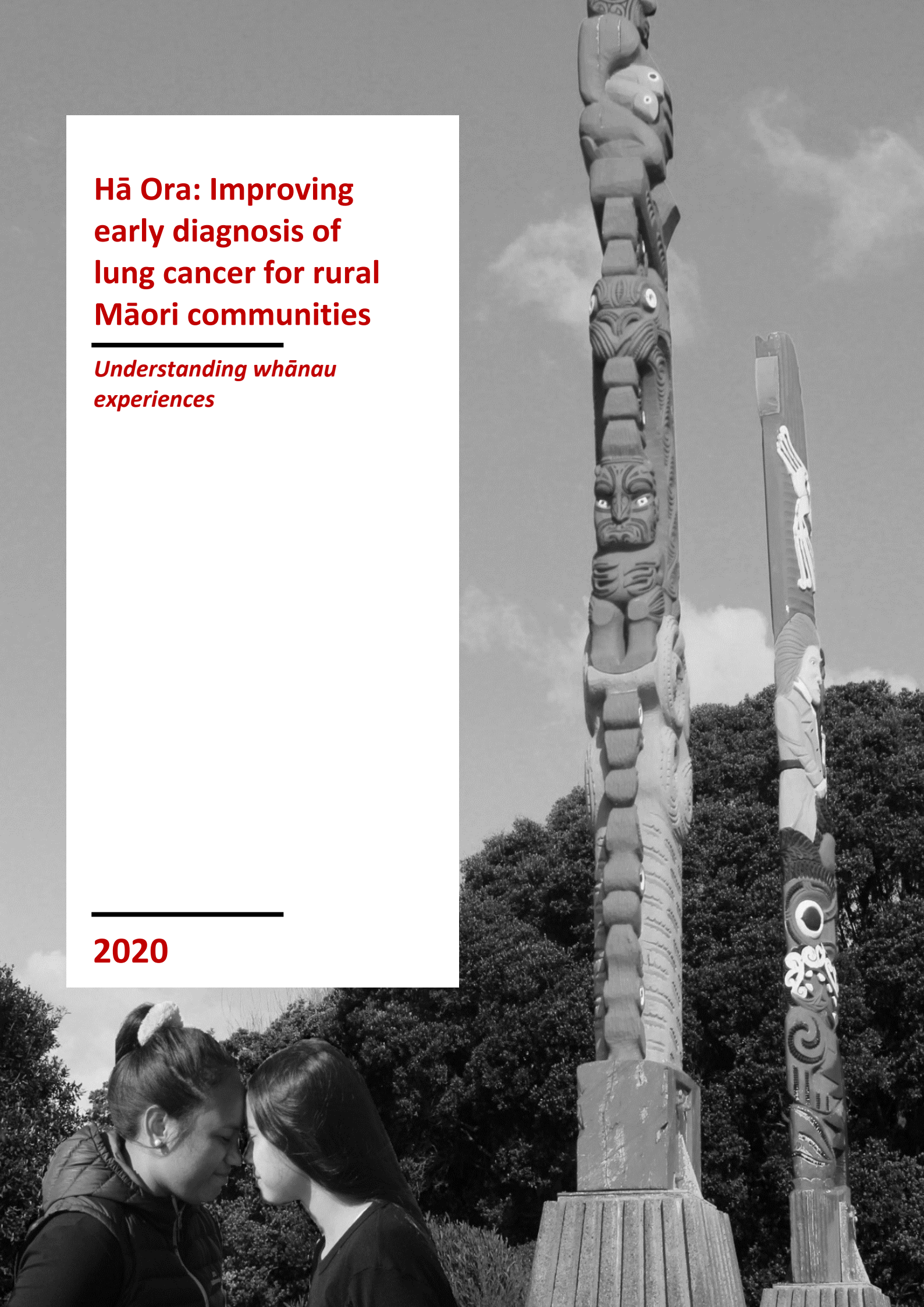


Hā Ora: Improving early diagnosis of lung cancer for rural Māori communities

*Understanding whānau
experiences*

2020



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He tino honore mātou e whakanui ana mātou te kaupapa Hā Ora ki ngā iwi e whakatinana, e whakaora ai tēnei kaupapa ā Hā Ora ki a rātou kōrerorero. Kā whakawhetai mātou ki ngā whānau e kōrero ana te kōrero e hīkoi ana te hīkoi ki tēnei huarahi, kahuri kia rātou hoki e wehi atu ki rangi whetu ma ki tua o te ārai ano kia rātou e ora tonu ai me ngā uri e heke mai nei, nōreira he honore ano i a mātou ki te whakanui ēnei rangatira me ā rātou whānau ki a whiri whiri ā rātou kōrero kia tau te rangimarie, te aroha me te whakapono Paimarire.

We are very honoured to acknowledge those who shared their stories and brought to life Hā Ora. We are forever thankful and dedicate this to them and their families for embracing Hā Ora. For talking the talk and walking the walk. To those who have passed on, who reside among the many stars of the heavens, to those living who remain with us, and for the generations to come. Again, it is indeed a great honour for us to acknowledge these rangatira and their families. May peace, love and faith keep you safe. Paimarire.



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Ko wai au? Who are we?

The Hā Ora Project was led by Ross Lawrenson. Our project kaumātua was Hemi Curtis. Team members included Jacquie Kidd (*Ngāpuhi*), Anna Rolleston (*Ngāti Ranginui, Ngāi te Rangi*), Brendan Hokowhitu (*Ngāti Pūkenga*), Rawiri Keenan (*Te Atiawa, Taranaki*), Melissa Firth, Denise Aitken, Janice Wong, Lynne Chepulis, and Shemana Cassim.

The team worked with people involved in health care, whānau who are going through a cancer journey or those who have supported others with cancer in five Midlands communities: Opōtiki, Te Kaha, Rotorua, Te Kuiti and Gisborne.



He kaupapa

Lung cancer has a chance of being cured if it is diagnosed early. We know that Māori whānau are usually not diagnosed early though, so we wanted to find out what the barriers were to being diagnosed, particularly for rural communities.

The areas we focused on were part of the Midland Region, which includes Waikato, Bay of Plenty, Lakes and Tairāwhiti. We worked with five communities: Opōtiki, Te Kaha, Rotorua, Te Kuiti and Gisborne.

Our key goals were to:

- ❖ Find out what barriers whānau faced on their journey to being diagnosed with lung cancer.
- ❖ Find out whānau and healthcare providers' views on barriers to early diagnosis of (lung) cancer in their rural rohe.
- ❖ Work together with whānau to create ways to overcome barriers, to learn more about lung cancer, and how to encourage whānau to see the doctor sooner if they are worried.
- ❖ Test the whānau ideas in each community.

What we already know

There is quite a bit of research into lung cancer globally, and in Aotearoa. There is also a lot of research looking at numbers of people with lung cancer and chances of surviving lung cancer for Māori. There is very little research that looks at Māori whānau experiences in the lung cancer journey.

Lung cancer in Aotearoa

- ❖ Lung cancer is the leading cause of death from cancer in Aotearoa, with approximately 1,650 people passing away per year [1].
- ❖ Māori are more likely to be diagnosed with lung cancer, and are also more likely to die from lung cancer, compared to NZ European people [1, 2].
- ❖ Lung cancer is usually diagnosed at a late stage. But, if it is found early, people can possibly be cured, with a 70% chance of surviving after 5 years [3].

Barriers to lung cancer diagnosis

Research from around the world says that barriers to lung cancer diagnosis can be related to things that happen in and around seeing your GP:

- ❖ GP – patient relationships
 - A lack of a long standing positive relationship between GPs and patients
 - A lack of trust between GPs and patients
 - Barriers in communication between GP and patients
 - GP practices not having permanent doctors
- ❖ Not knowing about lung cancer symptoms and treatment
 - GPs and patients not knowing a lot about lung cancer
 - GPs and patients thinking lung cancer symptoms were something else
 - Stigma because lung cancer is believed to be related only to smoking

- Patients believing that lung cancer was a death sentence
- ❖ Barriers in access to the GP or specialist
 - Difficulty getting an appointment
 - Long waiting times
 - Difficulty faced by GPs to get referrals for specialists
 - High cost of appointments, treatment and health insurance
 - A lack of transport to a healthcare centre [4]

Previous research from Aotearoa also shows that many Māori people with lung cancer go directly to the Emergency Department at hospital with symptoms, rather than by being referred by their GP. Barriers to diagnosis of lung cancer at hospital for both Māori and non-Māori people include:

- ❖ Differences in their ability to access the right sort of health care,
 - Delays in going to the doctor because people thought lung cancer symptoms were something else
 - Feeling that lung and breathing related symptoms were normal for a smoker
 - Worry that cancer treatment will not help
- ❖ Differences and delays in how care is provided
 - GPs not being able to recognize lung cancer symptoms, and so people experience delays getting diagnostic tests
 - Long waiting times for an appointment with a specialist
 - Barriers relating to resourcing (faxed referrals, which may get lost; hospital booking systems not being flexible; and equipment or staff being unavailable) [5]

These experiences were what we wanted to understand and improve for Māori whānau living in rural communities.

What did we want to know?

We wanted to know what barriers Māori people and their whānau experienced when trying to seek help for their worrying lung cancer symptoms, and through their lung cancer journeys.

Āku mahi? What did we do?

Our project had four phases and took place in Opōtiki, Te Kuiti, Rotorua and Tairāwhiti.

Table 1. The communities

Community	Description	Distance to nearest hospital	Who we worked with
Opōtiki	Small, relatively rural community	45 mins from rural hospital, 3.5 hours from regional hospital	Mariana Hudson
Te Kuiti	Small, rural community	1 hour away from regional hospital Has its own rural hospital	Mahina Joseph-Small, Maryanne Thompson and Tania Te Wano
Rotorua	Larger rural community	Well-equipped hospital. Still uses regional hospital for cancer treatment (1.5 hours away)	Aroha Mai Cancer Support Services, Lakes DHB, Te Arawa Whānau Ora
Tairāwhiti	Larger rural community	Well-equipped hospital. Uses regional hospital for cancer treatment (5 hours away)	Turanga Health

Phase one involved talking face-to-face with 23 newly diagnosed Māori lung cancer patients and their whānau in Waikato, Lakes and the Bay of Plenty. We asked them about their journey, and what barriers they had faced through diagnosis and treatment.

Phase two involved nine community hui in our five locations. Each community hui had between 8-21 people, including cancer patients, whānau, and anyone else in the community who liked to share their stories. We asked whānau what barriers they had faced in their or their loved ones' lung cancer journeys.

Phase three involved nine hui with local healthcare providers. Each healthcare provider hui had 1-6 staff members at the local GP practice, including the GP, nurses and other staff. We asked the healthcare providers what barriers they face in diagnosing their patients with lung cancer.

Phase four involved inviting whānau from each community hui to form four co-design groups with the Hā Ora team. And together we worked to create interventions for each community that would help whānau learn more about lung cancer, and go and see the doctor sooner if they had worrying symptoms.

We also worked with the Te Kaha community. But we found out that the barriers to early diagnosis of lung cancer for this whānau were mostly related to hospital and specialist care. The Te Kaha whānau had a great team at their local GP practice, who played a strong advocacy role to ensure that their patients got the best treatment and support possible. And so, we did not co-design an intervention with the Te Kaha community. Instead, the team agreed to re-visit and update them on how the project was progressing, and to discuss the barriers experienced by other communities, and the interventions that were co-designed.



Figure 1. Ross, Jacquie and Matua Hemi facilitating a hui at a local marae in Tairāwhiti



Figure 2. Sign at entrance of a meeting room for a community hui in Opōtiki

What did we find?

After we heard the kōrero of each participant's lung cancer journey, we grouped examples of ideas and experiences into eight themes around what did and did not help whānau go to see their doctor if they were unwell. In the sections below we have used real people's words wherever possible. The health professional's quotes have, for example (HCP#3) and a number to indicate that the quote came from the health care professional hui number three. For community hui we used (CH#3). For individuals who spoke to us, we made a name up with them so they can't be identified.

GP relationships and position in community

The relationship between patients and GPs can be a barrier to lung cancer diagnosis, or the relationship can be a good thing, encouraging the patient to see the doctor sooner. Some people had positive experiences with their GPs. Some of these experiences came from relationships that had been built over time:

Here, with [our GP], with his people was where [my husband] felt the most comfortable. And he didn't like having to go away to anything. He wanted to just be here. He felt comfortable here... the care that we had here was just great. Really amazing. Not just for [my husband] medically, but for our whole family. And especially for me, because I was a wreck. (CH#6)

My doctor keeps in touch all the time. He rings me up and sees how I am ... I think he just got a bit worried. So that's what made him send me to hospital ... and then when we got my results back for my scan, to see if it had spread ... he was so happy!! He was so happy that it hadn't spread. I just couldn't shut him up! [laughs] (Meri)

These positive relationships were also returned by the GPs:

People wait for me to get back from holiday just so they can see me – trust, relationship. (HCP#6)

Because I have known my patients so long they do tend to come in early for anything serious like coughing up blood. (HCP#2)

Sometimes GPs talked about how they have accessed the power of community relationships to help with caring for their patients:

I once had to ask a patient's cousin to go and check up on them, because they were not answering their phone and they had an appointment for a CT. (HCP#3)

But, longstanding GP-patient relationships were not always helpful for early diagnosis. One GP noted that knowing his patients for a long time could make him less likely to reach a diagnosis:

I know my patients too much. I may become complacent and slower at picking up the little stuff. (HCP#2)

The GP- patient relationship is affected by the mana that the GP holds in the community, as whānau discussed:

I guess from a Māori perspective it's that, the doctor is up there [holds hand up to indicate higher level than self], and that's what I was feeling as though, you've got all the knowledge, the mana [authority/prestige]. You've got the mana, us being Māori, will accept what you say. (CH#3)

We're trusting the fella with the tohu [qualifications]. With the doctor's certificate. So trusting. And we need to hear it from them. (CH#6)

The opinions that the staff at the local GP practice have of their patients and the communities that they work in can serve as barriers or enablers to early presentation and diagnosis. Some staff want to make sure that patients get the best possible care:

We are already putting up barriers for them. We want to break down those barriers. (CH#1)

Some whānau also said that their GPs did not understand what Māori were trying to say to them:

I think there are ways that Māori speak about what they're scared of that isn't recognised. My brother-in-law presented at the doctor saying "I haven't been able to ride my horse for 12 months". It wasn't that he [said he] was short of breath or he was swollen in the legs or anything like that, that was not what he went and said to the doctor. So when someone isn't searching for the cues of how we communicate as Māori, or they don't know how we communicate in that subtle way, I think it could be missed and then you end up getting treated for something else when actually there's something underlying the concern that is spoken. (CH#7)

GP – patient relationships are also affected by barriers relating to resourcing for rural communities. A lot of whānau and GPs talked about the lack of continuity among GPs:

Nurses also struggle, as well as the patients. . . . Patients go straight to the nurses not doctors. (HCP#1)

It usually takes about three days to get an appointment . . . [my husband] doesn't have the same one [GP], you know and then you repeat it to another doctor and getting to another doctor and then.. They are giving different medication each time we go, instead of treating one whole symptom or

whatever, you know and the records are already there, why put him on another pill, another pill, another pill. By the time he's got all the pills during the week it's like ten, twelve. When he should just be on one, you know. We try not to need it you know but it's sort of like...constant. (CH#1)

And so, the familiarity and trust between doctors and patients directly affected whether or not patients went to see their doctor promptly when they first noticed symptoms:

I'd rather go with my doctor. I will wait for 2 weeks [to see my own GP]. (CH#9)

I'd also waited a couple of weeks because of appointment times- I couldn't get in. ... I had built up that relationship with my doctor and I waited to sort of see him because I've got trust in his abilities and what have you. But they would offer another doctor if there was one available with a spare appointment. Because it's like going over and over and over, you know, telling them everything...whereas [my doctor] would just...he knows me, he knows my history and we can just get straight into the appointment type of thing.

(Hariata)

Health literacy

Health literacy is about being able to give information to people in a way that they understand, and people being able to use that information to make decisions about their health.

In each of our community hui we took care to ensure that a doctor who knows about lung cancer was available to answer any questions raised. In every hui, at a very early point, participants turned to the expert and asked for information. Their questions tended to focus on how they could know about lung cancer early, the availability of screening, and how likely it is that someone will get lung cancer. We also asked questions about the symptoms of lung cancer, and most people knew

that if they had a persistent cough and were coughing up blood, they need to seek help. They also identified smoking as the primary risk factor for developing lung cancer.

Most people thought a lung cancer diagnosis was a death sentence:

I didn't even know that there was a 70% cure rate. I just thought when she got it, that's it. Um yeah, so...that's how like, we hear it. (CH#3)

Fear was another thing that stopped people from going to see the doctor:

I have to go for a CT scan soon. Cause of my coughing, I have coughed up blood. But I reckon I shouldn't have waited. It was about 2 years ago that I coughed up the blood. I should have went then. I just waited because I was panicking. (CH#3)

Communication between the doctors, patients and whānau was sometimes not good enough, with participants expressing frustration:

I don't think the communication from health professional to whānau is good enough and we've experienced that in our own family, being just family members. It helps that we have a bit of health background, you know or nursing background um because then you might have an idea of what's required for treatment. (CH#1)

Patients and whānau questioned the information they was given, and searched out ways to help themselves:

I question everything. I questioned the drugs, the chemo, I questioned everything. (CH#6)

Patients and whānau described how health professionals used unclear and very complicated language:

A: They say all these big as words and we were like, can you like tell us in...

B: Tell us in layman's terms

A: Yeah, our lot's not scared to ask, we're not afraid to ask but that's it we don't understand a lot of the time. And it's the same thing can you break it down, break it down, give it to us straight aye you beat around the bush and beating us around it too. We up in the air just as much as aye... just tell us straight out, this is what's happening, okay, then we can deal, then the family can process and deal. And it makes that easier than sitting there going 'what did he just say, what is she talking about', then you get frustrated and walk out then miss a lot more... Or just switch off like we tend to do quite well, oh well you lost me that's it over... (CH#1)

Language was also sometimes a problem:

Her father-in-law only spoke Māori. So his understanding of what the processes were, were very hard and a lot of the time he didn't have anybody else in the room with him, so his understanding was...I don't think it was entirely there. But then nobody actually suggested to bring in somebody else, to speak Te Reo to him or to translate. But then he didn't really say anything either . . he would get home and talk te Māori at home, and then say 'he didn't even say this' or, 'I don't even know what this was about', or, 'where do I go to next'. (CH#1)

Pathways to diagnosis through the GP practice

This section focuses on the time from when a patient is first aware of symptoms through until they receive a diagnosis of lung cancer. As mentioned above, whānau

showed a good knowledge of the importance of symptoms such as a persistent cough and coughing up blood. Yet, that knowledge does not always result in deciding to go to the doctor. The expense of visiting the GP was also a barrier:

You know it's hard though, for beneficiaries. . . . \$18, [but it's] three times a week and, yeah and then they have to refill the script and then they give something else... (CH#1)

It was getting pretty expensive going to the doctor.... Going multiple times....though I've been having second thoughts about going because I was basically getting the same... [I] sorta held back until the pain was too much. ... I felt that I wasn't really getting anywhere going to see the doctor... And expense to my family you know. (Karaitiana)

Despite what patients say, some healthcare providers did not believe that cost was an issue:

There is no real 'cost' issues in this community when fees are so low and many ways to fund things. Often used as a reason but is not really the case. (HCP#2)

Lung cancer symptoms are sometimes vague, so it can be difficult to decide if a visit to the doctor is needed. Sometimes patients went to the GP with other symptoms, but were diagnosed with lung cancer:

She first went to the doctor complaining about a sore back . . . she stayed overnight at the Emergency thing, by about 4:30 she was diagnosed with lung cancer. (CH#2)

I have a patient [who had a] normal check-up in Feb. By April he started really presenting, but no clear symptoms. Swollen legs and weight loss.... Blood tests normal. Later he came back because he was breathless when tying his shoes. Wheezy and swelling on legs but otherwise ok. Chest x-ray, BNP (for heart failure) – normal. Rung hospital for advice . . . Sent for a CT [which found]

metastatic lung cancer (brain, kidneys everywhere) and he had a stroke. All in 4 weeks! So there's an issue with a lack of symptom presentation. (HCP#2)

When I went in first, I was in pain, I didn't realize that I had [lung cancer]. ... my stomach was out here... it was a bulge. It was big. And they said 'how long has your stomach been swollen?' And I was going 'what? I thought this is the normal way I am'. They said 'no. your stomach is swollen'. So that's when I heard I had lung cancer gone in the liver. (Nerita)

However, many participants told stories of delays between when they first went to the doctor and when they received a diagnosis:

I've had clients that have been backwards and forwards with a cough. Here's a prescription, and here's a prescription. And it's not until about 2-3 months almost later that they [GP] decide to do a chest x-ray, but then it's too late. We have happening time and time again. (CH#4)

When we came into our 50's, we were told by our GP at the time, whatever you do, to have regular checks, which we followed up with a GP every 4 months. Only to still come up short of the pace. My wife got a pain which came on suddenly. We followed it up promptly. She was prescribed antibiotics which would not cure her. So we kept going back to the GP and the pain was starting to get unbearable. So she was prescribed more tablets. After that, was sent for an x-ray which came up with nothing. Then was sent off to a physio, which made things worse. Next, a CT scan. Finally, 3 months later my wife is diagnosed with lung cancer. I am very very disappointed why it took this long after she got onto it promptly. (Emera's husband)

Whānau often described their attempts to get a diagnosis as a fight:

It gets to a stage where it's a fight. You have to fight. She had to fight. Other people I know had to fight to get to where they are. And that shouldn't be.

(CH#5)

Access to specialist care and treatment

Many participants talked about barriers in the hospital setting that they experienced leading up to, or immediately following their initial diagnosis. These barriers included long waiting times and GPs having to argue for their patients:

We have to travel across to [the hospital that is approx. one hour drive away]. Then sitting there waiting for four hours then [our whānau] get seen.... It's almost, may as well be a whole day, especially with young kids. (CH#1)

My whānau, they've had to wait almost an hour for an ambulance to get out to [my uncle's place]. And we lost that uncle... (CH#1)

After a GP refers a patient to the hospital, the hospital will assess the information and decide to either accept or decline the referral. All the GPs we interviewed described difficulties with the hospital, particularly related to the hospital agreeing to provide CTs for their patients. While some described frustration with the system, others have developed ways to get past the barriers to having a CT referral accepted:

I can just ring the radiologist that I know and get an endorsement, which lets me refer for a CT. Or I'll do a CXR first – but if we can't find any of the above criteria, I'll just lie and tick the [high suspicion of cancer] box (HCP#2).

It was 3 weeks till the patient could be seen for a CT. Even that was after I had a conversation with the respiratory physician. GPs need to navigate it. You can't just send a referral through and just leave it. (HCP#6)

Engagement with specialists and hospital staff

Patients and whānau also discussed negative and stressful experiences relating to their interaction with the specialist. This person's story relates to waiting to hear what his wife's diagnosis would be, during a difficult specialist appointment:

We sat there absolutely petrified, waiting to squeeze every little bit of information they had in that little half an hour session. A secretary from upstairs came down twice to present some other patient's case. And it just broke... I was just angry after that. ...I thought we were going to get their devoted attention. (CH#6)

Several whānau expressed frustration about how information was shared with them and the differences between what clinicians and whānau understand by specific terms such as radiotherapy and chemotherapy:

For me it's about sensitivity. Or the lack of it. My brother, when he was diagnosed, they said, why don't you go through 6 week radiotherapy. And after that he came home, we get a phone call, and the phone call says well if it doesn't work out you can go on chemo. From the best case of beating it, to the next step might be chemo? And to Māori chemo means, you're just about to get pushed off a cliff. It's a death sentence. They just told him you're at the cliff edge. And he just said, no. I might as well carry on drinking, smoking and dying that way... From saying you've got cancer, it can be beaten! And then they say oh you're going on chemo. It's ridiculous. (CH#6)

Specifically, patients and whānau said that doctors needed to give them a little hope, even if there was no more hope of a cure. They talked about still needing information about how to manage symptoms like tiredness and nausea so they could still care for their loved one. In the quote below, the participant describes finding a remedy (ginger) for ongoing nausea on Google:

My husband had 3 rounds of chemo and it didn't work, and then they said "sorry". That was pretty blunt. "Sorry, can't do anything else". What really annoyed me was after being with them for that long, they didn't have anything else. They didn't even - or couldn't or wouldn't - refer you to anything natural. To give it a go. Cause what have we got to lose? Where does he go from here? Surely you can send us somewhere. Give us some hope. It was old Google that helped us in the end. It didn't help us fully. But we got on there and had a look at what was being offered naturally. (CH#6)

In contrast, the specialists who worked with Kiritopa organized multiple kanohi-ki-te-kanohi hui (face to face meetings/gatherings) for him and his whānau to discuss his treatment plan:

They had 3 whānau hui. And one of his cousins just came up to see him and we were going to have a whānau hui. So we said oh come on sit in on this - 'Am I allowed to have my say?' 'Yes, you're allowed to have your say'. Everybody was allowed. Even my daughter-in-law, they had questions that they wanted to ask. And they were able to do that and have an answer. And so she even wrote stuff up on the whiteboard so that we could actually see in words what would happen. I thought that was just brilliant. (Kiritopa's wife)

Some participants also said that the Clinical Nurse Specialist was an important help, and helped them to make sense of the large amount of information being received from the hospital:

I've also got a nurse...clinical... [CNS's name]. She keeps in touch with me all the time. And I can ring her and talk to her and all that. Because I was getting bombarded here with letters and e-mails. Yeah. So I just have to ring [CNS's name] up and she'll tell me. (Meri)

Cultural values and respect

Whānau in the community hui discussed the importance of having hospitals value tikanga (customs and values) processes. Whānau talked about experiences that showed gaps in the health system's ability to cope with tikanga Māori. Some of the main things they pointed out were the importance of involving the wider whānau in the hospital journey (rather than a focus on only the patient) and showing respect to elderly patients:

. . . the whole tikanga within the process. Knowing that we come with many whānau members, children, aunties, uncles, everybody wants to come, so shared rooms don't really meet our needs. Having somewhere for our children, so that they're not being a distraction or a hōhā [nuisance], but that they need to be there and their koro's [grandfathers], their nans, they need them there. ... This is part of your healing process, this is what is going to make it better for you. 'Cause in here it's a positive outlook for them and that will improve their treatment response. (CH#1)

Some whānau described experiences of racism that resulted in fierce protectiveness of the patient. Most stories stemmed from institutional rules and expectations about how patients and whānau should behave that did not reflect Māori forms of manaaki (respect/care):

Our koros and our kuia [elders]; their mana gets tramped on. Their wishes don't get respected. If you are tūturu to your Māori-ness [everything is subsumed by your Māori identity], you know that the whānau looks after their own. And when they are sick and they go to the hospital, that all goes out the window. It becomes, excuse me, the white man's rule. There is no negotiating. You do it this way or you get out. I don't get out. I got a mouth. And our old people, they don't want other people wiping their bums, washing them. That is what keeps their mana intact, having that respect. . . . Their [HCP] job is to look

after the tinana, but you need to look after the wairua too. Because that's what keeps the person going. (CH#2)

A participant also described how her mum's response of quiet listening and processing when receiving her diagnosis, was misinterpreted as her being deaf:

I walked into the room and the doctor was yelling, speaking incredibly loud. I said "you know what? She's not deaf!", "oh oh! I'm sorry!", the assumption that she was deaf, but she actually had a scarf around her head, and I think it was because she didn't respond to him. She'd just been told she had terminal cancer, and I think she really wanted to just bawl! But she just sat there looking, in her seat ... the assumptions that people have ... if they're old, if they're Māori, if they're female, there's this whole...yeah. And without them realizing, this bias against what's presented in front of them. We have to deal with that. The system has to deal with that. I think that's something the organization has to deal with. That institutional racism, unconscious bias and the attitudes that derive from that. (CH#7)

The strength of whānau

As carers, whānau were positive and practical, and many talked about how they had to actively fight the system and advocate for patients in the hospital:

My brother, he actually took me on. Because I was too ill to email and fight for my rights so he took my email and started to say look when am I gonna get treatment? And he just happened to be rung to say we're having this [PET] scan... And I was in there and he rung the oncologist and said my sister is in there now having a PET scan, please if you have a spare bed can she go in. And I went straight from there up, through my 1st round of chemo. But you have to fight as well for your treatment. And when you're too ill, get someone who can talk to the pathologist or radiologist, to say when is it going to happen. (CH#5)

Whānau also often maintain careful and accurate notes, and keep track of patients' appointment schedules. Rewi's son and daughter for instance, discuss how they share and oversee their dad's care, and maintain a record of treatment related paperwork in what they call their 'bible':

Son: we're working on [Dad] being very prepared when we go there. You know, so my sister's got all his notes from...all the things that they require and.. so there're no muck around.

Interviewer: aw that's good. So is it like a thing of all the appointment letters or scripts and all that..all that stuff all in one?

Son: yup

Rewi: The 'bible'

Son: You can't miss any little vital information. Instead of missing one little thing... We sat there last night having a debate over one of his...because me and [my sister's] partner thought we heard something different. And [my sister] thought she heard this and this, and we're like are you sure? Cause you know, that's not what we heard. No but it's good that we were able to sit there and we could go back to the notes and compare them. And we were wrong [laughs].

(Rewi and his son)

Whānau also made sure that their children were part of every step of the patient's journey so that they learned how to manage and find their way through the healthcare system in the future:

I will tell my kids exactly what's happening so they are aware and they understand . . . even though they were only young, to me they needed to know. So they could see all the stages that their grandparents were going through.

They seen the hair loss, they seen the sick, they seen the weak, the frail, they seen all of that. And they've sat in the chemo treatments talking to them. Getting food for her, helping in whichever way they could. They came to all the appointments and everything. So they knew exactly what was going on. And that's been a massive journey. I still think my kids are richer for that, having spent time with their whānau and their grandparents, and richer for being involved in those processes so that if ever they come across friends and family [who get sick], they understand and they know. So they can tautoko and help.
(CH#2)

Impact on whānau

Whānau members often become a carer to look after lung cancer patients. And so the impacts of this journey on them are also significant. These impacts stretched outside of healthcare, into other areas such as living situations and work:

I gave my job up to look after him. Tried to find a job that would do me from home. And I did, it's doable, and if you stick together you're alright. As long as you have one strong person in your family you'll be right. You just chug on.
(CH#1)

So we made that decision to come home [from abroad] . . . We managed to get a rental . . . and I went through all the processes, doc's visits, Chemo treatments that sort of stuff with my mother-in-law... (CH#2)

Overall, whānau are a very important part of the diagnosis and treatment journeys of Māori lung cancer patients.

Our interventions

Initially, the Hā Ora team thought that communities would each suggest similar interventions that they would co-design with the team. However, the reality of the project was that each community created four different interventions. The interventions included a Hā ora: Let's talk lung health website, lung cancer awareness video clips and waiata, a kaiawhina training programme and a 'pou pupuru oranga' (cancer navigator) role. We also held workshops with local GPs about lung cancer awareness.

"Hā Ora: Let's talk lung health" website

You can access the website here: www.haora.net.nz

Who did we work with?

The Hā Ora website was developed with whānau in the Opōtiki community, led by Mariana Hudson, and supported by Whakatōhea Māori Trust Board.

Who else helped?

We had help from a Computer Science student at the University of Waikato: Josh Fellingham. Josh developed the website as part of a Summer Student Project from the University. The graphic images for the website were created by a graphic designer, Hakopa Pore.

What does the intervention do?

The Hā Ora website has four main areas that whānau thought were important: my lung health, access support, planner, lung ailments. The 'my lung health' feature has a short questionnaire to check the health of the user's lungs. The 'access support' feature provides a list of local support services in and around Opōtiki. The 'planner' takes you to either your 'Manage My Health' log in page, or to a calendar

that you can download and use for GP appointments and other notes. The ‘lung conditions’ feature has YouTube videos and information on various lung diseases.

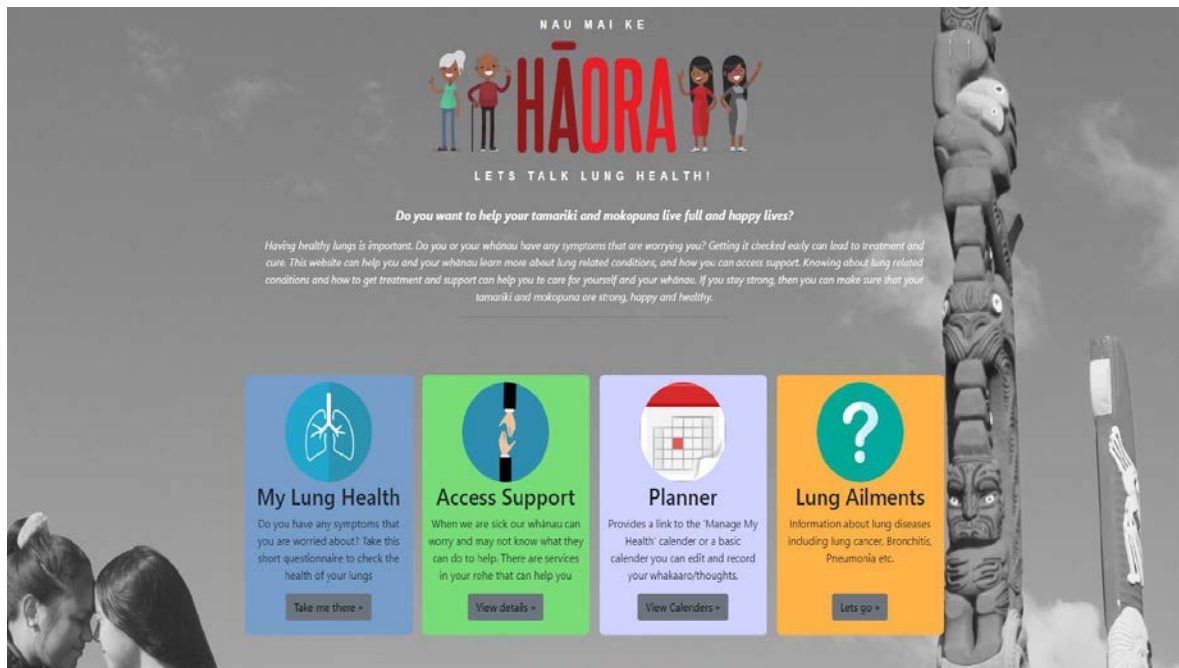


Figure 3. Screen shot of Hā Ora website



Figure 4. Publicity tent for Hā Ora at the kapa haka competition



Figure 5. Ross at the publicity tent for Hā Ora at the kapa haka competition

Kaiawhina and clinical staff training workshop

Who did we work with?

The team worked in partnership with Turanga Health in the Gisborne rohe.

Who else helped?

The workshops were led by Respiratory Cancer Nurse Specialists (CNSs) at the Waikato Hospital, and members of the extended Hā Ora team: Karen Middleton and Leonie Brown. The local CNS at the Gisborne hospital and a member of the local Hospice team in Gisborne also contributed brief sessions at the workshop.

What does the intervention do?

Two training workshops were organized: one for kaiawhina and one for clinical staff (nurses).

The workshops covered:

1. lung cancer symptoms,
2. pathways to diagnosis,
3. treatment options, and
4. information on palliative care.

The training workshops highlighted that if kaiawhina or nurses work with patients who have a persistent cough, they should get their patients to promptly go and see their GP, and for patients at risk of lung cancer to have a chest X-ray.

A 'kaiawhina training pack' was shared with Turanga Health with all the resources (powerpoint slides, information booklets etc.) used for the workshops so that they can continue providing these workshops to their staff in the future.



Figure 6. Karen facilitating a workshop



Figure 7. Leonie facilitating a workshop

Pou pupuru oranga cancer navigator

Who did we work with?

The third community intervention was a pou pupuru oranga cancer navigator in Rotorua, based at Aroha Mai Cancer Support Services. We worked with Bubsie and Haley at Aroha Mai.



Figure 8. Bubsie at Aroha Mai

Who else helped?

We also had support from Lakes DHB and Te Arawa Whānau Ora Collective.

What does the intervention do?

The pou pupuru oranga role overlapped with the services already being provided by Aroha Mai, and included many services for cancer patients and whānau such as:

1. guidance when required,
2. assistance/support for whānau,
3. a “listening ear”,
4. assistance with petrol vouchers (when available),
5. help/assistance for whānau to understand treatments and side effects,
6. awhiawhi whānau when requested, and
7. to provide culturally appropriate care that adheres to the principles of the Treaty of Waitangi.

“Wharo wharo wharo” lung cancer awareness videos

The videos can be viewed on the Hā Ora website: www.haora.net.nz

Who did we work with?

The final community intervention was with the Te Kuiti whānau group. We worked closely with Mahina Joseph-Small, Maryanne Thompson and Tania Te Wano.

Who else helped?

The Te Kuiti intervention was supported by Ngāti Maniapoto Marae Pact Trust and Maniapoto Whānau Ora Centre.

Dr Mary Simpson, a media communications expert at the University of Waikato and Rangimahora Reddy, the CEO of Rauawaawa Kaumātua Charitable Trust, also helped facilitate a media workshop in Te Kuiti. The project team also enlisted the help of Tom Goulter, a professional video editor, to develop the videos.



Figure 9. Maryanne and Mahina presenting at the media workshop



Figure 10. Mary and Rangimahora leading the media workshop

What does the intervention do?

The Te Kuiti group reached out to their whānau who lived locally, to compose and perform the waiata, and also acted out brief skits for the videos. The team supported the co-design group to put together the lung cancer awareness videos from the material they gave us. The messaging on the videos say: “**Kaua e wareware to maremare, to wharo haere ki te takuta - Don’t ignore your cough, go to the doctor**”.

GP intervention

The team also held a series of lung cancer awareness workshops with staff at the GP practices (GPs, nurses, social workers, other staff) at each of the four communities to complement each intervention. These workshops were led by Ross.

The information presented to GPs at the workshops was based on the 'A guide to help you understand your lung cancer and treatment' booklet.

You can access the booklet here:

<https://www.midlandcancernetwork.org.nz/assets/Lung-cancer-booklet-FINAL-October-2017.pdf>

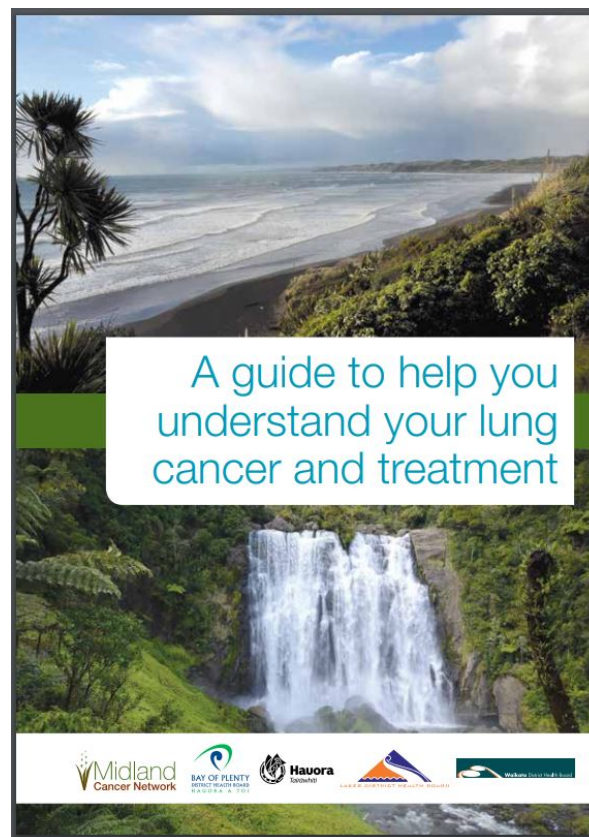


Figure 11. Cover page of the lung cancer booklet used for GP workshops

Recommendations

From the study we have some suggested recommendations to encourage whānau to see their GP sooner with worrying symptoms, and to help speed up the referral pathway with GPs, thereby improving early diagnosis of lung cancer. **We welcome your feedback on these recommendations.**

Recommendations for whānau

1. We recommend that whānau share information with the wider community that every worrying cough should be checked out by the GP, and that lung cancer can be cured if it's caught early enough.
2. We recommend that whānau share the community interventions like the Hā Ora website and the 'wharo wharo wharo' videos with your loved ones. We also recommend that whānau in Gisborne and Rotorua go to see Turanga Health and Aroha Mai if they feel they need support on their lung cancer journeys.
3. We recommend that whānau continue supporting and advocating for your loved ones.
4. Overall, we recommend that whānau carry on doing the amazing mahi that you are already doing for your whānau and for your communities.

Where to from here?

We plan to share all the interventions with all four communities – whānau as well as local healthcare providers, iwi providers, DHBs in the Midland Region, the newly established Cancer Agency and anyone else interested. We have also shared the Hā Ora website with the Cancer Agency and hope that it will contribute to their upcoming national lung health initiative. We also hope to share the ‘Wharo wharo wharo’ lung cancer awareness videos with Health TV so that the videos can be played at GP and other clinics who subscribe.

We have published some papers in medical journals to inform other health professionals about barriers experienced by whānau on their lung cancer journeys. The papers also contain more information about the research methods and findings. Links to the papers can be found here:

<https://www.waikato.ac.nz/nidea/medical-research-centre/lung-cancer>

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