



**Central**  
Cancer Network

DEEP DIVE

**Feedback Report**

**JUNE 2020**



*Whanganui River and Te Atihaunui-A-Paparangi Tribe  
Ko au te awa, ko te awa ko au  
I am the river, The river is me*

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*Images supplied by the Central Cancer Network*



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# He Waka Eke Noa “We are all in this together”

*This design by Paul Horton and Rangitāne iwi, sits atop He Ara Kotahi Bridge.  
The puriri waka represents the hole moths make when they burrow into the bark and the koru design represents the people.*

**He Ara Kotahi**  
**Palmerston North City Council**



*Te Ara Kotahi Bridge, Palmerston North  
He Waka Eke Noa  
We are all in tis together*

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Kia mōhio ai koe ki te āhua o te ara kei mua i a koe, uia ko ērā e hoki mai ana i taua ara<sup>1</sup>.

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<sup>1</sup> Prof. Rangi Matamua provided whakatauki in February 2015

# Glossary

## Te Reo Māori Translations

Māori terms used in glossary are *explanations* for use only in the context of this report. This report acknowledges the diverse dialects and relational contexts of iwi (tribes) by providing multiple translations for some Māori terms.

Māori	Translation
Aotearoa	Land of the long white cloud, New Zealand
Atua	Gods
Hapū	Subtribe
Hau kainga	Home people
He Pito Ora	Umbilical cord of well-being
Hinengaro	Emotional/Mental well-being
Hui	Meeting
Iwi	Tribe
Kai	Food
Kaiawhina	Community or hospital Māori support worker
Kanohi ki te kanohi	Face to face
Kapa haka	Māori cultural group
Karakia	Incantations, prayers
Kaumātua	Elder
Kaupapa	Topic
Kawa	Protocol
Koha	Gift
Kōhanga Reo	Learning nest/early childhood
Kōrero	Talk/discuss
Kura Kaupapa	Primary school
Manaakitanga	Hospitality, caring,
Manuhiri	Visitor
Mana Whenua	Local iwi
Marae	Gathering centres
Mau Rākau	Māori weaponry
Mihi whakatau	Informal welcome
Mihi	Acknowledgment

Mirimiri	Massage
Noa	Safe/free from sacredness
Pākehā	European
Papatūānuku	Mother earth
Pono	True/genuine
Potae	Hat
Ranginui	Sky father
Rohe	Region
Rongoā	Natural remedies
Te reo	Māori language
Taha wairua	Spiritual side
Tāne	Male
Taonga	Treasure
Tapu	Sacredness
Tikanga Māori	Māori customs/protocols
Tinana	Physical well-being
Tino Rangatiratanga	Autonomy/self determination
Tīpuna	Ancestors
Taonga	Treasures
Tōhunga	Expert/high priest
Wai	Water
Wairua	Spiritual well-being
Whaikōrero	Formal speech
Whakapapa	Genealogy
Whakamā	Shy
Whakataukī	Proverb
Whakawhanaungatanga	Establish relationships
Whānau	Family
Whanaungatanga	Relationship/kinship
Whenua	Land

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He aha te tohu  
o te ringaringa?



*Kuia and Mokokuna (Hutt Valley Community Hui)  
He aha te tohu o te ringaringa?  
What is the sign in our hands?*

# Executive Summary

Cancer is the leading cause of death in Aotearoa New Zealand and for Māori the burden of cancer is disproportionately higher compared with non-Māori across all stages of the cancer continuum.

In addition, Māori are more likely to experience access barriers to timely and quality cancer care compared with non-Māori. To address the issues faced by Māori, Sarfati (2019, September 7) argues Māori need to be able to share their experiences and identify what the solutions are from their perspective, which cannot be done by non-Māori. Subsequently, between August and December 2019 the CCN region, which includes the MidCentral, Whanganui, Taranaki, Hawke's Bay, Wairarapa, Hutt Valley, and Capital and Coast District Health Boards (DHB), organised seven community and four stakeholder hui to gather Māori experiences about accessing cancer care services and to collect views from those who work in this area.

The Deep Dive Feedback Report reinforces extensive research (Cormack, Robson, Purdie, Ratima, & Brown, 2005; Koia, 2019; Slater, 2016; Walker, Signal, Russell, Smiler, & Tuhiwai-Ruru, 2008) conducted with Māori over two decades. The findings highlight the problems and solutions that need to occur to improve cancer care services for Māori. It is important when reading and reflecting on this report to consider the impact of the health systems, including the wider health determinants and prioritise which systems can be changed immediately to better meet the needs of Māori.

Throughout the Deep Dive Feedback Report a range of views is presented from those who attended the seven community and four stakeholder hui. Key findings and recommendations are briefly covered.

## Community and Stakeholder Hui Findings

Whānau plays a pivotal role in facilitating and helping overcome access barriers to and through cancer care services (Koia, 2019; Slater, 2016; Wilson & Hickey, 2015). The community hui reiterated the critical and multiple roles of whānau, including promoting healthier lifestyles, educating whānau, providing supportive care, and., helping patients make sense of health information so they can participate in decisions (see graphs 2, 3, 4, 5, 6 and comments from respondents). Health professionals need to realise whānau have an important role to play in cancer care and can make a positive difference to patients' health outcomes if they are involved early.

Costs associated with accessing cancer care services including GPs fees, prescription charges, transportation, and maintaining healthy lifestyles can be expensive for many patients and their whānau. Free or low fees, review of the national transportation criteria, and delivery of cancer care services closer to where patients reside have the potential to address access issues for Māori. Further systemic factors include flexible appointment times and offering services after normal clinic hours or on the weekend as many patients and whānau find it difficult to get time off work.

Communication is another inhibitor to effective access of services and needs addressing for patients and their whānau to receive timely and quality cancer care service. Taking the time to build trusting relationships can go a long way to improving relationships between patients, whānau, and health professionals (Dinç & Gastmans, 2013; Koia, 2019; Mok & Chiu, 2004), using simple terminology and providing a friendly environment will substantially contribute to patients and their whānau feeling welcome and comfortable to engage. Helping whānau engage also includes improving the delivery of health information and exploring alternative venues where many Māori tend to deliver health promotion campaigns (refer to graphs 6, 7, 8, 9, 10, 12, 13, 14, 15, 16).

The findings also highlighted the need for more Māori GPs, Māori nurses, kaiawhina, Māori cancer and whānau ora navigators who are providing consistent and cultural support throughout patients' and whānau' cancer journey. Māori professionals understand the importance of offering rongoā (natural remedies) Māori options alongside medical interventions. However, these Māori roles should not be used in lieu to address cultural competency training for both medical and non-medical health workers.

## Summary and Recommendations

In Aotearoa, Māori continue to experience delays in timely access to primary and secondary health care that can be preventable. Challenges include accessing transportation, increased costs of health care, poor delivery of health literacy, and lack of cultural awareness by health professionals. Such significant barriers to accessing quality cancer care also influenced by the wider social determinants experienced by Māori. No longer can the health system ignore these contributors if they want to seriously improve health outcomes for Māori. Thus several recommendations are made:

- Better recognition and integration of whānau in the care of patients. including the significance of tōhunga (expert/high priest), and rongoā Māori such as mirimiri (massage) and karakia (incantation/prayer) in the care of patients across the continuum.
- Improve communication by all health staff, such as correct pronunciation of patient names. The Resource booklet *Best Health Outcomes for Māori: Practice Implications* prepared for the Medical Council of New Zealand would be useful.
- Improve timely transfer of information across the health sector.
- Improve frontline customer services by providing friendly and culturally responsive environments to address racism in the health services. Gaining a better understanding of Māori cultural practices and beliefs by all staff and greetings in te reo Māori are a useful start.
- Improve health literacy communication by not using medical jargon when communicating with patients and whānau, and involve kaiawhina, Māori cancer and whānau ora navigators, to explain health information that can be understood by Māori health consumers, patients and whānau.
- Data collection to include holistic information as determined by the patients and their whānau. Professor Sir Mason Durie's Te Whare Tapa Wha framework would be helpful in this process.
- Include Māori cancer and whānau ora navigators and kaiawhina in multi-disciplinary teams. These roles are essential as they have vital knowledge about the patient, their culture and community, which helps maintain continuity of care for patients.
- More flexibility with appointment times to accommodate patient circumstances.

- Ensure early referral to or offer of Māori supportive care (Māori cancer navigators, kaiawhina (community or hospital Māori support worker), whānau ora services for all Māori health consumers, patients and their whānau across the entire cancer continuum.
- Co-design with Māori to develop health promotion campaigns that include delivery at Māori events (i.e. national and regional kapa haka, Iron Māori), marae, and local community venues like schools. Campaigns like Smear your Mea and community garden interventions can provide guidance.
- Review mobile screening services to better facilitate access, particularly in smaller and isolated areas.
- Review the national transportation assistance fund eligibility and processes to make it easier and less stressful for patients and whānau to access; starting with removing the 100-km criteria.
- Review hospital parking policies to accommodate free parking for patients and their whānau.
- Build the Māori health workforce with focus on increasing the number of Māori GPs, Māori nurses, Māori cancer/whānau ora navigators, and kaiawhina roles across all DHBs, including better integration of the navigator/kaiawhina roles within cancer care services.
- Increase the funding to iwi and Māori health providers as they provide services outside their contract scope to support patients and whānau to gain timely access to cancer care services.

“Communication is another inhibitor to effective access of services and needs addressing for patients and their whānau to receive timely and quality cancer care service...”

“Ka noho au i te  
poho o Taranaki”



*Taranaki Maunga  
Ka noho au i te poho o Taranaki  
Here I sit within the heart of Taranaki*

# Introduction/Background

Cancer is the leading cause of death in Aotearoa with Māori experiencing poorer health outcomes than non-Māori.

**D**ifferential access to and the quality of health care adds to poorer survival rates for Māori (Ministry of Health, 2019c). This report provides feedback collected from Māori health consumers, patients, whānau and health/social/community professionals who work in this area to enhance Māori cancer health outcomes. The following provides a brief background about Māori and cancer care.

## Māori Society

Before contact with Pākehā (European), Māori lived a relatively healthy life, living collectively, assisting each other to sustain their overall well-being (Hiroa, 1949; Raeburn, 2018). The reasons for being unwell were mainly due to the breach of tapu (sacredness) and/or warfare between hapū (subtribe) and/or iwi (tribe). A range of practices, including, rongoā, mirimiri, karakia, tōhunga, and wai (water), were used to address the different health issues. From this perspective, health for Māori was, and remains, holistic, encompassing many factors including, the whenua (land), marae (gathering place), hapū, te reo Māori (Māori language), tinana (physical well-being), wairua (spiritual well-being), whānau (family), hinengaro (emotional/mental well-being), Atua (Gods), Ranginui (Sky father), and Papatūānuku (Mother earth). All these factors remain crucial to the well-being of Māori (Barlow, 1991; M. H. Durie, 1994; Hiroa, 1949; Mead, 2016).

At the core of Māori society was, and still is, whānau and hapū. Māori society was organised around whānau, hapū, and iwi (tribe) who whakapapa (genealogy) to a common tīpuna (ancestor). The well-being of Māori society was the responsibility of the tōhunga who was viewed as having sacred knowledge and able to manage and advise on the health problems of the whānau (Mead, 2016).

From 1840 onwards, significant changes occurred in the country, including an increase in migrants, and the signing of Te Tiriti o Waitangi/Treaty of Waitangi between the Crown and Māori. As a result, legislative changes saw whenua confiscated and abolishment of traditional practices like tōhunga and te reo Māori. These changes, along with the introduction of new diseases such as influenza (from the migrants), had a dramatic effect on Māori health, with the Māori population decreasing from approximately 100,000 in 1840 to 40,000 by 1900. Compare this with 2,000 Pākehā in 1840 to approximately 703,800 by 1900 (Ministry for Culture Heritage, 2014) and, according to the 2018 Census, Māori now comprise 16.5% of the total population compared with Pākehā with 70.2% (Statistics New Zealand, 2019). These changes, alongside increased poverty and urbanisation from the 1940s, led to increasing inequities in health between Māori and Pākehā.

## Health Reforms

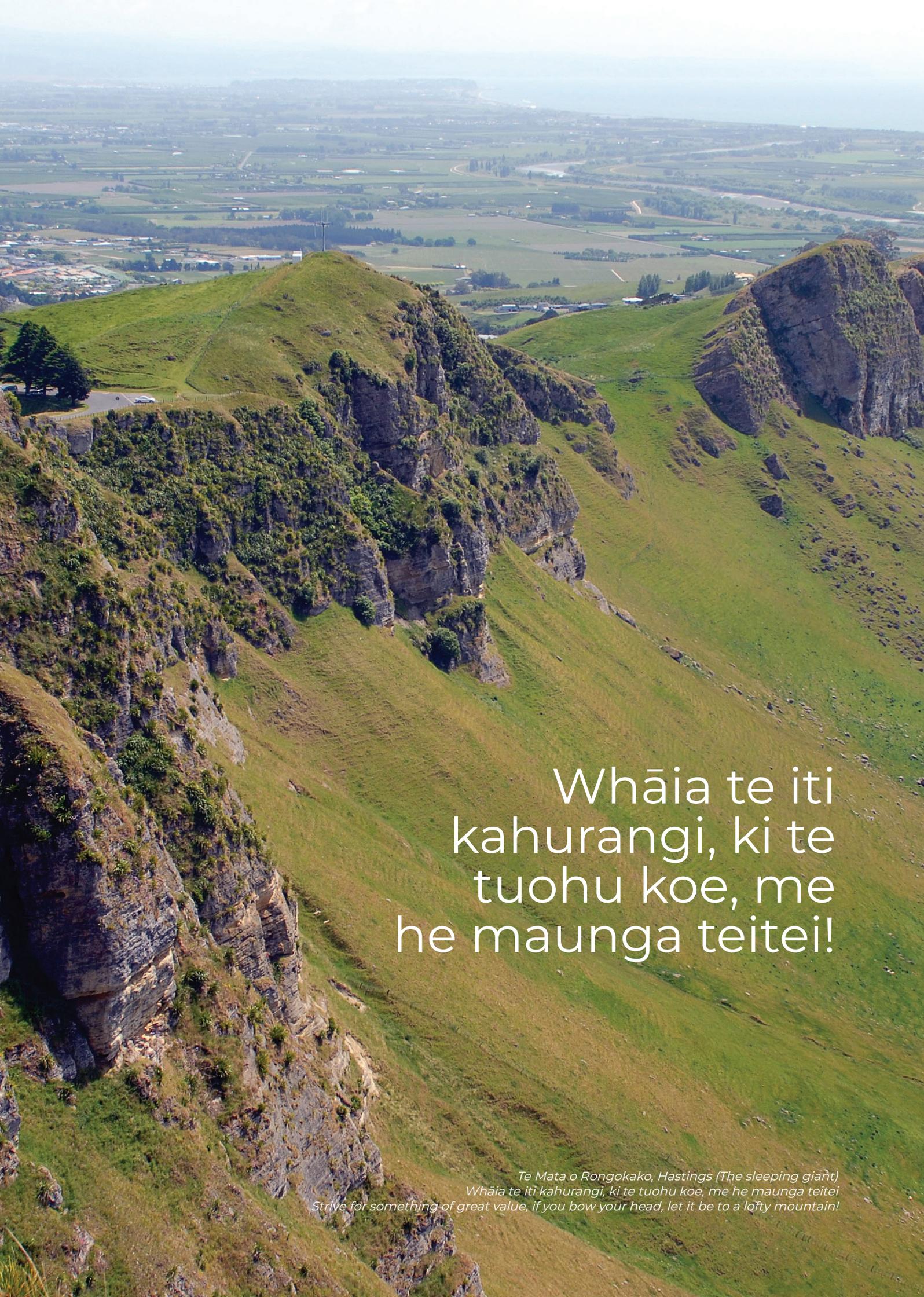
In colonised countries like Aotearoa New Zealand, Indigenous populations have poorer health outcomes compared with non-Indigenous peoples (Anderson et al., 2016). The “ethnic inequalities between Māori and non-Māori are the most consistent and compelling inequities in health” (B. Robson, Purdie, & Cormack, 2005, p. 3). This is evident in cancer care where the disparities between Māori and non-Māori will continue if “timely access to definitive diagnostic procedures, staging procedures, and optimal treatment or management of cancer” (Cormack et al., 2005, p. ii) is not addressed.

Major health reforms have been enacted over the last two decades in an attempt to address inequalities for Māori including; separating the role of purchasing and provision of health services and the establishment of various new service providers responsible for delivering services that were previously provided by the government (Ashton, 2005). The reforms saw the creation of iwi lead initiatives with the establishment of Māori health providers and the introduction of the New Zealand Public Health and Disability Act, 2000. The Act focuses on a more community-orientated system allowing for community involvement and an emphasis on a population-based funding model with the hope of better preventative health care services and reducing cost barriers that prevents people from accessing primary care (Ashton, 2005). However, regardless of these health reforms, Māori continue to experience poor health outcomes and are over-represented in the low socioeconomic groups. For example, the overall amendable mortality rate between the years 2000 and 2014 was considerably higher for Māori (196.8 per 100,000) compared with Pacific peoples (186.4 per 100,000) and the non-Māori, non-Pacific population (75.6 per 100,000) (Ministry of Health, 2018b).

In 2017, for the total population, there were 24,453 new cancer registrations (Ministry of Health, 2019b) and 9,638 deaths from cancer; a rate of 201.04 deaths per 100,000 population (Ministry of Health, 2019a). While a steady decline in several cancers such as cervical, lung and breast cancer has been documented for the non-Māori population in the last decade, Māori rates of such cancers remain disproportionately high (Ministry of Health, 2015b). Importantly, even for cancers in which the incidence rate is similar (colorectal) or even lower (prostate) in Māori than for non-Māori, the mortality rates among Māori for these cancers were higher than for non-Māori (Ministry of Health, 2015a).

## Māori and Cancer Care

In Aotearoa, cancer is now the leading cause of death for Māori and non-Māori. Breast, lung, colorectal, uterine, and cervical cancers are the major cancers affecting Māori females, while prostate, lung, colorectal, liver, and stomach cancers are the main cancers for Māori males (Ministry of Health, 2018a). In 2015, statistics from the Ministry of Health highlighted that the registration rate for Māori was 30% higher than the registration rate for non-Māori in 2015 (Ministry of Health, 2017c), with Māori cancer mortality rates for that same year being 75% higher than those for non-Māori (Ministry of Health, 2018e). These significant cancer inequities between Māori and non-Māori highlight more Māori are developing and dying from cancer than non-Māori (S. Hill et al., 2010; S. Hill, Sarfati, Robson, & Blakely, 2013; Ministry of Health, 2019c).



Whāia te iti  
kahurangi, ki te  
tuohu koe, me  
he maunga teitei!

*Te Mata o Rongokako, Hastings (The sleeping giant)  
Whāia te iti kahurangi, ki te tuohu koe, me he maunga teitei  
Strive for something of great value, if you bow your head, let it be to a lofty mountain!*

To improve cancer survival rates several important factors need to be actioned. These include determining the stage at diagnosis and the presence of co-morbidities. For Māori, co-morbidity conditions like diabetes and cardiovascular disease can affect treatment options and survival rate (Ministry of Health, 2012; Sarfati, Blakely, & Pearce, 2010). However, these factors do not completely explain the differential cancer survival rate between Māori and non-Māori. Other important factors contributing to lower cancer survival are system-level elements such as racism, costs of doctors' fees, travel costs to attend appointments, times of appointments, health literacy, access to and through services, poor communication with patients and whānau and between health professionals, and inadequate referral systems to ensure quality follow-up care and treatment (Cormack et al., 2005; Health and Quality Safety Commission New Zealand, 2019; Koia, 2019; B. Robson & Ellison-Loschmann, 2016; Wepa, 2015).

The CCN region, which incorporates MidCentral, Whanganui, Taranaki, Hawke's Bay, Wairarapa, Hutt Valley, and Capital and Coast DHBs represents 19% of the New Zealand total population (914,000) (Central Region Technical Advisory Service, 2019). The CCN region was reported as having an incidence rate of 3% and mortality rate of 4% higher than New Zealand's average between 2014 and 2016 (Central Cancer Network, 2019). In the CCN region it has been well documented that health disparities continue to exist across the cancer continuum between Māori and non-Māori, highlighting the need for collective commitment (Doherty, 2006; Koia, 2019; Signal, 2008; Walker et al., 2008). A collective approach from the seven DHBs in this region enabled Māori to come together to identify opportunities to enhance cancer care services for Māori particularly at a time when the government was introducing a new cancer action plan.

# Report Process

The data for this report were based on information collected by the CCN team, who partnered with DHB Māori health teams from MidCentral, Whanganui, Taranaki, Hawke's Bay, Wairarapa, Hutt Valley and Capital and Coast including local cancer stakeholders in those DHB regions. Information was gathered between August 2019 and December 2019 from seven community hui and four stakeholder hui.

The aim of these hui was to gather Māori experiences about accessing cancer care services and to collect views from those who work in this area in order to explore different options to enhance Māori cancer outcomes. Te Mata o te Tau, Massey University were contracted by CCN to perform data analysis on the secondary information that was supplied, and to prepare a feedback report.

The framework used to analyse this information was the model He Pito Ora by Koia (2019). This model is the result of research that explored the roles of Māori cancer navigators in the central region with Māori health consumers, patients, whānau, Māori cancer navigators, and clinical and non-clinical health professionals. The principles underpinning the model are illustrated in Figure 1 with further explanation.

Figure 1 Adapted He Pito Ora Model (Koia, 2019)



*He Pito Ora model represents the umbilical cord of well-being. For Māori, well-being is holistic, incorporating many factors, including whenua, whakapapa, identity and spirituality. The centre of the main koru represents the Māori health consumers, patients, whānau and their pito, depicting the start of their life journey and signifying they are the most important factors in cancer care services. The three parts of this model: (1) whanaungatanga; (2) whakamōhio; and (3) manaakitanga, are interrelated and are viewed as being critical **every time** Māori health consumers, patients, and whānau access cancer care services.*

### Whanaungatanga

The principle of whanaungatanga, includes whakapapa and concentrates on building and strengthening the relationships (Mead, 2016) between health professionals, patients, and whānau, as well as between the health workers themselves and taking the time to do this. From this perspective a collective view is prioritised through the enactment of whakawhanaungatanga (a process of building and strengthening relationships between people).

### Whakamōhio

Whakamōhio relates to the process employed to collect and exchange information in accordance with Māori values and beliefs such as whanaungatanga, manaakitanga, kanohi ki te kanohi and, at times, whānau involvement. The key factors are trust, and respect between patients, whānau, and health professionals and among health professionals and how the information gathered is looked after and used. Patients and whānau feel less whakamā (shy) to share information and ask questions about their illness.

### Manaakitanga

Manaakitanga is focused on caring and nurturing patients and their whānau including health professionals supporting each other. The principles of whanaungatanga and whakamōhio processes are closely connected with manaakitanga, which enable people to whakawhanaungatanga and share their knowledge and information to nurture each other and provide quality care.

### Health System

The health systems institutional structures, funding, policies, location of services, and organisational culture, is represented by the outer circumference. This demonstrates the impact it has on Māori health consumers, patients, and whānau access to cancer care services.

### Information Collection

The CCN team designed and collected the information for this report from the seven community and four stakeholder hui.

CCN in collaboration with the General Manager Māori from the seven DHBs, and the local iwi and Māori health providers distributed the invitation to their community. Travel assistance was provided by CCN for the community to attend hui.

Underpinning each hui were tikanga Māori (Māori customs and protocols) principles, including mihi whakatau (informal welcome), and karakia by mana whenua (local iwi), and/or Māori staff from the venue where the hui was held. After mihi whakatau and karakia, kai (food) was shared to transition from tapu to noa (safe/free from sacredness) and enact whakawhanaungatanga and manaakitanga.

At each hui, CCN staff, Māori and non-Māori health professionals and researchers delivered presentations, as did patients who shared their cancer journey. Following the presentations, those who attended the community hui were asked to separate into groups that were most relevant to their needs and interests. These groups represented prevention, screening, diagnosis, treatment, palliative, and supportive care. A similar process occurred at the four-stakeholder hui, with participants being divided into subgroups. The first hui focused on supportive and palliative care, second hui theme was prevention and screening, the third hui concentrated on diagnosis and treatment, and the last hui was enablers, exploring data, workforce, and research. Participants at both the community and stakeholder hui were asked a series of questions (refer to Appendix 1) by facilitators, and information was recorded on flip charts.

Participants also had the opportunity to voluntarily complete a hard copy survey at all hui. Both surveys were developed by CCN. The survey presented at the community hui is attached as appendix 2 and consisted of a series of questions that covered demographics, screening, health promotion, diagnosis, treatment, palliative care, and an evaluation of how they found the hui.

The stakeholder hui had an open-ended feedback survey (refer to Appendix 3). The survey of eight questions consisted of respondent ethnicity and how improvements can be made across the different stages of the

cancer continuum, including Māori cancer data, workforce, and research.

The survey information was cleaned and entered by CCN staff on to SurveyMonkey with the assistance of Te Mata o te Tau. A quality check of the information entered into SurveyMonkey was completed by Te Mata o te Tau staff and any queries addressed with CCN. During the quality check it became evident there was missing information; for example, demographics of respondents at each hui and partially completed surveys. This may have been due to the design and methodology employed by CCN.

## Information Analysis

As noted in the beginning of this section the framework used to structure the analysis for the open text of both the community and stakeholder hui was Koia (2019) He Pito Ora model. For the remainder of the community survey a descriptive analysis was also conducted to provide basic information in the form of graphs and tables.

Also, during the analysis, it became evident that there was a high number of partially completed community surveys (75.6%, 413n); however, as valuable information was provided in those surveys, it was decided to analyse all surveys.

In the design of the community hui survey, the term 'whānau' was generalised when referring to a Māori health consumer, patient or whānau member. Therefore, it was important for the analysis to define the different Māori health consumer groups in this report to acknowledge the multiple roles of Māori as health consumers, patients and whānau. The first group are Māori who access detection or screening services and have not yet received a histologically confirmed diagnosis of cancer, referred to as Māori health consumers. The second group is Māori patients who have confirmed diagnosis of cancers. The third group is whānau and are classified as Māori health consumers and those whānau supporting the patient.

# Community Hui Feedback

As noted in the previous section, seven community hui were organised by the CCN team and held in MidCentral, Whanganui, Taranaki, Hawke's Bay, Wairarapa, Hutt Valley and Capital and Coast DHB regions to capture Māori health consumers', patients', and whānau experiences and views about their cancer care journeys.

The feedback below is constructed on stories from the subgroups, and information recorded on the surveys. No information from those under the age of 16 was used in the analysis except in the demographics. **The structure of this section is based on the survey layout, with some subheadings determined by the main point of each question.** The demographics are based on the information of those Māori respondents who completed the survey.

## Demographics of the Māori Respondents from the Survey

A total of 546 Māori attended the seven community hui organised in the Capital and Coast (7.9%, n43), Hawke's Bay (16.2%, n88), Hutt Valley (9.3%, n51), MidCentral (16.3%, n89), Taranaki (12.4%, n68), Wairarapa (17%, n93), and Whanganui (20.9%, n114) DHB regions. The survey was answered by 546 Māori, of which 24.35%, n133 answered all questions. As noted in the information analysis section, 546 surveys were analysed. The survey was completed by a range of Māori, including Māori health consumers, patients, whānau, health researchers and others based across each of the DHB regions.

Table 1 below represents the demographics of the Māori respondents who completed a hardcopy survey at their specific community hui.

Table 1 Demographics of Māori Respondents from the Survey

Ethnicity	%	(n)
Māori	100	546
Gender	%	(n)
Male	20.9	114
Female	77.3	422
Diverse	0.55	3
No response	1.28	7
Age Range	%	(n)
Under 15	0.4	2
15-19	1.8	10
20-24	3.1	17
25-29	3.7	20
30-34	2.4	13
35-39	2.2	12
40-44	2.9	16
45-49	3.8	21
50-54	6.4	35
55-59	7.1	39
60-64	8.4	46
65-69	6.0	33
70-74	8.2	45
75-79	6.2	34
80-84	3.1	17
85+	1.1	6
No response	33.0	180
DHB Location	%	(n)
Capital Coast	7.9	43
Hawkes Bay	16.2	88
Hutt Valley	9.3	51
MidCentral	16.3	89
Taranaki	12.4	68
Wairarapa	17	93
Whanganui	20.9	114

# “Ruia te Taitea, Kohia te Rangiura”



*Te Rangiura o Wairarapa Kapahaka Group  
Ruia te Taitea, Kohia te Rangiura  
Purge the bad things, Gather the good things*

## Health Promotion

When asked about the best ways to promote health with whānau, participants were able to select more than one answer from the six options provided and, also had the opportunity to provide further comment.

The information shows that Māori events (72.9%, n398) and marae hui (70.3%, n384) were the most preferred ways of building awareness of cancer care services. The next preferred method of building awareness of cancer care services was through social media, for example Facebook (57.7%, n315). More detail is provided in Graph 1 below.

Graph 1 Health Promotion



As demonstrated in the above graph, over half the respondents believe Māori organised events and hui are the best ways to promote good health. This was reinforced by respondents who further commented that kanohi ki te kanohi is the most appropriate way to build awareness with whānau. This is reflected in the following comments.

*“Tell a whānau member word of mouth” 12*

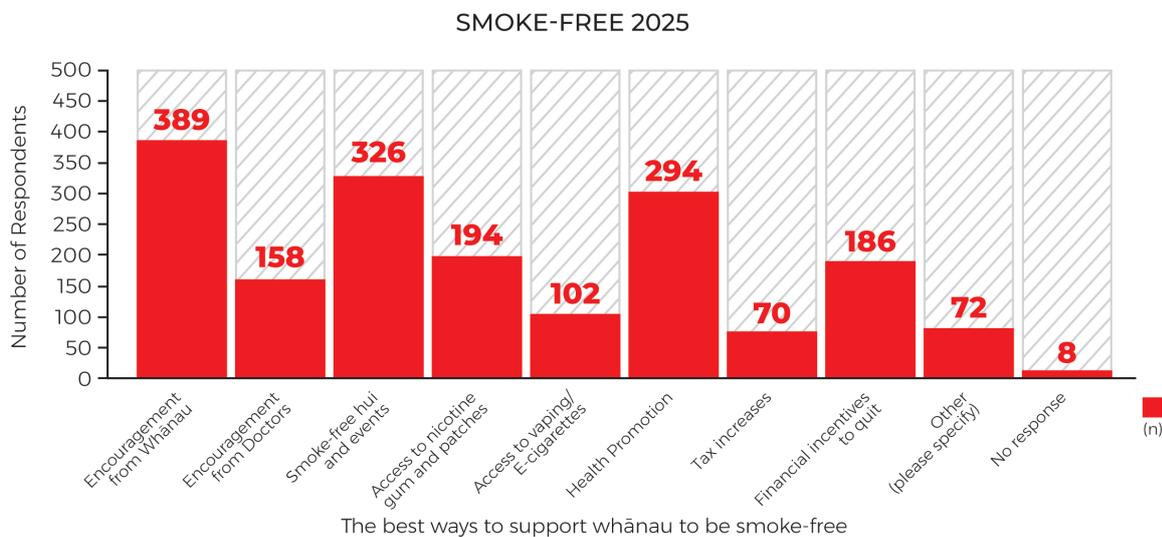
*“At whānau gathering kanohi ki te kanohi” 69*

Exploring alternative ways to promote good health was seen as being very important for building better awareness among whānau so they have healthier lifestyles.

## Smoke-free 2025

Smoking is one of the highest risk factors for cancer and, Māori have a higher rate of smoking and, higher death rate from smoking than non-Māori (Health Promotion Agency, 2016). Building awareness among whānau about the risk factors associated with smoking and encouraging those whānau who smoke to become smoke-free should be a priority for everyone. Encouragement from whānau (71.2%, n389) and smoke-free hui and events (59.7%, n326) were identified as the most appropriate ways to support whānau in becoming smoke-free. Graph 2 provides more information.

Graph 2 Smoke-free 2025



Further comments emphasized the importance of whānau to take control in becoming smoke-free.

*“Encouragement from whānau not lectures” 16*  
*“Let the whānau lead what is the best way for them” 67*

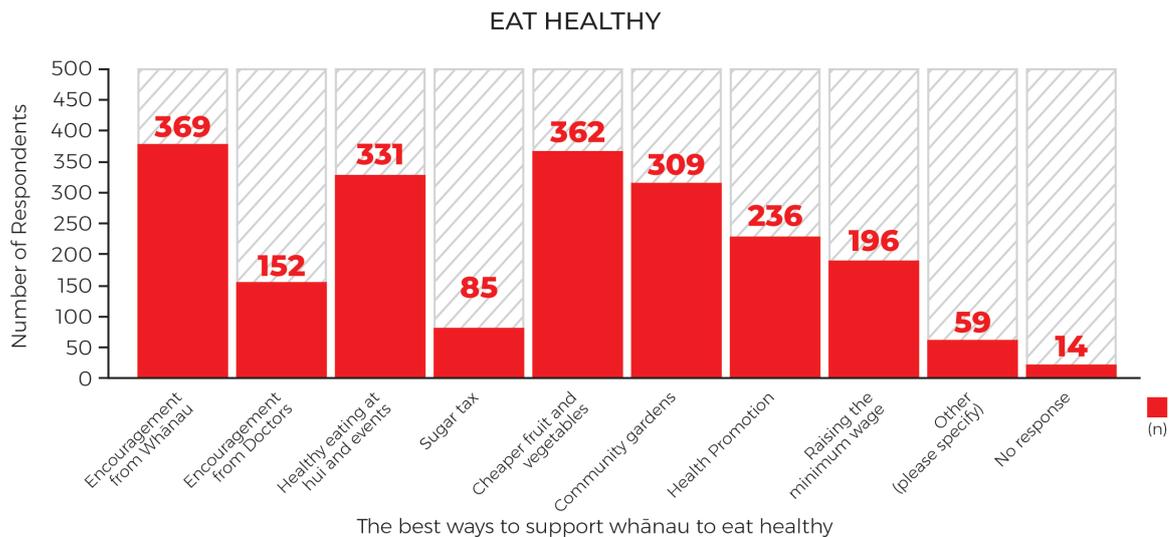
## Encourage and Support Healthy Living

Many illnesses are preventable through healthy living and being more active (Ministry of Health, 2018c). Respondents were asked three questions about their views on healthy eating, active lifestyles and the level of intake of alcohol. The responses from each question are illustrated in three separate graphs in this section.

## Eat Healthy

In regard to healthy eating, respondents believed encouragement from whānau (67.58%, n369), healthy eating at hui and events (60.62% n331), and having access to cheaper fruit and vegetables (66.30% n362) were important steps towards the goal of healthy living. Graph 3 provides more detail.

Graph 3 Eat Healthy



An additional suggestion by respondents was whānau doing their own home garden.

*“Growing own veggies etc and sharing” 38*

*“Individual home gardens” 52*

Planting, caring, and harvesting from a home garden offers a number of benefits to whānau; however, some whānau may need guidance, and opportunities to be involved in community gardens could be one way of learning and sharing knowledge.

*“Develop personal/skills opportunities to increase knowledge to grow own kai” 24*

*“Maara kai wanānga.[meeting about vegetable gardens]” 39*

## Exercise and Get More Active

Respondents were also asked about the best ways to support whānau to be more active. Most of the respondents identified encouragement from whānau (65.57% n358) as the most appropriate way to support whānau to exercise. As an incentive, respondents believed access to free/cheap gym membership (65.38% n357) and, free/cheap sports clubs (53.85%, n294), would increase and sustain whānau physical activity goal. Graph 4 provides detail on the views respondents had regarding whānau activity.

Graph 4 Exercise and Get More Active



Traditional Māori activities were seen by respondents as a way of increasing physical well-being. These activities included kapa haka (Māori cultural groups) and mau rākau (Māori weaponry).

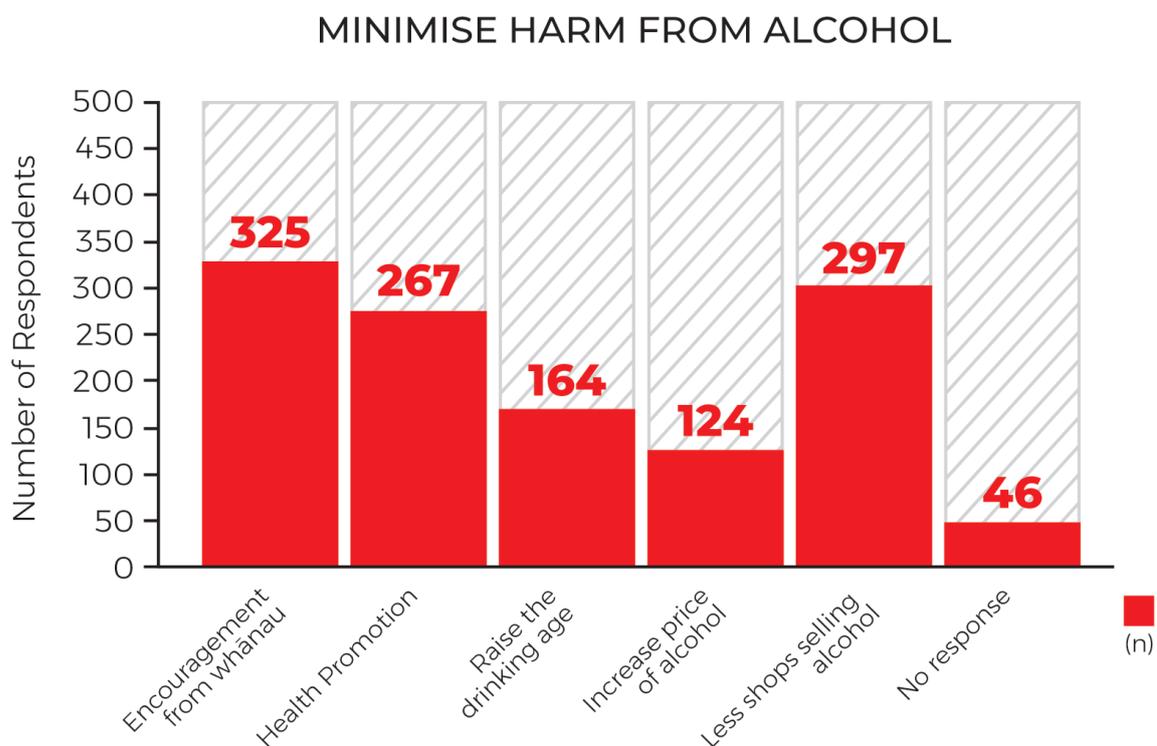
*“Kapa haka group” 7*

*“Māori exercise traditional to resurrect” 17*

## Minimise Harm from Alcohol

As part of healthy living, the level of alcohol consumption has been identified as another high-risk factor for cancer (Ministry of Health, 2019c). Reducing the consumption of alcohol can minimise harm to your health. Again, encouragement from whānau (59.52%, n325) was viewed as the most appropriate way to support whānau members to reduce their intake of alcohol. To aid in this process, limiting access or ease of access by reducing the number of shops selling alcohol (54.39%, n297) would assist whānau to minimise harm from alcohol. Health promotion (48.9%, n267) activities were ranked as the third choice by respondents. Graph 5 provides further detail.

Graph 5 Minimise Harm from Alcohol



The best ways to support whānau to minimise harm from alcohol

Respondents were then asked a series of questions related to several viruses or bacteria that may contribute and possible increase the risk of cancer.

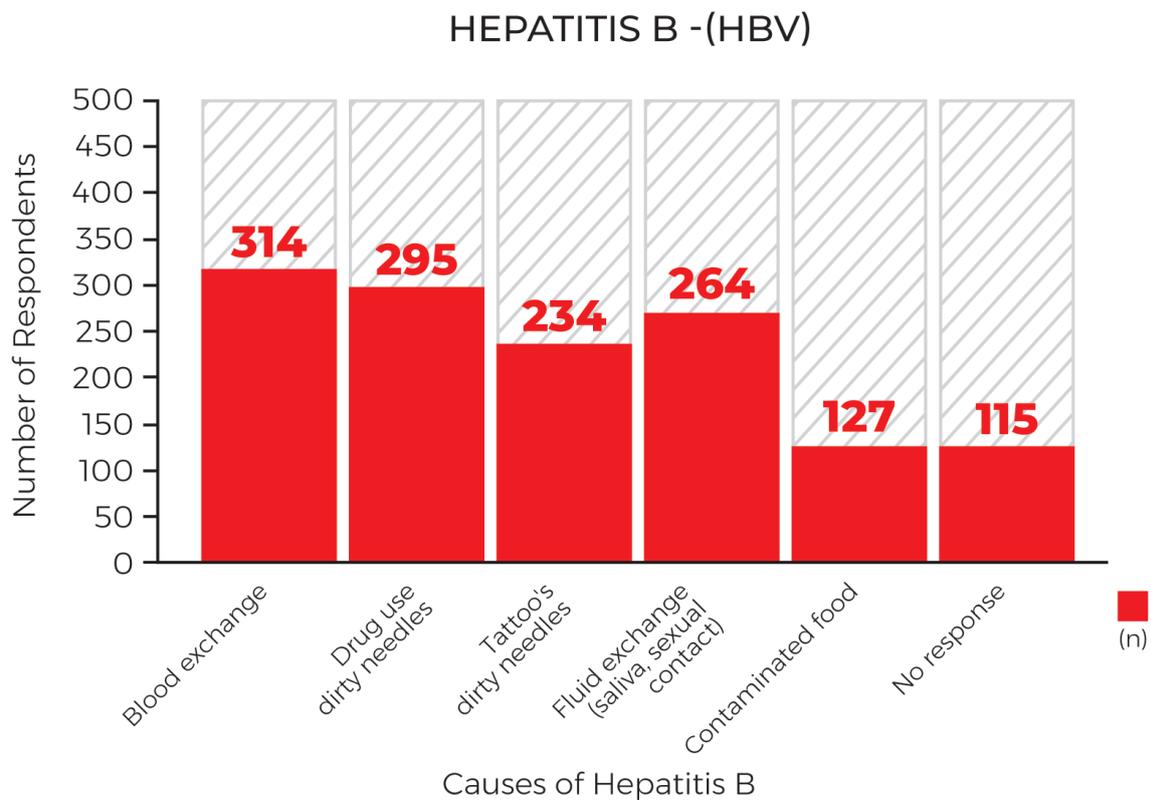
## Cancer and Infections

To gain an understanding of the level of awareness in the Māori community, respondents were asked two questions relating to Hepatitis B Virus (HBV), Hepatitis C Virus (HCV), Human Immunodeficiency Virus (HIV), Human papillomavirus (HPV), and Helicobacter pylori bacterium (H. pylori), which is believed to cause or, increase the risk of cancer. The first question asked respondents whether they had ever heard of each of the viruses and/or the bacterium. The follow up question asked whether respondents knew the cause of each specific virus and bacterium (they were asked to choose from the options provided on the questionnaire).

## Hepatitis B (HBV)

For HBV, 65.93% (n360) answered yes, while 10.07% (n55) said *no*, and 23.99% (n131) *did not answer the question*. Over half the respondents (57.51%, n314) identified blood exchange, including sharing of needles (54.03%, n295) as the main cause of passing on HBV. Fluid exchange also had a high response rate (48.35% n264). Further details are outlined in Graph 6. It is interesting to note that several respondents (23.26%, n127) identified an incorrect mode of transmission, such as contaminated food.

Graph 6 Hepatitis B

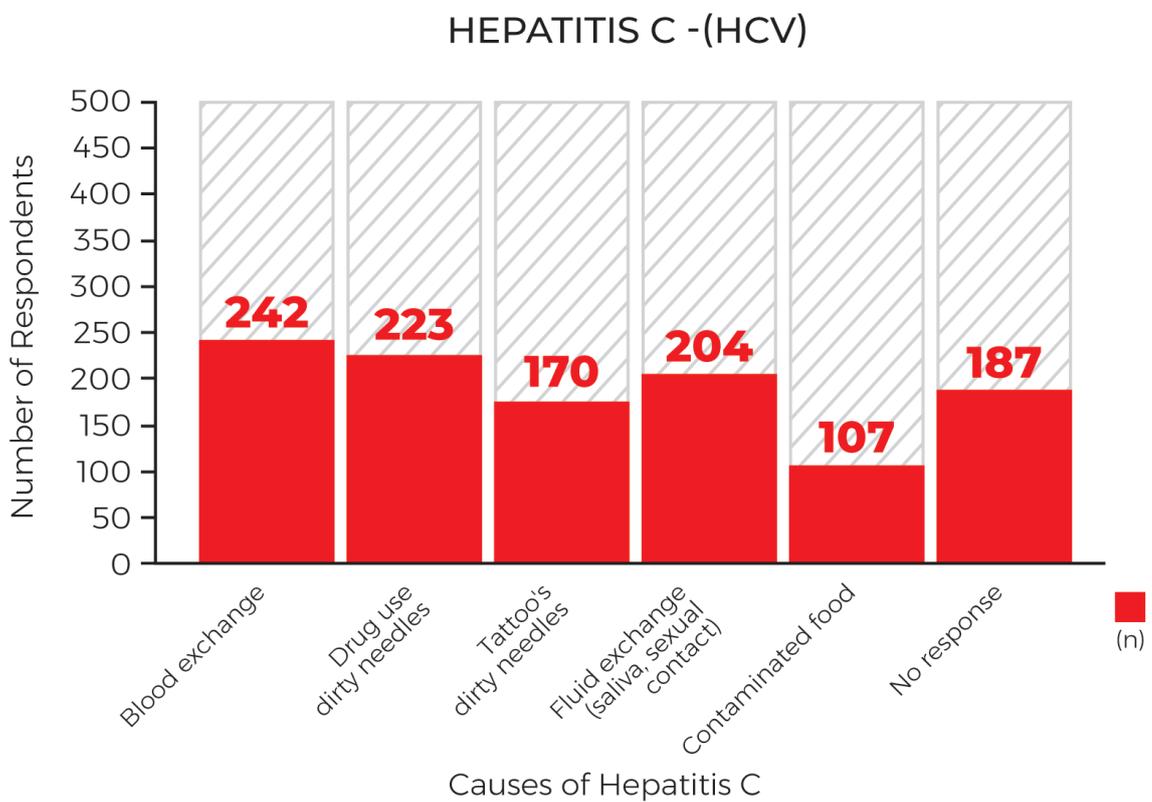


## Hepatitis C (HCV)

In regard to HCV, there were slightly less people (52.01%, n284) who answered yes to the question on whether they knew about HCV, 18.86%,(n103) answered *no*, while 29.12% (n159) respondents did not provide a response.

Slightly less than half the respondents were aware of the ways in which HCV was passed on. Blood exchange (44.32%, n242) and drug use through dirty needles (40.84%, n223) were the main modes of transmission, and fluid exchange (37.36%, n204) was ranked third. However, there were incorrect responses, where 19.60% (n107) identified contaminated food as a transmission mode for HCV (this incorrect mode of transmission was also previously identified with HBV). Graph 7 outlines more details.

Graph 7 Hepatitis C

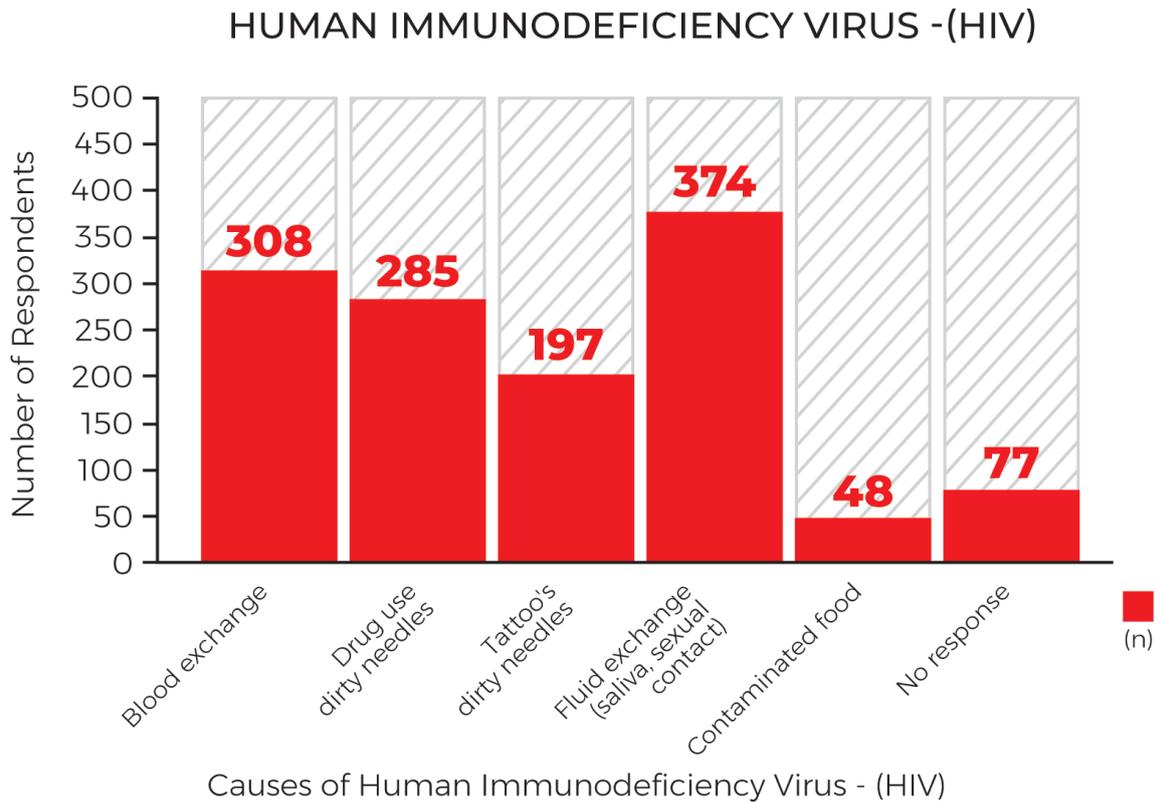


## Human Immunodeficiency Virus (HIV)

The survey also asked if people knew the term HIV aids and what some of the methods of transmission might be. Of those who responded to the first question, 67.58% (n369) answered yes, and only 4.95% (n27) chose *no*. There was *no response* from 27.47% (n 150). However, an increased number of respondents answered the second question.

It appeared that many respondents who answered *no* or *did not respond* to the first question selected answers to the second question. It is unclear why this occurred. The most common form of transmission of HIV was exchange through fluid (68.50%, n374) or blood (56.41%, n308), followed by use of dirty needles (drug use) (52.20%, n285). For the third time in this survey, (along with HBV and HCV) contamination from food (14.10%, n77) was incorrectly chosen as a method of transmission of HIV. Graph 8 has more details.

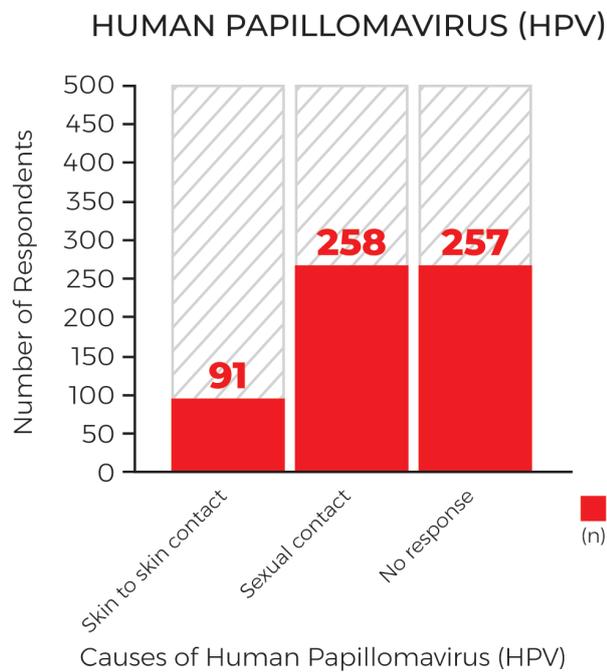
Graph 8 Human Immunodeficiency Virus - HIV



## Human Papillomavirus (HPV)

Less than half the respondents were aware of HPV, with 40.48% (n22) answering yes, 35.35%, (n193) said no, and 23.81% (n130) did not answer. However, when asked how HPV infection was caused, 47.25% (n258) reported through sexual contact, and 16.67% (n91) from skin to skin contact, both of which are correct. However, almost the same percentage 47.07% (n257) did not respond. Given that for question one, over half of the respondents either answered no or did not respond, and for question two just under half did not respond, this raises the question whether there was a lack of knowledge as to how HPV was transmitted or whether this particular medical term was unknown thus creating confusion. Graph 9 below illustrates respondents' response to how HPV was caused

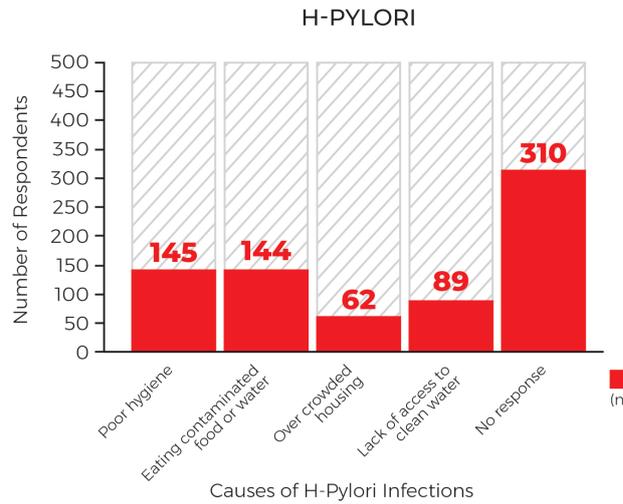
Graph 9 Human Papillomavirus HPV



## H-Pylori

Only 23.99% (n131) respondents answered yes to having heard about H-Pylori and that it could cause stomach ulcers. The other respondents either answered no 50.18% (n274) or did not respond (25.82%, n141). These results suggest respondents are unfamiliar with and/or lack knowledge of H-Pylori, its transmission, and its role in diseases such as stomach ulcers and cancer.

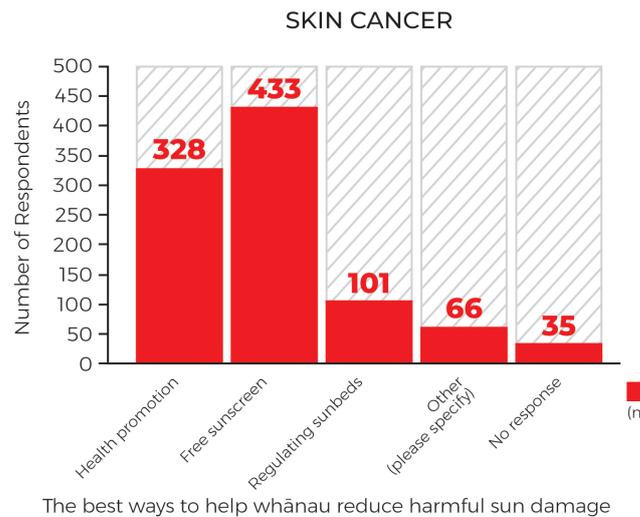
Graph 10 H-Pylori



## Skin Cancer

When asked about the best ways to help whānau reduce harmful skin damage, the majority of respondents answered free sunscreen (79.30%, n433) and more health promotion (60.07%, n382). Graph 11 provides further detail.

Graph 11 Skin Cancer



Further comments from respondents also suggested that covering up, and wearing a hat might also help.

*“Wear protective clothing” 41, “Cool potae (hat)” 1*

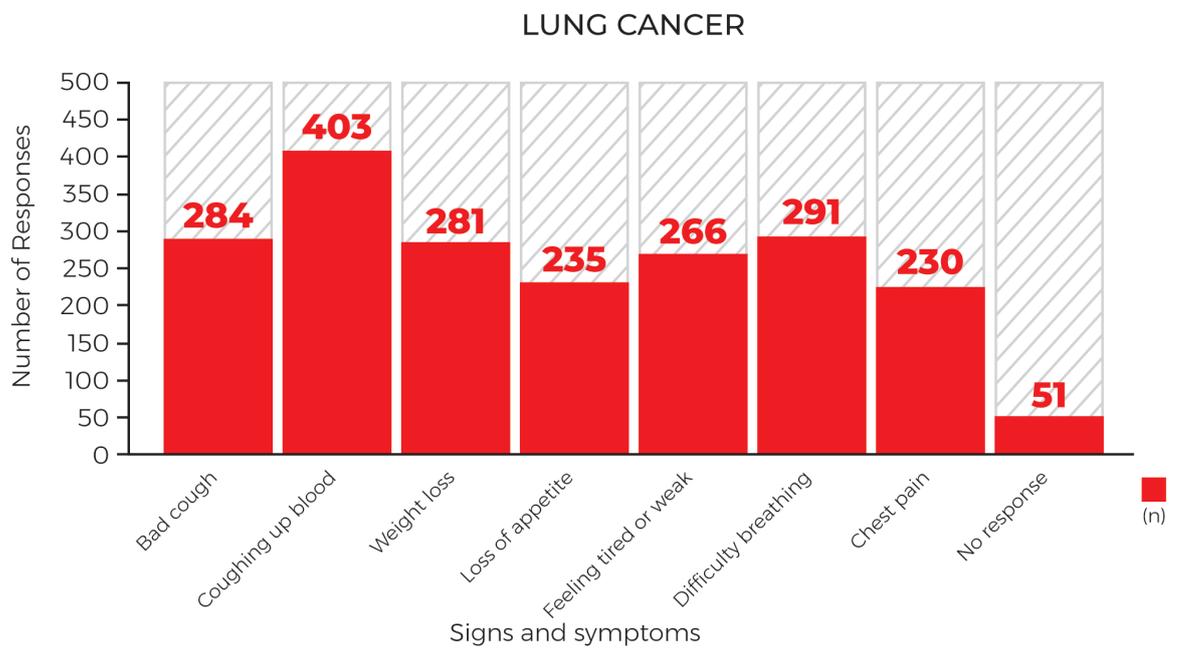
## Early Detection of Cancer

Increased awareness of possible signs and symptoms is crucial in helping improve cancer survival rates. Thus, respondents were asked about the signs and symptoms of the five most common cancers occurrence for Māori: lung, breast, cervical, prostate, and bowel cancers (Ministry of Health, 2018a). Graphs for each of these cancers are presented below.

### Lung Cancer

Most of the respondents selected coughing up blood (73.81%, n403) and difficulty in breathing (53.30%, n291) as the two most common signs of lung cancer. Graph 12 outlines further information.

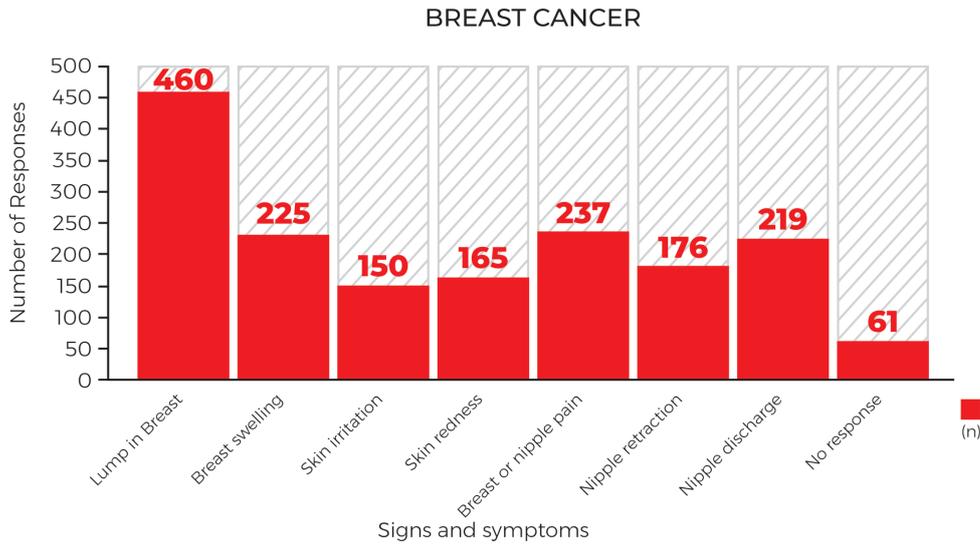
Graph 12 Lung Cancer



## Breast Cancer

If found early, breast cancer survival rates can be high. The symptom that people were most aware of for breast cancer was a lump in the breast (84.25% n460). Breast swelling (41.21%, n225) and nipple pain (43.41%, n237) were also commonly identified. Graph 13 provides further information.

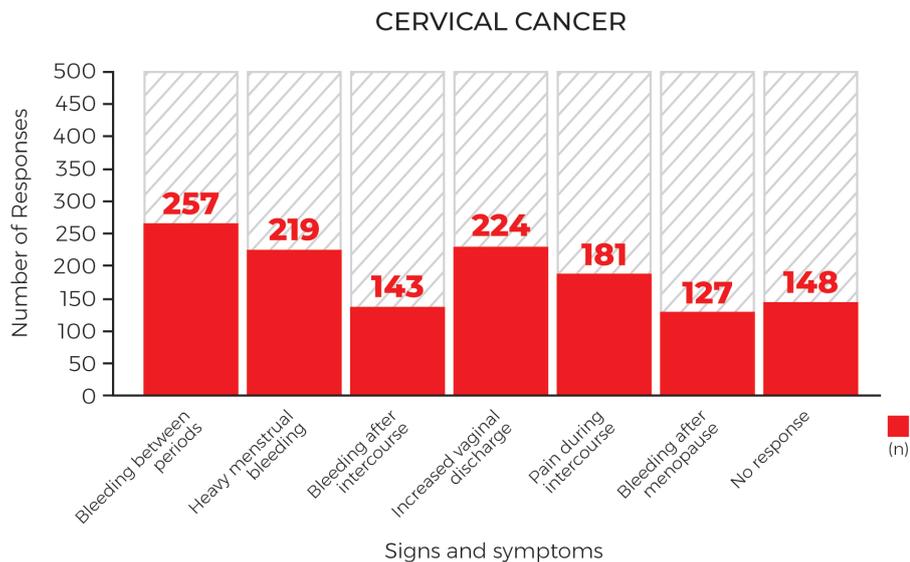
Graph 13 Breast Cancer



## Cervical Cancer

Cervical cancer can be caused by HPV infection (Cancer Net, n.d). The most common symptoms with which respondents were familiar were bleeding between periods (47.07%, n257), increased vaginal discharge (41.03%, n224), and heavy menstrual bleeding (40.10%, n219). Graph 14 outlines more details.

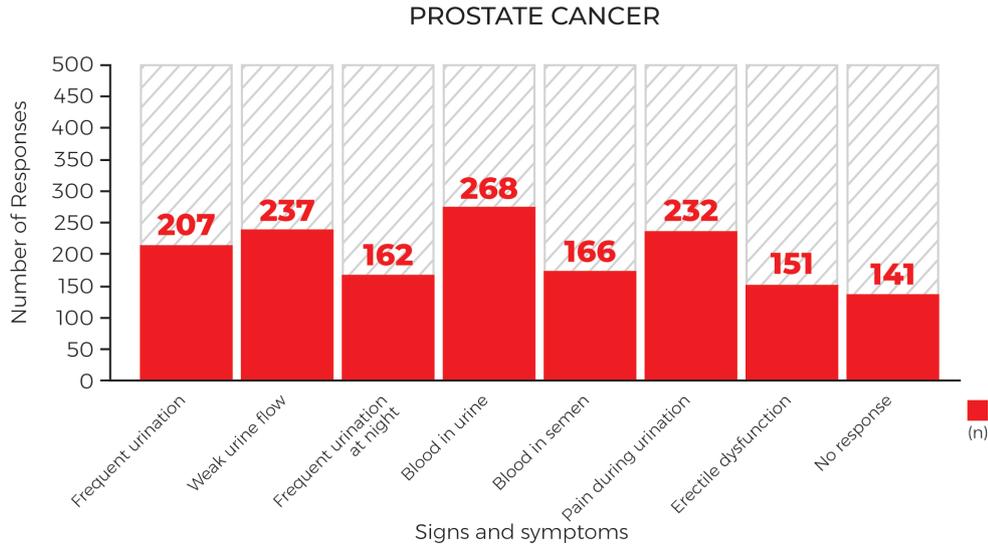
Graph 14 Cervical Cancer



## Prostate Cancer

Prostate cancer is the most commonly diagnosed cancer among men (Ministry of Health, 2018a). If diagnosed early there is a better chance of successful treatment. The common signs identified by respondents were blood in the urine (49.08%, n268), weak urine flow (43.41%, n237) and pain during urination (42.49%, n232). Graph 15 provides further details.

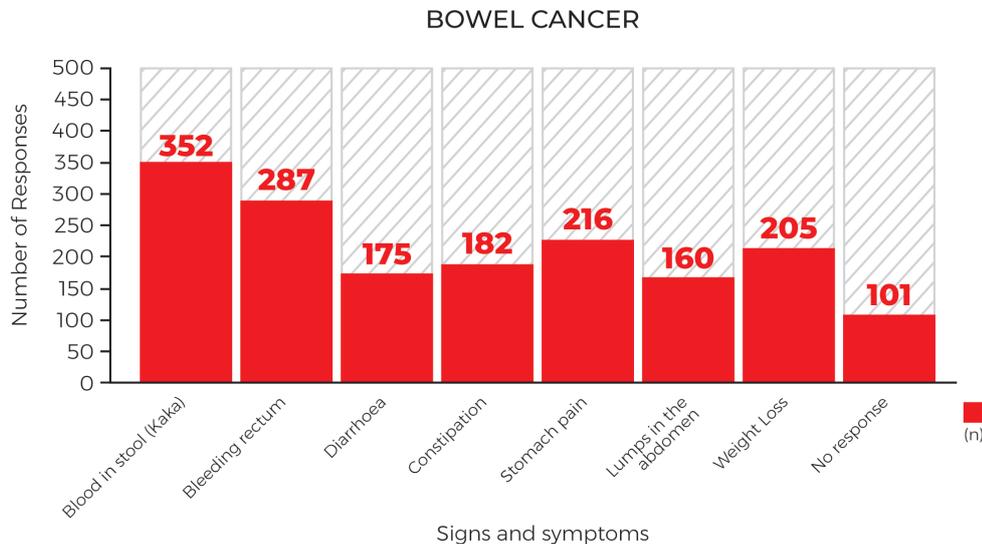
Graph 15 Prostate Cancer



## Bowel Cancer

Bowel cancer is also of concern for Māori. Detected early, treatment can be successful. Over half the respondents associated blood in the stool (64.47%, n353) and bleeding from the rectum (52.56%, n287) as the signs for bowel cancer. Graph 16 below has more detail.

Graph 16 Bowel Cancer



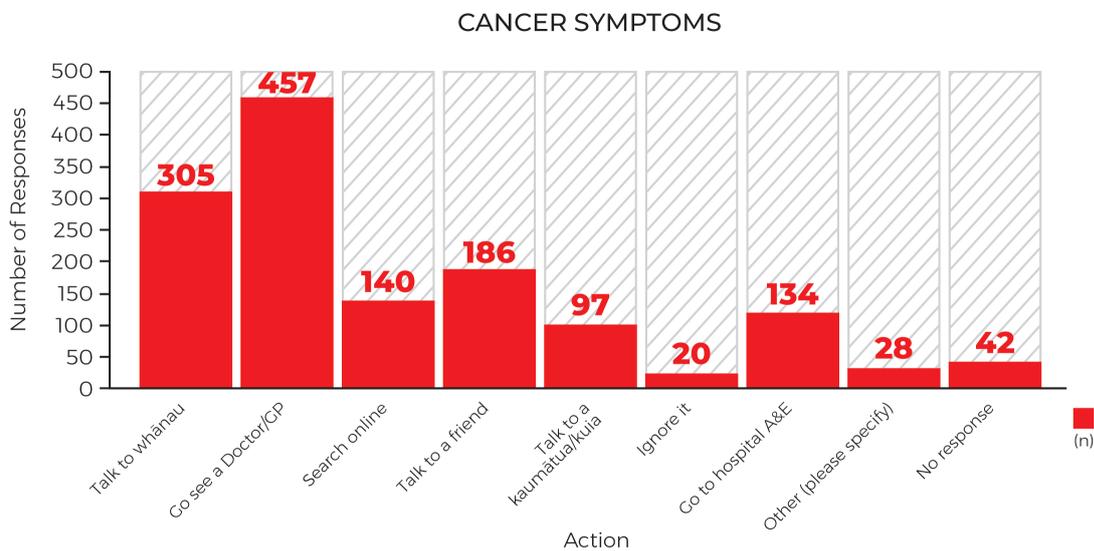
## Primary and Community Care

In this section, respondents were asked a series of questions related to who they would contact if they experienced any cancer symptoms highlighted in the five cancers mentioned above and which factors that might improve access and the quality of primary care.

### Cancer Symptoms

In relation to who respondents would contact, they were offered seven choices and could select more than one, with an option to provide further comment. Many answered that they preferred to go and see their doctor/GP (83.70%, n457) and/or discuss the matter with their whānau (55.86%, n305). Graph 17 provides further information.

Graph 17 Cancer Symptoms



Narratives provided by respondents related to the cost seeing a doctor included,

*“Drs and GPs cost too much to go to. So, don’t go” 2*

Other respondents preferred to contact a Māori or iwi health provider and talk with a rongoā practitioner or a whānau ora navigator. The Māori or iwi health providers have a better understanding of the patients and their communities compared with many of the clinical health professionals across the health sector. This enables Māori or iwi health providers to understand the influence of the social determinants of health that impacts on patients and their whānau.

*“Ring local Iwi provider” 26*

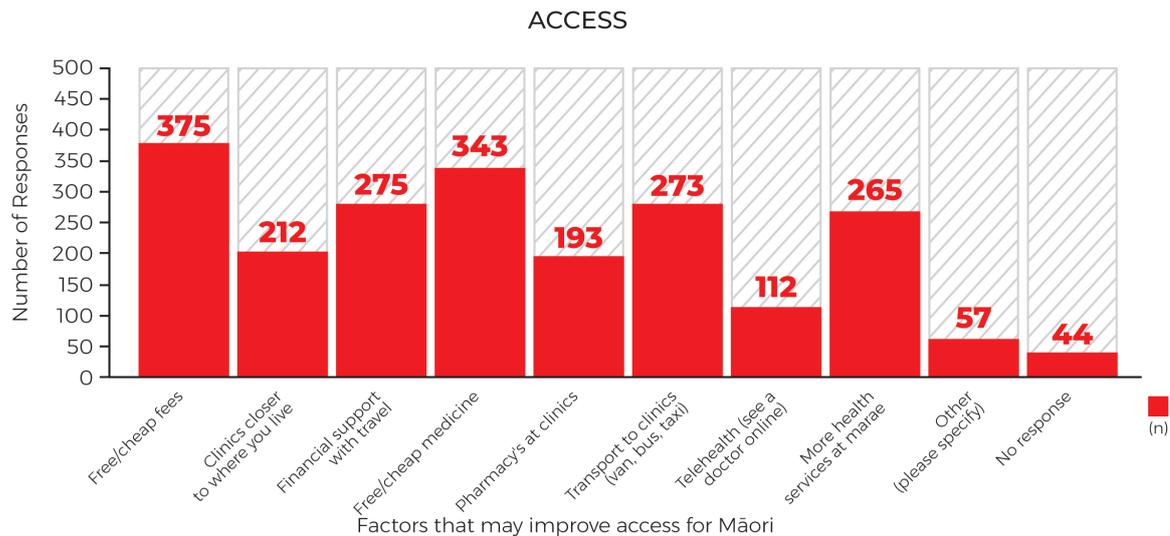
*“Whānau ora navigator (cancer support)” 27*

*“Rongoā practitioner” 5*

## Access

To improve timely access to primary care services, respondents felt the cost of accessing primary care service and prescriptions needed to change as things were too expensive. Free fees or low-cost services (68.68%, n375) and medication (62.82%, n343) were identified as being crucial to improving access for Māori. This is illustrated in Graph 18.

Graph 18 Access



Respondents also made further statements highlighting the extended length of time some whānau must wait to see a doctor. They suggested patients should be made aware of this and given the option of seeing a practice nurse or provided with an alternative solution.

*"Able to access Doctors instead of a 2/3 week waiting time" 40*

*"[Access to] Nurse clinics. Time delays in GP appointments. Too booked up" 26*

Once patients have an appointment, they face further challenges of poor frontline service and lack of cultural understanding by staff. Ongoing cultural development of all staff was viewed as being necessary.

*"Improve attitudes of staff at frontline like receptionist" 21*

*"GPs to be more culturally understanding, more training in taha wairua [spiritual side] and the Māori world view" 38*

Another important area highlighted by respondents was the need for more Māori health professionals in primary health care. Access to more Māori GPs and health providers and the provision of some form of culturally safe environment for whānau were noted.

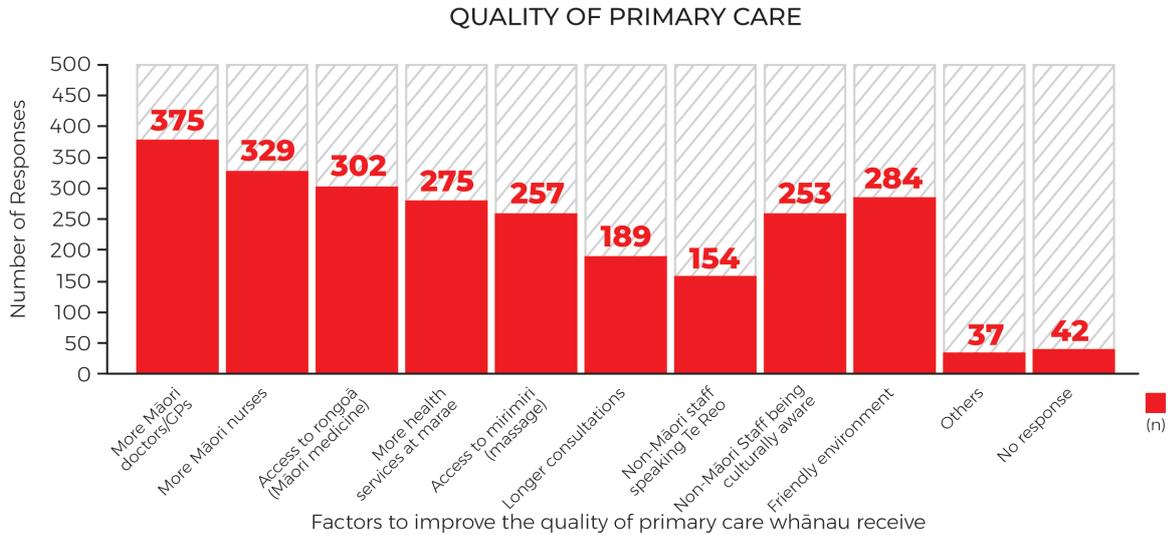
*"Navigators, Iwi advocates to walk with whānau" 55*

*"More Māori GPs" 9*

*"More Non-Government Organisations NGO's Māori Service Providers" 1*

Once again cultural support was identified as crucial to improve Māori patients and whānau experiences. Respondents highlighted the need for building the Māori health workforce for Māori doctors and GPs (68.68%, n375) and Māori nurses (60.26%, n329). Offering all patients access to rongoā Māori (55.31%, n302) was also viewed as being important in providing holistic care. Graph 19 provides further detail.

Graph 19 Quality of Primary Care



Further comments were made by many respondents identifying what an appropriate environment should look like, including being nice, culturally responsive, and more welcoming by greeting Māori patients in te reo Māori.

*“More welcoming clinics for Māori, greeted in Māori, manaakitanga, whanaungatanga” 39*

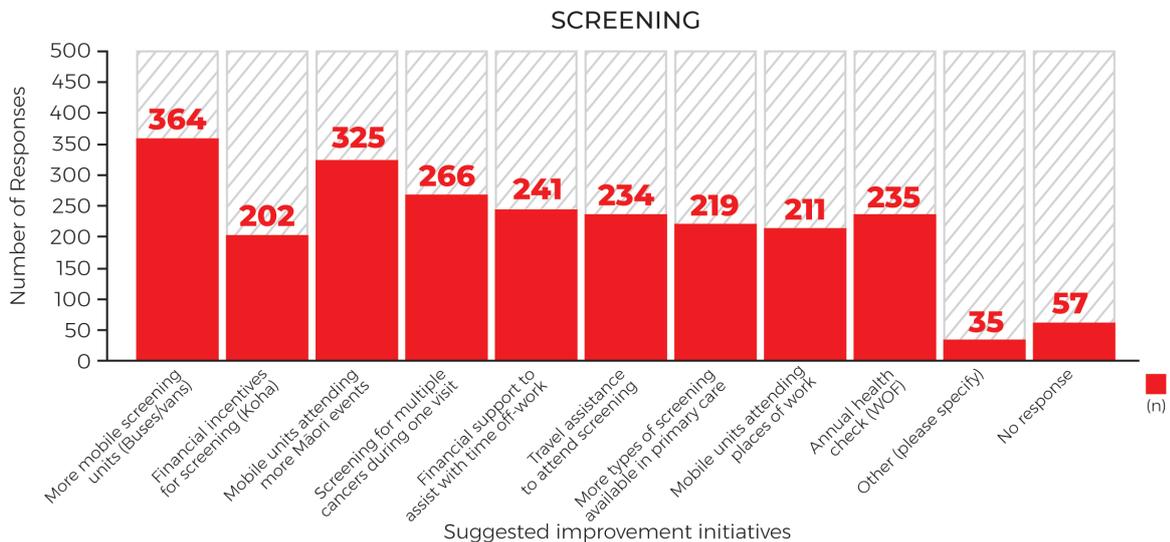
*“Family friendly” 33*

*“Be Kind” 17*

## Screening

Respondents were asked to choose from a series of options as to what they thought would help improve screening for Māori. Over half the respondents selected mobile screening units (66.67%, n364) and said these units should be present at more Māori events (59.52%, n325). Graph 20 provides further explanation.

Graph 20 Screening



Respondents made further comments identifying the need for mobile units to consider visiting other venues where large numbers of Māori gather, such as the marae, schools, and tāne, wāhine and youth groups.

*“Mobile units at Marae” 10*

*“Attending schools. 31”*

*“Have group clinics for example, women’s church group, [and] youth group clinics”30*

Difficulties with inflexible appointment times was also problematic for some participants. Taking time off work, finding caregivers to look after children while their parents attend screening appointments, were two examples given by respondents. They suggested more flexibility be considered.

*“Alter times i.e. access at night as whānau can’t get off work or no childcare” 31*

In addition, respondents highlighted the importance of feeling safe and respected when accessing screening programmes. Building trusting relationships with health providers was viewed as being crucial in improving Māori health and well-being.

*“I have built trust and rapport with them.” 19*

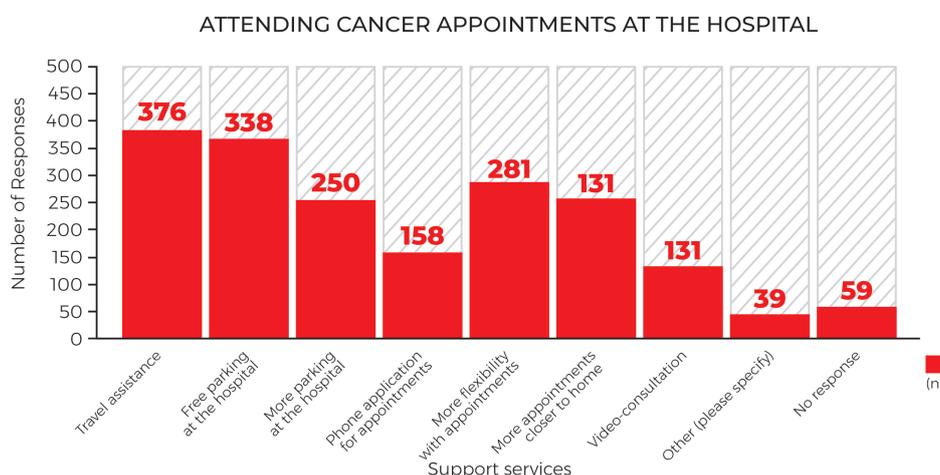
*“Māori feel. Making checks comfortable” 16*

## Diagnosis and Treatment

Timely access to diagnosis, treatment, and quality hospital care is crucial to cure or extend the life of a cancer patient. Respondents were asked three questions pertaining to diagnosis and treatment. Respondents selected from multiple options provided on the questionnaire. The first question was about the different types of support needed for whānau to attend their cancer appointments at the hospital.

The financial impact of attending appointments can play a significant role in treatment. Many whānau did not have the financial means to attend their appointments or pay for parking while they were at hospital clinics. Several of the respondents did not live close to hospitals and found it difficult to get to their appointment on time or were feeling too unwell to organise transport. Travel assistance (68.86%, n376), availability of free parking at hospitals (61.90, n338), and flexible appointment times (51.47%, n281) were identified as very important in helping whānau get to the hospital. Graph 21 provides further details.

Graph 21 Attending Cancer Appointments at the Hospital



Respondents also made further comments and reiterated the need for flexible appointment times.

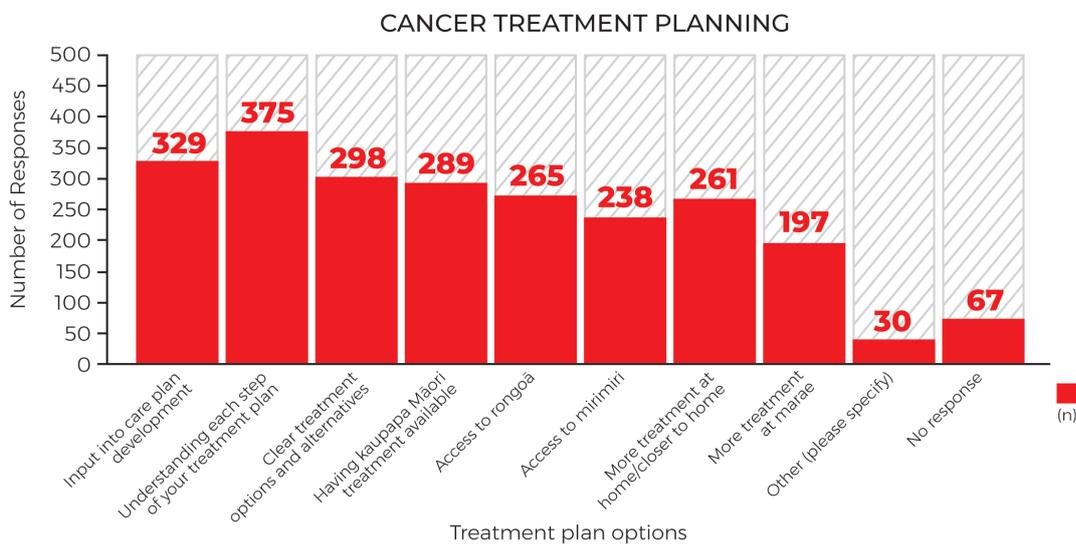
*“Appropriate times of day, for example, for Kapiti patients who have appointments @ CCDHB to get [an] 8am appointment is not realistic for my kaumātua [elder] to get to, let alone one at 4pm” 6*

*“Later hours as many have to take a whole time off work for the sake of half hour appointment” 14*

Respondents were also asked what would improve cancer treatment planning for whānau before receiving treatment. Being able to make an informed decision was seen as the most important aspect in this area.

At least 68.32% (n373) wanted to understand each step of their treatment plan and 60.26% (n329) wanted to have input into the development of their care plan. Graph 22 gives more information.

Graph 22 Cancer Treatment Planning



Respondents also provided further comments identifying how crucial whānau involvement was the success of their whole cancer journey.

*“Whānau involved in the whole process” 10*

*“Make sure all whānau members know exactly what has happened, and what needs to happen, the whānau role” 15*

To assist the patient and their whānau, access to a support person like a cancer care or whānau ora navigator would assist patients and whānau understand what they are being told by health professionals.

*“Support person to translate all medical information” 1*

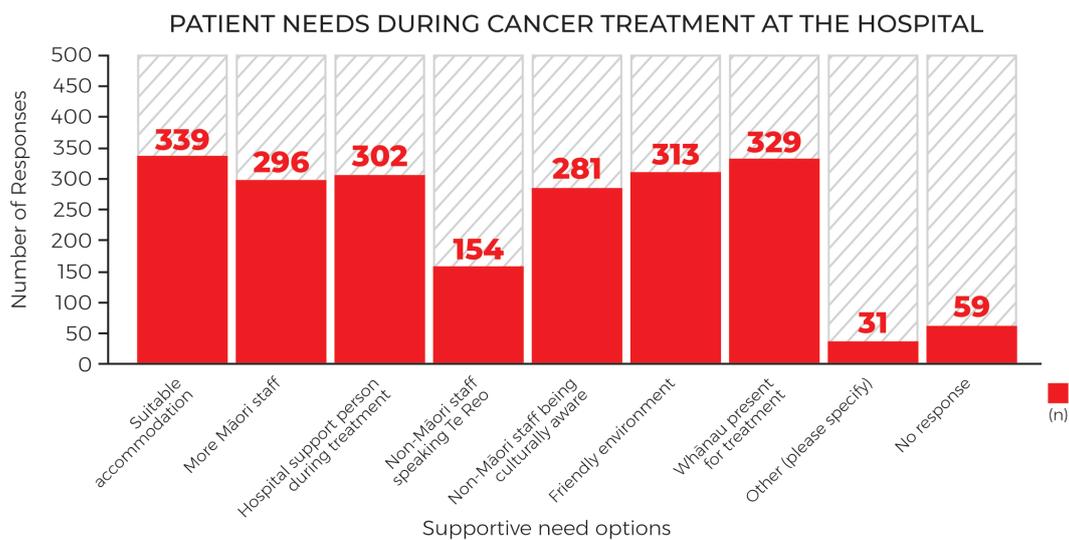
*“A support person at consultation” 29*

*“[Access to] Whānau ora ...navigators” 28*

Supporting patients during their cancer treatment while at the hospital is also crucial. Respondents were asked to identify, from a number of options, the factors they thought would improve patients experiences in this area.

The two most important factors were suitable accommodation (62.09%, n339) and having their whānau present for treatment (60.26%, n329). A friendly environment (57.33%, n313) so patients and whānau would feel welcome and comfortable during their hospital stay also made a difference to patients' overall wellness. Graph 23 provides further detail.

Graph 23 Patient Needs During Treatment at the Hospital



Further comments made by respondents described the friendly environment as a space where they felt culturally safe, cared for, and treated with respect. For some, this was expressed as being treated by staff who were culturally aware and competent. This included having an appropriate knowledge of Māori cultural practices.

*“Be Kind” 16*

*“Respectful staff” 14*

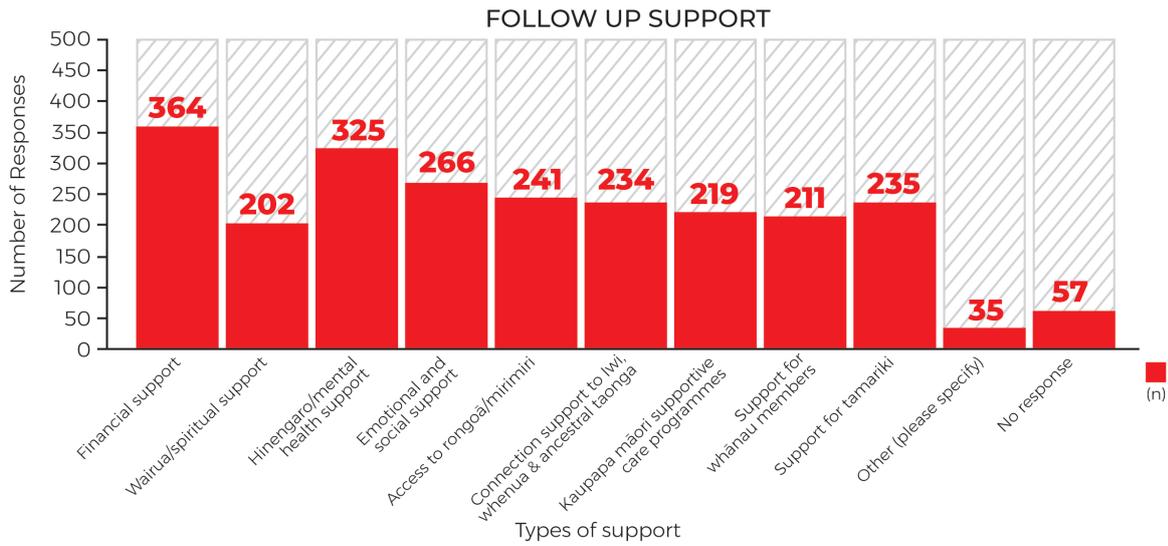
*“All staff should be culturally aware” 1*

*“Understand Māori place of wellness” 8*

## Follow Up Care

Respondents were asked how supports for whānau recovering from cancer treatment could be improved. Respondents could choose from a series of options. Support for whānau members who were assisting with the care of patients was regarded as important (62.09%, n339), as was financial assistance (59.89%, n327) for whānau. Wairua/spiritual support (56.23%, n307) also play a pivotal role in after treatment. Graph 24 provides further detail.

Graph 24 Follow Up Support



Further comments were made highlighting the need for better funding for whānau caregivers (62.09%, n339) when patients require respite care.

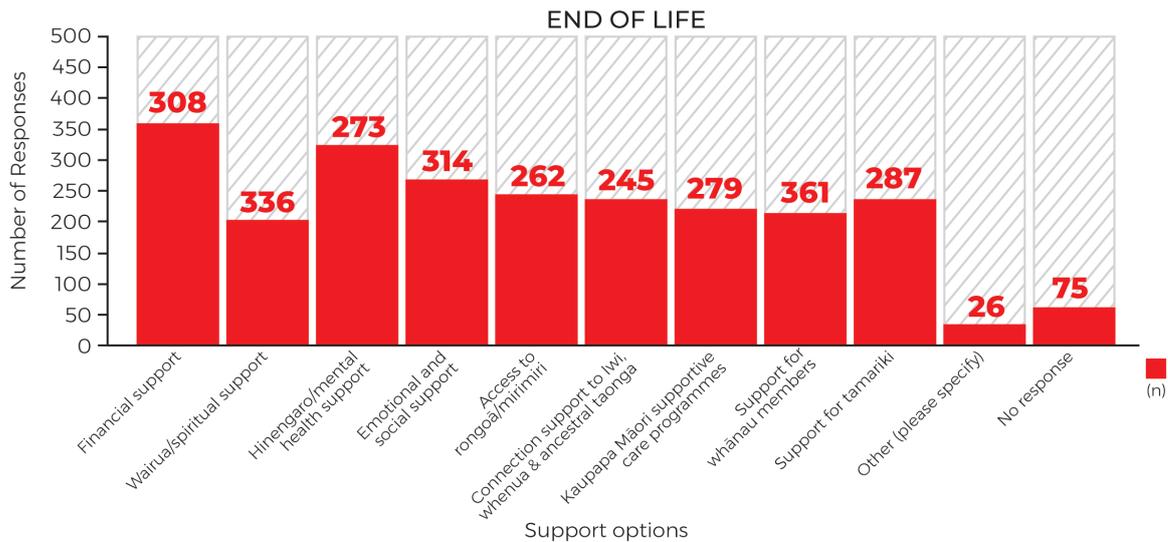
*“Funded home help over night to give whānau reprieve” 4*

*“Home help especially at night. More respite” 10*

## End of Life

Respondents were also asked how supports could be improved for patients at the end-of-life stage of their journey. Again, whānau support (66.12%, n361), access to wairua/spiritual support (61.54%, n336), and financial support (56.41%, n308) were identified as very significant. Graph 25 has more detail from respondents.

Graph 25 End of Life



Many Māori whānau do not talk about preparing for death. For some, this is viewed as being tapū and seen as calling for someone to die earlier than expected. However, respondents spoke about the need for support to talk with the wider whānau to prepare for when their loved one dies.

*“Help with setting affairs, ‘will’, Advance Care Planning” 14*

*“Facilitated whānau hui to develop advanced care plan” 18*



Naku te rourou,  
nau te rourou,  
ka ora ai te iwi

*Theresa Patu & Ropata Maxwell (Taranaki)  
Naku te rourou, nau te rourou, ka ora ai te iwi  
With your food basket and my food basket the people will thrive*

# Stakeholder Hui

The purpose of the stakeholder hui was to gather the views from those that access and work in cancer care services to improve cancer outcomes for Māori.

**F**our stakeholder hui were organised: two in Palmerston North and, two in Wellington. In Palmerston North, one hui focused on supportive and palliative care and the other concentrated on prevention and screening. The hui in Wellington focused on diagnosis and treatment and, the other hui explored the health system enablers (data, workforce, and information).

The feedback below is constructed from information recorded on the stakeholder feedback survey that asked eight open-ended questions and was structured on Koia's (2019) He Pito Ora model. The demographic information is based on all those that completed the feedback survey.

## Demographics from the Stakeholder Hui

The only available demographic information recorded was ethnicity, outlined in Table 3 below. No information was available to provide a breakdown of gender, age, occupations, and DHB locations.

Table 2 Demographics from the Stakeholder Hui

Ethnicity	%	(n)
Māori	42.86	33
NZ European	50.65	39
Samoaan	2.6	2
Indian	2.6	2
No response	3.9	3

## Whanaungatanga

When talking about engaging with health services, respondents identified the importance of building trusting relationships. This includes kanohi ki te kanohi, spending more time with patients and whānau, and providing friendly and safe environments so patients and whānau can feel comfortable attending appointments.

*"Consumer trust in services" 4*

*"Services that are approachable, non-intimidating and flexible" 5*

*"Spend more time so can cover the whole person. Make Māori people feel comfortable" 48*

Many patients and whānau are shy and do not know what questions to ask, how to navigate cancer care or access resources. Seeing more Māori staff across the entire cancer continuum helps patients and whānau build trust and feel safe in the health service.

*"Whānau need prompting. They need ongoing support to push through the barrier of being whakamā. Every whānau needs a Māori registered nurse!" 22*

*"Kaiawhina services more readily available, across primary and secondary services" 3*

## Whakamōhio

The manner in which health professionals communicate information to patients and whānau by using simple language, actively listening, and looking after patients and whānau was viewed as being crucial in making them feel valued and involved in their care.

*“COMMUNICATION – listen to patients and what is important to them BEFORE we give treatment” 13*

*“Speak in a language that our whānau would understand, forget about the medical terminology” 55*

*“Talk to the whānau “Kanohi ki te Kanohi”. 55*

Responses also emphasised the importance of timely information when patients transition between the health sectors. This would help patients receive continuity of care.

*“Keep communications between secondary care and primary care open” 52*

*“Clear communication and handing over of Māori patients to next phase of continuum” 28*

Trusting relationships between Māori staff involved in cancer care and clinicians can help in the timely sharing of information about patients and whānau. Roles such as kaiawhina, and Māori cancer/whānau navigators can assist and are knowledgeable about cultural, community, patient and whānau dynamics, services, and resources. They play a vital part in patients receiving timely consistency of care, which may make the cancer journey less stressful.

*“Less silo and Māori Multi-disciplinary team [MDT] approach” 12*

*“Recognise and respect skill/expertise of Kaiawhina. Include them in MDT as key members” 3*

Collecting quality cancer data helps prevent and control cancer (Ministry of Health, 2019), improves patients care, and provides more accurate data for service providers (Curtis,

Wright, & Wall, 2005). Respondents reported the need for health data to be holistic, correct, relevant, and readily available.

*“Consistent data. Not just health system data – outcomes data too. Data about more than clinical pathway” 2*

*“Improved accuracy of data and consistency of reporting between DHB’s” 3*

*“Consistency of information” 1*

## Manaakitanga

Location of services was identified as being crucial to overcoming access barriers to cancer care services. Respondents believed cancer services should be provided closer to where people live and there should be flexibility in opening hours as many patients and whānau find it more difficult to attend their appointments (including mobile screening services). This difficulty was also an issue identified by respondents who attended the community hui.

*“Consideration of where services are provided from, more community access, avoid barriers of location, mobile services to get to remote patients” 3*

*“Closer to home, better community access to Radiology” 8*

*“Chemotherapy clinics in community locations, out into suburbs” 15*

*“Flexibility of scheduling & accessibility” 24.*

Concerns were also raised about the administration and criteria of the national travel assistance fund. Many patients might not be eligible have access to vehicles or to public transport or are not financially able to pay for transport to either attend primary or hospital appointments.

*“Travel, accommodation, access. National travel policy needs to start in Primary Care” 1*

Another area highlighted was the need for all health staff to be culturally competent. Responses showed this was pivotal to providing holistic care to Māori patients. Health professionals require a better understanding of and, respect for patients' cultural beliefs.

*"More understanding within the health profession around tikanga Māori" 14*

*"Using Māori Models of Health and developing cultural acceptability and appropriateness in all health care areas (in diagnosis & treatment space)" 61*

Respondents also commented on the need for better collaboration between primary care, non-government organisations, and secondary and tertiary care with Māori in the delivery of cancer care services. Involvement at the beginning of any initiatives designed to address Māori cancer health outcomes was viewed as being important in making a difference.

*"Education on prevention and screening at Māori focused spaces: primary health / Māori health providers kōhanga reo day care /playgroups kura kaupapa /mainstream schools, kaumātua groups marae, hapū, iwi, whānau Work collaboratively with community services, DHB's promoting the same information re Māori Cancer Prevention and Screening!" 2*

*"Co-design with Māori leading – focus on desired outcomes, i.e. what would good care LOOK like? What would it FEEL like? How can we make sure this is consistently available?" 24*

# Evaluation of the Community and Stakeholder Hui

Respondents who completed the community and stakeholder surveys were asked to evaluate the hui they attended.

## Community Hui

For the community hui, respondents were asked about their attendance and how this may have helped increase their knowledge in a variety of areas. Their responses are shown in the Table below.

Table 3 Evaluation

Now that you have attended this hui please rank your experience between 1 and 4, with 1 being low and 4 high. By attending this hui has it increased your:	1		2		3		4	
	%	(n)	%	(n)	%	(n)	%	(n)
Knowledge about how to prevent cancer for you and your whanau	1.83	10	10.62	58	31.50	172	43.77	239
Knowledge of possible signs and symptoms of some common cancers	2.75	15	12.82	70	33.70	184	39.93	218
Willingness to participate in cancer screening programmes	2.93	16	6.23	34	26.01	142	54.58	298
Level of comfort to seek help from a health professional	2.20	12	5.86	32	27.11	148	56.04	306
Knowledge about where you can seek this help	1.83	10	4.95	27	24.18	132	58.42	319

Respondents were also asked about what was good about the hui, what was not good, and how this type of hui could be improved in the future.

### Good:

Being able to come together in a safe environment to share stories about whānau experience of cancer care was a common view.

*“Manaakitanga friendly” 4*

*“Having a culturally supportive environment” 6*

*“Opportunity for whānau to share their stories have a Māori voice.” 7*

*“Having whānau with lived experiences share kōrero (talk, discuss) of their journey – a forum for whānau to share kōrero” 255*

Many whānau also stated that the hui was an opportunity for them to have their say about cancer care service supports.

*“Community getting to have a say. Need to do this more” 158*

*“Māori voices being heard and provide way forward initiated by Māori” 160*

*“Opportunity to have a voice” 174*

### Not good:

Some whānau found the hui was a bit long,

*“It was long but still good” 7*

while many whānau wished the hui had gone on longer,

*“Not long enough” 133*

*“Not enough time to go to all workshops” 132.*

### Improvements for future hui:

A common theme from the feedback was the need for similar hui to be held more regularly, closer to whānau and allowing more time for whānau to share their stories.

*“More hui needed” 3*

*“More hui in the rohe [region], invite more whānau and make it a bigger day” 7*

*“Longer talking sharing times” 1*

The community hui provided an opportunity for Māori to come together and share their knowledge of, and experiences about cancer care.

### Stakeholder Hui

Respondents who completed the survey were also asked about what they thought of the hui. Views were mixed, but the majority were positive, with many highlighting the opportunity the hui provided for people to come together to share experiences and discuss solutions. This is reflected in the comments below.

*“Networking with others. Hearing specifics & what good for Māori would look like. Good venue. Great kai.” 2*

*“Meeting and networking with others that work in cancer care and knowing they are here as they want to improve wellness outcomes” 29*

*“Discussion, kōrero, sharing of experiences and knowledge, thought provoking” 14*

However, some respondents suggested that more time was needed for people to share their stories and that hui should be held on a marae as they were about Māori health.

*“How many of the hui have been held on a Marae? Supposed to be a focus on Māori outcomes, but hui all held at mainstream locations” 23*

*“Time ran out as we started to get into the nitty gritty” 16*

Kia mau ki te aka  
matua, kei mau  
ki te aka tāepa



*Doug Edwards & Huataki Whareaitu (MidCentral District Health Board)  
Kia mau ki te aka matua, Kei mau ki te aka tāepa  
Cling to the parent vine, not the loose one*

# Discussion

Community and stakeholder hui were held to gather the views from Māori and the wider health and social service providers of cancer care.

The feedback from these hui evaluations emphasised the importance of having these types of hui to ensure Māori are involved throughout all aspects of cancer care services. The discussion has been structured using the key elements of the He Pito Ora model; whanaungatanga, whakamōhio, and manaakitanga. The He Pito Ora model illustrates continuity of care for Māori is a collective process involving these elements and the role that the health system has across all stages of the cancer care continuum (Koia, 2019).

## Whanaungatanga

The principle of whanaungatanga is built on whakapapa, whānau, and kinship with a focus on building and strengthening the relationships with and between people. It is also a way in which Māori understand the world and make connections (Mead, 2016). Hence, for Māori, collectiveness, where whanaungatanga, and the process of whakawhanaungatanga (building kinship and the strengthening of relationships between people) are central to building trusting relationships between both patient/whānau and health workers as well as among the health workers themselves (Koia, 2019).

From the feedback findings, whanaungatanga was about the critical and multiple roles whānau contributed in supporting patients, including manaakitanga, encouraging, advocacy, care, sharing knowledge, and navigating the health system.

## Critical and multiple roles of whānau

It was not surprising then, that the feedback from the community and stakeholder hui identified the critical and multiple roles whānau played in championing good health. Whānau were viewed as playing an invaluable role in cancer care, providing manaakitanga, encouragement, support, advocacy, care, navigation, and knowledge of traditional cultivation of kai for their loved one across the whole cancer continuum. From the community hui, encouragement from whānau accounted for 71.2% of responses to become smoke free (Graph 2), 67.58% for healthy eating (Graph 3), 65.57% to exercise and become more active (Graph 4), and 59.52% related to minimise harm from alcohol (Graph 5). This highlights that Māori value the support from whānau and believe health promotion campaigns should be co-designed with Māori leading the project. The report also signals the support of whānau to be visible at Māori events (72.9%) such as national kapa haka and on marae (70.3%) (Graph 1). Whānau can also play a key role in educating whānau about certain viruses and bacteria such as HBV, HCV, HIV, HPV and H-Pylori. These infections may be preventable if whānau are fully informed and understand the causes. Sadly, feedback shows that many whānau were not familiar with some of these viruses or bacteria, for instance, only 40.48% were aware of HPV. This raises concerns that information about these viruses or bacteria are not reaching Māori in the most appropriate forms. Also, while whānau response to some of the cancer and infection questions was relatively low, it is clear they have an understanding of symptoms for early stages of selected cancers. Regardless of this early stage awareness, studies show Māori are

diagnosed late and experience access barriers throughout their cancer journey (Cormack, et al. 2005; Ellison-Loschmann et al., 2015; Harris et al., 2012; Koia, 2019; Seneviratne, Campbell, Scott, Coles, & Lawrenson, 2015).

The other important function whānau was recognised for is the role of caregiver. They play a big part in the patients' cancer care by acting as an advocate to access relevant services early, comprehend health information, and are knowledgeable about the patients' personal information. Feedback also identified that whānau themselves need support in the form of respite care as they had limited access to other whānau for assistance. Provisions of respite care for whānau caregivers was viewed as being crucial not only to the well-being of the patient but also to the whānau caregiver.

Health promotion existed in ancient China through art forms like Tai Chi (Lan, Wolf, & Tsang, 2013) and in ancient Greece in Olympic game events. In Aotearoa, there are similarities for Māori such as the art of kapa haka, which promotes collectivism, and spiritual, mental, and physical endurance. Māori health promotion is seen as part of Māori development and located in a Māori worldview making it "inseparable from Māori realities and perspectives. Māori people are central, and a secure Māori identity is a critical process and outcome measure" (Ratima, Durie, & Hond, 2015, p. 43). Current health promotion in Aotearoa is based on a two-tier service specification with a generic framework. Health providers responsible for informing whānau are able to determine if, when, and how they focus on Māori (Ministry of Health, 2016). Policy makers also independently develop policy, providing no co-design opportunity with Māori until the implementation stage. Slater's (2016) study of community-based cancer care for Māori highlighted whānau are crucial change agents for promoting health and well-being through traditional Māori activities such as kapa haka. She argues that more Māori are likely to engage and be receptive if information was provided by Māori. Whānau can also act as information disseminators sharing their own experiences of making healthy choices.

Strong, evidence-based research reinforces the importance of whānau in patients' care (Boulton, Tamehana, & Brannelly, 2013; Dew et al., 2015; Durie, Cooper, Grennell, Snively, & Tuanie, 2010; Edwards, McCreanor, & Moewaka-Barnes,

2007; Hayes, 2016; Health and Quality Safety Commission New Zealand, 2019; Koia, 2019; Slater, 2016; Tania Slater et al., 2013; Walker et al., 2008; Wilson & Hickey, 2015). However, many health professionals continue to exclude whānau in patient care (Waitangi Tribunal, 2019) until it's too late. In 2008, Mauri Ora Associates produced a resource booklet Best Health Outcomes for Māori for the Medical Council of New Zealand. Contributions by the late Dr Paratene Ngata and Professor Sir Mason Durie provide detailed guidance for health professionals when dealing with Māori patients and their whānau. Examples include acknowledging the importance of the whānau role in patients care and health professionals taking the time to learn to pronounce their Māori patients name correctly. This would go a long way to enhancing communication between health professionals, patients and their whānau.

## Whakamōhio

The principle of whakamōhio is about the steps taken to collect and exchange information in accordance with Māori values and beliefs (Koia, 2019). For Māori patients and whānau, this involves whanaungatanga, manaakitanga, kano ki te kano, and whānau participation in communication and sharing of information, specifically between patients, whānau and health professionals, and among health professionals themselves. Thus whakamōhio is underpinned by trust and respect and *"how relationships are developed with patients and whānau as well as how information will be looked after and used to enhance patients and their whānau journey"* (Koia, 2019, p. 174).

The findings from these hui are strongly related to the principle of whakamōhio, including whanaungatanga as a crucial part of good communication. It was no wonder then, that patients and whānau felt safe, able to share information, and ask additional questions about their care when communication practices are based on Māori values and beliefs like kano ki te kano, use of simple language, and actively listening to patients and whānau.

## Good Communication Practice

The feedback from the hui also emphasised the importance of good communication so Māori health consumers, patients, and whānau are well informed. Kanohi ki te kanohi, health professional's ability to listen to patients and whānau, and the use of simple language instead of medical terminology were identified as the most preferred way of communication for Māori. As noted in the previous section, whānau play an important part by being the voice for the patient, they have access to holistic information about patients' circumstances, beliefs, values, and community that most often clinical health professionals do not have, that would be vital in delivering quality care. Health professionals were also viewed by respondents as playing a crucial role in the delivery of health information. The feedback showed many patients and whānau find it difficult to understand medical terminology used by health professionals resulting in patients and whānau not engaging and being fully informed about their care.

The feedback also revealed good communication is important at the interface of health services. Respondents stressed the need for friendly frontline primary and hospital staff as they are pivotal in helping patients and whānau access cancer care services. The respondents felt patients and whānau are not listened to or feel uncomfortable when poor communication and behaviour happen. Having their whānau present, or access to a kaiawhina or Māori cancer navigator or Māori staff member were ways to address these situations. Better understanding by all staff about Māori values and beliefs could help facilitate patients and whānau to share information. Patients can engage more if staff take time to pronounce their names correctly and involve their whānau.

Quality communication has been well documented (Cormack et al., 2005; Koia, 2019; Reid, et al, 2020; Shahid, Finn, & Thompson, 2009; Slater, 2016; Wynia & Osborn, 2010) and efficient cancer care relies on building trusting relationships (Koia, 2019) and coordination of care between services (Cormack et al., 2005). Research by Koia (2019) into the role of Māori cancer navigators in the central region with Māori cancer navigators, kaiawhina, patients, their whānau, and clinical and non-clinical health professionals identified poor

communication continues to exist among service providers across the health sector and between providers, patients and their whānau. Koia found the health system needs to take responsibility for the health literacy problems encountered by patients and their whānau. Roles like Māori cancer navigators and kaiawhina were seen as helping patients understand health information and facilitate the communication between patients and health professionals, including mediating poor behaviour exhibited by frontline staff to patients and their whānau. Māori cancer navigators and kaiawhina roles were also viewed by clinical and non-clinical health professionals as having valuable cultural and community knowledge that can help in patient care. Thus, the findings showed that better integration of these roles in cancer care and inclusion in multidisciplinary teams, could improve the flow of information, but does not negate the responsibility of health professionals to address health system communication issues.

## Manaakitanga

The principle of manaakitanga involves the caring and nurturing of patients and their whānau, including health professionals supporting each other. The principles of whanaungatanga and whakamōhio, including the steps that underpin these principles, are intertwined with manaakitanga, where people come together to share their knowledge and information to provide quality care and to nurture each other (Koia, 2019).

The provision to gain access to and through cancer care services and receive consistent support is a key component of manaakitanga. The feedback from the hui showed factors that influence manaakitanga Māori health consumers, patients and their whānau accessing cancer care services are the health system in terms of cost, location of cancer care services, cultural competency of health professionals, and funding of services.

## Access to cancer care services

These hui identified cost as a major access barrier for many patients and their whānau. The respondents highlighted the reasons why many whānau did not live a healthy lifestyle were because fruit, vegetables and gym memberships were too expensive. Providing the support for whānau (through Māori health promotion activities), such as growing their own vegetables and fruit, and helping them connect to traditional Māori arts like kapa haka could help whānau take responsibility for their own health and well-being. Many respondents also highlighted that they could not afford GP charges, prescription fees, and medication costs or did not have access to transport. This can contribute to delays in seeking medical attention and follow-up care. In order for patients and whānau to attend their hospital appointments the feedback (61.90%, n338) showed the importance of accessing free parking.

Another issue raised was that many patients and whānau do not live close to screening services or cancer treatment centres, which contributed to the logistical issues of accessing services. For many Māori health consumers and patients, attending their screening, medical appointments and treatment may sometimes require them to take time off from work or find childcare. This can sometimes be difficult as the cost of childcare would need to be covered, and/or appointment times may not be suitable, particularly if that person is the only one working in that whānau. Some respondents suggested mobile services consider calling into other venues such as marae and schools where many Māori are present.

Patients and whānau spending time attending treatment outside their area and having to move into accommodation close to the hospital found this process highly stressful. Having access to suitable accommodation and to Māori supportive care to cater for them and their whānau was viewed as one way of reducing this stress. Patients and whānau would feel more culturally safe if they were able to talk with someone who understood their cultural needs.

Building Māori health cancer workforce capacity in primary and tertiary care was identified as

being vital in both clinical and non-clinical roles. Respondents highlighted the importance of having more Māori GPs, nurses, kaiawhina, and Māori cancer and whānau ora navigators who are well versed in tikanga Māori and community knowledge. They understand the significance of including cultural practices such as rongoā Māori, wairua, and karakia alongside medical interventions. They also understand the reality and challenges many Māori patients face that are not experienced by non-Māori patients. However, increasing the Māori health cancer workforce does not address the need for better cultural competency by both non-Māori health professionals and non-medical health staff, who are the main people that engage and communicate with patients and whānau (Came, 2014).

There is strong evidence of the importance of gaining timely access to consistent care for cancer patients' treatment and recovery (Haggerty et al., 2003; King et al., 2008; Koia, 2019; Lauria, 1991; Reid, Haggerty, & McKendry, 2002; Young, Walsh, Butow, Solomon, & Shaw, 2011). The findings from the two hui regarding access are again consistent with the research conducted by Koia (2019) about Māori cancer navigator roles, as noted in the previous section of whakamōhio. Her findings revealed health systems seriously impact on Māori accessing cancer care services. These health system factors include location of health services, national transportation criteria, cost of GPs, prescriptions charges, poor cultural competency and communication of both medical and non-medical health staff, lack of Māori health workforce staff, and a need for better funding of Māori health providers. Koia also stressed that the impact of social and economic determinants affects the ability of Māori patients and whānau to access cancer care services. Unless the social determinants of health and social justice are dealt with, there is unlikely to be much improvement in health outcomes (Casswell, Huakau, Howden-Chapman, & Perry, 2011; Duggan, 2011; J. Hill, Nielsen, & Fox, 2013; Bridget Robson & Reid, 2001), and health gaps between Māori and non-Māori will continue to widen, especially in cancer (Sheridan et al., 2011).

A close-up photograph of a Kawakawa plant. The image shows several large, heart-shaped green leaves with prominent veins and some small holes. Two bright yellow, elongated berries are visible on a reddish-brown stem. The background is dark and out of focus.

Mauri Ora!  
Whānau Ora!  
Māori Ora!

*NZ Kawakawa Plant  
Mauri Ora, Whānau Ora, Māori Ora!  
Healthy Within! Healthy Family! Healthy People!*

# Feedback Limitations

As this report is based on information collected by the CCN team; we would like to highlight a number of limitations to our work:

**T**he CCN team was responsible for the design and methodology of the survey questionnaire for the community and stakeholder hui, including recording and transcribing of information collected.

The sample size of respondents whose feedback we were able to use to construct the report is smaller than we anticipated.

Some of the information may lack authenticity, due to missing data and the inability to verify information like demographics and participant/respondent characteristics. Therefore, we cannot check whether it is biased or not.

The feedback we received may not be representative of the DHB areas that were surveyed.

We therefore make no representation or guarantee as to the accuracy, reliability, completeness or currency of the data in this report. The information, advice, and recommendations provided in this report are provided solely on the basis that users will be responsible for making their own assessment of the matters discussed herein and are advised to verify all relevant representations, statements, and information.

Tūtira  
mai ngā  
iwi, Tātou  
tātou e!



*Pou, Waitangi Regional Park, Napier  
Tūtira mai ngā iwi, tātou tātou e  
Stand together people, all of us, all of us!*

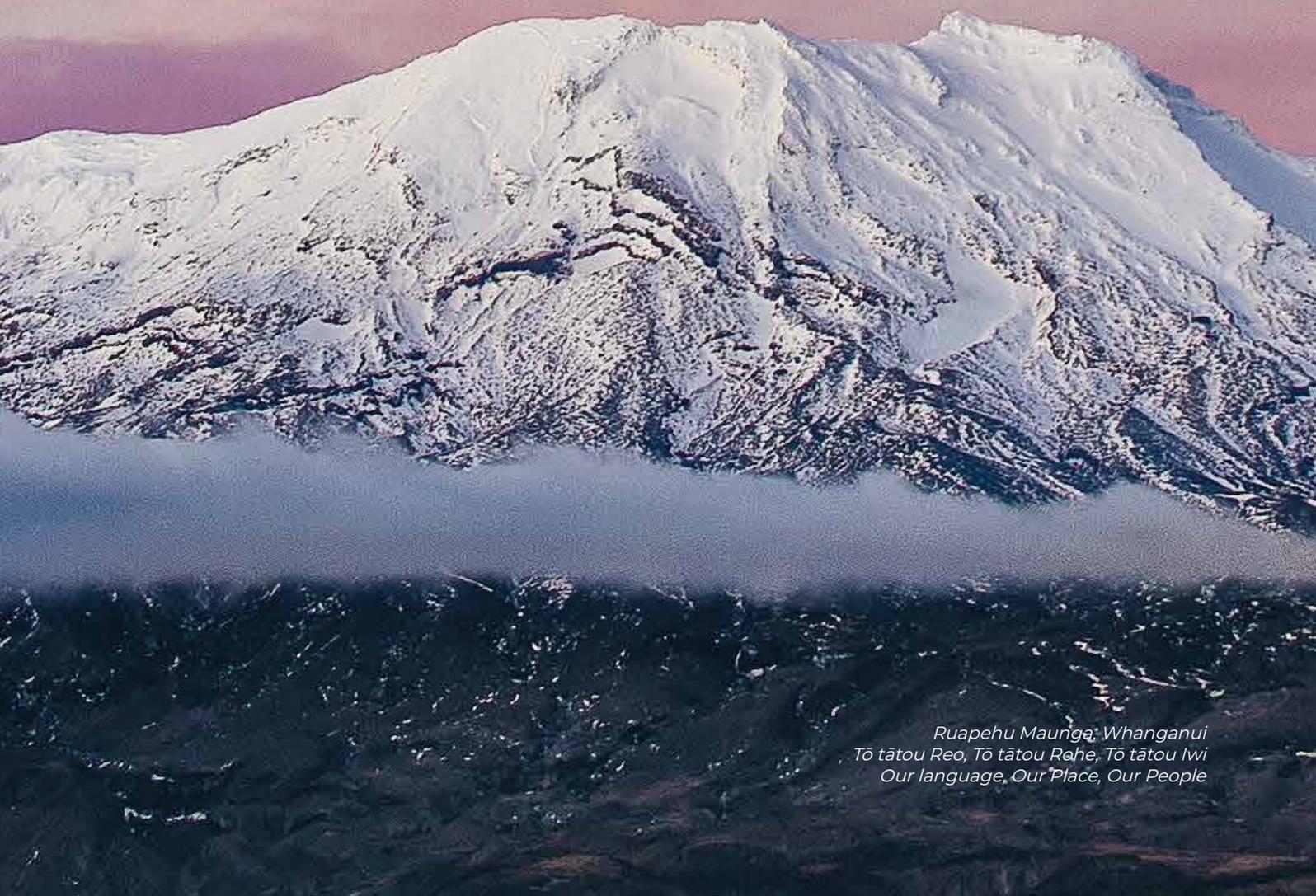
# Conclusion

The seven-community hui aimed to bring to the fore Māori views about cancer care, while the stakeholder hui sought to gain an in-depth understanding from both Māori who access and those who work in cancer care services.

**T**he feedback continues to show Māori experience more difficulty accessing cancer care services than non-Māori. The difficulties include the impact of wider social determinants, the health system, and patient level factors of which are present across the entire cancer continuum and beyond. These are not new and include the financial cost of transportation, GP appointment, and prescriptions, location of services, lack of cultural

understanding by health staff, collection of accurate data, poor communication and customer services, all of which negatively impact patients and whānau from accessing cancer care services. Health staff need to understand they play a vital role in reducing disparities faced by Māori. Māori cannot make these changes alone; it requires a Māori-led approach with collective commitment from everyone involved – otherwise nothing will change.

Tō tātou Reo,  
Tō tātou Rohe,  
Tō tātou Iwi



*Ruapehu Maunga, Whanganui  
Tō tātou Reo, Tō tātou Rohe, Tō tātou Iwi  
Our language, Our Place, Our People*

# Recommendations

The feedback from the community and stakeholder hui highlighted a number of areas where changes in cancer care services are needed if the health system is serious about improving cancer care services.

These areas include:

- Better recognition and integration of whānau in the care of patients, including the significance of tōhunga (expert/high priest), and rongoā Māori such as mirimiri (massage) and karakia (incantation/prayer) in the care of patients across the continuum.
- Improve communication by all health staff, such as correct pronunciation of patient names. The Resource booklet *Best Health Outcomes for Māori: Practice Implications* prepared for the Medical Council of New Zealand would be useful.
- Improve timely transfer of information across the health sector.
- Improve frontline customer services by providing friendly and culturally responsive environments to address racism in the health services. Gaining a better understanding of Māori cultural practices and beliefs by all staff and greetings in te reo Māori are a useful start.
- Improve health literacy communication by not using medical jargon when communicating with patients and whānau, and involve kaiawhina, Māori cancer and whānau ora navigators, to explain health information that can be understood by Māori health consumers, patients and whānau.
- Data collection to include holistic information as determined by the patients and their whānau. Professor Sir Mason Durie's Te Whare Tapa Wha framework would be helpful in this process.
- Include Māori cancer and whānau ora navigators and kaiawhina in multi-disciplinary teams. These roles are essential as they have vital knowledge about the patient, their culture and community, which helps maintain continuity of care for patients.
- More flexibility with appointment times to accommodate patient circumstances.
- Ensure early referral to or offer of Māori supportive care (Māori cancer navigators, kaiawhina (community or hospital Māori support worker), whānau ora services for all Māori health consumers, patients and their whānau across the entire cancer continuum.
- Co-design with Māori to develop health promotion campaigns that include delivery at Māori events (i.e. national and regional kapa haka, Iron Māori), marae, and local community venues like schools. Campaigns like Smear your Mea and community garden interventions can provide guidance.
- Review mobile screening services to better facilitate access, particularly in smaller and isolated areas.
- Review the national transportation assistance fund eligibility and processes to make it easier and less stressful for patients and whānau to access; starting with removing the 100-km criteria.
- Review hospital parking policies to accommodate free parking for patients and their whānau.

- 
- Build the Māori health workforce with focus on increasing the number of Māori GPs, Māori nurses, Māori cancer/whānau ora navigators, and kaiawhina roles across all DHBs, including better integration of the navigator/kaiawhina roles within cancer care services.
  - Increase the funding to iwi and Māori health providers as they provide services outside their contract scope to support patients and whānau to gain timely access to cancer care services.

# Appendices

## Appendix 1 Facilitator's questions and note schedule for subgroup hui

Community and Stakeholder Hui subgroup

Facilitators question and note schedule

### Context Setting

Professor Sir Mason Durie's outline on Māori Health Gains – The Next Phase

Māori Health Gains The Next Phase	
From	To Include
Treating an illness	Sustaining wellness & preventing illness
Knowledgeable Healthcare providers	Knowledgeable whānau (health literacy)
Disease Management	Addressing the cause of illness (determinants)
Sector focused strategies	Collective impact - collaboration Sectors - Iwi - Providers - NGOs
Māori models of treatment and care	Māori models for wellness and safety
Contracting for services	Commissioning for outcomes

**Cancer Action Plan 2019-29:** Survival Equity by 2030

### Question Guide

**Accelerating Māori wellness and cancer survival with a focus on (*focus group topic*):**

- Why is a focus on (*focus group topic*) key to achieving survival equity for Māori by 2030?  
What outcomes are we aiming to achieve?
- What is the current status quo? What are current approaches we can build off?  
What new approaches are required?
- What do we need to consider when we are planning (*focus group topic*) solutions for Māori?
- Who needs to be involved in this planning and how do we enable this to happen?

## Appendix 2 Community Hui Survey



### Community Hui Survey

Which Ethnic Groups do you belong to? (Please Circle)		
NZ European	Māori	Samoan
Cook Island Māori	Tongan	Niuean
Chinese	Indian	Other: Please Specify

Are you? (Please Circle)	
Male	Female

How old are you in years?

### Health Promotion

Health Promotion is about building community awareness of health kaupapa to achieve whānau ora.

What are the best ways to promote health with whānau? (Please Circle)		
Marae Hui	Māori Events	Sports Days
Schools	Social Media (Facebook)	TV and Radio
Pamphlets	Advice from Doctors	Other:

### Smoke-free 2025

What are the best ways to support whānau to be Smoke-free? (Please Circle)		
Encouragement from whānau	Encouragement from Doctors	Smoke-free hui and events
Access to nicotine gum and patches	Access to vaping/ E-cigarettes	Health Promotion
Tax increases	Financial incentives to quit	Other:

### Encourage and Support Healthy Living

What are the best ways to support whānau to Eat Healthy? (Please Circle)		
Encouragement from whānau	Encouragement from Doctors	Healthy eating hui and events
Sugar tax	Cheaper fruit and vegetables	Community gardens
Health Promotion	Raising the minimum wage	Other:

What are the best ways to support whānau to exercise/get more active? (Please Circle)		
Encouragement from whānau	Encouragement from Doctors	Health Promotion
Free/cheap gym memberships	Free/cheap sports clubs	Other:

What are the best ways to support whānau to minimise harm from Alcohol? (Please Circle)		
Encouragement from whānau	Health Promotion	Raise the drinking age
Increase price of alcohol	Less shops selling alcohol	Other:

## Cancer and Infections

Hepatitis B, Hepatitis C, HIV (Aids), Pap. Virus (HPV) and H-Pylori can cause infections that lead to cancer. Which of the following are you aware of? (Please circle)

Have you heard of Hepatitis B?		
Yes	No	
Hepatitis B can be caused by (Please Circle)		
Blood exchange	Drug use - dirty needles	Tattoo's -dirty needles
Fluid exchange (saliva, sexual contact)	Contaminated food	

Have you heard of Hepatitis C?		
Yes	No	
Hepatitis C can be caused by (Please Circle)		
Blood exchange	Drug use - dirty needles	Tattoo's -dirty needles
Fluid exchange (saliva, sexual contact)	Contaminated food	

Have you heard of HIV Aids?		
Yes	No	
HIV Aids can be caused by (Please Circle)		
Blood exchange	Drug use - dirty needles	Tattoo's -dirty needles
Fluid exchange (saliva, sexual contact)	Contaminated food	

Have you heard of Human papillomavirus (HPV) infection?		
Yes	No	
Human papillomavirus (HPV) infections can be caused by: (Please Circle)		
Skin to skin contact	Sexual contact	

Have you heard of H-Pylori Infections (Can cause Stomach Ulcers)? Y/N		
Yes	No	
H-Pylori Infections (Can cause Stomach Ulcers) can be caused by : (Please Circle)		
Poor hygiene	Eating contaminated food or water	Overcrowded housing
Lack of access to clean water		

## Skin Cancer

What are the best ways to support whānau to reduce harmful sun damage? (Please Circle)

Health Promotion	Free sunscreen	Regulating sunbeds
Other:		

## Early Detection of Cancer

Whānau have a greater chance of surviving Cancer if it is detected early. What are some of the signs and symptoms of the following cancers? (Please circle)

Lung Cancer (Please Circle)		
Bad cough	Coughing up blood	Weight loss
Loss of appetite	Feeling tired or weak	Difficulty breathing
Chest pain		

Breast Cancer (Please Circle)		
Lump in the breast	Breast swelling	Skin irritation
Skin redness	Breast or nipple pain	Nipple retraction
Nipple discharge		

Cervical Cancer (Please Circle)		
Bleeding between periods	Heavy menstrual bleeding	Bleeding after intercourse
Increased vaginal discharge	Pain during intercourse	Bleeding after menopause

Prostate Cancer (Please Circle)		
Frequent urination	Weak urine flow	Frequent urination at night
Blood in urine	Blood in semen	Pain during urination
Erectile dysfunction		

Bowel Cancer (Please Circle)		
Blood in stool (Kaka)	Bleeding rectum	Diarrhoea
Constipation	Stomach pain	Lumps in the abdomen
Weight loss		

## Primary and Community Care

If you experienced any of the cancer symptoms above what would you do? (Please Circle)		
Talk to whānau	Go see a Doctor/GP	Search online
Talk to a friend	Talk to a kaumātua/kuia	Ignore it
Go to hospital A&E	Other:	

Many Māori have difficulty accessing primary health care, this includes seeing a Doctor. Which of the following would improve access for whānau Māori? (Please Circle)		
Free/cheap fees	Clinics closer to where you live	Financial support with travel
Free/cheap medicine	Pharmacy's at clinics	Transport to clinics (van, bus, taxi)
Telehealth (See a doctor online)	More health services at marae	Other:

What would help to improve the quality of Primary care that whānau receive? (Please Circle)		
More māori doctors/GPs	More māori nurses	Access to rongoā (māori medicine)
More health services at marae	Access to mirimiri (massage)	Longer consultations
Non-māori staff speaking Te Reo	Non-Māori Staff being culturally aware	Friendly environment
Other:		

### Screening

Screening can help detect Cancer early giving whānau a greater chance of surviving. This is different depending on the type of Cancer such as an X-Ray for Lung Cancer, Mammogram for Breast Cancer, Smear Test for Cervical Cancer, Physical Exam by a GP for Prostate Cancer, Collection of Stool (Kaka) for Bowel Cancer.

What would improve cancer screening for whānau Māori? (Please Circle)	
More mobile screening units (Buses/vans)	Financial incentives for screening (Koha)
Mobile units attending more māori events	Screening for multiple cancers during one visit
Financial support to assist with time off-work	Travel assistance to attend screening
More types of screening available in primary care	Mobile units attending places of work
Annual health check (WOF)	Other:

### Diagnosis and Treatment

Diagnosis and Treatment includes many things such as Cancer Care Planning, Radiation Therapy and Chemotherapy.

What would support whānau to attend Cancer appointments at the hospital? (Please Circle)	
Travel assistance	Free parking at the hospital
More parking at the hospital	Phone application for appointments
More flexibility with appointments	More appointments closer to home
Video-consultation	Other:

What would improve cancer treatment planning for whānau before receiving treatment? (Please Circle)	
Input into care plan development	Understanding each step of your treatment plan
Clear treatment options and alternatives	Having kaupapa māori treatment available
Access to rongoā	Access to mirimiri
More treatment at home/closer to home	More treatment at marae
Other	

What would improve whānau experience at the hospital during Cancer treatment? (Please Circle)	
Suitable accommodation	More māori staff
Hospital support person during treatment	Non-māori staff speaking Te Reo
Non-māori staff being culturally aware	Friendly environment
Whānau present for treatment	Other:

## Follow-Up Care

Follow-Up Care includes all care after receiving Cancer treatment this includes being supported after being discharged from hospital, recovery from treatment and end of life care.

How can we improve support for whānau recovering from Cancer treatment? (Please Circle)	
Financial support	Wairua/spiritual support
Hinengaro/mental health support	Emotional and social support
Access to rongoā/mirimiri	Connection support to Iwi, whenua and ancestral taonga
Kaupapa māori supportive care programmes	Support for whānau members
Support for tamariki	Other:

How can we improve support for whānau who are near the end of life from cancer? (Please Circle)	
Financial support	Wairua/spiritual support
Hinengaro/mental health support	Emotional and social support
Access to rongoā/mirimiri	Connection support to Iwi, whenua and ancestral taonga
Kaupapa māori supportive care programmes	Support for whānau members
Support for tamariki	Other:

## Evaluation of Hui

Now that you have attended this hui has what you've experienced increased your: 1 is low 4 is high (Please circle)	
Knowledge about how to help prevent cancer for you and your whānau	1 2 3 4
Knowledge of possible signs and symptoms of some common cancers	1 2 3 4
Willingness to participate in cancer screening programmes	1 2 3 4
Level of comfort to seek help from a health professional	1 2 3 4
Knowledge about where you can seek this help	1 2 3 4
What was good about this hui?	
What was not good about this hui?	
How could we improve this type of hui in the future?	

## Appendix 3

Stakeholder Hui Feedback Survey				
Code				
Which Ethnic Groups do you belong to? (Circle)				
NZ European	Māori	Samoan	Cook Island Māori	Tongan
Niuean	Chinese	Indian	Other (please specify)	
<b>We want to improve Māori Cancer Outcomes across the Whole Cancer Continuum of Care and Enabler Areas</b>				
How can we improve Māori Cancer Prevention and Screening?				
How can we improve Māori Cancer Diagnosis and Treatment?				
How can we improve Māori Cancer Supportive Care? (Survivorship, Recovery, End of Life)				
How can we improve Māori Cancer Data, Workforce and Research?				
<b>Evaluation of Hui</b>				
What was good about this hui?				
What was not good about this hui?				
How could we improve this type of hui in the future?				

Mā ngā  
huruhuru ka  
rere te manu!



*NZ Tui Bird and NZ Harakeke (Flax)  
Mā ngā huruhuru ka rere te manu  
It is the feathers that enable the bird to fly*

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# Central Cancer Network

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