



# HE MAHERE RATONGA MATE PUKUPUKU CANCER SERVICES PLANNING

*A vision for cancer treatment  
in the reformed health system*

July 2022



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# HE KUPU NĀ TE MANAHAUTŪ

## FOREWORD FROM THE CHIEF EXECUTIVE



On 21 April 2021 the Government announced radical and far-reaching Health and Disability System reforms. Changes include the dissolution of District Health Boards, and the creation of two new health entities - Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora.

While there is a great deal that will change, Te Aho o Te Kahu will remain a departmental agency reporting directly to the Minister of Health and will work alongside these new entities, to guide and support their planning for cancer services delivery in the new system.

These reforms provide a once-in-a-lifetime opportunity to address inequities in the health system. Te Aho o Te Kahu is well placed to lead work to address the inequitable postcode lottery and variation in cancer care we know exist in Aotearoa New Zealand.

Our name *Te Aho o Te Kahu* refers to the central thread of the cloak and reflects the role of our Agency to lead and unite efforts to improve cancer outcomes for all New Zealanders. This document is a testament to the weaving together of the aspirations, experiences and expertise of many – including whānau with cancer, doctors, nurses, allied health professionals, non-government organisations, whānau Māori, policymakers, Te Aho o Te Kahu working groups and staff. Thank you for the taonga of your time and knowledge. Particular thanks goes to Hei Āhuru Mōwai (Māori Cancer Leadership Aotearoa) and He Ara Tangata (Te Aho o Te Kahu consumer reference group) for their input into the development of this report.

The guidance in this document provides the building blocks of a system where all New Zealanders are able to access cancer care that is high-quality, equitable, sustainable, and whānau-centred; which meets our Te Tiriti o Waitangi obligations and delivers equity for Māori and Pacific peoples, and those underserved by our current Health and Disability System.

I would like to acknowledge all those across Aotearoa who are affected by cancer. We have you at the very heart of our thinking. Please know we will not stop striving for cancer care which better meets your needs. Our vision is steadfast - fewer cancers, better survival, equity for all.

I would also like to take this opportunity to thank all the skilled and dedicated people who work in the cancer sector – you are making a real difference every day. I am humbled by the incredible commitment you show to ensure the wellbeing of whānau with cancer. My hope is that these reforms will make it easier for you to do just that.

Mauri Ora

**Professor Diana Sarfati**

Chief Executive and National Director of Cancer Control  
Te Aho o Te Kahu, Cancer Control Agency

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# HE KUPU NĀ Ā MĀTOU MĀTANGA FROM OUR ADVISORS

## Hei Āhuru Mōwai, Māori Cancer Leadership

*Kei tua i te ārai o mate, e tikapakapa ana ngā ringa manaaki a  
kui mā, a koro mā. Ka rongo te reo o te mokopuna e kī ana, me  
whawhai koe, me whaikaha koe. Heoi, ka huri rā taku titiro, ka  
pātai, kei whea rā koutou, kei whea rā koutou, auē kua ngaro  
nei koutou ki ahau.*

*Let your work be seen, let your caring hands be felt throughout  
the land, that I might find strength to resist the call of those  
who have gone before, that the pleas of our children gives  
energy and tenacity to fight on, to fight on, in the face of  
adversity. Let your work be seen.*

Hei Āhuru Mōwai Māori Cancer Leadership is a national network of Māori cancer specialists who provide Māori cancer control expertise and are committed to better cancer care and outcomes for Māori. As a Te Tiriti partner for Te Aho o Te Kahu, we are privileged to be involved with this work and to be invited to write this kōrero.

Cancer is a leading cause of avoidable death for Māori and of inequities in life expectancy between Māori and non-Māori. Every day, cancer services provide care and support for hundreds of individuals and their whānau. These services connect with whānau at times of great stress and need to be the best they can to deliver maximum improvements to quality of life, and to extend and save as many lives as possible.

Cancer care inequities exist in multiple cancer services throughout Aotearoa. These well documented differences in care contribute to the 30% lower chance of cancer survival for Māori compared with non-Māori. Achieving the “Cancer Equity by 2030” goal will require more than a highly trained, racism free workforce with ready access to technical and pharmaceutical products. Cancer services must be well planned, led and coordinated – and have strong quality infrastructure. This includes detailed monitoring so that problems can be readily identified and fixed. These components must be in place for all parts of cancer care for Māori as well as non-Māori.



The New Zealand government ratified the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), under the guidance of Dr Moana Jackson, in 2010. Meeting the requirements of UNDRIP to ensure that Māori have the opportunities and means to develop, test and deliver models of cancer care through Māori institutions is on the horizon. Meanwhile, work is in progress to develop the Māori cancer control infrastructure needed to ensure cancer services provide equitable access, timeliness, and quality of care.

The potential for equity improvements to deliver exponential wellbeing gains for all New Zealanders and to drive the achievement of a world leading cancer control system is considerable. Critical to this potential is the existence of Te Aho o Te Kahu – which is mandated to work in partnership with Māori to identify areas for improvement and to drive needed changes across the spectrum of cancer control.

Hei Āhuru Mōwai celebrate this report as an important step in the many actions required to achieve cancer equity in Aotearoa.

Āhuru ki runga, āhuru ki raro

**Dr Nina Scott and Gary Thompson**  
Co-Chairs, Hei Āhuru Mōwai Māori Cancer Leadership





# He Ara Tangata, Consumer Reference Group

Tena koutou e ngā ringa āwhina o ngā tai e whā, e kawea ake nei i ngā ara whaka ora ai i te mea nei ko te matepukupuku.

He Ara Tangata supports the work of Te Aho o Te Kahu by bringing oversight and advice from a consumer perspective. He Ara Tangata assists Te Aho o Te Kahu test the quality of what they hope to achieve in the Agency's constant effort to address the wide range of challenges and developments across the cancer continuum. The human element is a critical component of the many responsibilities of Te Aho o Te Kahu, and He Ara Tangata with broad membership representation from across communities and cancer experience is able to provide a very effective support role.

The work required to carefully scrutinise the different projects and workstreams of Te Aho o Te Kahu is valuable and requires time and consideration by each member – providing a link to consumer insights through this relationship.

As a consumer group, we work alongside and support Te Aho o Te Kahu, including in the development of this report. This approach is very much centred on quality, equity and service so that Te Aho o Te Kahu can provide leadership in the cancer field with confidence.

*“Whāia te iti kahurangi, ki te tuohu koe, me he maunga teitei.”*

Seek the treasure that you value most dearly, if you bow your head, let it be to a lofty mountain.

**Henare Kani**  
Chair, He Ara Tangata



# National Clinical Assembly

Over the past 20 years we have made slow progress in our fight against cancer. Over that time, countries with a sharp and dedicated focus have shown what can be possible with improvements in survival that far outstrip ours.

Right now, we have an opportunity that comes around once in a generation. We have the chance to prepare, plan, and transform our cancer services. We have a national cancer agency to coordinate, lead and plan. We have the birth of Health New Zealand | Te Whatu Ora. We have the Māori Health Authority | Te Aka Whai Ora. We have a passionate, engaged and enthusiastic sector. We have whānau, families, patients and advocacy groups working in partnership, and demanding we aim high.

This Cancer Services Planning Report is a critical step in this journey. The document represents the most comprehensive piece of thinking about the future structure of cancer treatment services that has been undertaken to date. It has had input from hundreds of clinicians, academics, whānau and patient representatives to give it the current form.

No single document can capture the enormous complexity or range of possible solutions for every scenario that we may face. But it is a map with a starting point that can be improved, refined, iterated, and enhanced by ongoing engagement, discussion, and debate.

Our sector is large, complex, diverse, and often noisy. Our country is small, but this is also our advantage – if we work together, united in focus and with a commitment to equity and improvement – we can achieve things other countries could only dare dream.

**Dr Christopher Jackson, medical oncologist**  
Chair of the Clinical Assembly





# HE WHAKAMIHI

## ACKNOWLEDGEMENTS

We would like to acknowledge the wide range of people who were involved with the development of this report. We thank you for sharing your time, knowledge and expertise.

In particular, we take this opportunity to acknowledge Hei Āhuru Mōwai, Māori Cancer Leadership Group. Hei Āhuru Mōwai gifted Te Aho o Te Kahu its name. The name translates as ‘the central thread (Te Aho) of the cloak (Te Kahu)’ and refers to the weaving together of all the people, organisations and services involved along the cancer continuum. Hei Āhuru Mōwai have worked alongside Te Aho o Te Kahu since its establishment and have provided considerable thought and input to this report.

We also thank members of He Ara Tangata, our consumer reference group, for their valuable input from the perspective of people with a lived experience of cancer.

Thank you to the many clinicians and people working in the health sector who contributed to this report, and who are working every day to improve outcomes for people with cancer.

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# **KO NGĀ PAI TAWHITI WHĀIA KIA TATA, KO NGĀ PAI TATA WHAKAMAUA KIA TINA**

The potential for what we achieve tomorrow  
depends on what we do today





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# HE KUPU WHAKATAKI

## INTRODUCTION

### Te horopaki

#### Context

Cancer is now the leading cause of health loss in Aotearoa, accounting for 18.5% of all health loss (1). Cancer treatment is complex, involving all parts of the health system, and the complexity is rapidly increasing, with the rate of growth of new technology, medicines and treatment increasing every day.

Currently, cancer treatment services deliver high quality care for most people, most of the time. However, of particular concern is the fact that our system does not serve everybody equally. Cancer treatment services in Aotearoa are not delivering against Te Tiriti o Waitangi expectations and obligations and are systematically failing to deliver equitable care. The persisting disparities in cancer incidence and cancer care between Māori and non-Māori are a large contributor to the life expectancy gap between Māori and non-Māori (2, 3).

Those working in the cancer care and treatment system are committed to providing the best care for their patients. However, staff repeatedly tell us that the system is under strain and not working as well as it could, meaning many New Zealanders are not able to access cancer treatment that is consistently high quality, equitable, sustainable and whānau-centered.

The New Zealand Cancer Action Plan (2019-2029) identified the need for a national cancer control agency that would take a whole of system approach to prevent cancer, improve outcomes and address inequities (4). As a result, Te Aho o Te Kahu, the Cancer Control Agency was established in December 2019. Hei Āhuru Mōwai, Māori Cancer Leadership Group, gifted the name Te Aho o Te Kahu to the agency. The name translates as ‘the central thread (Te Aho) of the cloak (Te Kahu)’ and refers to the weaving together of all the people, organisations and services involved along the cancer continuum.

Te Aho o Te Kahu has a mandate to provide national leadership for cancer control in Aotearoa. The Health and Disability System Reforms provide a rare opportunity to radically improve and future-proof these services (5). Whilst keeping a watchful eye on ensuring cancer services are supported during the health system reform process, Te Aho o Te Kahu has prioritised work to leverage this opportunity for change. Our goal is to provide evidence-based guidance to the forthcoming health care commissioning entities on how cancer treatment services in Aotearoa can be strengthened and future-proofed.

## **Te whāinga**

# **Purpose and scope of this document**

### **Purpose**

This document provides a summary of the current issues in adult cancer treatment services in Aotearoa and sets out key focus areas to improve cancer treatment in Aotearoa. It proposes a direction of travel which can be considered by decision-makers and service providers as they design and implement a reformed health system. Some of the detail contained in this report may change as reform work progresses, but it is expected that the high-level direction as described will remain consistent.

The aim is to create a cancer system that is equitable, of high quality, sustainable, and puts whānau at the centre. High quality cancer care is designed to meet the needs and expectations of patients, whānau and communities. It is focused on eliminating inequities in access, quality and outcomes. It is based on clearly articulated models of care with agreed pathways that are person and whānau-centred, based on evidence, and coordinate smoothly with other services. Quality control is built into the system and there is a focus on constant improvement. In an ideal system, research is incorporated into routine clinical practice and staff training and education is high-quality and ongoing, with the right staff doing the right job, at the right time. A high-quality system will have a balance between more complex services that are provided at a national or regional level, with those that are provided locally and within the community.



## Scope

This project identifies how to best organise adult specialist cancer treatment services to achieve optimal, equitable cancer outcomes and whānau experience. This document focuses on publicly-funded cancer treatment services in Aotearoa, including those provided in both public and private facilities. The document also includes consideration of the role of the not-for-profit sector. It is acknowledged that some cancer services are privately funded, and the impact this can have on equity of outcomes is recognised throughout the document; however, the provision of privately-funded services are out of scope of this work.

Child cancer treatment services are structured and delivered differently to adult cancer services and are out of scope of this project. Adolescent and young adult (AYA) cancer care is largely provided by adult cancer services and so face many of the same challenges that are outlined in this report. AYA cancer care also faces some unique challenges that require specific action, which are well described in the AYA Cancer Action Plan 2020-2025 (6).

Other critical elements of cancer care, including prevention, early detection and end of life care are out of scope for this report. Primary care and palliative care services play a critical role in cancer treatment. The specific structure and delivery of primary care and palliative care were out of scope of this report but are discussed in relation to their intersection with other treatment services.

## Te Tiriti o Waitangi

Te Aho o Te Kahu recognises the central importance of Te Tiriti o Waitangi, including ensuring working in partnership with Māori with a clear focus on achieving equity. Te Aho o Te Kahu recognises the five principles of Te Tiriti o Waitangi, as articulated by the Courts and the Waitangi Tribunal, to guide our obligations under Te Tiriti o Waitangi in our day-to-day work. These principles are set out in the Waitangi Tribunal's Hauora report (WAI2575) (25) and are as follows:

- **Tino rangatiratanga:** The guarantee of tino rangatiratanga, which provides for Māori self-determination and mana motuhake in the design, delivery, and monitoring of health and disability services.
- **Equity:** The principle of equity, which requires the Crown to commit to achieving equitable health outcomes for Māori.
- **Active protection:** The principle of active protection, which requires the Crown to act to the fullest extent practicable and to achieve equitable health outcomes for Māori. This includes ensuring that it, its agents, and its Treaty partner are well informed on the extent, and nature, of both Māori health outcomes and efforts to achieve Māori health equity.

- **Options:** The principle of options, which requires the Crown to provide for and properly resource kaupapa Māori health and disability services. Furthermore, the Crown is obliged to ensure that all health and disability services are provided in a culturally appropriate way that recognises and supports the expression of hauora Māori models of care.
- **Partnership:** The principle of partnership, which requires the Crown and Māori to work in partnership in the governance, design, delivery, and monitoring of health and disability services. Māori must be co-designers, with the Crown, of the primary health system for Māori.

Improving Māori health outcomes is also critical to upholding the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) (7). The current failure to achieve equity for Māori is a breach of Articles 23 and 24 of the UNDRIP. Both the UNDRIP and Te Tiriti o Waitangi provide guidance on the rights of Māori to health, equity and self-determination.

To ensure Te Tiriti o Waitangi principles and equity impacts were appropriately and consistently considered in this project and report development process, Te Aho o Te Kahu applied a Te Tiriti o Waitangi and equity framework. The purpose of the framework was to allow Te Aho o Te Kahu to examine its approach to this work to ensure that the analysis of cancer treatments and services was underpinned by robust analysis of existing inequities, and informed by best available evidence and the expert views and advice of external stakeholders.

The detail of this framework can be found in **Appendix I**. Central to this approach was the establishment of Te Kāhui Mana Taurite – the equity steering group – that met weekly to support and critique progress on the Report. The group consisted of a member from each internal working group, other Te Aho o Te Kahu equity leads, and a representative of Hei Āhuru Mōwai (the National Māori Cancer Leadership Group).



# Ka eke te mana taurite

## Achieving equity in cancer outcomes

A critical driver of this work is to improve equity in cancer outcomes in Aotearoa. Currently, cancer does not affect all groups within our population equally. Of note, Māori are more likely to get cancer than non-Māori, and once diagnosed with cancer, Māori are less likely to survive their cancer than non-Māori for almost every type of cancer (8). Several factors contribute to inequitable cancer outcomes for Māori, including institutionalised racism and white privilege, higher exposure to – and reduced protection from – cancer-causing risk factors, poorer access to cancer screening and primary and secondary care, higher rates of comorbidity and poorer access to best-practice treatment (2, 9, 10). The availability, affordability and acceptability of health services (including the cultural safety of the workforce) are key access barriers for Māori with cancer (11).

Pacific peoples also experience barriers to achieving equitable health outcomes, including poorer access to the resources that support good health, higher exposure to environmental factors that influence cancer risk, and barriers to accessing appropriate and high-quality screening services and primary and secondary health care (12-16). As a result, Pacific peoples are more likely to be diagnosed with, and die from, cancer than non-Pacific, non-Māori (17).

Inequities in health outcomes currently occur between many different groups in Aotearoa, including; populations living in socioeconomically deprived communities compared to socioeconomically advantaged communities (18-20), people living with mental illness compared to people living without mental illness (21, 22), disabled peoples compared to non-disabled peoples (23) and those living in rural areas compared to those living in urban areas (24). People who are SOGIESC-diverse (sexual orientation, gender identity and expression, and sex characteristics) may also experience barriers to accessing high quality health care (17, 25, 26).

Inequities in cancer outcomes arise both from inequity in access to services and inequity in the quality of service that is provided, including how services are designed and governed. This project aims to address issues with access, quality and governance in order to design an equitable cancer treatment system in Aotearoa. Te Aho o Te Kahu recognises that ensuring equitable cancer outcomes for all requires work across the whole cancer continuum, including addressing the unequal distribution and access to social determinants of health, alongside work on cancer prevention and early detection. This project is one piece of the wider work programme being undertaken by Te Aho o Te Kahu to improve equitable cancer outcomes in Aotearoa.



# Te aronga

## Approach to this work

Te Aho o Te Kahu is well-positioned to provide advice on the structure and approach to cancer treatment services in the context of current health system reforms. The health reforms provide opportunities to ensure cancer services are designed and delivered in a way that is safe, equitable, effective, cohesive and sustainable.

Te Aho o Te Kahu decided to focus first on specialist cancer treatment at national, regional and local levels. The Te Aho o Te Kahu Advisory Council helped develop the following problem definition:

### Problem Definition

Cancer survival is not improving as quickly in Aotearoa as other comparable countries. The current treatment service model for cancer in our hospitals *does not*:

- × meet Crown obligations under Te Tiriti o Waitangi & the United Nations Declaration on the Rights of Indigenous Peoples
- × have adequate focus on eliminating inequities in cancer survival
- × drive improvements to survival rates, as compared with other similar countries
- × provide a high-trust, racism free, whole of system approach that maximises wellbeing for individuals & their whānau
- × demonstrate strong, collective leadership & accountability across the sector
- × deliver efficient coordination of services to improve overall system costs.

Te Aho o Te Kahu established six workstreams, looking at different aspects of cancer treatment, to complete this work:

- 1) Coordination and support services
- 2) Radiation oncology
- 3) Cancer surgical services
- 4) Systemic anti-cancer therapies (including medical oncology and malignant haematology) and haematopoietic stem cell transplants
- 5) Allied Health
- 6) Clinical services: laboratory/pathology and radiology





Each of the six workstreams looked at the current state of the service in Aotearoa, completed an equity assessment of the current state, identified the current challenges with the service that are driving inequities, looked at international evidence and models of care, and identified potential solutions to improve services in Aotearoa. The teams also worked together to ensure that there was consideration of how cancer treatment services would work as a whole and that common solutions were identified and collated across workstreams, along-side workstream-specific solutions to ensure services were person and whānau-centred and addressed inequities.

To understand the current issues and potential solutions, each workstream undertook considerable stakeholder engagement. This included engagement with clinical working groups, health and disability system reform staff, clinicians from across the cancer sector, Māori health leaders, Pacific health leaders, DHB senior managers, allied health professionals, clinical nurse specialists and navigators. A list of stakeholders interviewed is included in **Appendix II**.

Advice, input and peer review was provided by members of Hei Āhuru Mōwai (Māori Cancer Leadership). Patient and whānau insights were gathered from He Ara Tangata (Te Aho o Te Kahu Consumer Reference Group), with each workstream assigned dedicated He Ara Tangata consumer representation on the team in an advisory capacity. Insights were also gathered from participants from Māori Community Hui – a series of 13 large hui organised by Te Aho o Te Kahu and held across Aotearoa during 2021 with a total of around 2800 attendees.

Each workstream also considered previous reports and plans on cancer services in Aotearoa. Over the past 10 years, reports have been published which research and analyse the distribution and delivery of cancer treatment services in Aotearoa, including, but not limited to:

- New Models of Care for Medical Oncology, Cranleigh Health 2011
- Medical Oncology National Implementation Plan 2012/13
- National Radiation Oncology Plan 2017-2021
- Haematopoietic Stem Cell Transplant Services in New Zealand, update 2018
- Deep Dive Feedback Report on Māori experiences of cancer services, Central Cancer Network 2020
- Cancer Action Plan 2019 –2029
- Health and Disability System Review 2020
- State of Cancer in New Zealand 2020

A further description of the project methodology is included in **Appendix III**.

# Te hanga

## Structure of this document

This report is presented in two parts, with both parts highlighting current issues and key focus areas to enable change.

Part 1 provides a system-level summary of the current issues that were found to be common across cancer treatment services and presents solutions across five key areas:

- 1) A transformative approach to cancer treatment and support
- 2) National system leadership
- 3) Clinical service distribution and delivery
- 4) Workforce
- 5) Coordination and support services

Part 2 of the report is presented by seven topic areas, to provide a more detailed view across areas of cancer treatment:

- 1) Coordination and support services
- 2) Cancer surgical services
- 3) Radiation oncology services
- 4) Systemic anticancer therapies and haematopoietic stem cell transplants services
- 5) Allied health services
- 6) Pathology and laboratory services
- 7) Radiology services

Each topic area in Part 2 includes:

- **Current state:** describes the current state of services in Aotearoa, including the distribution of services and the current state of the workforce.
- **Current challenges:** describes the current challenges with the service, including a focus on the challenges that are driving inequities in access, quality and outcome.
- **Inequity in the current state:** describes the cumulative impact of the current challenges and describes the inequities in the current state.
- **Evidence of ways to address challenges:** looks at local and international evidence to identify ways to address the challenges with the current system in Aotearoa.
- **Proposal for change:** presents a series of areas where health entities could improve cancer outcomes in Aotearoa.



# Ā kō ake nei

## Next steps

In order to deliver on the vision described in this document, Te Aho o Te Kahu is working with Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora to enable a joined up strategic and operational approach to transforming cancer services in Aotearoa. Within the reformed health system, each entity will have different roles and responsibilities and it will be critical to work collaboratively to make meaningful improvements to the cancer treatment system.

Cancer treatment sits in a context of a wider continuum of cancer care (from prevention to end of life care), and cancer care sits within a wider context of health care more broadly. As part of implementing this work, further work will be done to ensure changes to cancer services connect and link with the broader changes to health services.

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# WĀHANGA 1: TE PŪNAHA MATE PUKUPUKU PART 1: THE CANCER SYSTEM

A system-level overview of the current issues and potential solutions across cancer treatment services

# Ngā wero

## System-wide challenges

Each of the seven cancer treatment areas reviewed as part of this project are facing challenges. Whilst some of these challenges are specific to one treatment area, several are common to all areas. These challenges create inconsistencies in the care people receive, result in care that is often not patient centred and result in significant inequities in cancer outcomes in Aotearoa. The common challenges identified across treatment modalities were:

- **Fragmentation:** the current operating model has led to fragmented and inconsistent care, with variability in the provision of services across Aotearoa. This makes the system difficult to navigate and means patients fall through the gaps.
- **Distribution and access:** patients experience significant barriers to accessing cancer treatment, with the distribution of services contributing to inequity in quality and in access, and the current National Travel Assistance (NTA) scheme (to support travel and accommodation needs) is not fit-for-purpose.
- **Workforce:** the cancer workforce does not have the capacity to meet current demand, is unsustainable, is not representative of the population and is not always culturally safe. Some workforces (such as allied health and coordination and support services workforces) are not appropriately recognised.
- **Infrastructure:** the current facilities and infrastructure are insufficient to support the delivery of services, including inadequate data and information systems for collecting data, sharing data (eg common electronic health records) and telecommunications (eg telehealth, e-prescribing).
- **Acceptability of services:** services are often health-system focused rather than patient and whānau-centred. This includes appointments feeling transactional, with information provided to patients in a way that is inaccessible or inappropriate and patients often having issues with having multiple appointments with different specialities on different days.
- **Referral pathways and service integration:** referral and treatment pathways are ad-hoc, resulting in delays, inequitable care options and minimal opportunities for patient choice.
- **Recognition and funding:** allied health services and coordination and support services are often considered 'nice to have' rather than critical components of the cancer care pathway.
- **New technologies:** new technologies are considered and implemented locally, leading to inconsistent access.
- **Research and clinical trials:** currently there are challenges with the routine incorporation of research into standard of care, as well as issues with inequitable access to clinical trials.



- **Ability to monitor and improve the system:** there is limited data available on parts of the cancer system, with some data collected in a way that is focused on volumes and activity, rather than patient experience, unmet need and inequities.

All of the challenges facing the cancer treatment system are further exacerbated by:

- **Rapid increase in cancer diagnoses and cancer treatments:** it is estimated that there will be a 40% increase in new diagnoses of cancer in Aotearoa between 2020 and 2040 (27). Alongside this there is rapid growth in new technology, medicines and treatments. The current system is already struggling with stretched capacity, so will be unlikely to be able cope with this increase.
- **Increasing complexity of patients:** due to the aging population, people are being diagnosed and treated for cancer at an older age and with increasing comorbidities, leading to increased complexity and time required to deliver safe and effective treatment. Māori and Pacific peoples also have higher rates of comorbidity, so a system that does not work for complex patients will be contributing to inequities in outcomes.

Many of these challenges combine to create significant issues for cancer treatment services. For example, Multidisciplinary Meetings (MDMs) are frequently raised by stakeholders as an area of concern. Key issues with MDMs include: inconsistency in which patients are referred to MDMs, significant workforce challenges with increasing time requirement for clinicians to attend MDMs, inconsistent allied health participation with variable recognition of the value allied health professionals can add to the MDM processes and issues with data systems, including ability to monitor equity in regards to MDMs.

The current challenges with the cancer system mean people often have to wait to receive diagnostic and treatment services. As a result, some people opt to access private health care services to receive more timely access to diagnostic and treatment services and access to non-funded cancer medicines. There is wide variation in private health insurance coverage by ethnicity (28), which can contribute to inequities in cancer outcomes. It is important to have a public health care system that is working for all, to eliminate this inequity.



# Ngā hua

## System-wide solutions

Many of the common challenges across the cancer treatment system can be addressed through common solutions. These system-wide solutions are required alongside action to address specific challenges faced by individual treatment areas.

### 1. He aronga panoni ki te maimoa mate pukupuku me te tautoko | A transformative approach to cancer treatment and support

**Aim:** a refocused cancer system that prioritises accessibility and acceptability of treatment and care to eliminate inequities and improve outcomes.

Supporting patients through the length of their cancer journey is a critical aspect of improving cancer care and outcomes. This is especially important in the context of the fragmented and provider-centric nature of the health system, the complexity of cancer treatment and the substantial impact a diagnosis of cancer has on people and their whānau.

These issues, along with the impacts of racism and discrimination in the health care system and the effects of the social determinants of health mean that barriers to care are experienced disproportionately by Māori and Pacific peoples and their whānau, and so targeted work is required to overcome these barriers.

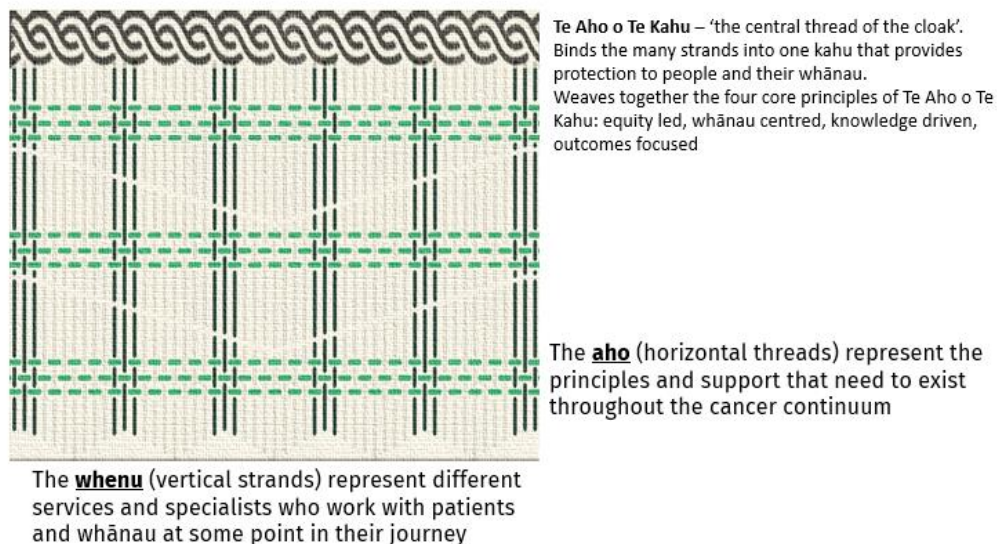
#### Recommended focus areas

1.1 Te Aho o Te Kahu to work in partnership with Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora to refine and implement a new approach to cancer treatment and support that:

- wraps a metaphorical kahu (cloak) of customised, holistic support around cancer patients and their whānau;
- reflects the interconnectedness needed to deliver a successful cancer care system, including specialist cancer treatment, allied health, non-clinical support, and mātauranga Māori services;
- offers patients and whānau cohesive and meaningful options for support and care coordination across all health and social services required as part of the cancer journey;
- crosses the boundaries of hospital, community and home-based services.



Figure 1: A transformative approach to cancer care requires a process to weave together the elements and parts of the cancer care journey, to ensure that each strand (whenu) of treatment and care is integrated and connected across the treatment pathway by the aho (binding threads).



## 2. Pūnaha ā-motu – whakahaere | National system leadership

**Aim:** strong system leadership to drive improvements in cancer treatment delivery and equitable outcomes. High quality data and information systems for sound decision making.

### Recommended focus areas

- 2.1 Te Aho o Te Kahu to work in partnership with Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora to provide national strategic and structural leadership of the cancer control system. This will include leadership structures that enable strong leadership from Māori, clinicians and people with lived experience of cancer. Functions that would benefit from strengthened national leadership are discussed further below.
- 2.2 Te Aho o Te Kahu to work in partnership with Health New Zealand | Te Whatu Ora, Māori Health Authority | Te Aka Whai Ora and Ministry of Health | Manatū Hauora to develop an operating model that ensures Te Aho o Te Kahu is consulted to provide subject matter expertise and advice in an agile and timely manner. This would apply to cancer-specific services, as well as services that are critical to, but broader than, cancer treatment such as pathology and laboratory, imaging, allied health and palliative care.
- 2.3 Te Aho o Te Kahu to maintain a strong partnership with Hei Āhuru Mōwai to support and strengthen Māori cancer leadership and support Māori cancer leaders to plan for future national, regional and local ways of working.
- 2.4 Te Aho o Te Kahu to continue to build and maintain strong networks and relationships with a range of stakeholders, to seek advice and insights that inform direction setting for future cancer treatment and care. These groups include:
  - people with lived experience of cancer;
  - clinical leaders and groups;
  - researchers and academic institutions;
  - cancer not-for-profit organisations and relevant public sector organisations e.g. Pharmac | Te Pātaka Whaioranga, Health Quality and Safety Commission | Kupu Taurangi Hauora o Aotearoa.
- 2.5 Te Aho o Te Kahu to continue to develop, implement and monitor a Cancer Information Plan to ensure quality system-level data and information is available for sound decision making. The Cancer Information Plan will:
  - provide complete, accurate, timely and shareable data to support clinical processes as well as service planning, monitoring and quality improvement;
  - make data accessible to empower understanding and decision making of patients, whānau, iwi and clinicians;

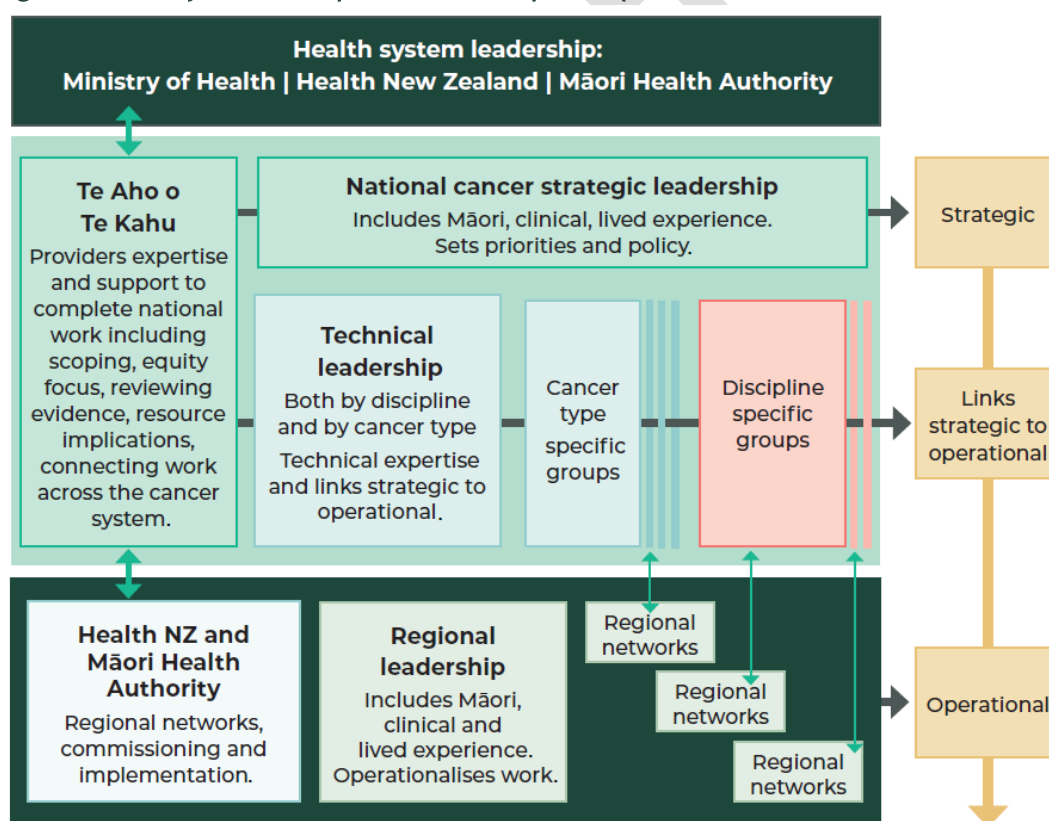


- provide guidance and direction for the national collection and sharing of cancer information;
- work towards developing ways of measuring patient experience of services;
- outline the standards, Māori data sovereignty principles, messaging, and national infrastructure to support this.

## What national system leadership could look like

There are three levels of leadership networks required to improve equitable cancer outcomes in Aotearoa: national strategic leadership, technical leadership, and regional leadership. Figure 2 presents a summary of the leadership structures in the new system, with each of the three levels described below and further discussed in **Appendix IV**.

**Figure 2: Summary of leadership structures to improve equitable cancer outcomes**



## National strategic leadership

**Requirements:** strategic leadership, planning and decision making at a national level. This includes determining priorities and approaches to work. To be effective at improving cancer outcomes and eliminating inequity, leadership structures must include strong leadership from Māori, clinicians and people with lived experience of cancer.

**In the new health system:** Te Aho o Te Kahu will continue to provide national leadership for cancer control. From 1 July 2022, Te Aho o Te Kahu will work to socialise the high-level strategic direction across agencies and establish how Te Aho o Te Kahu can work alongside Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora. This will also include considering how Te Aho o Te Kahu Māori, clinical and consumer leadership groups align with leadership groups in the new health system.

## Technical leadership

**Requirements:** technical (or subject matter) expertise is required by both cancer type (eg lung cancer) and by discipline (eg medical oncology or coordination services) to ensure quality and consistency of care and to manage integration of policy into practice. To be effective, technical leadership must provide a 'linking' function, connecting strategic thinking with frontline expertise and linking to the regional networks.

**In the new system:** Te Aho o Te Kahu will enable and support cancer-related technical expert groups to provide leadership. This advice will inform the work of Te Aho o Te Kahu, which in turn will support the operational roles of Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora. Technical expert groups will be a combination of permanent advisory groups, and those formed for a time-limited specific function to support specific pieces of work.

## Regional networks

**Requirements:** leadership is required at regional and local levels to implement change. Examples of this type of leadership include local application of treatment pathways, staff workload management and service resilience work.

**In the new system:** the structure and functions of regional leadership will be determined by Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora. Regional service delivery needs to be robust and resilient, and therefore regional groupings need to be optimised so that short term issues (such as leave, sickness, resignation, failure of recruitment) does not disrupt patient care. Te Aho o Te Kahu will largely stay removed from frontline operational matters, but will maintain an understanding of local issues and provide support through the four Te Aho o Te Kahu Regional Hubs.



## Functions that require national leadership

Across cancer treatment services Te Aho o Te Kahu identified several areas that require strengthened national leadership. These include:

- Planning and implementation of distribution of cancer services
- Workforce planning and forecasting
- Assessment and implementation of new technology, including horizon scanning
- Infrastructure planning and commissioning
- Consistent cancer care pathways
- Quality assurance and quality improvement
- Data systems for monitoring and reporting
- Coordination and support services
- Understanding potential threats or disruptions to cancer services (eg cybersecurity, pandemic) and proactively ensure strong national, regional and local responses
- Planning, implementation and monitoring of primary care, laboratory/pathology, radiology and palliative care services

Te Aho o Te Kahu has a different role across these functions.

- 1) **Lead:** Te Aho o Te Kahu leads the development and delivery of the work, and links with other health entities as key stakeholders. For example:
  - Development of consistent cancer care pathways
  - Cancer monitoring and reporting.
- 2) **Provide leadership, with implementation by others:** Te Aho o Te Kahu provides strategic leadership and advice, and implementation sits with other health entities and commissioning agencies. For example:
  - Workforce planning and forecasting
  - Planning and implementation of distribution of services and pathways
  - Planning and implementation around cancer specific infrastructure (eg LINACs).
- 3) **Provide advice to others:** work is primarily led out of another agency and Te Aho o Te Kahu can provide cancer subject matter expertise and advice as required. For example:
  - General infrastructure planning and commissioning e.g. physical buildings, integrated IT/patient management system
  - Assessment of new technology, including horizon scanning
  - Planning, implementation and monitoring of primary care, laboratory/pathology, radiology and palliative care services in relation to cancer care.

When Te Aho o Te Kahu is undertaking the third leadership function (providing advice to others) the roles in the leadership structure shift, with Te Aho o Te Kahu taking a 'Technical Leadership' role and other entities providing national strategic leadership.



### 3. Te tuari ratonga rongoā | Cancer service distribution and delivery

**Aim:** a deliberately planned distribution network of cancer treatment services that provide care as close to home as possible whilst maintaining safe, high quality, sustainable services.

#### Recommended focus areas

3.1 Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora to ensure planning and decisions around the distribution of cancer treatment services are made at a national level. This includes:

- consideration of distribution requirements based on criteria including service volume, complexity (patient and treatment) and other clinical service requirements (eg imaging, pathology, laboratories, allied health, palliative care).
- assessment and consideration of likely impacts of distribution on equity for Māori, Pacific, disabled, rural and socioeconomically disadvantaged communities, and the needs of these groups.
- consideration of integration across services, with the patient pathway mapped to ensure the care pathway is appropriate and mitigates potential inequities in access.
- consideration of regional planning requirements, in line with national planning.

3.2 Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora, the Māori Health Authority | Te Aka Whai Ora and other partners, to develop models of care to meet patient and whānau needs, provide choice, and include kaupapa Māori approaches to service delivery design.

- Models of care would consider a range of factors including equity, sustainability of delivery and the appropriate level for decision making across national, regional and local settings; noting that expertise and decision making do not need to occur in the same location as treatment delivery.
- Care is provided as close to home as is possible without compromising safety and quality. This reduces the requirement to travel for treatment, thereby improving the accessibility of services for patients and supporting the environmental sustainability of healthcare services. This includes the provision of outreach and virtual clinics with a particular focus on achieving equity of access to services in underserved communities.





- Where centralisation (provision of services in a small number of locations) is required to ensure quality or sustainability of services, this is always supported by critical implementation mechanisms to make sure care is person and whānau-centred and achieves equity of access and outcomes, including: well-defined patient pathways, accommodation and transport support, referral and communication protocols and shared care arrangements that support continuity of care.
- 3.3 Te Aho o Te Kahu to develop and monitor clear, person and whānau-centred clinical service pathways, outlining the 'default' in terms of treatment pathways, referral pathways, where and how MDMs are held, allied health requirements, follow-up/surveillance and palliative and end of life care requirements. Options are built into the system to address existing inequities, with opportunity for deliberate deviation from the pathway to meet patient/whānau needs, priorities and self-determination.
- Processes are developed to incorporate and integrate research and new technologies into cancer care pathways.
- 3.4 Appropriate technology is made available to support patient care, including ensuring patient clinical information is available across the health system and is supported by appropriate telehealth infrastructure and support.

## 4. Whakapūmau mahi | Workforce

**Aim:** there is a sufficient number of appropriately trained, diverse staff in the cancer workforce to deliver care in the right place, at the right time, in a culturally safe way. Those in the cancer workforce feel valued and are self-aware and address their own biases to help reduce systemic racism and achieve health equity.

Many cancer workforces are facing critical capacity issues and immediate action is needed to fill vacancies and support and strengthen those at greatest risk (in both hospital and community settings). Alongside this immediate action, a comprehensive future-focused cancer workforce plan is required, which incorporates and supports new models of care. Strengthening the cancer workforce will require close collaboration between Te Aho o Te Kahu, Health New Zealand | Te Whatu Ora, the Māori Health Authority | Te Aka Whai Ora and the Ministry of Health | Manatū Hauora.

### Recommended focus areas

- 4.1 Increase allocation of funding for education and training of the cancer workforce, including funding for replacement staffing cover and additional roles in cancer care. This includes consideration of:
  - the creation of more early career positions in cancer care, enabling experienced staff to work to top of scope and participate in education and training;
  - an increase in clinical nurse specialist and nurse practitioner positions in cancer care;
  - the creation of specialist cancer roles in allied health and exploration of extended scope of practice for some roles;
  - growth in the non-clinical cancer workforce (eg kaiāwhina, community-based whānau support staff, kaupapa Māori providers);
  - increased senior medical officer roles.
- 4.2 Consideration of changes to increase capacity within the cancer workforce, including:
  - working with training providers and the sector to fill vacant roles and training positions;
  - ensuring administrative and other systems are in place to support clinical staff in their roles;
  - ‘task shifting’ where appropriate, where specific tasks are delivered by health workers with shorter training, enabling staff to be used at the top of their scope of practice.
- 4.3 Continue to develop and implement approaches to systematically and deliberately increase Māori and Pacific cancer workforce capacity through targeted investment and active recruitment, with consideration of specific Māori, Pacific and equity roles.



- 4.4 Undertake work to ensure high quality workforce data is available to support planning. This includes accurate data on FTE as well as ensuring workload calculations include all aspects of care provision, including education, research and coordinating patient care between services.
- 4.5 Develop and implement a future focused approach to the cancer workforce that:
- creates a diverse workforce that reflects the population of Aotearoa
  - facilitates equitable distribution of care and treatment (geographically and for Māori and Pacific in particular) and enables new models of care and ways of working;
  - includes significant growth of nationally consistent advanced and extended practice roles in nursing and allied health;
  - includes access to continuing education;
  - creates a digitally capable workforce that is able to use telehealth to its full potential;
  - emphasises the importance of a strong team approach to cancer care
- 4.6 Development of processes to support, increase, and measure the cultural safety of the cancer workforce.
- 4.7 Further development of processes to ensure staff involved in cancer care are trained and able to communicate effectively with patients and whānau, in a considerate and culturally safe way.
- 4.8 Implementation of the Ao Mai Te Rā antiracism maturity model (currently in development) across the cancer system.

## 5. Ā ratonga āwhina | Coordination and support services

**Aim:** the primary focus of cancer treatment and support is on patient and whānau needs, and patients and whānau are actively supported to have equitable access to care. Holistic support services are accessible and appropriate for all who need them.

### Recommended focus areas

- 5.1 Te Aho o Te Kahu to work in partnership with the Māori Health Authority | Te Aka Whai Ora and Health New Zealand | Te Whatu Ora to establish a national cancer care coordination service across Aotearoa to support patients and whānau, reduce barriers and coordinate cancer treatment and care.
  - At a patient-level, this service would support patients and whānau, assess their needs, reduce barriers and work with the health and cancer care sector to coordinate all aspects of cancer treatment and care. This will help patients and whānau to receive treatment and care services at the most appropriate time and with as little distress as possible
  - Grow, strengthen and further develop the cancer coordination workforce, including establishment of new care coordination positions, with a particular focus on improving Māori and Pacific pathways of care.
- 5.2 Implement a holistic needs assessment process that takes into account all types of care a cancer patient and their whānau might need, including the needs of Māori, Pacific and disabled cancer patients.
- 5.3 Increase support for community-based Māori-led, kaupapa Māori and Whānau Ora services to enable options and access to mātauranga Māori in cancer care.
- 5.4 Ensure that the sustainability of essential services provided by cancer not-for-profit organisations is considered and supported in national cancer service planning.
- 5.5 Fully implement the recommendations from Phase 1 and Phase 2 of the National Travel Assistance (NTA) Review undertaken in 2018, alongside a secondary process to improve data collection, address regional variation and consider further improvements to enable greater access to travel supports for people with cancer.
- 5.6 Strengthen mechanisms that support patients, whānau and carers to access cultural, spiritual, financial and social support throughout all stages of the cancer journey.
- 5.7 Increase utilisation of modernised booking and scheduling tools, including patient led bookings to better meet the needs of patients and whānau.



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# WĀHANGA 2: NGĀ WĀHI MAIMOĀ MATE PUKUPUKU PART 2: CANCER TREATMENT AREAS

Topic specific sections looking at treatment modalities



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# WĀHI 1: RATONGA RURUKU, TAUTOKO

## SECTION 1: COORDINATION AND SUPPORT SERVICES

### He kupu whakarāpopoto Summary

#### Case for change

Across Aotearoa, cancer patients and their whānau repeatedly describe their cancer journey as both distressing and overwhelming. Many describe feeling lost and unsupported while navigating a complex medical system. Coordination and support services play a significant role in reducing the trauma of cancer diagnosis, increasing likelihood that someone will successfully complete their cancer treatment, and improving transition to survivorship. Although a wide variety of coordination and support services exist across Aotearoa, there is lack of visibility, awareness, and prioritisation of these services.

#### Proposal for change

Transformative changes are needed if Aotearoa is to create an equitable and accessible cancer care system. As well as making improvements across cancer treatment services, effective and consistent coordination and support services are critical to support system change.

A key change to improve care for people with cancer and their whānau would be to establish a national cancer care coordination service across Aotearoa. The care coordination function would involve assessing patient and whānau needs, identifying and reducing barriers to care, and working with specialists and care providers to coordinate cancer care. To be effective, these services would be available to patients and whānau in primary care, hospital, kaupapa Māori and community settings. Organisations who already deliver this form of support would be identified and supported to ensure this existing workforce is utilised and expanded upon.



Improving cancer care would also include identifying mechanisms that enable increased support for Māori-led, kaupapa Māori and Whānau Ora services to enable patients and whānau to have access to mātauranga expertise and to have the option of including traditional healing practices as part of their treatment and care.

Other key areas for change include ensuring the sustainability of essential services provided by cancer not-for-profit organisations and strengthening mechanisms that support patients, whānau and carers to access cultural, spiritual, financial and social support, including strengthening the equitable provision of palliative care across primary and secondary care settings.

To improve equitable access to cancer treatment services it will be critical to improve travel and accommodation support. This could be achieved through implementation of the recommendations from Phase 1 and Phase 2 of the National Travel Assistance (NTA) Review undertaken in 2018, alongside a secondary process to improve data collection, address regional variation and consider further improvements to enable greater access to travel supports for people with cancer.

## What would be different for patients and whānau?

- Patients and whānau would feel well supported during their cancer pathway and would have improved experience of cancer treatment
- Patients and whānau would have fewer barriers to accessing services, and have assistance coordinating appointments and tests.
- Patients and whānau would be well connected to appropriate services, including allied health, not-for-profit organisations and financial support, at all points of the cancer journey
- Patients and whānau would have a consistent, highly-trusted point of contact during the many stages of the cancer pathway
- Patients and whānau have access to holistic care, including mātauranga Māori and traditional health practices.



# Te tiro whānui

## Scope

This section focuses on the coordination and support services required to successfully support patients and whānau through their cancer treatment journeys. Coordination and support services are defined in this report as including the following functions for people going through cancer treatment:

- Care coordination, including liaison with clinical and non-clinical services as required (sometimes known as navigation)
- Holistic needs assessment
- Spiritual support
- Cultural support
- Social support
- Financial advice and support
- Travel and accommodation support

Historically, coordination and support services have not been clearly defined and are known by various terms including supportive care, wraparound care, integrated care and cancer coordination and cancer navigation. Allied health services are sometimes included within these terms, but they are discussed separately in this report (see Section 5: Allied Health).

# He kupu whakataki

## Introduction

Cancer is a frightening and disorienting illness for many patients and whānau. Not only do they face an enormous challenge to their physical wellbeing, but they are also impacted mentally, emotionally, socially, spiritually, and financially (29). Cancer patients and whānau have a wide variety of needs that are continuously changing during and beyond their cancer journey (30). Patients and whānau often report that these needs are often unrecognised, under-prioritised, and unaddressed by the current cancer care system in Aotearoa (29).

In this report the term 'coordination and support services' is used to describe largely non-clinical functions; however, it is recognised these functions may be provided by clinical staff or involve significant interaction with clinical staff, and that clinical staff play an important role in ensuring holistic care needs are met.



Coordination and support services can be based in multiple settings including primary care, community care, kaupapa Māori health providers, hospices and hospitals. A number of organisations currently offer some or all of these services across the country. Many of these have been established by not-for-profit organisations to address significant unmet needs within the community. Despite their best efforts, the scale of support required to address current needs is greater than these organisations can collectively provide.

## Why are coordination and support services important?

### Care coordination

*“When you are diagnosed, you are overwhelmed with anxiety. You need a supporter to help you navigate the system.”* Community Hui participant, 2021

The cancer system is a multifaceted and complex system to navigate (31). The illness and its treatments can be complicated to understand for patients and whānau. Treatment can require the involvement of many clinical and non-clinical services, which are not always available locally (31). When combined with the fragmented nature of the health system and the ongoing complexity of people's lives, these issues can make the cancer journey complex and inequitable (32).

*“We got lost in the process.”* Community Hui participant, 2021

Cancer treatment is currently delivered in ways that can create additional challenges for cancer patients. Current scheduling models focus on a single treatment or procedure, rather than considering the patient's overall burden of appointments or their unique circumstances. This can result in inconvenient or inaccessible booking times such as early morning appointments for patients who have to travel significant distances, booking multiple appointments on different days, or not considering the impact of treatment that is scheduled over several days. This can be costly and time consuming for patients and can be a barrier to access.

*“Booking rural patients for first thing in the morning – you can't do that to people, especially our kaumatua and kuia.”* Community Hui participant, 2021

### Holistic needs assessment

Cancer patients and whānau often have physical, social, emotional, informational, cultural, spiritual and financial needs that can be specific to their lives and their diagnosis. These needs can impact on patient outcomes and quality of life if they are not identified and addressed. Needs assessments are screening tools used to identify unmet needs and assess the priority and extent of support that is required to meet these needs.



## Spiritual services

*“The hospital deals with your physical problems, but they do not deal with your mental and spiritual problems.” (33)*

Spirituality, both religious and non-religious is important for many people with cancer (34, 35). Spirituality and active prayer are common forms of support sought by people with cancer as a means of drawing strength, remaining positive, maintaining determination and self-discovery (36).

Māori cancer patients often seek emotional and spiritual support from within Māori culture to complement medical treatment, including rongoā such as mirimiri (massage), the application of kawakawa leaves and karakia (prayer) (33, 36).

Pacific people also hold a holistic view of health and approximately 72% of Pacific peoples belong to some religious group (37, 38). Pacific peoples can view sickness as being associated with sickness of spirit and becoming well again involves a process of re-establishing spiritual wholeness among the individual and their family (37). This makes spiritual support critical to improving outcomes and experiences of cancer care.

## Cultural support

Culture is an important determinant of health and wellbeing. Māori cancer patients often report experiencing a cultural and spiritual disconnect within the medical system, with the experience of the health care system being alienating, inappropriate and lacking in cultural competence (36, 39). Ensuring appropriate cultural support is available for people during cancer treatment, and across the whole cancer care continuum, is important for improving care.

## Social support

Social support plays an important role in many peoples' cancer journeys. Social support can reduce the stress of a cancer diagnosis and improve treatment outcomes (40). Conversely, unmet social support needs are associated with psychological distress and worry and negatively associated with psychological well-being (41, 42). This makes the provision of social support services critical, particularly for people who do not have access to their own social support.

## Financial advice and support

The financial impacts of cancer on patients and whānau are immense, particularly those who have high levels of socioeconomic deprivation (43). Costs include direct medical costs (medication and treatment) and reduced income due to time off work (both for patients and whānau). Costs pertaining to hospital visits, childcare, cosmetic needs such as wigs or breast prostheses, travel, parking, and accommodation can be significant.



Financial strain for people going through cancer treatment is exacerbated by factors such as living rurally and having unexpected income changes. The need for financial support does not end once treatment ends, and people may incur ongoing cancer treatment related costs including rehabilitation, medication and counselling, which is often compounded by a reduced ability to work.

## Travel and accommodation support

Issues relating to the cost of travel and accommodation are frequently cited by cancer patients, whānau and their treatment providers as barriers to care and are recognised as drivers of inequity (44, 45). This burden disproportionately affects Māori, Pacific, low income, and rural and geographically isolated cancer patients and whānau (46-49). The financial cost of needing to travel long distances for treatment is reportedly linked to appointment non-attendance, or declining treatment (50, 51).



# Tō āianeī āhua mō ngā ratonga ruruku ratonga tautoko

## Current state of coordination & support services in Aotearoa

### Care coordination

*“I work in public health and I couldn’t understand it [the cancer system]. Those who don’t have health literacy haven’t got a chance.”* Cancer patient, Community Hui 2021

Cancer care coordination is being delivered to some cancer patients in Aotearoa, with several different models in use (see Table 1). These services are delivered in mainstream and kaupapa Māori health services by a range of professionals including nurses, social workers, cancer nurse specialists, palliative care nurses and supportive care nurses. Some aspects of the role are also delivered by non-health professionals (eg navigators, kaimanaaki, community workers, Whānau Ora navigators) and other people working in and around the health system. Primary care providers, including general practitioners and nurses, often take on a coordination role for patients, as do staff working in palliative care and within hospices.

**Table 1: Current cancer care coordination models being used in Aotearoa**

Model	Description
<b>Hospital-based cancer nurse coordinators / navigators</b>	<ul style="list-style-type: none"> <li>In 2012, the Cancer Nurse Coordinator Initiative funded cancer nurse coordinators in each DHB. These roles were established to support people newly diagnosed with cancer. There was significant variability in the interpretation and delivery of this service. Most DHBs directed these roles to balance individual patient support with work to improve the cancer care pathway (52).</li> <li>Adolescent cancer coordinators are based at hospitals in major urban centres with links to regional hospitals. They coordinate care for adolescent cancer patients and whānau (53).</li> <li>A number of DHBs now operate a hybrid model where cancer nurse coordinators collaborate with hospital- or community-based social workers to provide coordination support.</li> </ul>



<b>Kaupapa Māori health providers</b>	<ul style="list-style-type: none"> <li>• Māori health providers deliver a broad range of health services. These service providers are generally not funded specifically for cancer care coordination but have been informally doing this work for many years. In a few cases, DHBs now directly contract these service providers for care coordination work.</li> </ul>
<b>Whānau Ora navigation services</b>	<ul style="list-style-type: none"> <li>• Whānau Ora is a culturally-grounded, holistic approach to improving the wellbeing of whānau, and addressing individual needs within the context of whānau. Whānau Ora was established in 2009 and is supported by Te Puni Kōkiri and the Ministries of Health and Social Development. It is not a hospital- or health-based service.</li> <li>• Whānau Ora agencies support approximately 13,000 whānau in the community each year. The Navigator role is not confined to providing support in a certain way, time or under a particular practice construct. In practice this means that at times, Whānau Ora Navigators will support whānau undertaking cancer journeys.</li> </ul>
<b>Palliative care teams</b>	<ul style="list-style-type: none"> <li>• Palliative care teams (provided through DHBs and through hospices) provide a key linking and coordination service for people with a life-limiting cancer diagnosis. They provide holistic and whānau-centred care including symptom management, psychosocial and spiritual care as well as coordinating with other clinical services as required. Care is provided wherever the patient is - at home, in the hospital, residential care or in specialised palliative care units (hospices).</li> </ul>
<b>Emerging services</b>	<ul style="list-style-type: none"> <li>• There are a range of initiatives around the country to increase support for cancer patients in general or for Māori patients in particular. For example, the Oranga Tū project examined the non-specialist services working with whānau on a prostate cancer journey. They suggest that a key enabler is a 'kaioriori', a person based in the local community who is recognised as whānau. Their role is to introduce whānau to health services, stay with them while they choose which services they need, and get to know the health professionals who work there. They are an advocate and supporter, but not a navigator who is with the whānau throughout the cancer journey (54).</li> </ul>





## Holistic needs assessment

Needs assessment processes are common at a service level, but there is currently no nationally agreed approach to assessing the holistic needs of cancer patients and whānau. Examples of tools being used in Aotearoa include:

- The internationally credentialed Screening for Distress programme was used as part of the Cancer Nurse Coordinator Initiative. While very useful, it is not available nationally yet and has not been contextualised for Aotearoa (55).
- The adapted Whānau Hauora/Wellbeing Assessment is based on Te Whare Tapa Whā. This tool forms part of the referral pathway for the Cancer Psychology Social Support Service.
- The Cancer Society supportive care teams have an assessment process they undertake with each patient referred to them, but they do not use a specific tool. There were over 9,000 new referrals to the Supportive Care team in 2019-20 (17). The Cancer Society are currently developing a new model of care which will streamline the needs assessment process across all divisions and underpinned by a shared data system.
- A holistic whānau hauora needs assessment tool is being developed for the cancer pathway as part of the Whānau Hauora Integrated Response Initiative (WHIRI) project, but this work is still underway. It includes proactive management and navigation for Māori patients and whānau with longterm conditions. This kaupapa Māori whānau hauora assessment tool was utilised at Waikato Hospital in selected outpatient clinics and preassessment surgical lists as part of the Cyber Security recovery and COVID-19 response in 2021.
- There are holistic assessment tools used widely in palliative care utilised for cancer patients with a life-limiting diagnosis (56). Te Ara Whakipiri is a holistic assessment used for care of the dying, including cancer patients, aligned with Te Whare Tapa Whā and aimed at the last few days of life (57).

While not specifically needs assessment tools:

- A draft triage tool was developed as part of the Cancer Nurse Coordinator Initiative (See **Appendix V**). This was developed to help prioritise which patients most needed the support of a Cancer Nurse Coordinator. It was used in 19 DHBs but not across all cancer care coordination models.
- Mid Central DHB have developed a Te Whare Tapa Whā assessment tool for patients who have had primary lung cancer surgery.



## Spiritual support

Hospital Chaplaincy services provided by the Interchurch Council for Hospital Chaplaincy, are available for patients and whānau in inpatient DHB settings (58). There are also outpatient services available in some regions, for example Mid-Central District Health Board are developing a spiritual assessment that can refer outpatients to the spiritual care team. Palliative care teams include chaplains and spiritual support. Training resources for spiritual care have been developed in He Anga Whakaahuru; however, it is unclear whether these are currently utilised (59).

## Cultural support

Cultural support in Aotearoa, particularly for Māori and Pacific communities, is grounded in holistic care. Culturally appropriate and effective cancer treatment services should align with a Māori model of health such as Tā Mason Durie's Te Whare Tapa Whā model, which includes four domains of wellbeing: taha tinana, taha hinengaro, taha whānau, and taha wairua - mental and emotional, physical, social, and spiritual health (60).

Whānau and community support are often the foundational source of cultural support for Māori and Pacific cancer patients. Māori and Pacific patients can sometimes overcome health system barriers by drawing on their own system of care and using whānau to fill the gaps where the system couldn't meet their needs (61).

Cultural support resources within hospitals, such as cultural teams, Māori and Pacific workforce and cultural health models, are often limited (61). A whānau ora approach is becoming well established within the primary health care sector to provide cultural support. Many providers, particularly Māori providers, now employ whānau ora workers who work not just with individuals but the entire family (46).

There are examples of other services developing approaches to care to try and ensure services meet cultural needs. One example is Mauri Mate, a framework and philosophical approach to palliative care for hospices in Aotearoa (62). Mauri Mate was designed to address a gap in palliative care services led by Māori and uses Māori world views to strengthen hospice responses to patients and their whānau.



Māori health provider organisations deliver a wide variety of cancer care programmes including health promotion, advocacy, information and financial support (31). The long-term relationships and trust these health providers build with their communities enables them to connect community members with mainstream cancer support services. Church-based community initiatives for Pacific populations such as the Pasefika Lotu Mo'ui Health Programme provide similar ways of engaging community members (63).

## Social support

Social support is provided in different ways across the country. Some regions have cancer-specific social workers based in DHBs. Māori cancer support groups are available in both DHBs and communities for patients and whānau. This can change over time: for example, a roopu kakahu (Māori cancer support group) was initially founded by staff from MidCentral DHB but now operates independently.

Many of the community-based support options are created or facilitated by not-for-profit organisations. For example, the Cancer Society has local support groups in different regions, offers a 'Cancer Connect' service which puts patients in touch with people who have had a similar cancer diagnosis, and promotes the use of an app-based 24/7 cancer support service (64). In some regions the Cancer Society provides an educational and support programme known as Kia Ora – E Te Iwi which was developed alongside Māori health providers (65). It aims to increase patient and whānau knowledge of cancer, encourage discussion around common concerns and coping mechanisms, and encourage whānau to learn from each other.

Palliative care teams also provide a wide range of social support services for people with a life-limiting diagnosis. This involves providing holistic care wherever a person and whānau are – in hospital, hospice or within the community.

Community health workers support cancer patients through the provision of culturally tailored support, education, coaching and counselling. For example, kaiāwhina are community health workers in Aotearoa. They often come from the same communities as cancer patients and may themselves be cancer survivors. Māori health providers such as Tūranga Health in Tairāwhiti employ kaiāwhina to work as the first point of contact for whānau into the health system (66).

## Financial advice and support

Financial support or entitlements for patients and whānau exist in Aotearoa but access to these supports is inconsistent, especially for Māori (46). Government-provided support services include various entitlements administered by the Ministry of Social Development's (MSD) Work and Income service for individuals who meet set criteria (67). MSD also have benefit advocates who can advocate for MSD clients (68), but patients and whānau often report issues around navigating the Work and Income system.

Financial advice and support from not-for-profit organisations are available in many parts of the country. Support includes money-saving mechanisms such as volunteer drivers who get patients to and from appointments, and accommodation lodges that provide patients and whānau with a place to stay during treatment (69-72).

## Travel and Accommodation support

One initiative that attempts to address travel and accommodation issues is the National Travel Assistance (NTA) scheme run by the Ministry of Health | Manatū Hauora (73). This scheme was established in 2006 to support eligible patients who require ongoing specialist treatment, need to travel long distances and/or travel frequently to get to specialist treatments. Over 33,000 patients access NTA funding each year, including a large number of cancer patients.

Not-for-profit organisations provide travel and accommodation support which is essential to enable access to cancer care for many patients and their whānau. For example, the Cancer Society provides accommodation services across the country, volunteer drivers and shuttles for shorter distances and petrol vouchers for patients and whānau. The Cancer Society provides approximately 50,000 bed-nights per year across five Cancer Lodges and volunteer drivers provided more than 21,000 trips totalling one million kilometres. Other forms of support are available in parts of the country such as the West Coast's Whānau House which is a marae-style accommodation to support whānau of patients at the local hospital (74). Other charities provide similar support such as the Ozanam House Trust in Palmerston North (75).

Many cancer charities including Cancer Society, Child Cancer Foundation, Leukaemia and Blood Cancer New Zealand and the New Zealand Breast Cancer Foundation assist by supplying petrol vouchers to patients and whānau. In addition, a number of kaupapa Māori providers also help with transport to treatment particularly when whānau are required to travel to other regions for cancer treatment.



# Ngā wero mō ngā ratonga ruruku, ratonga tautoko

## Current challenges in coordination and support services

Coordination and support services currently face numerous challenges. To date, these forms of support have largely been undervalued and underfunded by the health sector. This has led to a fragmented, inconsistent and unsustainable range of support services that do not reach their full potential in meeting patient and whānau needs throughout their cancer journey. Resources are constrained and inequitably distributed, resulting in the burden of care falling on patients and whānau.

Although services providing coordination and support services are diverse, they face similar issues and challenges. This section of the report combines information from stakeholder interviews, Māori Community Hui, and published literature on the current challenges with coordination and support services in Aotearoa, with examples provided across different services.

### Lack of recognition and prioritisation

***Coordination and support services are often considered 'nice to have' rather than critical components of the cancer care pathway***

There is a lack of recognition and resourcing for the role coordination and support services play in ensuring patients and whānau receive equitable and high-quality cancer care that meets their needs. Stakeholder feedback made it clear that these types of services are often considered 'nice to have', but not essential, by both health professionals and the system more generally. Services and teams that provide this role, including palliative care, are often under resourced within the health system.

Mātauranga Māori services, cultural and spiritual support services are not routinely recognised as part of the current system and can be devalued as they do not align with Western biomedical models of health (76). Māori have also noted poor access to rongoā or traditional healing practices in the health system (77).



At a national level, there is a lack of leadership for coordination and support services and for palliative care services to ensure these functions work alongside other parts of the cancer care system.

## Resources and funding

### ***Coordination and support services are frequently underfunded***

*“One of the challenges for many Māori health providers who offer a wraparound service has been the limitation of funding contracts, which are often still based on ‘mainstream’ outputs that do not necessarily reflect the true work carried out by the organisations and where significant portions of their work may not necessarily be funded.”* Monica Ngaire Koia in He Pito Ora: Exploring the role of Māori Cancer Navigators (31)

Funding contracts are one of the challenges for Māori health providers who offer a wraparound service as part of their model of care (78). Commissioning models are often based on ‘mainstream’ outputs that don’t necessarily reflect the true nature or value of the work. Cancer care coordination is a clear example of this, as Māori health providers are predominantly funded for primary care services and much of the supportive cancer care and coordination provided by Māori health providers is not funded appropriately (79, 80). The recent Waitangi Tribunal report *Hauora* indicates that Māori primary health care providers who work with high-need Māori populations have been underfunded by many millions of dollars every year since the primary care capitation model was first introduced in 2002 (81).

There are also many issues and inequities with the current funding model in the National Travel Assistance (NTA) scheme. This includes the reimbursement model which is largely retrospective and provides subsidies rather than full reimbursement. The scheme does not adequately cater to people who cannot afford to pay up front and does not cover hospital parking fees, which can be costly in the main cities (up to \$80 per 24 hours at Christchurch Hospital, for example). A 2018 review of the NTA Policy acknowledged the issues associated with the scheme’s functioning and the need for significant change (82). Recommendations include changes to eligibility criteria, improving funding rates, and implementation of a prepaid funding model. Despite these ongoing concerns and the NTA Policy Review, changes to this scheme have not yet been implemented (82).

Cancer not-for-profit organisations often play a key role in the provision of coordination and support services and face a different set of challenges around funding uncertainty. While they often receive a small amount of public funding, they rely heavily on annual appeals to fund their services. This can vary significantly from year to year, for example the Cancer Society lost an estimated \$1 million after cancelling their 2020 and 2021 annual appeals due to COVID restrictions (83).



## Availability and accessibility of services

### *Coordination and support services are provided inconsistently across Aotearoa*

While DHBs in some regions offer some level of coordination and support services, this is inconsistent and variable and there is currently no national coordination and support services function in place. Coordination and support services provided by palliative care providers – including not-for-profit organisations (hospices) and DHBs – are similarly inequitable, with models and services differing depending on locality. DHBs have the discretion to choose what they offer in terms of support services, which leads to geographical inequities in care for patients and whānau (84).

For example, there is variability in the role of Cancer Nurse Coordinators (CNCs) across DHBs. Whilst some variability is likely appropriate (for example a sub-specialised CNC in a large tertiary centre, compared to a generalist CNC in a regional centre), the variability can also create and exacerbate inequities at patient, cancer-type and regional levels (52). The lack of cancer care coordination has been identified by patients and whānau as a barrier to receiving high quality care (29, 33, 39, 80, 81, 85). Where a coordination function is unavailable or over-subscribed, the responsibility for care coordination reverts to patients and whānau.

Stakeholders also described issues with support services only being available for part of the cancer pathway. For example, information vacuums often occur when patients are diagnosed with cancer and then wait weeks before being informed about their next scheduled appointment date. Specialty roles such as Cancer Nurse Specialists often become involved during this period, but their point of engagement varies according to DHB and current caseloads. Issues also arise at the other end of the cancer pathway, with patients and whānau often feeling ‘dropped’ once cancer treatment finishes, especially when the aim of treatment are palliative. The transition back to primary care or to specialist palliative care services are often challenging and not smooth. This is also exacerbated by other aspects of support, such as financial assistance, often not covering the diagnostic phase and stopping when treatment ends, despite patient needs continuing post-treatment.

When services are available, there are several barriers to accessing them, particularly for rural, low socioeconomic status, Māori, Pacific, elderly, and other minority populations. For example, access to appropriate home help and carer entitlements have been identified as an area of particular concern for Māori, who are less likely to receive support services they are entitled to due to differences in the availability of services and application of eligibility criteria (85).





Often information is provided on cancer charity websites that explain the types of support patients and whānau are entitled to, and the application processes. However, this can create unintended inequities due to lower rates of internet access. Māori, Pacific peoples, those living in country towns, and older members of society are comparatively less likely to have internet access, as are people living in social housing, unemployed people, and disabled individuals (86).

*"When they diagnosed me, there was no offer of support services like karakia. I know those services are in the hospital, but the clinician didn't mention them."* Cancer patient, Community Hui 2021

## Lack of awareness around what services exist

### ***Patients and clinicians are often unaware of what services are available***

Many of the current coordination and support services sit in not-for-profit and community settings and are often not visible within the public sector, which can create an information gap for patients and whānau. The health system inconsistently alerts patients and whānau to these supports, meaning they often must seek them out themselves. Not all cancer patients, or clinicians, are aware of what services exist and what they are entitled to. There is no single clear and appropriate information source (such as a website) that links patients and whānau to coordination and support services.

*"It took three months before they told us (about services like Cancer Society and Hospice)."*

*"Why do we continually have to ask to find out what is available?"*

Comments from patients and whānau at Community Hui, 2021

## Acceptability of services

### ***Services are not always appropriate for patients and whānau***

*"Where are our Māori advocates? We are being lost in that non-Māori world."* Community Hui participant, 2021

Some Māori believe that coordination and support services are tailored to Pākehā patients (36). For example, the NTA Policy subsidises only one support person to stay with the patient, and only if the patient is deemed to be eligible for NTA. NTA accommodation funding is capped at \$100 per night which does not cover the full costs of one motel room across the country. However, given the nature of many whānau support networks, many Māori noted during the Community Hui that they would like some ability to access more flexible support options, particularly for those who are dependent on whānau caregivers, or single parents with multiple children.





Whilst some services are whānau centred and include consideration of whānau support for cancer patients, these can be limited and inconsistently available across the country. Patients and whānau often rely on their wider community for support; however, community resources may become severely strained where access to formal support services is limited (87).

Stakeholders also discussed issues with stigma associated with accessing some services. For example, some cancer patients and whānau are reluctant to ask for help from services such as financial support from the Ministry of Social Development, due to the stigma that often surrounds entitlements or benefits.

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# Tō āianeī mana taurite kore

## Inequity in the current state

Coordination and support services can play an important role in improving equity in cancer care. However, the current challenges with services described above mean that many services are not running as well as they could, which may contribute to the inequity Māori and Pacific peoples experience compared to non-Māori, non-Pacific throughout the cancer pathway, as well as inequity based on where people live.

The absence of rigorous and systematic coordination and support services for cancer patients, creates several significant equity issues. The complexity of cancer treatment makes it difficult for patients and whānau to successfully navigate and complete their cancer journey on their own and can be particularly difficult for whānau Māori, Pacific peoples, rural populations and the elderly (17, 31, 81). The burden of coordination often falls back on patients and whānau, which is significantly harder for those with less resources (84). Māori and Pacific peoples experience several barriers to accessing and navigating care, meaning that Māori and Pacific peoples are overrepresented in missed appointments (Did not attend – DNAs). The lack of nationally standardised needs assessment processes means it is difficult to accurately identify and prioritise those with the greatest need (35).

The lack of recognition of the benefits of coordination and support services is an equity issue across multiple contexts. Mātauranga Māori, spiritual and cultural support services are not consistently recognised within the cancer care sector, resulting in people not receiving the holistic care they need. Whānau are often not recognised as part of the cancer care team, and whānau themselves have needs that are not identified or met (85, 88).

The NTA scheme is designed to provide support for people to access health services for which significant distance is a barrier. However, the retrospective reimbursement model relies on patients having money available up front, often doesn't cover the full costs of travel and accommodation, or the costs of attending a First Specialist Appointment. This system privileges those who have additional financial resources, and disadvantages those who don't.



People may experience multiple layers of discrimination, social isolation and psychological distress, negatively impacting their health outcomes. Māori in particular, experience multiple levels of socioeconomic disadvantage. Māori are more likely to live in rural areas compared with the total population (89), are twice as likely to be unemployed as non-Māori (90) and are less likely to be enrolled with a primary healthcare organisation (PHO) (91). These socio-economic factors contribute to inequities for Māori compared to non-Māori in cancer incidence, treatment outcomes and survival rates.

*A detailed equity analysis of how each of the challenges with the current system contributes to inequity in access, quality and outcome, and alignment to focus areas is included in **Appendix VI**.*

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# Taunakitanga hei whakatutuki wero

## Evidence of ways to address challenges

The Coordination and Support services function is defined in a variety of ways, which is reflected in international literature. 'Supportive care', 'patient navigation' and 'cancer care coordination' are the terms used most to refer to this body of work. Internationally 'palliative care' is sometimes used interchangeable with 'supportive care'. These terms are used interchangeably with Coordination and Support services in this section.

### Care coordination

*International and local evidence supports the use of system coordination roles in reducing cancer inequities and improving patient and whānau experiences*

Cancer care coordination services can be highly effective in supporting patients and whānau through their cancer journeys. Evidence shows that these roles provide numerous benefits for whānau Māori, including high-trust relationships and help in facilitating continuity of care (31, 80). For patients with colorectal cancer in Aotearoa, cancer care coordination has been estimated to improve the coverage of chemotherapy, reduce the time to surgery, reduce the time to chemotherapy and reduce patient anxiety for colorectal cancer in the Aotearoa context (92). There is also evidence that coordination services can be cost effective, with additional benefits and greater cost effectiveness for Māori compared to non-Māori (92-94).

Similar benefits were seen across multiple population groups through the Cancer Nurse Coordinator Initiative (55). Patient and whānau feedback was overwhelmingly positive and coordination of care improved through increased timeliness of referrals, diagnosis and access to treatment and other services (55). Although the feedback was positive, the specific resourcing was not continued once the pilot ended. The funding for the initiative was devolved to DHBs, with some choosing to use it on clinical resources rather than coordination resources. The funding for the central coordination (ie a 'Head Office' coordination role) was not continued.



There are two recent and comprehensive reviews of Māori cancer navigation services using kaupapa Māori research methodology (31, 95). Collectively these two pieces of research found that:

- Māori cancer navigators are one of the only roles that provide continuous supportive care to patients/whānau throughout their entire cancer journey, including support to whānau after their family member has died.
- Greater integration of Māori cancer navigators within cancer services will help address fragmentation in care and improve communication between health professionals and patients/whānau.
- Whanaungatanga, whakamōhio (good communication and the sharing of information) and manaakitanga are key areas, which may improve the quality of care and potentially make a difference to patient/whānau cancer outcomes.
- Primary care is pivotal in cancer prevention, detection, access to treatment, supportive and palliative care, and reducing inequities. Primary health care providers, particularly Māori health providers, assist whānau to navigate their cancer journeys, albeit with identified gaps in appropriate support services.
- Whānau hold multiple roles across care but engaging successfully with the cancer care and wider health system currently requires an individual rather than collective approach.
- Cancer control policy in Aotearoa does not adequately address Māori needs and cultural safety education should extend across all cancer services.

The Oranga Tū project examined non-specialist services working with whānau on a prostate cancer journey. They suggest that a key enabler is a ‘kaioriori’, a person based in the local community who is recognised as whānau (as described in Table 1 page 37).

International evidence also supports patient navigation programmes, which have been found to improve coordination and timely access to cancer care, particularly for indigenous peoples (96-99). A systematic review mapping the current state of indigenous patient navigators within Canada, United States, Australia and Aotearoa found six key domains of work within the role: social service navigation, holistic support of Indigenous people, advocacy/building capacity, health assessment, administrative navigation, and outreach. The review highlighted the importance of both lay and professional navigators and the value and effectiveness of indigenous navigators for indigenous patients (100).



In Australia, communication, collaboration and care coordination are identified as integral in the provision of quality cancer care for Indigenous Australians (101, 102). This was also reflected in America, where research with underserved African-American women with breast cancer found that the emotional, practical and family concerns of cancer patients need to be addressed; and that any coordination and support service must be available from time of diagnosis into long-term survivorship (103).

Cancer care coordinators also provide beneficial outcomes for patients and their families. For example, care is described as being more culturally safe, associated with better information, communication and increased participation in screening (104). Benefits are most effective when utilised shortly after screening or diagnostic testing and alongside thorough needs assessment systems (105). The level and intensity of care required varies between patients (106).

## Holistic Needs Assessment

***Holistic needs assessments are a valuable tool, and when used as a component of coordination and support services, could decrease inequity by connecting patients and whānau to critical services***

Internationally, unmet supportive care needs are frequently reported in the domains of daily living, psychosocial, information, and physical needs. Unaddressed psychosocial distress, malnutrition and poor functional status impact on the accessibility of cancer treatment, the tolerance and ability to complete treatment and recover from treatment to achieve optimal possible quality of life (107, 108).

A systematic holistic needs assessment is recognised as a crucial step in integrated and patient-centred cancer care (109, 110). Accurate and effective needs assessment can assist in prioritising care needs, allocating resources equitably, developing appropriate and cost-effective patient care strategies, and eventually improving health-related quality of life (111). Needs assessment tools are recommended as part of comprehensive cancer care in the UK and Canada, although they are not widely embedded into practice (112).

More than 20 cancer needs assessment tools are currently being used worldwide, and have been reviewed for consistency, reliability and cross-cultural validity (111). As well as using an appropriate assessment tool, the way the needs assessment is implemented is also important. Needs assessment must be used as a tool and not as an intervention in itself (113).



Some holistic needs assessment tools have been adapted specifically to suit the needs of Indigenous populations. These tools were found to be beneficial, easy to use and affirming for patients. Clinical staff reported multiple benefits of the needs assessment tools including support for universal screening for Indigenous cancer patients (114).

Holistic needs assessments and care plans have also been found to be cost effective, acceptable and useful for particular cancer types, e.g. for gynaecological cancer, where they were reported to achieve personal gains and maximise the use of health and social care resources (94).

Holistic needs assessment is a key component of a patient- and whānau-centred cancer care system. Holistic Needs Assessment tools align well with indigenous models of health such as Te Whare Tapa Whā and Fonofale (60, 115), although care needs to be taken to ensure that any tools used in Aotearoa are contextualised appropriately.

## Spiritual support

***Spiritual support is critical, but often relies on not-for-profit organisations and volunteers to provide it, with guidelines around spirituality not always being implemented***

International evidence suggests spirituality and spiritual support is associated with improved quality of life among cancer patients, as well as better physical health outcomes (116–118). Spirituality has been identified as playing an important role in the process of adjusting to a cancer diagnosis and is central to many individuals' cancer journey (119, 120).

Spirituality is particularly important among Indigenous populations throughout the care journey, including throughout the survivorship period (121). Understanding the role of spirituality in cancer survivorship is important to develop and deliver culturally safe health services that reduce the burden of cancer and ultimately improve outcomes for Indigenous cancer patients and their families (122).

Guidelines for the delivery of spiritual care exist (123), but it is not clear how well these are implemented in practice (124, 125). Clinicians often feel unable to meet the spiritual needs of their patients, with barriers including a lack of time, education and understanding of spirituality and spiritual care in a health context (126).



Similar to Aotearoa, internationally, not-for-profit organisations provide a number of spiritual support options to patients and their family. Support is often available from hospital or hospice chaplains who offer spiritual support to everyone, not just religious individuals (127, 128). Other forms of non-religious spiritual support are recognised, including volunteers who give non-religious pastoral support, art therapy, music groups and online discussion forums (129). Many services utilise technology to provide support online, for example a spiritual support workshop series conducted virtually; and these should be acknowledged as important components of a person's care pathway (130).

## Cultural support

### ***Health services need to take a holistic approach to care that includes cultural support to improve cancer outcomes, particularly for indigenous populations***

There is a large body of literature showing that Indigenous populations and ethnic/racial minorities experience poorer cancer outcomes at every stage of the cancer continuum (131). The social determinants of health and those embedded in Indigenous peoples' historical experiences (eg racism, social exclusion, and intergenerational trauma) are widely recognised as causes of disparities in health outcomes (61, 87). The role of cultural factors in influencing these outcomes is also gaining recognition. For example, the Western biomedical model may alienate populations who perceive health through a more holistic lens (132). In addition, a lack of cultural competence among healthcare staff reduces the accessibility and effectiveness of cancer care for these groups (131).

Internationally, interventions to improve cultural competency in healthcare for Indigenous people includes education and training of the health workforce, culturally specific health programmes and recruitment of an Indigenous health workforce (131). However, many support services are currently not culturally inclusive, available resources are often not appropriate and this is compounded by differences in language and information needs of Indigenous people undergoing cancer treatment (133)(134).

Culturally diverse and Indigenous groups turn to their own traditions, customs and communities to gain the support they need. The use of traditional and complementary medicine among Indigenous cancer patients in Australia, Canada and Aotearoa ranges from 19-57% (135). Traditional and complementary medicine is mostly used concurrently with conventional cancer treatments to meet patients' spiritual, emotional, cultural and social needs (135). Traditional healers can play an important role for many Pacific peoples (136).





Holistic care is paramount to Indigenous populations, with caregivers of Indigenous cancer survivors viewed as mediators between Western biomedical approaches to cancer care and Indigenous peoples' holistic and family-focused views of health and wellbeing (132). This includes access to traditional ways of living, culturally relevant communication, and family involvement (137).

## Social support

***Social support needs are often met by the not-for-profit sector, with the role of online support increasing***

Social support plays an important role in many peoples' cancer journeys (41, 42, 138, 139). A lack of social support during cancer treatment is associated with poorer physical and mental health related quality of life (140). Although many people gain social support from their family and close friends, cancer patients also need a balance between distance from, and closeness to, their social network (141).

Not-for-profits are often key providers of social support. The Cancer Council Australia has an information support phoneline, one-on-one support options, face-to-face group support and online community support groups (142). Similar services are available in the UK (143, 144). Some regions have tried to increase the accessibility of services, for example Cancer Care Ontario has a 'Community Service Locator' which helps people find a support community in their region (145).

An increasingly more common form of support is through online community forums (146, 147), which can contribute to positive outcomes, including a sense of belonging to a community of like-minded people and peer support (146). Online support can be particularly valuable for people living rurally, where in-person social support can be more challenging to access (148).

## Financial advice and support

***Cancer can put patients and their whānau in difficult financial situations, with assistance often needed to access financial support entitlements***

Financial distress is common during cancer treatment (43, 149) and is worse for those who live rurally, have a low income, or are a young cancer patient. There are often also significant financial burdens for caretakers due to having lower or no income and additional expenses to support the cancer patient (150).



Financial concerns influence decisions on treatment. For example, Australian Aboriginal cancer patients have opted out of participating in cancer treatment due to difficulties in accessing transport, accommodation, and travel support (151). There are a lack of proactive mechanisms around access to financial support services, which are sometimes only utilised by people who know how to navigate the system and identify the benefits they are entitled to (151, 152).

Not-for-profit organisations often provide financial support including through provision of a carer's allowance (153, 154), and financial planning and emergency financial assistance programmes (155, 156). Internationally, government benefits can be hard to access. A critical role of many not-for-profit organisations is to support access to benefits and entitlement through support in filling in application forms or by providing information on the benefits cancer patients are entitled to on their website (153, 157, 158).

## Travel and Accommodation support

***Governmental travel and accommodation schemes often struggle to meet the needs of patients and whānau***

Travel and accommodation are frequently cited as barriers to cancer treatment for patients across the world (159, 160). Although support exists (eg financial support for petrol or accommodation lodges), difficulties in accessing these forms of support remain a challenge. In Australia, barriers of access to cancer treatment for Aboriginal communities include out-of-pocket-costs, perceived cultural insensitivity from health service staff (159) and difficulties navigating the Patient Assisted Travel Scheme (PATS) support service (151).

Government-funded national travel and accommodation support is available in countries including Australia (161) and the United Kingdom (162). Despite the best of intentions these systems frequently do not meet the needs of patients. The financial burden of accommodation and travel can be a major source of stress for rural patients in particular, and is not matched by available financial assistance (163, 164).



# He tāpae hei panoni

## Proposal for change

Transformative changes are needed if Aotearoa is to create an equitable and accessible cancer care system. As well as making improvements across the cancer treatment services, effective and consistent coordination and support services are a critical enabler to support system change.

### Ngā wāhi hei mahi | Potential focus areas

#### System leadership

##### National system leadership

1. Te Aho o Te Kahu to work with Māori Health Authority | Te Aka Whai Ora, Health New Zealand | Te Whatu Ora and other partners, including Māori leaders, to establish a national cancer care coordination service across Aotearoa to assist people to navigate through their care. At a patient-level, this service would support patients and whānau, assess their needs, reduce barriers and work with the health and cancer care sectors to coordinate all aspects of cancer treatment and care. This would help patients and whānau to receive treatment and care services at the most appropriate time and with as little distress as possible. Cancer care coordination services would:
  - a. focus on Māori and Pacific cancer patients and their whānau initially and, once significant equity gains have been achieved, be extended to other high-need population groups,
  - b. be available in primary care, hospital, kaupapa Māori and community settings, and linked in to services that are currently operating,
  - c. undertake holistic needs assessments, provide support and link patients to services and other support as needed,
  - d. ensure patients are connected to appropriate cancer diagnostic, treatment, survivorship and end of life care services (including allied health and not-for-profit organisations), at all points of the cancer journey,
  - e. be flexible and recognise the wide range of scenarios seen in service delivery,
  - f. elevate the visibility of allied health and mātauranga Māori services,
  - g. be underpinned by monitoring and evaluation to measure the success and improvement to patient experience.



2. Te Aho o Te Kahu to work with Māori Health Authority | Te Aka Whai Ora, Health New Zealand | Te Whatu Ora and other partners, including Māori leaders, to design, plan, and assist implementation of cancer coordination and support services, including:
  - a. ensuring Māori and Pacific peoples are appropriately engaged in planning and decision making,
  - b. ensuring that coordinated care models are patient and whānau centred and informed by lived experience,
  - c. establishing appropriate leadership structures for cancer coordination and support services, that link into coordination and support systems across the health system more broadly, including palliative care services,
  - d. consideration of appropriate funding and commissioning models,
  - e. ensuring recognition of coordination and support services as a key component throughout the cancer pathway – from diagnosis, treatment, survivorship to palliative and end-of-life care,
  - f. supporting the development of kaupapa Māori and Pacific-specific models for the delivery of support services.

## Data Driven

1. Te Aho o Te Kahu to work with Māori Health Authority | Te Aka Whai Ora, Health New Zealand | Te Whatu Ora and other partners, including Māori leaders, to ensure that coordination and support services planning and decision making is informed by best available evidence, and considers:
  - a. the data needs of public, private, not-for-profit organisations and iwi service providers
  - b. the data needs across the cancer pathway, including palliative, end-of-life care and survivorship
  - c. how patients can access the support and information that they require
  - d. how service design and delivery can be informed by best practice and continuous improvement e.g. through monitoring and evaluation

## Workforce

1. Te Aho o Te Kahu to work with Māori Health Authority | Te Aka Whai Ora, Health New Zealand | Te Whatu Ora and other partners, including Māori leaders, to strengthen and develop the coordination and support services workforce, and establish new care coordination positions, with a particular focus on Māori and Pacific services. In particular to:
  - a. identify needs of current service providers offering coordination and support services
  - b. consider the range of skills and expertise required to undertake the various roles within coordination and supportive care services



- c. support and integrate the coordination and support services workforce within the wider health workforce
- d. improve cultural safety, cancer knowledge, understanding of community needs, and interpersonal skills among 'first-contact' and other support roles.

## Service Delivery

### Mātauranga Māori

1. Te Aho o Te Kahu to work with the Māori Health Authority | Te Aka Whai Ora, Health New Zealand | Te Whatu Ora and other partners, including Māori leaders, to identify mechanisms that enable:
  - a. increased support for community-based Māori-led, kaupapa Māori, and Whānau Ora services
  - b. opportunities for Māori to access mātauranga expertise (such as tohunga) and to discuss traditional healing practices as part of their treatment and care
  - c. support for Māori patients and their whānau to have conversations about the inclusion of traditional health and healing practices in their pathway of care.

### Not-for-profit organisations

1. Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora, the Māori Health Authority | Te Aka Whai Ora and other partners to:
  - a. acknowledge and support the not-for-profit sector, to ensure the essential services they provide are considered when planning sustainable national support services
  - b. provide easily accessible information to healthcare staff, and patients and whānau, on the cancer support services provided by the not-for-profit sector and how to access them.

### Access to Support

1. Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora identify mechanisms that enable:
  - a. a seamless transition between treatment and support services, through an integrated referral system that connects patients and whānau to appropriate community support services
  - b. healthcare settings to provide appropriate spaces/environments that meet cultural and spiritual needs during care eg whānau rooms and chapel/quiet spaces
  - c. patients, whānau and carers to access cancer-specific cultural, spiritual and social support, e.g. through hospital and community-based social workers, palliative care teams and support programmes
  - d. accessible support options via telehealth and other innovative delivery methods.



Te Aho o Te Kahu is well placed to provide cancer-specific input and support to this work, which is relevant to all aspects of the health system.

#### National Travel Assistance

1. Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora implement the findings of Phase 1 and Phase 2 of the NTA Review undertaken in 2018, alongside a secondary process to:
  - a. Improve data collection about who is accessing NTA and for what conditions/treatment (currently not known), and data collection about who is declined from accessing and for what reasons (also not currently known)
  - b. Address current regional variations and inequities in access and eligibility to NTA
  - c. Consider further improvements to NTA to enable greater access to support for those receiving lifesaving or life-extending treatments (such as cancer treatment)

Te Aho o Te Kahu is well placed to provide cancer-specific input and support to this work, which is relevant to all aspects of the health system.



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# WĀHI 2: NGĀ RATONGA HĀPARAPARA MATE PUKUPUKU SECTION 2: CANCER SURGICAL SERVICES

## He kupu whakarāpopoto Summary

### Case for change

Cancer surgery is a critical component of cancer care. Around six out of ten patients with cancer will require some sort of surgical procedure during their illness. Generally, cancer surgery in Aotearoa is of high quality; however, not all population groups are receiving the same benefit from surgical services and the surgical system as a whole is not operating as well as it could.

Currently there is no defined approach to the distribution and provision of surgical services in Aotearoa. Differences in distribution approaches are apparent, largely based on the complexity and frequency of the surgery involved; however, these have often evolved in an ad-hoc way. There has been no national, coordinated attempt to rationalise the distribution of cancer surgical services and this unplanned distribution contributes to inequitable access to high-quality surgery.

Patients experience barriers in access to surgical care, with ad-hoc referral and treatment pathways leading to delays and inequities in care. New procedures and technologies are considered and implemented locally, leading to inconsistent access across Aotearoa. The surgical workforce has a number of pressing challenges, including understaffing, concern about future workforce sustainability, poor workforce diversity and has an opportunity to practice with increased cultural safety.



## Proposal for change

Improving cancer surgical services in Aotearoa requires a nationally led process for the distribution of services, where high-complexity procedures with a clear, strong link between volumes and outcomes are centralised, and less complex cancer surgery is delivered as close to home as possible, practicable and safe. Decisions around the distribution of cancer surgical services should consider the geographical distribution of services for sustainability, resilience and access, with a focus on ensuring access for Māori, Pacific and socioeconomically disadvantaged communities. A strongly networked surgical system would enable surgeons to travel between hospitals to operate on selected patients at local hospitals where appropriate.

Where centralisation (provision of services in a small number of locations) is required to ensure quality and sustainability of services, this would be supported by critical implementation mechanisms to make sure care is person and whānau-centred and achieves equity of access and outcomes. Key requirements include: well-defined patient pathways, accommodation and transport support, outreach clinics, localised prehabilitation and follow-up, clear referral and communication protocols and shared care arrangements that support continuity of care.

Given the overlap between cancer surgery and non-cancer surgery, Te Aho o Te Kahu would work closely with Māori Health Authority | Te Aka Whai Ora and Health New Zealand | Te Whatu Ora to ensure that changes to cancer surgical services align with broader changes to the surgical system and ensure that changes do not have inadvertent negative impacts on non-cancer surgery.

This work would happen alongside work to grow and maintain the capacity and diversity of the cancer surgical workforce, with a focus on increasing Māori and Pacific in the workforce and robust planning to meet future increase in demand. This includes workforce planning to include consideration of new models of care that may require changes to staffing and a focus on improving cultural safety of staff.



## What would be different for patients and whānau?

- Patients would have access to the same high-quality surgical care regardless of who they are or where they live.
- Patients who are required to travel to access highly specialised surgery will be supported to do so and will be able to access aspects of care (such a prehabilitation and pre-operative assessments) close to home.
- Patients will experience connected and smooth care, with staff involved with their care connected and able to access all the relevant information and tests.
- Staff involved with surgical care of cancer patients are able to effectively communicate critical information and have difficult conversations in a compassionate and culturally safe way.



# Te tiro whānui

## Scope

Surgery is used across the cancer continuum, including to prevent and diagnose cancer. This section focuses on surgery used to treat cancer. Diagnostic pathways are out of scope for this report, but it is recognised that to improve equitable outcomes from surgical services, pathway to diagnosis and delays to diagnosis will need to be addressed (165-168).

It is also important to acknowledge that cancer surgical services are a subset of all surgical services, and changes to cancer surgery cannot be made in isolation without consideration of other surgical services. However, it is valuable to consider the role of cancer surgical services specifically and, in doing so, the process and models may be useful in any future considerations of non-cancer related surgical services.

# He kupu whakataki

## Introduction

Cancer surgery is a critical component of cancer care. Around six out of ten patients with cancer will require some sort of surgical procedure during their illness (169). The likelihood of requiring surgery varies by cancer site, for example around 22% for prostate cancer and up to 99% for testicular cancer (170). There are nearly 300 surgical procedures used to treat cancer that vary widely in terms of complexity.

Cancer operations form part of a wider surgical system that requires patient preparation for surgery, anaesthesia, pathology, imaging, peri-operative care, intensive care, recovery, palliative care and rehabilitation. High quality cancer surgery is therefore contingent on elements both within the surgical services and beyond.



# **Tō āianeī āhua mō ngā ratonga hāparapara mate pukupuku i Aotearoa**

## **Current state of cancer surgical services in Aotearoa**

### How surgical services are distributed

There is no defined approach to how surgical services are provided in Aotearoa. Differences in service distribution approaches are apparent across the country, largely due to the complexity and frequency of the surgery involved; however, these have often evolved in an ad-hoc way. There has been no national, coordinated attempt to rationalise the distribution of cancer surgical services.

Cancer surgery is undertaken in 26 hospitals, with a further 13 hospitals providing outreach outpatient and/or minor procedure clinics. In addition, minor procedures, including for skin cancer, are completed within primary care. Lower complexity cancer surgical care is provided across most hospitals, with higher complexity surgery in fewer hospitals.

Since 2010, the Ministry of Health | Manatū Hauora has run a programme for the consideration of National Services, including surgical services. New national services are considered and approved on the basis of an application from a prospective provider to the Ministry of Health | Manatū Hauora (171). Currently there are no formal national cancer surgical services provided through the National Services programme, although some services – such as peritonectomy, which is used to remove tumours from the lining of the abdomen – are run out of a single region, accepting referrals from across Aotearoa. Peptide Receptor Radionuclide Therapy (PRRT) is the only national service specific to cancer that was established through the formal National Services mechanism.



In some instances, bespoke surgical systems have been set up to meet a specific need. One example of this is New Zealand's gynaecological cancer services. Gynae-oncology services were recognised as a small and vulnerable service, with concerns around specialist skill shortage and disparities in access to care (172). Following a national review of services in 2010, a new hub and spoke model of gynaecological cancer services was implemented (173). Care is now based around three gynaecological cancer centres ('hubs') situated in Auckland, Wellington and Christchurch. These cancer centres are tertiary referral services providing a comprehensive range of treatments for people with gynaecological cancer. Secondary services are provided in gynaecological cancer units ('spokes'). These units are distributed more widely and provide some, but not all, treatment for people with gynaecological cancer. Lead gynaecologists in the local units connect with the tertiary referral centres and assist in coordinating multi-disciplinary meetings.

## Current state of the surgical workforce

The cancer surgical workforce is broad and includes surgeons, nurses, allied health, administrative staff, and staff across a range of other clinical services including anaesthetics, radiology, pathology and laboratories.

The majority of cancer surgery is performed by general surgeons, who perform a range of cancer surgeries. Within general surgery there are also subspecialties including: hepatobiliary (including liver, pancreas), upper GI (gastro-oesophageal), colorectal (large and small bowel), endocrine (thyroid and adrenal), breast and surgical oncology (skin, sarcoma). There is some overlap with other specialities, for example otolaryngologists will also undertake thyroid surgery and urologists may also operate on adrenal glands and retroperitoneal sarcomas, and other surgical specialities, such as cardiothoracic surgery and neurosurgery, also perform cancer surgery.

Table 2 outlines the number of anaesthetists and selected surgical specialists currently in the workforce. Some of these clinicians may be working part time, and accurate FTE data are not held nationally.



**Table 2: Surgical and anaesthetist workforce statistics (2021)**

Speciality	Total number	Number of Māori (%)	Number over 65 years (%)
Anaesthesia	931	20 (2%)	85 (9%)
General Surgery	321	8 (3%)	46 (15%)
Cardiothoracic Surgery	32	0	5 (16%)
Neurosurgery	24	0	3 (13%)
Obstetrics & Gynaecology	342	14 (4%)	40 (12%)
Orthopaedic Surgery	315	13 (4%)	41 (13%)
Otolaryngology Head & Neck Surgery	123	2 (2%)	26 (21%)
Plastic & Reconstructive Surgery	77	3 (4%)	11 (14%)
Urology	73	2 (3%)	4 (5%)

*Data source: Health Workforce New Zealand, Health Workforce dashboard as of quarter three 2021*

The number of nurses working in peri-operative and surgical settings has steadily increased over the past decade. In 2012 there were 3,159 peri-operative nurses and 5,343 surgical nurses, increasing to 4,184 perioperative nurses and 6,584 surgical nurses by 2021. Only 4% of perioperative nurses, and 5% of surgical nurses in 2021 were Māori (data from Health Workforce 2021).

The numbers of anaesthetic technicians have also risen steadily, from 702 anaesthetic technicians in 2015 to 816 in 2021 (data from Health Workforce 2021).



# Ngā wero o āianeī mō ngā ratonga hāparapara mate pukupuku **Current challenges in cancer surgical services**

This section of the report combines information from stakeholder interviews and published literature on the current challenges with cancer surgical services in Aotearoa. These challenges create significant inequity in access, quality, and outcomes for people with cancer.

## Distribution and access challenges

### *Unplanned service distribution leads to inequitable access to high-quality surgery*

High complexity cancer surgery requires a broader range of infrastructure than less complex procedures. One of the key issues debated internationally is how to manage the provision of complex surgical cancer care, with general agreement that a degree of centralisation of resources (including staff, infrastructure and experience) is necessary (174).

Currently there is no systematic national process to consider distribution of complex surgical services. This has resulted in highly complex surgeries being offered across multiple DHBs. For example, for major pancreatic resections, there is international evidence that centralisation of services and achieving minimum case numbers result in better survival outcomes (175) (discussed further in 'Evidence of ways to address challenges', page 83). However, due to ad-hoc planning around the distribution of services and lack of defined treatment pathways, in both 2019 and 2020, pancreatic resections were performed in 15 different hospitals in Aotearoa, with between 1 and 53 surgeries occurring per hospital. Aotearoa has lower pancreatic cancer survival rates compared to similar high-income countries (176) and the potential contribution of poorer surgical outcomes to these survival rates should be considered.





The issue of appropriately managing complex care was raised by stakeholders, who identified a need to centralise complex treatment services to create a critical mass of expertise and ensure all New Zealanders had equitable access to the highest quality care. However, it was also noted that centralisation inevitably means that some patients will need to travel further to receive care; this is a particular concern for Māori and Pacific peoples and those living rurally, who already experience disproportionate travel barriers to accessing care (see Section 1: Coordination and Support Services). Interviews with stakeholders also stressed that any centralisation of cancer surgical services must occur alongside support to maintain local surgical skillsets and services to manage acute emergencies and non-cancer surgery.

In contrast to highly complex procedures, there are some surgical services in Aotearoa that are currently only being delivered in major centres but could be delivered safely and effectively in more centres. One example of this is some reconstructive surgery, with the New Zealand Association of Plastic Surgeons/Te Kāhui Whakamōhou Kiri advocating for the expansion of reconstructive surgery services outside metropolitan centres to improve equity of access to specialist services.

### ***Patients experience barriers to accessing surgical care***

The current system relies on patients having to travel to receive the care they need. Financial resources and distance to treatment are often barriers to access, particularly for vulnerable groups. The current system to support this, the National Travel and Accommodation Scheme (NTA) is not fit for purpose and contributes to inequities. NTA is discussed further in Section 1: Coordination and Support Services.

Patients who live outside of main centres may be able to see specialists in an outreach clinic. However, outreach clinics are not as frequent as those in larger hospitals, and this may lead to delays in care and contribute to inequities. Specialists may move between hospitals, but this is currently often done through goodwill, sometimes in the clinician's own time, is inconsistent across the country and is not well supported by the current system.

Travel and accommodation barriers disproportionately impact Māori and Pacific peoples, partly due to factors such as higher rates of deprivation, comorbidity and rurality and contribute to inequity in cancer outcomes.



# Referral pathways and service integration

*Referral and treatment pathways are ad-hoc, resulting in delays and inequitable care options*

## Referral to other services

Patients requiring cancer surgery often need to be referred to a different hospital, service or sub-specialty. There are currently inconsistent referral and communication systems across the country, meaning that referrals between services often rely on goodwill and informal connections between clinicians. While these efforts are well-intentioned, what has evolved is a service that is fragmented, inconsistent and inequitable. “Work-arounds” are in heavy use, as one clinician interviewee said, *“the system is so broken that the work-arounds are no longer the way to navigate the system – they are the system”*.

The fragmented nature of the system can lead to delays in referrals, or referrals not being made at all. Stakeholders commented that this is likely a contributor to inequities.

Throughout stakeholder interviews several common referral issues became clear:

- Currently, there are no formalised referral pathways and/or referral standards for many complex surgeries, including hepatic resection, pelvic exenteration, pancreatic resection, oesophageal resection, sarcoma surgery and more. Referrals for highly specialised treatments are often word of mouth i.e. one surgeon knows another surgeon who they email, text or phone directly to refer.
- Funding is complex and not aligned to needs. Some referrals are declined because the DHB that receives the referral will only provide the service to patients from their own area due to the cost and/or restrictions placed by the DHB of domicile.
  - Inter-district flow (IDF) payments were widely regarded by respondents as not reflecting the real costs of treatment and care for often very sick patients. There were anecdotes of patients being denied access to surgery in another DHB because *“they couldn’t make the money work”*.
  - The issue of funding is compounded when combined with informal referrals pathways. The IDF process required a formal written referral for a patient to move between DHBs for treatment with multiple signoffs in each DHB for each patient. Obtaining this referral is the responsibility of the receiving clinician and the process is unnecessarily difficult and time consuming.



- Essential post-surgery information does not always flow smoothly back to the referrer in the DHB of domicile and/or the primary care provider. This can result in patients missing out on follow up care or adjuvant cancer treatment that is required after the primary treatment. Adjuvant therapy may include chemotherapy, radiation therapy, hormone therapy, targeted therapy, or biological therapy. Unfortunately, recommendations for adjuvant treatment can be received too late to implement. As a work-around for delays in letters being transcribed and sent, clinical correspondence may happen via email or text.

## Referral to MDMs

A common issue raised in stakeholder interviews was inconsistency in which patients were referred to multidisciplinary meetings (MDM). This leads to inequitable access to expert opinion on treatment pathways. Patients also noted a lack of transparency around the MDM process, with patients often not knowing when they were being discussed at a MDM.

An additional issue raised was that if a decision is made by the MDM to not offer surgery, there is inconsistency in whether the MDM develops an alternative care and treatment plan for that patient. This means that some patients are referred back to their local hospital with no clear way forward. The management of patients who are unfit for surgery, due to advanced disease or comorbidity, is complex and resource intensive. Currently, Māori and Pacific peoples are disproportionately impacted as they are more likely to have comorbidity and may be more likely to have advanced disease at diagnosis for some cancers (17, 168).

## Inconsistent post-treatment follow-up

### ***Some people are getting too much surveillance and some people get not enough***

A theme that emerged from stakeholder interviews was the longstanding variation in how post treatment surveillance is approached (17). In some regions, patients will stay under specialist follow-up for life, whilst patients in other regions will be discharged back to primary care.

Currently it is challenging for many working in primary care to take over cancer follow-up because of a lack of agreed guidelines, an inability for primary care to directly access imaging (CT, MRI) and difficulties accessing MDM support.

Although not quantified, post-treatment surveillance is thought to consume a large amount of resource, including specialist time and radiology capacity. It is likely that the current ad-hoc system is causing harm, from over-investigating some patients (with added harm from utilising resources that could be utilised elsewhere) and under investigating others.



## Consideration of new procedures

### *New procedures are considered and implemented locally, leading to inconsistent access*

The lack of national policy to consider distribution of services also has an impact on equity of access to new and emerging treatments. Often new treatments start as experimental, and over time they move to become part of routine care within the hospital where the service is provided. However, clinicians in other hospitals do not always know what treatments are available in other centres or when treatments are no longer considered experimental. This means that patients outside of major centres may miss out on these treatments, which is likely to disproportionately impact Māori. One example of this is cytoreductive surgery and hyperthermic intraperitoneal chemotherapy (HIPEC), which was brought to Aotearoa by a surgeon who had a specific interest and undertook training overseas. Waikato DHB is currently the only DHB offering HIPEC, accepting referrals from across Aotearoa.

Currently, applications for new national cancer services are considered and approved on the basis of an application from a prospective provider to the Ministry of Health | Manatū Hauora (171). This means the process is provider driven, rather than through a proactive process of identifying what services are required and then allocating them to an optimal provider.

During stakeholder interviews, clinicians also noted challenges with trialling and introducing new techniques as there was no nationally transparent process for assessing or prioritising such techniques, with huge variability in access across DHBs.

## Increasing complexity of patients

### *Inequitable access to prehabilitation to maximise access to, and outcomes from, surgery*

There is evidence that as their level of comorbidity increases, the likelihood of patients receiving curative cancer surgery reduces starkly (177). Māori cancer patients are more likely to have comorbidity than non-Māori cancer patients, and this inequity likely contributes to inequities in access to cancer surgery between Māori and non-Māori (10, 20, 178-182).

Māori and Pacific peoples are more likely to have high Body Mass Index (BMI) than non-Māori, non-Pacific, and there is some evidence that this reduces the likelihood of being selected for surgery, or can reduce options for where surgery is carried out (183).



Reducing levels of comorbidity, through addressing social determinants of health, health promotion, prevention and improving access to primary care, are outside the scope of this report. However, the way comorbidity is approached across surgical services is a challenge.

Prehabilitation is the process of improving the functional capability of a patient prior to surgery so they can better withstand the physiological effects of their treatment. Currently, the provision of prehabilitation varies across the country. In some hospitals there is a systematic way of identifying patients who would benefit from some form of prehabilitation – often through anaesthetic pre-assessment clinic – with those meeting set criteria referred for a nutrition or physiotherapy assessment. There are also new initiatives emerging across the country, with one region referring all people undergoing major bowel surgery for a pre-operative physiotherapy assessment.

In other regions there is no formal system for prehabilitation services, and ad-hoc arrangements have developed, which can heavily rely on personal relationships as highlighted by one clinician *“I have a deal with the geriatricians for them to see patients I am worried about and then I see some of their acute surgical patients in return”*. Many clinicians across Aotearoa report that most of the patients that would benefit from prehabilitation and optimisation are not getting it.

During stakeholder interviews, a common reported barrier to prehabilitation is a lack of resourcing, both for the completion of assessments, but also for the coordination of the assessments (184). In order for prehabilitation to be effective, assessments and interventions must be completed in a timely manner, which requires considerable coordination.

It was also noted that for many complex cancers, a large proportion of patients will not be suitable for surgery, either due to comorbidity or due to advanced disease (181, 185). The management of these patients is complex and focussed on maintaining quality of life (186). There is often a shortage of hospice beds, and so if patients require inpatient care they will often be admitted to general surgical/medical departments. Currently patients admitted to general surgical/medical wards have inconsistent access to palliative care across Aotearoa. This can create significant challenges and distress for patients, whānau and staff and can limit culturally appropriate practices at the end of life.



## Workforce issues

*The surgical workforce has a number of pressing challenges, including understaffing, concern about future workforce sustainability, poor workforce diversity and has an opportunity to practice with increased cultural safety*

There are currently 1529 surgeons registered in Aotearoa (Health Workforce 2021). This aligns well with a recent Lancet Oncology review, which estimated that the optimal surgical workforce in Aotearoa to be 1555 surgeons (187). Combined data from international entities estimates that in 2016 Aotearoa had a specialist surgical workforce<sup>1</sup> of 43 per 100,000 population, which was lower than the average specialist surgical workforce of 68 per 100,000 for OECD members, but comparable to the 44 and 45 per 100,000 for Canada and Australia respectively (188).

Most specialties that deliver cancer surgery are forecast to have significant shortages by 2030. Table 3 outlines workforce forecasts for 2030, based on average rates of new entry, re-entry and exit over the past 3 or 5 years. This forecast is based on current workforce provision and does not take into account current unmet need, workforce shortages or changes to models of care over time.

**Table 3: Surgical doctor workforce forecasts based on average rates of new entry, re-entry and exit over the past 3 or 5 years (HWFNZ).**

Specialty	Ratio of FTEs to relevant population (FTE per 100,000)		Percent change in FTE ratio to 2030
	2020	Projected 2030	
Cardiothoracic surgery*	4.0	3.0	-24%
Otolaryngology, Head and Neck Surgery	11.8	9.2	-22%
General Surgery	33.6	27.9	-17%
Urology	7.8	6.5	-17%
Neurosurgery*	2.9	2.4	-16%
Orthopaedic Surgery	36.1	30.7	-15%
Plastic and Reconstructive Surgery	8.4	7.4	-12%
Anaesthesia	91.6	83.5	-9%
Obstetrics and Gynaecology	18.1	19.4	7%
*These specialties have small workforces, hence percentage changes need to be treated with caution, because large percentage changes may reflect very small changes in FTEs.			

<sup>1</sup> For this set of data, the specialist surgical workforce is the number of specialist surgical, anaesthetic, and obstetric providers who are working in each country per 100,000 population





Nurses make up the largest component of the cancer workforce (17). Nursing shortages are a significant challenge for health services, with several stakeholders indicating that nursing shortages were a barrier to the effective delivery of surgical care. Currently there is no clear national view on nursing vacancies or where there are shortages of surgical nurses. Work done by Health Workforce New Zealand estimates that by 2031 there will be a 5 percent decrease in surgical nursing FTE ratio compared to 2021 FTE. As with other forecasting, this is based on keeping pace with projected population growth and demand for services and does not take into account current shortages.

Stakeholders were also concerned with the resilience of the cancer surgical workforce and a lack of proactive workforce planning. Many staff who work in specialised cancer surgical services are in sole person roles creating challenges for continuity of care, leave cover and succession planning. The growing demands and lack of cover can be stressful and can directly affect patient care, for example with the cancellation of specialist appointments if a surgeon is away, or the collapse of a whole service if the surgeon leaves.

Patients, whānau and consumer groups frequently raised cultural safety of the workforce as a concern. Despite the emphasis on this in the training of health professionals, patients and whānau were able to provide many examples of feeling unsupported, misunderstood, and culturally unsafe in the cancer care environment.

*“They were hōhā because we wanted 2 minutes for a karakia before they took him in for surgery.”* Community Hui participant, 2021

Although Māori make up 16.5 percent of the total population of Aotearoa, only 3% of general surgeons and 5% of surgical nurses identify as Māori (17). Increasing the number of Māori in the surgical workforce was frequently mentioned as being critical to improve care for Māori patients and whānau.

A common issue raised during stakeholder interviews was the feeling that staff often spent a lot of their time working ‘below-scope’. For example, rather than spending their time seeing patients, developing treatment plans and operating, some surgeons are spending significant amounts of time undertaking administrative tasks that could be completed by support staff.

### ***People feel like they are waiting too long for appointments***

Patients and whānau often raised the issue of waiting time for clinic appointments and surgery. Although cancer patients are prioritised in the surgical system, hospitals also have to consider waitlist targets and non-cancer critical surgeries. Surgical wait times are also impacted by capacity within non-cancer services (for example if a patient requires a preoperative cardiology appointment), as well as the availability of ward and ICU beds.



Faster cancer treatment (FCT) data aims to monitor timeliness of care. The aim is that 90% of patients receive their first cancer treatment within 62 days of being referred with a high suspicion of cancer. In 2019/2020, 55% of all patients on the FCT pathway had surgery as a first treatment. Of those patients, 88% of patients received their surgery within the 62-day timeframe; however, this was lower for Māori (82%) (17). It is important to note that FCT data only includes those on the 'high-suspicion of cancer' pathway, approximately 25% of all cancer patients.

If patients have private health insurance, or the ability to pay, they may choose to access more timely services privately, which can contribute to inequitable access and outcomes. For example, in breast cancer, the majority of the disparity in the timing of treatment following diagnosis between Māori and non-Māori is driven by differences in access to privately-funded care (189).

Clinicians noted that lack of time in outpatient clinics was an issue, causing tension between seeing as many patients as possible versus giving everyone the time they need to be properly assessed and asked questions. It was noted that outpatient clinics would frequently have people who did not attend an appointment, essentially 'wasted time' for the specialist, and an indication that the system is not working well for patients.

## Acceptability of services

### *Aspects of surgical care make having cancer even harder, rather than easier*

A common issue raised by patients and whānau was that surgical services were often health-system focused, rather than person and whānau-centred. This included clinic appointments feeling technical and transactional, without enough time to build relationships, process information and ask questions. This can also be unsatisfactory for clinicians, who have a large amount of information to pass on to the patient – including a legal responsibility to obtain consent – in a short amount of time.

There were also elements of the way services were structured and delivered that made having cancer even harder. For example, patients often reported issues with scheduling of appointments, including having multiple appointments with different specialities on different days. This was particularly an issue for people who have to travel long distances to appointments and for people who have difficulty getting time off work or who are the primary or sole caregiver for dependant whānau members.





The physical environment can create a barrier to patient-centred care. For example, outpatient clinic rooms are often too small to accommodate whānau support at appointments. The inpatient environment can also be a challenge for patients, with patients with complex cancers and high levels of care required to share a ward with general surgical patients. Patients and whānau frequently report that there often isn't room for whānau to attend appointments and that there is often limited privacy for private conversations to occur, particularly as an inpatient.

Language and cultural factors were frequently identified to impact access to care. An inability to speak English well and/or dissonance between the patient's culture and that of the health system led to a fear of being judged. It was noted that some patients also had poor health literacy which amplified access problems and affected patient/whānau decision-making. Many clinical stakeholders noted that these patients are more likely to 'get lost' in the system, missing appointments or disengaging, and as a result have poorer health outcomes.

All of the above factors disproportionately impact Māori, Pacific peoples and those who live rurally. Collectively these factors contribute to inequity in cancer outcomes.

## Increasing demand for cancer surgery

***The number and complexity of cancer surgeries is expected to increase over the coming decades, meaning that, without action, current issues will increase***

The estimated global number of cancer cases with an indication for surgery is projected to increase by an average of 52% from 2018 to 2040 (187). Table 4 shows the forecast increase in cancer surgeries in Aotearoa.

**Table 4: Annual number of cancer cases with an indication for surgery in 2018 and 2040 (projected), and percentage increase in Aotearoa (187)**

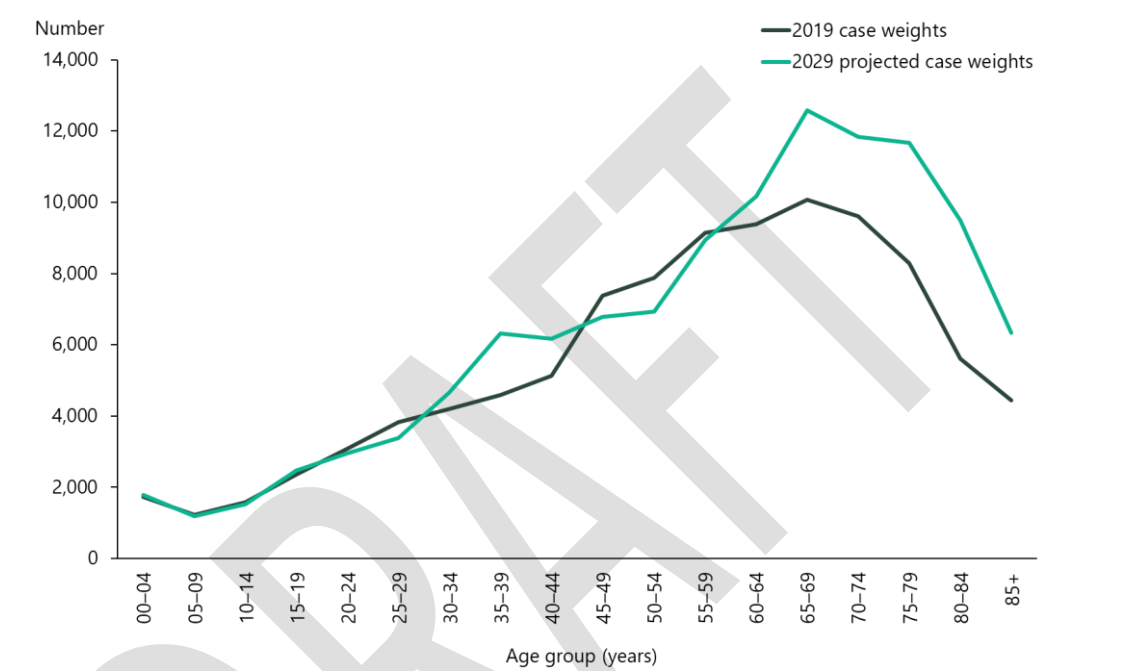
Cancer cases in 2018* (n)	Estimated cancer cases in 2040 (n)	Optimal number of cancer surgeries in 2018 ** (n)	Projected optimal cancer surgeries in 2040 (n)	Increase in cancer surgeries (n)	Percentage increase in cancer surgeries (%)
25,156	37,599	14,590	21,807	7,217	29

*\* this number excludes haematological and unspecified malignancies, \*\* based on a model developed to estimate optimal proportion of patients with an indication for surgery across different cancer types*



The degree of complexity of surgeries is also projected to rise in the next 10 years. Case weights measure the relative complexity of surgery, based on resources needed including theatre time and number of days in hospital. Figure 3 shows the total case weights for hospital discharges for general surgery (both cancer and non-cancer surgeries), in 2019 and projected case weights for 2029. This shows that case weights are projected to increase, particularly amongst older adults.

**Figure 3: Total case weights for 2019 and projected case weights for 2029 for hospital discharges with general surgeries by age group**



# Tō āianeī mana taurite kore

## Inequity in the current state

*"My main concern around surgical cancer services is certainly equity of access and how this affects surgical outcomes and mortality and morbidity for cancer patients. Pre-existing inequalities – such as cost, access to care, poor communication – lead to increased risk of post-operative complications and poorer long-term outcomes for patients".*

Cancer nurse specialist

Generally, cancer surgery in Aotearoa is of high quality and outcomes are comparable to other countries (17). However, not all population groups are receiving the same benefit from surgical services. All of the challenges described above collectively create inequity in access, quality and outcomes for Māori and Pacific peoples compared to non-Māori, non-Pacific, as well as inequity in care based on where people live. The cumulative impact of these system issues is summarised below, demonstrating the extent to which the current system is creating inequity in surgical care.

## Equity for Māori

### *Equity of access*

There is extensive evidence that Māori are less likely than non-Māori to receive curative cancer surgery. For example, Māori with non-small cell lung cancer are less likely to receive curative surgery than non-Māori patients (178), Māori with breast cancer wait longer for surgical resection compared to non-Māori (189) and Māori with localised prostate cancer are less likely to be treated with radical prostatectomy, and are more likely to be treated with active surveillance or watchful waiting than New Zealand European men (190). There is evidence that Māori are less likely to have access to definitive surgery for colon cancer (10), and, where that surgery is accessed, more likely to undergo emergency surgery than non-Māori (191, 192).

### *Equity of quality*

There is evidence of disparities in the quality of care received by Māori compared to non-Māori. In breast cancer, Māori are more likely to receive mastectomy rather than breast-conserving surgery than non-Māori, and less likely to receive breast reconstruction surgery following mastectomy (193). In stomach cancer, Māori are less likely to have a specialist upper-gastrointestinal surgeon than non-Māori patients, even when treated in main centres such as Auckland (182). In lung cancer, there is some evidence that Māori wait longer for curative treatment (surgical or radiotherapy) compared to non-Māori (165).



### *Equity of outcomes*

There is also evidence that Māori experience poorer post-operative outcomes than non-Māori patients, even after adjusting for confounding factors including age and comorbidity (194). Māori in the general population are 65% more likely to die than non-Māori within 30 days of an elective/waiting list procedure under general anaesthetic (195). In the context of cancer, Māori patients have the highest 90-day mortality following elective colon cancer surgery than any other ethnic group (192).

## Equity for Pacific Peoples

Pacific peoples experience significant barriers to accessing health care in Aotearoa (196). Pacific peoples are less likely to survive their cancer than non-Pacific, including due to differences in access to and quality of care (196). Pacific peoples have the lowest rate of curative resection for lung cancer of any ethnic group (197). Pacific women also experience difficulties in accessing plastic surgery services, and are less likely to receive post-mastectomy breast reconstruction than non-Pacific (183, 198). Pacific peoples are less likely to receive timely and optimal cancer surgery than non-Pacific peoples (166).

## Geographic variation

Not everyone in Aotearoa has equal access to cancer surgery by virtue of where they live. For example, between 2015 and 2018, 1,006 people with non-small cell lung cancer underwent surgical resection, an intervention rate of 16.7%. However, this varied by DHB ranging from 10% to 24% (197). There is similarly substantial variation in the use of curative surgery to treat prostate cancer, with the surgical resection rate ranging from 9.5% to 26.2% across DHBs (199). As well as variation in access, variation is also seen in surgical outcomes. For example, there was variation in post-operative mortality across DHBs following bowel cancer resection, for both elective and emergency procedures (192).

*A detailed equity analysis of how each of the challenges with the current system contributes to inequity in access, quality and outcome, and alignment to focus areas is included in **Appendix VI**.*



# Taunakitanga hei whakatutuki wero

## Evidence of ways to address challenges

This section of the report looks at local and international evidence to identify ways to address the challenges with the current cancer surgical system in Aotearoa.

### Service distribution

#### Centralisation of complex surgery

##### *Centralisation is important for some cancers*

There is evidence that high surgical volumes are associated with improved outcomes in cancer surgery, including lower operative mortality and morbidity and improved long-term prognosis (200-205). Volume may refer to the number of a specific procedure performed by either a surgeon or service. The importance of volume differs by cancer type, with not all surgical procedures having a strong and clear 'volume-outcome' relationship (201, 206, 207).

Surgical centralisation involves the concentration of resources – including staff, infrastructure, knowledge and research – aiming to increase volumes, improve outcomes and reduce variation in quality of care (174, 208-210). There are multiple mechanisms by which centralisation can improve outcomes, including increased volumes leading to greater technical expertise (174, 211). Volume may also act as a surrogate measure for other factors that improve outcomes, including the multidisciplinary services available in an institution to support surgical and postoperative care, with evidence that reductions in mortality in larger hospitals can be due to the ability to 'rescue' patients when they have a complication (212-218). In this sense, centralisation of care is not just about improving access to expertise in complex surgery, but also expertise in managing complications from complex cancer surgery (219, 220).

Centralisation can also improve access to innovative technologies, with high volume units often connected to research centres (221-223). Centralisation of highly complex care may have a positive impact on cost, due to reduced complications, improved long-term outcomes and more efficient use of resources (174, 224-227).



Policies on centralisation of complex cancer surgery are now common internationally, with a recent review of 22 European and North American countries finding only four countries did not have a policy on centralisation of gastrointestinal surgery (174). However, there is not a consensus on minimal volumes required to improve outcomes, for example policies on minimal number of pancreatic resections per year vary in volume from 10-80 (174, 228-231).

There is also variance in how centralisation is approached more broadly, with some jurisdictions basing policy on volumes alone, and others on criteria including volume, complexity, interdisciplinary care requirements, postoperative morbidity/mortality, infrastructure requirements, technical challenges of the procedure and evidence of volume-outcome relationship (174, 220, 232). Some centralisation policies are led nationally, with others emerging regionally, for example with centres taking a 'volume pledge' for complex surgeries to only be performed by the most experienced providers (220, 233, 234).

The Lancet Oncology Commission on Global Cancer Surgery recommends the centralisation of complex surgical procedures, that are resource and infrastructure dependent, to central training centres (169).

## Barriers to access and unintended consequence of centralisation

***Centralisation may create barriers to access and have unintended consequence, which must be mitigated for centralisation of complex surgery to be effective***

### Access and travel

Although centralisation can improve equity in quality of outcomes for highly complex surgery, there is a risk that this equity will not be realised if there are barriers to accessing centralised services (220). Centralisation is associated with increased travel requirements and, particularly for some population groups, this may pose a barrier to accessing high quality surgical care (228, 235-237). As well as the logistics of traveling to receive care, having to travel can also mean being separated from whānau, friends and other support networks.

A study from New South Wales found that, at the individual level, disparity in outcomes have been reported for patients with pancreatic cancer related to geographic remoteness and socio-demographic factors. However, even when reviewed at a specialist service level, the uptake of treatment by people at greater social disadvantage can be lower, highlighting the range of factors that influence receipt of surgery (238, 239).



Distance and time to travel have been identified as critical factors for patients' decision-making around accessing health care broadly (237, 240). In general, cancer surgery research has found that patients are often supportive of centralisation and are willing to travel to receive highly complex specialised surgical care if it will result in increased quality of care (174, 241). Patients may prefer to be treated in a high-volume centre if it is associated with a lower risk of complication and death and if it means they have better access to multidisciplinary care; however, this may be more likely for patients of higher socioeconomic status (208, 210). Willingness to travel varies with the magnitude of the potential outcome improvement (240, 242, 243).

To mitigate any potential harms from centralisation, there are key factors that need to be implemented to ensure care is person and whānau-centred and achieves equity of access, quality and outcomes. Patients have identified well-functioning care pathways, continuity of treatment with local providers, accessibility for contact and information, involvement in care planning and limited waiting time as critical components of centralisation (174, 241). In the Aotearoa context, travel and accommodation can already create barriers to access to care, which would need to be addressed alongside any centralisation policy (discussed further in Section 1: Coordination and Support Services). It is also important to remember that there is no 'typical patient'; with different patients making decisions on the basis of different circumstances and on different provider characteristics – not just outcomes (240), highlighting the importance of options being available.

Given the burden that travel poses on patients and their family, surgical centralisation should be carefully targeted to complex surgeries where there is a strong volume-outcome relationship (175, 244, 245).

#### Other considerations for centralisation

There are other aspects that need to be addressed when considering implementation of policy around surgical centralisation. These includes:

- **Provision of high-volume cancer and non-cancer care:** complex procedures requiring centralisation make up less than 5% of all surgical cases (170). There is a risk that 'hyper-specialisation' may have a negative impact on the delivery of general surgery outside of high-volume centres (224). There is also the risk that centralisation can limit the skills needed to diagnose cancer in the first place and to treat patients who are admitted in an emergency (246). Centralisation policy needs to consider the resource requirements of non-cancer surgeries (247).
- **Training:** centralisation is associated with increased specialisation and raises concerns around the training opportunities for surgeons (220, 248). It is important to maintain an appropriate balance between general and sub-specialised surgeons to maintain accessibility to high quality surgical care (174).





- **Capacity:** centralisation has the potential to introduce capacity issues. Policy needs to consider how to appropriately accommodate more patients at high-volume centres without increasing wait times (228)
- **Continuity of care:** centralising part of cancer care increases the risk of fragmentation of care (249). Continuity of care is important for patients and is associated with increased quality of life and decreased use of hospital services (241, 250-253). Patients with complex/rare cancers may undergo initial diagnosis, assessment and treatment across different hospitals. Processes to ensure continuity of care need to be considered when developing policy around centralisation (249).
- **Geography:** geographical remoteness and low population density can create challenges to centralisation. This was thought to be a concern in Finland a country with a similar land area, population and population density to Aotearoa. However, despite geographical challenges, Finland concluded that the improved outcomes from high-volume centres justified rationalisation of pancreatic surgery, so that two to three centres could undertake more than 40 pancreatoduodenectomies per year (175).
- **Interdisciplinary care requirements:** centralisation must consider the range of clinical services required to provide round-the-clock high-quality care, including interdisciplinary staffing requirements (174).

Despite many international jurisdictions having national minimum hospital volume policies, these are often either only partially implemented, or not implemented at all (174). Working through patient-level, local, regional and national issues is critical to the success of centralisation policy to improve outcomes for complex surgical care (174, 207, 254).

One example of effective centralisation of low volume services in Aotearoa is child cancer services. Since 2010, all children with cancer have been referred to one of two specialist paediatric oncology centres in Auckland or Christchurch. The child cancer service currently delivers consistent outcomes regardless of ethnicity, where people live or socioeconomic status (255). This is achieved through comprehensive support for travel and accommodation, with consistency of care supported by over 200 clinical guidelines and protocols, and clearly delineated responsibilities across the two specialist centres and the 14 shared care centres.





## Improving connection across the care pathway

### *Networks of care providers can be effective at improving surgical outcomes*

Internationally, networks between major centres and smaller hospitals have been used to train and build capacity across the surgical system (224). Clinical networks, that include multidisciplinary team meetings and quality-improvement initiatives, are increasingly being viewed as an important strategy for increasing evidence-based practice and improving models of care in cancer (256).

Networks of care can also mitigate some of the potential negative impacts of centralisation. By establishing solid links between hospitals of different sizes, patients can be transferred and have appropriate work-up and follow-up as needed (174, 257). This can include patients receiving the required work-up locally, using local staff, with close relationships and support from specialists in larger centres.

Strong networking enables smaller hospitals to have closer involvement with specialist centre staff, with the potential to improve quality of care across the whole system (208). The rotation of general surgeons to high-volume centres, particularly during training, is highly advisable to increase technical skill (174, 221). Networks can also enable high volume surgeons/surgical staff to travel to smaller centres to mentor staff, or for staff from smaller hospitals to follow their patients and support and provide care at high volume centres (207).

There is strong international support for networked multidisciplinary teams and meetings across low and high-volume hospitals (208, 209). Following centralisation, joint multidisciplinary team meetings can increase connection between low and high volume hospitals with the potential to improve quality of care across the whole system (258). It is also important to recognise that initial work-up, management and 'selection' for surgery is a critical component of surgical care, and so centralisation processes should include consideration of equitable access to MDMs (256, 259, 260).



***Service distribution planning must consider the whole pathway of care, not just focus on the location where surgery occurs***

High quality surgical outcomes rely on more than just the surgical procedure itself, the whole surgical pathway must be considered (224, 259). Once policies around service distribution have been developed, the policy needs to be implemented in a way that is accessible and is regularly updated.

Guidelines and surgical pathways, such as those from the National Comprehensive Cancer Network in the United States, can improve the quality of surgical care and can also support efficient and equitable use of resources (224, 244, 261). Well-functioning care pathways have been identified as highly important for patients (241) and there is good evidence that standardisation of care across treatment pathways reduces inequities (262).

Many health systems are moving away from 'clinical guidelines', and adopting a new approach that maps a patient's journey through the entire health system (263). Australia have recently published Optimal Cancer Care Pathways, which aim to improve cancer outcomes through consistent, safe, high quality and evidence-based care across the cancer continuum.

Clear referral pathways may help ensure patients have timely access to high quality surgical care (244). This is particularly important as there is some evidence that if patients are first seen at non-surgical centres they may be less likely to receive surgery than patients first seen at surgical centres (264, 265).

## Ensuring consistent, high-quality care

***Regardless of where surgery occurs, quality assurance and quality improvement need to be built into the system***

In terms of improving surgical quality, centralising a small number of highly complex procedures is relatively straight forward. Broader improvements in surgical outcomes requires ongoing quality improvement across the surgical pathway (233).

Quality assurance and quality improvement are about much more than surgical volumes and are a critical component of strengthening cancer surgical systems (224). Regardless of where surgery occurs, quality improvement should occur at each facility caring for patients with cancer (266, 267). This can include the development of reliable outcome measures that can inform local and regional quality-improvement programmes (266).



National surgical audits, with regular feedback, are one way of improving the quality of surgical systems (224). Internationally, more complex quality programmes are currently underway, including EUropean REgistration of Cancer CAre (EURECCA), which aims to improve outcomes through a multidisciplinary audit registry by standardising data collection, feedback on surgical performance and sharing knowledge and new initiatives (224, 268). Comprehensive audits, including all patients within a country, are an effective tool for quality improvement (269).

Quality assurance should also be built into care pathways. There is evidence that cancer outcomes can be significantly improved if accepted clinical guidelines are implemented in practice (224, 270). Work is needed to improve implementation practices, to ensure innovation and best practice are translated into clinical care (271).

## Increasing complexity of patients

### Prehabilitation

Increasing volume and complexity of cancer care is an issue being faced by countries world-wide. As well as focusing on prevention and access to primary care, countries are looking for ways to manage increasing comorbidity and complexity of surgical patients.

Prehabilitation is the process of improving the functional capability of a patient prior to surgery so they can better withstand the physiological effects of their treatment. Prehabilitation can improve cancer treatment outcomes (272). There are different models of prehabilitation, including personalised, home-based models designed to meet the needs of centralised cancer services (273). Prehabilitation is discussed further in Section 5: Allied Health.



# He tāpae hei panoni

## Proposal for change

Through stakeholder interviews and review of the literature it is clear there are challenges with the current approach to cancer surgical services, and opportunities to improve equity and quality of care.

The aim is to have a surgical system that is designed to meet the needs and expectations of patients, whānau and communities and is focused on eliminating inequities in access, quality and outcomes. A high-quality surgical system is one that is based on clearly articulated models of care with agreed pathways that are person and whānau-centred, coordinate with other services and are based on evidence. Quality control is built in and there is a focus on constant improvement. Staff training and education is excellent and ongoing. There is a balance between more complex services that are provided at a national or regional level, with those that are provided locally.

## Ngā wāhi hei mahi | Potential focus areas

### System leadership

#### National system leadership

1. Te Aho o Te Kahu to work in partnership with Health New Zealand | Te Whatu Ora, the Māori Health Authority | Te Aka Whai Ora, the Ministry of Health | Manatū Hauora and other partners, including Māori leaders, to provide national strategic leadership for cancer surgical services, with a Te Tiriti and equity focus. This will include:
  - Subject matter expertise for the distribution of cancer surgical services
  - Leadership for national cancer care pathways
  - Strategic advice around cancer workforce planningTe Aho o Te Kahu will provide subject matter expertise on cancer and a connection to the cancer sector to ensure broader changes to surgical services align with cancer-specific requirements.
2. Te Aho o Te Kahu to ensure that national leadership structures for cancer include surgical expertise.
3. Te Aho o Te Kahu to provide or facilitate cancer subject matter expertise to a national assessment process for innovative approaches to treatment, including horizon scanning for emerging techniques and supporting adoption and equitable implementation.



4. Te Aho o Te Kahu to support Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora by providing cancer subject matter expertise for infrastructure planning, to support the development of physical spaces that are conducive with the delivery of high-quality cancer surgical care, including outpatient clinic rooms having space for whānau, appropriate inpatient facilities and appropriate facilities for diagnosing and treating patients with very high BMI.

#### Data driven

1. Te Aho o Te Kahu to develop, implement and monitor a Cancer Information Plan to provide timely access to high-quality surgical data to support sound decision-making, including:
  - a. Making appropriate data accessible to those working across the surgical system to empower understanding and decision making for patients, whānau, iwi, clinicians as well as for regional and national planning.
2. Te Aho o Te Kahu to work with the Māori Health Authority | Te Aka Whai Ora to ensure they have access to high quality information about cancer surgical services and inequities to inform decision making to improve Māori health outcomes.
3. Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora to ensure quality assurance and quality improvement initiatives are built into the cancer surgical system and cancer care pathways, including:
  - a. Monitoring of quality and equity of surgical services through the ongoing roll out of quality improvement programmes, including institutional level data on volume and outcome to learn from high performing units and support lower performing units.
  - b. Work with cancer surgical networks to develop and implement quality improvement initiatives.
4. Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora to monitor the impact of changes to surgical systems as part of the health system reform, including a focus on:
  - a. The impact of any centralisation on access to surgery, patient experience, waiting times and outcomes, with a focus on equity across the measures.
  - b. Ensuring changes to the cancer surgical services does not have inadvertent negative impact on non-cancer surgery.

#### Clinical service distribution

##### National & coordinated clinical leadership

1. Te Aho o Te Kahu to work in collaboration with Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora to provide national oversight to a network of surgical cancer services across low and high-volume surgical centres.
2. National clinical leadership is considered by cancer type and includes surgical expertise to ensure quality and consistency of care, and to manage treatment guidance and integration into practice.



## Clinical Service distribution

Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora to implement a nationally led process around the distribution of surgical cancer services.

1. High-complexity surgical procedures with a clear, strong link between volumes and outcomes are centralised, whilst less complex cancer surgery is delivered as close to home as possible, practicable and safe.
  - a. Ensure implementation mechanisms are in place for centralised surgical services that are person and whānau-centred and achieve equity of access and outcomes. Key factors include: well-defined patient pathways, accommodation and transport support (see Section 1: Coordination and Support Services), referral and communication protocols and shared care arrangements that support continuity of care.
  - b. Consideration should be given to geographical distribution of services for sustainability, resilience and access, with a focus on ensuring access for Māori, Pacific and socioeconomically disadvantaged communities.
2. Surgical service distribution to consider integration across cancer services, with the patient pathway mapped to ensure the default care path is appropriate.
3. Role delineation to occur across centres to ensure delivery of high quality, sustainable and equitable surgical outcomes. All hospitals involved with cancer surgery will be assessed as having the appropriate level of clinical and support services for the procedures being provided at that hospital, including imaging, laboratory, allied health and community-based support services.
4. Distribution planning is a nationally led process and includes appropriate funding models to ensure that funding mechanisms do not create a barrier to patients receiving high quality care.
5. Surgical services be provided through a networked approach between major centres and smaller hospitals to build capacity and resilience across the whole surgical system.
  - a. Networks will provide support for surgeons and staff in smaller hospitals, through participation in MDMs, clear communication channels and timely support between centres and the opportunity for staff from smaller hospitals to work alongside staff from high-volume centres.
  - b. Strong collaboration within multi-institutional networks can improve continuity of care for patients.
6. Te Aho o Te Kahu to consider future-proofing multidisciplinary team meetings
  - a. National distribution planning includes consideration of the level (local, regional, national) of MDM
  - b. Care pathways include clear recommendations around referral to MDM to ensure equity of access to clinical expertise
  - c. MDM guidance to include information on development of care plans for patients who are not surgical candidates.



## Care close to home

Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora, the Māori Health Authority | Te Aka Whai Ora and other partners, including Māori leaders to provide care as close to home as possible without compromising quality of care.

1. Surgical services to provide outreach clinics to minimise travel requirements for patients and whānau, with a particular focus on achieving equity of access to services in underserved communities.
  - a. This can include upskilling of local clinical staff in a specific surgical specialty.
  - b. Where patients are required to travel to a high-volume centre for surgery, as much pre-assessment and follow-up as is possible should be provided locally, with support from high-volume centre/specialist.
  - c. For surgical procedures that are not required to be performed in a high-volume centre and where a local hospital can offer the appropriate level of support but does not have the required surgical skill locally, networked surgical systems would enable surgeons to travel between hospitals to operate on selected patients at local hospitals.
2. Telemedicine is developed, supported and utilised for advice and appointments – including use of community and rural health practitioners to support telehealth appointments with surgeons in larger centres.

## Implementation mechanisms

There are critical factors that must be implemented as part of policy for the national distribution of surgical cancer services. These factors improve care across the whole surgical system and are also crucial parts of any centralisation policy.

1. Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora to develop clear service pathways, outlining treatment pathways, where and how MDMs are held, allied health requirements and palliative and end of life care requirements.
  - a. Pathways will include clear referral information, so that clinicians across Aotearoa know where and how to refer patients with different cancer types
  - b. Surgical pathways will include prehabilitation and post-surgical care, including systems for information to flow back to local hospitals following centralised procedure (eg to ensure timely access to adjuvant chemotherapy)
  - c. Surgical pathways will be maintained and regularly updated to provide a mechanism for nationally agreed new techniques and technology to be translated equitably into clinical care
  - d. Surgical pathways will outline the 'default' pathway; however, options should be available that support deliberate and considered deviation from the pathway to meet patient and whānau need, priorities and self-determination





- e. Pathways will include consideration of those who are not suitable for surgery and include palliative care requirements.
- f. Pathways include post-treatment follow-up and surveillance guidance, including considering the role of primary care and nurse led clinics.

## Workforce

### Capacity

Te Aho o Te Kahu to support Health Workforce to grow and maintain the cancer surgical workforce in Aotearoa, including robust planning to meet future increase in demand.

1. Workforce planning to include a focus on nursing, with short-, medium- and long-term strategies to retain, succession plan and attract nurses into speciality surgical services. This includes projecting the optimal number required to support the development of new models and service distribution and develop a way of monitoring vacancies across surgical services.
2. Workforce planning will include consideration of new models of care that may require increased staffing (eg centralisation of complex care may require a sub-specialised surgeon to be on-call, which will need increased staffing to cover rostering).

### Diversity

1. Te Aho o Te Kahu to support the Māori Health Authority | Te Aka Whai Ora, Health New Zealand | Te Whatu Ora, Health Workforce, the Ministry of Health | Manatū Hauora, training institutions and other partners, including Māori leaders, to enable the surgical workforce to better reflect the population of Aotearoa, with a focus on increasing the number of Māori and Pacific in the surgical workforce.

### Cultural safety

1. Te Aho o Te Kahu to work with the Māori Health Authority | Te Aka Whai Ora, Health New Zealand | Te Whatu Ora, the Ministry of Health | Manatū Hauora, training institutions and other partners, including Māori leaders, to develop processes to support, increase, and measure the cultural safety of the cancer surgical workforce.
2. Te Aho o Te Kahu to support the Māori Health Authority | Te Aka Whai Ora and the Ministry of Health | Manatū Hauora to implement the Ao Mai Te Rā antiracism maturity model (currently in development) across the cancer treatment system.
3. Te Aho o Te Kahu supports the Māori Health Authority | Te Aka Whai Ora, Health New Zealand | Te Whatu Ora, Health Workforce, and the Ministry of Health | Manatū Hauora to ensure staff involved in cancer care have training and are able to communicate with patients and whānau, in an effective, considerate, and culturally safe way.





## Scope of practice

1. Te Aho o Te Kahu to work with Health Workforce to develop a future focused approach to cancer workforce that:
  - a. includes significant growth of nationally consistent advanced and extended practice roles in nursing and allied health;
  - b. includes access to continuing education;
  - c. creates a digitally capable workforce that is able to use telehealth to its full potential;
  - d. emphasises the importance of a strong team approach to cancer care.
2. Te Aho o Te Kahu to work with Health Workforce, Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora to ensure administrative and other systems are in place to support clinical staff in their roles, including staff to coordinate required prehabilitation assessments to ensure they are complete in a timely way.



DRAFT



# WĀHI 3: MĀTAI MATE PUKUPUKU

## SECTION 3: RADIATION ONCOLOGY

### He kupu whakarāpopoto Summary

#### Case for change

Radiation oncology services in Aotearoa are currently safe and effective, providing high-quality care, with active clinical leadership via a strong national working group. However, not all people in Aotearoa have equal access to the treatment they need. It is estimated that half of all New Zealanders with cancer would benefit from radiation treatment; however, currently only approximately 33% of people with cancer receive it. There are barriers to access to radiation therapy, with people often having to travel and stay long distances from home for weeks to complete treatment.

Currently, each radiation oncology centre operates autonomously and is individually accountable for equitable and timely access to treatment, clinical effectiveness, and investment in resources (including equipment workforce/infrastructure). This has resulted in variation in clinical practice and intervention rates across Aotearoa. This has also created capacity issues, with the current provision of linear accelerators (LINACs) insufficient to meet current and future demand. The current service model makes it difficult to appropriately fund new machines due to high costs and competing capital demands. Radiation oncology workforces are experiencing critical shortages, making the sustainability of delivery of services a concern.



## Proposal for change

Benefits could be gained through the development of a single system of care for radiation oncology in Aotearoa, operating under a standardised national radiation oncology service model. Transforming the currently distributed model to a single system of care within one network of radiation oncology public providers will require the development of a future focused leadership structure that drives a national programme of service delivery.

Ensuring equitable, high quality care requires work to standardise treatment delivery, maintain quality standards and work to ensure capital planning and changes to service distribution are based on best evidence to improve inequities in care. Improving the sustainability and accessibility of radiation therapy requires the implementation of a centrally managed programme for LINAC procurement and associated ancillary technology and facilities for all publicly funded radiation oncology treatment providers.

The transformation to a single organising structure – including questions of status, mandate, and composition – will need to be carefully stepped through to maximise the opportunities of this model, without compromising benefits of the existing system. This work would need to be done alongside a strong focus on increasing the capacity and diversity of the radiation oncology workforces through the implementation of a multi-step/multi-phased workforce recovery and sustainability plan.

## What would be different for patients and whānau?

- Patients will have access to the same quality and currency of treatments anywhere in Aotearoa with treatment delivered in a consistent way.
- Patients and whānau will have greater choice of where they receive their treatment i.e. should they wish to be closer to whānau in another part of Aotearoa.
- Radiation therapy will be a more accessible treatment option as the distribution of LINACs into regions is increased.
- Patient wait times will be reduced due to timely planning and investment in radiation oncology services including national monitoring and contingency planning.
- Patients who require it will have access to specialised radiation oncology services no matter where they live
- Critically, co-implementation of the coordination and support services focus areas will enable patients and their whānau to receive high quality, timely and equitable radiation oncology services.



# He kupu whakataki

## Introduction

Radiation oncology treatment, or radiation therapy, is a core aspect of cancer treatment and has been estimated to be involved in 40% of all cancer cures (274). Radiation therapy uses ionising radiation to destroy or damage cancer cells to stop them multiplying and growing. It can be used to cure cancer, to reduce the size of a cancer before surgery, to reduce the risk of the cancer returning after surgery and is also used in palliative care, to relieve pain and other symptoms.

The patient pathway for radiation therapy involves several steps to obtain the anatomical information needed to create a treatment plan which is, in the most part, delivered on a Linear Accelerator (LINAC). Because of the need for highly specialised facilities, radiation therapy tends to be delivered within main centres. These services require custom-built departments, specialised equipment and operate mostly in an outpatient setting, although access to inpatient care for certain treatments and to manage acutely unwell patients is needed.

Radiation Oncology Services are capital and resource intensive. As an example, LINACs (including associated equipment/resources) cost around \$4-5m per machine with a lifespan of up to ten years. Overall, radiation treatment is considered a cost-efficient treatment modality, with an Australian analysis estimating that radiation oncology services cost less than 9c in every dollar spent on cancer treatment (275).

There are different types of radiation treatment available, including:

- **External beam radiation therapy** – a LINAC creates a radiation beam (photon beam) directed at a site within the body. Computer software adjusts the beam's size and shape which targets the cancer while minimising the dose to healthy tissue. Most patients receiving radiation therapy treatment receive external beam therapy.
- **Superficial radiation therapy** – this is also a form of external beam radiation therapy but uses lower energy beams and does not require a LINAC to deliver the treatment. The superficial radiation beam only penetrates the surface of the skin. This type of therapy avoids deep tissue damage and is used in the treatment of superficial skin cancers.
- **Brachytherapy** – implants containing radioactive material are placed into the cancer or surrounding tissue within the body and deliver a very localised radiation dose. Implants may be permanent or temporary. Common indications include cervical and endometrial cancers.
- **Radioisotopes (theranostics)** – people swallow or receive an injection of radioactive material that targets cancer cells that take up the radioactive material. The radioactive material leaves the body over a few hours to days.



# Tō āianeī āhua mō ngā ratonga mātai mate pukupuku i Aotearoa **Current state of radiation oncology services in Aotearoa**

## Current service distribution

In Aotearoa, radiation oncology services are organised regionally, hosted by a single DHB for a sub region, that is referred to as the 'centre'. Each centre offers radiation therapy service to its local DHB population and the population of the regional DHBs it serves.

There are six public regional radiation oncology centres nationally, delivering to populations ranging from 350,000 – 1.9 million (see Table 5). Each of these centres operates autonomously and is individually accountable for equitable and timely access to treatment, clinical effectiveness and safety, risk management and sustainable investment in resources (equipment workforce/ infrastructure).

Due to the service configuration many patients and their whānau need to travel for some, or all, aspects of treatment. The centres usually, but not universally, provide outreach/visiting clinics to improve access for patients living in rural and smaller urban areas; but these are for consultation and review rather than treatment.

Currently, there are 24 LINACs delivering radiation therapy in Aotearoa public cancer centres, with a further eight in private cancer centres. To note, one of the private centres routinely provides publicly funded treatment for their DHB region under contract.

By 2025 one additional LINAC in a public centre will be operational in Northland bringing the total number of LINACs in the public sector to 25. There are two LINACs becoming operational in Hawke's Bay and Taranaki, which will replace two LINACs currently in service in Palmerston North. Several DHBs are currently actively considering procurement of additional LINACs for their district.



Table 5: Distribution of LINACs in Aotearoa

Region	Provider	Owner	Number of LINACs	Location
Northern Region	Auckland DHB	Public	6	Auckland
	*Northland DHB	Public	1 (additional LINAC - 2025)	Whangarei
	Auckland Radiation Oncology	Private	3	Auckland
Midland Region	Waikato DHB	Public	4	Hamilton
	Kathleen Kilgour Centre **	Private	2 (1 additional in 2022)	Tauranga
Central Region	MidCentral DHB	Public	4 (2 once regions operational)	Palmerston North
	*Hawkes Bay DHB	Public	(1 replacement LINAC - 2025)	Hastings
	*Taranaki DHB	Public	(1 replacement LINAC - 2025)	New Plymouth
	Capital and Coast DHB	Public	3	Wellington
	Bowen Icon Cancer Centre	Private	1	Wellington
Southern Region	Canterbury DHB	Public	4	Christchurch
	St Georges Cancer Care Centre	Private	2	Christchurch
	Southern DHB	Public	3	Dunedin

Number of LINACs – Public 24, Private 8

\*Regional LINACs, go-live 2024/2025 \*\*KKC routinely provides public radiation therapy funded by Bay of Plenty DHB

## Current service provision

The intervention rate (IR) is the proportion of all registered cancers that are treated with at least one course of radiation. Currently, there is not a set target intervention rate in Aotearoa (276). Instead, the focus has been on providing timely access for patients referred for radiation therapy and reducing barriers to accessible and high-quality treatment to improve patient outcomes. In 2018, the intervention rate in Aotearoa was 33 percent.



# Radiation Oncology Data

The Radiation Oncology Collection is a tool that provides information about who is accessing radiation therapy and how treatment protocols differ by DHB and treatment centre. The online tool makes non-identifiable and aggregated information transparent and available to cancer centres, DHBs and Regional Hubs to enable them to compare against one another and against national guidelines and to drive quality improvement.

NHI level data can be requested by appropriate parties such as researchers under the governance of the national Radiation Oncology Working Group (ROWG). Data can be linked to other work for example the Quality Performance Indicator Programme work and the Prostate Cancer Outcomes Registry (192, 197, 199).

The Radiation Oncology Collection is the first full public and private radiation oncology data collection in the world. The Collection is largely a sector-driven project and allows for more detailed analysis of how radiation oncology treatments compare to other cancer treatment modalities in Aotearoa.

## Previous reviews of radiation oncology services

In 2017, the Radiation Oncology Work Group and Ernst Young developed a National Plan for Radiation Oncology Services (276). Integral to this plan was a nationally agreed outcomes framework for Radiation Oncology Services. The recommendations of this plan remain largely unactioned and work is still progressing. The strategic priorities out of this review are:

- People have fair access to the treatment they need
- Radiation oncology services are safe and effective
- Radiation oncology services are sustainable.





The National Plan was informed by work from Cancer Research UK who developed seven prerequisites for a world-class radiation oncology service (277). The pre-requisites were determined from a broad analysis of literature, examples of global best practice and the views of leading practitioners. The seven prerequisites are for the radiation oncology services to:

- have sufficient capacity and activity volume to create economies of scale
- fully utilise up-to-date technology and equipment
- have enough trained staff to meet demand and develop the service
- invest adequately in capital, with an appropriate business model and commissioning structure to use it effectively
- conduct high-quality research and transfer research knowledge into practice
- create an evaluation culture by providing robust measurement tools to support evidence-based, high-quality practice
- have a work environment and an organisational culture, supported by effective leadership and management, that promote coordinated planning, multidisciplinary working, and good radiation therapy practices, standards, and research.

## Current state of workforce

The four core workforce groups for radiation oncology services are:

- radiation oncologists
- radiation oncology medical physicists
- radiation therapists
- radiation oncology nurses.

## Radiation oncologists

Radiation oncologists provide the medical care and management of patients with cancer through the conduct and supervision of radiation treatment, advice and provision of palliative and other supportive care, and advice and provision of other non-surgical cancer treatment. These include cytotoxic, hormonal and other drug therapies, participation in clinical trials and research related to cancer management (278).

According to the Medical Council of New Zealand, in 2021 there are 64 radiation oncologists in Aotearoa holding a current practicing certificate. There are 32 trainees currently in the Radiation Oncologist training programme, with the training programme lasting five years full time.



## Radiation oncology medical physicists

Radiation oncology medical physicists provide technical and scientific support to radiation oncology through a combination of direct support of patient treatment, routine quality assurance and quality control of treatment-related technology, and the development and improvement of treatment procedures along with radiation safety responsibilities for staff and members of the public (279).

Radiation oncology medical physicists ensure all radiation equipment and software meets international and national requirements so that the radiation dose prescribed by the radiation oncologist is delivered to the patient correctly.

Currently in Aotearoa there are 74 radiation oncology medical physicists, with 46% recruited from overseas. At present there are 10.6 vacant positions (15%) for qualified medical physicists in Aotearoa, largely within DHBs. Radiation oncology medical physicists have a 5-year training programme, with around 3 trainees qualifying each year. Currently there are 17 trainees with 3 vacancies (15%) across 7 training centres (6 DHBs and 1 private).

## Radiation therapists

Radiation therapists are responsible for the planning and delivery of radiation treatment according to the prescription of the radiation oncologist. Their competencies include, but are not limited to, patient care, treatment design and delivery, radiation safety, and quality assurance.

There are currently 436 registered radiation therapists working within the six public and four private cancer centres in Aotearoa. In 2019, there was a vacancy rate of 7% and a turnover rate of 8.8%, which is higher than other allied health professions in Aotearoa (280). On average, 22 graduates enter the workforce annually from a single training programme provided at the University of Otago. The workforce is female dominated (85%) and relatively young with an average age of 37 years (TAS, 2018).

Advanced practice roles for radiation therapists have been established in some centres in Aotearoa. These roles complement the work of radiation oncologists and radiation oncology medical physicists and assist in managing demand and patient flow. There is scope to increase and develop these roles further.

## Radiation oncology nurses

Radiation oncology nurses provide care for patients undergoing radiation treatment and chemoradiation. Radiation oncology nurses have specialist knowledge of cancer pathophysiology, radiation and chemotherapy treatment, health assessment, management of cancer and treatment related side effects and impact of treatment modalities on co-existing health conditions.



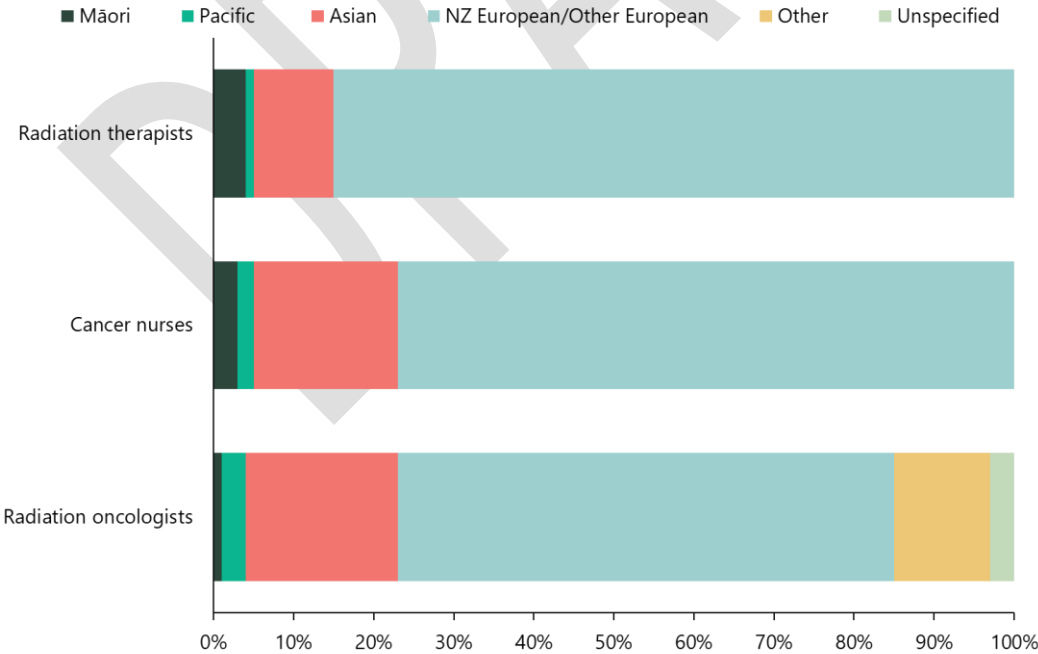
Nurses play a pivotal role in referring and collaborating with allied health and support services within the specialist centre, DHB and community. Nurses provide specialist clinical guidance on radiation treatment (and chemotherapy) to generalist nurses working with cancer patients outside of a specialist centre such as general practice, community health care and community palliative care services.

Currently there are nine clinical nurse specialists and one nurse practitioner working across Aotearoa with a focus on radiation treatment. Some centres have additional clinical nurse specialists that are specific to cancer types, covering both medical and radiation oncology. Some centres in Aotearoa have dedicated Māori and/or Pacific senior nursing roles to support these specific populations throughout treatment; however, these roles are variable and inconsistent from centre to centre.

# Diversity of the workforce

The radiation oncology workforce does not currently reflect the community it serves. Numbers of the workforce across all specialty groups that identify as Māori or Pacific are particularly low (see Figure 4).

**Figure 4: Ethnicity of professions involved in providing radiation therapy in Aotearoa, 2019/20.** Data from Health Workforce, prioritised ethnicity. Ethnicity data was unavailable for radiation therapy medical physicists at the time of publication.



# Ngā wero o āianeī mō ngā ratonga mātai mate pukupuku

## Current challenges in radiation oncology services

This section of the report combines information from stakeholder interviews and published literature on the current challenges with radiation oncology services in Aotearoa. These challenges create significant inequity in the access to, quality of, and outcomes from radiation oncology services.

### Service planning

#### *The current operating model has led to missed opportunities for centralised planning*

The current national operating model for radiation oncology, based around six regional centres servicing 20 DHBs, has limited the ability to develop consistent capital, workforce, and other planning processes in radiation oncology. This has resulted in an inability to strategically respond to growing demand, sporadic use of new models of care and long lead in times to establish new outreach sites.

Funding models in the current system have led to the establishment of highly transactional arrangements between DHB of domicile and DHB of service to facilitate exchange of population-based funding. While these Inter-district Flow arrangements work adequately in some aspects of healthcare, the significant level of investment in capital and workforce required for radiation therapy requires a more long-term funding model.

#### *LINACs require large capital investment and the current DHB model does not work optimally for these large costs*

Prior to the recent government investment in replacement LINACs, individual DHBs were required to manage LINAC replacement within their overall capital budgets. Given the multiple requirements for DHB funding across a range of capital equipment, DHBs struggled to allocate such large capital injections needed to fund LINACs. While the LINAC has the highest price tag of radiation oncology equipment, DHBs also need to replace planning technology and dedicated CT scanners, which puts additional pressure on constrained capital budgets.



Establishing a radiation oncology facility requires an up-front investment for the building of radiation-shielded bunkers and the purchase of the necessary equipment (such as a LINAC, a CT scanner and associated equipment and software). Currently in Aotearoa there are only two centres that have an empty bunker – both of which are in private facilities. The cost of building a bunker and the required rooms is upwards of \$20-\$30m, whether they are going into a hospital with pre-existing radiation oncology facilities or into a regional hospital without facilities.

The current stock of LINACs is ageing and, as a result, frequent outages caused by mechanical issues are an ongoing problem. LINAC replacement takes many months and specialist workforce hours to commission. Access to modern equipment and technology impacts all aspects of radiation oncology, not only in ensuring that people have timely access to quality treatment but also in departments' ability to attract and retain high quality staffing.

## Infrastructure

### ***More LINACs are needed to meet both current and future demand***

Currently all public radiation treatment centres are running at over 100% capacity, with some centres reaching 140% by running the LINACs afterhours through additional shifts. This is not sustainable in the long term.

Figure 5 shows the number of LINACs that are available in 2021 and the number that are projected to be required by 2037, with demand projections exceeding the presently available LINAC capacity. Projections are based on the number of LINACs required to treat patients and are calculated using the industry accepted average number of courses of treatment each LINAC can accommodate per year. It is acknowledged that LINAC throughput can vary based on the case mix of patients and service-related factors.

Projected LINAC availability over the next 16 years, at the national level, is presented across 3 scenarios based on the utilisation:

- Current national intervention rate and retreatment rate of 34% and 23%, respectively
- Best intervention rate and retreatment rate achieved by any DHB of 42% and 24%
- Theoretical/ideal intervention rate and retreatment rate of 50% and 24% (according to RANZCR)



**Figure 5: LINAC supply vs demand.** The intervention rate (IR) is the proportion of all registered cancers that are treated with at least one course of radiation therapy while the subsequent retreatment rate (RTR) is the proportion of all radiation therapy courses delivered to people who have already had at least one radiation treatment course for their cancer.



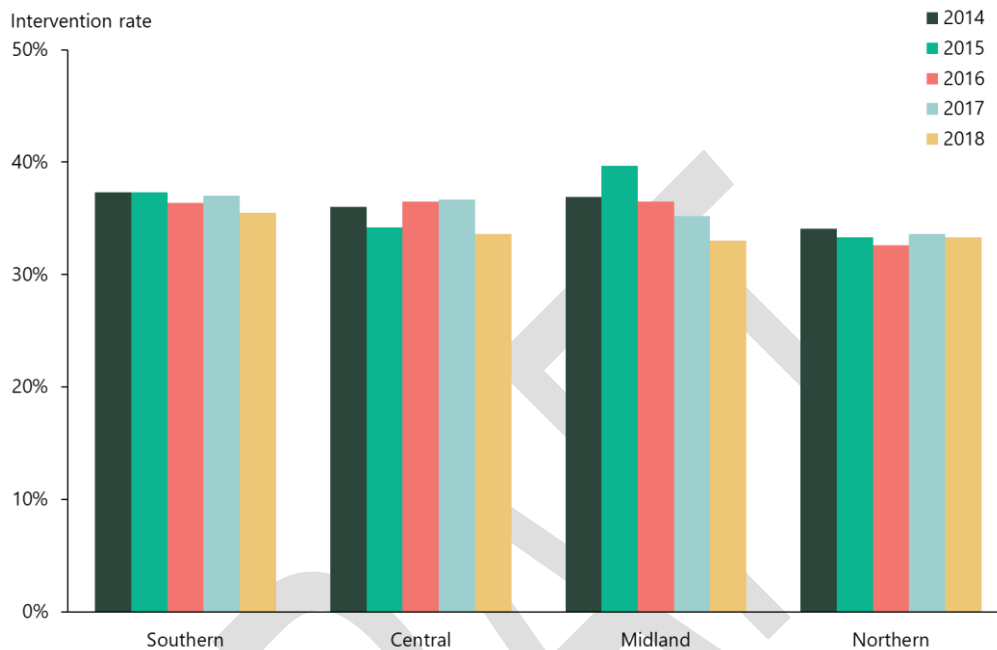
Stakeholders expressed concern around the consequence of the limited radiation oncology capacity, including delays in treatment times, over-stretched clinical teams and less than optimal intervention rates – all of which is contributing to the variation in access to care and poorer outcomes, especially for those who are disadvantaged or live outside the major urban centres.

Additionally, where service planning is unable to keep pace with increasing demand or accommodate unexpected surges in capacity, some services are critically reliant on outsourcing to private capacity to maintain timely access to treatment. This is an additional cost to the system. The private centres allow flexibility for unexpected surges in patients or sudden loss of public capacity.



Despite considerable efforts including installation of new LINACs, additional evening shifts, overtime, weekend shifts; Figure 6 shows that the intervention rate has not increased between 2014 and 2018. This highlights a system under pressure that does not have enough capacity to keep up with increasing demand.

**Figure 6: Intervention rate by region 2014-2018.** Intervention rate is the proportion of all registered cancers that are treated with at least one course of radiation.



### *Limited capacity to implement new techniques*

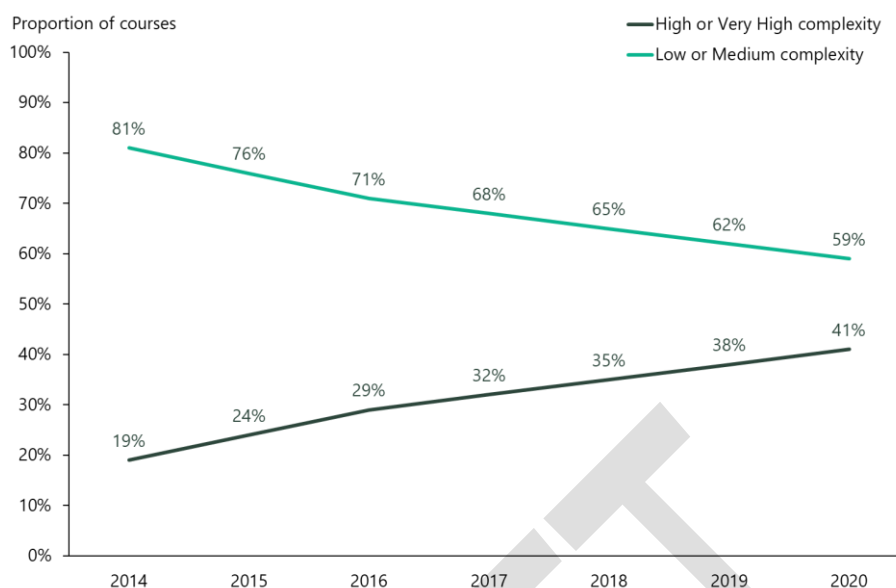
Radiation therapy techniques and delivery technologies continue to develop rapidly worldwide. As with other cancer treatments, radiation therapy continues to move towards delivering increasingly personalised treatment and increasing complexity of care (Figure 7). Internationally and in Aotearoa, the use of stereotactic ablative body radiation therapy (SABR)<sup>2</sup> and other complex treatments are increasing and becoming standard of care.

This poses a challenge to radiation therapy in Aotearoa, as to fully utilise more complex treatments and the benefits they provide not only requires modern LINACs with the capabilities to deliver these treatments, but an increase in the associated workforce. Complex treatments require more time to plan and there are increased quality assurance processes associated with them compared to more simple radiation plans.

<sup>2</sup> SABR is a highly specialised and complex radiation technique that delivers very high doses of radiation to a tumour either in a single or small number of treatments



**Figure 7: Proportion of radiation therapy courses that are high vs low complexity**



### ***Radiation therapy services are particularly vulnerable to disruption***

Due to heavy reliance on technology, radiation oncology services in Aotearoa are particularly susceptible to cyber-attacks, pandemics, or natural disasters. As an example, radiation oncology services were heavily impacted by the Waikato cyber-attack and the Christchurch earthquake. Therefore, services need robust business continuity planning for such events which is currently limited by a lack of latent capacity within the overall system.

## **Service distribution and access**

### ***Not everyone who would benefit from radiation therapy is able to access it***

Despite the potential benefits of radiation therapy for at least half of all people diagnosed with cancer, on average only 33 percent of people with cancer receive radiation therapy nationally and as low as 27 percent of people in provincial areas (see Figure 14). Barriers to accessing radiation therapy may mean that treatment choices are not always being made based on best clinical benefit.

Since LINAC machines are located in main centres, many people need to travel to have their radiation therapy. This often requires people to live away from home for periods of up to 6 weeks or more, which is different to other cancer treatments that are more episodic in nature. The distance to radiation therapy facilities, which is a surrogate for not only travel but also time away from work, home and supporting family or friends, has been reported as a potential factor in declining treatment. This was demonstrated in a study of women choosing mastectomy over breast conserving surgery and post-operative radiation therapy (281). The distance a patient lives from a radiation treatment provider can impact on whether they see radiation therapy as a viable treatment option.





An Australian study found there was a reduction in radiation therapy access with increasing road distance between where patients live and radiation therapy department (282). Patients were 10 per cent less likely to receive radiation therapy for each additional 100km distance from the nearest radiation therapy centre. Analysis of intervention rates in Aotearoa support that living far from a radiation treatment centre may reduce access to treatment. Populations of some DHBs that are over 160kms from a cancer centre have markedly reduced intervention rates.

Māori and Pacific peoples have higher levels of deprivation and proportionately more Māori live rurally and therefore are likely to be disproportionately burdened by the requirement to travel, including the cost and logistics associated with travel and accommodation, arranging care for any dependents remaining at home and the coordination of appointments (283-285). Current travel and accommodation options and funding often only have provision for a single support person, which is not conducive with ensuring whānau support during treatment.

There are other factors impacting access to radiation therapy, including clinical practice and referral practices within DHBs. One DHB with a low rate of radiation oncology review prior to radical prostatectomy found that radiation oncology consultations before radical prostatectomy were not being offered – rather than being offered and declined (199).

***Distribution planning can be challenging, as it balances regional access with the high cost of LINACs and the centralisation of high complexity treatments***

Ensuring access to radiation treatment for the geographically dispersed population of Aotearoa needs to be supported by long term planning of LINAC placement; however, this also needs to be balanced against the large cost of establishing new LINAC sites. Regional work, with Government support, is underway to place LINACs into smaller regions with oversight and management of the service remaining the responsibility of the main provider. For example, Hawke's Bay DHB will house the LINAC and MidCentral DHB will be the treatment provider.

Alongside regional LINACs, there are some high complexity low volume techniques and technology which should be centralised to ensure maintenance of standards and optimise outcomes. To some extent this has already been achieved in some areas through national agreement via the Radiation Oncology Working Group (ROWG), for example:

- Cone Based Stereotactic Radiosurgery (SRS) – one centre requiring specific high-cost equipment treating vascular malformations and small benign brain tumours. Volume 50 - 60 patients per year
- Brachytherapy – due to the need for specialised equipment and specialised staff only 4 public radiation oncology departments offer brachytherapy as this ensures high volumes are maintained. High volume brachytherapy units provide better outcomes and better use of resources.
- Proton therapy is a treatment technique used for specific indications such as certain paediatric tumours. This is a highly complex technique requiring a proton facility to deliver. This form of treatment is not available in Aotearoa. Currently patients travel overseas for treatment to international centres that have the volume of patients to maintain the required competence to deliver high quality care. Plans are underway to install a proton facility in Australia that would serve the populations of Australia and Aotearoa.

## Workforce issues

***The radiation oncology workforce has a number of pressing challenges, including understaffing, concern about future workforce sustainability, poor workforce diversity and has an opportunity to practice with increased cultural safety***

The major challenge in radiation therapy service delivery is workforce capacity. Projected increases in cancer incidence mean that large increases in workforce are needed so that all patients have timely access to radiation therapy in the future (286). Internationally, large deficits in radiation therapy workforce already exist, and more workforce is needed to meet current and future demand (286, 287).

The current workload of staff for some providers is above recommended levels and poses both a personal wellbeing and a clinical risk. In some regions staff are working longer hours, additional shifts, not taking annual leave, and not partaking in continuing professional development in order to keep up with waiting lists. Symptoms of burnout are commonly reported amongst all types of radiation oncology staff and in Aotearoa (288-290).



## Radiation Oncologists

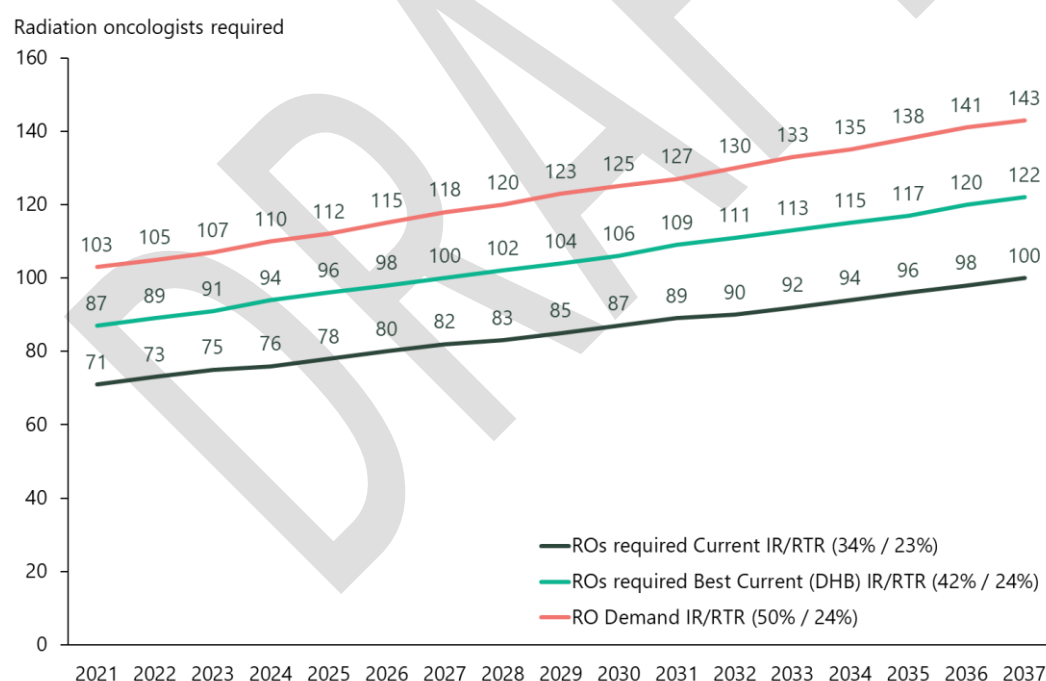
The radiation oncology workforce is ageing, and a significant proportion of doctors will be retiring over the next 5 years, with nearly 30% being 60 years old or above.

Modelling work undertaken by Health Workforce and Te Aho o Te Kahu shows the projected radiation oncologist demand over the next 16 years across three scenarios based on different intervention rates:

- Current national intervention rate and retreatment rate of 34% and 23%, respectively
- Best intervention rate and retreatment rate achieved by any DHB of 42% and 24% (also to predict unmet need)
- Theoretical/ideal intervention rate and retreatment rate of 50% and 24% (according to RANZCR)

Of note, currently there are 64 radiation oncologists in Aotearoa, which is already below the required number of radiation oncologists to meet the current intervention rate.

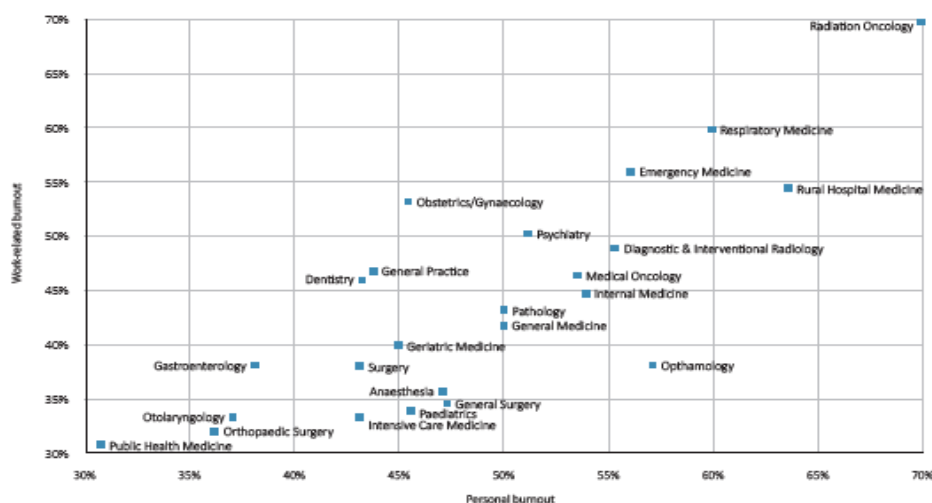
**Figure 8: number of Radiation Oncologists required under different scenarios**



In order to meet current demand, radiation oncologists continue to work significant overtime hours, leaving limited time to spend on research and non-clinical duties (291). Findings from recent research into Aotearoa doctor burnout showed that radiation oncologists topped prevalence for both personal and work-related burnout (see Figure 9) (292).



Figure 9: work-related and personal burnout by specialty 2020 (292)



The current workforce is unsustainable, with not enough trainees to replace radiation oncologists who are expected to retire or to accommodate preferences for part-time work and protected time for research. Additional trainees will be required to manage increased demand for radiation therapy and increased complexity of treatments (291, 293).

Although Māori make up 16.5 percent of the total population of Aotearoa, only two radiation oncologists (3% of radiation oncologists) identify as Māori (17). Increasing the number of Māori in the radiation oncology workforce was often mentioned by stakeholders as being critical to improve care for Māori patients and whānau.

The Ministry of Health | Manatū Hauora estimates that international medical graduates comprise over 55% of the radiation oncologist workforce. This reliance on overseas trained doctors makes cultural safety in the context of practicing in Aotearoa a critical issue.

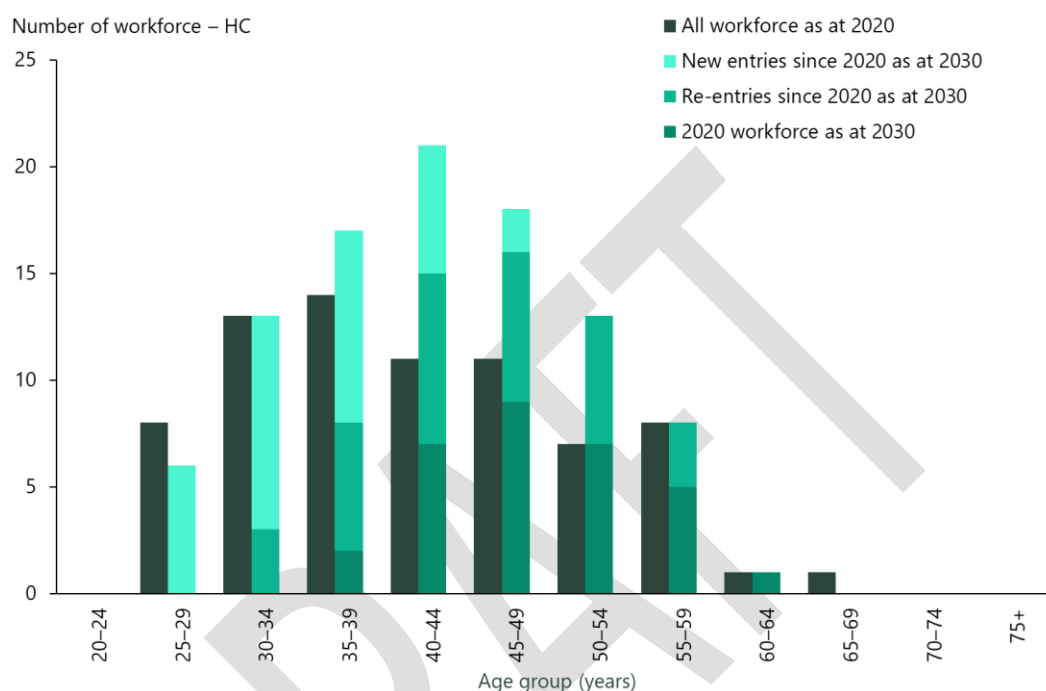
## Radiation Oncology Medical Physicists

Similar to radiation oncologists, over half of radiation oncology medical physicists are internationally qualified rather than Aotearoa New Zealand/Australian qualified. Trainees are spread unevenly across the six public centres and only one private provider has a trainee, which they self-fund. This reliance on overseas trained physicists makes the radiation oncology workforce vulnerable. Many radiation oncology medical physicists work over-time and have little time for research (12, 13).



Increasingly complex planning and treatment techniques require significantly more physicist input. Figure 10 shows that an additional 22 medical physicists are required by 2030 to keep pace with population growth and taking account of the demographics of the current workforce.

**Figure 10: Forecasted supply of medical physicists. New-entry practitioners includes new practitioners from training, and immigrations to New Zealand, and re-entering includes practitioners returning following a break in work.**



## Radiation Therapists

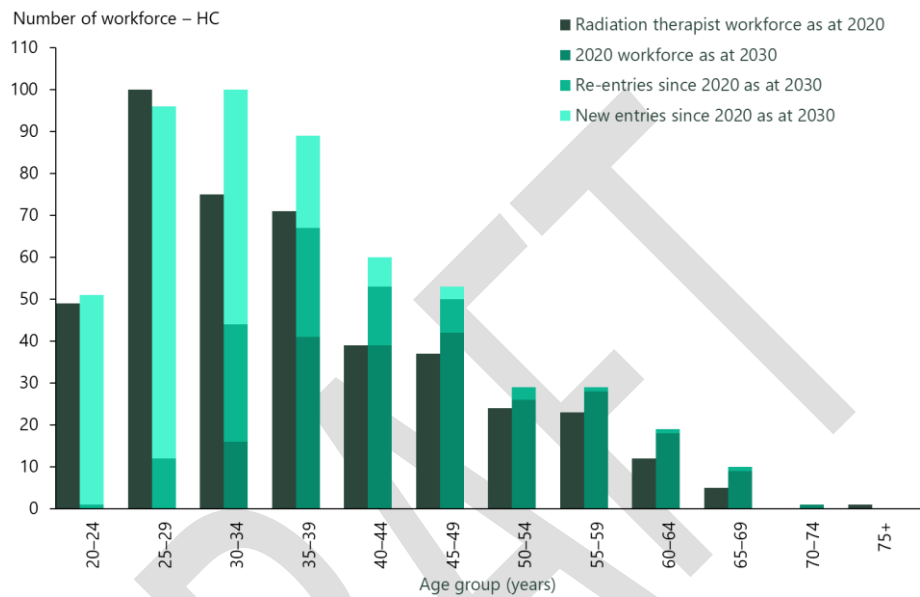
A 2019 national survey of radiation therapists (RTs) identified that one third of RTs are thinking of leaving their current workplace with 31% intending to leave within the next 12 months (280). Common factors influencing whether an RT was going to leave both the workplace and profession include workplace satisfaction, and career development opportunities.

Currently there is no formalised framework for RTs to expand their practice. Advanced practice roles, that challenge the RTs and allow them to specialise within their profession, have been identified as being critical for the sustainability of the workforce and radiation oncology services (280).



Figure 11 shows that an additional 101 radiation therapists are required by 2030 to keep pace with population growth and taking the demographics of the current workforce. There will likely be an increasing demand for radiation therapists due to the planned opening of regional sites.

Figure 11: forecasted supply of radiation therapists



## Radiation oncology nurses

A common theme in stakeholder interviews was a lack of awareness and visibility across the sector of the contribution of radiation oncology nurses. The role includes patient advocacy, extensive symptom management, and patient education.

Stakeholder interviews identified a range of models of care and dedicated nursing workforce within radiation oncology departments throughout Aotearoa. A national approach to radiation oncology nurse education and competency assessment for radiation oncology nurses, might provide a significant step towards lifting the standing of radiation oncology nursing. Articulating the contribution of this specialist nursing care, and the better outcomes it can support is crucial to the development of this workforce.

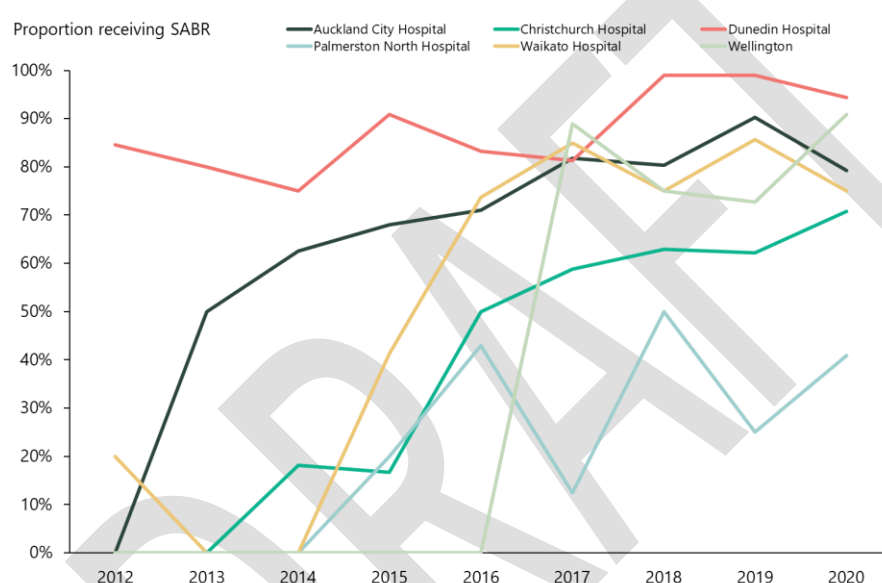


## Consideration of new techniques and technologies

### *New procedures are considered and implemented locally, leading to inconsistent access*

Data from the Radiation Oncology Collection shows unwarranted variation in clinical practice and inconsistent implementation of innovation across Aotearoa. For example, Figure 12 shows the time-lag for different centres in implementing Stereotactic Ablative Radiation therapy (SABR), an effective, low toxicity alternative to surgery for lung cancer patients.

**Figure 12: Proportion of stage 1 non-small cell lung cancer patients receiving SABR**



The rise in modern technology allowing personalised approaches and precision treatments is likely to increase exponentially over the next decade. Examples of this include improved delivery systems (MRI LINACs); improved diagnostic imaging (PSMA PET CT scanning for prostate cancer) identifying disease at a very early stage; and the rapid uptake of radiopharmaceuticals (theranostics) especially in the prostate cancer area. Without a systematic approach to assessment and implementation this is likely to create inequities and inconsistent access across Aotearoa and potentially contribute to inefficient use of the system.

The impact of Artificial Intelligence (AI) in the radiation oncology space is increasing. AI is widely implemented in radiation oncology planning as a part of current practice. The increasing sophistication of AI in the form of machine learning and neural networking is likely to expand the ability of radiation oncology to improve the quality of existing treatments and increase the ability to effectively manage new indications and retreat existing indications multiple times over a single patient's cancer journey.



# Tō āianeī mana taurite kore

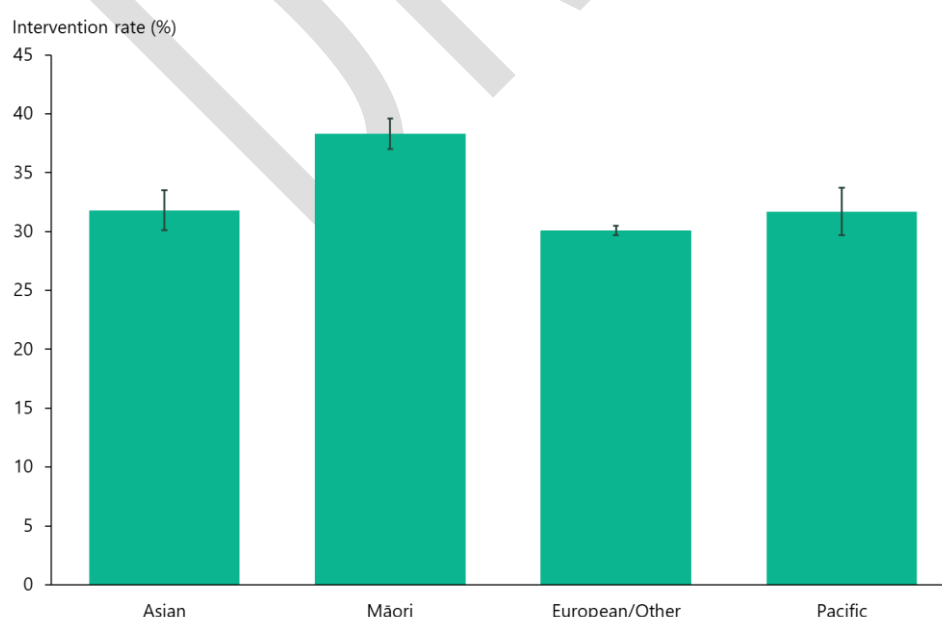
## Inequity in the current state

Generally, radiation therapy in Aotearoa is of high quality; however, not all population groups are receiving the same benefit from radiation therapy services. The challenges described above collectively create inequity in access, quality and outcomes for Māori and Pacific peoples compared to non-Māori, non-Pacific, as well as inequity in care based on where people live. The cumulative impact of these system issues is summarised below, demonstrating the extent to which the current system is creating inequity in radiation oncology care.

### Equity for Māori

Research suggests that Māori experience longer delays in receiving radiation therapy than non-Māori (294). At a national level, Figure 13 shows that Māori have a higher intervention rate for radiation therapy than non-Māori; however, it is unclear the extent this might be in response to lower access to other treatment options. It is important that radiation oncology data are viewed alongside surgical and systemic therapy data, as radiation therapy may be used when other treatments are not offered due to advanced stage at diagnosis or co-morbidity. This is supported by the evidence related to equity of access for Māori in the surgical section of the report and reinforces the importance of taking a whole of system approach to addressing inequities.

**Figure 13: Radiation therapy intervention rate by ethnicity 2019-2020. Intervention rate is the proportion of all registered cancers that are treated with at least one course of radiation.**





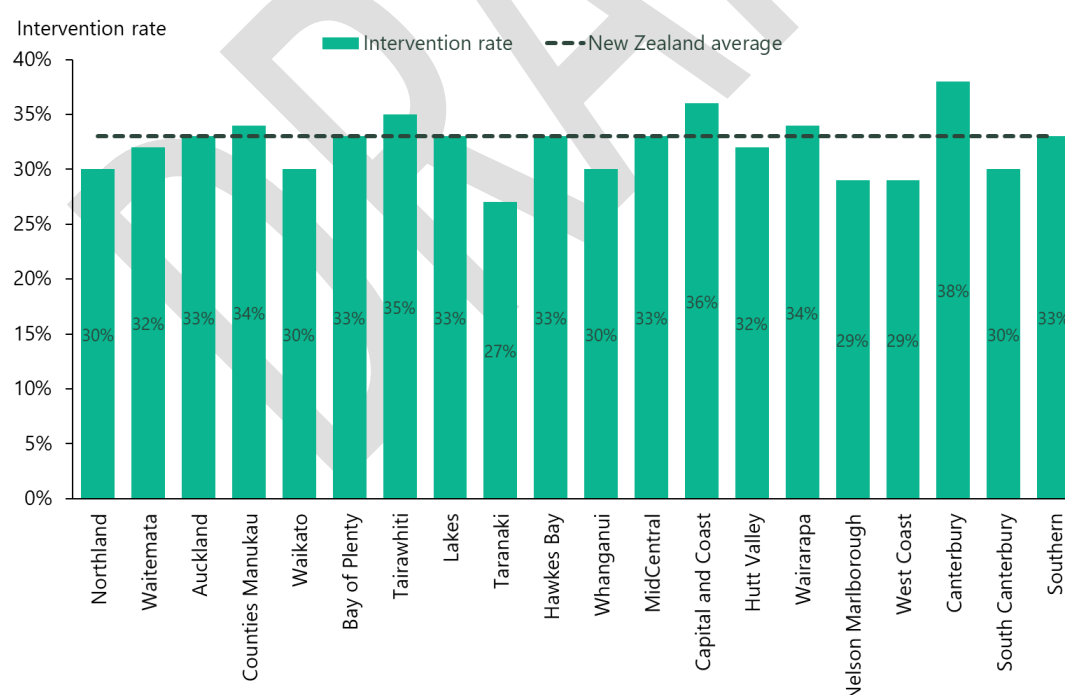
## Equity for Pacific peoples

Pacific intervention rates are between those of Māori and European/other New Zealanders (Figure 13). Research suggests that Pacific peoples experience longer delays in receiving radiation therapy than non-Pacific peoples (294). There is evidence of inequities in access to radiation therapy for specific cancers, for example surgical resection of the rectum is the most common intervention for the treatment of rectal cancer and is often used alongside preoperative radiation therapy treatment. Between 2013-2016, Pacific peoples had the lowest rate of pre-operative radiation therapy (47%) compared to 54% of the total population (192).

## Geographical variation

Radiation therapy in Aotearoa is currently only delivered in main centres. Data from the Radiation Oncology Collection shows that radiation therapy intervention rates vary by DHB (see Figure 14). Of note, areas that have the lowest intervention rate are often in areas where people need to travel to neighbouring DHBs to receive treatment.

**Figure 14: Intervention rate across Aotearoa 2018/19.** Intervention rate is the proportion of all registered cancers that are treated with at least one course of radiation.



There is also geographic variation in access to radiation oncology consultation. For example, it is recommended that most people being considered for radical prostatectomy for prostate cancer consult with a radiation oncologist before surgery (including through remote consultations), so they are able to make an informed treatment decision. However, this varies hugely by DHB, ranging from 4 percent to 46 percent (199). There is also geographic variation in people receiving preoperative radiation therapy prior to rectal cancer surgery, ranging from 30 percent to 70 percent across DHBs. This indicates large variation in clinical practice across Aotearoa.

*A detailed equity analysis of how each of the challenges with the current system contributes to inequity in access, quality and outcome, and alignment to focus areas is included in **Appendix VI**.*

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# Taunakitanga hei whakatutuki wero

## Evidence of ways to address challenges

This section of the report looks at local and international evidence to identify ways to address the challenges with the current radiation therapy system in Aotearoa.

### Service distribution

***Decentralisation of radiation oncology services will likely improve access, but needs to be balanced against cost***

Decentralisation of radiation therapy services aims to address the issue of underutilisation of radiation oncology for geographically dispersed populations (295, 296). A common approach to decentralisation of radiation therapy services is a hub and satellite model, where a large urban central radiation therapy service supports a smaller satellite service located a distance away. The central service delivers a comprehensive range of services, manages complex cases, and is responsible for the quality and treatment standards in the satellite unit. Radiation oncologists from the central service oversee the satellite site, either virtually or in person. The satellite unit may offer a limited range of services but delivers the same treatments as the central one.

The decision to decentralise radiation therapy requires weighing up considerations of access, efficiency, and quality. Decentralisation may benefit patients by improving access, increase options in terms of where to receive treatment and reduce travel time/costs, but the cost to the health system (staffing and operational costs) may be high, particularly if there is a low volume of cases (297). However, in contrast some studies comparing different radiation service delivery models found the centralised model to be the most expensive (in terms of costs to the patient *and* the health service) and satellite models the cheapest, as long as the distance between the centres was not too great (not more than approximately 170km) (298, 299). Geospatial modelling can be used to assess possible locations of new radiation services, based on measures of geographical access (300).



Another issue to consider is how staff at decentralised services can maintain professional competencies, engagement, and career progression (298, 301). This could be overcome with a model that allows cross-appointment of staff, peer review and leave cover across the centre and satellite services (302).

Defining clinical practice guidelines and benchmarks for monitoring standards is critical when setting up a satellite unit (303). To address quality concerns, an audit in Australia found that the standard of radiation therapy care delivered in satellite services with single machines was as high as that in the larger hub departments, demonstrating that quality standards can be maintained in decentralised models (304). In Alberta, Canada, the introduction of regional radiation therapy and systemic therapy services was found to improve wait times (301).

Successful decentralisation depends, in part, on effective implementation of telemedicine approaches. Telemedicine has the potential to improve access for people in rural areas to all types of cancer treatment (305). Telemedicine approaches include videoconferencing (for patient consults, staff meetings and discussions, multidisciplinary team meetings), transfer of medical imaging and treatment plans, and remote monitoring and treatment (298, 306-308). These approaches rely on technological support for high resolution imaging and high-speed data transfer. Telemedicine has been well utilised in the COVID-19 pandemic internationally to maintain access to radiation therapy services (309-311). It has also been used to improve access to proton radiation therapy in the US, which is a scarce resource (312).

## Workforce

### ***There is opportunity to increase the scope of practice for some key radiation therapy workforces***

Internationally, a variety of approaches to radiation therapy workforce planning have been developed for different categories of radiation oncology workers. Key considerations when workforce planning include:

- Radiation therapy workforce planning cannot be solely based on population estimates or cancer incidence given the technological advances in the field, which means that workload increases faster than would otherwise be expected (313). Models for calculating workforce requirements must consider new treatment techniques/modalities and technological advances in radiation therapy that lead to increased workload (314-316).
- Because of changes to models of care and workload over time, staffing models/levels need to be reviewed frequently and be kept up to date (315).
- Staffing models also need to consider non-clinical activities carried out in radiation oncology services that are not directly linked to patient care such as research, education, and administration (316, 317).



Internationally, the role of radiation therapists has been expanding, which has implications for workforce planning and service delivery (281, 318). For example, palliative radiation therapists in a Canadian cancer clinic, have adapted to take on different responsibilities as needed and provide patient-centred care (319). In Aotearoa, expanding roles of RTs could create more career opportunities and pathways for this workforce and redistribute some responsibilities from other radiation oncology workforce. However, it is necessary this expansion of roles is appropriately supported. For RTs to develop advanced practice, clear guidance and directives around advanced practice parameters/role definition and training requirements are needed (320).

It has been well documented that advanced oncology nursing roles, such as clinical nurse specialists (with extended scope of practice for RN prescribing), can add positive value to clinical workload and productivity, as well as improve patient care and outcomes (321, 322). Planning and development of such roles within a collaborative model of care in the radiation oncology multidisciplinary team provides opportunity to address the ever-expanding clinician workforce gap.

Increased recruitment and appropriate staffing will help to alleviate staff burnout, and address workload and time demands (323). Risk of burnout may also be reduced by interventions focused on competence, relatedness and autonomy both at a personal and an institutional level, as well co-worker and supervisory support (324, 325). Job satisfaction may be increased, and occupational stress reduced, through ongoing education, mentoring, post-graduate study, role extension, clinical supervision, and psychosocial support (288). To improve staff satisfaction and retain radiation therapists and radiation oncology medical physicists, workplaces could provide more opportunities to be involved in teaching, research and learning new technologies, provide supportive work environments and provide safe and flexible working conditions (326, 327).



# Leadership and coordination

## *National coordination and leadership will improve sustainability and equity of services*

Maintaining high quality radiation treatment, and improving access and sustainability, requires a strong and cohesive approach to building and sustaining sector capability (277). A single nationally organised radiation oncology system would leverage the opportunities of scale and integration within a decentralised service delivery model. Potential benefits of this approach include:

- Services will have greater confidence in their own sustainability through more coordinated approach to technology replacement and workforce development
- People will have equitable access to the same quality and up to date treatments regardless of where they live, through better planning and better coordination of investment
- Better service distribution will increase accessibility for those who were not previously able to utilise radiation therapy as a treatment option
- Timeliness of treatment is improved, due to effective planning and investment in radiation oncology services, as well as coordinated responses and national service continuance plans for unexpected challenges (eg 2021 Waikato cyber-attack and recent Palmerston North sudden equipment failure)
- People have more confidence in their treatment journey due to improved flow of information within, across and between services
- People experience quality care due to close monitoring of safe work practices, radiation safety and practice standards.

It is also important to note that national leadership and coordination does not overlook the benefits of individual regions developing ways of working that are reflective of their unique environment but rather it looks to harness these individual benefits alongside the advantages of a single system.



# He tāpae hei panoni

## Proposal for change

Benefits could be gained through implementation of a single system of care for radiation oncology in Aotearoa, operating under a standardised national radiation oncology service model. This needs to be done alongside a focus on increasing the capacity and diversity of the radiation oncology workforces and increasing the LINAC stock.

Changing the current radiation oncology structure to a single national service model overseen by a national governing body will involve making significant changes to the system structure, focusing on how radiation oncology services are collectively organised, held accountable and governed. This change aligns with the intent of current health reforms to leverage a nationally organised single system that is both integrated and agile.

The transformation to a single organising structure – including questions of status, mandate, and composition – will need to be carefully stepped through to maximise the opportunities of this model, without compromising benefits of the existing system.

## Ngā wāhi hei mahi | Potential focus areas

### System Leadership

#### National system leadership

1. Te Aho o Te Kahu to work in partnership with Health New Zealand | Te Whatu Ora, the Māori Health Authority | Te Aka Whai Ora, and the Ministry of Health | Manatū Hauora, to provide strategic leadership for a national radiation oncology service with a Te Tiriti and equity focus. Functions include:
  - a. Design and implementation of a centrally managed programme for LINAC procurement and associated capital investment of ancillary technology and facility for all public radiation oncology treatment providers, with procurement lead by Health New Zealand | Te Whatu Ora.
  - b. Leadership for national cancer care pathways, including standardising treatment delivery for radiation treatment.
  - c. Strategic advice around workforce planning to align with service delivery models.
  - d. Overseeing processes to manage unwarranted variation in clinical practice.



- e. Leading a continually evolving and agile quality improvement culture through clinical leadership, a drive for innovation and quality assurance.
- f. Facilitate radiation oncology subject matter expertise to a nationwide process for evaluating and adopting new technologies and exploring opportunities for specialisation to support more efficient use of high-cost technologies.

## Data driven

1. Te Aho o Te Kahu to support a national review of cybersecurity as it pertains to radiation oncology systems, with consideration of the use of cloud storage and software as a service.
2. Te Aho o Te Kahu to develop, implement, and monitor a Cancer Information Plan to provide timely access to high-quality data to support sound decision-making, including:
  - a. Making appropriate data accessible to those working across the radiation oncology system to empower understanding and decision making for patients, whānau, iwi, clinicians as well as for regional and national planning
  - b. Te Aho o Te Kahu will continue the ongoing management and use of the Radiation Oncology Collection (ROC) and be responsible for providing a national framework for managing cancer data and ongoing changes, combining relevant patient and cancer service data into cancer information for service and capacity planning, and analysing information to produce cancer intelligence and communicate it to stakeholders
3. Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora to ensure quality assurance and quality improvement initiatives are built into the radiation oncology system and cancer care pathways, including:
  - a. Routinely monitoring service capacity and capability to maintain oversight of system performance and to proactively manage service planning
  - b. Monitoring of quality and equity of radiation oncology services through the ongoing roll out of relevant quality improvement programmes
  - c. Monitoring will include a specific focus on Māori, Pacific and rural access, experience, and outcomes
4. Te Aho o Te Kahu to work with the Māori Health Authority | Te Aka Whai Ora to ensure they have access to high quality information about radiation oncology services and inequities to inform decision making to improve Māori health outcomes.

## Distribution of services

Reconfiguring radiation oncology services as a national network with decentralised services would ensure comprehensive, coordinated radiation oncology services for those who need them, with a focus on reducing the geographic barriers to access.





## National and coordinated clinical leadership

1. Te Aho o Te Kahu to work in collaboration with Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora to provide national oversight to a network of radiation oncology services across Aotearoa.

## Clinical services distribution

1. Radiation oncology services are planned nationally and reconfigured as a national network with satellite sites.
2. High-complexity radiation oncology that requires subspecialised expertise and/or equipment will be provided centrally with clear referral and access pathways to ensure services are an option regardless of where people live.

## Care close to home

1. Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora to support the ongoing roll out of LINACs outside of major centres to enable increased access to radiation therapy.
  - Distribution and location of new centres and satellite sites is planned nationally
2. Radiation oncology services continue to provide outreach clinics with a particular focus on achieving equity of access to services in underserved communities.
3. Telemedicine is developed, supported and utilised for advice and appointments – including use of community and rural health practitioners to support telehealth appointments.

## Implementation mechanisms

1. Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora to lead the development of clear service pathways, outlining treatment pathways, where and how MDMs are held, allied health requirements and palliative and end of life requirements.
  - a. Pathways would be maintained and regularly updated to provide a mechanism for nationally agreed new techniques and technology to be translated equitably into clinical care, including pathways to access subspecialised radiation oncology services as required
  - b. Pathways would outline the 'default' pathway; however, options should be available that support deliberate and considered deviation from the pathway to meet patient and whānau need, priorities and self-determination. Patients would have greater choice to where they receive their treatment i.e. should they wish to be closer to whānau in another part of Aotearoa this will be an option.
  - c. Coordination and care focus areas (discussed in Section 1: Coordination and Support Services) are critical to improve access to radiation oncology services.



## Workforce

The sustainability of radiation oncology services is critical to improve cancer outcomes and experiences in Aotearoa. Given the current shortages, and the predicted workforce capacity needed to achieve best intervention rates the approach to workforce will require an initial recovery strategy to address current issues, followed by proactive, long-term workforce planning.

### Capacity

Te Aho o Te Kahu to work in partnership with Health Workforce to grow and maintain the radiation oncology workforces, including robust planning to meet future increase in demand. This could include:

1. Maximising recruitment strategies including, but not limited to, targeted recruitment campaigns and consideration of focused packages to retain trainees.
2. Increasing the number of radiation oncology trainees - in order to maintain current levels of staffing by 2029, Aotearoa needs to double its radiation oncologist trainee intake (from around 5 each year to 10) (328).
3. Standardising terms and conditions of employment across all public radiation oncology providers, with changes lead by Health New Zealand | Te Whatu Ora.

### Diversity

Te Aho o Te Kahu to work with the Māori Health Authority | Te Aka Whai Ora, Health New Zealand | Te Whatu Ora, the Ministry of Health | Manatū Hauora, training institutions and other partners, including Māori leaders, to enable the radiation oncology workforce to better reflect the population of Aotearoa, with a focus on increasing the number of Māori and Pacific in the workforce. This includes:

1. Linking closely with the strategies outlined within Whakamaui: Māori Health Action Plan 2020–2025 and workforce recommendations contained in Ola Manuia: Pacific Health and Wellbeing Action Plan 2020–2025
2. Assessing pathways by which Māori and Pacific peoples can join the radiation therapy workforces, including working with educational institutions to look at eligibility requirements and make studying accessible.

### Cultural safety

1. Te Aho o Te Kahu to work with the Māori Health Authority | Te Aka Whai Ora, Health New Zealand | Te Whatu Ora, the Ministry of Health | Manatū Hauora, training institutions and other partners, including Māori leaders, to develop processes to support, increase, and measure the cultural safety of the radiation oncology workforce.
  - a. This would include assessing the current state of cultural safety training among the radiation therapy workforces given the low



portion of Māori and Pacific and the large proportion of immigrant specialists and improving and standardising the quality of cultural competency training.

2. Te Aho o Te Kahu to work with the Māori Health Authority | Te Aka Whai Ora, Health New Zealand | Te Whatu Ora and the Ministry of Health | Manatū Hauora to support the implementation of the Ao Mai Te Rā antiracism maturity model (currently in development) across the cancer treatment system.

### Scope of practice

1. Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora, Health Workforce, the Ministry of Health | Manatū Hauora, and training institutions to consider opportunities for advanced or specialist practice and return to practice programmes.
  - a. There are advanced practice opportunities for radiation therapists and nurses that provide career development opportunities and addition skills to alleviate radiation oncologist workload. Further work is needed to evaluate opportunities to delineate tasks and/or roles currently performed by radiation oncologists including:
    - i. Extending clinical scope for radiation therapists and nursing inclusive of appropriate training pathway
    - ii. Establishing standardised frameworks for career development in partnership with professional bodies and unions



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# WĀHI 4: NGĀ MAHI ĀRAI MATE PUKUPUKU ME NGĀ WHAKAWHITINGA PŪTAU PŪRORO

## SECTION 4: SYSTEMIC ANTICANCER THERAPIES AND HAEMATOPOIETIC STEM CELL TRANSPLANTS

### He kupu whakarāpopoto Summary

#### Case for change

There has been a rapid increase in the demand for, and delivery of, systemic anti-cancer treatments (SACT) and haematopoietic stem cell transplants (HSCT) in the last 10 years. In part, this is driven by an increase in the number of people being diagnosed with cancer. However, there has also been a dramatic increase in the number of anti-cancer treatments available in the last decade and an increase in the number of lines of therapy that a patient is on treatment for. This is seen alongside an increase in indications for HSCT and provision of HSCTs in older age groups. Ongoing growth is expected across SACT and HSCT over the next decade.



Currently, the increase in clinical need has been met by a reactive growth in services with limited inter-region coordination. The current service delivery model is unable to keep up with current demand, let alone further increases. Of particular concern, the current delivery of services is systematically failing to achieve equitable care and failing to uphold Te Tiriti o Waitangi obligations.

There are many challenges with the current system, including workforce and infrastructure capacity issues, fragmented and inconsistent care and barriers to access, with patients often required to travel to receive care. All of these challenges create significant inequity in access, quality and ultimately outcomes.

## Proposal for change

The aim is to see the needs of patients and whānau at the centre of the optimisation of existing models of care and the development of new models of care for SACT and HSCT. Improving SACT and HSCT services requires strengthened national leadership models, with a focus on planning that supports equitable, high-quality and sustainable services.

Improving the delivery of care requires a structured approach to determining clinical service distribution that considers the different levels of complexity across SACT and HSCT treatments. Critical to improving access to SACT and HSCT will be the development of models of care that support treatment to be delivered close to home where it is safe and appropriate to do so. This may include separating the location of MDM from the location of consultation and from location of treatment delivery.

These changes would be supported through the development of standardised pathways of care for SACT and HSCT and improved data solutions including linked prescribing software and a single electronic record providing universal data collection. There would also be a focus on developing national processes that support the incorporation of research into routine care and improves equitable access to clinical trials.

To ensure patients are able to access high-quality care, immediate workforce planning is needed that focuses on filling vacancies and short-term constraints. This would be considered alongside robust, future focused workforce planning to ensure there is appropriate workforce capacity and capability to align with changes to models of care and future needs of the cancer workforce. This includes consideration of opportunities to expand the role of some SACT and HSCT staff, such as nurses and pharmacists.



## What will be different for patients and whānau?

- Patients will be able to access SACT in the community closer to where they live.
- Patients who require a stem cell transplant will be able to access care in a timely way, regardless of where they live.
- Patients will have access to the same high-quality treatment regardless of who they are or where they live.

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# Te tiro whānui

## Scope

The focus of this section is on publicly funded systemic anti-cancer therapies and haemopoietic stem cell transplantation for malignant indications. It is acknowledged that some cancer treatments are provided by privately funded services, but these are out of scope in this report.

It is acknowledged that haematological malignancies are only a subset of the workload of Haematology Services. While non-malignant haematological disease is out of scope, any change to SACT/HSCT models of care would need to be implemented alongside wider consideration for how these changes impact the specialty as a whole.

Te Ratonga Toto o Aotearoa, The New Zealand Blood Service is also an important provider of services in the health system, including in the context of HSCT and SACT. However, the blood service is out of scope of this work.

Diagnostic pathways are out of scope for this report, but it is recognised that to improve equitable outcomes from SACT and HSCT, pathway to diagnosis and delays to diagnosis will need to be addressed (165-168).

# He kupu whakataki

## Introduction

Systemic anti-cancer therapy (SACT) is a collective term used to describe a growing number of pharmaceutical agents used in cancer treatment. SACT includes cytotoxic chemotherapy agents, targeted therapies, hormone therapies and immunotherapies. SACT is often prescribed as part of a regimen of multiple anti-cancer medicines. A regimen may also include supportive medicines to either limit toxicity such as anti-nausea and anti-diarrhoeal medicines, or to improve the efficacy of the treatment e.g. folinic acid with fluorouracil in colorectal cancer. SACT may be used with an aim of curing cancer, or to provide symptom relief and palliation. SACT can be given in conjunction with another treatment (eg combined chemoradiation) or as part of sequential therapy (eg neoadjuvant or adjuvant chemotherapy given perioperatively).





It is estimated that chemotherapy will be indicated for 50% of those newly diagnosed with cancer in Aotearoa<sup>3</sup> (329). This varies by cancer type, from around 13% for people with thyroid cancer, up to 95% of people with Hodgkin lymphoma (329).

SACT is prescribed by both medical oncologists and clinical haematologists. It may also be prescribed by other specialists (such as urologists), nurse practitioners, pharmacist prescribers and some treatments, such as hormone therapy, may be managed in primary care. SACT includes parenteral preparations (including intravenous, intramuscular or subcutaneous) delivered either in ambulatory or inpatient settings as well as oral anti-cancer medications dispensed via a community pharmacy.

Haemopoietic Stem Cell Transplantation (HSCT) is a highly specialised systemic therapy most commonly used for haematological cancers (like acute leukaemia, lymphoma and myeloma) or some conditions associated with bone marrow failure (myelodysplasia, myelofibrosis).

There are two main types of stem cell transplantations:

- Autologous – involves the infusion of the patient's own stem cells
- Allogeneic – involves the infusion of stem cells from another person. In allogeneic transplantation, blood stem cells may come from a matched sibling donor, a matched unrelated donor, unrelated umbilical cord blood or a haploidentical (half-matched) family member.

The treatment plan for HSCT is complex and can take several months to deliver. Transplant relies on other forms of therapy, typically involving high doses of conditioning chemotherapy and sometimes total body irradiation prior to stem cell infusion.

<sup>3</sup> This estimate includes targeted therapies, but excludes hormonal therapy and immunotherapy



# **Tō āianeī āhua mō ngā ratonga SACT, HSCT i Aotearoa**

## **Current state of SACT and HSCT services in Aotearoa**

### Distribution of services

SACT is provided in all districts in Aotearoa; however, the range and complexity of treatments given at each centre varies depending on service capability and resourcing. The main regional cancer centres in Auckland City, Waikato, Palmerston North, Wellington, Christchurch and Dunedin all deliver comprehensive inpatient and outpatient SACT treatments options. Smaller satellite sites at most DHBs offer some forms of outpatient treatments. The current exceptions are Hutt Valley and Whanganui, but a local treatment site is planned for Whanganui in 2022.

The majority of SACT is provided in an outpatient setting, in specially designed day units; however, some more highly specialised therapies may also require inpatient care.

Autologous and allogeneic HSCTs are provided at Auckland City, Wellington and Christchurch hospitals, with Palmerston North and Waikato hospitals offering autologous HSCT only. Transplant commonly occurs in the inpatient setting, usually requiring 16-20 inpatient days for an autologous HSCT and 4-6 weeks for an allogeneic HSCT. For selected patients, parts of the HSCT process can be delivered as an outpatient. Currently, services for autologous transplants delivered in the outpatient setting are established in Christchurch and Palmerston North, with some outpatient capabilities in Wellington.

The provision of systemic treatments is one part of the treatment pathway, which also includes regular outpatient review and acute care needs while on treatment. Where treatment is offered outside of a main centre, or where there is no local Senior Medical Officer (SMO), regular planned outreach clinics are held in person and via telehealth to support patients to remain closer to home during their treatment. Where an individual patient receives their treatment depends on the cancer type, the treatment type and patient condition.



## Current state of the workforce

The medical oncology and haematology workforce is broad and includes specialist medical oncologists, haematologists, trainee specialists, clinical nurse specialists, nurse practitioners, chemotherapy-trained nurses, general nurses, clinical trial coordinators, laboratory scientists and technicians, pharmacists, pharmacy technicians and other allied health professionals (including psychologists, social workers, physiotherapists, dieticians and bone marrow donor registry personnel). Allied health workforce is discussed further in Section 5: Allied Health. The SACT and HSCT workforce also work closely with other clinical teams to provide high quality care, including radiation oncology and palliative care teams.

Table 6 presents workforce statistics for selected disciplines within the SACT and HSCT workforces.

**Table 6: Workforce statistics for selected SACT and HSCT workforces (2021)**

Speciality	Total number <sup>3</sup>	Number of Māori (%)	Number of Pacific	Number over 60 (%)
Medical oncologists <sup>1</sup>	100	2 (2%)	1 (1%)	13 (13%)
Haematologists <sup>1</sup>	65	2 (3%)	-	15 (23%)
Cancer nurses <sup>1</sup>	722	27 (4%)	15 (2%)	94 (13%)
Pharmacists <sup>2</sup>	4062 practising	2%	(1%)	154 (4%) over 65

<sup>1</sup> Health workforce data Sept 2021, <sup>2</sup> Pharmacy Council 2021 (330). <sup>3</sup> **Note** that many of these clinicians are working part time and number reflects number of people, not FTE. Accurate FTE data are not held nationally.

**Medical oncologists and haematologists** are trained through the specialist medical and pathology colleges (Royal Australasian College of Physicians and Royal College of Pathologists of Australasia). Medical oncology and clinical haematology training spans a minimum of eight years post-graduation and joint haematology takes a year longer due to the additional pathology training.

There are several **nursing** roles involved in the care of patients receiving SACT and HSCT. Chemotherapy nurses are registered nurses who have undertaken training to safely deliver SACT and manage side effects. Clinical nurse specialists (CNSs) are experienced registered nurses who have substantial clinical experience and have completed post-graduate study. CNSs may work across tumour types (eg breast cancer nurse) or speciality (eg haematology CNS). Nurse practitioners are highly skilled practitioners with advanced education, training and scope of practice. The scope of practice of NPs working in oncology includes prescribing SACT, requesting diagnostic tests, and performing acute procedures (eg drainage of ascites). In 2021 there were nine endorsed oncology/haematology nurse practitioners in the country.



**Pharmacists** play a critical role in the preparation and dispensing of SACT and its safe and effective use. Pharmacy is a relatively young workforce, with a median age of 37.5 years. The majority of practising pharmacists work in community pharmacies (approximately 78%) with 14% working in hospital pharmacy across Aotearoa (330). There are currently 20 pharmacist prescribers practising in New Zealand (330). It is currently difficult to quantify the amount of pharmacy resource dedicated to oncology and malignant haematology in Aotearoa and there is variation around the country in the clinical pharmacy services provided in the different services and settings across the country.

**Pharmacy technicians** also play an integral part of the pharmacy team, including in the dispensing of oral chemotherapy. In some institutions pharmacy technicians also carry out specialised roles such as aseptic compounding of chemotherapy agents and ensuring chemotherapy agents are procured and well stocked. Pharmacists and pharmacy technicians who are trained in the compounding of systemic anti-cancer treatments are highly specialised. The small number of people qualified in this area makes the workforce particularly vulnerable to workforce shortages.



# Ngā wero o āianeī mō ngā ratonga SACT, HSCT

## Current challenges in SACT and HSCT services

This section of the report combines information from stakeholder interviews and published literature on the current challenges with SACT and HSCT services in Aotearoa. These challenges create significant inequity in the access to, quality of, and outcomes from SACT and HSCT services.

The Cranleigh Health Report on New Models of Care for Medical Oncology was published in 2011 and outlined the current and future demands for medical oncology services, challenges and key principles and methods to improve the effectiveness and efficiency of service delivery (331). However, there has been little change to the way SACT is provided following this report, with the majority of the challenges still present and many of the recommendations for change still relevant today.

### Workforce issues

#### *Not enough staff to meet current demand, let alone projected increase*

There is a shortage of trained staff in several key areas which limits the ability to deliver SACT and HSCT. Stakeholders identified particular workforce constraints for trained specialist nurses, chemotherapy training for pharmacists and allied health workforce shortages, including psychologists (see Section 5: Allied Health).

**Nursing** shortages are an issue across several health care settings. Modelling done by Health Workforce New Zealand estimates that by 2031 there will be a 12 percent decrease in cancer nursing FTE ratio compared to 2021, based on average rates of new entry, re-entry and exit over the past 3 years. However, this modelling does not take into account current shortages (of which stakeholders report many) or changes to models of care that require increase in nursing staff.



There are currently around 8 **pharmacists** per 10,000 population in Aotearoa (330). This aligns with the International Pharmaceutical Federation estimate of an average of 7.6 pharmacists per 10,000 people in high-income countries (332). The Society of Hospital Pharmacists of Australia have published recommended pharmacist: patient ratios for inpatient oncology and haematology services, with 1.0FTE pharmacist recommended per 20 adult medical oncology inpatients, or 1.0 FTE per 10 to 15 adult haematology patients (allograft patients 1:10 and autograft patients 1:15) (333). Currently it is difficult to quantify the amount of pharmacy resource dedicated to oncology and malignant haematology in Aotearoa.

There are specific issues facing the pharmacy workforce in regard to SACT. There are currently no locally established training and development programmes in Aotearoa for pharmacists to specialise in SACT and no national training courses or programmes in chemotherapy manufacturing. Training largely occurs 'in-house' and varies across the country. The increasing complexity of medicines and the use of emerging technologies will mean that SACT becomes increasingly personalised. Pharmacists are medicines experts and can work as part of an integrated team to improve outcomes. One of the challenges is ensuring pharmacists have time to deliver clinically focused expertise, with a large amount of time currently occupied with the increasing demand of dispensing and supply services.

There is no international benchmark for the number of **medical oncologists** per capita. A recent Australian workforce review reported 633 medical oncologists registered in Australia, equivalent to around 2.5 per 100,000 population (334). This is higher than the current number of medical oncologists in Aotearoa, roughly 2.0 per 100,000 population. However, this is based on number of medical oncologists in each country, not FTE, and so may not be a completely accurate comparison.

Another metric for considering the medical oncology workforce is the number of new patients per physician per year, which has been estimated to be, on average, 175 per physician per year in high-income countries (329, 335). Around 160-175 new patients per physician per year has been considered a safe workload, with the expectation that around 150 of those will require chemotherapy (329). It is estimated that approximately 50%<sup>4</sup> of the 26,400 people diagnosed with cancer require chemotherapy in Aotearoa (329). This means that Aotearoa requires around 88 full time medical oncologist for a workload of 150 patients requiring chemotherapy a year. One challenge to assessing this metric is the lack of accurate FTE data in Aotearoa.

<sup>4</sup> This estimate includes targeted therapies, but excludes hormonal therapy and immunotherapy



Similarly, there are no international benchmarks for number of **haematologists** per capita. The Royal College of Pathologists Australasia reports 520 haematologists in Australia, around 2 per 100,000 population (336). This is higher than the number currently in Aotearoa – around 1.3 per 100,000 population, although again this does not take into account FTE of staff. Stakeholders report a growing workload pressure on medical staff, particularly those with transplant experience due to the growth in demand for HSCT.

Stakeholders noted that haematology training is currently limited by the number of training posts, particularly the availability of the laboratory component of training. Many laboratories embedded in public hospitals are run by private necessitating more complex contractual and collaborative arrangements to facilitate training than training programmes solely within public services.

Stakeholders described an increasingly stretched workforce with an increase in demand for SACT and HSCT due to expanding clinical applications, broadening eligibility and overall population growth. Historically, people with cancer would have been offered a single line of treatment. However, with advances in treatments, people may be offered several different treatments over many years. The increasing complexities of supportive care needs in the landscape of an expanding armamentarium of anti-cancer therapies adds to the workload of on-treatment review and follow-up care. Staying on top of the new and emerging treatment options makes it increasingly difficult to practice as a generalist.

Additionally, the burden of administrative duties has increased including:

- *Increasing time for MDMs:* medical oncologists and haematologists are key members of multi-disciplinary cancer teams, and their participation in multi-disciplinary meetings (including tumour boards) to review and discuss patients is an increasing part of their work. As with other specialties, this time is often not adequately accounted for.
- *General administrative duties:* a common issue raised during stakeholder interviews was the feeling that staff often spent a lot of their time working 'below-scope'. For example, rather than spending their time seeing patients and developing treatment plans, clinicians are spending significant amounts of time undertaking administrative tasks that could be completed by support staff. For HSCT this includes an increasing requirement for data management and reporting to transplant registries.





### ***The current workforce is not representative of the population***

Although Māori make up 16.5 percent of the total population of Aotearoa (17), only 2% of medical oncologists, 3% of haematologists, 4% of cancer nurses and 2% of pharmacists identify as Māori (see Table 6, page 137). Increasing the number of Māori in the medical oncology and haematology workforce was frequently mentioned as being critical to improve care for Māori patients and whānau.

Due to growing workforce demands and staff shortages there is an ongoing reliance on overseas-trained staff. Although these staff are often highly trained and skilled, they have not trained to operate in the unique environment of Aotearoa, and in particular need additional education in cultural awareness, competence and understanding of Te Tiriti o Waitangi, to be able to work safely and effectively with Māori cancer patients and their whānau.

*“Health professionals who are trained overseas should have to undertake cultural competency training before they can practice in New Zealand.”*

Community Hui participant, 2021

## **Infrastructure**

### ***There is insufficient, and often inadequate, facilities to support the delivery of services***

The current service delivery model of SACT largely relies on patients coming into hospital settings to receive treatment. Many of these facilities are beyond their expected lifespan, which is a significant constraint to managing increasing demand and improving patient experience. The majority of medical oncology and haematology services are facing physical constraints in both inpatient and outpatient/day ward settings.

There has been limited substantive growth in the size or scale of cancer treatment facilities in at least the past two decades. Where facility upgrades have occurred, this has largely been piecemeal attempts to make best use of existing buildings rather than a significant change to increase floor space. Additionally, the age of facilities mean that they often lack modern design that can improve workflow or enable effective use of technology.





Insufficient inpatient bed capacity is a particular issue for the delivery of HSCT, with bedspace limiting the number of transplants that can be completed in some regions. Within medical oncology and haematology, inpatient capacity is often impacted by the broader capacity issues experienced by New Zealand hospitals. Population growth, increasing emergency presentations and the impact of COVID-19 are constraining all aspects of the hospital services with pressure on bed capacity.

The physical infrastructure and capacity constraints can also lead to challenges with making services whānau-centred. Patients and whānau report that there often isn't room for whānau to attend appointments and that there is often limited privacy for private conversations to occur, particularly as an inpatient.

***Inadequate information systems and infrastructure mean that there is insufficient access to timely and accurate data for decision making, both at an individual and a population level***

Disparate and unconnected patient management systems are a significant challenge for both patients and clinicians, particularly as people move between providers and districts for treatment. Fragmented patient records have multiple implications including:

- A reliance on work arounds/manual processes to ensure complete information is available which wastes time and creates risk
- Repeat tests and scans when information is incomplete or unable to be reliably sourced
- Patient and whānau burden and anxiety to bridge gaps in transferring information between clinicians, hospitals and primary care

Like all pharmaceuticals, SACT is ordered via a prescription. Electronic prescribing systems can reduce errors and improve patient safety for prescribing, dispensing and administering of systemic therapies (337, 338). While some providers have e-prescribing systems, this is not consistent. These systems are also foundational to collecting consistent and standardised data about treatment effectiveness.

At a population level there is currently no systematic way to measure treatment/intervention volumes, levels of complication, consistency of protocols and effectiveness of interventions. This creates challenges for ensuring safety and consistency of treatment and for benchmarking. Te Aho o Te Kahu is currently undertaking work to improve information on SACT, including the Anti-Cancer Therapy – Nationally Organised Workstreams (ACT-NOW) programme. ACT-NOW aims to better understand how chemotherapy is being delivered across the country by collecting treatment and treatment-related data from public and private chemotherapy providers and working with clinicians and other stakeholders to identify opportunities to improve services.



## Access and cost of new medicines and technologies

***It is a challenge to balance the rapid development and increasing cost of new medicines against improving access to new medicines that improve outcomes***

In Aotearoa, Pharmac | Te Pātaka Whaioranga is the government agency responsible for deciding which medicines to fund across all areas of health, while the Government is responsible for deciding how much funding is allocated to new medicines.

Affordability and accessibility of cancer medicines is a challenge facing countries worldwide (339). New cancer medicines are being developed at a rapid pace, treatment for many cancers is continuously evolving and the cost of new cancer medicines has risen more quickly over time than for most other health conditions (340). The availability of new cancer medicines is a common concern for clinicians and patients, with some cancer medicines that are currently unfunded in Aotearoa having the potential to offer significant clinical benefit (341). A key current challenge for Aotearoa is how to ensure equitable access to effective cancer medicines in an environment where the costs of cancer medicines are rising and spending on cancer medicines is increasing globally. The cost of medicines must also be balanced with other investment opportunities across the cancer continuum and the health system more broadly.

***There is an inconsistent approach to assessing and introducing new technologies across Aotearoa***

Whilst Pharmac | Te Pātaka Whaioranga provides a national approach to assessing new medicines, there is currently no national approach to assessing and introducing new technologies, meaning they are frequently introduced inconsistently and inequitably across DHBs. This is a problem across all cancer treatment modalities. Molecular testing plays an increasingly important role in SACT. Inconsistency in access to molecular testing is a growing challenge and is discussed further in Section 6: Pathology and Laboratory Services). Another example is the variable access to PET-CT, which can impact on SACT treatment pathways for patients (PET-CT is discussed further in Section 7: Radiology Services).



### ***Availability of new medicines or technologies is not a guarantee of accessibility***

Across both new medicines and technologies, there are challenges in accessibility even when they have been publicly funded. For example, the accessibility of medicines for Māori, Pacific peoples and other population groups is influenced by many things in addition to whether they are listed in Pharmac's Pharmaceutical Schedule. These include barriers of cost, time, travel and trust, as well as health system factors. Māori and Pacific peoples experience specific inequities when it comes to accessing systemic anti-cancer therapies. Examples include poorer access to trastuzumab and adjuvant chemotherapy in breast cancer (294, 342), and adjuvant chemotherapy in stage III colon cancer (191, 343).

When new medicines are funded by Pharmac | Te Pātaka Whāioranga, they often require additional health system resources in order to deliver them, such as infusion capacity with its associated pharmaceutical compounding, chair/bed time, medical specialist time, nursing care, as well as associated blood testing, molecular testing and radiological follow-up. When a new medicine is funded, this can often result in a large number of patients becoming eligible for treatment at once, often with a short notice period. This can result in demand surges with inadequate time for services to plan, respond, and ensure equitable delivery of new medicines.

## Research and access to clinical trials

### ***There is variability in access to clinical trials across Aotearoa***

Clinical trials are an important part of cancer research. Clinical trials also provide access to treatments that would not otherwise be publicly available for patients. Research has been embedded in many centres as a fundamental part of routine patient care, but access to this around the country varies substantially. Clinical trials are usually limited to a subset of the tertiary cancer centres and often patients being treated in affiliated peripheral hospitals are unable to gain access to the trials unless they travel to the tertiary centre. This travel is not covered by the National Travel Assistance scheme and is often not fully covered under trial budgets either.

Overall, Aotearoa is thought to have low participation rates in cancer clinical trials compared to other jurisdictions and to international targets (344). There is currently significant variability in the infrastructure and experience to conduct clinical trials across DHBs and a lack of awareness of patients and clinicians about existing trials (17, 345).



### *The value of clinicians undertaking and supporting research is not recognised*

Medical oncologists and haematologists play a central role in the development of novel treatments and regimens and have been a central part of the progress of anti-cancer therapies over recent decades. Specialists have a key role in clinical and translational research, particularly in clinical trials; however, this important role is often not recognised, with participation in clinical trials and research rarely recognised as core parts of clinicians' roles. Fewer than 10% of oncologists have a part-time academic appointment, despite research being central to improving the relatively poor outcomes for many advanced cancers.

## Service planning

### *A lack of national planning has led to fragmented and inconsistent care*

Due predominantly to the autonomous nature of the 20 DHB service delivery model there has been uncoordinated – and insufficient – growth in SACT/HSCT services. A lack of nationally led systems for developing, monitoring, maintaining and modernising service models has resulted in inconsistent care across Aotearoa. As a result, currently:

- There is variability in treatment pathways, meaning people receive different care depending on where they live
- Inconsistent post-treatment follow-up, with some patients followed-up by surgical services, some by oncologists and some discharged back to primary care. Stakeholders reported missed opportunities to maximise connection with primary care due to a lack of consistent guidance around follow-up and surveillance.
- Variable resourcing for, and access to, palliative care, particularly for those living outside of major centres. This will become an even bigger issue as the demand for palliative care services increases, with modelling suggesting that the number of people needing palliative care will increase by more than 50 percent between 2016 and 2038 (346).
- Wait times for HSCT exceed recommendations in some centres resulting in people accessing transplant beyond optimal timeframes, requiring additional cycles of SACT to manage their cancer or missing curative treatment options due to capacity constraints at local facilities. Stakeholders report barriers to innovation and to improving services, such as transitioning from inpatient to outpatient HSCTs or to facilitate earlier discharge back to local hospitals.
- There is no consistent national process for establishing where new services should be based.
- There is an ongoing tension between generalist care and sub-specialisation, with inconsistent pathways to support decision making/care for complex/rare cancers and limited inter-region coordination.



## Access challenges

*Patients experience significant barriers to accessing of SACT and HSCT, and aspects of care make having cancer even harder, rather than easier*

*“Why is it the sick person that has to do all the travel?”* Community Hui participant, 2021

The current model for provision of SACT is largely hospital-centric. Patients are often required to travel to the hospital regularly to receive SACT. This can create barriers to accessing care and can come at a considerable personal and financial cost to patients, particularly for those who live rurally. Geographic barriers are not limited to the rural setting. As an example, in the Auckland region, most cancer patients from the Counties Manukau and Waitemata DHB catchment areas have to travel into the centrally based Auckland City Hospital to receive SACT. This travel burden is disproportionately carried by Pacific peoples with cancer given that nearly 40% of the Pacific population of Aotearoa live in Counties Manukau DHB region (347).

A study looking at the average time and travel costs of attending rural and base hospital outpatient clinics in Central Otago residents found that 61 percent reported that the cost of attending an outpatient clinic appointments had a significant impact on their weekly budget (348). Given that SACT may need to be delivered at regular intervals over a long period of time, the costs of travel to follow-up and treatment appointments for SACT can be significant and prohibitive. The cost and availability of hospital parking can also create a barrier to access to treatment. This is discussed further in Section 1: Coordination and Support Services.

*“Being close to whānau when undergoing treatment is rongoā.”* Community Hui participant, 2021

Similarly, HSCT and some SACT patients may need to re-locate away from their home for periods of time while having treatment. For HSCT patients particularly this can be for many weeks to months. This can come at a significant financial and psychological cost. The current system to support travel, the National Travel and Accommodation Scheme (NTA) is not fit for purpose and contributes to inequities. NTA is discussed further in Section 1: Coordination and Support Services.



Patients may also experience other financial barriers to care. For example, treatment may include oral anti-cancer medications or supportive medicines (such as antiemetics or antivirals) dispensed via a community pharmacy, which means patients are often required to pay the dispensing fee. This can contribute to inequities in care, with Māori 35 percent more likely to defer prescription medication due to cost than non-Māori, non-Pacific people (349). These barriers have been shown to reduce health status indirectly by reducing consumption of other health promoting resources e.g. nutritious food and by negatively impacting on people's Mana, due to the stigma associated with being unable to afford essential items (349).

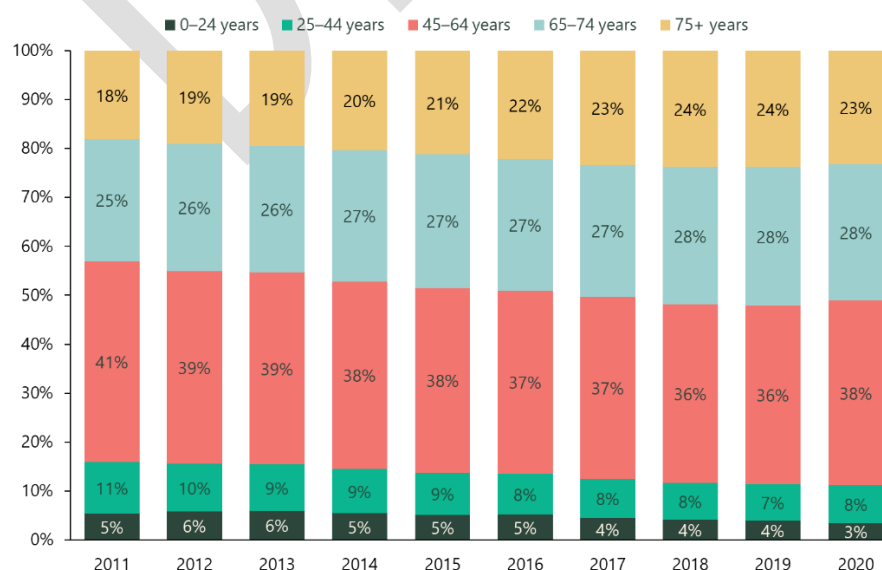
## Increasing complexity of patients

***People are receiving SACT and HSCT at an older age and increasing comorbidity, which increases the complexity of care***

Comorbidity is common among people with cancer and can increase the complexity and time required to deliver safe and effective treatment. The presence of comorbidity can impact both the diagnosis and treatment of cancer (350, 351). Māori cancer patients are more likely to have comorbidity than non-Māori cancer patients, and this inequity likely contributes to inequities in cancer outcomes between Māori and non-Māori (10, 180).

Developments in SACT care also mean that people are receiving SACT at an increasing age (Figure 15). In 2011, 18% of patients were over the age of 75 and now nearly a quarter of all patients receiving SACT are older than 75 years. Elderly patients frequently experience more comorbid medical conditions making management more complex.

**Figure 15: Age distribution of patients receiving SACT (haematology and medical oncology) 2011-2020. Data Source: Ministry of Health | Manatū Hauora Pharmaceutical Collection**



## Increase demand for services

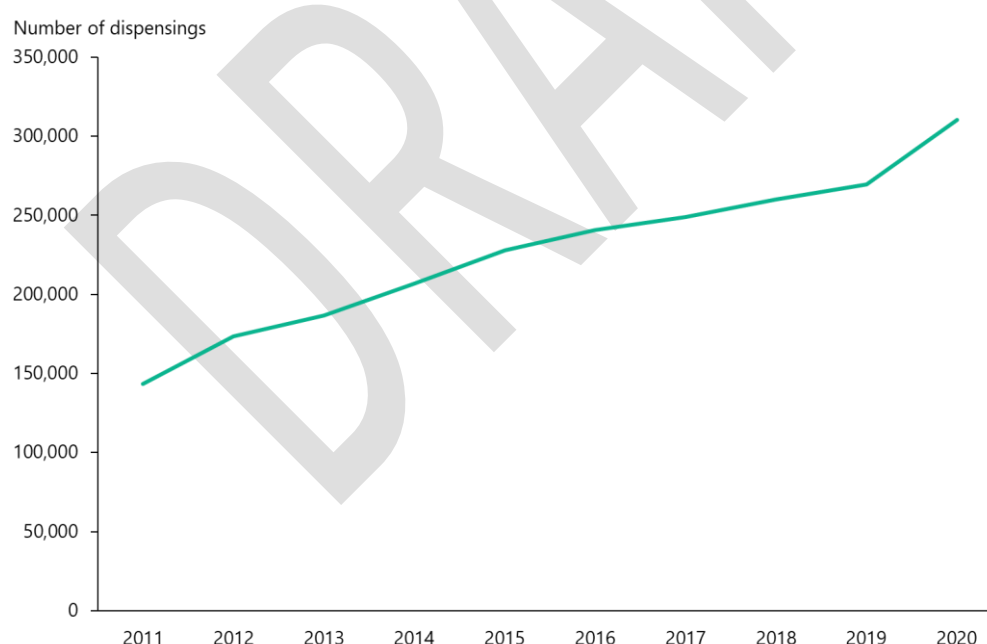
*The rapid and substantial increase in demand for SACT and HSCT is placing considerable strain on services, and exacerbating all of the challenges described above*

### Systemic anticancer treatment

There has been a rapid and substantial increase in SACT delivery over the last two decades. One way to measure SACT volumes is through dispensing data. SACT is typically dispensed to patients on a per-cycle basis, with each anti-cancer medicine dispensed counting as one 'dispensing'.

Figure 16 illustrates a more than doubling of dispensing for SACT between 2011 and 2020. There are a number of factors at play here: an increase in the number of people being diagnosed with cancer, an increase in the number of anti-cancer treatments available, an increase in the number of lines of therapy that a patient is on treatment for and an increase in the length of time that the patient remains on treatment.

**Figure 16: Dispensing of SACT 2011-2020.** Data source: Ministry of Health | Manatū Hauora Pharmaceutical Collection



The ongoing rapid increase in SACT demand and complexity means that services are under constant pressure and are struggling to deliver treatment in a consistent and timely manner. Many of the challenges described above are being made evident and exacerbated by this rapid increase in demand for services.

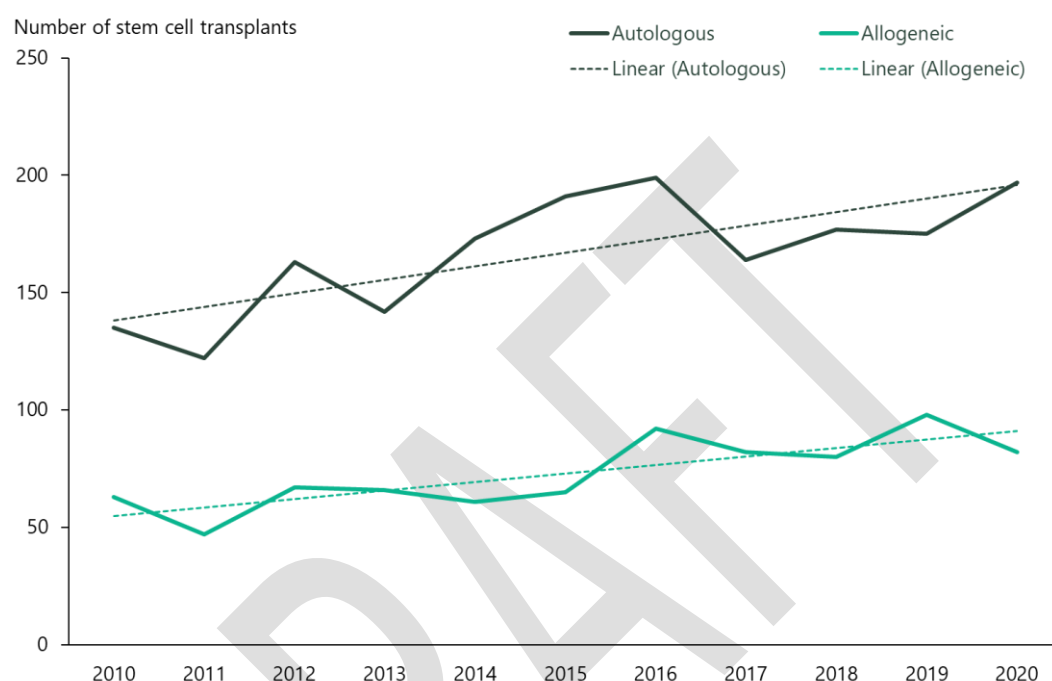




## Haematopoietic stem cell transplants

Over the last decade there has been an increase in the number of both autologous and allogeneic transplants. Figure 17 illustrates a nearly 50% increase in the number of autologous transplant and 30% in allogeneic between 2010 and 2020.

**Figure 17: Adult stem cell transplants completed in Aotearoa 2010-2020**



There are multiple drivers of this increase, including an increase in the incidence of blood cancers (17), an ability to transplant patients at an older age, increasing disease indications for HSCT and the greater availability of suitable HSCT donors, particularly haplo-identical donors.

Reports outlining the increase in demand and issues with the delivery of HSCT were published by the Ministry of Health | Manatū Hauora in 2011 and updated in 2018 (352, 353); however, there has been little change to the way HSCT are provided and few additional resources have been made available. Services are now struggling to meet current demand.





# Tō āianeī mana taurite kore

## Inequity in the current state

Generally, SACT and HSCT services in Aotearoa are high quality, with outcomes comparable to other countries (17). However, not all population groups are receiving the same benefit from services. All of the challenges described above collectively create inequity in access, quality and outcomes for Māori and Pacific peoples compared to non-Māori and non-Pacific, as well as inequity in care based on where people live. The cumulative impact of these system issues is summarised below, demonstrating the extent to which the current system is creating inequity in SACT and HSCT care.

### Equity for Māori

Māori experience significant barriers in receiving high quality SACT. Several studies have found that Māori are less likely to receive chemotherapy than non-Māori, including adjuvant chemotherapy for colon and breast cancer (342, 343, 354). Māori also experience significantly longer delays in receiving adjuvant treatment for breast cancer than non-Māori, with inequities persisting after adjusting for deprivation and rurality (294). Māori also experience barriers to completing SACT regimens, including adjuvant endocrine therapy for breast cancer (355).

There is currently a lack of robust data on equity of access, quality and outcomes related to HSCT.

### Equity for Pacific peoples

Pacific peoples also experience barriers to accessing SACT and are less likely to receive adjuvant chemotherapy for colon cancer and are more likely to experience delays in receiving treatment than non-Pacific peoples (343, 354). Pacific peoples with breast cancer are less likely to receive adjuvant chemotherapy than non-Māori, non-Pacific and are more likely to experience delays in treatment (294, 342).



## Geographic variation in care

There is variation in SACT use across Aotearoa that warrants review. For example, between 2015-2018 the proportion of patients with non-small cell lung cancer who received SACT varied by DHB, from 13 to 38 percent (197).

*A detailed equity analysis of how each of the challenges with the current system contributes to inequity in access, quality and outcome, and alignment to focus areas is included in **Appendix VI**.*

DRAFT



# Taunakitanga hei whakatutuki wero

## Evidence of ways to address challenges

This section of the report looks at local and international evidence to identify ways to address the challenges with the current SACT and HSCT system in Aotearoa.

### Models of care for the delivery of SACT

Internationally many jurisdictions are decentralising less complex SACT to community hospitals, with more complex treatments being provided in regional centres (331). This approach has potential to improve patients' wellbeing by keeping them closer to their support networks during treatment and reduce access barriers by reducing the need to travel. Common mechanisms to implement this include clear role delineation outlining the minimum requirements for services providing different levels of systemic treatment, common treatment guidelines and care pathways across centres, and shared care agreements with clear responsibilities (331, 356-359).

One example is in Ontario, Canada, where SACT treatment is organised around four levels of care based on complexity of treatment (356). Levels of service range from the provision of highly complex specialised SACT (Level 1) to low-risk treatment under the direction of a medical oncologist who may not be onsite (Level 4). Figure 18 outlines some of the key differences in facilities across the four levels. Patients may receive all treatments at one facility, or may receive treatment in a shared care model, with consultation at one facility and treatment at another location closer to their home.



Figure 18: Levels of SACT in Ontario, Canada. Key differences between facility levels based on complexity of care (356)

Complexity	Level 1 (RCC)	Level 2 (RCC)	Level 3 (Affiliate)	Level 4 (Satellite)
Experimental Investigational New Drug Program	✓	✗	✗	✗
High complexity procedures including: Concurrent Head and Neck Chemorads and/or Radiolabelled Conjugates	✓	✓	✗	✗
Medical oncologist on site determines treatment plan	✓	✓	✓	✗
1 <sup>st</sup> dose of high risk systemic treatment	✓	✓	✓	1 <sup>st</sup> dose if approved by the RSTP
All other systemic treatment	✓	✓	✓	✓

✓ = Yes    ✗ = No    Chemorads = chemotherapy in combination with radiation therapy;    RCC = regional cancer centre

It is recognised that patient complexity, including comorbidities, symptom burden, nutritional needs, psychosocial support and patient engagement also impacts on the safe delivery of treatment (359). BC Cancer (British Columbia) has attempted to capture the intersection of complexity of treatment and patient complexity in their Tiers of Service as outlined in Figure 19.

Figure 19: BC Cancer Tiers of Service, patients appropriate to receive services at each tier based on patient and systemic therapy complexity (359)

			Focused Outpatient Systemic Therapy Service			General Outpatient Medical Oncology Service			Comprehensive Outpatient Medical Oncology Service			Regional Subspecialty Outpatient Medical Oncology Service			Provincial Subspecialty Outpatient Medical Service		
			T2			T3			T4			T5			T6		
			Patient Complexity			Patient Complexity			Patient Complexity			Patient Complexity			Patient Complexity		
		Relative Frequency	Low	Mod	High	Low	Mod	High	Low	Mod	High	Low	Mod	High	Low	Mod	High
Systemic Therapy Complexity	Low		X				X				X			X			X
	Mod						X				X			X			X
	High	Common							X	X	X	X	X	X			X
		Uncommon										X	X				X
	Concurrent therapy required											X	X	X	X	X	X

To support the decentralised delivery of SACT, some jurisdictions have also created new workforce roles. One example is general practitioners in oncology (GPOs), which is a growing role in parts of Canada. GPOs can have a wide range of roles as part of the cancer care team, including: clinical supervision of SACT, management of the physical and psychosocial effects of cancer treatment, follow-up and survivorship care and palliative care (360).

There are several other enablers being utilised internationally that aim to facilitate the provision of care closer to home, particularly in rural and remote areas.



**Tele-chemotherapy** is a model of care whereby selected patients are able to receive low-risk SACT locally – and often in remote areas – with the support of specialist clinicians in larger centres via telehealth. Several jurisdictions have developed tele-chemotherapy delivery models. One example is the Queensland Remote Chemotherapy Supervision (QReCS) model (361). In this model a rural generalist nurse can administer select SACT under the direct supervision of chemotherapy-proficient nurses at larger centres using videoconferencing technology. Rural generalist medical officers and pharmacists provided local support at rural centres and medical oncologists and oncology pharmacists from larger centres provided support via teleconference (361).

Tele-chemotherapy is currently utilised in some regions of Aotearoa, but there is scope for it to be enhanced and more consistent.

**Mobile Chemotherapy Units** have been in use in the UK since 2007. In this nurse-led model, a van is converted to accommodate several treatment chairs. The service includes two nurses and a driver. The driver picks up compounded systemic anti-cancer treatments before parking the van in grounds of community hospitals. The units operate independently of the hospitals where they are parked; however, further assistance is available in the event of a medical emergency. This model has been used to deliver a range of systemic anti-cancer treatments, including cytotoxic compounds, targeted therapies and supportive medications (362).

**Home-based delivery** is another model to move SACT out of hospital settings by staff travelling to, and delivering care, in patients' homes. Home based therapy has been shown to be safe, patient centred and cost-effective and can reduce the contact time of immunocompromised patients with the hospital environment (363-370). However, there are concerns around home infusion of anticancer therapy, with American Society of Clinical Oncology (ASCO) releasing a policy statement against the routine use of home infusions largely due to safety concerns except in "exceptional circumstances where the benefits of home infusion outweigh the potential risks to patients" (371). The Victoria State Government in Australia has developed a home-based cancer care framework and toolkit to outline the governance, models of care and funding structures to assist Victorian health services in establishing and delivering safe, high-quality SACT treatment in the home (372).



Prior to implementation, new models of care for the delivery of SACT would need to consider:

- **Equity implications:** community delivery of SACT is thought to be a powerful tool to remove barriers to accessing care and improve equity. However, eligibility assessment criteria for remote cancer care would need to be carefully considered in a New Zealand context to ensure that new models did not have the potential to worsen inequities. For example, exclusion criteria around comorbidities and home environment have the potential to increase inequities. Additional supports and resource for coordination of care and proactive management and monitoring of comorbidities would need to be considered for these populations to ensure equitable access.
- **Safety:** the safe delivery of SACT would require consideration of compounding, storing, transporting, administering and disposing of agents. Critical safety principles – including verification by more than one practitioner and managing adverse events – also need to be considered.
- **Staffing requirements:** currently an oncology nurse in a hospital setting can supervise the infusion of SACT for more than one patient at once, whereas this would require 1-on-1 care in remote or home settings. There are current staffing challenges within oncology nursing, so any changes to model of care would need to carefully consider and plan staffing requirements.
- **Cost to patients:** given prescription cost is already a barrier to access of medicines in the community, caution is needed to ensure that any shifting of SACT into the community is not associated with a shift in some of the cost of the pharmaceuticals to patients.

## Cranleigh Health Review

The Cranleigh Health *Report to the Ministry of Health New Models of Care for Medical Oncology* in 2011 described many of the same challenges still evident today (331). The recommendations from the Cranleigh Health report have been considered alongside international models of care. The key recommendation from the Report was a proposed model of care, which included three key components:

- A delineated service centre component that defines the expected service delivery levels into a four level hub-and-spoke model. It describes the services provided, minimum resourcing and support requirements expected at each level;
- A role definition component that delineates and defines the future roles, tasks and functions of the key clinical and non-clinical staff groups on the medical oncology treatment pathway. This includes endorsing a broader scope of practice for specialist nursing and introduces alternative medical staff in hospitals and communities to increase the medical oncologist capacity at key care delivery points; and



- A tumour-based component that describes how services are linked, potential sub-specialisation approaches and the role of a possible subspecialty national hub and spoke model based on different tumour types.

To support this model of care, a number of key enablers were also recommended:

- Developing national treatment guidance, standards and protocols with defined escalation and specialist access processes and supporting tools to enable information sharing and access.
- Implementing an appropriately coordinated national and regional MDM framework to support treatment planning and care delivery across multiple locations;
- Developing and implementing accreditation standards and credentialing systems to ensure centres can safely and effectively provide care;
- Developing and implementing regional and national medical oncology training processes to reduce duplication of efforts and support the devolution of care to other clinicians (eg national standards, protocols and training programmes to support greater care management by specialist nurses, Medical Officers of Special Scale or General Practitioners); and
- Aligning the DHB funding framework to improve the national and regional focus on care delivery in the proposed model.

## Models of care for HSCT

The growth in demand for HSCT has increased significantly worldwide in the past 20 years. Keeping pace with the growing demand has required a rethink to the way in which transplants are delivered that will ensure quality of patient care and reduce the demand for hospital admissions.

Outpatient HSCTs provide an alternative model of care. There are different models for HSCT, including delayed admission, early discharge, mixed inpatient/outpatient or total outpatient model (373, 374). Outpatient HSCTs can provide benefits for both the patient and the health system, including improved quality of life and reduced overall costs in hospital stays (375, 376). For selected regimens and indications outpatient HSCT appear to be safe and effective (377-383); however, are highly dependent on social support and caregiver availability (381, 384).



The delivery of acute hospital care to patients at home has been investigated in Australia for the management of patients following autologous HSCT, driven by inpatient capacity shortages. This has been made possible by advances in outpatient and supportive care (eg improved antimicrobial prophylaxis), simplified pre-transplant conditioning and non-myeloablative regimens, novel formulations of medicines such as pre-filled syringes for subcutaneous administration or oral formulations and the use of programmable and portable infusion devices. Using a hospital in the home care delivery model was found to be feasible and safe for appropriately selected patients (385).

There are several considerations for expanding the delivery of outpatient HSCTs including: integration between the outpatient program with the inpatient unit, access to experienced support including after hours and the availability of caregivers.

## Telehealth

Telehealth is a critical component for many alternative models of treatment delivery outlined above and can also be utilised for outpatient appointments and acute assessments. Telehealth has the potential to improve access to appointments by reducing the indirect patient costs such as travel and time off work, particularly for deprived and rural populations.

Internationally, telehealth has been used for decades in the management of patients receiving SACT for cancer. Telehealth has been shown to be useful for both routine follow-up and for emergency care (368, 386-388).

A UK study of chronic myeloid leukaemia patients during the COVID-19 pandemic found that only 19% of patients had experienced a remote clinic (video or telephone clinics) prior to the pandemic, versus 91% afterward. The percentage of patients who were positive about a remote clinic significantly increased from 34% to 52% after having personal experience. When patients were asked to compare their preference for follow-ups, 48% preferred face-to-face, 17% preferred remote clinics and 35% had no preference. The study highlighted the importance of patients having options about what type of follow up works best for them, with 72% of patients favouring future models of care that include remote appointments and 61% preferring a mixed model of some face-to-face and some remote appointments (389).

Technology can be utilised to improve access to limited specialist resource, including through e-consultative services. These may be useful in reducing referrals and patient evaluations for diseases such as early stage chronic lymphocytic leukaemia or indolent lymphomas where the initial work-up can be completed by the referrer and active surveillance is often the recommended standard of care (390, 391).





Community provision of care may also be able to be supported by remote patient monitoring, utilising web-based systems and wearable sensors. This may improve symptom management and decrease use of acute and emergency services, with studies underway to look at the effectiveness of remote monitoring (392-394).

## Improving access to clinical trials

Improving access to clinical trials is an issue across all treatment modalities and an issue faced by many countries. Internationally, a number of approaches are being used to increase access. In 2001 the UK established the National Cancer Research Network (NCRN) (395). The NCRN was established to provide infrastructure for clinical cancer research and to coordinate, support and deliver research through the provision of research support staff across England (395). This model increased accrual into clinical trials and also supported faster trial delivery, going from accrual of 3.5% in the late 1990s, to 14% participation in 2007 (396). Similar strategies have been used in New South Wales and in Victoria.

In Australia, rates of enrolment in clinical trials for rural and regional cancer patients are considerably lower than for patients in metropolitan settings, and lower than international recommendations and benchmarks (397). This has led to the development of the Australasian tele-trial model. The tele-trial model gives patients living in smaller centres the opportunity to participate in clinical trials without having to travel to major centres. In a tele-trial model, the primary trial site works with 'satellite sites' to enrol, consent and treat patients in clinical trials. The patient then receives face to face care in the region where they live (397). The tele-trial pilot found that tele-trials could be safely and ethically implemented and increased access to clinical trials in rural and remote sites, meaning more patients have access to clinical trials closer to community support and without disruption to continuity of care (397, 398).



# He tāpae hei panoni

## Proposal for change

The rapid and ongoing growth in demand for both SACT and HSCT means the existing models of care are no longer fit for purpose, are not responsive Te Tiriti o Waitangi obligations and are creating significant inequity in access, quality and outcome. Achieving high quality care for people accessing SACT and HSCT will require refocus, revision and change. This will involve medical oncology and malignant clinical haematology services aligning with nationally led cancer service models. The aim is to see the needs of patients and whānau at the centre of the optimisation of existing models of care and the development of new models of care for SACT and HSCT.

Models of care within SACT/HSCT services will include models relating to provision of SACT/HSCT as well as the care needs around the time of SACT/HSCT, including: referrals, communication/supervision between services, pre-treatment assessments, on treatment assessment, acute assessment (including inpatient care), post treatment cares, symptom management, survivorship and palliative care.

## Ngā wāhi hei mahi | Potential focus areas

### System Leadership

#### National system leadership

1. Te Aho o Te Kahu to work in partnership with Health New Zealand | Te Whatu Ora, the Māori Health Authority | Te Aka Whai Ora and other partners as appropriate to provide strong, well-defined national leadership for medical oncology and malignant haematology, with a Te Tiriti o Waitangi and equity focus. A strong national approach to SACT and HSCT services would include:
  - a. Consideration of distribution and models of care for SACT and HSCT
  - b. Strategic workforce planning
  - c. Development and monitoring of national cancer care pathways including for SACT and HSCT related care
  - d. Supporting the incorporation of research into routine care, including equitable access to clinical trials for SACT and HSCT
  - e. Overseeing processes to monitor access, quality and outcomes of SACT and HSCT services, and manage unwarranted variation in clinical practice and outcomes
  - f. Supporting quality improvement of SACT and HSCT through clinical leadership, a drive for innovation and quality assurance



- g. Contribution, as appropriate, to strong cancer medicines policy by collaboration with Pharmac | Te Pātaka Whaioranga and support transparency around medicines funding
- h. Facilitating SACT and HSCT subject matter expertise to a national assessment process of new technologies e.g. PSMA PET, genomic testing and non-pharmaceutical technologies.

## Data Driven

1. Te Aho o Te Kahu to work to ensure short- and long-term planning is supported by high quality data, including:
  - a. Supporting nationally consistent and equitable uptake of electronic prescribing systems for SACT to assist in reducing unwarranted variation in practice and to improve safety, efficiency, quality and effectiveness of SACT. Te Aho o Te Kahu will continue work underway on the ACT-NOW project to agree and standardise prescribing regimens. ACT-NOW will support the alignment of regimens and other SACT data.
  - b. Utilisation of national collections (eg SACT collection data) to model scenarios and models of care and their likely impact on resourcing and requirements for infrastructure.
  - c. National data can be used to proactively collaborate with Pharmac | Te Pātaka Whaioranga to identify gaps and options for funding and to contribute to pharmacoeconomic analyses.
2. Te Aho o Te Kahu to continue to support work to strengthen national data collections, to enable more accurate forecasting of potential impacts on services to be completed, and more detailed planning, modelling and resourcing to ensure equitable and successful implementation.
3. Te Aho o Te Kahu to work with partners to explore opportunities to establish new centralised data sources, including a register of clinical trials and participation.

## Clinical Service Distribution

### SACT service delivery and distribution

1. To improve access to SACT, Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora, the Māori Health Authority | Te Aka Whai Ora and other entities as appropriate, to deliberately configure the distribution of SACT services and develop new models of care that are sustainable, accessible, safe and culturally appropriate. Model of care considerations include:
  - a. Patient and whānau needs at the centre of service development and services are culturally safe and appropriate
  - b. The development of kaupapa Māori Services, including incorporation of rongoā Māori
  - c. A focus on providing care close to home where/when it is safe and appropriate to do so



- d. Utilising a broader range of the workforce for the delivery of care, with staff supported and enabled to work at the top of their scope of practice, including consideration of:
    - i. Increasing the scope of practice of nurses and pharmacists to increase the provision of SACT
    - ii. Greater partnership with primary care
  - e. Appropriate level of care based on complexity, considering both treatment and patient factors, recognising that specialised input and MDM may not be co-located with SACT provision
  - f. Services are well networked, with both national and regional leadership
  - g. Utilisation of telehealth to support the delivery of care closer to home
  - h. The need for an overarching framework that provides tumour-specific national leadership and local, service-delivery related leadership and balances the tensions of a generalist workforce to improve access with sub-specialist expertise
  - i. Incorporation of research within SACT services
2. To support care closer to home, there will need to be further development of key components to support care in the community. This includes consideration of:
    - a. Expected resource, staffing and supporting infrastructure required across different service delivery levels
    - b. Roles and responsibilities of key staff across sites (including assigned leadership roles)
    - c. How services are linked, networked and their coordination frameworks/mechanisms (including organisational, structural and technological e.g. e-prescribing, telehealth, electronic medical record)
    - d. Workforce development and training requirements to facilitate community SACT care
    - e. Development of kaupapa Māori approaches to service delivery design.
  3. Consideration is given to novel formulations of SACT that support administration in primary care, the community or self-administration to further reduce the burden of travel on patients and whanau, as well as reducing demand on outpatient and inpatient cancer services.
  4. To ensure equitable implementation, wrap-around services would be required to provide additional support to those who need them, for example additional support for patients with other chronic conditions or disabilities. This is discussed further in Section 1: Coordination and Support Services.



## HSCT service delivery and distribution

A proactive, nationally cohesive approach to service design and distribution is needed to improve access to high quality HSCT services. This is needed to improve access in the immediate term, as well as setting a more sustainable course for the future. Given the relatively small numbers of service providers, HSCT services are highly amendable to national planning and coordination.

1. A national service model for HSCT would leverage the inherent opportunities of scale and integration within a decentralised service delivery model, enabling patients and whānau to benefit from a more cohesive, standardised and nationally monitored system of clinical care. This would enable:
  - a. Fair and timely access to treatment regardless of where people live - through better service planning, coordinated service delivery and national monitoring.
  - b. Services to be sustainable through more cohesive investment strategies and dependable roadmaps to infrastructure and workforce development, as well as the ability to activate national service continuance plans for unexpected challenges.
  - c. People to have more confidence in their treatment journey due to improved flow of information within, across and between services
  - d. Consideration to be given to model of care for HSCT that enable aspects of care to be given outside the hospital.
2. Initial steps would be to design and understand the implications of a nationally configured HSCT service, including implications for Clinical Haematology Services in the broader sense.

## Workforce

### Capacity

Te Aho o Te Kahu to work alongside Health Workforce to grow and maintain the SACT and HSCT workforce, including robust planning to meet future increase in demand.

1. Immediate workforce planning focuses on filling vacancies and short-term constraints, particularly in nursing.
2. Workforce planning should be considered alongside the development of new models of care to ensure there is appropriate workforce capacity and capability to align with changes to models of care and future needs of the cancer workforce. This includes working with training institutions to consider opportunities to expand the role of some SACT and HSCT staff such as:
  - a. Specialist SACT and HSCT training for nurses and pharmacists;
  - b. Develop scope of other health professionals e.g. community pharmacists;
  - c. develop scope of primary care with provision of clear treatment/surveillance guidelines



3. High quality, accurate workforce data are required to support planning. This includes accurate data on FTE as well as ensuring workload calculations include all aspects of care provision (including coordinating patient care between services) to ensure planning and staffing is adequate.
4. Adequate administrator/data entry staff are employed to enable all clinical staff to work to top of scope.
5. When procuring and contracting for laboratory services, specific consideration is given to training capacity and allowances within pathology and laboratory service providers to support the training of haematologists. This is discussed further in Section 6: Laboratory Services.

### Diversity

1. Te Aho o Te Kahu to work with the Māori Health Authority | Te Aka Whai Ora, Health New Zealand | Te Whatu Ora, Health Workforce, the Ministry of Health | Manatū Hauora, training institutions and other partners, including Māori leaders, to enable the SACT and HSCT workforce to better reflect the population of Aotearoa. This includes strategic planning to increase the number of Māori and Pacific in all levels of the SACT/HSCT team including haematologists, medical oncologists, chemotherapy trained nurses, CNSs and pharmacists.

### Cultural safety

1. Te Aho o Te Kahu to work with the Māori Health Authority | Te Aka Whai Ora, Health New Zealand | Te Whatu Ora, the Ministry of Health | Manatū Hauora, training institutions and other partners, including Māori leaders, to develop processes to support, increase, and measure the cultural safety of the SACT and HSCT workforce. This includes specific consideration for the needs of staff who have trained internationally.



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# WĀHI 5: HAUORA HAUMI

## SECTION 5: ALLIED HEALTH

### He kupu whakarāpopoto

### Summary

#### Case for change

Cancer allied health provides essential care and support services that help facilitate access to cancer treatment, minimise morbidity from cancer treatment and maximise quality of life before, during and after cancer treatment.

As the number of people diagnosed with cancer, who live longer with cancer and whose survival with cancer increases, the role of cancer allied health becomes even more critical to manage both short- and long-term consequences of treatment.

There are currently multiple issues with the provision of allied health service in Aotearoa, which results in cancer allied health services being fragmented, complex, inconsistent, and difficult to access. This contributes to significant inequities in cancer outcomes and experiences for different groups of patients and whānau.

#### Proposal for change

Ensuring that cancer allied health is recognised as an essential component of cancer care will provide benefits to patients and whānau, will improve cancer experience and outcomes and will contribute to the reduction of cancer inequities.

Improving cancer allied health in Aotearoa will require services to be funded and prioritised as a critical component of cancer treatment, care and support. Coordinated work is needed to ensure cancer allied health is planned, distributed and organised to meet the needs of patients and whānau, so that all patients and whānau have access to the allied health services they need during their cancer pathway.



Focused work is required to ensure that the cancer allied health workforce is strengthened and appropriately recognised, alongside work to develop, collect and utilise cancer allied health data.

## What would be different for patients and whānau?

- Patients and whānau will have greater access to allied health that meets their cancer treatment and rehabilitation needs across the cancer continuum.
- Patients and whānau will have access to clear information about the cancer allied health services available to them in community and hospital settings.
- Patients and whānau will receive the allied health support they need across different settings.



# Te tiro whānui

## Scope

This section focuses on allied health services in cancer care. Whilst the focus of this report is on the treatment phase of the cancer care pathway, the allied health findings in this section are relevant to the contribution of allied health before, during and after cancer treatment. Allied health includes services provided in hospital and in the community.

For the purposes of this report cancer allied health includes care delivered by professions such as occupational therapists and social workers who may be traditionally defined as allied health practitioners, and services and care that may be delivered by a range of practitioners such as lymphoedema therapy, which may be delivered by nurse specialists, physiotherapists, prosthetists and occupational therapists. Whilst dentistry is not usually included as an allied health service, for the purpose of this work, dentistry services are included as they are allied to cancer treatment and are important to include when discussing cancer care.

# He kupu whakataki

## Introduction

Allied Health professionals are a diverse group of qualified practitioners with expertise in the prevention, diagnosis, treatment and support of a range of health conditions and illnesses across health care settings. Allied health practitioners work collaboratively and in multidisciplinary teams and bring a breadth of scope and a range of models of care to health care.

In Aotearoa, allied health includes over 40 different professions who are not part of the medical or nursing professions (399). Each allied health profession has its own distinct specialised body of knowledge and skills and is regulated through the Health Practitioners Competency Act (2003) (eg physiotherapy, psychology, dietetics), the Social Workers Registration Act (2003) or self-regulated through a professional body (eg New Zealand Speech Language Therapists Association) (399, 400).

Allied health services are an essential component of cancer care and provide a critical role in improving cancer outcomes. They play a unique role in providing interventions and support that helps facilitate access to cancer treatment such as social work intervention to enable patients and whānau to attend treatment appointments or prehabilitation to improve functional capacity to receive treatment.



Allied health services also work to minimise morbidity from the cancer diagnosis and treatment, and to maximise quality of life before, during and after cancer treatment such as lymphoedema therapy to prevent or minimise lymphoedema and rehabilitation to improve physical conditioning and functioning. Allied health services form an essential part of the palliative care team and are well placed to support patients and whānau during their journeys with a life-limiting illness.

Some allied health professionals are also critically involved in the delivery of cancer treatment (eg pharmacists, radiation therapists) or other clinical services required to provide cancer diagnosis, treatment and care (eg laboratory scientists, medical radiation technologists). These specific services and the workforce who deliver this care are discussed in the sections aligning with that treatment modality.

The World Health Organization has identified that unaddressed psychosocial distress, malnutrition and poor functional status impact on the accessibility of cancer treatment, the tolerance and ability to complete treatment and recovery from treatment (401). Allied health services have an important role in addressing these issues, therefore providing comprehensive, planned and funded allied health care is critical for optimal cancer care (402). Cancer allied health interventions provide benefits at multiple levels; they can benefit individual patients and whānau, improve the effectiveness of medical interventions, and can prevent avoidable ill health which benefits the overall health system (403, 404).

A recent NZEIR (2021) report noted that the allied health workforce represents the '*greatest opportunity for transformational change*' and that lack of integration into the primary and secondary care service would inhibit the ability to address, '*quality, equity, efficiency, and sustainability*' issues in the health and disability system (400). It noted that the core skills of allied health professionals were well aligned to improve health outcomes for Māori and other population groups. The report recommended greater integration of allied health services into Tier 1 care delivery and increasing scope of practice of allied care workers.



The morbidity associated with a cancer diagnosis and treatment can be significant, encompassing multiple domains of life (405). Pain, fatigue, lymphoedema, anxiety, depression, fear of recurrence and relationship disruption are frequently reported following a cancer diagnosis and treatment (405). Allied health services are well placed to provide interventions to address these effects, in the short and long term, to reduce the burden on patients, whānau and the health system.

The importance of allied health interventions in health care as well as in cancer care has previously been acknowledged in a number of reports, frameworks and guidance documents in Aotearoa (4, 24, 399, 400, 406-408). This section builds on this previous work by focusing specifically on the context, challenges and recommendation for the design of cancer allied health care in Aotearoa.



## Service example: Cancer dietitians

Dietitians provide food and nutrition expertise to patients, whānau and other health professionals by translating scientific evidence into practice strategies for people to achieve and maintain health and wellness (409). In cancer care, dietitians provide a range of interventions to minimise nutrition risk, to assist in the tolerance of treatment and to aid in the recovery from treatment. Interventions include nutritional therapy that focuses on managing symptoms, preventing weight loss and maintaining optimal nutritional status.

In Aotearoa, most dietitians meet the criteria to be non-medical prescribers enabling them to prescribe approved nutrition related products (409). Table 7 outlines examples of dietetic interventions in cancer treatment. These interventions can be delivered in different settings depending on the type and location of treatment and where the care is best suited for the patient.

**Table 7 Cancer care dietetic interventions (410)**

<i><b>Cancer treatment type</b></i>	<i><b>Dietetic intervention pre-treatment</b></i>	<i><b>Dietetic intervention during treatment</b></i>	<i><b>Dietetic intervention post treatment</b></i>
Stem cell transplantation *all patients at nutritional risk	Nutritional assessment and care plan	Ongoing assessment, nutritional support & advice, prescription	Support to return to optimal weight, advice to minimise infection risk from foods, safe food handling, strategies for weight maintenance
Surgery *some cancer types have increased nutritional risk *some procedures have increased nutritional risk	Malnutrition assessment and intervention, care plan for specific surgical procedures e.g. head and neck, gastrointestinal tract	Ongoing assessment, nutritional support & advice, prescription	Education and support for special diets, support to return to optimal weight, strategies for weight maintenance
Radiation Therapy *some cancer types have increased nutritional risk	Malnutrition assessment and intervention, care plan for specific cancer types e.g. head and neck, gastrointestinal tract, thorax	Ongoing assessment, nutritional support & advice, prescription	Education and support for special diets, support to return to optimal weight, strategies for weight maintenance
Chemotherapy *some patients at nutritional risk	Malnutrition assessment and intervention	Ongoing assessment, nutritional support & advice, prescription	Education and support for special diets, support to return to optimal weight, strategies for weight maintenance
Dieticians also play a critical role in palliative care, when the nutritional goals should be aligned with palliative care goals. Palliative care dietetic interventions can include reviewing rationale for previous dietary restrictions (with restrictions liberalised where possible), education and support and establishment of food for comfort feeding.			



# **Tō āianeī āhua mō ngā ratonga hauora haumi i Aotearoa**

## **Current state of cancer allied health services in Aotearoa**

Cancer allied health services vary in their structure, location, funding and workforce. Cancer allied health services are provided by a wide range of providers across primary and community care, hospital-based care, not-for-profit organisations and in private practice. Cancer allied health care may be provided by generalist allied health professionals (eg hospital social workers) or by allied health professionals with skills specific to cancer (eg cancer rehabilitation physiotherapists).

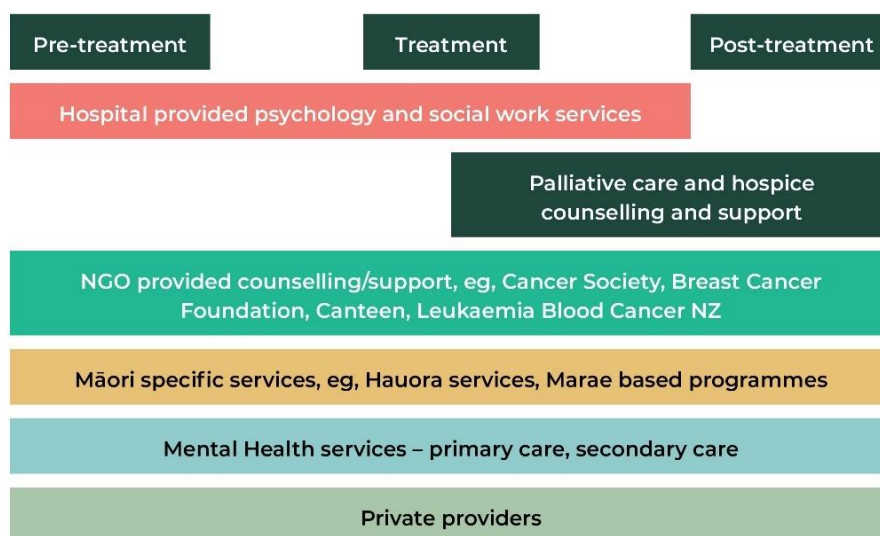
Given the diversity of allied health it is difficult to provide a comprehensive picture of how all services are currently delivered in Aotearoa. This section outlines three examples of cancer allied health services and outlines how services are provided.

### **Service example: Cancer Psychosocial Support Services**

There are several providers of cancer psychosocial support, with each service having different eligibility criteria, funding arrangements, capacity, referral systems and processes. Figure 20 outlines the psychological support providers available during and after cancer treatment.



Figure 20: Psychological support providers during cancer treatment



The Cancer Psychological & Social Support Initiative funded social work and psychology positions for all 20 DHBs in 2015 to provide psychosocial support for people with high and complex needs during cancer treatment. An evaluation of the Initiative found that it provides vital care and produces significant positive outcomes (408).

*“This (service) has literally saved my life. I wouldn’t have been able to have my treatment without it”*

*“I really believe he (husband) would have been dead by now without this service. Treatment and chemo and all that medical stuff is necessary, but it was this service that made him well.”*

Some cancer and palliative care not-for-profit organisations provide counselling and support for patients and whānau during and after treatment. There are a variety of ways in which these services are delivered. For example, the Cancer Society Auckland division employs a team of psychologists and the Breast Cancer Foundation contract a counselling provider to deliver 3 counselling sessions for people affected by breast cancer.

Specific Māori cancer psychosocial support services are available in some areas. For example, the Cancer Society provides the Kia ora - E te iwi programme in some divisions, and the Mana Wāhine - Te Mauri programme, which is a Marae based programme supported by Māori health providers in the Wellington region.

Mental health services are available in primary care via the Integrated Primary Mental Health and Addictions service for mild to moderate mental health and wellbeing needs and support, and in secondary care for moderate to severe mental health and addiction needs. Hospices also provide psychological support for patients and whānau through a range of therapies including counselling, art/music therapy, complementary therapies, relaxation and education. These services are not specific to cancer.





Private counselling and psychology providers are available throughout Aotearoa, with some specialising in cancer support. Some medical insurance policies will cover some of the costs of these services, but not all.

### Service example:

#### Prehabilitation/rehabilitation/physical therapy

There are several different providers of prehabilitation, rehabilitation, exercise and physical therapy across Aotearoa. Each service has their own referral and eligibility criteria, funding arrangements and some may or may not have cancer specific expertise. Services may differ by region.

Hospital based physiotherapy can include pre-surgical assessment and intervention for some procedures in some DHBs; however, provision of prehabilitation services varies across Aotearoa. Inpatient physiotherapy is provided for acute needs and outpatient physiotherapy is available for specific needs and conditions.

Community and not-for-profit organisations provide cancer prehabilitation and rehabilitation programmes in many locations throughout Aotearoa. For example, Pinc & Steel Charitable Trust provide programmes and funding support for patients and training, certification and networking for rehabilitation practitioners. The Breast Cancer Foundation and the Prostate Cancer Foundation provide funding support for rehabilitation programmes; however, in some places patients are required to pay a surcharge. Tū Tonu, based in Hamilton, is a kaupapa Māori health organisation that specialises in rehabilitation and provides cancer rehabilitation programmes.

Private physiotherapists and exercise physiologists are available throughout Aotearoa, with some specialising in cancer prehabilitation and rehabilitation.

### Service example: Northern Region Head and Neck Cancer Service

The Northern Region Head and Neck Cancer Service was reviewed in 2017 and resulted in service configuration and provision of care recommendations that included allied health care. Using international best practice and the New Zealand provisional head and neck cancer standards of care, referral triggers to allied health services and patient pathways were defined (411).



**Figure 21:** examples of Northern Regional Head and Neck Allied Health patient journey (412)





# Ngā wero o āianeī mō ngā ratonga hauora haumi

## Current challenges in cancer allied health

This section of the report combines information from stakeholder interviews and published literature on the current challenges with allied health services in Aotearoa. These challenges create significant inequity in the access to, quality of, and outcomes from allied health services.

Allied health services face a number of challenges. In 2019, the Ministry of Health | Manatū Hauora Chief Allied Health Professions Office outlined five challenges for allied health to inform the direction of the Ministry of Health and the sector (399):

1. To articulate the position of allied health within the New Zealand context locally, nationally and internationally
2. To ensure that allied health is able to articulate its role to be more useful to services that are aligned to meeting population health needs
3. To support allied health in providing accessible services that are equitable across the population and meet consistent outcome standards
4. To work with key stakeholders on the supply of allied health professions to meet the changing demands on services in the health and disability system
5. To work with key stakeholders on developing efficient models of care, advanced scopes of practice and transdisciplinary models of service delivery

There are multiple specific challenges in cancer allied health that are aligned with the five general allied health challenges described above. These challenges result in fragmented, complex, inconsistent and difficult to access care that may contribute to inequities in cancer outcomes and experiences. There are specific challenges for each cancer allied health discipline and service as well as challenges that apply across all cancer allied health disciplines and services.



## Lack of recognition and funding

***Allied health services are often considered 'nice to have', rather than critical components of cancer care and as a result are often underfunded***

The importance and impact of allied health is often unrecognised within cancer care, with allied health services not always recognised as a core part of cancer treatment services (413, 414). Many cancer-specific allied health services, particularly those provided by community providers, are not always visible to all cancer care providers, which contributes to a lack of understanding of the value and contribution that allied health brings to cancer treatment and rehabilitation.

Many community-based allied health services are not publicly funded and so require funding from not-for-profit organisations, health insurance or require patient self-funding. Many cancer-specific allied health functions end up being provided by not-for-profit organisations because of a lack of funding in the public sector. For example, not-for-profit organisations provide lymphoedema therapy in some regions because the service is not funded by the DHB.

Currently, cancer allied health services provided by DHBs are frequently at capacity due to a lack of resourcing, with referral volumes exceeding available resourcing in many areas. Stakeholders noted that eligibility criteria for cancer allied health services may reflect capacity rather than patient and whānau needs. This will become an increasing problem as the number of people being diagnosed with, and surviving, cancer increases and the need for allied health support during survivorship increases.

***There is a lack of robust data on allied health***

Comprehensive data on allied health services in Aotearoa are extremely limited. There are no cancer-specific allied health datasets and no dataset that include primary, community and hospital service data. This means that having a comprehensive picture of clinical interventions, service provisions and outcome is extremely difficult. There is also limited allied health workforce data available, particularly for those who are not regulated by the Health Practitioners Competence Assurance Act 2003 and are not required to hold an annual practising certificate. The lack of robust data make workforce forecasting and planning extremely difficult.



## Availability of services

### *There is wide variation in the provision of cancer allied health services across Aotearoa*

The availability of cancer allied health services varies depending on where you live in Aotearoa, with decisions about what allied health services are funded for people with cancer made, to date, by individual DHBs. For example, some DHBs provide fully funded lymphoedema therapy and others do not, and some regions have access to funded specialist hospital dental services during specific cancer treatments and others do not.

Whilst some cancer allied health services are fully funded in the public sector, others are only funded for specific points on the cancer care pathway. For example, hospital-based cancer psychology services are funded during active cancer treatment but not available once treatment is completed. The lack of coverage across the cancer continuum was recognised in the evaluation of the Cancer Psychological & Social Support Initiative (408). Inequitable provision of, and lack of funding for, palliative care allied health services also leads to differing services offered in different geographical regions across the country.

Similarly, cancer allied health services may be provided for only certain cancer types. For example, a dietitian may provide care to people receiving treatment for head and neck cancer but not to people receiving hospital-based treatment for other types of cancer.

In many parts of the country, allied health interventions that can provide significant benefits to people receiving cancer treatment are not routinely provided. For example, the provision of prehabilitation varies across the country. In some hospitals there is a systematic way of identifying patients who would benefit from some form of prehabilitation – often through anaesthetic pre-assessment clinic – with those meeting set criteria referred for a nutrition or physiotherapy assessment. In other regions there is no formal system for prehabilitation services, and ad-hoc arrangements – often relying on personal relationships – have developed. Many regions across Aotearoa report that most the patients that would benefit from prehabilitation and pre-operative optimisation are not getting it (this is discussed further in Section 2: Cancer Surgical Services).

As well as allied health services, stakeholders also noted difficulty accessing allied health equipment when required. DHBs will provide functional equipment on short term loans to cancer patients, but this is often for a maximum of 12 weeks and, in some cases, patients are not eligible for this equipment until they are deemed palliative.



## Referral pathways and service integration

### *Allied health services are not always integrated into services and care pathways*

Referral pathways to cancer allied health services are inconsistent, which can make services difficult to access. Some cancer treatment centres have clear referral and care pathways for certain allied health services, whereas in others areas it will depend on individual cancer treatment specialists assessing the need for an intervention and making referrals if care is available (415). Allied health services are often not included in clinical pathways and pathways do not always include services across all health settings, reducing the visibility of community-based services in particular (400).

*“Why do we continually have to ask to find out what is available?”* Community Hui participant, 2021

The lack of referral pathways often leads to a reliance on patients and whānau to identify and self-report needs, advocate for a referral or self-refer to cancer allied health services. However, this is made more difficult due to a lack of clear, patient facing information about what cancer allied health services are available and to how to access them.

*“I had to do all the work to reach out for support.”* Community Hui participant, 2021

Allied health services can be fragmented and uncoordinated, both within their own sector and within cancer care. There is also often a disconnection between allied health services and other parts of the treatment team, with allied health involvement in cancer MDMs hugely variable across Aotearoa and between cancer types.





## Workforce

*The cancer allied health workforce is not always appropriately recognised, not representative of the population and there are insufficient workforce numbers to meet current need*

Despite allied health being the second largest clinical workforce employed by DHBs there is a lack of robust workforce data, which makes it a challenge to get a comprehensive picture of the workforce (400). However, stakeholder interviews identified several issues currently facing the allied health workforce.

There is a balance between general and specialised cancer allied health, with some allied health practitioners specialising in caring for cancer patients and others with all population groups. Generalist allied health practitioners do not always have access to the resources needed (information, training, equipment, access to subject matter experts) to treat cancer patients in the most effective way. This creates inequities based on the type of allied health practitioner the patient is able to see and also potentially creates the risk of doing unintentional harm.

There are currently not enough cancer allied health positions to meet the needs of the population; however, there is also a recognition that if new positions were created to meet the needs of the population, there wouldn't be enough workforce to fill all positions. There are currently staff shortages across a range of allied health professions; however, the lack of nationally available data makes quantifying and systematically planning for staffing requirements challenging.

Allied health faces similar challenges to other parts of the health workforce, with the current workforce not reflecting the diversity of the New Zealand population. Recent reports suggest only 6% of DHB allied health and scientific staff are Māori (26). This is seen across several different allied health professions, for example of the 3,602 occupational therapists registered in 2021, 198 were Māori (5%) and 74 Pacific (2%)(416). A similar picture is seen with the dietician workforce, with 4% identifying as Māori and 1% as Pacific (417). Several allied health workforces are also very female dominated, with 92% of occupational therapists and 95% dieticians being female (416, 417).





## Acceptability of services

### *Services are not always appropriate for patients and whānau*

Many allied health services utilise western views of health and wellness and do not include the health and wellness of whānau (418). For example, hospital provided cancer psychosocial support services are often not able to provide care for whānau members, which can be a barrier for patient care and support. Specific programmes that support whānau Māori are not consistently funded publicly and are only available in some places.

A common theme during the Community Hui was that services were focused on the cancer diagnosis, not the person and their wellness.

*“Shift the focus to the patient, not the illness.”* Community Hui participant, 2021

*“The tumour’s not the patient, I’m the patient.”* Community Hui participant, 2021

Often allied health services and the service delivery model are focused on the tumour rather than the person, with services not always culturally acceptable or appropriate. Some services are better designed to ensure services are acceptable, for example allied health practitioners are an essential part of palliative care teams and work towards ensuring holistic care is provided.



# Tō āianeī mana taurite kore

## Inequity in the current state

All of the challenges described above collectively create inequity in access, quality and outcomes for Māori and Pacific peoples compared to non-Māori, non-Pacific, as well as inequity in care based on where people live.

High quality, comprehensive data regarding access to allied health services is not currently collected at a national level, including data that can be analysed according to population groups known to experience disparities in cancer outcomes. This can create challenges when assessing equitable access to services and outcomes for different populations groups.

However, the current provision of allied health services and challenges these services face are likely to not only create equity issues related to cancer allied health, but also contribute to inequities in cancer outcomes. Patients and whānau experience inconsistent access to allied health services, as services may not be available locally, or may be inaccessible due to the cost of the service or the cost of travelling to a service (24, 407). This is likely to disproportionately impact Māori, rural patients and those with limited financial resources.

In many cases services are solely for the patient, rather than patient and whānau (85). This disproportionately affects Māori and Pacific peoples who prefer holistic health models such as Te Whare Tapa Whā and Fonofale (419).

The fragmented and uncoordinated nature of cancer-specific allied health services also creates inequities. The lack of consistent referral pathways means that patients and whānau often have to advocate to receive services. This can create significant barriers to access and disproportionately affect patients and whānau with limited health literacy and agency.

The lack of Māori in the allied health workforce is also an equity issue (420). Having a strong Māori workforce is crucial in reducing health inequities (421, 422). Growing the Māori allied health workforce and providing Māori leadership capacity and capability will contribute significantly to reducing inequities (423).

*A detailed equity analysis of how each of the challenges with the current system contributes to inequity in access, quality and outcome, and alignment to focus areas is included in **Appendix VI**.*



# Taunakitanga hei whakatutuki wero

## Evidence of ways to address challenges

As described earlier, in Aotearoa allied health includes over 40 different groups of professions. Internationally the definition of allied health and the services which are included in cancer allied health varies but allied health services are also included under umbrella terms such as 'supportive care', 'cancer rehabilitation', 'palliative care', 'survivorship services', and 'personalised cancer care'.

Emerging evidence supports specific allied health led interventions in the management of cancer symptoms and treatment side effects. For example, exercise is effective in the reduction of cancer related fatigue (424), and cognitive behavioural interventions are effective in the reduction of nausea and vomiting and in the management of anxiety in breast cancer (425).

Numerous studies have highlighted a high proportion of people affected by cancer with unmet needs including psychosocial (eg anxiety, low mood), physical (eg fatigue, pain) as well as daily living needs such as mobility (402, 405, 426, 427). Cancer allied health service are important in addressing these unmet needs (404, 406, 428).

## Cancer prehabilitation

Prehabilitation is the process of improving the functioning capacity of a patient prior to cancer treatment so they can better withstand the physiological effects of their treatment. Ideally, prehabilitation has four components: medical optimisation, nutritional support, physical exercise, and psychological support (429). Prehabilitation interventions can be used to decrease morbidity, improve physical and psychological function and wellbeing, increase tolerance and resilience to the effects of cancer treatments, improve access to treatments, decrease hospital readmissions and reduce direct and indirect health care costs attributed to cancer (430).



Prehabilitation is increasingly becoming a key part of cancer care guidelines and pathways. For example, the European Society of Thoracic Surgery recommends that lung cancer surgical candidates be referred for pre-operative and perioperative fitness programmes (431). The Australian Optimal Care Pathways include referral for prehabilitation for a number of different cancer types (432). In the UK, Macmillan Cancer Support recommend that prehabilitation be incorporated into routine cancer care and as early as possible to maximise the potential benefits.

## Cancer rehabilitation

Cancer rehabilitation includes exercise rehabilitation and multidisciplinary rehabilitation. Cancer patients who are more physically active have a reduced risk of mortality and reduced risk of cancer recurrence, with exercise therapy effective in improving cardiorespiratory fitness for people with cancer (433, 434). Exercise can also have a positive impact on the management of cancer and treatment symptoms such as fatigue (435).

The UK takes a multidisciplinary approach to cancer care with a range of allied health services and disciplines (eg physiotherapy, occupational therapy, dietetics, psychology) providing rehabilitation interventions through and beyond cancer treatment. Evidence suggests that these rehabilitation programmes improve quality of life and can prevent avoidable ill health, which can also reduce hospital bed days and readmissions (404).

Australia and Canada offer rehabilitation programmes in some public health settings as well as in community and private settings. However, despite referral to rehabilitation service being considered best practice, this has not been incorporated into usual cancer care (436). A number of barriers to the development and implementation of cancer rehabilitation programmes as standard cancer care have been reported in the literature. These include a misconception that rehabilitation is additional and not integral to patient care, a lack of funding and resources, poor awareness of the benefits of rehabilitation, care pathways not explicitly including cancer rehabilitation and a lack of specialist cancer allied health professionals (404, 413, 437-439).



## Cancer survivorship

“An individual is considered a cancer survivor from the time of diagnosis through the balance of his or her life” (427). Survivorship includes those on a curative or non-curative pathway as well as their whānau and others affected by cancer (440). The US Institute of Medicine includes four essential components of survivorship care (427, 441):

- 1) Prevention of recurrence and of new cancers, and late effects
- 2) Surveillance for cancer-spread, recurrence or secondary cancers; assessment of medical, physical and psychosocial acute and late effects
- 3) Intervention for consequences of cancer and its treatment such as lymphoedema and sexual dysfunction, pain and fatigue, psychological distress, disabilities of function and daily living, and concerns related to social participation including employment
- 4) Coordination between specialists and primary care providers to ensure that all of the survivors’ health needs are met.

Whilst survivorship care is much broader than allied health care, allied health services play a vital role in each of these components, in particular symptom management, preventative care and addressing late effects. However, often post treatment care remains focussed on medical care rather than on quality of life and optimising outcomes (427).

Many countries have developed consensus and evidence based survivorship care guidelines, including Aotearoa (440), Clinical Oncology Society of Australia (COSA) (427), American Society of Clinical Oncology (ASCO) and the National Comprehensive Cancer Network (NCCN) (442). International models of survivorship care often include personalised care that is collaborative, planned and coordinated. Guidelines highlight the need for care that is integrated across the sector including specialist services, primary and community care with services stratified depending on assessed risks and needs. However, the translation of statements and guidelines into practice varies internationally and the implementation of these, the quality of care and current state is hard to measure (441).

A variety of different strategies have been implemented in the UK to improve survivorship services, including personalised care plans, stratified care pathways, and cancer quality of life surveys (402). A number of important considerations have been reported in the implementation of survivorship care, including the importance of data collection. Measuring cancer survivors’ needs and unmet needs underpins the design of care pathways and services, the development of appropriate patient information and the ability to focus on improving quality of life and outcomes (402).



## Palliative care

Allied health professionals are a critical part of the palliative care team and bring a broad range of knowledge and interventions that can improve the quality of life for people with a life-limiting diagnosis (443). Allied health involvement in palliative care teams can support cancer patients to maintain function, wellbeing and quality of life, and enable patients to stay within their own homes for longer (444).

Internationally, many guidelines and pathways recommend the inclusion of allied health in palliative care for cancer patients, but similarly to guidelines on survivorship, there is often inadequate data to assess how well these recommendations are being put into practice (443).

While the role of allied health professionals in palliative care is well recognised internationally, inclusion in undergraduate training and opportunities for professional development and upskilling is often lacking (443-445). This can lead to allied health professionals feeling unprepared to work in palliative care, and highlights the need for accessible training and development for allied health professionals (446).

## Care plan and pathways

Allied health services, care and interventions feature in a number of international cancer care guides and pathways.

- National Institute for Health and Care Excellence (NICE) guidelines refer to allied health services in a range of cancer types pathways, e.g. non-drug interventions for breathlessness in lung cancer (physiotherapy or occupational therapy), and the guidance for improving supportive and palliative care for adults with cancer (447, 448)
- National Comprehensive Cancer Network (NCCN) e.g. NCCN guideline Head and Neck – multidisciplinary team (449)
- Optimal care pathways (Australia) a whole of pathways approach from prevention to end of life, with government endorsement and implementation for a number of different cancer types (436)



These guidelines and pathways recognise the value and importance of cancer allied health care; however, it is unclear the extent to which these guidelines and pathways are followed in clinical care, in particular with the provision of allied health care.

Including cancer allied services in care pathways is important for patients and whānau to receive best care and support. Pathways allow for appropriate referral to services that are both hospital and community based. Pathways also enable service delivery to be nationally consistent and assist in the planning for future care and service development.

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# He tāpae hei panoni

## Proposal for change

Allied health input is an essential component in cancer care. Cancer allied health provides a significant contribution to cancer outcomes and experiences, by:

- facilitating access to treatment e.g. prehabilitation, social work interventions
- minimising morbidity from the cancer diagnosis and treatment e.g. nutritional support, dental therapy and psychosocial support
- maximising quality of life during and after cancer treatment e.g. lymphoedema therapy, rehabilitation, palliative care

Ensuring that cancer allied health is recognised as an essential component of cancer care will provide benefits to patients and whānau, will improve cancer experience and outcomes and will contribute to the reduction of cancer inequities.

The following focus areas are designed to improve the access, consistency, equity, and quality of cancer allied health in Aotearoa. Cancer allied health is a part of broader allied health services and therefore it is important for Te Aho o Te Kahu to work alongside the Ministry of Health | Manatū Hauora, Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora to implement change.

## Ngā wāhi hei mahi | Potential focus areas

### System leadership

#### National system leadership

1. Te Aho o Te Kahu to ensure that national cancer leadership structures for cancer include allied health expertise.
2. Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora and Māori Health Authority | Te Aka Whai Ora to ensure that cancer allied health is included and considered in decisions about cancer services, including distribution, workforce planning and cancer treatment pathways.
3. Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora to identify unmet cancer allied health needs to plan for future service development, provision and improvement.
  - Identify cancer allied health service gaps in both hospital-based and community-based settings, across the continuum of care.





4. Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora to support cancer allied health services across the sector to participate in quality assurance activities to ensure high quality, consistent care, with Te Aho o Te Kahu monitoring the quality and equity of services through the ongoing quality performance programme.

#### Data driven

1. Te Aho o Te Kahu to work with the Ministry of Health | Manatū Hauora, Health New Zealand | Te Whatu Ora and Māori Health Authority | Te Aka Whai Ora to prioritise the development, collection and utilisation of cancer allied health data, including workforce, service utilisation and clinical data. Once developed and collected, this data can be included in the Cancer Information Plan.
2. Te Aho o Te Kahu to undertake further work into measuring survivorship needs and unmet needs to assist in future care planning.

#### Clinical service distribution

1. Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora to ensure cancer allied health requirements are included in decisions around the distribution of cancer services.
2. Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora to include allied health requirements into cancer clinical and patient pathways for each cancer type. The following will be included in the care pathways:
  - Hospital-based and community-based allied health services
  - Survivorship/follow up care
  - Palliative and end of life care
  - Prehabilitation and rehabilitation programmes
3. Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora and Māori Health Authority | Te Aka Whai Ora to support non-acute, community cancer allied health to be delivered as close to home as possible.
4. Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora to make cancer allied health services accessible by implementing telehealth initiatives and by providing appropriate transport and accommodation support for those who are unable to receive care close to home.
5. Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora to ensure that national planning around multidisciplinary team meetings include consideration of allied health input.
6. Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora to ensure appropriate cancer allied health support is available to whānau e.g. psychosocial support services.



## Workforce

1. Te Aho o Te Kahu to support Health Workforce to identify and quantify the cancer allied health workforce to enable effective workforce planning and monitoring.
2. Te Aho o Te Kahu to provide cancer specific advice to Health Workforce, Health New Zealand | Te Whatu Ora, the Māori Health Authority | Te Aka Whai Ora and training providers to:
  - a. Help define cancer allied health career frameworks, training guidance and workforce development, with a focus on supporting the growth of Māori and Pacific allied health services.
  - b. Include allied health practitioners in work to support, increase and measure the cultural safety of the cancer workforce
  - c. Support the creation of specialist cancer roles in allied health and advanced scope of practice.



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# WĀHI 6: NGĀ RATONGA MĀTAI MĀUIUI, TAIWHANGA SECTION 6: PATHOLOGY AND LABORATORY SERVICES

## He kupu whakarāpopoto Summary

### Case for change

Pathology and laboratory services are critical to any health system, including to a consistent and modern cancer care system. In Aotearoa these services are unnecessarily fragmented and inconsistently delivered in the cancer treatment setting. Planning and investment decisions are largely reactive. This leads to variation in access across the country, missed opportunities for introducing new technologies and challenges in addressing health inequities for cancer.

### Proposal for change

The health reforms provide a unique opportunity to build a national leadership structure for pathology and laboratory services. This leadership structure would be consistent with the principles of Te Tiriti o Waitangi, and enable a strategic, proactive, forward-focussed approach. Other countries with similar approaches to health care have acknowledged the need for national leadership for laboratory and pathology services and implemented changes accordingly. This means that Aotearoa can learn from these experiences.

Whilst not specific to cancer, a nationally coordinated pathology and laboratory network would enable consistent and modern cancer care to be delivered. Without well-functioning pathology and laboratory services, the other recommendations made in this report are unlikely to deliver the objectives of improved cancer treatment for New Zealanders.



As the national leaders for cancer control, Te Aho o Te Kahu is not in a position to provide the infrastructure for the leadership of a sector that plays such a critical role across the entire health system. However, Te Aho o Te Kahu welcomes the opportunity to work with the Ministry of Health | Manatū Hauora, Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora to provide cancer-related subject matter expertise in the development, implementation and maintenance of a national pathology and laboratory strategy, leadership function and network.

## What would be different for patients and whānau?

- Patients will have access to the same quality and up to date pathology and laboratory services regardless of who they are or where they live in Aotearoa.
- Both patients and their treating clinicians will have access to pathology and laboratory information and test results in the right way and at the right time to enable shared treatment decision-making.
- When patients interact directly with pathology and laboratory services, these will be accessible and culturally safe.



# Te tiro whānui

## Scope

This report provides a summary of the current state and key changes required to improve cancer *treatment* services in Aotearoa. Pathology and laboratory services do not generally administer treatments to patients, but the diagnostic information and expertise they provide are fundamental to cancer treatment decisions. An important exception to this is haematologists, one subgroup of pathologists, some of whom are also dual trained as clinical haematologists who work with patients to make treatment decisions. Malignant haematology treatment is covered in the systemic anti-cancer therapies and stem cell transplant section of this report.

The focus of this section of the report is on laboratory and pathology services that inform treatment decisions and monitoring of treatment response. Pathology and laboratory services are critical across the entirety of the cancer control spectrum including in environmental health monitoring, screening programmes, risk assessment, and surveillance. These aspects are out of scope of this report but underscore the importance of a well-functioning laboratory and pathology service to cancer control in Aotearoa. The changes outlined in this section of the report are likely to deliver improvements for cancer control beyond the treatment setting.

The New Zealand Blood Service is also an important provider of laboratory services in the health system, including in the context of blood cancers. However, the Blood Service is out of scope of this work.

Pathology and laboratory services are critical to the overall health care system, far beyond cancer care. For any cancer-specific changes to be implemented, they would need to work within the broader pathology and laboratory system of Aotearoa.



# He kupu whakataki

## Introduction

Pathology and laboratory services are those that conduct tests on blood, tissue and other bodily substances. Scientists and doctors (pathologists and haematologists) working within these services analyse and interpret the results. This work informs health-related decision making from the level of the individual patient through to the population level. Pathology and laboratory services are therefore critical to clinical decision making across all areas of the health sector. The global COVID-19 pandemic has highlighted this (450). It is often quoted that 70% of all diagnoses can only be made because of the work of laboratory and pathology services (451, 452). While this figure is difficult to validate, the critical importance of laboratory and pathology services is clear (453).

However, often these services are “invisible” parts of the patient’s pathway, and perhaps as a result of this become a forgotten part of the healthcare system. This is true for cancer care, as it is for other areas of the health sector (452, 454). Challenges within the pathology and laboratory sector are long-standing and have been identified previously, and yet they persist (455, 456).

A recent analysis of cancer and noncommunicable disease control plans from 157 countries found that pathology and laboratory medicine is included in only 14% of national cancer strategies (457). Stakeholder feedback suggests that pathology and laboratory services appear to be forgotten or ignored in health sector planning, particularly in the early stages. It is important for cancer care that Aotearoa does not repeat this mistake as it fundamentally reforms its health system.





# **Tō āianeī āhua mō ngā ratonga mātai māuiui, taiwhanga i Aotearoa**

## **Current state of pathology and laboratory services in Aotearoa**

How pathology and laboratory services are  
organised and delivered

### System leadership

The Ministry of Health | Manatū Hauora established a National Pathology and Laboratory Round Table in response to the observation that service access for laboratory services in Aotearoa was inconsistent both in terms of the range of services available and the cost of services to consumers (458). The Round Table represents the public and private parts of the sector and is tasked with providing national leadership and independent advice to the Director-General of Health regarding clinical, scientific and strategic aspects of the sector (459).

The Round Table has established a strategic framework for the laboratory and pathology services sector, but this does not appear to have been updated or reviewed since 2014 (452). The Round Table continues to meet on a regular basis, but DHBs and contracted service providers are not accountable to this Round Table. Individual DHBs have developed their own strategies for laboratory and pathology services, while others have developed regional strategies across multiple DHBs (458, 460-462).

### Laboratory and collection centre distribution

Each DHB has access to at least one laboratory within its geographic area, and some DHBs have several laboratories within the area. Some laboratories have more specialised services and equipment than others.

For laboratory tests where a blood (or other body fluid) sample is required, there are collection centres located throughout the country. These are in hospitals, health clinics and other community locations. The community-based collection sites are predominantly operated by private laboratory service providers. There are far more collection sites than there are laboratories. Specimens are transported from collection sites to laboratories using couriers, in some cases a substantial distance away from the patient.



For laboratory tests where tissue specimens are required, the collection often happens in an operating theatre or other specialised units. Surgical services are discussed in more detail in Section 2: Cancer Surgical Services.

## Public and private providers

In Aotearoa, publicly funded pathology and laboratory services are delivered in the community and hospital settings by a mix of public and private service providers (see **Appendix VII**). There are no pathology and laboratory facilities dedicated purely to cancer.

Contracts with private service providers are negotiated and agreed by individual DHBs. The contracts may be set up in a fee for service, or a bulk funding manner (463). There is no national laboratory contract, or a readily available list of contracts. A single private service provider holds contracts with 13 of the 20 DHBs. Some DHBs use only private service providers, while others have a mixed model. West Coast DHB uses public laboratories exclusively.

## Provision of tests

There is no national schedule of laboratory tests. Because individual DHBs contract for pathology and laboratory services, decisions regarding what tests are utilised and the introduction of new tests and technologies happens at a DHB level, or within the business decisions of specific private providers. Individual DHBs decide whether it is the DHB or the patient who pays for access to the test. In 2013 a laboratory tests schedule was developed by DHB Shared Services; however, the schedule has not been updated since (464). Some DHBs continue to use this schedule, whilst others have developed their own (465).

The New Zealand Genetic Health Service is a national service that provides clinical genetics healthcare to individuals and families across Aotearoa. This includes ordering tests for inherited genetic conditions, including cancer conditions. There is only one clinical geneticist who has sub-speciality training in cancer.

## Current state of the pathology and laboratory workforce

The workforce of medical laboratories in Aotearoa generally includes pathologists, medical laboratory scientists and laboratory technicians. Each of these roles is essential in the delivery of pathology and laboratory services. Table 8 presents descriptive statistics of the current pathology and laboratory workforce.



## **Pathologists**

Pathologists are medical specialists whose postgraduate training includes, but is not limited to, the selection of, conduct, use and clinical interpretation of laboratory tests. They may be trained solely in laboratory pathology, or dual trained in laboratory and clinical pathology (452, 466).

The Royal College of Pathologists of Australasia (RCPA) recognises nine different sub-specialised disciplines within the field of pathology. These include anatomical pathology, haematology, and genetic pathology (467). Many pathologists involved in cancer treatment decisions will be from one of these three sub-specialties. In some cases, pathologists within these sub-specialties will further specialise to focus on particular types of cancers.

An RCPA workforce survey in 2016 found that of 288 pathologists in Aotearoa, 152 were anatomical pathologists, 70 haematology pathologists and there were no genetic pathologists (336). Stakeholder feedback indicates that there are now two genetic pathologists in Aotearoa, both employed by a single DHB.

To become a pathologist, a medical doctor must complete advanced training and become a Fellow of the RCPA. Candidates for this fellowship are required to undertake training in more than one teaching laboratory. There is no formal co-ordination of training positions at a national level. Many of the advanced trainee positions are offered by DHB laboratories, and stakeholder feedback indicates that public funding for training positions within private laboratories is inconsistent.

## **Medical laboratory scientists**

Medical laboratory scientists (MLS) are generally university-trained scientists. They conduct, analyse and interpret laboratory tests, and may work with clinicians to directly contribute to patient treatment decisions. In general, these scientists have completed a four-year Bachelor degree in Medical Laboratory Science (BMLSc). Some medical laboratory scientists will have completed postgraduate training as well. Medical laboratory scientists must be registered with the Medical Sciences Council of New Zealand. In order to achieve this registration, an MLS must have completed their BMLSc or an equivalent qualification and a period of supervised practice. Recertification requirements include continuing professional development.

Medical laboratory scientists can specialise in different analytical disciplines, for example histopathology, cytology, haematology or diagnostic genetics (468). Expanded scope of practice focussed on improving patient outcomes is possible under the Medical Sciences Council registration framework (469). In at least one DHB there are specific roles called scientific officers – experienced medical laboratory scientists with advanced training and skills. Having roles such as these that empower scientists to work to their full scope of practice can further enhance the efficiency and capability of medical laboratories (470).



### Medical laboratory technicians

Medical laboratory technicians (MLT) are trained “on the job” within medical laboratories. They may also have a biological science qualification from a university. They collect and prepare specimens for testing, and conduct testing under the supervision of an MLS or pathologist. Medical laboratory technicians must also be registered with the Medical Sciences Council of New Zealand. These individuals are required to pass a specific MLT examination prior to registration, or to provide evidence of a university qualification. A period of supervised practice is also required.

Similar to medical laboratory scientists, an MLT may specialise in particular analytical techniques. Expanded scope of practice focussed on improving patient outcomes is possible for MLTs under the Medical Sciences Council registration framework (469).

**Table 8: Pathology and laboratory workforce statistics. Data source: Health Workforce New Zealand**

Workforce	2021 count	% of total
Pathologists	330	-
Aged 65 or over	49	15
Female	158	48
Male	172	52
European/other	256	78
Asian/Indian	58	18
Māori	3	1
Pacific people	2	1
Unspecified	11	3
Medical laboratory scientists	1743	-
Aged 65 or over	125	7
Medical laboratory technicians	784	-
Aged 65 or over	45	6

### Other non-technical staff

It is important to acknowledge that clinicians, scientists and technicians are not the entire workforce that is essential to the pathology and laboratory system. Other staff such as administrators, couriers and maintenance staff are also critical. There is not currently information available on the current state of these parts of the workforce.



# Ngā wero o āianeī mō ngā ratonga mātai māuiui, taiwhanga

## Current challenges in pathology and laboratory services

This section of the report combines information from stakeholder interviews and published literature on the current challenges with laboratory and pathology services in New Zealand. These challenges create significant inequity in the access to, quality of, and outcomes from laboratory and pathology services.

### Service planning

#### *A fragmented laboratory/pathology service creates challenges for national coordination and service design*

Feedback from the sector indicates that pathology and laboratory services are unnecessarily fragmented and that a coordinated national approach is needed. Currently the National Pathology and Laboratory Round Table has produced a strategic framework for the sector; however, there appears to have been little progress towards delivering this strategy to date (458).

Sector feedback suggests that laboratory contractual arrangements are inconsistent across the country and including in relation to performance standards, reporting requirements and accountability processes, multi-disciplinary team participation and professional development support. Contracts are held confidentially and therefore this information has not been able to be validated.

Molecular testing (ie testing genetic material and molecular products of genes) is one area of particular relevance to a modern cancer care system, and where national leadership and governance is notably absent in Aotearoa. In 2003, and again 2015, the National Health Committee recommended that urgent attention be given to a national, coordinated approach to the delivery of genetic testing (472, 473). The pace at which molecular testing in cancer is developing is rapid, and that lack of considered national leadership and governance means that complex matters related to molecular testing, including but not limited to ethics, bioinformatics, indigenous data sovereignty and research priorities are not systematically considered.



# Infrastructure and technology

## *There is variable access to specialised testing infrastructure and expertise*

Basing laboratory services within communities means that tests can be conducted closer to home. However, this means that in some cases individual service providers do not have the capital to invest in specialised technologies. The introduction of new tests and technologies happens at a DHB or private company level leading to inconsistencies across the country, and lost opportunities for efficiency and cost-effective investment in new technologies. Given the population size that DHBs serve, it is difficult to achieve economies of scale. This means that technological advances in areas such as digital pathology, next-generation sequencing and the accompanying complex bioinformatics may be out of reach for some DHB budgets. This is important for cancer, particularly in the area of molecular testing. Personalised medicine is evolving rapidly in cancer treatment, and the necessary instruments and consumables required can be high cost.

Furthermore, there can be a dilution of expertise when complex, highly subjective pathology tests are conducted across multiple sites and in some cases using different analytical techniques (474). This can result in inaccurate and inconsistent test results. The types of pathology techniques used in cancer care can be highly subjective and therefore rely heavily on the experience and expertise of the technicians, scientists and/or pathologists performing the analysis and interpretation. This means that for complex and rare tumour types and analysis methods, there is likely to be benefit in terms of quality through service consolidation. Stakeholder feedback has raised examples where quality has been compromised through a lack of coordination, with direct impact on patient experience and outcomes.

The need for local solutions should be balanced with the need for consistent quality, and economies of scale (475). As specimens can be transported around the country without the need for the patient to travel, specific expertise can readily be concentrated in a small number of centres, or difficult cases referred for expert review. However, the current competitive and fragmented model reduces collaboration between different laboratories, and poorly developed referral pathways and networks hinder timely expert referral.

# Access to testing and results

## *There is no national schedule of tests, resulting in inequitable access to testing*

Because there is no national schedule of tests it is not clear what tests are publicly funded across the country, and at what cost, including variation in out-of-pocket costs to patients. Stakeholder feedback indicates that a patient in one DHB can have their test fully funded, while another in a neighbouring DHB will need to pay for the identical test themselves. This includes variation in access



to molecular and other specialised testing for cancer (for example genetic/genomic testing of tumours). Clearly this can result in unintended variation in access to care across DHB boundaries.

Furthermore, it is not clear which tests are available within Aotearoa. Stakeholder feedback suggests that even within DHBs there can be significant variation between clinicians regarding what specialised cancer tests are ordered. There is no process to align the introduction of new molecular and other specialised tests for cancer that are required for new cancer medicines (ie companion diagnostics) with medicine funding decisions. For specialised molecular testing, pathologists and scientists rely largely on word of mouth to find out where a test can be performed.

There is currently a lack of nationally agreed pathways for cancer treatment in Aotearoa. This likely leads to unwarranted variation in what tests are used for different cancer types across the country. There is a need for greater national standardisation of the tests used, and of specimen collection, preservation, and transportation to avoid variation in specimen quality and subsequent utility and result interpretation.

***There is no national laboratory information system, meaning results can be difficult to access***

Requests for, and results of, tests are communicated between the requestor and the pathologist in a variety of ways. There is no national laboratory information management system or approach. Stakeholder feedback suggests that this means in some cases not all relevant individuals can access the results in a timely manner, including patients and their whānau. This can result in unnecessary duplication of tests, and delays to treatment.

Testing information is often presented in a way that is not easily interpreted by non-medical individuals. Stakeholder interviews with patients found that they often find laboratory results information useful in informing their decisions about cancer treatment, but they are not always readily available, and are often presented in a way they can't interpret.

The visibility of what services are being delivered is challenging due to a lack of access to complete, accurate, timely and structured data. The Ministry of Health | Manatū Hauora collects data from laboratories providing community tests, but these data are limited. There is no national data collection of tests conducted in the hospital setting.



## Workforce

### ***Current laboratory and pathology workforce is not sustainable and not representative of the population***

In 2018, the Royal College of Pathologists Australasia (RCPA) found that Aotearoa had a lower level of supply of pathologists at 61.4 per million population, compared to the national Australian supply of 78.4 per million population (336). This was lower than every state and territory in Australia apart from the Northern Territory. Current New Zealand laboratory and pathology workforce statistics are presented in Table 8 on page 202. This aligns with stakeholder feedback, that the laboratory and pathology workforce in Aotearoa is insufficient to meet current demand.

The pathology workforce has been identified as vulnerable by Health Workforce New Zealand, with an 11% FTE deficit forecast by 2030 based on average rates of new entry, re-entry and exit over the past 3 or 5 years. This forecast is based on current workforce provision and does not take into account any current unmet need or workforce shortages.

Fifteen percent of the current pathology workforce are aged 65 or over – the age at which many New Zealanders retire (476). In 2018, the RCPA estimated that an additional 14-18 registrars (ie postgraduate trainees) were needed to compensate for impending retirements, and a predicted testing growth rate of between 3.4 and 3.8% per annum (336). Stakeholder feedback indicates that there are limited training positions available, and that the programmes and experience offered varies across the country. While the RCPA requires experience at multiple laboratories for qualification as a pathologist, there is no national coordination of training rotations.

Changes in technologies and health sector requirements over time will likely mean that the skill mix of the workforce must also evolve. Areas such as bioinformatics and more effective utilisation of the scientific workforce to their highest scope require detailed consideration (475). Whilst referred to in the strategic framework for the pathology and laboratory services sector, there is no detailed workforce development plan in place (452).

The current workforce lacks diversity. While Māori represent around 17% of the New Zealand population, just 1% of the pathology workforce are Māori (see Table 8). The situation is similar for Pacific ethnicities (477). The RCPA has formulated an Indigenous Steering Group with the view to implement strategies to recruit and retain indigenous pathology trainees in Aotearoa and Australia. Gender and ethnicity data are not available for medical laboratory scientists and technicians.





# Tō āianeī mana taurite kore

## Inequity in the current state

All of the challenges described above collectively create inequity in access, quality and outcomes for Māori and Pacific peoples compared to non-Māori, non-Pacific, as well as inequity in care based on where people live. The cumulative impact of these system issues is summarised below.

### Limited data to monitor inequities

High quality, comprehensive data regarding access to laboratory testing for cancer treatment-related diagnostics are not currently collected on a national level, including data that can be analysed according to population groups known to experience disparities in cancer outcomes. This means that it's not possible to directly determine whether Māori and Pacific peoples are experiencing inequities in access to pathology and laboratory services, or to look for groups who may be experiencing inequities in access. However, inequities in Māori and Pacific access and health care utilisation in Aotearoa are well established (17), and this likely extends to pathology and laboratory services – particularly as other health services almost universally act as the gateway to pathology and laboratory services.

### Equity of access to collection sites

There is no specific data available on access to collection sites. However, it is well documented that there are marked inequities in access to other community health services, for example 5.5% of Māori and of those living in the most deprived quintile, 7.6% of disabled people and 4.8% of Pacific Peoples did not visit a GP when they needed to due to lack of transport, compared to 2.1% of European, 0.6% of people living in the least deprived areas and 1.9% of non-disabled people (478). These same barriers likely exist for access to community-collection sites.

For people based in regional locations, community-based sample collection can occur in health settings outside formal collection centres – for example a GP clinic or regional hospital – which can make laboratory tests more accessible than other forms of testing (such as radiology imaging). However, stakeholder feedback indicates that in some rural locations collections sites are only open on certain days of the week, or substantial travel is still required. It is likely that people based in remote areas may have more difficulty accessing these services than those living in urban areas. In urban areas there are also issues with collection sites often only being open during office hours, often with a long wait time, making services difficult to access for people who are unable to get time off work.



Whilst community-based collection sites are located around Aotearoa, stakeholder feedback has indicated that limited consideration has been given to cultural safety within these facilities, which may contribute to access barriers for some population groups.

For specimen acquisition that requires surgical intervention, the access inequities are well documented in the surgical services section of this report.

## Equity of access to specific tests

The variation in the way in which tests are funded in different DHBs, with patients required to pay for certain tests in some DHBs, immediately creates an equity issue, particularly disadvantaging those who experience financial hardship. Similarly, if new technologies are introduced locally into specialised settings without consideration to access equity, then there is potential to further widen equity gaps (475).

For complex molecular testing where a reference genome is required, it is possible that the reference genomes used do not appropriately reflect the genomic diversity in the New Zealand population (479). In particular, Māori and Pacific have substantially different genomic variations, which is likely to disproportionately impact on the success and benefits of genomic medicine for these groups and may have implications for inequitable access to and interpretation of results (480).

## Equity for Māori and Te Tiriti o Waitangi considerations

No clear national leadership structure exists for laboratory and pathology services, and there is no systematic involvement of Māori in the governance of these services. A strategic framework for the pathology and laboratory services sector exists; however, this strategy does not appear to have been developed in partnership with Māori, nor does it seem to have included specific consideration to health inequities (452).

The pathology workforce has inadequate Māori representation (see Table 8). No data are available on Māori representation within the medical laboratory scientist and technician workforce.



Specimens of human tissue, cells and cellular molecules are generally considered tapu (sacred) by Māori. It is critical that there are clear guidelines for tikanga that keep individuals, whānau and health sector workers culturally safe (481). Individual laboratories have policies, procedures and protocols that cover tikanga for specimens; however, these are not coordinated on a national level. The PUKUmahi! project is an example that provides a model for Māori kaitiakitanga and governance over the management of Māori tissue or DNA and health data and sets out a roadmap and evaluative approach to implementation (482).

For some tests needed in the cancer care setting, specimens are sent to laboratories in other countries outside Aotearoa. This is either because the appropriate equipment and expertise is unavailable within Aotearoa, or because an international laboratory is able to offer a lower price or faster turnaround time, or both. When specimens are sent off-shore, patients should provide informed consent. However, this practice can have complex implications for sovereignty, particularly for Māori, regarding the specimen and the associated data.

*A detailed equity analysis of how each of the challenges with the current system contributes to inequity in access, quality and outcome, and alignment to focus areas is included in **Appendix VI**.*

# Taunakitanga hei whakatutuki wero

## Evidence of ways to address challenges

### England

The English NHS has recognised that service consolidation is critical to respond to the future trends for pathology and laboratory services, including for cancer. This was, at least in part, a result of the 2008 and 2010 Carter reviews of pathology services (483, 484). At that time, laboratory services were largely provided by public service providers, in the context of a national, publicly funded health service (485). Recommendations included consolidated laboratory networks across England, with a national laboratory test formulary that is subject to health technology appraisal and incorporates robust horizon scanning. A national network was thought to also deliver better value from procurement activities (483). This model has been implemented in some parts of England, and the success of this implementation has been reviewed and critiqued. The involvement of private service providers has increased over this time, and the benefits of increased collaboration have been recognised (451, 485-487).

Barriers identified to more consistent implementation include fragmented commissioning and payment systems, a focus on costs rather than quality, ineffective leadership and insufficient recognition of the value of pathology and laboratory services as integral to the overall health system and patient pathways. The importance of pathologists working collaboratively with other clinicians was noted. In some areas there have been substantial cost savings, but aspects such as staff retention and service quality have not been assessed (485).

The English service continues to evolve, and the ongoing need for strong leadership at all levels, and full establishment of networks has been subsequently identified, particularly in light of the COVID-19 pandemic (475, 488). The most recent review reinforces the need for improvements to data collection, commissioning arrangements, and to ongoing monitoring and evaluation (488). The importance to cancer care and control is highlighted.



In September 2021, a Getting It Right First Time (GIRFT) review of pathology was published (489). This report highlights the importance of considering pathology as an end-to-end service. It also noted that challenges in access to high quality data including to look at practice variation was impacting on the delivery of service excellence for pathology. A series of recommendations was made to improve pathology services in England. At this point, such a report would likely not be possible to produce or implement in Aotearoa, given the absence of overarching leadership or accountability for the pathology and laboratory sector.

Importantly for cancer, the NHS England also provides a national genomics medicine service which incorporates testing for hereditary mutations associated with cancer risk, and testing mutations within cancer that can provide diagnostic, prognostic and predictive information about an individual's cancer. This service uses a hub and spoke approach for laboratories and clinical services, with the specialised testing done in a centralised manner. This service includes a national genomic test directory which enables consistency in access to these types of tests (490).

## Australia

Australia has a publicly-funded universal health insurance scheme called Medicare, which works in partnership with the Australian Pharmaceutical Benefits Scheme (PBS). Medicare has a list, or schedule, of medical services that are eligible for rebate in health care settings *outside of the public hospital*. This list, called the Medicare Benefits Schedule includes pathology and laboratory tests and services, alongside many other medical services such as GP and specialist consultations, surgical procedures, imaging and optometry tests (321). It sets out eligibility criteria and a fee for service, and eligible patients are able to claim a rebate of a percentage of that service fee.

Service providers may choose to charge a fee that is higher than the MBS fee for service, in which case the balance of the cost is borne by the patient (or their private health insurer) (491). Sector feedback indicates that the fees for service are often inadequate to cover the cost to the provider (492). This highlights the need for an effective and transparent mechanism of price and fee review (493).

In Australia, the majority of publicly-funded pathology services in the community are provided by the private sector, and in 2016 it was reported that two companies controlled more than 75% of the market (493). Australia is addressing challenges of cost-containment associated with this model, as well as working to ensure the system remains responsive to a rapidly changing health care environment (491, 493).



In the hospital setting, pathology and laboratory services in Australia are predominantly delivered by public laboratories (494). These services are organised in different ways across the different states and territories of Australia, but most use a state/territory-wide service approach. An example is in South Australia where a state-wide public pathology service was established through the consolidation of a number of separate hospital pathology laboratories in 2007 (492, 495-497). This state-wide service has been reviewed recently, with a number of recommendations made to improve its service and business performance (497).

## Global

The Lancet Oncology Commission on global cancer surgery describes the central importance of pathology as part of cancer surgery (169). Whilst focused on low and middle-income countries, the Commission reports that there can be high discordance rates between low- and high- volume laboratories even in high-resource settings. It highlights the global need to train more pathologists and sets out some minimum principles for pathology provision in the cancer surgery context. These principles include consistent specimen collection and preservation, consistent and structured pathology reporting, clinically relevant turnaround times, the importance of the pathologist in the multi-disciplinary team and connected laboratory information management.

The Lancet has also published a series on pathology and laboratory medicine in low and middle-income countries (498). Again, while Aotearoa is a high-income country, the principles remain relevant to our context. The authors recommend a national strategic laboratory plan delivering a networked laboratory system as a central element. They also recommend appropriate financing, including for molecular diagnostics and the involvement of pathologists in national leadership roles (499).

More recently, building on the important experiences of the COVID-19 pandemic, the Lancet published a commission on diagnostics, including for pathology and laboratory services as well as diagnostic imaging. The recommendations again included a national diagnostics strategy and appropriate financing. Further to this, the Commission recommends a focus on improving access and availability in the primary care setting, health workforce expansion and upskilling, and robust governance arrangements (450).



# He tāpae hei panoni

## Proposal for change

The health reforms provide a unique opportunity to build a national leadership structure for pathology and laboratory services. This leadership structure would be consistent with the principles of Te Tiriti o Waitangi, and enable a strategic, proactive, forward-focussed approach. Other countries with similar approaches to health care have acknowledged the need for national leadership for laboratory and pathology services and implemented changes accordingly. This means that Aotearoa can learn from these experiences.

Whilst not specific to cancer, a nationally coordinated pathology and laboratory network would enable consistent and modern cancer care to be delivered. Without well-functioning pathology and laboratory services, the other recommendations made in this report are unlikely to deliver the objectives of improved cancer treatment for New Zealanders.

As the national leaders for cancer control, Te Aho o Te Kahu is not in a position to provide the infrastructure for the leadership of a sector that plays such a critical role across the entire health system. However, Te Aho o Te Kahu welcomes the opportunity to work with the Ministry of Health | Manatū Hauora, Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora to provide cancer-related subject matter expertise in the development, implementation and maintenance of a national pathology and laboratory strategy, leadership function and network.

## Ngā wāhi hei mahi | Potential focus areas

### Transformative approach

1. Priority would be given to pathology and laboratory services when considering options for national coordination and improvement. Aotearoa needs pathology and laboratory services that are interconnected both for equitable cancer care and for high quality health care across the health system.

### System leadership

#### National system leadership

1. The transition unit to work with the national pathology and laboratory Round Table, the Ministry of Health | Manatū Hauora, the Māori Health Authority | Te Aka Whai Ora and Health New Zealand | Te Whatu Ora to create a well-resourced, national leadership function specifically for pathology and laboratory services, with a Te Tiriti and equity focus.





- a. This leadership function must include Māori, clinical and scientific representation.
  - b. Ideally, the leadership function would include specialised cancer pathology technical expertise, which Te Aho o Te Kahu can help to facilitate.
2. The national leadership function would include responsibility for:
  - a. Considering the strategic framework for the pathology and laboratory sector with a particular focus on health outcomes equity and Te Tiriti compliance.
  - b. Strategic planning and forecasting for national pathology & laboratory services, including for infrastructure, workforce (with a particular focus on Māori representation) and information management.
  - c. Reviewing and prioritising investment decisions for introducing new infrastructure and technologies.
  - d. Procurement of pathology & laboratory services, including new technologies.
  - e. Contracting with service providers in a consistent manner that supports sustainability, appropriate training & development, and integration with other clinical services.
  - f. Establishing and maintaining a networked approach to service provision within the pathology and laboratory sector.
  - g. Monitoring the impact of changes to the sector on service delivery and patient outcomes, with a focus on equity.
  - h. Consideration of systems for Māori kaitiaki and governance over Māori DNA, tissue samples and data.

This leadership function would have responsibility for pathology and laboratory services across the health system and not limited to cancer treatment. Therefore, it would not be appropriate for Te Aho o Te Kahu to deliver this function. Te Aho o Te Kahu could provide cancer services subject matter expertise, and directly contribute to cancer-related projects.

## Data driven

1. The national leadership function for pathology and laboratory services to give priority to the implementation of a national approach to laboratory information management. This should be set up in a way that enables:
  - a. Te Tiriti compliance with particular regard to Māori governance and data sovereignty
  - b. Interoperability between different laboratory information systems, and integration with electronic patient management systems
  - c. Timely, secure, electronic communication of consistent and structured laboratory results to the people who need them to make treatment
  - d. Communication of results to national collections where appropriate (for example, the New Zealand Cancer Registry) to enable decision making at population levels





- e. Adaptation to, and implementation of, future changes to technologies and work processes (including digital pathology and complex bioinformatics associated with molecular testing)
  - f. Monitoring for performance of quality and equity of pathology and laboratory services and associated patient outcomes, in particular for Māori and Pacific peoples
  - g. Consideration to patient access to laboratory data, in a safe and appropriate manner.
2. Te Aho o Te Kahu to develop, implement and monitor a Cancer Information Plan.
    - a. Te Aho o Te Kahu can provide cancer subject matter expertise to the laboratory information infrastructure in a way that would support an effective Cancer Information Plan. This includes structured pathology request and reporting requirements for effective delivery, monitoring and planning of cancer services.
    - b. It is anticipated that information from a national laboratory information system would be used to monitor the impact of changes resulting from the implementation of focus areas throughout this report, including the impacts for Māori and Pacific peoples.

## Clinical service distribution

### National and coordinated clinical leadership

1. A national schedule of tests to be developed and maintained by the national leadership function. A schedule of tests, aligned to clinical guidelines and pathways would provide national consistency regarding:
  - a. Which tests are funded by the public system, and at what price
  - b. Who is eligible to access these tests
  - c. How new technologies are reviewed and introduced
  - d. Horizon scanning regarding new testing requirements
  - e. the schedule of tests is developed within the context of inequities for Māori, Pacific peoples and other population groups who experience cancer outcome inequities. For example, this could be in the form of differential access for certain population groups, or in the consideration of which tests are and are not funded.
2. Decisions regarding which tests are and are not made available to be aligned with pharmaceutical funding decisions made by Pharmac | Te Pātaka Whaioranga.
3. Development of clinical cancer pathways to include pathology tests and expertise, with the involvement of specialised pathologists throughout the process.

### Planned distribution

1. In procurement of pathology and laboratory services, the leadership function to give due consideration to the distribution of specialised laboratory technology and expertise.



- a. For highly specialised methodologies used in cancer (for example, specialised histopathology and molecular testing), a small number of laboratories would enable the concentration of expertise, and economies of scale.
  - b. Investment in high-cost equipment on a national level is likely to be more achievable than it is currently by individual DHBs or service providers.
  - c. Ideally the equipment and expertise would be located in close proximity to the relevant surgical or other clinical centres where specimens are collected, and other clinical expertise is located.
  - d. It would be critical that specimen transportation infrastructure is in place to support this, with consideration given to safety, security, timeliness and tikanga.
  - e. Consideration should be given to contingency planning for the scenario where a central laboratory became compromised.
2. For high volume methodologies, consideration could be given to efficiencies in distribution, but it is likely that these should continue to be offered by the majority of laboratories.
  3. When new treatment services are developed, it is critical that the availability and distribution of pathology and laboratory services is considered.
  4. Procuring and contracting for pathology and laboratory services to account for the contribution of pathologists and clinical scientists to the clinical multi-disciplinary cancer care team.

### Care close to home

Unlike many other aspects of cancer treatment covered in this report, much of the contribution of pathology and laboratory services happens in locations where the patient is not present. This means that, as long as there is appropriate specimen transportation infrastructure in place, being “close to home” becomes less critical. However, patients and whānau visit collection centres, and these are not always a welcoming and culturally safe environment.

1. When procuring and contracting for laboratory services, priority would be given to collection centres that are patient-centred, accessible and culturally responsive. This should include consideration of mobile collection services where possible, that can be brought to the patients’ home and eliminate the need for travel. In particular, specific provisions to improve access should be prioritised for Māori and Pacific peoples who may be disproportionately disadvantaged.

### Implementation mechanisms

1. A national laboratory information system to be implemented in a way that is connected to the electronic medical record to enable timely access to people caring for patients.
2. When procuring and contracting for national laboratory information systems, specific consideration is given to patient access to laboratory



data (including for cancer-related data), with plain language explanations where appropriate. This should be done in a coordinated manner that enables the appropriate context and support to be available to patients and whānau when laboratory information is communicated. The risk of harm caused by misinterpretation of data should be actively considered.

## Workforce

### Workforce capacity

1. The national leadership function to work with professional groups, private laboratory service providers, and Health Workforce New Zealand to establish a clear plan for growing and maintaining our national pathology and medical laboratory workforce.
2. When procuring and contracting for laboratory services, specific consideration is given to training capacity and allowances within pathology and laboratory service providers.

### Workforce diversity

1. The national leadership function to work with professional groups and Health Workforce New Zealand to collect data on the profile of the medical laboratory scientific and technical workforce, in particular the numbers of Māori and Pacific people working within these professions.
2. The national leadership function to work with professional groups and Health Workforce New Zealand to improve the alignment of the profile of the pathology and laboratory with the diverse population of Aotearoa, particularly for Māori and Pacific peoples in alignment with the Māori Health Workforce Action Plan and the workforce recommendations contained in Ola Manuia: Pacific Health and Wellbeing Action Plan 2020-2025.

### Cultural safety

1. The national leadership function to provide guidance to service providers on how to support and increase the cultural competence of the pathology and laboratory workforce, including giving consideration to national guidance for the appropriate management of Māori tissue, DNA and data.
2. The national leadership function to implement monitoring of the cultural safety of pathology and laboratory workplaces.

### Scope of practice

1. Within the strategic planning for the sector, the national leadership function to consider ways to enable technical and scientific staff to continuously develop their scope of practice. This should be done in a way that provides career progression opportunities, improved work satisfaction and staff retention.



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# WĀHI 7: NGĀ RATONGA HAUMANU HIHIORA SECTION 7: RADIOLOGY SERVICES

## He kupu whakarāpopoto Summary

### Case for change

Radiology services are fundamental to good cancer care. They are necessary at every step of the cancer pathway, from cancer screening and diagnosis through to staging, treatment planning, assisting in delivering treatment itself, and monitoring. A consistent, modern, and equitable cancer care system relies heavily on radiology services. The growing number of people with cancer, as well as trends in cancer care, requires radiology services that are high-quality, accessible, consistent, and sustainable over time. Cancer demands on radiology services will also always need to be managed alongside competing needs from non-cancer areas of health.

Radiology services in Aotearoa are challenged by insufficient capacity (across workforce, equipment, and IT systems), but also by an unnecessarily fragmented and reactive approach to designing radiology services, planning, investment, and introducing new technologies. Additionally, despite the accepted importance of radiology services in cancer care, policy decisions in cancer may not routinely account for the knock-on impact on radiology services. For people with cancer needing radiology services, these challenges collectively manifest as access barriers, delays in timeliness, and inconsistencies in care, and are contributing to inequities for Māori, Pacific peoples and other priority population groups.



## Proposal for change

Radiology services would benefit from development of a national, population-based approach to organising and planning radiology services, with a focus on Te Tiriti and equity. In the future, this national leadership function would ideally be held by Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora. With its networks and advisory groups, Te Aho o Te Kahu would be well positioned to provide a cancer perspective.

To improve the provision of radiology services, investment in capacity and diversity of the workforce, equipment, and IT is needed to meet both current and future demand. These should be tackled as parts of a national plan, rather than as stand-alone local or regional initiatives. In addition to growing capacity over time, it is necessary to make the best use of the radiology resources already in place. Areas where gains can be made include using evidence-based guidelines to standardise how imaging is used in cancer staging and surveillance and how cancer multidisciplinary meetings (MDMs) are conducted.

## What would be different for patients and whānau?

If radiology services are working well, then regardless of who people are or where they live:

- Patients will be offered imaging that is appropriate for their cancer needs
- Patients will have choices in terms of where they get their imaging, flexibility in timing of appointments, no out-of-pocket costs and assistance for transport and travel if needed
- Patients will have timely and high-quality scanning and reporting that maximises the quality of their cancer care
- Patients and whānau will feel safe, supported, welcome and respected in their interactions with radiology services



# Te tiro whānui

## Scope

In keeping with the other sections, this section covers radiology services from the point of cancer treatment onwards. This includes radiology services used to stage cancers and inform treatment planning, deliver treatment and symptom management, assess treatment response, and provide post-treatment follow-up.

While this section does not directly cover radiology services used to screen for cancer or confirm a diagnosis of cancer, the changes suggested here are likely to apply more broadly than cancer treatment in any case. The scope is limited to publicly funded radiology services, regardless of whether they occur in public or private settings.

# He kupu whakataki

## Introduction

Radiology services are fundamental to good cancer care. They are required throughout the cancer pathway, from cancer screening and diagnosis through to staging, treatment planning, delivering treatment itself, and monitoring. The purpose of this section is to outline the current state, main challenges, and suggestions for improving radiology services in Aotearoa. It is written from a cancer perspective, although the suggestions will apply broadly to other areas of health too.

Radiology is characterised by the production of images of the internal structure of the body. Radiology services use many imaging modalities including, but not limited to, X-ray, fluoroscopy, ultrasound, computed tomography (CT), magnetic resonance imaging (MRI) and positron emission tomography (PET). Interventional radiology is a specialised and growing area of radiology that uses radiological images to perform minimally invasive, targeted procedures. Examples of interventional radiology procedures include using image guidance to sample suspected tumours or metastases, site long-term vascular access to deliver cancer treatment, ablate tumours and place stents or tubes to relieve symptoms from cancer complications (500).

The application of information from imaging services needs clinical expertise and shared decision-making with patients, whānau and other clinical colleagues. Radiology services rely heavily on IT systems that support patient management, scheduling, and tracking, as well as image storage, access, review, and reporting.





The radiology workforce includes diagnostic and interventional radiologists, medical imaging technologists, MRI technologists, nuclear medicine technologists, ultrasonographers, nurses, radiology assistants, service personnel, administrators for radiology IT systems and general administrative staff. There are three key perspectives in radiology services: users of radiology services (patients with cancer and their whānau), requestors of radiology services (eg physicians, surgeons, medical oncologists, radiation oncologists, palliative care clinicians, haematologists and nurse practitioners), and providers of radiology services (radiology workforce as described above).

Radiology services for cancer care has several distinct features:

- Cancer care typically requires more complex imaging modalities such as CT, MRI and PET.
- The time-dependent nature of cancer and its treatments usually means shorter time frames for imaging and reporting.
- Radiology input is integral to cancer multidisciplinary meetings (MDMs). MDMs are regular meetings involving a range of health professionals with cancer expertise, to facilitate best practice management of people with cancer.
- Interventional radiology is increasingly important in the diagnosis and treatment of cancer.
- The growing number of people with cancer, as well as trends and advances in cancer care, mean that there is a disproportionate demand on radiology services from cancer.

# Tō āianeī āhua mō ngā ratonga haumanu hihiora i Aotearoa

## Current state of radiology services in Aotearoa

How radiology services are organised and delivered

### System leadership

The Ministry of Health | Manatū Hauora currently has accountability for radiology services, albeit with limited internal capacity (less than 2 FTE), supported by the Radiology Collaborative Aotearoa Advisory Group. The group provides direction and advice to the Ministry and to DHBs, with the objective of improving timely and equitable access to radiology diagnostic services.

At the time of this report, the Ministry of Health | Manatū Hauora also had oversight of DHB infrastructure and capital projects relevant to radiology facilities and equipment. Several other directorates within the Ministry of Health | Manatū Hauora have work that will impact radiology services, including: Health Workforce New Zealand (provides strategic leadership for health workforce challenges including workforce forecasting and planning) and Data and Digital (responsible for ensuring that the Ministry's data collections and digital technology adequately support the health system).

Outside of the Ministry of Health | Manatū Hauora and Health New Zealand | Te Whatu Ora, there are various entities that provide national, regional, and local leadership for different aspects of radiology services, including professional colleges (eg the Royal Australian and New Zealand College of Radiologists or RANZCR), registration authorities (eg the Medical Radiation Technologists Board), national sector advisory groups (eg the National Radiology Advisory Group) and regional radiology networks (eg the radiology network affiliated with the South Island Alliance). Regional radiology networks can be varied in terms of the functions they perform, ranging from shared buying power for equipment, sharing expertise, coordination of training, harmonising IT infrastructure, workforce planning, etc.



## Provision of radiology services

Radiology services provided by DHB hospital services are outlined in the Service Coverage Schedule, and includes the following requirements: provision of diagnostic radiology services, provision of interventional radiology services, supporting cancer MDMs, being monitored against agreed wait times for CTs and MRIs, and provision of assistance for patient travel and accommodation as specified in the National Travel Assistance Policy (501, 502).

Publicly-funded radiology services are provided by both public and private providers. The rationale for public-private arrangements vary and may be in place where private provider services complement those available at DHBs (such as by having multiple community imaging sites for primary care), for reasons of capacity (where demand for radiology services exceeds capacity), or for reasons of capability (where private providers have technology or clinical expertise not available at DHBs such as for PET scans).

The mix of public and private provision of radiology services is different in each DHB and reflects the local context. For example, some DHBs contract all their radiologist services from private providers, including those provided within public facilities. Other DHBs use private providers more specifically, such as for out-of-hours reporting. Rural DHBs with fewer private providers (eg West Coast, Tairāwhiti) rely more heavily on public DHB radiology services.

## Imaging volumes and facilities

Generally, in terms of volumes, (plain) X-ray is the most frequent imaging modality, followed by ultrasound, CT, MRI and PET scans. As a rule of thumb, the same order applies for cost (least costly to most costly) and availability (most widely available to least available):

- **X-ray:** widely available nationally in public and private facilities, even in small centres. There are also some mobile X-ray services available.
- **Ultrasound:** widely used in diagnosis, staging, and surveillance. Ultrasound services are widely available nationally in public and private facilities, even in small centres. However, there are workforce challenges due to insufficient sonographers.
- **CT:** widely used and fundamental in cancer care for diagnosis, staging, and surveillance. There are approximately 45 CT scanners in public facilities and 35 in private facilities. Some small centres have CT (eg Oamaru and Clyde).
- **MRI:** used in diagnosis, staging, and some surveillance. There are approximately 28 MRI scanners in public facilities and 50 in private facilities. Some smaller centres have MRI (eg Queenstown and Timaru).
- **PET-CT:** used in staging and surveillance. There are 5 PET-CT scanners, all in private facilities and contracting to DHBs (2 in Auckland, and 1 each in Hamilton, Wellington, and Christchurch).



National collections do not currently allow assessment of imaging volumes related to cancer. Overall national CT volumes, across all indications, ranged from 14,500 to 18,800 per month in the year ending June 2021. The equivalent for MRIs was 13,500 to 16,100.

## Radiology IT systems

The Picture Archiving and Communication System (PACS) system provides image storage, display, and sharing with other PACS sites. The Radiology Information System (RIS) is used in conjunction with PACS for patient management, from image request and scheduling through to providing a report. Radiology networks rely on the RIS-PACS system to be able to provide 24-hour cover for ED or ICU, or to allow radiologists to provide reporting cover from home or other remote sites when required.

## Current state of radiology workforce

The radiology workforce includes diagnostic and interventional radiologists, medical imaging technologists (previously known as radiographers), MRI technologists, ultrasonographers, nuclear medicine technologists, radiology assistants, radiology nurses (including interventional radiology nurses), RIS-PACS administrators, general administrators, and health care assistants.

- **Diagnostic and interventional radiologists:** In 2021, there were 629 radiologists, with an estimated 12.5 radiologist FTE per 100,000 population. About a third were female (unchanged since 2013), and only 1% of radiologists identified as Māori and 1% as Pacific.
- **Sonographers:** In 2021, there were 527 sonographers i.e. about 10.3 sonographers per 100,000 population.
- **Medical imaging technologists (MITs):** In 2021, there were 1,614 MITs i.e. about 31.5 per 100,000 population.
- **MRI technologists:** In 2021, there were 250 MRI technologists i.e. about 4.9 per 100,000 population.
- **Nuclear medicine technologists:** In 2021, there were 53 nuclear medicine technologists i.e. about 1.0 per 100,000 population.

Appendix VIII provides a summary of the radiology workforce numbers over time.



# Ngā wero o āianeī mō ngā ratonga haumanu hihiora

## Current challenges in radiology services

This section of the report is largely based on information from stakeholder interviews, some published information on radiology services, and radiology-relevant feedback on the New Zealand Cancer Action Plan. These challenges create significant inequity in the access to, quality of, and outcomes from radiology services.

### Service planning

#### *A fragmented and partly privatised radiology service creates challenges for national coordination and service design*

There is insufficient capacity centrally to lead aspects of radiology services that are best handled at a national level. Existing service models and public-private arrangements often come about in a reactive and ad-hoc way. This, combined with insufficient capacity, may limit access to and through radiology services. One key example is that access to imaging for primary or community care may be limited by overtly restrictive local access criteria to DHB radiology services, or due to DHB radiology services having insufficient capacity and therefore needing to prioritise patients in secondary and tertiary care. An unintended consequence of this situation is that some patients who could be managed safely in the community end up being referred to secondary care, partly as a means to access radiology services.

Similarly, there is currently no national approach to radiology service forecasting, planning, investment, and procurement. Existing radiology service capacity is insufficient to meet current demand and the growing number of people with cancer, as well as trends in cancer care, will only increase the demand for radiology services. At the same time, cancer demands on radiology services need to be managed alongside competing needs from non-cancer areas of health.



One of the obstacles to meaningful service planning is that policy decisions in cancer (eg funding a new service or medicine that has an accompanying imaging requirement) do not always consider knock-on impacts on radiology services, which makes timely service planning difficult. Radiology services are often an afterthought, or it is assumed that radiology services can expand to accommodate new demands. Examples include where new services are established or new cancer drugs are funded, without adequate planning for associated imaging requirements.

While there are examples of existing initiatives to try and better respond to radiology demand, these are fragmented, occur at a local or regional level, and usually focus on equipment or workforce in isolation, as opposed to a comprehensive national approach.

## Consideration of new techniques and technologies

### ***No national approach to assessing or introducing new imaging technologies leading to inequitable access***

There is currently no national approach to prioritising new, and existing, imaging technologies. Without a robust and consistent approach to assessing new technologies, there can be ad-hoc introduction without adequate consideration of equitable access, equitable outcomes, risks and benefits, costs, feasibility and sustainability. For example, there is currently inconsistent access to PET-CT. Initially, there was a nationally agreed list of indications for which PET-CT was publicly funded, but without a sustainable and formal national mechanism to update the list in response to new evidence, DHBs made their own regional arrangements for funding new PET-CT indications, resulting in inconsistent access to PET-CT across DHBs.

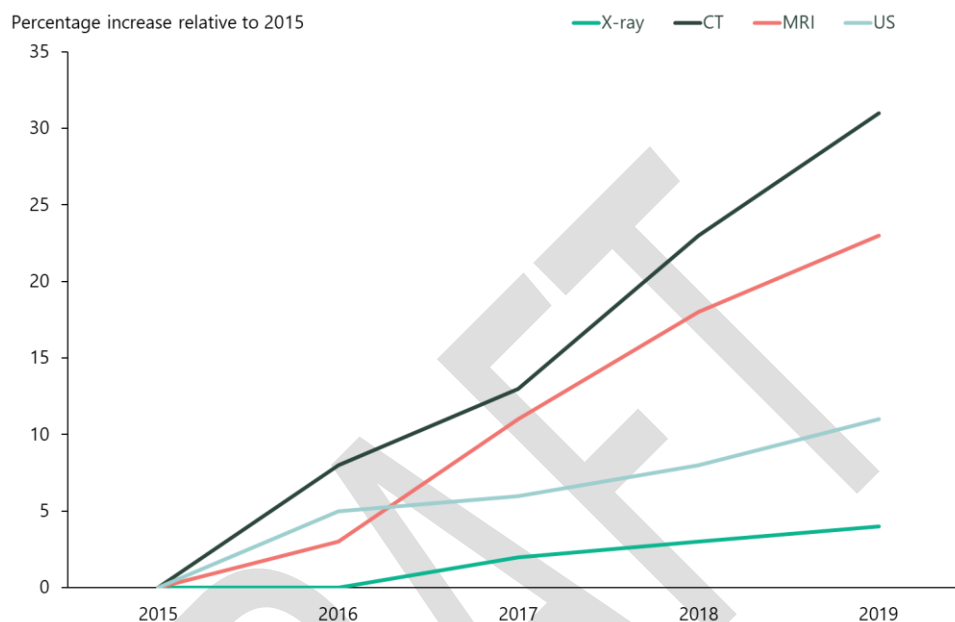


## Infrastructure

### *There is insufficient infrastructure to meet current demand for imaging services*

All imaging modalities are increasing in activity. Figure 22 shows that CT volumes have increased by more than 30% since 2015, and MRI volumes by over 20%.

**Figure 22: Increase in imaging volumes relative to 2015, by modality**



However, the increase in imaging volumes hasn't been associated with a similar increase in infrastructure. Shortfalls in CT and MRI are particularly urgent. In the absence of detailed forecasting, the Radiology Collaborative Aotearoa advisory group estimates that approximately 45 CT machines and 40 MRI machines are required to meet demand over the next decade. This does not include imaging requirements related to new national initiatives that may be introduced in the future, such as CT screening for lung cancer.

Stakeholders noted a lack of planning around infrastructure, with the procurement of new equipment typically done too late, once waiting lists have become unmanageable. However, individual DHBs are balancing competing capital demands, and the large upfront cost of radiology equipment is a significant financial barrier for DHBs.

There is significant variation in radiology equipment provision internationally, with no general guideline or international benchmark. As context, in a study comparing PET-CT provision across seven high-income countries, estimates ranged from 0.04 per 100,000 in Wales to 0.66 in Denmark, with New Zealand at about 0.10 per 100,000 (503). Similarly, in 2017 New Zealand had 17 CT scanners and 14 MRI scanners per million population, compared with the OECD average of 27 and 17, respectively (504).





A similar situation exists with IT infrastructure as with radiology equipment, with issues due to a shortfall in capacity combined with a lack of centralised or national planning (505). Although there are some regions where multiple DHBs are on the same systems, there is no nationwide RIS-PACS system, or an agreed pathway for getting to a functionally single system. There are multiple platforms in use, and some are out-dated. Depending on location, current systems:

- May be inefficient in the storage and transfer of patient information and images. This affects the quality and speed of reporting, limits collaborative working, limits access to historical images or those done in other public or private centres, and may mean that imaging needs to be repeated, exposing patients to unnecessary imaging and wasting services.
- May not have other minimum requirements such as electronic referrals or patient scheduling
- May not interconnect with other medical IT systems such as shared patient records
- May not allow meaningful and standardised data collection to drive efficient clinical practice, support quality improvement initiatives, monitor and act on inequities, or inform future service planning (505).

The lack of investment and national coordination will also potentially limit the ability of the radiology sector to take advantage of new technology such as artificial intelligence (AI)-supported reporting, which can enhance detection, improve consistency of reporting, reduce errors, and reduce processing and reporting times.

## Workforce

***There is insufficient radiology workforce capacity to meet current demand, and the workforce is not representative of the population***

There is a lack of national planning when it comes to the radiology workforce, as well as existing workforce shortages across both public and private sectors. DHBs train most of the radiology workforce but the numbers trained are typically driven by local requirements and available funding, rather than by national need.

For radiologists in particular, there is competition for workforce due to rising demand, and DHBs are often disadvantaged in terms of their ability to recruit or retain staff. It takes about 5-6 years to train a radiologist. The Radiology Collaborative Aotearoa advisory group estimates current shortage of radiologists at 50-100 FTE. There is significant reliance on international medical graduates, estimated at 11% of the radiologist workforce as of July 2019 (505).





Other critical shortages in the radiology workforce include sonographers and MRI technologists, in part because training for these specialist roles only exist as post-graduate options currently, rather than as undergraduate programmes, which means it takes a much longer time to train.

The radiology workforce lacks diversity. For example, Māori and Pacific peoples represent only 1% of the radiologist workforce. There are also concerns about whether the radiology workforce is being utilised in the most effective way. It is widely reported that all trained radiology staff spend a disproportionate amount of time on administrative or logistical tasks.

## Accessibility of radiology services

### *There is variable and inequitable access to radiology services across Aotearoa*

National radiology data are currently mostly collected in a way that is focused on volumes and activity, rather than unmet need and inequities. This limits the ability to directly assess access to, timeliness of, and outcomes from radiology services and limits the ability to act on inequities in these areas.

In terms of timeliness, the current target is for 95% of people to get a CT scan within 42 days (6 weeks or less) of an outpatient/community referral being accepted. In October 2021, the national average was 76%, with four out of 20 DHBs meeting the target. For MRI, the target is for 90% of people to get an MRI scan within 42 days of a referral being accepted. In October 2021, the national average was 53%, with one DHB meeting the target (506). While not specific to cancer, this measure indicates significant wait times for CT/MRI even once someone is 'in the system'. This data are not currently disaggregated by ethnicity/deprivation/rurality, but priority populations are likely to be disproportionately affected.

Capacity issues are not unique to public providers of radiology services with private providers also impacted. This limits the ability of both sectors to offer choice and flexibility in terms of locations or appointment times. This situation will disproportionately affect population groups for whom time, cost, and travel are already significant barriers in accessing healthcare.



# Tō āianeī mana taurite kore

## Inequity in the current state

The current challenges in radiology services described above (across service planning, infrastructure, workforce and accessibility) will be driving inequities in access and quality experienced by people with cancer and their whānau. This will be contributing to inequity in cancer outcomes.

The lack of cancer radiology data limits direct insights on unmet need and inequities. However, inequities in accessing healthcare generally for Māori and Pacific peoples compared to non-Māori, non-Pacific, and groups experiencing socioeconomic deprivation are well documented, and these inequities are likely to extend to radiology services as well.

Capacity constraints in radiology workforce and infrastructure, variations between DHBs in imaging used for cancer staging and follow up, variations in how MDMs are conducted, and variations in how new imaging modalities are introduced all create inconsistencies in access to and delays within radiology services. In addition to geographic inequities, priority populations such as Māori, Pacific peoples, and groups experiencing socioeconomic deprivation are likely to be disproportionately affected by inadequate capacity and lack of standardisation in clinical practice.

People who are unable to access publicly-funded radiology services (or who are waiting too long for their appointments) will opt to access private radiology services if they can afford it, or if they have private insurance. This situation will be creating inequities in access based on ability to pay, disproportionately affecting Māori, Pacific peoples, and groups experiencing socioeconomic deprivation (505).

Needing to travel to where scanners are located presents additional barriers to access, compounded by inconsistent application of the National Travel Assistance policy (507). For example, all five PET-CT scanners in Aotearoa are located in private facilities across four major cities. This situation will be creating inequities in access based on ability to travel, take time off work, be away from family, or cover the costs of travel. This will have a disproportionate impact on Māori, Pacific, and low-income communities, particular those living in rural and remote communities.



Across cancer healthcare appointments, people with cancer and their whānau have raised that whānau are not always welcome. This may apply to radiology services too, although physical space constraints and the nature of imaging will also play a role, in addition to the diversity and cultural responsiveness of the service. This impedes the provision of patient and whānau-centred care.

*A detailed equity analysis of how each of the challenges with the current system contributes to inequity in access, quality and outcome, and alignment to focus areas is included in **Appendix VI**.*

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# Taunakitanga hei whakatutuki wero

## Evidence of ways to address challenges

### Similarities of radiology to other diagnostic disciplines

Existing reviews commonly address radiology alongside other diagnostic disciplines, most commonly pathology and laboratory medicine (508, 509). This is in recognition of the similarities between diagnostic disciplines:

- Optimum patient care, such as in cancer, hinges on integrating the results of diagnostic testing into decision-making.
- Diagnostic disciplines tend to have similar challenges of insufficient financial support, insufficient workforce capacity, and inadequate infrastructure.
- Globally, diagnostic disciplines tend to have low visibility, despite being critical to providing high quality care. The interdependence of diagnosis and treatment is under-recognised, making it difficult to advocate effectively for national approaches, sustainable funding, and prioritisation within the health system (508).

Addressing diagnostic disciplines collectively provides a 'critical mass' for advocacy, and a common framework for defining problems and potential solutions.

### Key components of organising radiology services

Reviews of radiology services generally agree that national approaches to organising radiology services should include the following components: leadership and governance, financing, service design, workforce, infrastructure, information systems, and data collection that enables monitoring and evaluation (508, 509). No single component is enough to improve access and quality by itself, and all components are interdependent. While this means national planning and organisation is more complex, it also means that coherent improvements across these areas collectively are likely to make a significant difference to radiology services. Globally, national strategic plans for diagnostics are scarce (508).



## Radiology service design

There are multiple considerations in designing radiology services to maximise appropriate access, quality, and equity. For example, public-private partnerships have the potential to improve access and quality, but may also inadvertently create equity issues. Careful design of incentives is necessary to maximise benefits and minimise unintended consequences (508).

Commissioning levers for diagnostics (such as national pricing, contracting arrangements, service specifications, and quality requirements) should be reviewed to make sure that incentives match with strategic intentions. Another service design area to consider is in the separation of emergency/acute radiology services from planned care, traditionally not the case in Aotearoa. Such separation, when coupled with adequate capacity, can provide more convenient and timely access to patients, as well as reducing the pressure on acute sites (509-511).

## Workforce

Significant shortfalls in workforce capacity is a barrier to improving access and quality of radiology services. Workforce planning, as with infrastructure planning, should be guided by country-specific projections of demand, good data about projected supply, and an understanding of how the radiology workforce functions.

Task shifting or skill-mix initiatives can be particularly useful in radiology. Task shifting is defined as “a process whereby specific tasks are moved, where appropriate, to health workers with shorter training and fewer qualifications”, enabling qualified staff to be used at the top of their scope of practice (508). One example is the use of assistants to take on work usually done by radiographers. Task shifting has the potential to make more efficient use of existing workforce, but simply shifting activity from one area to another will not be helpful unless it is accompanied by other measures such as increasing capacity in other areas, appropriate remuneration, proper training, adequate infrastructure, and effective management (508-510, 512, 513). Newer technology such as artificial intelligence (AI) can enhance radiology workflows (such as by using computer-aided detection algorithms to help radiologists identify abnormalities), once properly evaluated and supported by other key components such as IT infrastructure (509, 513)

## Infrastructure

Widespread shortages in radiology equipment and facilities is an issue globally. Initiatives that could be helpful include more efficient use of existing infrastructure by better management, and pooling procurement to enable better pricing and equipment standardisation. Another critical part of radiology infrastructure are IT systems. Robust IT systems can enable better real-time patient management systems, disease tracking and reporting, the collection of



quality indicators to improve health system performance, and remote working in areas with workforce shortage (508-510, 514).

## Access, quality and inequities in both areas

For radiology services to optimise cancer care, they need to be available, accessible (in terms of location, timing, transport and travel) and affordable for people with cancer. In general, evidence shows that greater distance is associated with poorer uptake of health services (515). Systematic reviews across a range of countries also document the association of lower socioeconomic status with poorer participation in screening programmes (516, 517). There are also inequities by gender and race, with longer time delays from symptom recognition to diagnosis for breast cancer in African American women than for white women (518).

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# He tāpae hei panoni

## Proposal for change

Radiology services would benefit from development of a national, population-based approach to organising and planning radiology services, with a focus on Te Tiriti and equity. In the future, this national leadership function would ideally be held by Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora. With its networks and advisory groups, Te Aho o Te Kahu would be well positioned to provide a cancer perspective.

To improve the provision of radiology services, investment in capacity and diversity of the workforce, equipment, and IT is needed to meet both current and future demand. These should be tackled as parts of a national plan, rather than as stand-alone local or regional initiatives. In addition to growing capacity over time, it is necessary to make the best use of the radiology resources already in place. Areas where gains can be made include using evidence-based guidelines to standardise how imaging is used in cancer staging and surveillance and how cancer multidisciplinary meetings (MDMs) are conducted.

If radiology services are working well, then regardless of where people live:

- Patients will be offered imaging that is appropriate for their cancer needs
- Patients will have choices in terms of where they get their imaging, flexibility in timing of appointments, no out-of-pocket costs and assistance for transport and travel if needed
- Patients will have timely and high-quality scanning and reporting that maximises the quality of their cancer care
- Patients and whānau will feel safe, supported, welcome and respected in their interactions with radiology services

## Ngā wāhi hei mahi | Potential focus areas

### System leadership

#### National system leadership

1. Establish strong national leadership for radiology services that covers all aspects of population-based radiology services, with a Te Tiriti and equity focus. The national leadership function would include:
  - a. Strong Māori leadership
  - b. Representation from groups most likely to experience inequities in radiology services
  - c. Clinical leadership, including connecting with radiology expertise via sector advisory groups and stakeholders.



2. Establish additional and adequate central capacity within Health New Zealand | Te Whatu Ora and Māori Health Authority | Te Aka Whai Ora to provide national leadership, coordinate different radiology-related initiatives into a cohesive whole and reduce duplication.
  - a. Te Aho o Te Kahu, with the help of its advisory groups and networks, would be well positioned to provide cancer expertise to the national radiology leadership function.
3. A national approach to radiology services would include:
  - a. Deliberate design of the radiology system, with a willingness to consider whether existing service delivery models are fit for purpose.
    - i. For example, considering more strategic optimising of public and private radiology capacity to improve access to imaging for primary and community care in a way that allows for more choice of locations (fewer access barriers) and decreases the acute load on hospital services (fewer interruptions to planned care).
  - b. Service forecasting and planning, including a national plan for growing capacity in workforce and infrastructure to meet current and future demand.
  - c. Contributing to a national process to prioritise new and existing technologies, including imaging technologies.
  - d. Developing national standards for access and quality of radiology services, that services are monitored against.
  - e. Collective negotiation for outsourcing to the private sector e.g. a national fees schedule for imaging and reporting
4. National leadership would be supported by regional leadership, which would include partnership with Iwi health providers.
5. National leadership would consider increased investment in radiology facilities/equipment, with planning and procurement occurring at a national level.
  - a. Modelling should be undertaken to determine the demand and financial tipping points at which additional scanners are required.
6. Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora, Māori Health Authority | Te Aka Whai Ora and the Ministry of Health | Manatū Hauora to ensure that policy decisions in cancer (eg new guidelines, medicines, services and screening programmes) consider and plan for the knock-on impact on radiology services

#### Data driven

1. Centralised leadership to consider investment in radiology IT infrastructure. This includes developing a nationally shared understanding of the minimum requirements for IT infrastructure, including:
  - a. Systems that support safe and efficient workflows
  - b. Efficient storage and transfer of patient information and images
  - c. Single or functionally single system that supports access to radiology information done at other centres (historic images, public/private facilities)
  - d. Interconnects with other medical IT systems such as shared patient records, primary care systems, secondary care systems





- e. Other functionalities such as e-referrals, online booking systems, remote access to enable teleradiology so that regions with more capacity can support underserved regions, artificial intelligence supported workflows, systems that allow closed loop communication of actionable radiology findings, peer learning, image quality, and analytics.
2. Te Aho o Te Kahu to work with Ministry of Health | Manatū Hauora, Health New Zealand | Te Whatu Ora and Māori Health Authority | Te Aka Whai Ora to ensure that data submitted to national collections is fit-for-purpose for monitoring access and quality of cancer radiology services, tracking and responding to inequities (including having high-quality ethnicity data), forecasting, and service planning.

## Service distribution

### Clinical service distribution

1. A national approach to the distribution and location of new radiology services. Radiology infrastructure placement decisions should consider:
  - a. Location in relation to other cancer services, as well as resilience and business continuity contingencies should a scanner lose operational function.
  - b. Accessibility for patients and whānau
  - c. Involvement of Iwi Health Providers

### Implementation mechanisms

1. Te Aho o Te Kahu to work with Health New Zealand | Te Whatu Ora to lead the development of clear service pathways outlining treatment pathways, where and how MDMs are held and radiology requirements.
  - a. Pathways will include standardised, evidence-based guidelines for the use of imaging in staging cancers, follow-up and surveillance
2. Te Aho o Te Kahu to ensure radiology input into standardised guidance for MDMs, with a focus on a transparent and equitable approach, particularly when MDM demand exceeds capacity.

## Workforce

### Capacity

1. Additional investment to be made in radiology workforce. Shortages in radiologists and MRI technologists are the most pressing for cancer care. For example, RANZCR currently accepts about 20 new trainees each year into the radiologist training programme. It has been estimated that this should increase to 30-50 new trainees each year, with a need to re-evaluate annually. Any such increase would also need to be accompanied by a corresponding increase in the number of radiologist posts nationally.
2. Establish a national approach to investing, planning for, recruiting, and retaining the radiology workforce.
3. Consider if current training pathways are fit-for-purpose. For example, RANZCR intends to develop a training pathway that balances



requirements for generalist and specialist interventional radiology training (519, 520). There is also consideration of undergraduate specialisation for medical imaging technologists, MRI technologists, and sonographers-rather than the current postgraduate structure (NZ is an outlier internationally in this regard).

### Diversity

1. The national leadership function would include a priority focus on increasing Māori and Pacific representation across the radiology workforce.
  - a. National leadership is required to do this in a deliberate and considered way, not just providing funding, but targeted recruitment, funded training, mentorship/support, appropriate remuneration, culturally supportive workplaces, and other measures to ensure retention.

### Scope of practice

1. A national approach to radiology workforce would consider how the skill mix of the existing radiology workforce could be used in the most effective way. Skill-mix initiatives could include:
  - a. Developing the role of support staff to include administrative or logistical tasks (such as contacting and escorting patients) or for radiology registrars to do more independent work earlier in their training (such as X-ray reporting). Such initiatives would need to be supported by training pathways, legislation, medicolegal frameworks, and standardised job descriptions.



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# NGĀ ĀPITI HANGA

## APPENDICES

### Āpitihanga I: Te anga Tiriti o Waitangi me te mana taurite

### Appendix I: Te Tiriti o Waitangi and equity Framework

To ensure Te Tiriti principles and equity impacts were appropriately and consistently considered in this project and report development process, Te Aho o Te Kahu applied a Te Tiriti o Waitangi and equity framework. The full detail of this framework follows in this table:

Te Tiriti o Waitangi principles	Processes to enact Te Tiriti o Waitangi
Tino Rangatiratanga	<p>The goals, principles and aspirations of the establishment of a Māori Health Authority   Te Aka Whai Ora were considered in the development of the Report including:</p> <ul style="list-style-type: none"><li>• an understanding that the Māori Health Authority   Te Aka Whai Ora would be a lead commissioner of kaupapa Māori services, focusing on expanding and developing provision of services targeted at Māori communities and a co-commissioner for all other health services, working jointly with Health New Zealand   Te Whatu Ora to ensure that hauora Māori is prioritised</li><li>• the health system reinforces Te Tiriti o Waitangi principles and obligations at all levels, with rangatiratanga shaping care design for Māori, so Māori models of care flourish</li><li>• ensuring that Health New Zealand   Te Whatu Ora and the Māori Health Authority   Te Aka Whai Ora have access to high quality information about cancer related inequities and the current state of specialist cancer treatment services, along with</li></ul>



	<p>the best available evidence of optimal future specialist cancer service design and organisation, to inform future decision-making and service commissioning towards improving Māori cancer outcomes.</p>
Equity	<p>Establishment of Te Kāhui Mana Taurite – an Equity Steering Group, which met weekly to support and critique progress on the Report. The group consisted of a member from each internal working group, other Te Aho o Te Kahu equity leads, and a representative of Hei Āhuru Mōwai (the National Māori Cancer Leadership Group).</p> <p>Te Kāhui Mana Taurite developing an appropriate evidence base about existing inequities in specialist cancer treatment services and service design options for reducing inequities was developed to inform the <i>Report</i>:</p> <ul style="list-style-type: none"> <li>• literature search requests identified information needs to address inequities in cancer outcomes for Māori, Pacific, and other groups experiencing barriers to equitable cancer care</li> <li>• articles were reviewed systematically, including those published by Māori and Pacific academic scholars to understand the specific equity issues for these communities</li> <li>• literature reviews identified equity issues specific to each work stream as well as equity issues impacting on cancer related inequities, e.g. impact of comorbidities, poverty, structural and interpersonal racism</li> <li>• key findings from literature reviews were peer-reviewed as required by relevant experts</li> </ul>
Active protection	<p>Māori and Pacific members of He Ara Tangata (lived experiences of cancer advisory group) were invited to participate in a workshop to identify the cancer care and treatment issues for Māori and Pacific experiencing cancer, and their whānau.</p> <p>Strategic intentions from the Health &amp; Disability System Review are considered in the development of the Guidance i.e. A health system which achieves pae ora with a focus on delivering:</p> <ul style="list-style-type: none"> <li>• <b>Equity</b>, tackling the gap in access, quality and outcomes between different groups of New Zealanders, particularly for Māori compared to non-Māori, Pacific peoples compared to non-Pacific</li> </ul>



	<p>peoples, disabled people compared to non-disabled peoples, and other vulnerable groups.</p> <ul style="list-style-type: none"> <li>• <b>Partnership with Māori</b>, in how healthcare is designed, delivered and governed, and empowering everyone to help design systems which work for them.</li> <li>• <b>Sustainability</b>, preventing and reducing health need instead of just addressing illness, and promoting efficient, high quality care.</li> <li>• <b>Person and whānau-centred care</b>, which empowers everyone to manage their own health and wellbeing, giving people, their carers and whānau meaningful control.</li> <li>• <b>Excellence</b>, ensuring consistent, high-quality care everywhere, supported by clinical leadership, innovation and new technologies to continuously improve services.</li> </ul> <p>Feedback from wānanga at the Māori Community Hui – a series of 13 large hui organised by Te Aho o Te Kahu and held across Aotearoa during 2021 with around 2800 attendees – to be incorporated into the Report where relevant and appropriate as this information comes available.</p> <p>A workshop on potential models of care was held with Hei Āhuru Mōwai.</p>
Options	<p>This Report includes recommendations aimed at ensuring:</p> <ul style="list-style-type: none"> <li>• specialist cancer treatment and care for Māori is accessible and consistently outstanding, with a national network ensuring excellent care is accessible despite geographical distribution of services;</li> <li>• ensuring that appropriate enablers are considered and identified to mitigate any existing or potential inequities in the delivery of future cancer treatment services;</li> <li>• access to services is improved for Māori, including providing cancer care close to home where feasible;</li> <li>• the Māori cancer care workforce, including nurses, clinical staff, whānau ora navigators, and allied health are increased, valued, supported, well-trained and equitably funded;</li> </ul>



	<ul style="list-style-type: none"> <li>• Māori are able to access appropriate tikanga, mātauranga Māori, and rongoā services and support during their cancer treatment;</li> <li>• non-Māori working in the cancer care sector are explicitly required to show competence and continued professional development that delivers culturally appropriate care;</li> </ul> <p>Patients and whānau are empowered and enabled to feed back when services are not delivered in ways that meet their needs, and there are clear pathways to do so.</p>
Partnership	<p>Supported Māori, Pacific, and consumer input into the development of the Report:</p> <ul style="list-style-type: none"> <li>• Hei Āhuru Mōwai represented on Te Kāhui Mana Taurite;</li> <li>• members of Hei Āhuru Mowai were invited to participate in relevant workstreams and the development of the Report;</li> <li>• members of Hei Āhuru Mowai reviewed the report and invited to write a forward;</li> <li>• people with lived experience of cancer were invited across all workstreams in this project;</li> <li>• each workstream included Māori clinical expertise and consumer input where this is feasible;</li> </ul> <p>Stakeholder engagement with Māori and Pacific occurred during the development of the Report.</p>



# Āpitihanga II: Ka Hono Ki Te Hunga Whaipānga

## Appendix II: Stakeholder Engagement

List of groups who have been engaged and contributed insights to this work

Group	Representatives
Te Aho o Te Kahu Advisory Council	<ul style="list-style-type: none"> <li>Shelley Campbell - CEO (Waikato/Bay of Plenty Cancer Society)</li> <li>Keriana Brooking - CEO (Hawke's Bay DHB)</li> <li>Dr Christopher Jackson - Medical Oncologist (Southern DHB)</li> <li>Graeme Norton - Chair (Health Consumer Councils of New Zealand)</li> <li>Dr Nina Scott - Chair (Hei Āhuru Mōwai - Māori Cancer Leadership Aotearoa), Public Health Physician (Waikato DHB)</li> <li>Dr Richard Sullivan - Director Cancer and Blood (Auckland DHB), Director of Northern Cancer Network</li> <li>Professor Jonathan Koea - Surgeon (Waitemata DHB), Professor (Auckland School of Medicine)</li> <li>Dr Apisalome Talemaītoga - General Practitioner, Pacific Health Advocate</li> </ul>
Hei Āhuru Mōwai (members listed provided detailed contribution across project workstreams and/or hui)	<ul style="list-style-type: none"> <li>Moahuia Goza - CEO (Hei Āhuru Mōwai)</li> <li>Professor Jonathan Koea - Surgeon (Waitemata DHB), Professor (Auckland School of Medicine)</li> <li>Dr Myra Ruka - Haematologist (Waikato DHB)</li> <li>Shelley Campbell - CEO (Waikato/Bay of Plenty Cancer Society)</li> <li>Tira Albert - Manager (Mana Wahine)</li> <li>Dr George Laking - Medical Oncologist (Auckland DHB)</li> <li>Lisa Te Paiho - Equity and Bicultural Practice Programme Lead Cancer Focus (MidCentral Health)</li> <li>Dr Jason Gurney - Senior Research Fellow and Director (Cancer and Chronic Conditions), Research Portfolio Leader, Department of Public Health (University of Otago)</li> <li>Rachel Miller - Cancer Nurse Coordinator (Southern DHB)</li> <li>Assoc. Professor Jacquie Kidd - Deputy Head of School - Teaching and Learning Lead (Auckland University of Technology)</li> <li>Gail McLauchlan - Māori Relationship Manager (Canterbury DHB, Community and Public Health)</li> <li>Kendall Stevenson - Research Fellow (Victoria University of Wellington)</li> <li>Dr Kimiora Henare - Research Fellow (Victoria University of Wellington)</li> <li>Dr Monica Koia - Senior Research Officer (Massey University)</li> <li>Assoc. Dean Leanne Te Karu - Assoc. Dean (Māori) School of Pharmacy (Otago University)</li> </ul>





<p>He Ara Tangata (Te Aho o Te Kahu Consumer Reference Forum/lived experience) <i>(all members provided detailed contribution across project workstreams)</i></p>	<ul style="list-style-type: none"> <li>• Brian Sheppard</li> <li>• Christine Sapwell</li> <li>• Diana Ayling</li> <li>• Heather Browning</li> <li>• Henare Kani</li> <li>• Jo Stafford</li> <li>• Leilani Jackson</li> <li>• Libby Burgess</li> <li>• Marj Allan</li> <li>• Mary Bradley</li> <li>• May Seager</li> <li>• Ngāroimata Reid</li> <li>• Sarah Koopu</li> <li>• Theona Ireton</li> <li>• Vivian Hahipene</li> </ul>
<p>Te Aho o Te Kahu Clinical Assembly</p>	<ul style="list-style-type: none"> <li>• Dr Christopher Jackson - Medical Oncologist (Southern DHB)</li> <li>• Dr Claire Hardie - Radiation Oncologist (MidCentral DHB), Chair Radiation Oncology Working Group</li> <li>• Dr Richard North - Medical Oncologist (Bay of Plenty DHB), Chair Medical Oncology Working Group</li> <li>• Dr Tom Middlemiss - Palliative Care Specialist representing, Hospice NZ, Hospital Palliative Care NZ and ANZSPM (Hutt Valley DHB, Te Omanga Hospice)</li> <li>• Dr James Entwisle - Radiologist, Clinical Director - Strategy, Innovation &amp; Performance (Capital and Coast DHB)</li> <li>• Dr Chris Hemmings - Clinical Director Anatomical Surgical Pathology, Canterbury Health Laboratories (CHL)</li> <li>• Mary-Ann Hamilton - Clinical Nurse Specialist/Cancer Co- ordinator - Equity and Access, (Waikato DHB); Representative, Cancer Nurses College, NZNO</li> <li>• Dr Humphrey Pullon - Haematologist (Waikato DHB)</li> <li>• Dr Suzanne Beuker - Urologist (Nelson/Marlborough DHB)</li> <li>• Sue Waters - Director of Allied Health, Chair of the National Directors of Allied Health (Auckland DHB)</li> <li>• Justin Gulliver - Advanced Practitioner, Social Work, Cancer Support Team, NZ rep. OSWANZ (Capital and Coast DHB)</li> <li>• Dr Scott MacFarlane - Clinical Lead, National Child Cancer Network (Auckland DHB)</li> <li>• Heidi Watson - Clinical Lead, Adolescent and Young Adult (AYA) Cancer Network (Auckland DHB)</li> <li>• Dr Alex Henderson - National Clinical Leader, Cancer Genetics (Capital and Coast DHB)</li> <li>• Professor Ian Bissett - Surgeon (Auckland DHB)</li> <li>• Professor Jonathan Koea - Surgeon (Waitemata DHB), Professor (Auckland School of Medicine)</li> <li>• Dr Ineke Meredith - Breast Surgeon (Capital and Coast DHB)</li> <li>• Dr John McMenamin - General Practitioner (Whanganui General Practice), Representative, The Royal New Zealand College of General Practitioners</li> <li>• Laura Clunie - Pharmacist (Canopy Cancer Care, Auckland)</li> <li>• Catherine D'Souza - Palliative Medicine Lead, South Canterbury DHB; University of Otago</li> </ul>
<p>Te Aho o Te Kahu Radiation Oncology Working Group</p>	<ul style="list-style-type: none"> <li>• Working Group chaired by Claire Hardie (Radiation Oncologist (MidCentral DHB)) and made up of clinical leads (public and private), recognised experts nominated by their organisation, sector or speciality group</li> </ul>



Te Aho o Te Kahu Medical Oncology Working Group	<ul style="list-style-type: none"> <li>Working Group chaired by Richard North (Medical Oncologist (Bay of Plenty DHB)) and made up of clinical leads, recognised experts nominated by their organisation, sector or speciality group</li> </ul>
Te Aho o Te Kahu Haematology Working Group	<ul style="list-style-type: none"> <li>Working Group made up of recognised experts nominated by their organisation, sector or speciality group</li> </ul>
Te Aho o Te Kahu National Bowel Cancer Working Group	<ul style="list-style-type: none"> <li>Working Group chaired by Ian Bissett - Surgeon (Auckland DHB), and made up of recognised experts nominated by their organisation, sector or speciality group</li> </ul>
Sector expertise working group (Medical Oncology)	<ul style="list-style-type: none"> <li>Dr Ben Lawrence - Medical Oncologist (Auckland DHB)</li> <li>Dr Chris Jackson - Medical Oncologist (Southern DHB)</li> <li>Dr Fritha Hanning - Medical Oncologist (Auckland DHB)</li> <li>Dr Garry Forgeson - Medical Oncologist (MidCentral DHB)</li> <li>Dr George Laking - Medical Oncologist (Auckland DHB)</li> <li>Dr Kate Gregory - Medical Oncologist (Nelson Marlborough DHB)</li> </ul>
Cancer Society NZ	<ul style="list-style-type: none"> <li>Shayne Nahu (Advocacy and Research Manager)</li> <li>Yuliya Evdokimova (National Advisor: Supportive Care &amp; Policy)</li> <li>Marie Wales (Supportive Care Manager, Otago &amp; Southland)</li> <li>Michelle Gundersen-Reid (Supportive Care Manager, Auckland/ Northland)</li> <li>Pauline Farquhar (Supportive Care Manager, Central Districts)</li> <li>Jenni Drew (Supportive Care Manager, Wellington)</li> <li>Kate Velenski (Supportive Care Manager, Christchurch)</li> <li>Hazem Abd Elkader (National Office)</li> </ul>
NZ Nurses Organisation / NZ Cancer Nurses College Committee (representatives of)	<ul style="list-style-type: none"> <li>Sarah Ellery</li> <li>Mary-Ann Hamilton</li> <li>Courtney Morgan</li> <li>Lynda Dagg</li> <li>Kirstin Wagteveld</li> <li>Nadine Gray</li> <li>Ellyn Proffit</li> </ul>
New Zealand Hospital Pharmacists' Association Compounding, Nutrition and Oncology Special Interest Group (NZHPA CNO SIG)	<ul style="list-style-type: none"> <li>Maxine Handford – Senior Pharmacist (Waikato DHB), Co-Convenor (NZHPA CNO SIG)</li> <li>Cath Oliver – Haematology Pharmacist (Auckland DHB), Co-Convenor (NZHPA CNO SIG)</li> <li>Laura Clunie – Pharmacist (Canopy Cancer Care)</li> <li>Chloë Campbell – Professional Practice Pharmacist (Pharmaceutical Society of New Zealand)</li> <li>Kay Lengyel – Pharmacist (Northland DHB)</li> <li>Billy Allan – Pharmacy Manager (Ministry of Health)</li> <li>Joanna Buchanan – Pharmacist (Harbour Cancer Centre)</li> </ul>
DHB Pharmacy Managers	<ul style="list-style-type: none"> <li>Working group chaired by Gail Edwards – Chief Pharmacist (Wairarapa DHB) and comprised of DHB pharmacy managers from all DHBs in New Zealand</li> </ul>
Royal Australasian College of Surgeons (RACS)	<ul style="list-style-type: none"> <li>Miss Philippa Mercer (Chair NZ National Board)</li> <li>Mr Andrew McCormick (Deputy Chair NZ National Board)</li> <li>Professor Spencer Beasley (Surgical Adviser Aotearoa New Zealand to RACS Council)</li> </ul>
Health Workforce New Zealand (Ministry of Health)	<ul style="list-style-type: none"> <li>Laura O'Sullivan</li> <li>Emmanuel Jo</li> <li>Amy Wilson</li> </ul>



National Collections (Ministry of Health)	<ul style="list-style-type: none"> <li>Data Services &amp; Data Management Teams</li> </ul>
Health System Reforms Transition Unit	<ul style="list-style-type: none"> <li>Chris Mules</li> <li>Dr David Galler</li> <li>Dr Mataroria Lyndon</li> <li>Kris Macdonald</li> <li>Dominique Squires-Newby</li> </ul>
Royal Australian New Zealand College of Radiologists (RANZCR)	<ul style="list-style-type: none"> <li>NZ Branch Manager</li> </ul>

List of individuals who have been engaged and contributed insights to this work

Individual	Role
Andrew Connolly	Chief Medical Officer (Ministry of Health)
Anthony Doyle	Chief Radiology Advisor (Ministry of Health)
Apisalome Talemautoga	General Practitioner, Pacific Health Advocate
Betty Savage	Equity Navigator (Hawkes Bay DHB)
Caroline Aberhart	Pharmacist (Blenheim)
Charis Frethey	Programme Manager (NZ Telehealth Leadership Group)
Cheree Shortland-Nuku	Māori Health Directorate (Ministry of Health)
Chris Hemmings	Clinical Director of Anatomical Pathology (Canterbury DHB)
Claire Hardie	Radiation Oncologist (MidCentral DHB)
Darien Montgomerie	Site Manager (Bowen ICON Cancer Centre)
Denise Redwood	Radiation Therapy Services Manager (Auckland Radiation Oncology)
Ellyn Proffit	AYA CNS Midland Region (Waikato DHB)
Gerardine Clifford-Lidstone	Director Pacific Health (Ministry of Health)
Hector Matthews	Executive Director Māori and Pacific Health (Canterbury DHB)
Heidi Watson	Clinical Lead (Adolescent & Young Adult (AYA) Cancer Network Aotearoa)
Humphrey Pullon	Haematologist (Waikato DHB) / Clinical Advisor (Te Aho o Te Kahu)
Ian Bissett	Colorectal Surgeon (Auckland DHB)
James Entwisle	Radiologist, Clinical Director - Strategy, Innovation & Performance (Capital and Coast DHB)
Jeremy Webb	Division of Rural Hospital Medicine
Jim Green	CEO (Tairāwhiti DHB)



John Windsor	Professor of Surgery (Auckland University), Consultant Surgeon (Auckland DHB)
Jonathan Koea	Surgeon (Waitemata DHB), Professor (Auckland School of Medicine)
Julie Hook	Disability Services Transformation Programme (Ministry of Health)
Justin Gulliver	Advanced Practitioner, Social Work, Cancer Support Team, NZ rep. OSWANZ (Capital and Coast DHB)
Kath Fuohy	General Manager Dietitians NZ, Allied Health Aotearoa President
Kim Gear	Dentist (Auckland Head & Neck Specialists)
Leanne Tyrie	Radiation Oncologist, Clinical Director/Chief Operating Officer (Kathleen Kilgour Centre)
Lisa Te Paiho	Equity and Bicultural Practice Programme Lead Cancer Focus (MidCentral Health), Hei Āhuru Mōwai
Lou James	Founder – Pinc & Steel, Cancer Rehabilitation Trust
Louise Simonsen	Service Clinical Director Radiation Oncology, Te Pūriri o Te Ora Regional Cancer and Blood Service
Lynne Greig	Chair, Lead Radiation Oncology Medical Physicists Group
Mandy Robinson	Navigator (Hawkes Bay DHB)
Martin Chadwick	Chief Allied Health Professions Officer (Ministry of Health)
Mary-Ann Hamilton	Clinical Nurse Specialist/Cancer Co-ordinator - Equity and Access, (Waikato DHB); Representative, Cancer Nurses College, NZNO
Megan Purves	New Zealand Branch Manager (Royal Australian and New Zealand College of Radiologists)
Michael Taylor	Chair, Radiation Therapy Advisory Panel
Moahua Goza	CEO (Hei Āhuru Mōwai)
Myra Ruka	Haematologist (Waikato DHB), Hei Āhuru Mōwai
Peter Ferguson	CEO, Leukaemia & Blood Cancer New Zealand
Rachel Miller	Cancer Nurse Coordinator (Southern DHB), Hei Āhuru Mōwai
Renee Wood	Rehabilitation Physiotherapist, Tū Tonu
Richard Egan	University of Otago & Cancer Society Research Collaboration Unit
Richard Sullivan (UK)	Professor, Cancer & Global Health at Kings College (London, UK)
Sarah Ellery	Oncology Clinical Nurse Specialist (Canterbury DHB)



Scott Macfarlane and Elizabeth Ryan	National Child Cancer Network NZ
Shaun Costello	Radiation Oncologist (Southern DHB) / Clinical Advisor (Te Aho o Te Kahu)
Sue Crengle	Chair, Te Waipounamu Māori Leadership Group for cancer, Professor in Department of Preventive and Social Medicine (Otago University), Hei Āhuru Mōwai
Sue Waters	Chair of DHB Directors of Allied Health, Chief Health Professions Officer (Auckland DHB)
Terry Taylor	NZ Institute of Medical Lab Scientists
Tira Albert	Manager (Mana Wahine), Hei Āhuru Mōwai
Tory Crowder	Clinical Manager Nutrition and Dietetics (Canterbury DHB)
Viv Ali	Practice Manager (St George's Cancer Care Centre)



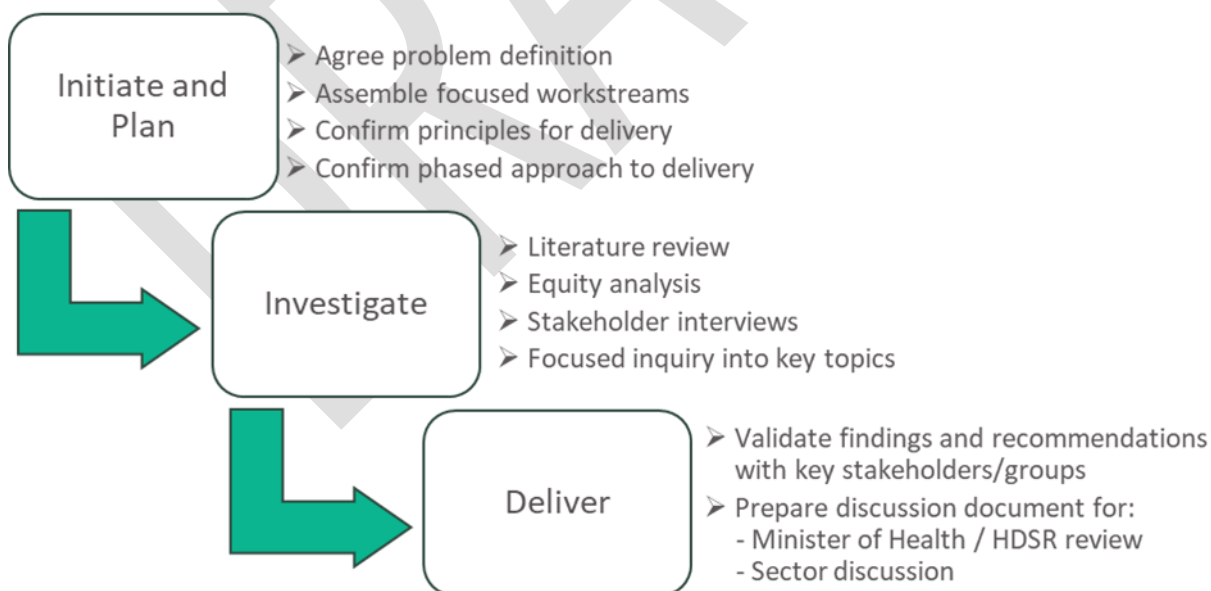
# Āpitihanga III: Te tukanga

## Appendix III: Project methodology

The Cancer Treatment Services Planning project engaged several components of project methodology to ensure delivery of the final products, consisting of a Recommendations Summary and supporting Technical Report. These core components included:

- Scope definition
- Strategic alignment
- Project team structure (role definition, organisation and operationalisation)
- Project governance (definition and operationalisation, including risk review and management, budget management)
- Equity analysis (consistent framework application)
- Stakeholder engagement (planning, delivery)
- Literature search/analysis (current state review)

### Project Approach



### Stage One: Initiate and Plan

After delivery to the Government of the HDSR report, Te Aho o Te Kahu identified that the Agency was well-positioned to provide advice on the structure and approach to cancer treatment services. The reforms would provide opportunities to provide leadership to ensure cancer services were provided to New Zealanders in a way that is safe, effective, cohesive and sustainable.



After discussions with HDSR, the recommendation was to focus first on specialist cancer treatment at national, regional and local levels. Te Aho o Te Kahu supported this approach, and the Advisory Council developed the following problem definition:

### **Problem Definition**

Cancer survival is not improving as quickly in Aotearoa as other comparable countries. The current treatment service model for cancer in our hospitals does not:

- meet Crown obligations under Te Tiriti o Waitangi & the United Nations Declaration on the Rights of Indigenous Peoples
- have adequate focus on eliminating inequities in cancer incidence, survival & mortality
- drive improvements to survival rates, as compared with other similar countries
- provide a high-trust, racism free, whole of system approach that maximises wellbeing for individuals & their whānau
- demonstrate strong, collective leadership & accountability across the sector
- deliver efficient coordination of services to improve overall system costs.

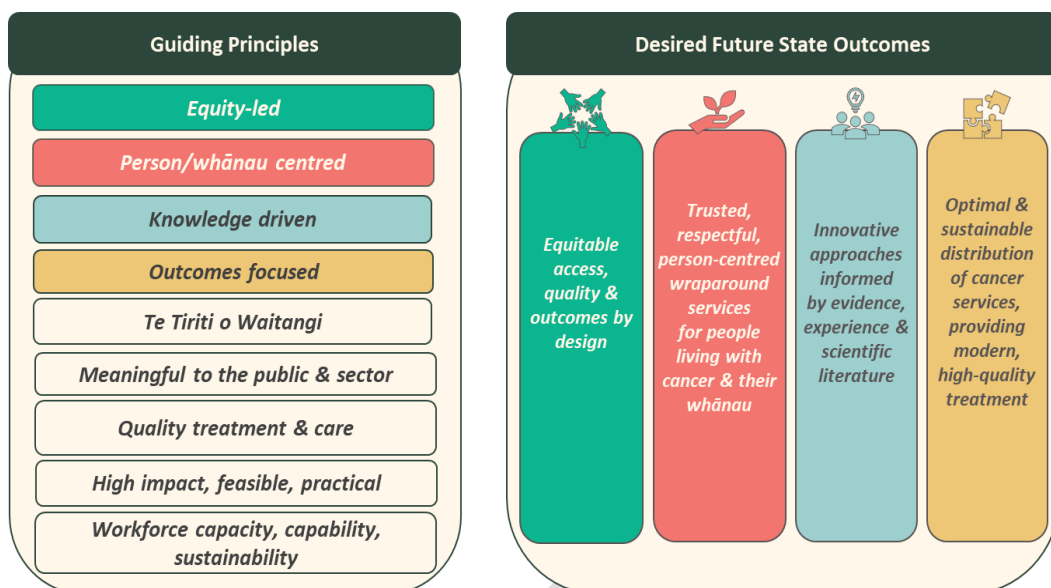
Work to improve cancer services needed to include bringing care ‘closer to home’ as much as is safely possible, ensure services are person and whānau-centred, identify how and where highly specialised services could be located, how integration and coordination could be enhanced, and, most importantly, identify how services could be equitably delivered.

Once the focus on cancer services planning was identified, Te Aho o Te Kahu established workstreams and governance structures to enable delivery.

The project sought engagement and support from its Consumer Reference Group (He Ara Tangata) to ensure that the whole project was framed with people and whānau at the centre. Engagement and support was also accessed from Hei Āhuru Mōwai, Māori Cancer Leadership.

The project agreed a phased approach to delivery (ie schedule implementation across a number of years based on Te Aho o Te Kahu, Health New Zealand | Te Whatu Ora and Māori Health Authority | Te Aka Whai Ora agreed priorities) and engaged set of principles as a guiding approach throughout delivery, which are summarised below. Te Tiriti alignment was enabled through a further set of principles developed and driven by the Equity Steering Group.





## Stage Two: Investigate

As part of the investigation stage, teams were tasked with conducting literature searches and analysis (to inform a current state review of international evidence and trends) for their respective workstream focus areas. This consisted of both national and international literature searches, and also, where relevant, included grey literature.

Each workstream was also tasked with completing an equity analysis across their content; this was a consistent format applied to each workstream, and completed by a dedicated equity team member within each workstream.

A stakeholder engagement mapping exercise was undertaken to ensure comprehensive identification of stakeholders and a series of face-to-face interviews was undertaken throughout 2021. Comments were also received by email and phone. Those interviewed included clinical working groups, HDSR, He Ara Tangata, Hei Āhuru Mōwai, clinicians from across the cancer sector, Māori health leaders (including members of Hei Āhuru Mōwai, Māori Cancer Leadership), Pacific health leaders, DHB senior managers, allied health professionals, clinical nurse specialists and navigators. A full list of stakeholders interviewed is included as an appendix of the Recommendations Summary.

Patient and whānau comments were gathered from He Ara Tangata (Te Aho o Te Kahu Consumer Reference Group), and from Hei Āhuru Mōwai. Each workstream had a dedicated He Ara Tangata consumer represented on the team in an advisory capacity, and Hei Āhuru Mōwai members for peer review, advice and input.





Interview questions were tailored to each interviewee and were broadly based on the interview questions below. Following completion of the interviews, a thematic analysis of interview notes was carried out.

#### Interview questions

- In relation to cancer treatment in Aotearoa New Zealand, in your view:
- What works well?
- What doesn't work well?
- What barriers do health professionals face when trying to provide quality cancer treatment/ wraparound support services?
- What barriers do patients/whānau face when trying to access quality cancer treatment/ wraparound support services?
- What opportunities are there to do better? What should we change?
- Do you have any examples of changes that have been tried, and to what extent they worked?

As the project progressed, focused inquiry into emerging key topics was undertaken. This included accessing relevant scientific literature, surgical data, and details of current practice in Aotearoa and comparable countries.

### Stage Three: Deliver

The thematic analysis from the content of the stakeholder consultation was initially summarised into key themes for improvement in cancer treatment service delivery. Following this initial analysis, these findings and possible future options for the distribution and delivery of cancer treatment services were presented as a Recommendations Summary, driven from the common results found across each workstream through engagement and analysis:

- The need for a transformative approach to cancer treatment and support
- National system leadership
- Clinical service distribution
- Workforce
- Coordination and support services

The Recommendations Summary report, as well as this more detailed report, describe and discuss the findings and outline potential action areas to improve services.



# Āpitihanga IV: Ngā hanga tātaki

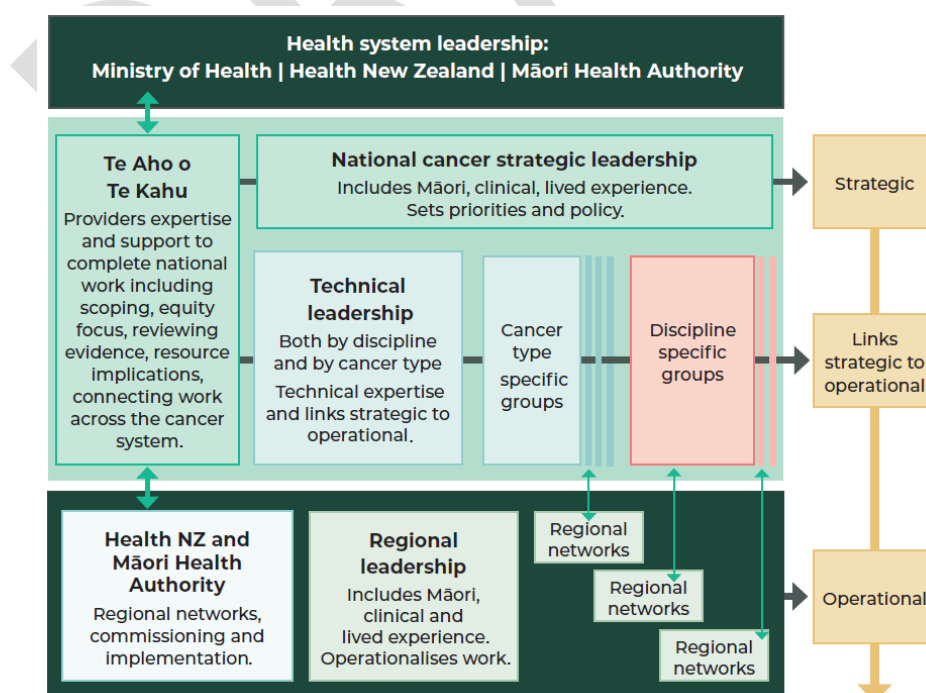
## Appendix IV: Leadership Structures

Many of the challenges that have emerged across the cancer system are from uncoordinated and ad-hoc planning, leading to variation in the structure and delivery of services and, ultimately, inequitable outcomes.

Te Aho o Te Kahu was established in 2019 in response to these issues, to provide strong national leadership across cancer control. Through the Cancer Services Planning work, and other work undertaken by Te Aho o Te Kahu over the last two years, there are three levels of leadership networks required to improve cancer outcomes: national strategic leadership, technical leadership, and regional leadership.

As Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora are established other leadership structures across the health system will become clearer. Part of the role of Te Aho o Te Kahu will be to connect with these entities to align work. Figure 23 presents a summary of the leadership structures in the new system, with each of the three levels described below and further discussed in

Figure 23: Leadership structures to improve equitable cancer outcomes



## National strategic leadership

**Requirements:** strategic leadership, planning and decision making at a national level. This includes determining priorities and approaches to work. To be effective at improving cancer outcomes and eliminating inequity, leadership structures must include strong leadership from Māori, clinicians and people with lived experience of cancer.

**Current structure:** Te Aho o Te Kahu has a mandate to provide national leadership for cancer control in Aotearoa and improve equity across the cancer system. This function is currently supported by:

- **Advisory council:** the Advisory Council supports the leadership and ongoing direction of Te Aho o Te Kahu. It helps ensure a whole-of-system focus by providing oversight and advice across prevention, detection, diagnosis, treatment and care. Members include clinical and non-clinical cancer leaders, with equal numbers of Māori and non-Māori.
- **Hei Āhuru Mōwai:** Hei Āhuru Mōwai is the Māori Cancer Leadership Group. Its membership and Chair are determined by its own internal processes and include members with a range of expertise relating to Māori (including clinical, community care, epidemiology, health services management and research). The Chair of Hei Āhuru Mōwai is also a member of the Te Aho o Te Kahu Advisory Council.
- **Clinical Assembly:** the Clinical Assembly provides clinical advice and expertise to support the strategic direction of Te Aho o Te Kahu. It includes representatives from a broad range of disciplines, including medical oncology, surgery, radiation oncology, allied health specialists and nursing. The Chair of the Clinical Assembly is also a member of the Te Aho o Te Kahu Advisory Council.
- **He Ara Tangata:** the purpose of the He Ara Tangata (Consumer Reference Group) is to provide lived-experience expertise and advice to Te Aho o Te Kahu. 50% of the group identify as Māori. The Chair of He Ara Tangata is also a member of the Te Aho o Te Kahu Advisory Council.

**In the new health system:** Te Aho o Te Kahu will continue to provide national leadership for cancer control. From 1 July 2022, Te Aho o Te Kahu will work to socialise the high-level strategic direction across agencies and establish how Te Aho o Te Kahu can work alongside Health New Zealand | Te Whatu Ora and Māori Health Authority | Te Aka Whai Ora. This will also include considering how Te Aho o Te Kahu Māori, clinical and consumer leadership groups align with leadership groups in the new health system.



## Technical leadership

**Requirements:** technical (or subject matter) expertise is required by both cancer type (eg lung cancer) and by discipline (eg medical oncology or coordination services) to ensure quality and consistency of care and to manage integration of policy into practice. To be effective, technical leadership must provide a 'linking' function, connecting strategic thinking with frontline expertise and linking to the regional networks.

Technical cancer-related leadership and expertise must be supported and facilitated by Te Aho o Te Kahu as an Agency. The role of the Agency is to 'do the doing', as well as ensure consistency of the approach to work and alignment with the strategic direction.

**Current structure:** this function is provided by a number of clinical advisory groups to Te Aho o Te Kahu. This includes discipline specific working groups - Radiation Oncology Working Group (ROWG), Medical Oncology Working Group (MOWG) and Haematology Working Group (HWG) – and tumour specific working groups e.g lung cancer working group, bowel cancer working group. The role of these working groups is to provide expert advice to Te Aho o Te Kahu.

**In the new system:** Te Aho o Te Kahu will enable and support cancer-related technical expert groups to provide leadership. This advice will inform the work of Te Aho o Te Kahu, which in turn will support the operational roles of Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora. Technical expert groups will be a combination of permanent advisory groups, and those formed for a time-limited specific function to support specific pieces of work.

## Regional networks

**Requirements:** leadership is required at regional and local levels to implement change. Examples of this type of leadership include local application of treatment pathways, staff workload management and service resilience work.

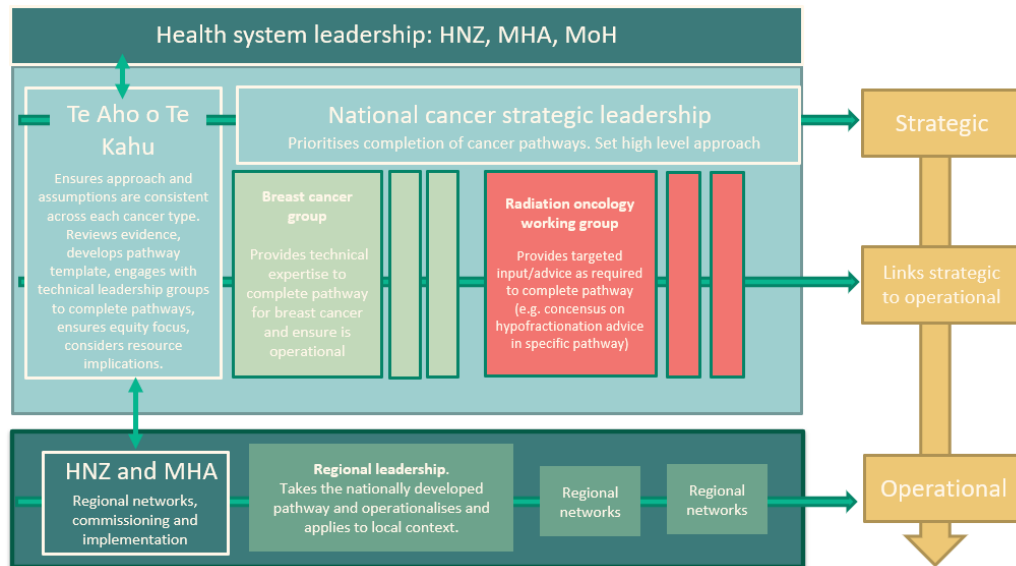
**In the new system:** the structure and functions of regional leadership will be determined by Health New Zealand | Te Whatu Ora and the Māori Health Authority | Te Aka Whai Ora. Regional service delivery needs to be robust and resilient, and therefore regional groupings need to be optimised so that short term issues (such as leave, sickness, resignation, failure of recruitment) does not disrupt patient care. Te Aho o Te Kahu will largely stay removed from frontline operational matters, but will maintain an understanding of local issues and provide support through the four Te Aho o Te Kahu Regional Hubs.



## How this looks in practice

One example of a 'function' that requires system leadership is the consistent treatment pathways for different cancers type. The different roles and functions are outlined below:

**Figure 24: Example of leadership structure for cancer service pathways**



## Functions that require national leadership

Across cancer treatment services several areas were identified that require strengthened national leadership. This included:

- Planning and implementation of distribution of cancer services
- Workforce planning and forecasting
- Assessment and implementation of new technology, including horizon scanning
- Infrastructure planning and commissioning
  - Cancer specific: LINACs
  - General: physical buildings, integrated IT/patient management system etc
- Consistent cancer care pathways
- Quality assurance and quality improvement
- Data systems for monitoring and reporting
- Coordination and support services
- Understanding potential threats or disruptions to cancer services (eg cybersecurity, pandemic) and proactively ensure strong national, regional and local responses
- Planning, implementation and monitoring of primary care, laboratory/pathology, radiology and palliative care services in relation to cancer care

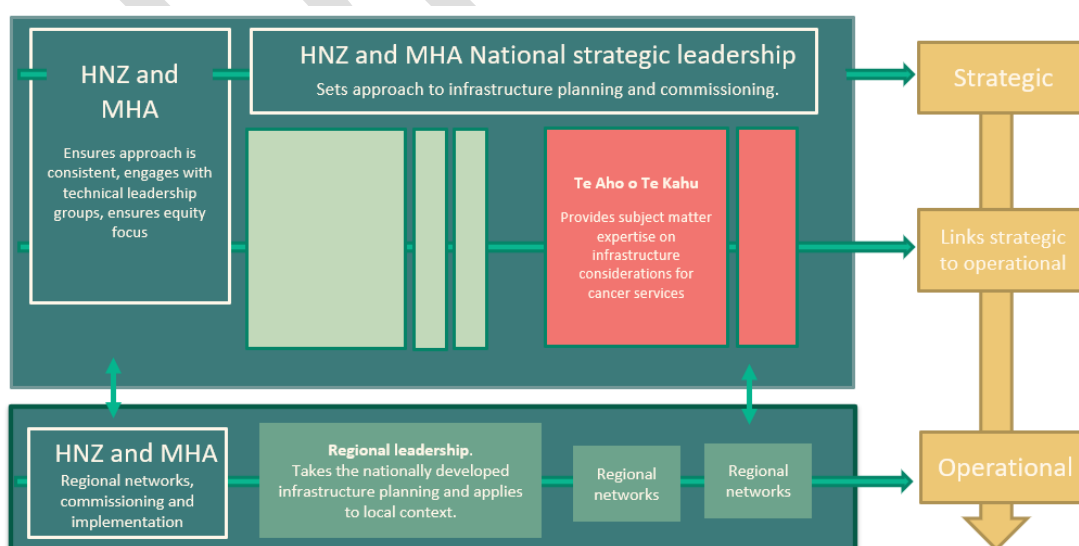


Te Aho o Te Kahu has a different role across these functions.

- 1) **Lead:** Te Aho o Te Kahu leads the development and delivery of the work, and links with other health entities as key stakeholders. For example:
  - Development of consistent cancer care pathways
  - Cancer monitoring and reporting.
- 2) **Provide leadership, with implementation by others:** Te Aho o Te Kahu provides strategic leadership and advice, and implementation sits with other health entities and commissioning agencies. For example:
  - Workforce planning and forecasting
  - Planning and implementation of distribution of services and pathways
  - Planning and implementation around cancer specific infrastructure (eg LINACs).
- 3) **Provide advice to others:** work is primarily led out of another agency and Te Aho o Te Kahu can provide cancer subject matter expertise and advice as required. For example:
  - General infrastructure planning and commissioning e.g. physical buildings, integrated IT/patient management system
  - Assessment of new technology, including horizon scanning
  - Planning, implementation and monitoring of primary care, laboratory/pathology, radiology and palliative care services in relation to cancer care.

When Te Aho o Te Kahu is undertaking the third leadership function (providing advice to others) the roles in the leadership structure shift, with Te Aho o Te Kahu taking a 'Technical Leadership' role. Figure 25 provides an example of the role of Te Aho o Te Kahu to provide technical leadership in the planning and commissioning of infrastructure.

Figure 25: Example of leadership structure for planning and commissioning of infrastructure



# Āpiti hanga V: Te Tauira Taputapu Maimoa hei Ruruku Tapuhi Mate Pukupuku

## Appendix V: Cancer nurse coordinator initiative Draft Triage Tool

Sourced from Cancer Nurse Coordinator Initiative Evaluation Final Report 2016

Triage Category	Presentation	Action	Outcome
1	Confirmed diagnosis Requires psycho-social support AND/ OR Has complex care coordination needs Has poor understanding of treatment trajectory Nurse Coordinator acts as primary nurse	Comprehensive assessment Liaise with MDM to identify a coordinated plan of care Act as first point of contact Lead role in facilitating care Patient care is focused on symptom management, information and supportive care Recognise barriers in care and opportunities to progress service development	Patient is enrolled in care of Cancer Nurse Coordinator
2	High suspicion of cancer or confirmed diagnosis Requires psycho-social support AND/ OR Has complex care coordination needs Clear treatment pathway identified Engaged with HCP at key points on treatment trajectory	Comprehensive assessment Liaise with MDM to identify a coordinated plan of care Patient care is focused on support and information Manage transition between treatment services Referral to support services Recognise barriers in care and opportunities to progress service development	Patient is enrolled in care of Cancer Nurse Coordinator
3	Confirmed cancer diagnosis Single modality treatment Psychosocial needs are met Does not meet DHB criteria for complex care coordination Engaged with established treatment team	Review referral and patient information Liaise with treatment teams as necessary Signpost availability of information and education materials Update patient records as required Maintain data	Patient registered with Cancer Nurse Coordinator  Patients care will be managed by established DHB (cancer) services
4	High suspicion of cancer Psychosocial needs met Does not meet DHB criteria for complex coordination Patient has clear understanding of the diagnostic pathway	Review referral and patient information Liaise with treatment team as necessary e.g. GP, MDM Update patient records as required Maintain data	Patient registered with Cancer Nurse Coordinator Initiative





# Āpitihanga VI: Te kupu whakarāpopoto mō ngā take mana taurite me ngā mahi hei mahi

## Appendix VI: Summary of equity issues and proposed focus areas

Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	Topic-specific solutions to address inequity Note: some solutions are shorted for space, refer to specific sections for full details
<p><b><u>The need to travel creates barriers to accessing treatment</u></b></p> <p>The distribution of services and service delivery model mean that patients often have to travel to receive treatment. Barriers include both the cost associated with travel (discussed further below) and also the time and separation from whānau and time off work, both of which create inequity in access.</p>	<ul style="list-style-type: none"> <li>• “Why is it the sick person that has to do all the travel?”</li> <li>• “Being close to whānau when undergoing treatment is rongoā.”</li> <li>• “Life admin is harder when you have cancer”</li> <li>• “Bring care to where we live – don’t make us travel long distances to you.”</li> <li>• “Why can’t clinicians do the travel? Don’t make the</li> </ul>	<p><b>Distribution of services</b></p> <ul style="list-style-type: none"> <li>• Decisions around the distribution of cancer services occur at a national level and consider: <ul style="list-style-type: none"> <li>○ Stratification of services based on criteria including volumes, complexity and support service requirements.</li> <li>○ Decisions about service distribution assess and consider likely impacts on equity for Māori, Pacific, geographically remote, and</li> </ul> </li> </ul>	<p><b>Coordination and support services</b></p> <ul style="list-style-type: none"> <li>• Design, plan, and implementation of cancer coordination and support services.</li> <li>• Acknowledge and support the not-for-profit sector, to ensure the essential services they provide are considered when planning sustainable national support services.</li> </ul> <p><b>Surgery</b></p> <ul style="list-style-type: none"> <li>• Nationally led process for distribution of surgical cancer services. High-complexity surgical procedures with a clear, strong link between volumes and outcomes</li> </ul>



Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	Topic-specific solutions to address inequity Note: some solutions are shorted for space, refer to specific sections for full details
<ul style="list-style-type: none"> <li>• People often have to travel to receive <b>surgical care</b>, and there is a risk that any centralisation of complex services may create inequity in access.</li> <li>• Requirement to travel long distances to receive <b>radiation therapy</b> can limit the ability for patients to choose this as a therapy option</li> <li>• <b>SACT</b> delivery model often relies heavily on people travelling to hospitals to receive SACT.</li> <li>• A patient's primary <b>supportive care</b> services are provided by their DHB of residence and don't necessarily follow them when they have to travel away for their treatment</li> </ul>	<p>sick person do all the travel."</p> <ul style="list-style-type: none"> <li>• "Ease transport barriers"</li> <li>• "Need coordinated travel and accommodation support"</li> <li>• "Establish treatment clinics in the community."</li> <li>• "Every time I needed a biopsy, that meant a whole day off work. Plus another day each time the results came through."</li> </ul>	<p>socioeconomically disadvantaged communities.</p> <ul style="list-style-type: none"> <li>◦ Integration across services is considered, with the patient pathway mapped to ensure the default care pathway is appropriate and mitigates potential inequities in access</li> <li>• Care is provided as close to home as is possible without compromising safety and quality. This includes the provision of outreach and virtual clinics with a particular focus on achieving equity of access in underserved communities.</li> <li>• Where centralisation is required to ensure equity of quality, this does not occur without critical implementation mechanisms to make sure care is person and whānau-centred and achieves equity of access and outcomes, including: well-defined patient pathways, accommodation and transport support, referral and communication protocols and</li> </ul>	<p>centralised and less complex cancer surgery delivered as close to home as is possible, sustainable and safe.</p> <ul style="list-style-type: none"> <li>• Centralisation does not occur without critical implementation mechanisms to ensure care achieves equity of access and outcomes. Key factors include: <ul style="list-style-type: none"> <li>◦ well-defined patient pathways</li> <li>◦ accommodation and transport support</li> <li>◦ outreach clinics and localised prehabilitation and follow-up</li> <li>◦ referral and communication protocols and shared care arrangements that support continuity of care.</li> </ul> </li> </ul> <p><b>Radiation therapy</b></p> <ul style="list-style-type: none"> <li>• Support the ongoing roll out of LINACs outside of major centres to enable increased access to radiation therapy.</li> <li>• Radiation oncology services continue to provide outreach clinics with a particular focus on achieving equity of access to services in underserved communities.</li> </ul> <p><b>SACT/HSCT</b></p> <ul style="list-style-type: none"> <li>• Provision of SACT in the community by a broader workforce</li> </ul>

Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	Topic-specific solutions to address inequity Note: some solutions are shorted for space, refer to specific sections for full details
		<p>shared care arrangements that support continuity of care.</p> <ul style="list-style-type: none"> <li>• Appropriate technology is made available to support patient care, including ensuring patient information is available across the health system and is supported by appropriate telehealth infrastructure and support.</li> </ul> <p><b>Coordination and support services</b></p> <ul style="list-style-type: none"> <li>• Establish a national Cancer Care Coordination Service across Aotearoa to support patients and whānau and reduce barriers coordinate cancer treatment and care.</li> <li>• Ensure travel and accommodation barriers to treatment are removed, including fully implementing the recommendations from Phase 1 and Phase 2 of the NTA Review undertaken in 2018 alongside a secondary process to address regional variation and consider further improvements to enable greater access to support.</li> </ul>	<ul style="list-style-type: none"> <li>• Consideration is given to novel formulations of SACT that support administration in primary care, the community or self-administration</li> <li>• Consideration given to model of care for HSCT that enable aspects of care to be given outside the hospital.</li> </ul> <p><b>Allied health</b></p> <ul style="list-style-type: none"> <li>• Allied health requirements are included in decisions around the distribution of cancer services</li> <li>• Support non-acute, community cancer allied health to be delivered as close to home as possible</li> <li>• Make cancer allied health services accessible by implementing telehealth initiatives.</li> </ul> <p><b>Pathology and laboratory</b></p> <ul style="list-style-type: none"> <li>• Procuring and contracting for laboratory services include consideration to mobile collection services that can be brought to the patient's home and eliminate the need for travel. In particular, specific provisions to improve access should be prioritised for Māori and Pacific peoples who may be disproportionately disadvantaged.</li> </ul>

Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	Topic-specific solutions to address inequity Note: some solutions are shorted for space, refer to specific sections for full details
			<b>Radiology</b> <ul style="list-style-type: none"> <li>National approach to the distribution and location of new radiology services. Radiology infrastructure placement decisions should consider: <ul style="list-style-type: none"> <li>Accessibility for patients and whānau</li> <li>Involvement of Iwi Health Providers</li> </ul> </li> </ul>
<b><u>Cost creates barriers to accessing treatment</u></b> The cost of accessing treatment and care services can be a significant barrier for many patients and whānau and create inequities in access to services. This includes: <ul style="list-style-type: none"> <li>Direct costs e.g. hospital parking fees, accommodation, wigs, prostheses, having to pay for unfunded allied health services</li> <li>Indirect costs e.g. reduced income for both patients and whānau.</li> </ul>	<ul style="list-style-type: none"> <li>“Parking costs are huge.”</li> <li>“In order to be reimbursed [NTA], you have to be able to afford to travel in the first place”</li> <li>“No-one told us we could have a mortgage holiday.”</li> <li>“Currently cancer patients don’t have free access to exercise programmes backed by trained physiotherapists or councillors.”</li> <li>“Income support is needed”</li> </ul>	<b>Distribution of services</b> <ul style="list-style-type: none"> <li>Care is provided as close to home as is possible without compromising safety and quality. This includes the provision of outreach and virtual clinics with a particular focus on achieving equity of access to services in underserved communities</li> </ul> <b>Coordination and support services</b> <ul style="list-style-type: none"> <li>Establish a national Cancer Care Coordination Service across Aotearoa to support patients and whānau, reduce barriers and coordinate cancer treatment and care.</li> </ul>	<b>Coordination and support services</b> <ul style="list-style-type: none"> <li>Identify mechanisms that enable: <ul style="list-style-type: none"> <li>a seamless transition between treatment and supportive care, through an integrated referral system that connects patients and whānau to appropriate community support services</li> <li>patients, whānau and carers to access social support, e.g. through hospital and community-based social workers and support programmes</li> </ul> </li> <li>Te Aho o Te Kahu to work with Health NZ and the Māori Health Authority to: <ul style="list-style-type: none"> <li>acknowledge and support the not-for-profit sector, to ensure the essential services they provide are considered when</li> </ul> </li> </ul>

Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	Topic-specific solutions to address inequity Note: some solutions are shorted for space, refer to specific sections for full details
<p>There are many issues and inequities with the current funding model in the National Travel Assistance (NTA) scheme.</p>		<ul style="list-style-type: none"> <li>Recommendations from Phase 1 and Phase 2 of the National Travel Assistance (NTA) Review undertaken in 2018 are implemented alongside a secondary process to improve data collection, address regional variation and consider further improvements to enable greater access to support for those receiving lifesaving or life-extending treatments (such as cancer treatment).</li> </ul> <p>Identify mechanisms that support patients, whānau and carers to access cultural, spiritual, financial and social support</p>	<ul style="list-style-type: none"> <li>planning sustainable national support services               <ul style="list-style-type: none"> <li>provide easily accessible information to healthcare staff, and patients and whānau, on the cancer support services provided by the not-for-profit sector and how to access them.</li> </ul> </li> <li>Findings of Phase 1 and Phase 2 of the NTA Review undertaken in 2018 be fully implemented</li> </ul> <p><b>Surgery</b></p> <ul style="list-style-type: none"> <li>Ensure centralisation does not occur without implementation mechanisms which ensure care is person and whānau-centred and achieves equity of access, quality and outcomes. Key factors include: well-defined patient pathways, accommodation and transport support, referral and communication protocols and shared care arrangements that support continuity of care</li> </ul> <p><b>Radiation oncology</b></p> <ul style="list-style-type: none"> <li>Support the ongoing roll out of LINACs outside of major centres to enable increased access to radiation therapy</li> </ul>

Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	Topic-specific solutions to address inequity Note: some solutions are shorted for space, refer to specific sections for full details
			<p><b>Allied health</b></p> <ul style="list-style-type: none"> <li>• Ensure cancer allied health is recognised as an essential component of cancer care</li> <li>• Ensure that cancer allied health is included and considered in decisions about cancer services, including distribution, workforce planning and cancer treatment pathways</li> <li>• Include allied health requirements into cancer clinical and patient pathways for each cancer type</li> </ul> <p><b>Pathology and laboratory</b></p> <ul style="list-style-type: none"> <li>• A national schedule of tests is developed and maintained including which tests are funded by the public system.</li> </ul> <p><b>Radiology</b></p> <ul style="list-style-type: none"> <li>• Collective negotiation for outsourcing to the private sector e.g. a national fees schedule for imaging and reporting.</li> </ul>
<p><b><u>Lack of awareness of available services creates barriers to access</u></b></p> <p>Many of the current coordination and support services sit in the not-for-profit and community</p>	<ul style="list-style-type: none"> <li>• “I had to do all the work to reach out for support.”</li> <li>• “Why do we continually have to ask to find out what is available?”</li> </ul>	<p><b>National system leadership</b></p> <ul style="list-style-type: none"> <li>• Te Aho o Te Kahu provides or facilitates cancer subject matter expertise to a national assessment process for innovative approaches to treatment, including horizon</li> </ul>	<p><b>Coordination and support services</b></p> <ul style="list-style-type: none"> <li>• Te Aho o Te Kahu to work with Health NZ and the Māori Health Authority to: <ul style="list-style-type: none"> <li>○ acknowledge and support the not-for-profit sector, to ensure the essential services they provide are considered when</li> </ul> </li> </ul>

Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	Topic-specific solutions to address inequity Note: some solutions are shorted for space, refer to specific sections for full details
<p>settings and are often not visible within the public sector, which can create an information gap for patients and whānau.</p> <p>Coordination and support services support often needs to be sought out and requested by the patient. In some cases (eg National Travel Assistance policy), patients must get approval from clinicians in order to access non-clinical services. This is particularly challenging for Māori and Pacific peoples and reinforces a patient-clinician power imbalance.</p> <p>There is no single clear and appropriate information source that links patients and whānau to coordination and support services.</p> <p>There is low awareness among patients and whānau of the benefits of <b>Allied Health services</b>, and their role in improving the cancer journey and outcomes.</p>	<ul style="list-style-type: none"> <li>• “They acted like it was their own money that they were forking out.”</li> <li>• “Why do we have to chase all the time? What’s wrong with the system?”</li> <li>• “It took three months before they told us [about services like Cancer Society and Hospice].”</li> <li>• “When they diagnosed me, there was no offer of support services like karakia. I know those services are in the hospital but the clinician didn’t mention them.”</li> </ul>	<p>scanning for emerging techniques and supporting adoption and equitable implementation.</p> <p><b>Service distribution</b></p> <ul style="list-style-type: none"> <li>• Te Aho o Te Kahu to work with Health New Zealand to develop clear service pathways, outlining treatment pathways, where and how MDMs are held and allied health requirements.</li> <li>• Pathways regularly updated to provide a mechanism for nationally agreed new techniques and technology to be translated equitably into clinical care</li> </ul> <p><b>Workforce</b></p> <ul style="list-style-type: none"> <li>• Strengthen and further develop the support services workforce, including establishment of new care coordination positions, with a particular focus on improving Māori and Pacific pathways of care</li> </ul> <p><b>Coordination and support services</b></p> <ul style="list-style-type: none"> <li>• Establish a national Cancer Care Coordination Service across Aotearoa to support patients and</li> </ul>	<p>planning sustainable national support services</p> <ul style="list-style-type: none"> <li>◦ provide easily accessible information to healthcare staff, and patients and whānau, on the cancer support services provided by the not-for-profit sector and how to access them.</li> <li>• Ensure that planning and decision making is informed by best available evidence, and considers how patients can access the support and information that they require</li> </ul> <p><b>Allied health</b></p> <ul style="list-style-type: none"> <li>• Include allied health requirements into cancer clinical and patient pathways for each cancer type</li> </ul> <p><b>Pathology and laboratory</b></p> <ul style="list-style-type: none"> <li>• A national schedule of tests is developed and maintained including which tests are funded by the public system.</li> </ul> <p><b>Radiology</b></p> <ul style="list-style-type: none"> <li>• Pathways include standardised, evidence-based guidelines for the use of imaging in staging cancers, follow-up and surveillance</li> </ul>

Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	Topic-specific solutions to address inequity Note: some solutions are shorted for space, refer to specific sections for full details
There can also be a lack of awareness amongst clinicians about what specialised or experimental treatments are available in other centres.		<p>whānau, reduce barriers and coordinate cancer treatment and care.</p> <ul style="list-style-type: none"> <li>• Develop a holistic needs assessment process that takes into account all types of care a cancer patient and their whanau might need, including the needs of Māori, pacific and disabled cancer patients</li> <li>• Increase support for community-based Māori-led, kaupapa Māori, and Whānau Ora services to enable options and access to mātauranga Māori in cancer care.</li> </ul>	
<p><b><u>Variation in the quality of care that is provided</u></b></p> <p>There is considerable variability in the delivery of care across Aotearoa. Including:</p> <ul style="list-style-type: none"> <li>• Variation in intervention rates for <b>radiation therapy</b></li> <li>• Variation in <b>SACT</b> treatment regimens and variation in access to clinical trials</li> </ul>		<p><b>National system leadership</b></p> <ul style="list-style-type: none"> <li>• Te Aho o Te Kahu to work in partnership with Health NZ and the Māori Health Authority to provide national strategic and structural leadership of the cancer control system, with a focus on Te Tiriti and equity.</li> <li>• Quality system-level data and information is available for monitoring and sound decision-making.</li> </ul>	<p><b>Coordination and support services</b></p> <ul style="list-style-type: none"> <li>• Design, plan, and assist implementation of cancer coordination and support services</li> <li>• Ensure that planning and decision making is informed by best available evidence, and considers how service design and delivery can be informed by best practice and continuous improvement e.g. through monitoring and evaluation.</li> </ul>

Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	Topic-specific solutions to address inequity Note: some solutions are shorted for space, refer to specific sections for full details
<ul style="list-style-type: none"> <li>• Inconsistencies in the availability of <b>laboratory and radiology</b> services across regions</li> <li>• Some allied health practitioners specialise in caring for cancer patients, whereas other allied health practitioners work with all population groups. Generalist allied health practitioners do not always have access to the resources needed (eg information, training, equipment, access to subject matter experts etc) to treat cancer patients in the most effective way.</li> </ul>		<p><b>Service distribution</b></p> <ul style="list-style-type: none"> <li>• Clear, person and whānau-centred clinical service pathways are developed, outlining the ‘default’ in terms of treatment pathways, referral pathways, where and how MDMs are held, treatment-related diagnostics, follow-up/surveillance, allied health requirements and palliative and end of life care requirements. Options will be built into the system to address existing inequities, with opportunity for deliberate deviation from the pathway to meet patient and whānau needs, priorities and self-determination.</li> </ul>	<p><b>Surgery</b></p> <ul style="list-style-type: none"> <li>• Ensure quality assurance and quality improvement initiatives are built into the cancer surgical system and cancer care pathways, including: <ul style="list-style-type: none"> <li>○ Monitoring of quality and equity of surgical services through quality improvement programmes, including institutional level data on volume and outcome to learn from high performing units.</li> <li>○ Work with cancer surgical networks to develop and implement quality improvement initiatives.</li> </ul> </li> </ul> <p><b>Radiation therapy</b></p> <ul style="list-style-type: none"> <li>• Changing the current radiation oncology structure to a single national service model overseen by a national governing body</li> <li>• Leadership for national cancer care pathways, including standardising treatment delivery for radiation treatment.</li> <li>• Overseeing processes to manage unwarranted variation in clinical practice</li> <li>• ensure quality assurance and quality improvement initiatives are built into</li> </ul>



Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	<b>Topic-specific solutions to address inequity</b> Note: some solutions are shorted for space, refer to specific sections for full details
			<p>the radiation oncology system and cancer care pathways</p> <p><b>SAC/HSCT</b></p> <ul style="list-style-type: none"> <li>• Nationally led service models for SACT and HSCT</li> <li>• ACT-NOW project to agree and standardise prescribing regimes for SACT</li> <li>• Electronic prescribing systems for SACT to assist in reducing unwarranted variation in practice and to improve safety, efficiency, quality and effectiveness of SACT.</li> </ul> <p><b>Allied health</b></p> <ul style="list-style-type: none"> <li>• Support development, collection and utilisation of cancer allied health data, including workforce, service utilisation and clinical data, to enable effective planning and monitoring of service</li> <li>• Identify unmet cancer allied health needs to plan for future service development, provision and improvement.</li> <li>• Support the creation of specialist cancer roles in allied health and advanced scope of practice</li> </ul> <p><b>Pathology and laboratory</b></p> <ul style="list-style-type: none"> <li>• Establishment of a Te Tiriti-compliant, well-resourced, national</li> </ul>

Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	Topic-specific solutions to address inequity Note: some solutions are shorted for space, refer to specific sections for full details
			<p>leadership and commissioning function for pathology and laboratory services</p> <ul style="list-style-type: none"> <li>Development and maintenance of a national schedule of tests to provide consistency regarding which tests are and at what price.</li> </ul> <p><b>Radiology</b></p> <ul style="list-style-type: none"> <li>Developing national standards for access and quality of radiology services, that services are monitored against</li> <li>Ensure that data submitted to national collections is fit-for-purpose for monitoring access and quality of cancer radiology services, tracking and responding to inequities (including having high-quality ethnicity data), forecasting, and service planning</li> </ul>
<p><u><b>Some services are inconsistently available due to a lack of recognition and funding.</b></u></p> <p>Many allied health and support services are unrecognised and underfunded.</p>	<ul style="list-style-type: none"> <li>“When they diagnosed me, there was no offer of support services like karakia. I know those services are in the hospital, but the clinician didn’t mention them.”</li> </ul>	<p><b>Workforce</b></p> <ul style="list-style-type: none"> <li>Strengthen and further develop the supportive care workforce, including establishment of new care coordination positions, with a particular focus on improving Māori and Pacific pathways of care.</li> </ul>	<p><b>Coordination and support services</b></p> <ul style="list-style-type: none"> <li>Design, plan, and assist implementation of cancer coordination and support services</li> </ul> <p><b>Allied health</b></p> <ul style="list-style-type: none"> <li>Identify unmet cancer allied health needs to plan for future service development, provision and improvement.</li> </ul>

Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	Topic-specific solutions to address inequity Note: some solutions are shorted for space, refer to specific sections for full details
<p>This includes mātauranga Māori spiritual services and cultural support. This disproportionately affects Māori and Pacific peoples and people who prefer holistic models of care.</p>	<ul style="list-style-type: none"> <li>• “They were hōhā because we wanted 2 minutes for a karakia before they took him in for surgery.”</li> </ul>	<p><b>Coordination and support services</b></p> <ul style="list-style-type: none"> <li>• Establish a national Cancer Care Coordination Service across Aotearoa to support patients and whānau, reduce barriers and coordinate cancer treatment and care.</li> <li>• Ensure that sustainability of essential support services provided by cancer not-for-profit organisations are considered and supported in national cancer service planning.</li> <li>• Identify mechanisms that support patients, whānau and carers to access cultural, spiritual, financial and social support.</li> </ul>	<ul style="list-style-type: none"> <li>○ Identify cancer allied health service gaps in both hospital-based and community-based settings, across the continuum of care.</li> </ul> <p><b>Pathology and laboratory</b></p> <ul style="list-style-type: none"> <li>• Development and maintenance of a national schedule of tests to provide consistency regarding which tests are and at what price</li> </ul> <p><b>Radiology</b></p> <ul style="list-style-type: none"> <li>• Developing national standards for access and quality of radiology services, that services are monitored against</li> </ul>
<p><b><u>The system is fragmented and difficult to navigate, meaning people fall through gaps</u></b></p> <p>Cancer journeys can be highly complex, involving multiple clinical and non-clinical providers, different funding models, highly</p>	<ul style="list-style-type: none"> <li>• “We got lost in the process.”</li> <li>• “Speak in a language that our whānau would understand, forget about the medical terminology”</li> </ul>	<p><b>Transformative approach to cancer treatment and support</b></p> <ul style="list-style-type: none"> <li>• Te Aho o Te Kahu to work in partnership with Health NZ and the Māori Health Authority to refine and implement a new approach to cancer treatment and support that:</li> </ul>	<p><b>Coordination and support services</b></p> <ul style="list-style-type: none"> <li>• Design, plan, and assist implementation of cancer coordination and support services</li> <li>• Te Aho o Te Kahu to work with the Māori Health Authority and Health NZ to identify mechanisms that enable increased support for community-based Māori-led,</li> </ul>

Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	Topic-specific solutions to address inequity Note: some solutions are shorted for space, refer to specific sections for full details
<p>technical terminology and inconsistent access.</p> <p>This can be difficult for patients and whānau to successfully navigate and results in inequitable outcomes.</p> <p>The current system is heavily siloed, meaning the responsibility and burden of care coordination often falls on patients and whānau. This is significantly harder for patients and whānau with the least resources.</p> <p>Allied health services are fragmented and uncoordinated, both within their own sector and within cancer care. For example, a patient with cancer pain and fatigue may be referred to the cancer pain service, fatigue clinic and palliative care at the same time. This can create conflicting opinions and additional burden on patients and whānau.</p>	<ul style="list-style-type: none"> <li>• “[We need a] support person to translate all medical information”</li> <li>• “I had to listen to the message nine times before I could understand it.”</li> <li>• “I could advocate for [my parents] – but only because I knew the system. And the doctors and nurses hated it.”</li> <li>• “Where are our Māori advocates? We are being lost in that non-Māori world.”</li> </ul>	<ul style="list-style-type: none"> <li>○ wraps a metaphorical kahu (cloak) of customised, holistic support around cancer patients and their whānau;</li> <li>○ reflects the connection needed to deliver a successful cancer care system, including specialist cancer treatment, allied health, non-clinical support and mātauranga Māori;</li> <li>○ offers patients and whānau cohesive and meaningful support and care coordination across all health and social services required as part of the cancer journey;</li> <li>○ crosses the boundaries of hospital, community and home-based services.</li> </ul> <p><b>National system leadership</b></p> <ul style="list-style-type: none"> <li>• Te Aho o Te Kahu to work in partnership with Health NZ and the Māori Health Authority to provide national strategic and</li> </ul>	<p>kaupapa Māori, and Whānau Ora services</p> <ul style="list-style-type: none"> <li>• Health NZ and the Māori Health Authority identify mechanisms that enable a seamless transition between treatment and supportive care, through an integrated referral system that connects patients and whānau to appropriate community support services</li> </ul> <p><b>Surgery</b></p> <ul style="list-style-type: none"> <li>• Surgical service distribution will consider integration across cancer services, with the patient pathway mapped to ensure the default care path is appropriate.</li> <li>• Te Aho o Te Kahu to work with Health New Zealand to develop clear service pathways. <ul style="list-style-type: none"> <li>○ Pathways will include clear referral information, so that clinicians across Aotearoa know where and how to refer patients with different cancer types</li> <li>○ Surgical pathways will include prehabilitation and post-surgical care, including systems for information to flow back to local hospitals following centralised procedure (eg to</li> </ul> </li> </ul>

Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	Topic-specific solutions to address inequity Note: some solutions are shorted for space, refer to specific sections for full details
		<p>structural leadership of the cancer control system.</p> <p><b>Service distribution</b></p> <ul style="list-style-type: none"> <li>Decisions around the distribution of cancer services occur at a national level and consider integration across services, with the patient pathway mapped to ensure the default care pathway is appropriate and mitigates potential inequities in access</li> <li>Appropriate technology is made available to support patient care, including ensuring patient information is available across the health system</li> </ul> <p><b>Coordination and support services</b></p> <ul style="list-style-type: none"> <li>Establish a national Cancer Care Coordination Service across Aotearoa to support patients and whānau.</li> </ul>	<p>ensure timely access to adjuvant chemotherapy)</p> <p><b>SACT/HSCT</b></p> <ul style="list-style-type: none"> <li>Patient and whānau needs at the centre of service development</li> <li>The development of kaupapa Māori Services</li> <li>National service model for HSCT with improved flow of information within, across and between services</li> </ul> <p><b>Allied health</b></p> <ul style="list-style-type: none"> <li>Allied health requirements included into cancer clinical and patient pathways for each cancer type. Including: <ul style="list-style-type: none"> <li>Hospital-based and community-based allied health services</li> <li>Survivorship/follow up care</li> <li>Prehabilitation and rehabilitation programmes</li> </ul> </li> </ul> <p><b>Pathology and laboratory</b></p> <ul style="list-style-type: none"> <li>Create a well-resourced, national leadership function specifically for pathology and laboratory services, with a Te Tiriti and equity focus</li> </ul>
<u>Services are not always appropriate</u>	<ul style="list-style-type: none"> <li>“We need to be listened to, I want to be heard.”</li> </ul>	<p><b>National system leadership</b></p> <ul style="list-style-type: none"> <li>Te Aho o Te Kahu maintains a strong partnership with Hei Āhuru</li> </ul>	<p><b>Coordination and support services</b></p> <ul style="list-style-type: none"> <li>Design, plan, and assist implementation of cancer</li> </ul>

Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	Topic-specific solutions to address inequity Note: some solutions are shorted for space, refer to specific sections for full details
<p>The services provided are not always culturally appropriate and are not always person and whānau-centred. This can create barriers for everyone, but also create inequity for minority populations as services generally suit the majority population first and foremost.</p> <ul style="list-style-type: none"> <li>• Appointments can feel technical and transactional</li> <li>• Locations where diagnostic services are delivered (eg imaging facilities, blood collection centres) are not always culturally safe.</li> <li>• Patients do not always know if the services available are ‘for them’ and will meet their needs in a culturally safe manner.</li> <li>• Some allied health services and/or service delivery models are not culturally acceptable or appropriate.</li> </ul>	<ul style="list-style-type: none"> <li>• “Clinicians don’t have knowledge of our needs.”</li> <li>• “The system offers you one thing but you need something else.”</li> <li>• “Whānau need to be welcome at all appointments”</li> <li>• “Don’t just look at the patient with cancer, whānau matter too”</li> <li>• “Whānau need support – who helps the helpers?”</li> <li>• “I’m the only one in my whānau with a health qualification. So whenever somebody gets cancer, they pull me in to help them understand what the doctors are saying. That’s a lot for me to handle across the whole whānau, and there’s no support for me.”</li> <li>• “Where are our Māori advocates? We are being lost in that non-Māori world.”</li> </ul>	<p>Mōwai to build and support strong Māori cancer leadership, and reviews current Māori cancer leadership structures to plan for future national, regional and local ways of working.</p> <ul style="list-style-type: none"> <li>• Te Aho o Te Kahu to work with the Māori Health Authority to ensure they have access to high quality information about cancer services and inequities to inform decision making to improve Māori health outcomes.</li> </ul> <p><b>Service distribution</b></p> <ul style="list-style-type: none"> <li>• Care is provided as close to home as is possible without compromising safety and quality. Models of care are developed to meet patient and whānau needs and include development of</li> </ul>	<p>coordination and support services, including:</p> <ul style="list-style-type: none"> <li>◦ ensuring Māori and Pacific peoples are appropriately engaged in planning and decision making</li> <li>◦ ensuring that coordinated care models are patient and whānau centred and informed by lived experience</li> <li>◦ development of a holistic needs assessment process that considers all types of care a cancer patient and their whanau might need, including the needs of Maori, Pacific and disabled cancer patients</li> <li>◦ supporting the development of kaupapa Māori and Pacific-specific models for the delivery of support services</li> </ul> <ul style="list-style-type: none"> <li>• Identify mechanisms that enable: <ul style="list-style-type: none"> <li>◦ increased support for community-based Māori-led, kaupapa Māori, and Whānau Ora services</li> <li>◦ opportunities for Māori to access mātauranga expertise and to discuss traditional</li> </ul> </li> </ul>

Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	Topic-specific solutions to address inequity Note: some solutions are shorted for space, refer to specific sections for full details
<ul style="list-style-type: none"> <li>• Often support and services are not available once active treatment has finished.</li> <li>• Support services are largely unavailable for whānau supporting a patient with cancer.</li> </ul>	<ul style="list-style-type: none"> <li>• “Flexible appointments”</li> <li>• “Scheduling – don’t book a rural patient for an 8.30am appointment”</li> <li>• “The need for care doesn’t stop when treatment finishes.”</li> <li>• “The system offers you one thing but you need something else.”</li> <li>• “The need for care doesn’t stop when treatment finishes.”</li> </ul>	<p>kaupapa Māori approaches to service delivery design.</p> <p><b>Workforce</b></p> <ul style="list-style-type: none"> <li>• Develop processes to support, increase, and measure the cultural safety of the cancer workforce.</li> </ul> <p><b>Coordination and support services</b></p> <ul style="list-style-type: none"> <li>• Develop a holistic needs assessment process that takes into account all types of care a cancer patient and their whānau might need, including the needs of Māori, Pacific and disabled cancer patients</li> <li>• <b>Increase support for</b> community-based Māori-led, kaupapa Māori, and Whānau Ora services to enable options and access to mātauranga Māori in cancer care.</li> </ul>	<p>healing practices as part of their treatment and care</p> <ul style="list-style-type: none"> <li>○ support for Māori patients and their whānau to have conversations about the inclusion of traditional health and healing practices in their pathway of care.</li> </ul> <p><b>Surgery</b></p> <ul style="list-style-type: none"> <li>• National strategic leadership for cancer surgical services, with a Te Tiriti and equity focus</li> <li>• Support the development of physical spaces that are conducive with the delivery of high-quality cancer surgical care, including outpatient clinic rooms having space for whānau, appropriate inpatient facilities and appropriate facilities for diagnosing and treatment patients with very high BMI.</li> <li>• Monitor the impact of changes to surgical systems as part of the health system reform, including a focus on the impact of any centralisation on access to surgery, patient experience, waiting times and</li> </ul>

			<p>outcomes, with a focus on equity across the measures.</p> <p><b>Radiation oncology</b></p> <ul style="list-style-type: none"> <li>• Provide strategic leadership for a nation radiation oncology service with a Te Tiriti and equity focus.</li> <li>• Develop processes to support, increase, and measure the cultural safety of the radiation oncology workforce. This will include assessing the current state of cultural safety training among the radiation therapy workforces given the low portion of Māori and Pacific and the large proportion of immigrant specialists and improving and standardising the quality of cultural competency training</li> </ul> <p><b>SACT/HSCT</b></p> <ul style="list-style-type: none"> <li>• Strong, well-defined national leadership model for medical oncology and malignant haematology, with a Te Tiriti and equity focus</li> <li>• Patient and whānau needs at the centre of service development</li> <li>• The development of kaupapa Māori Services</li> <li>• Strategic planning to increase the number of Māori and Pacific in all levels of the SACT/HSCT team</li> </ul> <p><b>Allied health</b></p> <ul style="list-style-type: none"> <li>• Include allied health practitioners in work to support, increase and measure the cultural safety of the cancer workforce</li> </ul>
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			<ul style="list-style-type: none"> <li>Ensure appropriate cancer allied health support is available to whānau</li> </ul> <b>Pathology and laboratory</b> <ul style="list-style-type: none"> <li>Procuring and contracting for laboratory services prioritises collection centres that are patient-centred, accessible, and culturally responsive.</li> </ul>
<p><b><u>Capacity constraints create barriers to timely access to high quality care</u></b></p> <p>Capacity constraints – due both to workforce and infrastructure issues – create inequities in access to, and timeliness of, services.</p> <p>Those unable to access publicly funded services (or are waiting too long) may opt for private services creating inequities in access based on ability to pay.</p> <ul style="list-style-type: none"> <li><b>Radiology:</b> inadequate radiology capacity limits flexibility, choice of time, and choice of location. This situation will</li> </ul>	<ul style="list-style-type: none"> <li>“Timeliness of care is important”</li> <li>“You have no idea where you sit in the queue [for treatment].”</li> <li>“Shorter oncology wait times”</li> <li>“Quicker response to referrals.”</li> <li>“Navigators are really helpful”</li> <li>“Delays to diagnostics problematic, long wait, back and forth to GP”</li> <li>“GPs should be allowed greater access to diagnostic services (eg ordering CTs)”</li> </ul>	<p><b>National system leadership</b></p> <ul style="list-style-type: none"> <li>Te Aho o Te Kahu to work in partnership with Health NZ and the Māori Health Authority to provide national strategic and structural leadership of the cancer control system, including: <ul style="list-style-type: none"> <li>distribution of cancer services;</li> <li>workforce planning;</li> <li>adoption and integration of innovative approaches to treatment and care;</li> <li>quality system-level data and information available for monitoring and sound decision-making.</li> </ul> </li> </ul>	<p><b>Coordination and support services</b></p> <ul style="list-style-type: none"> <li>Design, plan, and assist implementation of cancer coordination and support services.</li> <li>Strengthen and develop the support services workforce, and establish new care coordination positions, with a particular focus on Māori and Pacific services.</li> </ul> <p><b>Surgery</b></p> <ul style="list-style-type: none"> <li>National strategic leadership for cancer surgical services, with a Te Tiriti and equity focus. This will include strategic advice around cancer workforce planning</li> <li>Ensure quality assurance and quality improvement initiatives are built into the cancer surgical system and cancer care pathways</li> </ul>

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<p>disproportionately affect groups for whom time, cost and travel are already significant barriers in accessing healthcare.</p> <ul style="list-style-type: none"> <li>• <b>Allied health:</b> patients experience inconsistent access to allied health services due to workforce shortages</li> </ul> <p>As a result of capacity constraints wait times can vary between service providers</p> <ul style="list-style-type: none"> <li>• Māori, Pacific peoples and those living rurally have been shown to experience significantly longer delays in receiving <b>radiation therapy</b>.</li> <li>• Māori, Pacific peoples and those living rurally have been shown to experience significantly longer delays in receiving <b>SACT</b>. Wait times for treatment also vary between service providers</li> </ul>	<ul style="list-style-type: none"> <li>• “Diagnostic facilities to be mobile and targeted to communities with poor access”</li> </ul>	<p><b>Workforce</b></p> <ul style="list-style-type: none"> <li>• Increased allocation of funding for education and training of the cancer workforce, including funding for replacement staffing cover and additional roles in cancer care. Including consideration of: <ul style="list-style-type: none"> <li>○ creation of more early career positions in cancer care, so that more experienced staff can be freed up to participate in education and training for advanced and extended practice roles;</li> <li>○ more clinical nurse specialist and nurse practitioner positions in cancer care;</li> <li>○ create specialist cancer roles in allied health and explore extended scope of practice for some roles;</li> <li>○ grow the non-clinical cancer workforce (eg</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Monitor the impact of changes to surgical systems as part of the health system reform, including a focus on: <ul style="list-style-type: none"> <li>○ The impact of any centralisation on access to surgery, patient experience, waiting times and outcomes, with a focus on equity across the measures.</li> </ul> </li> </ul> <p><b>Radiation therapy</b></p> <ul style="list-style-type: none"> <li>• The implementation of a single system of care for radiation oncology in Aotearoa, operating under a standardised national radiation oncology service model.</li> <li>• Changing the operating model to a centrally led, one system – multi site network. <ul style="list-style-type: none"> <li>○ Implementing a plan for recovery given current and predicated deficits in Radiation Oncology capability, capacity, and sustainability.</li> <li>○ Implementation of a centrally managed programme for LINAC procurement and associated capital investment of ancillary technology and facility for all public radiation oncology treatment providers</li> </ul> </li> </ul>

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		<p>kaiāwhina, community-based whānau support staff, kaupapa Māori providers);</p> <ul style="list-style-type: none"> <li>○ increased senior medical officer roles;</li> <li>○ ensure administrative and other systems are in place to support clinical staff in their roles.</li> </ul> <ul style="list-style-type: none"> <li>• Work with training providers and the sector to fill vacant training positions e.g. radiation oncology medical physicists, Māori nurse practitioners.</li> <li>• Develop and implement a future focused cancer workforce plan.</li> </ul>	<ul style="list-style-type: none"> <li>○ Overseeing processes to manage unwarranted variation in clinical practice</li> <li>• Reduced wait times for patients due to timely planning and investment in radiation oncology services including national monitoring and contingency planning in place</li> </ul> <p><b>SACT/HSCT</b></p> <ul style="list-style-type: none"> <li>• A strong national approach to services including: <ul style="list-style-type: none"> <li>○ Strategic workforce planning</li> </ul> </li> <li>• Services are well networked, with both national and regional leadership</li> <li>• Utilising a broader range of the workforce for the delivery of care, with staff supported and enabled to work at the top of their scope of practice, including consideration of: <ul style="list-style-type: none"> <li>○ Increasing the scope of practice of nursing and allied health professionals</li> <li>○ Greater partnership with primary care</li> </ul> </li> <li>• Adequate administrator/data entry staff are employed to enable all clinical staff to work to top of scope.</li> </ul>

			<p><b>Allied Health</b></p> <ul style="list-style-type: none"> <li>• Identify unmet cancer allied health needs to plan for future service development, provision and improvement.</li> <li>• Identify and quantify the cancer allied health workforce to enable effective workforce planning and monitoring</li> </ul> <p><b>Laboratory and pathology</b></p> <ul style="list-style-type: none"> <li>• Strategic planning and forecasting for national pathology &amp; laboratory services, including for infrastructure, workforce and information management</li> <li>• Establishing and maintaining a networked approach to service provision within the pathology and laboratory sector.</li> </ul> <p><b>Radiology</b></p> <ul style="list-style-type: none"> <li>• National population-based approach to organising and planning radiology services, with a focus on Te Tiriti and equity. A national approach would include: <ul style="list-style-type: none"> <li>◦ Designing the radiology system more deliberately to improve access and timeliness (including reviewing existing service delivery models and optimising the use of public and private capacity)</li> <li>◦ Centralised forecasting, planning, investment and procurement of radiology equipment/facilities, workforce and IT infrastructure (including</li> </ul> </li> </ul>
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			<p>decision-making about where radiology facilities are located)</p> <ul style="list-style-type: none"> <li>○ Efficiencies in how radiology infrastructure and workforce can be used (consider how the skill mix of the existing radiology workforce could be used in the most effective way, developing standardised evidence-based guidelines for radiology</li> <li>• A national approach to radiology workforce would consider how the skill mix of the existing radiology workforce could be used in the most effective way</li> <li>• Consider if training pathways are fit-for-purpose</li> </ul>
<p><b><u>Increasing complexity and needs of patients</u></b></p> <p>The needs of cancer patients are becoming increasingly complex and diverse, making the historical model of care increasingly unfit. Without a systematic needs assessment process, patients and whānau with the greatest needs</p>	<ul style="list-style-type: none"> <li>• “Give access to care on the basis of need first - prioritise them in the system.”</li> <li>• “Need to make sure whānau needs are responded to – and the needs can be different for each whānau member.”</li> </ul>	<p>Increase capacity within the cancer system as described above.</p> <p><b>Coordination and support services</b></p> <ul style="list-style-type: none"> <li>• Develop a holistic needs assessment process that takes into account all types of care a cancer patient and their whānau might need, including the needs</li> </ul>	<p><b>Coordination and support services</b></p> <ul style="list-style-type: none"> <li>• Design, plan, and assist implementation of cancer coordination and support services</li> <li>• Identify mechanisms that enable a seamless transition between treatment and supportive care, through an integrated referral system that connects patients and whānau to appropriate community support services</li> </ul>

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<p>cannot be identified and prioritised.</p> <p>The increasing complexity of cancer patients also contributes to increased complexity of treatment and time required to deliver safe and effective treatment. There is currently inequitable access to prehabilitation to maximise access to, and outcomes from, cancer surgery</p>		<p>of Māori, Pacific and disabled cancer patients</p>	<p><b>Surgery</b></p> <ul style="list-style-type: none"> <li>• Develop clear service pathways, outlining treatment pathways and allied health requirements. Surgical pathways will include prehabilitation and post-surgical care</li> <li>• Ensure administrative and other systems are in place to support clinical staff in their roles, including staff to coordinate required prehabilitation assessments to ensure they are complete in a timely way</li> </ul>
<p><b><u>New technology is considered and implemented locally, leading to inconsistent access</u></b></p> <p>This is seen across treatment modalities, with individual DHBs making assessments and decisions around new technology.</p> <ul style="list-style-type: none"> <li>• New <b>surgical treatments</b> often start as experimental and over time they move to become part of routine care within the hospital where the service is provided. However, clinicians in other hospitals do not always</li> </ul>	<ul style="list-style-type: none"> <li>• “Better use of technology to improve coordination, transparency, standardisation”</li> <li>• “Access to clinical trials”</li> <li>• “Access to the latest treatment protocols and recent research”</li> </ul>	<p><b>National system leadership</b></p> <ul style="list-style-type: none"> <li>• We recommend that Health NZ develops a national process to assess new technologies to ensure equitable access, including horizon scanning, with appropriate technologies/techniques built into cancer pathways.</li> </ul> <p><b>Service distribution</b></p> <ul style="list-style-type: none"> <li>• Clear, person and whānau-centred clinical service pathways are developed, outlining the ‘default’ in terms of treatment pathways, referral pathways, where and how MDMs are held, treatment-related</li> </ul>	<p><b>Surgery</b></p> <ul style="list-style-type: none"> <li>• Facilitates cancer surgical matter expertise to a national assessment process for innovative approaches to treatment, including horizon scanning for emerging techniques and supporting adoption and equitable implementation.</li> <li>• Develop clear service pathways. Surgical pathways will be maintained and regularly updated to provide a mechanism for nationally agreed new techniques and technology to be translated equitably into clinical care</li> </ul>

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<p>know what treatments are available in other centres or when treatments are no longer considered experimental. Patients outside of major centres may miss out on these treatments, which is likely to disproportionately impact Māori.</p> <ul style="list-style-type: none"> <li>• In <b>radiation therapy</b> technology is not uniformly implemented across NZ resulting in differences in availability of treatment options in different areas</li> </ul>		<p>diagnostics, follow-up/surveillance, allied health requirements and palliative and end of life care requirements.</p>	<p><b>Radiation oncology</b></p> <ul style="list-style-type: none"> <li>• Facilitate radiation oncology subject matter expertise to a nationwide process for evaluating and adopting new technologies and exploring opportunities for specialisation to support more efficient use of high-cost technologies.</li> <li>• Treatment pathways will be maintained and regularly updated to provide a mechanism for nationally agreed new techniques and technology to be translated equitably into clinical care</li> </ul> <p><b>SACT/HSCT</b></p> <ul style="list-style-type: none"> <li>• Facilitate SACT and HSCT subject matter expertise to a national assessment process of new technologies.</li> </ul> <p><b>Allied health</b></p> <ul style="list-style-type: none"> <li>• Include allied health requirements into cancer clinical and patient pathways.</li> <li>• Support non-acute, community cancer allied health to be delivered as close to home as possible.</li> </ul>

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			<ul style="list-style-type: none"> <li>• Ensure that national planning around multidisciplinary team meetings include consideration of allied health input</li> </ul> <b>Laboratory and pathology</b> <ul style="list-style-type: none"> <li>• We recommend that the national leadership function would include responsibility for:               <ul style="list-style-type: none"> <li>◦ Reviewing and prioritising investment decisions for introducing new infrastructure and technologies.</li> <li>◦ Procurement of pathology &amp; laboratory services, including new technologies.</li> </ul> </li> <li>• A national schedule of tests is developed and maintained by the national leadership function. A schedule of tests, aligned to clinical guidelines and pathways would provide national consistency regarding:               <ul style="list-style-type: none"> <li>◦ How new technologies are reviewed and introduced</li> <li>◦ Horizon scanning regarding new testing requirements</li> </ul> </li> </ul> <b>Radiology</b> <ul style="list-style-type: none"> <li>• Contributing to a national process to prioritise new and existing</li> </ul>



Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	Topic-specific solutions to address inequity Note: some solutions are shorted for space, refer to specific sections for full details
			technologies, including imaging technologies
<p><b><u>Whānau are often not recognised as part of the care team.</u></b></p> <p>The differential rates of carer entitlement means that ‘strangers’ are paid at a higher rate than whānau, arguably endorsing ‘stranger’ care rather than a patient and whānau centred approach to cancer care.</p>	<ul style="list-style-type: none"> <li>• “I know more about her meds than any of the doctors – but they wouldn’t listen to me.”</li> <li>• “Make sure all whānau members know exactly what has happened, and what needs to happen, the whānau role.”</li> </ul>	<p><b>Workforce</b></p> <ul style="list-style-type: none"> <li>• Develop processes to support, increase, and measure the cultural safety of the cancer workforce.</li> <li>• Grow the non-clinical cancer workforce (eg kaiāwhina, community-based whānau support staff, kaupapa Māori providers);</li> </ul>	<p><b>Coordination and support services</b></p> <ul style="list-style-type: none"> <li>• Design, plan, and assist implementation of cancer coordination and support services, including: <ul style="list-style-type: none"> <li>○ ensuring Māori and Pacific peoples are appropriately engaged in planning and decision making</li> <li>○ ensuring that coordinated care models are patient and whānau centred and informed by lived experience</li> <li>○ development of a holistic needs assessment process that considers all types of care a cancer patient and their whānau might need, including the needs of Maori, Pacific and disabled cancer patients</li> <li>○ supporting the development of kaupapa Māori and Pacific-specific models for the delivery of support services</li> </ul> </li> </ul>
<p><b><u>The cancer workforce does not reflect the population</u></b></p>	<ul style="list-style-type: none"> <li>• “We need Māori people there to support us before we get the diagnosis. They</li> </ul>	<p><b>Workforce</b></p> <ul style="list-style-type: none"> <li>• Continue to develop and implement approaches to</li> </ul>	<p><b>Coordination and support services</b></p> <ul style="list-style-type: none"> <li>• Strengthen and develop the supportive care workforce, and</li> </ul>

Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	Topic-specific solutions to address inequity Note: some solutions are shorted for space, refer to specific sections for full details
<p>The importance of ethnic diversity in the health workforce. Currently there is a lack of Māori and Pacific in the cancer workforce.</p>	<p>help us to translate what we're hearing."</p> <ul style="list-style-type: none"> <li>• "Where are our Māori advocates? We are being lost in that non-Māori world."</li> </ul>	<p>systematically and deliberately increase Māori and Pacific cancer workforce capacity across all specialities through targeted investment and active recruitment.</p>	<p>establish new care coordination positions, with a particular focus on Māori and Pacific services</p> <p><b>Radiation oncology</b></p> <ul style="list-style-type: none"> <li>• Assessing pathways by which Māori and Pacific peoples can join the radiation therapy workforces, including working with educational institutions to look at eligibility requirements and make studying accessible.</li> </ul> <p><b>SACT/HSCT</b></p> <ul style="list-style-type: none"> <li>• Strategic planning to increase the number of Māori and Pacific in all levels of the SACT/HSCT team</li> </ul> <p><b>Allied health</b></p> <ul style="list-style-type: none"> <li>• Ensure appropriate cancer allied health support is available to whānau</li> <li>• Improve allied health workforce data</li> </ul> <p><b>Laboratory and pathology</b></p> <ul style="list-style-type: none"> <li>• Improve data collection on the profile of the medical laboratory scientific and technical workforce, in particular the numbers of Māori and Pacific people working within these professions</li> </ul>

Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	Topic-specific solutions to address inequity Note: some solutions are shorted for space, refer to specific sections for full details
			<b>Radiology</b> <ul style="list-style-type: none"> <li>Deliberate and considered approach to increasing Māori and Pacific in the radiology workforce. Not just providing funding, but targeted recruitment, funded training, mentorship/support, appropriate remuneration, culturally supportive workplaces, and other measures to ensure retention</li> </ul>
<p><b><u>The cancer workforce does not always work in a culturally safe way</u></b></p> <p>There is a lack of cultural safety across many workforces. This can make patients and whānau feel unsupported, misunderstood and unsafe in the cancer care environment and can contribute to disengagement from services.</p>	<ul style="list-style-type: none"> <li>“Health professionals who are trained overseas should have to undertake cultural competency training before they can practice in New Zealand.”</li> <li>“They were hōhā because we wanted 2 minutes for a karakia before they took him in for surgery.”</li> <li>“Cultural competency is very important.”</li> </ul>	<b>Workforce</b> <ul style="list-style-type: none"> <li>Develop processes to support, increase, and measure the cultural safety of the cancer workforce.</li> <li>Implement the Ao Mai Te Rā antiracism maturity model (currently in development) across the cancer treatment system.</li> <li>Continue to develop and implement approaches to systematically and deliberately increase Māori and Pacific cancer workforce capacity through targeted investment and active recruitment.</li> </ul>	<b>Coordination and support services</b> <ul style="list-style-type: none"> <li>Design, plan, and assist implementation of cancer coordination and support services, including ensuring Māori and Pacific peoples are appropriately engaged in planning and decision making</li> <li>Strengthen and develop the supportive care workforce, and establish new care coordination positions, with a particular focus on Māori and Pacific services. In particular to: <ul style="list-style-type: none"> <li>consider the range of skills and expertise required to undertake the various roles within coordination and support services</li> <li>improve cultural safety, cancer knowledge, understanding of</li> </ul> </li> </ul>

Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	<b>Topic-specific solutions to address inequity</b> Note: some solutions are shorted for space, refer to specific sections for full details
			<p>community needs, and interpersonal skills among ‘first-contact’ and other support roles.</p> <p><b>Surgery</b></p> <ul style="list-style-type: none"> <li>• Develop processes to support, increase, and measure the cultural safety of the cancer surgical workforce</li> </ul> <p><b>Radiation oncology</b></p> <ul style="list-style-type: none"> <li>• Develop processes to support, increase, and measure the cultural safety of the radiation oncology workforce. This will include assessing the current state of cultural safety training among the radiation therapy workforces given the low portion of Māori and Pacific and the large proportion of immigrant specialists and improving and standardising the quality of cultural competency training</li> </ul> <p><b>SACT/HSCT</b></p> <ul style="list-style-type: none"> <li>• Strategic planning to increase the number of Māori and Pacific in all levels of the SACT/HSCT</li> <li>• Increased scope of practice of health professionals within the cancer workforce may also increase the</li> </ul>

Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	Topic-specific solutions to address inequity Note: some solutions are shorted for space, refer to specific sections for full details
			<p>number of Māori able to prescribe and administer SACT.</p> <p><b>Allied Health</b></p> <ul style="list-style-type: none"> <li>• Include allied health practitioners in work to support, increase and measure the cultural safety of the cancer workforce</li> </ul> <p><b>Laboratory and pathology</b></p> <ul style="list-style-type: none"> <li>• Support and increase the cultural competence of the pathology and laboratory workforce, including giving consideration to national guidance for the appropriate management of Māori tissue, DNA and data.</li> </ul>
<u>Inconsistent access to, and support for, mātauranga Māori and rongoā</u>	<ul style="list-style-type: none"> <li>• “Bring mātauranga Māori in right from the start.”</li> <li>• “More acceptance and support needed of complementary/holistic methods”</li> <li>• “More research and access to services is required.”</li> </ul>	<p><b>System leadership</b></p> <ul style="list-style-type: none"> <li>• Te Aho o Te Kahu to work with the Māori Health Authority to ensure they have access to high quality information about cancer services and inequities to inform decision making to improve Māori health outcomes</li> </ul> <p><b>Workforce</b></p> <ul style="list-style-type: none"> <li>• Grow the non-clinical cancer workforce (eg kaiāwhina,</li> </ul>	<p><b>Coordination and support services</b></p> <ul style="list-style-type: none"> <li>• Identify mechanisms that enable: <ul style="list-style-type: none"> <li>○ increased support for community-based Māori-led, kaupapa Māori, and Whānau Ora services</li> <li>○ opportunities for Māori to access mātauranga expertise (such as tohunga) and to discuss traditional healing practices as part of their treatment and care</li> <li>○ support for Māori patients and their whānau to have</li> </ul> </li> </ul>

Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	Topic-specific solutions to address inequity Note: some solutions are shorted for space, refer to specific sections for full details
		<p>community-based whānau support staff, kaupapa Māori providers</p> <ul style="list-style-type: none"> <li>Continue to develop and implement approaches to systematically and deliberately increase Māori and Pacific cancer workforce capacity through targeted investment and active recruitment.</li> </ul> <p><b>Coordination and support services</b></p> <ul style="list-style-type: none"> <li>Increase support for community-based Māori-led, kaupapa Māori, and Whānau Ora services to enable options and access to mātauranga Māori in cancer care.</li> </ul>	<p>conversations about the inclusion of traditional health and healing practices in their pathway of care.</p> <p><b>SACT/HSCT</b></p> <ul style="list-style-type: none"> <li>Development of kaupapa Māori services and access to rongoā services</li> </ul>

<p><b><u>Lack of robust data on some aspects of care make monitoring and improving equity and issue</u></b></p> <p>Limited ability to assess inequities in access, timeliness, and outcomes in some areas due to national data not being collected/reported in a way that can expose unmet need and inequities.</p>		<p><b>National system leadership</b></p> <ul style="list-style-type: none"> <li>Te Aho o Te Kahu to work in partnership with Health NZ and the Māori Health Authority to provide national strategic and structural leadership of the cancer control system, including: <ul style="list-style-type: none"> <li>quality system-level data and information available for monitoring and sound decision-making.</li> </ul> </li> </ul>	<p><b>Coordination and support services</b></p> <ul style="list-style-type: none"> <li>Ensure that planning and decision making is informed by best available evidence, and considers: <ul style="list-style-type: none"> <li>the data needs of public, private, not-for-profit organisations and iwi service providers</li> <li>how service design and delivery can be informed by best practice and continuous improvement e.g. through monitoring and evaluation</li> </ul> </li> </ul> <p><b>Surgery</b></p> <ul style="list-style-type: none"> <li>Develop, implement and monitor a Cancer Information Plan to provide timely access to high-quality surgical data to support sound decision-making, including: <ul style="list-style-type: none"> <li>Making appropriate data accessible to those working across the surgical system to empower understanding and decision making for patients, whānau, iwi, clinicians as well as for regional and national planning.</li> </ul> </li> </ul> <p><b>Radiation oncology</b></p> <ul style="list-style-type: none"> <li>Continue the ongoing management and use of the Radiation Oncology Collection (ROC) and be responsible for providing a national framework for managing cancer data and ongoing changes, combining relevant patient and cancer service data into cancer information for service and capacity planning, and analysing</li> </ul>
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			<p>information to produce cancer intelligence and communicate it to stakeholders</p> <p><b>SACT/HSCT</b></p> <ul style="list-style-type: none"> <li>Nationally consistent uptake of electronic prescribing systems for SACT to support accurate monitoring</li> <li>Establishment of a central data source for advertising and collecting data on enrolment in clinical trials to enable monitoring of participation.</li> </ul> <p><b>Allied health</b></p> <ul style="list-style-type: none"> <li>Support development, collection and utilisation of cancer allied health data, including workforce, service utilisation and clinical data, to enable effective planning and monitoring of service</li> <li>Te Aho o Te Kahu undertakes further work into measuring survivorship needs and unmet needs to assist in future care planning</li> </ul> <p><b>Laboratory and pathology</b></p> <ul style="list-style-type: none"> <li>Implementation of a national approach to laboratory information management to improve quality of data available to monitor equity of access and quality of pathology and laboratory services and associated patient outcomes, in particular for Māori and Pacific peoples</li> </ul> <p><b>Radiology</b></p> <ul style="list-style-type: none"> <li>Ensure that data submitted to national collections is fit-for-purpose for monitoring access and quality of cancer radiology services, tracking and responding to</li> </ul>
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Summary of drivers of inequity	What we have heard from patients and whānau about these issues	System-wide solutions to address inequity	Topic-specific solutions to address inequity Note: some solutions are shorted for space, refer to specific sections for full details
			inequities (including having high-quality ethnicity data), forecasting, and service planning.

# Āpiti hanga VII: Ngā kaiwhakarato taiwhanga ā- Poari ā-rohe me te wāhi

## Appendix VII: Laboratory service providers by DHB and setting

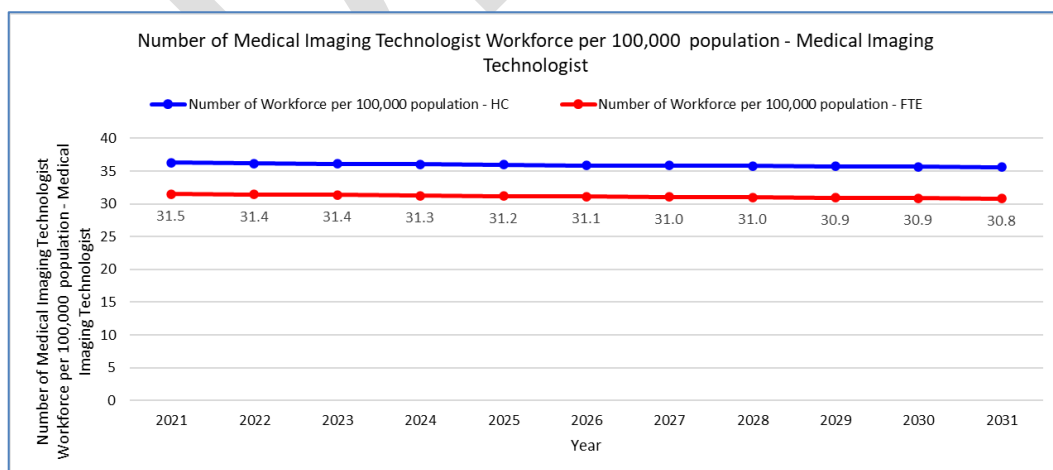
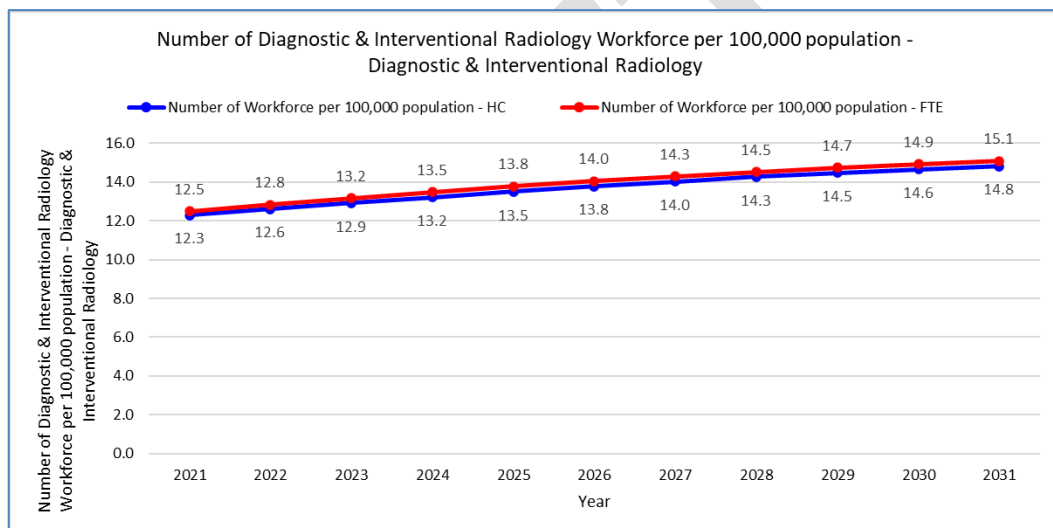
DHB	Community	Hospital
Northland	APHG - Northland Pathology	DHB
Waitemata	APHG - Lab Tests	DHB
Auckland	APHG - Lab Tests	DHB (LabPLUS)
Counties Manukau	APHG - Lab Tests	DHB
Bay of Plenty	Pathlab	Pathlab
Waikato	Pathlab	DHB
Lakes	Pathlab	Pathlab
Tairāwhiti	TLAB	TLAB
Taranaki	APHG - Taranaki Pathology Services	DHB (LabCare)
Whanganui	Medlab Central	Medlab Central
Hawkes Bay	APHG - SCL Hawkes Bay	DHB
MidCentral	Medlab Central	Medlab Central
Wairarapa	APHG - Wellington SCL	APHG - Wellington SCL
Hutt Valley	APHG - Wellington SCL	APHG - Wellington SCL
Capital & Coast	APHG - Wellington SCL	APHG - Wellington SCL DHB (Wellington Regional Genetics Laboratory)
Nelson Marlborough	APHG - Medlab South	APHG - Medlab South
West Coast	DHB	DHB
Canterbury	APHG - Canterbury SCL DHB (Canterbury Health Laboratories)	DHB (Canterbury Health Laboratories)
South Canterbury	APHG - Medlab South	APHG - Medlab South
Southern	APHG - Southern Community Laboratories	APHG - Southern Community Laboratories

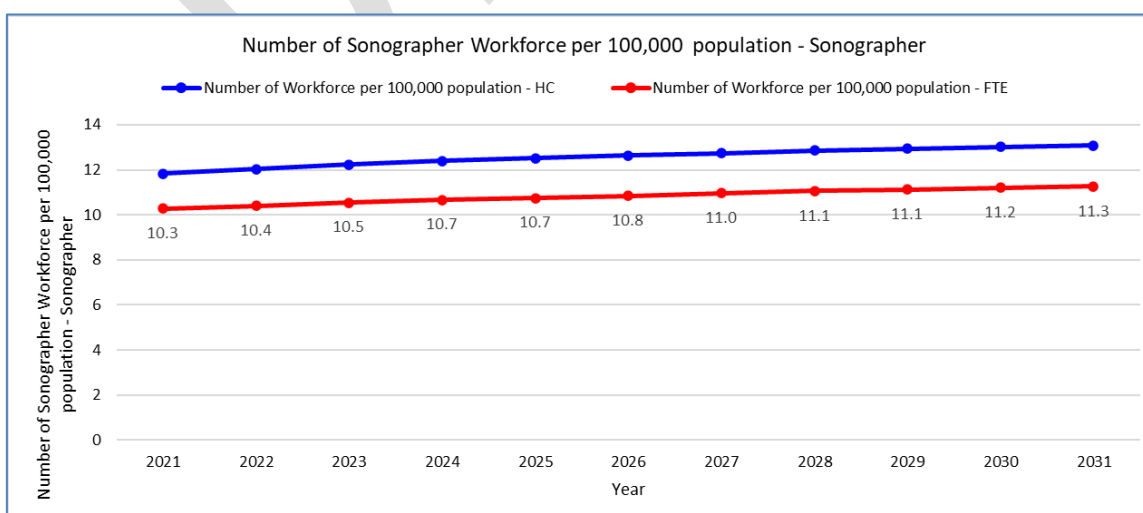
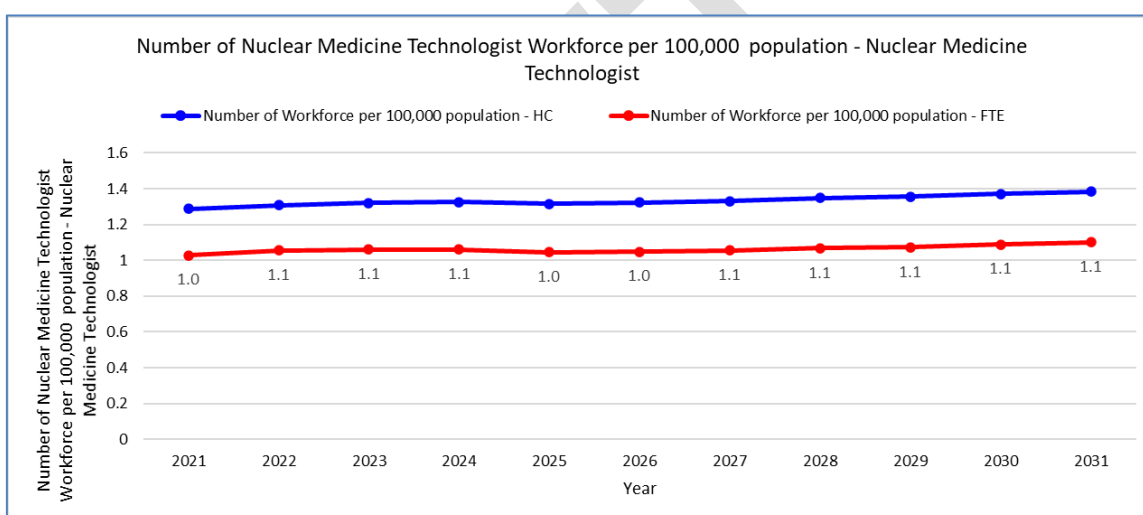
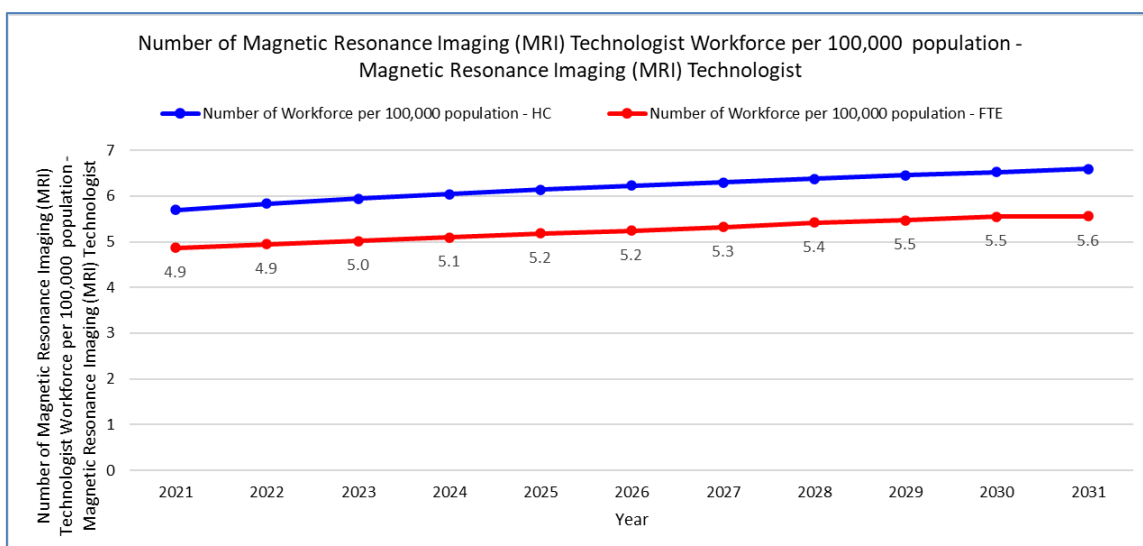
APHG, Australasian Pacific Healthcare Group; DHB, District Health Board; SCL, Southern Community Laboratories.



# Āpitihanga VIII: Ngā Arawhata mō te ahumahi haumanu hihiora

## Appendix VIII: Graphs of radiology workforce numbers over time





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