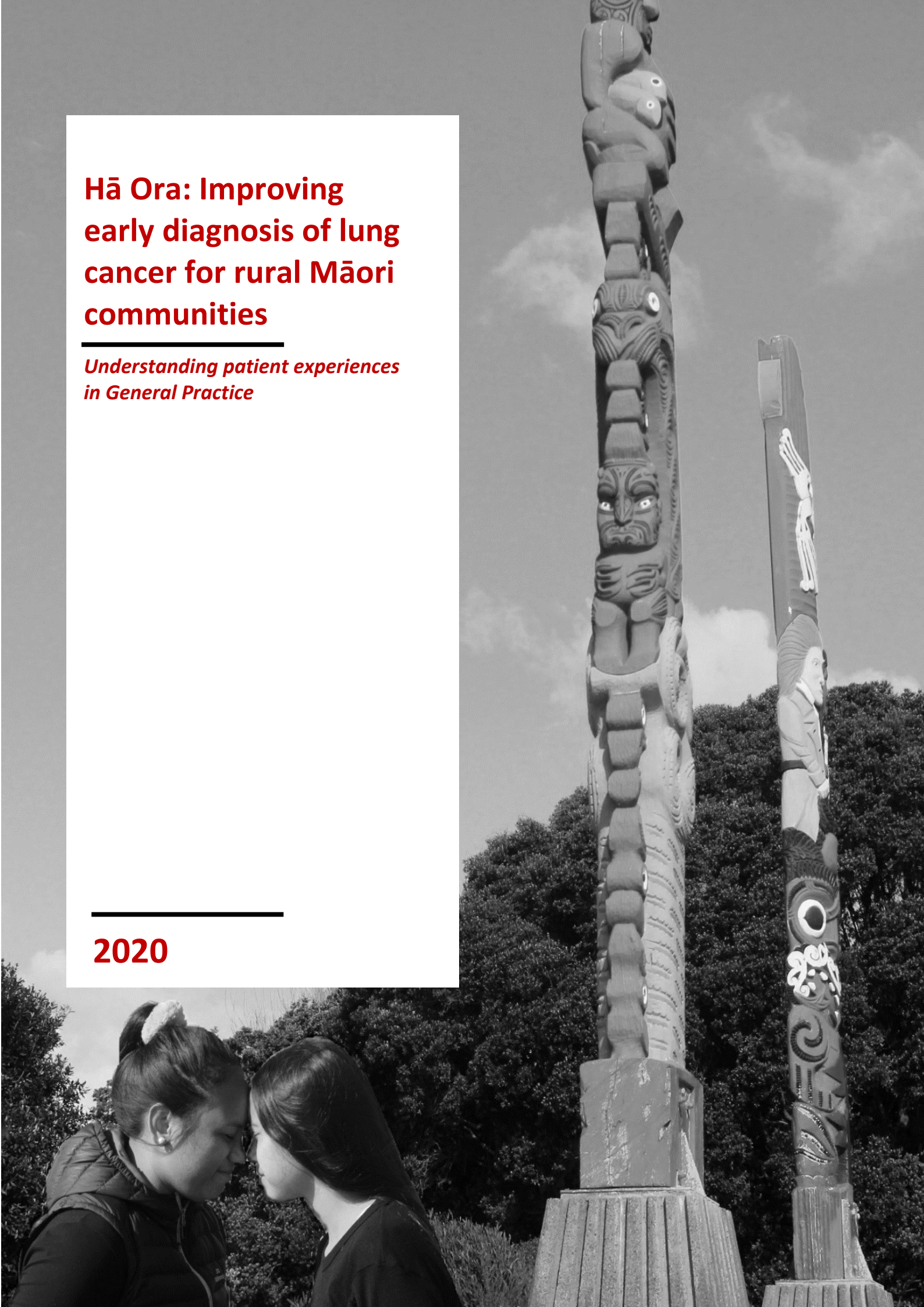


# Hā Ora: Improving early diagnosis of lung cancer for rural Māori communities

*Understanding patient experiences  
in General Practice*

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.*



# Executive Summary

There were two main objectives for this report. The first was to identify the barriers to early diagnosis of lung cancer experienced by Māori lung cancer patients and whānau. Second was to co-design a multi-pronged intervention alongside rural Māori communities to improve early diagnosis of lung cancer for whānau in their localities.

The team worked in the Waikato, Lakes, Bay of Plenty and Tairāwhiti districts of the Midland Region. Semi-structured interviews were carried out with 23 Māori lung cancer patients and whānau recruited through respiratory or cancer nurse specialists (CNSs) based at the hospitals of each district. Nine community hui (focus groups) and nine primary healthcare provider hui were carried out in five rural localities: Te Kuiti, Opōtiki, Te Kaha, Rotorua and Gisborne. Community hui included cancer patients, whānau, and other community members. Healthcare provider hui comprised staff members at the local primary healthcare centre, including General Practitioners and nurses. Study data were thematically analysed.

Findings of the study highlight:

1. Barriers in primary care, including symptom ambiguity, accumulating costs, barriers and enablers relating to GP – patient relationships
2. Barriers in secondary care, including a lack of access to diagnostic tests, long waiting times, barriers and enablers relating to communication between HCPs and patients.
3. The importance of whānau as carers and advocates for Māori patients on their lung cancer journey.

The interventions co-designed with each community included a Hā Ora website, a series of lung cancer awareness videos (entitled 'wharo wharo wharo'), a kaiawhina training programme and a 'pou pupuru orange' (cancer navigator).

We suggest strategies that aim to improve early diagnosis of lung cancer for rural Māori communities. **We welcome your feedback to us regarding these recommendations.**



# Governance Structure & Stakeholders

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Waikato District Health Board – Te Puna Oranga  
Lakes District Health Board  
Tairāwhiti District Health Board  
Bay of Plenty District Health Board  
Midland Cancer Network  
Aroha Mai Cancer Support Services  
Te Arawa Whānau Ora  
Ngāti Maniapoto Marae Pact Trust  
Maniapoto Whānau Ora Centre  
Turanga Health  
Whakatōhea Māori Trust Board  
Hei Pa Harakeke

## ***Stakeholders***

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# 1.0 Introduction

Lung Cancer is one of the most common causes of death from cancer worldwide [1]. It has been estimated that nearly one in five deaths globally are due to lung cancer, with 1.59 million deaths reported in 2012 (19.4% of the total). Overall survival rates for lung cancer are poor, with five year survival rates being 10–20% post diagnosis in most countries including New Zealand, Canada, Australia and Sweden [2-4]. A key reason for poor outcomes in lung cancer survival is the fact that it is typically diagnosed at a late stage when the patient has presented with symptoms. Population based screening for early stage lung cancer using LDCT (low dose computerised tomography) has been shown to be effective in identifying cases at an earlier stage and in reducing lung cancer mortality [5]. However, there is a high cost and a high false positive rate in using LDCT as a screening test [6]. Consequently uptake has been very slow and further research is ongoing in assessing whether there are particular high risk populations where screening for lung cancer can be justified.

An alternate strategy is to focus on the reason for late diagnosis. These can be due to patient factors, system factors and tumour factors [7]. Lung cancer symptoms can be different from person to person, and while most people show at least some early symptoms, some show none [8, 9]. Moreover, symptoms particular to lung cancer may be subtle and not directly related to the lungs and chest (e.g. tiredness and weight loss are sometimes the presenting symptom) [9]. Consequently, symptoms are often misinterpreted or misattributed by both patients and General Practitioners (GPs). Misinterpretation can be exacerbated by the existence of co-morbidities, which can result in delayed diagnosis or referral [10-13]. Studies across nine countries have shown differences in the delay in reporting symptoms, ranging from 7 days to 6 months [14]. However, if detected early, patients can potentially receive curative treatment [15, 16], with 5-year survival rates being at 70% [17].

Barriers to early diagnosis of lung cancer in primary care for Māori in particular are primarily related to General Practitioner – patient relationships, the health literacy of health providers and patients, and factors such as cost, symptom presentation and

delayed diagnosis [18, 19]. Consequently, previous NZ research indicates that many lung cancer patients initially present to secondary care through the emergency department (ED) rather than by referral from GP to a respiratory specialist [20]. However, this pathway also presents barriers to patients. Walton and colleagues [21] indicate that barriers to early diagnosis for patients (both Māori and non-Māori) presenting directly to a hospital ED involved disparities in access to services, and disparities and delays relating to processes of care. Māori lung cancer patients in particular, are more likely to be admitted via ED and tend to have different treatment plans to non-Māori [17, 22]. Further research is needed to identify the barriers to early diagnosis of lung cancer in primary care particularly for Māori.

## *1.1 Research aims*

We aimed to understand the barriers to early diagnosis of Māori at risk of lung cancer identified by rural Māori patients, whānau and Primary Healthcare Providers. Then, through a community based co-design process we aimed to develop and implement a multi-pronged intervention to improve early presentation of at risk Māori.

## *1.2 Structure of the project*

This project was developed with the assistance of multiple people and organisations. The key project partners were the University of Waikato, the Midland Cancer Network and the Waikato District Health Board (DHB).

This study took a kaupapa Māori philosophical approach. Particular emphasis was placed on the relationship between the research team and the Māori communities that the team worked with. This involved prioritising community engagement prior to the research, communication throughout the project and ongoing dissemination and discussions after the project ended. Participating communities and stakeholders were involved in co-designing each step of the resulting interventions.

Governance of the project comprised three levels: two advisory groups; an Academic and Clinical Steering Group including senior managers from the Midland Cancer Network, clinical specialists and primary care experts, and a Māori Advisory Group including expert

Māori academics, researchers and figures working in the healthcare space; and local stakeholder groups for each of the study sites. Kaumātua support for the project was provided through the team's relationship with Te Puna Oranga (Māori Health Service) of the Waikato DHB, and covered all the governance groups as well as ongoing involvement in the study.

This project would not have been possible without the support and guidance of our governance and advisory groups and the project kaumātua Hemi Curtis. We extend our sincere thanks to members for their time and invaluable contributions to this project.

## 2.0 Methods

Data collection occurred through qualitative interviews and community hui with Māori lung cancer patients and whānau, and primary healthcare providers in four districts in the Midland Region (comprising both rural and urban localities): Waikato, Bay of Plenty, Lakes and Tairāwhiti.

The purpose of the interviews and hui were to identify each group's experience of barriers and enablers to early diagnosis of lung cancer.

### *2.1 Interviews with Māori lung cancer patients and whānau*

Semi-structured interviews were carried out with a total of 23 Māori lung cancer patients and whānau (comprising 16 patients, and seven whānau members). Nine participants were male, and 14 were female. Patient recruitment was carried out by respiratory or cancer nurse specialists (CNSs) based at the hospitals of each district. The nurses approached potential participants to explain the aims of the project and inquire if they would be interested in participating. If interested, then with their consent, contact details were forwarded onto the researcher. The Māori researcher contacted the participant, further explained details of the project and scheduled the interview. Each interview was 1-2 hours in duration and occurred at the participants' homes. Interviews commenced with whakawhanaungatanga (a process of building connections between the interviewer and participants), and often opened and closed with karakia (prayer).

It is also important to note that many of the patients who gave the project their time and expertise have now passed away. We acknowledge their contribution at the beginning of this document.

## *2.2 Hui with Māori communities and local primary healthcare providers*

Community and healthcare provider hui were carried out in five rural localities: Te Kuiti, Opōtiki, Te Kaha, Rotorua and Gisborne.

All community hui were organised in conjunction with key Māori stakeholders in each community, followed local tikanga (protocols), and were led by Māori members of the team. Participants were recruited using ‘snowball’ sampling. Personal contact with local stakeholders and/or primary care providers was followed by the distribution of written materials to each community, inviting them to participate in hui (see work by Kidd et al [23] for further details of the community engagement process). A total of nine community hui (CH) were carried out, each comprising between 8-21 participants, which included cancer patients, whānau, and other community members affected by (lung) cancer.



*Figure 1. Team members facilitating a hui at a local marae in Gisborne*

Healthcare provider interviews or hui (depending on the number of staff in a practice) were carried out in the five rural localities mentioned previously. Overall, a total of nine primary healthcare provider hui (HCP) were carried out. Each healthcare provider hui comprised 1-6 staff members at the local primary healthcare centre or General Practice, which included the General Practitioners (GP), nurses and/or other staff.

## *2.3 Data analysis*

Interview and hui data were recorded via an audio-recorder and as field-notes. Audio recordings were transcribed and anonymised. Pseudonyms were used to maintain anonymity of interview participants. Transcripts and field-notes were thematically analysed [24]. Analysis was carried out by two researchers (SC and JK) independently and then together, to ensure a rigorous analysis process.

## *2.4 Co-design process*

Following the community hui, whānau from each hui were invited to form four co-design groups with the Hā Ora team. 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 concerning symptoms.

The team also worked with the Te Kaha community, but found out that the barriers to early diagnosis of lung cancer for this community 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. Therefore, 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.

## 3.0 Results

### *3.1 Barriers and enablers in primary care*

#### **3.1.1 Symptom ambiguity**

Our research highlighted that the ambiguity of lung cancer symptoms was a significant barrier to early diagnosis, experienced by both patients and HCPs. Reported symptoms included pain and a swollen stomach, a sore back, flu-like symptoms, swollen legs, weight loss, and breathlessness. Symptom ambiguity delayed patients from going to see their GPs assuming that the symptoms would pass, or misattributing their symptoms to other pre-existing conditions.

#### **3.1.2 Fear and lung cancer as a death sentence**

Most patients and whānau associated a lung cancer diagnosis with a death sentence. Fear was identified as a barrier preventing people from help-seeking. Most whānau were unaware that 70% of lung cancers can receive curative treatment if diagnosed early. Whānau expressed that they would like to learn more about specific lung cancer symptoms.

#### **3.1.3 Accumulating costs**

Another barrier identified was the mounting cost of attending GP appointments. Despite the fees at many GP practices being low, patients often visited the GP multiple times. Therefore, patients and whānau indicated that they often could not afford the accumulating costs of appointments, refilling scripts for medication as well as travel and childcare. Some HCPs did not consider cost as an issue due to the perceived low cost of fees for an appointment.

#### **3.1.4 Difficulty getting appointments**

Some patients reported difficulties getting appointments in a timely manner, often having to wait for two weeks to get an appointment to see their GP. The delays in



getting appointments are also exacerbated due to Māori patients wanting to see *their* GP, rather than whoever is available at the time.

### **3.1.5 GP continuity**

Levels of familiarity and trust between doctors and patients directly affected whether or not patients went to see their doctor promptly following symptom onset. A lack of GP continuity was a barrier that prevented the establishment of familiarity and trust between Māori patients and their GPs.

### **3.1.6 GP-patient relationship**

While trust and relationships between patients and GPs caused delays in help-seeking for some participants, this also served as an enabler to others. For instance, positive and longstanding relationships with GPs meant that patients were prompt in their help-seeking behaviour. Some HCPs also reported positive long-standing relationships with their patients, serving as enablers to earlier diagnosis. HCPs also reported occasions where they have reached out to their community networks to enhance their care, by checking up on patients who did not answer their phones.

### **3.1.7 Delayed diagnosis**

Some participants noted that despite promptly going to see their GP, there were delays in diagnosis and referral by the GP. Patients and whānau indicated that communication barriers contributed to late diagnosis. Māori patients in particular often communicated their symptoms in a way that was not understood by GPs. For instance, a lung cancer patient presented to their GP indicating that they were too tired to ride their horse, rather than stating that they were experiencing shortness of breath and fatigue. This miscommunication can be exacerbated when there is a lack of relationship between the patient/whānau and the doctor.

Patients also indicated that they were prescribed various medications for their symptoms following multiple GP appointments, all of which did not work. It was only after about 2-3 months of medication, referrals and tests that they were diagnosed with lung cancer.

## *3.2 Barriers and enablers in secondary care*

### **3.2.1 Access to diagnostic tests**

Even once the GP sent through a referral, there were occasions where X-ray results did not pick up the cancer. All the primary care providers we interviewed also described difficulties with secondary care, particularly related to accessing CTs for their patients. Some described frustration with the system, where a majority of their requests for high suspicion of lung cancer were declined.

Some GPs however, describe strategies to actively overcome barriers to progressing to CT scans in the diagnostic pathway, such as ringing the radiologist or respiratory physician personally to get an endorsement, or ticking the high suspicion of lung cancer box for patients who did not strictly conform to the guidelines.

### **3.2.2 Waiting times**

Many patients and whānau highlighted barriers related to secondary care that included long waiting times. Many rural patients reported having to travel for hours to the hospital, and then having to wait for 3-4 hours to get seen by the specialist. Long waiting times to access secondary care was a barrier that was also mentioned by HCPs.

### **3.2.3 Coordination**

Many participants highlight that a key barrier in secondary care is a lack of coordination between HCPs or various departments in the hospital when setting up appointments. Particularly if they also have comorbidities, cancer patients and whānau find themselves having to navigate the bombardment of appointments for treatment. A lack of communication and coordination was also clear across hospitals or DHBs.

### **3.2.4 Communication and information delivery**

Patients and whānau also discussed negative and stressful experiences relating to their interaction with the specialist. Several participants were frustrated about how information was shared and the differences between what clinicians and whānau understand by specific terms such as radiotherapy and chemotherapy. Specifically, patients and whānau indicated that HCPs needed to give them a little hope, even if they had exhausted their treatment options and were instead looking for symptom relief.

The mode of communication when delivering information regarding a diagnosis or treatment, determined whether or not it was a barrier or an enabler. For instance, when an HCP contacted a patient via phone, and insisted that they only speak to the patient, if this patient is elderly and perhaps overwhelmed by the entire process, then this served as a barrier.

### **3.2.5 Whānau hui**

Some HCPs however, also organized multiple kanohi-ki-te-kanohi hui (face-to-face meetings/gatherings) for patients and their whānau to discuss treatment plans, which served as an enabler.

### **3.2.6 CNS support**

Some participants also indicated that the CNS was a key enabler who would provide clarity on the myriad of information being received from the hospital. Patients reported being able to ring and speak to CNSs if they had any questions. Others indicated that various community health services (e.g. Aroha Mai Cancer Support Services, Turanga Health) were a great support in advocating for them and promoting help-seeking.

### **3.2.7 Cultural values and respect**

Participants in the community hui discussed the importance of having hospitals value tikanga (protocols, customs and values) processes, where their experiences

highlighted gaps in the health system's ability to cope with tikanga Māori. Key points discussed were an awareness of the involvement of wider whānau in the specialist care journey (rather than a focus on only the patient) and showing respect to elderly patients.

Overall, an acknowledgement of these barriers and enablers can allow for the establishment of (culturally) relevant and appropriate initiatives to improve access to early lung cancer diagnosis.

### *3.3 Importance of whānau*

Whānau are a central part of the diagnosis and treatment journeys of many Māori lung cancer patients. Often whānau were the key figures prompting or initiating help-seeking behaviour.

#### **3.3.1 Whānau as carers**

Whānau play an active role as carers, and serve as enablers by often maintaining meticulous notes, and keeping track of patients' appointment schedules. For example, one group of whānau described how they share and oversee their dad's care, and maintain a record of treatment related paperwork in what they call their 'bible'.

#### **3.3.2 Proactive whānau**

As carers, whānau were proactive, and many recounted how they had to actively fight the system and advocate for their family members.

#### **3.3.3 Impact on whānau**

The journey through secondary care had significant impacts on whānau members, who often took on the carer role. Such impacts stretched beyond healthcare, into other areas such as living situations and work. Whānau reported often having to

leave their jobs and relocate (e.g. moving house, or moving to New Zealand from Australia) to care for patients.

### **3.3.4 Intergenerational health literacy**

Whānau ensured that even their children were part of every step of the patient's journey so that they learned how to manage and navigate the healthcare space in the future.

Overall, participant accounts demonstrate the resilience and agency of patients and whānau to learn, support and advocate for each other.

## 4.0 Interventions

Initially, the Hā Ora team envisioned that communities would 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. Overall however, all interventions had a health literacy focus, promoting help-seeking through either providing more information to communities about lung cancer, or by supporting or upskilling pre-existing local community health services. The interventions included:

- ❖ A 'Hā Ora: Let's talk lung health' website,
- ❖ Lung cancer awareness video clips,
- ❖ A kaiawhina training programme, and
- ❖ A 'pou pupuru orange' (cancer navigator) role.

We also held workshops with local GPs about lung cancer awareness.

### 4.1 “Hā Ora: Let's talk lung health” website

The website can be accessed via this link: [www.haora.net.nz](http://www.haora.net.nz)

The Hā Ora website was aimed at helping community members learn more about an array of lung diseases (including lung cancer).

The Hā Ora website was developed with whānau in the Opōtiki community, supported by Whakatōhea Māori Trust Board. We had help from Josh Fellingham, a Computer Science student at the University of Waikato. 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.

The Hā Ora website has four main areas that whānau thought were important: my lung health, access support, planner, lung conditions. 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 2. Screenshot of Hā Ora website homepage



Figure 3. Publicity for the Hā Ora website at the Opōtiki kapa haka competition



## *4.2 Kaiawhina and clinical staff training workshop*

The workshops were aimed at upskilling kaiawhina and clinical staff to support and advocate for their clients at risk of lung cancer.

The team worked in partnership with Turanga Health in the Gisborne rohe (area). The workshops were facilitated by Respiratory CNSs at the Waikato Hospital, and members of the extended 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.

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.

The information booklet used in the workshops is also available via this link:

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

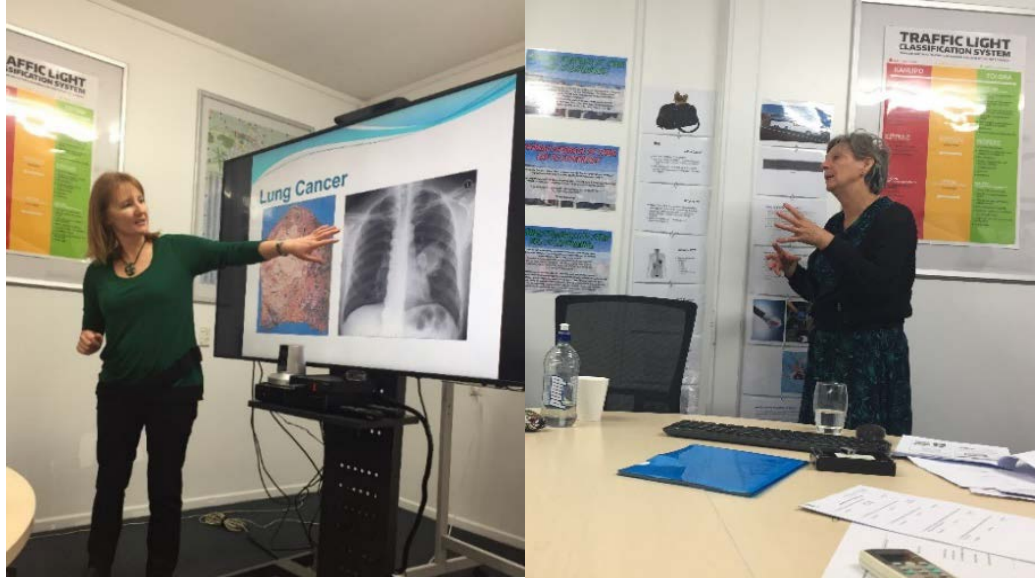


Figure 4. The team facilitating workshop for kaiawhina and clinical staff

### 4.3 Pou pupuru orange cancer navigator

The aim of the intervention in Rotorua was to demonstrate the value of a health navigator for cancer patients. The pou pupuru orange cancer navigator, was based at Aroha Mai Cancer Support Services, which was a community based organisation, rather than being a formal healthcare provider. We also had support from Lakes DHB and Te Arawa Whānau Ora Collective.



Figure 5. CE of Aroha Mai Cancer Support Services

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.

#### *4.4 “Wharo wharo wharo” lung cancer awareness videos*

The videos can be accessed via the Hā Ora website: [www.haora.net.nz](http://www.haora.net.nz)

The aim of the videos were to promote help-seeking behaviour if whānau have a persistent cough. In particular, the videos are intended to promote tamariki (children) and rangatahi (youth) to convince their whānau to see the GP if they notice worrying symptoms.

This intervention was with the Te Kuiti whānau group. 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.

The Te Kuiti group reached out to their wider whānau, to compose and perform the waiata, and also enacted brief skits for the videos. The team supported the co-design group to put together the lung cancer awareness videos from the material the community provided. The messaging on the videos states: “Don’t ignore your cough, go to the doctor”.



*Figure 6 The team and community stakeholders facilitating media workshop in Te Kuiti*

## **4.5 GP intervention**

The team also held a series of lung cancer awareness workshops with primary care staff (GPs, nurses, social workers, other staff) at each of the 4 communities to complement each intervention. These workshops were led by Professor Ross Lawrenson.

The information presented to GPs at the workshops was based on the ‘A guide to help you understand your lung cancer and treatment’ booklet. The booklet can be accessed via this link: <https://www.midlandcancernetwork.org.nz/assets/Lung-cancer-booklet-FINAL-October-2017.pdf>

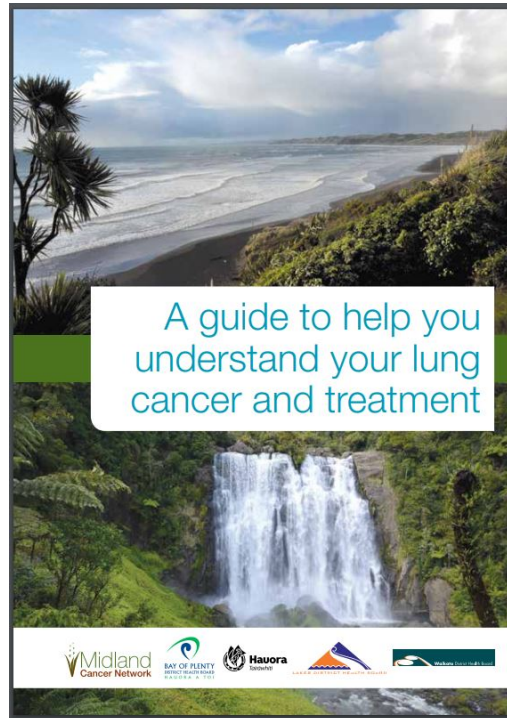


Figure 7. Cover page of the lung cancer booklet used for GP workshops

## 5.0 Discussion

### *Barriers to early diagnosis*

This study has identified the key barriers for Māori patients and their whānau in their diagnostic pathway.

Firstly, the symptoms of lung cancer are not always clear cut, and so a low threshold is needed for patients presenting to the healthcare system. Tiredness, flu-like symptoms etc. can be the first signs. We have worked with four rural Māori communities to develop resources that will help patients and their whānau understand when it is appropriate to present to their healthcare provider.

Second, the prevailing fear and the belief that lung cancer was incurable among patients and whānau, were reflective of their past experiences. The interventions co-designed with each community reinforces messaging around early diagnosis of lung cancer, highlighting that 70% of lung cancers can potentially receive curative treatment if detected early.

Third, patients and whānau noted the barriers that they often faced in primary care. Cost is a barrier for many even when their practice is a 'low cost access' practice. More important, is an ability to make an appointment with a doctor that is familiar. This is not always possible. It is suggested that when meeting Māori patients for the first time, that healthcare staff prioritise whakawhanaungatanga before exploring clinical needs. This is important to Māori patients and will help with ongoing patient management.

Fourth, the study has also provided accounts where there have been delays in accessing specialist diagnostic services. We are encouraging a low threshold for ordering chest X-rays and for referrals to respiratory specialist care especially for high risk patients (e.g. those with COPD or a history of smoking).

Finally, this research demonstrates that whānau support is essential in helping patients navigate the healthcare system, and in keeping patients engaged with health services.

We encourage primary and secondary care services to involve whānau throughout a patient's cancer care journey.

## *Community interventions*

Overall, the community interventions designed as part of the current project, where intended to improve early diagnosis by promoting health literacy and educating communities about lung cancer, and by supporting local community health services to assist lung cancer patients along the healthcare pathway. In particular, the interventions provided culture-centred and culturally safe initiatives to improve early diagnosis of lung cancer.

Additionally, this research demonstrates that, in order to carry out a successful co-design process in which the community is truly involved and thus also ensures greater uptake of the resulting intervention, community-driven engagement is vital. Community interventions need to be co-produced *with* whānau and/or key stakeholders so that the intervention reflects the realities of the communities involved. Community engagement involves walking away if communities indicate that they do not want to work with you. It also involves lengthy, often unpredictable timeframes and flexibility based on the community context. Community engagement involves taking information and ideas back to the communities and getting their feedback on how the process was for them.

Finally, researchers, health service providers and/or Governments tend to assume a 'one-size-fits-all' approach to healthcare interventions, especially for Māori. It is assumed that if a pilot can work in one locality, it can be generalisable, and thus successfully implemented at a national level. However, our research demonstrates why such assumptions are problematic, and may lead to unsatisfactory uptake of related interventions. Rather, this research clearly illustrates that communities will provide different solutions that they think work for them, which may not work for others. This is clear from the diverse dynamics that characterised the communities we worked with in terms of the stakeholders we engaged with, the kawa (protocols) of each location, and the different interventions they devised.



## *Future developments*

Currently in NZ, there are several initiatives being developed to promote lung cancer awareness and early detection. First, is a social media campaign relating to health literacy in lung cancer. This proposed initiative aims to also provide education and support for HCPs. Second, the National Lung Cancer Working Group has submitted a proposal to the Ministry of Health to re-implement the “cough, cough, cough” early diagnosis of lung cancer campaign, which was briefly piloted in Rotorua in 2010. Finally, a recent bid was submitted to the Ministry highlighting the need to carry out ongoing monitoring of lung cancer incidence and mortality through the Midland Lung Cancer Register. We hope that the findings of this research will inform these developments.

Project related publications can be accessed via this link:

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

## 6.0 Recommendations

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

### *6.1 Recommendations for primary care*

6.1.1 We found that lung cancer is a disease that features symptom ambiguity. Moreover, patients diagnosed with lung cancer often have an array of other respiratory or lung related diseases. We recommend that primary care providers consider regular lung health checks for high risk patients and have a low threshold for ordering chest X-rays.

6.1.2 We recommend that primary care providers prioritise culturally safe care, particularly when working with Māori patients and whānau. Striving to ensure continuity of care, and building relationships with patients through whakawhanaungatanga, and involving whānau in patient interactions are key to providing culturally safe care.

6.1.3 We recommend that PHOs increase their efforts in providing cultural safety training for practices.

6.1.4 We found evidence that CT scans sometimes picked up lung cancers that were not detected by chest X-rays. Moreover, our results indicated that GPs often had to employ strategies such as personally contacting respiratory physicians to get a CT scan referral approved. We recommend that primary care providers continue advocating with PHOs for better access to diagnostic tests for lung cancer such as CT scans, in particular for at risk Māori and ex-smokers.

6.1.5 We recommend that PHOs and DHBs work together at ensuring better access for patients at risk of lung cancer to both primary and specialist services.

## *6.2 Recommendations for DHBs*

6.2.1 We encourage DHBs to engage with the communities they are working with on ways of achieving earlier diagnosis for patients at highest risk of lung cancer.

6.2.2 We recommend that DHBs improve access to CT for patients at risk of lung cancer.

6.2.3 We recommend that DHBs and PHOs work together at ensuring better access for patients at risk of lung cancer to both primary and specialist services.

6.2.4 We encourage DHBs to provide sustained funding and support for culturally safe initiatives developed locally by rural communities, such as targeted lung cancer screening, cancer navigators, health literacy resources and other lung cancer awareness campaigns.

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