# HE URUPARE

Responding to the experiences of whānau Māori affected by cancer

TE AHO O TE KAHU
CANCER CONTROL AGENCY

Note: Te Aho o Te Kahu has published three documents on the hui series:

1. *Rongohia Te Reo, Whatua He Oranga,* which shares the experiences, insights, and aspirations of thousands of whānau Māori affected by cancer.
2. *Te Tikanga* summarises our kaupapa Māori approach to the hui series
3. *He Urupare* (this report) outlines some of the work Te Aho o Te Kahu and other health agencies are doing that responds to, or aligns with, whānau insights

These are all available in both English and te reo on our website, **teaho.govt.nz**.

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# He kupu whakamihi
# Acknowledgements

Te Aho o Te Kahu sincerely thanks the many individuals who contributed to the hui series including:

- patients and whānau who attended and shared their stories and insights with us
- local organisations and mana whenua that hosted each hui
- large numbers of local and national health organisations that collaborated in the planning and delivery of the hui series
- many kaumatua and kuia who joined us to tautoko both the kaupapa and the whānau in attendance at each hui
- kapa haka rōpū, singers and musicians who supported and entertained whānau during the hui
- numerous health professionals who chose to attend the hui and hear directly from patients and whānau.

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# He whakarāpopoto matua
# Executive summary

In 2021, Te Aho o Te Kahu was grateful to meet with more than 2,500 whānau Māori affected by cancer, via 13 hui held across the motu. The aim of the hui series was simple - to hear the stories and experiences of whānau Māori, so that their voices could help shape the future direction of cancer care in Aotearoa. The hui series also provided an opportunity for our newly-formed agency to build relationships with Māori cancer patients and whānau, along with the many other Māori organisations and individuals involved in cancer care.

The hui series took place from February to July 2021 and was supported by mana whenua and representatives from local cancer, health and community organisations.

A deliberate choice was made to use a kaupapa Māori approach through all stages of the hui planning and delivery process. Following the hui series, Te Aho o Te Kahu staff analysed the data and sense checked the themes with Māori working in the wider cancer sector. Content for three reports was then collaboratively drafted by Māori staff from Te Aho o Te Kahu and peer reviewed by selected members of Te Aho o Te Kahu, Hei Āhuru Mōwai and He Ara Tangata.

The suite of three reports includes:

1. *Rongohia Te Reo, Whatua He Oranga*,, which shares the experiences, insights, and aspirations of thousands of whānau Māori affected by cancer.
2. *Te Tikanga* outlines the kaupapa Māori principles that we used to design and deliver the hui series.
3. *He Urupare* (this document) describes some of the work Te Aho o Te Kahu and other health agencies are doing that responds to, or aligns with, whānau insights.

All three reports are available on our website, **teaho.govt.nz.**

As the agency tasked with providing national cancer leadership across the health system and overseeing the delivery of the *New Zealand Cancer Action Plan 2019-2029*, it was important for Te Aho o Te Kahu to present the reports in a way that could drive

our current and future work. This report is presented using the framework of the *New Zealand Cancer Action Plan 2019-2029*, as it sets out the four main outcomes that will drive action to ensure better and more equitable cancer outcomes. These outcomes are:

- New Zealanders have a system that delivers consistent and modern cancer care
- New Zealanders experience equitable cancer outcomes
- New Zealanders have fewer cancers
- New Zealanders have better cancer survival, supportive care and end-of-life care.

The details in this report are not a comprehensive stocktake of all activity across the health and social sectors but rather, some examples of work currently underway that address whānau insights and experiences as detailed in *Rongohia Te Reo, Whatua He Oranga*. Where pieces of work contribute to multiple outcomes of the *New Zealand Cancer Action Plan 2019-2029*, we have listed them under the outcome where they create the greatest impact.

Te Aho o Te Kahu profoundly thanks the many individuals and organisations who contributed to the hui series. In particular we acknowledge all of the patients and whānau who attended and shared their stories and insights with us. Although it was painful at times for whānau, they willingly shared their thoughts, insights, experiences, and aspirations. These taonga are meaningful insights that will help us to affect change and address Māori cancer inequities. We also sincerely thank the local organisations and mana whenua that created safe and welcoming spaces for whānau to share these taonga with us.

These reports are being published at a time of great change within the health sector. We look forward to working with Te Whatu Ora - Health New Zealand, Te Aka Whai Ora - Māori Health Authority, and all other heath organisations to ensure the voices of whānau are embedded in our work to create fewer cancers, better survival, and equity for all.

# 2 Arohia ana ō ngā whānau whakaaro mātau
# Addressing whānau insights

# OUTCOME 1:
# A CONSISTENT AND MODERN CANCER CARE SYSTEM

*New Zealand Cancer Action Plan 2019-2029*

**He pūnaha atawhai**

New Zealanders have a system that delivers consistent and modern cancer care

**Key focus areas**

- Leadership and governance
- Health workforce
- Data and information
- Research and innovation.

**What this outcome means**

New Zealanders should expect to receive high-quality cancer care services, both now and in the future. Strong governance, accountability and stewardship are needed to achieve this. It also requires leadership at all levels, a skilled and sustainable workforce and access to high quality information so that the best decisions are consistently made. Communities should also have a say in the services they want and need, and in how they are designed and delivered (Health and Disability System Review, 2020). This is particularly needed to address the persistent failures of the health system to respond to the health care needs of Māori.

A system that delivers high-quality and equitable cancer care requires:

- leadership and governance frameworks that are agile and reflect the communities they serve
- a workforce that is well-trained, diverse, and culturally competent with a wide range of clinical and non-clinical skills and expertise
- high quality data and information systems that identify unwarranted variations and support better decision making at patient, organisation and system levels
- a system that supports research and innovation, including enabling mātauranga Māori to be embedded at each stage of the cancer continuum.

## Whānau attending the hui series told us that:

The system needs to empower shared decision making and co-design

Increased collaboration is needed between cancer leaders and the community

Māori cancer leadership is needed at every level

The Māori cancer workforce needs growth and support

The cultural capability of the non-Māori cancer workforce needs to improve

Mātauranga Māori must be supported throughout the cancer workforce

Whānau want rangatiratanga over their cancer data

Whānau information needs must be addressed

Innovative, whānau-centred care is needed

See *Rongohia Te Reo, Whatua He Oranga* for more details – available from **teaho.govt.nz**

# LEADERSHIP AND GOVERNANCE

**Since the hui series concluded, there have been several significant changes within the health system that will over time address many of the whānau insights as summarised above. Some of the key structures and programmes of work within Te Aho o Te Kahu also reflect these whānau insights.**

Changes at a national health system level include:

- The passing of the Pae Ora (Healthy Futures) Act 2022, which sets out the Government's vision for health system reform ("Pae Ora (Healthy Futures) Act," 2022)
- The amalgamation of the country's 20 district health boards into a single crown agency, Te Whatu Ora – Health New Zealand
- The establishment of Te Aka Whai Ora – Māori Health Authority, whose role is to lead and monitor transformational change in the way the entire health system understands and responds to the health and wellbeing needs of whānau Māori (Te Aka Whai Ora, 2022)
- The creation of Iwi Māori Partnership Boards across the country, who will ensure Te Aka Whai Ora has a direct understanding of the inequities and barriers experienced by local communities and providers (Te Whatu Ora, 2022)
- The release of *Te Pae Tata, the interim New Zealand Health Plan 2022*. This is the first New Zealand Health Plan published under the Pae Ora legislation. It is an interim plan outlining the work plans of Te Whatu Ora and Te Aka Whai Ora for 2023-24. Five priority areas have been identified to improve health outcomes, including 'Mate pukupuku | people with cancer'
- *Te Pae Tata* also notes that in the cancer context, Te Whatu Ora and Te Aka Whai Ora will in 2023-24 focus on the delivery of equitable care right across the cancer continuum. There will also be a focus on:
  - improving Māori participation in breast, cervical, and bowel screening through targeted approaches with Māori community providers
  - pathways to support rapid diagnosis of cancer and enable equitable access to cancer treatment
  - national pathways to access transport and accommodation to support equitable completion of cancer treatment.

This work will be done in partnership with Te Aho o Te Kahu and Hei Āhuru Mōwai.

Since our inception, Te Aho o Te Kahu has also worked hard to incorporate Māori world views into our governance and leadership structures. Key agency initiatives include:

- A partnership with Hei Āhuru Mōwai, Māori Cancer Leadership Aotearoa. The two organisations have a signed oati (oath) and meet regularly to discuss key areas of work. Hei Āhuru Mōwai members also provide expertise on key projects and programmes across Te Aho o Te Kahu
- The creation of the Advisory Council, which supports the leadership and ongoing direction of cancer control in Aotearoa. The council is 50% Māori and includes a Māori co-chair
- The establishment of He Ara Tangata, the consumer advisory group that provides lived-experience expertise and advice. At least 50% of the membership is reserved for Māori and group members contribute advice and guidance across a range of work within the Agency
- The introduction of Te Tiriti analysis as part of all major projects and programmes of work. Project teams must identify where and how the work aligns with the five principles of Te Tiriti o Waitangi, as expressed by the Waitangi Tribunal: tino rangatiratanga; equity; active protection; options; and partnership
- The hui series itself, with its focus on whakawhanaungatanga and hearing the voices of whānau Māori.

## Snapshot: Cancer Services Planning programme

In 2021, Te Aho o Te Kahu began a programme of work designed to complement the health system reforms. The goal is to enable a transformative approach to cancer treatment and support. We will do this by providing evidence-based guidance to commissioning entities on how cancer treatment services in Aotearoa can be strengthened, future proofed and designed to achieve equity.

Our report *He Mahere Ratonga Mate Pukupuku, A vision for cancer treatment in the reformed health system*, was published in July 2022. It identifies system-wide issues and potential solutions; and then looks in more detail at specific areas of cancer treatment, for example, cancer surgical services, radiation oncology, systemic anticancer therapies and haematopoietic stem cell transplants, coordination and support services, sometimes known as navigation; and allied health).

Since then, seven key transformation projects have been identified and are underway. These focus on creating new models of care and service designs in the following areas.

- Cancer Care Coordination
- Cancer Surgical Services
- Systemic Anti-Cancer Therapy (chemotherapy, hormone therapy etc)
- Stem Cell Transplants
- Radiation Oncology
- Optimal Cancer Care Pathways
- Workforce Planning

We are engaging with Te Whatu Ora and Te Aka Whai Ora at multiple levels to ensure that this advice is fit for purpose and can be considered for implementation. Members of Hei Āhuru Mōwai and He Ara Tangata are involved in all seven transformation projects.

# HEALTH WORKFORCE

Improving the diversity and cultural safety of the health and cancer workforce is a complex challenge that requires changes at multiple levels. In May 2022, the Government announced a Workforce Taskforce to address these issues. The taskforce has five workstreams currently underway which focus on:

- building an international recruitment centre within Te Whatu Ora
- establishing a campaign that will attract nurses back into the profession and attract young people into nursing
- supporting qualified professionals into Aotearoa though the registration process
- providing funding for Nurse Practitioner training
- growing the kaiāwhina workforce who play an important role supporting individuals and their whānau during their treatment.

The taskforce includes hospital- and community-based health professionals along with representatives from Te Whatu Ora, Te Aka Whai Ora, primary health organisations and the Tertiary Education Commission. Te Aho o Te Kahu is supporting several workstreams with cancer-specific advice and support.

In addition, the Cancer Services Planning programme (see Snapshot on page 10) has identified specific cancer treatment workforce needs and includes a focus on:

- increasing the number of Māori working in the cancer workforce
- increasing training and support for Māori already working in the cancer system
- ensuring that the non-Māori workforce have appropriate training and skills to provide culturally safe care for Māori.

Other initiatives currently in place across the wider health sector include efforts to better support Māori students to train in health subjects. For example, Otago University and the University of Auckland both have longstanding policies which aim to increase the number of Māori training in medicine.

# DATA & INFORMATION

Accurate, robust and timely data and information are critical to the delivery of high-quality cancer services. Information needs to be accessible, relevant, and easily understood by whānau to enable them to make informed decisions about their cancer treatment and care (Ministry of Health, 2019).

Te Aho o Te Kahu is currently developing a collection of services and tools called CanShare to improve the sharing of cancer information. The platform will include:

- the ACT-NOW project (Anti-Cancer Therapies – Nationally Organised Workstreams), which will enable the standardised collection and sharing of medical oncology treatments across the country (see page 32 for more detail)
- an updated Radiation Oncology Collection (ROC), so that all data collected on radiation oncology treatments meet CanShare standards (see page32 for more detail)
- Structured Pathology Reporting of Cancer, which will standardise and improve the reporting of structured pathology data
- Guidance, direction, and leadership in national cancer informatics.

Other work underway to develop better data and information includes:

- an equity-led monitoring framework to help assess our progress towards achieving the aspirations of the *New Zealand Cancer Action Plan 2019-2029*. Using this framework, we will report on eleven broad indicators that give a snapshot of the current state of cancer control in Aotearoa. The monitoring report will also present activities being undertaken to achieve the outcomes and actions of the *New Zealand Cancer Action Plan 2019-2029*.
- work on data sovereignty including the release of a position statement on improving the collection of ethnicity reporting, and participation in the Māori data sovereignty rōpū established by Manatū Hauora.
- Regular reports on how COVID-19 impacted the delivery of cancer services. The first report was published in May 2020, and are currently released every three months.

Across the wider health system, *Te Pae Tata* has highlighted health insights, data, and intelligence as a key system enabler. This includes developing a nationally consistent system of data capture, analytics, and intelligence. Māori sovereignty principles will also be embedded in the way health agencies manage and use data.

Te Whatu Ora has a significant digital transformation programme currently underway called Hira. Hira will fundamentally change the way health information is accessed and will create a virtual health record for all New Zealand citizens and residents. By ensuring health information can be delivered wherever and whenever it is needed, Hira will also support clinicians to make better decisions on treatment and care.

Hira is being co-designed with Māori, with the work being overseen by a Māori advisory group, Te Rangapū Tiriti. Te Aho o Te Kahu is represented on both Te Rangapū Tiriti and the wider Hira Governance Group.

# RESEARCH AND INNOVATION

In 2021, Te Aho o Te Kahu collaborated with the Health Research Council and Manatū Hauora to create a $6.2 million research fund, specifically aimed at addressing the stark inequities in cancer care and survival for Māori and Pacific peoples in New Zealand. In January 2022, six research projects received funding in areas including lung cancer screening, pre-diagnostic experiences of uterine cancer and the use of Whānau Ora navigation in local delivery of oncology care.

Te Aho o Te Kahu is also involved in a range of other research and innovation projects including:

- collaborating with Hei Āhuru Mōwai to better understand the challenges faced by whānau Māori living with both COVID-19 and cancer
- supporting Manatū Hauora in their work to develop clinical trial infrastructure for all conditions, including cancer
- supporting the University of Auckland to develop core infrastructure that supports cancer teletrials in Aotearoa.

In addition, Te Aho o Te Kahu is working on several telehealth projects including a survey of all publicly funded cancer services to understand their experiences with and attitudes towards telehealth. We have also worked with the New Zealand Telehealth Leadership Group to create a rōpū for people interested in using telehealth in cancer care and have supported two student interns on telehealth projects that cover aspects of cancer care.

# OUTCOME 2:
# EQUITABLE CANCER OUTCOMES

*New Zealand Cancer Action Plan 2019-2029*

**He taurite ngā huanga**
New Zealanders experience equitable cancer outcomes

**Key focus areas**

- Mātauranga Māori framework for delivery
- Equity by design
- Addressing racism and discrimination.

**What this outcome means**
Equity is a key driver of the *New Zealand Cancer Action Plan 2019-2029*: all New Zealanders should experience the best treatment and care, regardless of where they live or who they are. The plan commits to developing service models for cancer care that better support Māori and Pacific peoples to improve their outcomes and experiences. Essential to this is increasing the number of Māori and Pacific people in the cancer health workforce, as well as developing cultural safety across the wider workforce.

This outcome focuses on:

- the development of a mātauranga Māori framework for delivering the *New Zealand Cancer Action Plan 2019-2029*
- embedding equity within system design, which requires a system-level response rather than a focus on individual patient behaviours
- addressing racism and discrimination, which are modifiable determinants of health that can impact mental and physical health (Paradies et al., 2015) and lead to poorer health outcomes for Māori (Harris et al., 2012).

## Whānau attending the hui series told us that:

Mātauranga should be integrated throughout the cancer journey

Rongoā is important to whānau

The current system isn't designed for Māori

Whānau need cancer navigation services

Whānau regularly experience racism and discrimination

Whānau deserve to be treated with empathy

The expertise of cancer survivors should be utilised

Whānau often feel unable to trust the health system

Holistic care is needed for both patients and whānau

Information overload is a common concern

Many whānau don't see or hear enough positive cancer stories, reinforcing the strong association Māori have between cancer and death.

See *Rongohia Te Reo, Whatua He Oranga* for more details – available from **teaho.govt.nz**

# MĀTAURANGA MĀORI FRAMEWORK FOR DELIVERY

The term mātauranga Māori is commonly used to describe Māori knowledge systems. It incorporates knowledge originating from many sources including Māori ancestors, the Māori world view, Māori creativity and cultural practices (Hikuroa, 2017; Mead, 2003). The importance of mātauranga Māori is being increasingly recognised, particularly as a vehicle to improving Māori health and wellbeing (Health and Disability System Review, 2020). This is reflected in a number of key strategic documents that drive work across the health sector. For example, ensuring mātauranga Māori is included and protected throughout the health and disability system is one of the four intended outcomes of *Whakamaua: Māori Health Action Plan 2020–2025*. Mātauranga Māori is also referenced in a number of areas within *Te Pae Tata* including:

- the development of health pathways that incorporate mātauranga Māori
- the establishment of a Te Ao Māori intelligence and insights function, that includes use of mātauranga Māori

# EQUITY BY DESIGN

As an agency that is explicitly equity led, Te Aho o Te Kahu is working to integrate equity into every aspect of its work. Some examples of this are detailed below.

- Organisational structure: we have created Equity and Whānau-centred Care teams within the organisational structure, which allows for expert advisors to support kaimahi across the Agency to build their capability in these areas. Staff are also supported to conduct analysis during project planning and implementation to ensure they embed the principles of equity and whānau-centred care in their work.
- Equity rōpū: we have established Te Kāhui Mana Taurite, a cross-organisational internal group focused on embedding equity into key pieces of the Agency's work. The rōpū was formed as part of the Cancer Services Planning programme but has potential to support other current and future programmes and projects within the Agency.
- Cancer care coordination services: this project is part of the Cancer Services Planning programme and details our suggestions on how to establish cancer care coordination services across the motu. The aim is to establish services that better support Māori and Pacific patients and whānau to enter and complete cancer treatment. The proposed services would reflect key principles of te ao Māori including manaakitanga, hauora and whānau-centred care. See the Snapshot on page 19 for more details.
- Optimal cancer care pathways (OCCP): equity led and whānau centred care are two of the key principles embedded in the OCCP project. Work is underway to identify and address known inequities along the cancer continuum for each tumour stream. Once identified, steps should be taken to address the inequity. Approaches to address inequities and the importance of Mātauranga Māori to improve Māori health and wellbeing are integrated throughout the OCCP.

Across the wider health sector, there is an increasing emphasis on equitable design of health services and systems. This includes a greater level of support for rongoā Māori (traditional Māori health systems developed using a distinctly Māori world view) (Wikaire, 2020). Rongoā is applied in totality to bring about wholeness or interconnectedness of body, mind, emotions, spirituality, energy, society, culture, relationships and environment. This is a key application of mātauranga Māori in the health and disability system (Ministry of Health, 2020). The values of wairuatanga, whanaungatanga, kotahitanga, manaakitanga, kaitiakitanga, and ultimately rangatiratanga are embedded within mātauranga Māori and rongoā approaches and pursuits (Wikaire, 2020).

Work is underway at a system level to elevate rongoā Māori across and alongside the health and disability system. Some of the changes underway or announced since the hui series ended are listed below.

- In December 2022, Te Aka Whai Ora launched a new strategic rongoā Māori kaupapa which will empower Māori to determine the protection and support for rongoā to flourish. The voices of tohunga, mātanga rongoā, whānau, hapū, and iwi Māori will lead and guide this mahi, which focuses on two things:
  - Māori priorities and aspirations, navigating the broad system settings to deliver on those priorities, and exploring funding paths and resources to support the immediate and long-term needs for the sustainability of rongoā.
  - Raising awareness of the Therapeutic Products Bill (currently proceeding through the Parliamentary process) including the implications of the Bill for rongoā Māori.

- The number of publicly-funded rongoā Māori services is very limited, and an early priority for Te Aka Whai Ora has been to increase access to rongoā. This includes a recently announced investment of $17.6 million in mātauranga Māori services, te ao Māori solutions and population health, including rongoā Māori. Te Aka Whai Ora acknowledges much more will be required across the health system, to support and enable the system of rongoā Māori to thrive and contribute fully to improving health outcomes in Aotearoa New Zealand.
- Manatū Hauora has signed a relational agreement with Te Kāhui Rongoā, a national body of rongoā practitioners. This provides a mechanism for an enduring relationship between Manatū Hauora and Te Kāhui Rongoā.
- In 2022, Manatū Hauora reviewed its' funding of rongoā services. The purpose of the review was to identify the current state of rongoā services funded by Manatū Hauora, and the challenges and opportunities to strengthen evidence and expand access to rongoā Māori services.
- Manatū Hauora is currently leading a programme of work to determine how rongoā may be appropriately scheduled in the Therapeutic Products Bill. This work entails understanding how rongoā may be protected, whilst providing for the assurance of patient safety, and ensuring access to export markets for rongoā practitioners.

## Snapshot: Cancer Care Coordination

Whānau attending the hui series consistently spoke of the difficulties involved with navigating their cancer treatments. This is backed by a large body of research that shows how navigation support can benefit indigenous cancer patients, both in Aotearoa and overseas (Burhansstipanov et al., 2015; Koia, 2019; Slater et al., 2016).

The insights from the hui series have significantly influenced a key piece of our work. As mentioned earlier (see page 10), Te Aho o Te Kahu has begun a large programme of work focused on cancer services planning. One of the key recommendations in this work was to establish nationwide cancer care coordination services across Aotearoa. As whānau articulated in the hui series, these services play a significant role in reducing the trauma of cancer diagnosis, increasing the likelihood that someone will successfully complete their cancer treatment and improving the transition to survivorship. Although a variety of coordination and support services currently exist across Aotearoa, there is lack of visibility, awareness, and prioritisation of these services.

We are currently preparing a package of advice and guidance for Te Aka Whai Ora and Te Whatu Ora, to assist with any future commissioning of cancer care coordination services. We see these services being available to patients and whānau in a range of settings including primary care, hospitals, community care and kaupapa Māori services. We are working with patients and whānau, Hei Āhuru Mōwai, cancer clinicians and current and potential cancer care coordinators to ensure this advice is equity-led, robust and reflects the voices of lived experience.

This work aligns with several key areas within *Te Pae Tata* including:

- the expectation for customised, holistic, high-quality services that seamlessly support patients and whānau through their whole cancer journey
- specific actions focused on equitable access to cancer treatment for Māori
- the creation of comprehensive primary and community care teams
- the need for whānau-focused integrated care models.

This work also reflects the aspiration shared by a whānau member who attended the hui series:

*'We have an opportunity to create models of care that work for Māori – a navigator – engaging in full aroha with whānau, assessing needs, and connecting with services. It sounds basic but it's something that's not done.'*

Te Aka Whai Ora has also recognised the need for investment in cancer care coordination services for whānau Māori. Guided by *Te Pae Tata*, the agency in November 2022 announced $2.8million of funding to support Hauora Māori partners to deliver cancer care coordination services.

# ADDRESSING RACISM AND DISCRIMINATION

Eliminating all forms of racism is critical to achieving health equity and the Government's vision of Pae Ora – Healthy Futures for all New Zealanders. *Ao Mai te Rā: the Anti-Racism Kaupapa* is a Manatū Hauora initiative to support the way the entire health system understands, reacts, and responds to racism in health. To date, Ao Mai te Rā has released a podcast series and a position statement which formally outlines the Ministry's position on racism. The position statement also signals expectations for the broader health system to take collective action against all forms of racism and racial health inequity.

Te Aho o Te Kahu has been supporting Manatū Hauora on the development of Ao Mai Te Rā. In addition, several pieces of our work aim to create checks and balances, specifically looking for any intended or unintended racism and bias.

- The Cancer Services Planning programme is specifically designed to identify areas of inequity and design cancer treatment services that enable equitable outcomes for all cancer patients and whānau. This includes a project focused on optimal cancer care pathways, which details expectations within publicly-funded cancer treatment services (see page 28 for more details).
- The Quality Performance Indicator programme aims to highlight variation in cancer treatment and outcomes. It will, in time, provide information on the full cancer pathway from referral through to diagnostics, treatment, survivorship and palliation (see page 34 for more details).

These projects will collectively make it harder for bias and racism to occur and will help to minimise their impacts on cancer outcomes.

# OUTCOME 3: CANCER PREVENTION

*New Zealand Cancer Action Plan 2019-2029*

**Kia whakaiti iho te mate pukupuku**
New Zealanders have fewer cancers

**Key focus areas**

- Smokefree by 2025
- Encouraging and supporting healthy living
- Preventing cancers related to infection
- Reducing avoidable skin cancer
- Reducing exposure to work-related carcinogens.

**What this outcome means**

Investment in the prevention of cancer will ultimately make the largest contribution to reducing the burden of cancer in New Zealand and to achieving equity in outcomes. Around 30-50% of all cancers are potentially preventable (Te Aho o Te Kahu, 2021). The most common cancers for Māori (lung, liver, stomach, and pancreas) are also the most preventable and these cancers have also been linked to living in high-deprivation communities (Te Aho o Te Kahu, 2022).

Environmental factors, including social, economic, and political factors coupled with colonisation and racism combine to create and perpetuate cancer inequities for Māori, and significantly impact on exposure to cancer risk factors. These risk factors include:

- Smoking (tobacco is one of the leading contributors to avoidable cancer risk, causing almost 80% of lung cancers and significantly contributing to at least nine other cancers (Te Aho o Te Kahu, 2021))
- Infectious illnesses (Māori have significantly higher exposure to infectious illnesses such as: *Helicobacter pylori (H.pylori)*; human papillomavirus (HPV), hepatitis B and hepatitis C that can contribute to cancers of the stomach, cervix, and liver (Te Aho o Te Kahu, 2021))
- Poor nutrition
- Insufficient physical activity
- Excess body weight
- Sun exposure
- Occupational exposure to workplace carcinogens (Te Aho o Te Kahu, 2021).

## Whānau attending the hui series told us that:

Whānau look at prevention holistically

Whānau want to see an increase in kaupapa Māori prevention and health promotion

More work is needed on smoking

Preventing infectious illnesses is critical

More knowledge is needed on workplace carcinogens

See *Rongohia Te Reo, Whatua He Oranga* for more details – available from **teaho.govt.nz**

We know that up to half of all cancers diagnosed every year could be avoided with stronger prevention measures. To support this work, Te Aho o Te Kahu released *Pūrongo Ārai Mate Pukupuku, the Cancer Prevention Report in 2022* (Te Aho o Te Kahu, 2022). The report outlines internationally accepted, 'best practice' interventions to prevent cancer across six key cancer risk factors:

- tobacco
- alcohol
- poor nutrition and excess body weight
- insufficient physical activity
- excessive exposure to ultraviolet radiation
- chronic infections.

The report summarises how Aotearoa is doing in each of those risk factor areas, and highlights where we could do better.

*Te Pae Tata* has also highlighted the importance of public health and prevention, not just for cancer prevention but to create environments where people, whānau and communities can thrive. 'Pae Ora | Better health in our communities' is one of the priorities for improving health outcomes and equity. This priority area includes work that aligns with cancer prevention as listed below:

- Implementing healthy public policies locally and regionally, to reduce harm from alcohol and other drugs, tobacco, unhealthy foods, and obesogenic environments.
- Implementing the Smokefree 2025 Plan with the Public Health Agency.
- Improving Māori and Pacific participation in breast, cervical and bowel screening through targeted approaches with Māori and Pacific community providers.

Across the wider health sector, other work is underway that aligns with the holistic themes and insights on cancer prevention expressed at the hui series. This includes:

- Healthy Families NZ, a large-scale initiative which aims to improve people's health by taking a dynamic systems approach to preventing chronic disease. This approach is place-based and utilises local community leadership to create change. There are currently ten Healthy Families locations throughout the country. The work is led by iwi organisations, councils, Pacific-led organisations, and regional sports trusts.
- *Amohia Te Waiora – We're stronger without alcohol* is a strengths-based approach to alcohol harm reduction. It was developed by Te Hiringa Hauora | Health Promotion Agency, which is now part of Te Whatu Ora. Amohia Te Waiora is a message of mana motuhake which aims to make wellbeing a priority, and support community-led change that minimises alcohol harm.
- The National Tobacco Control Advocacy Service, which is run by Hāpai Te Hauora, aims to identify and promote effective public health and advocacy interventions that will create positive Smokefree policies. The service works closely with Māori and Pacific communities to ensure their voices inform the work. This service is just one of the ways that Hāpai Te Hauora contributes to Māori public health leadership.

# OUTCOME 4:
# CANCER SURVIVAL, SUPPORTIVE CARE AND END-OF-LIFE CARE

*New Zealand Cancer Action Plan 2019-2029*

**He hiki ake i te oranga**
New Zealanders have better cancer survival, supportive care and end-of-life care

**Key focus areas**

- Increased early detection of cancers
- High–quality population screening
- Improved cancer diagnosis and treatment outcomes
- Support and information for people living with cancer
- Quality of life through palliative and end-of-life care.

**What this outcome means**
Surviving many cancers is dependent on early diagnosis and a cancer care system that is well coordinated and information rich, with a focus on improving outcomes in a timely, effective, and appropriate way. This outcome focuses on the range of services within cancer detection, diagnosis, treatment, and care. This includes areas such as:

- timely access to primary care services
- support to access and complete cancer treatment including supportive, palliative and end-of-life care.
- The *New Zealand Cancer Action Plan 2019-2029* notes that a cultural shift is needed in the way such health services are delivered, particularly for Māori, Pacific peoples, and other priority populations.

## Whānau attending the hui series told us that:

Improvements are needed in early detection

Whānau face multiple barriers to primary care

Screening should be more patient-centred

Diagnosis can be unnecessarily traumatic

Treatment doesn't feel fair

Effective supportive care models reflect the te ao Māori worldview

Cancer creates many financial barriers for whānau

Whānau feel forgotten when treatment ends

More conversation is needed on palliative care and end-of-life-care

See *Rongohia Te Reo, Whatua He Oranga* for more details – available from **teaho.govt.nz**

*Te Aho o Te Kahu is undertaking many pieces of work focused on improvement across these areas of the cancer continuum. Many of these projects are informed by the expertise and guidance of our consumer advisory group, He Ara Tangata. The work is also supported by Hei Āhuru Mōwai, our clinical Advisory Council and several clinical working groups.*

## Snapshot: Cancer Services Planning

As mentioned earlier (see page 10), Te Aho o Te Kahu is currently working on a transformation programme focused on cancer services planning. This programme will provide evidence-based guidance to commissioning entities on how cancer treatment services can be redesigned for equitable outcomes. This includes:

- developing a hospital capability and capacity matrix linked to surgical complexity and volume. The aim is to enable more flexibility in surgical management, encourage improvements to service capabilities, support building strong inter-hospital networks which in turn promotes a 'close to home' experience for patients
- developing new and transformative models of care for the delivery of systemic anti-cancer therapy (eg, chemotherapy, hormone therapy) within and outside of hospitals
- developing a new model of care and implementation plan to improve access to haematopoietic stem cell transplant services across the country
- designing a nationally led and locally implemented system of care for radiation oncology services, with standardised clinical practice that is more equitable, accessible and sustainable.

These four treatment-focused projects are underpinned by three wider projects focused on enabling improvements across the cancer treatment journey.

- Producing optimal cancer care pathways (OCCPs) to describe the expected publicly funded cancer care for each tumour type. The OCCP is a tool designed for health care provider organisations and services to achieve equity, drive quality assurance and service improvement in the delivery of care, leading to improved experience and outcomes for whānau.
- Creating an establishment plan for nationwide cancer care coordination services that will initially support Māori and Pacific cancer patients and their whānau to enter and complete cancer treatment (see page 19 for more details).
- Strategic workforce planning focused on three key areas: in the immediate and short-term, increasing capacity among the cancer workforce including the development of the current Māori and Pacific workforce; developing workforce planning and implementation plans to meet the increased workforce requirements of the wider transformation programme; and supporting work to recognise and grow allied health as an essential component of the cancer workforce.

Over time, this programme of work will create change that reflects and builds on many of the whānau insights articulated in Rongohia Te Reo, Whatua He Oranga. This programme is a priority for the agency with more than 45% percent of staff directly involved in the mahi.

# INCREASED EARLY DETECTION OF CANCERS

Primary care plays a critical role in the early detection of cancer. There is good evidence that early access to diagnostics in primary care may assist with early diagnosis and access to cancer treatment. Conversely, people who present with cancer via the emergency department (ED) are more likely to have advanced, incurable disease and often have worse cancer care experiences (Beatty et al., 2009; Sharples et al., 2018). Accessibility to primary care is variable across population groups and late diagnosis represents a significant driver in inequities in cancer outcomes (Rubin et al., 2015). Māori are both more likely to be diagnosed late with cancer, and more likely to be diagnosed via presentation to emergency departments (Te Aho o Te Kahu, 2021).

Work is underway at multiple levels to support improvements in early detection, as seen in the following examples.

- The Planned Care Taskforce was convened in 2022 by the Government. It was asked to provide advice to the Chief Executives of Te Whatu Ora and Te Aka Whai Ora on actions to improve equity, increase access and reduce waiting lists for planned care. Their recent Reset and Restore Plan included recommendations to improve processes to allow primary care specialists to access the right 'next step'; and improve primary care access to diagnostic imaging. Of the 101 recommendations received from the report, 30 are in the implementation stage and others will be phased in through a multiyear programme of work.
- Te Aho o Te Kahu is working to better understand the state of primary and community health care in Aotearoa with respect to cancer. This is a three-phase project that involves a stocktake of the current state, a literature review and consideration of actions across the continuum of care where primary health care can be better supported and optimised.
- We also commissioned the independent, not-for-profit health professional educational organisation Best Practice Advocacy Centre New Zealand (bpacnz) to develop evidence-based packages on the early detection and surveillance of lung cancer and melanoma. These information packages are designed specifically for general and nurse practitioners and supported by peer group discussion points and a quiz to help with ongoing medical education.
- We partnered with the Goodfellow Unit and Hei Āhuru Mōwai to present a webinar on lung cancer in November 2022. The purpose of the webinar was to raise awareness of lung cancer symptoms, improve early detection and referral processes to secondary health care for patients with a high suspicion of lung cancer, and increase awareness of new treatment paradigms.

# HIGH–QUALITY POPULATION SCREENING

There are three national cancer screening programmes in Aotearoa, which focus on bowel, breast, and cervical cancer respectively. These are managed by the National Screening Unit within Te Whatu Ora. There are several projects underway to improve these services.

- Screening Support Services are available to assist wāhine/whānau who experience barriers to accessing breast and cervical screening, assessment, and treatment services. Additional funding is in place for the support services that help priority women get to screening, including money to provide more free cervical screens for women in need.
- All people aged 60-74 years old now have access to free two-yearly bowel screening through the National Bowel Screening Programme. This means bowel cancer screening in now available for approximately 800,000 people throughout the country. Previously bowel screening was only available in some regions. Over the past five years since the programme began, it has posted out over 1.3 million test kits and detected cancer in more than 1700 New Zealanders. It has also removed potentially cancerous polyps (bowel growths) in hundreds more.
- Funding of $36 million was announced in Budget 22 to shift the eligible start age for bowel cancer screening for Māori and Pacific people, to address a health inequity. This is identified as a Government priority in Te Pae Tata. Waikato and Tairāwhiti have been selected as the first districts to lower the starting age from 60 to 50 years for Māori and Pacific people participating in bowel cancer screening. The two districts will test different approaches to service delivery, which will then inform the future implementation throughout the country.
- From July 2023, the primary test for cervical screening will change to a human papillomavirus (HPV) test. This change means that self-testing will become a choice for participants. The test can be taken at a health clinic either by the patient or a clinician, or it can be taken at home or in a community setting with clinical oversight. Te Whatu Ora will be looking at ways to make screening more accessible in future and has commissioned research to identify the most effective and acceptable service model for women which could include mailing out self-testing.
- BreastScreen Aotearoa and the National Cervical Screening programme are piloting co-design processes with service users and providers to create system and service level changes across the breast and cervical screening programmes. The overall aim of the project is to support equitable breast and cervical screening participation and health outcomes, especially for Māori and Pacific women.
- Work is underway to replace the Information Communication Technology (ICT) supporting the breast and cervical screening programmes. This piece of work is critical for improving the

data collected about screening participants. For the first time, the proposed systems will also provide population health-based registers. This will enable identification of priority groups, ensuring effective use of resources that can be directed to areas with the greatest need and greatest inequity. This will also equip the programmes to better reach underserved groups, who may include disabled people, people who do not speak English, prison populations, the homeless and the LGBTQI+ community.

- As mentioned earlier (see page 13), Te Aho o Te Kahu co-funded a $6.2 million research fund focused on cancer inequities. Lung cancer was a particular focus given the extent of the inequities that exist between Māori and non-Māori. One of the six projects to receive funding is focused on lung cancer screening and will assess the suitability of an international lung cancer screening model for use in the Aotearoa context.

# IMPROVED CANCER DIAGNOSIS AND TREATMENT OUTCOMES

There are several ways in which Te Aho o Te Kahu is working to improve cancer diagnosis and treatment outcomes. In addition to the work already underway as part of the Cancer Services Planning programme (see Snapshot on page 10 and page 28), other key projects are listed below.

- In 2022, Te Aho o Te Kahu completed some analysis to help us better understand the gaps in the availability of cancer medicines in Aotearoa. We released *He tātari i te wāteatanga o ngā rongoā mate pukupuku, Cancer Medicines Availability Analysis* which compares the availability of cancer medicines here (medicines publicly funded via Pharmac) with that of Australia – not only in terms of the number of medicines funded, but also in terms of clinical benefit. We identified 20 different medicine-indication pair gaps, across nine different solid-tumour cancer types, where the medicines were publicly funded in Australia and not in Aotearoa. In each of these 20 medicine-indication pairs, the analysis indicated that the medicine would offer substantial clinical benefit. The aim of this work was to provide useful insights to Pharmac, the Government, health sector and public. This analysis was conducted separately to the independent review of Pharmac announced by the Government in March 2021, but the preliminary results were shared with the Pharmac Review Panel.
- Te Aho o Te Kahu is working with Te Whatu Ora to model and plan for an increase in the number of linear accelerators (the machines that deliver radiation therapy) available across the country. These additions will mean that people with cancer who require radiation therapy will be able to access their treatment closer to home. Following the announcement in 2019, work continues on the development of the radiation oncology satellite sites in the Northern and Central regions.
- The ACT-NOW project which is part of Canshare (see page 12) aims to establish a national systemic therapy (chemotherapy) data collection and analytics programme. This will enable the equitable prescription and delivery of systemic therapy. ACT-NOW will measure and monitor which patients have access to systemic therapy, the timing of treatments particularly in relation to diagnosis, the location of treatment (ie, how far people are having to travel to receive systemic therapy) and the types of medicines being accessed.
- Aotearoa is one of the first nations in the world to develop a comprehensive, high-quality collection of radiation therapy data. The Radiation Oncology Collection (ROC) collects data on treatment delivery which can be reported on at district, patient demographics and service provider levels. Results from ROC have highlighted areas of treatment variation, for example, it has prompted increased uptake of hypofractionation for curative prostate and breast cancer treatment and for palliation of bone metastases. Ultimately ROC will support ongoing and equitable access to radiation therapy across Aotearoa.

- The Cancer Services Planning programme is particularly focused on improved treatment outcomes (see Snapshot on pages 10 and 28). For example, the Optimal Cancer Care Pathways project includes a monitoring aspect to inform performance and outcomes. Monitoring care along the cancer pathway will provide transparency of inequities and unwarranted variation, provide a focus for action; and the impact of actions taken.

*Te Pae Tata* identifies several key actions that are required over 2023-24 to improve treatment experience and outcomes, including:

- Developing new, joined-up pathways to facilitate rapid diagnosis of suspected cancer, beginning in primary care to support equitable access to cancer diagnostic and treatment options
- Establish the agreed radiotherapy satellite sites for LINACs to improve people's access to treatment in their community and ensure equity of access to radiotherapy
- Implementing national pathways to access transport and accommodation to support the equitable completion of cancer treatment
- Working with Pharmac to support the equitable implementation of new cancer drugs approved for use in Aotearoa.

## Snapshot: Quality Performance Indicator programme

Te Aho o Te Kahu has established a large programme of work on quality performance indicators (QPIs). The programme aims to provide information so that the quality of cancer services improves, and better outcomes are delivered for people diagnosed with cancer across Aotearoa.

The programme develops, calculates, and reports on QPIs using national data collections. Regional comparisons are possible for each indicator within each cancer type, which enables comparison between cancer care providers. The intention is to highlight variation in treatment and outcomes and to identify where further investigation might be needed to support quality improvement actions.

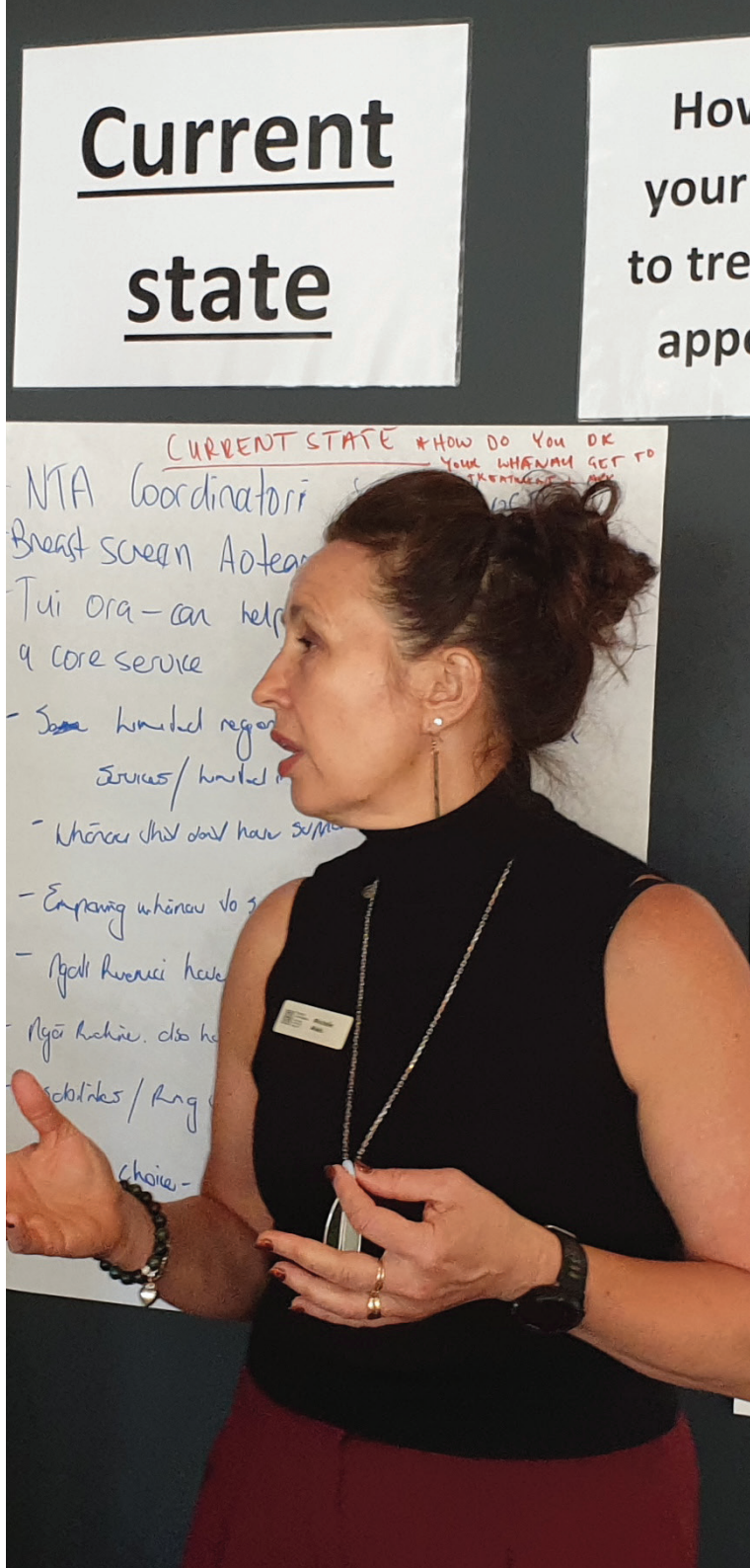
The programme will in time provide information on the full cancer pathway from referral through to diagnostics, treatment, survivorship, and palliation. However, due to data limitations in national collections, the current QPIs are focused on treatment.

The programme has developed and reported on cancer specific quality improvement indicators for bowel, lung, and prostate cancers. Breast and pancreatic cancer QPIs are currently in development. Every three years the indicator results will be updated with more recent data to show what changes have occurred. This work is completed in partnership with expert working groups including people with lived experience.

# SUPPORT AND INFORMATION FOR PEOPLE LIVING WITH CANCER

Supportive care is a critical part of the cancer continuum. There are a number of projects underway to improve this part of the cancer and health system.

- The Cancer Care Coordination project (see Snapshot on page 19) is specifically designed to support patients and whānau through their cancer treatment. It will initially focus on supporting Māori and Pacific whānau due to the significant cancer inequities that exist for these two population groups.
- Te Aho o Te Kahu has been working to better understand the impacts of the National Travel Assistance (NTA) programme on cancer patients and service providers. We have provided advice to Te Whatu Ora on how equitable improvements to the scheme could be made.
- As part of the Workforce Taskforce (see page 11), Te Whatu Ora is working to increase the number of kaiāwhina available throughout the health system who support patients and whānau undergoing treatment.
- Te Aho o Te Kahu has joined the New Zealand Telehealth Leadership Group and is working on several telehealth related projects (see page 13) to create options for care closer to home.
- Te Pae Tata also identifies a number of priorities to improve support and information for patients and whānau. This includes:
  - The localities planning approach and the creation of primary and community care teams
  - The development of integrated health pathways that are easy for patients and whānau to understand
  - Better coordination and easier navigation of services, particularly where people need to access multiple specialties and/or care is provided across multiple locations.

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# 3 He kupu whakakapi
# Closing remarks

This report stems from the aspirations of Te Aho o Te Kahu to understand the lived experiences of whānau with cancer and build meaningful relationships with Māori working in the wider cancer sector across Aotearoa. This hui series allowed the newly-formed Agency to connect with over 2,500 Māori cancer stakeholders. Collectively, their voices have further illuminated the challenges and obstacles Māori face when engaging in cancer care services, and their aspirations for change.

Although it was painful at times for whānau, they willingly shared their thoughts, insights, experiences, and aspirations. These taonga are meaningful insights that will help us to effect change and address Māori cancer inequities. The Māori staff at Te Aho o Te Kahu were extremely thankful for the opportunity to work together and engage meaningfully with our communities in this way. The hui series also provided a unique opportunity for non-Maori staff in Te Aho o Te Kahu to learn directly from whānau about their issues and challenges. These learnings will better inform their work today and into the future.

This mahi was not without limitations. While this report represents the voices of many Māori cancer patients and whānau, it cannot represent all. A limited budget restricted the number of hui that could be held, while COVID-19 limited the ability of some whānau to attend and participate. Community and health service providers juggled their support of this kaupapa against the wider backdrop of COVID-19 and announcements of significant system change. For some providers, their commitment to support the hui series was impacted by the rollout of COVID-19 vaccination strategies in their efforts to keep whānau Māori safe and healthy.

While this report highlights many areas for change among cancer services, ultimately a systems-wide commitment from those in key decision-making positions is critical to enacting and effecting the necessary change required to reduce Māori cancer inequities. In that respect, the voices of whānau have already had a significant impact on the mahi of Te Aho o Te Kahu, with their insights driving changes across many key areas of work. There are also a number of areas where the insights of whānau as shared in this report directly align with the vision and priorities areas outlined in Te Pae Tata.

The wero we have set ourselves is to continue engaging purposefully with whānau who have lived experiences of cancer, so that our work continues to reflect whānau needs and aspirations. We must also nurture our relationships with Māori and community stakeholders throughout the country. These relationships are critical, particularly as we move into a new health era where reducing Māori cancer inequity and increasing Māori engagement are now at the forefront of cancer service delivery.

Once again we thank the many whānau who supported this kaupapa. We will carry your voices with us as we share this report with organisations across the health sector and look to drive change that creates fewer cancers, better survival and equitable cancer outcomes for all.

Note: Te Aho o Te Kahu has published three documents on the hui series:

1. *Rongohia Te Reo, Whatua He Oranga,* which shares the experiences, insights, and aspirations of our whānau who attended the hui series.
2. *Te Tikanga:* summarises our kaupapa Māori approach to the hui series.
3. *He Urupare:* (this report), which outlines some of the work Te Aho o Te Kahu and other health agencies are doing that responds to, or aligns with, whānau insights.

These are all available in both English and te reo on our website, **teaho.govt.nz.**

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