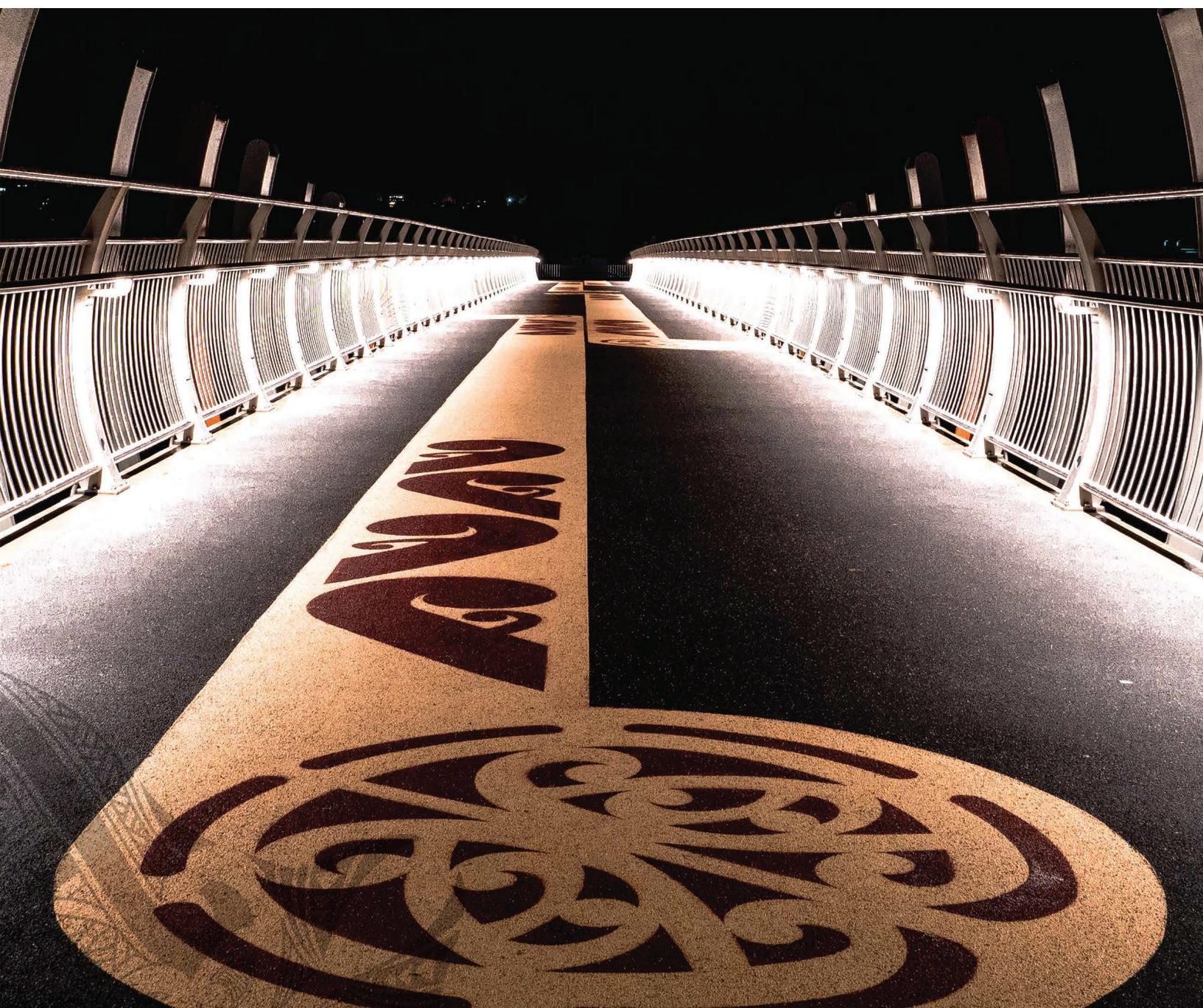




Central
Cancer Network

DEEP DIVE
**Co-Design
Report**
MAY 2020



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



Artwork: Jade Beazley

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CANCER IS A
WHĀNAU
AFFAIR

Hospice
r Network

Above: Steph Turner and Mike Grace – Consumers Speaking at Wairarapa Hui 2019

Introduction

This report describes a programme of work undertaken by the Central Cancer Network (CCN) to engage with Māori communities and providers across the region utilising kaupapa Māori and co-design principles and explores the complementary nature of these two approaches.

As a result of the pre-engagement work that CCN had already done, a modified co-design programme was delivered to the project teams. Four teams were involved in delivering projects within an overarching programme of work. This is a cumulative case study for all the teams.

This case study is part of a suite of products developed from the Regional Cancer Deep Dive Programme. The other products are described later in this document and include:

- Literature Review
- Kaupapa Māori Evaluation
- Feedback Report

All documents can be found on the CCN website using the following link
<https://centralcancernetwork.org.nz/>



Above: Kura Moeahu speaking at the Hutt Valley community hui held at Waiwhetu Marae 2019.

Background

Cancer is the main cause of death of people in New Zealand, and Māori have significantly higher cancer incidence and mortality than other ethnic groups.

The New Zealand health system has yet to adequately address cancer health inequities.

CCN is one of four regional cancer networks in New Zealand. Cancer networks work across boundaries to improve the outcomes for patients by:

- reducing the incidence and impact of cancer
- increasing equitable access to cancer service and equitable outcomes with respect to cancer treatment and cancer outcomes.

To date, CCN has not engaged robustly with Māori communities to hear their stories, needs and aspirations in relation to cancer. Under new leadership, CCN planned and delivered the Regional Cancer Deep Dive programme of work during 2019–20 to address this priority area.

Project overview

Our Regional Cancer Deep Dive programme was an in-depth investigation focusing on improving cancer outcomes for Māori and included the following activities.

Literature Review

A literature review was undertaken with an equity focus looking at:

- the cancer burden for Māori, including cancer registrations and mortality
- a review of New Zealand cancer plans in relation to their intent to address equity for Māori and their impact

- research relating to addressing equity across the cancer continuum of care
- identifying how various cancer care enablers, including policy, leadership, workforce, data, research and evaluation, can be utilised differently to address equity
- wider Māori health equity issues.

Analysis

An analysis was undertaken of regional and national cancer data in relation to access to cancer services and outcomes for Māori.

Community hui

Seven Māori cancer community hui, one in each district health board (DHB) area, were planned and delivered in partnership with DHB Māori health teams, local Māori, and cancer service providers. The hui were aimed at hearing a Māori community voice and aspirations for cancer care. The hui programme included speakers, both clinicians and consumers from the local area, who provided contextual information on cancer experiences and services. Participants then broke into three focus areas (prevention and screening; diagnosis and treatment; and supportive care) where whānau shared their mamae, their experiences, and their aspirations for their cancer care.

During the hui, participants were also encouraged to complete a survey that asked a range of questions on awareness of cancer signs and symptoms, and health system issues and solutions. The survey included evaluation

questions seeking feedback on what went well with the hui, what was not so good, and any improvements we could make going forward.

Regional Māori cancer stakeholder hui

Following the seven community hui, the CCN team partnered with the Health Quality & Safety Commission's Partners in Care team to plan and deliver four regional Māori cancer stakeholder hui. Māori cancer stakeholders are identified as any cancer care provider who provides services for Māori. A continuum approach was taken to organising the hui to provide the opportunity to engage widely with DHBs, primary and community care providers, and cancer non-governmental organisations (NGOs). The fourth hui focused on those enablers that are important across all services. Information gained from the community hui was used to define the key subject areas for each hui.

The focus and key subject areas of the four hui were:

- prevention and screening (health promotion, primary care, screening)
- diagnosis and treatment (cancer pathways, comorbidities, rongoā)
- supportive care (psychosocial care, survivorship, palliative care)
- enablers (data, workforce, research).

The programme for each hui followed the same approach, beginning with an overview of the Regional Cancer Deep Dive programme and mahi to date. Presentations were then delivered by Māori experts in each subject area and consumer representatives. Following this, participants self-selected a focus group where they participated in a facilitated discussion on ways to improve cancer outcomes for Māori in that focus area. During the hui, participants were also invited to complete a survey that enabled them to provide insights about other parts of

the cancer continuum, recognising that many of them could only attend one of the hui. Hui evaluation questions were also included in the survey.

Deep Dive Feedback Report

The initial intention was for a five-year implementation plan to be developed from the information gained through the Regional Cancer Deep Dive process. However, with the recent release of the New Zealand Cancer Action Plan 2019–29 and the establishment of the Cancer Control Agency, this work will now inform the Agency's overall work programme.

Methodologies

Kaupapa Māori and co-design were the two methodologies used to plan and deliver the engagement aspect of the Regional Cancer Deep Dive programme.

Kaupapa Māori

Kaupapa Māori is literally 'a Māori way'. GrahStepham Smith (1990) describes kaupapa Māori as:

- related to 'being Māori'
- connected to Māori philosophy and principles
- taking for granted the validity and legitimacy of Māori
- taking for granted the importance of Māori language and culture
- concerned with the 'struggle for autonomy over our own cultural well-being'.

Kaupapa Māori principles are outlined below, and more information can be found within key literature, including Cram et al 2015,

Tino rangatiratanga – the principle of self-determination

Tino rangatiratanga relates to sovereignty, autonomy, control, self-determination and independence. The notion of tino rangatiratanga asserts and reinforces the goal of kaupapa Māori initiatives allowing Māori to control their own culture, aspirations and destiny.

Taonga tuku iho – the principle of cultural aspiration

This principle highlights the importance of te reo Māori (Māori language), tikanga Māori (Māori customs and practices) and mātauranga Māori (Māori knowledge) as essential to a Māori way of knowing and understanding the world.

Ako Māori – the principle of culturally preferred pedagogy

This principle acknowledges teaching and learning practices that are unique to Māori and that are preferred by Māori. This is based on mātauranga Māori and may include students and teachers at the centre of the educative process, life-long intergenerational learning, gradual learning from a familiar starting point, recognition and encouragement of giftedness, and learning and teaching conducted from the students' strengths. This can be through wānanga, marae, whānau hui, pōwhiri, kapa haka and tikanga processes.

Kia piki ake i ngā raruraru o te kainga – the principle of socio-economic mediation

This principle focuses on addressing the need to alleviate the disadvantages experienced by Māori communities due to socioeconomic determinants of health. For whānau Māori this includes disparities in employment, education, housing, transport, access and money for treatment-related costs. For Māori kaimahi and providers, this includes the same disparities for whānau and also a lack of support through career pathways, Māori skill sets being undervalued, being underpaid, and Māori health being underfunded within the DHB system and for NGOs.

Whānau – the principle of extended family structure

The principle of whānau sits at the core of kaupapa Māori. The importance of whānau has been reaffirmed through Māori health models like Te Whare Tapa Whā and the national Whānau Ora programme. The principle of whānau sets a challenge for those implementing a Māori approach to ensure that whānau and all manuhiri are treated in a respectful way.

Kaupapa – the principle of collective philosophy

The principle of kaupapa recognises the collective vision and aspirations of Māori instead of just the individual or a few. This includes connections to hapū, iwi and the wider Māori community.

Te Tiriti o Waitangi – the principle of the Treaty of Waitangi

The Treaty of Waitangi is New Zealand's founding document and highlights the special relationship between Māori and the Crown. Chamberlain (2018) identifies that the Treaty of Waitangi is mentioned in many DHBs' organisational strategies, with some DHBs specifically acknowledging and taking action on the articles of the Treaty of Waitangi.

Treaty articles:

- Kāwanatanga – partnering for mutual benefit
- Tino rangatiratanga – Māori retain chieftainship over their taonga, lands, resources, mātauranga
- Ōritetanga – all New Zealand citizens have the right to the same outcomes – equity
- Wairuatanga – spiritual diversity is assured.
- Āta – the principle of growing respectful relationships

The principle of Āta was developed by Pohatu as a transformative approach to social services. It acts as a guide to understanding, building and nurturing relationships with Māori.

An evaluation examined CCN's kaupapa Māori approach in engaging with Māori cancer patients and whānau through the community hui design and implementation, including:

- investigating the ways in which CCN has engaged Māori cancer patients and whānau
- identifying the critical success factors in utilising kaupapa Māori approaches
- identifying the contextual factors impacting on kaupapa Māori approaches.

Co-design

The Health Quality & Safety Commission's Partners in Care programme describes co-design as:

- an important part of a process to engage people; consumers, family and staff, capture their experiences and ideas, organise the learning that it brings to create new understanding and insight from the perspective of the care journey and emotional journey, come together in partnership to review learning and ideas, plan and implement improvements then finally; review what difference that has made.

The co-design approach includes the following stages:

- Project start up: scope, plan, aim
- Engage: consumers, families and staff
- Capture: consumer, family and staff experiences using a range of methods
- Understand: emotions and 'touch points' along the journey of care
- Improve: work together to identify and prioritise what to improve
- Measure: check to see if experience is improving

The Partners in Care Programme identified cancer as the focus for 2019–20 and engaged

with the regional cancer networks to facilitate the development of project teams and initiatives. Co-design training and ongoing support for the project teams was provided by Partners in Care via workshops and a series of webinars.

The approach that CCN took with this opportunity was to integrate this methodology, alongside the kaupapa Māori approach, into the Regional Cancer Deep Dive programme with a focus on the planning and delivery of the regional Māori cancer stakeholder hui. Project teams aligned to each of the four hui were established, and they engaged in the training, planning and delivery of the hui.

This case study is the product from the approach taken by CCN.

Engagement hui

Following the seven community hui, the four regional Māori cancer stakeholder hui were held between August and December 2020. Over 1,000 Māori attended the community hui and 212 Māori and non-Māori attended the stakeholder hui.

Kaupapa Māori practices were core to the planning and delivery of the hui, including:

- partnering with tangata whenua to plan and deliver these hui
- budgeting appropriate pūtea to enable a quality hui to be delivered
- following tikanga appropriate to the rohe we were in, including whakatau and karakia
- providing an environment where Māori felt comfortable to wānanga about cancer
- utilising venues that would encourage Māori to attend, including marae
- funding and arranging transportation to facilitate attendance
- engaging local kapa haka groups, raranga and rongoā practitioners to participate in the hui
- valuing the information collected via kōrero and survey responses, including providing a koha to Māori who completed the surveys

- utilising Māori researchers to take the raw data and develop the report
- delivering health services at the community hui, including cervical screening, health screening, mirimiri, rongoā consults, primary care registrations and health promotion
- committing to take action on what we were hearing along with collecting information for the report – we were able to directly address issues impacting on individuals/whānau at the time along with identifying initiatives for immediate action (see next steps)
- being accountable to the communities by committing to an ongoing relationship, including repeat hui
- taking a health and wellness approach using positive messaging and imagery.

Between hui the CCN team were able to reflect on improvements to the way the hui were delivered, and these learnings were built into future hui. By the end of the seven community hui there was a wealth of information gathered, and an initial analysis was undertaken to inform the key themes for the stakeholder hui.

The CCN team were comfortable that via the community hui process we had delivered the early stages of the co-design approach, which had allowed us to engage, capture and understand the Māori community voice, and we valued the opportunity to build on this for the stakeholder hui.

At this point we joined with the Partners in Care programme and established project teams for each of the stakeholder hui. Again, a co-design approach was utilised drawing on learnings from the community hui process. These project teams consisted of both Māori and non-Māori consumers and providers from across the region. As this project was already underway, the Partners in Care approach was modified to take this into account noting there had already been significant consumer input. This resulted in some decisions being predetermined by the initial engagement, including the timing and venue for the hui and key themes.

The project teams developed the following elevator speech for the pānui, which was sent out to contacts on the CCN database (over 600 individuals and organisations):

The Central Cancer Network (CCN) is committed to working together with Māori and cancer stakeholders to improve cancer outcomes. Over the past three months, we have held a series of community hui in partnership with Māori providers from across the region, and heard the kōrero of whānau.

In the near future, we will hold four stakeholder hui to ensure their voices are acted on. The aim of these hui is to hear a cancer stakeholder perspective on how we can best work together to achieve excellence and equity in Māori cancer outcomes.

This kaupapa resonated with stakeholders, and many recipients of the initial pānui shared it amongst their wider networks.

The project teams worked collectively to develop the approach for the focus group section of the programme and supported CCN to facilitate these sessions. They also advised on Māori experts to be invited to present at the hui. Again, we took a learning approach between hui, engaging the project teams to advise on changes to subsequent hui so they could be as successful as possible. The influence of Māori in determining how the hui needed to be run and adjusted is a core component of a co-design approach, which asserts that those who are delivering and receiving services should be involved in designing them.

The stakeholder hui would not have been as successful without the involvement of the Partners in Care team and the project teams (see Appendix 1 for a list of those involved).

Discussion

The experience of all the teams involved in this programme is that kaupapa Māori and co-design methodologies complemented each other in the planning and delivery of this work. Both approaches aim to design projects in a way that meets the needs of the population group/consumers of services instead of designing projects in the way that we personally believe

is best. Both approaches require genuine engagement and a commitment to being responsive.

Working with Māori communities is key to understanding their challenges, aspirations and solutions to addressing cancer health inequities. This includes projects that are specifically targeted for Māori as well as general projects to ensure they also meet the needs of Māori. For projects that are not specifically targeted to Māori, including kaupapa Māori approaches alongside the traditional co-design process will ensure Māori are engaged and supported to participate.

This work has reinforced the wider concept of the ‘consumer’ that is used by the Partners in Care programme. Māori take a broader view of ‘consumer’ rather than a traditional view, which can focus on just the individual with a lived experience of the topic being addressed. For Māori, their understanding of consumer is that it includes their whānau because what impacts the individual impacts the whānau. It is also important to include hapū and iwi voices in projects that have widespread implications to ensure the collective vision and aspirations of Māori are heard. It is therefore important when scoping co-design projects with Māori that resources, including time, engagement processes and funding, are appropriate to the scale of the project.

In addition, some may believe that non-Māori shouldn’t be included in the delivery of kaupapa Māori projects. In our experience, having Māori and non-Māori involved in the project provided a safe and supportive environment for Māori to be themselves and for non-Māori to gain greater understanding of Māori, including people, concepts and appropriate services. This will aid non-Māori to improve services that they deliver to Māori. The important thing is that the kaupapa Māori method is Māori-led, and we need to build capability and capacity into the system to enable this.

The team’s experience of implementing a kaupapa Māori approach alongside the co-design approach has been successful, and we will continue to integrate these into our project approaches going forward.

Next Steps

The purpose of both the community and the stakeholder engagement hui was to bring people together to share examples of the current cancer journey and to identify learning and ideas that would improve that journey for those delivering and those receiving services. Through the hui the following initiatives were identified for immediate development:

Rongoā Māori Hui Days

The interest from communities in rongoā and how this traditional medicine approach can support them in illness and wellness resulted in a next series of hui being planned in each DHB region with a focus on providing communities with more information and access to rongoā services. This will also be an opportunity to update communities on what had happened with their kōrero since the last hui.

Clinical Training Days

Kōrero from the community hui identified that Māori felt that primary and community care staff would benefit from additional training on engaging with their Māori patients/whānau, especially in relation to cancer. These training days in each DHB region will target primary and community care teams and offer a continuing medical education (CME) accredited programme on Māori and cancer.

Massey University’s Pūhoro STEM Academy

Māori want to see a health workforce that reflects them. This activity is a workforce pipeline initiative where Year 11–13 Māori students in the Manawatū rohe are exposed to cancer careers via cancer career expos and internships.

Cancer Control E-learning Resource

Presentations from the stakeholder hui along with presentations from other sector experts

will be packaged into an e-learning tool for national dissemination, with a particular focus on upskilling primary and community care providers.

Re-development of Local Networks

Following provider involvement in the planning and delivery of these hui, some DHB regions were keen to re-establish and re-focus their local cancer networks to be more inclusive of Māori providers and cancer outcomes for Māori. CCN will support them to transition to an improved partnership model.

Kaupapa Māori and co-design practices will continue to be used, and built on, in the planning and delivery of these initiatives.

References

Chamberlain, N. (2018). Health Services and Outcomes Kaupapa Inquiry: Evidence Dr Nick Chamberlain. Wai 2575.

Cram, F., Kennedy, V., Paipa, K., Pipi, K., & Wehiipeihana, N. (2015). Being culturally responsive through kaupapa Māori evaluation. *Continuing the journey to reposition culture and cultural context in evaluation theory and practice*, 289-311.



Above: Traditional Māori Healing Modality of Rongoā provided by "The Rongoā Collective of the ART Confederation" at the Capital & Coast community hui held 2019.

Appendix 1: The project teams

Name	Role	Organisation
Fletcher Beazley	Sponsor	CCN
Jo Anson	Project Manager, Diagnosis and Treatment	CCN
Lee Benjamin	Project Manager, Supportive Care	CCN
Sheryll Hoera	Project Manager, Prevention and Screening	CCN
John Manderson	Project Manager, Enabler	CCN

Each project manager has a team sourced from the sector (health professionals and consumers) supporting the planning and delivery of the hui.

Name	Hui	Role	Organisation
Jane Lyon	Diagnosis and Treatment	Senior Advisor	Ministry of Health
Virginia Signal	Diagnosis and Treatment	Researcher on C3 Project	Otago University
Dr David Hamilton	Diagnosis and Treatment	Clinical Lead	Wellington Blood & Cancer Centre
Brian Sheppard	Diagnosis and Treatment	Consumer	
Hannah Barnes	Diagnosis and Treatment	Cancer Audit & Service Development	MidCentral DHB
Kevin Sharkey	Diagnosis and Treatment	Insights & Analytics	Central Region Technical Advisory Services (TAS)
Don Baken	Supportive Care	Regional Lead Psychologist	Massey University
Jeanine Stairmand	Supportive Care	Researcher on C3 Project	Otago University
Chrissy Paul	Supportive Care	Cancer Iwi Coordinator	Te Wakahuia
Jennifer de Ridder	Supportive Care	Service Manager Cancer Services	Capital & Coast DHB
Sheldon Ngatai	Supportive Care	Consumer	
Kathleen Holloway-Smith	Supportive Care	Consumer	
Candace Sixtus	Prevention and Screening	Portfolio Manager	Waitematā DHB
Lisa Te Paiho	Prevention and Screening	Tumu Kaitokeke Ai Me Kaitikanga A Rua, Pae Ora – Paikaka Hauora Māori, Radiation Oncology	MidCentral DHB
Yvonne Hewson	Prevention and Screening	Breast Screening Promotions Coordinator	Best Care (Whakapai Hauora) Charitable Trust
Dr Moira Smith	Enabler	Researcher on C3 Project	Otago University
Stephanie Fletcher	Enabler	Consumer	
Jay Patel	Enabler		TAS
Monica Koia	Enabler	Researcher	Massey University
Rose Simpson	Enabler	Principal Clinical Advisor	Cancer Control Agency

Appendix 2: Māori terms

Hui	to gather, congregate, assemble, meet
Kai	to eat, consume, feed (oneself), partake, devour
Kaimahi	worker, employee, clerk, staff
Kapa haka	concert party, haka group, Māori cultural group, Māori performing group
Karakia	to recite ritual chants, say grace, pray, recite a prayer, chant
Koha	gift, present, offering, donation, contribution – especially one maintaining social relationships and has connotations of reciprocity
Kōrero	to tell, say, speak, read, talk, address
Mahi	to work, do, perform, make, accomplish, practise, raise (money)
Mamae	ache, pain, injury, wound
Manuhiri	visitor, guest
Māori	native, indigenous, fresh (of water), belonging to Aotearoa/New Zealand, freely, without restraint, without ceremony, clear, intelligible
Marae	courtyard – the open area in front of the wharenu i, where formal greetings and discussions take place
Mātauranga	knowledge, wisdom, understanding, skill
Mirimiri	to rub, soothe, smooth, stroke, fondle, smear, massage, rub on, rub in
Pānui	to announce, notify, advertise, publish, proclaim
Pōwhiri	invitation, rituals of encounter, welcome ceremony on a marae, welcome
Pūtea	fund, finance, bank account, sum of money
Raranga	to weave, plait (mats, baskets, etc)
Rohe	boundary, district, region, territory, area, border (of land)
Rongoā	to treat, apply medicines
Tangata whenua	local people, hosts, indigenous people – people born of the whenua; ie, of the placenta and of the land where the people's ancestors have lived and where their placenta are buried
Taonga	treasure, anything prized – applied to anything considered to be of value including socially or culturally valuable objects, resources, phenomenon, ideas and techniques
Te reo Māori	the Māori language
Tikanga	correct procedure, custom, habit, lore, method, manner, rule, way, code, meaning, plan, practice, convention, protocol – the customary system of values and practices that have developed over time and are deeply embedded in the social context
Tino rangatiratanga	self-determination, sovereignty, autonomy, self-government, domination, rule, control, power
Wānanga	seminar, conference, forum, educational seminar
Whakatau	to decide, settle, prepare, determine, arbitrate, adjudicate
Whānau	extended family, family group, a familiar term of address to a number of people – the primary economic unit of traditional Māori society. In the modern context the term is sometimes used to include friends who may not have any kinship ties to other members.



Above: Work of Tania Cresswell, Raranga Practitioner Hawkes Bay community hui 2019



Central Cancer Network

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