1.50 in 2007 to 2.01 in 2023
- Uncertain behaviour of lymphoid, haematopoietic and related tissue: 1.66 in 2007 to 2.03 in 2023

Myelodysplastic Syndrome showed the fastest growing rate in average number of ED events per patient.

Total ED costs reached $2.4 million in 2023 with an average of $749 per patient. Per-event cost calculation would not be possible as admission and discharge is not included in this view.

Over the past 15 years, total ED cost increased from $1.5m in 2009 to $2.4m in 2023 – 1.6x increase. The average ED cost has a higher magnitude than total at 2.4x (from $439 in 2009 to $749 in 2023)

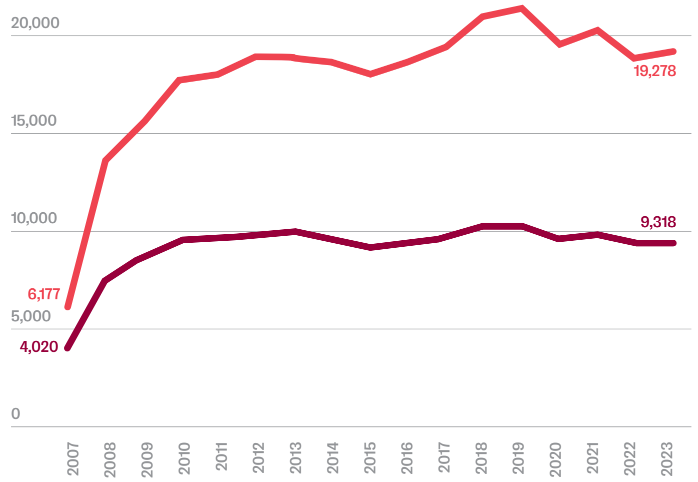

Figure 61
Unique ED count and events from 2007 to 2023
Source: Integrated Data Infrastructure

Age group	Total unique person	Total outpatient events	Avg event per person	Total outpatient cost	Avg cost per unique person	Avg cost per event	Avg cost per event
00-04	60	1,050	17.5	$640,457	$10,674	$610	1.1%
05-14	306	2,472	8.1	$1,470,531	$4,806	$595	2.6%
15-24	348	2,232	6.4	$1,438,948	$4,135	$645	2.5%
25-44	960	5,163	5.4	$3,370,152	$3,511	$653	5.9%
45-54	1,068	6,234	5.8	$4,185,488	$3,919	$671	7.4%
55-64	2,514	15,720	6.3	$10,710,456	$4,260	$681	18.8%
65-74	4,008	23,901	6.0	$16,545,252	$4,128	$692	29.1%
75+	5,046	26,406	5.2	$18,508,424	$3,668	$701	32.5%

Table 28
Outpatient activity in 2023 by age group
Source: Integrated Data Infrastructure

Ethnicity	Total unique person	Total outpatient events	Avg event per person	Total outpatient cost	Avg cost per unique person	Avg cost per event	% of total outpatient cost
Asian	876	5907	6.7	$4,117,005	$4,700	$697	7.2%
Māori	1005	6210	6.2	$4,317,647	$4,296	$695	7.6%
Other	11919	67947	5.7	$46,200,886	$3,876	$680	81.2%
Pacific	510	3111	6.1	$2,234,170	$4,381	$718	3.9%

Table 29
Outpatient activity in 2023 by ethnicity
Source: Integrated Data Infrastructure

DHB domicile	Total unique person	Total outpatient events	Avg event per person	Total outpatient cost	Avg cost per unique person	Avg cost per event	% of total outpatient cost
Auckland	1,197	7,383	6.2	$5,518,005	$4,610	$747	9.7%
Bay of Plenty	873	5,064	5.8	$3,410,531	$3,907	$673	6.0%
Canterbury	1,743	8,814	5.1	$5,402,492	$3,100	$613	9.5%
Capital and Coast	969	7,029	7.3	$5,038,861	$5,200	$717	8.9%
Counties Manukau	1,197	8,493	7.1	$6,245,827	$5,218	$735	11.0%
Hawkes Bay	570	3,108	5.5	$2,639,158	$4,630	$849	4.6%
Hutt Valley	486	2,910	6.0	$1,970,369	$4,054	$677	3.5%
Lakes	366	1,944	5.3	$1,271,796	$3,475	$654	2.2%
MidCentral	600	3,333	5.6	$2,216,631	$3,694	$665	3.9%
Nelson Marlborough	639	2,271	3.6	$1,303,039	$2,039	$574	2.3%
Northland	669	4,068	6.1	$2,647,187	$3,957	$651	4.7%
South Canterbury	162	654	4.0	$381,501	$2,355	$583	0.7%
Southern	1,128	6,531	5.8	$4,476,683	$3,969	$685	7.9%
Tairawhiti	150	561	3.7	$346,125	$2,307	$617	0.6%
Taranaki	423	2,208	5.2	$1,310,322	$3,098	$593	2.3%
Waikato	1,299	6,615	5.1	$4,472,111	$3,443	$676	7.9%
Wairarapa	213	1,266	5.9	$792,191	$3,719	$626	1.4%
Waitemata	1,464	9,453	6.5	$6,530,765	$4,461	$691	11.5%
West Coast	102	369	3.6	$213,594	$2,094	$579	0.4%
Whanganui	243	1,092	4.5	$682,518	$2,809	$625	1.2%

Table 30
Outpatient activity in 2023 by DHB region
Source: Integrated Data Infrastructure

Cancer Type	Total unique person	Total ED events	Avg event per person	% of unique person
Leukaemia	2388	4899	2.1	25.6%
Hodgkin Lymphoma	399	810	2.0	4.3%
Immunoproliferative cancers	195	384	2.0	2.1%
Non-Hodgkin lymphoma	3111	6255	2.0	33.4%
Myelodysplastic Syndrome	648	1623	2.5	7.0%
Myeloma	1458	3042	2.1	15.7%
Uncertain behaviour of lymphoid, haematopoietic and related tissue	1116	2265	2.0	12.0%
Total	9315	19278	14.7	100%

Table 31
ED activity in 2023 by blood cancer type
Source: Integrated Data Infrastructure

Year	Total unique person	Total ED events	Avg event per person	% of unique person	% of unique person
2009	3,447	5,124	1.5	$1,511,713	$439
2010	3,687	5,367	1.5	$1,559,711	$423
2011	3,648	5,211	1.4	$1,514,505	$415
2012	3,603	5,217	1.4	$1,482,424	$411
2013	3,759	5,277	1.4	$1,477,718	$393
2014	3,690	5,193	1.4	$1 ,478,934	$401
2015	3,504	4,989	1.4	$1,520,996	$434
2016	3,567	5,112	1.4	$1,647,621	$462
2017	3,702	5,421	1.5	$1,773,921	$479
2018	3,750	5,355	1.4	$1,801,828	$480
2019	3,630	5,244	1.4	$1,838,901	$507
2020	3,423	4,929	1.4	$1,881,572	$550
2021	3,570	5,031	1.4	$2,174,483	$609
2022	3,171	4,344	1.4	$2,092,640	$660
2023	3,186	4,452	1.4	$2,386,096	$749

Table 32
Emergency department utilisation and cost trends, 2009-2023
Source: Integrated Data Infrastructure

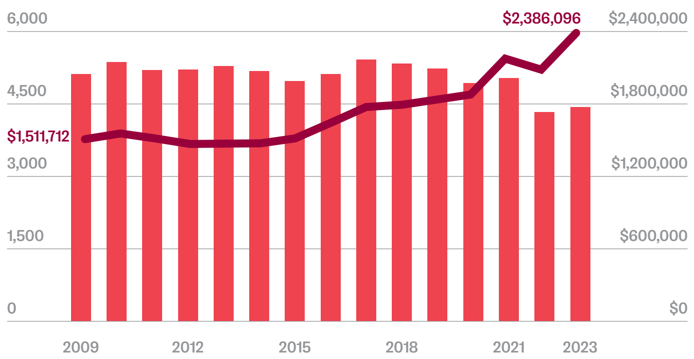

Figure 63
Total ED events and cost from 2009 to 2023
Source: Integrated Data Infrastructure

Cancer Type	Total unique person	Total ED events	Avg event per person	Total ED cost	Average cost per unique person	Average cost per event	% of total ED cost
Asian	141	168	1.2	$87,674	$622	$522	3.7%
Maori	348	555	1.6	$298,905	$859	$539	12.5%
Other	2,568	3,558	1.4	$1,907,034	$743	$536	79.9%
Pacific Peoples	129	174	1.3	$92,483	$717	$532	3.9%

Table 33
ED activity in 2023 by ethnicity
Source: Integrated Data Infrastructure

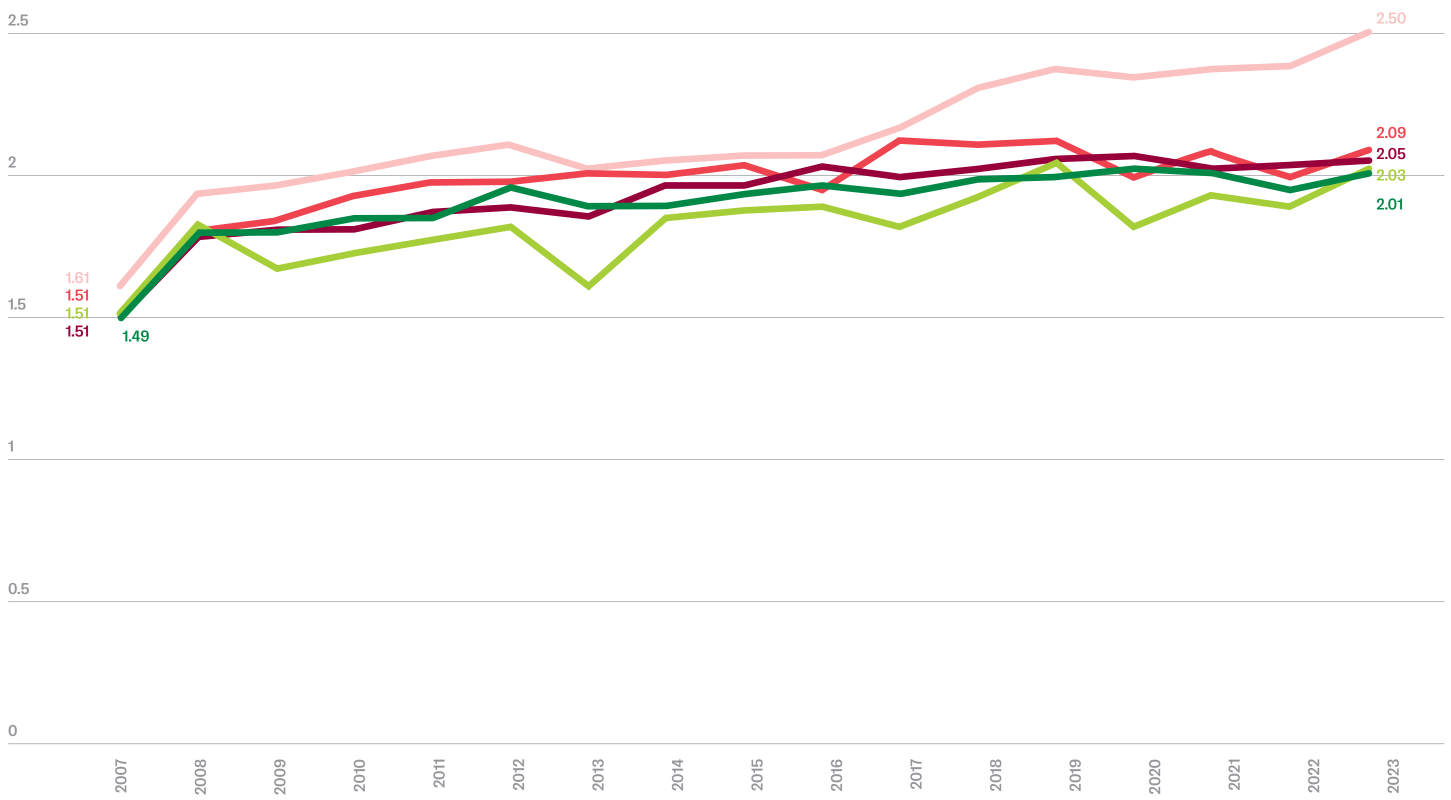

Figure 62
Average ED event per patient by cancer type from 2007-2023
Source: Integrated Data Infrastructure

DHB domicile	Total unique person	Total ED events	Avg event per person	Total ED cost	Avg cost per unique person	Avg cost per event	% of total ED cost
Auckland	114	138	1.2	$73,142	$642	$530	3.1%
Bay of Plenty	171	225	1.3	$120,563	$705	$536	5.1%
Canterbury	516	720	1.4	$377,369	$731	$524	15.8%
Capital and Coast	84	90	1.1	$47,105	$561	$523	2.0%
Counties Manukau	171	207	1.2	$107,946	$631	$521	4.5%
Hawkes Bay	138	183	1.3	$101,738	$737	$556	4.3%
Hutt Valley	78	99	1.3	$49,905	$640	$504	2.1%
Lakes	159	267	1.7	$141,010	$887	$528	5.9%
MidCentral	93	123	1.3	$64,487	$693	$524	2.7%
Nelson Marlborough	165	249	1.5	$127,362	$772	$511	5.3%
Northland	210	297	1.4	$166,539	$793	$561	7.0%
South Canterbury	66	81	1.2	$42,136	$638	$520	1.8%
Southern	372	534	1.4	$298,172	$802	$558	12.5%
Tairawhiti	72	102	1.4	$51,603	$717	$506	2.2%
Taranaki	144	249	1.7	$133,486	$927	$536	5.6%
Waikato	297	435	1.5	$245,031	$825	$563	10.3%
Wairarapa	54	72	1.3	$36,905	$683	$513	1.5%
Waitemata	228	288	1.3	$149,838	$657	$520	6.3%
West Coast	0	0	n/a	n/a	n/a	n/a	n/a
Whanganui	69	96	1.4	$50,133	$727	$522	2.1%

Table 34
ED activity in 2023 by DHB region
Source: Integrated Data Infrastructure

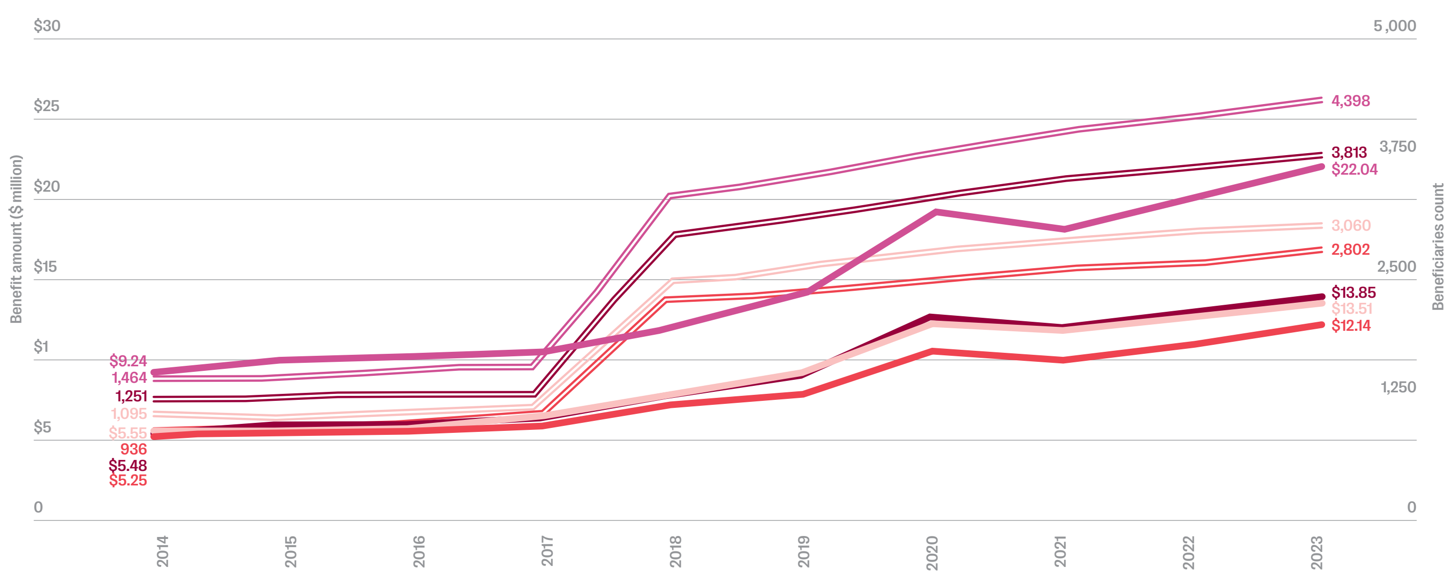

Figure 64
Total benefit amount and number of beneficiaries, by region, 2014-2023
Source: Integrated Data Infrastructure

5.4.2 Social system use

There are currently around 14,300 individuals with blood cancer accessing a social benefit. On average, each beneficiary received around $4,000 in benefits annually. The total social benefits incurred amounted to more than $56.3 million as of June 2024.

Benefits were categorised into work-related, health-related, and other kinds. In 2024, 471 people received work-related benefits ($3.3 million), 5,256 received health-related benefits ($29.1 million), and 13,611 received other types ($23.9 million). Health-related benefits were the highest in value. Māori received the highest average benefits across work-related and health-related categories. Other ethnicity group represented the majority of benefit recipients, a logical outcome given they are the largest blood cancer population.

There were two primary types of benefits accessed:

Main Benefits:

- Over 2,600 beneficiaries received main benefits, which include the Job Seeker Benefits and other Supported Living Payments.
- Main benefits constituted 60% of the total benefits amount, averaging $12,900 per person per year.
- Approximately $33.8 million was allocated for main benefits.

Supplementary Benefits:

- Over 14,000 beneficiaries received supplementary benefits, which include Disability Allowance and Accommodation Supplement.
- Supplementary benefits averaged $1,600 per person per year.
- Approximately $22.6 million was allocated for supplementary benefits.

Around 2,480 individuals, or 17.3% of the blood cancer beneficiaries, received both types of benefits.

Trends and Changes Over Time

The sharp increase in beneficiaries in 2018 is likely due to funding changes in BPS 1[11], this change has allowed the expansion of intensive case management services for jobseekers with a health condition or disability from 8,000 to 20,000.

The proportion of individuals receiving main benefits has decreased from 70.8% in 1995 to 60% in 2024. Despite this decline in proportion, the number of beneficiaries receiving main benefits has surged by 43.3% between 2014 and 2024. This increase is complemented by a 44.2% rise in the average main benefit amount per beneficiary, leading to the overall main benefit amount doubling over the same period.

In parallel, supplementary benefits have seen a dramatic rise. The number of beneficiaries has skyrocketed by 221.4%, more than tripling since 2014. Although the average supplementary benefit amount per beneficiary has decreased by 23.4%, the significant growth in beneficiary numbers has driven a 146.1% increase in total supplementary benefit payments.

Overall, the total number of beneficiaries has risen by

66.3% in the last ten years. However, there has been a notable decline in the proportion receiving both main and supplementary benefits, dropping from 31.4% in 2014 to 17.3% in 2024. These trends highlight a shift in benefit distribution, with more individuals accessing some form of support but fewer relying on both types concurrently. The most commonly accessed benefits were:

- Job Seeker Benefits: Approximately 1,200 individuals received Job Seeker Benefits, accounting for about 4.5% of the total blood cancer population.
- Job Seeker Health Condition & Disability: Represented 15% of total benefits paid.
- Supported Living Payment – Health Condition & Disability: Made up 32.4% of total benefits paid.
- Accommodation Supplement: also represented for 15% of total benefits paid.

Additional assistance such as the Disability Allowance and Winter Energy Payment are also widely utilised. Over 13,000 individuals accessed the winter energy payment, 4,250 the disability allowance, and 2,600 accommodation supplement.

[11] The Treasury Budget 2017 Information Release
Aide Memoire T2016/2017: Aide memoire for Vote Social Development baseline discussion - 31 October 2016 - The Treasury - Budget 2017 Information Release

Cancer Type	Unique Persons	Total benefit	Average benefit per person	% of Unique persons	% of total benefit	% of blood cancer population
Leukaemia	3,573	$14,694,092	$4,113	25.0%	26.1%	49.3%
Hodgkin Lymphoma	636	$ 5,616,714	$8,831	4.5%	10.0%	31.4%
Immunoproliferative cancers	333	$ 798,245	$2,397	2.3%	1.4%	60.7%
Non-Hodgkin lymphoma	5,571	$18,302,508	$3,285	39.0%	32.5%	55.8%
Myelodysplastic Syndrome	714	$ 2,029,244	$2,842	5.0%	3.6%	68.6%
Myeloma	1,773	$ 6,065,351	$3,421	12.4%	10.8%	61.4%
Uncertain behaviour of lymphoid, haematopoietic and related tissue	1,692	$ 8,833,684	$5,221	11.8%	15.7%	55.3%
Total	14,292	$56,339,839	$30,110	100.0%	100.0%	53.3%

Table 35
Benefits access amounts per person by blood cancer type
Source: Integrated Data Infrastructure

5.4.2.1 Job Seeker Benefits and Associated Trends

In 2024, blood cancer beneficiaries accessed approximately $9.9 million in Job Seeker Benefits, averaging $8,200 per person. The most common types of benefits among these recipients were "Job Seeker Health Condition & Disability" and "Job Seeker Work Ready." Notably, the financial support for those needing Job Seeker Work Ready benefits has surged by 243.8%, becoming 3.4 times higher than a decade ago in 2014. Similarly, Job Seeker Health Condition & Disability benefits have grown by 161.7%, or 2.6 times higher over the same period.

5.4.2.2 Disability Allowance and Supported Living Payment Health Condition & Disability

Approximately 4,250 individuals, accounting for 15.9% of individuals living with blood cancer, accessed the Disability Allowance in 2024. Additionally, 1,330 individuals (5%) received the Supported Living Payment tailored for those with health conditions and disabilities. Over the past decade, Supported Living Payment benefits have grown by 73.4%. The Disability Allowance also fluctuated, showing a 6.8% increase from 2014 to 2024.

5.4.2.3 Demographic trends

The demographic analysis of beneficiaries living with blood cancer receiving financial support highlights notable patterns. Across recipients, 81.8% are aged 65 and older, likely reflective of the older age of people living with blood cancer. Although the majority of beneficiaries are seniors, 71.2% of the benefits disbursed cater to individuals under 65. Notably, beneficiaries aged 45 to 54 receive the highest average annual benefit of approximately $16,200.

Age-related trends from 2014 to 2024 reveal significant increases in benefit recipients, particularly in the 65-74 age group, which saw a remarkable 375.2% rise in recipients and a 189.8% increase in total benefits, although with a 39% decrease in average annual benefits. Similarly, those aged 75 and above experienced a 261.7% rise in recipients and a 157.5% increase in total benefits, coupled with a 28.8% reduction in average benefits. Overall, all age groups saw a substantial increase in overall benefits received during this period.

Gender demographics show that females constitute 46.6% of beneficiaries living with blood cancer, while males make up 53.4%, with more male beneficiaries (7,626) than female (6,657) in 2024.

Female beneficiaries received 52.2% of total benefits, averaging $4,400 annually, compared to $3,500 for males. Despite males accounting for a larger increase in beneficiaries from 2014 to 2024, total benefits received by females exceeded those by males by about 9%.

Across ethnic groups, disparities were evident:

- Māori have the highest proportion of beneficiaries at 62.7% within their blood cancer cohort, comprising 8% of total beneficiaries and receiving 18% of overall benefits
- Pacific Peoples follow with 41.6% receiving benefits, making up 3.7% of total beneficiaries, and receiving 6.9% of total benefits.
- Asian beneficiaries have the lowest proportion at 34.3%, comprising 4.4% of total beneficiaries, and 5.9% of total benefits
- Other' ethnicities show a higher benefit reception rate at 54.8%, making up 83.9% of total beneficiaries, sharing 69.2% of total benefits.

'Other' ethnicities and Asian beneficiaries experienced a greater increase in number of recipients compared to Māori and Pacific people between 2014 to 2024. However, total benefit amounts for Māori and Pacific beneficiaries increased more significantly than for Asian and other ethnicities. Overall, Māori and Pacific blood cancer beneficiaries receive the highest average benefits, approximately $8,870 and $7,390 annually, respectively.

More than 75% of Asian and other ethnic groups receiving benefits were aged 65 and above, whereas Māori and Pacific peoples had a more varied age distribution, though higher%ages were still in the 65 and above group.

Beneficiaries across all ethnicities were predominantly from higher deprivation areas, indicating a socioeconomic influence on benefits distribution.

Deprivation analysis shows that 41.6% of beneficiaries reside in high deprivation areas, collectively receiving 57.5% of total benefits. Quintiles, compared to deciles mentioned previously, divide the population into 5 equal groups, with quintile 1 being the least deprived and quintile 5 the most deprived.

Quintile 5 beneficiaries receive the highest average benefit amount of about $6,580 annually, followed by quintile 4 at approximately $4,390. Over the past decade, lower quintiles have seen a greater increase in beneficiaries compared to higher quintiles, yet the trends show a decrease in average benefit for lower quintiles, while an increase for higher ones.

Sources of Tables and Figures

Please note this report draws on analyses from multiple entities.

Entity	Provider of
Blood Cancer NZ	Tables and figures with a source reference: New Zealand Cancer Registry
University of Auckland	Tables and figures with a source reference: University of Auckland epidemiological study
Deloitte	Tables and figures with a source reference: Integrated Data Infrastructure (IDI); Patient and Caregiver Survey; Clinician Survey

Authorship

Blood Cancer NZ and Deloitte, with input from leading haematologists, the University of Auckland, and other partners.

List of tables

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Blood Cancer NZ

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EVERY BLOOD CANCER . EVERY PERSON . EVERY JOURNEY

State of Blood Cancer in New Zealand

April 2026

bloodcancer.org.nz

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