TE AHO
O TE KAHU
CANCER
CONTROL
AGENCY

# Briefing to the Incoming Minister

December 2023

**Mā te whiritahi, ka whakatutuki ai ngā pūmanawa o tāngata**

Together weaving the realisation of potential

# Contents

# Welcome

Tēnā koe e te Minita.

Congratulations on your new role, Minister.

We at Te Aho o Te Kahu | Cancer Control Agency (the Agency), are excited to work with you on continuing to improve cancer services and outcomes for all people in Aotearoa New Zealand. I look forward to meeting with you and discussing how we can work together to reduce cancer incidence, improve cancer survival, enhance the quality of life of people with cancer, and advance equity across the cancer pathway. We are committed to providing advice and support towards achievement of the Government's 100-day plan and direction.

Your appointment as Minister of Health comes at a time of change and opportunity across the health system. Our role as Te Aho o Te Kahu | Cancer Control Agency is more critical than ever to ensure that the needs of whānau with cancer, the leading cause of death in Aotearoa New Zealand, are considered in every part of the new system's design and service delivery.

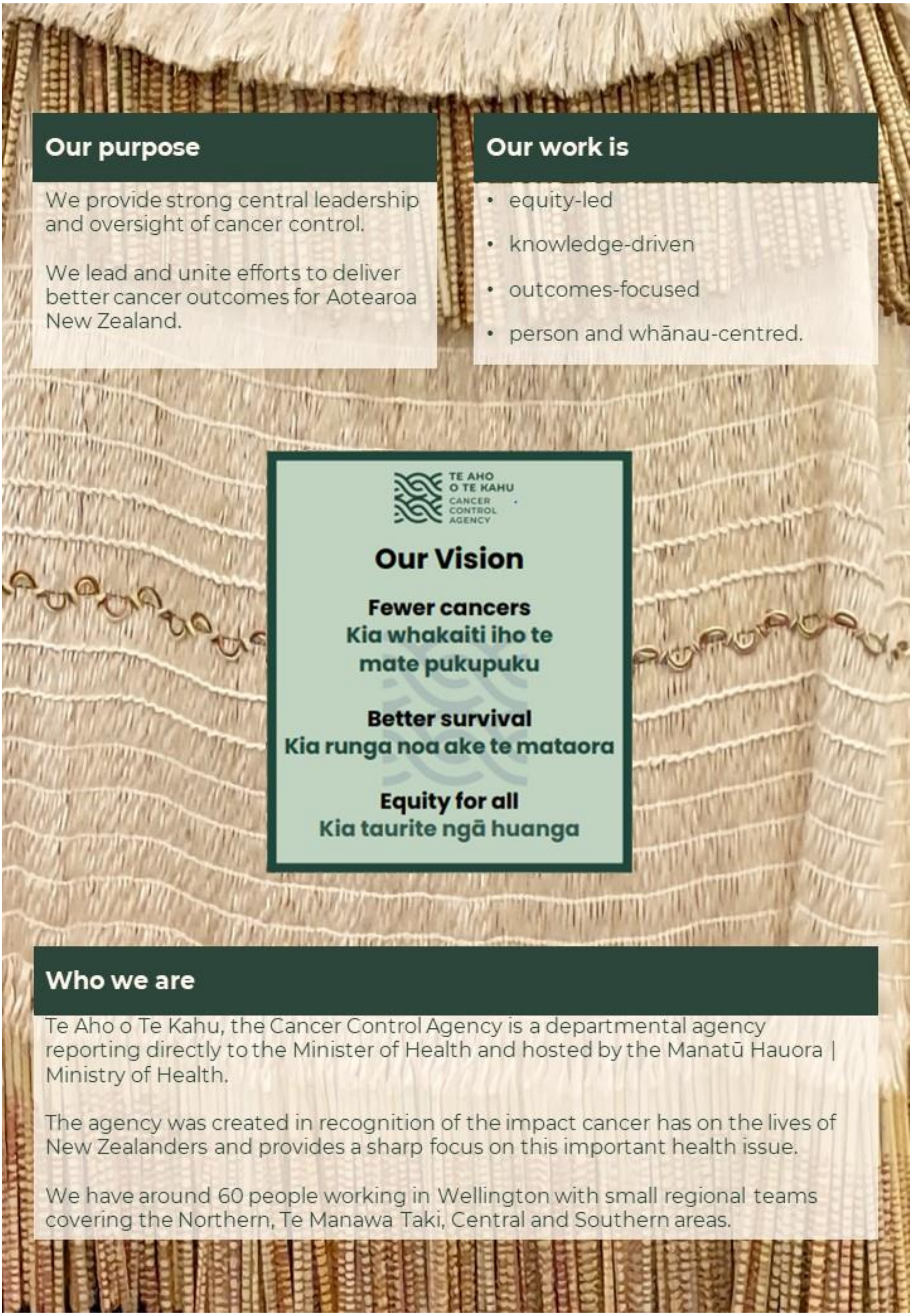
The Agency is well placed to build on its strong track record of leading transformational change in the cancer system, through our balanced range of work. This work spans the continuum from preventing cancer and detecting it early, to ensuring fast and equitable access to effective treatment, to supporting cancer survivors post treatment and ensuring high quality, culturally safe, palliative and end-of-life care is available when needed.

We will work closely with your office to advance government priorities and keep you informed on progress with our work programme, discuss opportunities for new initiatives, and alert you to risks in a timely manner. While the challenges of the health system are many, we at the Agency are ready to contribute in a meaningful way towards your commitment to New Zealanders to provide timely access to quality care. We will do this through delivering solutions that are evidence-based, meet the needs and expectations of patients and whānau, and that are pragmatic and implementable.

We will work with your office to agree timely reporting mechanisms to provide oversight of our work programme and performance. In the meantime, I leave you with this document that provides information on: who we are; the work we do and our priorities; the challenges we face and how we are responding; and the strategic opportunities for improvement.

Ngā manaakitanga

Rami Rahal
**Tumuaki | Chief Executive**
**Te Aho o Te Kahu**



## Our purpose

We provide strong central leadership and oversight of cancer control.

We lead and unite efforts to deliver better cancer outcomes for Aotearoa New Zealand.

## Our work is

- equity-led
- knowledge-driven
- outcomes-focused
- person and whānau-centred.

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## Our Vision

**Fewer cancers**
**Kia whakaiti iho te mate pukupuku**

**Better survival**
**Kia runga noa ake te mataora**

**Equity for all**
**Kia taurite ngā huanga**

## Who we are

Te Aho o Te Kahu, the Cancer Control Agency is a departmental agency reporting directly to the Minister of Health and hosted by the Manatū Hauora | Ministry of Health.

The agency was created in recognition of the impact cancer has on the lives of New Zealanders and provides a sharp focus on this important health issue.

We have around 60 people working in Wellington with small regional teams covering the Northern, Te Manawa Taki, Central and Southern areas.

# Who we are

Te Aho o Te Kahu | the Cancer Control Agency (the Agency), is a departmental agency of the government reporting directly to the Minister of Health. The Agency was created in response to the disproportionate impact cancer has on the lives of New Zealanders and in recognition of the need to have a coordinated, national effort focused on it. The Agency was set up to ensure that attention and focus on cancer is not diluted by the broader demands of the health care system.

The Agency has around 60 staff most of whom are subject matter experts in cancer control (including public health physicians, radiation therapists, health economists, epidemiologists, biostatisticians, project managers, and public policy/government relations experts). Our main office is in Wellington, with four small regional offices in Auckland, Christchurch, Hamilton and Palmerston North to ensure we are closely connected and responsive to regional and local contexts.

The Ministry of Health provides accommodation and corporate functions to the Agency through a purchased service agreement.

We have been working with Te Whatu Ora |Health New Zealand and Te Aka Whai Ora | Māori Health Authority to ensure that what we produce in terms of knowledge and advice on optimal cancer control is adopted and translated into real changes in how care is planned and delivered.

## Our purpose: an agency focused on cancer

Cancer presents some unique challenges to the health system.

- The number of people diagnosed with cancer is projected to double over the next two decades.
- The costs and complexity of care, and pace of change present major challenges for our health systems and services.
- Māori and Pacific peoples have worse cancer survival rates and higher incidence than other New Zealanders.

Cancer survival is improving in Aotearoa New Zealand, but our rate of improvement is slower than those in comparable countries, so we need to take steps to prevent us falling further behind.

To respond to these challenges, the Agency provides strong leadership and oversight of cancer control. We lead and unite efforts to deliver better cancer outcomes for Aotearoa New Zealand. We also ensure there is transparency in our country's progress towards achieving the goals and outcomes outlined in the **New Zealand Cancer Action Plan 2019–2029.**

In practice, we deliver this leadership and oversight across a wide range of domains including:

- providing advice to Government and the Ministry of Health about the future design and function of cancer services and options for resolving medium- to long-term strategic and operational issues

- enabling system improvements through the development of knowledge products, decision support and change management tools, evidence-based and person-centred models of care, advice on health workforce and resource planning, quality measurement and improvement, and recommendations for solutions to gaps
- developing and sustaining strong partnerships between health entities and supporting them to develop policy, planning and delivery related to cancer
- assembling and disseminating cancer data and information to inform decision-making and service delivery; this includes building an advanced and capable cancer data infrastructure
- providing support for cancer service providers when service is, or is likely to be, disrupted or is not meeting demand or expectations.

The cancer continuum intersects with every aspect of the wider health system. It remains critical to have a stand-alone, strong state entity to coordinate across the many stakeholders involved in cancer care and control.

International benchmarking shows that countries that have a dedicated agency focused on cancer control perform better than those who include cancer control in a broader commissioning entity.

## Our operating environment

The Agency is the principal advisor on cancer to the Minister, and national leader for cancer control. We connect and unite health entities and the wider cancer sector, providing expertise and advice to improve outcomes for whānau with cancer.

The health system reforms have not changed the role of the Agency; however it has been necessary to adjust our approach. With the creation of Te Whatu Ora | Health New Zealand and Te Aka Whai Ora | Māori Health Authority, the Agency is refining its partnership approach accordingly. This includes national, regional, and local engagement across our shared areas of responsibility.

Our te reo Māori name is a taonga, gifted to us by Hei Āhuru Mōwai | the Māori Cancer Leadership Aotearoa in June 2020. This name is central to who we are and how we work.

Te Aho o Te Kahu means ‘the central thread of the cloak’. This thread (aho) binds the many strands (whenu) into one cloak (kahu) that protects people with cancer and their whānau.

**Te Aho**: The central thread symbolises our agency and our role as a leader and connector across the cancer control continuum. **Te Kahu**: The cloak symbolises all the services, organisations, communities, and people that work with those affected by cancer.

As the central thread of the cloak, one of our key functions is to liaise with the many parties and organisations involved with cancer prevention, promotion, diagnosis, treatment and care. In the country’s reformed health system, this includes direct relationships between the chief executives of the Agency and other key partners including:

- Te Whatu Ora | Health New Zealand
- Te Aka Whai Ora | Māori Health Authority
- Manatū Hauora | Ministry of Health including the Public Health Agency

- Te Pātaka Whaioranga | Pharmac
- Te Tāhu Hauora | Health Quality & Safety Commission New Zealand.

The responsibility for commissioning and delivery sits with our partners. Through engagements at the chief executive level, supported by collaborations at the tier 2 and tier 3 levels, we are building partnerships that leverage the distinct roles of each of the health entities. Increasingly, we are looking to have a shared collaborative approach to common priorities and workstreams. As Te Whatu Ora | Health New Zealand is progressing its development, we are forging strong constructive and collaborative relationships and building connections to turn our vision and priorities into action.

The relationship between our agency and the Ministry of Health is particularly important and is supported through co-location and an interdepartmental agency agreement. This reinforces our place within the health system and the contribution our cancer-focused work can make to the wider work of the Ministry of Health.

Te Aho o Te Kahu receives an operating budget through Vote Health of $15.541m per annum.

# What we do for you

We provide you with advice on cancer related topics and issues. This includes supplying information and advice to you and Associate Ministers to help inform policy, key decisions, and parliamentary requests. We support you by providing leadership and oversight to the wider health system to ensure the delivery of cancer diagnosis and treatment is timely and aligned with Government priorities. The Agency will also raise issues and opportunities with you as they arise.

As mentioned, the Agency provides national leadership with a programme of work that sets the direction for improved cancer outcomes for the people of New Zealand. We are already in discussions with the Ministry of Health and Te Whatu Ora | Health New Zealand about appropriate measures and health targets relevant to cancer.

Our programme of work is based on the four outcomes of the Cancer Action Plan 2019-2029 which sets out the government's direction for cancer care. The Plan has a strong emphasis on delivering and targeting all cancer services to ensure equitable outcomes for all New Zealanders. The Agency has responsibility for ensuring the New Zealand health system remains committed to delivering on the Plan.

Our priorities and work programme are summarised below:

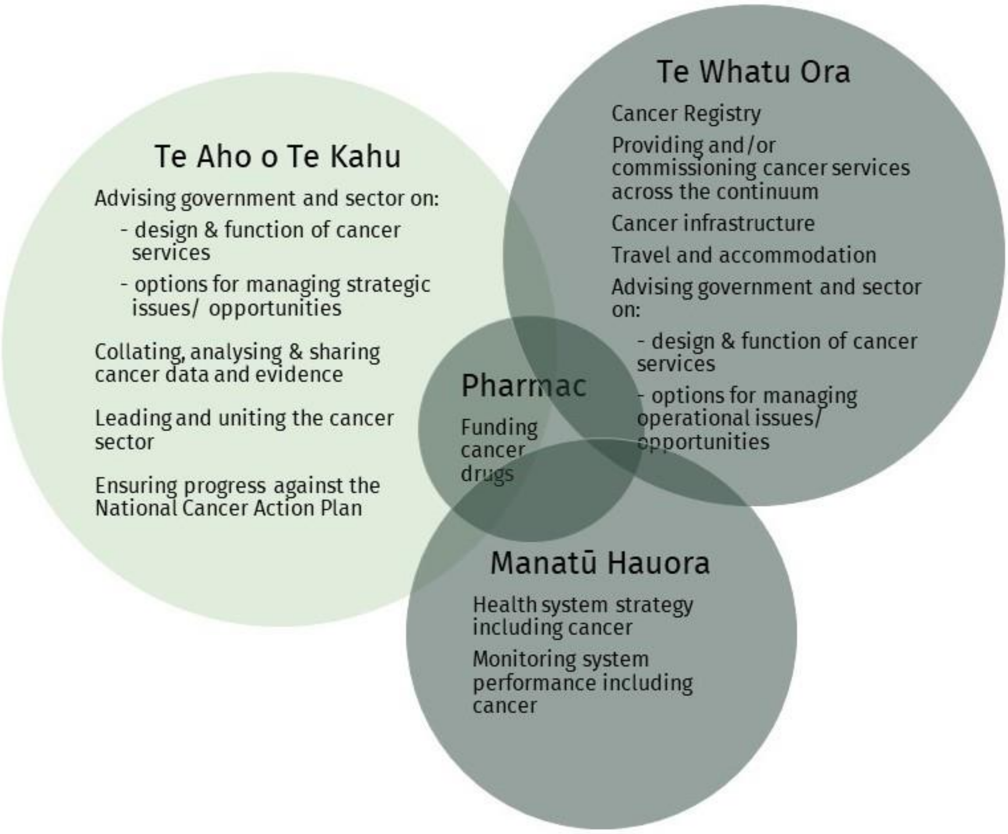
| **Outcome 1: New Zealanders have a system that delivers consistent and modern cancer care** | |
|---|---|
| **Agency priorities** | **Agency work** |
| Supporting a system that delivers consistent and modern care | Building a high-performing agency Commitment to capability building<br>Systems and processes<br>Active health sector support<br>COVID-19<br>Cancer service quality performance indicators |

| | |
|---|---|
| Transforming the future of cancer service delivery | Seven cancer services planning projects (more detail on page 7) |
| Developing a monitoring framework | Delivering the first monitoring report<br>Cancer service quality performance indicators |
| Providing better quality, more connected data | CanShare (more detail on page 8) including:<br>Anti-Cancer Therapies – Nationally Organised Workstreams (ACT-NOW)<br>Structured Pathology<br>National Radiation Oncology Collection (ROC)<br>Collaboration across data and digital health |
| **Outcome 3: New Zealanders have fewer cancers** | |
| **Agency priorities** | **Agency work** |
| Achieving fewer cancers through a focus on prevention | Cancer Prevention Report<br>Cancer research<br>Primary health care project<br>Advice for primary care |
| **Outcome 4: New Zealanders have better cancer survival, supportive care and end of life care.** | |
| **Agency priorities** | **Agency work** |
| Improving cancer survival | Quality improvement programme<br>Cancer medicines availability analysis<br>Clinical trials |
| **Outcome 2: New Zealanders experience equitable cancer outcomes** | |
| **Agency priorities** | **Agency work** |
| Improving equity of cancer outcomes | Māori community hui<br>Embedding equity-led thinking<br>Pacific research project<br>Disability and cancer project initiated<br>Supporting equity-led work across the sector<br>Cancer service quality performance indicators |

We are currently considering refreshing the Cancer Action Plan given what we have learned since its release four years ago and the subsequent changes to the structure of the health system. We will update you on this proposal when we have the opportunity to meet.

There are some key areas of the health system relating to cancer for which you will receive your primary advice from other agencies (e.g. screening, workforce). However, we are consulted, and usually provide joint advice, on these areas when opportunities or issues arise.

**Who leads the specific areas of cancer control**



# Spotlight on our key work

The Agency has a planned work programme. We are also agile and responsive to enable a focus on emerging priority issues and responding to opportunities with the greatest potential to improve outcomes, particularly in areas of inequity. Below is a summary of some of the key work we have underway.

## Transforming cancer services

We are currently undertaking a programme of work to drive transformative change and ongoing quality improvement in how cancer treatment services are organised and delivered. This work builds on the recommendations in our *He Mahere Ratonga Mate Pukupuku – Cancer Services Planning report* (2022).

This **Cancer Service Planning Programme** is developing models of care and pathways that describe what optimal cancer care looks like for different cancer treatments and types of cancer. This work is particularly important given the differences in standards and practices still experienced between and within districts and regions.

There are five projects within the programme. Four are focused on the optimal model of service delivery for different cancer treatment types (radiation therapy, systemic anti-cancer treatments, stem cell transplant and complex cancer surgery). The fifth project is developing Optimal Cancer Care Pathways which describe expectations for different cancer diagnoses across the cancer continuum, spanning prevention activities through to end of life care.

Each project has taken an equity-led approach which evaluates/combines international evidence, patient experience and opportunities for innovation. Using this approach, the models and pathways draw together a comprehensive whole-of-service and whole of system perspective. These are intended to provide a solid foundation from which targeted improvement can occur nationally, regionally and locally. We are now commencing work with health system partners, primarily Te Whatu Ora | Health New Zealand, to action and realise this improvement. This work aligns with the Cancer Service Delivery Programme being led by Te Whatu Ora | Health New Zealand.

The Cancer Service Planning programme also has a specific focus on cancer workforce and has nominated workforce leads to ensure this development work is both informing, and integrating with, national workforce initiatives and priorities.

## CanShare

CanShare is a new national health informatics platform being developed by the Agency that aims to allow the timely sharing of relevant and accurate cancer data. CanShare will enable the collection of complete and accurate cancer data, joining currently disparate data siloes and providing a means to share clinical cancer information as needed.
The primary intent of the CanShare programme is to support clinical and whānau decision-making at the point of care. The Agency is closely connected with work on other national technology initiatives such as Hira, to ensure that developments are consistent, interoperable and leverage the learning and progress made by each project team.

Other outcomes from this work will include advanced analytics capability supporting up-to-date monitoring of cancer care throughout the country.

Connections have been established with Te Whatu Ora | Health New Zealand, a cloud database has been built and there has been progress in the individual programmes comprising CanShare, some of which are outlined below.

- **Anti-Cancer Therapies – Nationally Organised Workstreams (ACT-NOW)** is a national systemic anti-cancer therapy (SACT), eg, chemo and other types of therapies, data collection and analytics programme. Stakeholders have collaborated to agree on SACT treatment definitions - meaning that treatment regimens can be compared and therefore standardised across the country. This can support identifying unwarranted variation, so that it can be investigated, and quality improvement activities instigated.

- The **Structured pathology** project develops and supports the national adoption of data standards so pathology information can be easily shared for clinical decision-making. Alongside standard development, we are building productive relationships with pathology vendors and providers to plan implementation of the standards over the coming years.

- **National radiation oncology collection (ROC)** is a central repository of detailed radiation oncology information to give a better understanding of radiation oncology service delivery (and the ability to identify unwarranted variation), and linear accelerator capacity, utilising and planning. This supports actions to improve access to radiotherapy and drive more cost-effective treatment.

- The Agency led the release of eighteen **HISO (Health Information Standards Organisation) standards** last year, with more currently in development. These standards ensure data systems can 'talk to each other' and support the vision of a fully interoperable digital health system to facilitate sharing cancer information for decision-making, quality improvement and research.

## System monitoring and Faster Cancer Treatment reporting

The Agency works closely with regional cancer service providers to understand system performance and identify potential issues early.

Timely access to quality care is a foundation for improving outcomes for cancer patients. Faster cancer treatment (FCT) indicators are a significant mechanism to support building relationships and drive service improvement at a regional level.

The indicators require districts to collect standardised information on patients who have been referred urgently with a high suspicion of cancer and provide information around timely access to treatment once a 'decision to treat' is made. The Agency is currently partnering with Te Whatu Ora | Health New Zealand on quality improvement and consistency of these indicators and definitions through implementation of recently updated FCT business rules.

Te Aho o Te Kahu are well positioned to support the implementation of an FCT target in line with the first 100 days plan. The Agency has continued to collect and manage FCT data while the wider system underwent reform. In line with system performance monitoring frameworks, we intend for this function to be passed to Te Whatu Ora | Health New Zealand as soon as possible. In the meantime, we have provided advice to the Ministry of Health on the development of FCT targets and are available to support target development and monitoring, as relevant to cancer, and as useful to the Ministry of Health and Te Whatu Ora | Health New Zealand.

## Workforce

A sustainable current and future cancer workforce is a priority for the Agency. Future cancer service delivery is heavily dependent on the actions that are taken collectively now. In 2022, the Agency delivered the 'Cancer Workforce Implementation Plan Phase 1 Priorities' to the Workforce Taskforce Lead. The Plan identified both short- and medium-term workforce priorities that would address some of the current workforce issues faced across the cancer sector.

The priority solutions identified in the Plan were the result of consultation and, where possible, modelling. This was undertaken using available data to determine workforce supply and demand into the future. For example, there needs to be an increase in radiation oncology training – because of our work, agreement has been reached with Te Whatu Ora | Health New Zealand to increase the number of training places in 2024 with an additional five places available annually across services. This investment will support future sustainability for this key workforce. We have initiated a project with Te Whatu Ora | Health New Zealand that will, when complete, provide information on the cancer nursing workforce's current state and will enable an informed understanding of the future nursing pipeline requirements.

We have completed and distributed guidance to support radiation services to enable their radiation therapists to work to the top of their scope of practice within the system. This would have a positive impact on the work undertaken by radiation oncologists and support retention of radiation therapists by providing a pathway of development.

## Quality Performance Indicators

The Quality Performance Indicator (QPI) programme aims to identify unwarranted variation in the cancer diagnosis, treatment and outcome pathway. To date we have developed and reported on QPIs for bowel, lung, prostate, and pancreatic cancers. Breast cancer QPIs are in development. The process of identifying these indicators involves substantial clinical engagement, broad consultation, and consensus that the indicators selected, developed, and published are appropriate. We are also working with cancer QI experts and looking to overseas examples to develop non-tumour specific QPIs that will investigate and report on performance at a cancer service system level (rather than at the tumour-type level).

Once the indicators are identified, we can then provide information about how each Te Whatu Ora | Health New Zealand district is doing in relation to each of those indicators, and whether there is inequity between population groups. Where variation is seen, we work with Te Whatu Ora | Health New Zealand (at national, regional and district levels) to understand the causes of the variation. We can also support them to develop and implement programmes of work that address the unwarranted variation.

Where the creation and monitoring of targets is seen as helpful, we can provide evidence-based advice to help Te Whatu Ora | Health New Zealand set targets that drive improvements in timely access to quality care.

## Regional engagement and support

The Agency has four regional teams that work directly with the clinical and operational leaders of cancer services. This includes:

- developing positive working relationships with stakeholders, maintaining links with regional and local, clinical and service leadership
- promoting the Agency’s national work programme
- providing insight into service performance data and working with clinicians and service staff to identify and implement appropriate responses
- understanding regional and local needs and the challenges they face
- promoting a regional perspective and a focus on the needs of the population
- supporting a regional service/quality improvement focus.

### Improving the National Travel Assistance (NTA) policy

Since the Agency was formed in 2019, we have been actively working to understand how the National Travel Assistance policy impacts both patients and whānau affected by cancer, and the wider cancer and health system. It is clear that while well-intentioned, the policy is now actively increasing inequities for patients and whānau, and is highly likely to be contributing to system inefficiency, particularly through non-attendance (‘DNA’) rates for specialist appointments.

After speaking with patients, whānau, clinicians, health system administrators, the primary care sector and community care providers, we developed advice on travel and accommodation for the then-Transition Unit. This content was used to inform Te Pae Tata, the interim New Zealand Health Plan; which includes an action to ‘implement national pathways to access transport and accommodation to support the equitable completion of cancer treatment’.

We are now collaborating with Te Whatu Ora | Health New Zealand to develop and pilot changes to the NTA policy. This will in time create a policy that is fit for purpose, supports equitable access to specialist health care, and reduces the administrative burden on patients, whānau and the health sector. We look forward to discussing this with you once Te Whatu Ora | Health New Zealand has briefed you on this work.

### Hearing the voice of whānau Māori

In 2021, the Agency partnered with mana whenua and local health organisations to hold 13 community hui across the country. The aims were to understand the lived experiences of whānau Māori affected by cancer, and to connect with local organisations working in cancer and health care.

Collectively, the Agency spoke with more than 2,500 whānau Māori, including patients, whānau and Māori working in cancer care or the wider health and social sectors. Following the hui series, we analysed the themes and insights identified by whānau and released three reports in March 2023 (Health Report number: H2023020820).

This hui series and the resulting insights have helped to shape our work programme, which now includes work on cancer navigation services, travel and accommodation support as mentioned above, and telehealth in cancer care. We are also supporting work led by other agencies on key system enablers such as workforce and data systems.

# Risks and mitigations

Te Aho o Te Kahu | Cancer Control Agency is constantly evaluating the risks which could impact the ability of the health system to improve cancer outcomes and proactively identifying mitigation strategies for the system to manage those risks.

## Operational service delivery challenges

Many parts of the health system are currently facing challenges with delivery of consistent, timely and high-quality cancer services. Service providers frequently turn to the Agency to provide advice on addressing these challenges. While our agency has been able to add value through our expertise and support in this way, addressing acute operational crises in the system is not a core role of the Agency. There is a risk that an over commitment to addressing short-term issues could detract from our ability to effect enduring improvement in outcomes through medium- to long-term change. We are working with partner agencies where appropriate to mitigate this risk.

## Workforce

The current pressure on the cancer workforce in Aotearoa New Zealand is one of our areas of greatest concern. There are a large number of vacancies across cancer services and modelling demonstrates that more clinicians and support workers are required to meet future demand. While these workforce issues are shared with the rest of the health sector, the complexity of cancer treatment and the level of specialist capability and capacity required to deliver it sustainably, carry inherently greater risks.

As mentioned, the Agency is working in partnership with other health entities to develop solutions that will address these issues. We look forward to discussing in more detail how the cancer workforce can be strengthened going forward.

## Transformation of the health system

As a stand-alone entity focused on the complex issue of cancer, our independence has enabled us to bring together partners from across the sector to work in a collaborative and solutions-focused way.

While the reforms of the health system created some expected disruptions, we are optimistic that a more nationally co-ordinated and directed system will have positive impacts on cancer outcomes. However, we are also acutely aware that despite our very strong relationships with the new entities, disruption of the entities and structures that deliver health care services will make it more challenging for the Agency to engage with key stakeholders in a timely and productive manner.

Our Cancer Services Planning programme has brought together considerable detailed information about the current and potential future arrangements for the delivery of cancer care. This has established a strong basis for further engagement with the new health entities to support their progression of this work, which can mitigate this risk. A robust approach to the development and implementation of new models of care, supported by a strengthened workforce will give the opportunity for system transformation - in line with the wider goals of the health reforms. Effective engagement with Te Whatu Ora | Health New Zealand and Te Aka Whai Ora | Māori Health Authority will be a major enabler in realising this opportunity.

## Cancer medications

The public funding and availability of cancer medicines is a complex, fast-paced and challenging area of cancer care. New, increasingly targeted medicines are being developed at a rapid pace. On the one hand, this provides much needed hope and options for people with cancer. On the other hand, the rapid pace of development and the high cost of cancer medicines can make it difficult for governments worldwide to assess any additional clinical benefit new medicines offer, how much public funding should be allocated towards new cancer medicines, and the opportunity cost in other areas of investment.

Cancer medicines are an integral part of cancer care. Better cancer outcomes are more likely to be achieved when there is equitable access to effective medicines. However, cancer medicines do not and should not exist in isolation. The full benefits of cancer medicines can only be realised if the whole continuum of cancer care (from prevention to screening and early detection through to diagnosis, staging, treatment, follow-up and supportive care) is fully resourced to work well and equitably.

As you know, the Agency released a report in 2022 describing the availability of cancer medicines in Aotearoa New Zealand.[1] Our analysis found that - for solid tumours - there were a number of medicines funded in Australia but not in Aotearoa New Zealand that were likely to be associated with substantial clinical benefit at a population level (although for the majority of the unfunded medicines, this benefit was related to non-curative life extension and/or improved quality of life and not  increases in cure rates).

Substantial clinical benefit was determined using the European Society of Medical Oncology's Magnitude of Clinical Benefit Score (ESMO-MCBS) tool, an internationally developed, validated and recognised tool for assessing clinical benefit of cancer medicines at a population level. A substantial proportion of these unfunded gaps were already on Pharmac's options for investment list. This mean that these medicines would be funded when there was sufficient budget available.

At the time of our analysis, we were unable to assess the magnitude of clinical benefit at a population level of medicines for blood cancers. This is because the ESMO-MCBS tool had not been validated for assessing blood cancer medicines. Blood cancer treatment is heavily reliant on the use of medicines, given that other non-medicine options, like surgery or radiotherapy, are often not an option. We suspect that the conclusions of this analysis (which is focused on solid tumour medicines) would be similar if not more compelling for blood cancers. Since the report was released, an updated and validated version of the ESMO-MCBS tool has subsequently been published which can assess clinical benefit in blood cancers. We are in the process of repeating our analysis for blood cancer medicine gaps.

We have also been engaging with the Ministry of Health and other agencies to support the development of options for funding the 13 cancer medicines identified in the current

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[1] Te Aho o Te Kahu. Understanding the Gap: an analysis of the availability of cancer medicines in Aotearoa New Zealand. April 2022: https://hcmsitesstorage.blob.core.windows.net/cca/assets/T_Ao_TK_Cancer_medicines_availability_analysis_FINAL_2782afa08a.pdf

government's election commitments.  We will continue to work with you and the Ministry of Health to identify the best approaches for moving forward on this initiative.

## Meeting high expectations

Ambitious goals have been set to address inequity of access and outcomes for people affected by cancer. Stakeholders are looking to our agency to resolve a large range of complex and long-standing issues relating to cancer and the wider health system. As a relatively small agency with limited levers to effect change, we have often exceeded expectations, primarily through our influence on other entities. However there is always a risk that stakeholder expectations will exceed our ability to deliver results.

Areas of high interest and expectation from stakeholders include the sustainability of current cancer services delivery.  Across the sector, there is broad recognition that simply providing 'more of the same' is not feasible and will not address the fundamental drivers of inequity.

Our engagement with Māori communities and leadership has highlighted the difficulties experienced by Māori in accessing care and treatment. It has also raised expectations of change that will not only achieve equitable cancer outcomes for Māori, but also meet their needs and aspirations. Resolving this will require effective partnerships with Māori and all health entities to drive change and improvement.

Our approach to mitigating these risks is:

- engaging stakeholders in the development of clearly articulated prioritisation processes
- committing to realistic deliverables without overpromising
- developing and maintaining clear programme and project plans, with risk and mitigations strategies in place
- developing and delivering communication strategies which are mindful of both opportunities and risks, and meet the broad range of needs of our stakeholders
- socialising the need for change and building a consensus around agreed actions.

# Strategic opportunities

Te Aho o Te Kahu believes that the areas described below represent the best strategic opportunities for the future.

Te Aho o Te Kahu also has advice about the best investments that can be made in the short-term to bring about rapid improvement in cancer service delivery. We look forward to discussing these options with you.

## Strategic direction and sustainability

We have found the Agency is very well placed – as an entity with a singular focus on cancer – to provide the health system with a strategic direction for cancer care and sustainable solutions for delivery of that care in the face of growing demand. As the Chief

Executive of Te Whatu Ora recently noted, it is very useful for her, as the leader of a large organisation responsible for **providing** cancer care to know that she has the advice and support of the CCA to do the **thinking** about how those services can be delivered, which her organisation can then act on.

Te Aho o Te Kahu plays a crucial role for Te Whatu Ora and other health entities, by identifying potential actions to improve cancer care. Ensuring alignment to the priorities and focus for the wider health system will enable engagement and action. The CCA's connection to the cancer sector, especially through its strong relationships with clinicians and people with lived experience of cancer, is crucial.

These factors provide an opportunity for Te Aho o Te Kahu to lead and drive significant improvement across the cancer continuum.

## Prevention and early diagnosis

To date, the main focus of our work programme has been on improving treatment and extending survival. This has been important given the significant expectations of stakeholders, the level of public concern about access to cancer treatment, and the support/advice that the then-DHBs urgently needed during COVID-19. However, we also recognise the substantial opportunity to reduce cancer incidence and improve cancer outcomes by having a greater focus on cancer prevention, early detection, and diagnosis.

The completion of our Cancer Prevention Report in February 2022 highlights where cancer prevention efforts can be strengthened. It aims to help shape policies that will prevent cancers, as well as other conditions for the people across Aotearoa New Zealand. The report focuses on six key areas: tobacco, alcohol, poor nutrition and excess body weight, insufficient physical activity, excessive exposure to ultraviolet radiation and chronic infections.

The establishment of the new Public Health Agency within Manatū Hauora | Ministry of Health provides us with the crucial partner to advance this work. We will work to support initiatives to minimise and prevent the incidence of cancer, and to bring a cancer perspective to all relevant prevention activities.

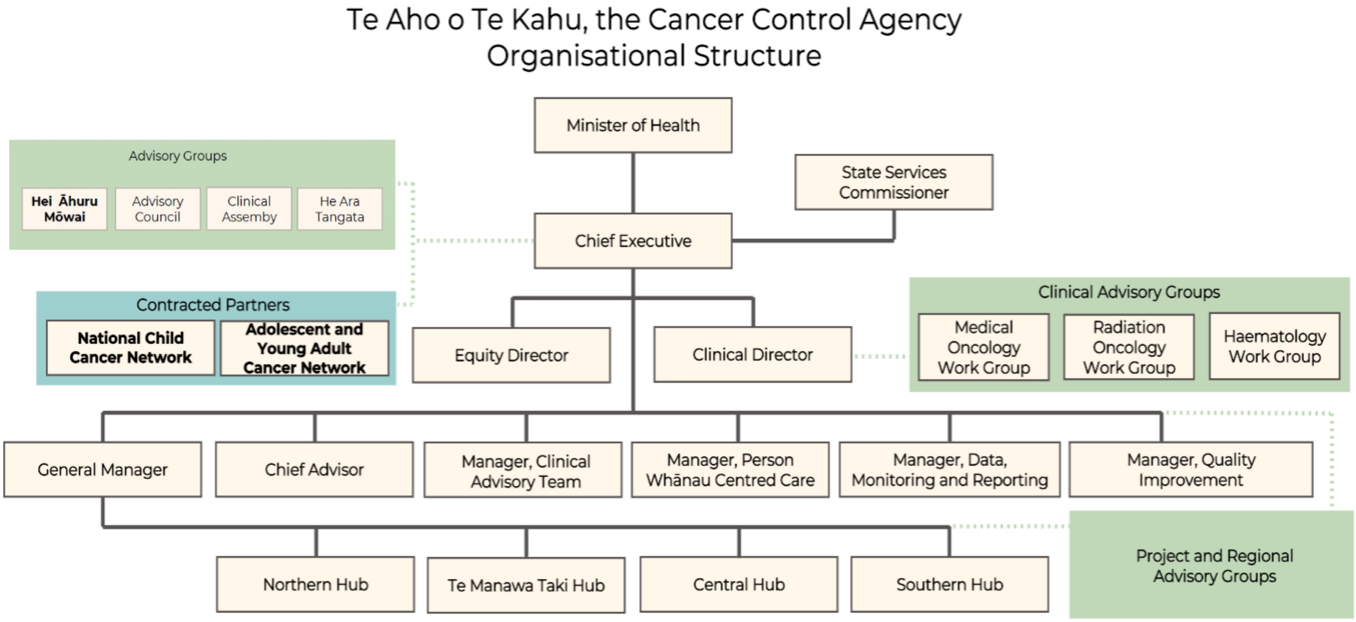
We are also scoping potential ways to improve cancer outcomes and experiences through primary and community care. This pathway is often difficult for patients and whānau, in many cases due to a shock cancer diagnosis via the emergency department or other unplanned hospital admissions. Our work in this area will include a programme of initiatives that support primary and community care organisations to help people affected by cancer, particularly the pathway from symptom detection to definitive diagnosis. The first of these initiatives is likely to be partnering with Te Whatu Ora on the Te Pae Tata priority to streamline access to diagnostic tools by primary care practitioners. We understand the challenging environment that primary care practitioners operate in and will work with them to provide resources and tools that are fit for purpose and sustainable.

## Equity

Cancer does not impact all groups within our population evenly. There are inequities at every step along the cancer continuum – from an individual's exposure to risk factors and their likelihood of developing cancer in the first place, access to screening, access to assessment, and the speed with which they are diagnosed, to their ability to access appropriate cancer treatment, and their timely referral to supportive, palliative, and end-of-life care. This creates inequitable experiences and outcomes for particular population groups, and also reduces the health system's ability to operate efficiently and effectively. More information is available in Appendix 1 and in our report, The State of Cancer in New Zealand.

Te Aho o Te Kahu is working to understand the extent of the current inequities, and pursue changes at system and service levels that will create better outcomes both for these population groups and the wider health system. The population groups we currently focus on include Māori, Pacific peoples, disabled people, and people living in rural areas. When we have capacity, we will extend that work to include people affected by mental distress, the SOGIESC community and migrant and refugee populations. This focus is being reflected through our entire work programme. An example within our Cancer Services Planning work, is the development of Optimal Clinical Care Pathways (OCCPs). These pathways aim to clearly describe how health care providers should deliver optimal cancer care. The OCCPs can be monitored to identify unwarranted variation and inequity. Actions taken to address these can be similarly monitored, linking back to the Quality Improvement approach mentioned above. Highlighting the impact of current inequities offers the opportunity to build a consensus around the actions required to address them. Another example involves our advice to Te Aka Whai Ora on how to best invest in cancer care coordination services.

# Our organisation



**Organisations in bold are external**

## The people you will work with

Chief Executive | Tumuaki – Rami Rahal

Rami has over 30 years' experience of health system leadership, with a particular focus on improving cancer outcomes. For the last 12 years, Rami has held senior leadership roles at the Canadian Partnership Against Cancer (Canada's national cancer agency), most recently Vice President, Cancer Systems, Performance and Innovation. In this role, Rami was responsible for implementing large scale cancer policy, planning and research projects. He was appointed as Chief Executive in June 2023.

General Manager | Pou Whakahaere Mātāmua – Nicola Hill

Nicola has been General Manager at the Agency since 2019, and for the 2022/23 year, Nicola was the Agency's Acting Chief Executive. Nicola has 17 years' experience at the Ministry of Health, including periods advising the Director-General of Health and as Acting Group Manager of the Health System Strategy Group in the Strategy and Policy Directorate.

Clinical Director | Tumutuarua Haumanu – Dr Elizabeth Dennett

Liz is a specialist general and colorectal surgeon and, in addition to her clinical practice, she is an Associate Professor of Surgery at Otago University. She was the first New Zealand female general surgeon appointed to the Court of Examiners RACS.

Liz joined Te Aho o Te Kahu in 2020 as Clinical Director.

Equity Director | Tumutuarua Mana Taurite – Sasha Webb

Sasha has spent 20 years working with public, private, and not-for-profit organisations and has a background in communications and systems change. She joined in 2020 as Kaiwhakahaere Kaupapa Mana Taurite | Senior Project Manager Equity before moving into the role of Equity Director in April this year.

Chief Advisor | Kaitohu Mātāmua – Dawn Wilson

Dawn joined the Ministry of Health in 2015 where she first worked in the Addictions team as a Senior Project Manager, before taking on the role of Manager, Cancer Services in April 2017.

In early 2020, Dawn supported the Cancer Services team through a transition to new roles in the Agency and took up her current position of Chief Advisor.

### Our teams

**Equity Team** provides support across the Agency in the development and delivery of pro-equity planning, decision-making and implementation. This work acknowledges and addresses cancer-related inequities, particularly for Māori and Pacific peoples. The Equity Team is led by Sasha (see above).

**Person and Whānau-centred Care Team** supports cancer care and support services to be designed and delivered in a way that is whānau-centred and reflects the needs and values of our community. This role is currently being recruited for.

**Clinical Advisory Team** provides broad clinical capability to inform the work of Te Aho o Te Kahu and progress the goals of fewer cancers, better survival, and equity for all. The Clinical Advisory Team is led by Bridget Kerkin. Bridget has extensive experience working in the health sector as a midwife, lecturer and most recently in the Te Whatu Ora Healthy Ageing Team.

**Quality Improvement Team** is focused on understanding and working with cancer care providers on areas where unwarranted variation is present and quality improvement is needed. They support improvement efforts, alongside effective measurement of change. The Quality Improvement Team is led by Gabrielle Nicholson, who has worked in health system and healthcare process QI, both in New Zealand and overseas, since 2008.

**Data, Monitoring and Reporting Team** leads the implementation of an integrated approach to collecting and analysing cancer data. They produce high quality and actionable intelligence to inform planning, quality improvement and monitoring activities across the cancer sector – improving equitable cancer outcomes for all New Zealanders. This team is led by Dr John Fountain.

The teams based in our Wellington office are joined by **four regional hubs** in Auckland, Hamilton, Palmerston North, and Christchurch. The hubs support our engagement with the sector at a regional level, and increasingly work to support the delivery of our national work programme. The hubs support the delivery of system improvement across the four regions. (These teams report to the General Manager, Office of the Chief Executive.) From left to right below: Heather Walker, Northern Hub Manager; Jan Smith, Te Manawa Taki Hub Manager; Cushla Lucas, Central Hub Manager; and Nicholas Glubb, Southern Hub Manager.

## Our partners

We regularly connect with our key partners (shown in green and blue in the organisational structure diagram on page 16) to strengthen our work programme and hear what is 'happening on the ground'. The role and functions of these groups is regularly reviewed to ensure we make best use of their valuable time and expertise.

- **Advisory Council** supports our Chief Executive to oversee system-wide development and coordination of the cancer care system. The Council provides insights and advice on how to get the best value for investment in cancer prevention and care. As part of our commitment to Te Tiriti, the Council has 50% Māori membership and a Māori co-chair.

- **Hei Āhuru Mōwai (Māori Cancer Leadership Aotearoa)** is a Māori cancer leadership network. Its membership brings together a range of expertise, including clinical, community care, epidemiology, health services management and research. The Chair of Hei Āhuru Mōwai is a member of the Advisory Council. We support the leadership and rangatiratanga of Hei Āhuru Mōwai through operational and project funding. Hei Āhuru Mōwai works closely with us and provides expertise and support for negotiated strategic work and projects centred on improving Māori cancer outcomes.

- **National Clinical Assembly** provides clinical advice to support our long-term strategic direction for reducing cancer incidence and improving cancer services across the cancer continuum. The Assembly includes clinicians from a broad range of cancer-related medical, nursing, and allied health specialities.

- **He Ara Tangata** is our Consumer Reference Group, providing insights and solutions from a lived-experience perspective. He Ara Tangata members are embedded on projects across our work programme, and their input ensures our work remains focused on the needs of people across the continuum of cancer care. Like our Advisory Council, our Consumer Reference Group currently has 50% Māori membership and a Māori chair.

- **Other advisory groups** - to ensure we remain connected with those on the ground, and hear directly from them, we have three primary clinical working groups (Medical Oncology, Radiation Oncology and Haematology) and more than 17 other advisory groups, involving over 200 health professionals and consumers. We meet regularly with these working groups, and their input feeds into our work at all levels.

- **Disability and cancer advisors** - Te Aho o Te Kahu has appointed three advisors to its Disability and Cancer Project. The project is currently focused on building the Agency’s knowledge of the incidence, experience and outcomes for disabled people who experience cancer in Aotearoa New Zealand. The advisors bring experience living with a disability and navigating the cancer system and are helping us understand inequities to access and services that many disabled people experience.

- **Contracted partners** - we contract National Child Cancer Network New Zealand (NCCN) and Adolescent and Young Adult Cancer Network Aotearoa (AYA) to deliver care for children and young people with cancer. We collaborate on the direction of their work programmes, meet regularly to discuss progress and issues, and provide support on programme delivery.

## Our commitment to Te Tiriti o Waitangi

We strive to achieve the following four goals of Te Tiriti o Waitangi, as expressed by Manatū Hauora | Ministry of Health in terms of mana.

**Mana whakahaere**
Encouraging effective and appropriate stewardship or kaitiakitanga over the health and disability system. (This goes beyond the management of assets or resources.)

**Mana motuhake**
Enabling Māori to be Māori; to exercise their authority over their lives and to live on Māori terms and according to Māori philosophies, values, and practices, including tikanga Māori.

**Mana tangata**
Achieving equity in health and disability outcomes for Māori across the life course and contributing to Māori wellness.

**Mana Māori**
Enabling ritenga Māori (Māori customary rituals), which are framed by te ao Māori (the Māori world), enacted through tikanga Māori (Māori philosophy and customary practices) and encapsulated within mātauranga Māori (Māori knowledge).

The principles of Te Tiriti outlined below, provide the framework for how we will meet our obligations under Te Tiriti in our day-to-day work.

**Tino rangatiratanga**
The assurance of tino rangatiratanga provides self-determination and mana motuhake for Māori in the design, delivery and monitoring of health and disability services.

**Equity**
The principle of equity requires the Crown to commit to achieving equitable health outcomes for Māori.

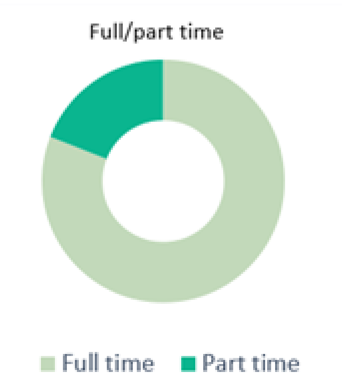
**Active protection**
The principle of active protection requires the Crown to act to the fullest extent practicable, to achieve equitable health outcomes for Māori.

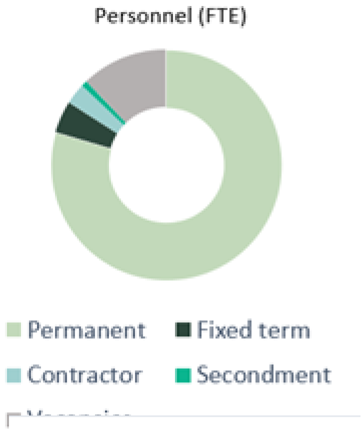
**Options**
The principle of options requires the Crown to provide for and properly resource kaupapa Māori health and disability services. Furthermore, the Crown is obliged to ensure that all health and disability services are provided in a culturally appropriate way.

**Partnership**
The principle of partnership requires the Crown and Māori to work in partnership in the governance, design, delivery and monitoring of health and disability services, especially in regard to development and delivery of the primary health system for Māori.

# Our people as of September 2023

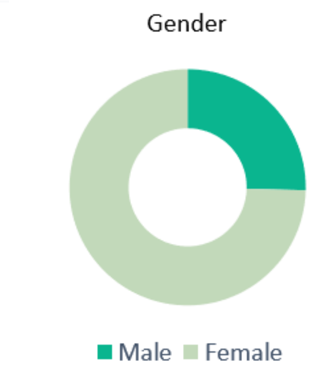
- 63 people employed
- 59.6 Fulltime Equivalent (FTE) employees
- 2.1 FTE additional contracted resource and 0.6 FTE secondees
- 56.4 FTE employed on permanent contracts
- 3.2 FTE fixed term
- 8.6 FTE vacancies (2.6 on hold, 6 undergoing recruitment)
- 20% of our permanent staff work part-time

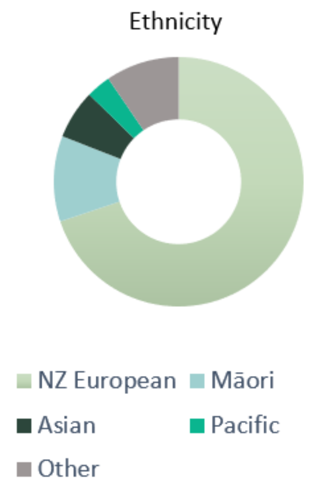




75% of our staff are female

- 11% of staff are Māori
- 2 Māori secondees (additional to staff)
- 3% of staff are Pacific
- 30% of staff are non-European



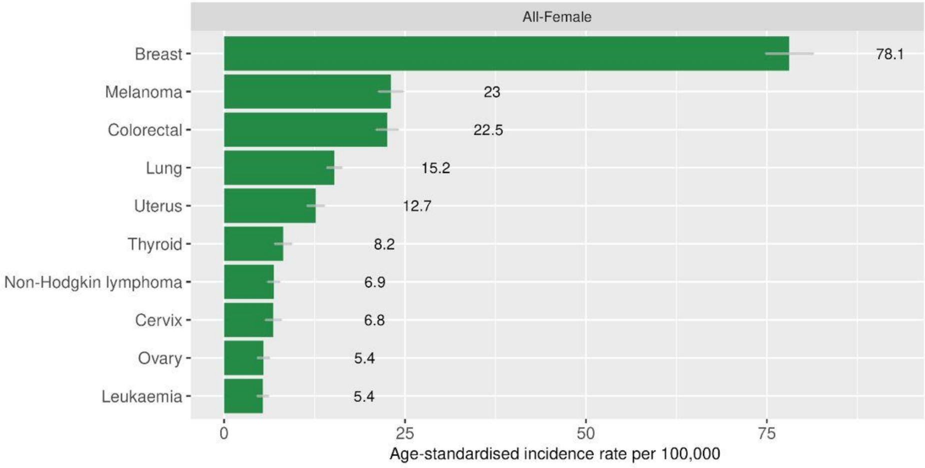


# Appendix 1: The current state of cancer in New Zealand

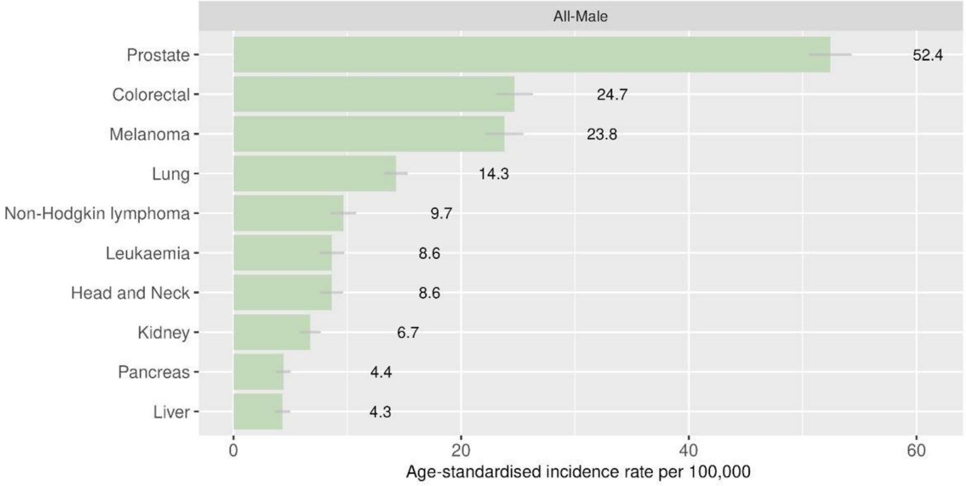
A more comprehensive 'snapshot' of the most recent data available on cancer incidence, mortality and rates is available on our website under the **New Zealand Cancer in Numbers tab.**

Data for the incidence and mortality figures came from the New Zealand Cancer Registry from 2016 to 2020 and Mortality collection from 2015 to 2019. Figures showing changes over time were taken from the Manatū Hauora | Ministry of Health's **Historical summary of cancer registrations and deaths.**

## Incidence of cancer by type across all New Zealanders by sex

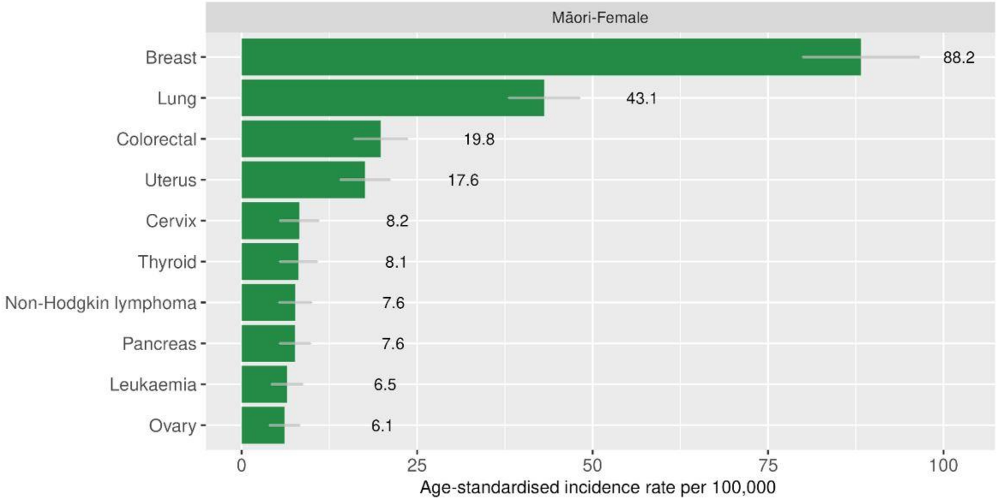


- About 3,400 Kiwi women are diagnosed with breast cancer each year.
- About 1,500 are diagnosed with colorectal cancer.
- About 1,200 are diagnosed with melanoma.

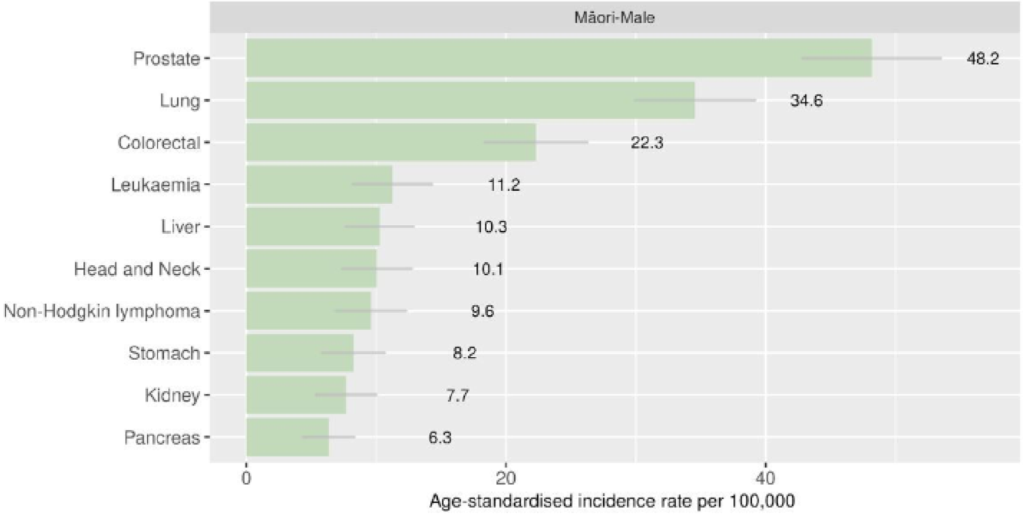


- About 3,900 Kiwi men are diagnosed with prostate cancer each year.
- About 1,700 are diagnosed with colorectal cancer.
- About 1,500 are diagnosed with melanoma.

## Incidence of cancer by type for Māori by sex

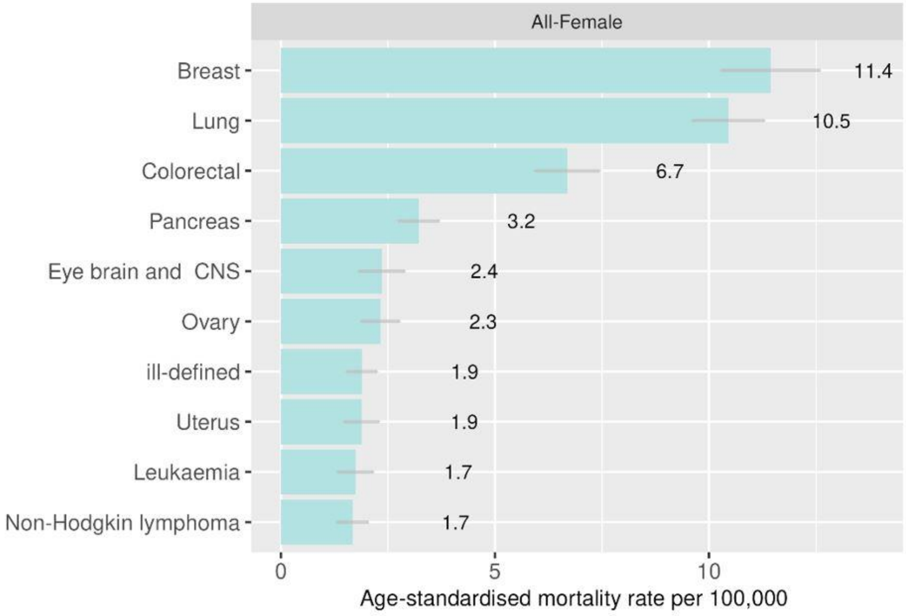


- About 450 Māori wāhine diagnosed with breast cancer each year.
- About 250 diagnosed with lung cancer.
- About 100 diagnosed with colorectal cancer.



- About 300 Māori tāne diagnosed with prostate cancer each year.
- About 200 diagnosed with lung cancer.
- About 100 diagnosed with colorectal cancer.

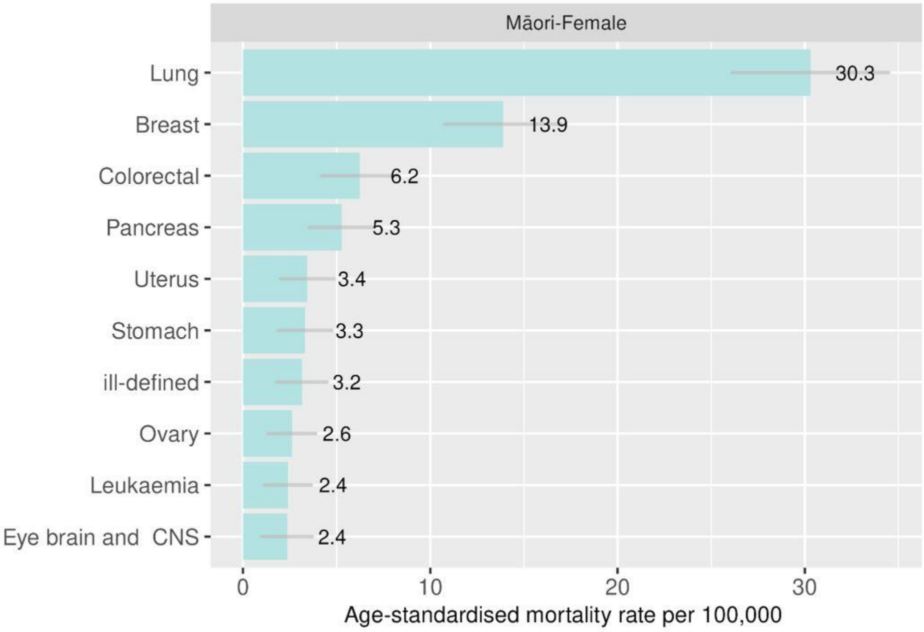
## Cancer mortality by cancer type for all New Zealanders by sex



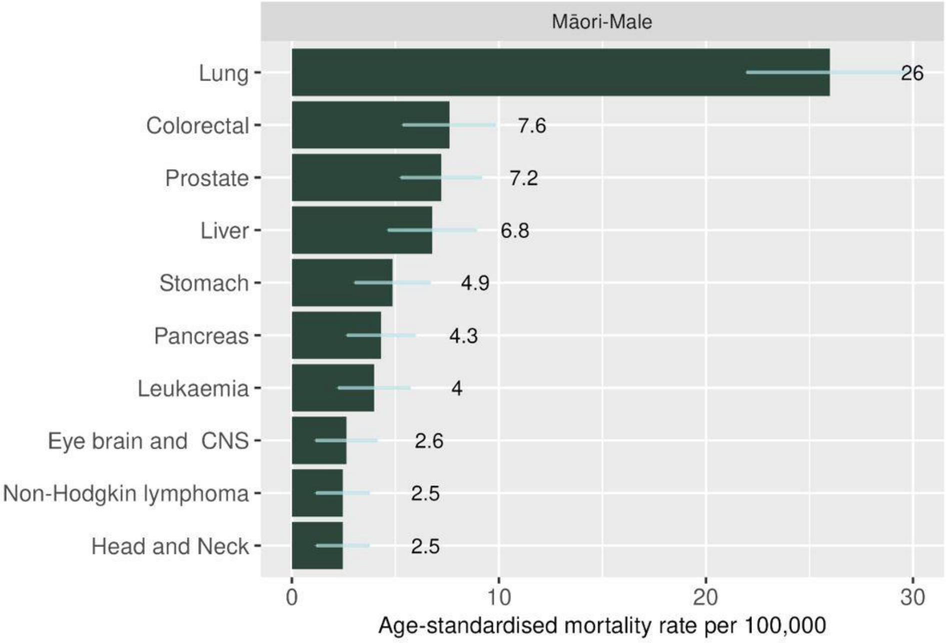
- About 850 Kiwi women die of lung cancer each year.
- About 650 die of breast cancer.
- About 600 die of colorectal cancer.

- About 900 Kiwi men die of lung cancer each year.
- About 650 die of colorectal cancer.
- About 650 die of prostate cancer.

### Cancer mortality by cancer type for Māori by sex

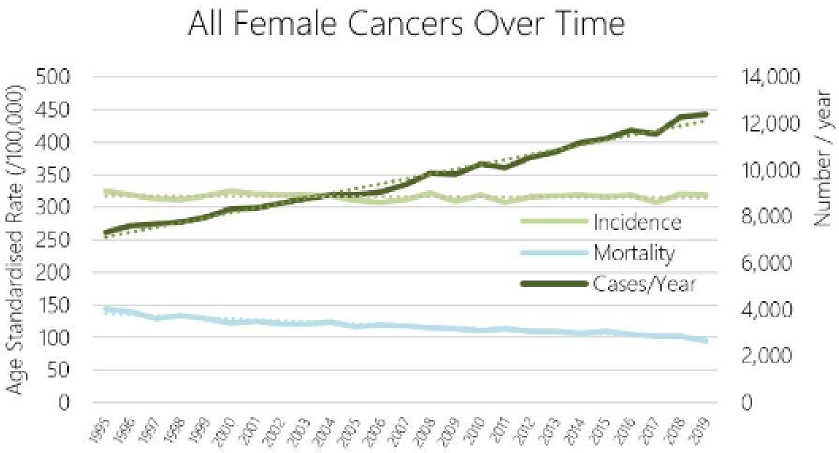


- About 200 Māori wāhine die of lung cancer each year.
- About 80 die of breast cancer.
- About 40 die of colorectal cancer.



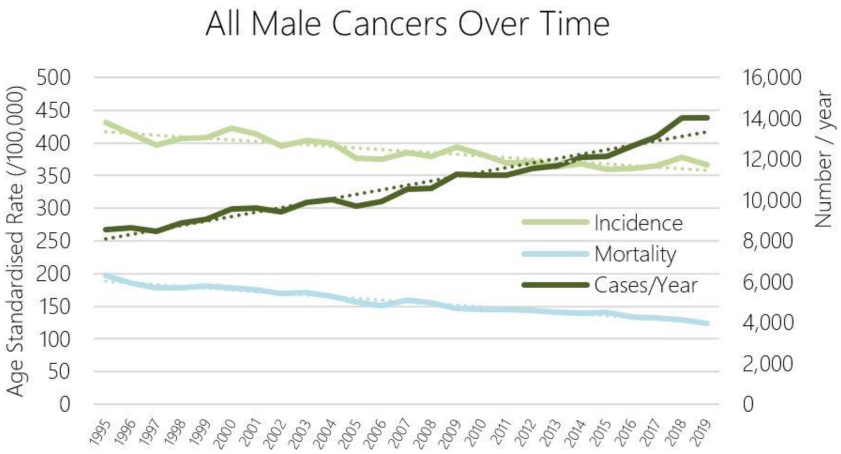
- About 160 Māori tāne die of lung cancer each year.
- About 50 die of colorectal cancer.
- About 40 die of liver cancer.

## Rate of new cancers over time for all New Zealanders by sex



Over the last 25 years:

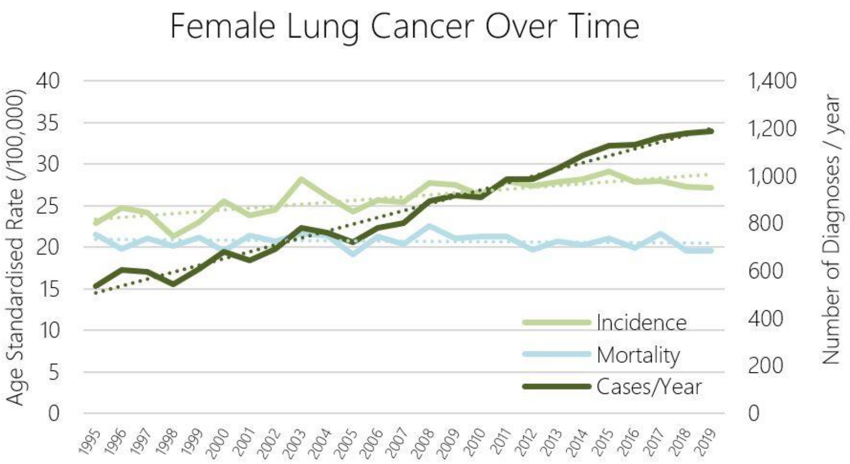
- the rate of new cancers per 100,000 Kiwi women is largely unchanged, but the actual number of new cancers per year has increased by around 65%.
- the rate of cancer deaths per 100,000 Kiwi women has dropped by around 30%.



Over the last 25 years:

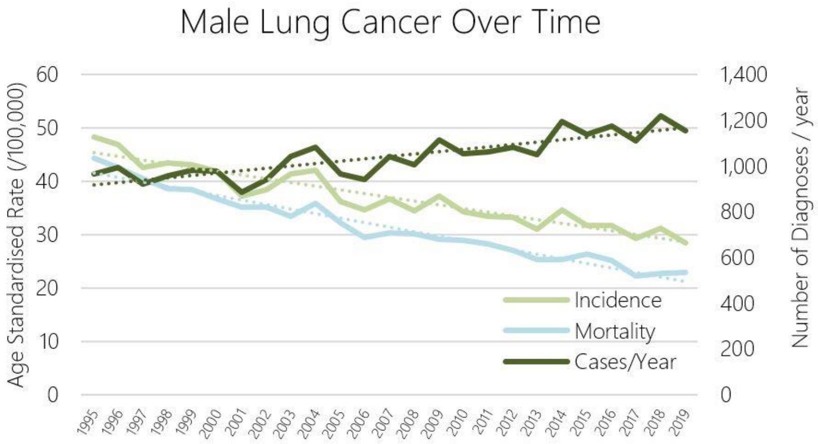
- the rate of new cancers among Kiwi men has reduced by around 10%, but the actual number of new cancers per year has increased by around 60%.
- the rate of cancer deaths among Kiwi men has reduced by around 30%.

## Rate of lung cancer over time for all New Zealanders by sex



Over the last 25 years:

- the rate of new lung cancers among Kiwi women has increased by around 5%.
- the actual number of new diagnoses per year has increased by around 100%.
- the rate of lung cancer deaths among Kiwi women is largely unchanged.



Over the last 25 years:

- the rate of new lung cancers among Kiwi men has reduced by around 40%.
- the actual number of new diagnoses per year has increased by around 10%.
- the rate of lung cancer deaths among Kiwi men has reduced by around 50%.

## Proportion of people with lung cancer who are diagnosed following presentation to an emergency department

The data sources for this indicator are the New Zealand Cancer Registry (NZCR), which is a population-based register of all primary malignant diseases diagnosed in New Zealand, excluding squamous and basal cell skin cancers, the National Minimum Dataset (NMDS), which captures hospital events, and the National Non-Admitted Patient Collection.

The NZCR is complete up to the end of 2021, so that is the most recent year provided below. The following graph shows the changes over the years 2015-2021 inclusive.