# RONGOHIA TE REO, WHATUA HE ORANGA

The voices 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* (this report)
2. *Te Tikanga* summarises our kaupapa Māori approach to the hui series
3. *He Urupare* 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.

# He kupu whakataki
# Foreword

## TE AHO O TE KAHU

Te Aho o Te Kahu, the Cancer Control Agency was created in 2019 in recognition of the impact cancer has on the lives of people in Aotearoa New Zealand. As an equity-led organisation we knew from the outset the voice of whānau Māori must inform our efforts to achieve our vision of fewer cancers, better survival, and equity for all.

While a large amount of hard work has already been done to improve Māori cancer outcomes, inequities still exist. Some of the issues whānau experience can be solved in the short term, however many are complex and will take a sustained effort over a long period of time to resolve.

We recognised that we must work collaboratively with Māori cancer stakeholders to find solutions to meet the needs of Māori, so we set about organising a series of 15 hui in partnership with Māori cancer service providers, communities, and stakeholders around the motu. Each was co-designed with local partners so that local priorities could be explored, and local solutions championed. I want to acknowledge each of our partners who so worked hard to make these hui happen, bringing whānau into a safe space and encouraging kōrero on cancer. We would not have this taonga without you - nga mihi nui ki a koutou.

To the whānau who shared their kōrero at a hui, thank you. Your experiences and aspirations are captured in this report and will be used to inform our work and the cancer advice we provide across the new health system. We recognise the challenges experienced by those who have received a cancer diagnosis, are undergoing treatment, are supporting whānau with cancer, or have survived cancer and continue to deal with the impact of cancer everyday – we are humbled by your courage.

This report is dedicated to those living with cancer and those who are now among the stars — our whānau who have died from cancer.

**He aha te mea nui o te ao? He tāngata, he tāngata, he tāngata.** What is the most important thing in this world? It is people, it is people, it is people.

**Fletcher Beazley**
(Ngāti Mahuta, Ngāti Rehua, Ngāti Maraeariki)
Pou Whakahaere Mana Tangata - Manager
Person-Whānau Centred Care
Te Aho o Te Kahu

# HEI ĀHURU MŌWAI

Rahirahi tonu mai, nō te whānau te āhurutanga.

Hei Āhuru Mōwai was established in 2012 and is a network of Māori cancer leaders including mōrehu matepukupuku, clinicians and experts in mātauranga, research, and health service delivery.

Hei Āhuru Mōwai is a registered charity that works to influence national policy. We have four objectives; Māngai - to provide an expert Māori voice in cancer control, Rangahau – to conduct research and to influence researchers to deliver better cancer outcomes for whānau, Mātauranga - to provide and build Māori cancer expertise, and Āhuru - to provide a safe space for Māori cancer specialists to connect, collaborate and create.

Our vision is ‘Ko te matepukupuku ki te pō, ko te whānau Māori ki te whei ao, ki te ao mārama’. Our mission is to embed rangatiratanga into cancer control, ensure that cancer inequities between Māori and non-Māori are eliminated and that better cancer prevention and outcomes are achieved for whānau Māori.

It is both mamae and heartening to read the kupu in this report, and we humbly acknowledge all the morehū and whānau who gave their time, aroha and whakaaro to help its formation. Kāore i ārikarika ngā mihi.

Hei Āhuru Mōwai fully support and endorse the whānau centered insights of;

1. Rangatiratanga in cancer control - nationally, regionally and at whānau level
2. Mātauranga Māori and rongoā as a norm in cancer prevention and care
3. Māori designed prevention, diagnosis, treatment and care pathways
4. A thriving Māori cancer workforce and a racist free Pākehā workforce

Nā te whānau Māori te kī - the whānau Māori voice is the authoritative voice for cancer control in Aotearoa. We look forward to Te Aho o Te Kahu and the health system - in its entirety - responding to and implementing these insights with speed.

Āhuru ki a Rangi, āhuru ki a Papa, āhuru ki te ūkaipō

**Moahuia Goza**
(Ngāti Kauwhata, Ngāti Matakore, Ngāti Raukawa, Ngāti Unu)
CEO/Tumuaki

**Dr Nina Scott**
(Ngāpuhi, Ngāti Whātua and Waikato)
Co-chair

**Gary Thompson**
(Ngāti Pāoa, Ngāti Hauā)
Co-chair

# HE ARA TANGATA

He Ara Tangata is the consumer reference group for Te Aho o Te Kahu, the Cancer Control Agency. We provide lived experience expertise to inform the Agency's work programme. As individuals we span the motu, with a range of experiences of diagnosis, treatment, and living with cancer - both for ourselves and our whānau. It is a requirement that 50% of our members are Māori, and currently we have a Māori chair.

Many members of He Ara Tangata attended the hui series in 2021 and our insights form part of this report, *Rongohia Te Reo, Whatua He Oranga*. He Ara Tangata plays a critical role in Te Aho o Te Kahu and I am proud to provide a foreword on behalf of our rōpū.

The purpose of this report is to hear the voice of whānau Māori and provide whānau-generated solutions to the issues we are facing. This report will be a tool to assist Te Aho o Te Kahu as they focus on the needs of whānau across all areas of cancer care.

Within this report are the stories of many who have courageously faced cancer. What is sad - and should trouble us all - is that for many it was not the disease which was the most traumatic element - but their experience of the health system.

Too often Māori have felt lost, misunderstood, or worse, mistreated when navigating the cancer system. On behalf of He Ara Tangata members, I am grateful for those who have gifted their time and lived experience to this report. Your insight and wisdom is invaluable.

Our hope is that the report will be a rich resource for those within the wider health system. Improvements are unlikely to be lasting until everyone in the health sector fully appreciates what it feels like for Māori as they navigate clinical appointments, talk with specialists, and undergo treatment.

I want to acknowledge Te Aho o Te Kahu and all the local Māori partners for designing the hui in a way that allowed whānau across the motu to share their experiences. The hui provided a space where people felt safe to share their kōrero and that is reflected in this report.

I finally want to thank those who wrote the report, condensing hours of powerful kōrero into these pages. It is the desire of He Ara Tangata that this report is a guiding light for all in the health system as it continues to undergo significant change.

**Vivian Hahipene**
(Ngāi Tai, Ngāi Te Hapū, Ngāti Awa, Te Aitanga a Māhaki, Te Patuwai, Tūhourangi)
Chair
He Ara Tangata

# Ngā ihirangi
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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 many of the other Māori organisations and individuals involved in cancer care.

The hui took place from February to July 2021 and were 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. Data analysis and sense checking with Māori working in the wider cancer sector followed. Three reports were then collaboratively drafted by Māori staff from Te Aho o Te Kahu and then peer reviewed by selected members of Hei Āhuru Mōwai and He Ara Tangata.

*Rongohia Te Reo, Whatua He Oranga* shares the experiences, insights, and aspirations of thousands of whānau Māori affected by cancer. It is a powerful collection of voices that paints a clear picture of what is not working for Māori in our cancer care system. It also highlights examples of excellence, key factors that drive positive engagement with whānau Māori, and opportunities for change.

The report begins by outlining some key information about cancer in Aotearoa, particularly in relation to tangata whenua and the cancer inequities they face. Our planning processes for the hui series are briefly outlined before whānau insights and stories are highlighted.

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 map these whānau insights in a way that could drive our current and future work. We have deliberately chosen to present the whānau voice using the framework of the *New Zealand Cancer Action Plan 2019-2029.* This framework sets out the four main outcomes that will drive action over the next 10 years to ensure better and more equitable cancer outcomes. These 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.

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 and 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.

*Rongohia Te Reo, Whatua He Oranga* has been 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 other health organisations to ensure the voices of whānau are embedded in our work to create fewer cancers, better survival, and equity for all.

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

1. *Rongohia Te Reo, Whatua He Oranga* (this report)
2. *Te Tikanga* summarises our kaupapa Māori approach to the hui series
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These are all available in both English and te reo on our website, **teaho.govt.nz**.

# 1

# Te mate pukupuku i Aotearoa

# Cancer in Aotearoa

As in many other countries, cancer casts a long shadow over Aotearoa. Each year, approximately 25,000 people are diagnosed with cancer and around 9,000 people die from it (Te Aho o Te Kahu, 2021). Patients and their whānau have for many years attempted to navigate the complexities of cancer care. However the system design has often meant that many whānau cannot exercise their autonomy and manage their cancer treatment and care in ways that work for them. As a result, whānau often describe their cancer journeys as distressing and overwhelming, with many struggling to successfully engage with the complex medical system.

In 2021, the first comprehensive report on the state of cancer for the people of Aotearoa was published. It showed that while our national cancer survival rates are improving, we are still falling behind many other OECD nations. It also highlighted significant cancer inequities faced by many population groups, particularly Māori (Te Aho o Te Kahu, 2021).

Cancer inequities exist for Māori across all key indicators. In terms of incidence, Māori are more likely than non-Māori to be diagnosed with a range of cancers including breast, liver, lung, pancreatic, stomach and uterine cancers (Te Aho o Te Kahu, 2021). Substantial gaps remain in cancer survival rates between Māori and non-Māori (J. K. Gurney et al., 2020; Robson et al., 2010; Te Aho o Te Kahu, 2021). Mortality rates are higher for Māori for most common cancers, with the highest disparities in cancer mortality seen in breast, liver, lung, pancreatic and stomach cancers. Overall Māori are twice as likely as non-Māori to die from their cancer (Te Aho o Te Kahu, 2021).

When looking at cancer rates, three key indicators are typically used to measure progress:

**Incidence:** how many people get cancer
*Driven by changes in exposure to cancer risk factors, such as smoking*

**Survival:** how many people are alive after a certain period of time e.g. five years after diagnosis
*Driven by changes in the way we diagnose and treat cancer*

**Mortality:** how many people die from cancer
*Driven by changes in both incidence and survival*

There are a number of factors driving these inequities including access to healthcare, quality of cancer treatment and patient comorbidity. All of these factors have been associated with poorer cancer survival (Dew et al., 2015; J. Gurney et al., 2020; Hill et al., 2010; Seneviratne et al., 2015; Signal et al., 2015; Walker et al., 2008). System level factors including the availability, affordability and acceptability of quality treatments heavily impact Māori; as does inequitable access to early detection. In addition, research has highlighted how racism has been implicated as a major contributing factor to the persistence of Māori health inequities (Borell et al., 2009; Gracey & King, 2009; Harris et al., 2012; Harris et al., 2006; Johnstone & Kanitsaki, 2010; King et al., 2009; Pack et al., 2016; Palmer et al., 2019; Reid & Robson, 2000).

The determinants of optimal health are complex and extend beyond the health system. In Aotearoa there is uneven access to the determinants of health including: healthy homes and living conditions; employment, wealth and income; good education; access to justice; and strong cultural identity (Health Quality & Safety Commission (HQSC), 2019; Sarfati et al., 2020). Systemic racism and the inequitable distribution of resources has prevented Māori from accessing these determinants and these all play a contributing role to Māori health inequities.

*While many people often think of cancer services as focused solely on treatment, there is also a much wider range of critical activities that take place. The phrase 'cancer continuum' is used to describe all aspects of cancer services, from prevention, screening, and early detection, through to treatment, palliative care, survivorship, and end-of-life care.*

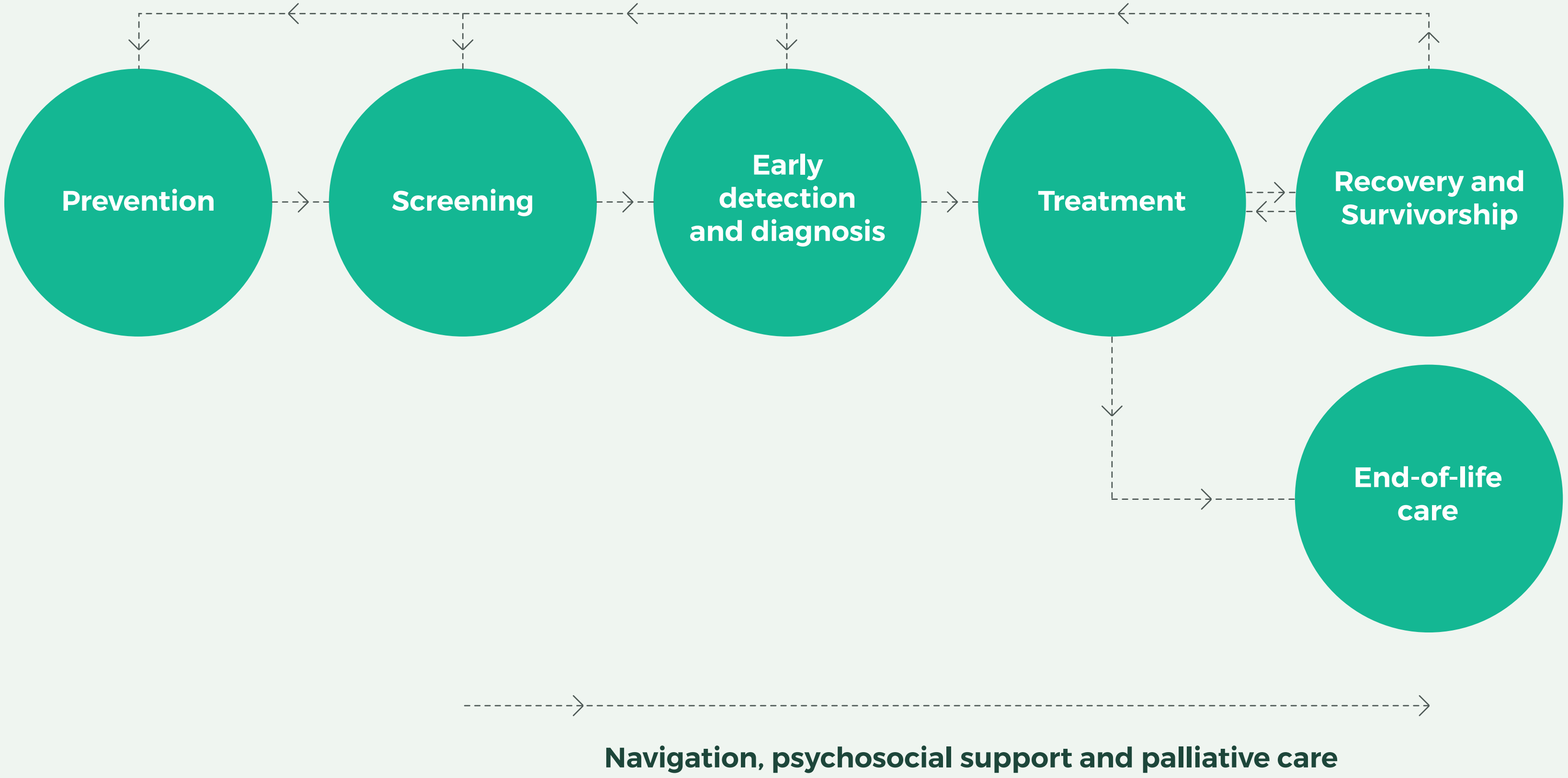


Figure 1: Cancer continuum

# TE TIRITI O WAITANGI

As a nation, Aotearoa has dual accountability to address the significant cancer-related inequities for Māori. Firstly, the Government recognises that inequities in health are avoidable, unfair, and unjust (Ministry of Health, 2019a). Secondly, and arguably more important, is our commitment and obligation to honour Te Tiriti o Waitangi.

Māori have a unique relationship with the Government – not only as tangata whenua, but as indigenous people with rights. The current cancer inequities between Māori and non-Māori is evidence of the failure of the health system to enable Māori to exercise authority over their health and wellbeing, and the failure to engage effectively with diverse Māori realities (Came et al., 2020; Ministry of Health, 2020). In response to the recent Health Kaupapa Inquiry (WAI 2575), the Waitangi Tribunal recommended the implementation of five Te Tiriti principles to drive the future delivery of health care in Aotearoa (New Zealand Waitangi Tribunal, 2019).

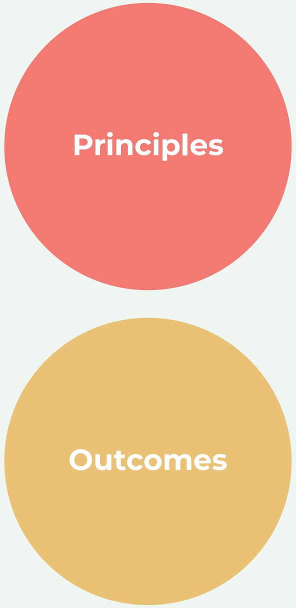
- **Tino rangatiratanga** – which provides for Māori to exercise self-determination in the design, planning, implementation, monitoring, and evaluation of health care for Māori.
- **Equity** – the commitment of the Government to ensure equity in health access and outcomes for Māori.
- **Active protection** – ensuring the Government and its agencies undertake all reasonable actions to achieve equity, as well as to inform Māori of the extent and nature of these efforts and subsequent impact on Māori health outcomes.
- **Options** – ensuring the Government provides support and resourcing of kaupapa Māori services and ensures all mainstream services are delivered in a culturally acceptable and safe manner.
- **Partnership** – ensuring Government agencies work in partnership for the governance, design, delivery, and monitoring of health services for Māori.

The recent health system reforms and the establishment of Te Aka Whai Ora (see page 17) are intended to respond to and address the aspirations of Māori, including the principles outlined above, within the health sector. This report identifies many opportunities for these principles to be applied across the cancer continuum.

# THE GOVERNMENT RESPONSE

## The creation of Te Aho o Te Kahu

In 2019 the *New Zealand Cancer Action Plan 2019-2029* was launched, proposing a range of improvement actions. It is driven by the following principles and outcomes:



**Principles**

- Equity-led
- Whānau-centred
- Knowledge-driven
- Outcomes-focused

**Outcomes**

1. He pūnaha atawhai
   New Zealanders have a system that delivers consistent and modern cancer care
2. He taurite ngā huanga
   New Zealanders experience equitable cancer outcomes
3. Kia whakaiti iho te mate pukupuku
   New Zealanders have fewer cancers
4. He hiki ake i te oranga
   New Zealanders have better cancer survival, supportive care and end-of-life care

Figure 2: Principles and Outcomes of the New Zealand Cancer Action Plan 2019-2029

In 2019, Te Aho o Te Kahu was established as a new government agency to provide national cancer leadership across the health system and oversee the delivery of the *New Zealand Cancer Action Plan 2019-2029*.

The work of Te Aho o Te Kahu is driven by the four principles of the *New Zealand Cancer Action Plan 2019-2029*: equity-led, whānau-centred; knowledge-driven; and outcomes focused (Ministry of Health, 2019c). We work with policy makers and funders, as well as with clinical services, clinicians, researchers, and community leaders to identify potential solutions and opportunities to improve cancer outcomes. We work closely with Hei Āhuru Mōwai, Māori Cancer Leadership Aotearoa. Hei Āhuru Mōwai is a key agency partner and gifted us our name, which gives significance to the work we do. 'Te Aho o Te Kahu' means to be the binding thread of the cloak (see Figure 3). It symbolises the threads that weave across the cloak connecting and binding the many diverse strands to form a strong and enduring garment providing warmth and protection.

**The aho** (binding thread) weaves together the core values of Te Aho o Te Kahu:

- Equity-led
- Knowledge-driven
- Outcomes-focused
- Person and whānau-centred

**The whenu** (strands) represent different services and specialists who work with cancer patients and whānau at some point in their cancer journey, including:

- Clinical support: tumour treatment (e.g. surgery, chemotherapy, radiation oncology), allied health (e.g. physiotherapy, psychosocial, prehabilitation, rehabilitation), palliative care, pathology, radiology, diagnostics
- Non-clinical support: cultural and spiritual support, travel and accommodation, financial support, social support, care coordination and navigation

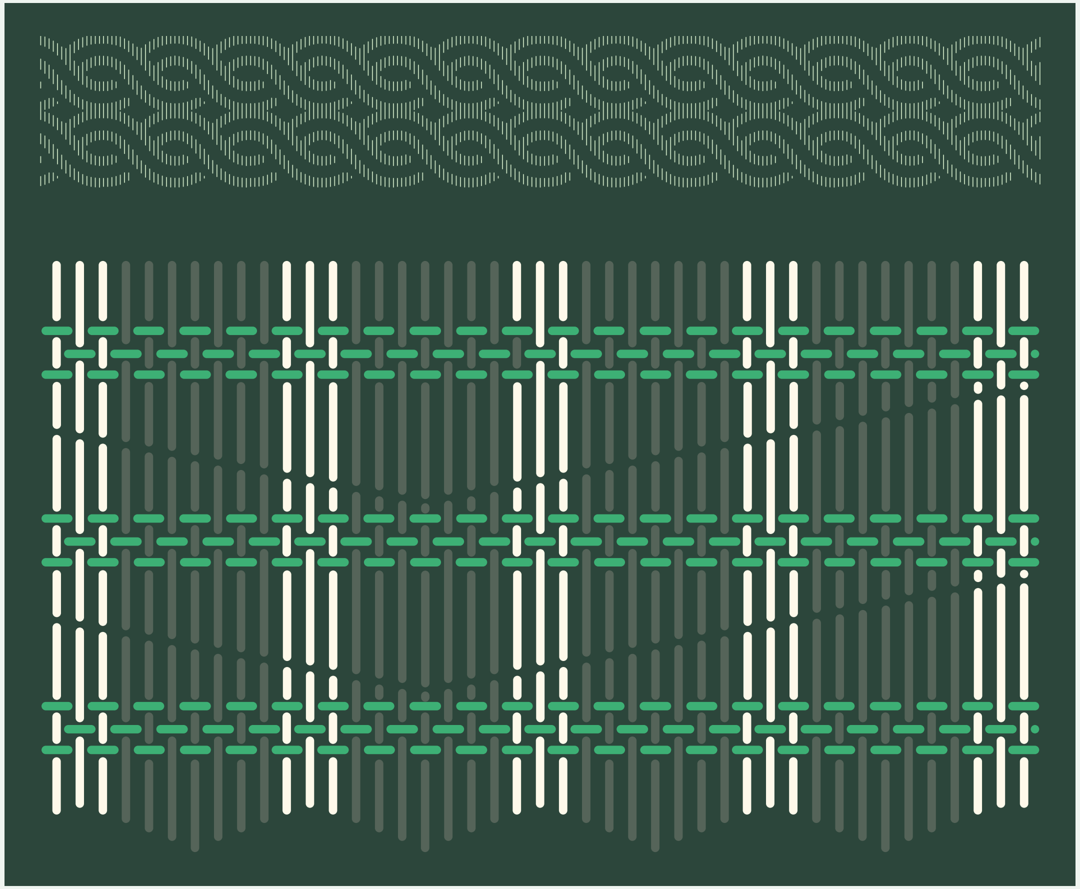


Figure 3: Concepts underpinning the naming of Te Aho o Te Kahu

# THE HEALTH SYSTEM REFORMS

The delivery of cancer treatment and care sits within the wider New Zealand health system which is undergoing significant change.

In 2018, the Government commissioned an independent review into the New Zealand health system, with the final report being published in 2020 (Health and Disability System Review, 2020). The Government's response to this report focused on transformation which aims to create a health system that is:

- people-centred: a system that brings together the voice of all communities
- equitable: a system that focuses on working in partnership with Māori and honouring Te Tiriti o Waitangi
- accessible: a system that offers more equitable, convenient, and integrated access to services for all New Zealanders
- cohesive: a national health system that delivers locally, supported by co-ordinated planning and oversight.

The reforms included the creation of two new health entities, Te Aka Whai Ora and Te Whatu Ora, and an updated role for Manatū Hauora.

**Manatū Hauora - Ministry of Health** remains the steward of the health system and the principal advisor to the Minister of Health. They monitor and report overall system performance, set national priorities and manage the overall budget for the health system.

**Te Whatu Ora - Health New Zealand** replaces the 20 District Health Boards. Te Whatu Ora is the operational lead for the health system and is responsible for planning and commissioning primary, community, and hospital services throughout the country. It also owns and operates hospitals on behalf of the Crown, and provides clinical leadership for the health system.

**Te Aka Whai Ora - Māori Health Authority** works alongside Te Whatu Ora and Manatū Hauora to develop strategic policy and establish priorities for Māori health. It leads the commissioning of kaupapa Māori services, and partners with Te Whatu Ora to co-commission other services accessed by Māori. Te Aka Whai Ora will also partner with Manatū Hauora on strategy and policy for Māori health outcomes and supports Iwi Māori Partnership Boards.

The role of **Te Aho o Te Kahu** is unchanged: we provide leadership and oversight of cancer control. This means that we monitor the performance of cancer services; provide advice on cancer control services and activities; and support clinical cancer leadership. We will work as a connector between all of these government entities in relation to cancer control, and will continue to be guided and informed by Māori cancer leaders including Hei Āhuru Mōwai.

As a result of these system reforms, there are new and ongoing opportunities to address Māori cancer outcomes and inequities. As a newly established organisation in 2021, Te Aho o Te Kahu saw whakawhanaungatanga and engagement with Māori across the motu as critical. Hui were seen as an ideal mechanism for regional and local engagement. This report summarises the thoughts, needs and aspirations of whānau Māori who attended the hui series, using the four principles of the *New Zealand Cancer Action Plan 2019-2029* as a framework.

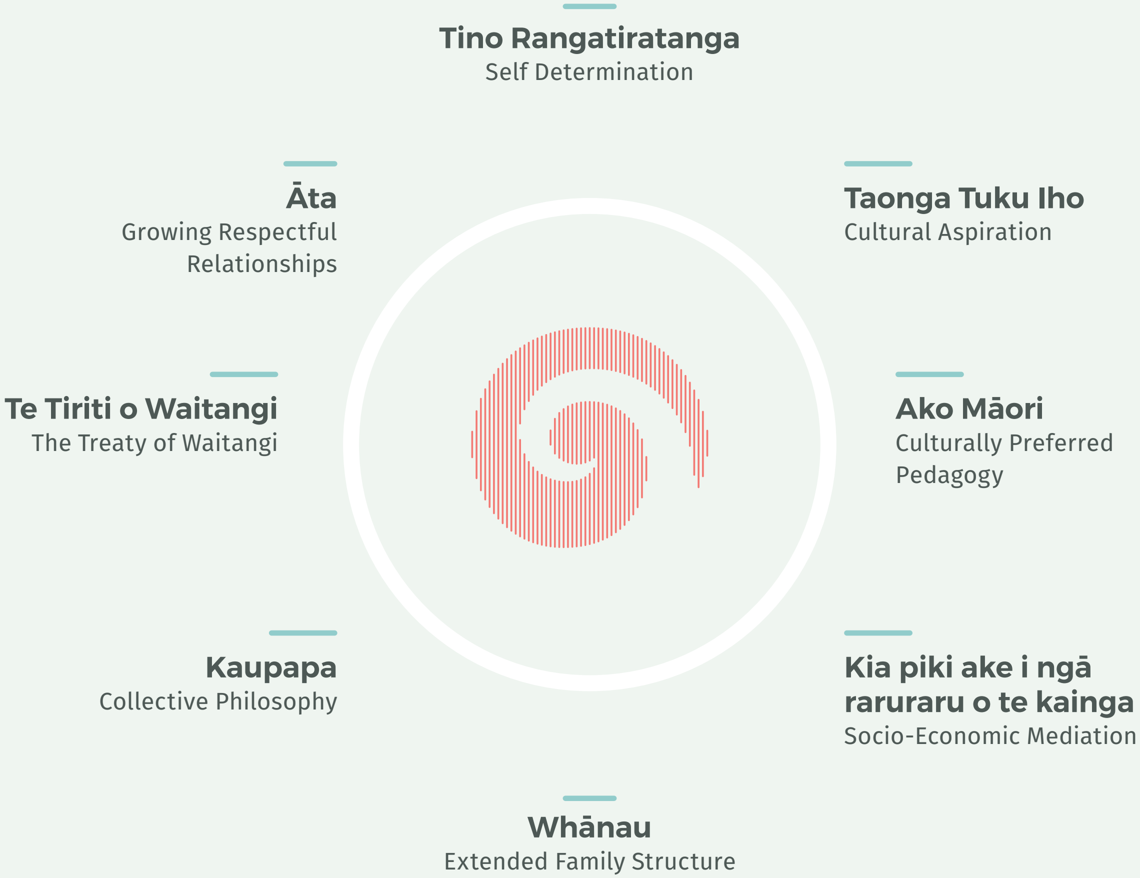
# 2

# Te rārangi hui mate pukupuku ā-motu 2021

# National cancer hui series 2021

The idea of a national hui series focused on the voices of whānau affected by cancer was envisioned in 2020, when Te Aho o Te Kahu was less than six months old. A deliberate choice was made to use a kaupapa Māori approach through all stages of the hui planning process. As an indigenous methodology, kaupapa Māori is premised on the foundations of mātauranga encompassing Māori knowledge, worldviews, perspectives and practices (Haitana et al., 2020). In this regard, kaupapa Māori not only privileges and normalises Māori knowledge (Pihama et al., 2002), but is also a ‘by Māori for Māori’ approach which can be applied in a range of settings (Tuhiwai Smith, 2021).

Te Aho o Te Kahu leant heavily on the processes and tikanga of a similar hui series undertaken by the Central Cancer Network in 2019, prior to the establishment of the national agency. That hui series was grounded in the principles of kaupapa Māori as seen in Figure 4, and produced a range of reports (Beazley, 2019; Beazley et al., 2020; Koia et al., 2020) including a kaupapa Māori evaluation (Beazley, 2020).



**Tino Rangatiratanga**
Self Determination

**Āta**
Growing Respectful Relationships

**Taonga Tuku Iho**
Cultural Aspiration

**Te Tiriti o Waitangi**
The Treaty of Waitangi

**Ako Māori**
Culturally Preferred Pedagogy

**Kaupapa**
Collective Philosophy

**Kia piki ake i ngā raruraru o te kainga**
Socio-Economic Mediation

**Whānau**
Extended Family Structure

Figure 4: Kaupapa Māori principles embedded in Central Cancer Network hui series

The aim of the 2021 national hui series was for Te Aho o Te Kahu to engage with whānau Māori across the motu, so that their voices could help shape the future direction of cancer care in Aotearoa. The hui series also provided an opportunity for the 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.

### Aim

Hear the voice of whānau Māori

### Purpose

Ensure that Māori voices shape the future direction of cancer care in Aotearoa

### Outcome

13 public hui, underpinned by more than a hundred planning and analysis engagements

Figure 5: Māori Cancer Community Hui series 2021

Through this hui series and despite the challenges posed by the COVID-19 pandemic, Te Aho o Te Kahu was able to connect with over 2,500 Māori patients and whānau through the hui series.

As noted in the Acknowledgements (page 1), we sincerely thank the many individuals who contributed to the hui series including:

- many whānau who attended and shared their stories and insights with us
- local organisations and mana whenua rōpū that hosted each hui
- large numbers of local and national health organisations that collaborated in the planning and delivery of the hui series (pages 26-27)
- 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 hui and hear directly from patients and whānau.

Figure 6: Hui locations

# PLANNING AND DELIVERY

Significant planning, collaboration and coordination took place to deliver the hui series. This was made possible through the efforts of many local organisations and mana whenua representatives across the country. The process we followed is summarised on (pages 24-25) and detailed in a separate report which is available on our website, teaho.govt.nz.

The hui series took place from February to July 2021. It would not have been possible without the support and partnership of many organisations. Two leading Māori organisations joined us for the full hui series: Hei Āhuru Mōwai and Hāpai Te Hauora.

**Hei Āhuru Mōwai Māori Cancer Leadership Aotearoa**

Established in 2012, their vision is for whānau to have control over their cancer journey and receive equitable, mana-enhancing and mauri-restoring services for all. The membership of Hei Āhuru Mōwai includes specialists in oncology, haematology, kaupapa Māori research, mātauranga Māori research, Māori health management, bio-medical cancer research, wairua healing, gastroenterology, health promotion and kaupapa Māori supportive care.

During the hui series, Hei Āhuru Mōwai worked with whānau to understand their aspirations for Māori cancer leadership.

**Hāpai Te Hauora**

Hāpai Te Hauora has been a leader in Māori public health for more than 20 years. Initially created to support Māori public health across the greater Auckland region, the organisation now also works across the motu in key areas of public health including tobacco control, gambling harm prevention, Sudden unexpected death in infancy (SUDI) prevention and workforce development.

Hāpai Te Hauora attended the hui series to discuss Māori public health leadership with cancer patients and whānau.

## High level discussions

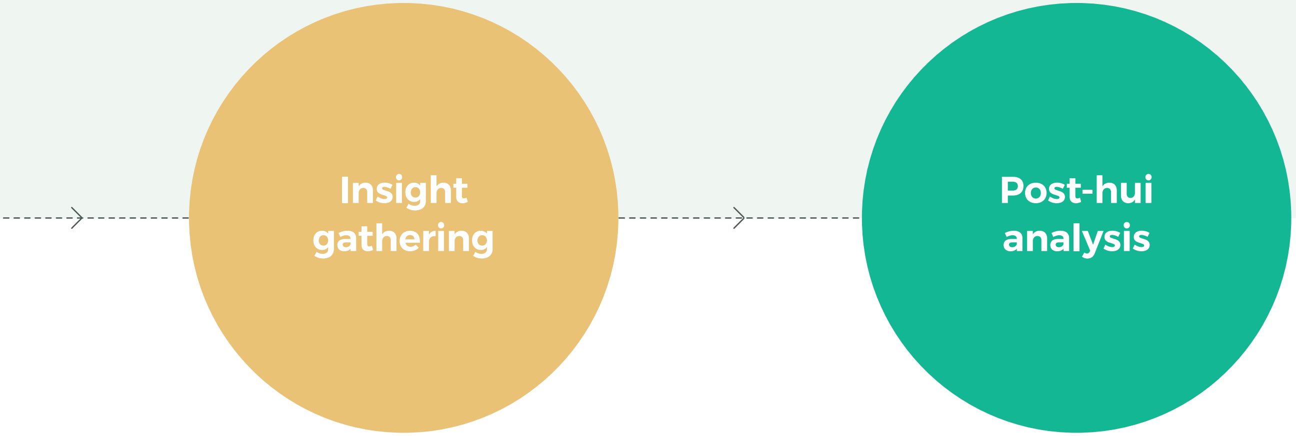
- Formal discussions about the proposed hui series took place with Hei Āhuru Mōwai and with Te Tumuwhakarae (the General Managers Māori from each of the then-District Health Boards) to determine the level of support for the kaupapa.
- After many discussions, it was decided that 15 Māori cancer community hui would be held across the motu (two had to be cancelled due to COVID-19 related issues).

## Reflecting the local rohe

- Local rōpū were established in each hui location to plan and manage the event. These rōpū included mana whenua, along with Māori working in the wider cancer and health sectors. Te Aho o Te Kahu provided rōpū with a budget to finance each hui.
- A template for the hui agenda was customised to suit each location. Invitations and signage used local imagery, including maunga, awa, moana, mahinga kai, kapa haka and whakatauki.

## Hui held

- Local community health providers and whānau Māori including weavers and other artists were invited to set up stalls in each venue.
- Each hui opened with pōwhiri or mihi whakatau, before participants heard from guest speakers and participated in a range of workshops.



- The workshops focused on gathering whānau insights on specific cancer topics: primary care, equity, Māori public health, Māori cancer leadership, early detection, mātauranga Māori and the whānau cancer journey.
- The majority of the workshops were facilitated by staff from Te Aho o Te Kahu, with Hapai Te Hauora and Hei Āhuru Mōwai also facilitating some workshops.

- All data from the workshop sessions were analysed by staff to identify strong themes. These themes were then categorised into relevant sections of the *New Zealand Cancer Action Plan 2019-2029*, before a review by the wider project team and a small group of Māori working in the wider cancer sector. The project team then collaborated to draft and review three reports, with all content peer reviewed by Hei Āhuru Mōwai and He Ara Tangata.

Figure 7: Hui process

**The planning and delivery of the hui series incorporated key principles and aspects of kaupapa Māori including:**

**whakawhanaungatanga**
**tikanga**
**kawa**
**hau kainga**
**manaakitanga**
**rangapū**
**mahi tahi**
**whakapapa**
**kōrero**

**Within each region, we worked with mana whenua and local health and support services to create each hui. We are grateful to the many organisations who joined us for this kaupapa, including:**

- Arai te Uru Whare Hauora
- Aratika Cancer Trust
- Arohanui Hospice
- Auckland District Health Board*
- Bay of Plenty District Health Board*
- Bowel Cancer NZ
- Breast Cancer Foundation NZ
- Breastscreen Aotearoa
- Cancer Concern
- Cancer Society
- Canteen
- Canterbury District Health Board*
- Child Cancer Foundation
- Cranford Hospice
- Dove Hospice
- Eastern Bay Primary Health Alliance
- Hawkes Bay District Health Board*
- He Waka Tapu
- Health Quality & Safety Commission
- Heart Foundation
- Horowhenua District Council
- Hospice Mid-Northland
- Hospice Tairāwhiti
- Hospice Taranaki
- Hospice Waikato
- Kahukura Rongoā
- Kenzie's Gift
- Korowai Aroha Health Centre
- Lakes District Health Board*
- Leukaemia & Blood Cancer New Zealand
- Look Good Feel Better
- Mahitahi Hauora
- Maketu Health & Social Services
- Manaaki Ora
- Māori Women's Welfare League
- Mercy Hospice
- MidCentral District Health Board*
- Ministry of Health
- Ministry of Social Development
- Muaūpoko Tribal Authority
- National Bowel Screening Programme
- Nationwide Health & Disability Advocacy Services

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*Now part of Te Whatu Ora - Health New Zealand

- Nelson Marlborough District Health Board*
- Ngā Kete Mātauranga Pounamu
- Ngā Rangatahi o Te Tauihu o te Waka o Māui
- Ngai Tuhoe
- Ngaruahine Iwi Health Services
- Ngāti Kahungunu
- Ngāti Porou ki Waitaha Taurahere
- Ngāi Te Rangi Iwi
- Ngati Ruanui Healthcare
- Northable
- North Haven Hospice
- Nurse Maude
- Ora Toa Health Services
- Ōraka Aparima
- Pani Balms
- Pinc & Steel
- Prostate Cancer Foundation NZ
- QE Health
- Rauawaawa Charitable Trust
- Raukawa Whānau Ora
- Rotorua Breast Cancer Trust
- Rotorua Community Hospice
- ScreenSouth
- #Smear Your Mea
- Southland District Health Board*
- St John
- Stroke Central New Zealand
- Stroke Foundation
- Sweet Louise
- Tahu FM
- Taranaki Disabilities Information Centre
- Taranaki District Health Board*
- Te Arawa Whānau Ora
- Te Awakairangi Health Network
- Te Hau Ora O Ngāpuhi
- Te Hauora o Ngāti Rārua
- Te Hiku Hauora
- Te Piki Oranga
- Te Pou Oranga O Whakatōhea
- Te Puna Ora O Mataatua
- Te Roopū Hauora O Te Arawa
- Te Rūnanga a Rangitāne o Wairau
- Te Rūnanga o te Ngāti Rārua
- Te Tohu O Te Ora O Ngati Awa
- Te Waipounamu Māori Cancer Leadership Group
- Te Waka Huia a Manawatu Trust
- Te Wānanga o Aotearoa
- Te Whare Maire o Tapuwae Whānau Ora Wairoa
- THINK Hauora
- Tu Tonu
- Tui Ora
- Turanga Health
- University of Otago
- Victoria University of Wellington
- Waikato District Health Board*
- Waipu Hauora
- Waitematā District Health Board*
- Well Women & Family
- Whaioranga Trust
- Whakawhiti Ora Pai


TAUIRA SUCCESS
SERVICES

# 3

# Te reo ā-waha o ngā whānau Māori

# The voices of whānau Māori

Te Aho o Te Kahu was humbled to see so many patients and whānau support the hui series. Many patients and whānau shared their stories and insights with us, with the aim of prompting system change so that future patients and whānau would have improved experiences and outcomes.

This report summarises those thoughts, aspirations, insights, and experiences. These taonga are presented using the structure of the *New Zealand Cancer Action Plan 2019-2029*, which has four outcomes (see page 15), each with accompanying key focus areas.

Two terms are used in this report to indicate where feedback came from:

### Whānau

This term refers to all who attended our hui series. This includes patients, relatives and carers with direct knowledge of those being affected by cancer. It also includes Māori leaders, health managers, researchers and clinicians working in the area of cancer.

### Māori working in the wider cancer sector

This term refers to the clinical and non-clinical staff working in health and/or cancer care. These stakeholders either attended our hui series, spoke to us as part of our planning phase and/or took part in the post-hui analysis. Many of these kaimahi also have lived experiences of cancer themselves, or within their whānau.

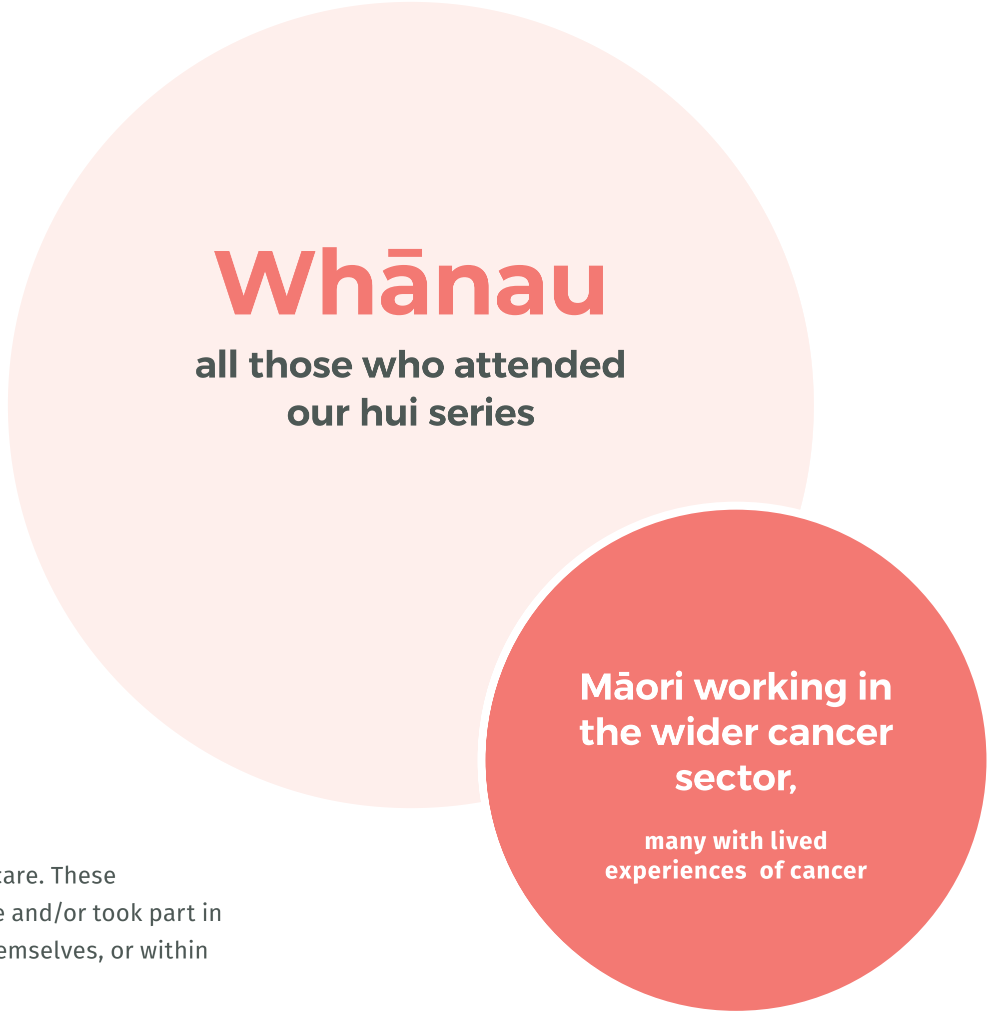

Figure 8: Terms for indicating where feedback came from

# 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 voice**

“We need to be at the table or else it is all in vain.”

“Don’t tell us about leadership, just get on and do it to support the kaumātua and whānau with their journey throughout the system.”

“Cancer leadership hasn’t been a priority – we don’t just focus on one disease.”

“The health system does not trust each other, but they need to trust us Māori to know what we need.”

## Whānau insight:
## Kāwanatanga - empower shared decision-making and co-design

Whānau regularly spoke about shared leadership and decision-making. Hui participants acknowledged that the system does have some mechanisms to engage with Māori (eg, Māori Health Teams in DHBs[1], Māori Advisors on governance groups etc), but many whānau felt that Māori were still not genuinely engaged in cancer decision-making processes. Some whānau felt that the current mechanisms within the system were tokenistic. These views were reinforced by some iwi leaders, who felt that there was inconsistency in the way they were engaged with.

Some whānau noted that when a loved one was undergoing treatment, the whānau were able to achieve good relationships and shared decision-making in their care. Others felt like they had no voice or were ignored, especially when they expressed views or aspirations that were not shared by clinicians and/or health managers.

Meaningful kaupapa Māori engagement was seen as the best way to improve relationships with iwi, and whānau identified that a key part of this is building mana-enhancing relationships with shared power. However, many Māori working in the wider cancer sector were frustrated that after expressing this aspiration for years through multiple health system engagements, there are still unnecessary inconsistencies in engagements with Māori.

The hui series was held as the Health & Disability System Review was taking place (see page 17). Some concerns were shared that system changes were happening at pace, but that Māori had not been '... informed about changes or what has been put in place'. The importance of 'Cancer Consumer Groups' as an '...avenue for whānau cancer issues to be heard' was also raised.

Both whānau and Māori working in the wider cancer sector expressed their aspirations that the proposed Māori Health Authority would be enabled to address many of their concerns about opportunities for Māori engagement and leadership. They noted the importance of the proposed Iwi Māori Partnership Boards and identified a desire to see these boards given the 'same value and authority as DHB Boards.' Some frustration was expressed about the need to move on from the rhetoric towards action and stronger accountability.

> *“We need Māori outcomes and measures... to make sure that changes happen... more than talking about having change BUT making it actually happen!”*

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[1] These hui were held when the DHB (District Health Board) system was still in place. While this has now been replaced by a single national system comprising multiple health districts, we have retained the term 'DHB' where it was used by whānau.

## Whānau insight:
## Kotahitanga - increase collaboration between cancer leaders and the community

Whānau felt that there was a lack of Māori cancer leadership including at local, regional, and national levels and across the whole of the cancer continuum. Reasons suggested for this varied: some whānau viewed the current leadership as ineffective, while others saw them as under-resourced or not connected into the communities they serve. Some whānau felt that Māori cancer leadership lacked visibility, possibly due to it operating in a health-specific 'silo'. Several whānau identified the value of a 'Whānau Ora' approach as a 'complete package'.

Many Māori working in the wider cancer sector noted they feel isolated and would value more opportunities to come together and connect, make decisions, and work collaboratively. The importance of Māori leadership working more collaboratively in contrast to the current competitive model was also raised.

*"We need to think about what influence we have together as iwi and not be in competition with each other."*

## Whānau insight:
## Tino Rangatiratanga - Māori cancer leadership is needed at every level

There was significant feedback that Māori whānau want to exercise their right to have control over their own health and wellbeing. This includes having an environment where Māori cancer leadership is valued and supported to thrive towards improving Māori cancer outcomes. A strong theme from the hui was for Māori leadership to be supported at local, regional, and national levels. This includes support for iwi leadership, Māori clinical and cultural leadership, consumer and whānau leadership, rangatahi and tamariki leadership, kaumātua and kuia leadership, as seen on the following page.

The hui series was largely completed prior to the Government's announcement of significant health reforms. As part of these reforms, Te Aka Whai Ora – Māori Health Authority has been created. It will lead and monitor transformational change in the way the entire health system understands and responds to the health and wellbeing needs of whānau Māori.

**Specifically, Te Aka Whai Ora will:**

- work with Te Whatu Ora to design and deliver services to improve Māori health
- work with Manatū Hauora and Te Puni Kōkiri to monitor outcomes for Māori
- support Iwi Māori Partnership Boards to strengthen the voice of whānau
- commission te ao Māori solutions and services developed by Māori for Māori
- improve service delivery and outcomes for Māori
- promote public health and commission public health programmes.

## Tino Rangatiratanga - What does Māori cancer leadership look like at every level?

### Leadership at a systems level

Many whānau and leaders expressed a concern that for too long they had been constrained by a Western, monocultural system that excluded them from participating at the decision-making table. Many were aware of the health system reforms and optimistic about the opportunity it created for building Māori leadership but did not want to lose important kaupapa and tikanga Māori values in the process.

“Tino rangatiratanga and kāwanatanga at different levels – different leadership at different levels in the regions and up to the top.”

“The health system does not trust each other but they need to trust us Māori to know what we need.“

### Leadership from whānau

During the hui we heard numerous stories and accounts from whānau who had received cancer treatment that felt their voices had been silenced, that clinicians and health providers were not interested in their thoughts and views about how they wished to receive their cancer care. Many of the hui participants expressed a desire for a system and services that was more empathetic and responsive to their needs, and where they were actively supported to be part of the decision-making about their care.

“Community support networks needed for whānau.”

“We need navigation to help whānau rather than slipping back into the same old thing.”

### Cultural & clinical leadership

It was acknowledged that there was a place and role for the combination of both cultural and clinical skills in delivering care to whānau. A number of hui participants noted that clinical skills needed to be backed by capability in te ao Māori, mātauranga Māori, and tikanga and vice versa, and that this was important for developing and realising Māori clinical leadership.

“Clinical perspective is only one part.”

“Workers must have Pākehā tohu, mātauranga Māori and experience - all these elements matter.”

## Leadership by providers

Concerns were raised during the hui that health care providers were not being held accountable for poorer care and cancer outcomes for whānau Māori, and there was a call both for greater incentives (or sanctions) and stronger accountability measures to drive system and service performance.

“We have leadership in our providers that care and advocate for our people.”

“The health system does not trust each other but they need to trust us Māori to know what we need.”

## Regional leadership

Māori communities and leaders want to be able to lead, design and deliver cancer actions for their own people. While there was acknowledgement of the good work our current leaders have achieved and continue to achieve, Māori want more support than is currently given.

“How do we be effective in our regions, communities, to ensure leadership at the coal face is there (working in isolated communities).”

“How can we build regional capacity to start to address issues at a local level with national support?”

“Strengthen relationships with mana whenua.”

## Leadership for the next generation

The intergenerational nature of whānau Māori meant that for many, a key focus of growing stronger Māori health and cancer leadership was about paving the way for the next generation of leaders, but also in ensuring that the next generation received better care and improved outcomes.

“Need to advocate so our moko get a better deal from the system.”

“Better healthcare for our people … I have … 36 mokopuna … what will it look like for them?”

“My leadership is teaching the young ones to treat patients as sacred.”

“Golden egg solutions are not sustainable – consequences for our actions on current generations but also generations for come.”

Figure 9: What does tino rangatiratanga look like at every level?

## Whānau insight:
## The Māori cancer workforce needs growth and support

**Whānau voice**

“Kei hea ngā takūta, ngā takūta rangatira Māori i te hohipera me te hāpori?”

“Rather than train overseas people why not train our own people… want more Māori nurses to help care for us.”

“Growing the scope of practice… sustainability and continuity plans to ensure we maintain existing workforce needs.”

Whānau and Māori working in the wider cancer sector all agreed that the number of Māori being trained and supported to take up specialist roles in cancer care needs to increase. This included both treatment and supportive care roles. It was often noted that most cancer services only had one or two Māori staff that whānau could access. In one case, whānau noted they had received awhi and advice on rongoā from a cleaner. Although whānau acknowledged there is work currently underway to grow and increase the Māori workforce, they identified multiple ways in which this could be improved.

There was a strong and consistent call for more training and support for the next generation of rangatahi Māori to pursue careers in cancer or health generally. A range of suggestions were offered to support rangatahi into health roles, including scholarships and funding, inviting Māori clinicians to talk to rangatahi at kura, supporting academic aspirations (particularly in maths and science), expos and work experience initiatives. There were also suggestions to support Māori already working in health roles to specialise in cancer. A view was expressed that older whānau were regularly overlooked for training and support to work in roles in Māori health.

While many agreed increasing the numbers of Māori staff is a good aspiration, whānau felt that efforts to make workplace environments attractive to Māori are limited. There was a sense that both the training and working environments were neither supportive nor safe for this development to occur, although this was starting to improve.

*“It’s a hostile environment going through medical school as a Māori – this is starting to change.”*

There was discussion from many hui attendees about the ‘above and beyond’ role that many kaimahi Māori bring to their role, and a recognition that they were often called upon to bring an additional level of care for Māori patients and their whānau. For Māori working in cancer care, there was a sense of ‘duty of care’, and they felt an obligation to follow up on behalf of the whānau who were not being appropriately supported. Some also noted the importance of being able to provide holistic care in their scope of practice and that this was in essence what culturally- and whānau-empowered care looked like.

It was also acknowledged that kaimahi Māori played an important role in helping Māori patients and whānau, particularly through connecting them to other whānau and support services, and in helping them to understand and navigate their cancer care pathway. Several whānau shared their stories of seeking out Māori or even Pacific nursing staff to look after them and assist with hygiene and personal care, as this was seen as being more comfortable and connected. However, many raised concerns that the lack of resources and low levels of Māori staff meant that providing holistic care to Māori whānau was unsustainable and that there was a risk of ‘burnout’ for Māori working in the hospital setting. There was a call for ‘more manaaki for existing staff’.

‘Support Māori working in DHBs, it’s exhausting... people need to be in these roles 24/7... the patient will know in the first five minutes if they can trust you... if they do, they will cling forever.

*“Support Māori working in DHBs, it’s exhausting... people need to be in these roles 24/7... the patient will know in the first five minutes if they can trust you... if they do, they will cling forever.”*

## Whānau insight:
## The cultural capability of the non-Māori cancer workforce needs to improve

**Whānau voice**

"Non-Māori workforce generally lacks cultural competency and safety..."

"Staff from overseas – don't understand Māori, ...limitations of one day workshops."

"...they thought we couldn't afford options for care because we were brown faces – so they just never offered."

There was a strong theme about the need for greater training and accountability for non-Māori clinicians and staff to ensure that they were able to provide culturally-capable and safe care to whānau Māori. There were numerous stories from whānau where they felt that they had been offered different or substandard care because of the ignorance or racist behaviour of their clinicians or health staff. Some whānau found ignorance to be a particular issue when working with staff who had immigrated from other countries.

Many whānau cited negative examples from their own experiences in receiving care or supporting someone through care. Many gave examples where the lack of cultural understanding and practice left them feeling unsafe. Some examples included a sense that racial prejudice was impacting on the range and types of care they were being offered. Many whānau felt there was a need for 're-educating Pākehā around the 'isms'... racism, capitalism, colonialism' and that this would require more than 'online tokenistic cultural competency courses.'

Many mentioned concerns that the cultural training currently being provided to non-Māori was inadequate and a 'tokenistic add on' to clinical training. Whānau shared that they want non-Māori clinicians to allow them to exercise their mana and enable them to access cultural care and support during their treatment. They were also seeking a higher level of capability in terms of the cultural support they were receiving and reassurances that this would be delivered in a way that was tika.

*"Are our workforce doing things that are tika, if not, what are the consequences?"*

## Whānau insight:
## Mātauranga Māori must be supported throughout the cancer workforce

**Whānau voice**

“Whānau need to have a choice of services including rongoā, mirimiri etc… and know how to access tohunga, particularly for whānau who may be disconnected from te ao Māori.”

“We don’t have karakia… we want to see more integration of wairua with rongoā, karakia…”

The call for improved mātauranga Māori capability was also supported by a desire for improved accountability. Whānau also want a shift of power to enable kaimahi Māori to exercise their mana in providing culturally-resonant care for their Māori patients and whānau. Māori staff consistently face obstacles to kaupapa Māori solutions and Māori worldviews being included in Pākehā service design and delivery. There was a sense from many hui attendees that the way treatment and care is delivered is driven by Western-based curricula which fail to accommodate taha Māori solutions or approaches. There was a call to ensure that models of care allowed whānau to access tikanga and mātauranga Māori support during their cancer treatment. Many whānau noted that Māori are now seeking a wider range of expertise including kaumātua and whānau support during their cancer care.

While current activities to improve the cultural awareness and competency of the non-Māori workforce were generally seen as an improvement, many whānau expressed their frustration that the emphasis appears focused on upskilling non-Māori staff rather than supporting existing Māori staff to upskill. It was emphasised that many Māori staff already have a lifetime of cultural training that improved the experience and care of Māori cancer patients. Many Māori working in the cancer sector felt that this cultural expertise is not being recognised or valued in recruitment and advancement processes. Some suggested that the focus should be on recruiting as many Māori as possible to work in cancer roles and then supporting them to develop their cultural, clinical or leadership expertise.

> *“We don’t just want brown faces - we want workers who know taha and te aō Māori.”*

## Whānau insight:
## Whānau want rangatiratanga over their cancer data

**Whānau voice**

“Our data should belong to us.”

“Reporting of Māori health statistics – we need to reframe the dialogue to ensure we are showing Māori in a positive light and showing where the system is failing.”

“Whānau as custodians of patient data – so the patient can focus on getting well.”

“Why is it so hard to get my patient records?”

Many hui participants asserted rangatiratanga over their cancer data and information and noted that a critical part of this is about having access to data and information in a way that meets their needs. Many Māori felt that data can be ‘dehumanising’ especially when it is not presented in a transparent and appropriate way, which can then leave whānau feeling ‘disconnected and disempowered’. There was also a sense from some that there was a need to reframe the discourse, saying that Māori cancer data was sometimes used as a tool for ‘victim blaming’.

Many whānau felt that, where appropriate, it was important for whānau members to be able to access cancer data and information. This is to ensure the patient going through the treatment understands what is happening, but also allows whānau to advocate for patients when they are not able to do so themselves. However, this raised conversations about the privacy considerations of such an approach. Many whānau, particularly kuia and kaumātua, also disclosed that they had waited until they had more information about their cancer treatment before they told their wider whānau. This was because they did not want to burden them with ‘bad news’ or cause whānau to worry about them.

During the hui, whānau shared frustrations at the lack of data integration, noting that information did not seem to move with people as they shifted between treatment providers. This meant that patients and whānau were often required to endlessly repeat information about their condition to new clinical or care teams, which many saw as ‘traumatising’. Some people shared experiences of keeping their own journal because they felt there was no other way to keep track of who they had seen or what treatment they had received, and because the data was not readily available to them otherwise.

> “Telling our story over and over is really draining, and traumatic for some people.”

## Whānau insight:
## Whānau information needs must be addressed

Many whānau shared their experiences of feeling shocked and distressed at their initial diagnosis. For most, this was not a good time to provide lots of information about their prognosis and cancer treatment plans.

There was agreement from many whānau that cancer information needs to be delivered in a staged way that uses simple and easy-to-understand information. Many whānau commented that the information they were given about their diagnosis, treatment and care was 'complicated, complex, and confusing' and not designed for patients and whānau.

> *"You can't think when you are first diagnosed."*

> *"The language is so hard to understand. I thought 'metastasised' was something that happened to cows."*

There was a sense from many that the cancer system worked best for only those who understood it. This was reinforced by some whānau who were working in other areas of health and supporting whānau through cancer treatment.

> *"I could advocate for [my parents] – but only because I knew the system."*

Whānau Māori want information delivered in different formats and in ways that are easily accessible and understandable. Whānau repeatedly raised the idea of online directories that let them know what resources and support are available for them during their cancer treatment and care. Many wanted more information that they could take away with them. Others suggested that follow-up phone calls or appointments would be beneficial, so they and their whānau could ask questions after having time to absorb the initial shock of the diagnosis.

> *"Sometimes we get too much info – tell me what I need to know at that point."*

Whānau provided a wide range of aspirations and potential solutions for how they could receive information about cancer, their care, and what support was available to them. These included presenting data and information in a range of formats such as infographics, phone apps, national campaigns with social media and online ads, and kanohi ki te kanohi discussions with health professionals and at marae-based hui. Whānau expressed a preference for initiatives to be designed and delivered in a kaupapa Māori way. There was also a call for information to be provided in a way that was appropriate to the demographic, for example, kuia and kaumātua vs younger Māori.

There were conflicting views over the use of hard-copy resources such as information booklets. Some kaimahi see these as outdated and an ineffective use of money. However many whānau and kaimahi still view hard-copy resources as a valuable and essential tool for the dissemination of information to Māori, especially when used in conjunction with kanohi ki te kanohi approaches. The critical aspect is the quality of the resource and cultural relevance of the information (eg, does the resource use Māori imagery, te reo, accessible language; is it concise and written at a patient level).

Whānau understand the need for support from many different places when they are receiving difficult or complicated information about their diagnosis and treatment. As well as having whānau support, many noted the importance of being able to access members of their treatment team or other health support people, including the ability to have a follow up session.

## Whānau want information that is…

### …accessible and understandable

"Package info in [an] understandable format."

"Identify clear support options & groups available."

"…information in the right way – eg, with graphics, use more images and pictures to help get information."

### …provided at the right time

"Currently there is info overload at diagnosis."

"Don't cram it down my throat."

"Staged info process – multiple times explain data and info."

### …in a supportive environment

"The value of having clinical teams – the wraparound members can talk through and explain data and info to patients."

"Recognise we are all different, there isn't just one way to do it."

Figure 10: Whānau information needs

## Whānau insight:
## Innovative, whānau-centred care is needed

Hui participants want to see more innovation that puts whānau at the centre of service design and delivery. This includes a greater acknowledgement of the existing innovations that are community led, designed, and delivered. Whānau are frustrated when grassroots initiatives show effectiveness and promise yet seem to go nowhere due to a lack of support from the system. Whānau are hopeful that the Māori Health Authority will be able to identify, support and better fund more grassroots initiatives that recognise the important role that whānau play in all aspects of cancer care.

Although kanohi ki te kanohi is still seen as the ideal way to engage with whānau Māori, many are open to and/or currently taking advantage of the benefits that telehealth can bring to the care of their loved ones. This is especially the case with the added pressure and dangers of COVID-19. Whānau noted that the benefits of telehealth include a reduced need to travel, and reduced costs associated with travel – petrol, accommodation, hospital parking etc. Many also liked that whānau who live remotely or who could not attend in person were still able to participate via telehealth. Some also appreciated the flexibility to be able to digitally access cancer data and information.

*“Gives whānau the ability to be in touch with doctors and specialists in other cities.”*

*“If we can get telehealth right, it will be great.”*

However, there were also several concerns expressed about telehealth. These include addressing digital poverty, whānau accessibility to devices, and ensuring reliable and affordable internet connections are available for both whānau and service providers. There was also some recognition that moving to a digital or telehealth environment may also pose a challenge or be confronting to some clinicians, because it is significantly different from in-person appointments. This was seen as a potential barrier to success.

*“The tech is almost the easy part... hard part is training doctors and nurses well for success to happen.”*

Another way to support innovation and system change is via research. While it wasn’t a topic that was discussed much at the hui series, there were some comments from whānau about the need for more holistic and whānau-centred research that ‘elevates lived experience as evidence’. Some whānau felt that the current research focus needed to change, saying that ‘research should seek out solutions rather than always trying to find problems’.

## Theona's kōrero: One patient's experience of cancer

'It was nineteen years ago my GP told me I was being referred to the hospital because it was likely I had cancer. It was a big journey, but we got through it.

There were some highs and some lows. Because I had to have a bone marrow transplant, my cancer journey forced me to find out more about my whakapapa, which was a real blessing. I now work with cancer patients, and it certainly helps having my own lived experience.

There are still a lot of improvements which are needed within the health system. We need to address the unconscious bias – and racism – which is rife. This has to start with our GPs. They are the gatekeepers to our health system and, when not on their game, can cause massive harm in not referring people upward when they need help. There are amazing people out there doing amazing things, but there are also massive roadblocks for Māori who want to be part of the health system. We need more Māori wāhine in leadership positions, I think that would make a huge difference.

The establishment of the Māori Health Authority is giving people a lot of hope. People feel like this might be the change we have been looking for. Māori certainly need to be allowed to do things in our way - I believe this would be better for all people. Alongside this we need to continue to emphasise things like screening and Smokefree. These initiatives could have a huge impact on our people.'

**Theona Ireton** (Te Atihaunui a Pāpārangi, Tuhoe, Ngāti Kahungungu, Ngāti Porou, Ngāti Rangi)

# 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 (see pages 38-41 for more discussion on 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 voice**

“The system offers you one thing, but you need something else.”

“The Western system is illness focused.”

“Why isn’t mātauranga Māori a recognised skill set?”

## Whānau insight:
## Integrate mātauranga Māori throughout the cancer journey

Many whānau who attended the hui series want to see mātauranga Māori integrated across all aspects of cancer care, from prevention through to survivorship, palliative and end-of-life care. This aligns with the findings of the Health & Disability System Review, which supports mātauranga Māori being embedded as an integral part of the health and disability system (Health and Disability System Review, 2020). Whānau often noted that current and future medical staff will also require additional training and support if mātauranga is to be successfully embedded.

*"Mātauranga Māori shouldn't be 'other'... needs to be integrated... not a bit on the side."*

Many whānau who experienced mātauranga Māori spoke of its benefits and how they see it as an important component of their cancer care. Others shared that they did not know how to access many aspects of mātauranga Māori and sometimes felt whakamā about this. Karakia was the most common example of mātauranga Māori that was offered to patients, with many wanting to see this as a standard component within the cancer and health system. Some whānau noted that as health professionals working in non-cancer roles, they knew services such as karakia were available within hospital settings; but they were not offered these services when they became patients.

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

There was also broad agreement among whānau that Māori must lead the work to better integrate mātauranga Māori throughout the health system, as 'mātauranga belongs to iwi, hapū and whānau'. There was a strong desire among whānau Māori to ensure mātauranga Māori is not further colonised within Western healthcare models. Many felt it essential that people understand mātauranga Māori is not about the health system nor is it defined by the health system. Instead, mātauranga Māori belongs to te ao Māori and the expressions, applications, and definitions of mātauranga Māori must come from te ao Māori.

*"The system should recognise, enable, empower and support [mātauranga] – but not lead."*

There was also feedback about how mātauranga Māori varies across the country and that this variation needs to be incorporated in system changes. Whānau want to see new plans and/or frameworks that recognise mātauranga commonalities between iwi and rōpū but are also flexible enough to allow for regional variations.

*"Some things are the same, but [we must] respect the different approaches for different iwi, different traditions and worldviews."*

## Thomas' kōrero: One patient's experience of cancer

'I first noticed symptoms in 2016. I had swollen lymph glands on my neck. I'd had cysts before, so initially I ignored the lump. When I started working for a new organisation, they offered a health care plan and life insurance. As part of that, I had biopsies taken which were inconclusive.

Further tests were done, and it was discovered I had cancer. When I was told I had cancer, I was by myself. Nobody had told me to bring a support person which was hard. When I underwent treatment, I had to go to Christchurch. We stayed in Daffodil House; accommodation run by the Cancer Society. The manager was a Māori woman. There was a lot of manaakitanga, there were kuia who would come in and help support those staying there. The whole atmosphere was really nice. Now I tell people, 'If you notice any changes in your body which you are concerned about, go and get checked'. The earlier people are diagnosed, the better chance we have of surviving. We definitely need more tikanga-based treatment and more brown faces in oncology. That doesn't necessarily mean more Māori oncologists, but we do need more support people who are Māori in those spaces. People who can help lead others through the process, attend treatment sessions and come to meetings.'

**Thomas Ngaruhe** (Waikato and Ngāti Maniapoto)

## Whānau insight:
## Rongoā is important to whānau

**Whānau voice**

“How do we keep it (rongoā) protected in a system that has continued to hurt us?”

“The kōrero around rongoā is post diagnosis, but rongoā is actually preventative, maintenance.”

“With rongoā, we need to get the message out… people don’t know what is out there.”

Rongoā was discussed extensively throughout the hui series. Many whānau felt that rongoā is misunderstood and undervalued by the health system. This has led to rongoā being excluded, underfunded, and underutilised within cancer care. Most whānau attending the hui saw rongoā as complementary to Western cancer care, rather than an alternative. They recognise the need for treatments such as medical, radiation and surgical oncology and want to also have access and support to rongoā before, during and after these treatments. Using rongoā as a prevention tool was also raised by whānau on several occasions.

*“The difference in his wellbeing after rongoā was huge. He was still dying, but he didn’t look sick anymore.”*

Some forms of rongoā are currently available through, and funded by, the health system, including mirimiri (massage), karakia (prayer), and whitiwhiti kōrero (cultural support) (Ministry of Health). The use of rongoā within the health system is supported by Te Kāhui Rongoā Trust, which was established in 2011 to protect, nurture and promote rongoā Māori. Some rongoā practitioners are funded via contracts with Te Whatu Ora and/or the Accident Compensation Corporation (ACC). Other rongoā practitioners operate privately, with iwi support or on a koha basis.

Currently, many whānau do not know how to access rongoā services and ‘some whānau feel whakamā to bring rongoā up’ with their doctors. Reasons for this included a perception that clinicians wouldn’t understand, were against rongoā or would belittle or dissuade them from using rongoā. This was mainly for rongoā rākau and mirimiri, whereas cultural support via kaumātua or whānau support via a Māori psychologist or social worker was seen as more acceptable to clinicians.

Some whānau could identify current hauora providers that integrate rongoā and primary care very well. Māori working in the cancer and health care sectors suggested more needs to be done to encourage and support non-Māori clinicians to offer or refer patients on for rongoā.

*“Support for Māori practice within hospitals… requires support for medical staff during training so they understand.”*

The governance and leadership of rongoā was identified by both whānau and rongoā practitioners as a key issue. Both want to ensure Māori can assert rangatiratanga over rongoā, regardless of whether the rongoā practices are funded by the health system or in other ways.

## Whānau insight:
## The current system isn't designed for Māori

**Whānau voice**

"There's so much uncertainty and no understanding or support from the people who ring you up."

"What is the next step? You get lost."

"They don't care about us [Māori patients]."

The need for changes to cancer services and systems were repeatedly, and sometimes heartbreakingly, displayed by whānau at the hui series. Whānau repeatedly told us about the difficulties they faced during their cancer journeys. Their stories and insights consistently showed how systems that are inadequate, culturally unsafe, and often racist can impact on patients and whānau. The complexity associated with cancer treatment meant that many 'got lost in the process'.

> *"Make the [cancer] journey a straight road. The odd curve or loop is ok, but right now there are too many detours and way too much roadworks."*

However, some whānau were able to identify positive cancer services and initiatives. This included kaupapa Māori smokefree initiatives, some hauora and primary healthcare providers and non-government organisations, along with individuals working in roles including cancer nurse specialists, cancer navigators and Whānau Ora navigators. Across the hui series, whānau repeatedly noted the following factors were often contributing to positive experiences and/or outcomes (see Figure 11).

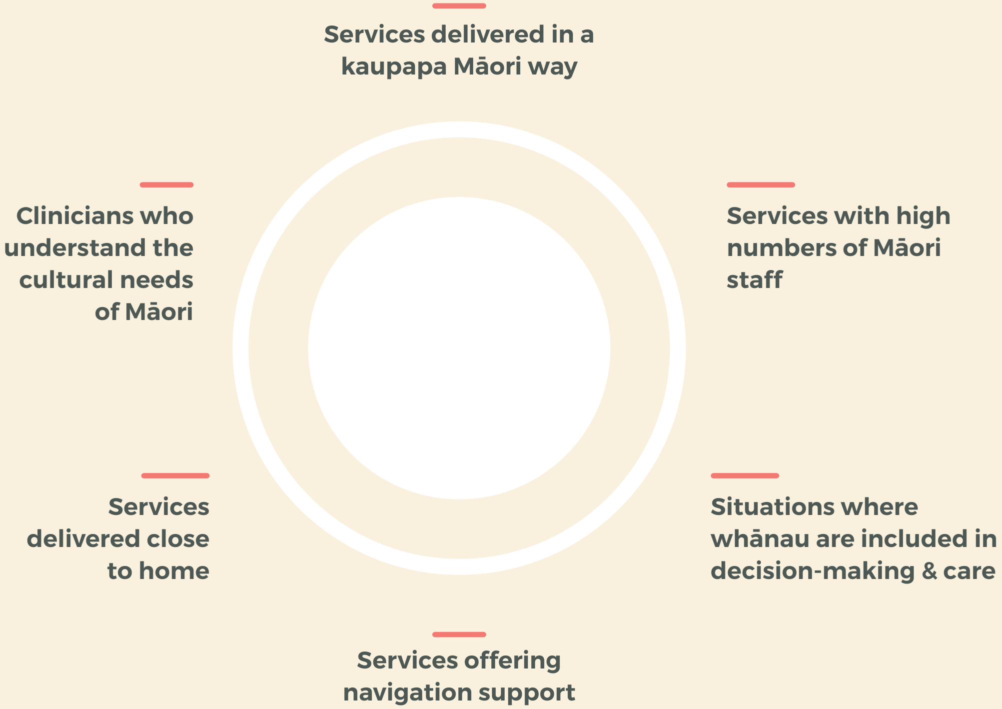


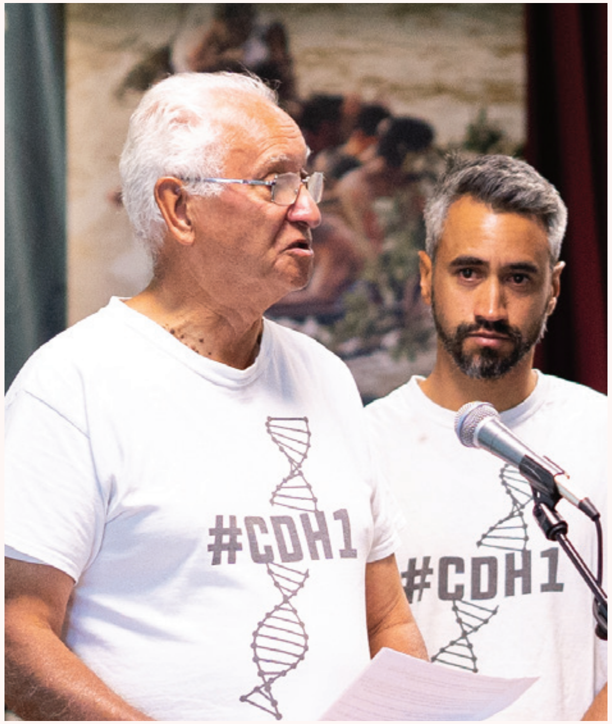
Figure 11: Factors contributing to positive outcomes

## Roydon’s kōrero: One whānau experience of cancer

‘Moana started our whānau cancer story. She was our eldest of eight children and was 31 when she passed away with stomach cancer in May 1999. Mary is our youngest daughter, who in 2015, had cancer preventative surgery by having her stomach and her breasts removed when she too was 31 years old. Colleen my beautiful wife began to have back pain. After many consultations, medications, and other conversations she was finally diagnosed with stomach cancer too. Sadly, the cancer was also in other parts of her body. We were told to get our affairs in order and that Colleen would likely have about six months – she passed three months later.

A meeting was convened with the oncology team. That meeting was horrible – they were terrible, cold, and unfeeling. It was a ‘you follow our way or the highway’ attitude with no empathy or humanity. This made me very angry and we felt disrespected. Colleen was admitted to Mary Potter Hospice for palliative care. They were wonderful and provided care so the whānau could spend time with their mum. Colleen was brought home to pass away in December 2014, surrounded by myself and all our children, she was 67 years old.

Our journey has not been easy, and it has shown us the health system needs to be improved for Māori. We need a place for whānau to seek help If they feel lost. We need to offer rongoā. We need to offer and recognise the value of spirituality and wairua in care for Māori. We need to empower people to talk about their symptoms. We need help and care pathways to be put into place during the journey of care, so whānau are more confident’.



**Royden and Wiremu Wineera** (Ngāti Toa)

## Whānau insight:
## Whānau regularly experience racism and discrimination

Whānau gave multiple examples of their experiences of racist behaviour. This included racist comments, microaggressions and behaviour by staff — from front desk administrators to senior clinicians. Whānau were more likely to bring up examples of interpersonal racism, but structural racism was also discussed.

**Whānau voice**

'I told him three times how to say my name properly – but he wouldn't listen and kept saying it wrong.'

'Receptionists can be the worst – they are awful sometimes. And they are the gatekeepers.'

'No-one talks about it, but we all know – the system is racist.'

'How are we addressing the known biases against Māori?'

Māori staff working in cancer care also shared their experiences of racism and discrimination.

> ***"Māori nurses have been 'told off' for speaking in te reo. Staff at work have cried because of this."***

While whānau understand that health professionals can undertake training on Te Tiriti o Waitangi, racism, and bias, many feel this is not resulting in significant behaviour change and that there is still a lot of denial. Many also spoke of a focus on individual or interpersonal racism but felt other types of racism were being ignored.

> ***"[Kaupapa Māori] programmes not being funded is systemic racism."***

Māori working in the wider cancer sector noted the potential of incoming policy changes such as Whāinga Amorangi and Ao Mai Te Rā, and the introduction of the Māori Health Authority (see pages 17 and 35).

## Karen's kōrero: One patient's experience of cancer

Navigating through the health system was harder than our ancestors navigating the Pacific. The journey began in 2018. Two years passed before they admitted they missed my diagnosis. I kept asking questions but kept being told there was nothing to worry about - that is despite getting sicker and sicker. I was losing weight and turning yellow before they admitted something was wrong.

When I began treatment, things only got worse. There are numerous stories we have of racist and appalling treatment. My family did not feel safe leaving me in the hospital, in many ways the actual stay was worse than the treatment.

Whānau is how we heal - but of course this was a roadblock. The system worked against us at every turn. Something as simple as having a whānau visit became a problem. One time my son flew down to see me. We were having dinner in the TV room and were told that he had to go, otherwise security would be called. It was shocking.

And then there were those who would almost mock us for the way we wanted to do things. They would leave me to have to look after myself and say, 'Is your whānau coming to make your bed?'

These experiences are not new. The disparity between Māori and non-Māori is huge - and as a result, generations of young people are growing up not knowing their grandparents.

I am grateful I had a voice and could speak up when things were not going right. But there are so many who would not know what to say or not want to cause any upset.

There is a lot the health professionals need to learn. Is there ever going to be any change for Māori? Because there is so much that needs to change.'

**Karen Morgan** (Kai Tahu, Kai Tarewa, Kati Irakehu)

*Te Aho o Te Kahu acknowledges Whaea Karen for her courage in gifting us this story before her passing in 2022. Moe mai ra, e te whaea. I roto i te rangimarie ki tua o te arai. Nei ra matau e mokemoke ana mōu.*

## Whānau insight:
## Many whānau need cancer navigation services

Navigation support for cancer patients and whānau was repeatedly raised as a potential solution to several issues within the cancer treatment system, including feeling lost and being unable to understand key information. High praise was given for treatment services, hospitals and health districts that have Māori cancer navigators to support whānau through the complex cancer system. Where navigators were in place, they were described as ‘the link, the constant’ for whānau.

Attendees at a hui in a small provincial region spoke of the significant impact a local cancer navigator had, saying ‘we need more people like Betty’. However, this feeling was not restricted to any one region, with the importance of cancer navigators being recognised by whānau right across the motu.

> *I’d like to see some sort of navigation services right from diagnosis to later on.*

Some kaupapa Māori health services pointed out that they already do this work, but it is not recognised or funded appropriately. In addition, some whānau also recognised that these services are not available to all, ‘so what you receive depends on where you live’.

While there is broad agreement about the need for navigation services, there are mixed views about the settings and models of delivery. Some whānau believe the roles should be hospital-based to ensure good coordination with treatment services. Others think this role should be community-based and focused on the entire cancer continuum. Some Māori working in the wider cancer sector are tired of the focus on disease-specific coordination roles and think that broader health navigators are a better use of resources. It was reiterated by many that this function already exists within Whānau Ora. Many called for more support for Whānau Ora navigators to improve their knowledge and understanding of the cancer system, so they can in turn support whānau. While there isn’t consensus on some of the more detailed factors, the majority agreed that improved cancer care navigation will result in significant Māori health gains.

## Whānau insight:
## Whānau deserve to be treated with empathy

**Whānau voice**

“To be treated as a person not a statistic… health professionals need to open their ears and not just to talk.”

“He just walked away after telling me I had cancer.”

“…diagnosed in a cubicle – 18 other people could hear it.”

Whānau shared many stories and experiences of the diagnosis and treatment process where they felt unsupported or where their clinical team lacked empathy. In some cases, they felt that they had not been able to maintain their dignity. Many whānau reported experiences where they were not listened to, or where their views were discounted. They expressed a desire for clinicians to take more care and consideration about what it was to receive a diagnosis of cancer, and better understand what it means for cancer patients and their whānau.

Whānau expressed a desire for health services that are ‘able to relate to whānau… it’s not just about medical or social qualifications’. Whānau often said they were told of their diagnosis by clinicians who either expressed very little empathy, left them alone immediately afterwards or did not wait for other whānau members to be present.

> *He told me I had cancer, and then he left me alone for about 15mins. I was in shock.*

## Whānau insight:
## Utilise the expertise of cancer survivors

**Whānau voice**

"Draw on the lived experience of patients. We've been there, we know what it's like."

"It can't be just bureaucrats who design the systems. You must co-design with patients and whānau."

"The answer is in working with survivors."

Many hui participants spoke of the unique expertise that lived experience brings, and how this needs to be better incorporated into system review and design. Both whānau and Māori working in the wider cancer sector want to see people with lived experience involved in the co-design of systems and services. These insights align with the thoughts on shared decision-making and co-design (see page 33). Whānau suggested a range of ways their lived experience and expertise could be better utilised. These included sharing their positive cancer stories as part of prevention programmes; and creating resources such as booklets and videos.

Whānau identified a range of issues which contribute to a lack of whānau-centred care. These include an inability to trust the health system, their needs not being met through biomedical- or disease-focused models, and information overload.

**Whānau often feel unable to trust the health system, with some feeling that the system and clinicians don't have their best needs at heart.** This is sometimes caused by many Māori feeling disrespected, sometimes unintentionally.

- 'I walk in the door and I'm not welcomed in my language, then you mispronounce my name. It just goes on and on… it all determines my level of trust.'
- 'He told me I had cancer, and then he left me alone for about 15mins. I was in shock.'
- 'Māori mistrust the services & the kumara vine works well.'
- 'Build trust first - sometimes it's about having a cup of tea with patients and whānau.'

**Whānau repeatedly spoke of the need for holistic care for patients and whānau, rather than disease-focused treatment just for patients.** They get frustrated and sometimes traumatised retelling their story every time they meet a new clinician and often find out about services they could have accessed but didn't know about.

- 'Health services need to be able to relate to whānau… it's not just about medical/social qualifications.'
- 'Shift the focus to the patient, not the illness.'
- 'Yes, the physical part was hard – but the mental and emotional part was far more traumatic.'
- 'The need for care doesn't stop when treatment finishes.'

**Information overload was a common concern.** This included confusing terminology during consults, a lack of time to digest information, a lack of support in this process and a lack of understanding over what care options were available and where to access those services.

- '[At diagnosis], we need time to think, to absorb the news.'
- 'What do the grades and stages mean? I've had cancer three times and nobody has explained that to me.'
- 'It took three months before they told us [about the support services that were available].'
- 'No one acknowledged this was new to us and explained things.'

**Many whānau feel that they don't see or hear enough positive cancer stories, reinforcing the strong association Māori have between cancer and death.** Hearing from survivors and understanding that good journeys and experiences are possible would go a long way to build trust with Māori communities.

- 'Cancer is associated with death.'
- 'When you hear cancer, you think 'mate' (death)'.
- 'Everyone thinks that if you go into hospital with cancer, you'll come out in a box.'
- 'We need to hear from survivors – we want to hear the good journeys.'
- 'For many, cancer is a comma, not a fullstop.'

Figure 12: Barriers to whānau-centred care

# 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 voice**

‘It’s better to prevent!’

‘What is going into our bodies… food and water… environment, smoking etc.’

‘How do we get everyone talking about healthy living?’

## Whānau insight:
## Whānau look at prevention holistically

A strong theme from the hui series was about the need for stronger focus on prevention as a mechanism to improve overall wellbeing for whānau Māori. The importance of taking a whānau-wide approach to topics such as healthy eating and exercise was raised by many Māori during the hui series. In particular, the importance of teaching the next generation of tamariki and mokopuna was seen as important.

While some felt that this work should be delivered through schools, others also suggested that it was important that this be based on mātauranga Māori knowledge. This included knowledge about how access kai from the moana and the ngahere, and how to grow your own kai. Restoring the role of healthy kai as a form of rongoā was also identified, as was the importance of staying active and keeping fit.

These themes were echoed by Māori working in the wider cancer sector. They noted that working with tamariki and rangatahi was an important focus of prevention and health promotion messages, and that these messages needed to be accessible and relevant for younger people.

Whānau shared several practical suggestions on ways to improve health promotion messaging. These could be grouped into three broad areas:

**How**

- 'Use images & pictures that help us to get info about where we can get help'
- 'Help us to take the messages & tell them in our language, using our words, in ways that work for us'
- 'Use words that people understand'

**Where**

- 'Use Tik Tok for information and to spread the word, Facebook, Twitter, whatever's next'
- 'Connect at kapa haka, marae and community events'

**Who**

- 'Speaking to people who have had experience – it gives real information and they can speak from lived experience'
- 'Use community leaders, church leaders, kaumātua, parents, teachers'
- 'Advertising – put real people on TV, telling their story to help others'

Figure 13. Suggestions for improving health promotion messaging

## Whānau insight:
## Increase kaupapa Māori prevention and health promotion

**Whānau voice**

"[What works?] - Whānau, iwi on the ground doing the mahi... giving people that are on the ground the resources to do this work."

"Use community leaders, church leaders, kaumātua, parents, teachers..."

"Knowledge exists in whānau, hapū, and iwi... traditional knowledge exists on the right ways to eat and stay well."

A common concern raised during both the hui series and the post-hui discussions with Māori working in the sector was that current national health promotion activities are largely ineffective for Māori. Many whānau thought there needs to be a greater level of collaboration across health promotion programmes, and that there was an opportunity to work more closely with Māori communities and providers.

Many hui participants expressed a desire to see Māori values and beliefs embedded in health promotion activities. Kaupapa Māori activities that are community driven and led by Māori were seen as being transformational for Māori. Examples raised by hui participants included: health promotion activities at Te Matatini; the 'Smear your Mea' campaign led by the kapa haka community; and the expansion of the Ngā Manu Kōrero competition so that rangatahi can explore wellbeing and prevention concepts.

Many whānau spoke of Māori leaders, role models and influencers who share their health knowledge and experiences. These were seen as an effective form of health promotion and could assist in increasing knowledge and supporting healthier lifestyles. Whānau also recognised the value of hearing stories from hapū, iwi, kaumātua, kuia and kaimahi Māori.

There was a call at some hui for health promotion campaigns and actions to be based on mātauranga Māori knowledge systems and beliefs, with a concern that Western science had ignored or pushed aside hauora Māori systems which have protected whānau for generations. Almost all agreed that cancer health promotion resources targeted at Māori need to include te reo Māori, have Māori imagery, be mana enhancing and strengths based. Importantly, these resources should be designed by Māori with lived experience along with kaimahi Māori working in the cancer sector.

Many whānau feel that mātauranga Māori is still applicable in a modern context. Many hui participants identified a desire to be able to access mātauranga Māori hauora systems. These systems would enable Māori to deliver their own kaupapa-driven prevention actions and options, as an integral part of health promotion. Examples offered included:

- understanding the maramataka (moon phases) to know when to plant and harvest
- returning to traditional practices around kai as a form of rongoā
- restoring the hauora knowledge of kuia and koroua
- using te reo Māori and Māori images and beliefs as a way of transmitting knowledge and information
- using 'role models to promote... whole of life wellbeing'.

## Whānau insight: More work is needed on smoking

During the hui, there was acknowledgment that some promotional campaigns had been '...done well in smokefree areas...' but many whānau felt that more work needs to be done. Preventing children's exposure to tobacco through smokefree cars and restricting access to tobacco products were raised as other actions that were important. This kōrero was echoed by Māori working in the wider cancer sector – where tobacco control was identified as the number one focus for cancer prevention for Māori.

Across a number of hui, there were discussions about tobacco-related cancers and how smokers diagnosed with cancer often felt an acute sense of shame or self-blame. While some identified an element of personal responsibility, the ability of health professionals to provide non-judgemental and empathetic cancer care and support for whānau was seen as being highly influential.

> *"Manaakitanga is important. I thought it was all my fault for being a smoker – the doctor said no, it wasn't."*

## Whānau insight: Preventing infectious illnesses is critical

During post-hui discussions with Māori working in the wider cancer sector, there was a specific focus on the prevention of infectious illnesses, particularly HPV (related to cervical, oropharyngeal and anal cancers), and hepatitis (related to liver cancers).

There was discussion about importance of HPV vaccinations among rangatahi as a significant prevention strategy, and the need to address vaccine hesitancy for both HPV and hepatitis. Key enablers to improving vaccination rates included:

- whānau and iwi leadership at a community level
- improvements in the quality and dissemination of information on the benefits of vaccination
- improved integration of screening and vaccination campaigns
- a greater focus on the benefits of HPV vaccination for boys.

## Whānau insight: More knowledge is needed on workplace carcinogens

Exposure to workplace carcinogens, including excess sun exposure is associated with several cancers, such as leukaemia and cancers of the lung, skin, and nasal cavity. Māori are 1.4 times more likely to report being exposed to workplace carcinogens than non-Māori (Te Aho o Te Kahu, 2021). While it was not widely raised in the hui, a small number of whānau related experiences of working in hazardous environments including sawmills, where they felt that tāne Māori were being exposed to high levels of toxic contaminants.

They expressed concern that little was being done to ensure regular health checks were being offered for tāne working in these industries. Contamination of whenua and waterways near these sites and the potential impact on environmental contaminants was also raised.

> *"... lots of us worked in dangerous environments, places with asbestos etc... very worrying for us."*

# 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 voice**

"We need education and awareness for whānau about the signs and symptoms, and how to advocate and not let our concerns be ignored. We need to teach our whānau how to demand and expect that they receive the care they need."

"It's important to educate our own people... target mokopuna to better themselves and to learn."

"There is a lot of stuff out there, but awareness is lacking."

## Whānau insight:
## Improvement is needed in early detection

Many whānau attending the hui series understood that cancer can sometimes be caught early. However, there was a sense that this understanding was often overpowered by the strong cultural association that Māori have between cancer and death, due to the persistent inequities in cancer mortality.

> *“When you hear cancer, you think ‘mate’ (death).”*

> *“In my whānau, cancer means start prepping for a tangi.”*

> *“Cancer is intergenerational. In te ao Māori, it’s all about whakapapa. Every whānau has lost people to cancer.”*

Many whānau pointed out that stigma and a hesitancy to talk about cancer, particularly among older generations, also contributes to late presentation. One whānau member shared how they had waited 10 years before going to the doctor, because they were ashamed to say they had ‘blood in my kaka’. They noted that the language clinicians use is important and can help overcome this sense of shame.

However, some whānau also talked about positive efforts to increase awareness of cancer signs and symptoms. While some whānau recognise certain symptoms (eg, that coughing up blood may indicate lung cancer, a lump may indicate breast cancer, poor urine flow may indicate prostate cancer), many feel that more work is needed to improve the understanding of signs and symptoms of cancer among individuals, whānau, hapū and iwi. Many whānau noted that marae- and community-based efforts to engage the whole whānau appear more successful than individual approaches. They feel these options give whānau the confidence to seek advice from their service provider that can result in earlier detection.

> *“Marae- and hui-based wānanga are an effective way of communicating and are what Māori want.”*

Whānau want to see more support and resourcing for kaupapa Māori initiatives to increase awareness of the signs and symptoms of cancer to whānau, hapū and Iwi. Many also thought the development of easy-to-understand cancer information resources using a variety of mediums should be a priority. Messaging needs to resonate with whānau (eg, waiata, kapa haka, information resources). Some mentioned the positive nature of the *Protect our Whakapapa* campaign developed for COVID-19.

## Whānau insight:
## Whānau face multiple barriers to primary care

During the hui whānau consistently raised concerns about their ability to access and engage with primary care. The barriers largely fell into three themes: the inability to effectively access primary care; difficulties building trusted relationships with primary care staff; and internal beliefs that prevent many whānau from asking for medical advice (see Figure 14 for details).

Many whānau want to see primary care delivered from an 'iwi/whānau point of view', including a 'whole wraparound approach' to providing care. A number also identified the importance of being able to access more care and support in the home or 'outside of the GP practice'.

The use of locum GPs was raised many times, particularly in rural areas. Feedback was mixed: some whānau found that locums tend to 'defer the hard decisions'; while others noted that in some cases locums came with a more open mind and were more likely to investigate more fully or recommend additional tests.

Whānau at the hui series raised concerns about the power imbalance between the GP and their patients, particularly for kuia and kaumātua who would not question their GP, did not feel able to ask for a second opinion, or were unable to say they did not understand what they had been told during the consultation.

> *"You should see my father in front of the GP… he shrivels up so small, he's usually an outspoken man."*

Whānau also talked about the importance of the person at the front desk and how a negative interaction could impact on their experience of primary care. It was noted that in some cases whānau were turned away from accessing even free services (eg, screening) if they owed money to the clinic. Many whānau noted front desk staff often make comments that are embarrassing for patients, particularly if they owe money. These comments are often heard by other patients in the waiting room.

> *"Need to have a warm and friendly face to greet people when they come into the primary care clinic."*

> *"I walk in the door and I'm not welcomed in my language, then you mispronounce my name. It just goes on and on… it all determines my level of trust."*

Sadly, many whānau spoke of their health concerns not being fully addressed and many felt that this contributed to delays in their cancer being identified. There is a perception that primary care providers are often racist and/or biased, dismissing or ignoring signs and symptoms, or assuming the symptoms are due to comorbidities. Many hui participants experienced racism at these initial points of entry into the health system and feel that this needs to be addressed before anything else.

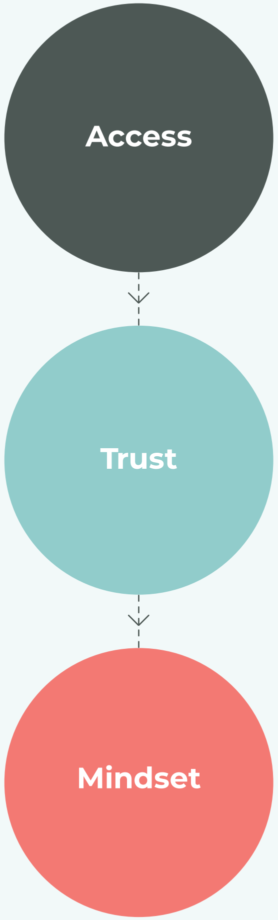
> *"They [whānau] have a pain for weeks, months, years… GP says we will change your meds, give you a painkiller."*

> *“We need to be listened to; I want to be heard.”*

Many of the themes identified by whānau during the hui series were echoed by Māori working in the wider cancer sector. A particular concern was the lack of Māori GPs, despite years of work to try and increase this number. There was a call to consider different models of care, and a move away from the 8am-5pm clinic model because it is not working for Māori. This included a desire for ‘Māori health providers to be more in the community instead of expecting whānau to travel to receive Māori health services’. Māori working in the wider cancer sector also suggested free primary care for Māori and supported a more direct link to access specialist care.

Whānau noted that whakawhānaungatanga is a good way to combat many of these issues. Simple examples were given, such as a GP who chatted with a patient about kina before discussing the reason for their visit; or a primary care practice that offers a cup of tea to patients to help them feel settled. Whānau also agreed that having someone familiar to act as an advocate during their appointment was often very helpful.

## There are many system barriers that reduce whānau access to primary care



**Primary care is not accessible to whānau**

- Cost to see a GP
- Too hard to get an appointment, especially since COVID
- GPs unable to take on new clients
- Cannot get to GP during working hours
- Too far to travel, especially in rural areas
- Hard to get a second opinion

**Whānau struggle to trust primary care professionals**

- Too many locums mean whānau cannot build a relationship with GP
- Whakamā discussing body parts
- Whānau concerns aren’t addressed
- Appointments are too short for whakawhanaungatanga
- Racist or biased staff

**Impact of whānau beliefs and experiences**

- “I don’t want to know”
- Brought up not to go to the doctor
- “She’ll be right”
- Too shy to ask questions

Figure 14. System barriers that reduce access to primary care

## Jo's kōrero: One patient's experience of cancer

'I was misdiagnosed at 40. I went to the doctor in excruciating pain and as my family doctor couldn't see me for a few days, I was seen by a female intern who sent me for scans. Upon viewing the scans, she was about to initiate blood tests but needed the confirmation of her managing GP, an aged Pākehā male. He entered and left the consultation room within a minute, deciding on the spot it was an STD, not something more serious. I remember the intern looked at him shocked. She diaried follow up scans for six months for her 'peace of mind'. I went back six months later and, sure enough, by then I had advanced testicular cancer. I had urgent surgery to remove the cancer. I was lucky, the surgery did the job, and I am now cancer free.

I advocate for other whānau who are going through the cancer system now. I tell them all the same thing - prepare for a poor experience, which is sad. But I want them to be prepared that, while the system is not designed for them, it can work for them if they can tough it out and ignore its racism. I also want to make sure they stay within the system, so they can get the treatment they need.

What will create the change that is needed? We need a whole government approach to changing the health system. In particular, we need to move away from a model of public health care underpinned by a business model funding 'time' in a consultation chair. This drives the poor impersonal behaviours. We need to remember that patients are people with a family, a history, and a story. We are not just numbers and data points. I have reflected a lot on my diagnosis, I believe if I was a Pākehā, I would have been diagnosed earlier. I think the doctor jumped to a conclusion based on a range of factors - including the fact I was Māori.'

**Jo Stafford** (Ngāti Maniapoto, Ngāti Rārua)

## Whānau insight:
## Screening should be more patient-centred

**Whānau voice**

"We went to screening as a group...
we could awhi each other."

"Take bus to remote communities and small towns to undertake screening."

"Education and screening at marae would be good."

"I had a kaiwhakahaere (navigator) from Breastscreen. She was integral in helping me navigate my way through the health system."

Whānau identified multiple barriers to participation in screening services. These include cost (travel, time off work, babysitters for children etc), a lack of trust in screening services, the lack of kaupapa Māori screening services, few Māori staff within the services, limited health literacy and a perception that screening is not a priority. Whānau believe that screening services should be led, developed, and delivered by Māori. Smear Your Mea was highlighted on multiple occasions as a kaupapa Māori initiative that is more accepted by Māori.

Some whānau also suggested that kaupapa Māori screening campaigns could be holistic and not focused on one tumour type. Instead they could include other health kaupapa, for example, screening for cardiovascular disease or diabetes. Some whānau suggested screening should be community driven and include local Māori role models to promote the screening activities.

Māori working in the wider cancer sector want more support for lung cancer screening pilots that are designed and delivered by Māori. Many also felt their voices had been ignored in discussions about changing the criteria for Māori and Pacific peoples to access free bowel screening. They want support for HPV self-testing for cervical cancer prevention which is seen as a simpler, more convenient, less invasive and mana-enhancing process for wāhine Māori.

## Ngaroimata’s kōrero: One patient’s experience of cancer

‘Cancer has been in my whānau for generations. My grandmother died really young and my Dad passed away from cancer when he was 48. My sister was diagnosed with cancer in 2017, and I was diagnosed in 2019 with breast cancer.

That history is important, I see my cancer journey through the journey of my whānau members. I made an effort to engage in screening programmes from an early age as I knew members of my family had cancer. When they discovered my cancer I was devastated, but I was also grateful. That is what screening is for, to find the cancer before it spreads. When I was diagnosed, I cried for weeks and weeks. I was blessed to have a huge amount of support. I had a kaiwhakahaere from Breastscreen Waitematā DHB. She was integral in helping me navigate my way through the health system. She helped to explain what was happening in a kaupapa Māori way which meant a lot to my husband and me. When I was diagnosed, I found it helpful to talk to others who were also living with cancer. I got to know so many strong women who were on the same journey.

I know not everyone gets connected or has the same experience as I did. That is why I now do advocacy work. I want to try and help those who are struggling to find their way in the system. My biggest piece of advice I give to wāhine now is to get screened. I know some people would rather not know whether there is something wrong. But do you know what? Your life is far too precious to take that gamble.’

**Ngaroimata Reid**
(Ngātiwai, Te Rarawa, Ngāti Kahungunu, Rangitāne)

## Whānau insight:
## Diagnosis can be unnecessarily traumatic

**Whānau voice**

“Enable GPs to order diagnostic testing directly… speed up the pathways.”

“Scheduling…. don’t book a rural patient for an 8.30am appointment!”

“Health services need to be able to relate to whānau… it’s not just about medical or social qualifications.”

Whānau consistently shared stories of how it took them multiple visits, sometimes over several years presenting with the same symptoms before their primary health provider would order a diagnostic test. Combined with a general lack of access to primary care and lack of trust in the system, many whānau see this as one of the key reasons why Māori are diagnosed late.

Hui participants were also concerned by a perceived resistance to diagnostic tests being offered in primary and/or secondary care. Reasons for this varied from clinicians being dismissive or biased, a lack of resources, and perceptions of Māori not being prioritised for diagnostic testing. Māori working in the wider cancer sector were frustrated at the lack of recognition for projects that remove barriers to diagnostic testing, such as direct diagnostic testing referrals from primary care.

Whānau also spoke of feeling unsafe and/or unsupported at critical times during the diagnostic process. Many were alone with a health professional when they were told of having cancer and in hindsight wished they had been able to have whānau or an advocate with them. Some whānau spoke of health professionals leaving them alone immediately after diagnosis, often feeling in shock at the time.

> *“I could only take one of my siblings… It was too hard to choose, so I went on my own. I regret that now.”*

## Whānau insight:
## Treatment doesn’t feel fair

**Whānau voice**

“You have no idea where you sit in the queue [for treatment].”

“Why can’t clinicians do the travel? Don’t make the sick person do all the travel.”

“I could advocate for them but only because I knew the system. And the doctors and nurses hated it – they called me ‘that bitch from Wellington’.”

Hui participants said they want all available treatment options explained to them, so they can make informed decisions for their whānau. This also includes treatment options that may be costly. Clinicians should not assume that whānau cannot afford any treatment options, including those that are privately funded. Whānau are also unhappy that more cancer medicines aren’t publicly funded and want Māori involved in prioritising which drugs are funded.

Whānau reiterated the importance of whakawhanaungatanga to develop high trust relationships. Building a trusting relationship with the people providing cancer treatment services requires appropriate and clear communication skills along with empathy and flexibility, particularly when it comes to appointment times for rural patients. The availability and presence of whānau advocates was also seen as important.

*“They don’t know what it’s like for us [rural patients]. They have absolutely no idea.”*

While most hui participants would prefer to have treatment closer to home, they understand that travelling is sometimes required to receive the best treatment. But for this to happen, whānau need to be well supported to enable them to travel long distances, if required. Issues around travelling for cancer treatment are discussed in more detail on page 76.

Where possible, whānau would like treatment delivered by Māori. Cancer medicines that are self-administered at home were discussed, along with the possibility of chemotherapy being delivered outside of hospitals. However, whānau want assurances that home-based and community-based chemotherapy are as safe and effective as hospital-based chemotherapy.

A key issue that was identified is a lack of accountability for treatment experiences and outcomes. Māori working in the wider cancer sector noted that performance measures focus on the delivery of services and outputs, with less emphasis on equity or the quality of care that whānau receive. Māori working in the wider cancer sector also want any cancer quality improvement actions to have equity and whānau-centred care embedded in their design, delivery, and evaluation. They felt that Māori leadership and clinical, consumer and cultural expertise must be part of this process.

## Whānau insight:
## Effective supportive care models reflect the te ao Māori worldview

**Whānau voice**

"Shift the focus to the patient, not the illness."

"Yes, the physical part was hard – but the mental and emotional part was far more traumatic."

"Sometimes you're on the way and the appointment gets cancelled – you're halfway there already."

"What if we could say who we wanted to be referred to in the community, and they get sent our info?"

One of the consistent themes raised throughout the hui series was the importance of holistic models of health. Some whānau called this wellbeing, others spoke of hauora and Te Whare Tapa Whā, while some called it supportive care. While the labels were sometimes different, the key components that were consistently mentioned were:

- support for patients' spiritual, mental, and emotional health needs
- the ability to integrate complementary and traditional health treatments alongside clinical cancer treatments
- financial and logistical support, particularly around travel and accommodation
- support for both patients and their whānau.

Figure 15 on the following page gives some examples of the issues commonly raised by whānau, and how they are all interrelated.

## The importance of balance: Te Whare Tapa Whā

### **Taha hinengaro**
Mental and emotional wellbeing

Whānau recognise that cancer can have a significant effect on the mental and emotional health of both patients and whānau. They need support for mental wellbeing throughout the cancer journey.

- 'It's not what's the matter with this person, it's what matters to them.'
- 'Where was my wellness plan?'
- 'Need to make sure whānau needs are responded to – and the needs can be different for each whānau member.'

### **Taha whānau**
Social wellbeing

Whānau spoke of the expertise that lived experience brings, and how many cancer survivors want to support others through their journeys. Whānau and community connections are also seen as vital during this time.

- 'Build connections with us – whakawhanaungatanga is critical.'
- 'Having a support person is really important to advocate, look and learn.'
- 'Draw on the lived experience of patients. We've been there, we know what it's like.'

### **Taha wairua**
Spiritual wellbeing

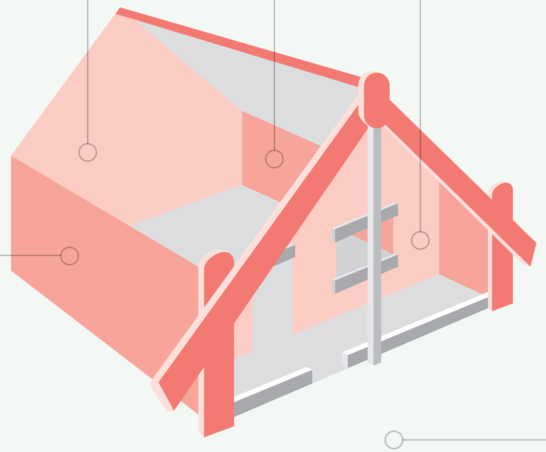
Wairua is a Māori concept which recognises the spiritual essence of a person and their life force. Hui participants reiterated the effects that cancer can have on the wairua of both patients and whānau and the importance for many of faith and religion.

- 'Karakia every morning creates an environment for wairua (spirit) to be present.'
- 'Whakapono is entrenched in our bloodlines.'
- 'Tohunga told me to trust the specialists so I felt more comfortable.'

### **Taha tinana** Physical wellbeing

Whānau understood the need to support their physical wellbeing during cancer treatment. Nourishing kai, gentle exercise, rongoā, beauty and hair treatments were given as important examples.

- 'When we lose our hair, it's huge. Our hair is tapu. I felt like I lost my mana.'
- 'Food is our rongoā.'



### **Whenua** Land, roots

Whānau talked about the importance of the environment and connections to physical places during cancer treatment, particularly in relation to rongoā. They also spoke of the importance of managing logistical issues: earning income and managing finances while undergoing cancer treatment; juggling childcare; and finding travel and accommodation options when they needed to travel for treatment.

Figure 15: Balance across Te Whare Tapa Whā model

Whānau who received services from mental health professionals such as psychiatrists, psychologists and social workers voiced both positive and negative experiences. Whānau preferred services that were whānau-centred, offered flexibility with appointments, and had kaupapa Māori options available. Where mental health support is not available locally, telehealth was raised as a possible way to connect with mental health professionals including Māori mental health workers.

Whānau spoke of various ways to support their physical wellbeing, including nourishing kai, gentle exercise, and supportive body treatments such as massage. Hui participants regularly talked of wanting to include traditional Māori healing methods such as rongoā as part of their cancer treatment and care (see pages 41, 49 and 51 for more discussion on mātauranga Māori and rongoā). As with other treatment types, some whānau understand that traditional healing can relieve symptoms, but care must be exercised to avoid any negative interactions between traditional Māori healing methods and conventional cancer treatments.

Whānau spoke of social wellbeing in two broad ways: the importance of whakawhanaungatanga; and the importance of being able to connect with and learn from people with lived experience. Whānau see whakawhanaungatanga as vital at all levels, from interactions between patients and clinicians, to connecting with people in their communities who can empathise with and support them through their cancer journey. Whānau also frequently urged policymakers and services designers to use the lived experience of cancer patients and whānau to improve service delivery.

> *“Draw on the lived experience of patients. We’ve been there, we know what it’s like.”*

Whānau recognise the effects that cancer can have on the wairua of the person and their whānau. Spiritual wellbeing is central to whānau although there are varied views as to what it means.  Many whānau feel that colonisation has affected the way in which wairuatanga is viewed, with traditional views being mixed with Western religion. Others interpret wairuatanga as a connection to whenua, ngahere, moana; and reverence of Ranginui, Papatūānuku and their children.

The Medicinal Cannabis Scheme (the Scheme) came into effect on 1 April 2020 with the commencement of the Misuse of Drugs (Medicinal Cannabis) Regulations 2019. The purpose of the Scheme is to improve access to quality medicinal cannabis products for patients (Ministry of Health).

There are diverse views among Māori when it comes to the use of medicinal marijuana in cancer care. Some whānau are completely against the use of marijuana, while others advocate the use of marijuana as an effective form of pain and anxiety management for cancer patients.

Whānau raised concerns about the high cost and limited access to medicinal marijuana, particularly during end-of-life care. They felt this may drive whānau to access marijuana via the black market. Some whānau felt that those who have terminal cancer should have access to a variety of subsidised medicinal marijuana products.

There are also concerns around the stigma attached to using medicinal marijuana, which might lead to whānau not declaring their use. Whānau want more information and clarity around options for the use of medicinal marijuana, particularly in palliative and end-of-life care planning, so that those who choose to use it do not feel marginalised by the system.

## Whānau insight:
## Cancer creates many financial barriers for whānau

**Whānau voice**

“Every time I needed a biopsy, that meant a whole day off work. Plus, another day each time the results came through.”

“I had appointments at 10am and 2pm, which meant the Cancer Society driver had to wait all day with me. I felt terrible.”

“No-one told us we could have a mortgage holiday.”

Given the complex nature of cancer treatments, many whānau noted they sometimes struggle to manage day-to-day logistics during their cancer journey. This particularly included earning income, managing finances, and arranging travel and accommodation for treatments away from home. Many whānau did not know they could arrange things such as mortgage holidays, while others had never used government benefits or other entitlements before and were unfamiliar with the processes to access them. Whānau spoke of needing lots of time away from work to support patients during cancer treatment, while patients talked of how this often made them feel guilty.

Whānau regularly raised the issues of travel and accommodation which continue to be a significant barrier, particularly for whānau living in rural or remote areas.

*“A lot of people need to travel hours to get to an appointment and don’t have vehicles or family support.”*

While there is some support available through the National Travel Assistance Scheme (NTA) (Ministry of Health, 2019b), WINZ and non-government cancer organisations, whānau often found some of these options difficult to access. NTA was frequently cited as a source of frustration for both whānau and Māori working in the wider cancer sector. Whānau shared stories of inflexibility, racism, and bias in how the NTA program is currently delivered, concerns over the minimum distance criteria to access funds, gatekeeping by staff and a lack of flexibility in accommodation options such as the use of koha to pay for accommodation.

Given that NTA is based on a reimbursement model, some Māori working in the wider cancer sector described NTA as ‘a failure in itself... you must pay for the journey before it is of use to you. What if you don’t have that money in the first place?’ Māori working in the wider cancer sector are frustrated that the recommendations from a 2018 review of NTA have not been implemented.

## Whānau insight:
## Whānau feel forgotten when treatment ends

**Whānau voice**

“Important to recognise, once the treatment stops the problems don’t stop.”

“This [cancer] changed me and I need help adjusting to that.”

“I’m not the person I was before treatment, but I’m expected to be that person.”

There was a consistent view from whānau that the post-treatment phase of cancer care needs improvement, as ‘the need for care doesn’t stop when treatment finishes’. Many whānau felt that having cancer changed them as a person, but they did not feel that was acknowledged by clinical cancer treatment services. Some whānau talked about the sudden drop in interactions with health professionals once their specialist cancer treatments ended, saying they felt ‘that safety net had been taken away’. Others spoke about ‘having a ‘before cancer’ life and an ‘after cancer’ life’. Some shared that as survivors they were grateful for a second chance at life, but the trauma of the cancer experience hung over them and they often did not know how to deal with the physical, psychosocial, and emotional consequences.

Another issue that was frequently raised was the need to share more stories of whānau who survive cancer. Some hui participants wanted others to know that for them, ‘cancer is not a full stop, it’s a comma… there is life after cancer’. There was broad agreement that whānau need to hear more good stories about cancer journeys, in part to rebut the preconceptions many have about cancer always being terminal.

## Henare’s kōrero: One patient’s experience of cancer

‘I had a sore shoulder which wouldn’t go away. I then noticed a small lump, I left it for a while but decided to get it checked. I went and saw my GP in Wairoa, who took a sample. It turned out to be skin cancer. I was surprised when I was diagnosed. Being Māori, I didn’t think I could get skin cancer. I had surgery and had the cancer cut out. My doctor was honest with me and said there is a chance it would return. I appreciated that honesty.

I had a good experience of the health system when I was diagnosed. I think what helped was having a good relationship with my doctor – my wife’s family knew him. He was very open and awesome. At the time, I was quite scared as I had whānau who had cancer and it hadn’t gone well. However, the system worked well. I was contacted regularly and informed each step of the way. Being in a small town may have helped – everyone knows everyone.

My hope for these hui is that Māori are diagnosed earlier. The earlier the diagnosis, the better. I really hope we are able to help one another to understand more about cancer, to share our stories and support each other. I know that it is scary to think about cancer. But being proactive is the best way forward. I still get a little tingle in my shoulder from time to time, that is a reminder to keep the conversation about cancer alive.’

**Henare Kani**
(Rangitāne, Ngāti Kahungunu, Tuwharetoa)

## Whānau insight:
## More conversation is needed on palliative care and end-of-life-care

**Whānau voice**

“Palliative care is a tapu space and requires a careful, holistic approach.”

“Care is inconsistent. Some hospices have Māori liaison support people, whereas others don’t – they need to be everywhere.”

“What about having kaimahi in the palliative care space? They don’t seem to cover this part of health, whānau are passed over to the Pākehā system when they reach palliative care.”

Whānau acknowledged the term palliative care is unfamiliar and confusing, with some thinking that palliative care is a disease itself. Others suggested that new terminology be used, for example ‘mauri mate’. Mauri Mate is currently used by Hospice New Zealand as its Māori Palliative Care Framework. However, given that ‘mate’ means death, concerns were raised that this could add to the confusion between palliative care and end-of-life care.

Stories were heard from whānau about the system being generally inconsistent and unsupportive of kaupapa Māori options.  Whānau had examples of practical issues they faced with caring for whānau at home such as home care not showing up, oxygen not being available, a lack of responsiveness from clinicians (especially on weekends) and a lack of rongoā options.

End-of-life care was on the minds of many hui participants, particularly given the recent end-of-life choice referendum. Views on death varied from person to person and whānau to whānau.  In te ao Māori, death is seen as a tapu topic. Death and dying can be a difficult subject to raise with whānau especially if they have had a negative experience due to inadequate care of a loved one in the last days of their life.

Whānau were concerned at the implications of the assisted dying service for whānau, especially those going through a cancer journey who might be in a vulnerable situation, experiencing depression or mental health issues, or receiving substandard palliative and end-of-life care. Given the magnitude of the assisted dying kaupapa, whānau raised concerns over the lack of meaningful discussion with Māori throughout the referendum, legislation, and service formation.

Māori cancer stakeholders involved in referendum discussions were concerned that their voices had not been heard and that overall it had been a rushed kaupapa.  They felt strongly that non-Māori clinicians should not be making these decisions in isolation from Māori expertise.  Although there are privacy issues with assisted dying, the importance of the role of whānau should recognised and included within the process.


To tātou iwi.
TE AHO O TE KAHU
CANCER CONTROL AGENCY
TE AHO O TE KAHU
CANCER CONTROL AGENCY

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# 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-Māori 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 ability 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 interim New Zealand Health Plan.

The wero for Te Aho o Te Kahu 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 inequities 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* (this report)
2. *Te Tikanga* summarises our kaupapa Māori approach to the hui series
3. *He Urupare* 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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# Ngā tohutoro
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