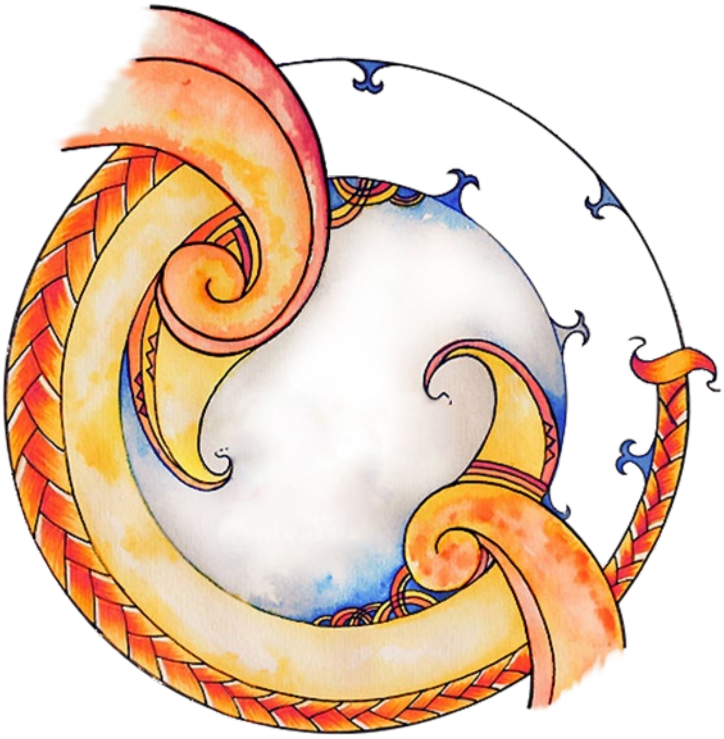
Oranga Tū: A healthy stand

a kaupapa Māori prostate cancer project



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This project received ethical approval from the University of Otago Human Ethics Committee (Refs D17/167; F18/003; H18/110)

Mihi

E ngā mana, e ngā reo, e ngā karangatanga maha, tēnā rā koutou katoa.

E ngā mate o te wā, koutou kua takahi i te ara o te hunga hokinga kore ki muri, okioki mai rā koutou, kei te kāhui pō kau

Hoki rawa mai ki te pito ora, ka mātua rere ngā mihi ki ngā ringa hāpai i te kaupapa o Oranga Tu, otirā, ki a koutou e whakapau kaha nei mō ō tātou tane Māori te painga.

E tika ana kia wānangahia te taha ki tēnei kāhui e tūhuratia ai he māramatanga whai take ki a rātou.

Ka rere hoki ngā mihi ki a koutou katoa kei ngā tini hapori, kei ngā tini marae o te motu, i whai wāhi mai ki tēnei rangahau e pa ana mate pukupuku repe tātea.

Nā koutou i tuku mai ā koutou kōrero, ā koutou āwhina anō, me te aha, kua rangatira tēnei kaupapa i a koutou, nei rā te aumihi te rere atu nei.

Huri, huri, tēnā koutou, tēnā koutou, kia ora huihui mai tātou katoa.

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Oranga Tū has been gifted with the time, expertise and energy of a large group of people, for which we are immensely grateful.

In the first instance, we acknowledge the wisdom and generosity of Matua Rea Wikaira. Rea shared his whakaaro about having prostate cancer but still living his best life. His words on the very first day we all came together have shaped and guided this project. He said, “once my wairua was intact I was able to do anything”. Wairua is hardly ever considered as a part of western health care, but without it there is no true health.

The national Kaitiaki group was where the project was conceptualised and reviewed. For their expertise and support while we got up and running, we thank Ross Lawrenson, Stephen Mark, Charis Brown, Lynette Jones, Marie Wales, Tim Stokes, John Broughton, Peter Ellison, Marama Fox, Hemi Curtis, Rod Calver, Tiffany Schwass, Graeme Woodside, and Danny Bedingfield.

Our co-design rōpū have been the source of unwavering support and expertise throughout the project and beyond. We are immensely grateful for them all.

Finally, and most importantly, we acknowledge the taonga of the stories from ngā tāne and their whānau, and the people who work with them to support and care during their prostate cancer journey. We thank you from the bottom of our hearts for everything you brought to the project; you know we couldn’t have done it without you.

“Ma te rongo, ka mohio, Ma te mohio, ka marama,
Ma te marama, ka matau, Ma te matau, ka ora.”
“From listening comes knowledge, from knowledge comes understanding,
From understanding comes wisdom, from wisdom comes well-being.”

Tohu

Artist: Marama Fox

The taura is the Taura Tangata – the whakapapa that binds us all no matter the outcome, no matter the ups and downs of life, that never changes, ie: links us to our Whenua – Te Kōpu o Papatūāuku and our mother.

The center is that tunnel that leads to the light – Oranga Tu

The rua kumara represents the times of plenty where we store up the strength needed to overcome adversity.

It is the trials that make us strong and the two Koru are the tohu of our ups and downs, the culmination of which brings us to our present and makes us who we are. It's the ability of us as Maori becoming resilient in times of controversy and challenge.

Contents

Ko wai au? Who are we?

The project had three co-leaders: Rawiri Blundell (Ngati Porou ki Uawa), Jacquie Kidd (Ngāpuhi) and Richard Egan (Pākehā).

This photo shows many of the people who formed the co-design rōpū in Waikato and Dunedin. It was taken at our last combined hui where we discussed what the project had achieved and what needs to happen next.

Left front: *Rawiri Blundell, Howie Brown, John Broughton, Stella Black, Teresa Manahi, Christine Maxwell, Max Noda, Rueben Moses*
Back row: *Rangimahora Reddy, Hemi Curtis, Jacquie Kidd, Ross Lawrenson, Gary Thompson, Rawiri Keenan, Richard Egan, Jeff Morgan.*

The co-design rōpū in each area include people who manage or provide services to tāne Māori who have prostate cancer, researchers, clinical specialists and tāne with experience of prostate cancer.

In Dunedin the co-design rōpū included Christine Maxwell (CEO) and the crew at Te Roopu Tautoko Ki Te Tonga, Teresa Manahi & Shelley Kapua (Kaiwhakahaere), Arai Te Uru Whare Hauora & Te Kaika, and the Otago Southland Cancer Society.

In Hamilton the co-design rōpū included Rangimahora Reddy and the team at Rauawaawa Kaumātua Charitable Trust, Matua Hemi Curtis (Oranga Tū project kaumatua), Professor Ross Lawrenson and Tiffany Schwass from Otago DHB, Dr Rawiri Keenan, Dene Ainsworth from the Prostate Cancer Foundation, and Charlie Poihipi and Wayne Borrell from the Waikato-BoP Cancer Society.

He kaupapa

Māori men who have prostate cancer and their whānau should receive good care from culturally appropriate community-based health and social services. We were asked to find out about the non-specialist services who are working with whānau going through the prostate cancer journey.

The areas we focused on were around Dunedin and Tauranga. Hospital-based and specialist cancer treatment services were not included in the study.

We wanted to find out how the health sector can:

- Support men and their whānau who are affected by prostate cancer to focus on staying healthy and connected to the places, people and activities that matter to them.
- Support the whānau ora of men who are newly diagnosed with prostate cancer.
- Contribute to making a difference in health services for men with prostate cancer and their whānau.

What we already know

There is quite a bit of research into Māori men's health. There is also a lot of research that looks at prostate cancer. There is very little research that focuses on Māori men with prostate cancer.

Hauora tāne Māori: Māori men's health

- The health status of Māori men is generally poorer than non-Māori. This is associated with the longstanding effects of land theft and colonisation, especially poverty and the lifestyle that goes with having limited resources (Graham & Masters-Awatere, 2020; Reid & Robson, 2007)
- Māori men generally prioritise their whānau and work rather than their own health, which means they delay visiting the doctor until they are forced to go either by severe symptoms or by their whānau (Kidd, Gibbons, Kara, Blundell, & Berryman, 2013)
- Māori health services are providing cultural programmes that enable tāne to take control of their lives and improve their health (Rolleston et al., In press)

Mate pukupuku repe tātea: Prostate cancer

- About 3,000 men are diagnosed with prostate cancer each year in Aotearoa New Zealand and about 600 men die from it (Ministry of Health, 2018)
- Early diagnosis (when the cancer is fully within the prostate and has not spread) leads to better outcomes (Obertová, Scott, Brown, Stewart, & Lawrenson, 2015)
- There is no prostate cancer screening programme in Aotearoa New Zealand, but it has been discussed. A key problem with screening is the high level of falsely positive results which can lead to unnecessary invasive tests and anxiety (Ilic, Neuberger, Djulbegovic, & Dahm, 2013)

- Treatment options include radiotherapy, chemotherapy and surgery. These approaches are often combined to give the best outcomes (Ministry of Health, 2013)
- About 7 Māori men will be diagnosed with prostate cancer in each of the DHB regions each year (Ministry of Health, 2015)
- Māori men are more likely to be diagnosed later, be sicker, and die earlier than non-Māori men (Lao et al., 2016)

Health care for whānau with prostate cancer

Whānau can be cautious about seeking non-urgent health care. Figure 1 was developed from other research into Māori health (Kidd, Black, Blundell, & Peni, 2018; Kidd et al., 2013). It shows many of the reasons whānau might not want to leave the safety of the hau kāinga (home base) to ask strangers for help.

FIGURE 1: BARRIERS TO SEEKING HELP FOR WHĀNAU

The research says that whānau dealing with the very personal diagnosis of prostate cancer can face the barriers of whakamā about their symptoms, and worrying about having their private business shared among the wider community in addition to the common barriers of:

- living too far from services (geography)
- being poorly treated or disrespected because of being Māori (racism)
- travelling to services, paying for some services, taking time off work (finances)
- not knowing about the services that are available, why they are important and how to access them (health literacy of services and whānau)
- feeling miserable, sad and angry about the diagnosis (depression), and
- feeling like you don’t deserve health care, you deserve to be sick, or that it’s too late for you to benefit from health care (stoicism)

These barriers can leave a whānau feeling isolated and alone. An example of this is that we heard of whānau who couldn’t find any support at all once they left the hospital system because they couldn’t overcome the barriers on their own and they couldn’t find anyone to help them. But on the other hand, we heard stories from whānau who were delighted with the extra support they received from their community-based health service. These different experiences were what we wanted to understand and improve.

What did we want to know?

We wanted to know how whānau found and accessed services in their communities, and what either helped or blocked their ability to find services that met their needs.

Āku mahi? What did we do?

Our project had two phases and took place in the Dunedin and Tauranga areas. We spoke to a total of 46 people.

The first phase involved talking to service providers. The people we spoke to were kaimahi or managers who worked in 18 Māori and 13 non-Māori community health services. We asked them if their service cared for Māori men with prostate cancer and their whānau. We asked how whānau came into the service (especially if they were they referred by someone) and whether they referred whānau to other services that might be more useful to them. We used a process called ‘network mapping’ to draw a map of where each service was located, the other services that they shared referrals and close contact with, and the ones that they knew of but didn’t communicate with.

The second phase involved talking face to face with 15 Māori men who have a diagnosis of prostate cancer. Many of the interviews also included wives, whānau or support people. We asked them about their journey, the community-based services they had used and if they thought there were ways to improve services for whānau going through prostate cancer.

What did we find?

Whanaungatanga: belonging and connection

We have called the major finding from the first phase of this project (network mapping with service providers) *‘Te Pā Ora’*, meaning that it’s OK when you’re inside of your home community. This represents the feeling of safety and security of having access to health and social services that have a presence inside the pā where whānau feel comfortable.

Each whānau may have a different way of describing where their pā is and who sits inside it. For some whānau the pā is a traditional structure that consists of a marae as central to a hapū based community, while others might have their own whānau close by with an urban health centre and the wider whānau all around the country, or live alone but connect through phone, email and internet with whānau who are overseas. There are lots of ways to live as Māori in this modern world. In all these cases, though, whānau have a safe space where their health concerns can be discussed, and their needs are met.

Sometimes the safety of te pā ora is provided by whānau members who are health professionals and can act as advocates and navigators. In this situation whānau who would usually feel as though they're isolated from the health care they need can feel safe and supported throughout their journey. The actions of the health professional whānau member can help the patient whānau to overcome the barriers (shown in Figure 1) and the gaps we discuss below that would otherwise prevent them from seeking or receiving health care.

Te wehenga: isolation and disconnection

After completing this mapping project, we can clearly see where the gaps and missed connections are for whānau. They are shown on Figure 2 with blue starbursts.

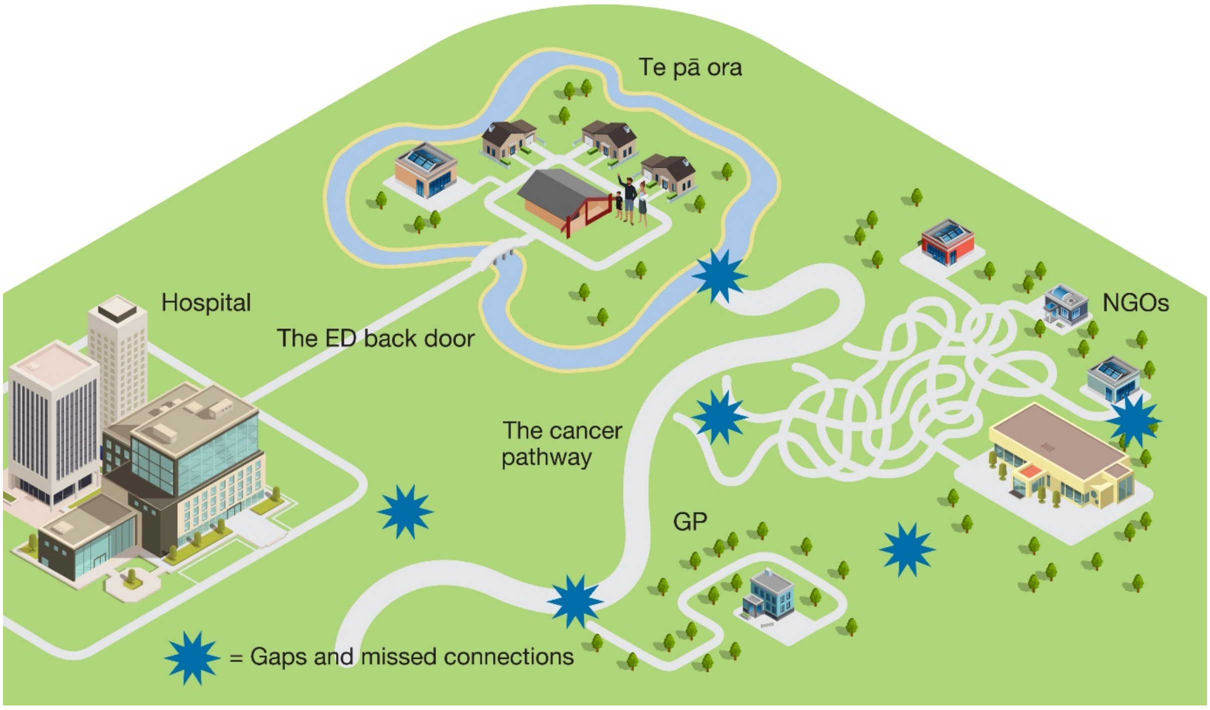

FIGURE 2: MAPPING THE GAPS IN SERVICE PROVISION

This picture shows a general map of community-based health and support services. The whānau can be seen in their pā ora, which includes their local community and a small health service which might be a Māori health provider or local GP. The whānau are both protected and restricted by the awa that surrounds them (this was explained above in Figure 1). Outside the pā ora is a major pathway that is travelled when the whānau receive a diagnosis of prostate cancer, but this pathway is not always well connected to the whānau in their pā, their GP if that service is outside their pā, the hospital, or the small services that are available but can be hard to find. The small services can include things like the Cancer Society or the Prostate Cancer Foundation, incontinence physiotherapists, sex therapists, wellness programmes or financial services. The label on these services is NGOs, or Non-Government Organisations because they are usually not funded by the Government.

Each of the stars on the picture represent a place where whānau can slip through the gaps and can miss the opportunity to receive all the care that is available to them in the community.

- In an emergency there is a ‘back door’ into the Emergency Department, so whānau can get direct access to health care there. This back door is often not connected to any other services, so whānau don’t always get follow-up care once they return home
- The barriers that interfere with accessing health care (from Figure 1) are very difficult for whānau to overcome on their own. This is a big problem if the service or support they need for their prostate cancer journey is not found in their pā ora. There is a gap in health services that actively help whānau to cross the river of barriers to get help
- Once the whānau is on the specialist cancer pathway it is often not clear how they can get access to community services for support. Also, the community services might know that there are whānau on that pathway, but they can’t find out who they are to offer help
- Community health care services range from very big and well known services to small services that most people don’t know about. Sometimes the bigger services can act as a barrier to the smaller services, even when the smaller services might be exactly what a whānau needs. There is a gap where sometimes referrals are not sent to more appropriate, but small, services
- There are very few connections between GPs or other primary health services and the community service network. This can mean that whānau are

not referred simply because their GP does not know that the community service exists or how to access it for their patients

- The connection between the whānau on the cancer pathway and their GP can be confusing for both the whānau and the GP. There is a knowledge and communication gap in this area
- There is often a similar communication gap between the hospital and the GP, which means information about whānau experiences, worries and needs might not be passed on to each other. This can leave whānau feeling isolated and struggling to manage on their own

He Hikoi Hauora (A Health Journey) for Tāne

In the second phase of the project we talked face to face with 15 Māori men who have a diagnosis of prostate cancer. We have divided their kōrero into four sections, each relating to an aspect of Māori health. These are based on the work of Tā Mason Durie (Durie, 1985) and include;

- *Te taha wairua* (the spiritual dimension) pertains to the spiritual beliefs and practices of Māori, their connection to the *Atua* (Gods) and to their *tupuna* (ancestors), especially through karakia (prayers and incantations).
- *Te taha hinengaro* (the mental dimension) includes both the mental well being of the individual as well as the mental well-being of the *whānau* (family).
- *Te taha whānau* (the social or family dimension) is concerned with the immediate and extended family in which the individual lives, works and identifies with.
- *Te taha tinana* (the physical dimension) refers to the physical human body.

We have included some quotes from the stories shared by ngā tāne:

Te taha wairua

"I was sitting there and she [the nurse] came out and I was sitting there, she said, "What's the matter koro?" And I said, "Oh nothing." "Oh, but I think there's something wrong with you. I'll get the padre to come and talk to you." So she went and organised it. She was only young but I don't know how the hell she picked it up, but she just knew."

"A prayer circle with whānau and work mates. I got great wairua support from him in both a work capacity and personal capacity."

Te taha hinengaro

"Yeah, yeah that's the scary one. Yeah, it's what you were saying before that bloody word cancer, it hits you like a baseball bat, yeah."

"It has been hard emotionally, for both myself and my family. The most difficult thing that I found wasn't so much telling my wife, but telling the kids and grand-kids. That was the most difficult thing. Emotionally, that was hard. But having got through that, I now don't find those conversations that hard, I think it's just about having the confidence to do it."

"You have to listen to what people are saying you know and not block out; things you didn't want to hear. You've got to have that right attitude to listen, like the nurses and your wife. But it is important to have that attitude because that helped me quite a lot to get through."

"I put my head in the sand. I couldn't go to a *tangi* (funeral) for a long time after, and I didn't want to know about people who had anything to do with cancer, because I didn't want to have the conversation, people asking, you know, "How are you going with it all?” However, down the track I do understand the importance of the *kōrero* and getting over yourself.”

Te taha whānau

“It’s about having grand children and wanting to be there for them, wanting to see them grow up, and wanting to see them succeed.”

“They (the ward staff at the hospital) never said anything to me about the *whānau* coming in, except the day he had his operation and had his hematoma. That’s when I stopped the *whānau* from coming, or for anybody coming in, because I didn’t want them seeing him like that. And he wouldn’t want them being there. It’s hard having to saying that to the family, saying, ‘Can you *taihoa* (hold back) for a minute?’”

“Some *whānau* came down from Wairoa, Whanganui. Mainly siblings, nieces and nephews. So he got a lot of *aroha*, after we shared it, yeah. And they have been very supportive.”

Te taha tinana

“What was bad for me was that I went to toilet sometimes four or five times a night all of the time. And my biggest worry was when the doctor said that they were going to cut it, knowing that that’s the main valve. *Aue,* (alas) man it might make me *mimi* (urinate) the bed aye. But luckily, that hasn’t happened yet.”

“I was diagnosed with prostate cancer at age 60. I am ex-army so I always used ANZAC Day as “my go get a medical day.” Initially I did it as part of the conditions for my heavy duty truck licence, and I continued doing that since leaving the Army. At 52, I started getting prostate checks including the ‘finger up the bum’ as they say, as part of annual check-up with the GP. At 59, the prostate check was all good, but when I went back when I was 60, the GP said, ‘Oh, there is something wrong here.’”

"They gave me the option of how I wanted to do the treatment. Would I do surgery or would I do chemotherapy? And they did say if I do the chemotherapy and they don't get it all you can't go to the surgery because it's too late. So I chose the surgery, and they told me it was a good choice. It was because if they don't get it all in the surgery you can go to the chemo. So I thought okay, I did the surgery option."

What improvements are needed?

Our vision is for a healthcare map for whānau where all the services are connected, and where whānau can see and know all the services that are available to them. This includes whānau knowing how to get in the front door of all services, and the services reaching out to support whānau as they are choosing the service that meets their needs.

There are two key things that need to happen for this vision to become reality. The first is whanaungatanga, and the second is Kaioriori.

Whanaungatanga

We believe that the single most important action by health services to improve the lives of whānau with prostate cancer is whanaungatanga. When we described te pā ora for whānau we described a place where connections between people, their whakapapa, te taiao, and ātua have been made and nurtured. This is what makes te pā ora a safe and healthy space, whether it is a physical place or a spread-out network of whānau members. Whanaungatanga holds all whānau members together.

The same value of kanohi kitea (the face that is seen) and acknowledging connections should apply to health services. Most of the Māori health services we talked to were viewed as pā ora; they were an active part of the Māori community so were kanohi kitea. Whānau know who is in the service, how to find them, and what to expect when they go through the door. Often the people from Māori health services and whānau either know each other before health care is needed, or they each know at least one person who is related to someone in the service who can awhi the whānau and introduce them.

Outside of te pā ora, which is where many of the more complex or specialised community health services are, the lack of whanaungatanga can mean that whānau don’t get access to the help that is available. This happens because whānau can’t overcome the awa of barriers on their own, or because they don’t know what the external health services can do for them (or anyone who works there), or even that whānau don’t trust that the service will care for them respectfully and well.

We believe that closing the gaps between whānau and health services (from Figure 2) can be achieved if health services attend to the processes of whanaungatanga between themselves, and between each service and the communities where whānau live. For example, referral from one service to another (so whānau can get exactly the service that matches their need) does not work effectively if the people in each service don’t know each other. In the worst situation, they don’t even know the other service exists. Sometimes they might know *about* the other service but not know exactly what that service does or how to get whānau through their doors. This lack of knowing is often referred to as services working in ‘silos’. They are each occupied with their own business and are unaware of what is happening around them. This creates problems for whānau Māori who need to know *who* can help them with their prostate cancer journey. Whanaungatanga between services should be a standard practice to create a joined-up and accessible network of services for whānau.

Another example of where whanaungatanga is needed is between the health service and the Māori community. This is particularly a problem for the non-Māori services. Most of the non-Māori services we talked to wanted to work with Māori and wanted to do well for the whānau who come through their doors. But they also had a lack of understanding of the importance of whanaungatanga and the effort that is required on their part to make and keep connections with the Māori community. Many of them talked about having a single meeting several years ago and then not having any other contact. Some were unable to even achieve a single meeting with a Māori organisation in the community, possibly because their approach was not viewed as being sincere or useful to whānau within the Māori community. This meant that whānau were isolated from the services that could potentially have helped them.

Whanaungatanga is a fundamental part of providing good health care for Māori. We consider that building and nurturing connections with Māori should be a priority for health services, and that services should be accountable for this.

Kaioriori

The second important thing to support whānau on their prostate cancer journey is the inclusion of Kaioriori in health services. The concept of kaioriori can be associated with a person or place of safety and connectedness. Within many iwi (tribes) there were places that our old people felt connected to and they would chant in unison with nature and the surrounding environment. This can also be applied to today's environment where communities, navigators, and whānau feel comfortable, connected, and supported within the health services they access.

Navigators have become a part of many services that sit outside te pā ora, including hospitals. They support patients to make and attend appointments, and provide them with information about their cancer journey. Most patients and families appreciate this service and believe that it makes their cancer journey easier.

However, in our service mapping we found that navigators are mostly helpful if whānau are already involved with services and that many whānau are still isolated at home by the awa of barriers. We believe that whānau Māori need a different approach to navigating health services; one that isn’t focused on clinical or medical matters, and that includes tikanga and wairuatanga.

Kaioriori is a person who is based in te pā ora so is whānau and kanohi kitea. The kaioriori role is to introduce the whānau to the services that are outside the pā, stay with them while they choose which services they need, and get to know the health professionals who work there. The kaioriori role is one of advocate, supporter, Aunty and tuakana.

We believe that whānau should be cared for in ways that support their right to choose what works for them. Whānau should always feel safe and secure in their health journey. This is especially important when they are dealing with an illness such as prostate cancer. To do this, we need to close the gaps between whānau and health care in ways that are consistent with te ao Māori. Kaioriori can act as a bridge across those gaps for whānau.

Where to from here?

As a part of this project we have made a film about prostate cancer. It includes the stories of some of the men who talked to us about their prostate cancer journey.

We have shared the film with Universities and Polytechnics where health professionals are trained to help them understand what the barriers are for whānau and what they can do to help. We have also given the film to the Cancer Society to form a part of their whānau education programme called Kia Ora e te Iwi.

We have published some papers in medical journals to inform other health professionals about whānau needs and how to improve services. The papers also contain more information about the research methodology and findings.

Additional resources

- **Prostate Cancer Foundation**: provide peer support, advocacy and fund research, see: https://prostate.org.nz/
- **Cancer Society of New Zealand**: provide supportive care, advocacy and research across all cancer types across six division, see: https://cancernz.org.nz/
- **Kupe**: NZ Ministry of Health prostate cancer decision tool: https://kupe.net.nz/ which can help men to decide whether to get tested or not.
- Health Navigator: online information about all aspects of health in NZ, including medicines, healthy living and services, see: https://www.healthnavigator.org.nz/
- Healthline: 0800 611 116 free life health advice when you need it

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