# Te Aho o Te Kahu |Cancer Control AgencyAnnual Report 2020/21

**146**

Mā te whiritahi, ka whakatutuki ai ngā pūmanawa ā tāngata

Together weaving the realisation of potential

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| **Our purpose** |  | **Our work is** |
| We provide strong central leadership and oversight of cancer control.We lead and unite efforts to deliver better cancer outcomes for Aotearoa New Zealand. |  | * equity-led
* knowledge-driven
* outcomes-focused
* person and whānau-centred.
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|  | We have a system that delivers consistent and modern cancer care to achieve:* **Fewer cancers**He iti iho te mate pukupuku
* **Better survival**He hiki ake i te oranga
* **Equity for all**He taurite ngā huanga
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| **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 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 50 people working for us across six Wellington-based teams and four regional hubs. |

## He Mihi |Chief Executive Foreword

I am pleased to present the second Annual Report for Te Aho o Te Kahu, the Cancer Control Agency.

I’m delighted to take this opportunity to reflect on our progress and achievements over the last year. I am extremely proud of my team, the relationships we are building, the work we are doing and our growth as an agency over the last 12 months.

I am excited to illustrate how we have improved outcomes for whānau living with cancer right now, while at the same time progressing a wide range of projects that deliver on our vision of:

* Fewer Cancers
*Kia whakaiti iho te mate pukupuku*
* Better Survival
*Kia runga noa ake te mataora*
* Equity for All
*Kia taurite ngā huanga.*

Our work this year has been set against a backdrop of immense uncertainty and change with both COVID-19 and the Health and Disability System Reforms providing significant challenges and opportunities for the cancer sector and Te Aho o Te Kahu.

We have continued the establishment activity necessary to ensure our Agency can deliver on our vision.

Relationships are the key to delivering on our purpose of leading and uniting efforts to deliver better cancer outcomes. To that end, we have worked at all levels of the organisation to connect with, and listen to, our stakeholders – from whānau living with cancer to clinicians, non-governmental organisations (NGOs) to district health boards (DHBs), advocacy groups to advisory groups, local service providers to international cancer leaders. We are now using their shared insights to shape our work.

We have significant projects under way that put equity front and centre. Te Aho o Te Kahu hosted a series of community hui across the motu, enabling us to hear the voice of over 2,500 whānau Māori. Their humbling kōrero has already made an impact on our work programme.

Finally, I would like to acknowledge all those who are affected by cancer – we have you at the centre of our thinking and thank the skilled and dedicated people who work in the cancer sector making a real difference every day.

Ngā mihi
Professor Diana Sarfati
Tumuaki, Chief Executive and National Director of Cancer

## Anei Mātou |Who We Are

Te Aho o Te Kahu, the Cancer Control Agency (the Agency) is a departmental agency reporting directly to the Minister of Health and hosted by the 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.

### Tō mātou aronga |Our purpose: an agency focused on cancer

Te Aho o Te Kahu provides strong central leadership and oversight of cancer control. We lead and unite efforts to deliver better cancer outcomes for Aotearoa New Zealand. We are also accountable for ensuring transparency of progress towards the goals and outcomes in the National Cancer Action Plan.

In practice, this leadership and oversight is delivered through:

* providing advice to Government about the future design and function of cancer services and options for resolving operational issues
* bringing stakeholders together to progress and achieve shared objectives
* undertaking national initiatives to improve cancer outcomes for New Zealanders
* assembling and disseminating cancer data and information to inform decision making and service delivery
* providing support for cancer service providers when service is, or is likely to be, disrupted or is not meeting demand or expectations.

Cancer presents some unique challenges to the health system.

* The number of people diagnosed with cancer is projected to double in the next two decades.
* The costs and complexity of care, and pace of change present major
* challenges for our systems and services.
* Māori and Pacific peoples have worse cancer survival rates than other New Zealanders.
* Cancer survival is improving in Aotearoa New Zealand, but our rate of improvement is slower than rates in other comparable countries, so we are at risk of falling behind.

### Tō mātou whāinga |Our vision

We strive to achieve:

* Fewer cancers
* Better survival
* Equity for all.

We are also driven to achieve a work programme that is:

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

Our strong commitment to the goal of achieving equity is embedded in all our processes and work.

### Te taonga me te kupu taurangi o te ingoa |Our name: Te Aho o Te Kahu

Our te reo Māori name is a taonga that was gifted to us by Hei Āhuru Mōwai, the Māori Cancer Leadership Group in June 2020. This name is a core part of 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 provides protection to people 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, people and communities that work with those affected by cancer.



Equity is not only the priority of the Agency in its role as ‘Te Aho’; it is also central and is embedded into our architecture, processes, systems and tikanga.

### Ngā roopu tūhono |Our partners

This year we have continued to work with our partner groups to strengthen external advice and input into the operation of Te Aho o Te Kahu. The role and function of these groups have been continuously reviewed to make best use of the valuable time and expertise provided by the members of these groups.

#### Te Aho o Te Kahu**,** Cancer Control Agency Advisory Council

Te Aho o Te Kahu Advisory Council supports the Chief Executive to ensure a whole-of-system focus on preventing, treating and managing cancer. The Council supports the Chief Executive to oversee system-wide prioritisation and coordination of cancer care in New Zealand. It considers and provides advice on how to get the best value from existing cancer prevention and care investment.

#### Hei Āhuru Mōwai

Hei Āhuru Mōwai is the Māori Cancer Leadership Group. Its membership brings a range of expertise, including clinical, community care, epidemiology, health services management and research. The Chair of Hei Āhuru Mōwai is also a member of the Advisory Council.

Te Aho o Te Kahu supports the Hei Āhuru Mōwai leadership and rangatiratanga through operational and project funding, and Hei Āhuru Mōwai works closely with Te Aho o Te Kahu and provides expertise and support for negotiated strategic work and projects centred on improving Māori cancer outcomes.

#### Clinical Assembly

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

#### He Ara Tangata, Consumer Reference Group

He Ara Tangata, the Consumer Reference Group, provides Te Aho o Te Kahu with advice on whānau-centred solutions for people affected by cancer. He Ara Tangata ensures the work of Te Aho o Te Kahu focuses on the needs of people across the continuum of cancer care.

#### Other partners

One of our key functions is to liaise with the many parties and organisations involved with cancer prevention and care. In the current system, this includes direct relationships between the Chief Executive of the Agency and the Chief Executives of the Ministry of Health, Pharmac, Health Promotion Agency, Health Quality & Safety Commission and all 20 DHBs. The relationship between the Agency and its host the Ministry of Health is particularly important and is supported through co-location.

In addition to these core relationships, we have developed strong active links with Māori and Pacific health leaders, consumer-led groups, clinical leadership groups, NGOs and primary care practitioners. In the last year, these relationships have been established, embedded and strengthened.

#### Pūmau ki Te Tiriti |Our commitment to Te Tiriti o Waitangi

Te Aho o Te Kahu strives to achieve the following four goals of Te Tiriti, each expressed in terms of mana.

##### Mana whakahaere:

Effective and appropriate stewardship or kaitiakitanga over the health and disability system. This goes beyond the management of assets or resources.

##### Mana motuhake:

Enabling the right for 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 o Waitangi 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, 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, to achieve equitable health outcomes for Māori.

##### 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.

##### 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.

### Tō mātou whānau |Our people

As at 30 June 2021, Te Aho o Te Kahu employs 50 people or 47.6 FTE, supported by an additional contracted 5.9 FTE.

Two staff (4%) resigned from Te Aho o Te Kahu during 2020/21.

##### Personnel (FTE)

|  |  |  |  |
| --- | --- | --- | --- |
|  | Permanent |  | Fixed term |
|  | Contractor |  | Secondment |
|  | Vacancies |  |  |

We have 44 FTE employed on permanent contracts, with 3.6 FTE fixed term and 5.9 FTE contractors. Twenty percent of our staff work part-time.

##### Head count (full/part time)

|  |  |  |  |
| --- | --- | --- | --- |
|  | Full time |  | Part time |

The majority of our staff are female (78%).

##### Gender (all staff)

|  |  |  |  |
| --- | --- | --- | --- |
|  | Female |  | Male |

While we have employed a deliberate strategy to attract and recruit staff who identify as Māori, our proportion of Maori staff (to 8%) has dropped this year.

##### Ethnicity (employed staff)

|  |  |
| --- | --- |
|  | New Zealand European |
|  | Māori |  | Other |

##### Age group

|  |  |  |  |
| --- | --- | --- | --- |
|  | 25 to 34 |  | 35 to 44 |
|  | 45 to 54 |  | 55 to 64 |
|  | 65+ |  |  |

## Tō Mātou Takune |Our Intentions for 2020/21

The strategic direction of Te Aho o Te Kahu is articulated through the New Zealand Cancer Control Strategy 2003 and the New Zealand Cancer Action Plan 2019–2029. Our work is focused on achieving the New Zealand health system goal of Pae Ora: Healthy Futures and the three system outcomes – living longer in good health, improved quality of life and equity for all, through delivering our vision of fewer cancers, better survival and equity for all.



In 2020/21 Te Aho o Te Kahu developed a work programme to progress these goals. All aspects of the Te Aho o Te Kahu work programme include consideration of the likely or intended impact on improving equity in access, quality and outcomes. In particular our work programme has focused on:

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| **Supporting a system that delivers consistent and modern care** |
| **Strong leadership and governance** |
| Building a high performing Cancer Control AgencyA new model for delivery of cancer servicesGuidance and advice related to cancer during the COVID-19 pandemic |
| Better quality and more connected data and information |
| Nationally agreed chemotherapy protocolsNational standard for cancer-related pathologyNational cancer data intelligenceA system to monitor national radiation oncology practiceHe Pūrongo Mate Pukupuku o Aotearoa 2020, The State of Cancer in New Zealand 2020 |
| Better and more focused research and innovation |
| Supporting improved research that is better aligned to prioritiesImproving access to clinical trialsSupporting innovation |

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| **Helping New Zealanders to have fewer cancers** |
| Cancer prevention |
| Achieving fewer cancers through a focus on prevention |

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| **Improving cancer survival** |
| Diagnosis and treatment |
| National clinical quality improvement indicators, reports and plansClinical working and advisory groupsRegional clinical pathway and Multi-Disciplinary Meeting (MDM) projectsQuality of cancer treatment in regionsReplacement of Linear Accelerators (LINACs)Faster Cancer Treatment measuresResponse to service delivery disruptionCancer medicines availability analysisSupport and information |

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| **Increasing capacity and capability to improve equity in cancer care and outcomes** |
| Māori Affairs Select Committee Inquiry into Māori Health inequitiesMāori community huiMāori leadership and engagement |

## Tō Mātou Tutuki |What We Have Achieved

### He Pūnaha manaaki |Supporting a system that delivers consistent and modern care

#### Strong leadership and governance

##### Building a high performing Cancer Control Agency

In 2020/21 Te Aho o Te Kahu has continued to focus on building the necessary foundations of a high performing organisation, providing value to our stakeholders and maintaining a strong reputation for responsiveness and delivery. Building our Agency while also delivering on an ambitious work programme has not been without its challenges, and it has been critical to our success that we also have a strong focus on supporting staff wellbeing.

Our work programme and direction for 2020/21 were heavily influenced by the advice from our leadership and working groups. Our relationship with Hei Āhuru Mōwai has been particularly important, and it has provided Te Aho o Te Kahu with invaluable insights and guidance across our work programme, most notably for our cancer service planning work and our series of Māori community hui. The 2020/21 year also saw the significant step of the establishment of He Ara Tangata, our national cancer consumer reference group. This group consists of 16 cancer consumers (8 of whom are Māori and 2 are Pacific) who meet regularly to provide input into our work and share their experiences so that our Agency can better meet people’s needs.

Across all our workstreams, Te Aho o Te Kahu is fully committed to upholding our collective obligations to Te Tiriti o Waitangi and making an enduring contribution to being equity-led and whānau-centred in everything we do. These values are embedded in our Agency’s karakia and waiata. Our data and information work contributes to the work under way by Te Aho o Te Kahu and across the sector to drive equity-led decisions and better inform the measurement of health gain for Māori, Pacific peoples and other population groups that experience inequities. We require equity impact assessments for our projects to ensure equity is embedded in our approach and actions and we are growing the capability of our people to deliver against our Te Tiriti and equity obligations. Our approach is in its early stages and will evolve as we build our collective understanding and grow in confidence in 2021/22 and beyond.

Our Agency results in the 2020/21 staff satisfaction survey undertaken by the Ministry of Health (see the Our Performance section, page 172) were pleasing and provided a useful reaffirmation that we are on the right track. We have actively worked to address the areas that our staff rated lowest including improving our project management processes and documentation.

We have continued to develop our core policies and processes, such as risk management, conflicts of interest, financial management, business continuity and reducing our emissions. Many of these processes were formally agreed with the Ministry of Health through our shared work to develop our Departmental Agency Agreement, which was signed by the Chief Executives of both agencies in July 2021.

We have undertaken a significant amount of recruitment during the past year, successfully filling 39 roles. We have been very pleased with the capability and calibre of our new staff, who have a shared passion for our vision and making a difference for people affected by cancer.

Te Aho o Te Kahu has retained a key focus on building staff capability through 2020/21. First and foremost, this has been centred on building our capability with respect to te ao Māori, Te Tiriti o Waitangi and equity. We published E Tipu E Tipu, our Māori Language Plan, on our website in June 2021 and have developed a comprehensive Whāinga Amorangi Phase One Plan to empower Te Aho o Te Kahu staff through capability-building in Māori Crown relations. As an agency we are committed to making progress in all six competency areas highlighted in this plan. We will monitor our progress against the plan over the next 12 months. Our staff have also provided us with their aspirations to embed te ao Māori within our work, from an individual level up to an organisational level.

We have worked hard to provide the Government with evidence-based, robust advice to build trust and confidence. In 2020/21 Te Aho o Te Kahu contributed to 236 ministerials, Official Information Act requests and formal public queries, with all responded to within expected timelines.

On 1 July 2020 the Southern, Central and Te Manawa Taki Cancer Networks transitioned into our Te Aho o Te Kahu Regional Hubs. The Northern Hub joined us on 1 January 2021. These hubs are a critical part of the Agency, supporting the delivery of system improvement in the regional context and giving voice to the unique perspectives and diverse needs of local and regional communities in the development of national priorities.

##### A new model for delivery of cancer services

In 2020/21 Te Aho o Te Kahu worked alongside the Health and Disability System Transition Unit to determine how cancer services could be delivered in the future. The Cancer Services Planning project has a single goal of providing evidence-based recommendations to the new health entities (Health New Zealand and the Māori Health Authority) on how cancer treatment services in Aotearoa New Zealand should be organised and distributed to achieve optimal and equitable cancer outcomes.

Work on this project began in October 2020 and continues at pace. Each of the six workstreams within the project (surgery, radiation oncology, systemic treatments, clinical services, supportive care and equity) has been required to undertake extensive sector stakeholder engagement, equity analysis and to work closely with Hei Āhuru Mōwai and He Ara Tangata. We have applied a Te Tiriti principles-based framework to guide this work.

The project will deliver a recommendations document to inform the Transition Unit, Health New Zealand and the Māori Health Authority on how to create whānau-centred, equitable, high-quality and sustainable cancer services.

##### Guidance and advice related to cancer during the COVID-19 pandemic

Te Aho o Te Kahu worked with the cancer sector during the COVID-19 community outbreak in Auckland in August 2020 to ensure cancer patients continued to have access to cancer treatments. This outbreak presented new challenges – notably as it was the first time that regions had been at different alert levels – which caused initial disruption to people travelling to receive cancer care. Te Aho o Te Kahu reissued guidance outlining treatment delivery expectations at different hospital alert levels and responded to issues raised by the sector. This included working with the Ministry of Health, Auckland DHB and PHARMAC to resolve the issue whereby Aotearoa patients were unable to fly to Melbourne to receive Peptide Receptor Radionuclide Therapy (PRRT) a potentially lifesaving neuroendocrine tumour treatment. This led to the establishment of a temporary treatment service in Auckland, followed by a permanent service being stood up in July 2021. During the Auckland outbreak, the Agency also secured additional funding for the Cancer Society to address the increased accommodation, transport and support service needs during the COVID-19 lockdown.

Te Aho o Te Kahu continued to release regular reports on the impact of COVID-19 on cancer services until the end of December 2020 (<https://teaho.govt.nz/reports/cancer-care>). This included specific reports focused on the Auckland COVID-19 lockdown (report released October 2020) and lung cancer (report released December 2020). The Agency also led two peer-reviewed articles published in Lancet Regional Health Western Pacific Region outlining the response of the New Zealand cancer sector to COVID-19 and the impact COVID-19 had on cancer diagnoses and treatment. The Agency linked with international agencies and colleagues to share experiences of COVID-19.

In the context of COVID-19 and the move to deliver cancer care via virtual means, Te Aho o Te Kahu developed a report to look at the current state of telehealth for medical oncology, barriers to implementation and opportunities that may affect implementation of future systems. This work will inform an ongoing project to look at the role of digital and telehealth in future cancer care.

In 2021 the focus shifted to the COVID-19 vaccine. Te Aho o Te Kahu worked with clinical experts to develop advice on vaccination for cancer patients, releasing guidance in March 2021 (https://teaho. govt.nz/reports/cancer-care). The Agency connected with the Ministry of Health and the Immunisation Advisory Centre at the University of Auckland to ensure consistent advice for cancer patients and cancer clinicians.

#### Better quality and more connected data and information

##### Nationally agreed chemotherapy protocols

Te Aho o Te Kahu has continued the development of Anti-Cancer Therapy – Nationally Organised Workstreams (ACT- NOW). This programme produces clinically agreed, evidence-based anti-cancer drug regimens to support the national standardisation of treatment, equity of access to therapy, improved planning and efficient use of resource. In early 2021, Te Aho o Te Kahu launched the Systemic Anti-Cancer Therapy New Zealand (SACT) Regimen Library, which is an online repository of chemotherapy treatment definitions intended to support the harmonisation of practice within medical oncology and malignant haematology.

In 2020/21 over 160 regimens have been published in the SACT Regimen Library and 12 of the 20 tumour type regimen harmonisation sector workshops have been completed. Development of a SNOMED CT based Health Information Standards Organisation (HISO) standard for the description of chemotherapy regimens and a standard based implementation guide for the exchange of regimen data between systems has also been progressed. To support these other data improvement activities, we have progressed development of a draft national data standard, outlining key data items for collection from electronic prescribing systems to be used to support equity analysis, quality improvement and resource planning.

The ACT-NOW programme has been supported by Te Aho o Te Kahu Regional Hubs, with Te Manawa Taki and Southern Hubs testing implementation aspects of the new regimens.

##### National standard for cancer related pathology

At the start of 2021, Te Aho o Te Kahu commenced a project to develop structured pathology reporting to support national consistency in the data collected by clinicians requesting pathology services and pathologists reporting back the findings on a patient’s treatment pathway. This data will have a range of benefits from facilitating consistent clinical decision-making to strengthening our ability to monitor cancer outcomes nationally. This project involves the development of HISO data specifications for all cancers that outline the individual data items and their concise definitions using SNOMED CT to codify recorded data for enhanced accuracy and consistency in laboratory systems.

A proof of concept for lung cancer was undertaken to better understand requirements and test benefits in the first half of 2021. We are on track to deliver priority data specifications for lung, colorectal, prostate and breast cancers by the end of calendar year 2021 to support implementation planning with laboratory providers in late 2021 and into 2022. An ongoing partnership with the sector is required to ensure the data specifications remain clinically relevant and are implemented consistently across all providers.

##### National cancer data intelligence

Work has commenced with the Ministry of Health to create the infrastructure to collect, store and disseminate cancer information within the health sector. The CanShare programme will work with a range of stakeholders to provide complete, accurate, timely and shareable data to support clinical decision-making, services planning, cancer monitoring and quality improvement. This programme will provide guidance and direction for the national collection and sharing of cancer information. It will integrate with the other work of Te Aho o Te Kahu on ACT-NOW, structured pathology reporting and the Radiation Oncology Collection (ROC).

Te Aho o Te Kahu is also supporting the ongoing data quality improvement of Faster Cancer Treatment (FCT) reporting by DHBs. This data provides insights into whether care is being provided within set timeframes. To achieve this improvement, enhancements are being made to the transactional data business rules and we are working with DHBs and the Ministry of Health on data quality queries.

Te Aho o Te Kahu has continued to coordinate FCT data collection, reporting and dissemination and has responded to Official Information Act requests, Parliamentary Questions and ad hoc requests related to FCT reporting. Te Aho o Te Kahu Te Manawa Taki Regional Hub has also provided regional narrative reports for the DHBs in that region.

##### A system to monitor national radiation oncology practice

Te Aho o Te Kahu has used the ROC to progress several projects including:

* the development of an improved Radiation Oncology workforce demand model, which has been endorsed by the Royal Australian and New Zealand College of Radiologists (RANZCR)
* provision of key data for the He Pūrongo Mate Pukupuku o Aotearoa 2020, The State of Cancer in New Zealand 2020 report and the Cancer Services Planning programme
* the Northern region LINAC capacity planning project
* development of a prototype methodology to improve the completeness of the New Zealand Cancer Registry (NZCR) by identifying clinically diagnosed cancers that had not been notified to the NZCR.

In addition, Te Aho o Te Kahu is working with the Radiation Oncology Work Group (ROWG) on enhancements to the ROC system. This includes additional fields to be collected at a national level to better inform equitable access and outcome improvement efforts for radiation oncology treatment. A project was also established to develop the ROC DataMart and work with all private and public providers to collect the new data elements from June 2021. Currently Te Aho o Te Kahu is testing data files from all cancer centres for inclusion by December 2021, to be followed by a focus on data quality improvement in 2022.

##### He Pūrongo Mate Pukupuku o Aotearoa 2020, The State of Cancer in New Zealand 2020

In February 2021, Te Aho o Te Kahu released our inaugural report He Pūrongo Mate Pukupuku o Aotearoa 2020, The State of Cancer in New Zealand 2020 (<https://teaho.govt.nz/reports/cancer-state>).

This report provides a summary of the state of cancer from across the cancer continuum and identifies where issues and inequities exist along the cancer pathway. The report was the result of a huge collaborative effort across Te Aho o Te Kahu and with external stakeholders.

The report is a snapshot of a point in time – it does not make recommendations. It provides a baseline that can be used to measure the effectiveness of cancer control programmes, identify work priorities and inform funding proposals. It highlights the gaps in our knowledge – areas where more research is needed – and challenges the health sector to provide equitable, effective care for all who are affected by cancer.

He Pūrongo Mate Pukupuku o Aotearoa 2020, The State of Cancer in New Zealand 2020 represents the first stage in our ongoing critical analysis of the cancer care system. We intend to review the state of cancer in Aotearoa regularly to provide a benchmark for monitoring action and measuring improvement. This report was well received in Aotearoa New Zealand and internationally. We regularly see statistics from the report being used in external presentations, on websites, in funding applications, in research proposals and quoted in the media.

#### Better and more focused research and innovation

##### Supporting improved research that is better aligned to priorities

Alongside the Ministry of Health and the Health Research Council (HRC), Te Aho o Te Kahu contributed to a $6 million request for proposals (RFP) for research to drive equitable cancer outcomes. This RFP was announced in December 2020 with a clear focus on lung cancer and patient experience across the cancer journey for Māori and Pacific peoples. The Assessing Committee for this research met on 3 September 2021, with a strong group of proposals recommended for funding. They will be going through HRC Council approval process in late 2021.

Te Manawa Taki regional hub has supported a regional three-year Lung Cancer Research project which was completed and a report published in 2021. This research will help inform quality improvement and decision-making around lung cancer initiatives across Te Manawa Taki region.

Te Aho o Te Kahu is part of the advisory group for the WHIRI project, which is an HRC‑funded pilot in the Waikato region led by Hei Āhuru Mōwai. This project aims to test a wraparound approach to secondary and tertiary care for whānau Māori with cancer.

##### Improving access to clinical trials

Clinical trials are an important part of cancer research and care; however, there are large inequities in access to clinical trials in New Zealand, with smaller hospitals and rural areas having particularly poor access. Te Aho o Te Kahu is pleased to be supporting Cancer Trials New Zealand to undertake work to develop core infrastructure to initiate cancer teletrials in New Zealand.

##### Supporting innovation

A year ago, New Zealand patients with neuroendocrine cancers who would benefit from a treatment known as Peptide Receptor Radionuclide Therapy (PRRT), had to travel to Australia for this treatment.

PRRT is a type of radiation treatment where a radioactive medicine is attached to a special protein and injected into the bloodstream. This compound then delivers a high dose of radiation to neuroendocrine cancer cells in a targeted way. PRRT is an effective treatment option for people with metastatic neuroendocrine cancers. It can prolong survival, improve quality of life and manage symptoms where there are limited options.

The Ministry of Health was previously paying for urgent patients to receive PRRT in Melbourne, through the High Cost Treatment Pool. COVID-19 travel restrictions made this increasingly difficult. In September 2020, a collaboration between Auckland DHB, Te Aho o Te Kahu, Ministry of Health, PHARMAC, Mercy Radiology, the Cancer Society and the Unicorn Foundation NZ enabled patients needing urgent PRRT treatment during the COVID-19 pandemic to receive it in Auckland. In 2021, Te Aho o Te Kahu worked with these partners to create a permanent Auckland-based PRRT service, which was officially launched in July 2021.

Te Aho o Te Kahu has also commenced work on providing advice on a consistent national approach to cancer molecular testing and improving consistency of access to PET‑CT scans by standardising national indications for publicly funded PET-CT.

### Kia whakaiti iho te mate pukupuku |Achieving fewer cancers through a focus on prevention

#### Cancer prevention

Cancer is the leading cause of death in Aotearoa and is a significant contributor to inequities in mortality and life expectancy for Māori, Pacific and low socioeconomic communities. Cancer prevention is the ideal in cancer control, as the predicted increase in demand for cancer services over the next 20 years will likely be unsustainable. Up to 50% of cancers are caused by modifiable cancer risk factors, so are potentially preventable.

The majority of actions to reduce the incidence of cancer are led by other parts of the public health sector, particularly the Population Health and Prevention Directorate of the Ministry of Health, including the National Screening Unit, and DHBs. Te Aho o Te Kahu has engaged closely with these agencies to support their efforts.

##### Cancer Prevention report

To inform and support the initiatives of the partners noted above, in 2021 Te Aho o Te Kahu commenced work on a report that assesses cancer prevention activities in Aotearoa New Zealand compared with evidence-based best practice for a range of cancer risk factors including tobacco, alcohol and nutrition. This report, which is being developed in collaboration with Te Hiringa Hauora, the Health Promotion Agency, the University of Otago, Wellington and relevant Ministry of Health teams, will include options for what we could consider doing to strengthen cancer prevention. The report is scheduled to be completed in October 2021.

### Kia runga noa ake te mataora |Improving cancer survival

#### Diagnosis and treatment

##### National clinical quality improvement indicators, reports and plans

In 2020/2021 Te Aho o Te Kahu has continued to progress the Quality Performance Indicators (QPI) programme to improve the quality of cancer services and deliver better outcomes for people diagnosed with cancer. QPIs are selected by an expert cancer working group with consumer representation and a range of clinical experts involved in providing patient care. QPIs enable DHBs to compare their performance with other DHBs.

Once appropriate QPIs are selected and reviewed in consultation with the relevant cancer sector, a quality performance monitoring report is drafted and published by Te Aho o Te Kahu. These reports also compare our Aotearoa results with those of other countries where equivalent data is available.

Te Aho o Te Kahu uses the monitoring report to work with the sector to identify areas where there is unwarranted variation between DHBs and develop a quality plan with actions to improve services and outcomes. The expectation is that DHBs with poor performance or unwarranted variation will undertake quality improvement work that will improve outcomes for those who are diagnosed with cancer.

Following extensive consultation with sector experts, a *Lung Cancer Quality Improvement Monitoring Report* was published in March 2021 and a *Prostate Cancer Quality Improvement Monitoring Report* was drafted and published in September 2021. In March 2021, in addition to the publication of the *Lung Cancer Quality Improvement Monitoring Report*, an online interactive cancer data explorer tool went live on our website. This tool enables public access to information by each DHB on bowel and lung indicator performance. Filters can be applied giving access to more detailed demographic information including ethnicity.

On 8 April 2021, Te Aho o Te Kahu held a Lung and Prostate Cancer Quality Improvement Forum with key stakeholders from each DHB to collaborate and facilitate improvements for those diagnosed with lung and prostate cancers. This forum informed the development of quality improvement plans for lung and prostate cancers. These plans will include agreed actions for DHBs, Te Aho o Te Kahu and other relevant organisations to ensure improvements in care and outcomes for these cancers. Feedback from the forum was positive, with over 90 clinicians and stakeholders in attendance.

Ongoing work includes a review of the QPI programme to ensure it is being delivered efficiently and appropriately, supporting the recalculation of prostate and bowel QPIs and commencing the development of QPIs for pancreatic and breast cancer. In addition we are continuing to work with BPAC and clinical groups to produce primary care guidance based on QPI reports and producing clinical guidance as required for areas where significant variation in care is suspected or demonstrated.

Te Aho o Te Kahu regional hubs play a crucial role in the development and implementation of the QPI programme. In 2020/21, the hubs have supported DHBs to implement bowel and lung cancer quality improvement plans and take actions to resolve unwanted variation.

##### Clinical working and advisory groups

Clinical working and advisory groups are an important channel through which Te Aho o Te Kahu gains clinical insight and understanding, addresses identified variation in access and outcomes, becomes aware of systemic issues and progresses key elements of our work programme such as the QPI programme. Supporting these groups, including the Radiation Oncology Work Group (ROWG), Medical Oncology Work Group (MOWG), Haematology Work Group (Haem) and the Clinical Assembly, forms a substantial proportion of the work programme of the Treatment Quality and Standardisation Team of Te Aho o Te Kahu.

Te Aho o Te Kahu regional hubs also support and engage with valuable regional clinical and stakeholder groups. The Northern regional hub has taken on the secretariat tasks for head and neck, bowel, lung and Northern/Te Manawa Taki gynaecology tumour stream groups. This function may be reviewed in 2021/22. In 2020/21 the Southern regional hub strengthened the South Island cancer consumer group (including people living with cancer or beyond cancer, and their whānau carers) to better support our work and give insight into consumers in that region.

Te Aho o Te Kahu intends to review the role, function and distribution of its various national and regional working and advisory groups. We took the first step in 2020/21 with the completion of a review of the terms of reference of national working groups.

##### Regional clinical pathway and Multi-Disciplinary Meeting (MDM) projects

In 2020/21 Te Aho o Te Kahu regional hubs supported their regional DHBs to design effective, consistent and reliable approaches to information collection through MDMs. By supporting DHBs to meet the Cancer Multidisciplinary Meeting Data Standard, the regional hubs are enabling MDMs to be an activity that produces a rich source of significant clinical information and a starting point for improving the collection of cancer information to support the delivery of care across the cancer pathway.

This year, the Manawa Taki Hub has contributed to implementation of Phase Two of the regional Clinical Pathway and MDM Management System project. The system went live for colorectal and lung cancers and requirements have been agreed for breast, head and neck, and gynaecological cancers. Work is under way on requirements for urological and upper gastrointestinal cancers and lymphoma.

The Southern Regional Hub has completed the addition of the first two tumour streams (gynae oncology and hepatobiliary) on to its MDM reporting dashboard, enabling key outputs from the MDM to be measured along with patient outcomes.

##### Quality of cancer treatment in the regions

Te Aho o Te Kahu Regional Hubs have continued to progress a number of quality improvement initiatives in 2020/21.

Te Manawa Taki Hub have facilitated and supported its regional DHBs with initiatives to improve lung cancer access and outcomes. Working alongside Te Manawa Taki lung cancer work group, the Hub has completed a feasibility report into endobronchial ultrasound (EBUS) in Lakes and/or Waikato DHBs. Implementation of multi-speciality, one-stop rapid access clinics to improve timeliness to lung cancer surgery and management of follow-up for regional curative patients is in progress.

##### Replacement of Linear Accelerators (LINACs)

While one in two people with cancer would benefit from receiving radiation therapy, only one in three receives it. Barriers to treatment include workforce challenges, inequitable distribution of services and machine capacity. Ensuring equitable access to radiation therapy is one of the ways that we influence cancer outcomes in New Zealand. DHBs rely on LINACs to meet demand for radiation therapy, so we need to ensure that there is adequate provision across the system.

Through Budget 19 the Government invested $25 million to replace ageing LINACs in New Zealand hospitals. This replacement programme has been led by the Ministry of Health but is supported by Te Aho o Te Kahu.

In 2020/21 the Central Regional Hub worked with its regional DHBs to plan for the replacement of LINACs across the region. The Southern Regional Hub has facilitated the collection of information and advice to inform Nelson Marlborough DHB about the delivery of a local radiation oncology service.

##### Faster Cancer treatment measures

Faster cancer treatment (FCT) indicators were introduced by the Government in 2012, requiring DHBs to collect standardised information on patients who had been referred urgently with a high suspicion of cancer. There are two indicators:

* 31-day indicator – patients with a confirmed cancer diagnosis receive their first cancer treatment (or other management) within 31 days of a decision to treat
* 62-day indicator – patients referred urgently with a high suspicion of cancer receive their first treatment (or other management) within 62 days of the referral being received by the hospital.

Te Aho o Te Kahu is encouraging and supporting ongoing FCT data quality improvement through enhancing transactional data business rules and working with DHBs and the Ministry of Health on data quality queries. Te Aho o Te Kahu also coordinates FCT data collection, reporting and dissemination.

Through 2020/21 Te Aho o Te Kahu Regional Hubs have continued to support regional DHBs to improve their performance against FCT measures. Different regions have experienced differing needs and challenges, and therefore the support provided by each hub has varied. Collectively, the regional hubs have supported their DHBs with regional FCT analysis including provision of equity-focused reporting, contributing to local DHB cancer service improvement work groups, collating regional narrative reports and assisting with specific improvement initiatives.

##### Response to service delivery disruption

###### Waikato DHB cyber-attack

In May 2021, provision of cancer treatment at Waikato DHB was compromised as a result of a cyber-attack. Because Waikato DHB provides cancer treatment for patients residing in other DHBs in the region, this attack also had wider ramifications across the region.

Te Aho o Te Kahu worked with Waikato DHB to respond to the impact of the cyber- attack. Radiation therapy services were particularly impacted by the attack, with no radiotherapy able to be provided by the DHB for two to three weeks. Te Aho o Te Kahu supported the Waikato Regional Cancer Centre to coordinate a national response for radiotherapy. This included rapidly modelling national capacity to deliver radiotherapy with changes to different variables – for example, extending delivery hours and changing the way care is delivered. Te Aho o Te Kahu provided national leadership to support the coordination of radiotherapy provision, with patients treated in Auckland, Tauranga and Wellington.

Te Manawa Taki Regional Hub played an important role through this challenging period, providing extra resource to assist the DHB to identify patients in urgent need of treatment and co-ordinate their care. This issue is not entirely resolved and the Hub is continuing to provide the DHB with some resource to assist with this task.

###### Supporting service delivery challenges in DHBs

In early 2021, Southern DHB identified a significant increase in waiting times for patient access to radiation and medical oncology. Te Aho o Te Kahu has been actively working with the DHB to support it to address this issue.

In May 2021, the Chief Executive and Southern Hub Manager of Te Aho o Te Kahu met with clinical staff, clinical and service leadership, and executive management of Southern DHB. Since that meeting the Southern Regional Hub has supported Southern DHB to actively grow the workforce, including medical, nursing and allied health staff and further invest in nonsurgical cancer services. Te Aho o Te Kahu continues to reinforce the need for a strong focus on the impact of delays on the health and wellbeing of patients. While short term measures to address this impact are crucial, a robust approach to ensure services are sustainable on an ongoing basis is also required.

Te Aho o Te Kahu has also worked with Health Workforce NZ to understand capacity issues and think about initiatives to enhance recruitment and retention across Aotearoa New Zealand.

##### Cancer medicines availability analysis

Te Aho o Te Kahu has commenced work to assess the availability of cancer medicines in Aotearoa New Zealand. The goal of this analysis is to objectively assess the breadth of cancer medicines available in New Zealand and identify if and where there are substantial gaps between medicines with clear clinical benefit that are available in other comparable countries and those available here.

##### Support and information

The Southern Regional Hub has commenced a project to improve transition support for people who have recently completed treatment.

### Improving equity of cancer outcomes

#### Support Government Response to Māori Affairs Select Committee Inquiry into Māori Health Inequities

The Māori Affairs Committee Inquiry into Health Inequities for Māori was initiated on 16 March 2019 in response to letters from Māori users of the health system expressing concern and identifying shortcomings for Māori seeking cancer care. Te Aho o Te Kahu worked closely with Manatū Hauora (Population Health and Prevention and Health Workforce), Mō Te Pātaka Whaioranga, Mana Tohu Mātauranga o Aotearoa and Te Hiringa Hauora to provide advice to inform the Government’s response to this Inquiry, with that response tabled in Parliament on 14 April 2021. The Government’s response agreed, or agreed in principle, with 14 of the 19 Inquiry recommendations.

##### Māori community hui

In February 2021 Te Aho o Te Kahu embarked on a series of Māori Cancer Community Hui around the motu. Working alongside local DHBs, cancer service providers, Māori leaders, stakeholders and communities, we delivered 13 hui from Kaikohe to Invercargill – reaching over 2,500 whānau Māori.

The purpose of the hui was to hear the voice of whānau Māori as they shared their insights and experiences of cancer and cancer care in Aotearoa. At each hui we worked collaboratively with whānau Māori to codesign solutions to issues identified during workshop sessions. We also supported whānau Māori with free health checks, health promotional activities, primary care enrolment, and screening enrolment and delivery. Rongoā Māori (traditional Māori healing) and a focus on hauora (holistic wellbeing) were also important elements of the hui.

The hui had the additional benefit of raising the visibility of Te Aho o Te Kahu as a leader, and an agent for change, in the health system and the hui have solidified our relationships with many Māori providers, leaders and stakeholders.

#### Māori leadership and engagement

Alongside Hei Āhuru Mōwai, Te Aho o Te Kahu has been considering the best approach to engage genuinely with Māori leaders and communities at national and regional level to gain their insights and advice. This work is ongoing.

## Tō Mātou Whakahaere |Our Performance

Te Aho o Te Kahu is currently developing its approach to better understanding what is happening in the sector and our own performance. As an interim step, we intend to communicate our performance through the approach and measures outlined below, which will be regularly reviewed and improved to make sure we are focusing on the things that matter.

### Tō mātou ahu |Our approach

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| Accountability of relationships | **Why?**It is important that Te Aho o Te Kahu delivers on the government’s expectationsThere are some key questions we need to answer to support these relationships:* how can we best demonstrate our performance to fulfil accountability requirements? (A)
* how can we gain the best understanding of challenges being experiences in the sector in order to lead and support? (B)
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| **How?**Our intended approach is to develop five monitoring processes from which a selection of key indicators and information will be drawn and reported to the Minister. |
|  | **Outcome and intervention tracking**This will provide a view of whether Te Aho o Te Kahu is delivering on its purpose and meeting its goals of fewer cancers, better survival and equity for all.These indicators will likely be slow moving, and will require care with interpretation. | **Delivery of the Cancer Action Plan**A framework is being developed to track progress with delivering the actions described in the National Cancer Action Plan.This will likely consist of a mixture of indicators and project milestones. | **Early identification of service challenges**Our regional hubs have developed a framework for identifying service issues in their region in order to provide appropriate action and support.This builds on existing reporting mechanisms and relationships. | **Acknowledging achievements and challenges**Te Aho o Te Kahu has developeda more formal mechanism for identifying and reporting on our achievements, risks and challenges. | **Te Aho o Te Kahu corporate performance**Te Aho o Te Kahu has identified key metrics which can be used to track our internal performance as an agency.This consists of a mixture of throughput and people-related indicators. |  |
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| **What?** |
|  | The products to be delivered from this approach are still in development. They may include:* a quarterly dashboard provided to the Minister, and shared with the advisory council covering a selection of key indicators, progress reporting and risks
* monthly reporting collated by the Te Aho o Te Kahu regional hubs showing service performance and challenges in their region
* a tracking tool for each action described in the National Cancer Action Plan.

Yet to be determined is whether any of this reporting is appropriate to be shared publicly, eg, on the Te Aho o Te Kahu website, or with stakeholders. |  |
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### Ngā aronui mo tēnei wā |Our interim performance measures

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| **Outcome measures**These measures tell us if we are heading in the right direction and remind us of our purpose – they are the things that really matter to us. However, they are not solely attributable to Te Aho o Te Kahu and will likely shift slowly. |
|  | Outcome measures such as fewer cancers and better survivial |  |
|  | Age- and sex-standardised cancer rates 2008–2017 | Age- and sex-standardised cancer-related mortality 2007–2017 |  |
| If Te Aho o Te Kahu has a positive impact on equity, over time we would expect the difference in Māori and non-Māori incidence rates and mortality to reduce. |

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| **Better survival – service indicators**These indicators are drawn from regular monitoring to understand what is happening in the system. |
|  | CT/MRI wait times target | **80%** met | Wait for first specialist appointment | **14%** over time |  |
|  | Colonoscopy wait times target | **55%** met | Wait for treatment time | **25%** over time |  |
|  | Breast and cervical screening rates for Māori target | **58%** met | Patient experience\* |  |  |
|  | Access to travel support\* |  | % workforce Māori\* |  |  |
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| **Te Aho o Te Kahu agency indicators**These indicators provide insight into how Te Aho o Te Kahu is functioning as a public service agency. |
|  |  |  | Trend |  |  |  | Trend |  |  |
|  | Staff satisfaction | 7.3/10 | – |  | OIA timeliness | 100% | p |  |  |
|  | Sick leave taken | 3.1 days | – |  | % Māori staff | 8% | q |  |  |
|  | Staff turnover | 4% | p |  |  |  |  |  |  |
|  |

+ Per 100,000 population \* In development

### Explanation of measures

| **Measure** | **Explanation** |
| --- | --- |
| Cancer incidence rate | The number of people diagnosed with a new cancer per 100,000 people in the population. Most recent data is 2018.Numerator: the number of new cancers diagnosed in that year.Denominator: Aotearoa New Zealand population. |
| Access to primary care | NZ Health System Indicator.People report they can get primary care when they need it.Sourced from the Health Quality & Safety Commission (HQSC) adult primary care experience survey.Numerator: The number of people answering ‘no’ to the question: In the past 12 months was there a time when you wanted healthcare from a GP or nurse but you could not get it?Denominator: The number of people who answered the question: In the past 12 months was there a time when you wanted healthcare from a GP or nurse but you could not get it? |
| Cancer mortality rate | The number of deaths, with cancer as the underlying cause of death, occurring during the year. Cancer mortality is usually expressed as the number of deaths due to cancer per 100,000 population. Most recent data is 2018.Numerator: The number of deaths with cancer as the underlying cause of death.Denominator: Aotearoa New Zealand population. |
| Bowel screening participation | NZ Health System Indicator.This measure is yet to be developed. |
| Involved in care | NZ Health System Indicator.The number of people who report they can get primary care when they need it.Sourced from the Health Quality & Safety Commission (HQSC) adult primary care experience survey.Numerator: The number of people answering ‘yes’ to the question: Did the GP or nurse involve you as much as you wanted to be in making decisions about your treatment and care?Denominator: The number of people who answered the question: Did the GP or nurse involve you as much as you wanted to be in making decisions about your treatment and care? |
| CT/MRI wait times | The number of people accepted for a CT scan receive their scan within 42 days or less (target 95%).The number of people accepted for a MRI scan receive their scan within 42 days or less (target 90%).Numerator: The number of people who receive the diagnostic within the identified timeframe and people waiting for the diagnostic at the end of the period who have waited less than the indicated timeframe.Denominator: The number of people who have received the diagnostic and people waiting for the diagnostic at the end of the period. |
| Colonoscopy wait times | The number of people accepted for an urgent colonoscopy receive this in 14 days or less (target 90%).The number of people accepted for a non urgent colonoscopy receive this in 42 days or less (target 90%).The number of people accepted for a surveillance colonoscopy whose procedure is due prior to or within the month of reporting receive this in 84 days or less (target 90%).Numerator: The number of people who receive the diagnostic within the identified timeframe and people waiting for the diagnostic at the end of the period who have waited less than the indicated timeframe.Denominator: The number of people who have received the diagnostic and people waiting for the diagnostic at the end of the period. |
| Breast and cervical screening rates for Māori | Percentage of eligible women screened in the most recent 24-month period (target 70%). |
| Access to travel support | This measure is yet to be developed. |
| Wait for first specialist appointment | ESPI 2: All patients accepted for an first specialist appointment (FSA) should be seen within four months of the date of referral. The goal is to have no patients waiting more than four months for an FSA.Numerator: the number of patients waiting longer than four calendar months for an FSA.Denominator: total number of patients waiting at month end for an FSA. |
| Wait for treatment | ESPI 5: All patients given a commitment to treatment should receive it within four months. The goal is to ensure no patients with this status remain untreated after four months.Numerator: the number of patients with an assured status waiting longer than 120 days.Denominator: the total number of patients waiting with an assured status. |
| Patient experience | This measure is yet to be developed. |
| % workforce Māori | This measure is yet to be developed. |
| Staff satisfaction | Overall agency score in ‘Korero Mai’ staff satisfaction survey (out of 10). |
| Sick leave taken | The average number of sick leave days applied for and approved per permanent or fixed term employee in that financial year. |
| Staff turnover | The proportion of staff who resigned from Te Aho o Te Kahu in the financial year.Numerator: The number of people who resigned.Denominator: The number of permanent and fixed term staff. |
| OIA timeliness | The proportion of Official Information Act 1982 (OIA) responses that are sent to requestors within legislated timelines. |
| % staff Māori | The proportion of Te Aho o Te Kahu staff who identify as Māori.Numerator: The number of people who identify as Māori.Denominator: The number of permanent and fixed term staff. |

## Haepapa Tauākī |Statement of responsibility

I am responsible, as Chief Executive of the Cancer Control Agency (Te Aho o Te Kahu) for the accuracy of any end-of-year performance information prepared by Te Aho o Te Kahu, whether or not that information is included in the Annual Report.

In my opinion, the Annual Report fairly reflects the operations, progress, and organisational health and capability of Te Aho o Te Kahu.



**Professor Diana Sarfati**

Chief Executive

Te Aho o Te Kahu, Cancer Control Agency
23 November 2021